

**Belfast Health and Social Care Trust
(BHSCT)**

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

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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. 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

BHSCT continue to have in place:

- Named executive and non-executive PPI Leads at Board level.
- Named PPI operational lead.
- A PPI Lead has been appointed in all Directorates.
- A number of mechanisms across the organisation are in place to connect with service users/carers. Service user/carer representatives in attendance evidenced the different mechanisms in place to involve service users/carers.

BHSCT reported that:

- A PPI Standing Forum has not been established but Terms of Reference have been developed and the first meeting is scheduled to take place in May 2016. This would concur with service user/carer feedback that no central PPI mechanism for service users/carers is currently in place in the organisation.

Progress achieved against 2015 recommendations:

Recommendation	Progress
<p>1. In terms of the PPI point of contact model that the Trust proposes to introduce, it would be important to:</p> <ul style="list-style-type: none"> • Ensure that the individual PPI contact has capacity (protected time) to provide the advice and guidance in PPI to their Directorate colleagues. The Trust 	<p>The Trust confirmed that PPI Leads are in place in each Directorate and their PPI role is integrated into their core role. Formal time spent on PPI activity by the leads is not currently captured. The Trust shared the role description for the PPI Lead and support pack which includes supporting information for the</p>



<p>also needs to monitor the levels of demand on their time.</p> <ul style="list-style-type: none"> • 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 Lead, 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. 	<p>Lead to fulfil this role. Service user/carer representatives in attendance identified that the Trust PPI Lead was instrumental in the establishment and support for a number of service user groups in operation.</p>
<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 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 advised that PPI remains a key objective in the Corporate Plan, which is translated into practice in the individual Directorate Management Plans. BHSCT anticipate that the leadership role within Directorates will be strengthened through the roll out of the PPI training.</p>
<p>3. Consideration needs to be given to the resources that have been assigned to fulfil PPI responsibilities and the Statutory Duty of Involvement.</p>	<p>BHSCT reported that no additional ring fenced resources have been allocated for PPI. BHSCT noted that within existing Directorates resources, PPI has been progressed for specific engagement projects.</p>

Recommendations

1. It is recommended that the Trust continue to review the PPI Lead system in operation to:
 - ensure that the individual PPI 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.
2. It is recommended that the Trust continue to consider how it ensures that PPI leadership in each Directorate is strengthened, in order to ensure that staff and teams deliver against their PPI responsibilities, both at an individual patient care level and also at a more generic service development / change level.
3. It is recommended that the Trust continue to give further consideration to the resources that have been assigned to fulfil the PPI responsibilities and Statutory Duty of Involvement.
4. To ensure that there is a mechanism for service user/carer representation in Trust governance structures, the Standing PPI Forum should be established and be operational by December 2016. To support the work of this group
 - a. Clear terms of reference are to be developed and agreed with service user/carer representatives.
 - b. A communication plan should be developed to raise awareness of the Standing Forum to service users/carers already involved in BHSCT and be clear about how to get involved or input into the work of the Forum.
 - c. Clear and defined linkages between individual Directorate PPI models arrangements and the PPI Standing Forum should be agreed.

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 advised that PPI reports are submitted to the Trust Board via the Equality, Experience and Engagement Committee (EEEG).
- The Trust reported that every Trust Board meeting commences with a patient journey story. This can involve incidents or a reflection on their treatment. A key factor in this is identifying learning for future.
- The Trust advise that PPI is included in the quarterly accountability meetings for each Directorate. A PPI registration template has been developed and circulated to Directorates. This provides a structure to up-date and monitor PPI activity.
- In relation to the proposed new PPI Standing Forum, it would appear that:
 - The Organisational Framework for PPI (which includes the agreement to establish the PPI Standing Forum) was endorsed by the Executive Team in November 2015.
 - A meeting has not taken place. The Trust reported that it is anticipated this will take place in May 2016.
 - The establishment of the central PPI structure is not widely known about by service users/carers currently involved in BHSCT via other mechanisms.
 - The link to the EEEG group has not been agreed.
- A new PPI Operational Framework has been developed and agreed. The Framework includes an action to further embed PPI into the organisation, which includes working with Directorates to develop PPI Action Plans.
- A PPI Annual Report is produced and presented to provide an up-date of activity in line with the PPI Standards.

Progress achieved against 2015 recommendations:

Recommendation	Progress
<p>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. There is a potential risk that PPI is only considered by Trust Board when scheduled updates on PPI are brought forth through the Trust 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>The Trust reported that PPI is regularly discussed at Trust Board and Executive Team meetings. Formal reports are tabled through the EEEG to the Trust Board.</p>
<p>2. The Trust needs to ensure that the proposed new PPI Standing Forum has mechanisms in place to facilitate the involvement of the service users/carers not connected with collective / group perspectives, as well as those who represent advocacy or voluntary organisations.</p>	<p>The Trust provided evidence to show draft terms of reference for PPI Standing Forum have been developed. Plans are in place to promote the Forum, including via existing service user/carer User Groups and other interested groups including the community/voluntary sector.</p>
<p>3. There needs to be clarity about the exact role of the Forum and</p>	<p>The Trust outlined that the PPI Standing Forum will report to Trust Board via the</p>

<p>relationship with Trust governance arrangements. The Trust should consider how to ensure that the Forum represents a strong and clear voice for effective PPI throughout the organisation and work of the Trust.</p>	<p>EEEG. The Forum will have a role in shaping the PPI Action Plans in each Directorate. The PPI Action Plans will then be monitored as part of the Directorate accountability process.</p>
<p>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 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>In relation to the PPI models operating in each Directorate, the Trust reported that no formal review of this process has taken place.</p>
<p>5. The review and development / establishment of the new arrangements for PPI should conclude shortly and a clear timeline should be set down for when these will be operational.</p>	<p>The Trust provided a timeline for implementation via the PPI Operational Framework.</p>

Recommendations

1. It is recommended that the Trust continues to consider by December 2016, how it can ensure that PPI is regularly placed on the agenda of Executive and Board meetings.
2. It is recommended that the Trust continues to 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. A process to capture this information is to be established by March 2017.
3. There needs to be clarity about reporting arrangements between the PPI Standing Forum and the relationship with the Trust governance arrangements and in particular the EEEG. A mechanism for the service user/carer voice has to be incorporated to ensure there is a link between the EEEG and PPI Standing Forum by 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 a Central Register of PPI Opportunities is now available and evidenced on the corporate website. The comprehensive database has been circulated throughout the organisation and will be reviewed every six months.
- The Trust outlined a number of support mechanisms that the Trust has implemented to support service users/carers to get involved. This includes a number of Service User/Carer Groups, social media activity and targeted activity relevant to specific population groups ie people with hearing loss or BME communities.
- The Trust reported that there is a named contact for each engagement exercise.
- The Trust reported that feedback mechanisms vary on the type and scale of engagement and a number of methods are used including information boards, newsletters etc. The Trust has a PPI checklist and feedback is listed as a core activity as part of PPI, alongside the need for feedback being covered in the PPI training programme delivered by the Trust to staff.

Progress achieved against 2015 recommendations:

Recommendation	Progress
<p>1. The Trust, as outlined in the new PPI Framework, should develop a central register of opportunities for involvement, which is updated across all Directorates and readily accessible by the public.</p>	<p>The Trust reported that the Central Register of Opportunities has been developed and evidenced on the Trust Corporate website. The Trust will continue to maximise opportunities available across the Trust via this mechanism.</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>BHSCT evidenced the range of materials available for staff to support implementing PPI, including a PPI toolkit, PPI checklist and induction pack for service users/carers.</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 shared the core induction pack for service users/carers which can be adapted to service specific work. This included a range of information to provide background information to BHSCT, role description and what to expect as a service user/carer representative. Service user/carer representatives in attendance outlined that no specific training had been offered to support them to fulfil their role.</p>



<p>4. The Trust advised that an induction manual has been developed for the Carers Reference Group. The Trust should consider standardising this tool to support wider PPI activity across the organisation.</p>	<p>Aligned to the above recommendation, the Trust has developed and evidenced a standardised induction pack for service users/carers getting involved with BHSCT.</p>
<p>5. Feedback must be embedded as standard practice at all levels across the organisation. The Trust also needs to consider how this can be monitored to ensure that this essential element of good PPI is being complied with.</p>	<p>The Trust reported that feedback is promoted and encouraged as standard practice but is not formally monitored.</p>

Recommendations

<p>1. It is recommended that the Trust continues to effectively communicate and make accessible the range of its current training materials / resources which support the active involvement of service users / carers on an on-going basis.</p>
<p>2. It is recommended that the Trust continues to work with the PHA to showcase and share the Core induction pack for service users/carers as a model of good practice.</p>
<p>3. The PPI brand should be included in all materials relating to PPI and opportunities to get involved, including on-line and printed materials.</p>
<p>4. An on-going training needs review should be undertaken with service users/carers, to support their continued involvement with the Trust. This should</p>

be initiated by Service User Groups in existence as appropriate to need.

5. Review the monitoring mechanisms in the organisation to ascertain if feedback is embedded as standard practice across the organisation.



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 reported that PPI is covered in the corporate induction. Correspondence to highlight PPI information and e-learning training has been sent to all staff to promote PPI as part of local inductions arrangements.
- The Trust currently deliver PPI training covering:
 - Introduction to PPI
 - E-learning module
 - Team briefs
 - Tailored sessions for teams.
- The Trust reported to have in place HRPTS, which captures the uptake of training.
- The Trust indicated a number of other actions which are also in place to support the development of skills and knowledge for PPI including:
 - Communication and Consultation Good Practice Guide (includes PPI)
 - The Management of Change workshop includes a PPI section.
- The Trust reported that service users/carers are involved in training such as Serious Adverse Incident (SAI) training and complaints training.

Progress achieved against 2015 recommendations:

Recommendation	Progress
1. The Trust should ensure that individual job inductions include PPI,	Alongside disseminating information to staff, the Trust indicated that links had



<p>to make staff clearly aware of what PPI is and what their responsibilities are at a general level. This will support the information provided at the Corporate Induction and also provide an opportunity to direct to further sources of information and training available.</p>	<p>also been made with the Learning and Development team to promote PPI as part of local induction arrangements. The PPI e-learning module has been shared with all Co-directors and tier 4 staff to incorporate into local staff inductions.</p>
<p>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.</p>	<p>No action was reported.</p>
<p>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 uptake.</p>	<p>The Trust reported that the PPI e-learning training is available and has been promoted to all staff via the intranet. The Trust reported that the regional taught PPI training will be reviewed and a delivery plan will be put in place but this is dependent on current capacity within the Trust PPI and Community Development Team.</p>

Recommendations

1. The Trust should continue to ensure that individual job inductions include PPI, to make staff clearly aware of what PPI is and what their responsibilities are at a general level. This will support the information provided at the Corporate Induction and also raise awareness of the further sources of information and training available.
2. The Trust should continue to build PPI into future job descriptions as a key responsibility and also into staff development plans and appraisals as appropriate to their role by March 2016.
3. The Trust should continue to work with the PHA and other HSC organisations to consider and establish a plan to take forward the dissemination and roll out of the Regional PPI training programme across its organisation by March 2017.
4. The Trust should actively promote the new PPI e-learning programme and monitor up-take on a 6-monthly basis
5. 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.

KPI Findings

- A range of examples were provided to demonstrate where service users/carers have been actively involved in the development and delivery of Trust services.
- The Trust will engage the PPI Standing Forum to review how service users and carers are involved in monitoring and evaluating PPI activity.
- In relation to the involvement of service users and carers and their active involvement in all significant service developments/changes and investments, the Trust responded that PPI is built into all key planning and service change activities. The Trust noted that adequate involvement in the development and implementation of contingency plans is hugely challenging given the very short time frames. The Trust also highlighted a recent example where a decision was taken at short notice to protect safety and quality, and plans are in place to now consult about this decision and options for the future.

Progress achieved against 2015 recommendations:

Recommendation	Progress
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,	The Trust shared the PPI checklist in place to measure the impact of PPI at a project or service level. No evidence was provided to demonstrate how this

<p>helping to ensure that good practice is recognised and lessons transferred if appropriate. It should also highlight areas for possible improvement.</p>	<p>information is being collated or recorded.</p>
<p>2. The PPI monitoring mechanism employed by the Trust needs a verification element from the recipients of services to be built into it. This should help to make sure that the perspective of the service user / carer and public feedback is fully integrated.</p>	<p>The Trust recognises that this is an area to be developed and will engage the PPI Standing Forum when in place to review this mechanism.</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 reported that PPI is now included in the Chief Executives brief which is attended by all Trust Senior Managers. PPI information is reported to be cascaded across the organisation via the team brief process.</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>As noted above, the Trust reported that PPI is built into all key planning and service change activities and examples were provided.</p>
<p>5. The Trust should ensure that there is</p>	<p>The Trust recognises this remains a</p>

<p>continuity of PPI support for service users/carers that are accessing regional service.</p>	<p>challenge and continues to explore options for the involvement of service users/carers accessing a regional service.</p>
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Recommendations

<p>1. The Trust should continue to ensure that any PPI monitoring mechanism utilised by the Trust builds into it, a verification element from the recipients of services, to ensure that the perspective of the service user / carer and public feedback is fully integrated.</p>
<p>2. The Trust should 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.</p>
<p>3. The Trust should continue to evidence how PPI has been 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>4. The Trust should continue to ensure that there is continuity of PPI support for service users/carers that are accessing regional service by working with the PHA and HSC Trusts to identify potential areas for implementation.</p>
<p>5. Establish a recording mechanism, by March 2017, based on the PPI indicators in place, to ensure that good practice is recognised and lessons transferred if appropriate. It should also highlight areas for possible improvement.</p>

Conclusion

Belfast HSCT continues to demonstrate the range of PPI taking place at various levels within the organisation. Our evidence shows that there remains a hiatus in relation to the development of a central mechanism to provide a voice for service users and carers within the governance structures in BHSCT. Whilst there is an appreciation for the scale and complexity of the organisation, the focus for the next period of time should be on the establishment and operationalisation of the PPI Standing Forum. A meeting has been scheduled but it will take time for such a structure to become fully operational.

A key consideration for BHSCT moving forward will be the integration of the PPI Standing Forum into the Trust governance structures. A number of recommendations have been provided to support the development and implementation of the newly formed group and we also recommend learning from good practice across Northern Ireland, where service users/carers are integrated into the decision making processes of HSC organisations. The monitoring process has continued to identify barriers to PPI and the Trust has again raised the need for a dedicated resource, to support staff to integrate PPI into their areas of work.

As with all other Trusts, Belfast continues to evidence a range of good practice in this area throughout the organisation, which had really made a positive difference to service users and carers. There are a number of areas for replication and transferability both within the organisation and across the region which was clearly demonstrated in our engagement with service users and carers as part of this work.

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 area¹. 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.

¹ 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

