Patient and Client Council
Your voice in health and social care

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Minister Jim Wells, MLA
Department of Health, Social Services
and Public Safety
Castle Buildings
Stormont Estate
Belfast BT4 3SQ

Dear Minister Wells

PCC response to Donaldson Report - The Right Time, The Right Place

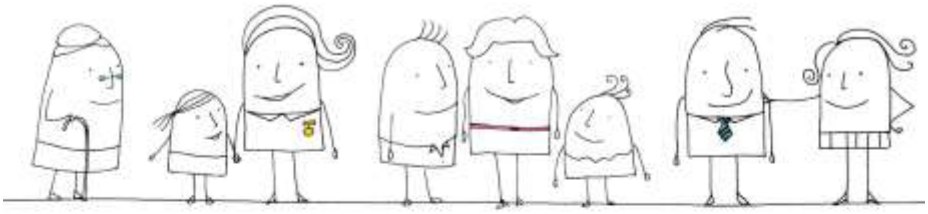
You made an oral statement to the Assembly on 27 January 2015, on Quality of Care in Northern Ireland and the publishing of the Donaldson Report, The Right Time, The Right Place. At that time you invited comments and views from the HSC Trusts and other stakeholders and I am pleased to submit the response from the Patient and Client Council (PCC) for your consideration.

This response builds on our initial thoughts which we set out in our letter to you on the 17 February. In that letter we outlined our intention to invite the public across Northern Ireland to comment on the Donaldson report. Those comments will inform the PCC response to the public consultation, which we will submit by 22 May 2015.

This response reflects the discussion we have had within the PCC Board, which has been informed by our Guiding Principles (see Annex 1), the evidence we have gathered from service users over the last six years as well as the experience gained from supporting people through the HSC complaints process. We have also had valuable input from the discussions with the Board, Local Advisory Committees, the Patient and Client Council Membership Scheme and public response.

As stated in our letter of 17 February, the PCC welcomes much of the Donaldson report, including the clarity of its delivery.

Recommendation 1: Coming together for world-class care
We recommend that all political parties and the public accept in advance the recommendations of an impartial international panel of experts who should be commissioned to deliver to the Northern Ireland population the configuration of health and social care services commensurate with ensuring world-class standards of care.



Response: 68% of the 136 members of the public who responded to the PCC on the Donaldson report either 'agreed or broadly agreed' with the Donaldson recommendations. They believe HSC has to change and are still supportive of the Transforming Your Care (TYC) journey but impatient at the slowness of implementation.

Whether or not an international panel of experts get engaged, the PCC welcomes evidence based change. Such evidence must be shared with the public to ensure that they are involved in the change and understand the need for it. These changes must be implemented urgently as patients' lives are at risk.

Recommendation 2: Strengthened commissioning

We recommend that the commissioning system in Northern Ireland should be redesigned to make it simpler and more capable of reshaping services for the future. A choice must be made to adopt a more sophisticated tariff system, or to change the funding flow model altogether.

Response: How commissioning is achieved is not the remit of the PCC. We do know that the public want to know what their options for services are, not necessarily how that decision has been made. People want to know what they can expect from their local Trusts and for regional services.

Commissioning must meet needs and should clearly elucidate what the public can expect and what their options are if Trust capacity is limited, including options within the community, voluntary and independent sector. There must also be clear lines of accountability in the commissioning process.

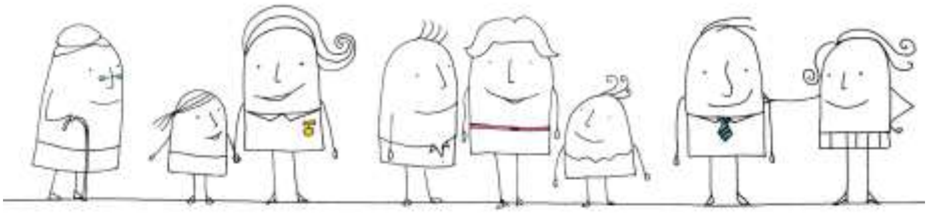
Patients report to us that they are given wrong information which mismanages their expectations. They want clarity and transparency. Some performance management data are collected but little apparent corrective action taken to improve services. This is unacceptable.

Commissioning and performance management needs to be based on true involvement if service users and carers and must include transparent performance management. There are good examples from our work where service users have improved the commissioning process and this should be built upon.

- **Rare diseases**
- **Older carers and future planning**
- **Chronic pain**

Recommendation 3: Transforming Your Care (TYC) – action not words

We recommend that a new costed, timetabled implementation plan for Transforming Your Care should be produced quickly. We further recommend that two projects with the potential to reduce the demand on hospital beds should be launched immediately: the first, to create a greatly expanded role for pharmacists; the second, to expand the role of paramedics in pre-hospital care. Good work has already taken place in these areas and more is planned, but both offer substantial untapped potential, particularly if front-line creativity can be harnessed. We hope that the initiatives would have high-level leadership to ensure that all elements of the system play their part.



Response: The PCC agrees that TYC needs to be implemented. The public were essentially in support of TYC, recognising the need for change, but frustration has set in as a result of the time being taken to implement.

There needs to be renewed momentum around the implementation of TYC and evaluation of the service change that has occurred. This needs to be shared with the public as people need to see improvement. The public recognises that implementation will be costly, but that TYC could help alleviate some of the pressures placed on hospitals and frontline staff. Additionally carers in particular are concerned that without proper resourcing and implementation of TYC, the burden on carers will continue to increase.

Recommendation 4: Self-management of chronic disease

We recommend that a programme should be established to give people with long-term illnesses the skills to manage their own conditions. The programme should be properly organised with a small full-time coordinating staff. It should develop metrics to ensure that quality, outcomes and experience are properly monitored. It should be piloted in one disease area to begin with. It should be overseen by the Long Term Conditions Alliance.

Response: Existing self-management programmes tend to be service user/patient peer led programmes/groups with staff support. Self-management needs support to ensure people are kept safe and enjoy a good quality of life. This is commonly from third sector organisations.

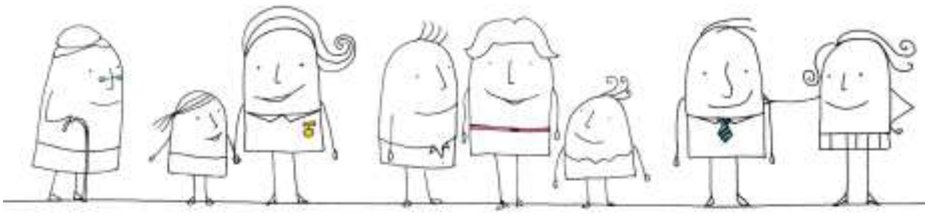
People have told the PCC that they want self-management which is appropriately supported and therefore this needs adequate resources both clinical and financial, including access to clinical advice.

Recommendation 5: Better regulation

We recommend that the regulatory function is more fully developed on the healthcare side of services in Northern Ireland. Routine inspections, some unannounced, should take place focusing on the areas of patient safety, clinical effectiveness, patient experience, clinical governance arrangements, and leadership. We suggest that extending the role of the Regulation and Quality Improvement Authority is tested against the option of outsourcing this function (for example, to Healthcare Improvement Scotland, the Scottish regulator). The latter option would take account of the relatively small size of Northern Ireland and bring in good opportunities for benchmarking. We further recommend that the Regulation and Quality Improvement Authority should review the current policy on whistleblowing and provide advice to the Minister.

Response: The introduction of a programme of unannounced inspections is welcomed. It is our belief that regulation will be strengthened by the incorporation of a stronger patient, family and carer voice, better use of patient experience standards and regulation which covers domiciliary and social care services. Regulation should be a tool to reassure the public that services are safe and thus must cover public and private sector services.

The regulator has an obligation to assure the public that services are safe, particularly where they are being reshaped. The public must know that there is no diminution of quality or safety.



Recommendation 6: Making incident reports really count

We recommend that the system of Serious Adverse Incident and Adverse Incident reporting should be retained with modifications:

Response: PCC would welcome any recommendation that improves their ability to get timely closure and resolution for people who have a complaint or suffered harm in the system. However, at this time the PCC primarily provides support and advocacy to people through the journey of an SAI and this is a role that people want and need. We are therefore keen that any greater powers to investigate or understand does not undermine this advocacy role.

The PCC has previously suggested that the work we have commenced on an online real time user feedback system would help strengthen the voice of service users and once established, it is conceivable that incident reporting could be added as a feature of this system.

The PCC held a Patient Safety conference in October 2014. At that conference the audience overwhelmingly supported the introduction of a duty of candour. On this basis and other evidence gathered through our complaints services, the PCC support this recommendation.

Recommendation 7: A beacon of excellence in patient safety

We recommend the establishment of a Northern Ireland Institute for Patient Safety.

Response: The PCC and the public would welcome enhanced accountability for patient safety and a transparent, user friendly mechanism that can reassure patients that service change will result in services that are just as good or better. Safety mechanisms should be built into the system, but further complexity is unhelpful.

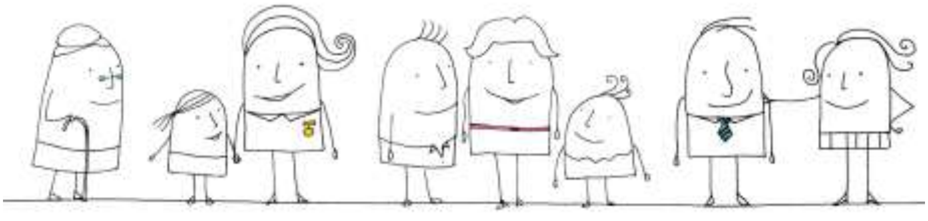
Recommendation 8: System-wide data and goals

We recommend the establishment of a small number of systems metrics that can be aggregated and disaggregated from the regional level down to individual service level for the Northern Ireland health and social care system. The measures should be those used in validated programmes in North America (where there is a much longer tradition of doing this) so that regular benchmarking can take place. We further recommend that a clinical leadership academy is established in Northern Ireland and that all clinical staff pass through it.

Response: Processes for gathering and using better system wide data and goals are essential as outlined in the document, however, we would insist that qualitative as well as quantitative data be gathered. Data gathered should be useful, capable of informing service improvements and should include clinical data as well as patient experience information. Data collected and used to inform the system should similarly be used to inform public engagement and involvement.

Recommendation 9: Moving to the forefront of new technology

We recommend that a small Technology Hub is established to identify the best technological innovations that are enhancing the quality and safety of care around the world and to make proposals for adoption in Northern Ireland. It is important that this idea is developed carefully. The Technology Hub should not deal primarily with hardware and



software companies that are selling products. The emphasis should be on identifying technologies that are in established use, delivering proven benefits, and are highly valued by management and clinical staff in the organisations concerned. They should be replicable at Northern Ireland-scale. The overall aim of this recommendation is to put the Northern Ireland health and social care system in a position where it has the best technology and innovation from all corners of the world and is recognised as the most advanced in Europe.

Response: There are a number of PCC reports that refer to the improved use of and need for wider use of modern technology in health care. For example, 'Views of Telemonitoring Services' report, April 2014, demonstrated positive experience by those who took part in the small scale study. Other reports, Access to GP Services (May 2014) and Young Peoples Priorities (May 2012), recommended increased use of technology to improve communication with healthcare providers. PCC welcomes intelligent use of new technology to improve patient experience whether better/faster diagnostics, decreased need for travel and hospital admission, or simply easier access to appointments at local or regional service centers.

Recommendation 10: A much stronger patient voice

We recommend a number of measures to strengthen the patient voice:

► more independence should be introduced into the complaints process; whilst all efforts should be made to resolve a complaint locally, patients or their families should be able to refer their complaint to an independent service. This would look again at the substance of the complaint, and use its good offices to bring the parties together to seek resolution. The Ombudsman would be the third stage and it is hoped that changes to legislation would allow his reports to be made public;

► the board of the PCC should be reconstituted to include a higher proportion of current or former patients or clients of the Northern Ireland health and social care system;

► the PCC should have a revised constitution making it more independent;

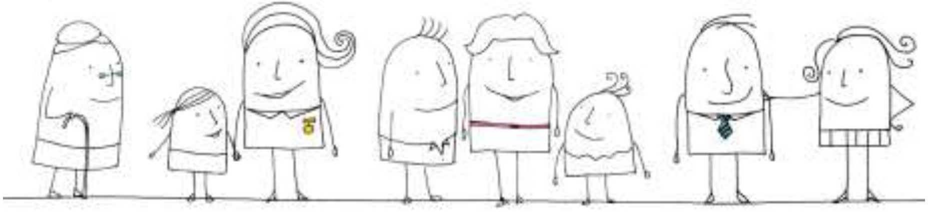
► one of the validated patient experience surveys used by the Centers for Medicare and Medicaid Services in the USA (with minor modification to the Northern Ireland context) to rate hospitals and allocate resources should be carried out annually in Northern Ireland; the resulting data should be used to improve services, and assess progress. Finally and importantly, the survey results should be used in the funding formula for resource allocation to organisations and as part of the remuneration of staff (the mechanisms to be devised and piloted by the Department of Health, Social Services, and Public Safety).

Response: This is so important to PCC work and inherent in our statutory functions, that it is necessary to respond in three parts:

- **independence in the complaints process**
- **independence of PCC and Board composition**
- **patient experience surveys.**

The PCC has four statutory functions in respect of the provision of health and social care in Northern Ireland. They are to:

- **represent the interests of the public;**
- **promote involvement of the public;**
- **provide assistance (by way of representation or otherwise) to individuals making or intending to make a complaint relating to health and social care;**
- **promote the provision of advice and information to the public by the HSC about the design, commissioning and delivery of health and social care services.**



a. Independence in complaints

The experience of dealing with 2500 complaints in the last two years leads the PCC to recommend a transparent, independent root and branch review of the complaints process. 10% of complainants come to the PCC for help because they find the current system unacceptable. This is likely to be the tip of the iceberg and we have work in our business plan to learn more about the public view of the current system. However, evidence to date would indicate that necessary changes address issues such as:

- the current system is focused on transactions rather than patient needs;
- speed of response rather than quality of response is a driver;
- timeliness and quality of response should be related to the severity and nature of the complaint;
- where second opinions are deemed appropriate, they should be truly independent;
- HSC organisations should be required to report what steps they have taken to improve services as a result of complaints received and evidence the improvement.

Currently getting the best outcomes for complainants depends on the tenacity of the PCC Complaints Support staff and the willingness of the HSC Trusts to help people to get a resolution to their complaints. If the PCC is to be more effective in getting satisfactory outcomes for people, then some more formal mechanism is needed that would require Trusts to be more responsive. One way to achieve this would be through a Memorandum of Understanding (MOU) which outlines in advance the commitment of all parties to come to a resolution which gives complainants closure to their concern. Such an MOU would supplement, but does not replace the statutory framework and affirms the independence of the PCC in its roles and responsibilities. Additional resources would be required if the PCC role in complaints was to increase as a result of the implementation of this recommendation or through a failure to achieve substantial improvements in the current HSC Complaints handling processes.

In whatever changes take place the PCC would not wish to see its advocacy role diminished by becoming part of any investigative process. The PCC provides an unequivocal voice for people in seeking to have their concerns addressed at an individual, community or regional level.

b. Independence of the PCC and Board Composition

We agree with Sir Liam that the independence of the PCC is of critical importance and will work to ensure that is maximised. The PCC values and seeks to safeguard its independence as outlined in statute. Nevertheless we are aware of the perceived lack of independence because of the architecture of the HSC system in Northern Ireland. While we will continue to research the views of the patient and service user and speak it into the system in an unbridled way there may be some further steps that could be taken to ensure the voice of the patient is heard more effectively by the system.

Such mechanisms could include:

i. **An MOU with the Department, HSCB/PHA and Trusts that would outline rules of engagement for both parties, and supplement the powers already in legislation. Namely requirements to**
- **consult the PCC and engage early in full, frank and open dialogue on emerging issues of patient concern;**
- **collaborate on furthering patient interests, using resources more effectively and avoiding duplication;**
- **openness - sharing information early that equips both parties to act in the best interests of patients and where appropriate respecting the confidentiality of such data;**
- **willingness to enhance resources of the PCC in order to optimise the patient voice and the capacity of PCC to fulfil its statutory functions.**

ii. **A power to issue a super complaint, where there is a system wide failure that is not being addressed in the patient/service user interest.**

iii. **Enhanced resources to allow PCC to follow through and ensure change takes place as a result of the patient voice. Currently the organisational capacity is too limited. We have set out objectives within current resources but could do much more, within our current legislative framework, had we the resource capacity to do so.**

iv. **A requirement to issue an Annual Report to the Minister that outlines the concerns of the patient/service user and that puts a stake in the ground on an annual basis. This would be based on our work throughout the year and would anticipate future challenges for the service.**

There are specific recommendations about the independence and composition of the PCC Board in the Report. The PCC has been considering the composition of the Board before the Donaldson report was published. The Board is very large, and we consider that a smaller number of members with the right skills can provide adequate governance for the organisation and fulfill our statutory responsibilities in this regard. This work is underway and we will be submitting these proposals to the DHSSPSNI in due course.

The intent of the additional recommendation from Donaldson that more current or former service users should be on the Board is one that the PCC are largely in agreement with. However, that role should be in advising the Board and grounding us as we do our work on behalf of the public. We would like to consider this further and discuss it with service users and expert patients, many of whom already work with us. Some form of 'Advisory Board' or 'Panel of Active Patients' up-skilled as necessary to take a broader user perspective might work well. We consider that the role of service users in the governance of the organisation requires further consideration.

We would welcome the opportunity for further discussion to ensure the Board, and indeed all of the work of the PCC, is representative of people across Northern Ireland. This will include consideration of our Equality duties, promoting inclusion, diversity and the participation of people with a disability in public life.

The PCC already has mechanisms in place to capture the public voice including:

- **15,000 strong Membership Scheme;**
- **targeted road shows;**
- **information obtained through our complaints process and helpline;**
- **Ongoing PPI work including the evidence that has been gathered through Patient and Client Council research over the last 6 years incorporating the views of 34000 respondents.**

Nevertheless the PCC would advocate an increased partnership approach with organisations and bodies with a health and social care agenda, specifically;

- **expanded engagement with the community and voluntary sector on specific areas of need/care;**
- **exploring the potential of the new Super-Councils community planning structures to ensure the patient voice is heard.**

c) Patient experience feedback and surveys

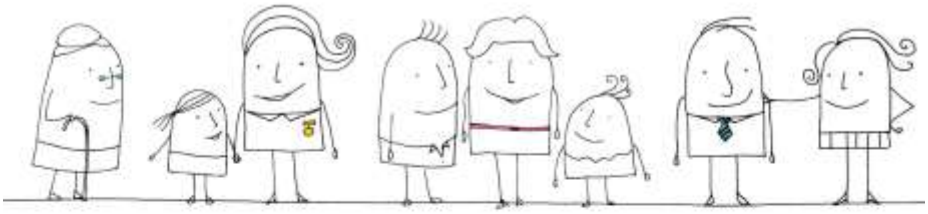
The Real Time Patient Feedback System business case has already been submitted to the Department and we would welcome an early decision so that this can be put into action. It has many advantages as outlined in the business case including the potential to gather positive as well as negative stories. Properly utilised it is a tool to drive service improvement. It is supported by the CEO's of the Trusts and the HSCB. It would seem unnecessary to reinvent this wheel.

The PCC acknowledges the seriousness of the situation as outlined in the report and the urgency of making the required changes. The plethora of issues, reports and conclusions without concomitant action is eroding public confidence. This confidence needs to be restored.

As an organisation representing service users and the wider public we again want to emphasise the importance of meaningful public engagement and genuine consultation about any change to services. This can only happen when evidence about the available options is made available to the public in order to inform the debates.

Yours sincerely

Maureen Edmondson
Chair



Annex 1

Patient and Client Council
Your voice in health and social care

January 2015

Patient and Client Council Guiding Principles

The Patient and Client Council Board accepts that difficult decisions are going to have to be taken about services in the future as savings have to be made. However, whilst acknowledging the reality of budgetary pressures facing health and social care organisations, the Patient and Client Council would want assurance for the public that there will be genuine engagement and consultation about any proposed changes to services.

The following principles will act as a guide and prioritisation framework for all Patient and Client Council activities. The principles will underpin communication and engagement with all stakeholders, including those within the Health and Social Care network, locally elected representatives and the media.

The principles are subject to review as required.

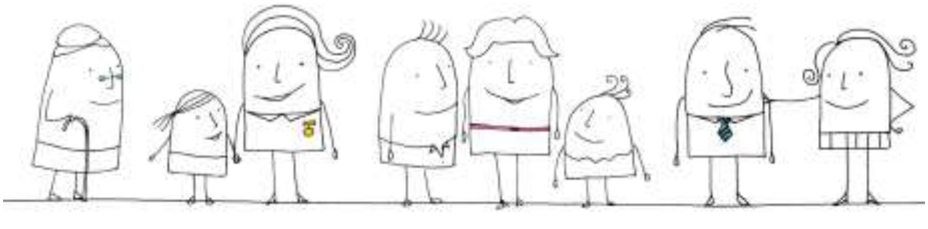
- **Safe Services**
  Changes to health and social care services must not result in a deterioration of patient safety. Health and Social Care organisations must provide evidential assurances that services are safe.

- **Access to care**
  Patients should have access to health and social care services across Northern Ireland in such a way as to take account of safety, equity and clinical need.

- **Fairness in balance of needs**
  Health and Social Care will have to take a balanced and fair approach to the services provided and changes made. Access to alternative equivalent services is necessary and clinical evidence may be needed in support of service change and that this new service will provide better health and social care outcomes for people and meet or exceed the standards for patient experience.

- **Communication**
  Health and Social Care organisations should put in place an effective communication strategy for each service change, to inform patients and carers of changes before during and after any service development and guide them through the changes.

- **Engagement**
  Health and Social Care organisations should ensure people are engaged on options for services and informed and supported in making the transition to alternate services. Service users and carers should be involved in any decision making about the individual care they receive. Changes to services should be effectively led and managed by health and social care organisations, in conjunction with service users. Consultation is only part of engagement and where consultations are carried out HSC organisations should ensure that their consultations are meaningful and robust.



- **Strategic direction in decision making**
  Health and Social Care organisations have already set out a clear strategy for the development and provision of services in Northern Ireland and within their area of responsibility. The delivery of this strategy should be clearly reflected and communicated in any decision making process. Changes in strategy should be clearly communicated to service users and carers.

- **Recognise some people have had no service**
  Service development should be inclusive and ensure that hitherto hard to reach groups are acknowledged and accommodated.

- **Recognise our most vulnerable members of society**
  Where changes to services involve the most vulnerable members of society then all of the above need special attention.

- **Focus on health issues**
  While recognizing that changes may affect staff, the Patient and Client Council will focus its work and energies on patient and carer needs and issues.

- **Patient and Service User views**
  The Patient and Client Council will continue to accurately reflect the views of the people it speaks to on health and social care issues. The PCC will expect HSC providers to clearly elaborate and evidence where these views are inconsistent with the best clinical and social outcomes for services users and engage accordingly.