

Patient and Client Council

Involving You

Why and how you can take part in our work

March 2018

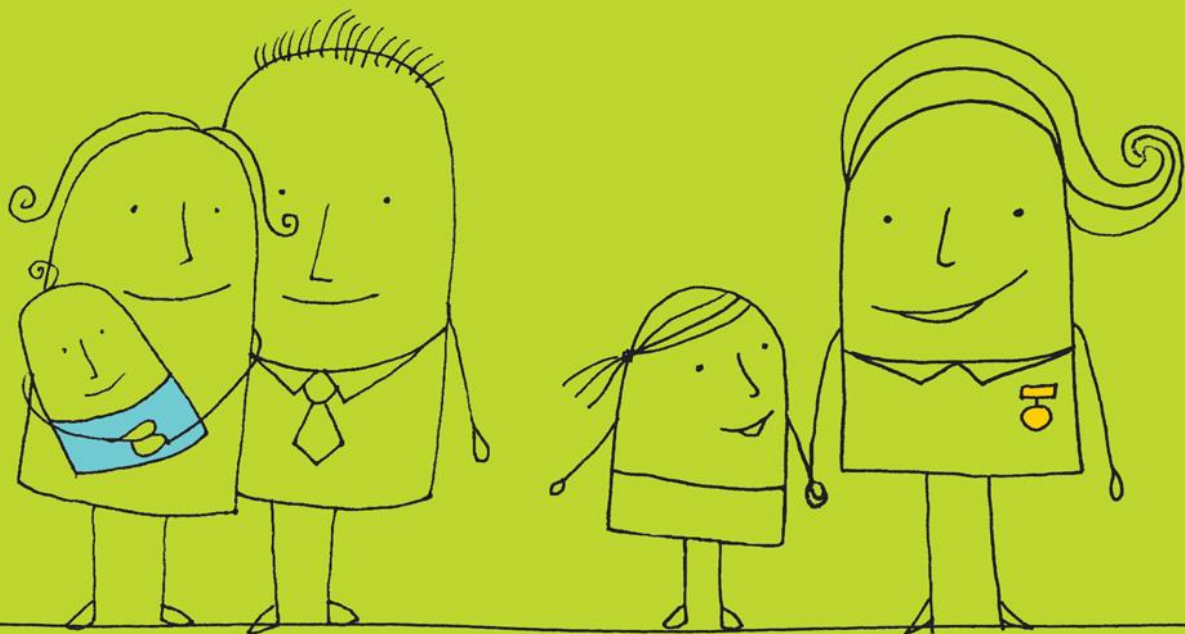


Table of Contents

1.0	Introduction	3
2.0	About Us	5
2.1	Our Vision	5
2.2	Our Purpose	5
2.3	Our Values	5
3.0	What we mean by “Involving You”	6
3.1	The need for people to get involved	7
3.2	How we developed this policy	9
3.3	Principles to underpin our policy for Involving People	9
	 Principle 1 - People will be involved in a way that is appropriate	 10
	Principle 2 - People will be involved in ways that are accessible	11
	Principle 3 - People will be kept informed	14
	Principle 4 - Involving people will make a positive difference	15
	Principle 5 - In partnership with you we will continually review what we do	17

This document can be made available on request and where reasonably practicable in an alternative format, Easy Read, Braille, audio formats (CD, mp3 or DAISY), large print or minority languages to meet the needs of those for whom English is not their first language.

Created - Louise Skelly	2016
Revised and Equality Screened – Jackie McNeill	March 2018

1.0 INTRODUCTION

Welcome to the Patient and Client Council's policy called "Involving You." This policy provides a guide for you on how we are going to involve people in our work. It describes a range of techniques that we will use to ensure our work is inclusive, innovative and makes a difference. This policy reflects what people have told us and it aims to put you at the centre of our work.

The Patient and Client Council was established to provide a powerful and independent voice for the public in Health and Social Care in Northern Ireland. We are guided in all we do by our vision, purpose and values which have been shaped by you, the people we serve.

The Patient and Client Council offers numerous opportunities for people to get involved. These include:

- Take part in PCC Panels
- Joining our Membership Scheme
- Taking part in research studies
- Participating in focus groups and questionnaires
- Meeting decision makers
- Responding to consultations

Nearly 35,000 people have shared with us their opinions, experiences and hopes about Health and Social Care. This information is now being used by

decision makers to help them make changes to the way that services are provided.

This policy has been developed by patients, service users, carers and communities (people) and sets out how the Patient and Client Council will involve people so that:

- The voice of all people on Health and Social Care is sought and listened to and
- The Patient and Client Council will make a positive difference through its work.

Each year Patient and Client Council will produce a plan which will describe how we will do this.

We would like to thank everyone for their input to this policy.

This policy has been screened in accordance with our statutory duties under Section 75 and human rights duties. The outcomes will be published as part of our regular screening outcome report.

2.0 ABOUT US

The Patient and Client Council is a powerful, independent voice for people on their health and social care services.

We have four main duties. They are to:

- **Represent the interests of the public;**
- **Encourage people to get involved;**
- **Help people make a complaint; and**
- **Promote the provision of advice and information on services.**

The Patient and Client Council has produced a corporate plan called “Our Plan” and in that document we set out our vision, purpose, and values as follows.

2.1 Our Vision

A Health and Social Care service that is shaped by patients, clients, carers and communities.

2.2 Our Purpose

To be an influential and independent voice that makes a positive difference to the Health and Social Care experience of people across Northern Ireland.

2.3 Our Values

- Putting people at the centre of all we do
- Using evidence from people to guide our work

- Speaking independently
- Working in partnership
- Being open and transparent

3.0 WHAT WE MEAN BY “INVOLVING YOU”

“Personal and Public Involvement” or “PPI” is used to describe how Health and Social Care organisations will involve the public in their work.

‘Personal’ refers to service users, patients, carers, consumers, customers, relatives, advocates or any other name used to describe individuals who use Health and Social Care services either as individuals or as part of a group.

‘Public’ refers to the general population and includes locality, community and voluntary groups and other collective organisations. ‘Involvement’ refers to consulting, informing, engagement, active participation and partnership working.

For the purposes of this document and the work of the Patient and Client Council we refer to PPI as ‘involving you’ and we will work to involve people and promote the involvement of people at every level of decision making within Health and Social Care in Northern Ireland.

3.1 The need for people to get involved

The need to involve people in decision making is a principle accepted across Health and Social Care and is fundamental to the reform of health and social care services through co design and co production.

We can demonstrate that decision making in the Health and Social Care sector benefits from the active involvement of people. We know that they can provide insights from experience of using a service, point to inefficiencies and frustrations, and suggest alternative approaches.

We believe that the services can only be transformed effectively through a process of continuous dialogue with and involvement of the people who use them.

Awareness and understanding of PPI and its tangible benefits to service users, carers, staff and the HSC in general, has been gaining momentum over the last few years. It would be important to reinforce, that co-production is integral to this and will build on this work. Co-production is part of the continuum of involvement and is regarded as the pinnacle of involvement. It is important that co-production is not seen as an entirely new concept, but rather, that it clearly acknowledges the relationship with PPI, whilst also advocating for the step change in the involvement ethos and that sharing of power, which is integral to co-production.

3.2 Co-Production

The Department of Health's vision document 'Health and Wellbeing 2026; 'Delivering Together' outlined its full commitment and support to adopting a

co-production approach to achieve the necessary changes required to deliver the world class health and social care services people deserves. It states;

“We must work in partnership - patients, service users, families, staff and politicians - in doing so we can coproduce lasting change.”

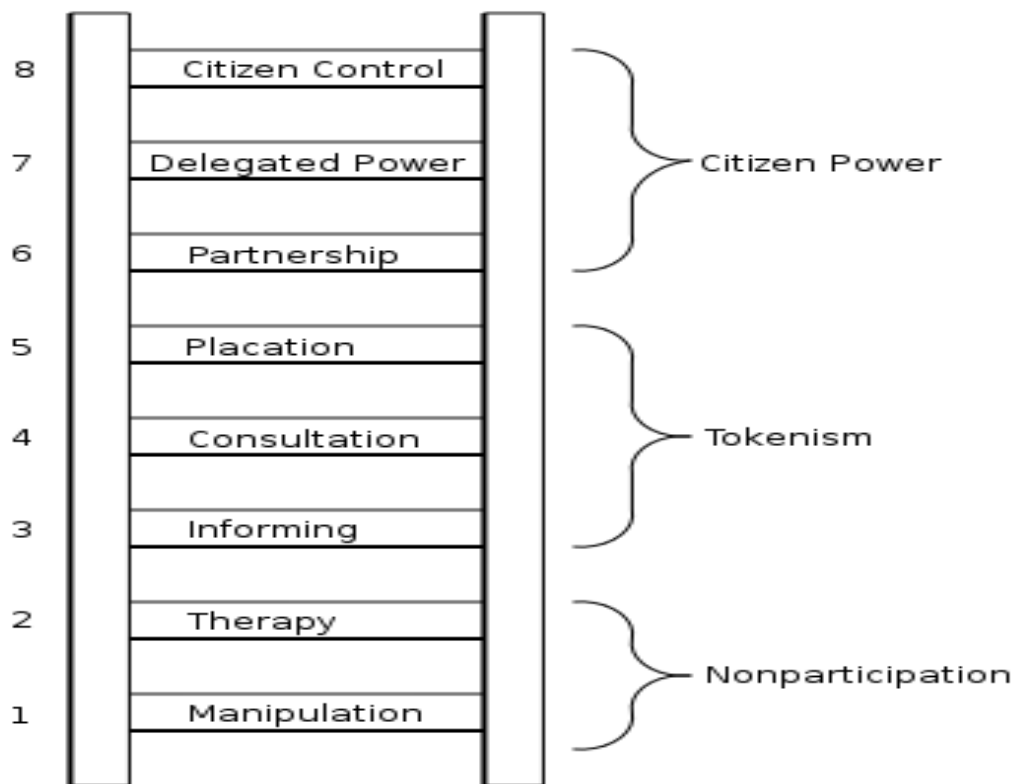
Figure 1 – Co-production



Health and Wellbeing 2016 (Department of Health, 2016) ¹

There are many perspectives which outline the importance and relevance of public involvement. Figure 2, below, summarises work by Sherry R Arnstein, which describes the development and challenges of achieving true participation.

Figure 2 - Eight rungs on the ladder of citizen participation²



The Patient and Client Council believes that service users are partners in every aspect of their work. This can only be achieved when those participating have the necessary skills, confidence and opportunity to be involved. Building capacity within people is therefore an important part of our work.

3.3 How we developed this policy

This policy document was developed as a result of direct dialogue with patients, service users, carers and community representatives. In addition, members of the Membership Scheme and community representatives helped us shape this policy.

3.4 Principles to underpin Our Policy for Involving People

The Patient and Client Council believes that the following principles should underpin all our work:

Principle 1 - People will be involved in a way that is appropriate

Principle 2 - People will be involved in ways that are accessible

Principle 3 - People will be kept informed

Principle 4 - Involving people will make a positive difference

Principle 5 - In partnership with you we will continually review what we do

Principle 1

People will be involved in a way that is appropriate

The Patient and Client Council uses numerous techniques to enable people to be involved. Examples include its Membership Scheme, citizen juries, public meetings, advisory groups, PCC panels, open forums, focus groups, surveys, phone in lines, one to one interviews, social media and “world cafes”.

We know from experience that it is important to choose methods that are suitable for the issue about which the service wants to engage.

For complex issues requiring in depth discussion and decision, a tailored approach may be required. One to one interviews are often used in these scenarios to capture more personal and qualitative responses. Within focus groups there tends to be more emphasis on challenge and discussion. Participants are provided with information on the topic to be discussed and encouraged to see them from a number of different perspectives. Discussions then allow them to explore the views of others and come to a collective decision.

Key Messages:

The approaches that the Patient and Client Council use will:

- **Be high quality involvement methods;**
- **Be appropriate for the people we want to engage;**
- **Be appropriate to the matter we aim to influence, ie the intended goal;**
- **Offer a range of different opportunities to participate; and**
- **Be cost effective.**

Principle 2

People will be involved in ways that are accessible

People have many reasons for taking part in our work. Some relate to collective incentives such as 'giving something back' while others are personal incentives, such as being given 'a chance to have a say'. In addition, there are also social incentives, with many people describing motivations in terms of enjoying meeting different people and discussing shared issues. Meeting other people is a key reason that participants give for wanting to get involved in engagement projects. Others are motivated by the successful outcomes of various involvement projects. We will continue to listen to what people tell us and build that into our methodologies.

How people are invited to participate is very important. People are more likely to participate when asked directly to do so. The Patient and Client Council invites people to participate through face-to-face contact or direct personal invitation. Simply putting a notice in the newspaper or dropping leaflets through doors and expecting people to respond is not effective. This is particularly evident from our experience of recruiting members for the Membership Scheme.

There are a number of considerations to be made when asking people to get involved. These include types of engagement, accessibility, resources and training.

Methods for engagement are developing all the time. A frequently used method across Health and Social Care is to ask people to express their views when they are writing a new policy or service change. This is described as public consultation. People find long documents written primarily for a

professional audience hard to understand and often meaningless. The Patient and Client Council will support people to respond to consultations by gathering evidence and reflecting the collective views of the interested population. It is essential that the views expressed are those of people and not organisations.

Accessibility and access issues are important when bringing people together. This includes physical accessibility and venues need to be accessible to people with disabilities. Location is also important and meetings should be held in communities close to where people live. This is particularly important for rural areas. Locations for engagement will be held in all communities across Northern Ireland reflective of the population.

Easy access by public transport is also key to people participating. Visual or hearing impairment and dietary requirements also need to be accommodated.

Timing can also be a significant factor. For instance, people who are working are unlikely to be available during working hours. However, people with caring responsibilities, or those who feel vulnerable going out in the evenings, might prefer daytime meetings. The Patient and Client Council involvement programme will use a very deliberate approach to meeting people on their terms, at times and in places that are convenient for them.

The ability of people to engage with Health and Social Care organisations also depends on whether they have sufficient resources or capacity to participate. Whilst money does not appear to be a significant issue that determines whether people are willing to participate, people should not be expected to pay, directly or indirectly, to participate in engagement exercises. The Patient and Client Council will consider in advance covering expenses such as travel costs, child care or other caring costs.

Other important issues for people are skills and confidence. A lack of confidence can be a barrier to participation. Training is linked with improved confidence to participate. We will continue to support people and offer skills training to enable effective engagement with Health and Social Care Services.

We value the partnerships we have developed with community and voluntary sector organisations, with academic institutions and Health and Social Care organisations to ensure specific target audiences are reached and engaged with. We recognise that certain involvement projects have the potential for better outcomes when we work in partnership with other organisations. This will continue to be a fundamental element of our work.

The PCC's engagement processes take into account that certain audiences require additional support. All PCC literature including surveys will be in a format suitable for those we engage with. This includes accessible formats such as easy read, other languages or large print. Where appropriate interpreting, including translating and sign language will be made available.

Key Messages:

The Patient and Client Council will work to ensure that:

- **Involvement will be accessible for all people;**
- **Provide support to encourage people to take part;**
- **Work in partnership with other organisations to maximise involvement; and**
- **Provide timely information on involvement opportunities**

Principle 3

People will be kept informed

Our experience shows that people are generally happy to give their opinions and want to share their experiences, particularly if it will improve things for themselves or other people who use services. The Patient and Client Council will provide feedback to people on how their involvement has led to real change.

The most successful involvement projects are those where people are kept informed of developments. While some very short projects move quickly to an outcome, many take a substantial amount of time to bring about change, and people can be left with the impression that nothing has been done with their contribution. We will keep in contact with participants through various media so that people are up to date with developments and can continue to provide feedback if they wish.

In larger projects which take place over a considerable period of time it is important to report back to participants periodically.

Key Messages:

The Patient and Client Council will work to ensure that:

- **People will know that their views will be used;**
- **People will be given the opportunity to be kept informed throughout the decision making process and of any outcomes through the Membership Scheme; and**
- **People will be told what will happen next after they have shared their views.**

Principle 4

Involving people will make a positive difference

Successful involvement starts with a commitment to listen to what people have to say and to act on that information. People want Health and Social Care to respect the views of people and act on them when planning service change.

The Patient and Client Council will work to ensure that Health and Social Care services listen and act on peoples' views.

A common criticism of engagement processes is that they are 'tick box' exercises, with the key decisions being made either in advance of engagement or despite concerns raised during engagement exercises.

We will make clear what the opportunity for involvement is, and where the boundaries are. Organisations frequently have to deal with internal or external constraints, which may affect the level of influence that people are able to exert. These pressures should be shared so realistic expectations of any involvement can be understood.

We believe that it is vital to engage people early in the policy development and decision making process. The Patient and Client Council will ensure that people shape consultation on major service changes in the early drafting stages and not just during formal public consultations.

It is good practice to plan from the outset how contributions made by people are to be recorded and analysed.

The Patient and Client Council is committed to ensuring that the information people share with us is communicated clearly and extensively to decision makers across all Health and Social Care organisations, the voluntary and community sector, other relevant stakeholders and the media. We continue to build on our communication opportunities to ensure that valuable information shared with us has a maximum impact on the future shape of services.

The Patient and Client Council have introduced info graphics when reporting on what people have told us about HSC services. We have also introduced summary documents to ensure key messages reach the right audience.

We will endeavour to clearly articulate outcomes that have come about as a result of people getting involved. It is challenging for the Health and Social Care system to demonstrate a link between the input provided by people and the eventual outcome of the decision making process. We will continue to work to develop this area of our practice and encourage Health and Social Care organisations to do likewise.

Key Messages:

The Patient and Client Council:

- **Is committed to listening to peoples' views and experiences and acting on the information;**
- **Will be honest about the opportunity to make an impact and any limitations;**
- **Will engage early with people to maximise the impact of involvement;**
- **Will ensure that all contributions will be analysed and reports of the analysis published and communicated to maximise their impact; and**
- **Will ensure that the Patient and Client Council reports on the impact they have had on HSC services including any challenges encountered.**

Principle 5

In partnership with the public we will continually review what we do

We will ask the following key questions about all of our involvement processes:

- Was it good value for money?
- Were people satisfied with the methods of engagement?
- Did the project successfully gather views from a range of people?
- Did the project result in better quality decision making?
- Were there other outcomes from the project, such as increased trust or stronger relationships with patients and service users?
- Was there on-going communication with those who were involved throughout and after the process?

We will also consider the wider impact of projects. For example, the impact on social cohesion, skills of staff and participants, greater public support for services or activities, better governance and continued learning.

Key Messages:

The Patient and Client Council will:

- **Seek to conduct both internal and external evaluations of its work;**
- **Plan evaluations from the outset and cover inputs, processes, outputs and outcomes; and**
- **Learn from our experiences and where practical, share successful examples of involvement with other Health and Social Care organisations**

Remember you can contact us by

Telephone

0800 917 0222

Email

info.pcc@hscni.net

Post

FREEPOST
PATIENT CLIENT COUNCIL

Follow us on



/PatientAndClientCouncil



@PatientClient