# South Eastern Heath and Social Care Trust (SEHSCT)

# Personal and Public Involvement (PPI) Monitoring Report

# May 2016

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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**

SEHSCT continue to have in place:

- Named executive and non-executive PPI leads at Board level.
- Named PPI operational lead.
- PPI Leads have been appointed in each Directorate and meet via the PPI Leads group which reports to the PPI Sub-Committee.

**Progress achieved against 2015 recommendations:**

| Recommendations | Progress |
|---|---|
| 1. In relation to the PPI leads model that the Trust has in place, it would be important to:<br><br>• 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.<br><br>• 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. | The Trust reported that a role description has been developed for the PPI Lead which includes protected time to attend PPI Leads meetings.   The PPI Leads model will be reviewed in 2016/17 as some Directorates are not attending meetings and there is recognition that there is a variance in knowledge, expertise and skills across the group. Work is underway to link into the complaints and patient experience programmes of work. |

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| • Have a clear role description for the PPI lead, setting out what they are expected to do and also ensure that others in the Directorate are aware of who the PPI lead is and what support is available through them. | |
| 2. The Trust should consider how it ensures that PPI leadership in each Directorate is strengthened, in order to ensure that staff and teams deliver against their PPI responsibilities, both at an individual patient care level and also at a more generic service development / change level. | It was reported that PPI is a core component of leadership workshops and the Trust's Annual Leadership Conference. The Trust reported there is strong leadership, but greater focus needs to be given as to how this is monitored through Action Plans and the Directorate Management Plans. |
| 3. Consideration needs to be given to the resources that have been assigned to fulfil PPI responsibilities and the Statutory Duty of Involvement. | The Trust reported that correspondence has been sent to the PHA to highlight the challenge in relation to resources to address PPI responsibilities. Internally, the Trust has been working with Organisational Workforce Development to develop more peer to peer support. There has also been an increased focus on stakeholder involvement at Trust leadership events and through Corporate and Directorate Plans, with a view to increasing the awareness and accountability for Directorates to undertake PPI. |

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**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.

Public Health Agency

**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**

- Based on information provided, it is our understanding that the following reporting structures are in place for PPI:

    o PPI Leads group – staff only group, which reports to the PPI sub-committee on PPI activity in the Trust.

    o PPI sub-committee – comprising PPI Leads and service user/carer representatives who are recruited from the Trust Service User Groups in operation. This sub-committee reports to the Safety and Quality Committee.

    o The Safety and Quality Committee reports to the Governance Assurance Committee and in turn reports to the Trust Board.

- PPI is a regular item on the Executive Management Team agenda.

- PPI is discussed at performance meetings and Department accountability reviews.

- PPI Action Plan 2016/17 is in place.

- A PPI Annual Report is produced and the 2015/16 report has been endorsed by Trust Board at the end of March 2016.

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**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 Trust Executive and Board meetings. There is a possibility that PPI is only considered when scheduled updates on PPI are brought through the Trust Safe and Effective Care Committee. 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. | It was reported that:<br><br>• PPI is discussed at Executive Management Team meetings on a regular basis. The Team also review the Directorate Management Plans and raise queries or concerns in relation to PPI in specific proposals for services.<br><br>• A PPI up-date is included in the Safety and Quality Committee meeting agenda and reports are presented via the PPI sub-committee. The Safety and Quality Committee reports any concerns in relation to involvement and consultation to the Trust Board. Any concerns are presented to the Trust Board as appropriate.<br><br>• The Trust Board meeting commences with a patient story. The Trust reported that the patient story seeks to highlight experience of Trust services, both good and bad, to show what has been learnt and how involvement how support the Trust to |

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| | enhance services in future. |
| 2. The Trust should give consideration as to how the various structures, mechanisms and reporting arrangements for PPI operate, in order to ensure ease of understanding and clarity, particularly from a service user / carer perspective. | Reporting structures for PPI presented above. |
| 3. In relation to the PPI sub-committee the Trust should:<br><br>   o  Consider the development of a robust mechanism to refresh membership, to ensure that service users and carers from across the Trust area of operations are recruited onto the PPI sub-committee, to share good practice and ensure consistency of approach to meaningful involvement in service developments etc.<br><br>   o  Consider how to strengthen the influence of the PPI sub-committee in the work of the Safe and Effective Care committee, including representation, agenda setting etc. | o  The Trust reported that the Terms of Reference for the PPI sub-committee has been reviewed but recruiting service users/cares remains an issue.<br><br>o  The Safe and Effective Care Committee conducted a review in February / March 2016 and the PPI Lead contributed on behalf of the PPI Sub-committee to this review. |

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| 4. In relation to service users and carer involvement with Directorates, 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. 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. | The Trust reports that all Directorates have a mechanism for involving service users/carers in their service area at an early stage of the planning process. |

**Recommendations**

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| 1. It is recommended that the Trust continues to ensure that PPI is regularly placed on the agenda of Trust Executive and Board meetings. |
| 2. It is recommended that the Trust continues to consider the PPI sub-committee, particularly in relation to: <br><br> o the development of a robust mechanism to refresh membership, to ensure that service users and carers from across the Trust area of operations are recruited onto the PPI sub-committee, to share good practice and ensure consistency of approach to meaningful involvement in service developments etc. <br><br> o Strengthening the influence of the PPI sub-committee in the work of the Safe and Effective Care committee, including representation, agenda setting etc. |
| 3. It is recommended that the Trust continues to review the mechanisms that |

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operate in each Directorate, to ensure that there are clear and transparent arrangements for involvement. The mechanisms and processes for involvement should be checked out with service users and carers to ensure that they are accessible, purposeful and encouraging for service users and carers.

**Standard 3 - Opportunities and Support for Involvement**

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

**KPI Findings**

- A Register of Opportunities has been produced and available on the Trust website, to inform service users of involvement opportunities.

- The Trust provided a limited up-date on the practical steps in place to support the involvement of service users, carers and the public.  Evidence presented demonstrates a range of activity to increase awareness to get involved compared to support which may be required to support involvement.  Service user/carer representatives in attendance reported that limited training in relation to Trust policy, PPI etc had been offered to support their involvement in the various groups.

- The Trust reported the PPI Lead is the named point of contact for all consultations.  For engagement exercises, the Service Lead is the named point of contact who links with the PPI Lead.

- The Trust reported that feedback is standard practice for all engagement exercises as included in the consultation checklist.

**Progress achieved against 2015 recommendations:**

| Recommendation | Progress |
|---|---|
| 1. The Trust should in line with their new draft PPI strategy, develop a central register of opportunities for involvement that is updated across all Directorates and is readily accessible by the public. | 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. |
| 2. The Trust should consider what PPI information and support tools are required by staff and how to most effectively communicate and make accessible these materials / resources to support the active involvement of service users and carers. | The Trust reported that a PPI toolkit is in place and available to all staff. |
| 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; information on the standards service users can expect from services; how to become involved; | The Trust reported that support is provided at a corporate level through the Service User Forum, the PPI sub-committee and the individual Service User Groups. The Trust outlined that it provided a range of materials and support which continue to be developed and assessed. Service users/carers in attendance reported that support to attend meetings was provided and |

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| | welcomed, however one representative was not familiar with the Reimbursement Policy for Out of Pocket expenses. There was also a concern that meetings focused on Directorate reports which were not always relevant to service users/carers and acronyms used were confusing. |
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| 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. | The Trust report that feedback is standard practice across the organisation. |

**Recommendations**

| 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. |
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| 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; information on the standards service users can expect from services; how to become involved; what your role could be etc. |
| 3. Alongside the Induction Pack, an on-going training needs review with service |

users/carers should be undertaken to support their continued involvement with the Trust.  This should be initiated by Service User Groups in existence as appropriate.

4. 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 continues to:

- Include PPI in organisation induction arrangements for new staff.

- Provide limited PPI training including a PPI Awareness session and peer to peer training.

- Involve service user/carers in co-designing and co-delivering training. Examples provided, include a PPI coaching programme and mental health IMROC training.

**Progress achieved against 2015 recommendations:**

| Recommendations | Progress |
|---|---|
| 1. The Trust should ensure that staff are clearly made aware of what PPI is and what their responsibilities are, at both the corporate induction and more specifically in individual job inductions.  Direction to further sources of information / training as appropriate should also be provided. | The Trust reported that the Corporate Induction programme has been up-dated twice in the last year to reflect changes in involvement guidance. |
| 2. The Trust should consider how it | The Trust reported that a reporting |

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| records uptake of current and future PPI training, including training which incorporates elements / aspects which may be relevant to responsibilities associated with PPI. | mechanism is being progressed with Organisational Workforce Development |
| 3. The Trust should consider how it plans to take forward the dissemination and roll out of the Regional PPI training programme across the organisation. | The Trust reported that the PPI e-learning will be available to all staff and a monitoring system will be put in place to capture up-take.  The PPI Leads will be instrumental in raising awareness, championing the training and reminding staff to undertake the training.  The Trust reported that work is also progressing to enable staff with no access to computers to access the e-learning on-line training. |
| 4. The Trust should build PPI into staff development plans and appraisals as appropriate to their role. | The Trust reported that PPI is incorporated at a team level but not in individual staff development plans or appraisals. |

**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.

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| 2. | The Trust should continue to establish a mechanism to record the uptake of current and future PPI training, including training which incorporates elements / aspects which may be relevant to responsibilities associated with PPI. |
| 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. |

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**Standard 5 – Measuring Outcomes**

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

**KPI Findings**

- The Trust reported that PPI monitoring is currently undertaken by the PPI sub-committee. The Trust evidenced through the Annual Report how a consideration is given to the impact and evaluation of involvement. A number of examples were provided which could be replicated or transferred to other HSC organisation.

- 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 due to a focus on engagement and pre-consultation to ensure involvement from the early stages of a proposal. The Trust reported that there are a number of arrangements in place to support and also identify if appropriate involvement has not taken place. For example, the Executive Management Team will review the PPI element of a proposal and if it has not been considered, the proposal will require further work before being approved. The Trust noted that adequate involvement in the development and implementation of contingency plans is hugely challenging given the very short time frames.

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**Progress achieved against 2015 recommendations:**

| Recommendations | 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, helping to ensure that good practice is recognised and lessons transferred if appropriate. It should also highlight areas for possible improvement. | The Trust reported that PPI indicators are in place. Good practice is shared across the Trust via case studies, annual report and the Directorate Management Plan includes a PPI section which is discussed with the Chief Executive at accountability meetings. |
| 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. | The Trust reported that this is currently undertaken through services individual monitoring processes. The Trust recognise that greater consistency is required at an organisational level. |
| 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 outlined that PPI is an item on the Executive Management Team agenda and also considered in Performance and Planning meetings. |
| 4. The Trust needs to ensure that PPI is | The Trust reported that PPI is routinely |

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| 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. | and consistently incorporated as a key element of planning, developing or changing services. |

**Recommendations**

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| 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. |
| 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. |
| 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. |
| 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. |

## Conclusion

South Eastern HSCT continues to demonstrate the range of PPI at various levels within the organisation.  A number of mechanisms and processes continue to be in place to support the organisation to meet their PPI responsibilities.

A key consideration moving forward will be the strengthening of the PPI Leads model and also the integration of the service user/carer voice in Trust governance structures.  We recommend learning from good practice across Northern Ireland, where service users/carers are integrated into the decision making processes of HSC organisations.  On-going support is required for both staff and service users/carers to effectively engage in PPI.  The new regional training programme will support staff and the PPI e-learning programme roll-out will help to raise awareness of PPI across the organisation.  On-going support is also required for service users/carers to enable them to meaningfully get involved in the Trust which can include training and access to resources.

As with all other Trusts, SEHSCT 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 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 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 it 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[1]. 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.

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[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 conductive 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.

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## 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**

| Stage 1 | Stage 2 | Stage 3 | Stage 4 | Stage 5 |
|---|---|---|---|---|
| **Self-assessment** | **Trust endorsement** | **Review** | **Verification** | **Final report** |
| HSC organisations complete PPI Assessment Monitoring Form in partnership with their PPI Panel/Forum. | • Clinical & Social Care Governance Committee or equivalent, reviews and approves the PPI return. <br><br> • Completed and approved PPI Assessment Monitoring return submitted to PHA. | PHA PPI Team review & analyse PPI returns producing summary assessment with input from service users/carers on the Monitoring & Performance Management Subgroup of the Regional HSC PPI Forum. | Verification visit undertaken by the PHA and service users/carers, with the HSC organisation accountable Director & PPI Lead to include access to service users/carers availing of services. | Trust fact check followed by development of final Monitoring report by the PHA with recommendations for consideration by the DoH in line with the accountability arrangements. |
| **6 weeks** | | **3 weeks** | **2 weeks** | **6 weeks** |
| **8 February – 14 March** | | **21 March – 4 April** | **11 April – 18 April** | **25 April – 30 May** |

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