

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

**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

The Trust reported up-dated leadership arrangements for PPI:

- The Director of Operations and Deputy Chief Executive are responsible for implementing PPI and providing assurance to the Trust Board.
- A new Non-Executive PPI Lead has been appointed who also co-chairs the Engagement, Experience and Equality Group.
- The PPI Operational Lead responsibilities have been transferred to the Head of Equality.
- The Trust reported that overall the organisation is restructuring which includes the leadership arrangements for PPI. The newly established Engagement, Experience and Equality Group (EEEG) will be responsible for ensuring compliance with PPI. This group is co-chaired by the Deputy Chief Executive and co-chaired by a Non-Executive member.
- The Trust reported that PPI Leads are in place across the organisation but these roles will be reviewed and this model will be strengthened to build on experience, but provide a clearer role and presence in Directorates.
- The Trust reported that it continues to work through service user panels across the Directorates. Service user and carer representatives confirmed that a central PPI Steering Group is not in operation in the organisation, which presents a lack of opportunities to involve service users/carers in the Trust strategic decision making processes.

Progress achieved against 2015 recommendations:

Recommendation	Progress
<p>1. In terms of the PPI contact system that the Trust has introduced, it would be important to:</p> <ul style="list-style-type: none"> • Ensure that the individual PPI named contact has capacity (protected time) to provide the advice and guidance in PPI to their Directorate colleagues. The Trust also needs to monitor the levels of demand on their time. • Ensure that the PPI contact has the appropriate level of knowledge, expertise and skill in PPI to be in a position to perform their role. • Have a clear role description for the named contact, setting out what they are expected to do and also ensure that others in the Directorate are aware of who the contact is and what support is available through them. 	<ul style="list-style-type: none"> • The Trust reported that it has reviewed the PPI governance structure and the PPI Leads model will be reviewed by the EEG.
<p>2. The Trust should consider how it ensures that PPI leadership in each Directorate is strengthened, in order</p>	<p>The Trust reported that all Directors will be represented on the EEG and they will be responsible for identifying</p>



<p>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>Divisional PPI Leads, who will be provided with information and resources to support staff.</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>The Trust outlined that via the restructuring process, the Equality Unit will now take the leadership responsibilities for PPI and ensure adequate resources are in place to continue to implement PPI. The need for additional resources was highlighted to support the implementation of PPI across the organisation.</p>

Recommendations

<p>1. It is recommended that the Trust continues to review and reconsider the PPI Lead system that the Trust has in place, within the restructured organisation. It would be important to:</p> <ul style="list-style-type: none"> • 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. • 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. • Have a clear role description for the named contact, setting out what they are

expected to do and also ensure that others in the Directorate are aware of who the contact is and what support is available through them.

2. It is recommended that the Trust continues to consider how it ensures that PPI leadership in each Directorate is strengthened, in order to ensure that staff and teams are able to deliver against their PPI responsibilities, both at an individual patient care level and also at a more generic service development / change level.
3. 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.
4. The Service User Panels currently in operation within the Trust act as a mechanism for involvement across the service areas. The Trust needs to consider and establish a central mechanism to ensure that there is service user/carer representation is built into the newly restructured Trust governance arrangements.

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 reported that it has up-dated the Governance and Accountability structures for PPI. The EEEG group will be responsible for providing assurance to the Trust Assurance and Improvement Group which reports through the Executive Team to the Trust Board.
- The Trust reported that the current PPI Action Plan is out of date. Working with Trust User and Carer Groups, plans are in place to develop a new Action Plan.
- 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:

Recommendation	Progress
1. The Trust should give consideration to involving service users/carers directly in the Trust User Feedback and Involvement Committee.	The Trust reported the EEEG will consider the involvement of service users/carers in this Trust governance structure.
2. In terms of corporate governance arrangements, the Trust should consider how it can ensure that PPI is regularly placed on the agenda of	The Trust reported that this will be considered by the new EEEG.



<p>Executive and Board meetings.</p> <p>There is a potential risk that PPI is only considered when the scheduled updates on the PPI are brought forth through the User Feedback and Involvement Committee reports.</p> <p>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>3. The provision of a patient account at Trust Board meetings is welcome. It is important however, that the Trust ensures that the distinction between PPI and Patient Client Experience (PCE) is made when such contributions are shared. In respect of PPI, the key matter here is how the person/group was/were involved, what that involvement entailed and the difference that involvement made.</p>	<p>The Trust stated that a patient story is presented at each Trust Board meeting. This agenda item demonstrates how lessons are being learnt and incorporated to improve quality and safety for Trust services.</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 with service users and carers. The</p>	<p>The Trust reported that Directors and PPI Leads are responsible for ensuring a formal record is maintained for PPI projects.</p>

<p>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>	
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Recommendations

<p>1. It is recommended that the Trust continues to give consideration to involving service users/carers directly in the newly established EEEG which has responsibility for providing assurance on PPI.</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 presented via the EEEG. 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>3. 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 with service users and carers. The mechanisms and processes for involvement should be checked out with service users and carers to ensure that they are accessible, purposeful and encouraging for service users and carers.</p>

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 outlined that a register of opportunities is currently collated at a Divisional level. Opportunities to get involved are available on the Trust website for service users/carers. Service user/carer representatives confirmed that opportunities were made available to get involved via their service user panels or via advertisements.
- The Trust reported to have in place a consultation database to disseminate information on consultations.
- The Trust outlined the support available to involve service users/carers including:
 - Toolkits to support staff to engage and involve are available via the intranet.
 - Documents available in different formats on request.
 - Engagement of User Groups to look at the needs of groups ie Learning Disability Forum
- Service user/carer representatives highlighted that an induction meeting was provided for members joining panels to support their involvement.
- The Trust outlined that the central point of contact for engagement is the Equality Unit, which then directs queries to the relevant service area.

- The Trust reported to developing feedback reports for consultation exercises and sharing widely via corporate website and staff intranet. Service user/carer representatives in attendance indicated there was not a formal feedback structure in place.

Progress achieved against 2015 recommendations:

Recommendation	Progress
<p>1. The Trust should develop a central register of opportunities for involvement that is updated across all Directorates and is readily accessible by the public.</p>	<p>The Trust reported that each Directorate has in place a list of opportunities. A central database is held to disseminate opportunities to get involved in consultations.</p>
<p>2. The Trust should consider how to most effectively communicate and make accessible, the range of its current PPI materials / resources to staff, which supports the active involvement of service users / carers.</p>	<p>The Trust outlined that a PPI toolkit and information for staff is included on the staff intranet.</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</p>	<p>The Trust outlined that information is included on the corporate website to outline the support available for service users and carers to get involved, for example, translated information.</p>

<p>expect from services, how to become involved, what your role could be etc.</p>	
<p>4. Feedback must be embedded as standard practice for all consultation and involvement activity at all levels across the organisation. The Trust also need to consider how they can ascertain if this is being done and to a satisfactory level.</p>	<p>The Trust reported that feedback from all consultations and involvement activity is provided via the Trust's Consultation Database and Trust's User Panels.</p>

Recommendations

<p>1. 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 on-going basis.</p>
<p>2. 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.</p>
<p>3. 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.</p>
<p>4. 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</p>

information.

5. 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 reported that it continues to include PPI as part of the corporate induction.
- The Trust outlined the PPI training available:
 - Face to face training has been provided for key staff to develop skills to engage with service users and carers.
 - Presentation slides for team leaders/managers have been developed for inclusion in awareness sessions with staff.
 - PPI has been incorporated into a range of training including disability equality training, carers’ assessment training and equality training.
 - The PPI e-learning module is now available for all staff.
- The uptake of PPI training will be captured via HRPTS.
- The Trust outlined how service users/carers are involved in the co-delivering specific training for staff, including disability awareness training and Traveller Cultural Awareness Training.

Progress achieved against 2015 recommendations:

Recommendations	Progress
1. The Trust should build PPI into future job descriptions as a key responsibility and also into staff developments plans and appraisals	The Trust reported that PPI is included in all new job descriptions. Divisional Directors have responsibility to ensure PPI is built into staff development plans



as appropriate to their role.	and appraisals.
<p>2. The Trust should ensure that in the corporate induction and more specifically, in individual job inductions, that staff are clearly made aware of what PPI is and their responsibilities at a general level. Direction to further sources of information / training as appropriate should also be provided.</p>	<p>The Trust reported that PPI is included in the Trust Corporate Induction. Divisional PPI Leads are to ensure PPI is included in individual job inductions. The Trust encourages staff to complete the PPI e-learning training.</p>
<p>3. The Trust should consider how it plans to take forward the dissemination and roll out of the Regional PPI training programme across its organisation.</p>	<p>The Trust outlined that it awaits the agreement for the regional roll-out of the PPI training and this will be monitored by the EEEG.</p>

Recommendations

<p>1. It is recommended that the Trust continues to develop a mechanism to record how PPI is being incorporated into staff development plans and appraisals as appropriate to their role.</p>
<p>2. It is recommended that the Trust continues to Include PPI in individual job inductions, to ensure 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>3. It is recommended that the Trust continues to work with the PHA and other HSC organisations to consider and establish a plan to take forward the dissemination</p>

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

- The Trust outlined that service users and carers are currently involved in monitoring and evaluating specific PPI activity.
- The Trust evidences the involvement of individuals and their families in the planning and delivery of care via the Annual Report.
- In relation to the involvement of service users and their active involvement in all significant service developments/changes and investments, the Trust responded that the majority of decisions have active involvement and will continue to ensure, that in the restructuring plans for the Trust, that PPI is clearly built into reporting and governance processes.

Progress achieved against 2015 recommendations:

Recommendations	Progress
<p>1. The Trust needs to establish mechanisms including the use of PPI indicators to record and capture evidence of PPI in practice across the organisation, to ensure that good practice is recognised and lessons transferred if appropriate. It should also highlight areas for possible</p>	<p>The Trust reported that the PPI Annual report demonstrates outcomes achieved as part of the involvement of service users and carers.</p>



improvement.	
2. Any PPI monitoring mechanism utilised by the Trust needs a verification element from the recipients of services to be built into it, to ensure that the perspective of the service user / carer and public feedback is fully integrated.	The Trust provided no up-date on the recommendation.
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.	The Trust advised that the Trust Executive Team is fully committed to PPI.
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.	The Trust advised that the Trust Executive Team is fully committed to PPI.

Recommendations

1. It is recommended that the Trust continues to establish robust mechanisms including the use of PPI indicators to record and capture evidence of PPI in practice across the organisation, to ensure that good practice is recognised and lessons transferred if appropriate. It should also highlight areas for possible improvement.
2. It is recommended that the Trust continues 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.
3. It is recommended that the Trust continues 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.
4. It is recommended that the Trust continues 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 continues 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.

Conclusion

It is evident that the Northern HSCT is currently undergoing a significant programme of restructuring. This has included and impacted on the leadership and governance responsibilities for PPI in the organisation. This process presents a real opportunity for PPI to be fully integrated into the leadership and governance arrangements within the Trust.

To truly make a significant impact, the recommendations need to be implemented in a timely manner and a timeframe has been included for implementation. The actions proposed by the Trust in relation to PPI are welcomed including the realignment and consideration of PPI Leads in the organisation and this will ensure that the momentum already in existence in NHSCT is not lost. Alongside service user/carer involvement within Divisions, consideration also needs to be given as to how the groups feed into a central mechanism to ensure the voice of the service user and carer is not lost at the Trust strategic level.

The Trust has continued to provide evidence of examples of good practice taking place across the organisation, which has made a positive impact to service users and carers. These have the potential for replication and transferability both within the organisation and across the region. The monitoring team welcomed the opportunity to engage with service user and carer representatives involved in the Trust and it was clear to see the impact of their involvement in different service areas.

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. 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.

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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

