

Valuing People, Valuing Their Participation

**A Strategy for Personal and Public Involvement for
the Public Health Agency
and
Health and Social Care Board**

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Foreword

Personal and Public Involvement (PPI) is about involving those who use Health and Social Care (HSC) services, or care for those who use services, with those who plan and deliver services. This involvement can sometimes relate to individuals (personal), or groups, or the wider community (public).

PPI may be a relatively new term, but it is not a new concept. Working in partnership and engaging with those who receive services are nothing new for our staff. The HSC system in Northern Ireland has been involved with service users, carers, advocates, communities and the wider public for many years. We have a rich and hugely productive working relationship with service users, carers, advocates, the Community and Voluntary sector and the public. The benefits for all those involved in this manner have become increasingly evident, especially over recent years.

PPI is a two way process. It is not solely an approach that we use when we want to hear the views of service users and carers on something which we bring to them for their consideration. People are no longer the passive recipients of health and social care services. Increasingly they expect to be actively involved in decisions that affect them. PPI also supports and facilitates service users, carers and the wider public in articulating their comments, feeding back concerns and issues which they want to be addressed.

PPI operates at a number of levels throughout the Public Health Agency (PHA) and Health and Social Care Board (HSCB). These range from one to one interactions with service users and carers, through to engagements aimed at assessing need, to service design and redesign, to service evaluation, to making investment decisions, to influencing commissioning priorities and policy development. These manifest themselves in a variety of formats with the aim of ensuring that PPI values and principles are embedded and mainstreamed into the work of the PHA and HSCB.

The Wanless Reports ¹ and the subsequent Appleby Report ² highlight the need to secure a “fully engaged” public in improving health and social well being. This approach is endorsed in Departmental (DHSSPS) Guidance in 2007 ³ and confirmed in the Health and Social Care Reform Act for Northern Ireland in 2009. ⁴ As a result, the involvement of users and carers is now a statutory duty for all those employed in statutory HSC organisations in Northern Ireland.

This Strategy shows the direction that both the PHA and the HSCB are committed to, in their development of PPI.

To help put PPI into operation from this Strategy, we intend to develop an Action Plan. This is a plan of what we are doing and will do, to make this Strategy a reality, outlining tangible actions that make a real difference for service users and carers and make PPI core to our way of working.

Executive Summary

The PHA working in partnership with the HSCB has developed this Strategy to guide the respective organisations in relation to PPI. This in turn will drive an improvement in our way of working to deliver an enhanced service for service users and carers. The Strategy has the support of the Regional Health and Social Care Personal and Public Involvement Forum, of which all HSC organisations in Northern Ireland are members.

There is a clear rationale for the development of the Strategy with a number of important policy initiatives supporting the adoption of PPI approaches by HSC organisations. There are also many good examples where such an approach can be seen to have a significant impact on the health and social well-being of individuals and the wider public as well as the staff involved. The Strategy recognises the importance of building on good work that is already happening, including learning from previous experience in HSC systems, locally, nationally and internationally.

The Strategy development process included a range of activities, from a review of the policy environment for PPI in relation to health and social well-being, to consultation with HSC staff and with the Community and Voluntary sector and individuals who either use services or care for those who use services. A Public Consultation exercise has also been completed on the Strategy. The feedback has directly influenced the redrafting of this document. A copy of the consultation report is also available to accompany this document on our websites.

The Strategy is based on the following vision, underpinned by a number of core values and principles and identified strategic priorities.

The PHA and HSCB are committed to embedding Personal and Public Involvement into our culture and practice. Personal and Public Involvement approaches will be embraced and operationalised to encourage more open, accountable and collaborative commissioning, service planning and delivery, with service users, carers and communities supported to actively take part in that process.

The Strategy will provide guidance to those who commission, manage, deliver and evaluate HSC services, on how to do so in a way which embraces PPI approaches for the benefit of our service users and carers. Six priority areas have been identified for inclusion in the Strategy. These are:

- **Cultural Integration of PPI**
- **Awareness and Understanding of PPI**
- **Training and Skills Development**
- **Impact Measurement**
- **Stakeholder Support**
- **Communication and Co-Ordination**

These strategic recommendations will be operationalised with the preparation of the Action Plan.

Purpose of This Document

The PHA and HSCB have developed this Personal and Public Involvement Strategy to support our respective organisations to deliver on our statutory requirement to engage service users and carers in our work. It will also provide strategic direction, guidance and co-ordination to PPI activities of the PHA and HSCB, improving our way of working, helping to deliver enhanced outcomes for service users, carers, the public and staff at all levels.

This Strategy represents the basis upon which to build awareness, understanding, and commitment to PPI as a way of working.

The Strategy:

- reflects on what PPI is and the underlying core values and principles;
- demonstrates the rationale for PPI to the HSC system, service users, carers the wider public and staff;
- explains how people were involved to inform the process of Strategy development;
- presents Strategy recommendations;
- offers suggestions for the implementation of the recommendations including a template for the creation of Action Plans aimed at addressing these.

What is Personal and Public Involvement?

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.

PPI can be quite a difficult concept to explain or define. There are various definitions from different sources.

In 2007 the Department of Health Social Services and Public Safety developed a circular entitled: "Guidance on Strengthening PPI in Health and Social Care."³ It outlines a working definition for PPI for use across Health and Social Care:

"Personal and Public Involvement 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."

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 more confidence and more opportunities to

influence the planning, commissioning and delivery of services in ways that are relevant and meaningful to them.

The guidance goes on to provide an interpretation of the terms “Personal”, “Public” and “Involvement”.

“**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, for example a family.

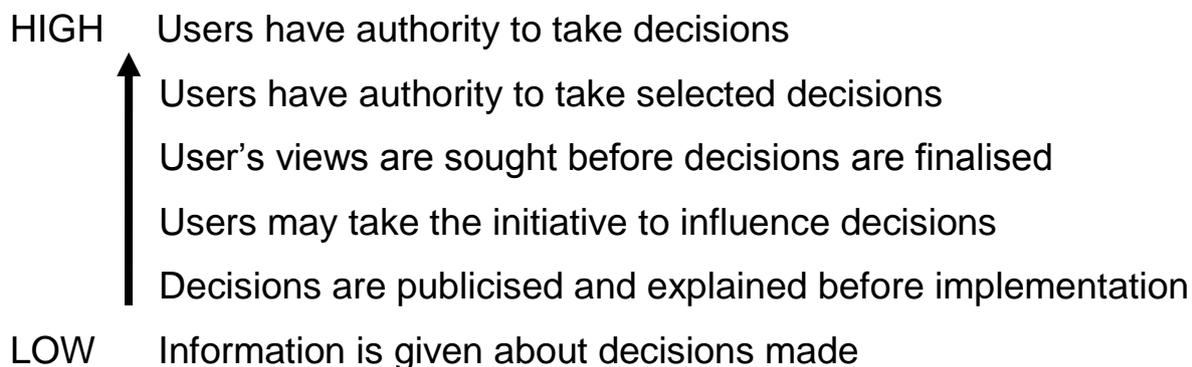
“**Public**” refers to the general population and includes locality, community and voluntary groups and other collective organisations. Individuals who use HSC services are also members of the general public.

“**Involvement**” means more than consulting and informing. It includes engagement, active participation and partnership-working.

There is much literature which seeks to define what “Involvement” is. Various models of Involvement have been developed which attempt to define involvement and yet others which attempt to categorise the different approaches.

Amongst the most well known are the Arnstein “Ladder of Participation” developed in the late 1960s⁵ and the Hoyes “Ladder of Empowerment”⁶ which was developed in 1993 utilising Arnstein’s model as basis.

LADDER OF EMPOWERMENT



In considering the various definitions and models in the literature, a sense can be gained of where the most favourable path would be. The PHA and HSCB believe that meaningful involvement, includes seeking the views and opinions of service users, carers, advocates and the public, listening to and acting upon these, through an appropriate mechanism or structure. This approach facilitates service users and carers to challenge, to influence and advise on the commissioning and delivery of services.

At the same time, it is essential that the professional input of the planner and HSC professional is equally factored into the decision making process, alongside other key considerations such as statutory obligations, resource availability and so on. PPI is about involvement and this requires meaningful engagement and valuing of all those who have signed up to it, workers, staff and managers as well as users and carers, equally.

The PHA and HSCB recognise that we are on a journey and that there are challenges ahead to ensure effective PPI

Personal and Public Involvement Relationships

In the development of this Strategy and the associated Action Plan it is important to recognise that PPI is closely connected to and complements other areas of work within the PHA and HSCB. These include; Quality Improvement, Patient Experience, Patient Safety, Complaints, Community Development, Equality, and Advocacy. All of these contribute to the drive to improve the quality of services in the HSC system. PPI is an integral and crucial aspect of the quality agenda, but also has clear connections to effectiveness and efficiency. Through the implementation of this Strategy and its associated Action Plan, we will work to ensure that there is consistency of approach and shared learning across these areas. See **Appendix 2** for more information about these areas of work.

While this Strategy is focused on PPI within the PHA and the HSCB, it is important to recognise the role of other organisations. In order to coordinate the regional approach to PPI, the PHA has established a Regional Forum which includes membership from across the full spectrum of Health and Social Care organisations in Northern Ireland. The community and voluntary sectors, service users and carers are also involved with the Forum.

The Forum operates through a collaborative approach to ensure the PPI agenda is driven forward across HSC organisations in Northern Ireland. Each organisation, however, retains its own individual responsibility for compliance with Departmental requirements and statutory obligations in respect of PPI.

This includes ensuring the implementation of the DHSSPS *Guidance on Strengthening Personal and Public Involvement in Health and Social Care 2007*³. The guidance specified five quality themes for HSC organisations. These are:

- strengthen PPI in every HSC organisation;
- promote greater uniformity and consistency in PPI activity across organisations;
- improve the quality of the individual's experience of HSC services by involving people in plans and decisions about their own care or treatment and learning from their experiences to improve service delivery;
- ensure HSC organisations take the public's views into account in the planning, commissioning, delivery and evaluation of services;
- support the integration of PPI into individual and organisational clinical and social care governance arrangements within organisations.

The products that emerge from the work of the Forum will be shared with all stakeholder organisations to facilitate their internal accountability and governance arrangements.

Why a Personal and Public Involvement Strategy?

The PHA and the HSCB are committed to promoting a unified approach to PPI. The development of this Strategy sets out our commitment to implement PPI in a meaningful and outcome focused way.

By becoming actively involved in helping to ensure the delivery of this Strategy and working through a PPI approach, Organisations, Departments, Staff teams and individual members of staff will:

- Increase Ownership
- Increase Self Responsibility
- Ensure Responsive and Appropriate Services
- Help in Priority Setting and Decision Making
- Reduce Power Imbalances
- Tackle Health and Social Well Being Inequalities
- Reduce Complaints and Develop a “Comments” culture
- Increase Levels of Service Satisfaction
- Recognise Expertise and Knowledge
- Acknowledge Rights
- Increase Levels of Accountability
- Improve Dignity and Self Worth
- Increase Staff and Patient Morale
- Help Identify and Address Local Needs
- Improve Communication

Further explanation on the benefits of PPI can be found in **Appendix 3**. There is a growing evidence base and body of research which demonstrates the rationale for and benefits from adopting a PPI approach in the commissioning, design and delivery of HSC services. An example of this is “Patient and Public Involvement in Health: The Evidence for Policy Implementation”⁷ published by the Department of Health (DH) in 2004. It is recognised that further locally based research in this field would be beneficial and the Strategy commits the PHA & HSCB to work to develop this area.

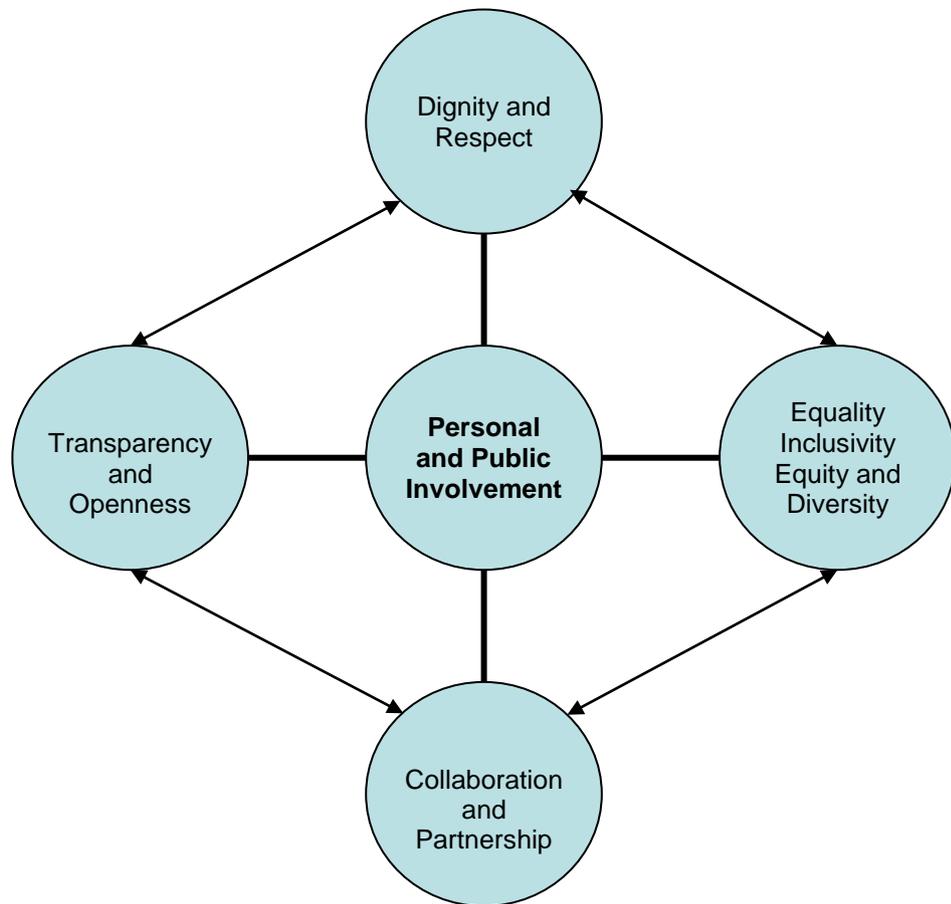
There is also a legislative context for PPI. Under the Health and Social Care (Reform) Northern Ireland Act 2009,⁴ HSC organisations have a statutory requirement to involve service users, carers and the public in the planning, commissioning, delivery and evaluation of services. Furthermore, the Modernisation and Improvement Programme Board (MIPB) in 2009, advised that the PHA would have lead responsibility for policy implementation of PPI given the important links of public involvement with improvements in health and social well being and partnership working. Priorities for Action targets for PPI, established in 2010⁸ also help to set the context for the PHA and HSCB to take forward the PPI agenda.

The involvement of people is not however, a one off project or exercise; it must be integrated in the culture of our organisations. It must be a part of everyday working practice, underpinning all our processes and decisions. It must be an integral part of commissioning, service design, development and delivery.

By committing to and following through on the values and principles of PPI, there are many demonstrable benefits to be secured for the service and, more importantly, for service users, carers and the wider public.

The Departmental Circular of 2007 ³ discussed in more detail under the policy context section outlines a set of core values and principles to which all HSC organisations are expected to adhere.

Core Values



Principles

The 12 principles are set out under three themes reflecting:

1. 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

2. 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

3. outcomes – making a difference.

9. Accessible and responsive
10. Developing understanding and accountability
11. Building capacity
12. Improving safety and quality

Detailed explanations of these values and principles are available within the Departmental Circular and are also summarised in **Appendix 4**.

Developing the Strategy - Methodology

The development of this Strategy has been guided and driven by the PHA working in partnership with the HSCB, operating together through the PHA and HSCB joint Personal and Public Involvement Working Group. The PHA's Regional PPI Lead has been responsible for overseeing the engagement process and for the composition of the Strategy.

Building the Picture

In trying to understand what the Strategy should entail and where it should take us, a complex picture was built up from a variety of sources;

- a review of the key literature, relevant strategies both current and from legacy organisations and the current policy environment was undertaken to clarify the rationale for and define the drivers of a PPI Strategy;
- recognising good practice and seeking to build upon it;
- a range of key stakeholders were approached for their views on the preparation, content and purpose of a PPI Strategy;
- workshops were held during the second half of 2010 specifically for Community and Voluntary sector partners to gain their insight into PPI and what HSC needed to do to embed it into our culture and practice and to make it tangible for people;
- further workshops were held during the first few months of 2011, throughout Northern Ireland, aimed at further involving HSC Staff,

Local Commissioning Group members, the community and voluntary sector, service users, carers and the general public;

- Targeted approaches have been adopted to secure input from marginalised and excluded groups.

Policy Context and Developments

The need for a PPI Strategy is supported by a range of precedents and policy drivers in health and social care. There are a host of initiatives in the legislative, policy and practice arenas, which contribute to the drive for change and have links to PPI. Between them, these impact significantly on the way the HSC conducts its business, on the work of staff whatever their role, and on the role of service users, carers, advocates and key community and voluntary sector partners. What follows is a short reflection on some of these and their link to PPI. Further information is provided in **Appendix 5**.

The Wanless Reports ¹

These reports produced in 2004 and 2005 have been accepted for some years now as major drivers of HSC policy, confirming the imperative to engage the public, and other partners in rising to meet the challenges of poor health and inequalities.

“Achieving the goal of a population ‘fully engaged’ in improving health, to avoid becoming sick rather than treating sickness, is a major prize for the whole community.” Securing Good Health for the Whole Population Wanless, February 2004.

Fair Society, Healthy Lives, The Marmot Review 2010 ⁹

This seminal report which takes a strategic review of health inequalities in England recognises the importance of involvement of service users, carers, the community and wider public. In one of the nine key messages in the report the authors state:

“Effective local delivery requires effective participatory decision making. This can only happen by empowering individuals and communities.”

DHSSPS Guidance Circular HSC (SQSD) 29/07 ³

This circular published in 2007 and currently being reviewed, provides HSC organisations in Northern Ireland with guidance to strengthen and improve service user and public involvement in the planning, commissioning, delivery and evaluation of services as part of their clinical and social care governance arrangements. It sets out the core values and principles which form the basis of this Strategy.

Health and Social Care (Reform) Act (Northern Ireland) 2009 ⁴

In establishing the new HSC structures envisaged through the Review of Public Administration (RPA) this legislation outlined the requirement for PPI in the work of these new organisations. This built upon relevant previous policies, initiatives and equality legislation. It puts involvement on a statutory basis, formally requiring engagement with services users,

carers and the public. It brought into being a new statutory Duty of Involvement for all the main HSC bodies. This required them to involve people at a personal and public level in making decisions about service design and delivery.

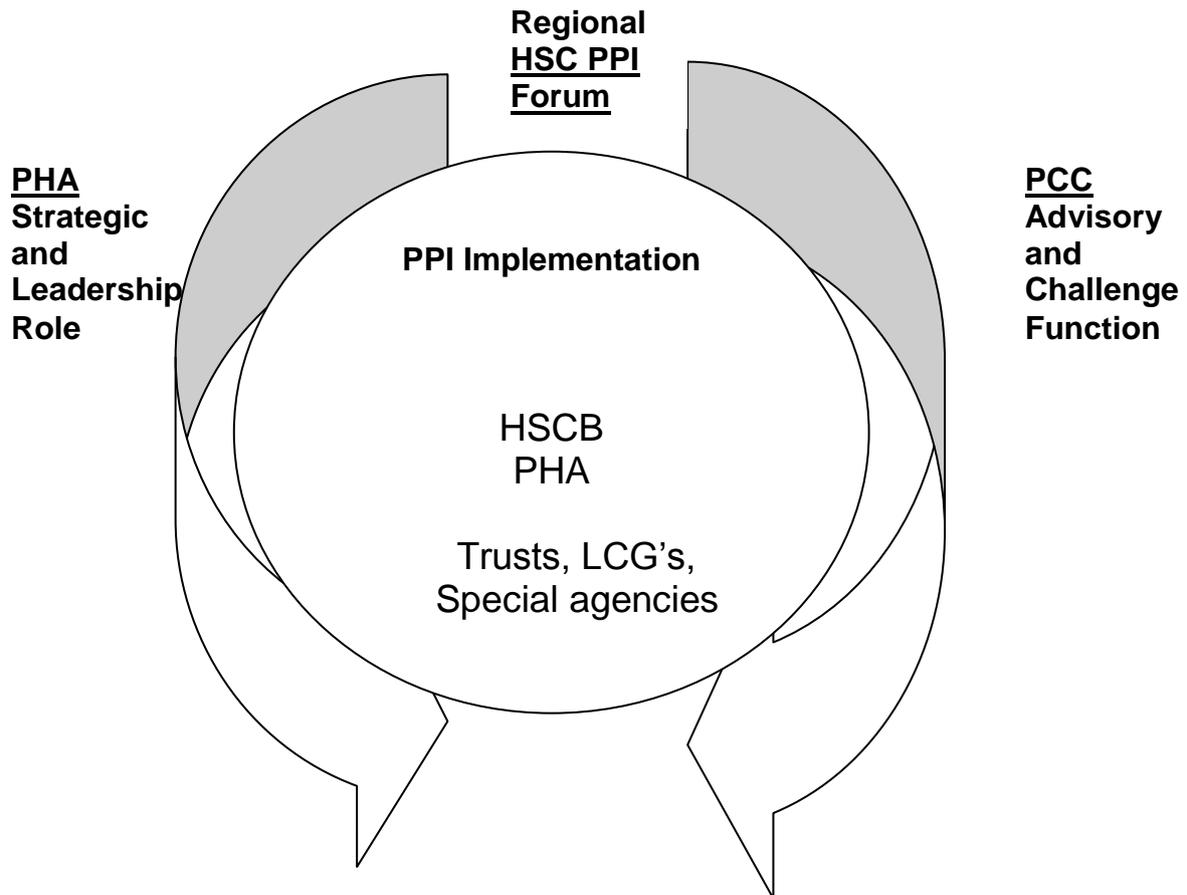
DHSSPS Quality 2020 – A 10 Year Strategy to Protect and Improve Quality in Health and Social Care in Northern Ireland (2011)¹⁰

The Quality Strategy is designed to provide a clear direction over the next 10 years to enable us to plan for the future while ensuring the principle of involvement and the focus on quality is preserved, whatever the challenges faced by the HSC.

Together these initiatives have made a positive impact on safety, effectiveness and patient/client focus. The 10 Year Quality Strategy aims to widen and deepen the impact of PPI over the next decade in terms of protecting and improving quality.

Organisational Context for Personal and Public

Involvement



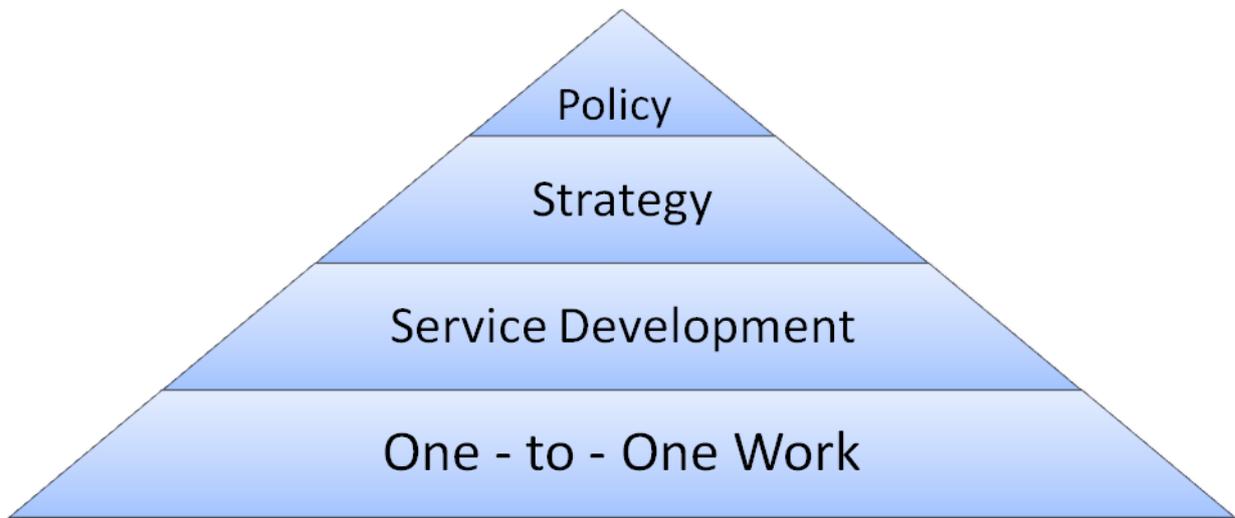
Recognising Good Practice

As has been consistently flagged up during the development of this Strategy, there have been and continue to be, excellent examples of where PPI approaches have been embraced and operationalised. This Strategy seeks to recognise, celebrate and build upon this.

The implementation of this PPI Strategy through the development of a PHA and HSCB joint PPI Action Plan and subsequent PHA and HSCB specific Action Plans will take account of PPI approaches which are already impacting on the health and social well-being of service users, carers and the wider public. The PHA and HSCB need to learn from these, be supportive of them and seek to complement and build upon them.

The Strategy represents an opportunity to bring a renewed focus to the concept and practice of PPI. There needs to be co-ordination of approach, driven by the PHA, particularly with those advocating and taking forward PPI approaches within the PHA and HSCB. There needs to be strong operational linkages established within and between the PHA and HSCB for PPI. Opportunities for joint and collaborative working with those who have Quality Improvement, Patient Experience, Patient Safety, Community Development, Equality, Complaints and Advocacy responsibilities should also be explored.

A variety of opportunities exist to embed PPI practice and principles into day-to-day service provision right across the HSC. The 'levels' at which staff in HSC can use PPI approaches are represented in the following model:



Most of the everyday activity of HSC staff is focused at the base of the triangle with the provision of HSC services to individual service users and carers. The greatest impact that will and can be evidenced through the fullest adoption of PPI, will be where that direct interaction takes place, that is, through patient and carer interaction with Doctors, Nurses, Allied Health professionals, Social Services and other HSC professionals. This is where as a system, we have the greatest opportunity to make a difference to the experience of service users and carers and to maximise the benefits of involvement.

There are also opportunities for PHA and HSCB staff at both commissioning / policy and operational level, to embrace and demonstrate the benefits of PPI to service users, carers, staff and our respective organisations. PPI values, principles and approaches can be realised through our work and interactions with service users, carers, community and voluntary sector and the wider public.

We are not starting afresh. There are established examples of good practice that we can look to. These can be evidenced across the different levels referred to. Some examples are cited in the following pages for consideration. Local Commissioning Groups (LCG's) for example, will play a central role in taking forward PPI at local level, through enhanced engagement with the public in the development of local commissioning plans.

It is important to note however, that there are barriers to PPI that need to be acknowledged and which we must overcome, if we are to genuinely involve service users, carers and the public. Barriers may include lack of knowledge and skills, lack of understanding, time and resource pressures and so on. Any proposed actions must contribute to addressing these barriers.

There are a number of documents which explore these barriers, and approaches to overcoming them in more detail. A number of these publications also provide some practical and tangible guidance on how to actually involve service users, carers and the public.

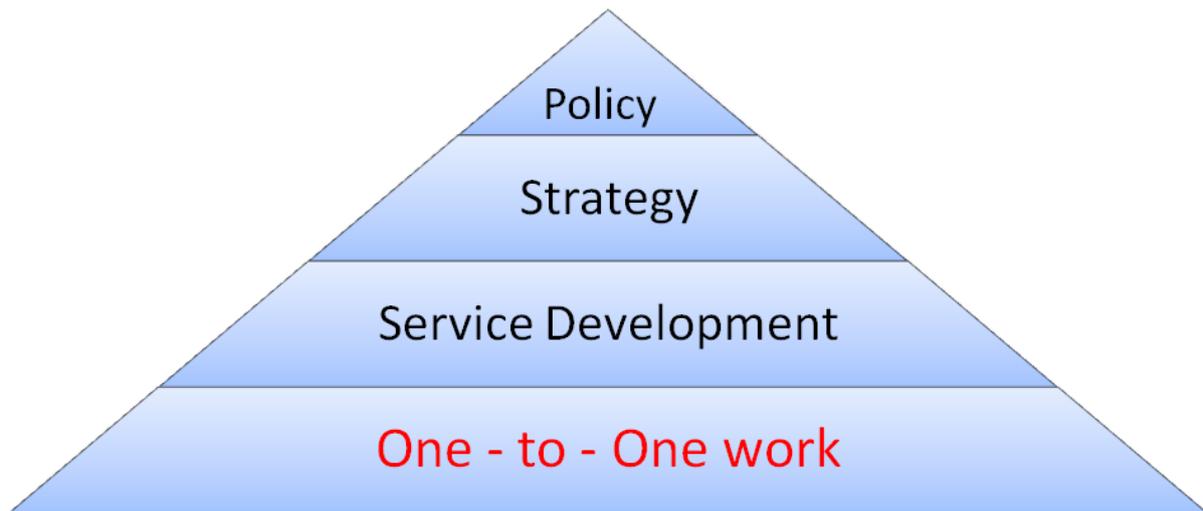
Amongst these are the following:

WHSSB A Guide to Public Involvement and User Engagement, ¹¹

CDHN Commissioner's Guide to Engagement Toolkit, ¹²

The NHSCT Involvement Toolkit ¹³

PPI and One-to-One work



PPI works on a one to one basis across the spectrum of care between service users, their carers and a variety of health and social care professionals. This personal involvement begins at the first appointment / consultation and continues through each individual's journey. Effective PPI at this level is essential to ensure that the views of each person are considered. This facilitates the provision of the highest quality of care and treatment appropriate to meet the needs of service users and carers. Using PPI on a one to one basis gives service users and carers a greater sense of ownership over their treatment and care.

An example of how this one to one involvement can be developed is shown through the Expert Patient Programme (EPP). This initiative was

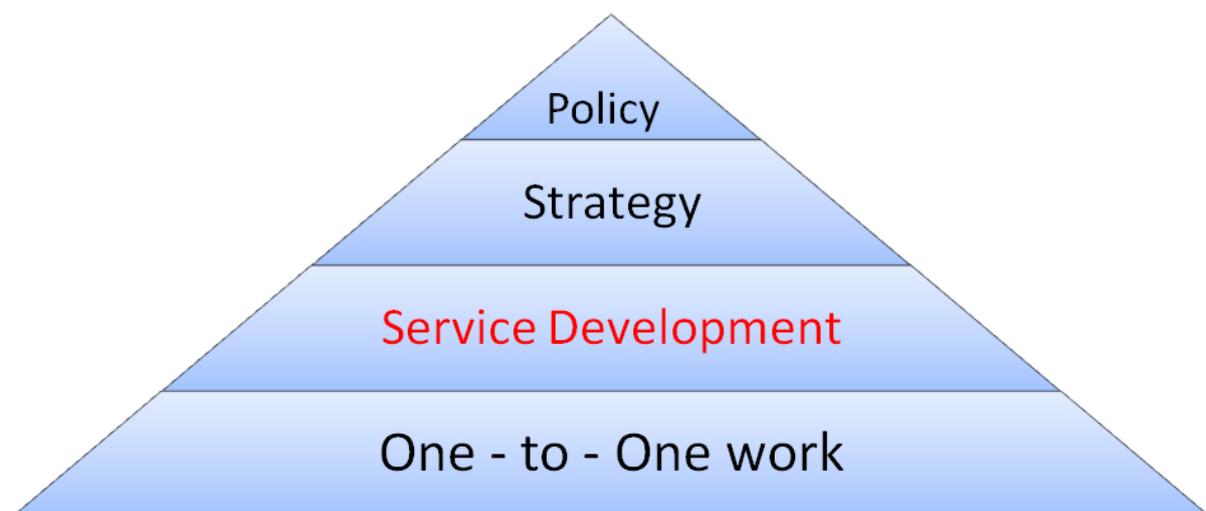
launched in 2002 to help patients with chronic conditions to take control of their lives. The basis of the programme is a training course that teaches people how to manage their conditions by using five core skills.

These are:

- problem solving
- decision making
- making the best use of resources
- developing effective partnerships with healthcare providers
- taking appropriate action

This initiative has been shown to reduce the need for GP consultations and unnecessary hospital admissions for those with chronic conditions. There is mutual learning and respect between the patient and the health and social care professionals for the knowledge and expertise that both bring to the management of the condition.

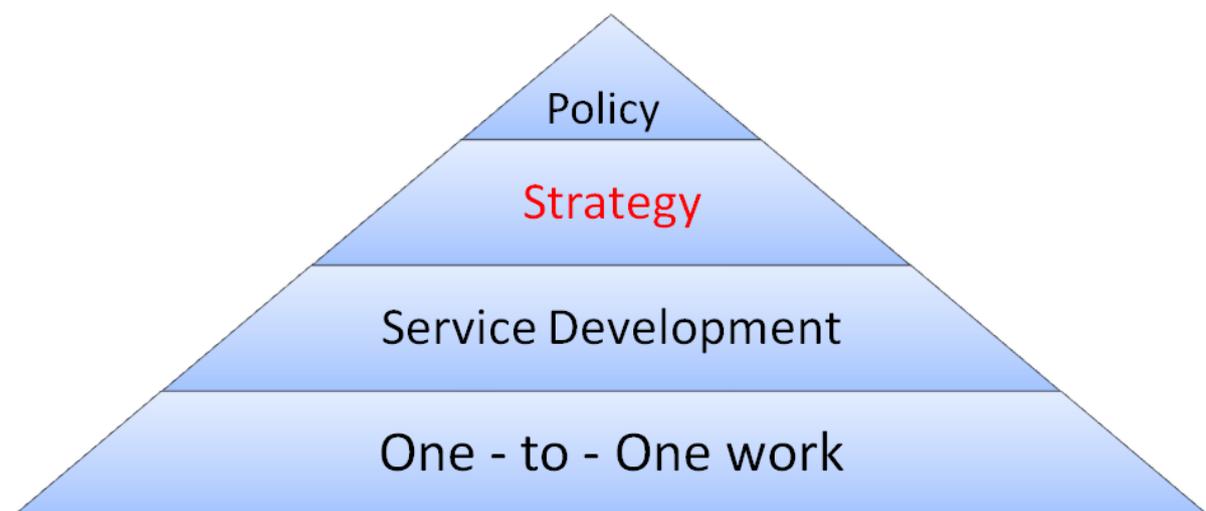
PPI and Service Development



Incorporating PPI approaches to service development is a positive way to introduce the views of service users, carers and the public at the beginning of service design. This approach allows service users and carers to identify what their priorities are in relation to a particular service. It also provides an opportunity to engage with and influence health and social care professionals and commissioners by providing a wider perspective.

An example of this is the work carried out by the Neurological Conditions Network in their “Speak out for Change - Neurological Conditions Survey” which captured the views of over 140 service users and carers to form the basis of recommendations to HSC Commissioners to shape the future of service development for people with Neurological Conditions.

PPI and Strategy Development

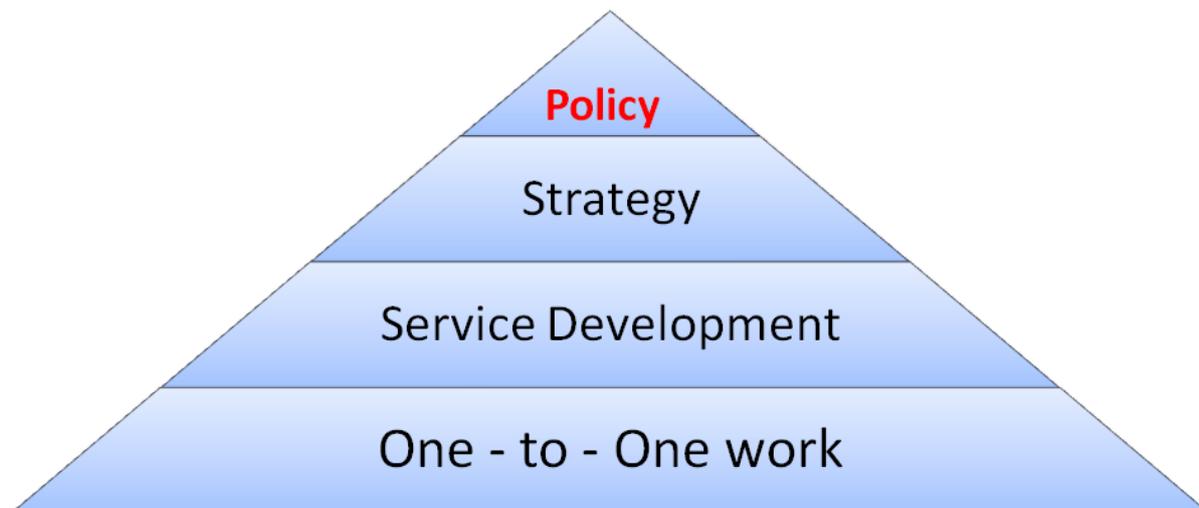


Using PPI approaches at a strategic level provides a tangible example of how PPI can be used to shape the future direction of the HSC. It shows leadership to staff and stakeholders and encourages greater involvement in every other aspect of the organisation or HSC system.

An example of this was the development of the “10 Year Quality Strategy”. This strategy was devised by a project team convened by the DHSSPS. Over 100 people, including HSC staff and service users and carers, came together at four workshops to discuss priorities for safety, effectiveness and patient/client focus. The outputs from each workshop were referred to an international reference group made up of 18 highly respected professionals and academics for quality assurance.

The essence of what was discussed at the workshops was also brought by the Patient and Client Council (PCC) to a wider cross-section of the public (circa 100 people) for comment. Focus group meetings were also held with over 150 frontline staff working in HSC at 10 venues around Northern Ireland. In all, some 350 people, from many different backgrounds, contributed significantly to the development of the quality strategy.

PPI and Policy Formulation



The setting of Departmental policy influences how HSC services are provided. The DHSSPS establish policy across all areas of Health and Social Care. Using PPI approach at this high level not only shows leadership but provides a solid basis for how services are provided across the HSC system..

An example of PPI at this level was shown when in June 2011 the Minister for Health, Social Services and Public Safety, Edwin Poots MLA, announced a review of HSC Services in Northern Ireland ¹⁶. This review examined the provision of a range of health services, including acute hospital configuration and primary health care. The recommendations from this review will form the Policy of the Department in shaping the provision of HSC Services in the future.

As part of the Review the team undertook a process of involvement with stakeholders, including the public; this involved workshops, meetings, a household survey and an online survey. By using PPI at this level, the

review team heard the views of service users, carers and the public and were influenced by their concerns and priorities. This involvement influenced the recommendations for future HSC planning for Northern Ireland, through the publication of the 'Transforming Your Care' Report in December 2011. Moving forward those charged with translating the report's recommendations into actions on the ground are required to develop an Engagement Plan to ensure involvement with stakeholders moving forward.

Analysing the Findings – Identifying Priority Areas

As indicated, a range of evidence to inform the development and content of the PPI Strategy has been collated, reviewed and analysed. From all the information / evidence gathered and analysed, a number of key priority areas of work have emerged.

The priority areas which were identified were as follows:

- Cultural Integration of PPI
- Awareness and Understanding of PPI
- Training and Skills Development
- Impact Measurement
- Stakeholder Support
- Communication and Co-ordination

In addition to these six areas, evidence also suggests that there needs to be:

- an acknowledgement that the process of involvement in itself is also recognised as extremely important ;
- a commitment to the principle of feedback.

A Vision for Personal and Public Involvement in the Health and Social Care

Emerging from experience gathered in this area over many years, the increasing literature and evidence base and the more recent policy developments, the case for PPI is now at its most persuasive and strongest. Reflecting on this and examining the feedback which has emerged through the engagement process for this Strategy and our consultation scheme, the PHA and HSCB have developed a vision for PPI and a series of strategic recommendations to help realise that vision.

“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 embraced and operationalised 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.”

Strategy Recommendations

The key Strategy recommendations previously identified are now broken down into more detail, providing guidance on practical steps which should assist on the delivery of the priority areas.

Cultural Integration of Personal and Public Involvement

The PHA and HSCB will commit to supporting a culture change that leads to full integration of PPI as a way of being and working. This will involve:

- Formal adoption of the PPI Strategy and its recommendations;
- Translating the PPI values and principles into reality through the development and implementation of Action Plans;
- Establishing a Joint PPI Steering Group across the two organisations to drive forward the PPI agenda;
- Identifying PPI Leads at Senior Management level and PPI “leads” in each directorate/ team;
- Including PPI as a core duty in job descriptions;
- Objectives and targets relating to involvement will be incorporated to the PHA and HSCB Corporate and Business plans;
- Developing a Protocol to be used to evidence compliance with PPI for commissioning, (re)design and implementation of services.

Awareness and Understanding of Personal and Public Involvement

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

- Developing a PPI Communication Plan to promote the awareness and understanding of PPI across a wide range of audiences, HSC organisations and staff, service users, carers the public and other stakeholders;
- Investing in a systematic and continuous improvement in understanding of PPI theory and practice;
- Improving the awareness of staff in respect of our collective and individual responsibility to involve and engage services users in a meaningful and tangible way;
- Ensuring that staff understand that the values and principles that underpin PPI and the benefits to be accrued from PPI;
- Ensuring that staff are aware and understand that engagement processes should happen at a number of levels: individual, service user, carer, community and wider public;
- Exploration and building of the linkages with areas which are related to PPI, including; Patient Experience, Patient Safety, Advocacy, Equality and Human Rights, Community Development, Complaints and Volunteering;
- Identification of gaps in research in PPI and work with colleagues, particularly in the PCC to facilitate research in this area.

Training and Skills Development

The PHA and HSCB will commit to supporting staff to understand how to engage. Staff will be supported to acquire and develop the skills necessary and appropriate to their role in this regard. This will involve:

- Developing a training pathway for staff and facilitating access to joint training for service users, carers etc;
- Working with staff, service users and carers and key partner agencies such as the PCC and the Community and Voluntary sector to identify and facilitate the training requirement of individuals, service users, carers and the wider public.
- Examining and availing of opportunities to contribute to the training and professional development of existing and future HSC staff;
- Identifying and supporting staff with significant engagement expertise, to act as mentors and advisers for others;
- Familiarising staff with existing Involvement toolkits and update if necessary;

Impact Measurement

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

- Working with those in the wider quality improvement arena to develop a new or to identify an existing system which captures appropriate quantitative and qualitative information to assist in measuring the effect / impact of PPI in the HSC;
- Gathering evidence of impact, change, added value, and / or outcome of the process;
- Developing a set of standards for DHSSPS consideration, based on the PPI values and principles, that the organisations and staff are 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 developing a range of support for 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;
- Exploring and developing partnerships with community and voluntary sector groups to support stakeholder involvement;
- Local Commissioning Groups will build on and develop appropriate systems to ensure local people are effectively supported to influence local commissioning;
- Ensuring the participation of groups and individuals who are marginalised and at risk of exclusion;
- Investigating new methodologies such as social media / networking, turning point and other innovative technology to support active involvement;
- Ensuring that the feedback loop is closed for each engagement process.

Communication and Co-Ordination

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

- Developing a communication and promotional strategy;
- Developing overarching and consistent key messages for PPI;
- Investigating the possible use of social media and web based platforms as a way of communicating;
- Developing partnerships with a range of organisations to share information regarding PPI;
- Redesign and re-launch the Engage website as a learning and sharing platform;

- Examining ways in which the PHA and HSCB can both internally and collectively co-ordinate our involvement and engagement exercises;
- Examining ways in which the PHA and HSCB can co-ordinate involvement and engagement exercises with HSC Trusts and with other sectors – particularly local government, education and social development;
- Developing a Partnership Plan/methodology to provide guidance and clarity on how the PHA/HSCB will promote partnership working and conduct partnerships with external bodies.

Cross-cutting Strategic Aims

Some cross cutting strategic aims also emerged which need to be factored into any programme of work that the PHA and HSCB devise to drive forward the PPI agenda:

- Identify secure funding streams to ensure that actions within the Personal and Public Strategy and Action Plan can be progressed in a professional and timely manner, working closely with Departmental colleagues to highlight the requirement for funding for PPI across the HSC in Northern Ireland.
- Improve communication internally within the PHA and HSCB and externally with the wider community, with the aim of encouraging involvement and supporting the understanding and promotion of PPI approaches by Health and Social Care.
- Develop an empowering and open approach among PHA and HSCB staff, enabling them to consolidate existing relationships and develop new processes with which to engage with service users, carers, advocates and the wider public.
- Take account of the existing good PPI practice by the PHA and HSCB, and to share the learning from these experiences with others who deliver HSC services.
- Develop a more transparent service which openly shares information about decision-making processes and which welcomes

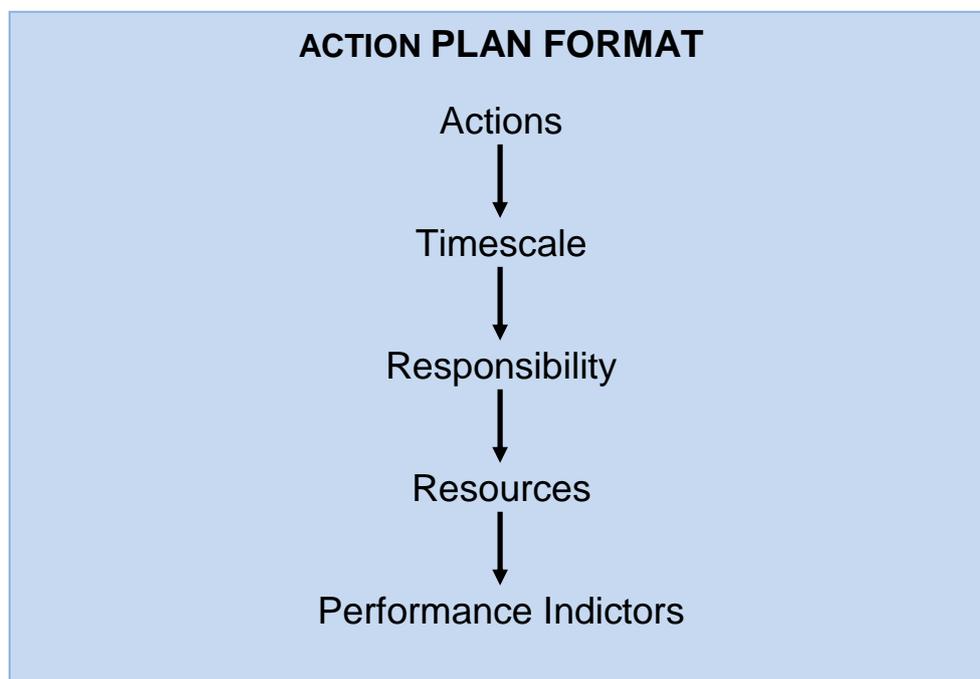
and enables the participation of service users, carers, advocates and the public in those processes.

- Ensure this Strategy is an active, working initiative which permeates all departments and levels within the PHA and HSCB.
- This Strategy will serve as a building block upon which health and social services will be enhanced by virtue of the fact that they are designed, implemented and delivered in such a way as to ensure that every effort is made to inform and involve local people in the process.
- This Strategy will encourage PHA and HSCB staff to welcome the empowerment of service users, carers, advocates and the wider public to challenge and inform policy, strategy and service design, delivery and evaluation.
- PPI will become even more important for our interaction with service users, carers and the public as we plan for the future in an era of restricted financial resources.

Strategy Implementation

This Strategy recognises that PPI should be integral to the work of the HSC system and in particular the PHA and HSCB. There are many instances where it can be readily demonstrated. The Local Commissioning Groups for example, who operate at the forefront of commissioning and are pivotal to taking forward PPI at local level, outlining in their local commissioning plans how service users, carers and the public have been involved in the development of these plans.

An Action Plan will be developed by the PHA and HSCB using the format outlined below. It should consider opportunities for collective action to deliver on common strategic objectives and steps should be outlined for joint partnership working.



The suggested Action Plan format is included in **Appendix 6**

It will include:

- actions to respond to the recommendations of the Personal and Public Involvement Strategy;
- timescale for delivery of action;
- responsibility for implementing each action;
- resource requirement;
- performance indicators, where feasible.

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.

The Action Plan will reflect and acknowledge the current position and build on existing structures, activities and approaches within the PHA and HSCB.

The PHA and HSCB Joint PPI Implementation Group will be the vehicle through which agreement on the best approach for performance review of the Action Plan will be determined. 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 be peer reviewed through the Joint 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, carers and the wider community.

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 it up to date and appropriate to the evolving needs of service users, carers, advocates, the wider public and HSC organisations and staff.

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APPENDICES

Appendix 1

Glossary of Terms

CDHN	Community Development and Health Network
DHSSPS	Department of Health, Social Services and Public Safety
DH	Department of Health - England
EPP	Expert Patients Programme
GP	General Practitioner
HSC	Health and Social Care
HSCB	Health and Social Care Board
LCG	Local Commissioning Group
NHSCT	Northern Health and Social Care Trust
PCC	Patient and Client Council
PHA	Public Health Agency
PPI	Personal and Public Involvement
RPA	Review of Public Administration
SHSCT	Southern Health and Social Care Trust
SHSSB	Southern Health and Social Services Board
SQSD	Safety, Quality and Standards Directorate
WHSSB	Western Health and Social Services Board

Appendix 2

Areas of work which complement Personal and Public Involvement

All of the areas of work below have distinct roles within the HSC system. Aspects of this work are relevant to PPI. We will work with our colleagues to maximise the information and expertise which exists to advance PPI.

Patient Experience

The DHSSPS in partnership with Northern Ireland Practice and Education Council (NIPEC) and Royal College Nursing (RCN) produced a document outlining five patient standards “Improving the Patient & Client Experience” (DHSSPS, 2008)

The five standards relating to: respect, attitude, behaviour, communication and privacy and dignity, clearly state what people can expect from the HSC service. Colleagues gather information from patients to find out how well these standards are being met across HSC through Patient Experience Questionnaires.

Patient Safety & Quality Improvement

The HSC Safety Forum was created in 2007 to support HSC organisations as they strive to provide safe, high quality care. The HSC Safety Forum:

- works collaboratively with stakeholders to assist the drive for improvement in safety and quality in Health and Social Care;
- helps service providers build and develop their quality improvement capability in line with internationally recognised theory and practice;
- facilitates engagement between patients, clients, commissioners and service providers in order to promote safety and quality.

Complaints

Each HSC organisation has a Complaints Policy in place. This means that complaints can be raised by service users, or former service users about the service or treatment they have received.

New arrangements for dealing with complaints became effective from 1 April 2009 and are consistent with "Complaints in Health and Social Care: Standards and Guidelines for Resolution and Learning"

Community Development

Community Development, whilst supporting engagement as a crucial approach, has a clear focus on the development of collective action within communities in order to bring about positive change. It works to ensure that communities are skilled and empowered to identify and help address their own health needs, whilst also building social capital. A joint Strategy for Community Development has been developed between the PHA and the HSCB.

Equality

As public bodies, all HSC organisations are required to promote equality of opportunity and good relations in carrying out our functions, under Section 75 and Schedule 9 of the Northern Ireland Act 1998. We are also obliged to ensure all decisions comply with the Human Rights Act 1998. Everybody in the PHA and HSCB has the responsibility to promote equality and good relations.

Advocacy

The DHSSPS are currently developing a 'Policy for developing Advocacy Services'. The policy is targeted at HSC services in Northern Ireland including the HSC Board, the PHA, LCGs and the five HSC Trusts. It aims to provide guidance on how to provide consistent and quality advocacy across Health and Social Care.

Appendix 3

Explanation of the Difference Personal and Public Involvement can Make

Increases Ownership. By enabling the service user 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 and carers 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 well being.

Responsive and Appropriate Services. If services are to be needs led, then it is vital that service users, carers 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, carers 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 however, from important issues which, directly affects their lives, 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 Well Being Inequalities. PPI is critical in the reduction of health inequalities and social exclusion. Through involvement of service users, carers 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. Services 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 the 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. (Ridley and Jones, 2001)

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 HSC 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 4

Explanation of Personal and Public Involvement Values and Principles

DIGNITY and RESPECT	Using a human rights approach each person is treated with dignity and respect. This includes individual responsibility to respect the views of all be they individuals, communities or HSC staff.
EQUALITY, INCLUSIVITY, EQUITY AND DIVERSITY	The PPI process should facilitate and encourage the inclusion of everyone. 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.

AN ATTITUDE OF MIND, A WAY OF WORKING

Principle 1: Leadership and accountability	
<p>The commitment to PPI will be reflected in the leadership and accountability arrangements in HSC organisations.</p>	<p>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.</p> <p>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.</p>
Principle 2: Part of the job	
<p>PPI is the responsibility of everyone in HSC organisations.</p>	<p>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.</p> <p>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.</p> <p>PPI requires staff to be confident and competent in engaging with individuals and the public in ways that</p>

	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.	<p>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.</p> <p>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.</p> <p>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.</p>
Principle 4: Valuing Expertise	
People have expertise whether by experience, by profession or through training which should be valued.	<p>The experiences and views of all participants are valid and should be respected.</p> <p>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</p>

	<p>the views and opinions of individuals, the public and professionals.</p> <p>This requires information sharing and dialogue between individuals, communities, and those planning, commissioning and delivering services including policy makers.</p>
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Principle 5: Creating opportunity

<p>Opportunities should be created to enable people to be involved at the level at which they choose.</p>	<p>PPI can occur at different levels:</p> <ul style="list-style-type: none"> • 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; and • Policy Level – being involved in developing local regional policies <p>The number of people who volunteer to give substantial amounts of time to PPI will always be limited and as such is a valuable resource. They may not, however, be fully representative of the population</p>
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	<p>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.</p> <p>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.</p>
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DO WHAT YOU DO, DO WELL

Principle 6: Clarity of purpose	
<p>The purpose and expectations of PPI are clearly understood.</p>	<p>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.</p>

	<p>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.</p> <p>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.</p>
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Principle 7: Doing it the right way

<p>Different forms of PPI need to be used to achieve the required outcomes and to meet the needs of the people involved.</p>	<p>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.</p>
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	<p>PPI may be a one-off event or a longer term arrangement involving regular dialogue between the organisation and the people involved.</p> <p>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.</p> <p>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.</p>
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Principle 8: Information and Communication

<p>Timely, accurate, user-friendly information and effective two-way communication are key to the success of PPI activities.</p>	<p>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,</p>
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	<p>during and after the PPI process.</p> <p>BEFORE</p> <ul style="list-style-type: none"> • 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. <p>DURING</p> <ul style="list-style-type: none"> • The need for participants to feel they are being actively listened to; <p>AFTER</p> <ul style="list-style-type: none"> • The need for timely feedback from the involvement activity; and • The need for follow-up communication on the impact of the involvement on decisions.
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Principle 9: Accessible and responsive

<p>The organisation’s commitment to PPI will be demonstrated through its recognition of the right of people to initiate engagement with it.</p>	<p>Traditionally, PPI has been shaped around the organisational priorities, rather than the concerns those in a local community identify as important.</p> <p>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.</p>
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MAKING A DIFFERENCE

Principle 10: Developing understanding and accountability	
<p>People's understanding of HSC services and the reasons for decisions are improved through PPI activity.</p>	<p>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 providers face.</p> <p>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.</p>
Principle 11: Building capacity	
<p>People's capacity to get involved is increased and the PPI processes are improved through learning from experience.</p>	<p>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 HSC and to make an informed contribution.</p> <p>This requires appropriate mechanisms for reviewing and learning from the involvement process and the outcomes of each PPI activity.</p>

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 HSC services.

(Source from DHSSPS Circular: HSC (SQSD) 29/07

Appendix 5

Further Information on Policy Developments Influencing Personal and Public Involvement

The Appleby Report

Commissioned in 2004 and reporting August 2005, this report while examining efficiency issues and the need for increased spending overall, also pointed up the benefits of increased service user and carer involvement and increased patient choice.

Targeting Social Need (TSN), Anti-Poverty and Social Inclusion

New Targeting Social Need, was a policy specifically developed to tackle poverty and social disadvantage by targeting efforts and available resources towards those individuals, groups and areas in greatest need. It is in the key policy areas of targeting need and promoting social inclusion, that the processes of involvement have a critical role.

Following on from New Targeting Social Need was “**Lifetime Opportunities**” the Government Anti-Poverty and Social Inclusion Strategy, which seeks to build upon this approach. This Strategy refers to:

“Greater awareness of the real value of participation in the process of developing policy”

Disability Discrimination Act 1995 and Section 75 Northern Ireland Act 1998

These pieces of legislation progressed the concept of participative democracy significantly in Northern Ireland. Policy and decisions makers were required under these Acts to consider the views of people affected by those decisions and to have due regard to the potential consequences of these. The implementation and effectiveness of these policies requires different ways of working and PPI is an essential component of a broader strategy to progress the objectives of equality, equity, inclusion and human rights.

The Human Rights Act 1998

The Human Rights Act is a UK law passed in 1998 which came into force in 2000. It means that an individual can defend his or her rights in the UK courts and that public organisations must treat everyone with fairness, dignity and respect.

The human rights that are contained within this law are based on the articles of the European Convention on Human Rights. The Act 'gives further effect' to rights and freedoms guaranteed under the European Convention. What this actually means is that it does two things:

- Judges must read and give effect to legislation (other laws) in a way which is compatible with the Convention rights.
- It is unlawful for a public authority to act in a way which is incompatible with a Convention right.

Public organisations also have a duty to promote human rights in their day to day work. Key to this is the need to develop a human rights approach to our work.

The Convention on the Rights of the Child introduced in 1989 and ratified by the UK in 1991

The Convention on the Rights of the Child was the first instrument to incorporate the complete range of international human rights. This included civil, cultural, economic, political and social rights as well as aspects of humanitarian law.

United Nations Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities is an international agreement which came into force in May 2008. It confirms that people with disabilities have the same human rights as everyone else and binds countries to protect those rights. It protects the rights of all people with disabilities in all areas of life including access to justice, personal mobility, independent living and freedom of expression.

Investing for Health

Investing for Health was launched in 2002, reviewed in 2006 and then again in 2010. This approach seeks to build upon World Health Organisation and European policy to drive the strategies of equity, citizenship, multi-sectoral partnership and community participation at national and local level with a view to improving health and social well being and reducing health inequalities. The core values and principles behind Investing for Health reflect those advocated by PPI.

Equality and Excellence: Liberating the National Health Service, July 2010 DoH Whitepaper.

This paper states that “shared decision making” will become the norm. The patient **wants to be** informed and **will be** involved in decisions regarding their care.

No Decision About Me, Without Me. 2010 DoH

“No decision about me without me” will be the principle behind the way in which patients in England are treated. Patients will be able to make decisions with their General Practitioner about the type of treatment that is best for them. Patients will also have more control and choice over where they are treated and who they are treated by.

Whilst the last 2 papers do not pertain to Northern Ireland, nevertheless, they are evidence of the continuing drive towards greater involvement and partnership working between service users, carers, and the HSC system throughout the United Kingdom.

Appendix 6 – Suggested Action Plan format

RECOMMENDATION				
Action	Timescale	Responsibility	Resources required e.g. staff time, financial resources, further guidance?	Performance Indicator/Outcome

