

TOWARDS A PATIENT CLIENT COUNCIL

**Stakeholder Engagement within the
Southern Area**

**Undertaken by the Southern Health &
Social Services Council**



**on behalf
of the DHSSPS Project Team on the
Patient Client Council**

June 2006

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BACKGROUND TO THE PRE-CONSULTATION EXERCISE

The Southern Health & Social Services Council welcomed the opportunity to feed into the DHSSPS Project Team charged with the development of the new Patient Client Council (PCC). The PCC will replace the four existing Health & Social Services Councils (HSSCs) in April 2008 under the Review of Public Administration.

The four HSSCs realised the important opportunity this presented to ensure that the PCC met the needs of patients, carers, communities and the public in representing the public voice within the health and social care system.

Therefore, at the request of the PCC Project Team, the four HSSCs carried out a pre-consultation exercise to inform the Project Team's deliberations. This exercise followed a 'best fit' approach given the very challenging timescale. The four HSSCs carried out a stakeholder analysis, with the aim of ensuring across the four HSSCs a varied cross section of individuals, communities and interests had the opportunity to comment.

This report captures some of the feedback received as a result of the SHSSC engagement exercise. As an iterative process it informed the SHSSC's input into the Project Team discussions. The report was submitted to the Project Team on 5 June 2006.

Stella Cunningham
Chief Officer
Southern Health & Social Services Council

June 2006

Summary of Stakeholder Engagement

Statutory HPSS Commissioners & Providers

Southern Health & Social Services Board
Craigavon & Banbridge HSST
Craigavon & Banbridge Health & Social Care Group

District Councils

Dungannon District Council
Banbridge District Council (telephone discussion)

Media

Newsletter
Mourne Observer
Lurgan Mail & Morton Group
Banbridge Leader (telephone discussion)
Banbridge Chronicle
Ulster Gazette

Voluntary & Community Groups

Rural:

South Armagh Women & Family Health Initiative
South Armagh Rural Women's Network,
Kilkeel Community Association
Birches Community Association
Aghalee Community Association

Black & Minority Ethnic:

WAH HEP Chinese Community Group
Chinese Patients' Forum Steering Group

Urban:

Craigavon & Banbridge Carers Group

Umbrella/Networks:

Meeting held in partnership with COSTA
Community Development Health Network Members' Meeting
TADA

Public Meetings

Public Meeting held in Armagh, 10 May 06

Public Meeting held in Newry, 11 May 06

Public Meeting held in Portadown, 18 May 06

Political Parties (As a four HSSC Initiative)

Democratic Unionist Party

Sinn Fein

Social Democratic Labour Party

E-Consultation

Undertaken jointly with the Community Development & Health Network, the four HSSCs carried out an e-consultation to broaden the scope of the consultation exercise. Responses from this have been collated separately and can be found on www.shsscouncil.net

Internal

Southern Health & Social Services Council Members

Southern Health & Social Services Council Staff

Key Messages

Overall Purpose

- PCC needs to have appropriate legislation in order to engage effectively with the other HPSS bodies.
- The PCC must be open and transparent and should encourage the rest of the HPSS to operate in a similar manner.
- A strong challenge function should be built into the PCC role and function.
- The areas of advocacy and training are important.
- It should create real accountability within the system.
- There needs to be a role in relation to independent contractors such as GPs and Dentists.
- A community development approach is needed.
- Carers aren't reflected in the proposed name.

Regional Function

- Should be an organisation that can deliver something.
- Needs to have a strategy for linking in with the voluntary sector.
- Shouldn't duplicate the work of other bodies such as the RQIA.
- Must be a strong advocate for the public.
- The regional function is important in terms of co-ordinating activity but it also needs to have a strong local presence.
- Develop a strategy for providing effective advocacy ensuring that this meets the needs of the general public.

- Would be beneficial if the new PCC could expedite issues directly to the Minister eg issues with Trusts performance.
- The PCC should utilise community development techniques at all levels throughout the organisation including at Council Member level.

Local Function

- A local presence is essential if the PCC is to have meaning with local communities.
- Local networks will be needed to support local offices if communities are to engage with the PCC.
- Needs to be well known locally and seen as useful.
- Highlight local issues and support local groups.
- Needs grass roots representation on the regional body.
- Should promote good practice and support capacity building.
- Should provide information in 'layman's' terms.
- Agreed that it was essential the PCC engage with patients, clients & communities and has a strong emphasis on representing individual patients and local communities.
- Act as an advocate for the public signposting to agencies such as legal aid or people who work in the community.
- PCC must have local offices based in the community.
- Should be co-terminous with the reformed District Council Structure.

Indicators of Success

- Should be additional resources eg staff provided to ensure that the PCC can carry out all of its role. The PCC needs to be well resourced and well staffed in order to deal with issues in a competent manner.
- Should have clear & transparent processes and outcomes.
- More people being involved.
- More feedback from the public.
- Seen as independent, well known and useful.
- Communication with community & voluntary groups at a high level.
- Actively lobbying.
- More multi-agency working / partnership working eg Chinese Patients Forum
- More people involved in health forums.

Summary of Responses to the Four Questions

The consultation was shaped around responses to four broad questions. The discussion was based upon the draft role and function paper agreed by the DHSSPS Project Team. The four questions used by the HSSCs for the events were:

- 1) **What sorts of things would you expect the PCC to do? Or, what should the PCC's overall purpose be?**
- 2) **What should the local function of the PCC be in your local community?**
- 3) **What should the local function of the PCC be in your local community?**
- 4) **What difference should the PCC make? Or, what should the indicators of success for the PCC be.**

The responses provided are listed on the following pages.

A further report, available on the SHSSC website, contains responses from an e-consultation also undertaken by the four HSSCs.

Overall Purpose of PCC

- Need for clarity about which body has responsibility for particular functions such as user participation.
- Need for clear role backed by legislation.
- Requirement to have a relationship with independent contractors working alongside the HPSS.
- Need to utilise a community development approach.
- Needs the powers to engage with the 'Super Trusts'.
- Do carers and the public fit into the PCC? They are not represented in the name.
- Must be independent if it is to be successful and taken seriously by the public.
- 'Honest Broker' is a term that can mean different things to different people. The PCC's role should be about ensuring that the process for decision making is transparent.
- Needs more teeth to make service providers accountable.
- Needs to challenge policy makers, commissioners, providers and regulators.
- Must be honest and transparent.
- Should provide citizenship and advocacy training.
- PCC needs to be able to do what it says it will do.
- Need to advocate for disadvantaged groups such as Travellers, children, etc.
- Advocate for individuals and communities.
- Challenge policy makers, commissioners, providers and regulators.

- Ensure that expectations and needs of the public are addressed however stated that they PCC needs to have more “teeth” than the current Health & Social Services Councils in order to make health care providers accountable for more serious issues.
- Also raised importance of lobbying eg.
- It needs to be a watchdog with real powers and remit and it must be able to take real action and create real accountability.
- It should have strong audit and investigative powers at its disposal.
- It should lobby for stronger accountability structures eg for Independent Providers such as GPs and Dentists.
- Proposed changes will not make much difference to the standing of the PCC in law. This may adversely affect the PCC's ability to engage with key players on an equal status both within the HPSS and outside it.
- Advocating on behalf of individuals, groups and communities is essential. Acting as an honest broker is also extremely important however both these roles must be achievable. It will be much more destructive to say that the PCC will carry out these functions and then not have the resources to fulfil this role than it will to not include it in our role.
- Genuine user involvement must be a key principle. User involvement should be carried out on a day to day basis. The PCC should act on the comments and complaints of service users. However public ownership will be difficult to develop because of the public's disillusionment with the HPSS eg closing of hospitals, too many consultations and nothing being changed when people raise issues in consultations.
- The PCC must ensure that honesty & transparency is evident to the public in order to get people to trust the health service.
- The PCC and the HPSS must start working in a new way to engage with communities and tell the truth (no matter how difficult).
- The PCC should work towards bringing NI up to national standards and the same level of modernisation as in Britain.
- It will need more resources eg staff to ensure its role is achieved.

- Need strong advocacy role eg in relation to capacity building, communication skills, negotiation skills and confidence for service users especially those with mental health problems or learning disabilities.
- Training could be provided by the PCC and also provided via community / voluntary groups or advocates.
- Provide advocacy to the general public in an independent and objective manner. Advocacy role especially important in relation to elderly patients and vulnerable adults however if it is to be successful the PCC needs to be able to fulfil what it says it will do.
- Needs to be legislation to ensure that the Trusts, Primary Care Providers and Local Commissioning Groups all must consult with PCC and that there is a reporting mechanism to the PCC.
- Should be written into the legislation how the Minister / DHSS&PS will take heed of the PCC and how the PCC's and public's voice will be listened to, heeded and given due regard by the policy makers, commissioners, providers and regulators.
- Completely independent body that has power and "teeth".
- Media representatives would like to see the role of an independent informed commentator to be continued by the PCC.
- District Councils are likely to value the expertise that the PCC can bring to issues around the community planning function.
- District Councils have not found it easy to have a fully engaged relationship with the HSSCs. A satisfactory mechanism for sharing information widely has not really been developed.

Regional Function

- Should be an organisation that can deliver something.
- Needs to be able to inform the public about health & social care issues.
- Needs to have a strategy for linking in with the voluntary sector.
- Shouldn't duplicate the work of other bodies such as the RQIA.
- Must be a strong advocate for the public.
- Agreed on the need for there to be a regional office to carry out the strategic regional functions and provide co-ordination to work of smaller offices but stressed need to have local presence in order to know what is happening on the ground.
- Group suggested that the PCC should continue to do what Health & Social Services Councils are currently doing but also ensure that Community Development approaches are used at all levels – from the regional strategic plans to the groundwork of the staff. Stressed need for both staff and Council members to use Community Development approaches.
- Set a policy / strategy for the economic value of participants time for consultations (Agree rate of remuneration for people attending consultation meetings and take into account problems people may experience in attending these meetings eg providing funding for child care, travel allowance etc).
- Co-ordinate the work of local offices setting policies and strategies in order to have more cohesive working.
- Setting standards for the region ensuring that all areas are meeting the same standards.
- Communities do not want another organisation that cannot deliver anything real or meaningful. The new PCC should be able to name and shame where standards are not being met or where patients have legitimate grievances.
- The PCC should be able to link in with specialist commissions such as the Equality Commission, Human Rights Commission and Legal

Services Commission etc to provide full advocacy service. Would be extremely beneficial if PCC could have joint protocols with these commissions for the provision of services to people that the PCC would signpost to them.

- Develop a strategy for providing effective advocacy ensuring that this meets the needs of the general public.
- Would be beneficial if the new PCC could expedite issues directly to the Minister eg issues with Trusts performance.
- Ensure that Super Trusts etc disclose to the general public how they spend their money.
- Create more effective / efficient structures for working and more cohesive working.
- Develop more cohesive, linked up working relationships including the new Super Councils.
- Develop a process for the flow of information. If acting as an advocate nurses / community workers could pass on the client's information to the PCC however there needs to be a clear path for the information flow, reporting mechanism, timescales etc.
- Advocate especially for the elderly and vulnerable people. Should consider setting up an advocacy group.

Local Function

- A local presence is essential if the PCC is to have meaning with local communities.
- Local networks will be needed to support local offices if communities are to engage with the PCC.
- Local newspapers require local interest stories if the PCC's work is to be relevant.
- Local newspapers welcome the opportunity to talk to an informed source that is independent of providers and commissioners.
- Needs close working links with local community and voluntary organisations.
- Needs to be well known locally and seen as useful.
- Highlight local issues and support local groups.
- Needs grass roots representation on the regional body.
- Should promote good practice and support capacity building.
- Should provide information in 'layman's' terms.
- Agreed that it was essential the PCC engage with patients, clients & communities and has a strong emphasis on representing individual patients and local communities.
- Questioned how the PCC could maintain or strengthen links with local communities, especially rural communities if it has only one base (the group automatically assumed that it would be Belfast – no other location was given any real consideration) and stated that local communities would definitely not feel supported by the PCC if it is only in Belfast.
- They stressed that issues in South Armagh are very different to issues in more urban areas. They especially highlighted that people in sparsely populated rural areas like South Armagh and South Down are already disadvantaged through only having a limited level of services in their local areas eg community centres, community care

etc and that moving the PCC to one centralised location would feel that they were losing another service in favour of urban areas.

- Act as an advocate for the public signposting to agencies such as legal aid or people who work in the community.
- PCC must have local offices based in the community.
- Work closer with community / voluntary groups – develop and maintain clear lines to the community
- Stressed importance of sub-regional offices coterminous with District Councils.
- Increase communication with local communities.
- Carry out consultations at local level.
- Disseminate information to members of the public & community / voluntary groups.
- Develop and maintain more links with community & voluntary group and subcontract pieces of work to them (eg facilitating consultations at a local level).
- Especially given that this group is specifically for women they noted the gender balance on the Southern Health & Social Services Council and stated that the PCC should have a gender balance with younger representation, more women and people from the Community & Voluntary groups. Staff were keen to not have Councillors or Politicians sitting on the PCC.
- Have targets clearly documented and SMART in order to them to be well monitored.
- Meet with Community Groups to make them aware of the work of the PCC and get them more involved in the work of the Council.
- Provide outreach support and practical help to the local community.
- Highlight local issues and take forward local issues to regional level where appropriate.
- Importance of local offices stressed in order to have link with local communities.

- Increase amount of work carried out with community and voluntary groups.
- The PCC should be well placed to take up issues such as the pressure on services that changes in demography mean. For example, the changing nature of the population in Dungannon, and specific needs of numbers of people unsure how the health system operates. Statistical information is not necessary truly reflecting need. The PCC both locally and regionally could have a role in highlighting these issues.

Evidence of Success

- Have fewer consultations and more people involved at start – at very least have face to face consultations and no paper exercises. Do not have consultations just to tick boxes.
- Should be additional resources eg staff provided to ensure that the PCC can carry out all of its role. The PCC needs to be well resourced and well staffed in order to deal with issues in a competent manner.
- Should have clear & transparent processes and outcomes.
- More people being involved.
- More feedback from the public.
- More people getting their voices heard.
- Funding provided for health & social care issues.
- Have more community / voluntary group representatives on PCC.
- Makes a real difference to the health and social services provided to ordinary people.
- Whilst the PCC should be independent it also needs to be seen as being independent. There is still a perception that the current Health & Social Services Councils are part of the health service – this might hinder them acting as an “honest-broker”.
- Should focus on a few key issues successfully rather than try to address too many issues.
- The HPSS in NI needs to be brought up to at least the same standard as England.
- Seen as independent, well known and useful.
- Communication with community & voluntary groups at a high level.
- Actively lobbying.
- More multi-agency working / partnership working eg Chinese Patients Forum

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DRAFT

PATIENT CLIENT COUNCIL (PCC) PROJECT TEAM

**PAPER ON THE ROLE, RESPONSIBILITIES AND FUNCTION OF
THE PATIENT CLIENT COUNCIL**

What is the PCC's overall purpose?

The purpose of the Patient Client Council (PCC) will be to:

- provide effective advocacy for individuals and communities
- challenge policy makers, commissioners, providers and regulators
- ensure that expectations and needs of the public are addressed in order that they get the very best from health and social care services.

How will the PCC do this?

The PCC will do this by being a powerful, independent body providing a loud and clear voice for:

- Patients
- Clients
- Carers, and
- Communities.

This will be achieved by continuous, positive and proactive engagement with patients and clients.

It will have a regional remit as well as a strong emphasis on representing individuals and local communities.

It will promote meaningful user participation in the Health and Personal Social Services (HPSS) on the assumption that user participation is a core function of all HPSS bodies.

It will link in with decision makers at all levels as well as service providers.

It will engage with regulators and monitoring bodies to ensure that the public interest is served.

What is the PCC's role?

Strategic

1. At a regional level the PCC will:
 - Act as the collective voice of public interest.
 - Be a strategic voice to act as a catalyst for change.
 - Engage with policy makers, commissioners, providers and regulators.
 - Set policy directions for the PCC's regional and local work.
 - Provide leadership and governance to the PCC's work at regional and local level.
 - Evaluate, monitor and internally assess the PCC's effectiveness and ensure that the organisation is fit for purpose.
2. To ensure that the PCC /public voice is listened to, heeded and given due regard by the policy makers, commissioners, providers and regulators.
3. To be accountable to the Minister/DHSSPS eg through work plan and external evaluation.
4. To maintain an awareness of the challenges and choices that the HPSS must address and inform debate amongst the public.
5. To promote standard setting and best practice for public/patient involvement.
6. To offer a strategic collective voice on change to existing services or the introduction of new services/policies.

Community

7. To undertake a proactive strategy to involve the public in the PCC's work eg community panels.
8. To research and analyse service users' views in order to achieve its overall purpose.
9. To act as an 'honest broker' between planners/providers and service users, as appropriate.

10. To contribute to capacity building and empowerment for communities, groups and individuals to advocate on their own behalf
11. To be accountable to the public eg through an annual public forum
12. To observe the range and quality of service provision eg visiting, analysing data and responding to public/media concerns.
13. To comment on the range of quality of service provision
14. To contribute to the community planning process.

Individual

15. To provide advice and support to complainants in respect of HPSS funded treatment and care across the statutory, voluntary and independent sectors.
16. To advocate for individuals, groups and communities.

What will the PCC need to do this?

The PCC will need to:

i) Be Independent:

- Be set up by statute as a Non Departmental Public Body (NDPB) with an appropriate Council/Board.
- Be accountable directly to the Minister/DHSSPS and the public.
- Be directly funded by the DHSSPS.
- Derive its legitimacy from the public and its authority from legislation.
- Work to its own agenda as approved by the Minister.

ii) Have a strong voice:

- Maintain a high public profile.
- Have a strong community engagement process.
- Have effective working relationships with policy makers, commissioners, providers and regulators.

- Contribute to capacity building and empowerment for communities, groups and individuals to advocate on their own behalf.
 - Challenge policy makers, commissioners, providers and regulators in relation to public, patient, and client participation.
- iii) Have the power through legislation of all HPSS bodies to:
- Place a duty on policy makers, commissioners, providers and regulators to engage with the PCC.
 - Influence decision making.
 - Be informed, listened to and responded to, including where appropriate, by action.

What values will the work of the PCC be based upon?

- Patient/client/community centred.
- Citizenship rather than consumerist model.
- Participation rather than consultation.
- Outcomes rather than outputs.
- Ethical, inclusive and just.
- Respect for equality, human rights and other legislation.
- Confidentiality.

What will success for the PCC look like?

- A better informed public, patient and client leading to a more appropriate use of services.
- A more responsive and flexible HPSS.
- Range of meaningful user participation models in place across the HPSS.
- Better public/user satisfaction.
- More confidence in the complaints process.
- The public taking an active role in their own health and well being.
- Increased public ownership of health and social care decisions.