

Regional Health and Social Care Personal & Public Involvement Forum

Annual Report 2017/18



**Personal and Public Involvement (PPI)
Involving you, improving care**

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Foreword

Welcome to the eighth annual report of the Regional Health and Social Care Forum on Personal and Public Involvement (PPI). As co-chairs of the Forum, we have been working with the members to continue to provide leadership to Health and Social Care (HSC) to drive forward involvement and to embed PPI into our culture and practice. This report outlines the work of the Forum for the 2017/18 period.

The HSC transformation programme of work as outlined in 'Delivering Together' has commenced and co-production is at the heart of this. During this period, the Forum has contributed to the development of a Guide for Co-production which has been developed by the Department of Health (DoH). This Guide will build on the foundations which have been developed as part of the PPI programme of work to embed involvement into practice. As part of the transformation programme of work, a number of work streams have been established and members of the Forum have been actively involved in the different areas of work to ensure the voice of the service user and carer is truly integrated from the outset.

The Forum has been proactively calling for the re-establishment of 'Engage', as a resource to support involvement. Funding was successfully secured and the re-developed Engage website was launched by the Chief Medical Officer in November 2017. The resource was co-produced with staff, service users, carers and the community and

voluntary sector and provides a range of resources and information to support involvement.

As part of Engage, the learning opportunities section includes a new e-learning programme for service users and carers to highlight the importance of having their voice heard.

Creating leadership for involvement has been a key role for the Forum. Working with staff, service users and carers, a new Leadership Programme for involvement and co-production has been developed. The first cohort successfully completed in March 2018.



Co-chairs: Donald Harley, service user and carer representative and **Mary Hinds** Executive Director of Nursing, Midwifery and Allied Health Professionals, Public Health Agency.

Personal and Public Involvement and its connection to Co-Production

Background

Personal and Public Involvement (PPI) is the active and effective involvement of service users, carers and the public in Health and Social Care (HSC).

The Health and Social Care (Reform) Act (Northern Ireland) 2009, put in place a Statutory Duty for all HSC organisations to involve people in the planning and delivery of health and social care services.

The Public Health Agency (PHA) in its strategic leadership role, oversees the implementation of PPI policy and compliance across the HSC as set down in the 2012 Circular. The Regional HSC PPI Forum is the vehicle through which the PHA takes forward much of this work.

In recent times there has been an increased focus on the concept of co-production. Those involved in the drive to push forward PPI warmly welcome this commitment, outlined by the then Minister O'Neill in her 'Delivering Together' strategy.

Co-production will empower patients, carers, service users and staff to:

- **design the system** as whole to ensure there is a focus on keeping our population well in the first place and ensuring that when people need support and help they receive safe and high quality care;
- work together to **develop and expand specific pathways of care and HSC services** which are designed around people and their needs, including setting outcomes to measure impact;
- be partners in **the care they receive** with a focus on increased self-management and choice.

(Delivering Together, Department of Health, 2016)

Co-production is a highly person centred approach which enables people to work together on an equitable basis to achieve positive changes in HSC services. It is deeply rooted in connecting people and realising value through peoples combined strength, knowledge and expertise.

Co-production is recognised as being the pinnacle of the involvement continuum and is something we have been encouraged to actively strive towards in the commissioning, planning and delivery of HSC services. The Department of Health (DoH) has now moved to bring PPI, co-production and related areas such as Patient and Client Experience together under the same Directorate. This should help to bring further clarity of direction and will help foster further synergies in the drive to ensure that the HSC is a truly person centred service.

Progressing PPI regionally

Regional HSC PPI Forum

The Regional HSC PPI Forum (the Forum) brings together HSC organisations, service users and carers to work collaboratively to progress HSC involvement in Northern Ireland. It is the vehicle through which the PHA operates to drive forward the promotion and advancement of this important approach to our work.

The Forum undertakes this work by:

1. sharing best practice;
2. jointly working on areas of common interest;
3. the active participation of service users and carers.

The Forum is governed by a terms of reference and among its objectives are the following:

- leading and supporting HSC organisations in complying with and implementing PPI policy;
- the provision of a platform for discussion on all aspects of Involvement and its relevance and impact on the work of HSC organisations and benefits for service users and carers;
- exploring opportunities for joint working between stakeholder organisations, encouraging co-ordination and consistency of practices, reduction of duplication and the sharing of best practice;
- encouraging, supporting and informing the development of understanding of PPI, and the advancement of involvement training across the HSC;
- encouraging, supporting and informing the development of PPI monitoring and evaluation across the HSC;
- the planning, development and implementation of an annual PPI Forum Action Plan.



Regional HSC PPI Forum members

The following sections outline the work of the Forum in line with the five PPI Standards.

Leadership

As part of its leadership function for PPI, the Forum, continues to bring together those with lead and professional responsibilities for involvement, to work alongside service users and carers who had lived experience and expertise. It does this to help take forward the Statutory Duty of Involvement, championing, supporting and facilitating the drive to embed PPI into the culture and practice of the HSC.

As part of its Leadership responsibilities, the PHA on behalf of the Forum, commissioned the first Involvement Leadership Programme, it aimed to:

- Enhance PPI leadership capacity;
- Develop new networks;
- Develop collective leadership skills across HSC organisations and with service users and carers;
- Support the development of individuals to their fullest leadership potential.



The programme was co-produced with HSC staff, service users and carers and delivered in early 2018. The programme is built on the collective leadership philosophy where HSC staff, service users and carers are participants of the programme and will help shape future programmes.

Each module focused on a different aspect of leadership methodology with a focus on involvement. These were:

- leading from within;
- leading for Quality Improvement & Innovation;
- leading to listen and understand;
- leading collectively;
- leadership power and politics.

Additional elements of the programme included:

1. Development of a virtual information hub on the Engage website.
2. The introduction of a leadership networking lunch with existing leaders in PPI and Co-production.
3. The opportunity for all participants to focus their learning from the programme through the use of professional coaching sessions.

Feedback:

One participant summed up their experience on the programme below:

“Overall, for me, the course focused on self-reflection and awareness. It has helped me think about my leadership style and how best to communicate with people. It was good to do this with a group of individuals with a focus on PPI and the inclusion of service users and carers on the group really enriched the process for me.”

The feedback from the programme indicates that it is substantially different from existing HSC leadership programmes for professional groups and management. The PHA will work with the HSC Leadership Centre to identify future programmes of this kind.

During this period, the Forum has:

- hosted three meetings and one workshop of the Forum;
- hosted the annual strategic meeting which brings together Directors responsible for PPI;
- supported the DoH to develop a draft guide for Co-production;
- met with the DoH policy branch lead, Dr Michael McBride, Chief Medical Officer, who endorsed the invaluable work of the PHA and the Forum citing the standards, training and monitoring work. He also commended the endeavours of Forum members in their work to support the focus on co-production moving forward.

The PHA is a partner in a UK four Nations project to develop a set of standards for involvement in research and the NI PPI Standards which were developed by the Forum, were used as the Pathfinder to help develop this work. The Standards were endorsed by the National Institute of Healthcare Research (NIHR) officially launched in March 2018 and available to view at

<https://sites.google.com/nih.ac.uk/pi-standards/standards>



Governance

The Forum has reviewed and up-dated the Action Plan for the period 2018-2020. Progress for the 2017/18 period is outlined below.

Action	Performance indicator/outcome	Progress as of March 2018
Work with the PHA to support the roll out and implementation of PPI Standards across HSC.	<ul style="list-style-type: none"> PPI Standards recognised and adhered to across HSC. 	<ul style="list-style-type: none"> Standards are promoted and widely recognised across HSC. Standards embedded into Forum and HSC Trusts' work. Standards used as pathfinder as part of 4 Nations project to establish Standards for Involvement in Research.
Regional Forum members to collaborate in the review and updating of HSC consultation schemes.	<ul style="list-style-type: none"> HSC consultation schemes reviewed and updated. 	<ul style="list-style-type: none"> Consultation scheme template finalised and endorsed by DoH for use by HSC organisations.
Work with the PHA to obtain support for the Engage website as a central resource for Involvement, with an accompanying outreach development programme.	<ul style="list-style-type: none"> Engage website launched. 	<ul style="list-style-type: none"> Website co-produced with Engage Steering Group. Resource launched in November 2017. Google analytics in place. Engage Phase II commenced.
Implement communication plan with an emphasis on raising awareness of PPI.	<ul style="list-style-type: none"> PPI brand utilised across HSC. Annual report produced. Increased social media activity. 	<ul style="list-style-type: none"> PPI brand utilised by HSC partners as appropriate, in line with brand guidance. Annual Report produced. Increased social media activity across HSC, including twitter.
Forum to work with the PHA to take forward plans for the Engage & Involve PPI training and development programme.	<ul style="list-style-type: none"> Engage & Involve available to HSC organisations. PPI e-learning for service users and carers developed. Involvement Leadership programme developed. 	<ul style="list-style-type: none"> Engage & Involve PPI training programme materials available to all HSC organisations. PPI e-learning programme for service users and carers developed and available via Engage. Involvement Leadership Programme developed and piloted.
Work with the PHA to undertake monitoring for PPI and review mechanisms for the future.	<ul style="list-style-type: none"> PPI monitoring undertaken. 	<ul style="list-style-type: none"> PPI monitoring completed with HSC Trusts for 2016/17 period.

Opportunities and support for Involvement

Engage – a central resource for involvement in Health and Social Care

Engage has been developed as a central resource for Involvement in HSC and co-produced and co-designed with staff, service users and carers. The website supports HSC staff, service users and carers to build their knowledge and skills on Involvement. It is a repository of Information, good practice, tools, guides and evidence of the benefits of involvement.

A Steering Group was established to guide the development of resource and a series of User Acceptance Tests were undertaken to get feedback on the structure and content of the website.

Dr Michael McBride, Chief Medical Officer officially launched the website and outlined “that Engage will develop into one of the most important resources that Health and Social Care uses”.

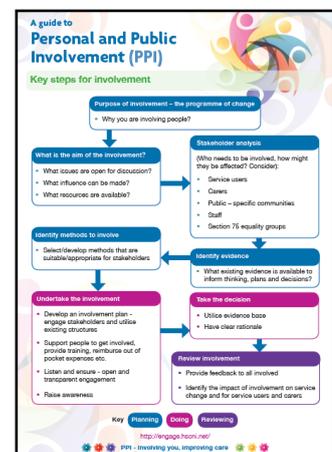
Check out Engage at <http://engage.hscni.net>.



Dr McBride (left), DoH, at the Engage launch event with event guest speakers.

PPI Guides

A series of PPI Guides have been developed with HSC staff, service users and carers. The guides are designed to provide practical information on **Planning, Doing** and **Reviewing** aspects of involvement work. The first guides focus on how to get started, how to develop an involvement plan and developing a role description. All Guides are available on Engage at <http://engage.hscni.net/get-involved/involving-people/guides-to-personal-and-public-involvement/quality-improvement/>. Work will continue during 2018/19 to build a suite of guides to support HSC staff to effectively engage and involve service users, carers and the public.



PPI small grant funding

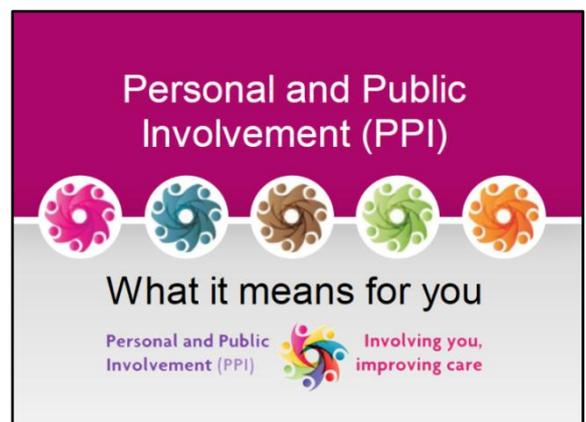
The PHA accessed non-recurrent funding during 2017/18 to roll out a PPI small grant programme. This was made available to HSC Trusts and other HSC organisations to provide support to embed PPI practices and test innovative approaches to involvement. Check out the PPI in practice section (page 12) to find out further information about projects funded.

Knowledge and skills

Engage & Involve

Engage & Involve, the DoH approved HSC involvement training programme, continues to be rolled out. Each organisation is required to have an involvement training plan to identify how this is being taken forward. At a PPI leads day in January 2018 it was agreed that it was timely to review and update the existing programme content and this will take place in 2018/19.

As part of the Engage & Involve training, a new e-learning programme for service users and carers has been developed through a partnership based approach. Service users and carers were actively involved as partners in identifying what was needed in developing the programme. The programme has been developed to help people understand what is PPI, how you can get involved and the difference it will make to them and the HSC. The e-learning programme is now available via Engage at <http://engage.hscni.net/ppi-training/training-for-service-users-and-carers/>.



Developing skills to understand and undertake consultation

In response to requests from Forum members and others for specialist advice and guidance specific to consultation, legal issues and emerging methodologies, a series of training was organised and delivered in the following areas:

- Preparing and managing consultation and engagement;
- Law of consultation in Northern Ireland.

The Northern Ireland Government has also developed a new platform which is known as Citizen Space. Citizen Space is an on-line platform to support hosting consultations and also surveys. The PHA working with Forum partners co-ordinated training for PHA and HSC colleagues to support the development of skills in using the platform.



Participants in attendance at the Law of Consultation training in March 2018 with Quintin Oliver (far right) from The Consultation Institute.

Measuring outcomes

HSC Trust monitoring

As part of the 2012 Policy Circular, the PHA working through the Forum is required to provide the DoH with assurances that HSC bodies and in particular Trusts, meet their PPI Statutory and policy responsibilities.

This work is led by the PHA in conjunction with the Forum Performance and Monitoring sub-group. During the 2017/18 period, a third round of monitoring was undertaken with HSC Trusts. We have continued to review the monitoring process and also set out to determine what actions have been implemented as a result of previous monitoring recommendations.

This year a similar process to previous years was undertaken:

- HSC Trusts complete a self-assessment;
- PHA review and analyse responses;
- Improvement visit undertaken;
- Final report and recommendations produced.

In line with previous years, the Improvement visit was broken down into two sections and undertaken by representatives from the PHA and two service user and carer members from the Performance and Monitoring sub-group. The approach was slightly adapted this year. The first part of the visit entailed meeting with the Trust Non-Executive Director and Director responsible for PPI alongside the PPI Operational Lead. The second part of the visit enabled the HSC Trust PPI Forum (or equivalent) service user and carer members to meet with the service user and carer members of the Improvement Visit team to determine how PPI was being embedded into practice into the organisation.

This monitoring round tried to establish a more Outcomes Based Approach (OBA) focused approach to determine the impact of service user and carer involvement in HSC work. This was only partially successful as robust indicators were a challenge to outline and consequently were not in place to determine what outcomes could be achieved. The Performance and Monitoring sub-group will continue to work towards exploring how an OBA approach to the monitoring process could be developed. This will include liaising with Health partners throughout Ireland, the UK and further afield.

PHA monitoring

In line with the monitoring of Trusts the PHA has for the first time undertaken an external monitoring process. An external monitoring team was drawn from service user, carer and HSC Trust members of the Forum. A robust monitoring exercise was undertaken by the team. The PHA will receive the final External Monitoring report in May 2018, this will progress through corporate governance structures. Recommendations made by the monitoring team will be progressed as part of the PHA PPI Action Plan.

PPI in practice across HSC

The following projects were funded as part of the PHA PPI Small Grants funding programme.

A number of case studies are also available on the Engage website to showcase Involvement in practice across HSC. This is available to view at <http://engage.hscni.net/what-is-ppi/testimonials/involvement-in-practice-case-studies/>

Title of project:

Hack the pain

Organisations:

Public Health Agency (PHA), Patient and Client Council (PCC), and Health and Social Care Board (HSCB).

Project overview

Following publication of the PCC Painful Truth report, the PHA and HSCB have led the multidisciplinary cross sectoral regional pain forum, which includes service user and carer representatives. aimed at improving services for people in Northern Ireland who have persistent pain. One of its four work strands is improvement of information available to people living or working with persistent pain.

The aim was to develop a website or similar virtual resource that meets the information needs of people living with persistent pain in Northern Ireland.

Through a series of consultation events facilitated by the PCC and the Innovation Lab Team at the Department of Finance (DoF), a survey, videos and narrative were produced. These were used to inform pro bono coders and web designers who were brought together for a hackathon under the umbrella of 'code for good', which is a group of people who seek to facilitate the development of software for good causes free of charge. The winning team supported by the DoF Innovation Lab Team will develop its prototype further free of charge in collaboration with the Digital Transformation Team within NI direct and produce an app for patients to monitor their symptoms while also developing a website that will be linked to the NI direct HSC portal. This work will be overseen by the Regional Pain Forum and governed through PHA and HSCB.



Further information is available at <http://engage.hscni.net/what-is-ppi/testimonials/involvement-in-practice-case-studies/hack-the-pain/>

Title of project:

A qualitative study to understand views of pregnant women on vaccination in pregnancy

Organisation:

Public Health Agency

Project overview

In Northern Ireland the vaccine uptake in pregnancy in 2015 is estimated to be around 63% for pertussis and 55% for influenza in 2015. Higher rates of vaccination could prevent illness in women and their babies. Improving vaccination services to meet the needs of pregnant women will first require an understanding of the factors that affect the ability and motivation of pregnant women to be vaccinated.

The project engaged with women, who were at least 16 weeks pregnant, in a group discussion about vaccination in pregnancy. The aim was to learn about the reasons why pregnant women decline or accept vaccination during pregnancy to then reduce practical, social and personal barriers to vaccination. The project will help tailor services and interventions to meet the needs of pregnant women and improve vaccination uptake during pregnancy.

The following outcomes were achieved:

- increased knowledge of pregnant women about vaccination in pregnancy;
- understanding of the attitudes and beliefs of pregnant women about vaccination during pregnancy;
- increased awareness of the practical barriers of pregnant women getting vaccinated;
- proposed ways to overcome barriers and to increase vaccine uptake in pregnancy have been identified.

Title of project:
Developing a young people's Forum

Organisation:
Northern Ireland Guardian Ad Litem Agency

Project overview

The Northern Ireland Guardian Ad Litem Agency (NIGALA) has been involved in an ongoing project to place children at the heart of decision making. Over the last year NIGALA has engaged with children and young people in relation to Judge Gillen's Family and Civil Justice Review, consulted with children and young people regarding office signage and décor, and consulted with children and young people in the development of resources for practitioners to engage with children and young people and to promote their participation in the Court process.

This work has led to the development of a Youth Forum which is currently a pilot project running in the North West area. The project aims to establish a Youth Forum made up of young people who have had experience of Court Proceedings in the Family Courts. The Forum would provide information on the experience of children and young people in the Family Court process, including what worked, and what could be improved. Such information can then be integrated into service development and delivery.

A pilot group was established in March 2017 and has met on two occasions. To date five young people have joined the Forum and another three have been nominated. The group has developed a charter of young people's expectations when engaged with the Family Courts and top tips for judges when meeting children and young people. This is a pilot project and learning from this exercise will inform us of the sustainability and viability of rolling out this group regionally.

The aim and rationale for involvement with children and young people in this type of Forum is to provide a means for incorporating the views of our main group of service users in our service development and delivery. This is a model that has been developed by our sister organisation in England and such Forums have also been established in Scotland and Wales.

To date the Forum has produced a charter of expectations for young people involved in the family courts, which has been shared within our agency, with the judiciary at a session on 15 May 2016 and with Children Order Panel Solicitors on 18 May 2016. The Local Judge in the North West has agreed to meet the young people. The children and young people's involvement in this work to date has great potential to impact on the service.

Further information is available at <http://engage.hscni.net/developing-a-young-peoples-forum/>



The PHA awarded the five HSC Trusts small grant funding to progress and test innovative approaches to involvement. The following section provides an overview of this work.

Belfast Health and Social Care Trust

Projects overview

The funding received was used to support the development of PPI in a diverse range of service areas across the Trust. A range of approaches were used to involve services users, parents and carers in areas that previously had limited involvement and where staff were keen to begin to engage.

This included involving parents in the development of short animation videos to illustrate in a simple way some of the procedures and conditions patients using the paediatric haematology service might experience.

The funding also supported a range of involvement events to inform the development of a new regional artificial eye service and to help develop patient information for a new colonoscopy service. Trust led Sure Start projects facilitated a series of café style conversations with parents to inform future plans and evaluation of current programme delivery for children aged 0-4 years.

A number of new service user groups were established with support from this funding including a podiatry service user group which will help shape future models of service delivery and a diabetes service user group to input into the development of education programmes for people with type 2 diabetes.

The Snowdrop group was established within maternity services. This is a group of parents who have experienced a stillbirth, neonatal bereavement or miscarriage and are now working with staff in the Maternity Hospital to improve services. The funding has helped provide a firm foundation for these groups for future involvement and co-production.

Northern Health and Social Care Trust

Projects overview

A range of initiatives were funded as part of the small grant award which supported the development of knowledge and skills with staff alongside the advancement of involvement in a number of project areas:

- Two facilitation training days were delivered for 22 Trust staff. Participants included a range of senior staff from across the Trust who are involved in shaping a new service or facility, a new project or improving how current services work.
- Over 40 service users, carers and Trust staff attended a workshop called 'Making Involvement Work' to learn how service users and carers want to be involved in decision making and to design our new Trust PPI plan. The workshop confirmed that participatory approaches to gathering views also offer participants the

opportunity to network and learn from each other.

- On 28 March we invited carers to join us to co-design the new carer support events plan for the next year. Working in partnership with the Northern Region Recovery College for mental health we will develop bespoke classes for carers to help them in their caring role.
- An Acute Co-Production Partnership was established which involves the development of the 'Expert Patient' who understands context of how the Trust functions, connecting services with service users, carers and other interested stakeholders to work together when undertaking service change.
- The Podiatry Department facilitated a half-day engagement workshop to showcase their podiatry policy document, along with the specialist diabetic, musculoskeletal and footwear care pathways.
- Mid-Ulster Locality hosted an engagement event to find out how service users and carers visualise the delivery future services in light of the increasing demands and complexities of an ageing population. There was a wide and varied programme for the day with highlights including presentations of service user and family experiences.
- Mental Health Older People Services have established a service user working group specifically focusing on service users with a functional mental illness. The Group has been set up in the Antrim and Ballymena locality initially.
- Workshops were held in four locations, starting with an introduction to compassionate communities followed by round table, assets based, conversations on past experiences, what is working well, gaps emerging and how the community could be involved in future. There were a number of emerging themes coming out of the day including communication, one point of contact-navigator and the importance of the community role.
- A death café style conversation was run in partnership with Cruse Bereavement and was initiated to increase the public's awareness of death, with a view to helping people make the most of their living.
- Cancer services ran two focus groups to gain an understanding of how users of the service view their current care and to identify if there were any improvements that could be made to the services in the future.

South Eastern Health and Social Care Trust

Projects overview

A range of initiatives were funded as part of the small grant award to support further development of Personal and Public Involvement using a range of approaches. Initiatives funded include:

- Personal stories of mental health told through a comic, involving the development of a comic book about what it is like to suffer from mental health difficulties, co-produced with service users of the Clinical Psychology Service.
- Engaging older people in community supported living through service user stories to improve care delivery. Using a service user story approach for social work, the initiative aimed to further develop partnership working with service users, using their stories as an improvement tool.
- The Prison and the Play – drama workshops facilitated by a theatre company to help prisoners and staff produce and perform a play based on their lived experience in prison.
- In Your Shoes, In Mine – an initiative to creatively explore communications and relationships between health care providers and patients (prisoners) through facilitated workshops, exploring the perception and experience of receiving and providing health care within the prison system.
- Story telling events involving prisoners, prison staff and health care staff.

Southern Health and Social Care Trust

Projects overview

Autism services – The involvement of young service users in the development of a social enterprise

Autism services working in partnership with young services users and the 'Print Room' at the Appleby Trust are developing a social enterprise to both support the transition process and further enhance employment opportunities. The social enterprise will be an art cooperative / art café designed by the service users who will also work on site. Funding from the PHA supported the initial stages of the planning process with a funding application to the Big Lottery Fund being co-produced by all stakeholders.

Autism services – The involvement of young service users in ASD awareness raising within local communities

Responding to feedback from earlier group-work and the 10,000 Voices Project, Autism services worked in partnership with young service users to co-produce a DVD to improve awareness and understanding of ASD within local communities. The young services users will also support the engagement with local communities and co-deliver awareness training.

Mental Health Division – Service Information Leaflets

The Mental Health Division working in partnership with the Implementing Recovery Through Organisational Change (ImROC) Communication Group co-produced information leaflets for first time clients and carers to help reduce anxiety and uncertainty. The ImROC Communication Group is chaired by the manager of the Mental Health Forum and includes representatives from the service user community and carers and is tasked with ensuring that all Trust documentation and information is user friendly and easily understood.

Community Dietetics – The redesign of children’s weight management service

Community Dietetics involved service users in the redesign of the 4 session weight management review pathway in clinics. Earlier feedback, gathered during 1-1 interviews with service users / carers who regularly attended the clinic suggested a reluctance to attend a group programme indicating that we need to tailor our approach to meet the needs of service users.

Promoting Wellbeing PPI Team – PPI Toolkit

Over the course of the last 18 months the PPI team has been updating the ‘PPI Toolkit for Staff’ in partnership with service users, carers, staff and external stakeholders. This toolkit provides staff and managers with information and advice on how embed and advance PPI within practice.

Western Health and Social Care Trust

Projects overview

Engage event 23 March 2018

The café style event provided an opportunity for the Trust to highlight PPI work, share learning and celebrate and showcase good practice in relation to PPI within the Trust. Over 100 service users/members of the public, community and voluntary representatives and Trust staff attended and had the opportunity to speak informally to service users/clients and staff involved in the planning, development and delivery of Health and Social Care Services in the Western Trust. Feedback from those in attendance has been extremely positive.

Community Development Health Network Training support - co-production bespoke 2hr workshops/sessions.

These workshops were arranged for the Trust PPI Forum to build on the work already in place within the Trust and look at new opportunities for development of the Forum.

Adult Learning Disability Services – Learning Disability Advisory Group

With funding from PHA, the Trust is co-producing with carers of adults with a learning disability an effective working model of engagement to ensure the voices of service users and carers are can influence the work of the Trust’s Adult Learning Disability (ALD) Service. With support from a Consultant Facilitator, an ALD PPI Advisory Group has been convened and in partnership with carers and ALD service users, the Hub and Spoke Model of Consultation was developed with a Communication Strategy and action plan to support easier involvement.

Conclusion and way forward

Conclusion

It is evident that the Forum has continued its work to provide leadership to HSC, to help embed Involvement in both strategic and operational outworkings.

During this period, the Engage website (<http://engage.hscni.net>) was finalised and launched which provides a central resource for Involvement in Health and Social Care. The Forum has worked tirelessly to highlight the need for this resource and also to co-produce its structure and content.

A core element of our work has been to continue to develop the knowledge and skills required for involvement, and a variety of methods have been utilised for this. The new e-learning for service users and carers provides an online resource to help understand the importance/value of the service user and carer voice in HSC.

Whilst the Involvement Leadership programme has been developed as a taught face-to-face resource, this will be further developed to support participants on an on-going basis via an online discussion forum. We will also evaluate and continue to grow this programme for future cohorts.

Through the work of the Forum, Northern Ireland has been identified as a pathfinder for the development of UK Standards for Involvement in Research. The PHA has been actively involved in this work and we look forward to working with Queens University, Belfast Cerebral Palsy Register who were selected as one of ten UK test-bed sites.

The way forward

The PHA in its strategic leadership role will continue to oversee the implementation of PPI policy and compliance across the HSC in line with the DoH Policy Circular 2012. The Forum will be the vehicle through which the PHA will take forward much of this work.

Plans for 2018/19 include:

- PPI Action Plan reviewed and developed for 2018-2020;
- Engage – Phase II to continue to grow the online resource;
- Regional workshop to review reimbursement and recompense for service user and carer involvement;
- Further guides to support HSC staff to embed involvement into their practices;
- A showcase event to identify, acknowledge and share good practice;
- Work with Queens University Belfast to test the new standards for Involvement in Research;
- Review and undertake monitoring of progress in involvement in the HSC.

Appendix 1: PPI Regional Forum members

The Forum has representation from all aspects of HSC. This includes the DoH, the PHA, the HSCB, the HSC Trusts and the Special Agencies. In addition, membership includes a number of individual service users and carers from other HSC PPI panels/forums who give us their perspective on our work and help guide the way forward in this important area.

Public Health Agency (PHA)		Health and Social Care Partners	
Mary Hinds – Co-chair		David Best	Department of Health (DoH)
Michelle Tennyson			
Martin Quinn			
Claire Fordyce		Fionnuala McAndrew	Health and Social Care Board (HSCB)
Service User/Carer Representatives (SU/CR)		Jacqueline Magee	HSCB
Anne Marie Murray		Jackie McNeill /Lynda Black	Patient and Client Council (PCC)
Anne Murray		Alison Geddis	Northern Ireland Blood Transfusion Service (NIBTS)
Brian O’Hagan		Kate Maguire	Regulation and Quality Improvement Authority (RQIA)
Caroline Kelly		Angela Reed	Northern Ireland Practice and Educational Council (NIPEC)
Donald Harley – Co-chair		Brenda Horgan	Northern Ireland Social Care Council (NISCC)
Gerard McWilliams		Mark McCarey	Northern Ireland Medical and Dental Training Agency (NIMDTA)
Martin Woods		Teresa Fallon	Northern Ireland Guardian Ad Litem Agency (NIGALA)
Peter Donnelly			
Sharon Doherty			
Thelma Dillon			
Torie Tennant			
Trusts			
Carolyn Agnew	Southern Health and Social Care Trust (SHSCT)		
Elaine Campbell /Naomi Dunbar	South Eastern Health and Social Care Trust (SEHSCT)		
Sandra McCarry	Belfast Health and Social Care Trust (BHSCT)		
Alison Irwin	Northern Health and Social Care Trust (NHSCT)		
Siobhan O’Donnell	Western Health and Social Care Trust (WHSCT)		
Jarlath Kearney	Northern Ireland Ambulance Service (NIAS)		

