

# Patient and Client Council

Your voice in health and social care

## Minutes of the seventy-sixth meeting of the Patient and Client Council held on Tuesday 18 September 2018 at 10.05am, in the Conference Room, PCC, Quaker Buildings, High Street, Lurgan, BT66 8BB

### Present:

Dr Maureen Edmondson (Chair)	Dr May McCann
Mr Brian Compston	Professor Hugh McKenna ( <i>left</i> <i>12.10pm</i> )
Mr Bill Halliday	Mrs Seána Talbot
Mrs Joan McEwan	

### Apologies:

Mrs Liz Cuddy  
Cllr Martin Reilly

### In attendance:

Mrs Maeve Hully, Chief Executive, Patient and Client Council (PCC) (*from 11.05am*)  
Mrs Louise Skelly, Head of Operations, PCC  
Mrs Jackie McNeill, Interim Head of Development & Corporate Services, PCC  
Mrs Suzanne Martin, Research Manager, PCC  
Mrs Helen Mallen, Board Secretary, PCC  
Mrs Michelle Tennyson, Assistant Director of Allied Health Professionals and PPI, Public Health Agency (PHA)

## 62/18 INTRODUCTION

Dr Edmondson welcomed everyone to the PCC Board meeting. She welcomed Mrs Tennyson who will be attending PCC Board Meetings on behalf of the PHA.

On behalf of the Board, Dr Edmondson offered Mrs Skelly condolences on the recent loss of her father.

Dr Edmondson also took the opportunity to congratulate Mrs Talbot on winning the Best Short Historical, Best First Book award.

## 63/18 CONFLICTS OF INTEREST

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

## 64/18 MINUTES OF THE LAST MEETING

The minutes of the meeting held on the 19<sup>th</sup> June 2018 were agreed as an accurate record of the meeting and signed by the Chair and Chief Executive.

## 65/18 MATTERS ARISING

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

- a. Item 91/17 Review of Standing Orders  
Standing Orders will be discussed as an item on the agenda.
- b. Item 50/18 Business Services Organisation (BSO) Shared Services  
Mrs McNeill had made enquiries with BSO about joining the BSO Working Group set up for stakeholders to review areas of concern with BSO services. BSO had provided Mrs McNeill some past papers of the group and it would appear that this group focuses mainly on Trust issues. Mrs McNeill said she feels the best place for the PCC to raise any concerns is at the Customer Forum and she will continue to attend these meetings.
- c. Item 53/18 Report on Experience of Annual Health Checks for People with a Learning Disability  
This report has been finalised and will be launched in October.
- d. Item 54/18 Research Committee  
The Research Committee had agreed to review the work due to be completed this year in order to identify which project plans they should see at an early stage.

Professor McKenna confirmed that the Research Committee had met that morning. He said that the Committee is comfortable that there are mechanisms in place to enable the Research Committee to provide early feedback.

He informed the Board that Mrs Martin will be leaving the PCC and thanked her on behalf of the Board for all her work as Research Manager and wished her well in her new position in the Northern HSC Trust.

- e. Item 96/15 (c) Myalgic Encephalomyelitis (ME)  
The PCC has worked with ME patients in campaigning for local services and recognition of their medical condition and needs. Mrs

Skelly updated the Board on an excellent event she and Mr Halliday had attended on the 17 September regarding the Management of ME/Chronic Fatigue Syndrome (CFS); adult and paediatric.

The keynote speaker was from Stanford University Medical School, and other doctors and service user had input into the programme. Dr McBride, Chief Medical Officer attended. Several of the Medical professionals started by apologising to patients for the length of time it has taken to have this condition recognised as a biomedical illness.

Mrs Skelly also reported that interviews are taking place for a part-time Medical lead for ME services in NI. The National Institute for Clinical Excellence (NICE) has also agreed to review the NICE guideline for diagnosis and management of CFS/ME. A service user from NI has agreed to be a lay representative on the group reviewing these guidelines.

The Board congratulated the service users and the PCC team for their persistence at getting the need for services recognised and advanced.

## **66/18 COMPLAINTS SERVICE, BOARD PAPER NO. 525**

The Members congratulated the team on this report which provides the annual statistics for the PCC Complaints Support Service. There were a number of areas where the Board asked for further detail to be provided, as follows:

- An explanation about the reduction in complaints as in Trust data, while our numbers are increasing - why might this be?
- Context and understanding about the increase in the number of people assisted by the PCC with complaints in the Southern HSC Trust area;
- The reasons for complaints about domiciliary care services;
- The ongoing systemic problem with communication and attitude and the actions taken by Trusts in learning from complaints about this.

In conclusion of discussion by the Board, a number of amendments to the report were agreed:

- Elaborate on the role of the PCC and the relationship with service users in their journey through the complaints process;
- Elaborate on the PCC service provided in the Southern area and the impact of a local presence on the number of people seeking assistance;
- The title on page 5 to be changed as the data does not just relate to 'themes';

- A five year trend analysis of complaint issues to be added to the report on page 7;
- More detail to be provided about reasons for complaints about domiciliary care;
- DoH statistics demonstrate a reduction in complaints across Health and Social Care, whilst the PCC has seen an increase in complaints support service work. It is important to clarify in the report that we are not comparing 'like with like' and consider reasons why.
- There is concern that communication and attitude still remain an issue for service users. If information is available to the PCC about improvements made by HSC Trusts as a result of lessons learnt from complaints this should be included in the report;
- In the conclusion section it is important to clarify the concept of health literacy and how this could be part of the solution in improving communication.
- There is currently no policy lead at the DoH for Health Information so the PCC will continue to be a catalyst for this and it will be considered in the PCC's Business Plan for 2019/2020. The PCC is also participating in a piece of work being undertaken by the University of Ulster on HSC communication and this may shed light on some of the above.

The Board thanked everyone involved in this work.

**Action:**

- 1. The Report is to be finalised by the Chair and Chief Executive;**
- 2. A media release will be planned as part of the launch of the report.**

Pending the agreed amendments Board Paper No. 525 was approved.

**67/18 FEEDBACK ON PCC HEALTH INFORMATION EVENT-PROVISION OF GOOD QUALITY INFORMATION, BOARD PAPER NO. 526**

This report provides an update on the Health Information Event in Crumlin Road Gaol on the 12 June 2018. The PCC held this event in partnership with the Patient Information Forum (PIF) to raise awareness of good quality health information. Delegates from across the sectors together with service users and carers, explored the accessibility and availability of health information in Northern Ireland. Delegates committed to taking forward a number of key actions to improve health information and health literacy locally.

Members agreed that Health and Social Care must provide people with factual, evidence based information to enable them to make

informed choices and to feel empowered and involved in decisions about their health and treatment.

The PCC will also visit the Healthcare Quality Improvement Department at the Scottish Government as there is a Health Literacy action plan in place and approved by government.

The PCC will run a follow-up event in the Spring 2019 to keep up the momentum on developing a health literacy plan for Northern Ireland. This work will be included in the PCC Business Plan for 2019/2020.

Board Paper No. 526 was noted.

### **68/18 UPDATE PCC MEMBERSHIP SCHEME, BOARD PAPER NO. 527**

Mrs Skelly presented the report on the plans for the PCC Membership Scheme. She explained that more investment is needed to fulfil the potential of the scheme and the DoH has confirmed funding of £50,000 which must be spent by March 2019.

The Board welcomed this additional funding with a view to improving how we engage with people and to develop how people can get more involved in working together with health and social care (HSC) to improve HSC services.

Professor McKenna said it is a great time to reinvigorate the Membership Scheme and recognise the potential of the scheme from a research perspective.

It will be important to have different approaches for reaching particular communities and encouraging younger people to get involved. The PCC will prioritise the work into phases depending on the cost and transformation money available.

The PCC must plan carefully how it will use the additional funding. Given the timescales it would be good if the revamped Membership Scheme could feature in the 10 year anniversary of the PCC.

Mrs McNeill had spoken to the Information Commissioner (ICO) who said that under the new General Data Protection Regulations (GDPR) it is good practice to write to Members who get the newsletter via email asking them every 3-4 years, if they are still happy to receive communication from the PCC. As this could potentially impact the number of Members who stay in the scheme Mrs McNeill was asked to confirm with the ICO if this is a legal requirement under GDPR.

**Action: Mrs McNeill to liaise with the ICO.**

The Board approved Board Paper 527.

**69/18 G&A COMMITTEE REPORT TO BOARD 06-09-18. Board Paper No. 528**

This report provides the Board with a summary of the G&A Committee meeting held on 6 September. Mrs McNeill outlined the main points from the meeting:

- IA BSO Shared Services Report – Payroll Services.  
When the G&A Committee reviewed the IA report on shared services in May 2018, they were still concerned about how long it is taking to improve services, particularly payroll services.

Mrs McEwan had written to Mr Liam McIvor, Chief Executive, BSO to reinforce these concerns. Mr McIvor actioned Mr Liam Mulholland, Head of Payroll, BSO provide the G&A meeting in September with a comprehensive update on the progress and further action being taken to address the issues. He will come back to the G&A Committee meeting in March/April 2019 to provide an update.

- IA Progress Report 2018/2019  
This report confirmed that 36% of PCC audit days have been used this year to date. A travel audit was carried out across HSC at the request of the Permanent Secretary. The PCC achieved a satisfactory level of assurance for this audit. IA made two recommendations around strengthening internal procedures and the PCC management have accepted these recommendations.

An audit of complaints advocacy also achieved a satisfactory level of assurance. Two recommendations around access to the complaints database and the dissemination of evaluation forms were accepted by PCC management.

- PCC IA Strategy 2018/2019  
The PCC had planned an audit of Board composition this year however, with the delay in new appointments, this audit may not be feasible this year. As some of the audit days had to be taken for the compulsory travel audit the G&A Committee proposed that the remaining days should be used to extend the financial review audit.

On discussion the Board asked that the decision on this be deferred to December. This will allow time to see if the Permanent Secretary will make appointments when the Secretary of State implements new powers in November 2018. If nothing further is announced between November and December, the Board will consider increasing the number of days for the financial review audit.

**Action: Mrs McNeill to inform Mr David Charles, IA, that the Board will review this decision in December.**

- PCC Governance Plan 2018/2019  
This paper has been updated from last year to include GDPR regulations assurance and to remove reference to the controls assurance standards.
- Mid-year Assurance Statement – This is being discussed as a separate item on the agenda.
- G&A Self-Assessment – The template for this assessment has reduced in size and the G&A Committee will complete this.
- Report to Those Charged With Governance. This was presented to the G&A Committee and demonstrated a clean report for the PCC.
- Risk Register – being discussed as a separate item on the agenda.
- Mid-year Assurance Statement – being discussed as a separate item on the agenda.

Based on the recommendations from the G&A Committee and discussion by the Board the following papers were approved:

- a) PCC Governance Plan 2018-2019
- b) Gender Identify and Expression Employment Policy
- c) PCC Gifts and Hospitality Policy

Board Paper 528 was noted.

## **70/18 PCC CORPORATE RISK REGISTER. Board Paper No. 529**

The Board had agreed at the Board meeting in June 2018, that the ratings on the PCC Corporate Risk Register would be reviewed in September 2018, specifically in relation to the PCC being a sustainable organisation and being able to achieve its Business Plan.

The G&A Committee had considered the Risk Register at their meeting on 6 September. Mrs McNeill outlined proposed amendments made by the G&A Committee. The Board discussed the proposals and the following was agreed:

- Risk 1a - PCC sustainable organisation. The risk rating is to be changed to high given the position on public appointments and loss of corporate memory when the Chief Executive leaves;
- Risk 2 – the wording will be amended given the risk to the organisation of recruitment for new Chief Executive and Head of Corporate Services;
- Risk 3b – the wording will be amended regarding the risk to the PCC around Voluntary Exit Scheme (VES) funds;
- Risk 4e – the wording to be amended regarding appointment of new members or extension of existing members.

In addition to the above amendments, the Board asked that a risk be added under '3c' on the impact to staff / PCC objectives on continuing reductions to the PCC budget.

**Action:**

- 1. Mrs McNeill to update the PCC Corporate Risk Register**
- 2. Mrs McNeill will liaise with Sponsor Branch about the exceptional circumstances of recruiting a new Chief Executive for the PCC and the additional cost of this.**

Pending the agreed amendments Board Paper No. 529 was approved.

## **71/18 REVIEW OF PCC STANDING ORDERS, Board Paper No. 530**

Given the reduction in the number of PCC Board Members and the impact of loss of experience and expertise on Board Committees, the Board had asked Mrs McNeill to review the PCC Standing Orders in relation to the option to co-opt people onto Committees of the Board. Mrs McNeill confirmed that there are options to co-opt onto Sub-Committees both in the PCC Standing Orders and in the PCC Membership and Regulations (NI) 2009.

Although people co-opted onto Sub Committees have no decision making powers, the Board can define powers and agree remuneration.

On discussion, Members said that the terms of reference for the individual Sub-Committees can be reviewed in relation to the scope of powers. Although people co-opted onto Sub Committees have no decision making powers, they can contribute to recommendations as part of the Sub Committee and these recommendations would be subsequently ratified by the Board.

Given that the Chair and three Board Members are due to leave on 30 September, Dr Edmondson proposed that the quorum for Board Meetings be reduced from 6 Members to 5 Members.

As the PCC Board legislation states that the PCC should have 16 Members plus a Chair, some Members expressed concern about reducing the quorum further and felt that it was not appropriate. However, on discussion the Board unanimously agreed that the quorum for Board Meetings can be reduced to 5 Members on a temporary basis to 31 March 2019. Members stressed that this is being done for the good of the organisation and the people it serves.

Board Paper No. 530 was approved.  
*(Professor McKenna left the meeting at 12.10pm)*

#### **72/18 DRAFT MID-YEAR ASSURANCE STATEMENT, Board Paper No. 531**

All Arms' Length Bodies are required to submit a Mid-year Assurance Statement to the Department. This enables the Accounting Officer to attest to the continuing robustness of the organisation's system of internal governance.

The G&A Committee had reviewed this paper on 6<sup>th</sup> September and recommended it for approval to the Board.

Board Paper No. 531 was approved.

#### **73/18 PCC EQUALITY UPDATE. Board Paper No. 532**

The PCC works in partnership with other regional HSC organisations on the equality agenda. This report details the PCC equality scheme as reported to the Equality Commission. It details the wide variety of target audiences that the PCC talk to through its operational work.

The Board discussed the paper and agreed that this fulfils equality requirements.

Board Paper No. 532 was approved.

#### **74/18 QUARTERLY PERFORMANCE REPORT. Board Paper No. 533**

Mrs Hully presented this report that provides an update to the Board on:

- Business Plan achievement
- Finance management
- Strategic environment

The current financial position is outlined on page 6 of the report and is monitored closely.

Mrs Hully confirmed that the work has commenced on the Inquiry on Hyponatraemia Related Deaths (IHRD) Programme Structure and Implementation Programme Management Groups.

Members agreed it will be important for the Department to ensure that the focus is not on the processes but on the outcomes achieved. The challenge for the system will be to ensure that the process is open and transparent and the outcomes clear. The PCC has representatives on a number of groups and the PCC must be consistent and open in its messages and feedback.

**Action:**

- 1. Mrs Mallen to ensure Mrs McEwan is on the mailing list for the Duty of Candour Group.**
- 2. Mrs Hully to agree:**
  - a. high level principles for PCC involvement across PCC staff and members involved on IHRD Programme groups**
  - b. identify a communication process across PCC representatives.**
  - c. continue to update the Board on progress with this work through the quarterly performance report.**

Board Paper No. 533 was approved.

**75/18 REVISED DRAFT PCC INVOLVING YOU POLICY. Board Paper No. 534**

This Policy was developed by the PCC some time ago and it has been updated in keeping with the principles of the new Co-production guide.

There had been discussion about the need for this policy given the availability of the Co-production Guide. However, Mrs McNeill had explained that the Equality Unit in BSO had welcomed this policy and said it provides a further reference to how the PCC consider equality issues throughout its work.

Dr McCann suggested that the name of the policy be changed in keeping with the spirit of co-production. She proposed it be called 'Working Together'. The Board agreed this proposal.

**Action: The title of the PCC policy to be amended to the 'PCC Working Together policy'.**

Pending the change to the name of the policy, Board Paper No. 534 was approved.

## **76/18 USER INVOLVEMENT IN THE HEALTH TRANSFORMATION PROCESS**

A service user had emailed the PCC to raise concern about the lack of service user involvement in the Health Transformation process. He had gathered information and provided this to the PCC Board, outlining the level of service user involvement on the Health Transformation working groups.

On discussion Members felt that the service user had raised a valid point and decision makers have a responsibility to support service users to join and remain on groups. It is recognised that this is challenging but there must be mechanisms in place to recruit, maintain and replace service users on groups.

Mrs Tennyson said that this is a constant challenge for HSC. It can be a struggle to recruit service users and carers to work at a strategic level and to give the time required, as these pieces of work can take years to work through to the implementation stage.

It is also difficult to retain people's interest if they have no connection with specific issues.

The Board agreed that this makes capacity building work more important to attract and support people to work with the system and to ensure service users know what their role is and is not.

Dr McCann said that it is important that the system utilises third sector voluntary and community groups. Third sector organisations could be used more for service user input as they are peers who are widely informed.

**Action: It was agreed that Mrs Hully should consider and report back to the Board about progressing the concerns raised about service user involvement in the Transformation Process.**

## 77/18 CHAIRS REPORT

In addition to the work listed Dr Edmondson has been heavily involved in the recruitment process for the new Chief Executive appointment.

The Chairs Report was noted.

## 78/18 ANY OTHER BUSINESS

### a. Electronic Board Papers

The Board has previously piloted Minute pad as an option for electronic board papers. Mrs McNeill said that it may be possible to have a Members section on the PCC website for access to Board Papers. She asked Members if they would still be keen to move to electronic board papers.

Members said they would move to electronic papers but the following must be considered. Members:

- don't want to have to use different devices/different email addresses;
- must be able to download papers to enable them to work off line at the meeting if necessary; and
- must be able to make reference notes on the downloaded papers.

Mrs McNeill will consider options and discuss further with the Board.

*(Dr McCann left the meeting at 12.50pm)*

### b. Future Search Report

Dr Edmondson referred to the report on the Future Search initiative and referred to the five next steps outlined on page 10. Members agreed that it is crucial that the Department demonstrates to the public, how the future search will be co-ordinated and developed into a collegiate process.

#### **Action:**

- 1. Future Search Report to be considered at the PCC Board Workshop in October.**
- 2. Senior Management to keep the Board informed of progress.**

### c. 10 year PCC anniversary

Dr Edmondson said that she would welcome ideas for how the PCC should celebrate 10 years of the PCC in April 2019.

## **79/18 INPUT FROM MEMBERS OF THE PUBLIC**

There were no members of the public present.

## **80/18 DATE OF NEXT MEETING**

The next meeting will be held on Tuesday 20<sup>th</sup> November 2018 at 10am in the Conference Room, PCC, Quaker Buildings, Lurgan, BT66 8BB.

The meeting closed at 1pm.

Signed \_\_\_\_\_ Signed \_\_\_\_\_

Date \_\_\_\_\_ Date \_\_\_\_\_  
Maureen Edmondson  
Chair of PCC  
Glynis Henry  
Interim Chief Executive of PCC