Valuing people, valuing their participation

Consultation document

A strategy for Personal and Public Involvement for the Public Health Agency and Health and Social Care Board
**Personal** refers to service users, patients, carers, consumers, customers, relations, advocates or any other term used to describe people who use Health and Social Care (HSC) services as individuals or as part of a group, such as a family.

**Public** refers to the general public and includes community and voluntary groups and other collective organisations. Individuals who use HSC services are also members of the general public.

**Involvement** means more than consulting and informing. It includes engagement, active participation and partnership working.
What is Personal and Public Involvement?

This strategy is about how we plan to improve our way of working with local people and groups to improve health and social care services.

Health and Social Care (HSC) organisations deliver services to people and communities that make a real difference to quality of life. People’s experiences and interactions with the HSC are instrumental in shaping their health and social wellbeing.

Personal and Public Involvement (PPI) is about service users, carers and the public influencing the planning, commissioning and delivery of HSC services in ways that are accessible and meaningful to them. PPI is also about involving local communities and the general population in issues of broad public interest, such as the location or nature of local services.

PPI is not a new concept. The HSC system in Northern Ireland has worked with service users and the wider public for many years. The health improvements to be gained by working in this manner are clear. These include:

- Increased ownership
- Increased self responsibility
- Responsive and appropriate services
- Better priority setting and decision making
- Reduced power imbalances
- Help tackling health and social wellbeing inequalities
- Reduced and transformed complaints
- Patient knowledge and expertise is recognised
- Increased levels of service satisfaction
- Rights are acknowledged
- Increases accountability
- Dignity and self-worth
- Increased staff and patient morale

Find out more about these in Appendix 1.

The Department of Health, Social Services and Public Safety (DHSSPS) has outlined a set of PPI core values and principles to which all HSC organisations are expected to adhere.

The core values of PPI are:

- dignity and respect;
- inclusivity, equity and diversity;
- collaboration and partnership;
- transparency and openness.
The 12 principles of PPI are:

1. leadership and accountability;
2. part of the job;
3. supporting involvement;
4. valuing expertise;
5. creating opportunity;
6. clarity of purpose;
7. doing it the right way;
8. information and communication;
9. accessible and responsive;
10. developing understanding and accountability;
11. building capacity;
12. improving safety and quality.

You can find out more about the core values and principles in Appendix 2.
Why do we need Personal and Public Involvement?

Under the *Health and Social Services (Reform) Northern Ireland Act 2009*, Health and Social Care organisations have a statutory requirement to deliver on Personal and Public Involvement (PPI).

To meet this requirement, HSC organisations will actively engage with those who use our services, carers and with the general public.

PPI is not, however, a one-off project or exercise; it must be rooted in the culture of our organisations. It must be a part of our everyday working practice, underpinning everything we do.

Many opportunities exist to incorporate PPI practice and principles into the everyday work of the HSC, most of which is focused on the direct provision of services to individual service users.

Adoption of PPI will have the greatest impact where this direct provision takes place: GP surgeries, outpatient clinics and through patient and carer interaction with doctors, nurses, allied health professionals and social services professionals.

This is where through PPI we have the greatest opportunity to make a difference to the experience of service users.

However there are also opportunities for PHA and HSCB staff at all levels to incorporate PPI into our work with service users, carers, the community and voluntary sector and the wider public.

The Boards of Directors of both the PHA and HSCB are committed to making PPI central to how we work. This means talking to those who use our services and the general public about:

- their ideas;
- our plans;
- their experiences;
- our experiences;
- why services need to change;
- what people want from services;
- how to make the best use of resources;
- how to improve the quality and safety of services.
Development of this strategy

The PHA and the HSCB have developed this strategy to provide guidance to our staff on how to incorporate PPI into their work in a way that best benefits service users.

To develop this strategy we reviewed relevant literature and PPI strategies from both current and legacy organisations. We also looked at existing good practice in the HSC.

We consulted with HSC staff, service users, carers and community and voluntary sector representatives by holding workshops and interviewing key people. We especially sought input from marginalised and excluded groups.

A vision for PPI

The Public Health Agency and Health and Social Care Board are committed to embedding Personal and Public Involvement into our culture and practice. Personal and Public Involvement approaches will be adopted to encourage more open, accountable and collaborative commissioning, service planning and delivery, with well-informed service users. Carers and communities supported to actively take part in that process.
How we will implement PPI

Following our review of the available evidence, the PHA and HSCB believe that PPI is central to the effective commissioning, design, delivery and evaluation of services. The best way to implement PPI is to actively seek the views and opinions of service users and the general public. Their views should be listened to and acted upon through an appropriate mechanism or structure.

This approach allows service users, carers and the general public to influence and advise on the commissioning and delivery of services while also considering the professional input of HSC staff, alongside other factors such as our statutory obligations and available resources.

The PHA and HSCB recognise that there are excellent examples of successful PPI approaches already in place throughout the HSC, improving the health and social wellbeing of service users and the general public.

The PHA and HSCB will learn from these, while also supporting, complementing and building upon them.

The PHA and HSCB will look for opportunities for collaborative working within the HSC and outside it.

This strategy sets out six priorities for the incorporation of PPI into our work. These are:

- **Cultural integration of PPI**
- **Awareness and understanding of PPI**
- **Training and skills development**
- **Impact measurement**
- **Stakeholder support**
- **Communication and coordination**

Each of these priorities is explained in greater detail below. We will also prepare an action plan for making each happen.
Priorities

Cultural integration of PPI

The PHA and HSCB will commit to supporting a culture change that leads to full integration of PPI into our work. This will involve:

- formal adoption of this PPI strategy and its recommendations;
- development of an action plan to integrate PPI into our work;
- establishment of a PPI steering group across both organisations;
- identification of PPI leads at senior management level and in each directorate and team;
- inclusion of PPI as a core duty in job descriptions;
- incorporation of PPI objectives into the PHA and HSCB corporate and business plans;
- development of a method of showing compliance with PPI in the commissioning, design and implementation of services.

Awareness and understanding of PPI

The PHA and HSCB will commit to ensuring that staff are aware of and understand the value of PPI. This will involve:

- investing in a systematic and continuous improvement in understanding of PPI theory and practice;
- improving the awareness of staff of our collective and individual responsibility to involve services users and the general public in a meaningful way;
- ensuring that staff understand the core values of PPI and the benefits of PPI;
- ensuring that staff are aware and understand that the involvement processes should happen at a number of levels: individual, service user, carer, community and general public.

Training and skills development

The PHA and HSCB will commit to training staff, service users and the general public in the skills necessary for effective PPI. This will involve:

- working with staff, service users, the general public and key partners such as the Patient and Client Council and the community and voluntary sector to train individuals, service users and the general public;
- developing training for staff and helping service users, carers and the general public access training;
- finding ways to contribute to the training and professional development of future and existing clinicians and HSC professionals and practitioners;
- identifying staff with significant relevant expertise and helping them to act as advisers for others;
- familiarising staff with existing PPI tools and updating these if necessary;
- investigating new ways of involving service users and the general public, such as social networking;
Impact measurement

The PHA and HSCB will commit to developing a robust and consistent system for measuring the impact of PPI. This will involve:

- gathering both quantitative and qualitative evidence of the impact, change, added value, and/or outcomes of PPI;
- developing a set of standards based on the PPI core values that HSC organisations and staff will be expected to comply with;
- measuring the extent of culture change within the PHA and HSCB;
- ensuring that leadership and accountability continues to come from the Board members and senior staff of the PHA and HSCB, with support from the Regional HSC PPI Forum.

Stakeholder support

The PHA and HSCB will commit to supporting stakeholders. This will involve:

- developing and providing ongoing support and training programmes;
- developing a single equitable reimbursement scheme;
- developing a checklist of practical arrangements for staff when working with stakeholders;
- developing partnerships with community and voluntary sector groups to support stakeholders;
- ensuring local people are effectively supported to influence local commissioning.

Communication and coordination

The PHA and HSCB will commit to clear communication and effective coordination regarding PPI. This will involve:

- developing a communication strategy;
- keeping our key messages consistent;
- developing partnerships to share information;
- investigating the potential redesign of the Engage website as a learning platform;
- examining ways in which the PHA and HSCB can coordinate our involvement and engagement exercises.
**Action plan**

To help incorporate PPI into our work, we will develop an action plan during 2011/12. The action plan will consider opportunities for collective action to deliver on common strategic objectives. Steps will be outlined for joint partnership working. The suggested action plan format is included in Appendix 3.

The action plan will include:

- actions to meet the recommendations of this strategy;
- timescale for delivery of actions;
- lead responsibility for implementing each action;
- performance indicators.

External partner organisations may wish to use this framework to demonstrate how their existing PPI plans fit with the aims, priorities and recommendations of this strategy.

It will be important to develop a realistic action plan which reflects and acknowledges its current position and which builds on existing structures, activities and approaches.

The PHA and HSCB Joint PPI Implementation Group will be the vehicle through which the action plan will be developed and progress monitored.

The approach which is suggested is one of effective and structured internal organisational reporting, supported by adoption of and measurement against standards and protocols. This would in turn then be peer reviewed through the Joint PPI Implementation Group, with sharing of and learning from best practice. The Annual PPI Progress Report would also be viewed as a means of demonstrating progress to the DHSSPS and to service users and the general public.

The action plan needs to show that it has a mechanism to accommodate feedback and to demonstrate how feedback will be accounted for and considered in keeping the document up to date and appropriate to the evolving needs of service users, carers, advocates, the wider public and HSC organisations and staff.
Conclusion

We want to hear what you think about this strategy, and your ideas on how we can better meet the needs of service users and the general public.

Key consultation questions

1. Have we made it clear what Personal and Public Involvement is, what benefits it can bring and why we think it is important?
   - If yes, have you any further comments?
   - If no, where do we need to provide further information?
2. We identified six priority areas to take PPI forward. Are there other areas that you think we should consider?
3. The detailed recommendations under each key area will form the basis of the actions we need to take to deliver on these areas. Do you think that they will help us do that? Are there other things we need to do?
4. Can you identify any outcomes that will demonstrate how PPI has made a difference in health and social care?
5. Have you any examples of good practice in PPI at any level that you would be willing to share with us for possible inclusion in the strategy?
6. Is there any area of the strategy that could be improved/needs further explanation? If so, please tell us about it.
7. The PPI strategy has been equality screened. The results of the screening are available for you to consider. We have concluded that the strategy promotes equality and human rights. What do you think? Are there other actions we should consider including?
8. Have you any other comments that you would wish us to consider in relation to the PPI strategy?

Responses should be sent by 4pm on Thursday 15 September 2011:

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Appendix 1

Detailed explanation of the difference PPI can make

Increases ownership

By enabling service users and the public to influence the HSC agenda, we can foster ownership of and commitment to HSC services. Decisions regarding changes to services are more likely to be viewed positively and accepted if people have had a role in making those decisions.

 Increases self responsibility

PPI promotes and facilitates constructive partnership working. Better informed service users make more informed choices and more appropriate use of services. As their contribution is valued, they more fully appreciate the importance of and benefits to be secured from taking more responsibility for their own health and social wellbeing.

Responsive and appropriate services

If services are to be needs led, then it is vital that service users and the wider community are facilitated in articulating those needs and their views on existing services. Through such involvement, services are more likely to be viewed as being responsive to need and coming from the community. They are more likely to be tailored to specific circumstances and capable of being flexible and responsive to change in need.

Helping priority setting and decision making

Treating service users and the public as partners in the process contributes to consensus, and acceptance of priorities and decisions. It does not always secure this, especially if people perceive that services are being altered in a way that they don’t like. Excluding people from important issues which directly affect their lives, however, tends to result in rejection of those decisions, frustration and even resentment.

Reduces power imbalances

A balanced relationship between service provider and recipient creates a more conducive environment for the application, administration, acceptance and implementation of agreed plans, resulting in more effective outcomes. It represents a move towards the concept of joint or communal responsibility.

Helps tackle health and social wellbeing inequalities

PPI is critical in the reduction of health inequalities and social exclusion. Through involvement of service users and the community who are regarded as marginalised and excluded, we will better understand the rationale for the difficulties they face and will be better informed as to how we might work with those individuals, communities and other partners to address some of the root causes of those inequalities that they face.
Reduces and transforms complaints

If PPI principles are applied when specific issues of concern arise and people are listened to and their concerns taken seriously and addressed, complaints, as might be expected, tend to be lower. This allows people to work collectively for service improvement rather than dealing with formal complaints which are time and often resource intensive.

Recognises patient knowledge and expertise

Service users know what it feels like to be ill and have detailed knowledge to enable them to advise on their experience in relation to the progression, regression, and impact of the illness and any treatment. These experiences should be valued and should be sought at all stages of someone’s journey through the HSC system. It can provide valuable insights into the illness to help inform the opinion and treatment options being considered by HSC professionals.

Increases levels of service satisfaction

Where PPI values and principles are adopted and are evident in the relationship between the HSC professional and the service user, increased levels of satisfaction are consistently shown.

Acknowledges rights

The Patients Charter back in 1991 gave patients the right to have any proposed treatment including risks involved and any alternatives explained to them before they decided about consent. People are now more willing to question professional views and opinions and have now come to expect policy and service decisions to be formally consulted on. With regards to their own personal health and social care requirements, treatments and so on, people expect these to be discussed and agreed with them. The new statutory requirement for involvement can readily be met, if HSC organisations formally and genuinely adopt and practice PPI values and principles.

Increases accountability

Increased accountability of public services improves public confidence and reduces any sense of “democratic deficit”.

Dignity and self-worth

For service users and their carers, being actively and meaningfully involved demonstrates the respect that the HSC has for people. The PPI values and principles if truly embedded and adopted into HSC culture and practice contributes to a sense of dignity and self worth amongst service users, carers and the wider public.

Increases staff and patient morale

If there are less complaints, increased levels of service satisfaction, evidence of a real value placed on genuine involvement and partnership working, this all contributes to increased staff and patient morale.
Appendix 2

Explanation of PPI values

Dignity and respect

Each person is treated with dignity and respect. This includes individual responsibility to respect the views of individuals, communities or HSC staff.

Inclusivity, equity and diversity

The PPI process should facilitate and encourage the inclusion of all those who need to be involved and who chose to do so. It must be sensitive to the needs and abilities of each individual. Each person’s background, culture, language, skills, knowledge and experience will be valued, accommodated and respected.

Collaboration and partnership

The PPI process is based on collaboration and partnership working. Each person has a responsibility to build constructive relationships with others involved in the process.

Transparency and openness

The PPI process should be open and transparent. Each person has a responsibility to be open and honest in their interactions and relationships with others.

Explanation of PPI principles

Principle 1: Leadership and accountability

The commitment to PPI will be reflected in the leadership and accountability arrangements in HSC organisations.

The leadership for PPI within organisations will be the key to creating the culture and environment whereby organisations can show they are accountable to the populations they serve.

This requires establishing and maintaining clear lines of responsibility and accountability for the planning, implementation, monitoring and evaluation of PPI activity as part of corporate governance arrangements within the organisation.

Principle 2: Part of the job

PPI is the responsibility of everyone in HSC organisations. PPI needs to be seen as the job of all involved in HSC organisations, integral and not incidental to their daily work. PPI should be part of staff development and appraisal.

PPI has significant implications for the way staff carry out their roles and responsibilities and their attitudes to the people who use the service. Recognising and seeking to minimise the power differential between those who provide the services and those who use the services is the first step.

PPI requires staff to be confident and competent in engaging with individuals and the public in ways that respect them as active partners with a right to be involved and voice their views about services.
Principle 3: Supporting involvement

Appropriate assistance is required to support and sustain effective PPI.

Successful PPI requires building the capacity of people to get involved as well as building the capacity of staff to involve individuals who use the services and the wider public.

The process of PPI needs to be supported by the organisation with dedicated time and resources to make it happen. Resources may include staff time, training and development and practical or financial support.

This requires PPI to be part of organisational planning and management processes including budgets, workloads and training plans to ensure the organisation’s commitment to PPI can be sustained.

Principle 4: Valuing expertise

People have expertise whether by experience, by profession or through training which should be valued.

The experiences and views of all participants are valid and should be respected.

It should be recognised that people may have different viewpoints. Understanding different, and at times, competing viewpoints and recognising that decision-making is complex and may involve hard choices is part of involvement.

Decisions should take account of the views and opinions of individuals, the public and professionals.

This requires information sharing and dialogue between individuals, communities, and those planning, commissioning and delivering services including policy makers.

Principle 5: Creating opportunity

Opportunities should be created to enable people to be involved at the level at which they choose.

PPI can occur at different levels:

- **Personal level** – being involved in plans, decisions or giving feedback about the individual care or treatment plan for themselves or for someone they are caring for;
- **Commissioning level** – being involved in the planning and commissioning of services to meet agreed local and/or regional needs;
- **Delivery level** – being involved in plans, decisions and giving feedback about the ways in which the services are run;
- **Monitoring and review level** – being involved in monitoring and review of the quality and effectiveness of services;
- **Policy level** – being involved in developing local regional policies.

The number of people who volunteer to give substantial amounts of time to PPI will always be limited and as such they are a valuable resource. They may not, however, be fully representative of the population profile. Opportunities, therefore, need to be created to enable a wide range of people to be involved who are representative and have a legitimate interest in the work.
Opportunities also need to be created to promote engagement with under-represented or unrepresented groups, including those who do not normally get involved or who may find it hard to give their views, for example because of age or ability. PPI needs to be flexible enough to adapt to the needs of those who need to be and wish to be involved. Some people may choose not to be involved and this choice should be respected.

**Principle 6: Clarity of purpose**

The purpose and expectations of PPI are clearly understood. Each PPI activity needs to have clear objectives, realistic timeframes and a shared sense of purpose communicated to all participants from the outset. Clear, succinct and understandable information needs to be available at the point of invitation to enable participants to make an informed decision about being involved, to be clear about expectations of involvement and to contribute meaningfully. People’s right to confidentiality and/or anonymity should be made explicit from the outset.

The purpose of the PPI activity will inform who should be involved. Decisions about who needs to be involved will depend on what you are asking people to be involved in and why. The aim is to gain the best representative spread of views from those who are affected or may be affected by the service or issue under discussion. Other individuals or groups (or representatives of these) who have a legitimate interest in the work should also be involved.

Decisions about the right time to involve people will depend on the purpose. If people are expected to contribute to planning they need to be involved from the start. However, if the purpose is to consult on proposals for implementation which have already been developed, involvement may come at a later stage. Involvement at an early stage can help prevent misunderstandings or accusations of tokenism at a later stage.

**Principle 7: Doing it the right way**

Different forms of PPI need to be used to achieve the required outcomes and to meet the needs of the people involved.

No single method or approach can be taken to constitute PPI. There are many different ways and methods of involving people from staff showing respect, listening actively and responding to what people say to more formal and explicit methods such as focus groups, citizen’s panels, surveys and community development.

PPI may be a one-off event or a longer term arrangement involving regular dialogue between the organisation and the people involved.

There are a range of targeting methods which can be employed to ensure appropriate representation and a range of voices from self-selection to specific invitation. The choice of method will depend on the earlier decision about who to involve.

Doing it the right way requires practical advice and guidance on the range of methods and approaches including training and development for those responsible for implementing them and learning from good practice both locally and internationally. Partnerships with community groups, voluntary organisation or self-help groups provide an excellent channel to involve a diversity of local voices.
**Principle 8: Information and communication**

Timely, accurate, user-friendly information and effective two-way communication are key to the success of PPI activities.

People need timely information to be able to be involved meaningfully; information needs to be presented in ways that can be understood by the target audience; people need to know how to make their views known, including how to make a complaint; and they need to be informed of outcomes and decisions.

This requires appropriate systems and mechanisms to be in place to facilitate ongoing dialogue and information exchange between participants before, during and after the PPI process.

**Before:** The need for advance information which is clear and focused on the purpose and topic for discussion with sufficient background information to support understanding and meaningful involvement.

**During:** The need for participants to feel they are being actively listened to.

**After:** The need for timely feedback from the involvement activity and the need for follow-up communication on the impact of the involvement on decisions.

**Principle 9: Accessible and responsive**

The organisation’s commitment to PPI will be demonstrated through its recognition of the right of people to initiate engagement with it.

Traditionally, PPI has been shaped around the organisational priorities, rather than the concerns those in a local community identify as important. Organisations need to be prepared to listen to the issues and concerns of individuals, groups or communities.

This requires a more open culture and a willingness to listen to what is important to people.

**Principle 10: Developing understanding and accountability**

People’s understanding of HSC services and the reasons for decisions are improved through PPI activity.

Making decisions about service provision can involve hard choices. The PPI process itself will not necessarily lead to a consensus about what should happen. However, the opportunity to register a viewpoint in a transparent and open process and to hear other viewpoints can foster a greater appreciation of the issues and competing perspectives involved and clarify the choices policy makers, commissioners and service provider's face.

This in turn can lead to a greater understanding of the reasons for decisions and accountability of the decision-makers to make explicit the reasons for their decisions based on evidence.
**Principle 11: Building capacity**

People’s capacity to get involved is increased and the PPI processes are improved through learning from experience.

The experience and learning from being involved should help build the capacity of individuals, communities and staff to be more confident and effective in engaging with and listening to each other. Being involved should help people to better understand the issues and the business of health and social care and to make an informed contribution.

This requires appropriate mechanisms for reviewing and learning from the involvement process and the outcomes of each PPI activity.

**Principle 12: Improving safety and quality**

Learning from PPI should lead to improvements in the safety, quality and effectiveness of service provision in HSC organisations.

PPI should support the clinical and social care governance agenda of developing an open culture that promotes and safeguards high standards and improvements in the safety and quality of services delivered to individuals and communities.

This requires a culture of openness, transparency, listening to the views of individuals, communities and staff, learning from feedback, where appropriate learning from an analysis of complaints, sharing information and working in partnership.

Through a partnership approach with people and communities, HSC organisations can improve the safety, quality and effectiveness of services and make them more accountable to the public. The difference PPI makes to the safety and quality of services should be communicated throughout the organisation to share and encourage good practice.

This requires appropriate mechanisms for evaluating the impact of PPI in improving the safety, quality and effectiveness of health and social care services.
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