

# Patient and Client Council

Your voice in health and social care

**Minutes of the seventy-third meeting of the Patient and Client Council held on Tuesday 20 March 2018 at 10.00am, in the PCC Conference Room, Quaker Buildings, High Street, Lurgan BT66 8BB**

**Present:**

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| Dr Maureen Edmondson (Chair)             | Dr May McCann ( <i>left at 12.35pm</i> ) |
| Mr Brian Compston                        | Mrs Joan McEwan                          |
| Mrs Liz Cuddy ( <i>left at 12.50pm</i> ) | Professor Hugh McKenna                   |
| Mr Bill Halliday                         | Cllr Martin Reilly                       |
| Mr Garrett Martin                        | Mrs Seána Talbot                         |

**Other Apologies:**

Mrs Lynne Charlton, Head of Nursing, Quality, Safety and Patient Experience, Public Health Agency (PHA)

**In attendance:**

Mrs Maeve Hully, Chief Executive, Patient and Client Council (PCC)  
Mrs Louise Skelly, Head of Operations, (PCC)  
Mrs Jackie McNeill, Interim Head of Development and Corporate Services (PCC),  
Mrs Helen Mallen, Board Secretary, PCC

## **12/18 INTRODUCTION**

Dr Edmondson welcomed everyone to the PCC Board meeting. She particularly welcomed Mr Halliday back following a period of illness and wished him well in his recovery.

## **13/18 CONFLICTS OF INTEREST**

There were no declared conflicts of interest for the items to be discussed on the Board meeting agenda.

## **14/18 MINUTES OF THE LAST MEETING**

The minutes of the meeting held on the 23<sup>rd</sup> January 2018 were agreed as an accurate record of the meeting and signed by the Chair and Chief Executive.

## 15/18 MATTERS ARISING

Dr Edmondson referred to the outstanding items from the minutes and Matters Arising sheet:

a. Item 5/18 PCC Report on Impact and Experience of being on a Waiting List longer than Ministerial Targets

This report was launched on 1 March. Mrs Hully confirmed that Mr Jackie Johnston, Deputy Secretary, Healthcare Policy, has committed to getting information out to the public about waiting times. He is setting up a group and has invited the PCC and service users to be involved, with a commitment to deliver this by 30 June 2018.

Mrs Skelly confirmed that Mrs Watts, Chief Executive, (Health and Social Care Board/Public Health Agency (HSCB/PHA) provided a copy of the report to all HSCB Board Members at a recent Board Meeting.

b. 87/17 Update from Chief Dental Officer (CDO) on project PCC contributed to Mr Simon Reid, CDO has previously said that the information gathered from service users by the PCC will help inform future contractual models for primary dental care.

It was agreed that the CDO should be asked if he would do a blog on the project to keep people who contributed to this project informed about progress.

**Action: Ask CDO if he would contribute to a blog.**

c. Item 91/17 Standing Orders

Standing Orders to be reviewed when new Board Members appointed.

d. Item 9/18 (b) Consultation on PCC Board composition and size

Mrs McNeill had emailed Sponsor Branch for an update on a number of issues in advance of the PCC Board Meeting today. Mrs Kim Coates had sent an update this morning.

The consultation on PCC board composition and size is not out yet and Sponsor Branch is currently reviewing the comments provided by the PCC Board following the last Board meeting.

Mrs McNeill also confirmed that in relation to recruitment of new Board Members, the interviews are scheduled to take place on 9, 10 and 11 May 2018. The Department has reviewed the make-up of the planned selection panel and the selection panel has changed with Mr Rodney Morton, Deputy

CNO, being replaced by Mr Paul Archer, Chair of the NI Ambulance Service (NIAS).

## **16/18 HSC ISSUES FOR PEOPLE AND THEIR CARERS LIVING WITH DEMENTIA, BOARD PAPER NO. 501**

Mrs Skelly presented this paper for approval. Phase 1 of the project completed last year identified a need to speak to younger people diagnosed with dementia to learn about their experience and impact of their diagnosis. The PCC spoke to 19 people and this report includes 10 case studies.

Mrs Skelly has spoken to the relevant Policy Lead in the Department and there is commitment that a new patient portal being developed will enable people living with dementia and their carers, to have secure on-line access to their own health and social care information by the summer of 2018.

In an email from Mr Seamus McErlean, Social Care Commissioning Lead at the HSCB, he confirmed that he had undertaken research on younger people with dementia in 2001 and that the findings were similar to those in the PCC report.

On discussion the Board highlighted the following:

- Reference to information portal – Patients need better explanations for some of the terms used in HSC.
- Impact of diagnosis of dementia on employment. There are some good examples in employment where people with dementia do not automatically lose their jobs but are retained in their current job or given an alternative role. Some organisations have adopted a dementia friendly status. It is important to people that this diagnosis does not necessarily mean losing your job and the Board felt this should be raised with the Equality Commission.
- It would appear that initial discussions and the breaking of bad news by professionals is done well, however, there appears to be a lack of immediate support following diagnosis and this should be highlighted in the recommendations.

In conclusion, the following was agreed:

1. A glossary of HSC terms to be included;
2. The recommendations on page 37 of the report should be numbered;
3. Modify the last recommendation in the report to include the need for immediate and appropriate support following diagnosis;
4. The report should be shared with the Equality Commission with a request that they consider employment rights of people given a diagnosis of dementia;

5. Mr Seamus McLean's research in 2001 to be included in the list of references in the report.

**Action: Pending the above amendments, Board Paper No. 501 was approved.**

## **17/18 EXPERIENCE OF RESIDENTS OF CARE IN NURSING HOMES, BOARD PAPER NO. 502**

Mrs Skelly explained that the original idea had been to work with the Regulation, Quality and Improvement Authority (RQIA) on this project. However, on discussion with RQIA it was agreed that the PCC should proceed solo as the relevant information is collected and analysed in a different way by RQIA. The PCC reviewed the complaints database to identify complaints about nursing home care in the last two years. Forty-eight cases were included in the final analysis.

A number of recommendations were made based on learning points identified.

On discussion the Board highlighted the following:

- There are concerns that current contractual arrangements allow nursing homes to evict residents at short notice and without consent
- Although the PCC project did not include young people with a physical disability living in nursing home care, it is an observation that sometimes young people or people with mental health problems are placed in nursing home care and it would be worth saying in the report that this is an area that should be looked at in the future.
- Members noted with interest, that it is mainly a female family member that raises concerns about a resident's care.
- EMI beds mainly used for residents with dementia are included in the total number of beds in the report. EMI beds still exist but some nursing homes have these beds dual registered.
- The Mental Capacity Act will have implications for residents.
- This report will be shared with decision makers in HSC and the PCC will interface with RQIA, HSCB and the PHA in relation to influencing nursing home standards and workforce agendas.
- It is hoped that the Real-time Feedback system will enable people to complain/comment quickly. This should help reduce the major barrier that people have to complaining in case it has a negative impact on their care.

In conclusion, the following was agreed to finalise the report:

1. In recommendation 9 it needs to be made clear that there should be a mechanism in place to identify the resident's next of kin. This may not

necessarily be a family member, but needs to be clear in the residents notes.

2. Add information on the number of specific EMI beds there are in the system;
3. Add a note that there is an observation that the appropriateness of care of younger people or people with a mental health issue living in nursing homes needs to be reviewed in the future;
4. Dr McCann confirmed that the Research Committee are also sending minor comments for consideration in finalising the report.
5. A cover letter should accompany this report, stressing the particular areas of concern in care of this vulnerable group of people.
6. The PCC will liaise with HSCB/RQIA and Trusts in relation to contracts as residents must be able to feel secure in their tenancy.
7. The PCC will raise the concerns highlighted in the report with Sponsor branch.

The Board commended Mrs Skelly and her team for the two reports presented.

**Action: Pending the above amendments, Board Paper No. 502 was approved**

## **18/18 CLOSING THE LOOP. FOLLOW-UP ON 6 PROJECTS TO DETERMINE PROGRESS, BOARD PAPER NO. 503**

This report provides an update on the delivery of outcomes across 6 PCC projects. The projects reviewed were, End of Life Care; Miscarriage; Future Planning; Myalgia Encephalomyelitis (ME); Fibromyalgia and Endometriosis.

On discussion, the Board noted disappointment with progress but shared the frustrations of the team in achieving effective change for patients in some areas. There are so many different layers and processes within HSC that must be considered when trying to achieve change. However, if it is difficult for the PCC, it is even more difficult for patients; the PCC must continue to ensure the patient's voice is fed into the system and to work through processes to achieve improvements for patients.

There are varying levels of progress made due to constraints around time, resources and processes, but the PCC continues to work in partnership with HSC and cross-departmentally to achieve improvement to HSC services.

The Board asked Mrs Skelly to strengthen the conclusion in the paper and consider how the PCC might link with policy leads in the Department at the project planning stage which may help achieve speedier outcomes.

Board Paper No. 503 was noted.

#### **19/18 PCC DRAFT BUSINESS PLAN 2018-2019, BOARD PAPER NO. 504**

Mrs McNeill referred to the draft PCC Business Plan for 2018-2019. A number of changes had been requested by the Board when the plan was discussed in January and the draft Business Plan was forwarded to Sponsor Branch for approval.

An update was received today from Sponsor Branch, confirming that the draft plan had been issued for comment around the Department. Sponsor Branch is now reviewing responses and will contact the PCC when this has been completed. The Board expressed disappointment that having submitted the draft to DoH in good time, no timely response had been forthcoming.

Members asked if there was any update on the report from the Future Search event. Mrs McNeill said that Sponsor Branch had received the draft report. The CNO will now focus on the next steps to support the development of a whole systems approach in implementing the Action Plan. The Future Search Report will be launched in April alongside the Co-Production Guide.

As this Business Plan will commence on 1 April, the Board gave their approval. Dr Edmondson asked the management team to review the timings for projects to ensure there is adequate phasing of projects throughout the year.

Mrs McNeill confirmed that there is no confirmation yet of the PCC budget allocation for 2018/2019.

Board Paper No. 504 was approved.

#### **20/18 PCC QUARTERLY PERFORMANCE REPORT, BOARD PAPER NO. 505**

This report presented by Mrs Hully, provided an update on the organisation covering Business Plan achievement; Finance update and Strategic Environment.

Dr Edmondson provided information about a recent NICON Chairs Forum meeting which had included discussion about the report on the Inquiry into Hyponatraemia related deaths. The report has raised a number of questions for Boards about the responsibility of Boards and Chief Executives in regard to safety.

In response to questions about the payment of the Apprenticeship Levy, Mrs McNeill said that enquiries had been made with the Department of Finance (DoF) as to the number of employees an organisation should have before they must pay the Apprenticeship Levy. The DoF had contacted HRMC in relation to this query. HRMC confirmed that HSC should be taken in its entirety with a percentage rate allocated to all HSC bodies. All 17 small agencies were grouped and the actual cost paid by the PCC was £3,755. This was a reduction of £822. on the figure noted in the report.

**Action: The Board asked Mrs McNeill to share the Apprenticeship Levy information with the G&A Committee.**

Board Paper No. 505 was approved.

## **21/18 PCC FRAUD POLICY/RESPONSE PLAN, BOARD PAPER NO. 506**

Mrs McNeill has reviewed this policy with the BSO Anti-fraud team. There were no major changes to the policy but the reporting process has been made clearer. The G&A Committee has reviewed this Policy and recommended it to the Board for approval.

Mrs McNeill confirmed that the PCC has had no incidence of fraud in the last year.

Cllr Reilly asked if the potential for fraud in connection with the PCC Membership Scheme has been considered. Although the PCC has a number of safeguards in place, Members asked Senior Management to consider if there are any potential areas open to fraud which could put Members or the PCC at risk.

Board Paper No. 506 was approved and the Executive will report back on the risk identified.

## **22/18 HSC PARTIAL RETIREMENT POLICY, BOARD PAPER NO. 507**

This is an HSC regional policy which enables employees in specific pension schemes to avail of part of their pensions by reducing their working hours. The G&A Committee has reviewed this Policy and recommended it to the Board for approval.

Board Paper No. 507 was approved.

## **23/18 PCC CORPORATE RISK REGISTER, BOARD PAPER NO. 508**

Mrs McNeill presented a revised risk register based on discussions held at the Board Workshop in February 2018. The revised risk register had been reviewed by the G&A Committee at their meeting on 16 March 2018 and the Committee had asked that some further amendments be discussed with the Board.

Mrs Cuddy said that risk number 1, in relation to the PCC no longer being a sustainable organisation, be considered different to the PCC not being legally compliant. She said that whilst the current Board strives to ensure good governance processes are in place, there is still a reputational risk to the PCC around not operating within its legislation. Mrs Cuddy felt strongly that a separate risk is required for legislative compliance, demonstrating that the PCC has tried to mitigate this risk through constant contact with the Department.

Following discussion, the Board agreed that this change should be incorporated as a reputational risk and reviewed following the current Public Appointments process.

Other minor amendments were noted to the scoring on the risk register. Mrs McNeill will update the report and finalise the PCC Corporate Risk Register which will be reviewed in June 2018.

**Action: Mrs McNeill to finalise the PCC Corporate Risk Register based on the comments made. The risk register will be reviewed at the Board Meeting in June 2018.**

Board Paper No. 508 was approved.

## **24/18 CHAIRS REPORT**

Dr Edmondson provided a brief update to the Board on the teleconference call with Professor Charlotte McArdle. A number of issues were discussed including Future Search, Consultation on Board composition and size and Real-time feedback.

Mrs McNeill had provided an update from Sponsor Branch earlier in relation to Future Search and the consultation piece. Sponsor Branch has also confirmed that a business case has been prepared for the Real-time Feedback project. The HSCB is currently working to appoint a project manager for the preparation of the system specifications.



Mrs Hully confirmed that a number of speakers have agreed to attend the PCC Board Meeting in April to provide information on progress with digital transformation, the patient portal, Real-time Feedback and MyNI.

The Chairs Report was noted.

## **25/18 ANY OTHER BUSINESS**

### **a. Administrative Data Research Centre (ADRC)**

Professor McKenna explained that the ADRC, funded by the Economic and Social Research Council (ESRC), is working in partnership with Queens and Ulster Universities and the NI Statistics Research Agency (NISRA) to increase access to routine administrative data for research purposes. The ADRC works with government departments in NI, including health, housing, education and justice. The Honest Broker initiative runs parallel with the work of the ADRC. Responsibility for safely transferring sensitive data into anonymised datasets for research purposes rests with the ADRC.

It was noted that the majority of people would want their information to be used in a way that will contribute to future research. However, the ADRC will need to ensure there is public involvement and communication to reassure people that their data is secure. She suggested the PCC engage with the ADRC.

### **b. Research Committee**

Professor McKenna said that he and Dr McCann will be leaving the PCC no later than September 2018 and stressed the need for Board Members with expertise in research.

Dr Edmondson reminded colleagues that she had asked the Department to include 'research' as a skill required in some new Board Members. However the Department declined to include it. Nevertheless she hopes the current recruitment process will see some new Members with a background in research as the organisation relies on these skills. There is also the option to co-opt people for specific pieces of governance such as the Research Committee.

### **c. Inquiry into Hyponatraemia Related Deaths**

Following previous Board discussions Dr Edmondson had written to Professor McArdle offering PCC commitment and support in implementation of the recommendations made in the Inquiry report. Professor McArdle has passed the letter to Mr Paddy Woods at the Department as he will be leading on this work.

d. HSC Complaints Process

Mrs Skelly brought to the attention of the Board an observation from a client supported by the PCC. This client had her complaint dealt with by the Ombudsman. Her observation was that sometimes patients can be harmed by the complaints process itself regardless of the outcome.

On discussion the Board recognised that there is a risk to people embarking on a complaint as the process can impact on their health and well-being and outcomes may not be what they expected. It is essential that the Patient Client Support Officers at the PCC take each person's case on its own merit, and clearly talk to the client in relation to their expectations and potential limitations.

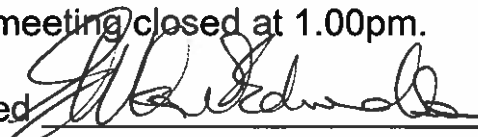
**26/18 INPUT FROM MEMBERS OF THE PUBLIC**

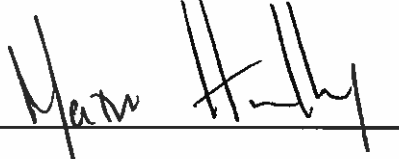
There were no members of the public present.

**27/18 DATE OF NEXT MEETING**

The next meeting will be held on Tuesday 17<sup>TH</sup> April 2018 at 1pm in the Riverview 3 Room, La Mon Hotel, Belfast

The meeting closed at 1.00pm.

Signed 

Signed 

Date 17/4/18  
Maureen Edmondson  
Chair of PCC

Date 17/4/18  
Maeve Hully  
Chief Executive of PCC