

**Western Health and Social Care Trust  
(WHSCT)**

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

**May 2016**

**Prepared by Martin Quinn and Claire Fordyce, PHA**

Personal and Public  
Involvement (PPI)



**Involving you,  
improving care**

## Contents

<b>Introduction</b> .....	2
Rationale for PPI.....	2
PPI Standards, Monitoring and Performance Management.....	3
Methodology .....	3
<b>Findings and recommendations</b> .....	4
Standard 1 – Leadership.....	6
Standard 2 – Governance .....	9
Standard 3 - Opportunities and Support for Involvement .....	13
Standard 4 – Knowledge and Skills .....	16
Standard 5 – Measuring Outcomes .....	19
<b>Conclusion</b> .....	22
<b>PPI in Practice – Learning Disabilities in hospital settings</b> .....	24
<b>Acknowledgement</b> .....	30
<b>Appendix 1: PPI Monitoring Process with HSC Organisations</b> .....	31



## **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. Delivering a HSC where service users, 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 including increased efficiency and effectiveness, tailoring services to need, reducing wastage and duplication, improving quality and safety, and increasing 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 Department of Health (DoH) in relation to the compliance with and progress of PPI in HSC Trusts. This process was initiated for the first time in 2015 and findings from the first monitoring round may be found at <http://www.publichealth.hscni.net/directorate-nursing-and-allied-health-professions/allied-health-professions-and-personal-and-publi-5>

## **Methodology**

The PPI monitoring mechanisms and arrangements were developed in partnership with members of the Regional HSC PPI Forum including service users and carers. The second round of the PPI monitoring, will continue to implement the process using the PPI Standards and associated Key Performance Indicators (KPIs) as a framework to gather information, to help assess Trust progress against compliance with PPI.

Experience and feedback from the initial monitoring has been incorporated into this programme of work and we continue to review and up-date as this work progresses.

The key components of the monitoring process are outlined below, with the associated timeline detailed in appendix 1.

- i. An initial baseline self-assessment questionnaire is completed by HSC 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 DoH as part of the accountability arrangements.

## **Findings and recommendations**

The following report is based on evidence gathered through:

1. The Trust PPI self-assessment monitoring return. This incorporates the KPI's aligned to the five PPI standards and also the recommendations made as part of the 2015 PPI monitoring.
2. Information collated during the verification monitoring visit, which was undertaken in three sessions:
  - a. HSC Trust PPI panel (or equivalent) members discussed PPI within the Trust with service user/carers from the Regional HSC PPI Forum.
  - b. HSC Trust PPI representatives and PPI panel (or equivalent) reviewed the HSC Trust self-assessment submission and addressed queries in relation to the 2015 PPI monitoring recommendations and progress against these.
  - c. PPI in practice session to explore the outworking of PPI in the organisation.
3. Additional evidence supplied by the Trust.

The report sets out the findings against the five PPI Standards and the 2015 recommendations. Recommendations for 2016 have been developed. Where the existing recommendations have not been fully addressed, these have been carried forward for further consideration and action. Alongside these, further recommendations where appropriate have been developed.



**Standard 1 – Leadership**

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

**KPI Findings**

WHST continue to have in place:

- Named executive and non-executive PPI leads at Board level.
- Named PPI operational lead (currently on long-term sick leave).
- A PPI Forum, which has been strengthened and comprises staff from all Trust Directorates, comm/vol sector and service user/carer representation. The Trust reported that service user/carer representation has increased and a co-chair is currently being recruited. Draft Terms of reference have been in place since the inception of the Forum and are currently being reviewed with the service user/carer representatives. The up-dated Terms of Reference will be presented again to the Trust Governance Committee for approval. The PPI Forum Terms of Reference will provide a clearer purpose for the group and clarity on representative’s role on the Forum.

**Progress achieved against 2015 recommendations:**

<b>Recommendations</b>	<b>Action</b>
<p>1. In terms of the PPI named contact system that the Trust has introduced, it would be important to:</p> <ul style="list-style-type: none"> <li>• Ensure that the individual PPI named contact has capacity (protected time) to provide the advice and guidance in PPI to their Directorate colleagues. The</li> </ul>	<p>The Trust reported that PPI Leads are operating across all Directorates.</p>



<p>Trust also needs to monitor the levels of demand on their time.</p> <ul style="list-style-type: none"> <li>• 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.</li> <li>• 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.</li> </ul>	
<p>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.</p>	<p>The Trust reported that a PPI Strategy and Action Plan has been produced in collaboration with the PPI Forum, and has gone through all the Trust approvals processes. All Directorates Action Plans include a PPI section.</p>
<p>3. Consideration needs to be given to the resources that have been assigned to fulfil the PPI responsibilities and Statutory Duty of Involvement.</p>	<ul style="list-style-type: none"> <li>• The Trust reported that no additional dedicated resource has been identified for PPI. In the absence of the PPI Operational Lead, the Trust outlined that the PPI leadership duties</li> </ul>



	<p>are being undertaken via the existing Performance &amp; Service Improvement Division resources through Health Improvement and Equality team resources. In the absence of additional resources, the Trust is looking at Directorate restructuring to enable further progress on PPI, but clearly outlined the gap locally in a resource for PPI.</p>
--	--

### Recommendations

<p>1. It is recommended that the Trust continues to review the PPI Leads model in operation in the Trust, and :</p> <ul style="list-style-type: none"> <li>• Ensure that the individual PPI Lead 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.</li> <li>• Ensure that the PPI Lead has the appropriate level of knowledge, expertise and skill in PPI to be in a position to perform their role.</li> <li>• 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.</li> </ul>
<p>2. It is recommended that the Trust continues to give further consideration to the resources that have been assigned to fulfil the PPI responsibilities and Statutory Duty of Involvement.</p>

**Standard 2 – Governance**

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

**KPI Findings**

- The Trust outlined the governance and reporting structures in place. The PPI Forum is a sub-committee of the Trust Governance Committee, which in turn reports to the Trust Board on PPI. The PPI Forum chair is a member and has PPI reporting responsibilities to the Trust Governance Committee.
- The Trust reported that PPI is identified as a risk on the Trust Corporate Risk Register and also the Directorate Risk Registers.
- The Trust has up-dated the PPI Strategy and Action Plan (2015-2017), which was developed in collaboration with the PPI Forum. Each Directorate Plan includes a PPI section and progress is reported at the Directorate quarterly monitoring process and also at the annual monitoring process.
- A PPI Annual report 2014-2015 was produced and available on the website demonstrating PPI in action across the Trust.

**Progress achieved against 2015 recommendations:**

Recommendations	Progress
1. 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.	The Trust reported that PPI is raised at Trust Executive and Board meetings but is not a regular standing agenda item.



<p>There is a potential risk that PPI is only considered when the scheduled updates on the PPI are brought forth through the Trust Governance 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.</p>	
<p>2. 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 of 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.</p>	<p>The Trust outlined the scoping exercise being undertaken to ascertain PPI across the organisation. This information will be used to get a clearer picture of involvement across the organisation.</p>
<p>3. In respect of the Trust PPI Forum the Trust should:</p> <ul style="list-style-type: none"> <li>• Consider how the advised mechanism to refresh membership could be made more robust, to ensure that service users and carers</li> </ul>	<p>The Trust provided an up-date on the PPI Forum membership, which now included additional comm/vol sector and service user/carer representatives. Service user/carer representatives in attendance commented on the low</p>

<p>from across the Trust area of operations are recruited onto the Forum to share good practice and to ensure consistency of approach to meaningful involvement in service developments etc.</p> <ul style="list-style-type: none"> <li>• Consider how to strengthen the influence of the Forum in the work of the Trust Governance committee, including representation, agenda setting etc.</li> </ul>	<p>number of service users/carers on the PPI Forum. At the meetings, representatives have the opportunity to input into the agenda and items for discussion but expressed that some of the Directorate up-dates were not always relevant and identified that some other inputs may be more beneficial such as the work of other Service User Groups or opportunities to get involved in other areas of Trust work.</p>
---	--

### Recommendations

<p>1. It is recommended that the Trust continues to 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 Trust Governance Committee reports.</p>
<p>2. It is recommended that the Trust continues to 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 Trust Governance Committee reports.</p>
<p>3. It is recommended that the Trust continues to consider the role of the PPI Forum in relation to:</p> <ul style="list-style-type: none"> <li>○ Reviewing the PPI Action Plans and regular reporting responsibilities to</li> </ul>

the Governance Committee.

- Continuing to actively recruit and engage service users/carers representatives onto the PPI Forum.

4. The Trust should review the findings from the scoping exercise to ensure that there are clear and transparent arrangements for involvement of service users and carers within each Directorate and where appropriate, identify gaps and areas for action. The mechanisms and processes for involvement should be co-designed with service users and carers to ensure that they are accessible, purposeful and encouraging for service users and carers. The scoping report and action plan should be in place for December 2016.

**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.**

**KPI Findings**

- The Trust reported that it has initiated a scoping exercise to ascertain the PPI activity currently taking place across the organisation. This work will be undertaken by the PPI Forum and form the basis for the development of a central register of opportunities.
- The Trust identified recent developments to support the involvement of service users, carers and the public including:
  - Revised PPI consultation scheme;
  - Good practice in consultation training for staff;
  - Annual Engage event to highlight good practice and present opportunities to get service users and carers involved.
- The Trust reported that there is no formal mechanism in place to determine if feedback is taking place.

**Progress achieved against 2015 recommendations:**

<b>Recommendations</b>	<b>Progress</b>
1. The Trust should in accordance with their new draft strategy proposals, develop a central register of opportunities for involvement that is	The Trust outlined plans to establish a central register of opportunities by end 2016, which will be based on the PPI scoping exercise currently underway.



<p>updated across all Directorates and is readily accessible by the public.</p>	<p>The PPI forum representatives outlined that there was a lack of awareness about opportunities to get involved across the Trust.</p>
<p>2. The Trust should consider how to most effectively communicate and make accessible the range of its current training materials / resources which support the active involvement of service users / carers</p>	<p>The Trust reported that an 'Involving you' section has been added to the Trust website and posters have been developed which are displayed across the Trust. The Trust outlined that it awaits the roll-out of the regional PPI training programme.</p>
<p>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.</p>	<p>The Trust outlined and evidenced the 'Have your Say' leaflets and posters which have been disseminated across the Trust.</p>
<p>4. Feedback must be embedded as standard practice 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.</p>	<p>5. The Trust reported that a feedback form has been developed but not embedded as standard practice. The Trust has identified that this cannot take place without a dedicated resource.</p>

## Recommendations

1. It is recommended that the Trust continues to develop a central register of opportunities for involvement that is updated across all Directorates and is readily accessible by the public by January 2017.
2. It is recommended that the Trust continues to consider how to effectively communicate and make accessible, the range of its current PPI materials / resources to staff, which supports the active involvement of service users / carers on an-going basis.
3. It is recommended that the Trust continues to 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. It is recommended that the Trust continues to ensure that 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.
5. The PPI brand should be included in all materials relating to PPI and incorporated into opportunities to get involved materials, including on-line and printed information.
6. A generic service user/carer induction pack should be developed by December 2016, which may be utilised by all staff when undertaking PPI. This will ensure that service users/carers are clear about PPI and its statutory duty, HSC structures and their role on the specific area of work. It is also recommended that a service user/carer co-delivers the induction process for new identified representatives.



**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.**

**KPI Findings**

- The Trust advised that PPI is included as part of the induction arrangements for new staff. Information on PPI is available via the Trust Staff Intranet.
- The PPI e-learning module is available and has been shared with staff via Trust Communication.
- The uptake of PPI training will be captured via HRPTS.
- The Trust reported that service users/carers were involved in developing the regional PPI training programme.

**Progress achieved against 2015 recommendations:**

<b>Recommendations</b>	<b>Action</b>
<p>1. The Trust should ensure that in the corporate induction and 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.</p>	<p>The Trust advised that PPI is included as part of the Trust induction for all new staff. No information was presented on the inclusion of PPI in individual job inductions.</p>



<p>The Trust should consider how it records uptake of current and future PPI training, including training which incorporates elements / aspects which may be relevant to responsibilities associated with PPI.</p>	<p>The Trust reported that the PPI e-learning and additional PPI training will be recorded on HRPTS.</p>
<p>2. 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 uptake.</p>	<p>The Trust advised that it is awaiting confirmation regarding the roll-out of the regional training and highlighted a lack of in-house resources to deliver training.</p>
<p>3. 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.</p>	<p>The Trust outlined that contact has been made with Human Resources to progress the inclusion of PPI into future job descriptions.</p>

### Recommendations

<p>1. It is recommended that the Trust continues to progress discussions and agree an action plan with HR to build PPI into future job descriptions as a key responsibility. Examples of practice in other Trusts are available to support the Trust to progress this recommendation by January 2017.</p>
<p>2. The Trust should actively promote the new PPI e-learning programme and monitor up-take on a 6-monthly basis.</p>

3. The Trust should develop a PPI Training Action plan to incorporate the roll out of Engage & Involve PPI Training.

**Standard 5 – Measuring Outcomes**

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

**Findings**

**KPI Findings**

- The Trust outlined that the PPI Forum will be responsible for leading the coordination, development, implementation and monitoring of the Trust’s PPI Action Plan.
- The Trust reported to have a flowchart in place for significant service developments/changes/investments to ensure that PPI was built into the process. PPI is linked to the equality work within the Trust and PPI is included in the equality screening process which acts as a mechanism for staff to involved service users and carer in any service developments.
- The Trust were able to evidence a number of good practice examples of PPI across the organisation which have resulted in tangible benefits for service users, carers and indeed staff and the Trust itself.

**Progress achieved against 2015 recommendations:**

<b>Recommendations</b>	<b>Actions</b>
1. The Trust should ensure that the mechanisms that it employs to record and capture evidence of PPI in practice across the organisation, includes the use of PPI indicators, helping to ensure that good practice	The Trust reported that it is currently developing a reporting and monitoring template which will be aligned to the PPI Action Plan.

<p>is recognised and lessons transferred if appropriate. It should also highlight areas for possible improvement.</p>	
<p>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.</p>	<p>The Trust did not present progress on this action</p>
<p>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.</p>	<p>The Trust outlined that the Head of Equality &amp; Involvement inputs into Directorate Senior Management Team meetings and encourages all Teams to return progress on PPI.</p>
<p>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.</p>	<p>5. The Trust outlined the inclusion of a section in the Equality Screening process which requires staff to evidence engagement with stakeholders as part of their statutory obligations.</p>

**Recommendations:**

1. It is recommended that the Trust continue to ensure that the mechanisms that it employs to record and capture evidence of PPI in practice across the organisation, includes the use of PPI indicators, helping to ensure that good practice is recognised and lessons transferred if appropriate. It should also highlight areas for possible improvement. This should be in place by March 2017.
2. It is recommended that the Trust continue to ensure that 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. It is recommended that the Trust continue to ensure that 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.
4. It is recommended that the Trust continue to ensure that Senior Management 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.
5. It is recommended that the Trust continue 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**

Western HSCT continues to build on a range of mechanisms and processes to address their PPI responsibilities. Evidence is in place to show a range of good practice throughout the organisation, which has 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.

There are a number of areas which the Trust needs to consider across the five PPI standards. The strengthened service user/carer voice contributing to the work of the PPI Forum will help to support the Trust moving forward. We recommend learning from good practice across Northern Ireland, where service users/carers are integrated into the decision making processes of HSC organisations. The scoping exercise will provide a wealth of information in relation to PPI currently operating across the organisation. This will give the Trust the information to identify areas which need strengthened to support staff to embrace PPI. Alongside staff there is also a need to ensure that service users and carers have the necessary skills for their various roles in the Trust structures. We welcome the work that has been achieved and a consistency of approach and compliance 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.

The WHSCT advocated the need for a dedicated resource in PPI, to enable them to ensure that there is greater compliance with their PPI responsibilities and the Statutory Duty of Involvement. This will support the Trust and provide guidance for staff to embed PPI into practice across the organisation.

The recommendations set out in the report 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 continue to work with the Trust in its endeavours to implement the recommendations in this report and in particular where it is clear that there would be merit in a collective approach across HSC organisations.





## PPI in Practice – Learning Disabilities in hospital settings

### Background

A PPI in Practice session is included as part of the PPI monitoring process to examine the outworking of PPI in an identified service area to illustrate how service users and carers are involved. Learning disabilities in hospital settings was selected to be included in this monitoring round. This area was initially identified by the Regional HSC PPI Forum Monitoring sub-group. This was reviewed to ensure that the service area:

- was common to all trusts ie not an initiative only taking place in one Trust;
- has not undergone in the last 2 years/or is currently subject to a period of change;
- is not currently being reviewed by another programme of work ie 10,000 voices.

Following on from this, the GAIN (Guidelines and Audit Implementation Network) guidelines on caring for people with a learning disability in general hospital settings were raised as a key strategic driver for this service area<sup>1</sup>. These guidelines outline 12 specific areas of improvement and focus on specific areas of the person's journey to and through the general hospital service, the transition processes and a number of clinical issues. The necessity of involving service users and carers is a core element of improvement in this work. Further to these guidelines, the RQIA (2014) reviewed how HSC Trusts were progressing and this highlighted there were still areas for improvement, particularly in relation to involving people with a learning disability and their carers into both personal care and service improvement initiatives. The GAIN guidelines and RQIA review helped to shape the structure of this section for the PPI monitoring visit.

---

<sup>1</sup> GAIN, (2010) Guidelines on caring for people with a learning disability in hospital settings, available at

## **Methodology**

After the corporate PPI monitoring verification visit in each Trust area, a separate meeting took place with representatives from learning disabilities. Each Trust was asked to invite a senior manager from the identified Service Area and if possible, service users, carers or advocates. A series of questions in relation to how PPI operated and was implemented 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 being involved in hospital services for people with a learning disability in that Trust area.

The following section provides an overview of the approaches being undertaken to involve and consult with people with a learning disability in hospital settings. The responses are presented as a collective for all HSC Trusts rather than individually. This approach was undertaken as it is recognised that within a short (30 minute) session it is impossible to report on the wide range of initiatives taking place in each HSC Trust.

## **Findings**

Overall, this session shared a range of practices on work which HSC Trusts are implementing with people with a learning disability in hospital settings. From the outset, we would like to thank the service teams, service users, carers and advocates for their time and for sharing a wealth of information as part of the session. There were a range of approaches from Trusts to this session with some only fielding staff to participate, while others engaged a wide range of stakeholders from direct service providers, managers, clinical professionals, advocates and service users themselves.

In relation to leadership for PPI in learning disability services, it was apparent that PPI was built into the structures at a management level, and was included as a core part of the manager's role, leading to a collective responsibility for PPI in all Trusts. Some Trusts also had a designated PPI Lead. In SHSCT, a PPI Action Plan for the

Directorate is in place and PPI is reviewed twice a year as part of this to RAG rate the work being progressed in the service area.

Whilst the service area to be explored was learning disability within hospital settings, it was evident that there were plans in place in community settings to support people with learning disabilities accessing hospital services. Health improvement work in community settings demonstrated the importance of messages being presented in easy read versions to raise awareness. From a service perspective the linkages between multi-disciplinary teams was evident between nursing, AHP and support teams in Day Centre settings. This was demonstrated as crucial to ensure that any visit to a hospital setting either for an elective care treatment or for an emergency, required a multi-disciplinary approach between teams to ensure the person with a learning disability received the appropriate level of care. The WHSCT provided an example to highlight the Fast track card for Emergency Department attendance. This showcased work to support a person with learning disabilities who is not able to wait for long periods of time. Where this is identified as a challenge, a pre-arranged form can be completed and authorised to enable the person to be seen quickly should such a situation arise.

From a regional perspective, 10 Health Facilitators work to support the transition of people with a learning disability to access a hospital service. This was highlighted as a key support mechanism between GP's and the acute sector in in the SHSCT. GP's have engaged with the Health Facilitator to support the transition of people with a learning disability to access services in hospital settings. Alongside this, an example was shared to illustrate the co-development of easy read documents with service users. The bowel cancer booklet was shared as an example, which was developed with a User Group in the SHSCT area and seen as a response to developing better resources to support people with a learning disability. This work impacts on hospital services by ensuring the person and carer has information in an easy read format to help their understanding of an identified procedure.

In SEHSCT, reference was made to the 'All about Me' hospital passport and the regionalisation of this support tool. The content is developed in partnership with the person with learning disabilities in preparation for a hospital admission. The passport will be piloted in the summer and launched in Autumn 2016.

The SHSCT also shared guidance on steps developed for the Day Procedure Unit to help facilitate patients with a Learning Disability and their families/carers when they require dental treatment under anaesthesia. This includes a specific list for learning disability patients to be seen on certain days and the need to create an environment that is conducive for patients who do not like a lot of noise. In operation in other Trusts is the Acute Liaison Nurse, who is a link between the acute setting and a person with Learning Disabilities to facilitate their visit to hospital. This model was raised by a number of Trusts.

The importance of the regional group on sharing best practice approaches to working with people with a learning disability was raised by all Trusts. The Patient Passport was highlighted by a number of Trusts to showcase the development of a regionally agreed process and approach to involving people with a learning disability in hospital settings. The passport provides details about the patient and what assistance is required for example if a patient needs to be fed and this information is then readily accessible on entry to a hospital unit. The TILLI (Telling It Like It Is) project has been in existence for a number of years and facilitates people with learning disability to have their voice heard. Trusts provided a range of examples to demonstrate how service users have been involved in developing information to support people with a learning disability, for example the BHSCT AAA screening leaflet.

At a Trust level, BHSCT outlined the Patient Council which has been established in Muckamore Abbey Hospital. This group involves service users in the decision making process in the hospital. A recent example was shared to show how service users were involved in reviewing how CCTV surveillance would be installed and how the information would be stored and used.

All Trusts have a contract in place with an Advocacy organisation such as ARC, Disability Action and Mencap who are engaged to fulfil this work via a contract awarded through a tender process. This support is in place to ensure there is more support to provide advocacy services for people with a learning disability.

All new staff working in Learning disability across Trusts are provided with an induction which includes PPI. Various examples were provided on how people with a learning disability are involved in training HSC staff on what a learning disability is. In SEHSCT, service users are actively involved in training staff to increase understanding of learning disabilities. In BHSCT, people with a learning disability are involved in the recruitment and selection of staff for Muckamore Abbey Hospital, which is supported by a training programme to build capacity for people with a learning disability to participate in this process. It was recognised that it is not mandatory for staff in other identified hospital settings ie Emergency Department, to receive training on involving people with learning disabilities. At a Trust level it can be difficult to engage with other Directorates and it was suggested that a rolling programme on 'what is a learning disability' is required. The role of the Link Nurse was shared as a crucial role.

The WHSCT outlined the Carers Voice Forum which meets twice a year in different localities across the Trust, to engage with carers to look at what is working and what can be improved. A recent area for consideration was the provision of short breaks which allowed an opportunity for carers alongside people with a learning disability to get involved in reshaping a service.

Service Users and Advocacy representatives in attendance at the meetings provided a range of examples of where they are involved in HSC Trusts. Not all examples provided were specific to learning disabilities in hospital settings but never the less it is excellent to evidence the wide range of examples where people with learning disabilities are involved in setting the direction of their own care and also in the HSC Trusts plans.

## **Conclusion**

By undertaking this session, the range of work being undertaken to involve and engage with people with learning disabilities and their carers is evident. It is also recognised that there is a regional programme of work associated with the Gain recommendations which supports the sharing of good practice and also consistency across Northern Ireland. This report therefore does not present further recommendations as involvement is already embedded into this regional work. There is a necessity to ensure that this work is actioned and outstanding recommendations or action required is progressed to ensure that the involvement of people with a learning disability is embedded into practice across HSC services.

This report presents a snapshot in time and it is hoped that this will input into both the regional and Trust level programme of work.

## **Acknowledgement**

The PHA would like to acknowledge the work of the service users and carers from the Regional HSC PPI Forum who co-designed the PPI monitoring process. This included reviewing the initial monitoring process undertaken in 2015, identifying areas for improvement and restructuring the monitoring process. We acknowledge the time commitment dedicated to this work to review the materials and participate in the meetings and thank members for their input into this area of work.

The PHA would also like to acknowledge the HSC Trust, PPI teams who co-ordinated the on-site visits and engagement with the PPI representatives and colleagues working in learning disability. We appreciate the time and commitment given to completing the self-assessment and verification meetings.

Finally, we give sincere thanks to service users and carers who participated in the meetings and sharing examples of being involved in areas of work to support people with learning disabilities across Trust settings. We truly appreciate your time and also your engagement to support services.



## Appendix 1: PPI Monitoring Process with HSC Organisations

