Personal and Public Involvement (PPI)

Involving you, improving care

Personal and Public Involvement (PPI) and its impact

Monitoring, measuring and evaluating the impact of PPI in Health and Social Care in Northern Ireland

MAIN REPORT

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Patient and Client Council
Your voice in health and social care

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Personal and Public Involvement and its impact - Monitoring, measuring and evaluating the impact of Personal and Public Involvement (PPI) in Health and Social Care in Northern Ireland.

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Executive Summary

Introduction

This report details the findings from research conducted across Northern Ireland's Health and Social Care Trusts during 2015 which examines the current state of Personal and Public Involvement (PPI). This is about how service users, carers and patients engage with staff, management and directors of statutory health and social care organisations. Most statutory health and social care organisations must, under legislation, meet the requirements of PPI. PPI has been part of health and social care policy in Northern Ireland since 2007 and became law two years later with the introduction of the Health and Social Care Reform Act (2009). It is, therefore, timely that PPI is now assessed in this systematic way in order to both examine the aspects which are working well and to highlight those areas where improvements need to be made. This has also been reinforced by the recent Ministerial Statement where Health and Social Care (HSC) organisations were directed to embrace involvement and to strive towards co-production in the development and delivery of services.

As far as possible, this Summary Report is written in an accessible way, avoiding jargon and explaining key research terms, so as to ensure it is widely understood. This is in keeping with established good practice in service user involvement research. This summary, therefore, gives a picture of PPI in Northern Ireland currently. There is also a fuller report which gives a lot more details about the research and findings. Information on this is available from the Public Health Agency and/or the Patient and Client Council.

Background

The Public Health Agency (PHA) promotes and aims to improve health and wellbeing and has a lead responsibility for PPI. The PHA is also responsible for health protection and provides professional input to the commissioning process (how funding is used to provide services). The Patient and Client Council is often seen as the voice of the service user, carer and patient and, as a result, also has a very keen interest in PPI and related issues.

Aims and Objectives

The research commissioners (the Public Health Agency and the Patient and Client Council) stipulated the following key aims and objectives for this study:

1. To identify best practice in PPI

2. To identify any barriers to effective involvement

3. To identify possible ways to overcome these barriers within the context of an integrated health and social care system

4. To identify valid and reliable ways of measuring and evaluating the impact of PPI activity.

5. To ensure that service users and carers are at the heart of this project in a significant and meaningful way.

Meeting the Research Objectives

As mentioned already, the research focused on five core objectives. Each of these objectives is now summarised with reference to the main findings from this research.

Objective 1: To identify best practice in PPI

The focus groups for service users, carers and staff included a specific question aimed at highlighting examples of positive practice and indeed best practice in regard to PPI in Northern Ireland. This was also addressed in the on-line survey. Importantly, the range of responses to this particular question leads the research team to conclude that there is much to feel positive about in regard to what has been achieved to date in Northern Ireland. The picture is therefore quite encouraging with a host of examples provided which evidence meaningful change and impact across a range of service user and carer groups. This report also has a section dedicated to highlighting examples of best practice in PPI from across Northern Ireland's HSC Trusts. From the perspective of service users and carers, what contributed to positive PPI were factors such as: Information, staff attitudes, training and preparation, good communication skills, getting feedback, a sense of trust, enthusiasm and genuineness on the part of staff, being listened to and attention to detail in regard to practicalities. From the perspective of staff, the things that were important in achieving good PPI were: Being skilled, having the right attitude, having

a commitment to PPI ‘from the top’, the values of the organisation and having resources in place, (particularly around administration, practical support and training).

Objective 2: To identify any barriers to effective involvement

The on-line survey, focus groups and literature review specifically addressed the question of barriers in the context of the types of things which could prevent PPI from being effective and meaningful. The findings from the staff on-line survey clearly indicate that inadequate funding is one of the most significant barriers to PPI. Not having sufficient resources was evident in staff not having enough time to give to PPI work as well as not having sufficient staff in place to also do and support this type of work. Further barriers noted related to staff not feeling knowledgeable and skilled in PPI work. The latter point also links with the finding that only half of the staff surveyed knew who was responsible for PPI in their organisations and that half of those surveyed regarded PPI as part of everyday work. There was also a perception that PPI was not the responsibility of senior managers. Training on PPI was identified as being patchy and uneven, but it was recognised that attempts were being made to address this by the PHA.

Service users and carers in the focus groups observed ongoing problems with the language of PPI, staff not giving sufficient attention to the practicalities that go along with PPI, staff having poor communication skills, the absence of respect and empathy, the presence of a power differential between service users involved in PPI and staff, instances of tokenistic involvement, procedural barriers in getting expenses paid and not being told about the impact of their involvement. Staff in their focus groups noted barriers such as: the working culture not being committed to PPI, staff not realising they were doing PPI work, not enough support from senior staff, the fact that good PPI takes time but without sufficient resource is very challenging, geographical unevenness in terms of PPI leading to a perception that some Trusts were better supported than others and the need for staff to be skilled in person centred working. These barriers are also consistent with the findings from the literature review.

Objective 3: To identify possible ways to overcome these barriers within the context of an integrated health and social care system

The following are key points identified from the review of the literature in addressing barriers that can prevent effective PPI:

- The need for training for everybody involved
- The need to have a commitment to achieving change on the part of those seeking involvement and for the public
- The need to recognise and promote diversity so as to involve a breadth of people's lived experiences
- The importance of relationship building skills
- The need for careful planning of involvement activities and to see these as integral to care planning and service development
- The need to have an *ethic of care* approach governing involvement which openly recognises power differences and the various roles and responsibilities of all parties involved in PPI work
- The need to have a staff member employed to have lead responsibility for involvement work and a dedicated team to provide practical support and develop resources to embed PPI as a way of working across the organisation, and finally,
- The need to provide feedback and evidence of impact following involvement.

The on-line survey highlighted the importance of PPI work needing to be better funded to deal with the feeling that staff expressed about being overburdened. The importance of training was also recognised as having a key contribution to make in ensuring that barriers to effective PPI can be minimised. Findings from the staff focus groups also echoed these sentiments, especially around the need to have PPI better resourced given this was a statutory duty, as distinct from Patient Client Experience, and also the need for improved training with a focus on skills. The resource issue was also related to needing to have service user and carer time remunerated for involvement work and the need to have staff time recognised as an important part of resource that good PPI demanded. Staff also expressed the view

that PPI needed to be better supported and championed at senior management level in organisations.

The service user focus groups also made the following types of suggestions in regard to overcoming these types of barriers:

- The need to recognise and respect the service user and carer experience
- The need to make the language of PPI more accessible
- The need to be involved at a level that is chosen by the service user/carer (the on-line survey noted limited examples of involvement at strategic level)
- Being made aware that a difference has been made
- Staff needing to be consistent in showing respect and having a positive attitude, attending to the practicalities of Involvement
- The need for service users to be offered training
- The need to address the power differential between services users and staff including the need to avoid tokenism in PPI work.

Objective 4: To Identify valid and reliable ways of measuring and evaluating the impact of PPI activity

The literature review includes examples of ways in which the impact of PPI activity has been measured and evaluated. One of the important findings in the literature is that the impact of PPI is under researched. It is also noted that there is a need to measure and evaluate PPI across the broad spectrum of health and social care. The literature does refer to more examples of where PPI has been evaluated in regard to its impact on research, but less so in the domain of health and social care. The challenges in this area are also recognised, particularly in regard to introducing more quantitative based approaches where statistical evidence can be used to evaluate impact. Whilst the literature recognises that this type of approach is complex, it is also noted that there has tended to be an overreliance on using descriptive and retrospective accounts of involvement which are more qualitative based. The literature review concludes with a very relevant article for this project in reference to

the work of Staniszewska et al. (2011a).[1] These authors argue in favour of thinking towards measurement approaches to involvement being co-designed with service users which can build on the more established methods of doing so using qualitative methods such as focus groups.

The on-line survey also included questions to address this objective. Highlighting the scale of the challenge in developing evaluation methods, only 17% of respondents (n=7) said their organisation always evaluated PPI activity with a further 41% (n=22) stating evaluation is undertaken sometimes. Thirty-seven per cent of participants were unsure if evaluation was undertaken and 6% (n=3) of respondents said PPI activities are not evaluated. Reported methods for collecting PPI evaluation data were wide and varied with the most common being surveys of PPI participants. Focus groups were the next most frequently used evaluation method. A wide range of organisational outcomes and impacts from PPI activities are included in evaluations with the most commonly cited being the effect of PPI involvement on services (56%) and the least common being a change in the budget allocation process (4%).

Evaluation of PPI activity is therefore an area for further development given the on-line survey's conclusion that thirty nine per cent of respondents noted the production of an evaluation report and twenty-nine per cent stating that no such report is produced. The cited perceived reasons for not producing an evaluation report related to a lack of resources particularly in regard to: lack of staff time (52%), lack of staffing resources (45%) and lack of funding (34%).

The focus groups also included specific questions in this area. From the perspective of staff, it was recognised that progress in the right direction was starting in regard to monitoring and evaluating PPI with the initiatives led on by the Public Health Agency. There were also examples of how methods such as Survey Monkey were being used to evaluate particular projects. What was absent however was a sense of

[1] Staniszewska, S., Adebajo, A., Barber, R., Beresford, P., Brady, L., Brett, J., et al. (2011a). Developing the evidence base of patient and public involvement in health and social care research: The case for measuring impact. *International Journal of Consumer Studies*, 35(6), 628-632.

consistency and coherency in regard to how monitoring and evaluating were being approached.

Staff also expressed the view that senior managers needed to accept and own responsibility for PPI, including accountability for monitoring its effectiveness and overall implementation. The need for service users and carers to be made aware of the outcomes and impact of their involvement activities was also recognised as being central to monitoring and evaluation processes. The point was also made that sometimes it was only the highly publicised PPI projects which were monitored and evaluated to the exclusion of other on-going ‘part of the job’ PPI activity. Having one overall action plan was also recognised by staff as being potentially helpful as a tool in coordinating the monitoring and evaluation of PPI at Trust level. The staff focus group analysis concluded with the view that monitoring and evaluation needed to be systematically captured.

From the service user and carer perspective, the focus groups underscored the importance of PPI being evaluated so as impact following involvement could be evidenced. Generally, the service users and carers in these focus groups evidenced limited awareness of evaluation and monitoring of PPI. However, there were some examples of where it had gone well and also room for improvement as evaluation and monitoring was considered to be ad hoc. Some PPI members pushed hard to get effective evaluation and monitoring in place.

In concluding this objective it is also worth highlighting the impact of an existing challenging and demanding environment within which PPI occurs. In the development and refinement of monitoring and evaluation tools, these would need clearly defined parameters and agreed priorities for recording, monitoring and evaluation. As noted in one of the service user focus groups, this does not have to be overly complex but having a standard template across Health and Social Care (HSC) or standard columns to add to mainstream action plans and progress reports would ensure the process is not time consuming for recording, collection and analysis.

Objective 5: To ensure that service users and carers are at the heart of this project in a significant and meaningful way

The research team was committed to collaboration and participation in regard to all aspects of design. The team involved two peer researchers from a service user background who have been fully involved in all aspects of the research from writing the original application for funding to contributing to this final report. In addition, the research was supported by a Research Advisory Group (RAG) with representation from a diverse range of service user and carer groups and individuals from across Northern Ireland. All of the research tools (on-line survey questions and focus group questions) were designed in close collaboration with the full research team and the members of the RAG. An accessible version of the research report has also been written by a research team member from a user background. Service user organisations in the community also helped accommodate the focus groups and assisted with the design and dissemination of the focus group flyers for service users.

Recommendations

Below are the ten key recommendations coming from this research. Each of the three methods of enquiry that we have used has been given a symbol and these are explained below. Many of the recommendations came from more than one of the methods used.

Key to Methods of Enquiry

Focus Groups **Focus Groups are symbolised by:**

On-line Survey **On-line Survey is symbolised by:**

Literature Review **Literature Review is symbolised by:**

The Recommendations below are based collectively on the findings from the different but interlocking strands of our research: Focus groups, on-line survey and the systematic overview of the literature. Delivery responsibility for each recommendation has implications at a number of levels across HSC.

The Department of Health (through its Safety, Quality and Standards Directorate) has responsibility for policy on PPI, including reviewing, developing and refining the policy. It is responsible for reviewing and issuing appropriate guidance as necessary, and for setting regional priorities and standards in this area. The Department is also be responsible for providing assurance to the Minister that HSC organisations are meeting the requirements placed upon them by the statutory duty of involvement as laid down in the Health and Social Care Reform Act (2009), including the requirement to develop consultation schemes.

The Public Health Agency (PHA) has responsibility for leading the implementation of policy on PPI across the HSC. This responsibility is taken forward through the Regional PPI Forum, which is chaired and serviced by the PHA. It includes

representation from all HSC organisations as well as community and voluntary sector representatives, service users and carers. The Forum is a key vehicle by which the PHA, working with other organisations, ensures the effective implementation of PPI policy across the HSC.

The Patient and Client Council (PCC) responsibilities in respect of PPI include representing the public interest, promoting/supporting the involvement of the public, and undertaking research into best methods/practices for involving and consulting the public in regard to HSC matters.

HSC Trusts are responsible for establishing appropriate organisational governance arrangements to meet their statutory duty of involvement, and for maintaining and building on progress already made in relation to embedding in line with the requirements contained in the 2007 PPI guidance circular [2].

If the HSC can begin to address these recommendations, this will go a long way to overcoming the identified barriers to involvement and help the HSC move forward to fully realising the benefits of embedding PPI into its culture and practice at all levels.

To progress the recommendations arising from the research, the joint commissioners should agree a joint action plan to take the findings in this work forward.

[2] Department of Health, Social Services and Public Safety. (2007). *Guidance on strengthening personal and public involvement in health and social care*. Belfast: DHSSPS.

Recommendation 1

For the development of effective PPI, adequate and dedicated resources are essential.

Context: This recommendation is even more pertinent in times of austerity when there are increasing demands on existing resources. It is critical to properly fund PPI with structured and ring-fenced funding. Time, as well as finance, is an important resource and this is as relevant to staff and their time as to service users and carers. Paying service users and carers for their time in structured involvement with the HSC should also be considered.

Recommendation 2

There should be an ongoing process of raising awareness of what PPI is and what it means for staff, service users and carers.

Context: Meaningful engagement should build mutual respect and result in mutual benefit for both those who use the service and those who provide it. While the HSC organisation remains the accountable body, PPI can change the clinician/service user power differential and help promote service users and carers as engaged experts in developing health and social care services. This recommendation will help promote the wider benefits of PPI for the organisations and staff and will also help to embed PPI in the culture of HSC organisations. Innovative ways should be explored for making such awareness more meaningful and effective. Raising the profile of PPI should also address the need to get a better balance of professionals and service users/carers at meetings, particularly seldom heard groups and individuals in addition to service user and carer involvement in the development and implementation of individual care and treatment plans.

Recommendation 3

PPI needs to be defined in a way that is explicit and meaningful to service users, carers, providers and the wider public.

Context*:* The language of PPI needs to be re-visited so it is distinct from other terms in current usage which may be confusingly similar to both staff and service users. If there is a way of coming up with a different term to PPI, then this should be explored (the term PPI is part of DOH policy language but is not used in the legislation). Other terms such as: citizen involvement/user/client involvement could be considered.

Recommendation 4

Each Trust should develop a PPI Champion staff role with a small team whose jobs will be entirely and specifically related to PPI at Trust level.

Context: Currently all Trusts have Director and operational PPI Leads, however none of these staff focus exclusively on PPI. As awareness of PPI is raised and staff understand their obligations and those of the Trust, there is an increasing demand for practical support which is both time consuming and resource intensive. In addition to this support, there is also a Departmental requirement to collate, analyse and report on the impact of PPI activity. For PPI to have a common purpose and the capacity to meet support and reporting needs will, therefore, require the designation of PPI Champions with a small team whose jobs will be entirely and specifically related to PPI at Trust level.

Recommendation 5

Social Media and Technology should be effectively utilised to promote PPI across HSC. This should include a one-stop website for information, guidance, support, resources, templates and good practice examples.

Context: In considering the impact of this recommendation, each Trust should review and monitor how currently their websites are promoting examples of PPI activity. The use of social media platforms such as Facebook and Twitter should continue to be maximised to further embed and raise awareness of PPI activity. The development of a mobile application on PPI could also be considered as part of this. There is also a need for a one-stop-shop website where all PPI information (links to local PPI leads, etc.) could be housed. This needs to be resourced so that the information remains current and relevant.

Recommendation 6

Structured evaluation must be built into PPI as a way to measure its effectiveness.

Context: The review of literature for this research indicated there is a gap in evaluation using quantitative approaches. Person-centered evaluation methods should be piloted, which become part of the job and non-onerous on staff time. In regard to the measurement of PPI impact, standardised quantitative measures should also be piloted with service users to evaluate their experiences of involvement and engagement following the service (for example, exit surveys, questionnaires, use of technology, etc.).

Recommendation 7

Feedback on the impact of involvement should be standard practice.

Context: Providing feedback in regard to the outcomes of involvement was quite sporadic and inconsistent in our research findings. This must be mainstreamed into all PPI practice as standard activity so as participants feel they are valued and are made aware of the impact of their PPI activities.

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Recommendation 8

Appropriate and dedicated PPI training should be made available for HSC staff.

Context*:* PPI awareness training should be a standard aspect of induction for all new employees. This could be made available as an on-line activity but all staff would have to show that they had completed this as a necessary feature of their introduction to the HSC organisation or for existing staff as part of their PDP (Personal Development Plan). All staff should then have to complete appropriate PPI training at a designated point in the early stages of their employment and refresher courses should also be made available and mandatory.

Recommendation 9

PPI should be a core feature of all Trust recruitment and performance/appraisal processes.

Context: This recommendation is aimed at embedding PPI into the mindset of those applying for HSC Trust positions and at also ensuring that this is kept very much to the forefront for staff at all levels in their ongoing work. Therefore, questions about reviewing PPI activity in appraisal and supervision meetings would concretely elevate its importance for staff at all levels. Having a basic range of questions around involvement, engagement and partnership working at interviews and having the perspective of service users and carers in staff selection would also be a firm way of assessing prospective employees' understanding of issues related to involvement.

Recommendation 10

PPI needs to be built into accountability structures and decision making processes at senior manager/director level.

Context: Our research consistently highlighted the importance of PPI being hinged on support from the top of the organisation. When this is in place, the likelihood of having meaningful PPI is increased. Senior managers should therefore be reporting to Trust Board level in regard to PPI oversight issues at a strategic level.

Chapter 1: Introduction

PPI – The Current Context in Northern Ireland

This section of the report, by way of providing generic background to the research, aims to outline and review the PPI policy and legislative context in Northern Ireland, how this has been translated into practice, the challenges presented, progress made and the current picture of PPI in Health and Social Care (HSC). The focus in this piece is on PPI implementation within the Public Health Agency, Health and Social Care Board and HSC Trusts. We have consulted with the PPI Lead staff from these organisations to ensure that this account is evidence informed, peer reviewed and accurate.

Policy and Best Practice Guidance

Within Northern Ireland, the Department of Health (through its Safety, Quality and Standards Directorate) has responsibility for reviewing, developing and refining policy on PPI. It is responsible for reviewing and issuing appropriate guidance as necessary, and for setting regional priorities and standards in this area. In specific regard to PPI, the duty to engage, consult and involve applies specifically to the following Health and Social Care organisations:

- Health and Social Care Board (HSCB)
- Public Health Agency (PHA)
- Health and Social Care Trusts including the NI Ambulance Service (NIAS)
- NI Blood Transfusion Agency (NIBTA)
- NI Medical and Dental Training Agency (NIMDTA)
- NI Guardian Ad Litem Agency (NIGALA)

There are a number of HSC organisations to whom the statutory duty of involvement and consultation does not however apply. Nonetheless, the Department encourages such organisations to put appropriate measures in place to ensure their service delivery arrangements are informed by the views of those who use their services.

The guidance circular HSC (SQSD) 29/07 issued in September 2007 outlined the rationale for PPI, its underlying values and principles and officially introduced the

concept of Personal and Public Involvement (PPI) as the agreed regional terminology for all aspects of user involvement and engagement within health and social care. This guidance was intended to provide agreed guidelines for service commissioners and providers to improve the level of service user and carer involvement across the HSC, as well as strengthening the impact of service user and carer involvement on decisions that are made about services. In turn, it was envisaged that this would support the implementation of effective and meaningful service user and carer involvement in clinical and social care governance and support the influence of user perspectives in the planning and decision-making processes of Health and Social Care Services.

The guidance was issued six months after the Health and Social Care Trusts were formally established under the Review of Public Administration[3] and, while it was introduced during a time of monumental change and uncertainty within health and social care, there was also an opportunity for the new Trusts and other HSC organisations to take account of these requirements when developing their new management structures.

Implementation within HSC Trusts

The five steps recommended in Circular HSC (SQSD) 29/07 to establish and promote PPI provided direction for the HSC organisations covered by the guidance. These are as follows:

Step 1*: Confirm or establish leadership and accountability arrangements for PPI*

Across the Health and Social Care Trusts, whilst leadership and accountability arrangements for PPI have been established, the approach is not uniform. (See Table in **Appendix 4**). The latter Table evidences that leadership roles for PPI sit within different directorates. A further complicating factor relates to inconsistency in

3 The Review of Public Administration was launched by the Northern Ireland Executive in June 2002 and concluded in March 2006. The purpose of this review was to develop a system of public administration which fully meets the needs of the people in Northern Ireland. It was a comprehensive examination of the arrangements for the administration and delivery of public services in Northern Ireland covering almost 150 bodies, including the 26 district councils, the Health Boards and Trusts, the five Education and Library Boards and about 100 other organisations. The Secretary of State announced the final outcome of the review in two parts. In November 2005 he announced final decisions on the future of local government, Education and Health and Social Service structures. In March 2006 he announced decisions on the remaining public bodies.

identifying specific PPI job roles. For example, across the Health and Social Care Trusts there is no commonly agreed title for the position of PPI Operational Lead, with three of the six Trusts using the term PPI in the job title. Furthermore, none of the PPI Operational Lead staff within the Health and Social Care Trusts focus exclusively on PPI. Over time, with the increasing challenging financial situation within the HSC and no additional financial resource identified, some PPI Operational Lead staff have taken on additional responsibilities which have further reduced the amount of time available to focus on promoting and embedding PPI across their respective organisations.

Step 2*: Using the principles in this guidance as a framework, review current PPI work to establish a baseline from which improvement can be made.*

Again all HSC organisations were required to complete this but the approach to establishing a baseline has varied. The Trusts' baseline reports were intended to *prioritise the areas for improvement (**Step 3**)* and to *develop and implement an action plan with clearly defined targets to strengthen and improve PPI, securing agreement and support for this plan across the organisation (**Step 4**).* In one Trust this included the development of a standard operational PPI action plan template and agreement that each director was responsible for promoting and embedding PPI within their areas of responsibility and reporting progress against agreed actions in the same way as they did for other areas of work. It also included the identification of tools and resources staff required to support them to fulfil their PPI obligations. In another Trust, a similar process was undertaken during 2008, the main purpose being to establish a baseline of PPI activity across the Trust in line with the PPI circular 2007 against the 12 principles. This baseline identified gaps and areas for improvement and, as a result, an action plan was put in place to promote and embed PPI across the organisation.

In the main, the PPI Action Plans developed are quite general with limited evidence for any monitoring of implementation or progress and there is little by the way of identification of resources to ensure the effective implementation of those plans. However, it should be noted that one of the Trusts appointed a PPI Officer from within their own resources to support the PPI Operational Lead. While another Trust

appointed an Equality and PPI Officer to support the PPI Lead, the other PPI lead staff did not have additional support to enable them to progress these steps.

Step 5*: Clarify reporting arrangements for PPI as part of organisational management and clinical and social care governance. Arrange for the inclusion of PPI as part of the organisation's annual report on what has been achieved and agree the priorities for the subsequent year.*

All HSC organisations covered by the guidance were able to demonstrate compliance at the Department's mid and end of year accountability meetings but there was no measurement of the quality of compliance as there was no minimum standard set. Although the PHA has responsibility for leading implementation of policy on PPI across the HSC, the fact that it was established two years after the establishment of the Trusts meant that the Trusts already had started to progress the 5 steps recommended by the DHSSPS. In addition, from 2009 - 2011 there was a period of re-adjustment while the PHA defined working relationships, clarified roles and developed its role as the regional lead for PPI. Much time and effort was spent by the Trusts on informing the regional direction and they looked to the PHA for leadership, and guidance on common challenges such as monitoring and evaluation and training. Mechanisms that had been established by some Trusts from within their own resources at risk to progress these issues were scaled down within those Trusts as it became apparent that no resource was being made available regionally to support the implementation of PPI at a local level.

Regional Developments

As part of the Review of Public Administration, the Public Health Agency, Health and Social Care Board and the Patient and Client Council were established in April 2009. The Health and Social Care (Reform) Act (Northern Ireland) 2009 placed a statutory duty of involvement on specific HSC organisations, including the requirement to develop consultation schemes detailing the arrangements they have in place, to involve and consult with service users, carers and the wider public, and the Patient and Client Council, in the discharge of their business. At the end of 2010, the PHA appointed a Regional Lead for PPI and established the regional HSC PPI Forum.

There was some coordination with regard to the development of the consultation schemes. The Patient and Client Council and the Department developed a template and gave the final approval before these were published by the HSC organisations in line with the Priorities for Action (PFA) target by 31st March 2012.

In order to progress those regional responsibilities assigned to the PHA from the 2012 Circular, a regional PPI Forum was established. This meant bringing 16 HSC partners on board, working with service users and carers. The primary role of the Forum is to provide leadership and support to drive forward the promotion and coordination of PPI across HSC organisations in Northern Ireland. It does this through:

- The sharing of best practice
- Joint areas of common interest
- Active participation of service users and carers

Until the end of 2012, there was a period of re-adjustment, whilst the PHA operating through the Forum, engaged with partners to define working relationships and to clarify roles and responsibilities. The DHSSPS then brought forward Circular (SQSD) 03/12 on PPI. This circular confirmed the leadership role for the PHA and set down specific responsibilities for PPI across HSC organisations.

The regional PPI Forum is now the key vehicle by which the PHA, working with other organisations, ensures the effective implementation of PPI policy across the HSC. It endeavours to operate in a collaborative manner, seeking to ensure consistency and co-ordination in the approach to PPI. The Forum also seeks to identify and share best practice in terms of PPI across the HSC. The PHA, working through the Forum, publishes an Annual Report on PPI activity. The first annual report for 2009/2010 outlined the roles of the HSC organisations in relation to PPI and provided a summary of their PPI work and progress, however from 2012/2013 the annual report now details the work and progress made by the Regional PPI Forum in its main priority areas namely:

- PPI Training

- PPI Standards
- PPI Monitoring and Performance Management
- Communication and Annual Reporting

PPI Training

In recognising the need for staff to engage well and to enhance their skills, a Personal and Public Involvement and Leadership training programme was developed in 2009 which was initially jointly funded between HSCB and PHA. This programme continues to be commissioned and funded by HSCB and the *Involving People Programme* is open to all Trusts, other agencies, community and voluntary sector. At the end of 2015, 100 candidates will have obtained an ILM Level 5 in Leadership. Within the Trusts, while PPI Awareness training and information sessions have been developed and delivered to staff, there was no standard format agreed across Trusts and delivery depended on the availability of staff to deliver and the capacity of teams to release staff from front line duties.

As well as recognising staff training needs, some work has been carried out to develop training for service users and carers. The Health and Social Care Board, in partnership with the Patient and Client Council, provided a pilot course *Leading in Partnership* during 2014. Places were limited and while there are no plans to continue with this course, the Health and Social Care Board has recently commissioned a Level 3 accredited training programme aimed at Service Users and Carers who work directly with the Board entitled *Finding Your Voice* which is due to commence in September 2015.

Working through the Regional Forum with HSC partners and service users and carers, the PHA has led on the development of a comprehensive PPI training programme for HSC staff. This was piloted from September to November 2014 with further pilots conducted in February 2015. The training programme seeks to ensure a consistent approach to PPI throughout Northern Ireland and includes:

- Good Practice PPI approaches (modular based programmes)
- PPI Team Briefing

- PPI Coaching
- PPI e-learning

At the time of writing, the PHA, working with the training sub group of the Regional PPI Forum, is currently reviewing feedback and finalising the training programme materials and anticipates that the programme will be available and launched by February 2016.

PPI standards

The PHA, working with the Regional PPI Forum, developed the first set of Standards for PPI, launched in March 2015. The aim of the Standards is to help embed PPI into HSC culture and practice. They set out what is expected of HSC organisations and staff in terms of Involvement. They will help standardise practice and support the drive towards a truly person-centred system.

The five PPI standards with key performance indicators have been endorsed by the Minister and approved by the Department. The Standards are:

- Leadership
- Governance
- Opportunities and Support for Involvement
- Knowledge and Skills
- Measuring Outcomes

PPI Monitoring and Performance Management

The PHA has responsibility for ensuring that HSC Trusts meet their PPI statutory and policy responsibilities/obligations. Working with the Regional PPI Forum, with significant input from service users and carers, the PHA led work on the development of a PPI Monitoring and Performance Management Framework. This was an example of co-design in practice with service users and carers involved from the outset, in developing the mechanisms and processes and also involved in conducting the monitoring and contributing to the development of the analysis and final report. The monitoring and performance management arrangements were

based on the new PPI standards. The HSC Trusts completed a self-assessment template in partnership with their PPI Panels/Steering Groups, had it approved through their internal governance structures and submitted to the PHA on 31st January 2015 together with supporting evidence. Following this, the PHA PPI Team in conjunction with Regional PPI Forum service users and carer members of the monitoring sub-group, carried out a verification visit with each Trust (March 2015) and provided a monitoring report that included a summary assessment report on PPI generally within the Trust and on a specific focus area (Cancer Services) with recommendations for consideration.

This process will be extended in 16/17 to other HSC organisations covered by the legislation that will also be required to complete this process

Current position within HSC

Currently within HSC organisations, PPI strategies and action plans have been developed and published. Information and guidance is available on what PPI is, the rationale and benefits and some resources and training have been developed to support staff to deliver effectively on their PPI obligations. In the absence of policy, interim Service User, Carer and Stakeholder Reimbursement Guidelines and Procedures were developed by one of the Trusts in 2009. This guidance was then adapted by the PHA and recommended for use across all HSC organisations until regional guidance has been developed and agreed by the DOH. All HSC organisations currently have a mechanism for reimbursement based on this guidance and some have tailored it to suit their own local circumstances.

Two of the Trusts developed a PPI Toolkit to provide staff and managers with information and good practice guidance to enhance Personal and Public Involvement within their area of service. The printing of one of the Toolkits was funded by the PHA through the PPI Regional Forum and each service team within that Trust received a ring-bound copy. Copies of this resource were shared with PPI leads in other Trusts so that they could tailor for use in their organisations if this resource was not already available or cross reference with existing toolkits for consistency.

Training provision across the Trusts varies hugely, with some indicating little or no training available / taking place. In some Trusts, Action Plan templates have been developed setting out the key actions required by teams to embed good PPI approaches in their day to day working practice. In others, Action Plans have been developed on a corporate basis. Again, the level and extent of these varies considerably from Trust to Trust and Directorate to Directorate within each Trust. There is also recognition that these action plans do not capture all the PPI activity that is taking place across the organisation.

Conclusion

Although PPI in Northern Ireland still faces a number of challenges, there has certainly been a great deal of work undertaken and a marked improvement particularly in coordination over the years. Progress has been slower than anyone would have liked however much of this has been achieved within existing resource. PPI in Northern Ireland is therefore still very much a developing process. In order to build on these foundations there is a need to ensure:

- Commitment at the highest level of Management to PPI
- That staff see it as their core business
- That staff and service users have the confidence and skills to practice and participate in effective PPI
- A shared understanding of PPI and agreed terminology
- Appropriate support
- Time and space
- Adequate recurrent resources and non-recurrent funding to test innovative approaches to PPI across the system
- Training to be available and accessible for all staff
- Effective and efficient methods of measuring impact
- PPI is pro-actively promoted to the public. People are made aware of their rights, understand how to get involved, have their voice heard.

This requires strong leadership, coordination and partnership working so that PPI is an integral part of the way the HSC does its business, not because it is a statutory

requirement, but because it is the right thing to do. Practicing PPI effectively is central to promoting a positive impact on the service user and carers' experience of the services delivered and to the HSC system delivering high quality services that meet the needs of the people who use them.

At the time of finalising our research for publication, the Minister of Health published *Health and Wellbeing 2026 – Delivering Together,* in response to the recommendations from the review led by Professor Rafael Bengoa who was tasked with ways of responding to the many challenges in Northern Ireland's Health and Social Care System. At the heart of the Health Minister's proposals is a call for partnership working, co-production and co-design with service users, patients, families and staff. Our research shines a spotlight on the many opportunities and indeed challenges that exist in the quest to achieve meaningful *involvement and engagement* at a very important time in Northern Ireland's Health and Social Care history. The findings of this research make it clear that operationalising effective approaches to PPI will deliver the meaningful partnership working aspirations of the Minister.

Chapter 2: Methodology (How we did the Research)

A group made up of academic staff from Queens University and Ulster University, Health Trust staff who have a particular interest in PPI and a number of service users and carers came together to carry out this research. This has been seen as an unusual approach to research involving people from different backgrounds, but it was hoped that this would lead to better engagement and involvement, using a wide range of skills and not just pure academic tools.

Central to all of this work was a strong service user and carer ethos, with service users and carers at the heart of all this work. It was agreed initially that the research would involve four key stages: Literature Review (using a Rapid Evidence Assessment (REA) approach)[4], On-line Survey, Focus Groups and, if required, follow-up telephone interviews. As sufficient information was gathered from the first three stages, the research team decided not to have the fourth stage. [5]

In addressing the research objectives, the team applied a *mixed methods* approach (different ways of gathering research information) using both *quantitative* (information expressed through statistics) and *qualitative* methods (information expressed as thoughts, opinions and ideas) to gather *data* (information) from key participants across Northern Ireland's health and social care sector alongside service users and carers.

The specific stages of the Methodology are as follows:

1. Stage one – Rapid Evidence Assessment

As the first stage of the project, the research team conducted a Rapid Evidence Assessment (REA) to search the international, national, regional and local literature on the following four key aspects of this project:

• Best practice in PPI internationally, nationally and in NI

[4] The literature review for the fuller report was undertaken using an approach described as a Rapid Evidence Assessment (REA). This process uses technical terms which must be used in the report to demonstrate the rigour with which this part of the research was undertaken.

[5] The research team decided not to conduct telephone interviews as sufficient depth was provided in the focus groups and on-line survey.

• Barriers to effective involvement

• Possible ways to overcome these barriers

• Valid and reliable ways of measuring and evaluating the impact of PPI activity

Rapid Evidence Assessments (REAs) provide an established methodology for using *systematic review methods* (structured ways of finding out what is already written on a topic) to identify and critically analyse the available literature and research evidence on legal, policy and practice issues. They are a rigorous, open and effective means of evaluating what is known and facilitating consideration of future developments and are particularly suited to projects which have a limited timescale such as in this instance.

2. Stage two – On-line Survey with Service Providers (number=138)

Information on PPI activities and the impact of these was collected through an on-line questionnaire administered to statutory/public sector, third sector (organisations that are neither public sector nor private sector such as voluntary and community based) and private organisations (see Appendix Item 3 in Main Report). The on-line questionnaire was piloted (tested out) in one Health and Social Care Trust area and the sample (those who would be taking part) for this stage of the study was guided by advice from the Personal and Public Involvement lead staff in each of the Health and Social Care Trusts. In total, one hundred and thirty eight (*n*[6]=138) respondents completed the on-line survey.

3. Stage three - Focus groups (number = 10)

The research team conducted ten focus groups across Northern Ireland aimed at establishing current experiences in PPI from the health and social care service user/carer and service provider perspectives in each of the five Health and Social Care Trust areas. Two focus groups were therefore conducted in each Trust area, incorporating these 'user' and 'provider' perspectives on PPI in separate focus groups. Each focus group took place in areas and community settings which we felt were geographically central and accessible to as many people as possible. The focus group questions were designed to reflect the research Objectives and were

[6] n = number

also shaped by the findings from both the literature review and on-line survey. Purposive sampling [7] was used to ensure that the focus group in each Trust area contained representation from service providers across statutory, private, third sectors and service users with experience of PPI in health and social care contexts. We also developed a Screening Tool to assist us in ensuring we had as broad a cross-section of the service user perspective as possible. Trust lead staff had a key role in publicising the research through Trust and other relevant networks. In total eighty nine (***n* = 89**) people participated in the focus groups (36 staff and 53 service users).

4. Stage four– follow-up telephone interviews

If the focus groups identified specific issues that were not explored in sufficient depth in the group, we agreed that these issues would be further investigated through follow-up interviews, with permission from the individual focus group participants who identified the issue. It was however not necessary to conduct any interviews such was the depth and quality of data the team was able to obtain through the focus groups.

Project Management

A Research Advisory Group was established to advise the research team on key aspects of the project. This was made up of staff representatives from across Health and Social Care Trusts, Service User and Carer Organisations and individual service users/carers with research interests and experience in PPI. Membership of this Advisory Group was informed by key contacts recommended by and already known to members of the Research Team. This Group met on two occasions over the six month duration of the research and was updated appropriately at key stages of the research process.

[7] Purposive sampling is where the decisions about who is to be involved in the focus groups is taken by the researcher because of the person's experience or knowledge in a particular area to do with the research

Ethical Review

This research was ethically reviewed by the following organisations:

1. The School of Sociology, Social Policy and Social Work Research Ethics Committee, Queen's University.

2. The Office of Research Ethics Committee, Northern Ireland.

3. The Research Governance Committees in Northern Ireland's five Health and Social Care Trusts.

The research project was also registered in the Queen's University Human Subjects Research Database.

Chapter 3: Literature Review

In the pursuit of evidence informed research, the research team committed itself to ensuring that any recommendations arising from this research have a clear link to evidence. This section of the report therefore provides a comprehensive and structured overview of Personal and Public Involvement in a local, national and international context. The first section of the literature review details key messages from published literature and research which connect to the research objectives. This systematic review then concludes with recommendations. Similarly, the next section of our literature review concentrates on current practice in PPI specifically within the Northern Ireland context. Again, this more localised overview is then concluded with recommendations.

Introduction

This literature review summaries the findings from searches of the international, national, regional and local literature on the four key aspects of this project:

- Best practice in PPI internationally, nationally and in NI
- Barriers to effective involvement
- Possible ways to overcome these barriers
- Valid and reliable ways of measuring and evaluating the impact of PPI activity

Methodology for literature review

The methodology used for this review of the literature is a Rapid Evidence Assessment (REA). REAs provide an established methodology for using systematic review methods to identify and critically analyse the available literature and research evidence on legal, policy and practice issues. They are a rigorous, open and effective means of evaluating what is known and facilitating consideration of future developments and are particularly suited to projects which have a limited timescale such as in this instance. The key features of the REA methodology are summarised below:

- Searching: Searching is the process of locating evidence that might be relevant to the review questions. We developed targeted and focused search strategies which were also considered by the Advisory Group. We then searched the following databases: Medline; Embase; International Bibliography of the Social Sciences (IBSS); EconLit.; Psycinfo; the Cochrane Library; and Web of Science. We also searched key websites to identify reports, official documents and other grey literature relevant to PPI.

Search strategies

The search strategies used were adapted for each database and included combinations of:
(Personal and Public Involvement OR Patient and Public Involvement OR Consumer Involvement OR Client Involvement OR Service User Involvement) AND best practice
(Personal and Public Involvement OR Patient and Public Involvement OR Consumer Involvement OR Client Involvement OR Service User Involvement) AND barriers
(Personal and Public Involvement OR Patient and Public Involvement OR Consumer Involvement OR Client Involvement OR Service User Involvement) AND implementation
(Personal and Public Involvement OR Patient and Public Involvement OR Consumer Involvement OR Client Involvement OR Service User Involvement) AND evaluation
(Personal and Public Involvement OR Patient and Public Involvement OR Consumer Involvement OR Client Involvement OR Service User Involvement) AND impact
(Personal and Public Involvement OR Patient and Public Involvement OR Consumer Involvement OR Client Involvement OR Service User Involvement) AND effectiveness

We limited the searches to studies published in English from the past ten years (since 2004) and key documents identified from before then.

- Screening: Screening was conducted to determine which of the located studies and documents were relevant to the project's questions. We used inclusion criteria to determine whether each document directly addressed at

least one of the key aspects of the project. Perhaps the most important inclusion criteria was the document had to address PPI in health and social care in general so most documents which focused on a very specific area, such as just on implications for one area of health care, were not included. The intention in a REA is not to identify and include everything that has been written on a subject but to focus on the key documents. There were no exclusion criteria based on methodology.

- Quality assessment: Each publication was assessed for quality and relevance to the review.
- Data extraction: We used a comprehensive data extraction approach to capture all necessary data, including, when relevant, study context, population, evaluation method and evaluation findings.
- Data synthesis: Data synthesis is the process by which we identified trends and themes from across the documents included in the review.

Findings

Using the search strategies and databases outlined above, 1195 documents were identified. Medline, Embase and Psycinfo enabled separate searches for the different aspects of the review and more general searches were completed of the other databases. The breakdown of these results is set out in Table 1 below:

Table 1 Findings from search strategy

	Medline	Embase	Psycinfo	Cochrane	Econlit	IBSS	Web of Science	Total
Best practice	7	20	4	1	22	103	171	1195
Barriers	33	48	44					
Implementation	37	57	40					
Evaluation	74	106	77					
Impact	58	121	76					
Effectiveness	20	44	32					
Total	229	396	273	1	22	103	171	1195

Of these 1195, 48 were selected based on their relevance to the main aims of the project and the quality of the research. In addition to these documents a further 21 documents were identified through grey literature searches, these were mainly on policy and best practice guidance, and a further 17 documents through discussions with the project team. The literature is reviewed in four sections below: definitions and theoretical perspectives; policy and best practice guidance; implementation - barriers and overcoming them; and measuring and evaluating the impact of PPI.

Definitions and theoretical perspectives

A key initial consideration, for developing methods to monitor, measure and evaluate the impact of Personal and Public Involvement (PPI) in Health and Social Care (HSC) in Northern Ireland, is what is meant by PPI?

In 2007 the Department of Health, Social Services and Public Safety (DHSSPS) published 'Guidance on Strengthening Personal and Public Involvement in Health and Social Care'. It acknowledged that there are a range of terms used to refer to the activities associated with PPI and in paragraphs 2.1-2.6 it provided a working definition of the concept:

"2.1 People have a wide variety of relationships with HSC organisations. Most obviously when they are users of these services. They can also be relatives, friends or neighbours of service users. They can be voluntary workers, members of community groups or employees of voluntary organisations. In short, there is already significant involvement by people and the public in relation to HSC services.

2.2 There is no consensus on the use of terms or definitions for these people and public. Therefore, for the purpose of this guidance '*Personal and Public Involvement*' is used as an umbrella term to encompass the many different terms in use.

2.3 "*Personal*" refers to service users, patients, carers, consumers, customers, relations, advocates or any other term used to describe people who use HSC services as individuals or as part of a group, e.g. a family. "Personal" is the preferred term for anyone who uses the service because:

- there is no consensus among people who use services about how they wish to be described;
- it is a generic term that is inclusive of persons in receipt of a health service or a social care service;
- it reflects the personal nature of the care or treatment people receive from our services.

2.4 "*Public*" refers to the general population and includes locality, community and voluntary groups and other collective organisations. Individuals who use health and social care services are also members of the general public.

2.5 "*Involvement*" means more than consulting and informing. It includes engagement, active participation and partnership-working…

2.6 PPI should be part of everyday working practice, underpinning communications and decisions regarding care or treatment. It should be an integral part of service planning, commissioning and delivery. It means discussing with those who use our services and the public: their ideas, your plans; their experiences, your experiences; why services need to change; what people want from services; how to make the best use of resources; and how to improve the quality and safety of services."

The Public Health Agency (PHA) (2012) has suggested that "Although there are different interpretations of PPI, the primary focus should always be on involvement. Personal relates to the individual, family and small groupings while Public concentrates on the wider community. The concept is based on the engagement of users and carers (whether individuals, groups or the community) with those who plan, design and provide services." (p.8).

Sections 19 and 20 of the Health and Social Care (Reform) Act (Northern Ireland) 2009 introduced a statutory duty of public involvement and consultation and the DHSSPS (2012) provided further 'Guidance for HSC Organisations on Arrangements for Implementing Effective Personal and Public Involvement Policy in the HSC'. This guidance specified that as part of their duty under the Reform Act organisations

should include in their Annual Reports and/or Annual Quality Reports a section on PPI which should "answer three broad sets of questions:

- What have we done? – Overview of PPI activities with feedback and learning from the process.
- What difference has it made? – a summary analysis of the outcomes and particular benefits, identified from effective involvement of people (users, carers, communities or the general public) in decisions and planning to improve the quality of services.
- What do we need to do next? – action planning for following year and beyond." (p.8).

In this report the DHSSPS (2007) and PHA (2012) definition of PPI will be used but the wide range of other possible terms (including Patient and Public Involvement; Consumer Involvement; Client Involvement; Service User Involvement) will be also be referred to depending on the literature being discussed. Wallcraft (2011) reports that it is the generally accepted view that PPI can be effective and is popular with service users, carers, professionals and policy makers but she also highlights these assumptions and intuitive appeal do need to be interrogated. It is therefore important to recognise that, in addition to the range of terms used to refer to PPI, there are a range of definitional and theoretical perspectives.

Rise et al. (2011) argue that definitions of PPI often do not integrate service users and service providers' views. When they interviewed these groups they found that they did share a common definition of patient and public involvement, based on the core concepts of mutual respect, dialogue and shared decision making, although they also found service users tended to emphasize the need for respect and providers focused more on the process of dialogue. Both worried about the other making sole decisions.

Warsh (2014) has also suggested that there are different perspectives and priorities contained within the broad term of PPI. He argues that "the current trend of grouping patient and public involvement together is problematic. One problem is that the justifications given in support of patient involvement and public involvement are not

typically the same…patient involvement in clinical settings is most often justified by autonomy-based arguments and a reaction against medical paternalism. Public involvement, on the other hand, generates a series of questions not about autonomy or independence, but about the impact of involvement on the quality and relevance of health care research and provision, and the structure of a liberal democratic system of decision making and accountability." (p.25). Although he accepts that patient and public involvement are related he maintains that "public policy formulated with the goal of advancing both patient and public involvement should be clear about what precisely it is aiming to accomplish: Patient empowerment? Greater health system responsiveness? Fulfillment of democratic norms?" (p.26)

The underlying theoretical perspectives on PPI may help explain some of the complexities involved in defining the term. Forbat et al. (2009, p.2548) have distinguished four models of involvement (Table 2) all of which may be referred to as PPI but are based on different theoretical or ideological drivers.

Forbat et al.'s (2009) Four models of involvement

Table 2 Models of involvement

Who	What	Ideological drivers
Patient as consumer	Purchase or choice of service	Free-market economics
Patient as citizen	Policy and service planning	Social-democratic
Patient as partner	Care practice	Experiential knowledge
Patient as researcher	Co-research	Emancipation and empowerment

Carr (2007) has argued that identifying and openly discussing the power issues involved in PPI is central to its effectiveness and that will involve exploring some of the tensions between these different theoretical perspectives, for example between approaches based on consumerism and those based on citizenship. Gibson et al. (2012) have also argued that the developments in PPI have tended to be been based on what are at times conflicting drivers: "A dualist approach, combining ideologies of democratic public engagement with an economically motivated 'consumerist approach' aiming at greater efficiency [later quality], continued to provide the overt inspiration for reform for much PPI work" (p.532). Drawing on the

work of Peter Beresford they suggest that PPI cannot be understood without considering the wider political context. Tritter (2009) also engages with the complex tensions that may be involved in PPI. He states that "PPI has emerged on the health policy scene as a response to a series of tensions - individual/collective; consumerism/patient-centred; rights/regulation - and is being adopted for diverse reasons from cost-containment and shifting responsibility to better tailoring of services to meet the needs of patients and communities." (p.284). Building on Arnstein's seminal ladder of participation, which identifies levels or a scale of power in participation, Tritter (2009) proposes a model (Table 3) which can be applied regardless of what the specific aim of the PPI activity is (whether it's care planning, service improvement, policy development, education, research) to examine the levels of direct decision making available to participants; whether they are involved as individuals or part of a group; and whether they are responding to a set agenda or helping to create it.

Table 3 Tritter's model of involvement (2009)

Level	Direct		Indirect	
Individual	Proactive	Reactive	Proactive	Reactive
Collective	Proactive	Reactive	Proactive	Reactive

Ives et al. (2013), focusing on involvement in research, have also provided a model for examining the range of motivations underlying PPI (Table 4). They argue that there tend to be two broad sets of motivation, one pragmatic and outcome orientated, and the other process orientated.

Table 4 Ives et al.'s Rationales for PPI (2013)

	PPI as 'means to an end'	PPI as 'end in itself'
Model	Consultation by invitation	Partnership/alliance
Approach	Top down Pragmatic Outcome oriented	Bottom up Rights based Process oriented
Purpose for research	Increases the relevance Increases the quality	Representation of community values and preferences Transparency and accountability Equalising elitist and exclusionary power imbalances between the public and the academic community
Nature of involvement	Information giving about decisions made Invitation to respond	Encourage new ideas and joint decision making
Relationship	Transactional	Cooperative

Ives et al. (2013) also discuss what they refer to as the professionalization paradox. This is the suggestion that the benefit of PPI is based on lay or non-professional perspectives influencing services but in order to facilitate involvement some degree of training or professionalization is needed. They set it out like this: “Through the process of formal training and ‘on the job’ familiarisation with research, the PPI agent will necessarily undergo some degree of professional socialisation. As a result, their ability to act as a lay person, representing the public interest, is undermined, and arguably can no longer bring the benefits of ‘layness’ to research.” (p.183). Their conclusion is that for some aspects of PPI, particularly the conduct of research, the concept is not internally coherent. In other words the lay-professional paradox cannot be resolved.

Learmonth et al. (2009) have also explored this issues which they refer to as ‘the Catch-22 in managing the public voice in health care?’ They frame the paradox as “you have to be ordinary to represent the community effectively, but, if you are ordinary, you cannot effectively represent your community” (p.106). They propose a possible solution is to not expect or demand people involved in PPI to have all the expertise needed to be a professional manager but to allow for a more diverse and organic approach to PPI to be allowed to develop that doesn’t impose HSC structures and processes on people who are unfamiliar with them.

Andreassen et al. (2014), exploring this issue in Norway, have suggested that the competence of those who provide their views through involvement activities is based on their personal experience rather than through education and/or professional training. It could also be argued that this proposed paradox does not exist in reality or certainly not in the binary way it is presented. People interact with others in numerous roles and it may be possible for a person who is a professional in one sphere to be a lay person in another. There are many factors that may influence a person’s approach to issues, whether in the role of a member of the public or as a professional, and so encouraging awareness and consideration of those multiple issues may better reflect the complexity of the processes involved.

Staley (2013), considering this in the context of PPI in research, has argued “the assumed paradox does not exist in many cases of PPI, because the training required to prepare people to the point at which they can contribute is fairly limited. Such training is about helping people understand the basics of research, not about training people to the level of being able to design and run the research. It is mistaken to conclude that lay people should always be involved without any ‘training in research’. Doing so might lead to PPI processes that might fail. It would also be wrong to conclude that the PPI processes that do require lay people to acquire the same skills as researchers should not be developed. Some of the major benefits of PPI, such as involving peer interviewers, can only be assured through such a collaborative approach. In these cases, providing ‘training’ for these roles far from reduces the impact of the lay perspective. When done properly, such training equips the lay person to conduct high-quality research and also prepares them to use their lay status to maximum advantage.” (p.186).

Wait and Nolte (2006) have emphasised that engaging with these definitional and theoretical debates is a crucial aspect of approaching the evaluation of PPI. If it is not clear what PPI is attempting to achieve then it will be very difficult to assess whether or not it has achieved it.

Policy and Best Practice Guidance

In addition to the range of definitions and theoretical perspectives on PPI there is also a range of best practice policy and guidance available. The literature identified from the searches is mainly from North America, Australia and the UK and provides direction on: the rationale for PPI; the principles underlying PPI; the methods which may be used to implement PPI; and some of the process issues which may be encountered.

Rationale for PPI

The DHSSPS (2007) has set out the rationale for PPI: “High quality PPI can really change things for people who use services, both in their experience of services and the quality and safety of care. PPI can also increase service responsiveness and accountability to local communities and the wider population by involving them in the debates and decisions about service provision. Staff morale and satisfaction can

also improve when staff know they are providing a responsive service that is valued by individuals and appreciated by the wider public." (para 4.1).

The Public Health Agency (2012) has also outlined some of the proposed benefits of PPI. These include that it: increases ownership; increases self-responsibility; helps services be more responsive and appropriate; helps priority setting and decision making; reduces power imbalances; helps tackle health and social well-being inequalities; reduces and transforms complaints; recognises patient knowledge and expertise; increases levels of service satisfaction; acknowledges rights; increases accountability; contributes dignity and self-worth; and increases staff and patient morale. As mentioned above, the Health and Social Care (Reform) Act (Northern Ireland) 2009 also introduced a statutory duty for HSC organisations to involve and consult the public (Section 19).

Capital Health (2011) summarised some of the main reasons for developing PPI with both individuals and the public (Table 5)

Table 5 Reasons for developing PPI

Patients/Clients/Consumers	Public and Stakeholders
To ensure appropriate treatment and care	To improve service design
To improve health outcomes	To set priorities for action
To reduce risk factors and prevent ill health	To manage demand
To improve safety	To meet expectations
To reduce complaints and litigation	To strengthen accountability

Sheedy (2008) suggests that the potential benefits include: making legitimate decisions; making better policy; overcoming polarization, reducing conflict, looking for common ground; building competent, responsible citizens; engaging citizens in political life; and including minorities.

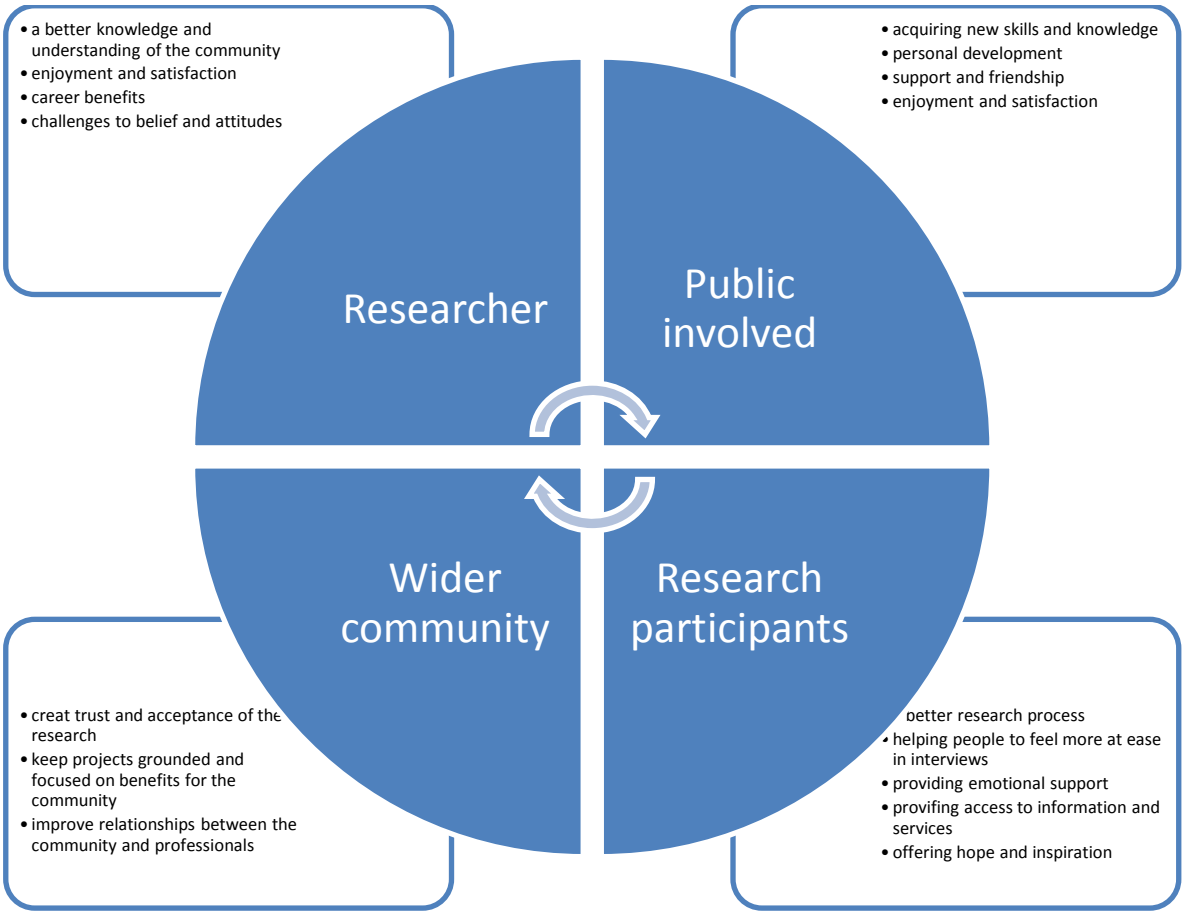
The University of Birmingham and NHS West Midlands (2009) stated that "Involving people can have an effect on how services are planned, organised, delivered and importantly how they are used. This in turn can have a positive effect on care outcomes as effective engagement can increase confidence and trust in services, can help people understand health conditions and treatments better and can make services more responsive to people's needs." (p.5).

In a review with the European Patients' Forum, Winder (2012) found that people reported that there were also some psychological benefits for participants which included:

- "Patients have an opportunity to meet other patients and share coping strategies
- Patients have access to more information about the latest treatments and technologies
- Patients become empowered through finding a positive aspect to the condition they are managing, being valued for their expertise and skills, representing others and seeing the results of their work
- Patients' strong motivation encourages and supports other project partners." (p.18).

Boyd and Grayson (2011) outline the potential benefits of PPI in research (Figure 1).

Figure 1 Benefits of PPI for research



The Joint Health and Social Care Regulators' Patient and Public Involvement Group (2010) have stated that "Without having patients and the public involved, and at the heart of regulation, it would be impossible to understand their concerns and interests and act effectively on their behalf." (p.6).

The King's Fund (2014) has also reinforced the rationale for PPI. In their recent review of staff engagement and empowerment they concluded that "There is compelling evidence that NHS organisations in which staff report that they are engaged and valued deliver better quality care. Superior performance is evident in lower mortality rates and better patient experience. The corollary is that organisations with a disengaged workforce are more likely to deliver care that falls short of acceptable standards." (p.7)

The Health and Social Care (HSC) Research and Development Division of the PHA reinforced the importance of PPI in their 2014 *Strategy for Personal and Public Involvement (PPI) in Health and Social Care research* stating that "Effective PPI is central to the delivery of safe, high quality services and, as such, is a key element of clinical and social care governance. Ensuring that PPI is a core responsibility of all HSC staff will improve the quality and safety of services, promote health and social wellbeing, address local and regional needs and priorities, strengthen local decision making and promote social inclusion." (p.1)

Principles underlying PPI

Based on research on user involvement in Northern Ireland, Duffy (2008) recommended that "Organisations seeking user involvement should commit themselves to an agreed set of principles/values that have been developed along with service users and carers." (p.x). Some examples of the types of principles that are proposed are presented below.

The Department of Health (2008) summarised the principles for NHS involvement practice stating it should be: clear accessible and transparent; open; inclusive; responsive; sustainable; proactive; and focused on improvement. The Office of Auditor General of British Columbia (2008) proposed a similar set of principles for more general community engagement: authenticity; accountability; inclusiveness; transparency; commitment and integrity.

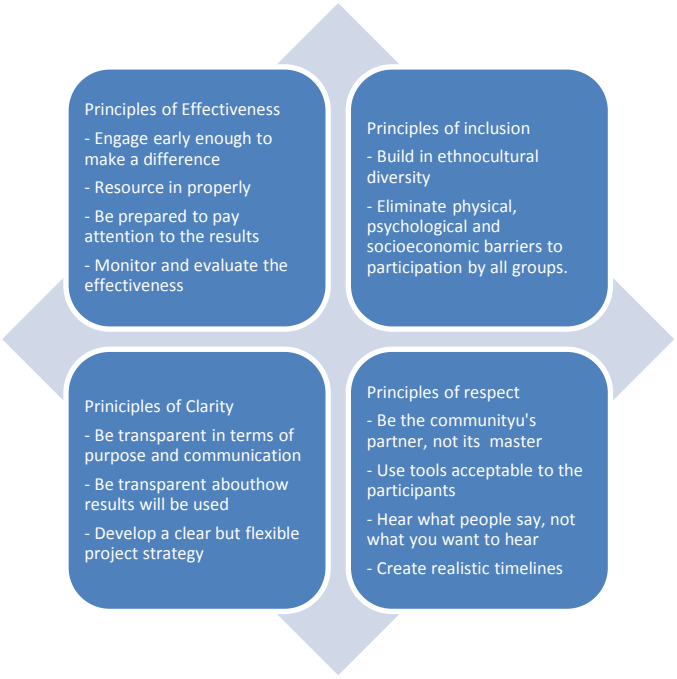
The National Consumer Council (2008) has proposed nine principles for effective deliberative public engagement:

1. The process makes a difference
2. The process is transparent
3. The process has integrity
4. The process is tailored to circumstances
5. The process involves the right number and types of people
6. The process treats participants with respect
7. The process gives priority to participants' discussions

8. The process is reviewed and evaluated to improve practice
9. Participants are kept informed

Ardal et al. (2006) present a diagramme providing an overview of the principles relevant to community engagement (Figure 2).

Figure 2 Principles for community engagement



The DHSSPS (2007) and PHA (2012) has also recommended a set of principles. The 12 principles are set out under three themes reflecting:

The organisational context – an attitude of mind, a way of working;

1. Leadership and accountability
2. Part of the job
3. Supporting involvement
4. Valuing Expertise

Implementation – do what you do, do well; and where we can improve;

5. Creating opportunity
6. Clarity of purpose
7. Doing it the right way
8. Information and communication

Outcomes – making a difference.

9. Accessible and responsive
10. Developing understanding and accountability
11. Building capacity
12. Improving safety and quality" (p.17).

The National Involvement Partnership (2014), which focuses on mental health services, has also produced Standards for Involvement. These present standards covering: principles; purpose; presence; process; and impact. Under impact they state: "For involvement to be meaningful, it has to make a difference; it should lead to the improvement of services and the mental health and wellbeing of service users and carers. Becoming involved can also have impact on the people who are involved (for example, increased skills and confidence). However, the purpose of involvement should always remain at the centre of any attempt to assess impact." (p.24)

Methods to implement PPI

The DHSSPS (2007) has recommended a series of steps for organisations to establish and promote PPI. These are:

"Step 1: Confirm or establish leadership and accountability arrangements for PPI;
Step 2: Using the principles in this guidance as a framework, review current PPI work to establish the baseline from which improvements can be made;
Step 3: Prioritise the areas for improvement;
Step 4: Develop and implement an action plan with clearly defined targets to strengthen and improve PPI securing agreement and support for this plan across the organisation;
Step 5: Clarify reporting arrangements for PPI as part of organisational management and clinical and social care governance. Arrange for the inclusion of PPI as part of the organisation's annual report on what has been achieved and agree the priorities and targets for the subsequent year." (para 10.3).

The DHSSPS (2012) subsequent guidance on implementation reinforced the need for reporting and monitoring, including regional monitoring, arrangements. Health Consumers Queensland (2012, p.15)) have set out the different levels at which PPI should happen (Table 6)

Table 6 Levels of PPI engagement

Level of Engagement	Where the engagement level occurs	Explanation of level
1. Individual	•Individual healthcare	This level focuses on engaging with the individual consumer and/or their family/carer as partners in their own healthcare, support and treatment
2. Service	• Program delivery • Service delivery • Facility/hospital	This level focuses on engaging with consumers and the community to have input into how programs, services, or facilities are delivered, structured, evaluated and improved
3. Network	• Local Health and Hospital Network • Medicare Local • Non-government Community Services Network	This level focuses on how health service organisations…engage with consumers and community at the regional level
4. System	• Local government • State government • Commonwealth government	This level focuses on how consumers and communities engage to influence and input on health policy, reform and legislation at the system level across local, state and Commonwealth jurisdictions

They also highlight the five elements of engagement which are based on the International Association of Public Participation Spectrum of Engagement which involve an increasing level of participation from: information; consultation; involvement; collaboration; to empowerment. Ardal et al. (2006) provide a summary Table of possible approaches to PPI with some of their strengths and limitations (Table 7)

Table 7 Possible approaches to PPI

Characteristics of the tools							
	# of people reachable at reasonable cost	Value for asking complex questions	Allows for multiple stakeholder interaction	Easy clarification of responses/ comments	Capacity to sustain an ongoing process	Ease in providing advance material	Specialised resources needed

Tools to reach and engage individual stakeholders							
1.Telephone surveys	Large	moderate	no	moderate	low	low	Surveyors and format designers
2. Mail-out surveys	Large	low	no	low	low	moderate	Format designers
3. Internet surveys	Large	low	no	low	low	high	Format designers
4. Face-to-face interviews	Medium	medium	no	moderate	moderate	high	Interviewers and format designers
Tools to reach and engage groups							
5. Public meetings	Medium	low	limited	moderate	low	low	Chairperson
6. Public hearings	Medium	low	limited	moderate	low	low	Chairperson
7.Open houses	Medium	moderate	limited	high	low	low	Chairperson
8. Focus groups	Small	high	high	high	high	high	Facilitator
9. Open space meetings	Medium	high	high	high	medium	medium	Facilitator
10.Task groups	Small	high	high	high	high	high	Task leader
11. Citizen panels	Small	high	high	high	low	high	Facilitator
12. On-line dialogue	Large	moderate	high	moderate	high	high	Format designer and moderator
13. Delphi technique	Moderate	low	moderate	moderate	high	high	Delphi facilitator

Involve (2005) also provided a list of possible methods for PPI including: Appreciative Inquiry; Citizens' Juries; Citizens' Panels; Community Empowerment Networks; Consensus Building/Dialogue; Consensus Conference; Deliberative Mapping; Deliberative Polling; Democs; Electronic processes; Future Search Conference; Participatory Appraisal; Participatory Strategic Planning (ICA); Planning for Real; Open Space Technology; User Panels; and Youth Empowerment Initiatives. The main message being that "The key to success is to understand the broad range and types of methods being used, what they are being used for and why you might choose one rather than another in a particular context and for a particular purpose." (p.52).

One example in practice, which focuses on PPI in research, is the James Lind Alliance, which is supported by the National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC). It "brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs). These partnerships

identify and prioritise uncertainties, or 'unanswered questions', about the effects of treatments that they agree are the most important. The aim of this is to help ensure that those who fund health research are aware of what really matters to both patients." (James Lind Alliance, 2014, p.2)

In Northern Ireland, the PHA and Health and Social Care Board (HSCB) (2014) "have led the implementation of the Patient/Client Experience 10,000 Voices Initiative with the six Health and Social Care (HSC) Trusts. The overarching aim was to provide a mechanism for patients not only to share their experience of the health service but to affect and influence the way services are commissioned and delivered. 10,000 voices is a metaphor for collecting patient experiences on a large scale to inform and change practice." (p.4) This initiative provides an ongoing structure for patient involvement to improve services for all.

Issues for implementation

The Joint Health and Social Care Regulators' Patient and Public Involvement Group (2010, p.13) have summarised some of the concerns that are sometimes expressed about PPI and possible responses (Table 8).

Table 8 Concerns about PPI

Concern	Possible response to concern
One or two people cannot be representative of patients	Nor can one of two professionals be representative of professionals – if we need a bigger range then we need to involve more people
Trained or professionalised members of the public cannot reflect the views of a typical patient – it is always the usual suspects	This depends on what you want people to do. For example, if you want someone to sit on a steering group then they might not be typical but they will be able to contribute important insights and present a range of people's views. Also just because they are actively involved and articulate does not mean they no longer use services
People won't understand what we need to do	Many people have been involved in the past and have made very useful contributions. There will be a need for the group to avoid jargon but this is useful to help everyone contribute
There are too many problems relating to confidentiality	We need to raise such issues with patients and the public as we do with anyone else and help them understand the reasons behind

	confidentiality policies
It is the job of health and social care practitioners to act as advocates for patients	Members of the public often have different priorities from professionals
How can people who are emotionally engaged in the topic be objective?	Nobody is entirely objective or neutral. People who use services bring a particular knowledge base with them that is different from those who provide services. Both will have some form of emotional engagement
It is too expensive and time consuming to involve patients and the public	It will take more money and time but not involving them is likely to compromise the relevance of the work and its quality. We will need to budget for it as we do with everything else
Members of the public may have unrealistic expectations	This need not be a problem if we explain how long it might take, what will be involved and any issues that might be encountered

The Joint Health and Social Care Regulators' Patient and Public Involvement Group (2010, p.25) also acknowledge that the effectiveness of PPI may be limited by a number of factors including:

"a. The attitudes of professionals

b. The values of the organisation

c. The diversity and complexity of patients and the public, which can make it difficult to understand how to involve people effectively

d. The knowledge base of patients and the public – and also of professionals

e. Power relationships, which can mean that an organisation's priorities dominate. Awareness and desire to share power can help redress the balance

f. Resources – a lack of time and money can prevent people from participating as can a lack of resources in an organisation to support effective PPI

g. Significant organisational change, which will dominate thinking and action

h. Policy that skews public involvement to short-term identifiable outcomes and undermines the development of more substantial ongoing forms of engagement."

The process of recruiting people to be involved also needs to be carefully considered and Natalie Simon, from Involving People, and Richard Stephens, from the National Cancer Research Network have provided some advice:

- "An appropriate involvement representative would depend on the needs of the research group and the needs of the public member/patients/carers.

- It is important to know what it is that you want the member of the public to do or to 'be' before considering from where and how you might recruit them.
- When exploring how to recruit involvement representatives, speak to someone who has already done it." (Marie Curie Palliative Care Research Centre, 2014, p.18).

Fraser Health (2013) has produced guidance specifically on engaging people not traditionally included or heard. This is important as "Patient engagement has the potential to make programs and policies more responsive to the public. As such it may also reflect and maintain health inequities by reproducing social marginalization through the engagement structure and process. The patterns that support some populations to participate while excluding other populations reproduce social and health inequities. In order to engage diverse populations, patient engagement must not only fit planners' needs, but also those of the patients' life contexts." (p.12). So PPI needs to be implemented in ways that facilitates involvement and doesn't further reinforce exclusion.

The Government of Western Australia (2006) have emphasised that the implementation of PPI is a dynamic process with ongoing opportunities for learning for everyone who participates so organisations need to critically reflect before, during and after these process.

The Scottish Government (2010) has highlighted that evaluation should be a routine part of PPI and the implementation and evaluation processes are considered in more depth in the next two sections: "Evaluation is an appraisal of how the informing, engaging and consulting activities undertaken worked; the impact they had on the service change; and the lessons to be learned for future involvement work to be carried out by the organisation. The process should be positive and constructive, designed to highlight areas which may need to be strengthened or developed." (para.41).

Implementation - barriers and overcoming them

In addition to the policy and guidance, which tended to provide more abstract principles and advice, the literature searches also identified research articles which

focused on the processes of implementing PPI in practice. Within this section there are three main themes. Accounts of the range of implementation, the barriers that people have encountered and strategies to overcome these barriers.

Implementation in practice

PPI is relevant across a very wide range of care, treatment, service planning, commissioning and delivery. Ryan et al.'s (2001) review of methods to implement PPI was outside the inclusion dates for the REA but was considered of sufficient importance to be included. It made the important and enduring point that "There is no single, best method to gain public opinion. The method must be carefully chosen and rigorously carried out in order to accommodate the question being asked." (p.iv). In another early systematic review of methods of involvement in developing healthcare policy and research, clinical practice guidelines and patient information material, Nilsen et al. (2006) found that although there was some evidence for the impact of involvement little research had been done to establish the most effective methods and most studies, if a control group was used, compared PPI with no PPI.

Beresford and Branfield (2006) provide an account of the Shaping Our Lives outcome project which made it possible for service users to consider what quality outcomes were important to them. Through a series of focus groups they "highlighted the need to include the subjective views of service users as an inherent part of outcome measures. They emphasised the essentially subjective nature of quality and quality measures. User-defined measures have tended to be devalued as subjective, but as service users indicated, all measures are valued-based and subjective." (p.440).

Rowa-Dewar et al. (2008) describe using a multi-site rapid appraisal method for PPI. This involves purposively selecting participants then using a range of methods such as demographic data and focus groups to relatively quickly collect data to inform policy. They conclude that the 'quick and dirty' reputation of rapid appraisals was not necessarily justified and that they could be implemented in a rigorous way to achieve meaningful public involvement.

Szmukler (2009) discussed the role of mental health service user involvement in research. He acknowledges that this is a relatively recent development, he suggests a little over a decade old, and that it is still evolving. He also accepts that although the supporting evidence is only developing the likely benefits include more relevant research, increased recruitment and more effective dissemination of findings. Interestingly though he argues that these ideas are just emerging and that perhaps current ideas about the potential and scope of involvement in research are not ambitious enough.

Boivin et al. (2010) examined patient and public involvement in developing clinical guidelines by holding a workshop with 56 guideline developers, researchers, and patient/public representatives from 14 different countries and emphasised the importance of drawing on international experiences. Legare et al. (2011) also reviewed the literature on PPI in developing clinical guidelines and provided an overview of the nature of this involvement: “Methods used to recruit PPIP participants included soliciting through patient/public organizations, sending invitations, and receiving referrals and recruits from clinicians. Patients and the public most often participated by taking part in a…working group, workshop, meeting, seminar, literature review, or consultation such as a focus group, individual interview, or survey. Patients and the public principally helped formulate recommendations and revise drafts.” (p.45).

Ellins (2011) focused on the individual level and suggested that patients can have three key roles in health care. These are:

- “evaluator: providing assessments of the care they receive
- consumer: making informed choices among providers
- co-producer: being active participants in their care.” (p.545).

Boote et al. (2011) focused on the role of PPI in the systematic review process. They clarify that this can be involvement “in one of more of the following review activities: (1) choice of review question; (2) development of review protocol (including search strategy and inclusion/exclusion criteria); (3) literature search; (4) appraisal of the literature including assessment of study relevance, data extraction and evidence

synthesis; (5) initial drafting of findings; (6) interpretation of findings; (7) final report writing." (p.106). Reflecting these activities they found that PPI can contribute to the process in five main ways: "(1) refining the scope of the review; (2) suggesting and locating relevant literature; (3) appraising the literature; (4) interpreting the findings; (5) writing up the review." (p.108).

Gagnon et al. (2011) conducted a systematic review of international experiences of introducing PPI to health technology assessment which is the process that considers the medical, social, economic and ethical issues relevant to the use of a health technology. Its traditional focus has been on clinical effectiveness and cost effectiveness but the patients' and public perspectives are increasingly being included. They selected 24 empirical studies of PPI in this area in their overview and concluded that "Our results underline the two substantive roles generally considered for patient and public participation in HTA. The first role consists of eliciting patients' or the public's perspectives to inform HTA and the second role refers to direct participation of patient or public representatives in the HTA process." (p.39). In terms of the effectiveness or impact of PPI they suggested that "Although many examples retrieved in this review showed that patients' or the public's perspectives could add important dimensions to the evaluation of health technologies and clinical interventions, the need remains for systematic and rigorous empirical studies of patient and public involvement in HTA." (p.40).

Coe (2012) analyses the use of Health Panels to facilitate PPI. These are panels usually recruited through quota sampling to promote representativeness of the area and the membership is regularly changed. She suggests that, based on her experiences with Somerset Health Panels that they can respond and adapt to consideration of a wide range of issues and there is a particular strengthen in the ongoing relationships between the participants, researchers and stakeholders.

Gillard et al. (2012) examined PPI in the co-production of knowledge, in this case a mental health research project. They highlight the importance of "reflecting on the involvement of all members of the research team in the process of knowledge production, and not singling out the involvement of service user and carer researchers as a "radical" addition to a conventional academic team." (p.1135).

Boivin et al. (2014) used an interesting design to look at the process of public involvement in setting priorities for health care improvement in Canada. They randomly assigned 6 health and social service centres to having either public representatives involved in the discussion or not; then observed 172 participants (83 public participants and 89 professionals) in 14 one-day meetings across the 6 centres and analysed the interactions to identify how the public influenced the development of priorities. They found that PPI did affect the priorities set, compared to the control centres, and that the professionals also had an impact on the public representatives increasing levels of mutual agreement. In an earlier study Wiseman (2005) had found that when she asked members of the public and professionals to individually set priorities the results were very similar and both groups strongly supported the use of public preferences to inform policy. She also made the important point that PPI does produce similar results to less inclusive methods it still may provide important benefits in terms of legitimacy and procedural justice.

Evans (2014) provides a documentary analysis of the development, since 1993, of the role of PPI in English health Research and Development policies. He identifies that the importance of evidence of impact is a relatively recent development: "Overall, R&D policy documents have made little attempt to justify the policy of PPI in research beyond simple assertions that it is beneficial without citing evidence, and until recently there was little effort to substantiate the policy with evidence. On one level this is not surprising, as these documents have been primarily concerned with improving the quality and delivery of research in the NHS, and PPI was only one of a number of mechanisms intended to contribute to these ends." (p.371). He concludes that "The emergence of PPI in health research policy is a significant development in the global relationship between research and policy; it is currently little researched and under-theorised, and merits further critical investigation." (p. 374). Mathie et al. (2014) also reviewed PPI in UK research but in the conduct of research and found that the most common way PPI was implemented was through inclusion on steering/advisory groups and in reviewing patient information leaflets. Staniszewska et al. (2014) highlight the potential role for PPI in the implementation of evidence in to practice. They argue that patients and the public could be involved in the three key aspects of these processes:

- “The creation of evidence through collaborative PPI in studies that make up an evidence base.
- Working collaboratively with patients and the public to provide insight into the contextual factors that need considering for successful implementation.
- Patients and the public informing the development of strategies to facilitate effective implementation of guidance.” (p.97).

Barriers to implementation

In an early study of Health Consumer Groups in the national policy process Jones et al. (2004) reported that there were a number of key barriers related to the wider political agenda, the consultation process, lack of resources and unequal power relationships. Klein (2004) also offered an early note of caution about PPI, “The rhetoric of public involvement should be invoked sparingly and in full awareness that it is a problematic concept. Getting involved carries costs in terms of the time and energy that have to be devoted. It also brings social and psychological benefits. The balance will vary for different groups of people so that the notion of ‘representativeness’ may always prove elusive. And before embarking on any further large-scale experiments with mutualism, we should perhaps remember that what works in small, homogeneous organisations may run into difficulties in large, heterogeneous organisations.” (p.212). In considering the role of legal duties to involve, Sang (2004) argues they are one method of overcoming some of the psychological and social barriers to involvement in the complex and difficult decisions involved in health policy and practice, “Powerful forces work against this opportunity: our own natural fear of death, disease, and disability; the inherent limitations of expertise and the entrenched vested interests of those who trade on our fear and enforced dependence on others’ expertise.” (p.190). Tritter and Koivusalo (2013) express concern that the more recent Health and Social Care Act 2012 in England and Wales may undermine and dilute the previous legal and policy commitments to PPI.

Beresford and Branfield (2006) reported that service users, in the Shaping Our Lives project to develop quality outcomes, identified “a series of barriers in the way of their

knowledge having the role and influence which they want it to have. These include: The devaluing of service-user knowledge…Problems of access and tokenism…The culture of health and social care organisations… [and] Resource Issues." (p.442). Hogg (2007) returns to the perennial issue of independence by asking "Can users become insiders and partners of managers and retain their independence and credibility?" (p.135). Reflecting on the development of patients' fora in England she suggests that the "nature of representation, accountability and governance were never addressed, leaving them open to criticisms of being undemocratic, unrepresentative and inconsistent." (p.137). She therefore concludes that these issues must be addressed in order for PPI to be credible. Martin (2009) also focusing on PPI in the NHS in England argued that the complexity and range of processes and purposes needed to be more clearly acknowledged, "Public involvement in commissioning may encompass a variety of interest groups, whose inputs may include population needs assessment, evaluation of service quality, advocacy of the interests of a particular patient group or service, or a combination of all of these. Each of these roles may be legitimate, but there are significant tensions between them. The extent to which the structures for public involvement proposed recognises these possible tensions is arguably limited." (p.123). In exploring some of the barriers to people with learning disabilities being involved, Chaplin et al. (2009) highlight the role of staff attitudes, policy and the political climate.

Boivin et al. (2010) reported that, in the process of using PPI to develop clinical guidelines, the goals of involvement are often not clear which makes it difficult to assess their impact and there can be tension between collective and individual perspectives or between population needs/expectations and individual rights/autonomy. Scourfield and Burch (2010) also highlighted problems that can arise when the role of participants, in terms of purpose, responsibility and accountability, is insufficiently clear. In their small scale qualitative study of older people's experiences they reported that involvement has caused those interviewed "a variety of unwelcome emotions, including anger, bitterness, self-doubt, frustration, a sense of failure, even shame. Unless every act of involvement has a positive outcome (which is highly unlikely), then such feelings are bound to be produced in some shape or form. Even where outcomes are more satisfactory than that reported in this study, it is still likely that individuals might be upset by the process, for

example where conflict has taken place or when it has touched on difficult personal issues. This raises critical questions for involvers about how to plan for and mitigate the effects of involvement initiatives that prove to be unsatisfactory." (p. 245).

Boote et al. (2011) identified some tensions in the process of PPI in systematic reviews. These aren't necessarily barriers but are relevant nonetheless. They reported that the following tensions were reported: "(1) time pressures; (2) resourcing problems; (3) continuity issues; (4) concerns about group dynamics; (5) Research Ethics Committee involvement; (6) tensions associated with the selection and representativeness of the members of the public involved." (p. 112).

At the level of individual care, Ellins (2011) highlighted the barriers created by inadequate information and poor communication. Boivin et al. (2014) tried to identify some of the key ingredients that could either promote or reduce the impact of PPI. They suggested the key issues were: the perceived legitimacy of those involved which could be increased by a diverse and balanced group; credibility, especially in terms of experience and expertise on the issues which undermines the Catch 22 concern about PPI; and issues of power which could be moderated through careful implementation.

Overcoming barriers to implementation

Beresford and Branfield (2006) found that service users identified four key strategies for overcoming some of the barriers to implementation and impact. These are: training and education; commitment to change from both services and service users; ensuring diversity; and networking. They also reported that service users identified the two main routes to more effective involvement were through campaigning and negotiation. Callaghan and Wistow (2006), in their study of PPI in the NHS suggest that it is not diversity or plurality themselves, but "how relationships are structured in diverse environments, that is more significant in shaping the local space for public involvement". (p.4).

Health literacy was identified by Coulter and Ellins (2007) as central to involvement at the individual level. This again suggests the proposed paradox of involvement may be an illusion. They argued that "A substantial evidence base exists for building

strategies to strengthen patient engagement. Any strategy to reduce health inequalities must promote health literacy and engagement… Interventions can improve patients' knowledge and experience, use of health services, health behaviour, and health status" (p.27).

Chaplin et al. (2009) suggest barriers to PPI can be overcome "by careful and thoughtful planning, equality in accessing information, and viewing involvement as an essential part of care planning, care delivery and service development." (p.33). Scourfield and Burch (2010) recommend a range of factors should be considered to prevent some of the negative experiences of involvement they reported and promote an ethic of care approach which attends to the need to build respect and trust and addresses issues of power. These include: clarifying roles, remit and expectations; providing guidance, support and training; establishing ground rules; and attending to endings.

Boivin et al. (2010) make the clear and important point that greater international collaboration and exchange of experience and expertise about addressing barriers to PPI will help further develop knowledge. Boote et al. (2011) identified a range of ways of improving PPI in their case studies of involvement in systematic reviewing. These included: "(1) funding and payment; (2) identifying a lead for public involvement; (3) training, briefing and information provision; (4) structured methods of involvement." (p. 113).

Ellins (2011) called for improved strategies and tools to enable patients to make decisions including developing environments that support their role in evaluation, making informed choices and participating in their own care. Purtall and Wyatt (2011) acknowledge the need to consider how to use resources and to measure impact but argue three points about the measurement of PPI: that there needs to be a debate about the purposes of involvement and measurement; then further debate about what criteria should be used to measure; and finally at what point/s in PPI should such criteria should be used.

Stewart et al. (2011), focusing on PPI in research, have argued that the "involvement of patients, carers and the public in research needs to continue to be embedded in a

culture that places the patient at the centre of clinical research. This includes activities to assist investigators to develop patient sensitive study design, membership of groups which develop new studies, and active involvement with study delivery teams to maximize recruitment to studies and sustain follow up (including contribution to problem solving).” (p.vii56). Boivin et al. (2014) reported that the practical arrangements for PPI can moderate some of the potential power issues in the dynamics involved. They suggested moderation, seating plans, ground rules and agenda setting can all be used to address perceived power imbalances.

Measuring and evaluating the impact of PPI

The previous sections have provided an overview of some of the key definitional, theoretical, policy, and implementation issues relevant to PPI. Much of that literature identifies the need for the impact of PPI to be further researched and recommends that should happen but this section concentrates on reviewing the literature that explores how that important and complex aim may be achieved. Three main aspects of that literature are presented. The first area for discussion concerns is what should be measured and evaluated. The second is how that can be achieved and finally, what implications does this literature have for this project.

What should be measured and evaluated?

In an early review, Carr (2004) brought together the findings from six reviews of participation in social care which had looked at the involvement of older people, children and young people, people with intellectual disabilities, people with physical disabilities, mental health service users and general user/consumer involvement. This reinforces the need to consider PPI across a wide range of health and social care areas as well as across a wide range of aspects of policy, planning, research and practice within each. Carr (2004) also identified the importance of openly considering the power issues involve in PPI although doesn’t suggest how this could be measured or evaluated.

Murie and Douglas-Scott (2004) provide an account of PPI in one area in Scotland and outline the wide range of activities that may facilitate PPI and whilst they report improvements to services based on this dialogue, the very diversity of methods used to enhance participation may make standardised measurement and evaluation of

impact more complex. Barber et al. (2011a) reviewed the literature on the impact of PPI on research and reported that there were accounts of impact on a wide range of aspects of research including: identifying and prioritising research; increasing the range of research topics; developing more complex research questions; informing the choice of methods; improving consent procedures; developing more ethically acceptable research design; improving recruitment rates; when involved as researchers, more open responses; clarifying analysis; questioning assumptions; influencing how findings are reported; and impact on the public involved and the researchers.

Barber at al. (2011b) used a two-round Delphi approach with 124 researchers, members of the public, research managers, commissioners and policy makers with a further 14 purposive follow-up interviews to seek views on what aspects of impact on research processes, outcomes and on stakeholders are feasible to evaluate, in other words, can it be done? They proposed a list of 16 possible aspects of impact of PPI which might be evaluated, divided into research processes, outcomes and stakeholders. Under research processes they suggested: identifying topics to be researched; prioritizing topics to be researched; commissioning research; research design; managing research; collecting data; analysing research findings; and interpreting research findings. Under outcomes they suggested: disseminating research; determining the usefulness of research findings; implementing research findings; the overall quality of public involvement in a research study or research-related activity; the overall quality of the research; and the overall impact of the research. And under stakeholders: the member(s) of the public involved in the research; and the member(s) of the research team. They found that there was consensus amongst the Delphi panellists that it was feasible to evaluate the impact of only 5 of these 16 aspects of PPI in research: the impact on identifying and prioritizing research topics, on disseminating research findings and on the public and researchers involved.

Brett et al. (2012) conducted a systematic review of the impact of PPI on research and based on the 66 included studies reported that: “The positive impacts identified enhanced the quality and appropriateness of research. Impacts were reported for all stages of research, including the development of user-focused research objectives,

development of user-relevant research questions, development of user-friendly information, questionnaires and interview schedules, more appropriate recruitment strategies for studies, consumer-focused interpretation of data and enhanced implementation and dissemination of study results…However, much of the evidence base concerning impact remains weak and needs significant enhancement in the next decade" (p.637).

Mockford et al. (2012) conducted a systematic review of the impact of patient and public involvement on UK NHS health care and found that "There is, surprisingly, a dearth of research about the impact of user involvement on services, how services have changed (the outcomes) because of it, the extent of changes or how much it costs the NHS to involve service users." (p.28).

Brett at al. (2014) also conducted a systematic review of the impact on those involved in PPI, again specifically in research, and found that "Service users reported feeling empowered and valued, gaining confidence and life skills. Researchers developed a greater understanding and insight into their research area, gaining respect and a good rapport with the community. The community involved in research became more aware and knowledgeable about their condition. However, lack of preparation and training led some service users to feel unable to contribute to the research, while other service users and communities reported feeling overburdened with the work involved. Researchers reported difficulties in incorporating PPI in meaningful ways due to lack of money and time." (p.387)

How can the impact of PPI be measured and evaluated?

Daykin et al. (2007, p.61), based on a systematic review, propose a possible framework for evaluating the impact of patient and public involvement. They were attempting to address the question 'What context and mechanism factors can be identified from empirical research that will lead to successful PPI outcomes?' They conclude this needs to be considered across the three domains of structure and resources; politics and discourse (including the micro-politics of engagement); and attitudes and culture. Within each domain the relevant context factors, mechanisms and outcomes can then be explored as set out in Table 9.

Table 9 Framework for evaluating impact of PPI

Context factors	Mechanisms	Outcomes
Structure and resources		
Community capacity; structure of partnerships between agencies	Support user involvement; education and support for staff and users; enhancement of staff competency and skill; mechanisms to identify the impact of user involvement on decisions	Micro-level service enhancements; containment, limitation and enrolment of users' agendas; discursive democracy
Politics		
Consumer/consultative or activist/independent models of involvement; local and national politics including pressure/pace of change; standpoints of different professional groups; c**ompeting discourses/ agendas; professional power**; r**adical/discursive democracy**; r**elationships of power and stake and their impact at micro level; ownership of PPI**	Staff discretion models e.g. grounded participation; resisting commodification of 'the public view'; standpoints, e.g. managers vs nurses; discursive strategies of engagement; professional discourse e.g. protectionism; bounded discourse, conversational technique and other discursive strategies of engagement	*U*sers' impact on decision making; extent of user's contribution not clear; management control; voice and legitimacy issues; impact of users' agendas on decisions; manipulation and control vs social and discursive transformation
Attitudes and culture		
*S***taff attitudes, professional culture and resistance; organisational ethos; bureaucratic procedures, capacity of staff and users to change**	Change and adaptation by service providers	Alienation of involved public; enhancements in service users' personal and social experiences. Subjective and social benefits of involvement

Building on the Daykin et al. (2007) framework, Evans et al. (2014) examined PPI in research through 8 case studies (88 interviews with 42 participants) and found "Case study data supported the importance of some aspects of our theory of public involvement in research and led us to amend other elements. Public involvement was associated with improvements in research design and delivery, particularly recruitment strategies and materials, and data collection tools. This study identified the previously unrecognised importance of principal investigator leadership as a key contextual factor leading to the impact of public involvement; alternatively, public involvement might still be effective without principal investigator leadership where there is a wider culture of involvement. In terms of the mechanisms of involvement, allocating staff time to facilitate involvement appeared more important than formal budgeting. Another important new finding was that many research proposals significantly undercosted public involvement." (p.v)

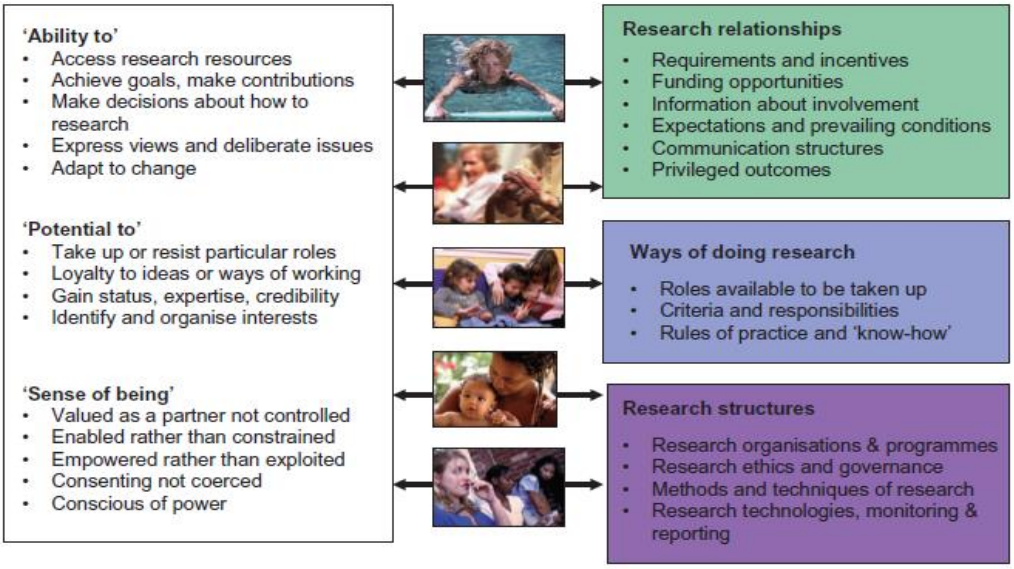
Staley (2009, p.89) focusing on the impact of PPI on research identified a number of reasons why it is difficult to assess the impact of involvement:

- “it is often too difficult or too costly to set up a comparison project without involvement, to assess the links between involvement and outcomes.
- the most valuable contributions from the public often come from personal interactions with researchers. These are hard to capture and evaluate.
- the public are often involved within the context of a committee or steering group. The complexity of decision-making processes in most committees makes it very difficult to assess the impact of any individual on the group’s decision.
- involvement activities are interconnected and link to several stages of the research process. This makes it difficult to pinpoint the precise impact of any particular aspect of the involvement.
- it may take many years for any detectable outcomes to emerge from a study.”

Staley et al. (2012) have also argued “a more intentional and explicit exploration of the links between context, mechanism and outcome, applying the principles of realistic evaluation to public involvement in research, should lead to a more sophisticated understanding of the factors that increase or decrease the likelihood of positive outcomes. This will support the development of more strategic approaches to involvement maximizing the benefits for all involved.” (p.1)

Morrow et al. (2010) also propose a model, the Quality Involvement Framework (Figure 3), and a measure, the Quality Involvement Questionnaire (Box 1), for quality service user involvement in research. These are both presented below.

Figure 3 Quality Involvement Framework



Box 1 Quality Involvement Questionnaire

Part 1: Personal Factors

1) Your ability

To what extent do you feel you are able to …?	*Not at all*	*Low*	---------->		*High*
	0	*1*	*2*	*3*	*4*
a. access research resources (e.g. money, facilities, information)					
b. achieve your own goals through the research					
c. make a contribution to the research					
d. make decisions about how to do the research					
e. express your views about research topics					
f. discuss research issues					
g. take on new research challenges					

2) Your potential

To what extent do you feel there is potential for you to …?	*Not at all*	*Low*	---------->		*High*
	0	*1*	*2*	*3*	*4*
a. chose the type of role you play in the research					
b. bring your own ideas and values to the research					
c. work in ways that suit you					
d. gain status, expertise or credibility because of your involvement					
e. identify and organise your research ideas and priorities					

3) Your sense of being

To what extent do you feel …?	*Not at all*	*Low*	---------->		*High*
	0	*1*	*2*	*3*	*4*
a. valued as a partner (not controlled)					
b. enabled (rather than constrained)					
c. empowered (rather than exploited)					
d. consenting (happy to be involved) not coerced (unhappy about it)					
e. it is acceptable that different people have different responsibilities and decisions to make about the research					

Part 2: Research Contexts

4) Research relationships

Thinking about research relationships, to what extent do you think …?	*Not at all*	*Low*	---------->		*High*
	0	*1*	*2*	*3*	*4*
a. the researchers have the right reasons for wanting to work with you					
b. there is sufficient funding to make involvement work					
c. you have enough information about involvement					
d. the way the researchers work with you is supportive					
e. the way the researchers communicate with you is supportive					
f. the types of goals that the researchers want are what you want					

5) Ways of doing research

Thinking about the research itself, to what extent do you think …?	*Not at all*	*Low*	---------->		*High*
	0	*1*	*2*	*3*	*4*
a. there is a clear role in the research for you					
b. the skills/experience needed for the role are clear to you					
c. the responsibilities for the role are clear to you					
d. you are aware of the legal and ethical 'rules' for doing research (e.g. confidentiality)					

5) Research structures

Thinking about the research organisation, to what extent do you think your involvement is …?	*Not at all*	*Low*	---------->		*High*
	0	*1*	*2*	*3*	*4*
a. not just part of a project, it is valued as part of the work of the organisation					
b. supported by research ethics and governance systems					
c. helped because of research structures (networks, links with other studies etc.					
d. noticed and recorded as part of the work of the research organisation					

Morrow et al. (2010, p.538) suggest that “Fulfilling the promise of service user involvement in research requires doing more to understand the processes and outcomes concerned. The model and key questions presented here could support research teams to reflect and report on these dimensions of their work.”

Staniszewska et al. (2008) provide an excellent summary of a range of issues with the research that has attempted to measure and evaluate the impact of PPI. They suggest these issues include: “poor conceptualization, variable and partial attempts at measurement, and the limited attention that has been placed on evaluating the impact or outcome of involvement. Research in this area has often been found to be of poor quality, and there have been difficulties related to attributing change directly to patient involvement. In addition, the focus on robust measurement of change and impact that exists in other areas, such as patient reported health outcomes, has not yet emerged in this area, despite the need to measure the impact of patient and public involvement in a valid, reliable and responsive way. The area is also limited by the lack of an agreed set of criteria specifically designed for assessing the quality of studies. Researchers have to rely on more general quality checklists which may not assess important aspects of patient and public involvement.” (p. 373).

An example of the approaches that are most often used to explore impact was conducted by Coad et al. (2008) who used an evaluation workshop to examine the impact of the involvement of a youth council on children’s service delivery in acute health services. They reported most of the young people felt that their involvement had improved Trust services and informed the decisions made by Trust staff but there was little detail reported of what evidence these views were based on.

In their review of the impact of PPI on research, Barber et al. (2011a) acknowledged that although a wide range of possible aspects of impact have been identified: “Systematic reviews on the topic reveal that much of the evidence consists of descriptive, often retrospective, accounts of involvement (Oliver et al., 2004; Smith et al., 2005; Brett et al., 2010).” (p.610). They then used a prospective, qualitative design to explore the impact of service user involvement in a study by obtaining the views of two service user researchers on the study’s advisory group and three of the service user researchers at regular intervals during the research process. The main

themes that emerged were around: trust and commitment, impact on the wider study, mutual learning and timing of service user involvement. They concluded that "The qualitative analysis identified perceived benefits to research, researchers and service user researchers that endorsed previous findings. The analysis also highlighted subjective and interpersonal aspects of service user involvement that have seldom been reported. This evaluation demonstrates the benefits of allowing time for structured reflection and adds to the understanding of the process and meaning of service user involvement in research." (p.609).

A Patient and Client Council workshop in 2011 on PPI included some discussion on how to address impact. It was suggested that there is a "need for evidence to support the move towards greater user participation. The current lack of data is hampering efforts to increase involvement. The workshop asked what types of measurement can build the evidence to bring more people on board and to make the case for greater involvement. The workshop examined the different types of expectations that exist in terms of involvement and how some standardised methodologies can help spread the ideas and the language to make it better understood. Some ideas included:

- Theory based evaluation – bringing users together to talk about what they want and developing an action plan to achieve this
- Protocol to evidence user involvement to lever funding." (p.10)

Staniszewska et al. (2011b) produced a GRIPP (Guidance for Reporting Involvement of Patients and Public) checklist to promote the quality of PPI reporting in research. This encourages better report of PPI in research to "strengthen the PPI evidence-base and so enable more effective evaluation of what PPI works, for whom, in what circumstances and why." (p.391)

The Department of Health (2013) in England have identified a range of tools to monitor and evaluate involvement at the individual level. These include: the National Inpatient Survey; GP patient survey; Patient Reported Outcome Measures (PROMS); Patient Activation Measure (PAM); Health Literacy Scale for Europe

(HLS-EU); Decision Quality Measure (DQM); SURE score which focuses on four areas – sure of myself, understanding information, risk benefit ratio and encouragement; and the LTC6 survey which focuses on self-management. These scales do provide important information on the areas and processes to consider but are focused on capturing the individual experience to inform services rather than measuring the subsequent impact of that process on health and social care.

Popay and Collins (2014) have developed a Public Involvement Impact Assessment Framework (PiiAF), based on work as part of the Medical Research Council's Methodology Research Programme, which provides guidance for researchers who are designing an assessment of the impact of public involvement in their research. It provides a range of tools (at www.piiaf.org.uk) which can be used to develop this process.

In an extremely in-depth qualitative study of the effects of PPI, Marston and Renado (2013) conducted a four year ethnographic study, 45 interviews with patient participants and 44 interviews with health professionals, to examine impact on a public health-care improvement initiative. They reported that the "effect of PPI is not captured in simple quantification of PPI elements (eg, patients reached, outcome measures improved). To define and assess the effects of PPI, we should take patient voices into account, and track the dynamic social processes and networks through which PPI contributes to health-care improvement. We present a framework for future assessment of PPI effect: how, whether, and when patient input is integrated into projects; level of sustained and expanded collaborative relationships created via PPI; changes in working relationships between multidisciplinary professionals; presence of new patient-led projects; institutional investment in PPI; and patient engagement in service improvement and self-care." (p.69).

Mockford et al. (2012) in their systematic review of the impact of PPI found that of the 28 studies they included there were: 20 case studies or reports; 5 evaluations; 1 survey; and 2 secondary data analyses. They found "This review found many and varied PPI activities in the UK NHS healthcare services but the studies did not provide robust evidence of its impact and almost no evidence of its cost. There was a lack of consistency of definition of public and patient involvement and no reliable

measurement tool." (p.35). They conclude that "there is an urgent need to develop the tools necessary for developing the evidence base. The development of clear concepts and robust forms of measurement will enhance an understanding of the impact of PPI alongside clearer economic evaluation." (p.37).

What are the implications of this review of the literature for the wider project?

In perhaps the most relevant article for this project, Staniszewska et al. (2011a) argue that "a paradigm change towards robust measurement of the impact of involvement in research is needed to complement qualitative explorations…that service users should be collaboratively involved in the conceptualization, theorization and development of instruments to measure PPI impact." (p.628). They acknowledge that the qualitative approaches more often used may have value, if more rigorously applied, but that they need to be complemented with more quantitative, standardised approaches that are based on a clear definition of PPI, what it is aiming to achieve and what should be measured. Staniszewska et al. (2011a) suggest that PPI may be considered as a complex intervention and so the Medical Research Council's (2006) Complex Interventions Guidance may be useful as it recognises that processes and contexts are important to measure and evaluate in addition to outcomes. They conclude that this approach to measuring and evaluating PPI would strengthen the evidence base for PPI by providing "a greater understanding of what works, for whom, in what circumstances and why." (p.629)

The PHA (2012), as outlined in the rationale for PPI section, have identified the proposed benefits of PPI and so this provides a foundation for considering the possible areas and groups in which impact could be measured and evaluated over time: ownership; self-responsibility; responsiveness and appropriateness of services; priority setting and decision making; power imbalances; health and social well-being inequalities; complaints; patient knowledge and expertise; service satisfaction; rights; accountability; dignity and self-worth; and staff and patient morale.

There are a wide range of existing frameworks and tools which have been developed, mainly focused on: the individual level; patient participation in their own

care; and on PPI in research but these existing resources also provide very useful direction on how to develop a more comprehensive and consistent approach to the evaluation of the impact of PPI.

Chapter 4: Research Findings

This section of our Report details the findings from the On-line Survey and the ten focus groups. In keeping with the commitment to evidence informed recommendations, the findings from both of these methods of data collection will lead clearly and directly to the Report's main Recommendations.

Findings from On-line Survey

The questions were derived from the literature and suggestions from members of the Research Advisory Group. A pilot study was undertaken with three people who are involved in PPI. Minor amendments were made to the questionnaire following the pilot study. The majority of questions had pre-determined responses with an 'other' option available for participants to note additional responses. Only those questions considering how PPI could be developed within organisations who plan and/or deliver health and social care services were free response (Questions 30-34).

Recruitment

The invitation to participate in the survey and the link to the survey were distributed by the PPI Leads in each of the five Health and Social Care Trusts, the Health and Social Care Board and PHA. From data provided it is known the survey was distributed to a wide range of personnel in statutory, voluntary and community organisations.

As the distribution email requested that the individual receiving the email forward this in turn to their colleagues it is not possible to estimate how many individuals received the request to participate. Hence, it is not possible to calculate the response rate. It should be noted that it is likely that multiple responses were received for some organisations.

Characteristics of respondents

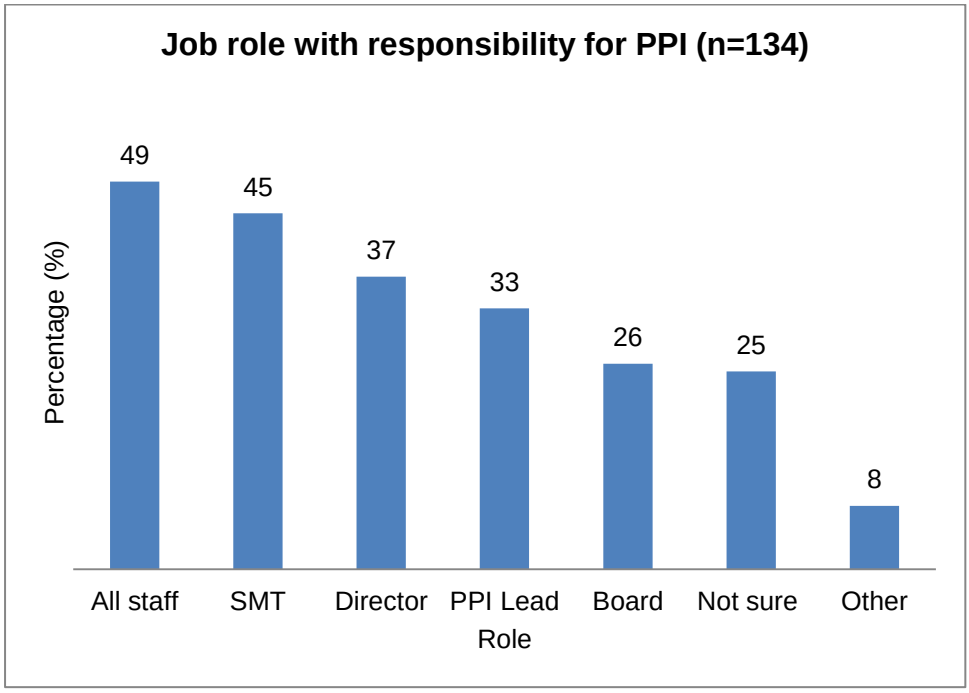
One hundred and thirty-eight (***n*=138**) responses were returned. All findings are presented as a percentage of the number of respondents who answered that specific question. It should be noted that where item response was low this is reported for specific questions. The majority of respondents (90%) work in the statutory sector, 1% in a charity or charitable organisation, 3% in the community and 4% work in both

the voluntary and community sectors. One respondent works in a partnership organisation, one in an arms length body and one in a company limited by guarantee.

Profile of PPI within organisation

Just over half of respondents (52%) reported there is an identified person with a responsibility for PPI in their organisation with a further 13% reporting there is no identified person. The remaining 35% were unsure if there is an identified person with a responsibility for PPI. Only 50% of respondents were clear if there is someone in their organisation whose *only* role is PPI; one-third (33%) stated there is not anyone and 17% of respondents said there is someone in their organisation whose only job is PPI. The cited job title for the majority of these is PPI Lead/ Manager/ Officer (n=10). Two of these posts reside within specific service areas – nursing and social care and children. It is encouraging that almost half of respondents (49%) reported that all staff in their organisation have a responsibility for PPI with 26% reporting that senior management have a responsibility. One-quarter of respondents (25%) were unsure who has a responsibility for PPI within their organsation (Figure 4).

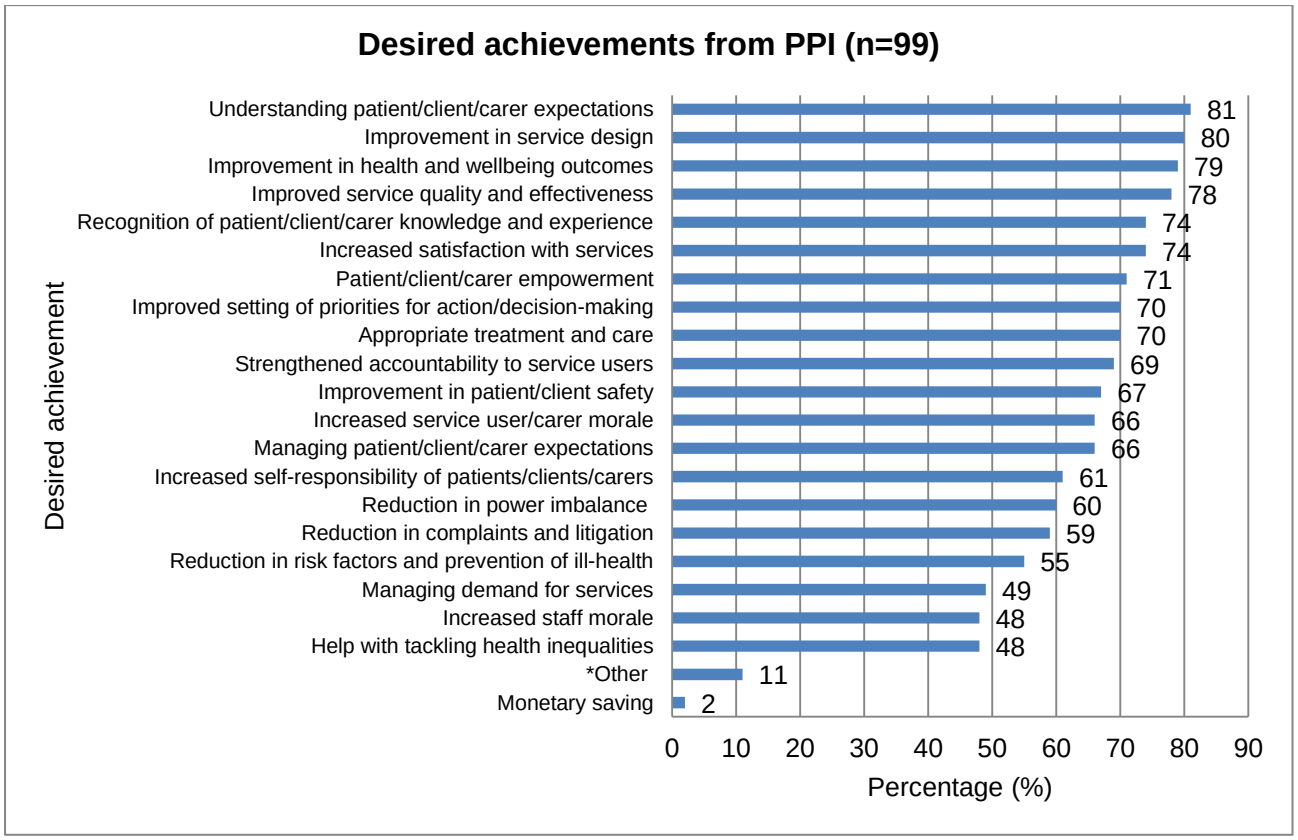
Figure 4 Job role with responsibility for PPI



Footnotes: % are not mutually exclusive
Other - self-selecting; designated person in each division; those involved in policy development; head of service

Two in ten respondents reported that no training is available for those with a responsibility for PPI with 36% reporting training is available in their organisation. Training is mainly in-house with some organisations offering both in-house and external training. Modes of delivery include modules, e-learning, formal accredited qualifications and traditional sessions. Both general e.g. induction training and bespoke training were noted. A number of respondents referred to the regional training pack which has been developed and is currently being piloted by the PHA. Encouragingly, the majority (48%-81%) of respondents cited desired achievements from PPI activities which related directly to services and/or outcomes for patients/clients/carers and/or their resident population (Figure 5).

Figure 5 Desired achievements from PPI activities



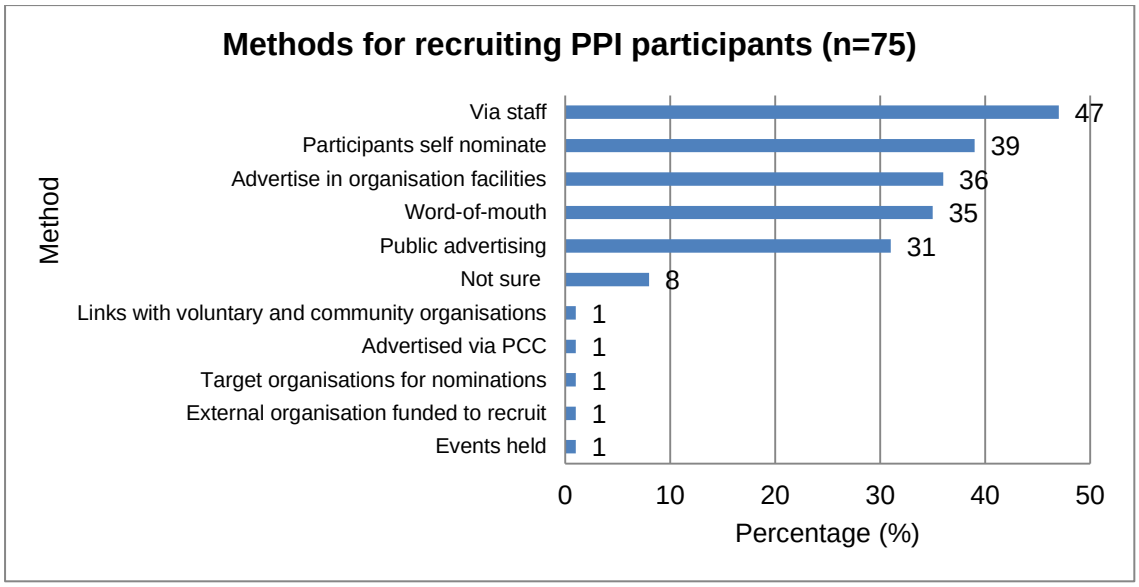
*contract out responsibility; a more engaged society; improved quality of research projects and outcomes; to appear to be taking involvement seriously

Recruitment and preparation for PPI participants

Just under half (46%) of respondents reported that each directorate/division is responsible for their own recruitment of PPI participants. The next highest categories are PPI Lead (27%) and participants self-nominate (25%). Twenty-eight per cent of participants are not sure who has responsibility for recruitment.

The most common method for recruiting PPI participants is via staff (47%), followed by self-nomination by participants (Figure 6).

Figure 6 Methods for recruiting PPI participants



Preparation for PPI participants

Preparation for PPI participants includes attendance at dedicated training events (43%); introduction to organisational structures (38%) and attendance at networking events (36%). The frequency of training and type of preparation varies across organisations (Table 10). Thirty per cent of respondents stated their organisation does not provide training for PPI participants.

Table 10 Preparation for PPI participants (n=77)

Preparation	Frequency of training
Attendance at dedicated PPI training events	When funding available
	Varies from service to service
	Dependent on identified need
	When requested
	Yearly/twice yearly/quarterly
	Ongoing
	Regular training from PHA
Introduction to organisational structures	Annually
	Induction/refresher
	Varies depending on project/team
	As required
Attendance at networking events	When funding available
	Varies from service to service and is dependent on identified need
	Every 2/3 months
	As opportunities arise throughout the year
	Every 2 years
Other preparation	Signposting to other relevant training provided by PCC, HSC, community and voluntary providers
	Clients supported for role on one-to-one basis by professional involved
	Person-centred care workshops
	Regular update meetings with co-ordinator

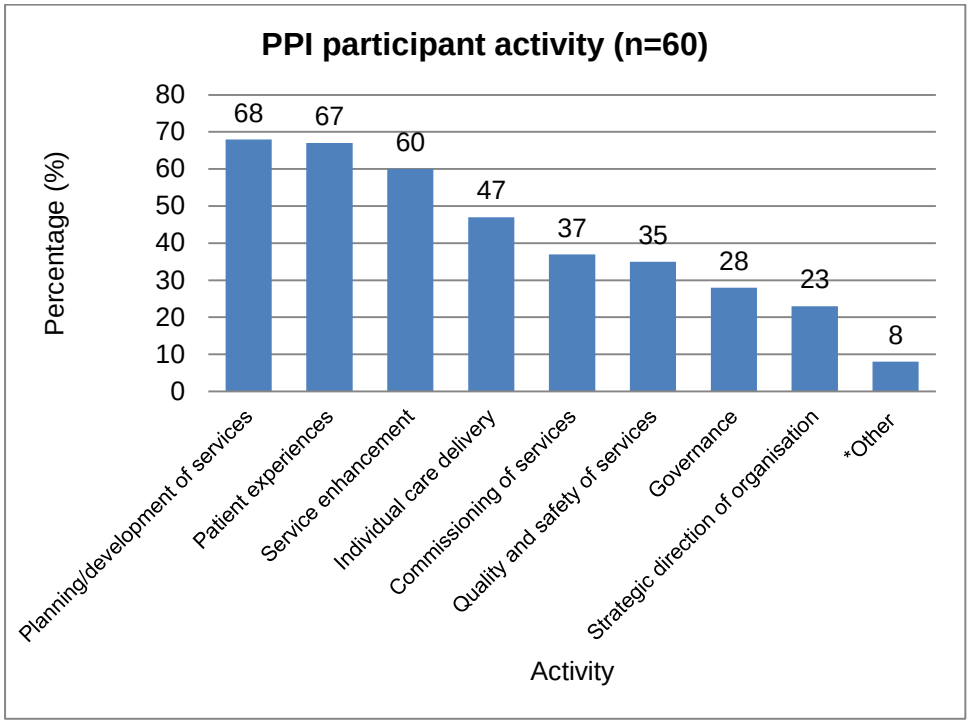
Footnote: PCC – Patient and Client Council; HSC – Health and Social Care

Types of PPI activities undertaken in organisation

The most commonly reported level of engagement is 'consultation', defined as asking views and using these views to inform decision-making. Just over half of respondents (51%) reported service users are actively involved in service planning/delivery and almost two-thirds (64%) reported that in their organisation there is active ongoing partnership with service users. Shared decision-making between service providers and service users was noted by 51% of respondents. A small number of respondents noted that PPI participants are members of funding panels and research steering groups and provide training for researchers on PPI in research. It is of concern that 18% of respondents reported that engagement with PPI participants is a one-way flow of information from service provider to service user with no mechanism for feedback.

PPI participants are involved in a range of health and social care activities ranging from individual care delivery to the strategic direction of the organisation with the most frequently cited activities being planning/development of services (68%), closely followed by patient experiences (67%) (Figure 7).

Figure 7 PPI participant activity

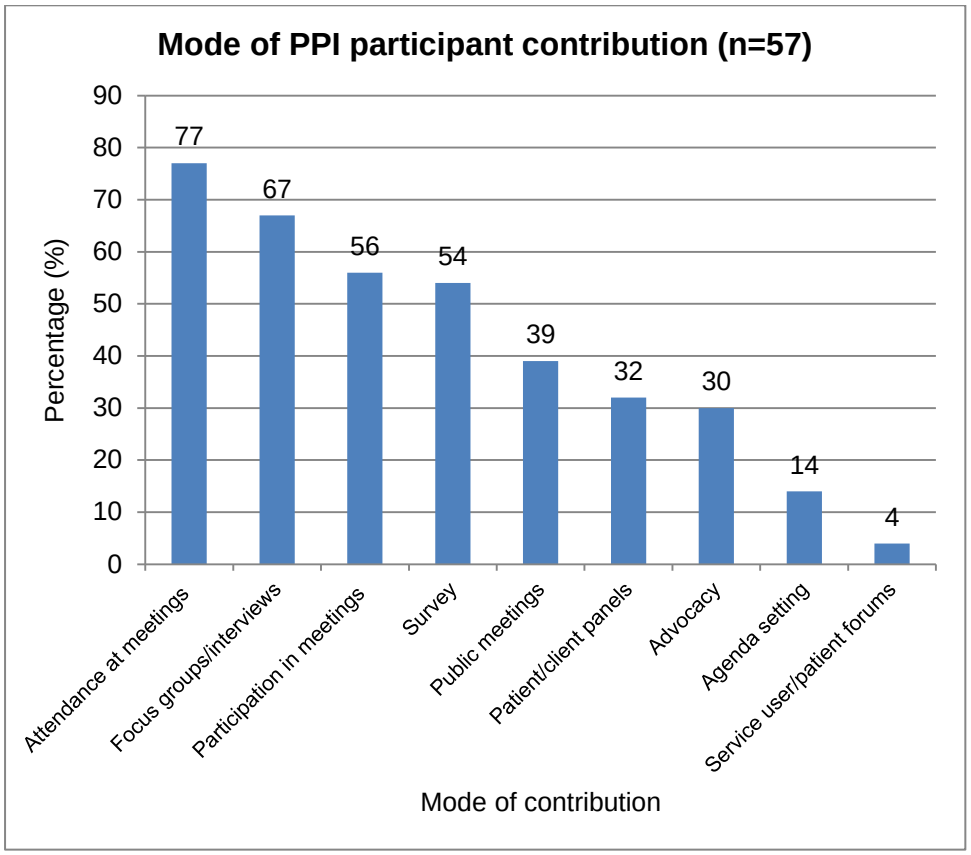


* prevention; research funding decisions; specific projects

The proportion of PPI participants involved at different stages of activity is similar for initial consultation (38%), planning (40%), delivery (37%) and evaluation (38%). Fifty-seven per cent of respondents stated that PPI participants are involved at all stages of activity.

PPI participants contribute through a variety of modes with a considerably higher proportion contributing through attendance at meetings (77%) compared to agenda setting (14%). Thirty per cent of respondents stated that PPI participants are advocates (Figure 8).

Figure 8 Mode of PPI participant contribution



Meeting types range from PPI forum planning committees to individual person-centred planning meetings (Table 11). From the information provided it was not always possible to gauge the level of responsibility PPI participants have in meetings but it is very positive that Chair and Vice-Chair were noted (Table 12). The role of participants varies from passive roles to very active roles. The frequency of meetings is dependent on need with a range from weekly to six monthly.

Table 11 Meetings: Type and participation/role (n=44)

Type of meeting	Participation/role
Public	Depends on willingness/capacity of service users and carers to take responsibility
Trust PPI forum planning committees	Chair (10-20 members)
Steering group	Membership Secretary
Working group	Vice-Chair
Patient group	Trustee
Advisory board for programme	Member
Individual person-centred planning	
Funding panels	
Research advisory groups	
Training for researchers	
Partnership	
E-groups/forums	

Potential facilitators and barriers for PPI

Respondents were asked to indicate which of a number of factors they had experienced as potential facilitators and/or barriers in implementing PPI. It should be noted that the number of responses was considerably lower for this question. The most frequently cited facilitator is the values of the organisation (74%). The most commonly cited barriers are related to lack of resources i.e. staff time (97%), funding (92%), staffing levels (82%) and staff knowledge (70%). A period of organisational change is also a common barrier (74%). Staff skills and training and the attitudes of professionals were the factors cited most frequently as both a facilitator and a barrier (Table 12).

Table 12 Facilitators and barriers to implementing PPI (n=36)

Factor	Facilitator (%)	Barrier (%)	No. of responses
Staffing levels	18	82	38
Staff knowledge	30	70	40
Staff skills	57	43	35
Staff training	47	53	36
Funding	8	92	37
Administrative support	18	82	33
Attitudes of professionals	43	57	35
Values of organisation	74	26	34
Managing patient and public expectations	47	53	32
Power relationships between professionals and service users	45	55	29
Lack of staff time	3	97	39
Period of organisational change	26	74	27
Continuity of PPI participants	44	56	32
Health literacy level of PPI participants	40	60	25

Further information elicited on those barriers which could not be overcome revealed that for those factors relating to staff the main reasons are staff are already extremely busy/overloaded with work and do not have the time or support to participate in PPI activities or to attend training to increase their knowledge of PPI. Furthermore, it was noted that involving service users requires additional time which is a challenge when working to ambitious timeframes.

Respondents identified lack of funding as having an effect on both PPI participants, as there are no mechanisms to reimburse participants, and staff as no additional funding is available to assist with the statutory requirement to implement PPI. Lack of administrative support increases the burden on professionals as they have to arrange meetings, venues and activities themselves.

Some viewed managing the expectations of patients and the public as not always being feasible as practice should be based on evidence and not 'on the back of local issues' and strategies take time to develop.

Monitoring and reporting of PPI activities

The majority of respondents stated there are reporting arrangements in place for PPI activity. Sixty-two per cent said reporting is to the Senior Management Team, 44% said to the organisation's Board with a further 44% stating through the Annual Report. Other methods of reporting include via departments/directorates, accountability reports to DOH and verification visits by PHA.

Fifty-four per cent of respondents stated their organisation has targets for PPI activities with 37% being unsure if any targets are set. Almost half of respondents (46%) said their organisation has monitoring systems in place for PPI; 24% reported having a central manual or electronic database and 22% reported using multiple records across the organisation. Over half of the respondents (51%) were not sure if monitoring systems are in operation. Other methods of monitoring PPI activity are the Annual Corporate Plan and directorate level PPI Action plan.

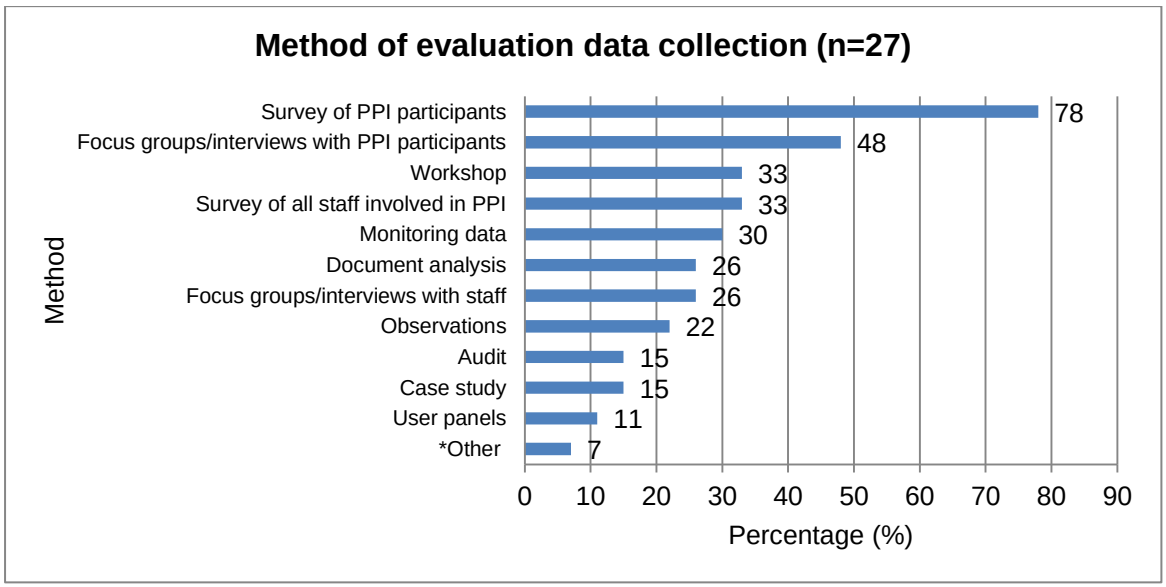
PPI participants are largely informed of the outcomes from their participation in the planning/delivery of services through meetings (45%) and written materials (34%). Other mediums include social media, posters, websites and email.

Evaluation of PPI activities

Only 17% of respondents (n=7) said their organisation always evaluates PPI activity with a further 41% (n=22) stating evaluation is undertaken sometimes. Thirty-seven per cent of participants were unsure if evaluation is undertaken and 6% (n=3) of respondents said PPI activities are not evaluated.

It should be noted that the following questions were completed by 26-30 respondents. Typically, evaluation is conducted in-house (71%) with 23% of respondents reporting external evaluation as being typical. Twenty-nine per cent of respondents were unsure how evaluation is undertaken. PPI participants (70%) and staff/managers (67% and 50% respectively) were the main groups involved in the evaluation of PPI activities. Involvement of researchers and data analysts was also noted by a small number of respondents. Methods for collecting evaluation data are wide and varied with the most common being surveys of PPI participants, 78% (Figure 9).

Figure 9 Method of evaluation data collection

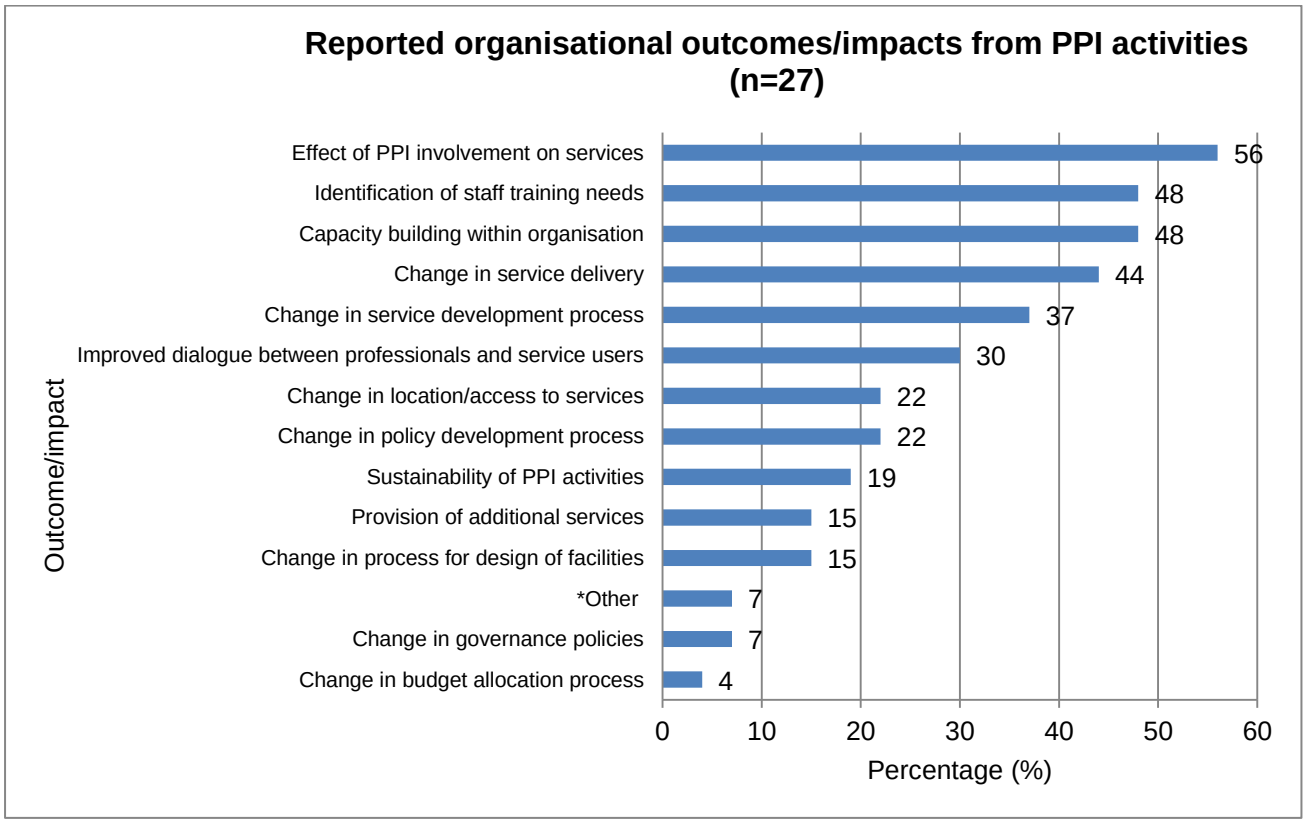


*personal contact; meetings

Typically, the main aspects of PPI included in evaluations are: activities PPI participants are involved in (77%); support for PPI participants (62%); implementation of PPI (54%); management support for PPI (46%) and recruitment of PPI participants (46%).

A wide range of organisational outcomes and impacts from PPI activities are included in evaluations with the most commonly cited being the effect of PPI involvement on services (56%) and the least common being a change in the budget allocation process (4%) (Figure 10).

Figure 10 Reported organisational outcomes and impacts from PPI activities

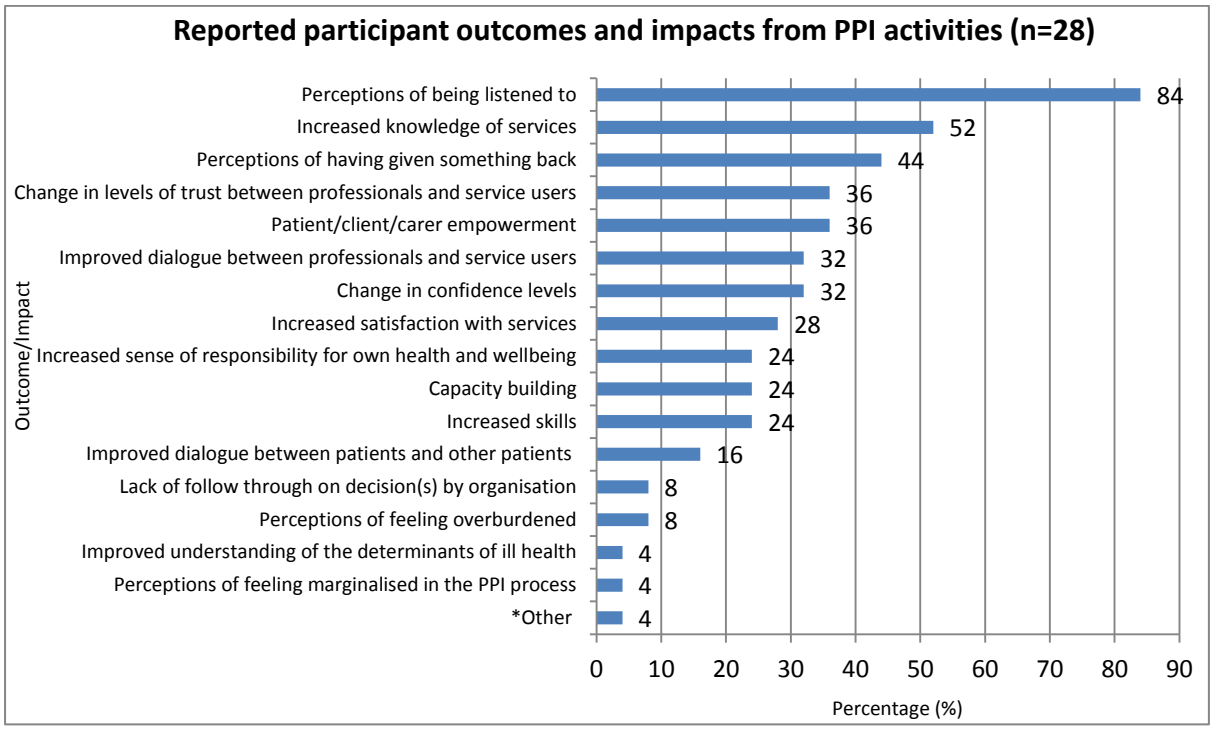


*what changed for the Trust; lessons learnt

The most commonly reported participant outcomes/impacts are perceptions of being listened to (84%) followed by increased knowledge of services (52%). Only a small

proportion of respondents reported that 'lack of follow through on decisions by organisation' is measured with PPI participants, 8% (Figure 11).

Figure 11 Reported participant outcomes and impacts from PPI activities



*Other - community involvement; service and care

Thirty-nine per cent of respondents noted an evaluation report is produced with 29% stating no report is produced. The cited perceived reasons for not producing an evaluation report are lack of staff time (52%), lack of staffing resources (45%) and lack of funding (34%). Just over one-third (31%) of respondents noted evaluation is not included at the planning stage of the PPI activity.

Evaluation reports are disseminated via a range of methods with the most frequent being email (64%), staff meetings (36%) and PPI workshops. Reports are also disseminated to the Senior Management Team (45%), the organisation's Board (27%) and via posters (18%) and staff newsletters (9%). It was reported by 36% of respondents that the findings of the evaluation are used to inform future practice and processes in PPI, maintain and improve services, shape approaches to planning and

improve training for PPI. One respondent noted learning from evaluations is shared with other teams.

The remaining questions were open-ended allowing participants to enter their own comments. The majority of those who responded to this question reported positive differences in the organisation due to PPI activities with the most frequently cited differences being related to service development and delivery (Table 13).

Table 13 Differences in organisation attributed to PPI activity (n=32)

Difference	No. of responses
Services tailored to need	9
Service users empowered to take more responsibility	2
Trust and good relationships built	4
Fewer complaints	1
Improved decision making	1
Improved outcomes for service users	1
Improved service delivery	10
Improved staff morale	1
Resources maximised through engagement	2
Reduced health inequalities	1
Improved patient experience	1
Improved planning of services	2
Research funding decisions	1
Greater commitment from senior management	1
Service users can influence planning for own agenda	1
Raises unrealistic expectations for service users	1
Not aware of any changes	3

Lessons learnt from partaking in PPI activities covered the total process from planning to include PPI activity to evaluation and reporting on outcomes (Table 14)

Table 14 Lessons learnt from PPI activities (n=28)

Lesson	No. of responses
Communication is key	3
Feedback needs to be timely	1
Planning necessary	2
Value of listening	6
Time intensive	4
Support, training and guidance required for staff	6
Consistency in personnel is important	1
Can influence decisions for funding	1
Should be integral part of role	3
Evaluation of PPI activities important	3
Organisation does not value PPI	3

Benefits for both service users and staff groups were perceived from undertaking PPI activities (Table 15). A number of limitations to PPI activity were also noted, mainly related to lack of human and financial resources to support service users and staff (Table 15). Suggested methods for overcoming the noted limitations were dedicated funding and staff, monitoring and evaluation of activities and recruitment of service users through the organisation's website.

Table 15 Perceived benefits and limitations of PPI (n=26)

Benefit/limitation	No. of responses
Benefits	
Service improvement	3
Increased capacity for service users	1
Efficient use of resources	2
Improved service user outcomes	4
Team building	1
Greater transparency in practice	1
Meaningful research funded	1
Limitations	
No dedicated PPI staff resources	3
No funding for staff support and training	2
Difficulties recruiting/retaining service users	3
No funding for PPI participants	2
Time intensive	2
Participants come with hidden agenda	1
Can create unrealistic expectations for service users	2
No noticeable change to practice	1
Non-clinical managers of PPI impose changes	1
Small pool of service users on a number of forums	1
Not embedded in culture of organisation	1
Outcomes difficult to capture	1

Generic comments on examples of good practice were that PPI is most effective when the activity can continue without staff support; service user participation in conferences; PPI on research funding panels and strategic committees and the support from the PPI team in the Trust. Examples of specific projects are provided in Table 16. All projects were noted once with the exception of the ImROC programme which was noted by four respondents.

Table 16 Examples of good practice in PPI (n=30)

Renal Support Group
Carers at the Heart of our Organisation
Consumer Panel for Cancer Clinical Trials
Use of Art
PPI Service User and Carer Panel
Trust Carers Reference Group
Trust Traveller Action Group
Race Equality Forum
Mental Health User and Carer Service Improvement Group
Maternity Services Liaison Committee
Cancer Service User and Carer Group
'Involving You' section of Trust website
Trust Facebook and Twitter
Palliative Care Experience Group
Implementation of ImROC* in mental health
Internal working group, chaired by Director plus annual recognition event for carers/users
Development of commissioning guide to PPI
Neurological Conditions Awareness Programme - e-learning and DVD
Hand Hygiene in Schools – DVD, posters, song
Patient Safety
LGB & T – e-learning for working with community
Street Pastors - volunteers serve tea and coffee to patients in A & E Friday and Saturday nights
Panel of PPI representatives to support divisional activities
Paediatric Cardiology Service Review

* The Implementing Recovery through Organisational Change (ImROC) programme aims to change how the NHS and its partners operate so that they can focus more on helping those people with mental health problems with their recovery. In mental health, 'recovery' means the process through which people find ways to live meaningful lives, with or without the on-going symptoms of their condition.

The final question invited respondents to provide any additional comments they may have on PPI. Comments not already covered in Tables 4-7 were: more regional work required; evidence required that PPI improves services for public; improved systems for monitoring and report development and include PPI in business plans and personal development plans.

Conclusions

The majority of respondents (90%) worked in the statutory sector with the remaining working in both the voluntary and community sectors (4%), the community sector (3%) or in a charity or charitable organisations (1%).

Knowledge on the structure of PPI within organisations appears to be patchy with one-quarter to half of respondents being unsure who in the organisation has a role or responsibility for PPI activities. Similarly, knowledge of PPI training is relatively low. These findings, together with the finding that 27% of respondents do not know who is responsible for the recruitment of PPI participants, suggest that either PPI for at least

one-quarter of respondents is at an individual care level or they do not partake of PPI activities.

It is concerning that three in ten respondents stated their organisation provides no preparation/training for PPI participants. This, together with lack of funding to reimburse PPI participants, may contribute to the problems of recruiting and retaining participants.

The awareness of monitoring systems for PPI activities is low and of those who stated their organisation has systems in place approximately one-fifth said these are multiple records across the organisation. The reporting arrangements to senior management could be viewed as an organisational commitment to PPI activities.

The aspirations for outcomes from PPI activities are high and are largely related to outcomes for service users. Good practice is evidenced through the input of PPI participants in organisational processes and procedures, notably, the planning, delivery and commissioning of services, governance and strategic direction of the organisation and also through the methods of contribution. Furthermore, many examples of good practice for specific projects were provided.

The barriers/limitations which were consistently reported are lack of funding, lack of training and lack of support mainly for staff but also for PPI participants. It is, however, good to note that progress is being made in the area of training. While the importance of evaluating the outcomes resulting from PPI activity was recognised, it is apparent there is room for improvement in this area.

In summary, respondents were positive about the practice and outcomes of PPI activities but consistently referred to being overburdened with work which, together with a lack of dedicated support and funding for PPI, limits their ability to fully embrace PPI activities at all levels.

Focus Group Findings

To ensure anonymity and confidentiality, the ten focus groups [8] are presented using the labels **A – E** in two pairings per Trust corresponding to either Service User [9] or Staff (Table 17). In this way, the particular identity of the Trust in question will not be revealed. The focus group findings have been analysed by examining the Themes which have arisen from closely reading and examining the transcription recordings. Each research team member therefore undertook a thematic analysis of the particular focus group they undertook. These Themes were firstly presented in table format with key supporting quotes identified and were then further presented in a summary narrative where the particular Themes were then expanded upon. Each focus group analysis concludes with Recommendations **(this is available to access as a separate Appendix Report)**. To add further rigor to our findings, the focus groups were also independently thematically analysed by a member of the research team not directly involved in data collection. The Report's final Recommendations can therefore be traced directly back to these individual focus groups, the on-line survey findings and the findings from the literature review.

Table 17 Profile of focus group respondents

Trust	Service Users	No. Males	No. Females	Staff	No. males	No. Females
A	16	5	11	6	2	4
B	6	3	3	6	1	5
C	21	11	10	6	1	5
D	7	1	6	10	0	10
E	3	0	3	8	1	7
TOTALS	53	20	33	36	5	31

Total number of Focus Group Respondents was eighty nine **(n=89)**

[8] The Northern Ireland Ambulance Service (NIAS) was not included in the focus groups. We did however include the NIAS in both the peer review of the current practice piece on PPI and also in the invitation to provide any examples of good/best practice in PPI.

[9] In the interests of brevity, the term Service User is used here in reference to service user, patient and carer. We recognise and understand that these are contested terms in the literature and therefore stress that this single use is for brevity purposes only.

Staff Focus Group Themes

The following is a summary of the key themes emerging from the staff focus groups. The six questions asked in the focus groups generated a range of key points and ideas, these are described as follows with supporting and representative quotes. The information below has been developed by examining and reading across the five transcripts from the staff focus groups in response to the questions we posed. The points made are therefore the themes which most commonly occurred across all of these staff focus groups.

Q1. What are your thoughts on PPI currently in Northern Ireland?

The under resourced nature of PPI was an issue that was identified in the focus groups in response to this particular question. The fact that quality PPI of itself required time and attention to practicalities was a point repeatedly made. The following quotes highlight this point further and typify the views expressed:

"Well in terms of Northern Ireland the first thing that springs to mind immediately is the fact that there are basically no resources attached to it, that we are expected to deliver PPI without any added resources….If you want to do a good piece of work around PPI, it is resource intensive. I don't care what anybody says and we recognise that because it is our daily bread and butter." (Trust A respondent)

"I do think a majority of staff do know they should be doing it. It's just… we'll put that off to the next one because I haven't time… I'll do that the next time, and time is a big factor" (Trust C respondent)

The view was also expressed across the focus groups that there was variation between and within Trusts in regard to PPI which needed to be addressed in regard to both consistency and standardisation. The following comment supports this last point:

"Within the Trust, PPI is high on my agenda and has been from the beginning of our project. But my knowledge would be limited, now, on PPI over Northern Ireland and what is happening out there. (Trust C respondent)

"It is better resourced in other areas…..majority of examples... in case studies were all from the XXXXX Trust." (Trust D respondents)

The need for improved awareness of staff in relation to the PPI aspects of their everyday work was also expressed. The point being made here was that staff do not always recognise that they are doing PPI in their everyday work. The following quotes help illustrate this point:

"A lot of our staff didn't know what PPI is. They didn't realise that they are doing it every day." (Trust D respondent)

"I would say that we all actually, without even realising it, do much more PPI than we think." (Trust B respondent)

The need for training on PPI for staff both during professional qualifications and in the workplace was also a point frequently highlighted as the following quotes endorse:

"The training really is essential, particularly for any staff, and that you can see, as you said, your simple interactions with every patient that you would do on a day to day basis, you can turn that round and make that your PPI, which every nurse can do. So I have found, having had some training myself, that that would be invaluable to actually have training for the staff. That will make a very good difference" (Trust E respondent).

"Well certainly in my experience it is certainly filtering through with the nursing and social work students. You can see that they know. They are coming out now and they are very aware of what PPI is. A few years back they wouldn't have had a clue of what you were talking about." (Trust A respondent).

The need to fully integrate PPI was also a view commonly expressed so as this would become part of the everyday pattern of working:

"I think part of the problem is that people will see things as a project. It shouldn't be. (Trust A respondent).
"You know, patient and public involvement should be bread and butter for everybody..." (Trust E respondent).

The importance of PPI being endorsed and supported by senior managers in an organisation was also a theme emerging across the focus groups and seen as crucial to the integration point just mentioned. The following are a sample of quotes on this point:

"The commitment to PPI from up above, just isn't there. And that's I think a big issue and that is I think one of the reasons why PPI hasn't been blossoming as much as it could have been." (Trust A respondent)

"I think it should be at least assistant director if not directors who sit at the meeting, if PPI is really important" (Trust E respondent)

The need to raise awareness of PPI with the public and other professionals was also consistently expressed. The point being expressed here relates to the unfamiliarity with PPI as a concept. The following are sample quotes on this point:

"And there is something about even the awareness raising of PPI at that level for everybody coming into the organisation. It is just trying to get it right so that everybody that works in the organisation, irrespective of what their role is, at least will have an understanding, albeit a basic understanding of what PPI is." (Trust E respondent).

"I don't think we have actually advertised it enough. We keep it very much within our own Trust and people using our services, but as a general public drive, there never has been….I know the standards have been launched, but that was very much kind of just with the people that know what PPI is. Where the general public just wouldn't have a clue about PPI, I think" (Trust C respondent).

The need to consider the language used particularly related to confusion between PPI and other terms in common usage such as community development and patient experience – was highlighted consistently in these staff focus groups as apparent in the following quotes:

"There is definitely confusion between patient experience and involvement and engagement. You know people say very clearly in training, it is not patient experience. This is taking it further. This is about involving people and engaging with people. So people find it difficult to get their heads round it." (Trust A respondent).

"it is a kind of misnomer term that people don't really get and it alienates people…….Why have an acronym at all? Why not call it involving people or something?" (Trust B respondent).

Q2. Can you please provide some examples of the types of PPI activities you are or have been involved in?

Responses to this question generated a mix of very interesting and innovative ways in which PPI is being undertaken across the Trusts we surveyed. The following are therefore some examples across the five Trusts of the types of activities that were shared. These should also be viewed alongside the additional best practice examples which are referred to in the **PPI Best Practice** section of this report.

Wellness Recovery Action Plans (WRAPs)

"We have got a lot of people coming and feedback is pretty good, it is quite positive, saying you know, I am learning how to not be so reliant on staff, on you as a social worker, to guide me. And I am learning to take responsibility for my own plans and what I want to do and you give me more ideas as to where… what I could achieve and what is out there for me." (Trust A respondent).

'Ten Thousand Voices'

"I was involved in the Ten Thousand Voices and giving out the questionnaires and sitting down with people and explaining it" (Trust B respondent).

Promoting Inclusion

"We would try and do focus groups each week and that. Just to try to improve the service. And then we also would try to have maybe separate focus groups with people who their first language isn't English, and that requires a wee bit more organisation, I suppose, but it is just to try to include their feedback as well, just to make improvements and that" (Trust C respondent).

Innovation in service design

"Service users have developed an information leaflet and a map that is more service user friendly as opposed to the standard one that was set up by the professionals. So they have been able to say this is what we would like because this is what we feel is important on the first letter, first appointment. So they have developed this and they have also taken pictures, developed their own little map and taken photos of the service itself and attached that to bring that into our service" (Trust D respondent).

Employment of service user consultant

"We have appointed a [paid] consultant by experience within mental health … and it is a person who has lived the experience of being mentally ill. That person attends all of our management meetings and has developed focus groups … where they are hoping to establish a really good connection with service users and keep them informed about plans within mental health … take ideas back from service users back to our management team to help inform them as to what people actually want and value in terms of their care. The other development really is that she is now going to meet with our director on a monthly basis and he has made a commitment to ensure that she is stitched into any management plans or pieces of work that are being developed. She has his ear every month" (Trust E respondent).

As is apparent from these examples, PPI is being approached innovatively across the Trusts in Northern Ireland, leading the research team to conclude that the picture is positive in regard to how PPI is being approached. In addition, there were many other examples provided such as: Questionnaires for evaluation, patient telephone help line, co-produced information resources such as leaflets, posters, DVD, a range of panels across cancer, older people, disability, children's services, experience

based design, Safety Quality Experience, planning of services - recovery college, new builds, service developments, family support hubs and mental health hubs, Trust inter and intra net, 'It's Okay to Ask' campaign, etc.

Q3. How are participants recruited to become involved in PPI activities in your organisation?

The following are a range of reported ways in which people are recruited to being involved in PPI activities: Posters, leaflets, word of mouth, phone, social media, advertising, direct invitations, link people and social media. Further detail in regard to these examples of approaches to recruitment are provided in the following quoted examples:

Directly asking people

"It is easy for me to ask people, so I can go in when the patients come in to me and sit down with them and ask if they are happy to be involved with improving the service. And I usually ask them how they found their experience of being… how they have come into our service and the treatment they have had. And then I would say well look, we are doing work, would you like to be involved? And some people say yes and some people say no." (Trust B respondent).

Telephone

"…randomly every month the team leader phones up mothers from health visitors' caseloads and you get a wealth of experience from that one to one contact, particularly around how can you improve the service…" (Trust D respondent).

Technology

"… We do have on our Trust intranet site, we talk about service users, but on the website, so the organisation's website, very clearly we are asking people, do you want to become involved? …." (Trust E respondent)

Challenges in recruitment

Issues around representativeness, accessing individuals, trying to involve people who are hard to reach/resistant, need for sensitive timing and avoiding over

involvement of the same individuals are themes also coming through in the staff focus group discussions as challenges in the context of recruiting participants to PPI. The following are illustrative quotes underscoring these points:

"I have struggled around particularly family and childcare because of the whole child protection thing. You know, because you are starting off in the wrong place to talk to parents about their experience, so I have struggled with that. I know other Trusts have struggled with it as well, because it is a difficult one." (Trust A respondent).

"And also people freeing up their time, and if they have carer commitments and other aspects, or they are working, it is a challenge. All I am saying is, sometimes it is challenging and you seem to exhaust the same people all of the time" (Trust E respondent).

Q4. What do you think makes for effective PPI in your organisation?

Having access to administrative and practical support were considered essential for effective PPI as the following two contrasting quotes highlight:

"I think we are very fortunate in the Trust with our PPI in that it is always very easily accessible and the support is always there, and I think that makes it very easy for health professionals to embed PPI in their daily work" (Trust C respondent).

"And there's no dedicated resource, like I don't have an admin staff or someone to help resource it…because if you don't have admin staff to help you with this who is going to do it" (Trust E respondent).

The skills and approach of the staff member involved in the facilitation and organisation of PPI were also emphasised as being core ingredients to effective PPI:

"We keep saying this, it is a bit like community engagement and all of that; it is very much down to the individual you know, and personalities, and I mean that's what we found. We find some staff are really brilliant at this." (Trust A respondent).

The pressures confronting staff, however, in a climate of restricted resources were also seen as a challenge to staff on the frontline:

"It is about focusing on the positive and maybe as an organisation in general, I think probably the whole Trust staff morale has taken a bit of a whacking in the last couple of years but people are still coming in to work to do the best they can and that needs to be emphasised. But also then selling how we can do things differently. So maybe it is doing everything slightly softer as well because you find a lot of people are looking at waiting lists and waiting times and forgetting that there is a person at this end working and a person at the other end as well. And it is not a million years away from all of us being that person at the other end as well too. That should be how you would like to be treated or your relative would like to be treated in a similar situation." (Trust D respondent).

Having a commitment to PPI at an organisational level was also found to positively relate to PPI being effective. Again, reference to the *personal* in such a commitment was felt to be a necessary part of this culture:

"If you get that one person on each team who is the innovator and who can drive it, then the staff will probably pick it up quicker from them because it is more meaningful for them'. (Trust B respondent).

This type of leadership was also felt to be an important managerial skill and attribute:

"You would get a variation depending on who the leader of that team is and how important they see that…..the commitment to PPI from up above, just isn't there. And that's I think a big issue and that is I think one of the reasons why PPI hasn't been blossoming as much as it could have been….there is variation depending on the team leaders and the ethos of the team or the ward, in how important they see that. So if you have got a really good leader who sees this as an important part, it is integrated into the day and daily work that they do." (Trust A respondent).

Q5. Can you think of ways in which PPI could be improved at an organisational level in regard to your particular work setting?

The issue of Resources again was very much to the fore in responses to this question with particular reference to the fact that PPI was still under-resourced as a key activity. The issue also arose about needing to properly recognise and remunerate service user time as a resource in supporting PPI activity. The following are a sample of quotes from the focus groups on this particular theme:

"We should be paying our service users for their time when they are coming along to things, because you would expect staff to get paid for whenever they come to different things, and yet the service users and carers don't get paid. So there needs to be something that is valuing the time and experience that people are giving us themselves when they come to things that are going to help us develop our services….. But there's some things that people will volunteer for once, but if you want somebody in a consistent way, you need to think about paying them." (Trust A respondent).

The challenges around needing sufficient time for effective PPI was also noted in regard to this wider Resource theme:

"Resources are being squeezed, so projects out there sometimes focus… on getting the thing done and maybe not engaging with the public, because they don't have the time to do it as well…I do think a majority of staff do know they should be doing it. It's just… we'll put that off to the next one because I haven't time… I'll do that the next time. And time is a big factor" (Trust C respondent).

The importance of PPI having clear leadership from the top was also a recurrent theme in the focus groups. One of the ways in which this could be addressed was the suggestion about having PPI Champions with a clearly designated role for the strategic implementation of PPI. The following quotes echo these points with more detail:

"I suppose it is the personality of the leaders. It goes back to leadership. If you've got good, strong leadership who have a really good mind-set that this is an important thing to do and it is an upright service to run, then the ethos, the culture of the team follows through. Whereas you don't get it if the leadership isn't there." (Trust A respondent).

To facilitate embedding PPI in the organisation, it was accepted that a culture change was required where, although there would be 'champions' for PPI, the responsibility for PPI rested with all staff. It was also suggested that senior managers should spearhead PPI within the organisation…Champions is a nice word too. PPI champions" (Trust E respondent).

Q6. How is the impact of PPI activity currently monitored and evaluated in your organisation?

It was recognised that progress in the right direction was starting in regard to monitoring and evaluating PPI with the initiatives led on by the Public Health Agency. There were also examples of how methods such as *Survey Monkey* were being used to evaluate particular projects. What was absent however was a sense of consistency and coherency in regard to how monitoring and evaluating were being approached which was at odds with the general staff view about 'doing PPI well'.

What follows are several illustrative quotes across the five focus groups to amplify these points further:

"The government putting it as a statutory obligation on its own is not enough. It needs to then have a monitoring mechanism. It needs to come up in reports to Donaldson. It needs to be a priority prevention target. Those are the things that drive the monitoring and reporting mechanisms of the organisation. And it does begin to infiltrate the culture, but I think there has to be something as well about influencing the culture as well from pre-registration, so that you mentioned about nurses and social workers; I think it needs to be embedded into people as they are doing their training. If you are going to become a health and social care professional, this is the way you think."

The point was also made in this focus group that senior managers need to accept and own responsibility for PPI, including accountability for monitoring its effectiveness and overall implementation.

"Somehow senior managers, directors level or chief executive level, when they do strategic documents for the Trust itself, completely for the Trust, they kind of think they are above PPI. Although they think all their staff have responsibility for it, they are not really liable for it." (Trust A respondent).

The need for service users to be made aware of the outcomes and impact of their involvement activities was also recognised as being central to monitoring and evaluation:

"And I think for PPI to be meaningful, especially for me, would be seeing the results of what patients say and then from that; right, OK well they have said this, let's work on this. And then reviewing it again to see what was effective and then for me the penny will drop. That worked really well, so if we did it with this part of the service, what else can we do?" (Trust B respondent).

Participants appreciated the value of monitoring and evaluating in terms of learning to improve practice and to demonstrate the effectiveness of PPI in service improvement and the need to include PPI from the start. The need for better coordination and linkages across with one overall action plan was also recognised as being helpful:

"…we are all tapping in, but nobody is really tapping each other…. I am just thinking for staff, that it is so well embedded in what they are doing, it is done on a daily basis, done on a weekly basis, that they are tweaking and changing things through feedback, which is user involvement, but should it have an action?"

It was also recognised that there was a great deal of PPI work being carried out that was not being captured:

"there are loads of other projects out there that we know nothing about, and it's how they know to link in and get that learning and feedback spread" (Trust C respondent).

"The best feedback that people can get in terms of PPI is that action is taken as a result of what they are saying….If you are just doing PPI for the sake of PPI, you may as well forget about it. So there has to be some sort of outcome." (Trust D respondent).

Another participant in this focus group emphasised collaboration or togetherness as a way of gauging the effectiveness of involvement:

"For our service what makes it more effective is that it is the service users and staff coming together." (Trust D respondent).

It was documented that a considerable amount of monitoring and evaluating of PPI takes place but currently it is mainly corporate projects which are consistently monitored and evaluated using a standardised process:

"So there's quite a lot happening but it may not be captured under PPI monitoring…Corporately it is probably the bigger things that are being monitored and evaluated and consulted upon and then there would be feedback around that. The Head of Equality sits on all of those consultation schemes and I know, because we had a verification visit recently from PHA around PPI monitoring, and obviously I sat on that meeting and very clearly, there is a clear mechanism where we monitor the bigger things"

The need for improved monitoring and evaluation processes to be systematically captured was therefore willingly acknowledged:

"If I talk about monitoring and evaluation of smaller projects, I am not sure that we do that well… because the regional five standards on PPI were issued in March of this year. … and the other one was around monitoring and evaluating the impact of PPI. We have tried to do it within the organisation but there is no standardised approach apart from what is managed by the Head of Equality, because obviously it would be

a proforma process, a database, feedback. But I think what we need to do across the organisation is standardise the approach. … And I think in line with the new standards, that's why it is timely that we review our strategy because out of that you put together an action plan that feeds into the directorates and then we have to come up with some of those actions around developing a mechanism, so that we have a standard to evaluate all PPI" (Trust E respondent).

Service User Focus Group Themes

Adopting a consistent approach to the analysis of the focus group findings, this section of the report addresses the findings emerging from the five service user focus groups. Themes will be presented as they emerged in response to the seven questions posed in these focus groups. Supporting quotes from the focus groups will be used to support and further illustrate the particular theme being discussed. These quotes are representative of the particular theme under discussion.

Q1. What is your understanding of the term Personal and Public Involvement, or PPI as it is known in short?

There was a consistency across all of the service user focus groups that the language of PPI and the term, of itself, presented real problems with service users not actually knowing and understanding what this meant. Lack of familiarity with the language was therefore felt to be something that could be detrimental to the effectiveness of PPI from a service user perspective. The following quotes illuminate these difficulties and challenges further:

"Well I have to admit I had never heard of PPI until I got the invite to come here…..It is very unfortunate, you get all these irritating text messages from people who want to sell you PPI. It is insurance of some sort?" (Trust A respondent).

In this focus group, there was equally a call for more accessible and detailed information as to what PPI means and also a call for more emphasis on the public aspect of PPI:

"I think people need to know what PPI stands for and what it means and what it is about." (Trust A respondent).

"At the moment PPI seems to be top secret. There are only a few knows where it is and understand it. It needs to be rolled out in a way that everybody knows it is there and understands it" (Trust C respondent).

and encouraged to be involved and made comfortable to be involved" (Trust D respondent).

"… there is no PR on TV about being on PPI. You never see it advertised in that way, whether it is social media or TV or whatever……Get out to the public, don't wait for the public to come to you. Get out there, tell them, be seen, and maybe that's a way of getting more" (Trust E respondent).

There was therefore a consistent sense that more could be done in regard to more effectively marketing and explaining to the general public about the concept of PPI and what this was aimed at achieving. More fundamentally, however, as also noted in the staff focus groups, at a conceptual level there are real problems for members of the public actually knowing what PPI is.

Q2. Please tell us why you got involved in PPI

People expressed a range of reasons for getting involved in PPI work. For some, this was rooted in a negative experience that they wanted to prevent ever happening to others in the future, it was also related to giving a voice for their loved ones, for some it was related to creating fundamental change in the system and for others PPI was part of staying in recovery, so it therefore had therapeutic value. The quotes that follow illuminate these points and others in further detail:

"It was personal to me, it was my daughter, and I have talked to other people who have been in a similar situation, which makes it something that needs to be brought to the fore, really….. just normal human communication. It is not sort of rocket science, you know?" (Trust A respondent).

"You want to make a difference."

"So it is not that things are bad, it is that they could be improved. And that's why I am involved, and that's why I think it is important that people say, and they are listened to. And it does happen." (Trust B respondents).

The following two quotes relate to a need to get to know how the 'system' worked and also the need to cut through the perception of a system that was overly bureaucratic:

"I got involved for one simple reason, I wanted to know how the system worked and the services we could get to help our son. That is quite personal and selfish if you want to put it that way but that was the reason, not through any sense of altruism or desire to help others or anything but that is the short answer as far as I am concerned."

"My introduction was probably the same thing because I had a dreadful experience. It wasn't that I wanted to get to know the system, I had a fair idea what the system was like, I wanted to get in and change it, make it more efficient and more practical. More meeting the needs of the people, the service users and the carers, meeting their needs and just getting rid of all this top level stuff like these policies and these strategies and they are coming at everyone with documents, there is paper flying all over the place, to try and get a basic service in the middle of all this paper, is something else." (Trust D respondents).

A variety of methods of entry into PPI also emerged in this final focus group:

"I got involved with xxx to start with and did quite a lot of work with them, helping to set up a network in my area … to get information out. … "

This initial venture into PPI appeared to snowball with invitations to join other forums from projects to committees with one participant mentioning six different forums she participated in. The belief was that this may be because of a lack of people to ask to be involved in PPI, resulting in a small number of people becoming overly involved in a large number of forums.

" ... And then from that I was invited to attend other meetings….but from that there I was then asked to join on to the xxx advisory group for the xxx Trust which again oversees the food and stuff in hospitals and things." (Trust E respondents).

Q3. When you think about your experiences of involvement in an aspect of health or social care, was there anything that made this a positive experience?

The range of answers we received across the focus groups to this question justify the overall view of the research that there is indeed much to feel positive about in regard to how PPI is being approached in Northern Ireland. The general themes emerging from this question relate to: *Information, attitudes, training, communication, feedback, trust, enthusiasm and genuineness, being listened to and attention to practicalities.*

The following quotes are examples of some of these themes across the five focus groups.

"If the organisation are say producing a leaflet, before they actually print it off they will send it to the user forum and we will say, no, I don't like this word, I couldn't understand that, or, that's brilliant and our views are always taken on board." (Trust A respondent).

"We are being very welcomed, every time we go in. and I think it is great that the patients feel, goodness, people who are listening to us". (Trust B respondent).

One of the service users was involved in the neurological conditions project funded by the PHA. She spoke very positively about this as a meaningful PPI experience.

"It would make a difference. Now it was a number of years in the making and it wasn't all plain sailing at times, we wondered are we going anywhere, getting anything, but I do believe it will. I believe it will because the people involved in it are actual service users and carers."

Another service user talked about his experience of Involvement through the Direct Payments scheme as being life changing.

"xxxxx feels personally whenever he was allowed to have a say on how he felt his care should be handled. It really just changed his life because he was then allowed to send out direct payments and he actually got to choose the people who work with him on a day to day basis. He is in control of that himself instead of somebody saying, here is somebody going to come into you, they have no idea how to work with you or communicate with you or that you don't even get on with."

This positive experience of meaningful involvement was associated as having other health and well-being benefits also for this service user.

"But whenever he began to be able to say, it just changed his life and even his quality of health and everything increased and he just feels people are listening. I suppose it is kind of ironic because he actually feels he has a voice in every sense now." (Trust C respondent).

Being valued, having the user/carer experience acknowledged and recognised as being important, were critical elements leading to positive involvement and such sentiments were repeated throughout the following focus group.

"Being allowed to get involved at the level of which I choose"…."If the people who are using the services, if they don't feel consulted and part of it, it hasn't worked"…."I think it is important that we hear what people have to say" (Trust D respondents).

Positive examples were also provided where service users were able to see the difference they were making to services and procedures.

''And I have been very, very impressed with the professionalism, the expertise that is there, the willingness to listen to what I had to say about the xxx, the willingness to change, the willingness to take on board and adapt measures" (Trust E respondent).

Q4. When you think about your experiences of involvement can you think of any barriers which made this a negative experience?

There were a number of barriers identified across the focus groups which contributed to the PPI experience being a partly negative one. The main barrier was many aspects of communication with respondents feeling that they were not treated with respect and often subject to poor two way communication. In addition, there was some evidence of a fundamental power differential with the professionals finding it difficult to relinquish their control. In addition some practical aspects such as transportation, access and timing of meetings were also identified.

As indicated, communication was seen to be a vital part of successful PPI with respondents with concerns raised that internal communication about PPI (both within and across Trusts) was poor resulting in PPI not being used to its full potential:

"*There are so many good projects out there where the organisation has benefited from talking to the people from the beginning, changing procedures, changing processes and saving money. And yet those are not sold to the people at the top who just don't see it as worthwhile. It is just not communicated well enough."* (Trust A Respondent).

Respondents also highlighted the reliance on and use of jargon in particular as problematic:

"*And I think for a lot of people, it is very, very daunting in the beginning when you go in and everybody is around and they all talk in this different language…"* (Trust B Respondent)

"*Just talk in plain English and I will know where you are coming from*" (Trust C Respondent)

There was also a need for the person leading the group to have good facilitation skills so that all views were represented.

"*One of the big barriers I find is that if you sit for two hours at a meeting and you are not even asked why you are there, you are not even asked for an opinion on anything. And I find that most frustrating."* (Trust B Respondent).

"*Some people are quite confident and vocal and can get their point across whereas other people are quieter, more wary of officialdom, don't know what to say, afraid to ask. The person you are talking to, I think they have to gauge that and maybe draw out the person a wee bit more or actually take more time*." (Trust C Respondent).

Some respondents felt there was a power differential with professionals maintaining control. This resulted in some respondents feeling that that they were not really a true part of the decision-making process or that their views were heard and acted upon.

"*To me it is a hard won battle and it is very slow, but I think it has improved over the years. …in my view a lot of it can be tick box. I've been to things, even recently, where you have been wheeled in as a patient basically, you know*." (Trust B Respondent).

"*But I think that is a big problem that if you are going to include service users and carers, you have got to make them feel … not important, but valuable*" (Trust E Respondent).

Some Service users had, as a result of experience, learned to be strategic about the PPI activities that they became involved in as lack of action or inclusion in decision-making was off-putting for respondents.

"*So we spent eighteen months and we eventually got two seats in the foyer, it took eighteen months***."** (Trust B Respondent).

"*I will be choosing those things where I see that there is going to be some results at the end of it. I am not prepared to go and sit at meetings and talk for the sake of talking…. I go to meetings because I want to achieve something, if I don't see myself achieving that, I will walk out"* (Trust C respondent).

Some respondents felt that respect for those individuals who took part in PPI meetings was not always apparent. Respondents identified lack of empathy and understanding from staff about the commitment given both in time and energy.

"*You know, very often they are tick box exercises and that really angers me. Because people are giving up their time and their energy and their trust."* (Trust B respondent).

"*One of the big barriers I find is that if you sit for two hours at a meeting and you are not even asked why you are there, you are not even asked for an opinion on anything. And I find that most frustrating*." (Trust B respondent).

Across the focus groups it was clear that transport, access and timing of the PPI meetings were important practical issues that needed be considered by respondents prior to getting involved. It was also highlighted that the staff organising the PPI meetings did not always consider these issues sufficiently.

"*Well my barrier would have been a transport barrier, and practicalities. The simple basics of where is it, how do you get there, is it on a bus route? The problem is that most people who set up meetings drive cars and they all come individually."* (Trust A Respondent).

"*All the meetings are always in the daytime. There's very few, unless they are run by patients or carers that are in the evening or weekends or times when you can get babysitters or you can get someone to take over".* (Trust B Respondent).

Q5. Do you have any suggestions for making improvements to the PPI experience for service users?

Respondents across the focus groups had a number of suggestions for improving the PPI experience of service users. These included: Training, better coordination of PPI activities/meetings, communication including the use of social media, sufficient resource allocation and further consideration of transport and access needs.

The need for staff to recognise that service users require training to ensure they are knowledgeable about the health service and the language used so they can make a meaningful contribution was a recurring theme. There were examples of where training had taken place and was a very positive part of the PPI experience but also an example where training for PPI was viewed negatively.

"*That they can understand and that things are explained before a meeting so they are not having to appear … not stupid, but unknowledgeable or whatever, and taking up time whenever they could be moving on to something else. So think that's important*" (Trust B Respondent).

… if we are going to sit on these committees, we need to be trained. We need to have induction courses on what is happening and be kept up to speed" (Trust E Respondent).

Equally, there were examples of where respondents had received training and found it helpful:

"*The willingness to actually inform me and train me and take me down and take me round the wards when they were doing on the spot inspections"* (Trust E Respondent).

Communication came through strongly as an issue that needed to be improved in order that the PPI experience was better:

"*There are so many good projects out there where the organisation has benefited from talking to the people from the beginning, changing procedures, changing processes and saving money. And yet those are not sold to the people at the top who just don't see it as worthwhile. It is just not communicated well enough."(*Trust A Respondent)

"*Communication, I always say is one of the things that fails in a lot of cases. And communication is two-way. You know, there is no point in us feeding all that*

information into PPIs and it dies in there, it doesn't come back out. And I think that's… communication, and I keep saying it at everything I go to, is vital". (Trust B Respondent)

The need to recruit more people to PPI was seen as important, so that the commitment would be less for those involved:

"*If you are the only PPI, you have to be there. You know whether it's your holidays or you are not feeling well or whatever it happens to be. I think that can put people off."* (Trust B Respondent)

It was considered that there needs to be a better balance of lay members and professionals at meetings as at times it was perceived that the meetings were dominated by professionals:

"*One of the things I found was this overweight of the professional side. Why does there have to be fourteen managers there*?" (Trust B Respondent)

"It is supposed to be personal and public, but it is actually not… at the current set up, it is professional, because all the involvement is from the professional side." (Trust B Respondent)

The availability of resources for PPI were considered important and not sufficient to meet the needs of meaningful PPI. There was recognition that Trusts often struggle to find money for PPI and that what was needed was a funding stream for PPI:

"*I am amazed at the amount of resources Trusts and health organisations put into patient experience, because that is a departmental requirement, it is not a statutory requirement. They do not match that on PPI. You could have teams of people on patient experience and only one person or half a person on PPI*." (Trust A Respondent)

"*Gap in funding for services* "(particularly relating to services for young people) (Trust D Respondent)

Some respondents also highlighted the need to make the processes for claiming expenses easier:

"*I think if they had a better way and a more open way of getting access to covering your travelling costs and stuff…they do it in such a complicated way. I might get it sometime (payment) I might not, I don't have a clue*" (Trust C Respondent)

There was a need for Trusts to promote PPI to encourage others to get involved through media campaigns and also through going into schools to speak with young people:

"I think people need to know what PPI stands for and what it means and what it is about." (Trust A Respondent)

"… but there is no PR on TV about being on PPI. You never see it advertised in that way, whether it is social media or TV or whatever. I mean if you want to have a cheap resource, and it is a cheap resource because you are not paying, and most people take themselves…"(Trust E Respondent)

Additionally, there were a number of challenges identified that needed to be overcome when being involved in PPI, including time and getting to and from meetings:

"The biggest barrier that we would sort of come up against, for me personally is basically time. A lot of the people we work with, they are carers 24/7 and that is not going to change." (Trust A Respondent)

"*If they want service users involved they have to arrange a better way of doing it. I was at xxx for five years, I was picked up at the door, I was took home from it direct to the door. Cost was never an issue it was arranged for me*." (Trust C Respondent)

Q6. Thinking about your experiences of involvement in PPI, what is your understanding around the impact of your involvement in influencing services?

Some respondents were able to articulate how their involvement was having a positive impact on research and also directly on services.

"*The success of the user forum has been the feeding back. It is a two-way communication. The staff are told the outcome of any research that we have done, and they are delighted how they come out. And I think that has been our big useful… is the two-way communication with staff, patients and with the users who represent the sort of general public if you like."* (Trust B Respondent)

"*My role at the minute is a lot more communication and trying to bridge that gap a wee bit … and trying to get those types of carers [elderly and rural] involved in carers groups as well so that they can find out more of their human rights and those types of things as well*" (Trust E Respondent)

An important way for PPI to influence what happened in the health service was thought to be getting information to the professionals and to bring service users and professionals together to focus on particular projects.

"*Showing that you could do things, we were able to pull something together that involved the clinicians and the patients and service users."* (Trust A Respondent)

"*But I must admit I have had very, very good feedback from the xxx Trust on one project that they wanted to start in an area and I gave them the lead-in into it and introduced them to different people and pushed the project. And they came back to let me know how it had gone, what the report back was, and gave me excellent feedback from that*" (Trust B Respondent)

Q7. What are your experiences of being involved in evaluating PPI activities?

There was limited awareness of evaluation and monitoring of PPI. However, there were some examples of where it had gone well and also room for improvement as evaluation and monitoring was considered to be ad hoc. Some PPI members pushed hard to get effective evaluation and monitoring in place.

"Because of my involvement in the xxx, we pressed to have a monitoring and evaluation process that was outside the actual health trust themselves and health organisation…So I was involved in three of those this year, and they were very useful. They highlighted good things, they highlighted bad things and there was a comparison across the Trust which means that when the report is produced, people will learn from the process as well as highlighting issues where people need to do more. Now that's going to be refined as each year goes on. This is the first year it has been tried. But it has been very useful." (Trust A Respondent)

"*I think evaluation is vital. Are you going in the right direction? Should we change direction? Is everything fine? Evaluation and a target, I think, are two of the most vital things."* (Trust B Respondent)

"Certainly as a member you wouldn't be made aware every time an evaluation for something was done" (Trust E Respondent).

Chapter 5: Best practice in PPI - examples from across Northern Ireland's HSC Trusts

Each of the HSC organisations has a range of examples of PPI practice available as case studies for use in training and awareness sessions to enhance learning and understanding. The following examples of good practice in PPI provided by each of the Lead Staff with responsibility for PPI in the HSC Trusts provide a flavour of PPI in action across programmes of care. Further details of the examples below and other case studies can be obtained by contacting the relevant PPI lead.

Belfast Health and Social Care Trust (BHSCT)

HIV Service user Forum

User satisfaction surveys were distributed to patients attending the HIV clinics during 2014. Patients were asked to submit contact details if they wished to attend a HIV service user forum. Relevant voluntary and support groups were also invited to attend. 94 questionnaires were returned with a number of people expressing an interest in getting involved with a service user forum. Several workshops were then facilitated to inform the development of the forum and following this the HIV Service User forum was established, with associated Terms of Reference and chaired by a service user. The Forum has worked closely with staff over the last year to identify a number of areas for improvement and develop ways to address these.

Regional Gender Identity Service

In 2014 the Regional Gender Identity Service asked for assistance with engaging with service users as there is not one group, which is representative of all sections of trans patients. Therefore the service wanted to explore different methods of engagement with service users directly. Letters were sent to all those registered with the service, inviting them to sit on patient panels to discuss different aspects of the service. A number of replies were received and three patient panels were organised on different topics, such as the GP guidelines on transgender patients, and plans for a pilot sexual health clinic for transgender patients. All the discussions were lively and patients participated fully. The patient panels will continue, as and

when issues arise, whilst other methods of engagement will continue to be explored. Outcomes of this process include

- the active involvement of different sections of transgender patients, such as different age groups, trans men and women and non-binary patients
- increased dialogue between patients and the service
- influence over decisions about future services

Paediatric Wheelchairs

During 2014/15, 4 families were involved in evaluating a range of paediatric wheelchairs which were potentially being added to the range offered by the Trust. The wheelchairs were technically and clinically evaluated by staff. The families were then involved in evaluating the wheelchairs from a service user perspective, using specific criteria. The involvement of the families in the evaluation process brought an added perspective and actively informed the decision to add 4 new chairs to the range offered.

Northern Health and Social Care Trust (NHSCT)

Supporting our User Panels

The Trust User Forums are established groups of individuals and representative organisations with a keen interest in the standard and quality of Trust services. They work in partnership with Trust staff to ensure their views are part of the planning, delivery and monitoring of services. During 2013/14 the Disability User Panel was instrumental in developing the Trust's Assistance Dogs Policy to ensure services are accessible to everyone and that assistance dog owners are not refused access to Trust premises. Members of the Panel also help to deliver disability equality training. We recognise that service users and carers bring their knowledge and their experiences to the training sessions and providing staff with the opportunity to hear things directly from their point of view is incredibly powerful.

Members of 'The Forum' are currently being trained to be involved in recruiting Trust staff. The Trust feels that including people who use services in recruitment is the pinnacle of user involvement and can fundamentally change the power dynamics

and culture of the interview process. We believe involving service users in interview panels makes a clear statement about the significance we attach to involving people who use our services and sends a strong message to candidates about our values.

Listening to family carers

We understand the importance of listening to our family carers. In partnership with Carers NI, we support the development of carer support groups and liaise extensively with the voluntary and community sector. Our Carers Register, set up as a means of engaging directly with carers, continues to grow. We continue to hold carer support events to help family carers to learn coping strategies, gain practical information and meet other carers. During Carers' Week 2013, we ran information stands in four GP practices and in partnership with Carers NI who facilitated an event for older carers called 'You're never too old to Care'. This event was attended by the Minister for Health and the Commissioner for Older People. Our Carers A – Z Directory was re-launched in February 2014 at our Trust Board meeting and Newtownabbey Carers Choir sang at meeting to support the launch of the Directory and raise the profile of carers.

Engaging with older people

In recognising that the community and voluntary sector play a vital role in the development and delivery of services for people in their own homes or local community, the Trust undertook a scoping exercise to identify the issues and challenges the voluntary and community sector face. As a result of this the Trust then developed an on-line Directory of Services for Older People for each council area within the Trust. The Directories are now available on the Northern Trust website at www.notherntrust.hscni.net. The Trust also held a series of four workshops, attended by a range of stakeholders, to further examine the opportunities for closer working. The common themes raised across all workshops were the need for openness, transparency and trust and the sustainability of collaborative working.

User Involvement in Mental Health Services

In 2014 the Trust appointed a Service User Consultant to make sure the perspective of people who use Mental Health Services is fully represented when making decisions. The establishment of a Service User Consultant post demonstrates the

Trust's commitment to prioritising service user participation and puts the voice of the service user at all levels of service delivery in a consistent way. This affects attitudes and behaviour and thus promotes a more recovery focused service and improved patient/client experience. The Trust also appointed a Recovery Facilitator to develop recovery focused practice across the Trust in partnership with Implementing Recovery through Organisational Change (ImROC).

South Eastern Health and Social Care Trust (SEHSCT)

Lakewood & Niacro Partnership Garden Mural Project

Lakewood Secure Care Children's Home based in Bangor accommodates up to 16 young people from across Northern Ireland. NIACRO Independent Representation scheme which works with the young people staying at the home was involved in a large scale mural design and painting project during August 2015. There are two gardens leading out from the living rooms with large arched boundary walls. Following feedback from the young people resident at Lakewood, the scheme felt that these walls would provide the perfect canvas for colourful murals for the young people to develop and express their ideas upon, whilst also being of great aesthetic benefit to the individual living areas. The young people were central to each stage of both the design and creation of each mural. Design workshops were facilitated and mural designs were based on discussions with young people around their interests, hopes, aspirations, dreams and personal journeys for those in secure care.

The designs portray important key messages that the young people in Lakewood wanted to share with other young people who would be staying in the home after they had left. The majority of young people resident were able to participate fully in the project and took ownership and a real pride in seeing their ideas materialise on the wall – the end result looks fantastic. Lakewood and the IR scheme held a celebration event to recognise the hard work that all the young people in the centre put into the project which was attended by the Children's Commissioner, employees from the South Eastern Health and Social Care Trust and NIACRO staff.

Bereavement Suite at the Ulster Hospital

The South Eastern Trust Bereavement Support Midwife established the 'Forget Me Not' group in October 2007. This Liaison committee of bereaved parents at the Maternity, Gynaecological and Paediatric wards of the Trust, was set up to improve and enhance the experience of parents bereaved through miscarriage, stillbirth, neonatal death or the death of a child. The group, a partnership between staff and bereaved parents, meets throughout the year to influence and enhance the care provided during the very sensitive time following loss. Led by individual service users of the Ulster Hospital, this project adopted a partnership approach to improving services for women and their families who sadly experienced the loss of a baby in the maternity unit. In the absence of a Health Building standard, the Trust looked to the parents and to the User group in the Trust to develop an appropriate specification for the design of the Labour Ward room to meet the needs of bereaved parents. The women and their families, who had experienced the profound loss of a much wanted and loved child before, during or after childbirth, clearly articulated to the Trust how the physical environment impacted on their experience during the critical time in the Maternity unit.

Dietetics Case Study – Primary Care and Older People

A new compact nutritional supplement was launched on the market and the purpose of the activity was to compare it with the current product used in the acute setting and determine which one was more acceptable to the user, from a taste perspective. The aim was to:-

- Develop and carry out a sensory analysis procedure to aid the selection of the most suitable compact nutritional supplement for use in the acute hospital setting.
- Analyse the results from the sensory evaluation tests
- Draw conclusions and determine the most preferred nutritional supplement by patients

Patients who were already on oral nutritional supplements were selected from a variety of wards to take part in the trial of supplements. The taste test was carried out on an individual basis at the patient's bedside. The bedside environment was different with each patient but the way in which the instructions were given, the samples and questionnaires all remained the same.

There were a total of 45 participants, which included a mixture of patients and dietetic staff. All users and staff were asked on an individual basis if they would be happy to take part in the trial. The majority of patients (83%) preferred the new product. From this feedback the plan is to introduce the new product into the acute hospital setting.
The impact of the change will be that users will be provided with a better tasting product to meet their nutritional needs. From the staff perspective they will now recommend a different product as first choice to users. The learning from this trial was the importance of trialling out new products with service users rather than staff only. It is important that products are trialled with people who are unwell and may have taste changes etc., to get a true evaluation of a product.

Southern Health and Social Care Trust (SHSCT)

The review and modernisation of bed based short break provision (Respite) for individuals with a learning disability and their carers.
Carers reported the importance of having access to regular flexible respite in supporting their own health and wellbeing to enable them to maintain their caring role. One of the significant concerns for the Southern Trust and carers, however, was the provision of bed based short breaks to enable carers and service users to have access to equitable short break opportunities in the areas where they lived.

Within Adult Learning Disability a robust and comprehensive consultation process was undertaken where the views of the 348 individual carers on which this impacted were sought. Five consultation workshops were held across the SHSCT area. Additional feedback was sought from any carer who had not been at the Information Sessions so that they were given the opportunity to contribute to the future vision for

short break services. All of the information which was gleaned from carers was used to inform an options appraisal as to the most effective form of bed based short break provision for service users and carers.
The options appraisal was developed by a number of Trust staff working in partnership with 4 carers from the LD Carers' Forum who had agreed to take part in the options selection process. The involvement of carers in this process helped Trust staff to have a greater understanding of the type of service they require. Carers also commented on the challenges being part of the appraisal process was for them and how detailed and transparent a process needs to be in order for it to be effective.

Following the options appraisal and the selection of the preferred model, other carers from the LD Carers' Forum agreed to take part in the development of the preferred model for respite. This included several meetings to examine the physical environment of a new facility, arrangements for day care, transport and more importantly governance for that facility. Meetings proved to be very informative from both Trust and carer perspectives and, importantly, maintained the value of the partnership as the underpinning basis for all discussions.

Outcome Based Care, Domiciliary Care

Historically the domiciliary care budget within the Southern Trust was overspent and the Trust struggled to meet the growing need for domiciliary care services. The Older People's division was aware that there were a number of issues with the current service model employed including time for task, lack of timely review, creation of dependency and inflexibility. In addition, a domiciliary care worker stated: "Where we are needed in a house we feel valued" which implies there were still homes that commissioned care was not considered necessary and could be tailored further. Work began to identify a better service approach with a greater focus on a quality service model involving those who currently used the service, their carers, the staff who delivered the service, managers and staff side. This included:

- Establishing a baseline picture
- Developing Project management structure

- Agreeing criteria and measures
- Independence focus – “with” not “for”
- Introducing new requirements - OT (professional functional assessment), caseload model rather that “Time for Task”, supervisor 70% out with clients / staff (back office support)
- Identification of pilot area to test new model
- Communication / engagement – clients, key workers, all community teams, GP’s, MLA’s
- Staff Training

Outcomes and findings to date:

- Responsive, timely assessment
- Greater efficiency and increased capacity (additional 30 packages accepted to date)
- Improved outcomes and independence focus
- Better collaboration across Teams
- Happy staff and clients, no complaints and positive feedback

Pre pilot questionnaires were completed for service users, staff, commissioners and further post pilot information will continue to be sought to enable comparisons with qualitative feedback and quantitative data to indicate successes to date. A planned phased roll out across all of Armagh and Dungannon will enable further testing of this model at scale with a view to developing in all Trust areas. This will inform the procurement of the independent sector domiciliary care services and indeed involvement and engagement with providers as partners in care across the commissioner provider split.

Western Health and Social Care Trust (WHSCT)

Working in Partnership Dementia Award

The Western Trust were the winners of the Northern Ireland Dementia Awards in the ‘Working in Partnership’ category announced on 15 September 2015. The Service Improvement Steering Group, which includes 2 service users, were nominated and won because of the sterling work in promoting and delivering services for dementia

and memory services across the Trust. This includes making Altnagelvin the first Dementia Friendly Hospital in Northern Ireland, accessible community memory clinics, rapid access to nurse led and consultant clinics and post diagnostic educational groups for patients and carers.

Promoting Resilience in Parents

A number of parents of children with complex healthcare needs in the Western Trust have been involved in a workshop as part of a research project on 'Promoting Resilience in Parents' through the development of a structured group-based Parent Support Programme. Parents/Service users were able to influence the development of an appropriate support programme. Essential information was provided by parents to enable staff to reconsider what is needed for the children. There is continuing work on the development of the programme.

Rheumatology Research Event

The Western Health and Social Care Trust hosted a Rheumatology Research Information Evening on 2 April 2015. Research innovation in the Derry/Londonderry area was presented. There was also discussion around setting up local research advisory groups and branches in the Western Trust area where service users would discuss their experiences of living with arthritis in order to support further research in the Western Trust.

A follow-up event took place on 21 October 2015, hosted by the Western Trust in association with the National Rheumatoid Arthritis Society (NRAS). The Rheumatoid Arthritis NRAS Group was launched, with the support of the NRAS and Altnagelvin Hospital's Rheumatology Team. In the future, it is hoped there will be regular NRAS group meetings where, alongside mutual support and information, service users will be given the opportunity to contribute to the development of long term patient care within the Western Trust and have regular interaction with health care professionals.

Northern Ireland Ambulance Service (NIAS)

10,000 Voices Workshop

10,000 Voices is a regional project commissioned by the Public Health Agency to engage with and gather stories from patients, clients and staff so that improvements can be made to the delivery of care. The PHA is carrying out the 10,000 Voices project across all HSC Trusts with the aim of introducing a more patient-focused approach to provision of services and shaping future healthcare.

NIAS, along with the other HSC Trusts, is collecting patient stories through the 10,000 Voices survey questionnaire which asks patients, families and carers to share their experiences of using the services we provide. NIAS is working with the Public Health Agency and service users on the evaluation of the stories in order to ensure learning from these leads to improved outcomes in terms of delivery of our services.

A workshop with the PHA and service users was held during June 2014 with the aim of reviewing the themes emerging from patient stories collected as part of the 10,000 Voices project. While it was recognised that emergency response times are critical, the importance a caring and compassionate approach, proper introductions and the need to keep patients informed were highlighted as major issues for our service users.

Transforming Your Care – Service User Engagement

Two service user engagement workshops were held June 2015 to look at proposals to introduce Alternative Care Pathways as part of the implementation of the regional TYC programme. The workshops provided an opportunity to outline the Trust's progress to date and future plans and to obtain feedback from those with experience of ambulance services. This feedback also informs further development of TYC work streams. Those who participated were largely supportive of the Trust's proposals and provided constructive ideas for progressing the work and engaging further with the public around it. This will help inform a public awareness campaign for TYC specifically and NIAS's services generally.

Regulation and Quality Improvement Authority (RQIA)

Mental Health and Learning Disability (MHLD) Easy Read Inspection Reports

The Regulation and Quality Improvement Authority (RQIA) is the independent body responsible for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland, and encouraging improvements in the quality of those services. As part of the RQIA Corporate Strategy 2012-15, RQIA is committed to engaging and communicating effectively with its stakeholders. One of RQIA's strategic objectives is to embed personal and public involvement (PPI) as a fundamental part of its work. A further strategic objective is to develop effective communication methods to meet the complex and varied needs of the Northern Ireland public**.**

As part of this commitment, the Director for Mental Health & Learning Disability (MHLD) and Social Work and Head of Programme for Mental Health & Learning Disability met with patient and patient representative groups from Muckamore Abbey Hospital (MAH) – The Tell It Like It Is (TILII) Group[10]; Patients Council MAH and Parents and Friends of MAH in March 2013. Patients highlighted some of the difficulties they experienced in accessing RQIA inspection reports**.**

To address this, the MHLD team agreed to take a lead in developing user friendly version inspection reports of learning disability hospitals.

As an organisation, RQIA have a responsibility to make reasonable adjustments for individuals with a disability. In 2014, The MHLD team considered this could be achieved by taking a universal design approach to inspection reports – an approach that caters for everyone irrespective of their age, ability or disability. Easy to read documents could potentially benefit more people than the target population including people who have literacy issues, those who are deaf, and where English is not their first language.

[10] Telling It Like It Is - Group of adults with a learning disability who are keen to have their voices heard - http://arcuk.org.uk/northernireland/influence-voice/telling-it-like-it-is/

It addition to the initial consultation with the TILII Group; Patients Council MAH and Parents and Friends of MAH, Mencap and Disability Action were also consulted, as part of the background research, to determine which organisations or people could assist RQIA in developing easy to read inspection reports. Service users and advocacy groups were involved in the initial design of the easy read inspection report format. To date, inspectors in the MHLD have completed an easy to read report for every inspection.

An evaluation of the response to the easy to read reports was undertaken. There were mixed responses. Wards where there were patients who required support with their communication found the easy to read reports useful. However some wards where there were patients who did not require support with their communication, did not find the reports useful. Following this evaluation the MHLD reviewed their processes for issuing the easy to read report. MHLD will continue to issue easy to read reports for every inspection. However, it is now at the ward manager's discretion which patients require access to the easy to read reports due to their communication needs.

Chapter 6: Conclusion

Although PPI in Northern Ireland still faces a number of challenges, this research has evidenced that there has been a great deal of work undertaken and a marked improvement, particularly in coordination, over the years since its first introduction as policy in 2007. The research **recommendations** in this report are framed to build upon the progress that has been achieved to date and are focused on both the leadership and implementation aspects of PPI and service development in this particular area. This research has found that progress has been slower than anyone would have liked but nonetheless the picture is quite positive. Much of this has been achieved within existing resources and it is evident that there is both a passion and desire from within Health and Social Care and from those who use the services to further embed effective PPI and develop the structures and mechanisms required to do this and to monitor the impact. PPI in Northern Ireland is still, therefore, very much a developing process which can be improved upon further in light of the recommendations from this research.

To continue embedding PPI and making it a reality for more service users and carers will, however, require strong leadership, coordination, partnership working and, allied to this, a fundamental rebalancing of the power differentials between those providing services and service users on the receiving end. The detailed review of the literature in this research concurs with our research findings that PPI success will ultimately depend on the evening out of power relationships where service user experiential knowledge can sit comfortably alongside the knowledge and contributions of professionals. The barriers to effective PPI were characterised by instances where staff lacked in empathy and communication insights, where tokenism continued to occur, where service users were left not knowing what the outcome/impact of their contributions were and where practical arrangements were ignored. The ten recommendations of this research can help to meaningfully embed the translation of PPI into more person centred and engaged relationships between staff at all levels of the HSC sector and service users. It is only when this happens, that we can truly claim that PPI is working the way it should and the way service users expect it to be. This will involve the need to look at the working culture of the HSC system in Northern Ireland. This examination will entail the need for organisations to self-assess and reflect on whether this culture has the ingredients necessary to cultivate

and nourish truly engaged ways of working alongside service users which ultimately is what PPI requires.

Adopting the recommendations of this research will, therefore, help ensure that PPI becomes more of an integral part of the way the Health and Social Care system does its business, not because it is a statutory requirement, but because it is the right thing to do in terms of targeting services to need, increasing efficiency, improving quality, safety and cost effectiveness. To build on the progress and achievements to date, and to recognise the efforts of everyone involved, HSC organisations should identify ring fenced funds or resources to further develop their PPI structures and enable them to provide support to staff so that they can incorporate PPI in their day-to-day work. This will contribute significantly to the development of PPI by positively impacting on the service user and carer experience and ensuring the continued delivery of high quality, safe and effective HSC services that meet the needs of the people who use them. The established leadership role of the Public Health Agency in providing a positive basis for PPI developments to date should be recognised and remains essential in progressing PPI across the HSC system.

There is also room for improvement in other key aspects of PPI, such as ensuring the public is clear about its meaning as well as having a structured way to evaluate the outcome and impact of PPI activity. The in-depth nature of this research project has provided the opportunity to explore meaningful ways in which PPI can become further improved, embedded and more part of the mainstream in Northern Ireland. The Recommendations in this Report, therefore present an opportunity to assist in a process of continuing improvement in regard to PPI in order to achieve truly person-centred services. Linked to this last point, it is apt to conclude with the following quote from a carer in one of the focus groups remarking on the profoundly positive impact PPI had on one service user's life:

".. It just changed his life and even his quality of health and everything increased and he just feels people are listening. I suppose it is kind of ironic because he actually feels he has a voice in every sense now."

Recommendations

1. For the development of effective PPI, adequate and dedicated resources are essential.
2. There should be an ongoing process of raising awareness of what PPI is and what it means for staff, service users and carers.
3. PPI needs to be defined in a way that is explicit and meaningful to service users, carers, providers and the wider public.
4. Each Trust should develop a PPI Champion staff role with a small team whose jobs will be entirely and specifically related to PPI at Trust level.
5. Social Media and Technology should be effectively utilised to promote PPI across HSC. This should include a one-stop website for information, guidance, support, resources, templates and good practice examples.
6. Structured evaluation must be built into PPI as a way to measure its effectiveness.
7. Feedback on the impact of involvement should be standard practice.
8. Appropriate and dedicated PPI training should be made available for HSC staff.
9. PPI should be a core feature of all Trust recruitment and performance/appraisal processes.
10. PPI needs to be built into accountability structures and decision making processes at senior manager/director level.

Appendix 1: Focus Group Questions for Service Users

1. What is your understanding of the term Personal and Public Involvement, or PPI as it is known in short?

It is recognised in the literature that the language and terminology of PPI is complex and potentially inaccessible. This question immediately engages participants in reflecting on this important issue.

2. Please tell us why you got involved in PPI

This question encourages participants to discuss their reasons and motivations for engaging in PPI. To prompt for additional discussion, convenors should then invite participants to share the types of PPI activities they have experience of and the recruitment process involved.

3. When you think about your experiences of involvement in an aspect of health or social care, was there anything that made this a positive experience?

This question refers to aspects of PPI experiences which participants felt were positive and helpful. This could, for example, involve focus group convenors prompting a further question around any training which participants may have received to support their involvement. Further questions should be asked about payment, timing of meetings, the experiences around accessibility in regard to paper work and documents which participants were expected to comment upon and the approaches/skills of those staff who were seeking service user involvement.

4. When you think about your experiences of involvement can you think of any barriers which made this a negative experience?

This question is aimed at encouraging participants to share their experiences of involvement activities which they found to be unhelpful or unproductive. A prompt question here should also address the issue of experience of PPI compared to time and effort input.

5. Do you have any suggestions for making improvements to the PPI experience for service users?

This question is designed to reflect on positive ways forward having discussed both positive and negative aspects of PPI in the previous two questions.

6. Thinking about your experiences of involvement in PPI, what is your understanding around the impact of your involvement in influencing services?

This question is intended to address participants' views on the perceived importance of undertaking PPI activities and the perceived/actual impact of PPI on health and social care outcomes.

7. What are your experiences of being involved in evaluating PPI activities?

This question relates to the issue of PPI evaluation, one of the study's objectives. It is important therefore to hear participants' thoughts on having been involved in the evaluation of PPI activities.

Appendix 2: Focus Group Questions for Staff

1. What are your thoughts on PPI currently in Northern Ireland?

This question can connect in a very general way to inviting participants to express their opinions at an early stage about PPI.

This question can then lead into inviting participants to provide more specific examples of PPI activities they have experience of.

2. Can you please provide some examples of the types of PPI activities you are or have been involved in?

This question is aimed at getting more specific examples by drawing out the direct experiences of participants.

3. How are participants recruited to become involved in PPI activities in your organisation?

This question is a follow-on from the previous question on PPI activities. By way of additional prompt points, it would also be important to have some discussion around: Training provided for PPI participants, Levels of involvement and any suggestions for improvements.

4. What do you think makes for effective PPI in your organisation?

This question connects directly to one of the study's stated objectives (to identify best practice in PPI). As a further prompt within this question, the convenor should ask for examples of PPI activity which could be regarded as '**best practice'.** This question can also open up further discussion both around how decisions are made about the remit for PPI in the organisation and the types of training available for staff with a responsibility for PPI.

5. Can you think of ways in which PPI could be improved at an organisational level in regard to your particular work setting?

This question addresses the organisational context within which PPI occurs and invites participants to reflect on ways in which this aspect of service might be better addressed and delivered within their own particular employing organisation.

6. How is the impact of PPI activity currently monitored and evaluated in your organisation?

This question also relates directly to one of the study's objectives (identify valid and reliable ways for monitoring, measuring and evaluating the impact of PPI). Additional prompt questions and areas to expand this discussion should include: perceived importance of undertaking these activities, barriers/facilitators to undertaking these activities, benefits to undertaking these activities (only applies to those that have experience of undertaking some/all of these) and the perceived/actual impact of PPI

on health and social care outcomes and suggestions for improvements in regard to monitoring and evaluating PPI.

Appendix 3: On-Line Survey Questions

9/1/2015

Default Question Block

Personal and Public Involvement and its Impact: Monitoring, Measuring and Evaluating the Impact of Personal and PublicInvolvement in Health and Social Care in Northern Ireland

Participant Information

We are inviting you to take part in a funded research study looking at the impact of Personal and Public Involvement (PPI) in Northern Ireland as you are involved in the planning and delivery of health and/or social care services and can provide us with valuable information about your views and experiences of PPI. "Personal and Public Involvement means discussing with those who use our services and the public: their ideas, your plans; your plans, their experiences; your experiences; why services need to change; what people want from services; how to make the best use of resources; and how to improve the quality and safety of services" (DHSSPS 2007).

PPI is also about involving local communities or the general population where the issues are of public concern or interest, such as the location or nature of local services. PPI is about empowering people and communities to give them the confidence and more opportunities to influence the planning, commissioning and delivery of services in ways that are relevant and meaningful to them.

Before you decide whether or not to participate in the study it is important for you to understand why the research is being undertaken and what it will involve. The study aims are:

1. To identify best practice in PPI
2. To identify any barriers to effective involvement
3. To identify possible ways to overcome these barriers within the context of an integrated health and social care system
4. To identify valid and reliable ways of measuring and evaluating the

impact of PPI activity

5. To generate options to inform the development of a robust and reliable framework to monitor, measure and evaluate PPI activity and its impact on our health and social care services
6. To ensure that users and carers are at the heart of this study in a significant and meaningful way

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time without giving a reason. Any information you provide before withdrawal will be used as part of the study.

What will happen to me if I take part?

You will participate in an online survey and will also be given the opportunity of taking part in a focus group.

What does the study involve?

You will be asked to complete an online questionnaire which will ask a series of questions about your views and experiences of PPI. It should take approximately 30 minutes to complete the survey.

What are the possible disadvantages and risks to taking part?

There are no perceived risks to participating in this survey.

What are the possible benefits of taking part?

There will be no direct benefit to you from taking part in the study but your participation will help inform the future development of Personal and Public Involvement in Northern Ireland.

Will my taking part in this study be kept confidential?

All information collected about you or your organisation during the online

survey will be kept strictly confidential. No individual or organisation will be identified in the results of the study. The Internet Protocol (IP) address collected by the online survey tool will only be used to identify duplicate questionnaires and will then be deleted.

What will happen to the results of the research study?

The results from this study will be shared with the funding bodies i.e. Public Health Agency (PHA) and the Patient Client Council (PCC). These organisations may decide to publish the results and make them available on their websites. The academic staff involved may also publish the results in academic peer reviewed journals and/or present at conferences both nationally and internationally. In reporting and publishing these results, neither your identity nor that of your organisation will be revealed.

During the study, all data from the online survey will be held securely on a password protected computer within Ulster University. On completion of the study, the data will be kept for no longer than five years by the Primary Chief Investigator, Dr Joe Duffy, Queen's University Belfast.

Who has reviewed the study?

The study has been reviewed by the School Research Ethics Committee (SREC), School of Sociology, Social Policy and Social Work, Queen's University Belfast, the Research Governance Committee of each Health and Social Care Trust in Northern Ireland and the Office for Research Ethics Committees for Northern Ireland (ORECNI).

Contact for further information: Dr Patricia Gillen
patricia.gillen@southerntrust.hscni.net

CONSENT

By completing and submitting the questionnaire you are indicating that:

- You have read and understand the information provided about the study
- You have had an opportunity to ask questions about the study and

received answers to your questions

- You understand your participation is voluntary and that you are free to withdraw at any time
- You understand that if you withdraw from the study, any information already collected will be retained in the study
- You are consenting to taking part in the study

What should I do now?

If you decide you would like to participate in the study, please click on the NEXT button below and this will take you directly to the questionnaire.

This question will be used to examine differences in Personal and Public Involvement (PPI) activities between statutory and and third sector organisations.

Which sector is your organisation in? (Please indicate all that apply)

- ○ Statutory e.g. NHS Trust
- ○ Community i.e. formal or informal group of people based in or around a 'community'
- ○ Voluntary e.g. charity or charitable organisation
- ○ Other (Please specify)
- ○ Other (Please specify)
- ○ Other (Please specify)

The following set of questions focus on the remit for PPI within your organisation.

Is there an identified person(s) in your organisation with a remit for Personal and Public Involvement?

- ○ Yes
- ○ No

Is there anyone in your organisation whose only job is PPI?

- ○ Yes (Please specify job title)
- ○ No
- ○ Not sure

Do any of the following have a remit for PPI in your organisation? (Please indicate all that apply)

- ○ PPI Lead
- ○ Director
- ○ Senior Management Team
- ○ Your organisation's Board
- ○ All staff
- ○ Other (Please specify)
- ○ Other (Please specify)
- ○ Other (Please specify)

Is any training available for staff with a remit for PPI?

- ○ Yes (Please specify training available)
- ○ No

- ○ Not sure

What does your organisation hope to achieve from PPI? (Please indicate all that apply)

- ○ Appropriate treatment and care
- ○ Improvement in health and wellbeing outcomes
- ○ Reduction in risk factors and prevention of ill-health
- ○ Improvement in patient/client safety
- ○ Reduction in complaints and litigation
- ○ Improvement in service design
- ○ Improved setting of priorities for action/decision-making
- ○ Managing demand for services
- ○ Understanding patient/client/carer expectations
- ○ Managing patient/client/carer expectations
- ○ Strengthened accountability
- ○ Improved service quality and effectiveness
- ○ Increased self-responsibility of patients/clients/carers
- ○ Reduction in power imbalance between professionals and service users
- ○ Help with tackling health inequalities
- ○ Increased satisfaction with services
- ○ Increased staff morale
- ○ Increased service user/carer morale
- ○ Recognition of patient/client/carer knowledge and experience
- ○ Patient/client/carer empowerment
- ○ Other (Please specify)

- ○ Other (Please specify)

○ Other (Please specify)

What preparation/training does your organisation provide for PPI participants? (Please indicate all that apply)

○ Attendance at dedicated PPI training events (Please specify frequency of provision of training)

○ Introduction to organisational structures (Please specify frequency of provision of training)

○ Attendance at networking events (Please specify frequency of provision of training)

○ No preparation/training provided

○ Other (Please specify and frequency of provision)

○ Other (Please specify and frequency of provision)

○ Other (Please specify and frequency of provision)

Who has responsibility for recruitment/selection of PPI participants? (Please indicate all that apply)

○ PPI Lead

○ Expert PPI Team

○ Each Directorate/Division

○ Participants self nominate

○ Other (Please specify)

○ Other (Please specify)

O Other (Please specify)

How are PPI participants recruited? (Please indicate all that apply)

O Advertising in organisation's facilities

O Public advertising (posters/media)

O Via staff

O Word-of-mouth

O Participants self nominate

O Other (Please specify)

O Other (Please specify)

O Other (Please specify)

The following set of questions focus on the types of PPI activities undertaken within your organisation.

What is the level of engagement of PPI participants? (Please indicate all that apply)

O Information i.e. one-way flow of information from service provider to service user with no mechanism for feedback

O Consultation i.e. asking views and using these views to inform decision-making

O Involvement i.e. service users are actively involved in service planning/delivery

O Collaboration/partnership working i.e. active ongoing partnership with service users

O Empowerment i.e. shared decision-making between service providers and service users

- ○ Other (Please specify)
- ○ Other (Please specify)
- ○ Other (Please specify)

What aspects of health and social care do PPI participants provide input to? (Please indicate all that apply)

- ○ Individual care delivery
- ○ Service enhancement
- ○ Commissioning of services
- ○ Planning/development of services
- ○ Quality and safety of services
- ○ Governance
- ○ Strategic direction of organisation
- ○ Patient experiences
- ○ Other (Please specify)
- ○ Other (Please specify)
- ○ Other (Please specify)

At what stage of the activity are PPI participants involved? (Please indicate all that apply)

- ○ Initial consultation
- ○ Planning

- ○ Delivery
- ○ Evaluation
- ○ All of the above stages
- ○ Other (Please specify)
- ○ Other (Please specify)
- ○ Other (Please specify)

Through what modes do PPI participants contribute? (Please indicate all that apply)

- ○ Survey
- ○ Focus groups/interviews
- ○ Attendance at meetings (Please specify number and type of meetings e.g. Advisory Group, Working Group)
- ○ Participation in meetings (Please specify number and role within meetings e.g. Chair, group member)
- ○ Public meetings
- ○ Patient/client panels
- ○ Agenda setting
- ○ Advocacy
- ○ Other (Please specify)
- ○ Other (Please specify)
- ○ Other (Please specify)

This question addresses the potential barriers and facilitators you may have experienced in implementing PPI within your organisation.

Please indicate if any of the following factors were facilitators and/or barriers to undertaking PPI activities in your organisation. (Please indicate all that apply in EACH of the three columns)

	Facilitator/Barrier		If it has not been possible to overcome an identified barrier, please indicate the reasons
	Facilitator	Barrier	Reason
Staffing levels	O	O	
Staffing knowledge	O	O	
Staff skills	O	O	
Staff training	O	O	
Funding	O	O	
Administrative support	O	O	
Attitudes of professionals	O	O	
Values of organisation	O	O	

Managing patient and public expectations	O	O	
Power relationships between professionals and service users	O	O	
Lack of time	O	O	
Period of organisational change	O	O	
Continuity of PPI participants	O	O	
Health literacy level of PPI participants	O	O	
Other (Please specify)	O	O	
Other (Please specify)	O	O	
Other (Please specify)	O	O	

The following set of questions explore the monitoring and reporting arrangements for PPI within your organisation.

Does your organisation have targets for PPI activities?

- O Yes
- O No
- O Not sure

What monitoring systems are in place for PPI in your organisation? (Please

indicate all that apply)

- ○ Electronic or manual central database
- ○ Disparate records across organisation
- ○ No monitoring system
- ○ Not sure
- ○ Other (Please specify)
- ○ Other (Please specify)
- ○ Other (Please specify)

What are the reporting arrangements for PPI activity in your organisation? (Please indicate all that apply)

- ○ To Senior Management Team
- ○ To your organisation's Board
- ○ Through Annual report
- ○ No reporting arrangements
- ○ Not sure
- ○ Other (Please specify)
- ○ Other (Please specify)
- ○ Other (Please specify)

How are PPI participants informed of outcomes from their participation in the

planning/delivery of services? (Please indicate all that apply)

- ○ Written dissemination
- ○ Meetings
- ○ Not informed of outcomes
- ○ Not sure
- ○ Other (Please specify)
- ○ Other (Please specify)
- ○ Other (Please specify)

The following set of questions focus on the evaluation of PPI activities within your organisation.

Does your organisation evaluate PPI activities?

- ○ Yes, always
- ○ Yes, sometimes
- ○ No

How was the evaluation undertaken? (Please indicate all that apply)

- ○ In-house evaluation
- ○ Independent evaluation
- ○ Not sure
- ○ Other (Please specify)
- ○ Other (Please specify)

- ○ Other (Please specify)

Who was involved in the evaluation of PPI activities? (Please indicate all that apply)

- ○ PPI participants
- ○ Staff
- ○ Managers
- ○ Researcher
- ○ Data analyst
- ○ Not sure
- ○ Other (Please specify)
- ○ Other (Please specify)
- ○ Other (Please specify)

What methods were used for data collection for the evaluation of PPI activities? (Please indicate all that apply)

- ○ Survey of PPI participants
- ○ Survey of all staff involved in PPI
- ○ Focus groups/interviews with PPI participants
- ○ Focus groups/interviews with staff
- ○ Document analysis e.g. records of meetings
- ○ Monitoring data
- ○ Case study
- ○ Workshop

- ○ Observations
- ○ User panels
- ○ Audit
- ○ Other (Please specify)
- ○ Other (Please specify)
- ○ Other (Please specify)

What aspects of PPI activities were included in the evaluation? (Please indicate all that apply)

- ○ Recruitment of PPI participants
- ○ PPI participant support (formal and informal)
- ○ Activities PPI participants were involved in
- ○ Implementation of PPI in organisation
- ○ Management support for PPI
- ○ Economic evaluation using Cost-effectiveness Analysis
- ○ Economic evaluation using Cost Benefit Analysis
- ○ Economic evaluation using Cost Utility Analysis
- ○ Other (Please specify)
- ○ Other (Please specify)
- ○ Other (Please specify)

What organisational outcomes and impacts from PPI activities were included in

the evaluation? (Please indicate all that apply)

- O Capacity building within organisation
- O Identification of staff training needs
- O Effect of PPI involvement on services
- O Change in policy development process
- O Change in budget allocation process
- O Change in service development process
- O Change in service delivery
- O Change in governance policies
- O Sustainability of PPI activities
- O Change in process for design of facilities
- O Change in location/access to services
- O Provision of additional services
- O Improved dialogue between professionals and service users
- O Other (Please specify)

- O Other (Please specify)

- O Other (Please specify)

What PPI participant outcomes and impacts were included in the evaluation? (Please indicate all that apply)

- O Increased knowledge of services
- O Perceptions of being listened to
- O Perceptions of having given something back
- O Perceptions of feeling overburdened
- O Increased satisfaction with services

- ○ Perceptions of feeling marginalised in the PPI process
- ○ Lack of follow through on decision(s) by organisation
- ○ Increased skills
- ○ Patient/client/carer empowerment
- ○ Change in confidence levels
- ○ Change in levels of trust between professionals and service users
- ○ Capacity building
- ○ Improved dialogue between professionals and service users
- ○ Improved dialogue between patients and other patients e.g. peer support group
- ○ Improved understanding of the determinants of ill health
- ○ Increased ownership of and compliance with treatment plans
- ○ Increased sense of responsibility for own health and social wellbeing
- ○ Other (Please specify)

- ○ Other (Please specify)

- ○ Other (Please specify)

Was an evaluation report produced?

- ○ Yes
- ○ No
- ○ Not sure

How was the evaluation report disseminated? (Please indicate all that apply)

- ○ Via email to all staff
- ○ Via staff meetings
- ○ Presented to Senior Management Team meeting

- ○ Via staff newsletter
- ○ Via PPI workshops
- ○ Via poster
- ○ Presented to organisation's Board
- ○ Was not disseminated
- ○ Dissemination pending
- ○ Other (Please specify)
- ○ Other (Please specify)
- ○ Other (Please specify)

Were the findings from the evaluation used to inform future practice in the area of PPI?

- ○ Yes (Please state how used)
- ○ No
- ○ Not sure

In your view, what were the reasons for not undertaking an evaluation of PPI activities? (Please indicate all that apply)

- ○ Lack of funding
- ○ Lack of time
- ○ Lack of staffing resources
- ○ Evaluation not included at planning stage for PPI activities
- ○ No known reason
- ○ Other (Please specify)

○ Other (Please specify)

○ Other (Please specify)

The remaining questions will help us to use your experiences of PPI to consider how PPI could be developed within organisations who plan and/or delivery health and social care services.

In your opinion, what difference, if any, has PPI made to the planning and/or delivery of services in your organisation?

Please tell us about any lessons you have learnt in relation to PPI activities.

Please indicate the perceived benefits and limitations of PPI.

Please tell us of any examples of good practice in PPI you are aware of within or outside your organisation.

Please include here anything further that you wish to add with regard to PPI activities in your organisation.

Thank you for your time and cooperation in completing this questionnaire.

In the second phase of this study we will be undertaking a limited number of focus groups to explore some of the responses from the survey in more depth. If you would like the opportunity to participate in one of the focus groups, please contact Dr Joe Duffy for further information using the contact details below.

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Appendix 4: PPI Implementation in HSC Trusts

Trust	Director PPI Lead	Non- Ex Director for PPI	PPI Operational Lead	Accountability arrangements
Belfast	Medical Director	Yes	Senior Manager for PPI and Community Development	PPI is reported on at the governance and accountability meetings of each Directorate Equality, Engagement and Experience group provide regular reports to Trust Board
Northern	Director of Nursing & User Experience	Yes	Trust Clinical & Social Care Governance Manager	Quarterly PPI Steering Group reports to Senior Management Team, User Feedback and Involvement Committee (subcommittee of Trust Board) Trust Board receives regular up-dates and formally approves the Trust's PPI Annual Report. All Trust Board meetings include a presentation from a service user or carer of their experience
South Eastern	Director of Planning, Performance and Informatics	Yes	Corporate Planning and Consultation Manager	PPI Sub –Committee reports to Safe and Effective Care Committee which reports to Governance Committee which reports to Trust Board
Southern	Director Older People and Primary Care	Yes	Head of Service User Involvement and Community Development.	Quarterly reports to Patient Client Experience Committee which is subcommittee of Trust Board. Trust Board receives regular up-dates and formally approves the Trust's PPI Annual Report. All Trust Board meetings include a presentation from a service user or carer of their experience
Western	Director of Performance and Service Improvement	Yes	Head of Service Equality, Human Rights and PPI	PPI Forum reports to Governance Committee which reports to Trust Board
NI Ambulance Service	Medical Director	No	Assistant Director Human Resources, Equality, PPI and Patient Client Experience	Quarterly reports to Equality and PPI Steering Group (sub-committee of Trust Board)

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