

# Regional Health and Social Care Personal & Public Involvement Forum

Annual Report 2012/13



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# Foreword



Welcome to the third Annual Report by the Regional Health and Social Care Forum on Personal and Public Involvement.

I am introducing this report in my role as

Executive Director of Nursing, Midwifery and Allied Health Professionals with responsibility for Personal and Public Involvement (PPI). In this role I am delighted to continue to chair the Forum on behalf of the Public Health Agency (PHA) and to promote PPI across the Health and Social Care (HSC) System.

This report was compiled by members of the Forum including, service users, carers and HSC staff with the aim of showcasing the Forum, its members and its achievements to date. We wanted this annual report to provide more insight into the people behind the Forum and the value that the Forum adds, not only for the promotion and advancement of PPI regionally but also as an opportunity for members to develop and support one another in an individual and collective fashion.

We have divided the report into four main sections, each focusing on a particular aspect of the Forum and its work. In these sections we introduce the concept of PPI, explain the role of the Forum, share the work that is being undertaken by the subgroups of the Forum, and focus on the achievements of the Forum including highlighting three PPI projects funded by the PHA in 2012 -13. We have also included a number of short quotes from members of the Forum and some useful information about PPI throughout the document.

The examples in this report only begin to show the positive impact that the incorporation of PPI into the core of HSC activity is having. The work of the Forum has driven PPI regionally and supported the statutory duty to involve and consult, HSC (Reform) NI Act 2009. In 2013-14 PPI will become increasingly enshrined across the HSC system as Transforming Your Care and Quality 2020 are implemented.

PPI is increasingly recognised and acknowledged as a critically important component of effective, efficient, quality focused HSC services, where the person truly is at the centre. We need to build on this momentum and ensure that we are not deflected from our focus.

I have received a warm welcome in my role as chair of the Forum and am pleased to support the further developments being progressed in 2013-14. I would like to take this opportunity to thank the HSC partners who participate in the Forum and in particular, the service users, carers and community and voluntary sector members who give up their time and make such a valuable contribution to the work of the Forum. My gratitude also goes to the PHA PPI staff who facilitate and support the work of the Forum.

I hope you are encouraged and energised by what you read in this report. I look forward to continued progress in the field of PPI in the HSC with tangible benefits for our service users and carers.

## **Pat Cullen**

Executive Director of Nursing, Midwifery and Allied Health Professionals

# What is Personal and Public Involvement?

Personal and Public Involvement (PPI) is about involving and empowering people and communities to give them more confidence and more opportunities to influence the planning, commissioning, delivery and evaluation of services in ways that are relevant and meaningful to them.

It is a two way process, not solely an approach that we use when we want to hear the views of service users and carers, on something which we bring to them for their consideration. People are no longer passive recipients of health and social care services. People have a right to be and increasingly they expect to be, actively involved in decisions that affect them.

PPI operates at a number of levels. These range from one to one discussions about care and treatment with service users, carers and their advocates, through to involvement in policy development, service design, redesign and evaluation.

Did you know that PPI is not just about your one to one care, it is also about making big decisions about how health and social care is delivered in your area and across Northern Ireland?



# Introducing the Forum

## What is the Forum?

The Regional Health and Social Care (HSC) Personal and Public Involvement (PPI) Forum was established by the Public Health Agency (PHA) in 2010 to provide an opportunity for HSC organisations to work collaboratively to progress PPI in Northern Ireland. The Forum includes representation from HSC organisations and from service users and carers. The primary role of the Forum is to provide leadership and support, in order to drive forward the promotion and advancement of PPI across HSC organisations in Northern Ireland. It does this through:

1. Sharing best practice.
2. Joint working on areas of common interest through sub groups.
3. Active participation of service users and carers.

## What does the Forum do?

The Forum has a number of key functions, these are to:

1. Lead and support HSC organisations to comply with PPI policy; the requirements of the Health and Social Care (NI) Reform Act 2009 in respect of PPI, the DHSSPS “Guidance on Strengthening Personal and Public Involvement in Health and Social Care” 2007, the 2012 Departmental Guidance on arrangements for implementing PPI and any further DHSSPS guidance.
2. Provide a platform for discussion on all aspects of PPI and its relevance to and impact on the work of HSC and benefits for service users and carers.
3. Explore opportunities for joint working between stakeholder organisations, encouraging co-ordination and consistency of practices, reduction of duplication and the sharing of best practice.
4. Encourage, support and inform the development of understanding of PPI and the advancement of PPI training across HSC.
5. Encourage, support and inform the development of PPI, monitoring and evaluation across HSC.
6. Plan, develop and implement an annual PPI Forum Action Plan.
7. Develop, co-ordinate and produce an Annual Report.

To achieve these functions, the Forum meets on a regular basis bringing together members from across Northern Ireland to discuss and advance issues central to the success of PPI. These large regional meetings take place three times a year and provide a platform to share experiences and best practice, as well as identify common areas where a regional approach can be applied to progress PPI.

## Who is in the Forum?

### Membership

The Forum is chaired and facilitated by the PHA. Membership is drawn from all HSC organisations. Service users and carers also play a vital role in the Forum and following a review of membership in 2012/13 now hold 13 places on the Forum.

The Forum membership consists of:

- One senior representative from each HSC organisation, who has PPI as a key responsibility.
- Service user, carer or voluntary/community sector representatives, two nominated via each HSC Trust PPI panel, with a further one nominee each from the Regulation and Quality Improvement Authority (RQIA), the Patient and Client Council (PCC) and the Northern Ireland Social Care Council (NISCC).

### Role of Members

Forum members:

1. Represent their organisation/networks/peers through active participation in the business of the Forum.
2. Share information and best practice in PPI from their respective organisations/experiences.
3. Lead on/participate in actions (by agreement) in respect of the Forum's Action Plan.
4. Take forward actions agreed by the Forum to their organisations/networks/peers for consideration and delivery.



### Forum Member Profile



#### Elaine Campbell

is the operational lead for PPI in the South Eastern Health and Social Care Trust (SEHSCT). Elaine sits on the Forum as their representative. Here Elaine shares her experience as a Forum member.

*"The Forum shows a strong commitment to embedding PPI at all levels within health and social care organisations. Working together on a regional basis drives the push for excellence across all HSC bodies."*

*The Regional Health and Social Care Personal and Public Involvement Forum in session.*

# The work of the Forum - how we progress PPI regionally

## PPI Action Planning

Each year the Forum holds an action planning workshop to identify key PPI priorities, these priorities form the basis of an annual action plan. The action plan includes specific actions, timescales, responsibilities and performance indicators. Areas of responsibility are then allocated and Forum subgroups established to lead on specific actions.

Did you know that Health and Social care Trusts have PPI toolkits to guide your PPI activity?

## PPI Forum Subgroups

In order to progress the agreed priorities of the Forum, a number of subgroups have been established using membership from the main Forum, with the opportunity to co-opt other members from HSC partners/ additional service user/carers as and when required. These groups meet on a more regular basis to complete tasks and actions. The Forum currently has four dedicated subgroups.

## PPI Training

The primary purpose of the Training sub group of the Forum is to work collectively to advance the development of PPI training and awareness raising across HSC. The sub group also supports the PHA to identify what is essential to be included in PPI training and to participate in work to commission the development of appropriate training. The subgroup advises how training should be rolled out / made available across HSC. The output from the group includes:

- Development of a specification for the design and piloting of a comprehensive PPI Training programme which will:
  - operate to an agreed standard.
  - be flexible enough to be relevant to different types of staff in different types of organisation.
  - be consistent, available in different formats and accessible right across HSC.
  - be appropriately structured and if possible, be accredited.

### What outcomes will be achieved?

The training programme developed by the Forum Subgroup will provide high quality standardised training available to all HSC Staff. The outcome of this will be:

1. Staff are informed about what PPI is, why it is important and what is expected of them.
2. Staff have the knowledge and skills to undertake PPI effectively.
3. Service users and carers will be integral to the design and delivery of PPI training in HSC.
4. PPI will be further integrated into the culture and practice of HSC, resulting in improvement in quality and experiences for service users and carers.

### PPI Standards

The purpose of the Standards Subgroup is to develop draft PPI Standards and Key Performance Indicators (KPIs) for consideration by the Department of Health, Social Services and Public Safety (DHSSPS), with a view to HSC wide adoption. The Standards developed will be used to support the Monitoring and Performance Management of PPI across HSC. The output from the group includes:

- Development of draft PPI standards and associated KPIs for DHSSPS consideration focusing on PPI processes including:
  - PPI Leadership.
  - PPI Governance.
  - Opportunities for Involvement.
  - Annual Reporting.

### What outcomes will be achieved?

It is expected that HSC organisations will strive to achieve compliance with the approved and published Standards. This will:

- Support cultural change across HSC.
- Facilitate measurement of PPI.
- Highlight the expectations from HSC organisations.
- Give clarity to Service Users and Carers who can refer to a regional set of standards.

### PPI Standards Subgroup Member Profile



**Brian O'Hagan** is the service user/ carer representative from RQIA. His role on the Forum is to contribute from the perspective of service users, carers and the public in shaping how PPI is designed, evolves and is monitored across the HSC. He also sits on the Forum Standards and Monitoring and Performance Management Subgroups. Brian explains that what works well in the Forum and Subgroups is *"The equal partnership approach at the Forum is genuinely supported in discussions and decision making. It is not a tokenistic approach; the views of the public members of the group are of equal standing to the views of HSC staff."*



## PPI Monitoring and Performance Management

The primary purpose of the Monitoring and Performance Management sub group of the Forum is to advise and inform the PHA on the way forward in this area. The sub group aims to:

- Guide and inform the development and operation of interim monitoring and performance management arrangements for PPI in HSC.
- Suggest ways in which Service Users and Carers could be facilitated to participate directly in monitoring and performance management arrangements, contributing to assessments of PPI progress and participating in verification arrangements.
- Help review and monitor the performance management processes and help develop recommendations for longer term arrangements for the consideration of the PHA.

### Outputs

- Design of interim KPIs.
- Contribute to research and review of interim indicators, and participation in development of final set of KPIs.

### What outcomes will be achieved?

- Assurance that PPI is progressing across Northern Ireland.
- Service users and carers helping to shape the monitoring and

Involvement means bringing together everyone who is affected by a decision to participate in decision-making.

- performance management programme.
- Service users and carers playing a central role in the evaluation of PPI activity.
- Greater understanding across HSC organisations of the importance of good communication, feedback and evaluation of PPI by involving and listening to service users and carers.

### Performance Management Subgroup Member Profile



**Donald Harley** is a service user and carer representative from Belfast Health and Social Care Trust (BHSCT). He sits on both the Monitoring and Performance Management and Standards Subgroup of the Forum.

*"I provide direct input to developing the Performance Management process without being fettered by the issues which may hamper the Trusts/ Agencies as they try to integrate PPI across their organisations. I am able to bring expertise by experience to the discussion of involvement practice and processes across the whole gamut of health and social services work. I can hopefully bring an external perspective and realism to the table and help form effective means to hold the health bodies to account."*

## PPI Communications/Annual Reporting

The purpose of the Communications/Annual Report Subgroup is to promote shared values and approaches and to communicate the activities of the Forum. The group aims to raise awareness of the Forum for a range of relevant stakeholders, including service users and carers, DHSSPS, HSC staff, the public, community and voluntary sector and other statutory agencies. The output from the group includes:

- Producing a Communications/Awareness Raising Action Plan to promote the Forum and its work.
- Co-ordinating the production of an Annual Action Plan for the Forum.
- Producing an Annual Report highlighting the achievements of the Forum.
- Working with the PHA to support the development of the Engage website.

### What outcomes will be achieved?

Clear communication and annual reporting are essential to share the work and best practice identified through the Forum. The outcomes of this subgroup will be:

- Greater awareness of the Forum, its members and its work.
- Consistent PPI messages being shared across HSC, service users, carers and the public.
- Active Promotion of PPI best practice across HSC, service users, carers and the public.
- Recognition of the achievements of the Forum across HSC, service users, carers and the public.

These KPIs will demonstrate continuous or sustained improvement in embedding PPI into HSC organisations' business including planning, shaping and the delivery of Health and Social Care Services.

### Communication/Annual Reporting Subgroup Member Profile



#### Angela Drury

represents the Northern Ireland Practice and Education Council for Nursing and Midwifery (NIPEC) on the Forum.

*“There is a diverse range of people at the table including service users and carers. The Forum has the opportunity, therefore, to provide a meeting place for representatives of large service provider and smaller support organisations that do not have direct service user contact, such as NIPEC, to engage in useful discussion and debate around how PPI is supported. The ultimate goal of participants is to actually impact services in a meaningful way. The added value of such discussions in this type of Forum should not be underestimated.”*

# Forum Achievements

Since the establishment of the Forum in 2010/11 a number of key tasks have been undertaken to progress PPI regionally. The Forum works at a strategic level, operating through genuinely participative and fully inclusive processes across 16 HSC organisations and with a large membership of service users and carers. Using such approaches to reach agreement by consensus and maintain relationships is critical to ensuring ownership of and buy into the concept and purpose of the Forum.

Year	2010 -2013	2013/14 – onwards
Forum Membership Development	<b>Service user and carer representation has continued to grow year on year. Following a review of membership, the number of service user and carer members has trebled.</b>	<b>This will be kept under review constantly exploring ways to facilitate HSC and service user and carer interaction.</b>
Strategic Leadership	<b>The Forum has continually provided strategic leadership for Health and Social Care. It has acted as a platform for sharing good practice, challenges and discussing/planning in a collaborative way. A number of regional priorities have been achieved including the development of:</b> <ul style="list-style-type: none"> <li>• <b>Interim Regional Reimbursement Guide for service users and carers</b></li> <li>• <b>PPI Training Framework</b></li> <li>• <b>Draft PPI Standards and KPI's</b></li> </ul>	<b>The Forum continues to progress PPI through:</b> <ul style="list-style-type: none"> <li>• <b>Training</b></li> <li>• <b>Standards</b></li> <li>• <b>Communications</b></li> <li>• <b>Monitoring and Performance Management</b></li> </ul>
Promotion and Advancement of PPI Fund	<b>Since the establishment of the Forum over 50 PPI projects have been funded by the PHA across HSC with an investment of some £300,000.</b>	<b>In 2013/14 the Forum will work to share the learning from PPI projects across HSC.</b>

# Supporting PPI

The PHA, working through the Forum, has for the last three years operated a programme of support for PPI across HSC. The purpose of the fund is to act as an action research initiative to test new approaches with the intention that good practice is identified, shared and replicated for the benefit of service users and carers.

The PHA has committed over £300,000 to progress the Promotion and Advancement Grant Programme for PPI in the last three years. It has been designed, led and managed by the PHA and has supported in excess of 50 projects/programmes.

Below is a list of projects funded in 2012/13. Evaluation reports for these and previous projects can be found on the PHA website.

Organisation:	Project:
Belfast Health and Social Care Trust	Listening to Children
Belfast Health and Social Care Trust	From Consultation to Participation in the Older People Services
Belfast Health and Social Care Trust	Sensemaker
Belfast Health and Social Care Trust	Travelling for Care
Belfast Health and Social Care Trust	Client Consultation Groups with people with mental health problems and physical and sensory impairment.
Northern Health and Social Care Trust	User Forum for people with a learning disability
Northern Health and Social Care Trust	Mental Health Client Consultation Groups
Northern Health and Social Care Trust	Tell us what you want: self- care in the community
Patient and Client Council	E-learning toolkit
Patient and Client Council	PPI in Practice: A Scoping Study

<b>Organisation:</b>	<b>Project:</b>
Public Health Agency	Promoting the participation of children and young people in their health and assessment plan.
Public Health Agency	Eating Disorder Service user and carer perspective on design and outcomes
Public Health Agency	Review of MDT Stakeholder involvement
Public Health Agency	Parents Focus Groups for the Implementation of the Speech and Language Communication Plan
Public Health Agency	Promoting the health needs of looked after children through active participation 2012.
Public Health Agency	Palliative and end of life care service user and care experience survey
Regulation and Quality Improvement Authority	Pilot project to involve care experienced patients in the Inspection in the Mental Health and Learning Disability Programme of Care
Regulation and Quality Improvement Authority	Engaging families with pre-school children receiving domiciliary care.
Southern Health and Social Care Trust	Promotion of Involvement through information screens in waiting area of emergency departments in Craigavon and Daisy Hill hospitals.
South Eastern Health and Social Care Trust	Get on the mend – Please attend (Reducing Did Not Attends (DNAs)
Western Health and Social Care Trust	Radiotherapy Unit Altnagelvin – Focus groups user engagement
Western Health and Social Care Trust	WHSCT – Engage Events
Western Health and Social Care Trust	Passport to Health
Western Health and Social Care Trust	Mind me at home – Interactive Workshop
Western Health and Social Care Trust	Enabling Older People and their Carers and informing best delivery of Primary and Community Care Services
Western Health and Social Care Trust	User Group Library

# PPI in action – How PPI is making a difference

## Regulation and Quality Improvement Authority – Funded PPI Project

### Title of Project

Personal and Public Involvement Pilot, Mental Health and Learning Disability (MHL),  
Regulation and Quality Improvement Authority (RQIA)

### What was the aim of your project?

The purpose of this pilot was to facilitate and support the involvement of care experienced people in the inspection of long stay hospital wards as a means of developing a true PPI focus for inspections. An evaluation of the pilot was agreed to be undertaken by June 2013.

The aim of this project was to:

- Help to embed the voices of people who use MHL services in the work of service improvement.
- Assist in ensuring the quality and safety of services.
- Support inspectors judgments in the process of evaluating their services. and
- Provide training to enhance the skills of the service users involved.

### Who was involved in developing/delivering your project?

RQIA Mental Health and Learning Disability Team, RQIA PPI Lead, Association for Real Change (ARC), service users and carers.

### What did you do?

In line with best practice in PPI, the project was designed to ensure involvement of people with a learning disability from the outset. It was agreed that no suggestions could be processed until they had the full consideration and agreement of the whole team.

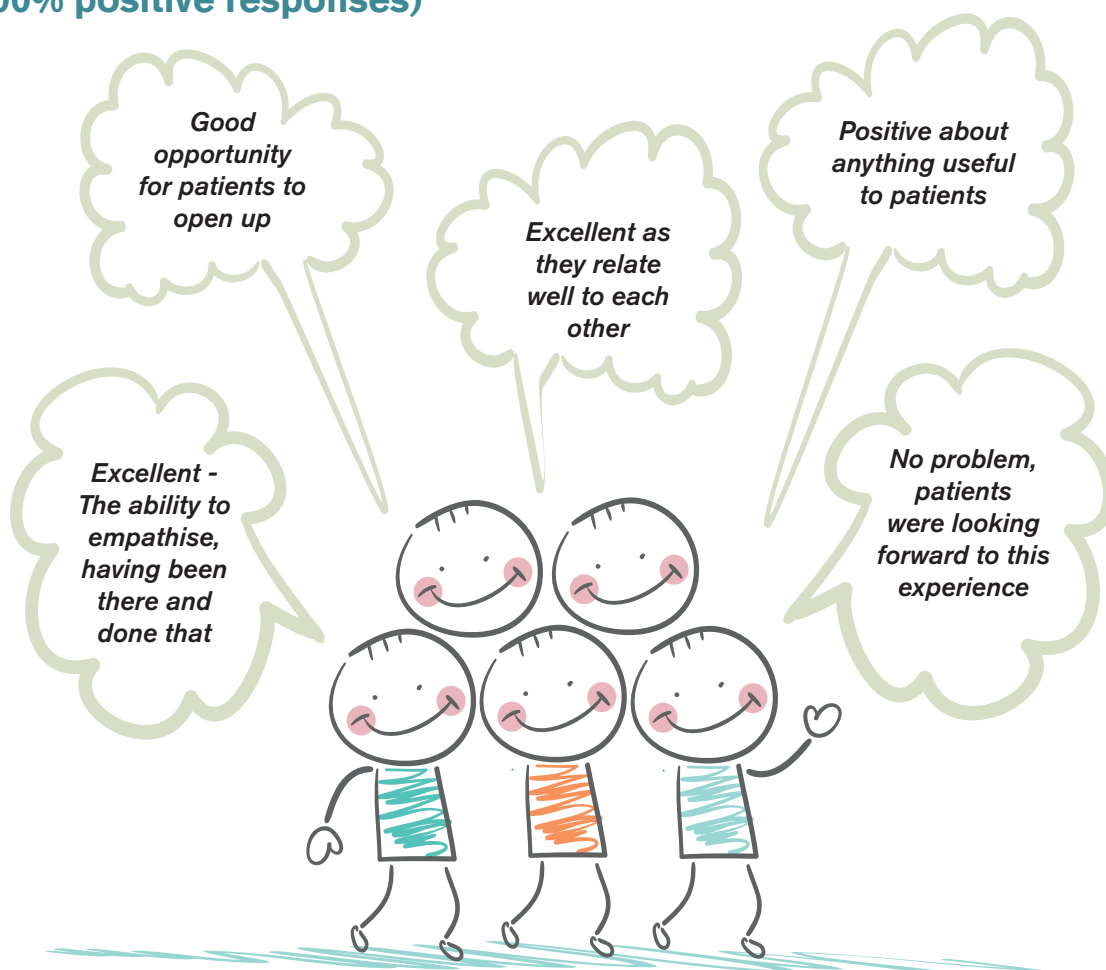
The care experienced people (also called Experts by Experience) worked in partnership with RQIA inspectors and senior managers to:

- Design questions and inspection documentation.
- Conduct inspections.
- Write inspection reports.
- Evaluate the pilot.

It was clear that using a PPI approach strengthened the Inspection process and in turn led to the identification of issues that may not have been picked up by RQIA inspectors.

The outcomes of the pilot were measured in a variety of ways. A Patient Questionnaire was filled out by patients on the wards inspected, asking them for their views of the experience. This was supplemented by focus groups with the Experts by Experience and staff to gain their feedback about the pilot.

## How did you feel about Experts by Experience interviewing patients (100% positive responses)



A focus group concluded that the pilot was very successful and the main expectation was that Experts by Experience would become an integral part of future inspections.

### Feedback

*"Patients found it easier to relate to expert patients. The inspection process is not so clinical when they are involved."*

*"I thought they brought a fresh perspective to the inspection. They tuned into things that I would not have noticed and referenced their own experiences to staff and what worked for them. They related very easily to the other service users".*

*Using PPI "Introduced a different perspective, brought equality and inclusivity to inspections. Inspection felt more thorough. Patients and staff responded very positively and I believe this improved the inspections (I participated in 2). Experts by Experience highlighted issues/concerns and ideas that inspectors may have missed."*

### Did PPI make a difference to this project?

The pilot demonstrated that it takes time and experience to develop true partnership working. The benefits of this pilot reflect those experienced in our research: all stakeholders indicated that the inspection process was more robust and more person centred.

- Experts by Experience talked to staff and provided feedback on what had been important to them as patients and what they had encountered that made a difference to them. This personal perspective brought a new and informative dimension to the process.
- Staff indicated that it was more meaningful to hear these recommendations from the Experts by Experience than from inspectors.
- Experts by Experience identified issues that neither staff nor inspectors were tuned into. For instance in one ward, an Expert by Experience examined locks in a toilet area and asked how staff would assist a patient to get out if they accidentally locked themselves in. On closer examination it was clear that there was a defect in the locking mechanisms.
- While the evidence from patients was feedback to the Project team, it was clear from observation by inspectors, that they were comfortable with and welcomed the Experts by Experience involvement in inspection.

## Public Health Agency – Funded PPI Project

### Title of Project

Promoting the Needs of Looked After Children through Active Participation 2012/13

### What was the aim of your project?

This project built on previous workshops held in 2011. The aim was to identify how best to meet the health needs of Looked After Children as had been requested by young people and foster carers. The PPI exercise undertaken was to gain the involvement and input of young people and carers of looked after young people in the development of a personal health Journal called “About Me”. The involvement exercise aimed to find out if this was something that would be useful and if so, what areas should be included, how should it be laid out and who should have access to the journal.

### Who was involved in developing/delivering your project?

This project was undertaken using a partnership approach. As young people in care are often referred to as ‘a hard to reach group’, it was important to use more than one approach to involve them and their carers. In order to gain the views of the young people we worked with Voices of Young People in Care (VOYPIC), a voluntary organisation representing the views of children and young people in care, who undertook an involvement exercise asking young people for their views on the development of an information tool to support young people in care. In addition to this, we worked with the Fostering Network to host an involvement event.



### What did you do?

The initial plan was to provide a half day (10am – 1.30pm) regional consultation event to consider how the health needs of Looked After Children can be most effectively met through an inter-agency plan that will be presented on the day. This plan has been informed by the consultation outcomes from the previous event held in 2011.

However, through the involvement of young people through VOYPIC, and Fostering Network, it was agreed to manage the event differently than the previous year.

Rather than focusing on all elements of an inter-agency plan developed by the Regional Looked After Children Health and Wellbeing Working Group, it was decided to focus on one – the need to improve Looked After Children's participation in their health assessments through the use of a personal health journal.

### What young people told us:

In general, the personal health journal was seen as a good idea by the young people who reviewed it. When asked if they thought the journal was a good idea the young people responded:

***“It is also good because it contains information that you can share with other people”***

***“Because there is important information that young people should know”***

One group thought that all young people should have a personal health journal, not just children and young people in care. Another group felt that the personal health journal is suitable for 12 to 15 year olds and becomes outdated and is not age appropriate for young people aged over 16.

### What Foster Carers told us:

Overall, the carers felt that the journal is a useful resource which would be helpful for children and young people and they could all see the merit of using it within the home environment with the children they foster. One person commented:

***“It could be very useful in helping a child to settle, to understand their circumstances and helps them in their development”.***

Participation events have been successful and the information gathered has been used to inform the development of a personal health needs journal for Looked After Children that will be piloted commencing September 2013 in all five Trusts.

Key messages were gathered:

1. The willingness of young people and foster carers to be involved.
2. The high priority on physical and emotional health as a means to promoting social well being. Young people want health information provided by a trusted health professional who know what they are talking about.

### Did PPI make a difference to this project?

PPI was essential to the success of this project. The funding received from the PPI promotion and advancement fund enabled us to think creatively about involving young people and foster carers in the development of an information tool. This involvement let us hear first hand what the priorities of the project should be, telling us:

- what should be developed.
- what should be included.
- who should have access to the information.
- who it should be aimed at.
- how it should look.

PPI will continue to be an essential part of this project. We are seeking core funding to progress this project using PPI methods. The ability to undertake this pilot project using PHA funding has provided clear evidence that using PPI approaches builds relationships and produces more powerful results than professionals working in isolation.



## Northern Health and Social Care Trust – Funded PPI Project

### Title of the Project

Tell us what you want: self care in the community personal and public involvement exercise

### What was the aim of your project?

The primary goal of this PPI initiative was to work with a range of service users and carers to give them the opportunity to 'Tell us what they want: Self-Care in the Community'. This initiative created opportunities where the individuals themselves were the key decision makers in developing a self-care programme for people with Diabetes, COPD, Heart Failure and also Dementia carers. Although the focus groups were only carried out over these four areas, each group presented similar themes and it is believed that they will also fit across all the long term conditions (LTCs).

It was intended that this initiative would create opportunities to develop a self-care programme for people with LTCs in the Northern Local Commissioning Group (LCG) area.

### Who was involved in the design/delivery of your project?

Focus groups involved a wide range of stakeholders including service users, carers, healthcare professionals and members of community and voluntary organisations. We firstly created 4 service user and carer panels for people with heart failure, diabetes, dementia and COPD and organised these groups in community venues.

Voluntary sector partners provided information, advice and care giver support. These voluntary organisations included:

- Respiratory – Chest, Heart and Stroke Association and British Lung Foundation.
- Diabetes – Diabetes UK.
- Cardiology – Chest, Heart and Stroke and British Heart Foundation.
- Dementia Carers – Alzheimer's Society.
- Stroke – Stroke Association.

### What did you do?

We hosted four Focus Groups focusing on different long term conditions. See table below:

Group	Date	Venue
Respiratory	15th January 2013	Antrim Forum
Diabetes	16th January 2013	Magherafelt Council Offices
Dementia	21st January 2013	Monkstown Village Centre
Heart Failure	25th February 2013	Mossley Mill

The primary goal of this project was to find out how professionals and service users could work in an integrated way. It was therefore essential that we had a range of different stakeholders present at the focus group. We also did not want to make the groups too large and tried to ensure all of the groups were as informal and relaxed as possible. This was to ensure that service users and carers felt as though they could speak openly. Confidentiality was also a key priority throughout the work.

Each of the venues were based in the community, ranging from council buildings to community centres. The venues were appropriate as it allowed us to discuss, within a community setting, the services which people would like to be developed in their own locality. Refreshments were also offered to the attendees, it was important to create a relaxed atmosphere where the service users would feel empowered to discuss their care and condition.

### Proposed Service from the PPI Initiative

In order to meet their needs and address the concerns of our service users from the focus groups, three self-care/management programmes have been proposed to provide effective education and support.

Programme	Criteria
Living Well	This programme is primarily for those who are at high risk of developing an LTC, but who do not yet have a diagnosis. Patients referred to the Living Well programme should present themselves as either overweight/obese, people who do not often exercise or are regular smokers.
Living Well with a Chronic Condition	This programme is designed for those who have been diagnosed with one LTC. Patients will be referred onto this programme within a reasonable time after diagnosis (approx. 4 weeks) and the programme will focus on rehabilitation and support.  Carers will also be referred into this scheme and will primarily focus on carers needs whilst caring for those with dementia.
Living Well with more than one Chronic Condition	This programme is designed for co-morbid patients with more than one long term condition. The programme will focus on how patients can manage their LTCs effectively and empower and support them.

### Did PPI make a difference to your project?

Yes, the proposed 'Living Well' programmes are reflective of the conversations had at each of the four focus groups and shows that there is a strong need for more structured patient education and support groups to aid people with a long term condition. It is hoped that from this project, we will be able to implement these plans not only through the Northern Trust but hopefully through all the Trusts in Northern Ireland.

Based on the PPI project, these plans have been presented to the LCG Commissioner and funding has been agreed to take forward this initiative.

# Conclusion and Way Forward

This Annual Report was developed by the Communications/Annual Reporting subgroup of the Forum. The aim of this report was to:

- Highlight good practice in PPI Regionally.
- Share learning from PPI approaches, bringing benefits for service users and carers.
- Identify progress on the Regional HSC PPI Forum Action Plan 2012/13.
- Provide an insight into the rationale for the Forum.

Significant progress has been made in 2012/13 on a number of fronts, with an improved awareness of and higher profile for PPI, especially through the promotion and advancement fund. We look forward to a productive year in 2013/14 as we aim to make further progress against our objectives, delivering beneficial outcomes to HSC, service users and carers.

In 2013/14 the PHA will lead on PPI monitoring and performance management arrangements for HSC. Service user and carer members have played a key role in the development of interim arrangements thus far with the pilot scheduled for late 2013. The PPI Standards and Key Performance Indicators drafted by the Forum in 2012/13 will be developed further and will help HSC organisations in their endeavours to meaningfully embrace the concept of PPI.

The journey we are on will continue for the foreseeable future, but what is clear from the work undertaken by the Forum and the feedback received from funded PPI projects, is that PPI is being embraced and is having a positive impact in shaping culture and practice across HSC.

Many people in the service naturally embrace PPI into their work but never recognise that they are doing so. It is important that we are able to demonstrate the impact of effective PPI both for HSC and for service users, carers and the wider public. We need to learn from each other, to identify best practice and to mainstream it for the benefit of HSC and most importantly for service users and carers. If you know of an example of effective PPI, please let us know. You can share these with PPI leads in the respective HSC organisations or Martin Quinn, the Regional Lead for PPI.

# Appendix 1

Regional HSC PPI Forum Action Plan 2012/13				
Action	Timescale	Responsibility	Performance Indicator/Outcome	Progress
Develop an Action Plan for the Regional PPI Forum	September 2012	Regional Forum, facilitated by PHA	Action Plan developed.  Clear objectives identified for 2012/13.	Action plan developed and agreed by Forum
Produce an Annual Report for 2011/12	December 2012	Regional Forum, facilitated by PHA	Published PPI Annual Report	2011/12 Annual report produced and published.
Develop draft indicative Standards and KPIs for PPI for DHSSPS Consideration	March 2013	Regional Forum Standards Subgroup facilitated by PHA	Standards shared with DHSSPS post March 2013 for consideration.	Draft standards and KPIs developed and shared with DHSSPS
Develop proposal for the design of PPI Training for the HSC	October 2012	Regional Forum Training Subgroup facilitated by the PHA	PPI Training programme specification developed	Proposal developed and shared.
Agree format and content of Consultation Schemes to ensure consistency across the HSC	March 2013	Regional Forum Consultation Scheme Review Subgroup	Proposal for revised Consultation agreed Scheme by Forum.	Consultation Schemes reviewed and amended in line with DHSSPS directive
Develop a Communication /Awareness Raising Plan	Jan 2013 onwards	Regional Forum - Communication Subgroup	Clear PPI messages agreed by the Forum. Roll out of communication plan.	Subgroup combined with Annual Reporting Subgroup.

## Appendix 2

### PPI Regional Forum Members

Public Health Agency (PHA)		Health and Social Care Partners	
Mary Hinds/Pat Cullen - Chair		Sandra O'Hare	Department of Health, Social Services and Public Safety (DHSSPS)
Michelle Tennyson			
Martin Quinn			
Roisin Kelly			
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Service User/Carer Representatives (SU/CR)		Fionnuala McAndrew	Health and Social Care Board (HSCB)
Peter Donnelly		Jacqueline Magee	HSCB
Andrew Martin			
Don Harley			
Geraldine Fennel		Charles Kinney	Northern Ireland Blood Transfusion Service (NIBTS)
Colin Devine			
Marion Smith			
Brian O'Hagan		Christine Goan	Regulation and Quality Improvement Authority (RQIA)
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Trusts			
Carolyn Agnew	Southern Health and Social Care Trust (SHSCT)	Angela Drury	Northern Ireland Practice and Educational Council (NIPEC)
Elaine Campbell	South Eastern Health and Social Care Trust (SEHSCT)	Sandra Stranaghan	Northern Ireland Social Care Council (NISCC)
Sandra McCarry	Belfast Health and Social Care Trust (BHSCT)	Anne McGlade	Business Services Organisation (BSO)
Martine McNally	Northern Health and Social Care Trust (NHSCT)	Mark McCarey	Northern Ireland Medical and Dental Training Agency (NIMDTA)
Paula Cunningham/ Siobhan O'Donnell	Western Health and Social Care Trust (WHSCT)	Lily Barr	Northern Ireland Guardian Ad Litem Agency (NIGALA)
Michelle Lemon	Northern Ireland Ambulance Service (NIAS)	Stella Cunningham	Patient Client Council (PCC)



# Appendix 3

## Partner HSC Organisations

The Forum has representation from all aspects of Health and Social Care from the Department of Health, Social Services and Public Safety to the Social Care Board, to the Public Health Agency, the Trusts and the Special Agencies. In addition, membership includes a number of individual service users and carers as well as community and voluntary sector nominees from other HSC Trust PPI panels who give us their perspective on our work and help guide the way forward in this important area.

Below we have provided a brief outline of the partner organisations in the Forum.

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### Public Health Agency (PHA)

[www.publichealth.hscni.net](http://www.publichealth.hscni.net)

The Public Health Agency has the key functions of improving health and wellbeing and health protection. It also provides professional input to the commissioning process. The Public Health Agency is jointly responsible (with the Health and Social Care Board) for the development of a fully integrated commissioning plan for Health and Social Care in Northern Ireland.

The Public Health Agency works in partnership with local government, key organisations and other sectors to improve health and wellbeing and reduce health inequalities. The Public Health Agency also provides the Regional Lead for Personal and Public Involvement. Martin Quinn is the current post holder. He can be contacted at [martin.quinn@hscni.net](mailto:martin.quinn@hscni.net).

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### Health and Social Care Board (HSCB)

[www.hscb.hscni.net](http://www.hscb.hscni.net)

The Health and Social Care Board is responsible for commissioning services, resource management, performance management and service improvement. It works to identify and meet the needs of the Northern Ireland population through its five Local Commissioning Groups which cover the same geographical areas as the Health and Social Care Trusts.

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## Health and Social Care Trusts

There are six Trusts in Northern Ireland. Five of these Health and Social Care Trusts provide integrated Health and Social Care Services across Northern Ireland: Belfast Health and Social Care Trust, South Eastern Health and Social Care Trust, Western Health and Social Care Trust, Southern Health and Social Care Trust and Northern Health and Social Care Trust. Health and Social Care Trusts manage and administer hospitals, health centres, residential homes, day centres and other Health and Social Care facilities and they provide a wide range of Health and Social Care Services to the community.

The sixth Trust is the Northern Ireland Ambulance Service, which operates a single Northern Ireland wide service to people in need and aims to improve the health and well-being of the community through the delivery of high quality ambulance services.

- [www.belfasttrust.hscni.net](http://www.belfasttrust.hscni.net)
- [www.southerntrust.hscni.net](http://www.southerntrust.hscni.net)
- [www.setrust.hscni.net](http://www.setrust.hscni.net)
- [www.westerntrust.hscni.net](http://www.westerntrust.hscni.net)
- [www.northerntrust.hscni.net](http://www.northerntrust.hscni.net)
- [www.niamb.co.uk](http://www.niamb.co.uk)

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## Patient and Client Council (PCC)

[www.patientclientcouncil.hscni.net](http://www.patientclientcouncil.hscni.net)

This is a regional body with local offices covering the geographical areas of the five integrated Health and Social Care Trusts.

The overarching objective of the Patient and Client Council is to provide a powerful, independent voice for patients, clients, carers, and communities on Health and Social Care issues.

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## Northern Ireland Blood Transfusion Service (NIBTS)

[www.nibts.org](http://www.nibts.org)

The Northern Ireland Blood Transfusion Service exists to supply the needs of all hospitals and clinical units in the province with safe and effective blood, blood products and other related services. The discharge of this function includes a commitment to the care and welfare of voluntary donors.

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## **NI Medical and Dental Training (NIMDTA)**

[www.nimdt.gov.uk](http://www.nimdt.gov.uk)

The Northern Ireland Medical and Dental Training Agency is responsible for funding, managing and supporting postgraduate medical and dental education within the Northern Ireland Deanery. It provides a wide range of functions in the organisation, development and quality assurance of postgraduate medical and dental education and in the delivery and quality assurance of Continuing Professional Development for general, medical and dental practitioners.

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## **Northern Ireland Guardian Ad Litem Agency (NIGALA)**

[www.nigala.hscni.net](http://www.nigala.hscni.net)

The functions of the Northern Ireland Guardian Ad Litem Agency are:

- To safeguard and promote the interests of children by providing independent social work investigation and advice in specified proceedings under the Children (Northern Ireland) Order 1995 and in Adoption (Northern Ireland) Order 1987. and
- To provide effective representation of children's views and interests.

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## **The Business Services Organisation (BSO)**

[www.hscbusiness.hscni.net](http://www.hscbusiness.hscni.net)

The Business Services Organisation is responsible for the provision of a range of business support and specialist professional services to the whole of the Health and Social Care sector including, Human Resources, finance, legal services, procurement, Information Communication Technology and other services.

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## **Regulation and Quality Improvement Authority (RQIA)**

[www.rqia.org.uk](http://www.rqia.org.uk)

The Regulation and Quality Improvement Authority is the independent Health and Social Care regulatory body for Northern Ireland. In its work, the Regulation and Quality Improvement Authority encourages continuous improvement in the quality of these services through a programme of inspections and reviews.

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## **NI Practice and Education Council for Nursing and Midwifery (NIPEC)**

[www.nipec.hscni.net](http://www.nipec.hscni.net)

The Northern Ireland Practice and Education Council (NIPEC) aims to improve standards of practice, education and professional development of nurses and midwives to facilitate the delivery of safe, effective and person-centred care.

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## **Northern Ireland Social Care Council (NISCC)**

[www.niscc.info](http://www.niscc.info)

Northern Ireland Social Care Council is the regulatory body for the social care workforce in Northern Ireland. Its aim is to increase the protection of those using social care services, their carers and the public.

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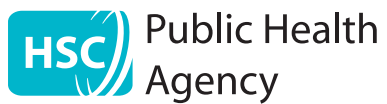
Regional PPI Lead

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