

**Personal and Public Involvement (PPI)
in the PHA
Overview Report
June 2016**



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Background

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.

The Public Health Agency (PHA) has responsibility for leading implementation of policy on PPI across the Health and Social Care (HSC) system. As part of this role the PHA has responsibility for ensuring the effective implementation of PPI policy across the HSC. There is therefore a dual responsibility; at HSC wide level to promote consistency and co-ordination in the approach to PPI; and at an internal level to establish appropriate organisational governance arrangements to meet the Statutory Duty of Involvement.

This report outlines an overview of the PHA's compliance with and progress of PPI and the Statutory Duty to Involve and Consult. The report contains a summary of the findings which have been extracted from self-assessment monitoring returns and presents recommendations to support the organisation to truly embed PPI into practice.

Legislative Context

PPI is a statutory responsibility as detailed in the HSC (Reform) Act (NI) 2009 through the Statutory Duty to Involve & Consult. Each HSC organisation, to which the legislation applies, is required to involve individuals in the planning and delivery of 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

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 and provide the basis for the structure of the monitoring and performance arrangements, which have been developed by the PHA.

This is the second internal PPI monitoring report for the PHA. Whilst it is not appropriate for the PHA to formally assess itself, the Trust monitoring process has been used none the less to look at PPI practice internally and produce a monitoring report and recommendations to support the organisation continue to embed PPI into its culture and practice.

Methodology

The monitoring process has used the PPI Standards and associated KPIs as a framework to gather information to help assess progress against compliance with

PPI. This process was developed in partnership with members of the Regional HSC PPI Forum including service users and carers. 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 each Division within the PHA, which helps inform assessment of progress in embedding PPI into the culture and practice of the organisation.
- ii. The self-assessment reports are reviewed and analysed by the PHA PPI staff.
- iii. Service users and carers undertake a verification meeting to review PPI in practice in a Division in the PHA.
- iv. All information is then reviewed and a final report produced for the PHA AMT and also for use in discussions with the Department of Health (DoH).

Scope of the Report

There are a number of factors which have influenced the range and depth of this monitoring exercise.

In the main, this monitoring exercise represents a review and analysis of PPI in the PHA and in particular, its integration within the PHA's Divisions, rather than a critique of the range and impact of the work undertaken by the PHA's PPI team which has both a HSC wide and internal PHA remit. The bi-annual Board update reports provide an in-depth overview of the range and extent of PPI work across HSC and this monitoring report does not set out to duplicate this but focus more on the internal workings within the PHA. Reference is made to the resources that the PPI team has developed which will collectively support HSC organisations including the PHA to meet its statutory duty.

It is recognised that the PPI Standards, whilst having been under development primarily during 2014, were only formally launched in March 2015. It will take some

time for these to be embedded into internal practices and processes. Moving forward, it is anticipated however, that compliance against the KPIs set down under each Standard will be expected and formally monitored.

Having now completed the second internal monitoring process, it is clear that the level of input required from a number of stakeholders, including staff, service users and carers is considerable. Further consideration needs to be given to a number of aspects, including the timeframe to undertake the assessment, how compliance is evidenced, the resources required and the support for service users and carers participating in the process.

While the monitoring process has been refined since 2014/15 and there has been an increased rate of response, a number of factors still remain to be considered for future arrangements.

- The nature of the work of the PHA and its responsibilities means that some Divisions / functions provide a facilitative / supportive role for the organisation / other partners. It is noted that this does not lend itself as readily to the production of evidence of PPI in action.
- Annual monitoring may not be the most effective way to gather evidence of PPI in practice. The introduction of on-going monitoring processes may support staff to complete the annual monitoring.
- While each Division provided PPI evidence, this required considerable work from Divisional PPI Leads to access and compile the data.
- A number of examples of good PPI practice were written up and shared, when it was clear that significantly more had been undertaken.

All of these factors will feed into subsequent discussions with Divisional PPI Leads and senior managers, in respect of building and improving upon the monitoring conducted in future, to ensure that the best possible arrangements, mechanisms and processes are in place to assess compliance against PPI responsibilities and the Statutory Duty to involve and consult.

The Review Team:

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Findings and Recommendations

Standard 1 – Leadership

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

Findings

Corporate Leadership

- The PHA has a named executive Director who carries responsibility for PPI along with an Assistant Director for PPI.
- The PHA has appointed a non-executive Board member as a PPI Champion.
- The PHA has appointed an additional PPI officer. The PHA now has three full time PPI officers, the only HSC organisation to do so. One of these officers is the Regional Lead for PPI across the HSC. The remit of these officers is wide ranging, including:
 - development and delivery of the PPI Strategy
 - providing leadership, advice and guidance in PPI across the HSC through the Regional Forum
 - development of support tools and systems for staff trying to embed PPI into practice
 - working to help ensure that the PHA meets its Statutory responsibilities in respect of PPI etc.
 - working to influence external education and training providers to introduce PPI into the curriculum for HSC students and staff

Strategic Leadership

The PHA in its strategic leadership role, continues to chair and facilitate the Regional HSC PPI Forum.

Operational Leadership

- Directorate leadership arrangements are in place. This is evidenced by the continued commitment to the PHA PPI Leads Forum. A PPI Lead and a Deputy has been appointed in each Directorate/Division. The nominated Deputy is in place to ensure consistency of engagement with the Leads group in the case of non-attendance by the Divisional Lead. A Terms of Reference is in place for the group, setting out the expectations from members.
- Divisional service user/carer reference groups have not been established, rather, the Divisions continue to use tailored structures and mechanisms aligned to specific projects, programme areas, to enable the voice of the service user/carer to be heard. Examples of how service users / carers are involved with the PHA include:
 - R&D PPI Panel,
 - Regional Pain Forum for service users established to improve pain management services,
 - Safety Forum PPI Panel,
 - Dementia Friendly Communities Steering Group.

Recommendations

1. PHA continues to consider the corporate, strategic and operational leadership objectives and actions to identify any areas for PPI development.

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

Corporate governance

- PPI is committed to in the Corporate Plan as a key approach to how the PHA does its business. The PHA has also a PPI Strategy which guides and directs the work of the organisation and its staff in this field.
- PPI is included as a criterion for AMT and Board level decision making. Providing an additional level of governance for all decisions.

Strategic governance

- The PHA has reviewed PPI activity and restructured their strategic action planning process. Two action plans have been developed for 2016-19; one focuses on the PHA's external leadership role while the other reflects the actions being undertaken to strengthen PPI within the PHA. These action plans together cover all of the strategic roles and responsibilities that the PHA carries in this area across the HSC.
- A range of reporting structures are in place for PPI including quarterly Directorate Update Reports to update on progress against the Strategy and Action Plan, bi-annual Board update reports and update reports to the DoH. PPI is reported on formally twice a year to the PHA Board however it is not a standing item on AMT or Board meetings.
- The PHA on behalf of the Regional HSC PPI Forum, published a PPI Annual Report (2014/15)

The PHA continues to build PPI into regional strategic initiatives including the regional AHP strategy, developed by the PHA to set the strategic direction for AHP services in Northern Ireland.

Operational governance

- Specific PPI Strategies or Action Plans for some Divisions in the PHA are in place including R&D, the Safety Forum and Health Protection. Others have PPI built into their plans and AHPs have developed a PPI Plan which is incorporated into the regional AHP Strategy, which applies to AHPs across the HSC from the PHA to Trusts etc.

Recommendations

1. Governance arrangements for PPI should be reviewed at a corporate and directorate level.
2. The PHA, through the PPI Leads group, should review and formally record mechanisms that operate in each Directorate/Division to ensure that there are clear and transparent arrangements for involvement with service users and carers. The mechanisms and processes for involvement should be reviewed with service users and carers to ensure that they are accessible, purposeful and encouraging for service users and carers.
3. Continue to map where and how PPI is factored into internal governance, planning, decisions, investments and reporting arrangements to ensure that service users, carers and the public are effectively involved in the work of the PHA.

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

Corporate opportunities for involvement

- The PHA does not maintain a formal central register of existing and future opportunities for involvement. However it was evidenced that there are a range of opportunities and ways in which service users, carers, voluntary / advocacy organisations and the public can become involved with the work of the PHA, helping to inform, shape and develop plans and priorities.

Strategic opportunities for involvement

- The DHSSPS provided funding to the PHA to initiate the re-establishment of the 'Engage' web resource. This web presence has the potential to provide an opportunity for the PHA and other HSC organisations to advertise opportunities for PPI.
- The PHA continues to offer opportunities for involvement through the HSC PPI Regional Forum and its sub-groups. In 2015/16 a review of membership was undertaken which increased opportunities for involvement for service users and carers.
- The PHA continually seeks opportunities for involvement at a strategic level and circulates information about these opportunities to service users and carers. Such opportunities include, facilitating PPI to be included on the Expert Panel agenda, input into the NICON conference.
- A named point of contact is in place via the Regional Forum.

Directorate opportunities for involvement

- Each Division has evidenced the involvement of service users, carers, voluntary sector partners and the public, including:
 - Membership of Steering Groups, Forums and Reference Groups
 - Membership of Task & Finish Groups
 - Attendance at and contributions to Public meetings
 - Attendance at and contribution to Workshops & Focus Groups
 - Co-design of projects and information materials
 - Community conversations
 - Development of case studies
 - Use of Social media such as Facebook and Twitter
 - One off responses to surveys / questionnaires
 - Public consultations

- A range of support available to involve service users/carers was outlined which included:
 - Bespoke induction Training (prepared to meet the needs of service users and carers).
 - Peer review in Cancer services.
 - Using peer facilitators in older people's services.
 - Use of Makaton to develop information for people with a learning disability.
 - Production of a Terms of Reference, detailing role of the group, expectations.

- Use of the Out of Pocket Re-imbursement Guide for Service Users & Carers.
- Practical Guidance on running meetings and partnership working.
- Both the R&D Division and the Safety Forum continue to support service users / carers to attend conferences and training to support them to fully participate as equal partners in PPI activities.
- Monitoring returns also provide evidence of a variety of feedback mechanisms are being used across the PHA. Some Divisions provide named points of contact for feedback for every involvement exercise, others provide it for thematic areas of work, but not necessarily for every engagement exercise. The PHA outline further work is required to streamline feedback mechanisms to provide consistency of approach.
- Responses also identified barriers to involvement from an organisational or staff perspective, rather than those faced by service users, carers or the public. A key barrier uncovered during the monitoring exercise was the capacity of staff to undertake meaningful involvement. Another issue that was raised was the difficulty of involving specific target groups such as children. Other issues such as time and financial cost associated with it were also identified.

Recommendations

1. The PHA should develop a central register of opportunities for involvement which is updated across all Divisions (where appropriate) and readily accessible by the public by January 2017.
2. A corporate PPI induction for service users and carers who are involved in our work should be co-designed with service users and carers.
3. The PPI brand should be included in all materials relating to PPI and opportunities to get involved, including online and printed materials.

4. The PHA should develop and circulate guidance materials on essential support that should be made available for the involvement of service users and carers.
5. Review the monitoring mechanism in the PHA to ascertain if feedback is embedded as standard practice in 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.

Findings

Corporate knowledge and skills

- PPI is a part of the generic corporate induction arrangements for the PHA but not currently built into the formal induction arrangements for most of the individual Divisions.
- There is a corporate commitment to developing knowledge and skills in PPI for staff, as such corporate communication processes have been used to promote the Engage & Involve PPI training programme with an initial focus on the e-learning element.

Strategic knowledge and skills

- At a strategic level, the PHA PPI team have led the development of the Engage & Involve PPI training programme. The programme was developed in partnership with service users and carers and piloted with a range of HSC staff and formally launched by the PHA on 22nd February 2016. Engage & Involve is an accessible and practical learning and development programme, aimed at HSC staff. The programme has been developed to bring consistency of understanding and approach to PPI in the HSC locally.

The Engage & Involve PPI programme is made up as follows:

- **PPI e-learning** – an on-line, self-taught introduction to PPI.
- **Modular based taught programme** – to facilitate learning based on identified needs. The modules are stand alone and can be chosen according to need. It covers areas such as practical involvement and consultation, facilitation, communication and measuring impact.

- The PPI Team delivered bespoke PPI training for HSC staff and the Higher Education sector throughout 2015/16 period. Approximately 300 staff and students from various professional disciplines including, Nursing, AHP, Pharmacy, Social Work and Public Health attended PPI training.

Operational knowledge and skills

- All PHA Divisions were aware that the PHA's PPI Team provided PPI awareness raising and training programmes on request and a number have availed of this on several occasions. This has taken the format of presentations, interactive planning sessions, workshops etc.
- Returns highlighted a number of initiatives taken by PHA Divisions to incorporate PPI learning opportunities into their on-going work. These include, PPI updates from Divisional PPI lead at team meetings, sharing of PPI Standards with teams, awareness raising and encouraging staff to undertake PPI e-learning, presentation for professional staff on PPI and outcomes, including PPI as an agenda item on team planning day.

Recommendations

1. Staff should undertake Engage & Involve e-learning, which should be monitored on a 6 monthly basis.
2. All staff undertaking PPI should complete the Engage & Involve training matrix to identify their training needs in relation to their roles and responsibilities and access training as required.
3. PHA should continue to build PPI into future job descriptions as key responsibility and also into job development plans and appraisals as appropriate to their role by March 2017.
4. PPI should be included in the job induction process.
5. The PHA should develop a PPI training action plan, to incorporate the roll of Engage & Involve PPI Training.

6. The PHA should continue to develop the Engage online resource.

Standard 5 – Measuring Outcomes

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

Findings

Corporate Outcome measuring

- The PHA were able to evidence a number of good practice examples of PPI systematically across the organisation which have resulted in tangible benefits for service users, carers and indeed staff and the PHA itself.
- At a corporate level the PHA has a robust system of PPI monitoring and reporting on PPI activities and outcomes. Monitoring is undertaken against the Strategy and Action Plan including quarterly Directorate Update Reports, bi-annual Board update reports and update reports to the DHSSPS. PPI is reported on formally twice a year to the PHA Board but is not a standing item on AMT or Board meetings.

Strategic Outcome measuring

- Service users and carers have been co-producers in the monitoring mechanism that the PHA introduced for Trusts in 2014/15. Following the first monitoring exercise the PHA worked with service users and carers to review and refine the monitoring process which is now being used for the 2015/16 monitoring.

Operational Outcome measuring

- The PPI team through the PPI leads group have developed and consulted on a draft monitoring checklist to capture operational PPI activity. This process

will be implemented in early 2016/17 to provide a more consistent process for monitoring PPI across all Directorates.

- R&D Division demonstrate a high level of involvement and are able to evidence PPI activity as core to their work, by:
 - actively seeking Patient Involvement Enhancing Research (PIER) members feedback,
 - Involvement in developing criteria for evaluating PPI in research proposals,
 - Participation in the monitoring and evaluation of research proposals.
- Health Improvement have include and monitor PPI as part the Contracts Monitoring returns which also include s75 categories.
- In Planning and Corporate Services PPI is now to be evidenced in determining the shape and scope of tendered services being commissioned.
- In the Nursing division through NICAN lay reviewers are incorporated into the peer review process.

In relation to where and how PPI has influenced/informed policy, investments, decisions and or service delivery and in detailing good PPI practice a significant number of examples were provided across the PHA. AHP colleagues outlined how service users and carers were central to informing the principles, values and key messages which are integrated to the regional model for AHP services. In addition PPI was central to the amputee rehab service through the Prosthetic User Forum.

Nursing colleagues provided a range of examples of direct impact as a consequence of PPI including work on the development of a patient passport which was drafted in consultation with service users and carers. The patient passport will be tested and monitored in relation to its effectiveness. This process will be undertaken in partnership with service users and carers, recognising the importance of their input and feedback.

The development of the Dementia Pathway lead by the Nursing Division has had significant service user and carer involvement throughout leading to influence and impact on the final pathway. This included input from 300 Dementia Champions and the introduction of the Dementia Navigator roles in memory clinics.

In Service Development and Screening, PPI approaches have been instrumental in informing and shaping the development of the Regional Pain Forum and also in areas such as antenatal and preconception services for women with Epilepsy as well as specialist services commissioning team's Regional MS sub-group.

In the Communication and Knowledge Management division they routinely include service user carer and public input to directly influence public campaigns for example the "Be Cancer Aware" Campaign.

Recommendations

1. Review, update and implement the PPI checklist.
2. Working through the Internal PPI Leads group, each division should ensure that it has effective and efficient monitoring mechanisms to record and capture evidence of PPI in practice.
3. Senior management should regularly reinforce the need for PPI considerations to be regarded.

Conclusions

The PHA recognises that it has both a Statutory Duty to Involve and Consult with Service Users, Carers and the public and that it also has a range of leadership responsibilities in respect of PPI across the HSC. This report primarily focuses on the progress of the PHA as an organisation, in terms of complying with the Statutory Duty of Involvement utilising an assessment against the 5 PPI standards which were developed under the leadership of the PHA

It is evident that the PHA has progressed against each PPI standard at corporate, strategic and operational levels. As a result of 2014/15 monitoring recommendations a number of key actions have been taken to embed PPI at all levels of the organisation, not least through leadership at a corporate, strategic and operational levels.

The examples of good PPI practice shared in the monitoring emphasise the excellent work and commitment of PHA staff to involving service users and carers in important pieces of work. This has led to a range of improvements in a number of areas including quality, safety and efficiency.

At a Corporate level there is a tangible commitment to PPI. While at a strategic level the PHA provides a high level of leadership and continues to strive for consistency in all aspects of PPI across the region. Operationally, each division within each directorate have evidenced that they had undertaken PPI in the course of their work. Across the organisation different levels of PPI are taking place, from high level strategic involvement to one off involvement exercises. In addition many high profile PHA lead initiative's now have specific or integrated PPI plans in place to support their development.

The monitoring responses highlight how PPI is being embedded into the culture and practice of the PHA. However it is clear that more support and training is required for PPI at an operational level. By committing to implement the recommendations contained in this report the PHA will continue to develop in its role as regional lead for PPI while focusing on the development of PPI at an operational level within the PHA.

PPI in Practice – HSC R&D Division

Background

As part of the PPI monitoring process in the PHA, it was agreed to engage with a service area to examine the outworking of PPI in practice. The PPI Leads were approached and the Research & Development (R&D) Division agreed to participate in the session. The following section provides an overview of the responses and reports on findings of PPI in practice within R&D. This will support the sharing of information and good practice across the PHA.

Methodology

A meeting took place between the PHA PPI team, a service user/carer representative from the Regional HSC PPI Forum, and the R&D PPI Lead and service user/carer representatives from the PPI panel. A series of questions in relation to how PPI operated and was implemented in R&D was addressed to the PPI Lead. Service user/carer representatives were then asked about their experiences in relation to their involvement in relation to the R&D Division.

Findings

In relation to leadership and governance, R&D reported a named PPI Lead was appointed and both PPI Strategy and Action Plan were in place. A £5,000 budget has been allocated to PPI activity within the Division which is used to host training workshops.

A PPI panel, the PIER group (Patient Involvement Enhancing Research), was established in 2009 and members at this stage were invited to submit an application and were called for interview before appointment. Eleven members currently sit on the panel and recognition was given to the need to recommence a recruitment process to increase membership. An acknowledgement was given to the need to engage with hard to reach groups in future. The panel is co-chaired by a service user and meets 4-6 times a year. A group Terms of Reference is in place.

The panel's role is to assess research funding proposals for PPI and representatives in attendance felt that their input had been used to enhance the applications and roll

out of the project. The panel is also utilised by researchers to engage with service users/carers to get involved in individual research projects.

Induction and on-going training is provided by the R&D Division to support service users/carers. This was recognised by representatives in attendance as core to supporting them to fulfil their role on the panel. Members of the panel also lead and participate in the Building Research Partnership training, which is delivered to educate researchers and support them to recognise what PPI can add to research projects.

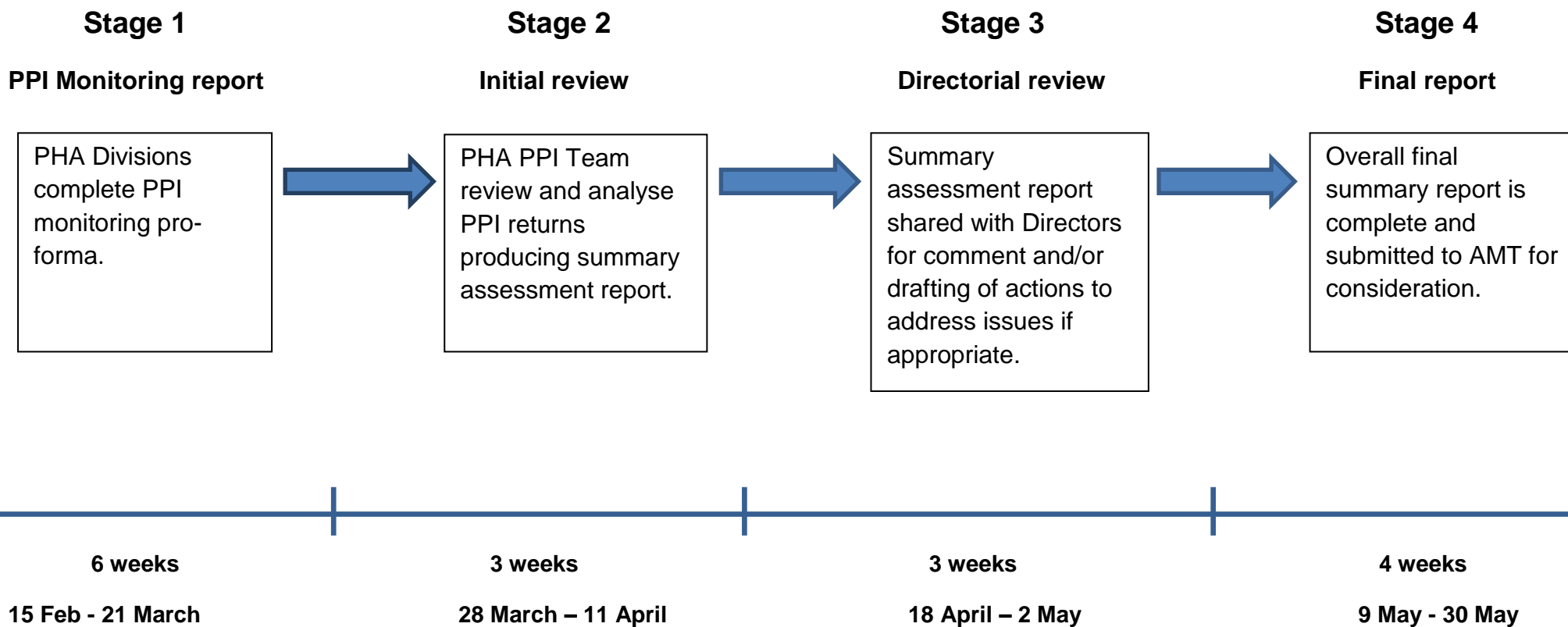
In relation to reporting mechanisms:

- At a Divisional level, the PPI Lead reports to the PHA on PPI activity on an annual basis.
- Feedback/evaluation is undertaken as part of the Building Research Partnerships training to evaluate the impact of the training.

From an evaluation perspective, representatives in attendance felt that there was no feedback loop in place. There was a suggestion to include a progress report on the proposals which had received funding to determine how PPI had worked in practice throughout the lifespan of the project.

Appendix 1

PHA PPI Internal Monitoring Process 2015/16



Annual Indicative Timeline (wk beg)