

**Northern Health and Social Care Trust
(NHSCT)**

**Personal and Public Involvement (PPI)
Monitoring Report**

April 2015

Prepared by Martin Quinn and Claire Fordyce, PHA

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Introduction

Personal and Public Involvement (PPI) is a process whereby service users, carers and the public are empowered and enabled to inform and influence the commissioning, planning, delivery and evaluation of services in ways that are relevant and meaningful to them. People have a right to be involved and increasingly they expect to be actively involved in decisions that affect them.

PPI is a statutory responsibility as detailed in the HSC (Reform) Act (NI) 2009 through the Statutory Duty to Involve & Consult. Each Health and Social Care organisation, to which the legislation applies, is required to involve individuals in the planning and delivery of Health and Social Care (HSC) Services. Specifically, sections 19 and 20 of the above legislation require that service users and carers are involved in and consulted on:

1. The planning of the provision of care
2. The development and consideration of proposals for change in the way that care is provided
3. Decisions that affect the provision of care.

Rationale for PPI

PPI is underpinned by a set of values and principles, but at its core, is the drive to achieve truly person centred services, where service users, the carers and the public are fully engaged in a partnership based approach to health and wellbeing, whether that is at the strategic, or individual level of care planning and provision.

The impact of PPI has been demonstrated in a range of areas from efficiency, and effectiveness, where services have been tailored to need, reducing wastage and duplication, to improvements in quality and safety, to increased levels of self-responsibility for one's own health and wellbeing.

PPI Standards, Monitoring and Performance Management

The Public Health Agency (PHA) has responsibility for leading the implementation of PPI policy across HSC organisations. This is outlined in the Department of Health Social Services and Public Safety (DHSSPS), PPI policy circular (2012). The PHA has a responsibility for monitoring PPI across the HSC system, but has particular responsibility for providing assurances to the DHSSPS in relation to the compliance with and progress of PPI in HSC Trusts.

As part of its leadership role for HSC, the PHA has for the first time in Northern Ireland, established a set of standards for involvement, helping to embed PPI into HSC culture and practice, supporting the drive towards a truly person centred system. The five PPI Standards and associated Key Performance Indicators (KPIs) were formally launched in March 2015 (appendix 1) and provide the basis for the structure of the monitoring and performance arrangements, which have been developed by the PHA.

A pilot monitoring exercise for PPI was conducted at the end of 2013/14. The results of this were used to inform the development of the first formal PPI monitoring arrangements with Trusts. This was initiated in late 2014/15, with a view to having reports completed and available for the Accountability meetings with the DHSSPS in May / June 2015.

Methodology

The monitoring process has used the PPI Standards and associated KPIs as a framework to gather information to help assess Trust progress against compliance with PPI. A direct assessment has not however been made against all KPIs for this report as the PPI Standards were only recently endorsed in March 2015.

The monitoring mechanisms and arrangements were developed in partnership with members of the Regional HSC PPI Forum including service users and carers.

Further discussion and input from the Health and Social Care Board (HSCB), the Patient and Client Council (PCC) and in particular, Regional Quality Improvement Authority (RQIA) helped shaped the final format of these arrangements. They were then shared with and agreed by the DHSSPS.

The key components of the monitoring process are outlined below, with the associated timeline detailed in appendix 2.

- i. An initial baseline self-assessment questionnaire is completed by Trusts in partnership with their PPI Panel (or equivalent) which helps inform assessment of progress in embedding PPI into the culture and practice of the organisation.
- ii. The self-assessment report is considered and approved by the Trust Clinical & Social Care Governance Committee (or equivalent), representing formal sign off by the Trust on their submission.
- iii. The reports are reviewed and analysed by the PHA working with in conjunction with service user and carer members of the Regional HSC PPI Forum Monitoring sub group.
- iv. A verification visit is undertaken with each Trust, probing the responses and evidence provided as part of the self-assessment.
- v. All information is then reviewed and a final report produced for the DHSSPS as part of the accountability arrangements.

Findings and Recommendations

The report is based on evidence gathered through:

1. The Trust PPI self-assessment monitoring return.
2. Information collated during the verification monitoring visit.
3. Additional evidence supplied by the Trust.

The report sets out the findings against the five PPI Standards and recommendations are provided for each area.



Standard 1 – Leadership

HSC Organisations will have in place, clear leadership arrangements to provide assurances that PPI is embedded into policy and practice

Findings

- The Trust Corporate Plan outlines Involving Service Users and Staff as a corporate objective.
- The Trust has an interim executive lead and also a non-executive PPI lead at Board level.
- The Trust has an Operational Lead for PPI, with a limited proportion of the post assigned to PPI responsibilities.
- The Directorate Governance Leads are also the nominated PPI Leads and are responsible for maintaining a list of PPI activity and sitting on the PPI Steering Group.
- The Trust report that service user/carer reference groups are in existence across most Directorates, with different models in operation and it is acknowledged that one model does not fit all e.g. Trust Disability Consultation Panel and Mental Health Forum which consists of 4 locality groups for a geographical spread. Children’s services do not have a service user or carer group, but link closely with voluntary/advocacy organisations to ensure the voice of the service user/carer is heard e.g. VOYPIC. The Trust identified that the establishment of a user group for acute hospital services presents a challenge however an agreement is in place with a group of patients to communicate on issues via email. Ongoing engagement in acute services is achieved using other methods such as ‘Your Views Matter’ and a range of patient satisfaction surveys.

Recommendations

1. In terms of the PPI contact system that the Trust has introduced, it would be important to:
 - Ensure that the individual PPI named contact has capacity (protected time) to provide the advice and guidance in PPI to their Directorate colleagues. The Trust also needs to monitor the levels of demand on their time.
 - Ensure that the PPI contact has the appropriate level of knowledge, expertise and skill in PPI to be in a position to perform their role.
 - Have a clear role description for the named contact, setting out what they are expected to do and also ensure that others in the Directorate are aware of who the contact is and what support is available through them.
2. The Trust should consider how it ensures that PPI leadership in each Directorate is strengthened, in order to ensure that staff and teams are able to deliver against their PPI responsibilities, both at an individual patient care level and also at a more generic service development / change level.
3. Consideration needs to be given to the resources that have been assigned to fulfil PPI responsibilities and the Statutory Duty of Involvement.

Standard 2 – Governance

HSC Organisations will have in place, clear corporate governance arrangements to provide assurances that PPI is embedded into policy and practice.

Findings

- The Trust is currently reviewing governance arrangements for PPI. As we understand it, the PPI Steering Group feeds into the User Feedback and Involvement Committee (Trust Committee) and PPI is a standing agenda item of this group. However it is noted that the structure of these arrangements are due to change.
- A patient account is provided at every Trust Board meeting.
- The Trust noted the difficulty in recruiting service users/carers for an overarching PPI group due to the nature of the discussions i.e. corporate rather than service area work. This is mirrored and identified as a common theme across Trusts.
- A PPI Action Plan is in place (2013-2015) which is reviewed by the PPI Steering Group. Individual Directorate PPI Action plans are not in place but are proposed under the new Draft Strategy and Action Plan, which the Trust is currently developing in conjunction with the PPI Steering Group. However Directorate Service Plans do include proposed actions for PPI activity.
- A PPI Annual Report is produced and available on the website demonstrating PPI in action across the Trust comprising information collated from each Directorate.



Recommendations

1. The Trust should give consideration to involving service users/carers directly in the Trust User Feedback and Involvement Committee.
2. In terms of corporate governance arrangements, the Trust should consider how it can ensure that PPI is regularly placed on the agenda of Executive and Board meetings. There is a potential risk that PPI is only considered when the scheduled updates on the PPI are brought forth through the User Feedback and Involvement Committee reports. Having PPI as a standing item on the agenda as it pertains to the on-going and daily business of the Trust, would help ensure that it is embedded into the culture and practice of the organisation.
3. The provision of a patient account at Trust Board meetings is welcome. It is important however, that the Trust ensures that the distinction between PPI and Patient Client Experience (PCE) is made when such contributions are shared. In respect of PPI, the key matter here is, how the person/group was/were involved, what that involvement entailed and the difference that involvement made.
4. The Trust should review and formally record the mechanisms that operate in each Directorate, to ensure that there are clear and transparent arrangements for involvement with service users and carers. The mechanisms and processes for involvement should be checked out with service users and carers to ensure that they are accessible, purposeful and encouraging for service users and carers.

Standard 3 - Opportunities and Support for Involvement

HSC organisations will provide clear and accessible opportunities for involvement at all levels, facilitating and supporting the involvement of service users, carers and the public in the planning, delivery and evaluation of services.

Findings

- The Trust does not have a formal central register of opportunities for involvement across the organisation. The Trust reported that it maintains a list of user groups/contacts for each Directorate to tap into when identifying service users, or when engaging on particular issues. The Trust has advised that it has an extensive and regularly updated ‘consultee list’ available on the website, which provides a list of contacts to disseminate information to and is used for all Trust public consultation processes.
- The Trust described the processes in place to support the involvement of service users/ carers and the public including:
 - Meetings - easy read documents and timing agreed with members.
 - Carers who sit on the Carers Strategy Steering Group have access to short breaks funding to allow for their effective participation.
 - Range of communication techniques promoted.
 - Key worker link – staff member appointed to a service user/carer to provide support and facilitate their input e.g. providing a map, or meeting the person in advance.
 - Reimbursement guidance disseminated across the Trust to pay actual cost of the service user/carer being involved and ensure no-one is out of pocket through getting involved.
- In relation to consultations, the Trust has advised that it ensures that a consultation feedback report is developed and sent back to all respondents and also placed on the Trust website.

Recommendations

1. The Trust should develop a central register of opportunities for involvement that is updated across all Directorates and is readily accessible by the public.
2. The Trust should consider how to most effectively communicate and make accessible, the range of its current PPI materials / resources to staff, which supports the active involvement of service users / carers.
3. The Trust should ensure that there is an appropriate level of materials and support made available directly to service users and carers, who may wish to become involved, be that at an individual level or in respect of service developments. This could include things such as information on the standards service users can expect from services, how to become involved, what your role could be etc.
4. Feedback must be embedded as standard practice for all consultation and involvement activity at all levels across the organisation. The Trust also need to consider how they can ascertain if this is being done and to a satisfactory level.



Standard 4 – Knowledge and Skills

HSC organisations will provide PPI awareness raising and training opportunities as appropriate to need, to enable all staff to deliver on their statutory PPI obligations.

Findings

- The Trust's Corporate Induction Programme references PPI and staff are directed to the PPI e-learning programme.
- The majority of PPI training hosted within the Trust is via the e-learning programme with small number of other training programmes being delivered on request. Approximately 20 staff have received specific PPI training in 2014/15. PPI training is also incorporated into other training. The disability and equality training incorporates elements which are key to effective PPI.
- Service users/carers are involved in the development, delivery and evaluation of training including disability and equality training. A recent example was provided to demonstrate how a family involved in a complaint are now involved in delivering complaints training.
- HRPTS will be the mechanism used to record PPI training in future.
- No formal training needs analysis (TNA) is undertaken for PPI, but the Directorate TNA identifies training requirements pertinent to PPI and an identification of some of the knowledge and skills relevant, or required to undertake PPI activity is recorded i.e. group work or, questionnaire development, some of which can be addressed by other Trust training courses.
- A PPI Staff toolkit is available to support staff to use the appropriate methodology to engage effectively with the full range of service users.

Recommendations

1. The Trust should build PPI into future job descriptions as a key responsibility and also into staff developments plans and appraisals as appropriate to their role.
2. The Trust should ensure that in the corporate induction and more specifically, in individual job inductions, that staff are clearly made aware of what PPI is and their responsibilities at a general level. Direction to further sources of information / training as appropriate should also be provided.
3. The Trust should consider how it plans to take forward the dissemination and roll out of the Regional PPI training programme across its organisation.

Standard 5 – Measuring Outcomes

HSC organisations will measure the impact and evaluate outcome of PPI activity.

Findings

- Directorates maintain a list of PPI activity.
- The Trust advised that it routinely involves and consults service users when developing a service, reviewing/evaluating a service, redesigning a service or withdrawing a service. It noted however, that consistency was a challenge and whilst there are examples of where it has worked well, there are examples for where it hasn't happened. The following response was recorded:
 - Developing a service – Trust reported that it fairly frequently involved service users.
 - Reviewing/evaluating – Trust reported regular service user input when reviewing/evaluating services.
 - Redesigning – Trust reported that involvement in redesigning services does occur, but not consistently. The Trust provided an example of service user involvement which informed the redesign of the Emergency Department.
 - Withdrawing – Trust advised that, following a recent issue, lessons have been learnt for the future, to ensure that service users are involved, even when service changes are temporary.

The Trust recognises that there is a need for more proactive involvement of service users and carers in this key area.

Recommendations

1. The Trust needs to establish mechanisms including the use of PPI indicators to record and capture evidence of PPI in practice across the organisation, to ensure that good practice is recognised and lessons transferred if appropriate. It should also highlight areas for possible improvement.
2. Any PPI monitoring mechanism utilised by the Trust needs a verification element from the recipients of services to be built into it, to ensure that the perspective of the service user / carer and public feedback is fully integrated.
3. Trust senior management should regularly reinforce the need for PPI considerations to be regarded an integral element of the responsibilities of staff and the organisation, whether operating at the individual care or, strategic planning level.
4. The Trust needs to ensure that PPI is clearly built in as a formal key step in respect of the planning and delivery of care for individuals and also for changes to services, with appropriate checks and balances built in to ensure compliance with the statutory responsibility.

Conclusion

PPI in the NHSCT is closely aligned with the Equality agenda and there is effective co-operation and joint working between these two linked areas. Corporately, the Trust has taken a number of key steps in respect of compliance with its responsibilities under the Statutory Duty to Involve and Consult. This is reflected in the fact that they have a PPI strategy in place, a PPI Steering Group and an Officer with PPI responsibility assigned to them.

The Trust has also been able to evidence examples of good practice in this field from throughout the organisation, which has really made a positive difference to service users and carers. These have the potential for replication and transferability both within the organisation and across the region.

The NHSCT in common with all the other Trusts, has highlighted a range of barriers to effective PPI. Whilst they advise that they are seeking to address these, the Trust has stated that a dedicated resource for PPI could help transform things and ensure that there is greater compliance with the Statutory Duty.

Consistency of approach and compliance with both the spirit and the letter of the Statutory Duty of Involvement and Consultation is a huge challenge for a large and complex organisation such as a Trust, but it is one which needs to be addressed robustly and comprehensively across the organisation. There are a number of areas which the Trust needs to consider across the five PPI Standards. The recommendations set out in this report, across the Standards, are aimed at helping the Trust to progress towards a position where PPI is fully embraced and embedded into culture and practice.

The PHA will work with the Trust in its endeavours to address the recommendations in this report, in particular, where it is clear that there would be merit in a collective approach across HSC organisations.

PPI in Practice – Cancer Services across the Trusts

Background

As part of the PPI monitoring process, it was agreed to engage with a service area to examine the outworking of PPI in practice. Cancer services was selected by the review team as the first area for review, as there was a recognition that there was already a focus on this service area through the Cancer Services Experience Survey.

The following section provides an overview of the responses and reports on findings of PPI practice within cancer services to support the sharing of information and good practice. A wealth of work is currently being undertaken in cancer services to involve service users / carers and this report, provides only a small snapshot of the activity at a point in time. We also recognise that regional cancer service meetings happen on a regular basis and encourage this report to be discussed at such meetings to share findings.

Methodology

After the corporate PPI monitoring verification visit in each Trust area, a separate meeting took place with representatives from cancer services. Each Trust was asked to secure a senior staff member responsible for the service area and if possible, a service user / carer from that area. A series of questions in relation to how PPI operated and was implemented in cancer services, was then addressed to the interviewees in a discussion type arrangement. Service user / carer representatives (where they were in attendance) were also asked about their experiences in relation to their involvement in regards to cancer services in that Trust area.

Findings

In relation to leadership and governance, all Trusts reported a named PPI lead was appointed.

Governance arrangements were not uniform across cancer services in the Trusts; however it was clear that PPI was a core element of the culture of all cancer services. Some Trusts had PPI Action Plans specifically for cancer services, whilst others attempt to build PPI in as an integral element to their Directorate / Service plan.

In terms of service user / carer involvement in the planning and delivery of cancer services, a variety of mechanisms were employed. The SHSCT and SEHSCT have a Service User Cancer Group in place and a PPI group for each tumour site, whilst WHSCT has a Cancer Services Locality Group and BHSCT are informally working to embed PPI into all activity. The NHSCT were the only area without a cancer services PPI group, but evidenced a range of work which engaged with service users either at a one-to-one level, or via involvement in regional work. This is in line with our findings from a corporate PPI perspective, as not one model of engagement suits all areas.

No specific budget is outlined for PPI work in cancer services, but all Trusts reported that reimbursement for out of pocket expenses is provided and some support for involvement activity is also provided via cancer charities.

At an individual care level, the role of the Clinical Nurse Specialist (CNS) in involving all service users was referred to by most Trusts. This role provides the opportunity for service users to discuss their needs and provides guidance and support before and after consultations, to involve patients in their own care. This role was also recognised as key to getting service users and carers involved in cancer specific PPI groups, either at a local or regional level. In the NHSCT, good practice was noted in that the CNS job description and job plan includes involvement as a key role which helps to embed PPI into practice in cancer services.

Given the increasing demand for care, people living longer and surviving cancer, the matter of providing appropriate support for people post treatment was raised by all Trusts. At a service improvement level, the Transforming Cancer Follow Up (TCFU) initiative was noted by all Trusts as providing a structure to facilitate and encourage

involvement. The Holistic Needs Assessment (HNA) process engages service users to review their own needs, which then empowers patients to drive forward their own care and deal with recovery. Health and Wellbeing events were noted again in all Trusts, which provide an opportunity to involve service users and carers in self-care, but some Trusts had also involved service users in developing and evaluating the events.

A wide range of examples were provided to demonstrate the involvement of service users/carers in a range of Trust developments. In the WHSCT, service users were involved in the campaign for the development of the radiotherapy unit for Altnagelvin. In SHSCT, service users and carers helped to plan and design the new Macmillan Information Unit in Craigavon Hospital. Service users and carers have also been recruited as volunteers to support the dissemination of cancer information. In BHSCT regional radiotherapy unit, the service evaluations conducted in partnership with service users / carers are reviewed and categorised into the top 5 things that are going well and the top 5 areas which could do better. As a result of this work, a number of practical changes to the way in which services were delivered and the adaptations to the physical surroundings for those availing of treatment, were identified and are being actioned. In the SEHSCT, a Results Clinic was established to provide a quieter area for patients away from the Outpatient Clinic. In NHSCT, Consultants attend advanced communications training to support the consultation process and this has been reported to be very beneficial and supports the involvement of patients in treatment.

Across all the Trust areas, feedback to service users/carers on service improvements / changes was not strong. Feedback is as an essential component of PPI, enabling information to be shared, to show how people the difference their involvement has made. This is an area which needs to be strengthened.

All Trusts provided the opportunity for carers or family members to be involved in consultations. Further support for carers was noted including accessing information or being involved in discharge care plans. The approach to the involvement of carers

however across cancer services, was neither standard, nor robust and could be strengthened.

Suggested Areas to Enhance Practice through PPI

- Trust cancer services are encouraged to have in place or to develop a PPI Action Plan and to monitor progress.
- The opportunities for involvement are clearly and regularly communicated e.g. have your say posters, websites, and opportunities raised at clinical/patient and carer interactions.
- Trusts should ensure that staff know who the responsible PPI lead is in cancer services.
- Trusts should ensure that there is a named point of contact for individual care and also for involvement in any wider PPI projects.
- It is important to ensure that there is a structured plan / mechanism to facilitate the voice of the service user/carers being heard. Where recruitment to groups is proving problematic consideration should be given to the use of surveys, social media and partnership arrangements with advocacy organisations in a planned manner.
- Trusts should ensure that there are clear mechanisms for staff to share and use knowledge gained from involvement with feedback from service users/carers.
- In developing, delivering and evaluating programmes, Trusts should always seek to identify opportunities to utilise service users / carers' knowledge and expertise.

- Trusts should assess the aspects of PPI knowledge/skills/training required by staff as appropriate to their post and build that into the service action plan.
- A more systematic approach to consider carers needs and how they can be involved would be beneficial. Linking this to the work with the Carers Co-ordinators which was noted by a few of the Trusts, may help in this regard.
- Trusts should capture/record how PPI approaches have impacted on outcomes for service users/carers, to inform learning and future practice.
- Feedback to service users/carers should be adopted as standard practice.

Acknowledgements / Thanks

The PHA would like to acknowledge the work of the service users and carers from the Regional Forum who helped co-design the PPI monitoring mechanisms and who participated in the verification visits and contributed to the assessment of the findings. The PHA also appreciate the work of Trust staff, in particular those with responsibility for PPI who led on the completion of the Trust self-assessment returns and for their contribution and time given during their participation in the monitoring verification visits. Finally, sincere thanks to the service users and carers in the respective Trust areas, who participated in the monitoring verification visits, sharing generously of their time, stories and personal experiences of Involvement.

Appendix 1: Personal & Public Involvement (PPI) Standards and Key Performance Indicators

Standard One – Leadership

Health & Social Care (HSC) Organisations will have in place, clear leadership arrangements to provide assurances that PPI is embedded into policy and practice.

Key Performance Indicators:

- PPI Leadership structure in place across the organisation to include:
 - Named Executive and Non-Executive PPI lead at Board Level, with clear role descriptions and objectives;
 - PPI Operational Lead;
 - PPI leadership structure throughout the organisation.

Standard Two – Governance

HSC Organisations will have in place, clear corporate governance arrangements to provide assurances that PPI is embedded into policy and practice.

Key Performance Indicators:

- Governance and corporate reporting structures are in place for PPI.
- Action plan with defined outcomes developed to demonstrate the impact of PPI.
- Annual PPI report produced, demonstrating evidence of compliance with PPI responsibilities and work undertaken to address challenges in this area.

Standard Three – Opportunities and Support for Involvement

HSC organisations will provide clear and accessible opportunities for involvement at all levels, facilitating and supporting the involvement of service users, carers and the public in the planning, delivery and evaluation of services.

Key Performance Indicators:

- Maintain an up-to-date register of existing and future opportunities for involvement at all levels across the organisation, which is accessible by the public.
- Support the involvement of service users, carers and the public to include:
 1. Provision of clarity on roles/responsibilities for those who are participating.
 2. Provision of training/support.
 - Advocacy support provided if required.
 3. Use of accessible/user friendly communications, mechanisms/procedures. E.g. use of plain English, easy read, jargon free etc.
 4. Good meeting etiquette.
 5. Application of Interim Service User, Carer and Stakeholder Reimbursement Guidelines and Procedures for HSC Organisations.
- Named HSC points of contact for each individual engagement exercise.
- Provide feedback to those involved on each engagement as standard practice.
- As part of your Action Plan, identify barriers to involvement and develop actions to overcome these.

Standard Four – Knowledge and Skills

HSC organisations will provide PPI awareness raising and training opportunities as appropriate to need, to enable all staff to deliver on their statutory PPI obligations.

Key Performance Indicators:

- Integrate basic PPI awareness raising into induction arrangements for all new staff.
- Evidence compliance with any annually agreed regional targets for the provision of/access to PPI training.
- Ensure a mechanism is in place to capture information on the up-take of PPI training.
- Demonstrate service user and carer involvement in the design, delivery or evaluation of PPI training.

Standard Five – Measuring Outcomes

HSC organisations will measure the impact and evaluate outcome of PPI activity.

Key Performance Indicators:

- Evidence service user and carer involvement in the monitoring and evaluation of PPI activity.
- Demonstrate through the Annual Report:
 - How the needs and values of individuals and their families have been taken into account, in the development and delivery of care;
 - The outcomes/impact (positive/neutral/negative) achieved by using PPI approaches in respect of policy, investments, decisions and service delivery across the organisation.

Appendix 2: PPI Monitoring Process with HSC Organisations

