

Patient and Client Council

The People's Voice

A summary of the work of the
Patient and Client Council 2009-2016

Revised December 2016

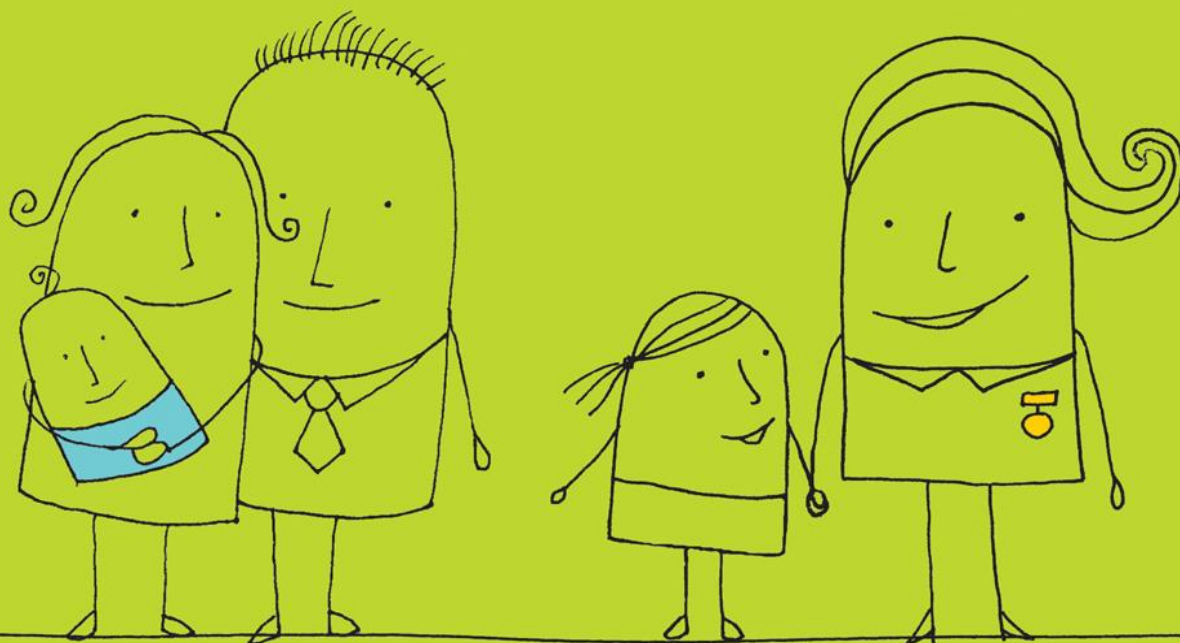


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Foreword

Dear Reader,

For the first time in a Programme for Government, the Northern Ireland Executive has made 'Improving the Quality of the Healthcare Experience' a key indicator. Patient experience is now at the heart of Executive thinking. To which the Patient and Client Council (PCC) says: "Rightly so and thank you."

This report describes key elements of the work of the PCC and its seven-year contribution to achieving this result. It highlights further challenges and opportunities for patients, their families and carers to engage proactively in Northern Ireland's healthcare system.

In 2009 the PCC was deliberately set up by statute to have an independent voice. Its purpose is to serve the priorities and concerns of the user public. The PCC's approach has always been based on clear principles:

- The gathering of robust evidence;
- Relaying this evidence into the system; and
- Creating mechanisms for open, independent and constructive engagement.

Put succinctly, this is transparency and independence. This approach has been key to achieving change in the system.

Throughout, the PCC has championed the involvement of users at all levels in the development and delivery of health and social care services. As a result it is now accepted that this is key to providing higher quality patient and user-centred care. PCC evidence says that experienced service users are often well placed to advise on how the gaps in the system can be filled. The PCC welcomes the current Executive's acceptance of this.

Going forward, it is no secret that the whole system needs radical change. A library of reports and a plethora of overlong waiting lists testify to that. The PCC continues to meet the ongoing challenge to make sure that those who deliver health and social care respond positively to the user's voice. We need a model where users are no longer seen as passive recipients of care. The new model must recognise that users: fund the service through their taxes; are consumers who deserve a high quality service; could be active partners involved in shaping their healthy lifestyles; and be patients willing to manage their own health and self-care if adequately supported by caring professionals.

The seven-year journey from fighting to be heard, through to being invited to speak into the health and social care system, to arriving as a key indicator on the Executive agenda has been challenging and worthwhile. Managing on a small budget of £1/citizen/year, the PCC is grateful for those who have listened and who now eagerly include service users in their planning. The PCC calls on more to follow that good example and is determined to keep trumpeting the service user's case.

None of this would have been possible without the team of dedicated staff who work tirelessly to seek out the unheard, listen to them and feed their voice into the system. Thank you to every one of them and to my Board colleagues who set the strategy, steward the resources, scrutinise the work and stretch, yet support, the team.

A handwritten signature in black ink, reading 'Maureen Edmondson'.

Dr Maureen Edmondson
PCC Chair

1.0 Introduction

The Patient and Client Council (PCC) was created on 01 April 2009 as part of the reform of Health and Social Care (HSC) in Northern Ireland. We act as a powerful, independent voice for patients, clients, carers and communities.

Our role is to be an independent, informed and influential voice that makes a positive difference to the health and social care experience of people across Northern Ireland. From the outset the PCC has been active in engaging with people and gathering their views through a variety of innovative methods. Our vision is a HSC service that is shaped by the needs and experience of patients, clients, carers and communities. In order to achieve this, we:

- Put people at the centre of all we do;
- Use evidence from people as a guide to our work;
- Speak independently;
- Work in partnership; and
- Are open and transparent about our work.

In the past seven years, we have spoken to tens of thousands of people to understand their views and priorities in order to influence and improve service delivery and to shape future service provision. Some key facts of the past seven years are outlined on **Figure 1** (pg. 5). Highlights of each year are also provided in **Appendix 1** (pg. 42) and a list of our publications is included in **Appendix 2** (pg. 45).

Most importantly, however, is how the PCC has used this engagement to not only shape our projects, but also to influence improvements in service delivery for patients and clients. An essential part of the work of the PCC has been to achieve and demonstrate positive outcomes for service users. This takes patience and determination, and success is evidenced in different ways. Influencing commissioning, starting a dialogue, creating forums for partnership working with clinicians and patients, and securing funding to improve services for hard-to-reach groups are examples of where asking, hearing and responding to the patient experience has resulted in service improvement. While there has been significant development, we remain disappointed on the lack of progress on some key aspects of the service, including waiting times and the learning from complaints.

The purpose of this report is to: review our experience to date and highlight some of our key successes; reflect on some of the challenges we still face and identify how the voice of people can be used to further improve patient experience.

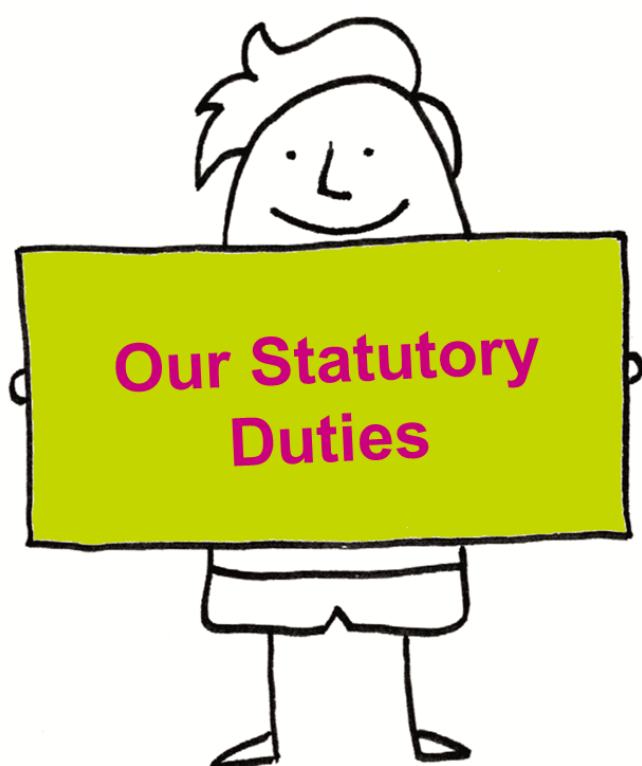
Figure 1: Seven years at a glance



2.0 Our statutory duties

The PCC has four main statutory duties that underpin our work (see **Figure 2**).

Figure 2: Our statutory duties



Statutory duty 1: Listen and act on people's views

To represent the interests of the public by engaging with them to obtain their views on services and engaging with health and social care organisations to ensure that the needs and expectations of the public are addressed in the planning, commissioning and delivery of health and social care services

Statutory duty 2: Encourage people to get involved

To promote the involvement of patients, clients, carers and the public in the design, planning, commissioning and delivery of health and social care

Statutory duty 3: Help people make a complaint

To provide assistance to individuals making or intending to make a complaint relating to health and social care

Statutory duty 4: Promote advice and information

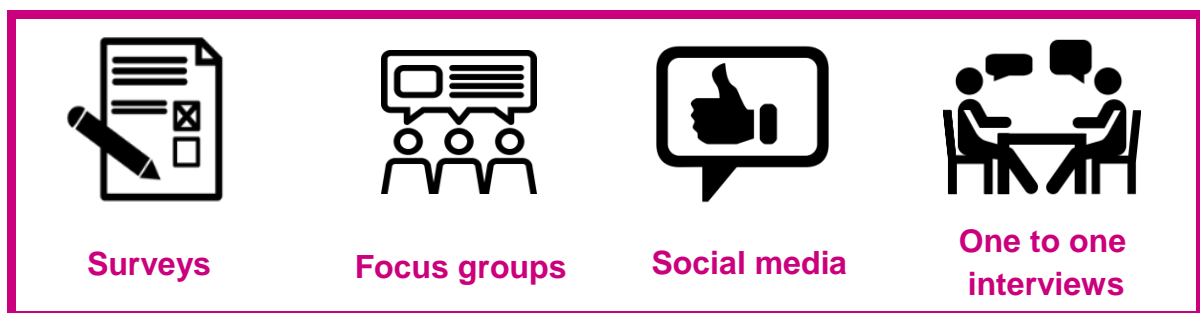
To promote the provision of advice and information to the public about the design, commissioning and delivery of health and social care services

This report provides an overview of how we have met these statutory duties, outlining some of the successes, challenges and lessons we have learnt along the way.

3.0 Statutory duty 1: Listen and act on people's views

From the outset the, PCC has been working directly with people to gather their views on health and social care using a variety of innovative methods (see **Figure 3**). We have engaged a wide cross section of the community in order to represent and promote the views of the public.

Figure 3: Methods the PCC has used to gather people's views



This has enabled us to complete a number of projects which reflect a wide variety of views on a diverse range of issues including:

- People's Priorities, including young people's and carers' priorities;
- Older people's experience of domiciliary care;
- Listening to the learning disability community;
- People's experience of chronic pain; and
- Rare diseases.

This is not an exhaustive list of our projects, but a selection of work that highlights the value of working in partnership with service users. The process of engagement and key findings from these projects is described in more detail overleaf.

3.1 People's Priorities (including young people and carers)

It is important that decisions that are made about HSC services address the needs and expectations of the public. From the outset, the PCC has been active in identifying people's priorities so that the planning and investment in health and social care reflects this.

What we did

In 2009, the PCC carried out a consultation exercise with the public to inform the Department's Priorities for Action 2010/11. The Report on Public Engagement on Priorities for Action included the recommendation that 'the process of engaging with the public in the setting of priorities should be further developed by the PCC in 2010 and beyond'.

Since then, there has been a series of People's Priorities projects to gather the public's views on their health and social care priorities. Specific projects on young people and carers have also been completed to gather a comprehensive range of views.

In total, more than 9,000 people have contributed to these projects through surveys, street consultations, focus group discussions and interviews.

Key findings

People want accessible services that provide timely and high-quality care, delivered by well-trained and supportive staff employed in sufficient numbers. Specific services such as mental health services, cancer services, and primary care, particularly GP services, have been identified as top priorities for the public in every People's Priorities to date. The cost of services and appropriate management of services within a constrained financial environment have also been raised.

Young People's Priorities (2010), People's Priorities (2014) and Carers' Priorities (2015) are detailed in **Table 1** (pg.9). While many of the priorities across the three groups were similar, health promotion and the provision of more up to date equipment for diagnosis and treatment were a priority for young people, and better support and recognition for their contribution was important to carers.

Table 1: Young People's Priorities (2010), People's Priorities (2014) and Carers' Priorities (2015)

	Young People's Priorities 2010	People's Priorities 2014	Carers' Priorities 2015
1	A&E services	Frontline health and social care staff	Better community care to support carers
2	Staffing levels	Waiting times	Increased focus on frontline staff
3	Waiting times	Quality of care	Better financial support for carers
4	Quality of care	Care of older people	HSC should value carers
5	Health promotion	A&E services	More respite / improved access to
6	Mental health and learning disability services	Funding, management, and cost-effectiveness	More support (general).
7	Care of elderly people	GP services	Improve HSC services
8	Funding	Access to a full range of health and social care services locally	Improved communication
9	Cancer care and research	Cancer services	Improve quality of care
10	Equipment	Health and social care services for children and young people	Reduce waiting times / increase appointment slots

What we achieved

In total, more than 9,000 people have contributed to the People's Priorities projects. The findings in these reports have shaped the PCC's subsequent business plans and the Commissioning Plans for the Health and Social Care Board (HSCB), Public Health Agency (PHA) and Local Commissioning Groups (LCGs). Indeed, the HSCB and PHA's Commissioning Plan 2015/16 included the top 10 issues raised by people across Northern Ireland as described in People's Priorities.

This innovative approach to gathering people's views has been recognised in Chartered Institute of Public Relations Awards in 2012 and 2013, and in the Northern Ireland Commissioner for Children and Young People Participation Awards in 2013.

The significance of influencing commissioning should not be underestimated. It represents a shift from a service-led approach to commissioning, to one that considers the priorities of citizens and, as such, represents a culture change that may not have happened without the robust independent evidence gathered through our work.

3.2 Older people's experience of domiciliary care

Providing high-quality health and social care to an ageing population has been identified in every People's Priorities to date. People want services they can have confidence in as they grow older, helping them to live as full and independent a life as possible within their own homes.

Recent policy developments in Northern Ireland have indicated a shift towards community care.¹ A growing and ageing population, however, means that community care faces challenges in terms of resources and increasing demands on the service.^{2,3} It was in this context that the PCC sought to understand people's views on domiciliary care services.

What we did

The PCC worked with the HSC Trusts to explore the experiences of older people and their carers receiving a domiciliary service, and their views on future service delivery. In total we spoke to 1,161 people through a questionnaire, interviews and focus groups.

Key findings

This project identified that domiciliary care was really valued. There were concerns about the quality of the service, however, and its future provision, especially with anticipated financial constraints.

Overall, most older people in receipt of domiciliary care and their carers acknowledged the value of the service, with many highlighting that they could not cope with the basic activities of daily life at home without it. Some people stressed the importance of the service as a source of social and emotional interaction for them.

"I am very pleased with my care package and without it I wouldn't be able to live independently in my own home. They treat me with dignity and respect and are always polite and courteous to me." **Care at Home participant**

However, the people we spoke to also had criticisms of the service. In particular, many people highlighted that the short duration of visits, as well as the inflexibility of the time of their visits impacted on their quality of life. Many people noted that they still relied heavily on relatives to support them in routine daily tasks. Others described how communication also proved problematic at times. People had concerns that budgetary constraints on the service would affect service provision and result in a loss of the service altogether.

"We never got a choice of times, always just whatever time they can fit you into a rota... the main problem is there's no flexibility at all." **Care at Home participant**

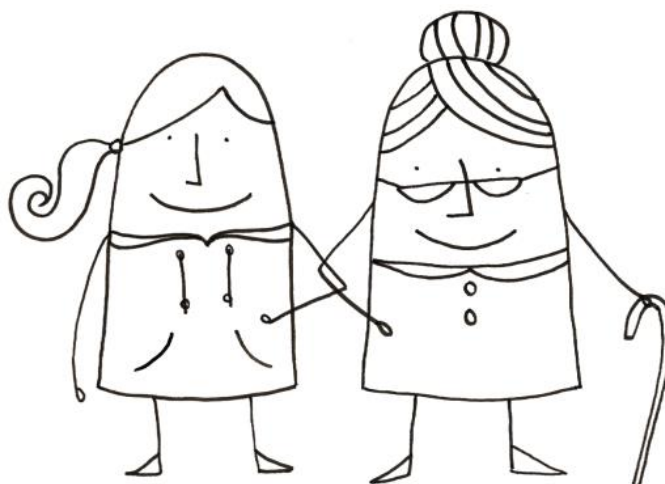
"Too rushed – they have too many people to see. They can't wash you properly. They don't have time to shower me so I only get washed with a cloth in the bedroom. It's not good enough." **Care at Home participant**

"The thing is she will always need this, she's not going to get better, we need it in place and we need it to stay in place." **Care at Home participant**

What we achieved

The experiences and recommendations in our report have informed the following work, which reflects the voice and experience of older people and their carers:

- The HSCB completed a major review of domiciliary care for older people and these outcomes are currently being implemented;
- The PHA undertook a review of service user experience as part of the '10,000 Voices' project; and
- The Department of Health has commenced work on a major reform of adult social care that will lead to changes in legislation.



3.3 Listening to the learning disability community

In conjunction with the Bamford Monitoring Group (see **section 4.4** pg.23) we have worked alongside people with a learning disability and their families. Two projects have achieved significant outcomes: 'My Day, My Way' and 'Future Planning for Older People Caring for Adult Dependents with a Learning Disability'.

3.3.1 'My Day, My Way'

The 'My Day, My Way' project looked at the experience of people with a learning disability who attended day centres that provided opportunities for learning life skills and recreation. These are commonly known as 'day opportunities'.

What we did

We asked a total of 1,190 people to tell us about their experiences of day opportunities.

Key findings

The majority of people with a learning disability said they were very happy with how they spent their day. People really valued having a variety of activities to do and places to go each day.

"You get to make your own decisions about your day." **My Day, My Way participant**

The majority of people said that they have some choice in their day. However, in most circumstances, people with a learning disability were only able to identify that they had choice in what activities they did at a centre, but few mentioned having a choice about which centre they went to. It was noted that flexibility is also highly important for people to be able to see if the options available meet their needs.

"We would just like to be busier and try new things, but we don't know what because we don't know what's available to us." **My Day, My Way participant**

"You don't know if you like something until you've tried it." **My Day, My Way participant**

What we achieved

The PCC made a number of recommendations in this project, including that the Department of Health should further develop day services and day opportunities, and that the HSCB and HSC Trusts should develop information and advice on day opportunities and services for people with a learning disability in Northern Ireland.

Following the publication of 'My Day, My Way', the HSCB used the findings in this report to inform its review of day opportunities currently being rolled out across the five HSC Trusts.

3.3.2 Future Planning for Older People Caring for Adult Dependents with a Learning Disability

In 2012 the PCC was approached by a small number of elderly carers who were caring for adults with a learning disability and were concerned for the future of their loved ones when they would no longer be able to care for them.

As a result of these conversations, the PCC worked to understand the needs of elderly carers with a view to championing change together.

What we did

A series of workshops were held to facilitate an opportunity for carers and key stakeholders to explore the issues in detail. It provided a unique opportunity for older carers to engage directly with policy makers and decision makers in an open and transparent way. We encouraged collaboration between organisations to identify innovative and practical solutions for future planning. People were invited to attend local workshops to take forward their concerns and work collaboratively with key stakeholders to find solutions to their needs.

This project and our involvement was aimed at supporting carers to engage with organisations across HSC services, as well as the Northern Ireland Housing Executive, to understand the extent of the problem and to facilitate discussions that could lead to practical solutions to support ageing carers.

Key findings

The workshops and discussions highlighted that carers had many concerns and unanswered questions surrounding the future care of their loved one (see **Figure 4**).

Figure 4: Workshop findings



What we achieved

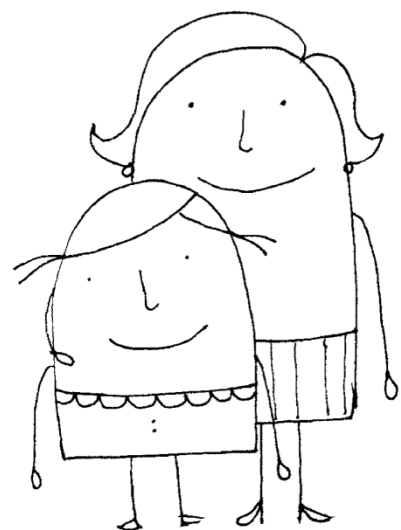
As a result of this project, future planning for older people caring for adult dependents with a learning disability is now a policy and commissioning priority. As a result a number of outcomes have been achieved.

The University of Ulster was commissioned to develop a training package for keyworkers and carers. The PCC supported carers, who have been recognised as having a lifelong wealth of experience, to assist in the development and delivery of this training. This training was offered to all keyworkers in 2014. A comprehensive portfolio of information has also been made available. The PCC is currently working to have this information made available online. The HSCB has also pledged additional training for keyworkers and social workers through the University of Ulster.

The HSCB undertook a needs assessment and business case on carers looking after adult dependents aged 35-plus. This led to ****service change** and recurrent funding being made available of £1 million in 2015/16, rising to £2 million in 2016/17. This is recurring revenue funding to support older carers across Northern Ireland to plan for the future of their dependents. This marks a significant breakthrough at policy, commissioning and service delivery level, and is currently being rolled out to all five HSC Trusts.

**** Post publication amendment to report on 16-12-16**

Another positive outcome is the establishment of local reference groups to enable carers to work directly with the Northern Ireland Housing Executive to further this work. Most significantly, the project is making a major difference to family life, providing people with the necessary support to make plans for the future. While much progress has been made, it has required continuous engagement by the carers, supported by the PCC, to get this far with the various organisations and departments. It will be important that momentum continues on this initiative, despite a period of organisational change in HSC services.



3.4 The Painful Truth

People who experience chronic pain approached the PCC to talk about their day-to-day lives and the difficulties they have engaging with healthcare services. They felt that the services available to them were not adequate and, as a result, they were not getting the care and support that they needed.

What we did

We established a small working group of patients and professionals, and worked collaboratively with the Pain Alliance of Northern Ireland (PANI) to develop a specific project.

This project aimed to provide a voice for people to describe how pain affects their lives, offer their views on treatment and care, and suggest how pain services should improve for them in the future. More than 2,500 people participated in this project.

Key findings

Based on our discussion with people who experience chronic pain we produced the Painful Truth report. The key findings included:

Pain affects three of the most central areas of people's everyday life – ability to work, home life and leisure activities. Many people also commented on the 'invisibility' of pain. People felt that healthcare staff did not acknowledge their symptoms and some suggested that the wider public, and family and friends can make assumptions that people who complain about chronic pain are really just 'lazy' or 'attention seeking'.

"You don't want to let people know how depressed the constant pain leaves you. How sometimes you wonder how futile life is. How your social life and friends disappear as you are too sore or drugged to go out." **The Painful Truth participant**

Getting a diagnosis can be difficult and, often, a lack of understanding by some health professionals contributed to a delay in their diagnosis.

"I have had a negative experience with regard to diagnosis and treatment. Over 10 years I have seen a multitude of doctors... it has been strenuous on me as an individual but also on my family." **The Painful Truth participant**

Health professionals should spend more time working with their patients to find more effective treatments, other than medication, to manage their pain. Some people felt that complementary therapies could help with chronic pain and should be more

widely available through the health service.

People with chronic pain want a coordinated, holistic service, providing ongoing medical, physical and emotional support by compassionate, understanding health professionals in the future.

What we achieved

The Painful Truth made 10 key recommendations that were endorsed by the Minister for Health. Following the publication of findings, the Department of Health acknowledged that chronic pain is a condition in its own right. The recommendations that are listed below are all in the process of being implemented.

- A scoping paper produced by the HSCB/PHA on chronic pain resulted in the development of the Regional Pain Forum. The PHA is leading this piece of work, with the HSCB and PCC as key partners in the initiative. The PCC is leading in the development of a Service User and Carer Reference Group to facilitate co-design in this service improvement exercise;
- The Regional Pain Forum is actively developing plans and specifications for increased access to community-based self-management programmes, better information, more primary care training and service provision, as well as the remodelling and strengthening of secondary care services;
- Patients have been offered a range of personalised pain-management care and support programmes, including supported self-management. Long-term pain management approaches are now to be embedded into Integrated Care Partnerships;
- The Painful Truth has been presented at both the European Union (EU) and Westminster, and is helping to shape international and national policy;
- The Queen's University School of Medicine, Dentistry and Biomedical Sciences has incorporated specific modules on pain management into the undergraduate medical course, while Ulster University's School of Health Sciences has included The Painful Truth as essential reading for its physiotherapy undergraduate course;
- **In 2016/17, the HSCB is exploring the potential for Integrated Care Partnerships to establish chronic pain as an additional priority area;
- Pain management has also been included in the Draft Commissioning Plan 2016/17 for the first time, where an extensive list of priorities has been attached to chronic pain.

This work has been welcomed by the PCC and is a good example of how co-production of solutions can make a positive change, both at policy and commissioning levels.

3.5 Rare diseases

There are people living with a range of rare diseases who have little or no voice in health and social care. A rare disease is defined by the EU as one that affects less than five in 10,000 of the general population.⁴ The numbers of people with an individual disease may be small, but their symptoms are often ill defined and wide ranging, therefore their healthcare needs are significant.

What we did

Working with a group of people with a rare disease and their carers, the following was achieved:

- A survey was completed to identify people's experience of getting a diagnosis; and
- A network to support people with rare diseases and their carers was established.

In total, 132 people responded to the questionnaire.

Key findings

Our findings clearly demonstrated the difficulties and frustrations faced by people affected by a rare disease. Many people went undiagnosed or misdiagnosed for long periods of time and found that their condition was misunderstood. In some cases this led to inappropriate treatment and care. Once diagnosed, patients often experienced considerable delays while waiting for services to start, particularly those provided by allied health professions.

"Because my disease is very rare, the GP hadn't heard of it... putting everything down to postnatal depression." **Rare Diseases: Experience of Diagnosis participant**

"Prior to diagnosis, I was basically told the illness was in my head and to get on with it." **Rare Diseases: Experience of Diagnosis participant**

Many carers provided care for more than 20 hours per day, with little support from HSC services and often with limited information and advice for carers and patients. People highlighted that the lack of information was a major concern.

"Generally with a rare condition it hits you hard... where do you go after that? Internet and use of information can be frightening, outdated or wrong." **Rare Diseases: Experience of Diagnosis participant**

What we achieved

The PCC facilitated the development of the Northern Ireland Rare Disease Partnership (NIRDP) (see **Figure 5**).

Figure 5: NIRDP aims

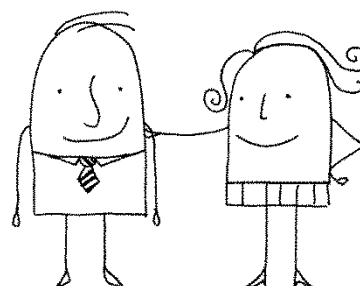


We provided administrative and logistical support for NIRDP in its first year of operation. NIRDP has since developed into an independent charity and has grown to around 150 members from an initial meeting involving 12-15 people. Members of the group sit on a number of steering groups including, the implementation of the NI Rare Disease Plan, the UK Rare Disease Advisory Group, the UK Rare Disease Forum, and on the board of the charity Rare Disease UK.

As well as lobbying on behalf of patients and carers, NIRDP has run training courses with the Royal College of Nursing in Belfast, and held seminars on rare diseases for medical students at Queen's University, as well as other interested parties. Members contribute to lectures on medical education to students, and regularly speak at conferences and other events on issues of rare disease, patient voice and equality.

NIRDP also hosts an annual Rare Disease Conference to coincide with European Rare Disease Day. Following the conference in February 2016, the Minister for Health announced a £190,000 new investment to ensure that patients from Northern Ireland had full access to new genetic tests for rare diseases. Furthermore, since the launch of the Northern Ireland Rare Disease Implementation Plan, the Department has invested £3.3 million to establish a genomics medicine centre to enable patients in Northern Ireland to participate in the UK 100,000 Genomes Project.

This work is a good example of how working in partnership with people can help lead to improvement in service delivery.



3.6 Summary of achievements

Through listening to people and capturing their views the PCC has been able to influence service delivery in line with the public's expectations. Achieving change, however, takes time – sometimes years. Each project required significant commitment from PCC staff and continuous engagement to get to this stage. **Table 2** provides an overview of the outcomes we have achieved from specific projects.

Table 2: Summary of key achievements

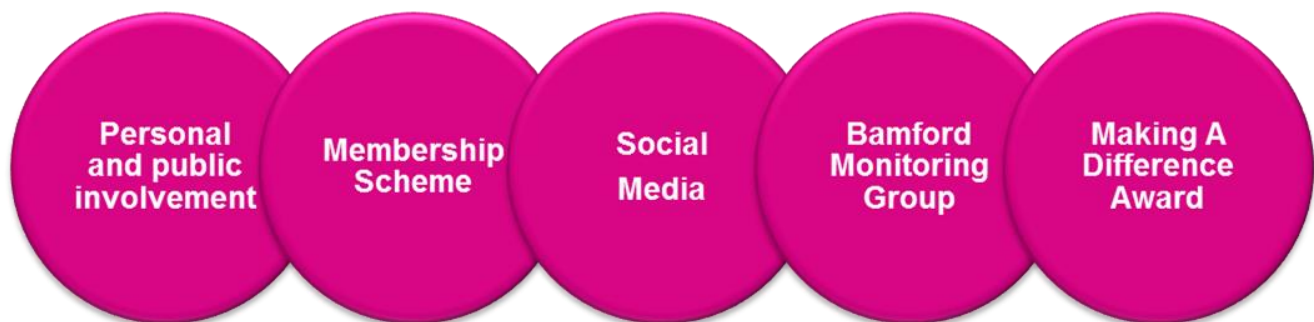
Project	What did we do?	Outcomes
People's Priorities for Health and Social Care	7,860 people contributed their views and opinions on health and social care.	The Regional Health and Social Care Board (HSCB) Commissioning Plan clearly demonstrates how the PCC People's Priorities has influenced the commissioning process.
Young People's Priorities	1,244 16-21 year olds contributed their views and opinions on health and social care.	Minister for Health endorsed this report. Local councils also welcomed findings and used them to help shape children and young people's services. The PCC was also invited to discuss findings with the Health Committee.
Older people's experience of domiciliary care	1,161 people shared their views and experiences of domiciliary care.	A number of initiatives are ongoing in this area, including the HSCB's review of domiciliary care and the reform of adult social care. The PCC is working to ensure that the user voice is heard during these initiatives.
My Day, My Way	1,190 people shared their views and experiences of day opportunities for people with a	The HSCB Regional Plan agreed to reform day opportunities. This is currently being implemented across the five HSC Trusts to ensure people have

	learning disability.	new and innovative day opportunities.
Future planning for older people caring for adult dependents with a learning disability	A workshop was attended by more than 70 older carers and key decision makers to explore issues in relation to future planning.	Future planning is now a policy and commissioning priority. There is also an additional £2m recurring funding to support older carers of people with a learning disability to plan for the future.
The Painful Truth	2,525 people contributed to this project by providing their views and experiences of the treatment, care and personal impact of long-term pain.	Minister for Health endorsed 8 of the 10 recommendations from this report and they are currently being implemented.
Rare diseases	Set up rare disease network.	The network lobbies for better services, additional money and recognition of rare diseases, resulting in £3.3m additional funding for a genomics medicine centre. The network also contributes to training undergraduate nurses and doctors.

4.0 Statutory duty 2: Encourage people to get involved

The PCC has a statutory duty to promote the involvement of patients, clients, carers and the public in the design, planning, commissioning and delivery of health and social care. The PCC has done this through a variety of methods as outlined below (see **Figure 6**).

Figure 6: How the PCC promotes involvement in health and social care



4.1 Personal and Public Involvement

The PCC has a team of Personal and Public Involvement Officers (PPIs). It is their role to promote the involvement of the public in health and social care across Northern Ireland. The team does this through going out into the community and directly speaking to members of the public, such as visiting community groups, meeting people in shopping centres and attending local events. They encourage involvement through a variety of ways and aim to promote our work and how people can be involved in health and social care. The team is also responsible for capturing the public's views on specific PCC projects.

4.2 Membership Scheme

One of the key ways that the PCC promotes involvement is through our Membership Scheme. This initiative is the first of its kind within HSC organisations in Northern Ireland and is open to everyone aged 16 and over who lives in or uses HSC services in Northern Ireland.

Launched in April 2010, the PCC Membership Scheme now has more than 12,400 members. It is made up of people from across Northern Ireland, and represents a diverse range of service users.

The scheme is an effective way of involving those who are interested in shaping the healthcare system in our country. It offers a straightforward and accessible means of obtaining viewpoints and opinions from people on a regular basis. Members can be involved in a number of ways – by post, online or face-to-face. Every so often, members meet to take part in discussions or debate tough decisions, giving service users, carers and members of the public genuine opportunities to have their say on issues that matter most to them.

The feedback that we receive from the Membership Scheme gives us evidence that helps inform and influence the development, planning and provision of healthcare services. The Membership Scheme has made a significant contribution to a number of projects including: hospital meals, car parking at HSC facilities, the HSC budget, rural dwellers' issues, and palliative and end of life care.

Members have also volunteered as lay representatives on projects initiated by HSC organisations. These include Integrated Care Partnerships (ICPs), Reference Groups for the Department, and Service Review Forums at Board and Trust level.

4.3 Social media

The PCC has promoted involvement of people through social media. We were the first HSC organisation to develop both Facebook and Twitter accounts. This enables us to communicate with people across Northern Ireland and is an extremely useful tool to encourage people to get involved when it is convenient for them rather than restricting involvement to meetings. In particular, using social media enables us to have a continuous dialogue with the public and is extremely useful to gauge people's views on topical issues in real time. The development of a weekly blog also encourages people to engage with us in a contemporary and immediate way.

4.4 Bamford Monitoring Group

At the request of the Department of Health, the PCC established the Bamford Monitoring Group (BMG) to monitor how changes being made to law, policy and services arising from the Bamford Review of Mental Health and Learning Disability⁵ are affecting people and communities, and how changes to these services are affecting those who use them.

Illustrations of the involvement from BMG members are clear and expressed in many ways. BMG members have been called to sit in a wide range of bodies established to forward the Bamford recommendations and the Government's Action Plan. The bodies include steering groups, strategy development groups, implementation groups, documentation groups and research groups in a wide range of different areas.

Over the past seven years, the BMG has also provided advice and support in the delivery of a number of specific PCC projects and reports. BMG members have been involved in identifying project areas, designing projects and sharing this information with key decision makers (see **Figure 7**).

Figure 7: Some examples of BMG projects



The BMG has been innovative in its approaches to Personal and Public Involvement (PPI) and has received a commendation award at the Innovation Elevation Awards in recognition of an easy-to-use approach in communication to support people with a learning disability.

Innovative approaches include:

- BMG is made up entirely of service users and carers.**
The BMG comprises 16 members, with equal representation from service users and carers, as well as people with a mental health or learning disability. The group meets monthly and is chaired and managed by service users.
- A triologue approach to mental health services.**
The Open Dialogue Mental Health Conference hosted by the BMG in conjunction with the Mental Health Triologue Network Ireland in June 2011

used a trialogue approach to help shape outcomes. This learning approach acknowledges that the collective expertise is greater than any one person or group of people. It is a three-way conversation (in this case service providers, service users and academia). In total 145 mental health service users, carers, healthcare professionals, university staff, voluntary organisations and community groups took part to discuss if Bamford was making a difference. It was the first time a trialogue approach was used to help shape HSC services in Northern Ireland.

- **Service users as researchers.**

The BMG completed a project entitled 'Support after leaving mental health hospitals, 7 Day Follow Up Patient Experience Evaluation'. This was significant because all the researchers on the project were mental health service users and, as such, could add insight and depth to the study that might not otherwise have been achieved. This form of research is gathering momentum but was ground-breaking at that time. This project was well received and findings were shared at the 2012 INVOLVE conference as an example of a best practice approach of PPI, demonstrating the importance and value of this project.

4.5 Making a Difference Award

The PCC Making a Difference Award celebrates the improvements that come as a result of HSC Trusts, patients and service users working together. Each year, HSC Trusts share examples of strong partnership working, and these examples are evaluated by a judging panel made up of members of our Membership Scheme – 'real people' from across Northern Ireland.

Services are truly patient-centred when people are involved and listened to. The Making a Difference Award is evidence that when people work together, services can change for the benefit of everyone.

5.0 Statutory duty 3: Help people make a complaint

One of the four statutory functions of the PCC is to provide assistance to individuals making or intending to make a complaint relating to HSC services. Our complaints support role is specifically defined in the HSC Reform Act 2009 as:

‘Providing assistance (by way of representation or otherwise) to individuals making or intending to make a complaint relating to health and social care for which a body to which this section applies is responsible’.

Our team of Complaints Support Officers provide a free, independent and confidential service to anyone wanting advice and assistance at any stage in the complaints process. The type of assistance clients require is outlined in **Figure 8**.

Figure 8: Type of assistance our clients require



Not all of the cases we deal with are formal complaints. Very often, people are simply looking for advice and information. That's why our Freephone helpline was set up in November 2014. Through the helpline we aim to support people to get issues or concerns resolved as quickly as possible. This often prevents a situation arising that can lead to a formal complaint. Since its establishment, Complaints Support Officers have assisted more than 2,000 people on the helpline by finding the answers to their query or directing them to their local HSC teams or to other appropriate external organisations for information.

Since 2009 we have spoken to more than 18,000 people through the Complaints Support Service. Major recurring themes in our work include HSC staff attitude, waiting times and communication. Often, the clients that we have supported through to the end of their complaints journey have said that they wanted simple but

important outcomes, namely:

- An explanation for what went wrong;
- Reassurance that it won't happen again;
- An apology; and
- Service change to ensure that what happened to them never happens again.

People also tell us that they experience frustration at a lack of information and poor communication in the handling of their individual complaint. The key challenges people tell us about include:

- Reluctance to make a complaint close to the source of their care in case it affects how they are treated;
- Not believing that making a complaint will make a difference;
- When a complaint is made, the process can be bureaucratic, intimidating and slow; and
- Not being listened to by the HSC Trust.

HSC Trusts have worked to address problems in the complaints service. In August 2015 the PCC Board met with senior executives of each HSC Trust, and the PCC was encouraged to learn about the variety and number of initiatives happening across the Trusts with a view to improving the HSC process, so that in future:

- Complaints are responded to within agreed timescales;
- People receive timely feedback on what organisations have learned and changed as a result of complaints;
- The system as a whole takes action to address the recurring causes for complaints; and
- There is a more collaborative resolution as to how complaints are dealt with.

Complaints can also lead to genuine systematic learning in health and social care, and have the potential to improve both patient experience and service delivery. The stories that follow are examples of actual complaints that our Complaints Support Officers have helped with and illustrate some of the outcomes we see in our day-to-day work. The examples are from across Northern Ireland and represent different complaints and outcomes. Each case study provides an example of how making a complaint can make a difference for the person involved and, in some cases, ensure that services change and improve in the future.

Case study 1

A client contacted the PCC following what they believed was misleading information about their care and treatment by a HSC Trust. This poor communication led to the patient having unnecessary major surgery because the Trust was not clear with them about the extent of their condition.

The client tried to sort this out directly with the Trust, but was frustrated when they did not receive a timely response and contacted our Complaints Support Service for advice.

Subsequent to our involvement, the client was accompanied by the PCC to a meeting with the Trust, where the following outcomes were agreed:

- The Trust apologised for poor communication;
- There is an opportunity for the client story to be shared as a learning tool;
- More support for junior doctors would be provided; and
- It was also noted that this story would be used as an example in postgraduate medical education in the Trust.

Case study 2

A client contacted the PCC for support to complain about a lack of information regarding travel arrangements for surgery outside Northern Ireland. This included flight times, airport transfers, accommodation, as well as a lack of information regarding payment for meals and accommodation.

The client spent six weeks trying to get information from the HSC Trust and, in the end, resorted to contacting the travel agent directly the day before the journey was to take place to find out what was happening.

The PCC supported the client to complain to the Trust. While the client was not satisfied with the Trust's response, the Trust made a sincere apology for the delays in paying the expenses claim and assured the client that there would be closer liaison between departments in the future.

The Trust advised that all patients travelling outside Northern Ireland for treatment were now given an information leaflet about the process and their entitlements. Despite the length of time to get the various issues resolved, the client was satisfied with this outcome.

Case study 3

The PCC was contacted by a client who was unhappy about the treatment and care their partner, who had Alzheimer's disease, had experienced in hospital. The client was also unhappy with the level of communication they received from staff. The client had made a verbal complaint to the ward manager, but the client was unhappy with the response and wanted to ensure that other patients would not be treated the same way in future.

The PCC supported the client with their complaint and the client received a response, where the following outcomes were outlined:

- The HSC Trust offered an apology on behalf of all staff concerned;
- They identified additional training and how it was going to be implemented;
- Specific measures the Trust committed to included attention to consultation and communication with families, and the maintenance of effective records to support good care and good communication;
- The Trust pledged to pass on lessons learned from the complaint through staff training and supervision, with an emphasis on the need to treat all patients as individuals and meet their needs within agreed care plans.

Case study 4

A client contacted the PCC a few months after their partner had passed away. The client's partner, who had Parkinson's disease, had been admitted into hospital where it was discovered they had terminal cancer and passed away a few days later. The client described a lack of understanding about Parkinson's disease among the staff caring for their partner and how this had resulted in a number of problems, such as the patient being left unsupervised. The client felt there were additional issues, such as failure to provide medication and issues with cleanliness on the ward. However, the client was most distressed over the fact that their partner had been told they only had a short time to live without the family present for support.

A Complaints Support Officer attended a meeting with the client and the HSC Trust:

- Offered an apology;
- Proposed an action plan to address the issues that had been outlined by the client;
- Measures proposed included more guidance from senior to junior staff on breaking bad news; the provision of name badges; making it clearer on the Trust website how patients could complain and to set up a visitors' clinic, to be held every day for two hours to give families the opportunity to discuss any queries with members of staff either at the bedside or somewhere more private.

6.0 Statutory duty 4: Promote advice and information

The PCC has a statutory duty to promote the provision of advice and information to enable people to make more effective use of our HSC services, as well as empower them to make more informed judgements about their care.

Since 2009, people have consistently raised concerns about the lack of information on HSC services. In every People's Priorities' publication, they have highlighted the need for more advice on health promotion, as well as up-to-date information on the services that are available to them.

In making our recommendations to the Department, HSCB and PHA over the past seven years, the PCC has argued that providing quality information will enable people to better manage their health and wellbeing, and make more effective use of HSC services.

In addition, it would also help patients to make fully informed decisions about their treatment and care. Information is not an optional extra – good health information is fundamental to delivering person-centred care, which is one of the changes the Department of Health promised in 2011 as part of Transforming Your Care.¹

Other parts of the UK have good information and advice services. Wales has NHS Direct Wales, England has NHS Choices and Scotland has NHS Inform. All of these have a 'one-stop shop' website for accredited information on health conditions, as well as the range of health services available in their areas.

Since 2012, the PCC has been advocating for the availability of similar information in Northern Ireland. The establishment of the HSC online project in 2012 was a major step forward. The objective of this project is to create a single portal that will be the primary source of information on all HSC services available in Northern Ireland, as well as promoting education and self-care.

This service is now being rolled out in three phases and will be accessed through the NI Direct official government website. It is currently undergoing some final refinements before going live to the public in the near future.

The website will cover a wide range of HSC topics, including preventative and self-management advice, healthy lifestyle choices, health conditions and available treatments. It will also signpost people to services and set out the standards to expect when receiving care.

There are two significant additions to the website that have come directly from our work:

- The inclusion of an online GP appointment booking and repeat prescription service is very welcome as this was flagged up in the 'Access to GP Services' project completed in 2013/14; and
- Information is now available on average waiting times for urgent care services. This real-time information helps people make informed choices about accessing emergency care. The PCC, in conjunction with service users, were instrumental in the development of this information, which was produced in response to findings in our report 'Care When I Need It, A Report on Urgent Care Services' published in 2013.

There will also be a directory of services available exclusively to healthcare professionals, which should enable them to make faster, more accurate diagnoses, prescribe appropriate treatments and/or referrals, and improve outcomes for the individual.

As the project commenced, we facilitated the patient, client and carer voice to be heard at every stage to ensure that service users had a strong voice and a key role in the design and functionality of the website.

Citizen workshops, coupled with small groups of service users in the 'task and finish' groups, quality assured the content and design of the website. Taking the time to listen to and take on board what people had to say before the content and design of the website was developed saved both time and, ultimately, money, as well as delivering a service that people actually wanted.

HSC Online is an ongoing project and, with the invaluable input of patients, service users and carers, we will work towards having a fully accredited HSC Online service that is accessible, comprehensive, user-friendly and accurate.

HSC Online can be accessed via the NI Direct government website at:
<https://www.nidirect.gov.uk/information-and-services/health-and-well-being>

7.0 Our work going forward

The PCC is continuing to work with people in order to champion change together. The following sections provide an overview of some of these ongoing projects including:

- Stage IV Endometriosis;
- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; and
- Recurrent Miscarriage

These summaries outline the desired outcomes and the progress to date.

7.1 Stage IV Endometriosis

Endometriosis is a condition that affects around 25,000 women of child-bearing age in Northern Ireland.⁶ It occurs when tissue similar to that lining the womb or endometrium is found outside the uterus, which 'induces a chronic, inflammatory reaction'.

There is no dedicated endometriosis centre in Northern Ireland or even a fast-track referral pathway. Since 2013, the PCC has been supporting women with severe (Stage IV) endometriosis to ensure their voices are heard by decision makers.

What we did

In January 2014, the PCC hosted a regional symposium in partnership with PANI, which was attended by the Minister for Health, decision makers, patients and professionals. The purpose of the symposium was to raise awareness of the condition, the need for a regional endometriosis centre, and a framework to care for and treat patients.

The PCC has consistently advocated on behalf of these women at HSCB meetings and at commissioner level. The PCC has also supported women to present personal testimonials on two occasions at public meetings of the HSCB. In November 2015, the PCC hosted two group discussions between officials from the PHA, HSCB and patients.

What we found

Through our discussions, we found that many women with Stage IV endometriosis are misdiagnosed and mismanaged for several years. People told us this has a major impact on their health, can lead to infertility and can have a detrimental impact on their academic and work life.

Currently, women with Stage IV endometriosis are referred to a clinic in Belfast, although it operates on an ad hoc basis, with a considerable degree of goodwill within the confines of the existing work schedules of the consultant staff involved.

Demand for this service has increased in recent years due to growing numbers of referrals from within and outside Belfast. Approximately 35-40% of the referrals suffer from severe endometriosis and the majority of the new patients are listed for surgery. Access to operating theatre time is limited and waiting times for surgery are now up to 18 months.⁷

In June 2013, the Health Committee recommended an integrated endometriosis centre to the Northern Ireland Assembly based on a single site and offering the full spectrum of medical and surgical treatments, alongside alternative therapies and counselling. The recommendations included dedicated staff including a specialist consultant gynaecologist, a pain management specialist, psychologist, colorectal surgeon, urologist, specialist nursing support, as well as research support.

In September 2014, Belfast HSC Trust submitted a business case via the Women's Services Co Directorate. To date this business case has not been approved.

What we've achieved so far...

While there has been a significant effort over the past three years on the part of patients, the PCC and PANI to increase awareness of the condition and the needs of the patients, there has been no betterment in terms of service delivery in that time.

As a direct outcome of our symposium in 2014, Altnagelvin Area Hospital in Derry/Londonderry applied for accreditation in 2016/17 as a local centre for the diagnosis of endometriosis. This will not, however, be a regional centre.

On behalf of the people we have been working with, we have asked, and will continue to ask for:

- The prioritisation of a regional specialist endometriosis centre manned by a dedicated, multidisciplinary team to support women with Stage IV endometriosis;
- An awareness campaign on the condition among young women;
- The provision of information and awareness raising of the condition at primary care level; and
- The inclusion of information on the condition during the training of doctors, especially GPs.

7.2 Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a long-term, debilitating illness that is difficult to diagnose, has no accepted cure and no universally effective treatment.⁸ It usually develops when people are in their early 20s to mid-40s,⁹ although children between the ages of 13 and 15, or even younger, can be affected.¹⁰ It is more common in women than in men.⁹

ME/CFS is a condition that has puzzled healthcare professionals and, for many years, the debate has been whether it actually is an illness at all. Specifically, there are more than 7,000 diagnosed cases in Northern Ireland, with 10% of patients suffering from moderate to severe symptoms.¹⁰

What we did

Following a presentation by Hope 4 ME and Fibro Northern Ireland to a PCC Board Meeting in 2013, the PCC agreed to further investigate the experience of people who are living with ME/CFS.

Key findings

- Service users are frustrated and dissatisfied with the current service provision;
- Misdiagnosis is common and other conditions such as cancer can go undiagnosed. This is supported by studies in this area¹²⁻¹⁴;
- Condition management programmes can aggravate symptoms in those with severe symptoms;
- The HSCB is considering further investment in this service of £250,000. This has not progressed but is in the 2016/17 Commissioning Plan;
- There needs to be a secondary care consultant in Northern Ireland;¹²
- There is currently no specialist service. The Belfast and Northern HSC Trusts provide an Occupational Therapist led service in line with National Institute for Health and Care Excellence (NICE) guidelines, once a diagnosis has been made;
- GPs do not receive any formal training in ME/CFS;
- People in Northern Ireland can pay for a private consultation with a specialist doctor who flies in from London once a month;
- There are a number of established charities in Northern Ireland that have been trying to get service improvement agreed (see **Figure 9**).

Figure 9: Patient-run charities in Northern Ireland



What we've achieved so far...

The PCC, alongside the charities, has facilitated opportunities for discussion and debate on the main service gaps, including the #invisibleME Symposium at the Riddel Hall in Belfast, which was attended by the Minister for Health, healthcare professionals, support groups, HSCB members and MLAs, as well as patients and carers. The HSCB Commissioning Lead for ME and fibromyalgia services in Northern Ireland spoke at this event and noted that the HSCB was considering an expansion of the Condition Management Programme that was being trialled by the Northern HSC Trust. The Commissioning Lead also spoke about investing £250,000 for the services and said that a model would be developed. A model, however, is yet to be developed. In the most recent draft Commissioning Plan for 2016/17, condition management is still the proposed model despite its limitations.

The PCC secured agreement that the HSCB would develop a proposal to re-establish a secondary care medical consultant post. This post is currently out for expressions of interest.

The PCC is continuing to get more recognition for people with ME/CFS to improve the existing services. The main priorities for service users are that:

- Patients are given a proper diagnosis using a standard clinical method that will establish a proper baseline for treatment/cure; and
- There is a specialist centre in Northern Ireland for the diagnosis and treatment of people with ME/CFS. The first step in this process is the reinstatement of a secondary care medical consultant to enable proper, timely diagnosis, and to support GPs with the treatment and care of patients.

7.3 Recurrent miscarriage

In June 2014 the PCC was approached by women who had recurrent miscarriage and who felt there could be improvements to the service offered.

What we did

We established a Pregnancy Loss Steering Group (PLSG) in April 2015. We hoped that, by establishing this group, women would have an opportunity to share their experiences and, with the support of the PCC, could influence future service provision. We also conducted a scoping exercise to establish current service provision in Northern Ireland.

The PCC held an event entitled 'One in Four – Putting Miscarriage on the Agenda' in October 2015. This event was held to facilitate a conversation between commissioners, service providers and families who had recurrent miscarriages to discuss how the service could be improved.

What we found

It is evident that miscarriage, particularly recurrent miscarriage, can affect women emotionally as well as physically. A dedicated recurrent miscarriage clinic and access to bereavement services were important to improve the current provision.

Although there is evidence to suggest that counselling is necessary after bereavement,¹⁵⁻¹⁶ specialist counselling is extremely limited and, in some parts of Northern Ireland, non-existent.

Currently, women have to qualify for a referral to a specialist miscarriage centre in the United Kingdom. It can be difficult to get such a referral and, for some, it is upsetting to have to travel to another part of the United Kingdom for advice and/or treatment at a vulnerable time. Others also noted that it is distressing to have to compete for a referral based on strict criteria.

What we've achieved so far...

The PCC and PLSG worked with the Miscarriage Association on early pregnancy loss literature to highlight that the charity's services are available in Northern Ireland. The Miscarriage Association also hosted a GP training session and ran an information session for midwives as part of the Clinical Education Centre's early pregnancy bereavement awareness training. Arrangements are now in place for the Miscarriage Association to take a more active role in HSC early pregnancy awareness bereavement training for all Trust areas.

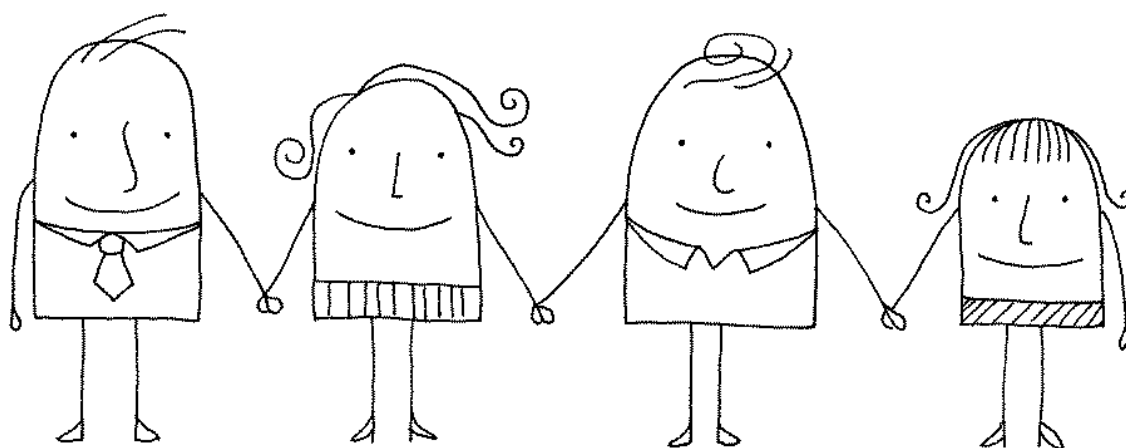
The PCC will continue to raise awareness of the gaps in service provision. There needs to be a review of existing services offered to women and their partners who experience a miscarriage across all five HSC Trusts to ensure quality patient-centred services are available throughout Northern Ireland.

7.4 Taking these projects forward...

It is our job to give a voice to people who may not be heard or – as in the case of ME/CFS patients who have been heard and not listened to – to help support them to get the services they deserve.

We have a unique privilege and position in the system to ensure that the voice of patients, service users, carers and communities is listened to, heard and acted upon in health and social care. The examples outlined above serve to illustrate that, while there has been much progress, there are still groups of people who feel marginalised and unsupported by the lack of progress and sometimes lack of any real service at all.

In 2016/17 and beyond, we will use people's experiences to advise decision makers about how better to design services that meet people's needs and expectations, now and in the future.



Conclusion: Driving Change

In the past seven years, the PCC has engaged tens of thousands of people on a wide range of health and social care-related issues. This is not only a testament to the hard work of our staff but also to the public's interest in improving HSC services. During that time many people have shared often difficult experiences with a view to helping others and improving HSC services. As a society we are both obliged and indebted to them.

Our journey to date shows that people need to be given an opportunity to share their experiences in ways that have an impact. The work of the PCC demonstrates what is possible when people are engaged as partners in their care. It also highlights how the experience of a few individuals can often shine a light on something that affects so many more. We would wish to acknowledge the relentless patience of many people who have championed different causes in their own time and at their own expense in order to improve outcomes for society as a whole.

People understand the challenges that HSC services face and want to be part of the solution. They want to contribute by managing their own wellbeing and helping to build better services for their community. It is vital that they have good advice and information services and the PCC welcomes recent progress made on the development of a HSC information website. It is a matter of concern that the people of Northern Ireland continue to have so little accredited information available to them in comparison with other regions of the UK and Ireland. There is a need to maintain momentum on this in 2016 and beyond.

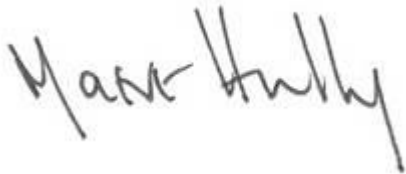
People also want the opportunity to share their views, both good and bad. Currently people in Northern Ireland have limited opportunity to do so. We know from experience that people are often reluctant to complain and when they do so they often find the process lengthy and ineffective. We also know from our work that people would welcome the opportunity to feedback on their positive experiences. There is a need for a regional real-time feedback system that would drive service improvement based on real-time lived experience.

It takes too long to effect change in health and social care. It often takes many years of evidence-gathering, campaigning and highlighting issues before change happens and services feel different. The work of the Bamford Monitoring Group on mental health and learning disability services demonstrates this.

This summary report highlights examples of the work of the PCC and illustrates the value of working in partnership with people to drive service change and improvement. We acknowledge that these successes are only possible whenever there has been strong clinical and managerial leadership, and a genuine

engagement with service users. This makes a positive difference, not only to individual experience, but to that of society as a whole. A change of culture to one that truly values a partnership approach is necessary and overdue.

In 2016 we move into a new era both in terms of political and wider organisational change and, as we do so, the PCC continues to encourage a stronger partnership between people and services. Embedding the patient experience as part of improving healthcare is now included in the Northern Ireland Assembly Programme for Government. This is a welcome recognition of the outcomes that have and can be achieved if patients are listened to and considered in service design and delivery. The PCC will continue to work to provide the “eyes and ears on the ground” at policy, commissioning and service delivery levels of health and social care. We will continue to act as the critical friend working with a strong evidence base of people’s needs and expectations so that, together, we can help to build sustainable patient-centred services.

A handwritten signature in dark ink, reading 'Maeve Hully'. The signature is written in a cursive, flowing style with a large initial 'M'.

Maeve Hully
Chief Executive

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Appendix 1: Highlights – Year by year

April 2009 – March 2010

643 people supported by the Complaints Support Service
PCC staff engaged with more than 4,000 members of the public
42 focus group meetings held across Northern Ireland
Work of the PCC presented to 26 borough and district councils
Five Local Advisory Committees established and 39 committee members recruited
Bamford Monitoring Group (BMG) on mental health and learning disability established
39 consultation requests completed based on patient and client input

April 2010 – March 2011

875 people supported by the Complaints Support Service
Membership Scheme established with almost 2,000 members recruited in the first year
222 people attended the 'Are You Being Heard' workshop run by BMG
Six roadshows held across Northern Ireland to enable people to engage directly with key HSC decision makers
Northern Ireland Rare Disease Partnership established and supported by PCC
PCC website launched in July 2010
In September 2010, PCC became the first HSC organisation to set up Facebook and Twitter

April 2011 – March 2012

980 people supported by the Complaints Support Service
Six roadshows held by October 2011 to increase awareness of the PCC and to enable people to speak directly to key HSC decision makers
47 people attended the 'How Involvement Can Liberate Health and Social Care' workshop
4,500 people recruited to the Membership Scheme. Dedicated membership database set up
Advocacy Toolkit for use in residential and nursing homes endorsed by the Department, and the Regulation and Quality Improvement Authority (RQIA) and issued to all homes
Mobile PCC unit is used to reach more diverse audiences
First video posted on YouTube

April 2012 – March 2013

1,181 people supported by the Complaints Support Service
Service set up in January 2013 to support prisoners who wish to make a complaint
Outreach clinic opened in Derry/Londonderry in partnership with the Citizens' Advice Bureau
150 people attended a Pain Summit to bring together patients, carers, employers, clinicians, commissioners and healthcare decision makers

11 roadshows on Transforming Your Care attended by 1,000 people
Agreement obtained from PHA and HSCB on the need for a single advice and information service
PCC received a number of awards endorsing our work: <ul style="list-style-type: none"> - Chartered Institute of Public Relations PRIDE UK Public Affairs Gold Award for The People's Priorities 2011 - External Publications Silver award for Someone to Stand Up for Me Advocacy Toolkit - Healthcare Silver Award for establishing the Northern Ireland Rare Diseases Partnership - Young People's Priorities project presented with an Excellence in Engagement award by the Northern Ireland Commissioner for Children and Young People

April 2013 – March 2014

1,935 people supported by the Complaints Support Service
150 people attended the User Carer Celebration event held at the Guild Hall in Derry/Londonderry
Outreach clinic opened in Downpatrick
New online complaints facility added to the PCC website
E-learning toolkit on Personal and Public Involvement launched in February 2014
Major symposium hosted with HSC leaders and professionals regarding establishing a regional endometriosis centre and care pathway for Northern Ireland
PCC receives the Gold Award from the Chartered Institute of Public Relations PRIDE UK Healthcare Campaign for The People's Priorities for Transforming Your Care report and Public Affairs Gold Award for the Young People's Priorities project

April 2014 – March 2015

2,308 people supported by the Complaints Support Service
150 people attended the InvisibleME symposium to raise the profile of myalgic encephalomyelitis/chronic fatigue syndrome and fibromyalgia to decision makers
150 people attended the Patient Safety Conference 'How Safe is My Care?'
New complaints clinic launched in Ballymena in September 2014
Introduction of advocacy support for service users and carers involved in Serious Adverse Incidents (SAIs)
HSCB and PHA commenced work on recommendations made in The Painful Truth
PCC recommendations included in the HSCB Annual Commissioning Plan 2014/15
Launch of the Leadership in Partnership Programme to enable service users to be more effectively involved in decision making
PCC leaflets and posters were delivered to every HSC facility in Northern Ireland in June 2014 as part of Complaints' Awareness Month
PCC research team articles from The Painful Truth report published in Northern Ireland Healthcare Review and British Pain Society's Pain News

April 2015 – March 2016

A Hidden Condition – Ten People Living With Fibromyalgia Tell Their Story published

1,952 people supported by the Complaints Support Service
We supported a group of women who had experience of recurrent miscarriage to develop the Bereavement Pathways being implemented by all five HSC Trusts
Altnagelvin Area Hospital in Derry/Londonderry has applied for accreditation as a local centre for endometriosis as a result of the PCC 2014 endometriosis symposium
Training on pain management is to be included in Year 4 undergraduate medical training following recommendations in The Painful Truth report
PCC worked with service users, HSCB and PHA to enable the public to check average waiting times at A&E departments online
As a result of our work supporting older people caring for adults with a learning disability, the HSCB invested £1M on a recurrent basis to help them to plan for the future

Appendix 2: List of PCC publications

The following reports are available to view or download at

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

1. A Hidden Condition - Ten People Living with Fibromyalgia Tell Their Story (Published June 2016)
2. What Matters To Me (Published November 2015)
3. What Matters To Me Easy-read (Published November 2015)
4. Carers' Priorities Report (Published November 2015)
5. Quality Report 2014/15. (Published November 2015)
6. Annual Complaints Report 2014/15 (Published July 2015)
7. Issues Faced By People Who Are Homeless In Accessing Health and Social Care Services (Published March 2015)
8. The People's Priorities: People's Views On Future Priorities For Health and Social Care in Northern Ireland (Published November 2014)
9. Quality Report 2013/14 (Published November 2014)
10. Annual Complaints Report 2013/14 (Published September 2014)
11. Access To GP Services - Full report (Published May 2014)
12. Views On Telemonitoring Services (Published April 2014)
13. The Painful Truth (Published February 2014)
14. Annual Complaints Report 2012/13 (Published October 2013)
15. 'Care When I Need It' A Report on Urgent Care Services (Published July 2013)
16. Support After Leaving Mental Health Hospitals, 7 day follow up patient experience evaluation. May 2013 (Published September 2013)
17. Exploring Public Awareness Of Palliative Care - April 2013 (Published May 2013)
18. Transport Issues in Accessing Health and Social Care Services - March 2013. (Published May 2013)
19. Emergency Admission to Hospital in Northern Ireland - December 2012 (Published February 2013)
20. Annual Complaints 2011/2012 (Published December 2012)
21. The People's Priorities For Transforming Your Care (Published November 2012)
22. Beating The Blues - The Experiences of People in Northern Ireland (Published November 2012)
23. Report of Older People's Reference Group (Published October 2012)
24. Care At Home: Older people's experiences of domiciliary care (Published June 2012)
25. Young People's Priorities in Health and Social Care (Published May 2012)
26. Someone To Stand Up For Me - Advocacy Toolkit (Published March 2012)
27. Experience of Diagnosis (Published February 2012)
28. Car Parking At Hospitals and Other Health and Social Care Facilities (Published January 2012)
29. The People's Priorities 2011 (Published December 2011)
30. What the Bamford Monitoring Group Did This Year - Easy-read (Published November 2011)
31. Respite - Short Breaks – Easy-read (Published November 2011)
32. Further Education - Easy-read (Published November 2011)

33. Is Bamford Making a Difference? Easy-read (Published November 2011)
34. My Day, My Way - Easy-read (Published November 2011)
35. Mental Health Information For Young
36. People On The Internet - Easy-read (Published November 2011)
37. Annual Report of The Bamford Monitoring Group (Published September 2011)
38. Online Mental Health Information For Young People (Published November 2011)
39. Further Education (Published September 2011)
40. My Day, My Way (Published September 2011)
41. Is Bamford Making a Difference? (Published September 2011)
42. Respite (Short Breaks) (Published September 2011)
43. Young Carers In Northern Ireland (Published July 2011)
44. People's Views About Prescription Charging and Products Available On Prescription (Published June 2011)
45. Rural Voices Matter (Published June 2011)
46. Report on How Involvement Can Liberate Health and Social Care (Published April 2011)
47. Survey of the Patient Experience at the Emergency Department of Antrim Area Hospital (Published April 2011)
48. Food For Thought: Views of Patients and the Public on Hospital Meals (Published March 2011)
49. The People's Priorities - Full Report (Published February 2011)
50. Talking Teeth: Patient Views of General Dental Services in Northern Ireland (Published February 2011)
51. The People's Response to Draft Budget Proposals For The DHSSPSNI Over The Period 2011-2015 (Published February 2011)
52. Swine Flu (Published February 2011)
53. Car Parking Changes at Altnagelvin Hospital (Published December 2010)
54. Shaping Information Knowledge and Access to Mental Health Services (Published November 2010)
55. Maternity Services (Published October 2010)
56. Mental and Emotional Health of 16-Year-Olds in Northern Ireland (Published October 2010)
57. The Ward Manager (Published October 2010)
58. Survey of Dental Practices Regarding Access to Dental Services (Published October 2010)
59. Young People's Thoughts About Young Life and Times (Published August 2010)
60. Annual Report of the Bamford Monitoring Group (Published August 2010)
61. Are You Being Heard? (Published June 2010)
62. Patient, Services User and Public Perspective on End of Life Care Strategy (Published February 2010)
63. Report on the Public Engagement on Priorities for Action (Published December 2009)

Appendix 3: Acronyms and abbreviations used

- **BMG** – Bamford Monitoring Group
- **HSC** – Health and Social Care
- **HSCB** – Health and Social Care Board
- **ICP** – Integrated Care Partnerships
- **LCG** – Local Commissioning Groups
- **NICE** – National Institute for Health and Care Excellence
- **NIRDP** – Northern Ireland Rare Disease Partnership
- **PANI** – Pain Alliance of Northern Ireland
- **PCC** – Patient and Client Council
- **PHA** – Public Health Agency
- **PLSG** – Pregnancy Loss Steering Group
- **PPI** – Personal and Public Involvement

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