

Patient and Client Council

Your voice in health and social care

**Minutes of the seventy-fourth meeting of the Patient and Client Council
held on Tuesday 17 April 2018 at 10.00am, in the Riverview 3 room,
La Mon Hotel, 41 Gransha Road, Castlereagh, Belfast BT23 5RF**

Present:

Dr Maureen Edmondson (Chair)	Mrs Joan McEwan
Mr Brian Compston	Professor Hugh McKenna (<i>left at 3.30pm</i>)
Mrs Liz Cuddy (<i>left at 3.00pm</i>)	Cllr Martin Reilly (<i>left at 3.35pm</i>)
Mr Bill Halliday	Mrs Seána Talbot
Dr May McCann	

Apologies:

Mr Garrett Martin

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 & Corporate Services, PCC
Mrs Joanne McKissick, External Relations Manager, PCC
Mrs Helen Mallen, Board Secretary, PCC
Mr Mark Lee, Director of Primary Care, Department of Health (DoH)
Mr Rodney Morton, Deputy Chief Nursing Officer (CNO), DoH
Mrs Eileen Curry, Digital Transformation Consultant
Ms Linda McRandle, Senior Change Manager, eHealth & External Collaboration, Health and Social Care Board (HSCB).

28/18 INTRODUCTION

Dr Edmondson welcomed everyone to the PCC Board meeting.

29/18 CONFLICTS OF INTEREST

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

30/18 MINUTES OF THE LAST MEETING

The minutes of the meeting held on the 20th March 2018 were agreed as an accurate record of the meeting and signed by the Chair and Chief Executive.

31/18 MATTERS ARISING

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

- a. Item 6/18 General Data Protection Regulation (GDPR)
PCC had assumed substantial work on GDPR. However at a meeting with BSO it was confirmed that as one of the PCC statutory functions in law is to 'encourage people to get involved' this waives a lot of the consent required. Mrs McNeill has drawn up an action plan and will be discussing this with staff.

- a. Item 9/18 Board Composition/Consultation
Cllr Reilly confirmed that NILGA have written to the DoH raising their concerns about the appointments process for the PCC. NILGA are concerned that representation of Councillors is diminishing. NILGA invite Permanent Secretaries to their monthly meetings and hope to discuss this with Mr Richard Pengelly in the near future.

32/18 WEB BASED INFORMATION PORTAL, PAPER NO. 510

An objective in the PCC Business Plan for 2017/2018 was to contribute to the development of a web based information portal by ensuring the voice of the citizens is part of the process. The PCC has advocated for a number of web based initiatives and this paper outlines progress to date.

Board Paper No. 510 was noted.

Guest speakers updated the Board on progress with various initiatives. Dr Edmondson thanked all the speakers for coming.

33/18 MULTI-DISCIPLINARY TEAMS, MR MARK LEE, DIRECTOR OF PRIMARY CARE, DoH

Mr Lee showed how health and social care (HSC) transformation will be delivered to fulfil the obligations in 'Health and Wellbeing - Delivering Together'. In order to deliver future services HSC must be reformed and this will require:

- Building capacity in community and prevention
- Enhancing support in primary care
- Reforming community and hospital services
- Organising to deliver change. This will require leadership, the right workforce, partnership working, eHealth and quality improvement.

The existing Primary Care model of services provided by a GP with nursing support is no longer adequate and multi-disciplinary teams are needed in general practice. A core group has been established to drive the multidisciplinary approach forward and Mr Lee confirmed that there are service users on this group.

Mr Lee outlined:

- The need for ongoing engagement and communication as this work progresses;
- The need for accurate information and IT systems to support this work;
- The need for early intervention and support. To fulfil this there must be adequate capacity in the community with the use of possible mental health hubs and a possible role for community social workers acting as a local community link with a social prescribing function;
- The local, national and international evidence available to support this work;
- The principals to underpin multidisciplinary teams (MDTs) which will be open to consultation.

The proposal is that MDTs will be tested in one or two geographical areas and the DoH will work on the model to be used, possibly linking to ICP/GP Federation populations. The Department wants to learn about possible barriers to this model so that it can take action to help remove these.

Mr Lee outlined the 6 objectives of the e-Health and Care Strategy. There is a vast regional work programme coming through on eHealth. The Encompass Programme is the key driver of transformation due to be delivered by 2022, updating ageing core systems and introducing new functionality.

Mr Lee confirmed the following in response to a number of questions from Members:

- there is no agreement yet as to who would be employing the MDTs, whether it would rest with a HSC Trust or the GP Federation;

- prescribing powers will be with senior staff such as nurse practitioner or practice based pharmacists. These people would all have prescribing licences thus reducing GP referrals;
- with more emphasis put on health and wellbeing, it will be important to link with community planning teams;
- there is complexity around infrastructures of GP services. Some GP practices are on Trust premises and where GPs' own their premises there are grant schemes available.
- there will be a technical challenge for cross border service availability relating to electronic systems. This is being considered.
- The Encompass Programme will be fully implemented by 2022. It will take a year for a business case to be agreed, a year for procurement and a year for planning and roll out. HSC Online and the Patient Portal will have a quicker timeframe but some systems will take longer to transfer.

Dr Edmondson thanked Mr Lee for his comprehensive presentation.

34/18 REALTIME USER FEEDBACK SYSTEM, MR RODNEY MORTON, DEPUTY CNO

Mr Morton said that the Department is determined to put peoples experience at the heart of health and social care service delivery. In terms of the Real time Feedback System, the Department is trying to engage citizens in a conversation to hear about their experience of HSC, but the Department needs to consider how the information is packaged to ensure meaningful feedback that will be understandable for teams and that will meet regulatory standards.

An electronic platform will be used for this and it must be capable of promoting what good practice is whilst identifying where improvement can be made. Algorithms will be used to analyse data submitted to the Feedback System and dashboards will be developed to feed into future planning, within the context of coproduction.

Although there have been delays in progressing the Real Time Feedback system, Mr Morton reassured the Board that this is a key strand of the coproduction framework due to be published soon.

The Board expressed some concern around delay, duplication and nugatory work since substantial consultation informed the previous PCC business case. There is a lot of work being done under the eHealth Strategy and these all need to be linked under the Person Centred Assessment Care and Evaluation (PACE) programme. The

Real time Feedback will contribute to the evaluation for PfG. The Department are about to set up a regional real time user collaborative group that will have representation from PCC, PPI, 10,000 voices practitioners, HSC experience leads, PHA, and eHealth project managers. The Business Case produced by the PCC will be revised and updated it is hoped that there will be a product in place in 2019/2020.

Future Search points to the need to integrate the various mechanisms we use to link with citizens. The system must use data from users to genuinely inform and support service reform and service delivery. The Future Search also points to the need to blend and use work from the PCC, PPI, patient experience standards, and coproduction in ways that make sense to the public.

In response to questions Mr Morton confirmed that:

- The Department does not want to add to bureaucracy. The Programme for Government (PfG) commits us to an outcome based approach and we need to learn if a user experience resulted in a better or worse outcome. It is necessary to enable complaints, comments and compliments to inform the system regarding outcomes.
- It is important to respect the different component parts while finding a way to avoid duplication.
- The system must be transparent. Board members reinforced the need for the public to be assured that the HSC system is listening and acting upon their input and be held account accordingly.

Dr Edmondson thanked Mr Morton for the update and said the PCC looks forward to contributing to the Future Search implementation plan.

35/18 DIGITAL TRANSFORMATION AND MYNI, MRS EILEEN CURRY

Ms Penney sent her apologies and Mrs Curry kindly presented this programme of work..

The Digital Transformation Service is testing and developing a Social Web Platform called MYNI as part of a NICS Strategy to move to a more linked online technology. This reflects a decade of change in digital behaviour by citizens. The Government Communication Service

is striving to link Government Information Services to make it easier for people to use. The MYNI site is to link all Government Services in NI.

MYNI is a fully interactive site, delivering pro-active communication on government services to individual citizens and linking them to existing government sites. People can opt-in or opt-out to all or part of the site. The site is referred to as a 'circular citizen engagement journey' which enables people to comment, review and share with friends.

Mrs McKissick explained that the Painful Truth has been selected as one of the three test campaigns running on the MYNI site. People can get good information and feel empowered to self-manage their condition.

Mrs Curry said that this initiative has Ministerial endorsement and Public Health is a partner. The Digital Transformation Service is currently recruiting for focus groups that will test the site. Four focus groups have already engaged and a meeting is planned with a focus group on pain. There has been feedback on the pain toolkit and people have been sharing and recommending the link to others.

The Beta-test phase commenced 17 weeks ago. Three campaigns are up and running:

- Food waste
- Dairy farming
- Pain management

In the next two months to June 2018, there will be a focus on more advertising, more stakeholder engagement, testing the site and its content with users and with focus groups.

The Beta testing will continue to August and a report will be provided to the Permanent Secretary in September 2018.

Mrs Curry said that all the campaigns on MYNI link to PfG outcomes. In the future, campaigns can remain on the MYNI site but a Campaign team will decide how long a campaign runs and ends.

On discussion Mrs Curry responded to a number of questions and comments from Members relating to:

- The great potential of MYNI for making the public more aware of government consultations and enabling public feedback;
- The importance of ethical safeguards on the site;

- The future potential to share information from other approved sources/third party contributors.
- The site is at a test stage and links have been shared with the HSC Trusts. Collaboration will be key to development and the PCC can help raise awareness and encourage people to get involved in testing and feedback.
- Partnership working is being established with local Councils with a view to identifying future campaigns.

Dr Edmondson thanked Mrs Curry for the detailed presentation and said that the PCC looks forward to seeing how this work progresses.

36/18 HSC ONLINE AND PATIENT PORTAL, MRS LINDA MCRANDLE, SENIOR CHANGE MANAGER

a. HSC online

Work is continuing to populate the HSC Online information portal with 319 conditions now on the system. There has been a lot of patient input into the design and content of the front page and further testing with service users is about to begin.

b. Patient Portal

Funding has been secured from the Atlantic Philanthropies, the Executive office and the DoH. The functions on the portal will let people see what is in their patient record including new and past appointments, some clinical documents, medications, notifications and alerts, laboratory, x-ray and scan results.

In developing the system, consideration must be given to how patients will interpret test results as it will be important not to make people more anxious after looking at results.

Mrs McRandle demonstrated the log in screen and examples of pages on the portal. Currently the portal relates to secondary care only but the plan is that this will eventually move to primary care.

The portal is currently being built around a dementia pathfinder project. An implementation group is working on development of the portal and the group includes patients, carers and an empowerment officer. They are all involved in adding background detailing the Alzheimer's Society tool 'This is Me', which is similar to the Patient Passport initiative.

- Phase 1 of the project will be completed by the end of the summer and a sample of people will be able to view appointments, a health library, shared files and their circle of care.

- Phase 2 of the project is due to be completed by the end of the year with the addition of access to goals and document service sections.
- Phase 3 will have the addition of medications and laboratory results.

Members discussed the following issues with Mrs McRandle:

- How people with terminal illness might use the Patient Portal in the future. These patients require different support and early access to support which is usually initiated by completion of a DS1500 form.
- The Patient Portal enables patients to have a real relationship with the professionals involved in their care and empowers patients to take responsibility for their care.
- Some clinicians may think that patients should not have access to their information and it will be important to ensure that barriers put in place are not mechanisms for protection.
- There will have to be clear parameters in place around access to records, for example parental access to children's records, which raises ethical questions.
- People will be able to use the portal to prepare for future appointments, preparing questions in advance. It can empower people to self-manage conditions and could help shift the balance of power.

Although the focus is currently on dementia, other clinical areas will roll out quickly such as neurology, long term conditions, rare diseases and midwifery.

A business case has been produced aimed at a minimum of 100 users, but it is hoped to get it out to a wide range of patients, carers and professionals for testing.

Dr Edmondson said that HSC online, the Patient Portal and Real time Feedback have all been championed by the PCC and it is rewarding for the PCC to see the enthusiastic implementation.

37/18 GOVERNANCE AND COMMITTEE REPORT TO BOARD 16-03-18, BOARD PAPER NO. 551

Mrs McNeill outlined the G&A Committee report to the Board and highlighted the following:

a. PCC Management Statement

The CNO wrote to the PCC confirming that she is content for Sponsor Branch to postpone finalising the PCC's Management Statement until

the outcome from Future Search and the consultation on Board composition is finalised.

b. Internal Audit Reports

IA confirmed that the PCC is in a good position as it approaches year-end.

c. BSO Shared Services Update

IA has raised the level of satisfaction from limited to satisfactory for Recruitment Shared Services.

d. IA Plan and Strategy 2018-2019

The G&A Committee reviewed the IA plan for 2018-2019 and recommended this to the Board for approval, with the understanding that the Board will review the plan in September to agree whether the audit of Board composition and skills mix is to proceed.

The Internal Audit reports were noted and the Board approved the IA Plan.

e. Controls Assurance Standards (CAS)

The CAS provides governance assurance to the DoH and the DoH will inform HSC what will replace the CAS which ceased on 1 April 2018. The G&A Committee had confirmed that they feel the PCC Governance Plan provides the Committee and Board with adequate governance assurance. IA also confirmed that the PCC has adequate internal controls in place to provide assurance to IA.

The Committee has asked the Chair of the G&A Committee to seek assurance from the BSO that the number of IA days is proportionate to the size and budget of the PCC.

f. Serious Adverse Incident (SAI)

The paper provided details of a SAI in October 2017 in relation to a problem with docking stations purchased for use with lap tops. The problem has since been resolved.

g. Corporate Risk Register

The Corporate Risk Register was reviewed at the Board Workshop in February and will come to the Board Meeting in June 2018.

h. PCC Governance Plan 2018-2019

The G&A Committee recommended this paper to the Board. The Board approved the PCC Governance Plan.

i. Policies for approval

A number of policies have been updated. A number of policies have also been created and upgraded under the new General Data Protection Regulations (GDPR). The G&A Committee recommended the following policies to the Board for approval:

- GDPR
 - Data Protection Policy
 - FOI Policy
 - Information Security Policy
 - Information Governance Policy
 - Information Risk Policy
 - Data Protection Impact Assessment Policy
- Whistleblowing Policy
- Involving You Policy
- Risk Management Strategy and Policy
- Adverse Incident Reporting
- Fire Safety Policy

Board Paper No. 551 was noted.

Action:

- 1. The listed policies will be sent via email to the Board for approval**
- 2. The Involving You and Whistleblowing Policies will be reviewed at a Board Workshop in May 2018.**

38/18 CHAIRS REPORT

Dr Edmondson had nothing further to add to her report and the Chairs Report was noted.

39/18 ANY OTHER BUSINESS

a. Public Appointments Process for PCC

Applications for the PCC Chair and Board Members have closed with interviews planned for May 2018.

b. Future Search

The Department plans to launch the report on Future Search with the Coproduction guidance in May 2018.

40/18 INPUT FROM MEMBERS OF THE PUBLIC

There were no members of the public present.

41/18 DATE OF NEXT MEETING

The next meeting will be held on Tuesday 19th June 2018 at 10am.
Venue to be confirmed.

The meeting closed at 4.05.

Signed Maureen Edmondson Signed Maeve Hully

Date 19/6/18 Date 19/6/2018
Maureen Edmondson Maeve Hully
Chair of PCC Chief Executive of PCC