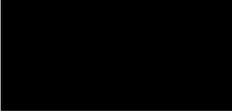


28<sup>th</sup> October 2013

Mr John O'Hara QC  
The Inquiry into Hyponatraemia-related  
Deaths  
Arthur House  
41 Arthur Street  
Belfast BT1 4GB

Tel:   
Local office :   
Fax : 

Web: <http://www.patientclientcouncil.hscni.net/>

Dear Mr O'Hara

## The Inquiry into Hyponatraemia-related Deaths

Thank you for the opportunity to provide information on the work of the Patient and Client Council. In your letter you have asked specific questions which I have responded to in the order in which they are posed. In addition I have enclosed a copy of our second Complaints report, for 2012/2013 and our Complaints Support Service report for the period April to September 2013. I hope that when taken together these will give you the information you require. All the information I have provided in this response is based on evidence that the Patient and Client Council has gathered through its work over the last four years. Our Board has agreed that the Patient and Client Council will only respond on issues for which we have clear evidence.

### **1. How does the Patient and Client Council think that the complaint system in relation to hospital services is now working, especially in relation to the extent to which complainants are involved in the investigation of complaints?**

Our evidence would indicate that people who complain to health and social care play no role in the investigation of their complaints. Occasionally Trusts may contact a complainant for clarification on the complaint but the investigation is carried out independently of the complainant.

### **2. How do you think the complaints system can be improved?**

Suggestions from people who have accessed support from the Patient and Client Council's Complaints Support Service on how the system could be improved include:

- a. Being more easily accessible;
- b. Minimising its complexity;
- c. Greater openness on the part of health and social care staff and the avoidance of defensive attitudes;
- d. Setting out what people can expect in the process more clearly;

- e. Swifter investigation of, and response to, complaints submitted;
- f. Health and social care organisations openly admitting where mistakes have been made;
- g. A greater willingness on the part of service providers to support and guide the complainant through the Complaints Process;
- h. Health and social care organisations demonstrating that changes have been made in response to complaints;
- i. Health and social care organisations informing complainants of advocacy and support services available to them, including the Patient and Client Council;
- j. Health and social care staff seeing complaints as a valuable source of service user feedback;
- k. Health and social care organisations providing an early apology and acknowledgement of the distress experienced by complainants, notwithstanding the actual outcome of the complaint itself.

**3. How well you think that medical and nursing staff communicate with children and their parents and listen to them when treating children?**

Between 1st April 2012 and 30th September 2013 the Patient and Client Council supported 38 parents of children of varying ages who wished to make a complaint. Staff attitude was a factor in 14 of these complaints and by far the largest single factor giving rise to complaints overall. Health and social care organisations and their staff must improve on their performance in this key area, particularly when engaging with parents of children. In the most recent Patient and Client Council Complaints Support Service update to October 2013, 20% of the 862 new complaints received were about communication and 16% about attitude and behaviour.

**4. Whether you think that the investigations of serious adverse incidents have improved in recent years and if so how they have improved?**

The Patient and Client Council has no role in the investigation of serious adverse incidents and cannot provide comment on its performance.

**5. How do you think the investigation of serious adverse incidents might be improved upon?**

The Patient and Client Council has had no involvement in serious adverse incident investigations and can provide no input as to how their investigation can be improved. However patients have indicated to us that they would like to see a more open and transparent process in the reporting of serious adverse incidents.

**6. How open do you think doctors, nurses and managers now are in discussing events which have occurred, accepting criticism and admitting failures?**

People have reported to us that there is reluctance among health and social care staff to discuss events which have occurred, accept criticism and admit failures. In addition people would say that once a written complaint is submitted they receive correspondence from the Trust complaints staff and rarely, if ever, actually have any communication from clinical staff involved in the incident. People find this very frustrating as those who know in detail about what happened are rarely part of any discussion with the complainant. Where this shared dialogue does take place outcomes are better.

**7. How well do you think the Patient and Client Council and its representatives are succeeding in their goal of providing a powerful independent voice?**

Since 2009 the Patient and Client Council has spoken to over 20,000 people across Northern Ireland. In those engagements we have listened to their views and concerns about their health and social care services. The Patient and Client Council derives its independence from the expressed views of these people.

Our campaign on engaging with people and raising their awareness of the organisation has been based on meeting people where they live and work. This grass roots approach is based on feedback we sought in our first year, where people told us they would prefer a face to face engagement rather than a series of leaflets and booklets. We have met 1,000's of people at public events such as the Balmoral Show and the Mela Festival and in shopping centres across Northern Ireland. We have also visited people in their workplace with employers such as Bombardier Aerospace, the Wright Group in Ballymena and the O'Kane Group. In total our staff attended 434 events from 1<sup>st</sup> April 2012 to the 31<sup>st</sup> March 2013.

A unique development in the Patient and Client Council has been the establishment of our Membership Scheme. Over 12,000 people have joined the scheme which allows them to be kept informed about health and social care issues and most importantly share their views to inform the work of the Council.

All the views we have collected have been used to inform a series of reports on issues including;

- a. Urgent Care Services, based on the views of 4000 respondents;
- b. Domiciliary Care, based on the views of 1500 respondents;
- c. Pain Management, based on the views of 2700 respondents;
- d. Young Carers, based on the views of 72 young carers; and
- e. People's Priorities for Transforming Your Care, based on the views of 13,000 people.

Increasingly the reports from the Patient and Client Council are being used to inform policy and service planning and delivery. This influence is reflected in the response the Council receives from health and social care organisations to its proposals. These changes take time but the Patient and Client Council follows up to see if changes are being delivered. In addition the Council has:

- Organised a series of roadshows to allow decision makers in health and social care to meet directly with the public and answer questions on the subject which interests or concerns them. Panels have included representatives from the Health and Social Care Board, Health and Social Care Trusts and the DHSSPSNI, including the Permanent Secretary;
- Secured agreement from the Public Health Agency and the Regional Health and Social Care Board to provide a much needed advice and information service for Northern Ireland; and
- Secured agreement on the development of a real time feedback system for people to share their experiences, both positive and negative, with service providers. This system will also require organisations to respond to comments and demonstrate where they have made changes to improve services. If used intelligently it will reduce the need for complaints, as issues can be dealt with quickly and at the point of service.

The Patient and Client Council Complaints Support Service is central to our work. I enclose a copy of our second annual report on the service and the six month update as presented to our Board in October 2013. We are not complacent about the service and seek to improve it.

The Council uses the data it gathers in helping people with their complaints, to inform its participation on groups across health and social care, to influence the system and encourage health care organisations to gather their own information on issues raised.

#### **8. How you suggest the Council's contribution to the Health Service might be improved?**

The Patient and Client Council has a budget of £1.8 million and a staff complement of 33, 6 of whom are dedicated to the Complaints Support Service. While the Health and Social Care system is to be congratulated on building such a "critical friend" into its architecture, the Patient and Client Council is a small organisation and must be selective in what we address and ultimately achieve. There are a number of on-going initiatives we are pursuing which will help to improve the contribution of the Council to the Health Service.

The Council is seeking;

- To establish an online forum where health and social care can have real time feedback on its services; and
- To increase the numbers of complainants supported by our services by ensuring that information about our complaints support service is included in all correspondence about complaints from service providers.

**9. The extent, if any, to which the Patient and Client Council accepts the validity of the concerns expressed in the May 2013 workshop about the Council and its work?**

The Patient and Client Council take seriously any expression of dissatisfaction with the service that it provides in support of complainants and the report of the Health and Social Care Board Public Workshop is no exception to this. The workshop was attended by 27 members of the public and raised two areas of note for the Patient and Client Council, awareness of our service and the quality of the service we provide.

As noted above I attach for your information our newly published Annual Complaints Report for 2012/2013 and the report on the first six months of activity in 2013/2014. You will see that use of our service continues to grow significantly. We believe this reflects an increased awareness of our service resulting from the significant, sustained campaign of public engagement pursued by this organisation since its establishment in April 2009.

We are reaching an increasing number of people who may wish to raise a complaint or concern about a health and social care service they have received. We supported 643 people in our first year, 875 in 2010, 980 in 2011 and 1181 last year. To date this year we have received 922 new contacts from people seeking help, advice and support.

In our most recent Complaints Support Service evaluation, contained in the Six Monthly Report April to September 2013, 89% of respondents who answered the relevant question rated the service they received from us as "good" or excellent". We will continue to review the experience of any clients who felt we could have done more for them.

**10. Any actions which have been taken in response to the concerns expressed at the workshop?**

To increase awareness of our services we have asked the DHSSPSNI and Regional Health and Social Care Board to ensure that reference to our service is provided in all correspondence relating to complaints an all health and social care services in Northern Ireland.

Yours sincerely



Maeve Hully  
Chief Executive  
The Patient and Client Council

*Enc. - Patient and Client Council Annual Complaints Report 2012/2013,  
- Patient and Client Council Complaints Support Service, Six Monthly Report, April to September 2013*