

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

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

**April 2015**

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**Personal and Public  
Involvement (PPI)**



**Involving you,  
improving care**

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## **Introduction**

Personal and Public Involvement (PPI) is a process whereby service users, carers and the public are empowered and enabled to inform and influence the commissioning, planning, delivery and evaluation of services in ways that are relevant and meaningful to them. People have a right to be involved and increasingly they expect to be actively involved in decisions that affect them.

PPI is a statutory responsibility as detailed in the HSC (Reform) Act (NI) 2009 through the Statutory Duty to Involve and Consult. Each Health and Social Care organisation, to which the legislation applies, is required to involve individuals in the planning and delivery of Health and Social Care (HSC) Services. Specifically, sections 19 and 20 of the above legislation require that service users and carers are involved in and consulted on:

1. The planning of the provision of care
2. The development and consideration of proposals for change in the way that care is provided
3. Decisions that affect the provision of care.

## **Rationale for PPI**

PPI is underpinned by a set of values and principles, but at its core, is the drive to achieve truly person centred services, where service users, the carers and the public are fully engaged in a partnership based approach to health and wellbeing, whether that is at the strategic, or individual level of care planning and provision.

The impact of PPI has been demonstrated in a range of areas from efficiency, and effectiveness, where services have been tailored to need, reducing wastage and duplication, to improvements in quality and safety, to increased levels of self-responsibility for one's own health and wellbeing.

## **PPI Standards, Monitoring and Performance Management**

The Public Health Agency (PHA) has responsibility for leading the implementation of PPI policy across HSC organisations. This is outlined in the Department of Health Social Services and Public Safety (DHSSPS), PPI policy circular (2012). The PHA has a responsibility for monitoring PPI across the HSC system, but has particular responsibility for providing assurances to the DHSSPS in relation to the compliance with and progress of PPI in HSC Trusts.

As part of its leadership role for HSC, the PHA has for the first time in Northern Ireland, established a set of standards for involvement, helping to embed PPI into HSC culture and practice, supporting the drive towards a truly person centred system. The five PPI Standards and associated Key Performance Indicators (KPIs) were formally launched in March 2015 (Appendix 1) and provide the basis for the structure of the monitoring and performance arrangements which have been developed by the PHA.

A pilot monitoring exercise for PPI was conducted at the end of 2013/14. The results of this were used to inform the development of the first formal PPI monitoring arrangements with Trusts. This was initiated in late 2014/15, with a view to having reports completed and available for the Accountability meetings with the DHSSPS in May / June 2015.

### **Methodology**

The monitoring process has used the PPI Standards and associated KPIs as a framework to gather information to help assess Trust progress against compliance with PPI. A direct assessment has not however been made against all KPIs for this report as the PPI Standards were only recently endorsed in March 2015.

The monitoring mechanisms and arrangements were developed in partnership with members of the Regional HSC PPI Forum including service users and carers.

Further discussion and input from the Health and Social Care Board (HSCB), the Patient and Client Council (PCC) and in particular, Regional Quality Improvement Authority (RQIA) helped shaped the final format of these arrangements. They were then shared with and agreed by the DHSSPS.

The key components of the monitoring process are outlined below, with the associated timeline detailed in appendix 2.

- i. An initial baseline self-assessment questionnaire is completed by Trusts in partnership with their PPI Panel (or equivalent) which helps inform assessment of progress in embedding PPI into the culture and practice of the organisation.
- ii. The self-assessment report is considered and approved by the Trust Clinical and Social Care Governance Committee (or equivalent), representing formal sign off by the Trust on their submission.
- iii. The reports are reviewed and analysed by the PHA working with in conjunction with service user and carer members of the Regional HSC PPI Forum Monitoring sub group.
- iv. A verification visit is undertaken with each Trust, probing the responses and evidence provided as part of the self-assessment.
- v. All information is then reviewed and a final report produced for the DHSSPS as part of the accountability arrangements.

## **Findings and Recommendations**

The report is based on evidence gathered through:

1. The Trust PPI self-assessment monitoring return.
2. Information collated during the verification monitoring visit.
3. Additional evidence supplied by the Trust.

The report sets out the findings against the five PPI Standards and recommendations are provided for each area.



## Standard 1 – Leadership

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

### Findings

- The Trust has named executive and non-executive PPI Leads at Board level.
- The Trust has an Operational Lead for PPI, with a limited proportion of the post assigned to PPI responsibilities. The Operational Lead is supported by Community Development colleagues.
- The Trust has advised that PPI is reflected in the Trust Corporate Plan.
- A PPI point of contact is currently in place in each Directorate. The Trust has a new Framework for PPI under development. It proposes to put in place more formal arrangements around the role and responsibilities for a named PPI Lead in each Directorate.
- The mechanism for engaging with service users/carers is not uniform across the organisation, which is similar to other Trusts. It was reported that each Directorate has links with service user/carer representative groups, but this is not captured in a central system.
- The new PPI Framework proposes three areas for accountability for PPI:
  1. Named person for PPI
  2. Named PPI priorities within the Directorate
  3. Staff attendance at PPI training.

### Recommendations

1. In terms of the PPI point of contact model that the Trust proposes to introduce, it would be important 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.
  - 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.
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.
  3. Consideration needs to be given to the resources that have been assigned to fulfil PPI responsibilities and the Statutory Duty of Involvement.





## Standard 2 – Governance

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

### Findings

- Based on the information made available, it would appear that:
  - There is currently no PPI Forum in place.
  - The Equality, Experience and Engagement Steering Group acts to provide assurance to the Trust in relation to PPI and in turn reports to the Trust Board on PPI.
  - PPI reports are included as part of the overarching Directorate Management Plans via the Senior Management Team meetings and in turn, bi-annual update meetings with the Chief Executive.
- It would appear that PPI is not currently a standing agenda item on Trust Board meetings.
- The Trust PPI Forum was stood down in 2013. The Trust reported in the self-assessment return that the new Framework will establish a PPI Standing Forum, with representation from a wide range of patient, service user, community and voluntary groups. The Trust reported that in the previous PPI Forum, it struggled to get an effective mechanism to engage with service users/carers.
- A corporate PPI Action Plan is currently not in place. A new PPI Framework is currently being consulted on and proposes a corporate PPI Action Plan, alongside the requirement for Directorates to produce PPI Action Plans.
- Currently, some Directorates and service areas have specific PPI action plans in place.
- Annual PPI reports have been developed and collate the PPI activity across the organisation. These reports do not seem to be readily available on the

Trust website. Evidence of BHSCT PPI activity was however, made available to the Review Team from a PPI scoping exercise conducted by the Trust.

## **Recommendations**

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.
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.
3. There needs to be clarity about the exact role of the Forum and 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.
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
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.

### Standard 3 - Opportunities and Support for Involvement

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

#### Findings

- The Trust does not maintain a formal central register of existing and future opportunities for involvement. However a number of informal mechanisms are currently in place to raise awareness about existing and future opportunities. This has been identified as a key action area for the new Framework and the development of a database of contacts has started for some service areas.
- The Trust described a number of internal support processes, materials and resources for service teams and staff, to support them to facilitate the involvement of service users/carers and the public which included:
  - Role descriptions for people involved within groups and support for developing groups.
  - Range of training and support available to facilitate engagement e.g. Carers training.
  - Induction training developed for specific service areas e.g. Carers.
  - Range of communication techniques promoted.
  - Reimbursement guidance disseminated across the Trust.
- The Trust reported that whilst barriers exist to undertake PPI such as time, cost and personnel, the organisation is looking to be creative as to how PPI is integrated into work.
- The Trust reported that a named point of contact is available for all engagement exercises as evidenced in the Scoping report.
- No process is in place to demonstrate that feedback is standard practice.

- The importance of the development of the Engage Website was mentioned to support the sharing of resources.

## **Recommendations**

1. The Trust, as outlined in the new PPI Framework, should develop a central register of opportunities for involvement, that is updated across all Directorates and readily accessible by the public.
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.
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.
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.
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.

## Standard 4 – Knowledge and Skills

**HSC organisations will provide PPI awareness raising and training opportunities as appropriate to need, to enable all staff to deliver on their statutory PPI obligations.**

### Findings

- The Trust's Corporate Induction Programme references PPI and the internal intranet hosts PPI information for staff; however the Trust has reported that they recognise that this requires up-dating.
- The Trust's Operational PPI Lead has expertise in PPI which has been acquired over a number of years and which is utilised when developing bespoke PPI Training for staff and Trust teams. The Lead can also call upon support from the Trust Community Development staff.
- The Trust has developed and delivers on a regular basis (4 times a year) an Introduction to PPI training. This course is also delivered on request to service groups and the Trust reported that bespoke PPI training will be delivered to Radiotherapists during June 2015. Numbers accessing training has not been provided but a Trust wide training record (TAS) is in place to capture up-take of PPI training.
- Service users/carers were involved in the design of the Introduction to PPI training but not in the delivery or evaluation.

### Recommendations

1. The Trust should 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 provide an opportunity to direct to further sources of information and training available.

2. The Trust should build PPI into future job descriptions as a key responsibility and also into staff development plans and appraisals as appropriate to their role.
3. The Trust should consider how it plans to take forward the dissemination and roll out of the Regional PPI training programme (once available) across its organisation and how it intends to record uptake.



## Standard 5 – Measuring Outcomes

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

### Findings

- The Trust has undertaken a scoping exercise to capture PPI activity across the organisation (January 2015). This provides a baseline alongside a brief overview of the impact of involvement on the service area.
- No formal work has been undertaken to develop a set of indicators for PPI, but it is anticipated that these will be developed as part of new accountability processes.
- The Trust recognises that a number of services provided on-site, have a regional remit. Attempts have been made to engage with wider groups, service users/carers from outside Belfast. Other mechanisms are adopted including telephone and on-line questionnaires to gain the views of the regional service users/carers.
- The Trust reported that a consistent approach is not currently in place across the organisation to routinely involve and consult when developing a service, reviewing/evaluating a service, redesigning a service or withdrawing a service.

### Recommendations

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.

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
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.
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.
5. The Trust should ensure that there is continuity of PPI support for service users/carers that are accessing regional service.





## **Conclusion**

The Trust is in a transition phase in respect of PPI. There has been a hiatus whilst the initial systems and processes that the Trust had in place for PPI were stood down and new arrangements were being discussed and designed.

BHSCT senior management have authorised their PPI Operational Lead to progress with a new Framework for PPI, which is currently under the final stages of development. The recommendations contained in this monitoring report should be taken into consideration by BHSCT in finalising this Framework.

The Trust's PPI Operational Lead and Community Development staff have knowledge, skills and expertise in PPI developed over a number of years, which is a significant benefit for the organisation. The Trust advise however, that with the magnitude of their organisation, with the diverse range of services they deliver and staff who provide them, with the pace of change and modernisation that they are facing under Transforming Your Care etc, that they need investment in capacity and expertise in this area to help them ensure that they meet their PPI responsibilities and the Statutory Duty of Involvement.

As with all the other Trusts, BHSCT has evidenced a range of good practice in this area throughout the organisation, which has really made a positive difference to service users and carers. These have the potential for replication and transferability both within the organisation and across the region.

There are however a number of areas which the Trust needs to consider, amongst these being consistency of approach and compliance with both the spirit and the letter of the Statutory Duty of Involvement and Consultation. It is recognised that this is a huge challenge, but it is one which needs to be robustly and comprehensively addressed.

It is also important that the plans for PPI contained in the new draft Framework, are quickly concluded and put into practice, to ensure that there is clarity around how the Trust will meet its responsibilities in respect of PPI.

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 work with the Trust in its endeavours to address the recommendations in this report, in particular, where it is clear that there would be merit in a collective approach across HSC organisations.



## **PPI in Practice – Cancer Services across the Trusts**

### **Background**

As part of the PPI monitoring process, it was agreed to engage with a service area to examine the outworking of PPI in practice. Cancer services was selected by the review team as the first area for review, as there was a recognition that there was already a focus on this service area through the Cancer Services Experience Survey.

The following section provides an overview of the responses and reports on findings of PPI practice within cancer services to support the sharing of information and good practice. A wealth of work is currently being undertaken in cancer services to involve service users / carers and this report, provides only a small snapshot of the activity at a point in time. We also recognise that regional cancer service meetings happen on a regular basis and encourage this report to be discussed at such meetings to share findings.

### **Methodology**

After the corporate PPI monitoring verification visit in each Trust area, a separate meeting took place with representatives from cancer services. Each Trust was asked to secure a senior staff member responsible for the service area and if possible, a service user / carer from that area. A series of questions in relation to how PPI operated and was implemented in cancer services, was then addressed to the interviewees in a discussion type arrangement. Service user / carer representatives (where they were in attendance) were also asked about their experiences in relation to their involvement in regards to cancer services in that Trust area.

### **Findings**

In relation to leadership and governance, all Trusts reported a named PPI lead was appointed.

Governance arrangements were not uniform across cancer services in the Trusts; however it was clear that PPI was a core element of the culture of all cancer services. Some Trusts had PPI Action Plans specifically for cancer services, whilst others attempt to build PPI in as an integral element to their Directorate / Service plan.

In terms of service user / carer involvement in the planning and delivery of cancer services, a variety of mechanisms were employed. The SHSCT and SEHSCT have a Service User Cancer Group in place and a PPI group for each tumour site, whilst WHSCT has a Cancer Services Locality Group and BHSCT are informally working to embed PPI into all activity. The NHSCT were the only area without a cancer services PPI group, but evidenced a range of work which engaged with service users either at a one-to-one level, or via involvement in regional work. This is in line with our findings from a corporate PPI perspective, as not one model of engagement suits all areas.

No specific budget is outlined for PPI work in cancer services, but all Trusts reported that reimbursement for out of pocket expenses is provided and some support for involvement activity is also provided via cancer charities.

At an individual care level, the role of the Clinical Nurse Specialist (CNS) in involving all service users was referred to by most Trusts. This role provides the opportunity for service users to discuss their needs and provides guidance and support before and after consultations, to involve patients in their own care. This role was also recognised as key to getting service users and carers involved in cancer specific PPI groups, either at a local or regional level. In the NHSCT, good practice was noted in that the CNS job description and job plan includes involvement as a key role which helps to embed PPI into practice in cancer services.

Given the increasing demand for care, people living longer and surviving cancer, the matter of providing appropriate support for people post treatment was raised by all Trusts. At a service improvement level, the Transforming Cancer Follow Up (TCFU) initiative was noted by all Trusts as providing a structure to facilitate and encourage

involvement. The Holistic Needs Assessment (HNA) process engages service users to review their own needs, which then empowers patients to drive forward their own care and deal with recovery. Health and Wellbeing events were noted again in all Trusts, which provide an opportunity to involve service users and carers in self-care, but some Trusts had also involved service users in developing and evaluating the events.

A wide range of examples were provided to demonstrate the involvement of service users/carers in a range of Trust developments. In the WHSCT, service users were involved in the campaign for the development of the radiotherapy unit for Altnagelvin. In SHSCT, service users and carers helped to plan and design the new Macmillan Information Unit in Craigavon Hospital. Service users and carers have also been recruited as volunteers to support the dissemination of cancer information. In BHSCT regional radiotherapy unit, the service evaluations conducted in partnership with service users / carers are reviewed and categorised into the top 5 things that are going well and the top 5 areas which could do better. As a result of this work, a number of practical changes to the way in which services were delivered and the adaptations to the physical surroundings for those availing of treatment, were identified and are being actioned. In the SEHSCT, a Results Clinic was established to provide a quieter area for patients away from the Outpatient Clinic. In NHSCT, Consultants attend advanced communications training to support the consultation process and this has been reported to be very beneficial and supports the involvement of patients in treatment.

Across all the Trust areas, feedback to service users/carers on service improvements / changes was not strong. Feedback is as an essential component of PPI, enabling information to be shared, to show how people the difference their involvement has made. This is an area which needs to be strengthened.

All Trusts provided the opportunity for carers or family members to be involved in consultations. Further support for carers was noted including accessing information or being involved in discharge care plans. The approach to the involvement of carers

however across cancer services, was neither standard, nor robust and could be strengthened.

### **Suggested Areas to Enhance Practice through PPI**

- Trust cancer services are encouraged to have in place or to develop a PPI Action Plan and to monitor progress.
- The opportunities for involvement are clearly and regularly communicated e.g. have your say posters, websites, and opportunities raised at clinical/patient and carer interactions.
- Trusts should ensure that staff know who the responsible PPI lead is in cancer services.
- Trusts should ensure that there is a named point of contact for individual care and also for involvement in any wider PPI projects.
- It is important to ensure that there is a structured plan / mechanism to facilitate the voice of the service user/carers being heard. Where recruitment to groups is proving problematic consideration should be given to the use of surveys, social media and partnership arrangements with advocacy organisations in a planned manner.
- Trusts should ensure that there are clear mechanisms for staff to share and use knowledge gained from involvement with feedback from service users/carers.
- Trusts should always seek to identify (as appropriate).
- In developing, delivering and evaluating programmes, Trusts should always seek to identify opportunities to utilise service users / carers' knowledge and expertise.

- Trusts should assess the aspects of PPI knowledge/skills/training required by staff as appropriate to their post and build that into the service action plan.
- A more systematic approach to consider carers needs and how they can be involved would be beneficial. Linking this to the work with the Carers Co-ordinators which was noted by a few of the Trusts, may help in this regard.
- Trusts should capture/record how PPI approaches have impacted on outcomes for service users/carers, to inform learning and future practice.
- Feedback to service users/carers should be adopted as standard practice.

## **Acknowledgements / Thanks**

The PHA would like to acknowledge the work of the service users and carers from the Regional Forum who helped co-design the PPI monitoring mechanisms and who participated in the verification visits and contributed to the assessment of the findings. The PHA also appreciate the work of Trust staff, in particular those with responsibility for PPI who led on the completion of the Trust self-assessment returns and for their contribution and time given during their participation in the monitoring verification visits. Finally, sincere thanks to the service users and carers in the respective Trust areas, who participated in the monitoring verification visits, sharing generously of their time, stories and personal experiences of Involvement.

## **Appendix 1: Personal and Public Involvement (PPI) Standards and Key Performance Indicators**

### **Standard One – Leadership**

Health and Social Care (HSC) Organisations will have in place, clear leadership arrangements to provide assurances that PPI is embedded into policy and practice.

Key Performance Indicators:

- PPI Leadership structure in place across the organisation to include:
  - Named Executive and Non-Executive PPI lead at Board Level, with clear role descriptions and objectives;
  - PPI Operational Lead;
  - PPI leadership structure throughout the organisation.

### **Standard Two – Governance**

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

Key Performance Indicators:

- Governance and corporate reporting structures are in place for PPI.
- Action plan with defined outcomes developed to demonstrate the impact of PPI.
- Annual PPI report produced, demonstrating evidence of compliance with PPI responsibilities and work undertaken to address challenges in this area.



### **Standard Three – Opportunities and Support for Involvement**

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

#### Key Performance Indicators:

- Maintain an up-to-date register of existing and future opportunities for involvement at all levels across the organisation, which is accessible by the public.
- Support the involvement of service users, carers and the public to include:
  1. Provision of clarity on roles/responsibilities for those who are participating.
  2. Provision of training/support.
    - Advocacy support provided if required.
  3. Use of accessible/user friendly communications, mechanisms/procedures. E.g. use of plain English, easy read, jargon free etc.
  4. Good meeting etiquette.
  5. Application of Interim Service User, Carer and Stakeholder Reimbursement Guidelines and Procedures for HSC Organisations.
- Named HSC points of contact for each individual engagement exercise.
- Provide feedback to those involved on each engagement as standard practice.
- As part of your Action Plan, identify barriers to involvement and develop actions to overcome these.

## **Standard Four – Knowledge and Skills**

HSC organisations will provide PPI awareness raising and training opportunities as appropriate to need, to enable all staff to deliver on their statutory PPI obligations.

Key Performance Indicators:

- Integrate basic PPI awareness raising into induction arrangements for all new staff.
- Evidence compliance with any annually agreed regional targets for the provision of/access to PPI training.
- Ensure a mechanism is in place to capture information on the up-take of PPI training.
- Demonstrate service user and carer involvement in the design, delivery or evaluation of PPI training.

## **Standard Five – Measuring Outcomes**

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

Key Performance Indicators:

- Evidence service user and carer involvement in the monitoring and evaluation of PPI activity.
- Demonstrate through the Annual Report:
  - How the needs and values of individuals and their families have been taken into account, in the development and delivery of care;
  - The outcomes/impact (positive/neutral/negative) achieved by using PPI approaches in respect of policy, investments, decisions and service delivery across the organisation.

## Appendix 2: PPI Monitoring Process with HSC Organisations

