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

SUMMARY REPORT

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Your voice in health and social care

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Summary

This report details the findings from research conducted across Northern Ireland's five 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.

Methodology (How we did the Research)

A group made up of academic staff from Queens University and Ulster University, Health and Social Care 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 spirit, 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)[1], 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. [2]

In addressing the previously stated research objectives, the team applied a *mixed methods* approach (different ways of gathering research information) using both *quantitative* (information expressed through statistics) and *qualitative* (information expressed as thoughts, opinions and ideas) methods to gather *data* (information) from key participants across

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[1] 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.

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

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
- 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

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[3]=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 also shaped by the findings from both the literature review and on-line survey. Purposive sampling [4] 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.

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[3] n = number.

[4] 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.

Meeting the Research Objectives

As mentioned already, the research was based around five 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 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 be proud of 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).

The following is one example of good practice in PPI from our research.

Resettlement from Learning Disability Hospitals in Northern Ireland: Ensuring Betterment, Parity and Learning

Following a decision by the Department of Health to resettle all long-stay patients from the three learning disability hospitals in Northern Ireland to accommodation offering a better life for the patient, the Trusts involved in partnership with the Health and Social Care Board and Disability Action developed a "Betterment Document". This would ensure that a person-centred approach was used throughout the process, there was accessible and appropriate information available, discussions were informal and that sufficient time was provided for people to consider their options and articulate their views.

Resettlement was to offer "betterment" for the patient by being clinically appropriate, meeting the patient's needs, and offering the potential to better the life of the patient. A range of engagement methods were used depending on the needs or preference of the individuals involved. The nature of the engagement often developed from an individual's or family's desire for privacy around what they identified as very sensitive and emotional issues. While this required a great deal of 1-1 work it allowed for individualised information to be imparted in a safe, non-judgemental environment. As a result of this transparent and inclusive, person-centered process Resettlement was completed ahead of schedule and almost 2 years on everyone remains in placement.

An evaluation of the project from an Independent Advocacy perspective concluded that the Betterment Documentation: helped prioritise individual and family views and increased ownership of services, increased levels of accountability, helped to reduce the perceived power imbalance between the service user / families and 'the bosses', helped to reduce complaints and deal more effectively with concerns at a local level and in a way that empowers rather than dis-empowers the service user and keeps the clear human rights of the individual to the forefront.

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 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, 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 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).[5] 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.

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[5] 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.

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 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	**On Line Survey**	**Literature Review**
Focus Groups are symbolised by:	On Line Survey is symbolised by:	Literature Review is symbolised by:
		

Research Recommendations

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[6].

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.

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[6] 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 utilized 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.

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.

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. 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.

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 one of the focus groups about the profoundly positive impact PPI had on one person'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."

Notes

Notes

Personal and Public Involvement (PPI)

Involving you, improving care

HSC Public Health Agency

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Tel: 0300 555 0114 (local rate).
www.publichealth.hscni.net

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