

**Southern Health and Social Care Trust
(SHSCT)**

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

April 2015

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Personal and Public
Involvement (PPI)



Involving you,
improving care

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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 and 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 and 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 has named executive and non-executive PPI leads at Board level
- The organisation has a named PPI operational lead but this post is only partially allocated to PPI. A full-time User Involvement Development Officer is in post. This was noted, as it is the only Trust which has made this investment.
- Directorate leadership arrangements are clearly in place and evidenced. A PPI contact/lead is appointed in each Division/ Directorate.
- A sub-committee of the Trust Board is responsible for leading the coordination, development, implementation and monitoring of the Trust's PPI Action Plan.
- Service user/carer groups are evident across the organisation. Challenges remain in relation to establishing the optimum mechanism to support and facilitate service user / carer input to / involvement with, different Directorates.

Recommendations

1. 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

- A Service User and Carer PPI Panel is in place and comprised of service users/carers representatives from across the Trust localities, programmes of care and Section 75 groupings. Its role is to provide feedback on how the Trust is progressing PPI, which includes looking at gaps across the organisation. The PPI Panel reports to the Trust Board Patient Carer Experience (PCE) Sub Committee.
- The PCE Committee is responsible for clinical and social care governance at a corporate level and provides assurance to the Trust Board that the Trust's services, systems and processes provide effective measures of involvement.
- The Chair of the Trust Board sits on the PCE Committee, alongside three representatives from the PPI Panel who are also full voting members. The PCE Committee is chaired by a non-executive Director, who is currently the lead Non-executive Director for PPI.
- PPI is an agenda item at each PCE committee meeting, which allows for PPI issues to be raised from the PPI Panel to the PCE Committee. Each Directorate reports on PPI based on the individual Action Plans in place. Any issues relating to PPI are then raised at the Trust Board level.
- An internal assurance framework is also presented to the Trust Board twice yearly.
- The Trust has a Corporate PPI Action Plan (2014/15) in place. Each Directorate has an annual PPI Action Plan and associated PPI indicators form part of the annual accountability and reporting mechanisms for each Director.

- An Annual Progress Report is produced and available on the website demonstrating PPI in action across the Trust.

Recommendations

1. In relation to corporate governance arrangements, it is noted that PPI is a standing item on the PCE committee, however the Trust should also consider how it can ensure that PPI is regularly placed on the agenda of Executive and Board meetings. 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.



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

2. The Trust does not maintain a formal central register of existing and future opportunities for involvement. However, each Directorate has compiled a register to disseminate engagement opportunities and the Trust website also promotes opportunities. The Trust has developed a mailing list which includes the community/voluntary organisations that are contacted and disseminate opportunities on behalf of the Trust.
3. The Trust provided a comprehensive overview of the support available to involve service users/carers which included:
 - A range of tools, factsheets and guidance ranging from one page practical how to guides e.g. good meeting etiquette, to full toolkits providing a range of detailed information on how to engage.
 - A range of training and support is available to facilitate engagement e.g. equality and cultural diversity. Other roles in the Trust also support engagement and involvement e.g. Patient Advocate roles and Carer's Co-ordinator.
 - The PPI Operational Plan references the use of accessible/user friendly communications and range of mechanisms provided.
 - Reimbursement guidelines adopted and disseminated across the Trust.
 - Apart from these resources, the Trust's User Involvement Officer is also on hand to provide support to staff on involvement matters in a number of different ways. This includes raising awareness and understanding of PPI, inputting into groups, providing direct assistance to staff to facilitate and

enable them to ensure that service users and carers are actively and meaningfully involved.

- A named point of contact is provided for each engagement exercise which is evidenced in the Impact template.
- In relation to feedback, a feedback template is provided and shared to encourage feedback to be included as part of any involvement exercise. However the Trust acknowledged that they cannot determine if feedback is always provided to those they engaged with and no monitoring arrangements are in place to record this.

Recommendations

1. The Trust should develop a central register of opportunities for involvement which is updated across all Directorates and readily accessible by the public.
2. Feedback must be embedded as standard practice at all levels across the organisation. The Trust needs to consider how it can embed feedback and also determine how this can be monitored.

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.
- Provision and access to PPI training is available on request. A range of Trust training programmes have also incorporated PPI e.g. Management Training Programme and the Lean Practitioner Master Class Programme.
- PPI is not currently built into staff Key Skills Framework as it is recognised that a full range of PPI training cannot be delivered to meet demand which is attributed to a lack of resources. The need for staff skill development has been noted as a major hurdle for PPI, but without additional resources the Trust advised that further PPI training cannot be delivered.
- The Trust reported since 2009, 725 staff and 310 students have received PPI training. A manual record of training is in place.
- The PPI Panel has supported the Trust to develop the PPI Awareness Training programme and supporting resources.
- The Trust advised that the development of the Regional PPI training programme and the delivery of the proposed Engage website are important developments which will help them and other HSC organisations in respect of the delivery of Standards 3 & 4.

Recommendations

1. The Trust should ensure that in individual job inductions, that staff are aware of what PPI is and what their responsibilities are at a general level. This will support and enhance the information provided at the Corporate Induction and also provide an opportunity to direct to further sources of information and training available.
2. The Trust should build PPI into future job descriptions as a key responsibility and also into staff development plans and appraisals as appropriate to their role.
3. The Trust should consider how it plans to take forward the dissemination and roll out of the Regional PPI training programme (once available) across its organisation and how it intends to record up-take.

Standard 5 – Measuring Outcomes

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

Findings

- The Trust previously mapped PPI activity in 2009/10 which provided a baseline for each Directorate.
- The Trust piloted a PPI Impact Template and has now rolled this out across the organisation to measure the impact of PPI. This is reported on a bi-annual basis and monitored against the Directorate PPI Action Plans. This is also captured in the Annual Report.
- The Trust were able to evidence a number of good practice examples of PPI systematically across the organisation which have resulted in tangible benefits for service users, carers and indeed staff and the Trust itself. A number of these have potential for replication and transferability both within the organisation itself and indeed across the region.
- The Trust has identified barriers to involvement and areas for improvement in respect of the involvement and consultation of service users, carers and the public in regards to the design, development and evaluation of services. The primary problem identified, revolved around the stage at which service users and carers are brought into the process. The Trust advised that they are actively working to address this issue at a number of levels throughout the organisation.

Recommendations

1. The Trust should build on its on-going endeavours to address the need for earlier involvement of service users and carers and 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.
2. The Trust has in place a PPI monitoring template. Consideration should be given to the mechanism to ensure this process includes a verification element from the recipients of services. This should help to make sure that the perspective of the service user / carer and public feedback is fully integrated.



Conclusion

On the basis of the evidence provided, the SHSCT are the most advanced Trust in relation to complying with the Statutory Duty of Involvement and Consultation. PPI is clearly on the agenda of the senior management team and widely embedded within policy and practice in the organisation.

The Trust has demonstrated leadership and has regularly shared good practice in this field across the HSC system. The strength of their commitment to service user and carer involvement has been demonstrated through its structures, through its monitoring and reporting arrangements and through the production of a wide range of support and guidance materials for staff and service users.

The Trust has a full-time dedicated PPI / User Involvement officer, which has assisted the Trust significantly in achieving this level of 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 challenge for all HSC bodies.

The Trust is a large and complex organisation and recognises the demands it faces in this regard, especially as the HSC system faces into a period of significant change. To this end, the Trust has indicated that further investment in PPI expertise, knowledge and skills will help to enable them to fully embed PPI into their approach and the practice of the organisation and their staff, in a consistent and high quality manner. The Trust position is that, such a development would enable them to much more effectively ensure PPI compliance, through the roll out of structured and systematic PPI awareness raising and training, the delivery of PPI support, advice, guidance and practical assistance and also through more effective recording and monitoring of activity and assessment and evaluation of impact.

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 and Public Involvement (PPI) Standards and Key Performance Indicators

Standard One – Leadership

Health and 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

