

TOWARDS A PATIENT CLIENT COUNCIL

Responses to an e-Consultation
carried out by
HSSCs and CDHN



on
behalf of
the Patient Client Council
Project Team

May 2006

BACKGROUND TO THE CONSULTATION

As part of the development of the Patient Client Council (PCC), and on behalf of the DHSSPS PCC Project Team, the four Health & Social Services Councils undertook a pre-consultation initiative to scope the public's views on the role and function of the proposed body.

This involved an extensive 'best fit' exercise against an agreed stakeholder analysis. An important stakeholder was identified as the voluntary and community sector. A number of consultation methods were utilised across the four HSS Councils to engage with this sector, including face to face discussions, public meetings, a workshop at a Community Development and Health Network (CDHN) members' meeting, etc.

However, the HSS Councils recognised the important of reaching as wide a catchment as possible and through CDHN carried out an e-consultation exercise. The responses to this consultation are set out in this report.

SUMMARY OF COMMON THEMES

Overall Purpose

- General agreement with the statement (See Appendix 1)
- Support the public in becoming better informed about issues
- Better complaints system required.
- PCC needs to have powers to fulfil its functions
- Act strategically to address problems in the system
- Represent the needs of service users and complainants.

Regional Function

- Public must know of the PCC's existence
- Be a direct line from the public to the Minister
- Be accessible to patients
- Work to minimise the postcode lottery
- Adopt a community development approach to supporting communities
- Support patients in greatest need.

Local Function

- Have an easy, local point of contact
- Ensure that services are relevant to local communities' needs
- Need to engage with local community
- Press HPSS bodies to make a difference to disadvantaged communities
- Be transparent
- Clear presence and good community relationships.

Evidence of Success

- General agreement with the indicators set out (See Appendix 1)
- Need for improved, two way communication
- Support a vision for health that is prevention led.

RESPONSES

COMMUNITY RELATIONS – DERRY CITY COUNCIL

In my role within council I deal with Community Relations - ie challenging sectarianism and racism and promoting peace building.

The only comment I have in this respect is that I have heard from a range of migrant communities that they have difficulty accessing the interpretation services they are legally entitled to under section 75 of the Northern Ireland Act within health services. Sometimes this means having to wait up to a fortnight for a suitable GP appointment. This is anecdotal information but perhaps its something which could be explored.

For any other comments from Derry City Council it would be better to consult the Community Development Officer - Gerry McColgan who is the head of the community services section as this work is more within their remit than mine. Tel: 71365151

Many thanks,
Sue Divin
Community Relations Officer
Derry City Council.

Please see the following response to the four questions.

Q1 I would like to see the PCC being more pro-active to address the gaps in services generally and particularly in local areas, and ensuring that all communities are receiving equitable services regardless of where they live. I do support the overall purpose statement.

Q2 I would like the PCC to ensure that the public know of their existence and their purpose. I would like to see more challenging of policy makers and ensuring that these policies are a direct response to community needs.

Q3 I think they need to engage with local community and statutory initiatives, i.e., Neighbourhood Renewal Boards to help ensure joined up working. Where clear gaps in service delivery in local areas exist they should be there helping the local communities to lobby and challenge to bring about the necessary changes.

Q4 They should be able to ensure that services are more appropriate to local community needs, and to help make sure that communities have a proper say in how services are to be delivered.

They should also be a vehicle to put pressure on Health Services, to ensure that those areas that have always been seen as disadvantaged, that real change begins to happen and making sure that when the next Census figures are produced in 10 years time, that there are clear indications that there has been a real attempt to address disadvantage in these areas.

I do agree with the evidence of success indicators.

Annie Armstrong, 40 Glasvey Rise, Twinbrook, Dunmurry BT17 0DZ

THE NEXUS INSTITUTE

I have responded on behalf of The Nexus Institute to your consultation to be submitted by 12th May.

1. What sorts of things would you expect the PCC to do?

I agree with purpose statement. The public would have to be furnished with a lot of information to fully inform them, rather than them assuming there is the possibility of a wish list for health care. Alternatively the PCC could provide the background information on why a decision has been made. To cover all aspects of healthcare provision - not just the higher profile aspects e.g. A&E departments, maternity units.

2. What would you like to see the PCC do regionally across NI?

Being accessible to public and patients; 2-way communication methods; address equal access to services in all areas - avoiding postcode lottery.

3. What should the local function of the PCC be in your local community?

- To collate patient/client opinions and experiences of local services.
- To inform public of any plans/changes for the area - preferably at same time as professionals.
- Local, easy accessible point of contact.

4. What difference should the PCC make?

I agree with the evidence indicators. To keep all better informed - to encourage 2-way communication. To have access to forums on behalf of clients/patients where things could be addressed and changed. To keep the

public better informed and to ensure they are consulted throughout processes not after decisions have already been made.

I trust these thoughts may be of some assistance.

Jacqui Swan (Mrs)
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**EAST BELFAST HEALTHY LIVING CENTRE
COMMUNITY HEALTH INFORMATION PROJECT
Patient and Client Advocacy Council**

Response to 4 questions.

1) What sorts of things would you expect the PCC to do?

- Be connected to other Government Departments.
- Address the negative attitudes of health professionals and support staff e.g. reception staff. In terms of their role as ‘service providers’
- Do more to support and keep families together by connecting up Specialist Teams with Voluntary and Community parenting programmes to deliver more holistic approaches.
- Tackle waiting lists.
- Have more power to affect change in service services.
- Enforce commitment to availability of Doctors appointments within 48 hours.
- Challenge the practice of prescribing cheaper drugs which are not always the most appropriate or achieve well being.
- Highlight approaches to common diagnoses like ADHD.
- Sort out free prescriptions for new/ increasing/ serious diseases.
- Change policy for men, specific men’s health policy and campaign for Saturday opening of relevant health services.
- Campaign for better measures to have more Doctors available.
- Sort out the General Medical Council.

Do you agree with the overall purpose statement? Yes.

2) What would you like to see the PCC do regionally across NI?

- A direct line to Government Ministers to present concerns.
- Support community work to unearth hidden health issues.
- Highlight community concerns.

- Tackle mixed messages, missed appointments etc. by providing support to connect with patients in great need. Also tackle waste of time, energy and resources in Doctors Surgeries by insisting on transparent practices between Nurses and Pharmacists.
- Tackle declining morale of health professionals by seeing that support mechanisms are in place.
- Champion more resources for prevention rather than acute treatment.

3) What should the local function of the PCC be in your local community?

- Direct access to community networks like EBCHIP.
- Support lay health information workers.
- More transparent.
- Challenge privatisation.
- Be East Belfast focused.
- Ensure a more personal service.

4) What difference should the PCC make?

- Take personal action.
- Solicitors don't make services things better.
- Support a new vision for health which is prevention led.
- See more Doctors on the ground.
- See more coordinated support for Parenting interventions.
- Protect Health Service free at the point of entry.
- Information reaching the community based on the experience of users and reaching the most excluded.
- Make it easier for people to feedback their views on the health service (& complain). We don't have the culture of complaining and people tend to see it as a very official, legal matter rather than a way of improving service provision.

- People tell us about their negative (and sometimes very serious) problems with the health service without ever feeling they have a way to have those issues heard. Likewise positive feedback is most useful.
- Maybe a suggestion of having feedback cards in surgeries which people are encouraged to fill out. This should have a knock on effect in terms of staff feeling more monitored and accountable....maybe! Or the idea of patient advocates who are accessible when services are failing a person....
- Health service staff need to be instilled with the attitude that they are providing a service which each person is worthy of and has in their own way paid for. 'Patient's need to be seen more as clients/ service users or anything a bit less sickly & passive.....

Do you agree with the evidence of success indicators? Yes.

ANONYMOUS

1) What sorts of things would you expect the PCC to do? Do you agree with the overall purpose statement?

- To represent the needs, concerns and complaints of service users
- Ensure communication of health service policy and procedures
- Monitor policy changes and their implications & communicate same to the public

The purpose statement seems fine.

2) What would you like to see the PCC do regionally across NI?

All of the above as well as ensuring clear communication lines sub-regionally

3) What should the local function of the PCC be in your local community?

As at number one but with clear communication lines to communities, clear presence and good community partnerships

4) What difference should the PCC make? Do you agree with the evidence of success indicators?

To answer this I'd need an evidence base of what the Councils achieved and I'm sure about the answer to that. Success indicators are a start but they need to be flexible to change.

COSTA -Consultation on the new PCC - Patient Client Council

NI Health & Social Services - General

We are so far behind in NI. We have a much inferior HSSPS than England. NI needs to be brought up to at least as high a standard as England.

There needs to be massive modernisation and shake up to make services far more efficient, function more effectively eg DNA's / Appointments / utilisation of resources, effective management, accountability structures etc.

It is time to "Get Real" - HPSS must cater for the *individual* needs of people and forget about distant national targets and tick boxing exercises that do not mean anything or do anything real for the individual patient, their needs, their health or well being.

Managers are failing to manage – we have managers for everything in the HS yet we are in a constant downward tail spin.

The whole culture of the Statutory and Public Services is responsible for our dying Health Service.

Representation

There needs to be a good cross-section of grass roots community representation from rural areas and West of the Bann on the new PCC Body both regionally and locally – not just Councillors and the "usual suspects."

We need at least 7 regional outreach offices with double or triple the provision that exists per office at present to even begin to be of any use to the public.

People do not know what the existing Health Councils do nor do they see any benefit whatsoever. We do not know what they have done for us. The public perception, and indeed the reality, is that they are little more than quango talking shops.

The current and proposed “Advisory role” is barely worth having – CAB or other organisations can act much better, effectively, and as a proper representative for patients / clients with complaints or issues.

Powers / Effectiveness

- What is in reality different from before?
- What new powers will there be?
- How will this be better?
- What actions can be taken when necessary?

I am very concerned that all I see is just more of the same which is of practically no use in even beginning to tackle the huge problems in our Health & Social Services. I do not see anything more in terms of powers or remit being given to the PCC.

All the items listed in the PCC’s remit, what it will deliver, and its proposed services sound very noble and no one would disagree that they are good to have – but how they can be delivered and translated to reality in this structure? With an organisation lacking in virtually any powers and which will not nearly be well enough resourced! no one knows! I certainly do not see this as remotely possible.

We need a Watch Dog with big sharp teeth that is not afraid to take a big bite!

There needs to be more capacity building for groups and individuals in making a stand with regard to complaints, user involvement, articulating the

citizen's voice, improving services, lobbying and campaigning etc – can we seriously expect any statutory agency to do this effectively? I certainly don't and just imagine if the masses were able to effect change for themselves! The powers that be cannot and will not allow this to happen and the PCC will deliver for them!

The Community and Voluntary Sector can help the PCC and statutory services to deliver – and indeed they often actually depend on these sectors – to help deliver their services, reach the grass roots communities, achieve their targets and outcomes. However, volunteers and community organisations need to be properly resourced to attend meetings, consultations, forums, carry out pieces of work etc. This needs to be done through a variety of means depending on the people / organisations that are doing the work eg voluntary expenses / service level agreements, contracts, grants and match / part core funding.

PCC needs to work towards a major culture change to promote: good practice, genuine involvement, less nanny state, promotion of rights etc and adherence to legislation.

In the past the previous (4) Health & Social Services Councils have had no powers as a Watchdog or anything else of any use for that matter. I think we need an Ombudsman or Commissioner to deal with HPSSPS alone and with the powers and remit that the current NI Commissioner has.

I would like to see the new PCC as having real teeth and powers to pull all Health organisations that come under their remit to task for their failings, to ensure compliance to the rights of citizens, to ensure health and safety, and cut out fraud, officiousness, discrimination, victimisation and sub-standard ness.

I would like to see fines and actual punitive measures brought in for organisations who make major breaches / errors, mal-administration, injure the feelings of public or do things wrongly – it is time we had a system that reinforces proper right doing and punishes wrong doing – at present the system reinforces liars, cover-ups, fraud, wrong doing. They simply know that they can get away with almost anything – especially Primary Care Services with GPs and GP Surgeries being among the worst offenders.

Under the current Complaints System there is absolutely no mechanism for the issues behind the complaint to be addressed – it is no one's remit!!! All the issues raised by complainants simply get swept under the carpet or buried and in fact it is the complainant that gets the raw deal while the organisation or person complained about gets off absolutely Scott Free!

I am concerned that the new PCC will be just more of the same and will not have the powers and resources to do what needs to be done and in the way that it needs to be done in order to improve services.

User Involvement

In the past, User Involvement has been largely talk, a high fillooting management-speak fob-off and little more. If they want to know what we think, they need to ask people while they deliver the services on a day-to-day basis, and then actually act on our comments and suggestions there and then – that is what management of services is supposed to be and what managers are there and paid very well to do.

Also if they were serious about our views they would listen and act more on complaints – complaints and complainants are swallowed up in a big black hole.

Most issues and serious shortcomings in our NHS are not to do with money or resources at all – they come down to in fact simple total

disrespect of patients and their rights as human beings, non adherence to often the most essential and basic legislation and guidance, incompetence on a grand scale, victimisation, systems that are vastly outdated, simply not working, or do not function correctly.

Complaints System / Process

The Current complaints system must be completely scrapped and a proper system brought in its place. The complaints system does not actually deal with the complaints as presented and it certainly does not deal with the issues raised nor does it in any way punish the offenders. Nothing can therefore change or improve through the complaints system which is very slow and totally farcical. The whole system is designed to cover up and protect the Health Service and attack complainants.

Currently legitimate complainants can at times be viciously singled-out, black balled, slandered, defamed, victimised and discriminated against particularly by the Primary Care Service providers, GPs / Practices in particular, patients can even find their rightful access to services impeded for making a legitimate complaint.

PCC should provide much more support to individuals, activists and groups who are pressing for changes, campaigning, or simply ensuring justice, improvements, and remedial actions.

If anyone has a legitimate complaint the system simply works together to cover it up and provide no satisfaction for the victim – you might be lucky if you get a half decent apology for something, they deny or lie about most things, bend the truth, or just provide a bland report or statement back but nothing ever changes. No one will ever be held to account unless the victim goes out of their way to do it for themselves!

The HPSS Complaints system is very complicated for the ordinary person and it simply does not have the remit or powers to actually address complaints or to do anything, also there are no powers within it to take disciplinary action or any other action against a staff member or organisation and it is deliberately set up this way. You can seek accountability for yourself – the system will not do it and cannot do it!

The entire HPSS Complaints system is a shambles, it simply does not work and it is designed and operated to in order to ensure this. It ensures that complainants have no rights and certainly far fewer rights than the body, staff or people that are complained against.

All complaints should be published in order to name and shame – that is what must be done in order to change things.

It is a fact that GPs and GP surgeries in particular can sometimes lodge patient complaints, and also can write about complaints, in patient medical files! How many members of the general public know about this? and further, health professionals can abuse complainant's medical files to blacken their name.

HPSS staff can write defamatory, false and slanderous material in your medical files but you cannot have it removed – however you too have a right to opinion, free speech and to have your concerns appended to the file but you have to fight hard for this justice and certainly no one is going to tell you can do this or in any way help you to do this! The citizen can fight back but they have to fight very long and hard and kick and scream very loud to do so!

The HPSS complaints system is designed to disable people from taking legal action where this course of action is applicable and vice versa – you cannot seek legal advice, or have legal representation (even though the

body concerned will, and they may have done training to deal with this). You cannot allude to, nor make any legitimate threat, of legal action. The complaints system is very slow and will also waste your time deliberately so that time limitations on certain actions / proceedings expire.

The HPSS complaints system keeps you in the dark and the health organisation complained about will be pals with one another – also they will leak out information between one another!

GPs and GP Practices must be reined in much more and even have fines imposed, conditions attached to their contracts on renewal, or GMS Contract terminated more easily when things go wrong – if they don't respect patients under the NHS then they can just go private altogether and the HPSSPS should impose this more harshly and stop pandering to Doctors – Doctors might act like the mafia but believe me they are not, and when they come under a heavy challenge there is little or nothing they can do about it – every citizen can do this!

Active Citizenship

Citizens need more power and it should be the role of the PCC to do this at all levels. They need to encourage genuine User Participation, real accountability, rein in Primary Care Services especially GPs and GP Surgeries, effective complaints system, improve all our HPSS and Name and Shame – this is essential if anything is ever to improve.

The General Public must complain more, fight much harder, and also use the relevant rights and legislation too.

We must stop reinforcing the bad things in our Public Services and fight for better services and better personal treatment – that is why things are in the bad state that they are.

We get what we deserve in life, if we let ourselves get walked over we will always be walked over. It is up to each individual to do their bit, take responsibility, and do their public duty!

The individual private citizen has much more powers and can take strong action against any public service or body. Any individual will have more powers than the PCC or the current HSSCs have – people think they are powerless, they are not, and it is high time citizens acted up to their full potential.

NI COMMISSIONER FOR CHILDREN AND YOUNG PEOPLE (NICCY)

Thank you for forwarding the e-consultation on Patient and Client Advocacy in the new Health and Personal Social Services Councils for the attention of the Northern Ireland Commissioner for Children and Young People (NICCY).

The Office of the Northern Ireland Commissioner for Children and Young People (NICCY) was established in November, 2003, with the principal aim of safeguarding and promoting the rights and best interests of children and young people in Northern Ireland. One of the functions of NICCY under The Commissioner for Children and Young People (Northern Ireland) Order 2003 is to 'keep under review the adequacy and effectiveness of services provided for children and young persons by relevant authorities'¹.

NICCY would like to make the following brief comments in relation to the questions posed in the consultation:

Q.1 Purpose Statement

NICCY fully supports the overall purpose statement and would like to see particular reference to advocacy support for children and young people. In addition, NICCY would encourage the PCC to gather regional information on child/young person related issues. This information needs to be analysed and used to lobby for changes to both policy and practice.

Q.2 At a regional level

NICCY would like to see standards for the delivery of Health & Social Care Services which meets the needs of children and young people in line with the provisions of the United Nations Convention on the Rights of the Child (UNCRC).

¹ The Commissioner for Children and Young People (Northern Ireland) Order, 2003, Article 7(3)

Q.3 Local function

It is NICCY's view that one of the local functions of the PCC should be to obtain the views locally of children and young people and use these to inform policy and practice change on a regional basis.

Q.4 Making a difference

As part of its work, the PCC should prioritise the needs of children and young people through meaningful and direct consultation with them, including those from vulnerable and marginalised groups.

We hope you find these comments helpful. If you have any further queries, please do not hesitate to contact me.



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E-Consultation

CDHN E-Consultation on behalf of the Health & Social Services Councils...

Please return your comments by Friday 12th May.

Patient and Client Advocacy in the new Health and Personal Social Services System

Who's speaking for you?

The **Health & Social Services Councils** would like ***your*** help to ensure that in the structural changes made by the Review of Public Administration, there will be a strong voice to advocate for the public, communities, patients and clients.

They will use the results of this e-consultation to impact on the development of the Patient Client Council (PCC), the body that will eventually replace the HSS Councils.

For more information, read on...

Background

There are four Health and Social Services Councils

latest news

E-Consultation [[read more](#)]

CDHN Networking in Western Board Area [[read more](#)]

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(HSSCs) in Northern Ireland – Northern (based in Ballymena), Southern (Lurgan), Eastern (Central Belfast) and Western (Omagh).

the site.

[How do I become a member?](#)

The HSSCs represent the voice of patients in the Health & Personal Social Services (HPSS) in Northern Ireland. The HSSCs were set up in 1991 to represent the views and opinions of the public. The HSSCs are independent from those who commission, manage and provide health and social care.

Their main functions are to:

- Act on your behalf to improve the range, type and quantity of services
- Continually monitor the quality of local services
- Represent public opinion about changes to existing services and the introduction of new services
- Find out what people think about services
- Provide you with sources of information on health and social care issues
- Offer advice and help if you wish to complain about a service.

In November last year, the Minister of Health announced the creation of the **Patient Client Council (PCC)** for Northern Ireland. He described the PCC as a “POWERFUL SINGLE health and social care users body.”

The PCC will replace the four HSSCs by April 2008. Over the next few months, the HSSCs want to hear the views of patients, service users and communities.

What would you like the Patient Client Council to do for you?

Please look at the following information on the New PCC and answer the 4 questions, this is your opportunity to have your say!

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.

Success for the PCC will result in:

- 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.

What the Health Councils would like from you?

To help the Councils make sure that the PCC meets the needs of local communities, they need to make sure that they get the basics right.

Please help them to do this by taking a few moments to give your views on the **following 4 questions.**

- 1) What sorts of things would you expect the PCC to do? Do you agree with the overall purpose statement?**

- 2) What would you like to see the PCC do regionally across NI?
- 3) What should the local function of the PCC be in your local community?
- 4) What difference should the PCC make? Do you agree with the evidence of success indicators?

Please forward your answers to kathymartin@cdhn.org or alternatively you can post or fax replies to Kathy Martin, CDHN, 30a Mill Street, Newry, BT34 1EY by **Friday 12th May**.

Thank you for your views and assistance with this consultation.

The results of this e-consultation will be fed into the DHSSPS PCC Project Team by mid-May and there will be a workshop exploring the issue at CDHN's Networking event in **Derry** on Thursday **1st June**.

You can obtain feedback on the survey on CDHN and the HSSC's websites and through 'Health Bytes'.

Related Links

<http://>
<http://>

LIST OF RESPONDENTS

Community Relations – Derry City Council

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The NEXUS Institute

East Belfast Healthy Living Centre

Anonymous

COSTA

NICCY