"Now We’re Talking"

A Practical Toolkit for Public & Patient Involvement in Healthcare
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Foreword

This Toolkit has been developed by the Irish Society for Quality and Safety in Healthcare (ISQSH) and Health Care Informed (HCI). The contents of this toolkit are thanks to all those have worked tirelessly in the area of patient involvement before us. Most significantly in this regard are the healthcare organisations, both voluntary and statutory, working in the United Kingdom, Australia, and Canada. It is their work that has made this framework possible.

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## Section 1 – Introduction to Public and Patient Involvement

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1.1 Overview

The importance of Public and Patient Involvement (PPI) in the planning and implementation of healthcare has been recognised in a number of international declarations. In 1978 the World Health Organization’s (WHO) Declaration of Alma-Ata set out a vision for primary healthcare, which stated unequivocally that ‘people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare’.

There is increasing evidence (Consumer Focus Collaboration, 2001. p. 2) that PPI in the provision of healthcare leads to better health outcomes and better quality of care. It has been shown that -

- active participation of individuals in decision-making about treatments leads to improvements in health outcomes;
- access to quality information facilitates decision-making and supports an active role for consumers managing their own health;
- effective consumer participation in quality improvement and service development leads to more accessible and effective health services;
- active involvement of consumers at all levels of the development, implementation and evaluation of health strategies and programmes is integral to their success;
- community engagement increases responsiveness to consumer/ community needs and issues, including communities with diverse backgrounds.

This evidence has not been lost in recommendations for the Irish health system. In 2008, the National Strategy for Service User Involvement in the Irish Health Service (Department of Health and Children) was published. The approach to the strategy is based on three levels of involvement; individual service users, the community and at national level. One of the objectives of the National Health Strategy, Quality & Fairness, A Health System for You is that “The patient is at the centre in the delivery of care” (Department of Health and Children, 2001, p79). To help achieve that,
“Individuals and families will be supported and encouraged to be involved in the management of their own healthcare (p80).

Unfortunately however, we have yet to fulfil this objective. The National Patient Perception of Care Survey, carried out by the Irish Society for Quality & Safety in Healthcare in 2004/5, demonstrated that even some of the basic concepts of patient involvement were not being implemented. The survey of almost 5000 patients highlighted that 70.2% received no printed information about the hospital, or its routines before or during their stay, while 44.6% stated that they were never told about such things as meal times or when they would see the doctor.

This PPI Toolkit has been developed in response to the deficit of consumer involvement in the Irish healthcare system. It aims to provide organisations with a framework and practical methodologies to develop patient partnerships. It is hoped that this will increase communication and involvement, and ultimately lead to better health outcomes and better quality of care.
1.2 Evidence Base for the Toolkit

This Toolkit is designed for people working in healthcare organisations who want to increase patient/client participation in the planning, management, evaluation and review of the health services. The Toolkit was developed by a Project Team with specific expertise in the area of patient-centred quality improvement in healthcare. The work was overseen by an expert Steering Group that included patient and healthcare representation. The development process involved consultation with major stakeholders and an extensive literature review. In addition, focus groups were held with acute and residential organisations to review the draft Toolkit. Feedback was used by the Project Team to produce a final document in consultation with the Steering Group. The Toolkit is fundamentally founded on evidence-based best practice and learning from current international initiatives.

The literature review considered much available evidence in the area of Public and Patient Involvement (PPI). The extent of international information regarding PPI is vast, and this Toolkit does not attempt to produce a comprehensive literature review on the topic. Rather, a substantial number of documents were consulted to establish themes and concepts central to PPI. These included journal articles, national strategies, position papers, guidance documents and practical resource documents. Documents were considered from both national and international sources, particularly those from the United Kingdom, Australia, Canada and America.
1.3 Framework for the Took-Kit: The *Plan, Do, Check, Act* (PDCA) Cycle

The framework for this Toolkit is modelled on the *Plan, Do, Check, Act* (PDCA) Quality Cycle as follows:

(Reference: *US Department of Health and Human Services*, 2004, p. 11)

**Plan (Toolkit Sections 1 and 2)**

The framework provides assistance to organisations in planning for the comprehensive involvement of the public and patients in their healthcare service delivery. This Toolkit provides information on:

- Background to Public and Patient Involvement (PPI) including the benefits, barriers and processes
- Identifying how organisations can plan for PPI
- Identifying how the organisation can use PPI effectively.
**Do (Toolkit Section 3)**

In the creation of effective PPI processes no single theory is dominant because services, populations, cultures, and contexts, as well as available infrastructure and resources, vary. This PPI framework draws upon sound health communication and involvement theories and models that offer different perspectives on the intended audiences and on the steps that can influence their change. Organisations can utilise this Toolkit to gain a better understanding of what systems work in different types of organisations. Systems used may range from patient councils to feedback from advocacy groups. An appreciation of various systems will help organisations understand how to:

- Review existing systems and processes
- Develop and test concepts and methodologies
- Decide what structures and methods to develop
- Develop structures, materials and methods
- Pre-test structures, materials and methods.

**Check & Act (Toolkit Sections 4 and 5)**

The underlying principle of the PDCA cycle is that an activity is not complete until evaluation shows that it has been effective. The PPI framework provides assistance to organisations in assessing the programme using specific outcome evaluation methods. Outcome evaluation is important because it shows how well the programme has met its objectives and what might need to be changed or improved to make it more effective. The framework will provide organisations with examples of how to use a combination of both qualitative and quantitative methods. Learning how well the programme has met its goals is vital for:

- Justifying the programme
- Providing evidence of success or the need for additional resources
- Increasing organisational understanding of, and support for, PPI
- Encouraging ongoing cooperative ventures with other organisations
- Focusing on continuous improvements.
1.4 How to use this Toolkit

This Toolkit has been designed to assist healthcare organisations and professionals with Public and Patient Involvement (PPI) in healthcare delivery. It does not intend to be an all-inclusive document reflective of all information and research in the area of PPI. It aims to guide organisations and professionals regarding the principles of successful PPI, and to describe effective tools which can be used during this process.

This Toolkit is divided into five sections. Section 1 is designed to provide an overview of the concept of PPI. Section 2 highlights the importance of planning and preparation prior to commencement of the involvement activity (“Plan”). It is recommended that those planning to conduct PPI processes should read the first section to establish an understanding of the key concepts and themes related to the process.

Section 3 consists of the tools and techniques that can be used for the implementation of PPI (“Do”). The tools and techniques are subdivided into levels, ranging from 1 – 4, with Level 1 representing the least involvement by public and patients and Level 4 the greatest. Each individual tool and technique is covered under the following headings:

- Key aspects
- Implementation
- Summary

The aim of Section 3 is to provide an overview of a number of different tools and techniques to enable healthcare professionals to determine which are most appropriate for use in their organisation. Organisations can then use the specific sections to determine how the tools and techniques can be administered effectively and efficiently.

Section 4 provides guidance in assessing the effectiveness of the tools and techniques used (“Check”). Finally Section 5 deals with how to utilise the information...
collected during the assessment process to continuously act and improve the PPI process (“Act”).

This Toolkit is designed to be a guide and resource for healthcare professionals and organisations participating in PPI. **It is not necessary for all individuals involved in PPI to read all sections of the Toolkit; relevant sections can be read independently of the remaining sections as required.** It is advisable, however, that key professionals in the involvement process have a good overview of the general themes and concepts pertinent to PPI.
1.5 What is Public and Patient Involvement?

Recent years have seen a slow but persistent shift towards the consideration of the patient as a consumer of healthcare services. As a result there have been major changes in the relationships between patients and healthcare providers, as both sides attempt to accommodate the new setting. To some extent, these new relationships are still being developed and considerable work is required in relation to ‘buy in’ – hence the need for a Toolkit such as this to assist in accelerating the necessary change.

Donabedian (1992) utilised the idea of “co-production” as a way to conceptualise the relationship between patients and the health services. The concept of a co-production is that citizen partnership is involved in the provision of any services (Brudney & England, 1983). This implies that not only are the services responsive to consumers, but there is also an acknowledgement of the role that consumers can and do play in the actual provision of services. They can do this at many levels from the contribution that they make, for example to health services, to the idea that it takes effort from the patient, carers, and health providers to overcome illness or prolong life (Draper, 1997).

While the concept of Public and Patient Involvement (PPI) is slowly but clearly becoming a reality in today’s provision of health services, comprehensible definitions are difficult to find. Cahill (1998) notes that there is no clear consensus on what patient participation means, or how far it should extend; no single term comprehensively describes this movement. Suggested descriptions include that by Saunders (1995) who asserts that:

‘patient participation is an active process which involves a patient performing clinical or daily living skills or partaking in the decision making process from time to time’.

Cahill’s review (1985) acknowledges that PPI has also been seen to focus on other aspects of care, such as patient compliance with treatment plans, self-medication (Webb et al, 1990), self-monitoring (Nelson 1977), patient education (Wilson-Barnett...
& Osbourne, 1983), goal setting (Janz et al, 1984) and sharing information and taking part in physical care (Macleod-Clark & Latter, 1990). The literature appears to suggest that patient participation is a very amorphous and ill-described concept. Operational documents regarding PPI have useful working definitions, such as that utilised in the NHS Lambeth Toolkit (2004):

‘Public and patient involvement is the active participation of patients, users, carers, community representatives and the public in the development of health services and as partners in their own healthcare.’

Finally, Stuart (1999) proposes four main themes in considering the concept of public and patient partnership:

- promoting patients' participation in their own care as active partners with professionals
- enabling patients to become informed about their treatment and care and to make informed decisions and choices about it if they wish
- involving patients and carers in improving service quality
- involving the public as citizens in health and health service decision-making processes.

For consistency, reference throughout this Toolkit to ‘public and patient’ is intended to be inclusive of patients, service users, families, carers and the public.
1.6 Why is Public and Patient Involvement Important?

Public and Patient Involvement (PPI) is increasingly being linked with improvements in the quality of healthcare and improved health outcomes. Person-centred care has become a central concept in healthcare as a response to:

- A general trend towards increasing attention to social inclusiveness and the needs of the consumer
- The rapidly increasing cost of healthcare and the imperative for effectiveness
- The focus on improvement of processes and outcomes of care (Al-Assaf, 1993)
- Increased access of patients/clients to information about healthcare treatments and options (Lutz and Bowers, 2000).

(The Health Boards Executive, 2003, p.9)

There are numerous reasons why PPI in healthcare is important - :

1. **Public and patient participation in healthcare delivery is their ethical right**
   Participation by the public and patients in decisions that relate to their own healthcare can be viewed as the ethical and democratic right of the public and patients. PPI programmes address the rights that patients have, for example, to information, choice, safety, fair treatment and redress. Consumer research continually receives from patients the statement that they want ‘to be treated with respect, like a person’ (Entwistle, 1997)

2. **Public and patient participation builds trust between the public/patient and the health services**
   Involving patients and the public in healthcare enhances trust and communication with staff. This enhances the relationship between the two parties, and may inspire confidence in the patient with respect to the healthcare organisation.
3. Public and patient participation in healthcare delivery improves health outcomes
PPI in healthcare delivery enables patients to have a better understanding of their conditions and treatment plans and hence, achieve better outcomes. There is growing evidence of the links between consumer feedback and participation in decision making in individual care leading to improvement in health outcomes (England et al, 1992, Fallowfield et al, 1990) and stronger therapeutic alliances (Chambers, 2003). (The Health Boards Executive, 2003, p.9)

4. PPI in healthcare delivery makes services more responsive to the needs of its public and patients
Involving patients and the public in healthcare delivery can have a large impact on service delivery levels such as the development of new services and improved interactions and understanding between health professionals and service users. Involvement may impact on policy and strategy through the utilisation of better information by organisations and providers of health services. This can result in measurable changes in policy and strategy, and community-generated proposals can be enhanced.

5. PPI in healthcare delivery progresses service quality and safety
Involvement of the public and patients in healthcare delivery can influence the Irish healthcare quality improvement agenda and provide an opportunity for organisational learning and development. It provides crucial information on what patients'/clients' expectations are and how they perceive the quality of care which they receive. The National Health Strategy (Department of Health and Children, 2001) confirmed this belief when it stated that:

“the ‘people-centred’ healthcare system of the future will have dynamic, integrated structures, which can adapt to the diverse and changing health needs of society generally and of individuals within it. These structures will empower people to be active participants in decisions relating to their own health” (p 8).

6. PPI in healthcare increases the effectiveness of treatment
Wilson (1999) states that involvement by individuals in their care increases the effectiveness of their treatment. This is important given the continuing escalation of healthcare costs and the increasing need to improve effectiveness.

Effective PPI strategies can:

- Lead to more accessible and effective health services (Draper and Hill, 1995)
- Facilitate participation by those traditionally marginalised by mainstream health services (Alexander and Hicks, 1998)
- Make organisations more aware of significant areas of dissatisfaction with care and services (Ovretveit, 1998)
- Give staff new insights into how people perceive aspects of their care (Draper, 1997)
- Increase consumer confidence (Chambers, 2003).

(The Health Boards Executive, 2003, p.9)
1.7 Key Principles of Public and Patient Involvement

Principles of Public and Patient Involvement (PPI) are the basis upon which programmes should be conducted. They act as a set of guidelines for consideration; key themes and concepts for both the public and patients, and the healthcare professionals and organisations.

It may be useful to consider the guiding principles for service user involvement identified in the *National Strategy for Service User Involvement in the Irish Health Service 2008-2013* (DOHC and HSE, 2008, p11) when considering policy development for, and practical implementation of, PPI activities.

- Service users, especially those whose voices are seldom heard, have a right to be involved in the development of the health and social services that they use and this is a key element in the delivery of patient-centred care.
- Commitment of management at all levels is essential to ensure leadership and delivery.
- Service users should be centrally involved in their own care.
- Open dialogue, trust and mutual respect are key ingredients of successful service user involvement.
- Involvement must be based on inclusion, diversity and equity – health services must engage socially excluded groups including those who are socio-economically disadvantaged, ethnic minorities and Travellers, people with disabilities, lesbian, gay, bisexual and transgendered people, children, young people and older people and users of mental health services.
- Clear channels of communication with the health service for service users are essential to effective involvement.
- Accurate and timely feedback and information to service users are key elements of successful user involvement.
- Service user involvement initiatives must be systematically evaluated and learning from service user involvement initiatives must be disseminated across the health and social services.
Successful PPI requires the healthcare organisation and professionals to establish partnerships, and this requires accepting uncertainty. By its very nature, feedback and outcomes from PPI are uncertain – if we knew what the outcomes were going to be, we wouldn’t need to do the consultation in the first place. Organisations need to provide a commitment to utilise the information provided, and this requires a commitment to change, both in the nature of how decisions are made and accepting the influence that PPI can have. PPI must be a bottom-up approach, but requires strong support from the top of an organisation to utilise the information provided and to operate effectively and efficiently. Strong emphasis on training, education, and communication, listening and people skills are fundamentally required, and these must be supported. Finally, PPI requires an organisational culture that is supportive of it to ensure trust and commitment by all parties.
1.8 What Public and Patient Involvement Can and Cannot Do

There is no doubt that Public and Patient Involvement (PPI) in healthcare delivery can be of enormous benefit to both the service user and to the healthcare provider. However, it must be recognised that the benefits are not limitless, and PPI should be utilised within specific areas and to achieve specific objectives.

**Patient and Public Involvement can:**

- Increase the public and patients' knowledge and awareness of a health issue, problem or solution
- Prompt action, from either the public and patient or the healthcare providers
- Influence perceptions, beliefs and attitudes that may change social norms
- Strengthen organisational relationships with the public and patient
- Demonstrate or illustrate healthy skills or attitudes
- Reinforce knowledge, attitudes or behaviour
- Demonstrate the benefits of behaviour change
- Advocate a position on a health issue or policy
- Increase demand or support for health services
- Refute myths and misconceptions relating to health and/or healthcare
- Cause sustained change in which an individual adopts and maintains a new health behaviour or an organisation adopts and maintains a new policy direction.

**Patient and Public Involvement cannot:**

- Compensate for inadequate healthcare or access to healthcare services.
- Produce sustained change in complex health behaviours and situations independently, i.e. PPI may require additional support to achieve ongoing change and improvements.
- Be equally effective in addressing all issues between the healthcare organisation and the public/patient. This may be because the topic or suggested behaviour change is complex, because the intended audience may have preconceptions about the topic or message sender or because the topic may be controversial.

*(US Department of Health and Human Services, 2004. p. 3)*
1.9 The Fears, the Barriers and the Ethics

1.9.1 Fears and Barriers

PPI is a relatively new concept. As with any change, it is one that can be accompanied by a number of fears from all parties. Often these fears are due to uncertainty about the process, its objectives and aims. There are also a number of barriers to PPI that are often contributory to the fears held by both parties. It is important to firstly realise and acknowledge the potential fears and barriers. Subsequently these can be addressed, to ensure that they do not impede involvement.

Fears regarding PPI can be held by both the public and patients themselves, and by the healthcare organisations and professionals. The public and patients often mistrust why they are being invited to participate, and may consider that their representation is merely a token gesture. They may consider that decisions have already been made, and that they are being asked to get involved purely from a PR perspective. On an individual level, patients may be reluctant to complain or criticise a service, possibly due to a lack of confidence, or the fear that they will subsequently receive different treatment from the healthcare organisation and professional.

Healthcare organisations and healthcare professionals can also have fears regarding PPI. These may include fears of being criticised. Professionals may view patient involvement as a potential acknowledgement that they are not doing their job properly and that there is a need to call in the patients to offer advice. Relinquishing power is another fear that may be held by both organisations and individuals, and this may impede any PPI initiative. Finally, a lack of knowledge and education regarding partnerships and how to conduct involvement can be a huge fear for professionals.

All of these fears are very real and do exist amongst both parties. Therefore it is imperative to address these issues at a very early stage and assure all parties of the objectives and reasons for involvement. Addressing the barriers can often reduce
fears and confirm the benefits for all involved. A number of barriers are outlined below, firstly barriers related to the public and patients, followed by barriers related to healthcare professionals and organisations:

**Public and Patients’ Barriers**

1. *Perceived lack of benefit from PPI*
   The public and patients may fear that the involvement process is merely a public relations exercise in disguise. This occurs when the decisions that the consultation is addressing have already been made. The public and patients are merely involved to give the impression of involvement, but true involvement has not actually occurred. This action is demoralising for patients, and also breeds a poor culture between the patients and the healthcare organisation. It also makes the public and patients reluctant to become involved in future involvement events.

2. *Lack of confidence, time, training and skills*
   Individuals’ lack of confidence, time, training and skills can deter ordinary citizens from joining in the discussions about the health service on equal terms. This barrier may be overcome by the provision of appropriate and suitable education and training by health professionals to the public and patient representatives that are involved. It is also important for the health professionals to use language, information, media and actions with which the public and patients are comfortable.

3. *Lack of representative sample*
   The public and patients who are involved in consultation with the healthcare organisation and professionals must be representative of the issue being discussed. If individuals are consulted on a topic which is of little relevance to them, they are unlikely to be able to provide substantial and useful information on the topic. This will also result in distancing the public and patients as they may feel unable to contribute and unwilling to participate in future involvement events.
4. **Fear of complaining**

The public and patients may have a concern about complaining or reporting bad experiences to the healthcare professional or organisation because of a fear that they will receive different or poorer care after they have voiced their opinion. To overcome this barrier, it is essential that the healthcare professionals and organisation assure patients that their care processes and that the quality of their care will not be altered irrespective of their views.

**Healthcare Professionals’ and Organisations’ Barriers**

1. **Inadequate planning and information**

Appropriate, sufficient and comprehensive planning is essential for successful patient participation (see Section 2). Planning enables professionals and organisations to determine specific objectives for the PPI process, and to determine how these objectives are going to be met. Poor planning can result in inappropriate patient representation, poor communication, inadequate resources and undefined objectives.

2. **Inability to relinquish power**

Traditionally, the public and patients have not been involved in healthcare service delivery. PPI is a relatively new phenomenon, and it can be difficult for some healthcare professionals and organisations to adapt. They may find it difficult to let go of some of their power, and allow the public and patients to become involved in decision making. Organisational culture is highly influential and this should be examined when attempting to deal with this barrier.

3. **Inadequate Training and Education**

Communication, listening, people and team skills are essential for a healthcare professional who is involved in PPI. The professional needs to know how to include patients and how to obtain information from them, in addition to being comfortable and confident with the entire PPI process. Professionals who do not have sufficient education and training to carry out this role will be reluctant to participate, and will be unable to maximise the benefits of PPI. This will have a subsequent effect on the
public and patient representatives, who will have reduced confidence in the system. Sufficient training in all aspects of PPI is essential for healthcare professionals participating in the process.

4. Inappropriate method(s) of consultation and inappropriate representatives

To ensure that the PPI process is successful, it is essential that the correct method of consultation is used with the appropriate public and patient representatives. Where inappropriate methods are used, with a consultation process that uses patients from an unrepresentative sample of the population, the benefits to both patients and the healthcare organisation will be minimal. It is essential that methods of consultation are not dependent on practitioners’ and commissioners’ preferences and limited capabilities rather than being the best method(s) for the aim(s) of a particular consultation.

5. Lack of involvement of leadership and management

Patient involvement must be a bottom-up approach; however it must also be supported by senior management. A lack of commitment from the consulting organisation or healthcare unit to act on the views obtained is a significant barrier to the success of the consultation process. Leadership and governance of the organisation must have a commitment to patient involvement, and this should, in turn, impact on the culture of the organisation regarding PPI.

6. Poor recognition of patient involvement outcomes

PPI should be conducted to utilise the resource of patients and to determine how the organisation can become more patient-focused. This may involve consideration of surprising and unanticipated results. While it is acknowledged, and should be explained to public and patient representatives, that not all recommendations can be automatically implemented or resolved, the results should undergo meaningful consideration. It is imperative that unwanted results are not disbelieved as being unrepresentative of the subject population and ignored.
7. Inadequate resources
Any attempt to conduct PPI programmes with insufficient resources will be unsuccessful, and reduce public confidence. It is imperative that necessary resources such as time, money and personnel are identified at the planning stage and are secured before the commencement of the involvement programme.

1.9.2 Ethics

In addition to fears and barriers, ethical considerations must also be addressed. While a considerable number of patients may wish to be involved in planning for health service delivery, it must be remembered that not all patients may welcome this involvement. The choice to participate in service delivery should always be that of the individual patient. The decision by a patient to participate or not should always be respected, and should in no way affect the care and services that the patient receives. It is very important to communicate this to patients. Anonymity and confidentiality should be maintained at all stages throughout the involvement process, and the public and patients should receive feedback and information on the findings and outcomes of PPI programmes.

Ethical considerations also apply to the use of information and data pertinent to the public and patients involved. Any data or information used or accumulated during the involvement process must comply with the regulations of the Data Protection Act 2003. Most involvement techniques do not have potential ethical implications for the public and patients involved nor the organisation. However, in situations where there is extensive PPI and/or the involvement process is addressing an ethically sensitive issue, it is advisable to contact the organisation’s Ethics Committee for advice prior to commencement of the programme.

It is inevitable that a certain number of barriers and fears will exist at the commencement of any PPI programme. Therefore, it is crucial to assess which ones exist, and how they can be addressed. The aim should be to create a culture of mutual understanding and trust, with open communication and a respect for patient ethics.
1.10 Integration with Other Systems

PPI is potentially of huge benefit to many aspects of the healthcare services. Information gathered from involvement may be utilised in a number of different areas within a healthcare organisation, and may be of benefit to areas outside of which it was originally intended. Therefore it is essential for healthcare organisations to ensure that there is an integrated, functioning patient involvement system and subsequent communications system along which the relevant information can be disseminated.

It is essential to integrate PPI with healthcare governance. This demonstrates a commitment to the process from the top down. PPI can be linked to a number of governance activities, such as clinical audit and review, monitoring and evaluation of service quality, service development and improvement, staff training and risk management. Forming substantial links between PPI and these (amongst other) governance activities will keep the organisations’ system connected to the needs, expectations and experiences of the public and patients.

Clinical audit is one area where PPI can be incorporated. Clinical audit involves improving the quality of clinical services given to patients, thus it should be focused on what matters most to patients. For example, if an organisation is auditing outcomes, consultation with the public and patients can suggest which outcome measures actually matter to them.

Ideally PPI should be a main priority for healthcare organisations in both strategic and operational terms. Organisations should aspire to setting specific goals and objectives regarding PPI on a routine basis. Once the overall goals have been set, the existing practice can be assessed against them to determine the achievement of the goals and the level of continuous quality improvement.

One of the predominant aims of PPI is to provide opportunities for the public and patients to influence decision-making by the healthcare organisations. Information
collected from PPI can be utilised either as feedback on the service quality, or as prompts for possible further action relating to user needs.

The promotion of meaningful patient involvement is critical in the development and promotion of patient-centred nationally agreed standards, both at clinical and corporate level. Additionally, PPI assists in assessing whether the health and personal social services are managed and delivered to ensure the best possible outcomes within available resources.

A key factor to the success of the integration of PPI within an organisation is effective communication. Developing a communications strategy (or a subsection of the organisation’s overall communications strategy) to address the issue of PPI can be hugely beneficial for an organisation. This will ensure awareness of activities within the organisation and ensure that important information and feedback is related and communicated to all relevant areas in the organisation and to stakeholders.
### Section 2 - Planning and Preparation

(“Plan” of the Plan, Do, Check, Act Cycle)

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2.1 Why Planning Is Important

Planning is the first step of the Plan, Do, Check, Act (PDCA) Quality Cycle, an improvement model, based on four stages of a structured approach to quality. Effective planning for Public and Patient Involvement (PPI) requires clarity about objectives. This means discussing what the organisation wants to achieve from participation, what motivates participants, what various agendas are held by different people for different reasons and how involvement should be organised. Establishing objectives ensures that all parties are aware of the rationale and purpose of the consultation.

Planning ensures that the right type of PPI occurs. It ensures that the information collected is truly representative by using appropriate methods of consultation with appropriate population representatives. It allows for evaluation of the different tools and techniques to ensure that the appropriate tool is used to maximise efficiency and effectiveness.

Adequate resources, management support and communication methods are all fundamental elements of successful PPI programmes. Extensive planning ensures that all of these areas are addressed, that the necessary resources are available and that the appropriate stakeholders and participants have been communicated with.

Planning for PPI should be carried out at the outset and should cover the entire range of the programme. This includes not only the initial consultation with representatives, but also the follow-up and utilisation of collected information. It is important that feedback and information gathered in the involvement process is utilised and communicated, and methods for achieving this should be detailed in the initial plan.

The plan for PPI should be developed in collaboration with a number of stakeholder representatives. These may include health professionals who will be involved in the process; management; and the public and patients themselves to ensure that the process will be as beneficial as possible.
While planning is a fundamental aspect of a successful PPI process, the plan should be sufficiently flexible to allow for changes as the involvement process develops. It should be regularly reviewed and amended as required once the process has commenced.

Planning provides a foundation for the entire PPI framework. It enables programmes to produce meaningful results rather than just boxes of materials. In summary, effective planning can help an organisation to:

- Understand the nature of PPI
- Set specific objectives for the PPI process
- Determine appropriate methods for PPI
- Establish a logical PPI programme
- Create a PPI process that supports the defined objectives
- Assign responsibilities
- Assess and monitor progress
- Use the information gathered to encourage improvements in service delivery.

*(US Department of Health and Human Services, 2004. p. 16)*
2.2 Leadership

It is essential that the management and governance of an organisation are supportive of PPI and committed to its success. While involvement is, by its nature, a bottom-up approach, there must be top-down collaboration for productive involvement to occur.

Successful PPI requires an appropriate organisational culture, and culture is bred strongly by the attitudes of management and governance. If a healthcare organisation’s management and governance is not supportive of PPI, this spreads to all levels of staff, and an apathetic attitude towards involvement is created. In the case where public and patients are willing to become involved in the process, but are not taken seriously by management, their confidence in the system will be reduced and most likely they will be reluctant to participate in any future activities.

Management and governance must commit to more than the initial support of the involvement activities being conducted. A more long-lasting commitment of management will ensure that the feedback and outcomes of the involvement process are adequately and appropriately utilised to continuously improve the service. This is a much greater undertaking, as it often involves a level of change and transition from the traditional management and governance decision-making processes.

There are many potential benefits for both management and governance in adapting and supporting the PPI process. Receiving feedback and information from direct service users is an invaluable resource when an organisation is deciding on its objectives or organisational goals, or involved in strategic planning. It ensures that management have ready access to comprehensive information regarding the experiences, needs and expectations of its service users.

Feedback information and outcomes from PPI can also be utilised in integrated governance related issues. As discussed previously, (Section 1.10) PPI can be linked to a number of governance activities, such as clinical audit and review, monitoring and evaluation of service quality, service development and improvement, staff training, risk management and accreditation.
2.3 Engaging Staff

Healthcare staff play a vital role in effective PPI. Staff interact daily with the public and patients, and are usually the first line of contact for the public and patients in terms of involvement. The methods that staff use in these interactions can directly affect how much the public and patients feel informed about, and involved in, their own care. A central role in the daily routine of a healthcare staff member often involves explaining and clarifying issues, sounding out peoples' views about healthcare needs and priorities and finding out what people think about the performance of the healthcare system. Subsequently healthcare staff are involved in PPI at many levels, and organisations should support and encourage staff to take on this role.

It is important that staff have a clear understanding of what PPI is, its potential benefits, and an appreciation of what it means to them. Clear guidelines are required about how it relates to them and their roles, and they should be provided with the confidence and competence to undertake it successfully.

Adequate training and education for staff is fundamental for effective PPI, as it gives staff the confidence to conduct the involvement properly. Communication with staff is essential, to ensure that they are aware of priorities and how they are linked to wider objectives of the organisation. The culture of the organisation regarding PPI will impact on staffs' views and attitudes towards involvement, and correspondingly staffs’ own views will enhance this culture. Therefore it is important to breed a culture of acceptance and involvement with staff so that they will, in turn, enhance the organisation’s culture.

For many staff, just as for patients, a motivational factor will be observing the actual utilisation of the information collected. This demonstrates to staff that management and governance are taking the process seriously, and that participation is worthwhile.
The NHS Wales *Signposts Two* (2003) document emphasises that the role of staff training and development in PPI is to:

- Raise awareness and understanding of its role and purpose
- Clarify particular roles and responsibilities within the organisation
- Examine patient and public needs and expectations and how these affect involvement practice
- Explain the difference between good and inappropriate practice
- Help prepare people for the specific tasks and duties they will have to carry out.

The level of training required by individual staff members will vary according to their level of involvement in the PPI programme. Those who are highly involved shall require extensive training, but those who are minimally involved, or involved with patients on a routine, clinical basis, shall still benefit from a certain level of education regarding the topic.
2.4 Resource Management

Public and Patient Involvement (PPI) in healthcare service delivery inevitably takes time, money and resources. Healthcare organisations must make a commitment to provide the necessary resources prior to the commencement of the involvement process. Attempts to conduct PPI programmes with insufficient resources will inevitably be unsuccessful, and have the added effect of reducing public confidence in the system and the healthcare organisation.

Necessary resources should be specifically outlined at the planning stage of the process. Fundamental resources include human resources, such as adequate numbers of trained staff to complete the programme sufficiently. Sufficient time must be allocated for the involvement to be conducted successfully and for the appropriate evaluation, communication and utilisation of the information after the involvement process. Infrastructural and support resources should also be available, such as facilities for conducting the involvement process (e.g. rooms for Focus Groups), communication with representatives (e.g. letters inviting public and patients to attend) and additional aids (e.g. IT Support, Dictaphone, written materials etc).

In some healthcare organisations, there may be information available on a related project that is ongoing or has already been completed. If there have been any previous PPI activities within the organisation, it is beneficial to access this information and attempt to utilise the experiences gained. If an organisation has not completed prior involvement activities, it may be useful to look outside to other healthcare settings who are participating in involvement, and try to benefit from their experiences.

Finally, it is imperative to establish at the outset where the funding will come from, e.g. the organisation’s overall budget, a specific department within the organisation or dual funding.
2.5 Planning Steps

As has been established in Section 2.1, planning is of fundamental importance for the successful implementation of PPI programmes. Plans for all PPI programmes will vary as a result of organisational differences and variation in the objectives of the programme. However, there are a number of basic steps within any programme plan:

1. Assess the current situation
2. Determine objectives
3. Review and determine population representatives required
4. Review and determine appropriate tools and techniques
5. Conduct the patient involvement process
6. Utilise feedback and outcomes
7. Consider communications process and integration with other systems
8. Evaluate and analyse PPI process
9. Ensure continuous quality improvement of PPI process.

1. **Assess the current situation**

   The current situation regarding PPI should be assessed prior to implementation of the process. This should include a review of available data and identification of existing activities and gaps. This shall enable the organisation to establish current activities in the area of involvement, and ensure that work is not being duplicated. It will also assist in identifying systems with which the process could be integrated, and be of benefit. The Evaluation Tool discussed in Section 4 is a useful framework for conducting this assessment. Analysis and assessment also allows for a full understanding of the involvement process prior to its commencement.

2. **Determine objectives**

   To maximise the benefits of the involvement programme, it is important to have defined and documented specific objectives prior to its commencement. This will ensure that all stakeholders are aware of the purpose and goals of the process. It
also allows for evaluation of the programme, to ensure that the project objectives have been accomplished.

The aims and objectives should be developed with all participants of the involvement programme. These include members of the healthcare organisation, such as the persons developing and conducting the programme; departments which may be affected by the process; and the organisation’s management and governance. It should also involve the public and patients who will be participating in the process. When the aims and objectives have been agreed, they should be communicated to all relevant stakeholders. This conjunct development and communication provides the opportunity for concerns, queries or questions to be identified and addressed at an early stage.

Objectives should be:
- **Specific** and supportive of the healthcare organisation’s goals
- **Measurable**
- **Achievable**
- **Realistic**
- **Timely** and prioritised, to direct the allocation of resources

3. **Review and determine population representatives required**
Based on the objectives, a population sample will need to be identified. While it may be difficult to get a sample that is reflective of the entire population, the sample should be as varied as possible. It will be necessary to consider how best to achieve this.

4. **Review and determine appropriate and suitable tools and techniques**
Based on the objectives set and the population target identified, the tools and techniques that are most appropriate for the involvement should be decided upon. The process should not be restricted to using one tool or technique. Physical settings for the involvement may need to be determined and individuals with specific skills and training may be required.
5. **Conduct patient involvement process**
   This stage includes the actual implementation of the involvement process. Here it is important to consider resources, including human resources, time allocated, personnel with adequate skills and training, infrastructure and support resources (e.g. IT, equipment etc).

6. **Utilise feedback and outcomes**
   Feedback and outcomes gathered from the involvement process should be used to continually improve the health service delivery. Where, when and how the information is used should be determined at the planning phase.

7. **Consider communications process and integration with other systems**
   Communication processes are of fundamental importance and must be established at the planning phase. Communication should be an integral aspect of the process at all levels from informing all relevant individuals of the proposal, to conducting patient involvement programmes, to communication of the feedback or outcomes of the programme. Identification of other organisational systems with which the involvement process can be integrated should be considered.

8. **Evaluate and analyse PPI process**
   Based on the *Plan, Do, Check, Act* Cycle, an activity is not said to be complete until evaluation has shown it to be effective. Thus, evaluation and analysis of the PPI process should be conducted to ensure that the process is maximising worth and meeting its objectives. Evaluation should be a formalised process, conducted on a routine basis, with the involvement of all parties and stakeholders.

9. **Ensure continuous quality improvement of PPI process**
   Information gained from evaluation and analysis in the previous phase should be utilised to continuously improve the process. This will ensure an efficient and effective process based on stakeholders’ needs and inputs.
2.6 Where Are We Now?

All healthcare organisations are unique, and hence are likely to have varying levels of Public and Patient Involvement (PPI). Subsequently, it is not possible for this Toolkit to recommend precisely where organisations need to start in relation to involvement of public and patients in healthcare delivery. What is necessary is for individual organisations to assess their current level of PPI, and to plan accordingly.

Assessing the current situation is an essential step for each organisation. This enables the organisation to see what level of PPI exists at present; what is being conducted by various departments within the organisation; and who is involved in promoting PPI. When this information has been established, organisations can then make an informed and realistic decision as to how to progress their public and patient agenda to have the most effective impact.

The Evaluation Tool outlined in Section Four of this Toolkit can be utilised by individual organisations to determine their current level of PPI. It can act as a benchmark to demonstrate where the organisation is at the moment and where it should be aiming for. The Evaluation Tool can also be used by organisations at regular intervals, to determine if their PPI process is progressing.
2.7 Levels of Public and Patient Involvement

This PPI Toolkit outlines a number of tools and techniques which can be used in the involvement process (see Section 3). Each tool and technique is described individually and organisations are advised to review the tools and determine those which most effectively suit their requirements.

The tools and techniques are divided into four categories, called ‘levels of involvement’. Each level represents a different extent and type of patient involvement. Organisations commencing a PPI process for the first time may be at the first level, where their principal involvement is through education and communication. Organisations whose PPI programmes are more developed, may be at a higher level, where they are actively involving their patients in service delivery. Healthcare organisations should aim to move up through the levels, increasing their PPI and utilising different tools and techniques for the involvement process.

The four different levels are:

**Level 1: Communicating – Inform and Educate**

The focus of Level 1 is on communicating with the public and the patient through various forms. These tools and techniques concentrate on relaying messages to the public and patient and providing information and education on various issues. They incorporate printed media, such as booklets and information leaflets, and audio/visual multimedia. The use of websites to convey information is also discussed, as are the educational possibilities of promotional campaigns and public meetings in conveying specific messages.

**Level 2: Listening – Gather Information**

Level 2 concentrates on information gathering from the public and patients. This incorporates feedback and complaint systems, both formal and informal. Telephone hotlines and comment cards which can act as ‘sounding boards’ for service users are discussed, as are patient shadowing techniques, patient diaries and surveys.
**Level 3: Engaging – Work to Involve**

This level takes PPI to an interactive level, where the healthcare organisation and professionals engage with the public and patients. This can be done on an individual basis (i.e. one-to-one with patients,) or through, for example, focus groups. Patient advocacy and liaison, patient commitment statements and patient councils are also methods of engaging with the public and patients in the involvement process.

**Level 4: Partnering - Develop Together**

Level 4 addresses how the public and patients can work together to maximise the mutual benefits. Methods for achieving this include the “Expert Patient” and public and patient representation on committees. It also describes the use of community forums and community partnerships.
2.8 Pre-testing the Public and Patient Involvement Process

Developing and pre-testing a Public and Patient Involvement (PPI) process enables an organisation to learn early in the programme which methods will be most effective. Organisations can save time and money by ensuring that they do not go through the entire involvement process using ineffective methods. Pretesting also has the dual benefit that positive results can also give early buy-in from the organisation.

The PPI planning process should consider required patient representatives, and the tools and techniques which will be utilised. The plan should be flexible to change depending on the results of the pretesting.

Pretesting involves testing or piloting the planned involvement process with a number of representatives. For PPI programmes, the pretesting will have two predominant objectives. Firstly, it will determine whether it is possible to access and recruit the required number of appropriate public and patient representatives to participate in the process. This is important as a programme may be planned around the assumption that it will successfully recruit a certain amount of individuals or groups to participate. In situations where there is difficulty in recruiting individuals or groups in the pretesting phase, it may be necessary to reconsider the criteria for inclusion of particular representatives to allow access to a larger population size.

Secondly, pretesting allows for a trial of the tools and techniques. The chosen tools and techniques should be used with a sample of the representatives, and an evaluation should be completed following the trial. The evaluation should include the input of the representatives, and focus on aspects which they considered good or poor with the tools and techniques used. Any concerns, comments and areas for improvement should also be included. The health professional(s) and/or organisation should also complete evaluation on the trial, specifically regarding the usefulness of the tools and techniques, their suitability and areas for improvement.
Pretesting of materials provides the opportunity for potential problems with elements of the chosen plan to be identified, and rectified, prior to implementation of the PPI plan. This results in an efficient programme, efficient use of resources and an increased likelihood of successfully meeting the programme’s objectives.
Section 3 - Tools and Techniques for Implementation

(“Do” of the Plan, Do, Check, Act Cycle)

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3.1.1 Printed Media

Level 1: Communicating – Inform and Educate

Key Aspects

Most organisations provide some form of printed information for their service users on the services they provide. This information is easily transferable and allows patients to take their time in reviewing it. However, poor literacy skills can make health information difficult to read and understand (National Adult Literacy Agency, 2002). Consideration must be given to those who do not have English as their primary language as well as those who may have low literacy skills.

Many organisations may consider that quantity often relates to quality when it comes to printed information. All healthcare providers are aware of the need for printed information. However this can result in a plethora of documentation which often goes without review, without use and without benefit. The effectiveness of publications depends on an understanding of user literacy, motivation, access at the right time, availability in appropriate languages, and appropriate and accessible writing and layout styles.

Printed information can provide understanding and comfort to patients who feel anxious about entering the world of healthcare. Printed documentation which is difficult to understand will only add to this sense of anxiety. Organisations that are considering developing information leaflets should attempt to involve the end user at the earliest stage. At the very least this should occur prior to publishing. It is practically impossible for an individual who reads well and has a good vocabulary to be able to presume what people will understand. Consideration must be given not just to the information developed in-house, but also that which is developed elsewhere and used within the organisation.
The use of an appropriate document control system, to ensure that the information being provided to patients is up-to-date and reflects current best practice, is also essential. Printed media which has no visible date of publication is often an indicator of poor patient information. Printed patient information should be developed as part of an overall strategy emanating from an overarching information document on the organisation. This should provide the basis for more specific areas to be developed, circulated, reviewed and used to assist the patient.

Printed media is often used to provide information on specific areas of treatment or treatment choices. In these occurrences, the printed media should be provided to supplement personal communications, and not as the primary channel for giving information. At an organisation level, publications should be considered as part of a wider spectrum of information-giving strategies that in turn may initiate dialogue with consumers.

The information leaflets that exist in your organisation should:

- Be easy to read, free of jargon and use simple text
- Capture the reader’s interest
- Be focused for the relevant population, age group, reading ability
- Be up to date
- Be comprehensive providing full details about treatments
- Give a balanced view.

**Implementation:**

There are a number of simple writing and design techniques which can greatly assist in the development of printed information. Central to all development techniques is the need to involve users and carry out simple pre-testing prior to publication. This pre-testing may be linked to other Public and Patient Involvement (PPI) methodologies such as Focus Groups.
Some key points to consider when developing printed media for patients and the public:

- **Only include the actual information needed to convey the message.**
  Strictly limit the content of the printed media. Poor readers struggle with every word, often reading letter by letter. Keep the piece short and focused on the objective of the information document. Avoid adding any additional information which you feel may be of interest to others or may promote your organisation’s work. A common mistake is attempting to utilise an information leaflet to educate both patients and staff.

- **Present the topics in the order that the reader will use them.**
  Some less skilled readers have particular difficulty connecting topics and processing the flow of an argument. It can be of benefit to group information into clear ordered and number formats, e.g. 1, 2, 3.
  - Put the most important points first and last.
  - Information presented at the beginning and end of an information leaflet has been shown to be remembered best.

- **Respect the intended audience.**
  You should always be careful not to talk down to the reader. This is a difficult balancing act in relation to assuring clarity and simplicity of information. Bear in mind that individuals with low-literacy skills encompass people of different ages, genders, cultures, and socioeconomic status.

Some further useful guidelines:

- Use short sentences and paragraphs.
- Clarify concepts with examples.
- Avoid the use of jargon, technical terms, abbreviations, and acronyms. If necessary include a glossary (but define key words within the sentence).
- Include action points for the reader, e.g. make an appointment, complete a form, etc.
• Use graphics and design to help increase understanding.

• Consider universal symbols, such as a stop sign, or an arrow rather than pictorial signs, symbols, and charts which are not always effective.

• Avoid using all capital letters; they are more difficult for everyone to read.

• Use bullets and other graphic devices to highlight key messages.

• Avoid right-justified margins.

• Use an easy to read typeface such as Times New Roman or Arial. Use no more than three type sizes on a page. Use no more than two different typefaces or fonts in any publication. Use 12-point type size for standard materials. Use 14-point type size for large print materials, such as materials for older people.

You should always test your printed material prior to its publication with some of the people who are likely to use it. Testing will save time and money in the long run. Unfortunately, there is no quick way to pre-test. Some organisations use readability scores to assess the level of the documents. These tests examine the use of polysyllabic words and use of long sentences. While these tests can be beneficial they should never be considered to fulfil the requirements of pre-testing with potential users. The two primary readability tests are:

• Flesch Reading Ease score (http://www.readabilityformulas.com/flesch-reading-ease-readability-formula.php)

• Simplified Measure of Gobbledygook (SMOG) (http://www.literacytrust.org.uk/campaign/SMOG.html)

Another more local useful recourse is The National Adult Literacy Agency (www.nala.ie), who provides a range of leaflets including one on writing and design tips, and has published a “Literacy Audit for Healthcare Settings” with the HSE (2009).
Summary:

- Printed information is easily transferable and allows patients to take their time in reviewing the information provided.
- Many people find written health information difficult to read and understand.
- Effectiveness of printed media depends on an understanding of user literacy and motivation, access at the right time, availability in appropriate languages, and appropriate and accessible writing and layout styles.
- Information should be presented clearly and simply.
- Appropriate document control systems are necessary to ensure that the information being provided is up-to-date.
- All material should be pretested prior to its publication.
3.1.2 Audio/Visual Multimedia

Level 1: Communicating – Inform and Educate

Key Aspects

The provision of patient information in multiple formats is necessary to ensure that the needs of all individuals, including those with special needs, are met. Audio/Visual formats include:

- Audio – CDs, Tapes, Audio downloads
- Audiovisual – Videos, DVDs
- Interactive – Web, Interactive Kiosks.

The provision of audio information, that complements printed media, is beneficial for those who are visually impaired or have literacy problems. The development of patient information in audio format can also be beneficial where dealing with multiple demographics. Information can now be recorded in digital format and downloaded from the healthcare organisation’s website without great production costs.

The utilisation of patient information videos and DVDs can make use of both audio and visual senses to help patients’ understanding. The use of such videos and DVDs can greatly reduce anxiety and increase patient knowledge and understanding. By seeing the healthcare organisation from their television, patients can become more familiar with it prior to their arrival. Similarly to the audio files, it is now possible to have streaming video information available on websites. Where properly developed, this allows for reliable, accurate and easy-to-understand information to be provided by the organisation. This information can also be made available while patients are still in hospital, at the time when they may be most interested in learning more about their medical condition.
The utilisation of audio/visual technology within a healthcare organisation does not have to be limited to patients’ rooms. The employment of a touch-screen kiosk-based health information system provides the opportunity for hospitals to present a user-enticing methodology to their organisation. These information kiosks can provide the public and patients with information and education utilising a multitude of methods including video, audio and text. Information kiosks can also be used to administer patient feedback, similarly to using Comment Cards.

**Implementation:**

The development of audio/visual materials should follow these simple rules to increase the benefit to patients:

- **Ensure the message is accurate**
  The accuracy of the message in any format is vital to producing desired outcomes. This is particularly important with the rapid changes that can occur in healthcare. Always consult with an expert on the topic you are presenting to check the contents. However, ensure that the information remains simple enough for the intended audience.

- **Be consistent**
  All messages in all materials and activities should reinforce one another. Recognise inconsistencies between the messages. Use the same graphic identity in all. If there is a logo or theme, use it in all materials. Graphics and messages should reinforce each other, not send different signals.

- **Be clear**
  Keep it simple. As with printed media, audio/visual material should contain as few technical/scientific/bureaucratic terms as possible. Omit information that the audience does not need in order to make necessary decisions or take desired
actions (such as overly detailed background about disease, treatment etc.). Prominently feature the action you want the intended audience to take. Give people an explicit recommendation of what you want them to do as a result of the message. Do not assume they will figure it out for themselves.

- **Be relevant**

  Choose a presentation style appropriate to the intended audience’s norms and expectations; people must be able to relate to what they are watching or listening. For example, intended audience preferences can help determine whether to take a rational or emotional approach, a serious or light tone. Use a light, humorous approach if appropriate, but retest to be sure that it works and it does not offend the intended audience. Responses to humour vary greatly.

- **Be appealing**

  Given the number of health and other messages that intended audiences receive, yours must stand out. The optimal way to command attention will differ among intended audiences. It can be useful to know what has interested them before, but concept testing and message testing will help ensure the correct approach. Produce high quality materials. If you feel you have to skimp on production, choose a simpler way of presenting the information. Producing poor quality materials wastes funds and can damage your professional credibility.
Summary:

- Audio/Visual Multimedia formats can include CDs, tapes, videos and interactive systems such as kiosks.
- Ensure that the needs of all individuals, including those with special needs, are met.
- Information in audio format can also be beneficial where dealing with multiple demographics.
- Videos and DVDs can utilise both audio and visual (including text) senses to help patients’ understanding.
- It is possible to have streaming video information available on websites.
- Information can also be made available while patients are still in hospital, at the time they may be most interested in learning more about their medical condition.
- Touch-screen kiosk-based health information systems provide the opportunity for hospitals to present a user-enticing methodology to their organisation.
- Accuracy of the message is vital to producing desired outcomes.
- Information should contain as few technical/scientific/bureaucratic terms as possible.
- Choose a presentation style appropriate to the intended audience.
- Entertain while you educate where possible.
3.1.3 Websites

Level 1: Communicating – Inform and Educate

Key Aspects

A website can often be the first way that patients find out information about a healthcare provider’s services. An increasing number of people in Ireland now have access to the internet. The number of households that have an internet connection has risen from 45% in 2005 to 62% in 2008 (CSO, 2008). Consideration should be given by healthcare providers to their website’s usability, the amount of information available and its overall functionality. Many healthcare providers’ websites provide only basic information on the organisation such as location and opening hours. Today’s technology however allows for the provision of patient education through video, practical tools and feedback mechanisms.

A website should be graphically appealing and provide information about the organisation and related health issues in a simple and informative manner. Many organisations do not give enough consideration to the ease of navigation. This should be kept in a logical sequence, grouping similar themes. Consideration might be given to the creation of specific sections that relate to health promotion or patient feedback. Many sites contain useful public health information and resources, but too often this information is buried within the site. Visitors will be kept interested in the site by making it easy to navigate.

The content should be easy to read and follow similar rules to those identified in Section 3.1.1 Printed Media. To assist in ease of access for those with special needs an international Web Accessibility Initiative (WAI) (http://www.w3.org/WAI.new/) has been created by the World Wide Web Consortium (W3C) (www.w3.org). Specific guidelines are available on how to make web content accessible to people with disabilities. Following them will also make web content more available to all users, and will help people to find information on the site more easily. These guidelines do not discourage the development of multimedia such as...
using images, video, etc., but rather explain how to make multimedia content more accessible to a wider audience.

Potential Benefits of Websites:

- Ease of access.
- Ease of use – particularly where guidelines such as W3C WAI guidelines are used.
- Dynamic – information can be changed regularly and inexpensively.
- High amount of content is possible – the amount of information is dependent on the organisation.
- Allows for multiple demographics - can incorporate multiple languages, subtitles etc.
- Availability of multimedia – possible to incorporate video, audio and patient feedback mechanisms as well as practical tools such as electronic Patient Diaries.

Implementation

As with many of the Public and Patient Involvement (PPI) tools, the inclusion of pre-testing is essential to maximise the benefits of your healthcare website. The best time to do this testing is during the development of the site, not after it is completed. If the site is not yet running on a computer, you can test it using paper or poster board mock-ups of pages.

The feedback from the testers should allow you to improve the site before it is used. Where there is a need to make major changes following consultation remember to carry out the test again. The key to user uptake is a site which is clean, simple and uncluttered - just look at Google! Information should be logically grouped and in plain and simple language; remember who you are targeting.

Your website is an invaluable tool to receive information as well as provide it.
Consideration should be given to simple mechanisms such as discussion forums and patient feedback forms. These allow patients and the public to provide you with feedback at any time, in a structured manner. Ensure to monitor discussion forums carefully to make sure that they are being used appropriately.

Website development is a specific area which most organisations subcontract out. Remember however that it is your responsibility to do the background work, the preparation, the testing and the usability acceptance. Developers can only provide the technical expertise.

Finally, no matter how well you develop your website it is of no use if people cannot find it! Make sure to register it with the main search engines such as Google and Yahoo. Ask other relevant organisations to put a web link on their sites, and ensure that all publications clearly identify your web address.

*Characteristics of a well designed website include:*

- W3C accessibility guidelines compliant, which ensure access to the web by all
- Clean, consistent and simple design (e.g. a simple background, legible type, a few carefully selected colours)
- A search engine for your site so people can find information easily
- Structured and understandable menus
- Multimedia to keep the interest of the user and thus increase the uptake
- Short concise pages
- Compatibility with major browsers
- The ability to track site usage and facilitate patient and public response.
Summary

- A healthcare provider’s website is often the first point of contact for patients.
- 62% of the population in Ireland have Internet access (2008).
- Graphically appealing sites with good information keep the user’s interest.
- Web Accessibility Initiative (WAI) guidelines assist users with special needs.
  Use of multimedia can greatly increase the functionality of your website.
- Keep the website clean, simple and uncluttered.
- Provide a mechanism for user input.
- Publicise your website.
3.1.4 Promotional Campaigns

**Level 1: Communicating – Inform and Educate**

**Key Aspects**

Promotional campaigns are generally organised to increase people’s awareness and understanding of a particular topic or set of issues. A campaign can include a number of different promotion methods, such as media advertising, pamphlet distribution, radio appearances, talks and workshops etc.

The general objective of healthcare promotional campaigns is to change the behaviour of patients or other key stakeholders in an attempt to influence health outcomes in some way. For example, residential care providers may develop a promotional campaign to reduce the incidence of falls by older people in the community.

A well-designed and implemented campaign will operate on a number of levels simultaneously. Healthcare promotional campaigns that aim to reach a large population size should disseminate information using a range of methods. In conjunction with providing information, campaign workers should identify potential allies, consult with them and if possible, develop partnerships. This will help to increase the impact of the campaign, and increase the chances of reaching the objectives. It is likely that some of these allies will be consumer groups.

**Comprehensive promotional campaigns should be:**

- Goal-oriented attempts to inform, persuade or motivate behaviour change in the target audience
- Aimed at individual, network, organisational and societal levels to promote maximum impact
- Aimed at a relatively large, well-defined audience (i.e. campaigns are not interpersonal persuasion on a one-to-one or one-to-few level)
- Providing non-commercial benefits to the public and/or individual patient
• Planned to take place during a specified time period (this may vary from a few weeks to many years)
• Inclusive of a combination of media, interpersonal and community events
• Inclusive of an organised set of communication activities.

Implementation

Comprehensive planning of a promotional campaign prior to implementation will increase the likelihood of its success. Consider the following steps:

1. Manage the Project
A comprehensive plan should be developed to address all aspects of the campaign development process including time, money, human resources, data gathering and interpretation, and decision-making.

2. Analyse your Audience
Promotional Campaigns will have the greatest impact when they are directed at a specific audience. Prior to commencing the campaign, information regarding the demographic, behavioural and psychographic (e.g. values and beliefs) of your chosen audience should be collected. This will enable an audience profile to be established. It will then be possible to review the characteristics of your audience to determine whether or not they can be segmented into smaller, more homogeneous groups (audience segmentation).

3. Develop an Inventory of Communication Resources
Communication resources include media outlets, community spokespersons, etc. within your organisation and the community. These resources should be assessed to determine their strengths, weaknesses and possibilities of getting your message delivered.
4. **Select Objectives**
Identification of clear objectives prior to commencing the campaign will assist in maximising its benefits. This should include identification of the ‘bottom-line’ changes that the campaign aims to achieve (e.g. increasing older peoples’ knowledge about steps that they can take to avoid injuries in the home).

5. **Select Communication Channels**
Channels are the means by which a message is sent (e.g., radio, television, the Internet, newspapers). Channels which are available for use and suitable for the campaign should be identified and chosen.

6. **Develop the Message**
Choose the key message, or messages, to be communicated by the campaign carefully. These should relate to the defined objectives for the campaign.

7. **Develop a Project Identity**
Create an identity that will clearly communicate your image and your intended relationship with the audience (i.e. the purpose of your communications campaign and why it is important).

8. **Develop Materials (Production)**
Develop specifications for each desired product (vehicle). Vehicles might include documentation, printed media and other products which will transport the message. There will be a need to select suppliers and manage the production process.

9. **Implement your Campaign**
Make it all happen in a co-ordinated way to ensure maximum impact.

10. **Evaluate your Campaign**
Collect and interpret information on the planning, implementation and results of the campaign in order to identify effective aspects of the campaign and areas where improvement is required.
Summary

- Healthcare Promotional Campaigns usually take the form of organised campaigns to increase people’s awareness and understanding of a particular health topic or set of issues.
- The aim to change the behaviour of the public or patients should operate on a number of levels simultaneously.
- The ‘bottom-line’ changes need to be identified.
- The key message needs to be carefully chosen.
- It should all happen in a co-ordinated way.
3.2 – Level 2 – Listening – Gathering Information

3.2.1 Feedback and Complaint Systems

Level 2: Listening – Gather Information

Key Aspects:

A Feedback and Complaint System allows for structured and recorded input and feedback to health services by the public and patients. While feedback mechanisms normally focus on complaints and negative feedback, the system employed should also allow for the provision of positive feedback. The intention of the system to capture both positive and negative feedback should be well advertised throughout the organisation.

The right of a patient to make a complaint was identified as part of the *Health Act 2004*, Part 9. In response, the HSE developed a policy and procedural manual, *Your Service, Your Say* (2008) for the management of comments and complaints. The manual was developed to provide staff with a comprehensive guide to the management of complaints received at all levels within the HSE. Standard 6 of the Health Information Quality Authority’s (HIQA) *National Quality Standards for Residential Care for Older People* deals with complaints - “The complaints of each resident, his/her family, advocate or representative, and visitors are listened to and acted upon and there is an effective appeals procedure” (2007, p.13).

Complaints are a source of Public and Patient Involvement (PPI) that are often not utilised to their full potential by healthcare service providers. While policies and procedures for complaints are usually in place, they may not always be consumer-friendly or well-used. There may be a tendency for processes to become slow and bureaucratic. From a patient’s perspective they may look intimidating, and as a result may not be used. For the provider there may be an element of defensiveness that also discourages patients from complaining.
The key feature of a user-friendly complaints system is to provide a speedy and personal response from an individual who is trained and authorised to solve the problem. The organisation’s staff should also be able to identify and follow up patients who are dissatisfied, but who have not formally complained. It is important that complaints are handled in ways that are culturally appropriate and in ways that make it as easy as possible for the person making the complaint.

When an organisation is encouraging PPI, it is necessary to encourage both positive and negative feedback. It is important to remember that if an organisation makes changes to become more patient-involved and encourages their patients and public to complain, that the level of complaints will likely rise initially. Although it may seem strange, this increased level of complaints is a sign of success, as it demonstrates that the feedback system is being used. The organisation now has clear directions for change and improvement from its most important stakeholders.

In the business sector complaints are seen as a message from consumers who, if dissatisfied, are likely to go elsewhere in the future. For healthcare providers, however, patients often do not have the option of going elsewhere. This means that complaints are all the more important in improving service quality.

A well handled complaint should:

- Tell an organisation what it is doing wrong
- Foster a learning organisation
- Enable an organisation to make appropriate adjustments
- Lead to a positive image with service users.

To maximise the benefits of a Feedback and Complaint System:

- The organisation must adopt a culture of accepting all feedback, including complaints, as positive.
- There should be a clear and concise written complaints process, which is publicly and easily available.
• Staff should be well trained in the management of complaints.
• The process of handling complaints should be culturally sensitive.
• Handling of personal feedback and complaints should not be neglected.
• The organisation should aim to become ‘complaints friendly’ and learn to seek out and welcome complaints.

Implementation

The Australian Council for Safety and Quality in Health Care (2005, p13) has identified 8 key guidelines which provide assistance to healthcare service providers when they are developing or improving a feedback and complaints management system:

1. **Commitment to consumers and quality improvement**
   Leaders in the healthcare service should promote a consumer-focused approach to complaints as part of a continuous quality improvement programme.

2. **Accessible**
   The service should encourage consumers to provide feedback about the service, including concerns and complaints, and make it easy to do so.

3. **Responsive**
   The service should acknowledge all complaints and concerns and respond promptly and sensitively.

4. **Effective assessment**
   The service should assess complaints to determine appropriate responses by considering risk factors, the wishes of the complainant and accountability.

5. **Appropriate resolution**
   The service should deal with complaints in a manner that is complete, fair to all parties and provides just outcomes.
6. Privacy and open disclosure
The service should manage information in a fair manner, allowing relevant facts and decisions to be openly communicated while protecting confidentiality and personal privacy.

7. Gathering and using information
The service should record all complaints to enable review of individual cases, to identify trends and risks, and report on how complaints have led to improvements.

8. Making improvements
The service should use complaints to improve the service, and regularly evaluate the complaints management policy and practices.

These guidelines are similar to the principles of best practice complaint management that the HSE aspires to deliver in relation to dealing with complaints (Your Service, Your Say, 2008). These are:

- Organisational Commitment
All persons must embrace and be committed to the effective management of complaints and be committed to ensuring corporate learning and quality improvements as a result of complaints.

- Leadership
Service Managers must demonstrate leadership by ensuring that complaints are dealt with at local level where possible.

- The rights of patients and consumers to complain
All patients/service users must know of their right to complain and of their rights throughout the complaints management process. A written complaints procedure must be available and the complaints procedure should be well publicised.
• **Fair**
The complaints handling process should be implemented without fear, favour or prejudice towards the complainant, the person or service about which the complaint was made. Neither the complainant nor the subject of the complaint should have a fear of recrimination of any kind at any stage of the process.

• **Equity**
A consistent and standardised approach must be adopted for the management of all complaints. The complainant and the service provider have an equal voice and are of equal importance in this process.

• **Accessibility**
The complaints system must be well publicised and be accessible to patients, service users, their families and representatives. Special attention must also be paid to the needs of people with special requirements e.g. older people, children, people with physical and sensory disability, literacy issues and disadvantaged groups.

• **Effective**
The complaints system must endeavour to effectively resolve all complaints for both the complainant and those who deliver the service about which the complaint was made.

• **Efficiency**
The emphasis must be on resolving complaints effectively and in a timely manner.

• **Impartiality**
It is essential that all complaints are dealt with in an impartial manner. Complainants must have the opportunity to be heard and the complaints must be investigated without prejudice to either the complainant or staff member/service implicated.
• **Appropriateness**
The complaints procedure must have the capacity to deal appropriately with all complaints being lodged. The complaints management process must be flexible enough to be applicable to any type of complaint in whatever manner it is presented e.g. verbal, written etc., taking into account language, literacy levels, disabilities etc.

• **Responsiveness**
The service must acknowledge all complaints and concerns and responds promptly and sensitively. The practice must be responsive to the complainant’s needs and must seek to try and achieve, where possible, client satisfaction and issue resolution as close to the source of the complaint as possible. Complaints need to be dealt with within a timely manner ensuring that the timeframes identified for dealing with the complaint take cognisance of the complexity of the factors involved in the complaint.

• **Confidentiality**
All information obtained through the course of complaint management must be treated in a confidential manner and meet the requirements of the Data Protection Acts 1988 and 2003 and the Freedom of Information Acts 1997 and 2003.

• **Farsighted**
The complaints process must be flexible to adjust to future demands and legislative requirements. It must be able to meet the needs of changing populations and patient/ service user expectations.

• **Accountability**
The complaints processes must ensure that, where warranted, action is taken on complaints to address the specific complaints, to prevent similar occurrences in the future and to inform service provision. Where action is not justified, the complainant must be advised as to why action should not be taken. A process of monitoring and evaluation will be implemented at all levels of the process and organisation to ensure that the processes are being adhered to and complaints are appropriately managed.
Summary

- A Feedback and Complaints System is a mechanism that allows a structured and recorded input for patients and public.
- A Feedback and Complaints System is not usually a stand-alone system.
- The right of patients wishing to make a complaint was identified as part of the Health Act 2004, Part 9. In response, the HSE developed a policy and procedural manual, “Your Service, Your Say” (2008) for the management of comments and complaints.
- Key features of a user-friendly approach to complaints are to provide a speedy and personal response.
- Complaints must be handled in ways that are culturally appropriate.
- It is necessary to encourage all feedback, both complaints and positive feedback.
- An increased level of complaints is an initial sign of success following implementation of a Feedback and Complaints System.
- The organisation should aim to become ‘complaints friendly’ and learn to seek out and welcome complaints.
3.2.2 Telephone Hotlines

Level 2: Listening – Gather Information

Key Aspects

A Telephone Hotline may be provided by healthcare organisations to allow the public and patients to provide feedback on aspects of the service in a simple manner. It is a method of patient involvement which attracts respondents fairly indiscriminately. It is highly reliant on skilled staff to maximise its effectiveness.

A Telephone Hotline is provided where healthcare services and providers wish to invite general public and patient comment, suggestions and complaints on their role and activities. This involvement is accommodated by publicising the provision of a free hotline that is a permanent feature of the organisation's Public and Patient Involvement (PPI).

There are a number of benefits to a Telephone Hotline:

- It can be a very accessible way for the public and patients to address ideas or issues. It can be particularly beneficial for those with limited mobility.
- It is a cheap and ongoing means of receiving feedback on the service. The calls can be categorised to show trends.
- It provides an opportunity to resolve patient dissatisfaction at an early stage.

For Telephone Hotlines to be successful, the public and patients need to be aware of their existence. They also need to know the purpose of the hotline, the kind of topics that can be addressed on it, when it is available (i.e. hours when it is manned) and how to access it (i.e. the number to dial). Thus the introduction and maintenance of a hotline must be supported by a communication strategy. This may involve providing the number and a brief description on a fridge magnet, on the back of appointment cards, on a large sign in the main building, etc.
Telephone Hotlines can also be used to obtain information about specific issues - often referred to as ‘phone-ins’. These are short-term strategies which aim to find out public opinion on particular issues such as proposed changes to the organisation or its services. Similar to the hotlines, phone-ins will only be successful if people know about them. They require additional publicity, and hence should not be used as a stand-alone strategy, but as an adjunct to a wider consultation process.

It is important to consider the characteristics of people who will use hotlines and phone-in facilities. The callers are not a randomly selected sample of the organisation’s service users. They comprise the public and patients who have been motivated to call; perhaps because of opportunity or the strength with which their views are held. Thus the callers should not be expected to represent the views of the wider population. They may, however, provide some insights into why people who hold those views do so. They may also provide a source that can be referred into other avenues of PPI such as focus groups, committees or patient support groups.

**Implementation**

The Telephone Hotline is one of the simpler PPI tools to implement. The creation of a free telephone number is quick and easily facilitated by Eircom or other telephone service provider. Prior to establishing a hotline:

- Define the purpose of the proposed hotline.
- Identify the target audience.
- Identify mechanisms for publicising its existence.
- Understand the importance of evaluation and monitoring.
- Evaluate staffing needs and priorities.
- Identify appropriate policies and procedures and their key elements.

Central to the effective implementation of the Hotline is the staff who is facilitating it. These may be full time staff or, where practical, volunteer staff. Either way the individuals taking the calls should be provided with training in areas such as:
• How to overcome the obstacles of communicating by telephone.
• How to listen and respond to callers effectively.
• What type of questions to ask callers, and when.
• Tips for giving information and signposting.
• When and how to end a call.

Consider the following points for the operation of your Hotline:

1. Finding out about the Hotline
There should be an effective process that makes existing and potential callers aware of the hotline and what it offers. This will include a communications strategy by the organisation.

2. Getting through to the Hotline
The hotline should be staffed, open and accessible as advertised. Provisions should be made for out-of-hours callers and busy times.

3. The call - establishing and maintaining interaction.
Hotline workers should respond to callers with courtesy. They should establish the nature and content of the call and interact with the caller so that the whole matter can be dealt with in the most effective and appropriate way.

4. The call - offering information, advice, signposting and referral.
Information and advice that is offered to callers should be up-to-date, accurate and appropriate to their enquiry, and signposting and referral should be made to an appropriate agency.

5. Complaints about the service
There should be a clear procedure for callers to the hotline to be able to make complaints about the service.
Summary

- The Telephone Hotline is provided to allow patients to provide feedback on aspects of the service in a simple manner.
- The Hotline relies on publicity and on the telephone being attended.
- It provides a cheap and ongoing means of receiving feedback.
- It must be supported by a communication strategy.
- Its success lies with the staff that is facilitating it.
3.2.3 Comment Cards

**Level 2: Listening – Gather Information**

**Key Aspects**

Comment Cards provide an easy-to-use mechanism of receiving patient and public input. They usually consist of some basic questions followed by space for general input or comments. Comment Cards however should not be seen as mini patient surveys; their benefit lies more in the fact that they provide a sounding board. Comment cards have significant limitations as a method for gathering quantifiable data. Poor design and insufficient thought given to methods of analyses can compound limitations.

Well-designed and focused Comment Cards can be very useful. However, it is important to consider the type of people who use Comment Cards. These people are predominately:

- Extremely happy with the level of care/service
- Extremely unhappy with the level of care/service
- Patients and public requesting changes (e.g. change in visiting times, availability of vending machines etc.)
- Patients who have the time (often as a result of waiting which can put them back to the “extremely unhappy” category).

A key word above is “extremely”. Generally satisfied patients are unlikely to take the time to say so. Thus, the people who fill out Comment Cards will not be a reflective representation of all service users, and so the analysis of findings should not be presented as an actual reflection of the service.

This does not mean that Comment Cards are not beneficial. As part of an overall Public and Patient Involvement (PPI) strategy, they can form an effective yet simple
starting point. Their effectiveness however can be dependent on the type of service being provided, e.g. Comment Cards would be of little use to the Ambulance Services where the time involved with the patient is minimal, but may be of benefit in the maternity service. It is important that organisations empty the collection boxes on a regular basis.

The questions asked on Comment Cards should be simple, clear, and few in number. The questions must be seen as indicators to issues, and as a result be broad in nature. To maximise benefit, consideration may be given to having a specific focus over a period of time, e.g. questions only relating to hygiene or staff communication. This needs to be publicised and staff should ask patients and visitors to consider completing a Comment Card. The more Comment Cards completed, the more useful information you can receive!

In general Comment Cards should be as user-friendly as possible. Questions should not overshadow the amount of space available for leaving general comments. The simpler the system and the better positioned the cards are, the greater the likelihood of their uptake. Whatever approach is taken, Comment Cards must form a part of a greater overall PPI strategy.

**Implementation**

The use of Comment Cards as a sole tool for PPI is often viewed as the stereotype of a token approach to patient involvement. Comment Cards can provide a useful tool for PPI but they must be incorporated into a larger process of data collection. Their advantages include low cost and requiring little staff time once they are in place. For patients, they are fairly anonymous which can add to the attraction of use, certainly where they feel extremely happy or extremely unhappy.
Points for consideration:

1. Comment Cards provide a simple starting point for patient feedback, but does your service allow the time for patients and the public to complete them?

2. Where will the Comment Cards be located? Will they be in a highly visible area? What additional promotion material and staff education will be provided?

3. The card design must be simple and straight-forward. Have you tested it before its final use?

4. Are the questions broad enough to be cues for the patient to give additional information? Are the Comment Cards going to focus on any particular area? Has plenty of room been left for patients’ comments?

5. Have you asked patients/public to leave contact details so that they can be followed up about their concerns if they wish?

6. Have you defined the process for maintenance, collection and analysis of feedback? Is each area responsible for its own information or will it be implemented centrally?

7. Bear in mind that negative feedback from individuals may be symbolic of a bigger issue in your organisation.
Summary

- Comment Cards are an easy-to-use mechanism for receiving public and patient input.
- Comment Cards are not mini patient surveys.
- Their benefit lies in providing a sounding board for patients.
- Generally satisfied patients are unlikely to say so.
- Success can also be dependent on the type of service being provided.
- Comment Cards with a specific focus can be helpful.
- Comment Cards must form a part of a greater overall strategy for PPI.
3.2.4 Patient Shadowing

Level 2: Listening – Gather Information

Key Aspects

The NHS Institute for Innovation and Improvement (2005) has outlined Patient Shadowing as a key method for involving patients. Patient shadowing occurs when another patient, volunteer or member of staff accompanies a patient or carer through the health system. It is preferable that the ‘shadower’ does not have previous knowledge of the service and is comfortable asking questions.

While the patient is being shadowed, their 'shadower' can use interview techniques and observation to support the information provided by the patient. Physical details, such as environment and waiting times can be recorded as well as perceptions of the service. Patient shadowing provides objective, observational feedback but needs to be balanced with other approaches, e.g. by obtaining the views of the staff providing the service.

Shadowing enables a comprehensive picture of an individual patient’s flow and movement throughout the system to be established. This information can be invaluable when trying to map what really happens on a patient’s journey within a service. Shadowing can also be used to monitor and measure performance as well as to identify training needs. It can be used as a training and development tool to help staff understand what is important to patients as they progress through the healthcare service. Shadowing can also be combined with the patient diary (NHS, 2005. p. 42).
Implementation

Patient Shadowing can be an effective yet simple mechanism for obtaining information from patients. Prior to implementation, there are a number of points which should be considered and developed. These are outlined briefly below:

1. **The Aim**
   Identify clearly what you are trying to achieve and how shadowing will help to reach your goal. What information do you want to collect? This may include:
   - The actual time spent waiting or being seen.
   - The standard of verbal, printed and signposted information given.
   - How staff respond to questions and specific needs, e.g. disability.
   - The ambience of each area visited.
   - Any specific points mentioned by patients and staff.

2. **How is it carried out?**
   - **Time**
     - Select a period for shadowing patients. This can vary between one to three weeks.
   - **Recruitment**
     - The 'shadower' must fully understand and be comfortable with his/her role.
     - Identify who will recruit staff and patients, and how. Recruitment of patients is usually carried out by the receptionist staff / nurse that usually meet them. They should provide information on the process and introduce the patient to their ‘shadower’. The ‘shadower’ ensures that the patient understands what will happen and follows the patient for the duration of the stay. It is made clear that at any time the patient can ask the ‘shadower’ to stop.
     - Provide support for the patient and ‘shadower’ and respect the contribution of time and effort from both.
• **Shadowing**
  
  o During the consultation or procedure, the ‘shadower’ either remains in the waiting area or discreetly in the background, observing. After each activity, such as briefing by the nurse or consultation with the doctor, the ‘shadower’ asks the patient for their reactions to what has happened. Information is collected in a concise way. The patient should be able to see what the ‘shadower’ is writing if they wish.
  
  o When the appointment is finished, the ‘shadower’ asks general questions about what could be done better and what was particularly good. They also provide an opportunity for the patient to add anything they choose. After the patient leaves, the ‘shadower’ adds his or her own comments in the box provided. Comments from clinic staff can also be recorded.

3. **What outcomes are to be expected?**
   
   • Monitored information e.g. waiting times.
   
   • Patient observations, e.g. benefits of services, such as catering in waiting areas.
   
   • Staff observations, e.g. relating to issues identified by the ‘shadower’.
   
   • An understanding of patient’s awareness of issues.

4. **Final points**
   
   • Provide feedback to the patient and the 'shadower' regarding how their work has helped with service improvement.
   
   • Practice will increase the creativity with which patient shadowing can be used.
Summary

- Patient Shadowing occurs when another patient, volunteer or member of staff accompanies a patient or carer through the health system.
- It provides objective, observational feedback.
- It should be balanced by other approaches, for example by obtaining the views of the staff.
- It can be used to monitor and measure performance as well as to identify training needs.
- The 'shadower' must fully understand and be comfortable with the role.
- Practice in the use of patient shadowing will increase the creativity with which it can be used.
3.2.5 Patient Diaries

Level 2: Listening – Gather Information

Key Aspects

Patient Diaries are a mechanism by which patients record both events that occur, and their personal thoughts, during their healthcare journey. It is a structured framework that allows the patient to maintain an active record of their perceptions of the care that they receive. Most commonly this takes the form of a written document; however the use of electronic diaries, as well as video recording equipment, is becoming more common.

Upon completion, information from the diary is shared with the organisation. The aim is to help get a better understanding of the patient’s journey, difficulties encountered and the level of anxiety relating to them. The amount of information shared is dependent on the patient. Diaries can be developed to either focus on the entire journey, or part of it, depending on the objectives.

The Patient Diary can assist the organisation by providing information on the service provided and specific aspects of care. A diary may identify issues that the patient may not remember to talk about later. The Patient Diary can also provide a form of therapy for patients as it can be designed to include their personal emotions in relation to their disease. In the provision of certain care services, the diary may also be used as a log of treatment changes which can be completed in conjunction with members of staff. In this case, the treatment details are kept separate from the patient commentary.

The individual events of a patient’s illness as well as the overall patterns of care can provide useful insights into the way a service is delivered and used over time. Such a retrospective overview is a valuable aid to the healthcare provider. It can also serve as a beneficial, reflective medium for a person who may have had a traumatic experience during their care. Equally, a positive encounter may provide an individual
with a good source of reference should they need to use another or similar service in the future.

The difficulties experienced in the use of Patient Diaries relate primarily to the patient’s understanding of their use. It may be difficult to recruit patients when they have been made aware that their records must be shared with the healthcare provider. Many may feel that this is overly intrusive. A more common problem is that many forget to use the diary. This is especially relevant when considering patients in an acute setting where their routine has completely changed and their anxiety levels have increased. There may be a need for healthcare staff to assist patients in keeping up-to-date with their entries. This however can cause its own difficulties as it may influence the content of the diary.

**Benefits of Patient Diaries:**

- Patients are given a sense of being listened to and their views acknowledged.
- Patients have an opportunity to reflect on issues that have occurred and provide suggestions on possible solutions.
- The Diaries provide information in real time that can assist in speedier rectification of issues.
- They may determine issues which could only be identified from a patient’s viewpoint.
- They may allow for a deeper examination of issues that have been previously flagged.
Implementation

A Patient Diary initiative can be implemented with varying degrees of detail and, as a result, cost. In their simplest form Patient Diaries may be no more than some loosely bound sheets of paper. In a more elaborate format, patients may be provided with Personal Digital Assistants (PDAs) or video recorders. In the vast majority of cases Patient Diaries take the format of small booklets that have been designed for ease of use. Other media should be considered for patients who have been identified as having poor literacy skills.

No matter what medium is used, it is essential that there is a clear structure. The danger of patients drifting off from the areas that you wish to focus on is ever present. This must be balanced with the need for qualitative information. A Patient Diary is not a tick box survey by another name. Guide questions must be developed to reflect the concerns and language of the patient, not the healthcare provider. However, there should also be the facility for the patient to incorporate information outside of the guide questions as they so choose.

Education should be provided to patients who have agreed to participate. This should not just be limited to the early stages of diary entries. Patients should be encouraged and supported on an ongoing basis. It is critical that patients have a clear understanding of what is required and of the potential benefits.

Upon completion of care the confidentiality of patients must be observed. The method by which information is shared with the organisation must be agreed at the outset. The amount of information to be shared should also be agreed.
Summary

- Patient Diaries are a mechanism by which patients can record both events and their personal thoughts
- Patient Diaries can be in written form or make use of digital equipment
- Information is shared with the organisation to get a better understanding of the patients’ journey
- Diaries can provide patients with a sense of being listened to and acknowledged
- Guide questions must be developed for ease of use
- Education and support should be provided to patients continuously
- Patient confidentiality must always be observed.
3.2.6 Surveys

**Level 2: Listening – Gather Information**

**Key Aspects**

Surveys enable organisations to gather information by means of questionnaires. Patient and public surveys are one of the most commonly used methods to receive feedback on healthcare services. They can be administered by an interviewer face-to-face or by telephone, or they can be sent through the post. In addition, they can be provided online via the web, for completion by the respondent (self-administered). The Irish Society for Quality and Safety in Healthcare administered by post the *Patient Perception of Acute In-Patient Care in Ireland* in 2004, the largest patient survey administered in the Irish health system.

The most common form of survey is a sample survey. This reduces the cost and time involved in surveying the whole population (a census), and uses a sample from which information can be inferred about the wider population. There are a wide variety of patient satisfaction questionnaires which vary in size, detail and focus. Some are detailed, multidimensional scales designed to assess the overall concept of satisfaction and have been tested for reliability and validity. Others are simpler one-off questionnaires designed for specific settings, which do not aspire to such sophistication. Less sophisticated surveys can provide valuable information if the following factors are considered:

- **Generic or specific measures**

  Satisfaction or dissatisfaction can be expressed around a number of aspects of healthcare (specific) and also in a global sense. If generic measures of satisfaction are to be useful, there needs to be a clear understanding of which specific aspects of that service influenced the rating. An overall satisfaction score should be supplemented by information on the more specific aspects of the service. It is of no
help to simply know that the majority of patients are satisfied in an overall sense with their experiences.

- **Question focus**
  The wording and presentation of questions can greatly influence responses. Questions may focus on patients’ actual experiences or on their evaluation of results. Short, clear questions are best. Over reliance on negative statements to elicit information about patients’ perceptions and views may provide a misleading picture. Asking patients if they agree with a negative description of their hospital experience tends to produce greater apparent satisfaction than asking if they agree with a positive description.

- **Validity**
  The measure of patient satisfaction should be a ‘true’ measure and not, for example, be a measure of general life satisfaction. Qualitative methods are needed to ensure that those aspects of health services most salient to the patients are included in the survey. Another concern about the validity of survey results relates to the reluctance of patients to make negative evaluations of the health service that they largely depend on for care. Consequently, every effort should be made to ensure views remain anonymous or confidential.

- **Reliability**
  Survey results should be consistent, meaning that, given similar experiences, patients would return similar ratings on the scales.
Implementation

Before undertaking the development and administration of a survey, it is essential that the survey is designed appropriately to find out what you want to know. To begin, look at your area of interest and decide if it is a suitable topic for a sample survey. It might be that the information you require can be gathered more effectively using qualitative techniques, e.g. Focus Groups.

To assist in your decision, as well as helping to identify steps in the development process, consideration should be given to a number of key questions grouped as follows:

- Questions to consider before identifying patients who will be invited to participate in the evaluation.
- Questions to consider when you are ready to begin involving patients.
- Evaluation questions.

1. Questions to consider before identifying patients who will be invited to participate in the evaluation

   - Why is patient satisfaction being measured?
   - What dimensions of quality / aspects of satisfaction are to be measured?
   - What difference to patients will this measurement make?
   - What is the management commitment and staff commitment to patient/client participation? And what is the commitment of the organisation to change?
   - Can the organisation develop ways to ensure that patients who participate will be listened to and their input valued?
   - What aspects of the organisation’s history may impact on patient/client participation? (HeBE, 2003, p.14)

2. Questions to consider when you are ready to begin involving patients.

   - Do you know who the patients are and how to recruit them?
   - Do you know how patients would like to participate in the organisation?
   - What dimensions of quality / aspects of satisfaction are to be measured?
   - Are there different levels that patients can participate within the organisation?
What kinds of skills will be required by patients to do this work?
How will you support those patients who provide their time and expertise to your organisation? (*HeBE*, 2003, p. 15)

3. Evaluation questions

- What is the most appropriate method for measuring the identified patient/client’s satisfaction?
- Is the chosen method appropriate?
- Are there any ethical issues to be considered?
- Who should conduct the measurement?
- How is the data to be analysed?
- What report format should be used?
- How will the report be disseminated and published? (*HeBE*, 2003, p. 16)

In relation to the administration of your survey, consider the following:

- Differences between postal and telephone response rates can be significantly reduced by telephone follow-up of postal non-respondents, although this adds to the costs.
- Impersonal and postal methods result in more criticism/less reported satisfaction because respondents’ anonymity is not compromised and there is no pressure for socially acceptable responses.
- Postal methods give more variability in responses (people who feel strongly either way respond), but there may be concealed proxies.
- Posting questionnaires 1-2 days post-discharge yields higher return rates than handout at discharge.
- On-site surveys under-represent low users in ambulatory populations.
- Qualitative approaches are more resource intensive but generate a different sort of information than structured questionnaires.

Regardless of which methodology is used to administer the patient survey, it must be seen as part of an overall quality improvement process. This should include evaluation and dissemination of results to key players, consultation and development
of plans for improvement, implementation of plans, and re-evaluation to measure gains and identify new priorities for improvement. This should not happen in isolation but rather as part of your overall PPI strategy.

Summary

- Surveys collect information by means of questionnaires.
- They can be administered face-to-face or by telephone interview, sent through the post, or provided online via the web.
- The most common form of survey is a sample survey.
- Sample surveys can provide valuable information if the right steps are followed.
- An overall satisfaction should be supplemented by information on more specific aspects of the service.
- The wording and presentation of questions greatly influences responses.
- Information you require may be gathered more effectively using qualitative techniques.
- Postal and telephone non-response rates can be significantly reduced by telephone follow-up.
- Surveys should be part of an overall quality improvement process.
3.3 - Level 3 – Engaging – Work to Involve

3.3.1 One-to-One Patient Interaction

Level 3 Engaging – Work to Involve

Key Aspects

One-to-one patient interaction with healthcare professionals is the most basic form of patient involvement, and is central to its effectiveness.

Most complaints made by patients and the public regarding healthcare services deal with communication issues rather than with clinical competency. The most common complaint is that healthcare staff do not listen. Patients want more and better information about their problems and the outcome, more openness about the side effects of treatment, relief of pain and emotional distress, and advice on what they can do for themselves. There are many different opinions on what makes good and effective communication and where it is achieved, but it is considered to greatly influence such aspects as compliance, patient education, and health outcomes.

Good one-to-one patient provider communication offers many tangible benefits. Many studies have found significant positive associations between healthcare professionals’ communication skills and patient satisfaction. Similarly good patient provider interaction has also been seen to affect patient outcomes such as emotional health, resolution of symptoms, function, pain control, and physiological measures such as blood pressure and blood sugar concentration.

Communication however is not a one-way system. Patients will also need skills and support to take part in decision making and raise questions about quality. In 2005 the Irish Society for Quality and Safety in Healthcare launched a booklet entitled “Let’s
Talk: A guide to becoming more actively involved in your healthcare”. This document aims to provide patients with:

- Information about what to expect from their healthcare team.
- An explanation of how to discuss concerns about their healthcare services.
- Tips for improving their healthcare management.
- Suggested questions to ask their healthcare team.

This document provides information on how patients can become better managers of their own care by becoming better communicators with their healthcare providers.

Learning communication skills, for both the patient and the healthcare professional, is dependent on an openness to change on all sides. Healthcare professionals must utilise effective listening skills and elicit and provide information using effective nonverbal, explanatory, questioning, and writing skills. These are skills that must be learnt and are not inherent abilities. Similarly the patient must work in partnership with the healthcare provider to become more actively involved in their treatment. This change will not happen overnight but must be supported, through the provision of information, education and support structures, by the healthcare organisation.

**Implementation**

One-to-one patient communication is a patient involvement mechanism which will occur regardless of any focused activity. Healthcare staff will always communicate with patients. The aim however is to maximise this interaction to assist in the overall patient outcome. This improved interaction is based on the provision of information, education and support for both the patient and the healthcare professional.
One to One Interaction: Patients

Patients should be provided with information, education and support to assist them in becoming involved with their care. They must be made aware that good healthcare is best achieved through an active and positive partnership between themselves and their healthcare team. Taking part in decisions that are made about their treatment is the single most important way for them to get the best possible care for their needs and to help prevent things from going wrong.

Patients should be encouraged to ask the healthcare staff questions, and to expect answers that they can understand. It may help patients if they write their questions down before their appointment and take notes or have a family member or carer with them. Patients should be reminded to pay attention to the care that they are receiving. This will help ensure that they are receiving the right treatments and medications from the right members of staff.

When supporting patients to become more involved, the healthcare provider should aim for the patient to:

- Be informed and agree on exactly what will be done during each step of their care
- Know how long their treatment will last and how they should feel
- Understand that more tests or medications may not always be better
- Keep a record of their medical history
- Be supported if they wish to seek a second opinion.

One to One Interaction: Healthcare Professional

The provision of education to staff regarding patient interaction should assist in the overall care of the patient. Education on patient interaction should encourage the healthcare professional to:

- Build a personal yet professional rapport with the patient.
- Use non-directive facilitation to encourage the patient to further disclose important issues, concerns, and all agenda items.
- Address the patient's feelings related to the reason for the visit.
• Use several skills to reach common ground when the patient and clinician differ about key elements of the diagnostic or therapeutic plan.

• Use active listening to understand the meaning behind patients’ expressions and behaviour, which imply but do not explicitly state issues and concerns. Active listening demonstrates an explicit and focused interest in what the patient believes may be going on or what their greatest concerns and expectations are.

• Be aware of the impact of non-verbal communication.

The skill levels of staff should be considered when initiating and developing any training or support systems. The overall ability of a healthcare professional to engage in effective one-to-one patient interactions can be assessed, and subsequently classified within the following categories:

1. Inadequate communication skills; likely to create significant clinical problems (Patient dissatisfaction or confusion).

2. Uses some communication skills effectively and others ineffectively; certain areas of communication might cause clinical problems (Patient dissatisfaction or confusion).

3. Uses most communication skills effectively; some interview behaviours present which, if modified, could lead to an even more effective impact on a real encounter.

4. Uses all communication skills effectively; minor suggestions for change are noted which are unlikely to have measurable importance on encounter.

5. At the level of an experienced clinician who is expert in using all communications skills effectively. Skills demonstrated such that a patient would likely note such skills to friends and family.
Summary

- One-to-one patient interaction with healthcare professionals is the most basic form of patient involvement.
- Patients want more and better information about their problems and the expected outcomes.
- Good one-to-one interaction greatly influences such aspects as compliance, patient education, and health outcomes.
- There are significant positive associations between healthcare professionals’ communication skills and patient satisfaction.
- Patients need skills and support to take part in decision making.
- Learning communication skills, for both the patient and the healthcare professional, is dependent on an openness to change.
- Healthcare staff will always communicate with patients. The aim is to maximise this interaction to assist in overall patient outcomes.
3.3.2 Focus Groups

Level 3: Engaging – Work to Involve

Key Aspects

Focus groups offer healthcare providers a simple method of gathering information from patients and the public on specific topics. They are one of the most common ways for gathering qualitative information from patients and the public. Focus Groups can also be used to receive input on proposals or plans currently being developed by the organisation.

Focus groups are a way of systematically establishing the issues, concerns, and opinions of patients. They play a valuable role in drilling down information which otherwise may not be accessible. Information from focus groups can assist in such areas as:

- **Strategic Planning**
  Gathering data relating to the services that matter to service users, e.g. finding out what aspects of care made a difference to patients while in hospital.

- **Development Discussion**
  Providing opinions on plans and concepts presented by the organisation to the group.

- **Development of Qualitative Techniques**
  Finding out about a range of participants’ experiences in order to prepare a survey questionnaire on these matters.

A focus group is not just a meeting of a selected group of people with something in common. The group should have a focused and defined purpose which reflects the size and composition of the group. Although there is no defined optimum number of participants it is general accepted that the minimum number is 6 and the maximum is
12. The participants are selected because they have characteristics in common, for example, are all ex-patients of a hospital, or are all carers of someone with the same or related conditions.

The distinguishing feature of focus group interviews is the explicit use of the group interaction to produce insights and understanding that would be less accessible without this interaction. Focus groups can achieve this because participants not only state their views about a particular topic, but also explain to the group members the reasons why they hold these views. Such participation occurs as participants question each other, or even challenge views, which might differ from their own. Participants are requested to explain the reasoning behind their own opinions allowing the researcher to explore and record such interaction.

As with all Public and Patient Involvement (PPI) methodologies there are some drawbacks to utilising focus groups. One of the primary limitations of a group is that it is not necessarily representative of a cross-section of the population. In this regard it must not be used for the collation of qualitative data on specific concerns. The group is not expected to reach a consensus but rather provide a better understanding. By increasing the number of focus groups held however, certain trends may become apparent which warrant further investigation. Another difficulty is that the benefit of the sessions is largely dependent on the facilitator. It is important that he/she is skilled in maximising a focus discussion. In addition, consideration must be given to marginalised groups who may be more difficult to get to participate. By identifying these limitations, it is possible to maximise the benefits of focus groups.

Fundamentally, focus groups are a way of listening to people and learning from them. Within the group there is a need for continual communication between the facilitator and the participants. Facilitators should be motivated to listen and learn from the participants. The facilitation of focus groups is by no means a passive process.

Benefits of Focus Groups:

- Insights are gained into public and patient perceptions
Detailed information is easily accessible
- Relatively low cost
- Can support other PPI methodologies
- Not dependent on literacy skills
- Can accommodate cultural diversity.

Implementation

Consider the following points when initiating a focus group:

1. **Purpose**
   Prior to the issuing of invitations to a focus group, organisers must clearly define the topics they wish to focus the discussion on and what they wish to learn. This must be provided to the participants in advance and, where relevant, background information on the topics should be provided.

2. **Participants**
   People who are selected to participate in focus groups need to be fairly open. This is not always easy and consideration should be given to providing a simple document that outlines peoples’ expected competencies. The participants involved should be able to express their feelings in front of a small group of people and be prepared to interact with them. Every group has its own dynamics. However it must be remembered that there is no magic formula and the exercise may have to be repeated.

3. **The Facilitator**
   Focus group discussions involve the participants and the facilitator in a highly interactive process. The facilitator must be skilled in group-work to ensure that proceedings operate in an orderly and meaningful manner. He/she should be skilled at establishing a non-threatening and supportive atmosphere for participants where everyone feels that their contributions are valued. The participants’ priorities need to
be acknowledged to ensure that they will express their thoughts and ideas. During the focus group it is important that the facilitator is not too controlling. He/she should not be involved in providing any of the services under discussion.

**Key points in facilitating a focus group:**

- Keep your focus at all times to ensure you do not miss any key points.
- Use a high level guide to keep order but allow flexibility.
- Use recording equipment, if agreeable with participants, to ensure all information is captured.
- Use probing open-ended questions.
- Don’t be afraid to act as “devil’s advocate” to provoke discussion.
- Expand ideas from individual points.
- Support everyone in the group to help include those who are not as vocal.
- Summarise points regularly to ensure that you understand what is being said.
- Provide feedback to the group on completion of the session and formally at a later stage.
- Thank them!

**Summary**

- Focus Groups are a simple method of engaging patients and the public.
- The number of participants can range from 6 to 16.
- Focus groups are not necessarily representative of the entire population.
- Participants are provided with a space to state their views and explain their reasons.
- Benefits are largely dependent on the facilitator.
- Facilitators should be motivated to listen and learn.
- Participants must not only be knowledgeable but open.
3.3.3 Patient Commitment Statements

Level 3: Engaging – Work to Involve

Key Aspects

Patient Commitment Statements are published standards, defined by the organisation, against which patients can measure the care and services that are provided. Patient Commitment Statements are usually identified in the form of patients’ rights of access to and receipt of services by the healthcare providers.

Patient Commitment Statements can play an important role in empowering patients by making them aware of their entitlements as individuals. These written patient rights and guarantees are provided to specify service conditions and identify mechanisms for complaints where they are not met.

The success of Patient Commitment Statements rests with the creation of realistic expectations and goals. Published commitments, often seen in the form of patient charters may have a limited possibility of being realised, due to limited resources. These only serve to frustrate and annoy patients who are led to believe that they have an entitlement to the services.

In 1992 the Department of Health developed a national Patient Charter which was circulated widely to hospitals. The Charter aimed to create a Patient Commitment in relation to access, courtesy, religion and information. In 2002, the European Charter of Patients’ Rights was also published. Organisational specific Patient Commitment Statements however differ from national and international charters in that they can be used to identify mutual responsibilities amongst the patient and the healthcare provider. They thus have the potential to be a mutually beneficial mechanism for both parties and to maximise the efficiency of the health service.
Implementation

Patient Commitment Statements can be an important mechanism of empowering patients by making them aware of their entitlements as individuals and consumers. Statements should in all cases be realistic with regards to expectations.

In developing an organisational specific Patient Commitment Statement, consideration must be given to defined rights through national and international strategies, agreements, charters and legislation. The key issues that need to be addressed by the organisation include:

- Quality of care
- Appropriate information
- Choice
- Participation and representation
- Respect for human dignity
- Confidentiality
- Redress for grievances.

Patient Commitment Statements are beneficial mechanisms for identifying the patients' and public's responsibilities. Patients and public should be involved at the development stage to help focus their responsibilities. These may include:

- Provision of information
- Involvement in education
- Understanding of limitations
- Adherence to instructions.

Consideration must be given to how each point in the Patient Commitment Statement can be measured for success. As previously stated there is little point in developing an ideological wish list that cannot be achieved! Where the commitments
are not being met the organisation should clearly identify what methods of redress are available, e.g. complaints process, patient advocacy, etc.

Patient Commitment Statements can often focus on the individual. Consideration must also be given to the wider population served. It is necessary to think at the whole community level and to whom the organisation will ultimately be accountable.

Remember to publicise your completed Patient Commitment Statement. If developed correctly it should be of benefit to both patients and staff. Your Patient Commitment Statement should be prominently displayed in public areas and on your website.

Summary

- Patient Commitment Statements empower patients by making them aware of their entitlements as individuals and consumers.
- The success of organisational specific Patient Commitment Statements rests with the creation of realistic expectations and goals.
- The Patient Commitment Statement is a mechanism by which patients' responsibilities can be publicised.
- Consideration must be given to defined national and international rights.
- A balance must be seen to exist between the individual requirements and that of the community.
- All points of a Patient Commitment Statement must be measurable with identifiable actions for redress.
- Patient Commitment Statements should be publicised.
3.3.4 Patient Councils & Residents’ Committees

Level 3: Engaging – Work to Involve

Key Aspects

A Patient Council consists of a group of patients who advise the organisation on service development relating specifically to patient care. The overall aim of a Patient Council/Committee is to work closely with the organisation and its staff to improve services for all patients.

Patient Councils/Committees have been established by some organisations as a mechanism for bringing together representatives of several consumer groups. Other organisations use the Council/Committee as a central tenet to their overall Public and Patient Involvement (PPI) programme. Councils/Committees are designed to:

- Help assess the current quality of service
- Recommend and provide input on new or modified services
- Review relevant policies and procedures
- Oversee the development of patient involvement initiatives
- Act as a communication conduit to a larger population.

Patient Councils and Residents’ Committees are comprised entirely, or at least predominantly, of patients and carers. They are established by healthcare providers through a genuine desire to work closely with their patients to improve services. Although it is up to each Council/Committee to decide the details of how it will work, it is necessary to be cautious that the meetings do not become a place of negativity and be seen purely as a complaints forum. Other tools should exist within the organisation to deal with these issues. Similarly the Patient Council/Committee should not be seen as a system for responding to a national agenda. Each Council should be unique in its own right, addressing issues specific to the organisation. In this way the Council/Committee can provide the greatest benefit. An unfocused Council can become very time consuming with little benefits.
The structure of the Council/Committee must be given due consideration. One of its benefits over other PPI initiatives is its longevity. Representatives should have tenure long enough to learn to be useful, but not so long that they become part of the organisation. Therefore it is important that members are recruited carefully. As previously mentioned some organisations utilise representation from other patient bodies and associations. Others run recruitment campaigns within their organisation. Whichever method is used, it is essential to have clear “Terms of Reference” for the Council/Committee as well as defined selection criteria, commitments and responsibilities.

Benefits of Patient Councils and Residents’ Committees:

- Help create service developments that are more responsive to patients’ needs.
- Allow for a central structure to oversee PPI strategies.
- Provide an ongoing review of initiatives due to the duration of their membership.
- Publicly highlight the organisation’s commitment to patient involvement.
- Increase local ownership of care services.

Implementation

The development of a Patient Council or Resident’s Committee is a significant undertaking. It is essential to do the homework before establishing such a body. There is a need for clarity with regard to all issues including:

- Role of the Council/Committee
  Defined “Terms of Reference” must be developed. What will be the scope of the Council/Committee? How will it interact with the rest of the organisation?
• **Membership**
  How many representatives will there be and who are they expected to represent? This may vary from 8 to 20.

• **Reporting Mechanisms**
  Who will the Council/Committee report to and to whom will they be accountable?

• **Appointment of Members**
  How will they be recruited and appointed and by whom?

• **Duration**
  What is the life expectancy of the Council/Committee? Will there be rolling membership? Under what circumstances can members be dismissed?

• **Resources**
  What supports will be available to the Council/Committee? Will members have access to research resources, administrative assistance, photocopying, etc?

• **Costs**
  What expenses will be met by the organisation? Will members be paid?
  There are both pros and cons to this.

Overall you need to think strategically about how the Council’s/Committee’s findings or advice will be used by the organisation. Is the organisation currently open enough to hear what the Council/Committee may come up with? How can the links between it and the organisation be maximised? A Patient Council/Committee has the ability to drive PPI in the organisation. However if it is ineffective it will quickly bring the strategy to a halt. Members of a dysfunctional Patient Council/Committee can often negate the benefits.

In short, for this involvement tool to truly function you must be sure that the organisation has the capacity and the commitment to patient involvement to support the Council/Committee and to see it through for the long run.
• Patient Councils and Residents’ Committees comprise groups of patients who advise the organisation on improving the service.
• They can act as a central tenet to all PPI.
• They are comprised entirely, or at least predominantly, of patients and carers.
• Patient Councils/Committees should not become places of negativity.
• Each Council/Committee should be unique in its own right and address issues specific to its organisation.
• Representatives need to have tenure long enough to learn to be useful, but not so long they become part of the organisation.
• Developing a Patient Council or Resident’s Committee is a significant undertaking. Is the organisation ready for this?
3.4 – Level 4 – Partnering – Develop Together

3.4.1 Expert Patients

Level 4: Partnering – Develop Together

Key Aspects

An Expert Patient is a term used to refer to a person who has experienced a condition or illness and who is prepared to share their knowledge about living with it with others. The term was first used in the UK National Health Service’s white paper, entitled *Saving Lives: Our Healthier Nation*, 1999. Research from the US and UK over the last two decades has demonstrated that people living with chronic illnesses are often in the best position to know what they need in managing their own conditions. Provided with the necessary 'self-management' skills, they can make a tangible impact on their diseases and quality of life more generally.

Through self-management programmes, the Expert Patient is enabled to train others with similar long-term conditions to develop skills in managing their illnesses. This creates a new generation of patients who are empowered to work with the health services to enhance their overall quality of life.

Under an Expert Patient programme, patients receive support to help them take more control of their own health and treatment and to make more appropriate use of health and social services. In the UK the pilot phase of the Expert Patient Programme was successfully completed in autumn 2004 with 19,000 participants having engaged with the programme. Without the benefit of a national programme of Expert Patients in the Irish health system, the focus must be placed on developing local, patient-led, generic chronic disease self-management courses (the core of an Expert Patient Programme) in partnership with voluntary organisations that have the ability to deliver these courses.

The aim of such self-management programmes is to ensure that patients’ knowledge of their condition is developed to a point where they feel able to take responsibility...
for its management, working in partnership with health and social care staff. Central to these programmes is the use of other Expert Patients, to assist participants with similar conditions to themselves. These programmes go beyond the purely medical view, to look at how chronic disease affects daily life. Usually run over six weekly sessions, the aim of these courses is not only to impart information but also to facilitate the development of self-management skills, such as problem solving and goal setting.

Implementation

Expert Patient programmes are not simply about educating patients about their conditions or giving them relevant information. Neither are they based on a model of care whereby a health professional educates or instructs a patient and then measures success on the basis of patient compliance. Programmes must be based on developing the confidence and motivation within the patients to use their own skills, and information and professional services to take effective control over living with a chronic condition. With adequate support, patients can take a lead in managing their own conditions, which can help to improve health, quality of life and reduce incapacity. To date in the UK there has been the creation of Expert Patient Programmes in such areas as:

- Arthritis
- Diabetes
- Asthma
- Substance Abuse
- Disabilities

The involvement of partners such as voluntary organisations is central to the development of an Expert Patient programme. These organisations can assist the healthcare provider in determining which chronic conditions should be focused upon and how they can be tackled. More importantly they are a key resource to identifying
content, structure and resources in the development of the self-management training courses which are central to the development of Expert Patients.

Self-management courses aim to help people manage their long-term condition, to adopt approaches that prevent their condition from getting worse and to reduce the risk of getting further complications. Course tutors usually have a long-term health condition themselves and are either paid tutors or volunteer tutors who have previously undergone the programme. They are, by their very nature, the Expert Patients. At the outset it is obviously not possible to have access to such experienced people, and consideration must be given to how this can be overcome.

The content of the courses should contain specifics regarding the chronic illness but also be reflective of the aims of the overall Expert Patient programme. The five core self-management skills have been identified as:

- Problem solving
- Decision making
- Resource utilisation
- Formation of a patient professional partnership
- Taking action.

Specific elements may include managing symptoms; dealing with stress, depression and low self-image; developing coping skills; relaxation; healthy eating; action planning; and working with health professionals and others who are caring for the patient.
Summary

• An Expert Patient is one who has experience of a condition or illness and who is prepared to share his/her knowledge about living with it to others.

• Provided with the necessary 'self-management' skills, patients can make a tangible impact on their diseases and quality of life.

• Expert Patients enable other patients to develop skills.

• Patients need to receive support and education to help them take more control of their own health and treatment and to make more appropriate use of health and social services.

• User-led self-management programmes are the principal route for creating Expert Patients.

• Expert Patients work in partnership with health and social care staff.
3.4.2 Patient & Public Representatives

Level 4: Partnering – Develop Together

Key Aspects

Patient or Public Representatives are individuals who act as representatives for a larger group of service users. These individuals provide a consumer perspective. The decision to involve a Patient/Public Representative in your organisation’s committees is a significant one and should not be taken lightly. Healthcare professionals generally feel comfortable with committees, their processes, and using them to make decisions and resolve problems. However, many patients and members of the public may not be used to committees and may feel uncomfortable and unable to contribute effectively.

Putting a consumer on a health service committee is usually a long-term strategy. As part of an overall involvement strategy, the use of Patient/Public Representatives on committees such as Management Committees, Ethics Committees and Quality & Safety Committees, as well as Accreditation Self-Assessment Teams shows a commitment to partnering with patients to help develop a more patient-centred process. However, using representatives on these committees requires a significant commitment from your organisation in terms of time, communication, support and often training.

The appointment of a Patient/Public Representative has limitations. No matter how capable the representative is, he/she cannot reflect the views of the entire community. At best, he/she can only hope to provide a view from outside the organisation. In this regard, it may be beneficial to appoint two representatives, rather than one, to organisational committees. This certainly applies in the case of higher committees such as management committees.

Prior to the instigation of any recruitment of Patient/Public Representatives, it is necessary to have clear “Terms of Reference” for the committee. Clarity needs to be
provided as to the role of the patient/public. Any potential representative must know and understand what kind of role and power the committee has. For example, can the committee make decisions? If not what other decision making structures need to be involved?

The issue of resources must also be considered when attempting to recruit representatives. The issue of payment is a thorny one, but needs to be considered. Payment may change the type of individual who applies to be involved. A detailed selection criterion must be used to ensure that this does not affect the final selection process. More practical is the need to discuss with potential representatives the type of supports they need, e.g. mileage, crèche facilities etc.

The key factor to maximising the benefit of Patient/Public Representatives is to choose the most appropriate individuals. The skills required do vary; however at a minimum, consider their ability:

- To analyse information from a range of sources and identify its potential relevance to the patient
- To see the possibilities of both short and long term outcomes
- To negotiate on issues
- To work as team members to achieve the desired outcomes
- To articulate their opinions.

**Implementation**

For Patient/Public Representatives to operate effectively, clarity is required on the following issues:

- The role of the committee in question
- The role of the Patient/Public Representatives
- The recruitment and selection process to be used.
Once you are clear on these three areas, recruitment will be guided by the role identified for the representative. Recruitment of a representative may begin with the organisation contacting a relevant patient advocacy body and requesting a nomination from there. This is particularly pertinent if the committee has a particular care focus, e.g. cancer care. It is important to provide the advocacy body with both plenty of information about the committee and the role, and sufficient time for them to consider who would be most suitable.

If this is not appropriate, or does not yield the type of individual required to fulfil your criteria, it may be necessary to advertise. This can be done through local newspapers, radio, or even internally in your organisation. A central contact should handle all inquiries. This member of staff can then help explain the process to those who express an interest in becoming representatives. Alternatively an open evening could be held to provide more information.

Irrespective of the recruitment process you use, it is essential that those interested provide a written explanation, based on the ‘job description’, as to why they feel they are suitable. This will allow you to reduce the number of applicants who do not meet the basic requirements. Interviews can then be carried out. Make sure that a Patient/Public Representatives is on the interview panel (perhaps ‘borrowed’ from another organisation). Remember if none of the applicants seem appropriate, do not be afraid to try again, possibly using a different strategy. Always remember to contact and thank those applicants who have been unsuccessful. If appropriate, advise them of the outcome.

Following the selection of a Patient/Public Representative it is necessary to spend time educating him/her on the activities of the organisation, the role of the committee and the expectations of the organisation. Equally important is the need to set aside time at the earliest opportunity to discuss his/her expectations. Understanding expectations is crucial to getting good results and avoiding disappointment and conflict at a later stage. Consider the following questions when discussing
expectations with your newly appointed Patient/Public Representative:

1. How do you feel your involvement in the committee can help you to achieve your own goals?

2. How can the committee and the organisation support you to participate, e.g.:
   - Crèche Facilities
   - Mileage
   - Expenses
   - Induction
   - A “buddy” to discuss issues
   - Interpreting
   - Counselling
   - Times/Dates of Meetings

3. What ongoing support would you like to receive?

Summary

- Patient or Public Representatives are individuals who act as representatives for a larger group of service users.
- Involving Patient/Public Representatives in committees requires significant investment by the organisation.
- Patient / Public Representatives must be seen as a long term strategy.
- Clarity must be provided on the:
  - Role of the committee in question
  - Role of the Patient/Public Representatives
  - Recruitment and selection process to be used.
3.4.3 Community Forums

Key Aspects

Community Forums can be a useful way for an organisation to hear the experiences and ideas of the community. In this regard, they are somewhat similar to Focus Groups. However, forums usually aim to involve a larger group of patients than focus groups and can include a small number of staff.

Community Forums are a useful method for educating people, sharing information about a specific issue or developing an appreciation of different viewpoints. Forums can take the form of a one-off event but are usually more effective as a series of meetings at which the public and staff discuss matters of shared concern. In addition to using forums to gain feedback about the care or service patients have received, they can also be used to enable the patient and public to achieve wider input into organisational decision-making and planning.

In implementing a Community Forum it is necessary to have:

- Commonly understood and agreed goals.
- A clear process for reaching those goals.
- An awareness that people come with their personal pre-occupations and feelings as well as an interest in the subject at hand.
- A sense of involvement in making decisions and the actions which follow the decisions. This means that all members should participate.

The aims of a Community Forum are to provide:

- Visible community involvement in the development of healthcare services.
- The community with the mechanism to:
  - receive information
Community Forums can provide an opportunity to discuss alternative policies or programmes, to get feedback and to refine proposals. For example, a Community Forum might be used to consult with community members about the location of a new healthcare facility; or to consult people from different ethnic groups about their perceived barriers to using the health service.

The staff members attending the forum should be flexible, prepared to listen and able to express themselves clearly and concisely. It should be clearly understood by all that the purpose of the forum is not to make final decisions, but rather to develop recommendations. Consideration should be given to the use of an external facilitator, which may enhance the effectiveness of the forum. Their role is to provide non-directive guidance in assisting the forum to come to decisions. Facilitators should ideally have a neutral role in relation to the matters being discussed. It is often helpful for facilitators to work with organisers to design the process beforehand, including formulating the agenda and suggesting forms of participation.

Implementation

The introduction of Community Forums is a significant undertaking by a healthcare organisation and signifies a major step towards enhancing Public and Patient Involvement (PPI). To maximise the involvement in, and thus the benefits of, the Community Forum, the following points should be considered:

1. Highlighting Awareness
Ensure that you have provided sufficient notice about the meeting(s). Use a range of methods to target the intended audience.

2. Accommodating Attendees
Make it attractive and easy for service users to attend. Provide a meal or light refreshments, free parking and childcare.

3. Opening the Forum
Depending on the topic of the forum, you may want to open with a guest speaker(s) formally addressing the group, providing information and sharing knowledge and ideas. This is a particularly useful approach for decision-making and planning forums.

4. Forum Process
Your process should provide consumers with information and the opportunity to ask questions at the beginning of the forum, and then the opportunity to participate in the development of further ideas or action plans through small group discussions.

5. Using a Facilitator
An experienced facilitator should be used. There should also be enough people with group experience to act as facilitators for the small group discussions.

6. Concluding the Forum
The conclusion of the forum should include a clear summary of the outcomes of the forum. It is important to ensure that participants are kept up to date.
Summary

- Community Forums are a useful way of hearing the experiences and ideas of the community.
- Forums can take the form of a one-off event but are usually more effective as a series of meetings.
- Forums are a useful way to gain wider input into organisational decision-making and planning.
- It is necessary to have an awareness that people come with their personal pre-occupations and feelings as well as an interest in the subject at hand.
- Staff members attending the forum should be flexible, prepared to listen and able to express themselves.
- Consideration should be given to the use of an external facilitator.
- Community Forums signify a major step towards enhancing PPI.
3.4.5 Community Partnerships

**Level 4: Partnering – Develop Together**

**Key Aspects**

Community Partnerships are structured cyclical planning processes with a specified role for the community in shared decision-making with healthcare providers. They are usually the result of years of development of Public and Patient Involvement (PPI) and a strong community focus and culture in the organisation.

Community Partnerships can take many forms. Essentially they involve the coming together of various community groups and organisations to implement or develop a specific initiative, for example, a substance abuse initiative. On occasions they may be established very quickly; to respond to local demands or to meet the criteria for, or timetable of, for example a new urban regeneration funding initiative. Joint planning partnerships between the community and providers are a significant form of PPI. These partnerships aim to combine resources to help tackle specific problems. These resources should not be limited to financial but should also include staff members and their expertise.

Partnerships may bring together organisations with differing histories, priorities and cultures. They may involve groups with different agendas and individuals with different goals and needs relating to their involvement in the partnership. Partner agencies may, or may not, therefore have a shared understanding of the goals, purpose or, indeed, partnership structures. Prior to implementation, it is essential that the healthcare organisation and the community partners are clear about how the partnership will work.
Implementation

When establishing a Community Partnership:

- Clarify your own aims and objectives in forming a partnership. What are you trying to achieve, and how will community partners assist?
- Identify the stakeholders in the project or programme.
- Consider who you really need as partners, and who would really want to be a partner.
- Before approaching potential partners, make sure you have support and agreement within your own organisation about working with others.
- Make informal contact with partners to find out about their attitudes and interests before putting out formal proposals.
- Communicate with your partners in language they will understand, focusing on what they may want to achieve.
- Plan the partnership process over time. Successful partnerships take time to establish formally.
- Use a range of methods to involve people in workshop sessions as well as formal meetings.
- Encourage ideas from your partners. Ownership leads to commitment.
- Be open and honest.

Summary

- Community Partnerships are structured cyclical planning processes with a specified role for the community in shared decision-making with healthcare providers.
- They involve the coming together of various community groups and organisations to implement or develop a specific initiative.
- These partnerships aim to combine resources to help tackle specific problems.
- Healthcare organisations and the community partners should be clear at the outset about how the partnership will work.
- Successful partnerships take time to formally establish.
## Section 4: Assessment

("Check" of the *Plan, Do, Check, Act Cycle*)

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4.1 Why Conduct Assessment?

This Public and Patient Involvement (PPI) framework is modelled on the Plan, Do, Check, Act (PDCA) Quality Cycle. This cycle works on the premise that the project is not finished when the action has been taken. To ensure that the involvement programme is achieving what it set out to do, an organisation needs to evaluate the process. The Evaluation Tool outlined in Section 4.2 can be used by organisations to conduct this process.

The predominant reason for evaluating PPI is to reflect on what works and what doesn’t. Assessing the effectiveness of the project ensures that the project objectives are being achieved, that the resources are being effectively utilised and that the stakeholders are satisfied with the project’s progress. This information strengthens evidence about the benefits of participation and informs organisations of the strategies most likely to support effective participation. It also provides healthcare organisations with a method of establishing opportunities for improvement in terms of their PPI processes.

Evaluation has been described by Baum, Cooke and Murray (1998):

‘evaluation opens up the project’s ‘black box’ and sheds light on the operation and dynamics of the project’

Evaluation should be linked to the original objectives set by the healthcare organisation, and should include an analysis of how the organisation defines successful PPI. Evaluation should reflect partnerships between the public and patient and the healthcare organisation; therefore the public and patient should be involved in the evaluation. Evaluation tools need to be respectful and sensitive to all of those involved, and acknowledge the complexities of human relationships and power sharing.
4.2 Using the Self-Assessment Evaluation Tool

In keeping with the framework of this Tool-Kit, the evaluation tool is based on the Plan, Do, Check, Act Quality Cycle. The evaluation is conducted by means of a self-assessment process. The self-assessment tool is in the form of a questionnaire (Appendix 1) and corresponding rating scale and analysis (Section 4.3). The questionnaire is designed to capture the current level of Public and Patient Involvement (PPI) in the healthcare organisation. The rating scale and analysis of results is designed to provide guidance to the organisation on areas where it is performing well and specific areas for improvement.

The evaluation tool can be used by any healthcare organisation when it is commencing PPI activities to assess the current situation in the organisation. This can act as a benchmark. The tool can then be used on a regular basis to assess changes and improvements in the involvement process, and progress can be monitored by the organisation against the original benchmark. Organisations are encouraged to identify other healthcare settings using the evaluation tool, and compare the evaluation ratings and experience. This will act as a further benchmark and may identify other areas in which the organisation can become involved.

4.2.1. Questionnaire (see Appendix 1)

The questionnaire is composed of quantitative and qualitative questions, the results of which will indicate the level of patient involvement and its prioritisation within the organisation. It is divided into two stages, as follows:

*Stage One: Assessment of current level of public and patient involvement*

Stage One is designed to identify the level of PPI which exists currently in the healthcare organisation. It includes questions related to planning, implementation, staff training, management and governance involvement, and assessment and continuous improvement of the involvement process. For many of the questions, organisations are required to rate themselves on a five point scale, as follows:
Agree Strongly = 5
Agree = 4
Neither = 3
Disagree = 2
Disagree Strongly = 1

At the end of the questionnaire, organisations are required to add up the scores given for each question, and subsequently will have one cumulative score for the analysis.

Stage Two: Reflection and Opportunities for Improvement
Stage Two is a descriptive and reflective section. It allows organisations to consider and reflect on the situation that exists at present, based on the information gathered in Stage One. Stage Two asks organisations to identify areas of PPI where they are doing well at present, and to consider the areas in which they wish to progress and what plans they are going to make to enable this.

4.2.2 Rating scales and analysis (See Section 4.3)
The analysis considers the two stages of the questionnaire.

Stage One: Assessment of current level of public and patient involvement
Each question is addressed and discussed individually in Section 4.3.1. For each question, there is a brief overview of its rationale and relevance. A qualitative overview of the rating that each organisation granted itself, on the scale 1 to 5, is given for each question. For example, where an organisation has given itself a 5 (or ‘agree strongly’), there is a qualitative description of the benefits that the organisation will have achieved from this, and suggestions of other factors that the organisation could consider to help move forward. Similarly, where an organisation has rated itself with a 1 or 2 (i.e. ‘disagree/disagree strongly’) the qualitative comments will highlight the potential benefits of addressing this situation and how to commence an improvement in the area.
At the end of Stage One of the questionnaire, organisations are requested to add up all of the quantitative scores achieved on each of the questions to give one cumulative number. A quantitative scoring section with four different bands (e.g. Band 1 is 0 – 20, Band 2 is 21-40, etc) enables organisations to identify the level at which they lie in terms of PPI. It is hoped that this will also provide the organisation with encouragement and ideas on how to progress and improve their involvement programme.

Stage Two: Reflection and Opportunities for Improvement
Stage Two of the questionnaire is designed to focus the organisation on its areas of excellence, areas for improvement and future plans for PPI. Results will differ for each organisation. Due to this individuality, it is not possible to offer a clear-cut analysis of the questions completed in Stage Two. However, to assist in the organisation’s analysis of Stage Two questions, suggestions and areas for consideration are outlined for each question in Section 4.3.2.
4.3 Analysis of Results

Organisations are encouraged to firstly complete the questionnaire provided in Appendix 1, and then use this section to review and analyse their findings.

4.3.1 Stage One: Assessment of Current Level of Public and Patient Involvement

Section 1.0 “Plan”

Question 1.1

There is an identified need for increased public and patient involvement in my organisation

Rationale

Organisations should be aspiring to have PPI performed as a response to needs assessment. Needs assessments can be conducted independently for PPI or can be conducted as part of a larger needs assessment for the organisation’s overall requirements. The analyses of needs assessments will provide information on the needs and objectives of the patients and will act as a basis for determining the required level of PPI.

Quantitative Rating:  

<table>
<thead>
<tr>
<th>Rating</th>
<th>Value</th>
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<tbody>
<tr>
<td>Agree Strongly</td>
<td>5</td>
</tr>
<tr>
<td>Agree</td>
<td>4</td>
</tr>
<tr>
<td>Neither</td>
<td>3</td>
</tr>
<tr>
<td>Disagree</td>
<td>2</td>
</tr>
<tr>
<td>Disagree Strongly</td>
<td>1</td>
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</table>

Qualitative Comments:

Agree / Agree Strongly = organisations utilising needs assessments as a basis for developing PPI programmes are demonstrating their commitment to stakeholder participation. Organisations should ensure that the needs
assessment is designed to obtain relevant and valid information from the patients. The frequency with which the assessment is conducted should be reviewed.

Disagree / Disagree Strongly = Organisations should consider how to commence a needs assessment for the public and patients. There is a need to consider the extensiveness of the consultation to be conducted and whether it will be an independent plan or part of a larger organisational plan.

Question 1.2

There is a specific planning process for public and patient involvement in my organisation

Rationale
Planning for PPI is crucial to the success of the programme. Sufficient planning enables the organisation to establish specific, measurable objectifies, identify necessary resources, and ensure the process is conducted efficiently and effectively.

Quantitative Rating:

<table>
<thead>
<tr>
<th>Rating</th>
<th>Score</th>
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<tbody>
<tr>
<td>Agree Strongly</td>
<td>5</td>
</tr>
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<td>Agree</td>
<td>4</td>
</tr>
<tr>
<td>Neither</td>
<td>3</td>
</tr>
<tr>
<td>Disagree</td>
<td>2</td>
</tr>
<tr>
<td>Disagree Strongly</td>
<td>1</td>
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</table>

Qualitative Comments:

Agree / Agree Strongly = Organisations which have specific planning processes for their PPI will reap greater rewards from the process. These programmes are more likely to reach their objectives and will make more efficient use of their resources.
Disagree / Disagree Strongly = A lack of planning can impinge on the entire process, resulting in unclear objectives, potential misuse of resources and an inability to utilise the process to its full potential. Organisations should be encouraged to plan the process fully prior to its commencement.

**Question 1.3**

**There are defined objectives regarding public and patient involvement**

**Rationale**

Specific and structured objectives should be developed with the input of all stakeholders and agreed upon by all prior to the commencement of the project.

Objectives state what the programme is attempting to achieve and allow an organisation to evaluate whether or not it has met the aims of the programme.

Objectives should be Specific, Achievable, Measurable, Realistic & Timely.

**Quantitative Rating:**

- **Agree Strongly** = 5
- **Agree** = 4
- **Neither** = 3
- **Disagree** = 2
- **Disagree Strongly** = 1

**Qualitative Comments:**

**Agree / Agree Strongly** = Organisations with defined objectives for PPI will have a clear vision of the purpose of the involvement programme. These organisations should evaluate the process for establishing the objectives, and ensure that they are agreed upon by all stakeholders prior to the commencement of the project.

**Disagree / Disagree Strongly** = Organisations without clear objectives for PPI will struggle to see the purpose and benefits of the involvement programme. It is advisable for all organisations to establish agreed objectives prior to the commencement of the programme.
Question 1.4

Stakeholders are consulted when objectives are being defined

Rationale
Consulting all stakeholders when the aims and objectives are being defined ensures that all participants are aware of the rationale behind the involvement programme. It enables all involved to work towards a common goal and outcome. It also allows any concerns, discrepancies or queries about the objectives to be identified and addressed prior to commencement of the involvement process. Stakeholders include individuals and groups within the healthcare organisation and the public and patient participants themselves.

Quantitative Rating:

- Agree Strongly = 5
- Agree = 4
- Neither = 3
- Disagree = 2
- Disagree Strongly = 1

Qualitative Comments:

Agree / Agree Strongly: Organisations who develop aims and objectives in association with their stakeholders will have a more effective and efficient involvement process. There is a greater likelihood that any discrepancies with the objectives will be identified at an early stage, and rectified. There is also likely to be greater ‘ownership’ of the project by all involved.

Disagree / Disagree Strongly: Organisations who do not involve stakeholders in the development of their objectives are more likely to encounter problems and misunderstanding of the aims of the project. Such organisations should be encouraged to identify all relevant stakeholder groups, and attempt to involve each group in the determination of objectives prior to commencement of PPI projects.
Section 2.0 “Do”

Question 2.1

Public and Patient involvement has been specifically incorporated into my organisation’s vision, mission and values

Rationale

Incorporation of PPI into the organisation’s vision, mission and values demonstrates that the organisation is actively prioritising involvement. It also informs the public and patients that the organisation is considering their needs in its service delivery. Furthermore, it demonstrates the commitment of management and governance to the process.

Quantitative Ratings: Agree Strongly = 5
Agree = 4
Neither = 3
Disagree = 2
Disagree Strongly = 1

Qualitative Comments:

Agree / Agree Strongly = Organisations which have PPI in their mission, vision and values are sending a clear message to their service users that they are attempting to be responsive to their needs. The methods for developing the mission, vision and values should be assessed, ensuring that they have complete stakeholder input.

Disagree / Disagree Strongly = Organisations should attempt to have the concept of PPI evident in their mission, vision and values. The organisation should review how the mission, vision and values are developed, how often they are reviewed and who is involved in their development, and consider the inclusion of PPI in the next revision.
**Question 2.2**

Public and patient involvement has been utilised in the development of my organisation’s strategic plan

**Rationale**

Inclusion of PPI in the organisation’s strategic plan emphasises the importance of involvement. It enables organisations to prioritise involvement and is evidence that management and governance acknowledge the benefits of involvement. It also encourages planning for involvement and the development of objectives for involvement.

**Quantitative Rating:**

- **Agree Strongly** = 5
- **Agree** = 4
- **Neither** = 3
- **Disagree** = 2
- **Disagree Strongly** = 1

**Qualitative Comments:**

**Agree / Agree Strongly** = Organisations that have included PPI in the development of their strategic plan should further assess the benefits that have accompanied its inclusion. Organisations can benefit from assessing and analysing the current activities in relation to involvement, and how much of these are reflected in the strategic plan.

**Disagree / Disagree Strongly** = Organisations should consider including PPI in the next strategic planning process. This will include analysis of the current situation regarding PPI and determining what should be included in the strategic plan.
**Question 2.3**

There is a defined strategy for maximising public and patient involvement in the development and delivery of the organisation’s services

**Rationale**

A defined strategy for maximising PPI can be part of the overall strategic planning process, or can be a separate strategy. This strategy should outline how the organisation plans to approach the issue of involvement to ensure maximum benefit to all participants.

**Quantitative Rating:**

- Agree Strongly = 5
- Agree = 4
- Neither = 3
- Disagree = 2
- Disagree Strongly = 1

**Qualitative Comments**

**Agree / Agree Strongly** = Organisations who have a defined strategy for maximising PPI should evaluate the strategy to assess the level of concurrence to the document. The organisation should ensure that the document is updated regularly to reflect changing needs of stakeholders.

**Disagree / Disagree Strongly** = Organisations should consider how to produce a strategy aimed at maximising involvement. This strategy can be part of the organisation’s strategy. Alternatively it can be a stand-alone strategy with the specific purpose of addressing PPI. Central to the development of the strategy will be consultation with all stakeholders. Recommendations should be based on observed and assessed needs, and on thorough planning and evaluation.
Question 2.4

There are clearly defined communication channels to disseminate information regarding public and patient involvement

Rationale
Patient involvement information regarding planning, outcomes of participation activities and evaluation must be communicated to relevant stakeholders. These include the public and patients themselves in addition to the organisation. Within the organisation there may be numerous departments which would benefit from the knowledge gained from the process, including (but not limited to) management, clinical departments, patient advocacy departments, complaints and quality departments. The organisation should have a process to assess the information needs of the various stakeholders and develop communication systems to provide suitable feedback.

Quantitative Rating:  

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<tbody>
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<td>3</td>
</tr>
<tr>
<td>Disagree</td>
<td>2</td>
</tr>
<tr>
<td>Disagree Strongly</td>
<td>1</td>
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</table>

Qualitative Comments:

Agree / Agree Strongly = Effective communication channels enable the information gained from the involvement process to be utilised to its maximum capacity. Organisations that have clearly defined communication processes should be assessing the effectiveness of the channels utilised. This ensures that appropriate information is getting to the individuals and groups that require it, and that the information is understood. Effective communication systems enable maximum benefit to be obtained from public and patient involvement.

Disagree / Disagree Strongly = Organisations without defined communication
channels are not utilising the information gathered from PPI effectively. They should commence by looking at the potential communication channels which they could use. They also need to identify potential stakeholder individuals and groups who may benefit from information regarding the process, and assess the level of information which they require and the most effective methods of communicating it. Organisations could develop a communications plan for PPI, using the method of developing plans outlined in this document (i.e. assess requirements, identify potential groups, choose communication methods, pre-test, implement, evaluate and continuously improve.)

**Question 2.5**

Activities are being conducted to promote a public and patient involvement culture

**Rationale**

Creating a culture conducive to PPI is essential for the process to be effective. This requires management and governance support and involvement and ‘buy-in’ from direct patient contact staff on the ground.

**Qualitative Rating:**

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<tbody>
<tr>
<td>Agree Strongly</td>
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<tr>
<td>Agree</td>
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<tr>
<td>Neither</td>
<td>3</td>
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<tr>
<td>Disagree</td>
<td>2</td>
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<tr>
<td>Disagree Strongly</td>
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**Quantitative Comments:**

*Agree / Agree Strongly* = Organisations which are promoting a culture of patient involvement will benefit hugely. This culture ensures involvement on a number of levels throughout the organisation. Organisations are encouraged to reflect on how they have succeeded in promoting the
culture and to share this information with other similar healthcare settings. They should be encouraged to continue to promote the culture to ensure its continued survival.

**Disagree / Disagree Strongly** = Organisations which are not promoting a culture of PPI will have increased difficulty in achieving ‘buy-in’ from staff and patients. The organisation should be encouraged to identify a number of methods to commence a change in the organisation’s culture, and review these methods on a regular basis. Sufficient time, resources, education and training needs to be dedicated to achieve the required culture.

**Question 2.6**

*The management of the organisation are supportive of the public and patient involvement process*

**Rationale**

Management participation and support are essential for effective involvement. Their support ensures that the information obtained from the process is utilised to its maximum capacity. It also motivates staff and demonstrates that the organisation is taking the concept of PPI seriously.

**Qualitative Rating:**

- **Agree Strongly** = 5
- **Agree** = 4
- **Neither** = 3
- **Disagree** = 2
- **Disagree Strongly** = 1

**Quantitative Comments:**

**Agree / Agree Strongly** = Organisations whose management are supportive of the PPI process will benefit from increased utilisation of the information sourced and a positive organisational culture regarding involvement. Management should be encouraged to participate in involvement.
activities on an ongoing basis to demonstrate continuous commitment
to the process.

_Disagree / Disagree Strongly_ = Organisations whose management are
not supportive of the PPI process will struggle to maximise the
effectiveness of the process and to enhance the organisation’s culture.
Organisations should be encouraged to demonstrate the benefits of
involvement to management, and to participate in activities as far as
possible.

**Question 2.7**

There are specifically designated staff with responsibility for promotion
of public and patient involvement

_Rationale_

The PPI process requires sufficient numbers of adequately trained and educated
staff for it to be successful. The number of staff required for each programme will
vary, predominantly based on the extent of the involvement process.

**Qualitative Rating:**

- **Agree Strongly** = 5
- **Agree** = 4
- **Neither** = 3
- **Disagree** = 2
- **Disagree Strongly** = 1

**Quantitative Comments:**

_Agree / Agree Strongly_ = Organisations with sufficient numbers of adequately trained
staff will find implementation of the patient involvement process easier.
The remit of the staff member(s) involved should be regularly reviewed,
and the scope of the remit should be determined (i.e. is the staff
member responsible for the implementation of activities only, or for
planning, or for communication of information, etc.)
Disagree / Disagree Strongly = Organisations without dedicated trained staff will struggle to implement PPI programmes. This will be manifest in a decreased confidence in the involvement process from both the public and patients and the healthcare professionals. Organisations should commence by assessing the required amount of staff needed to adequately provide the involvement service, and subsequently plan how to achieve the required staffing levels.

**Question 2.8**

**Staff have received training and education regarding participation in public and patient involvement**

**Rationale**

Ensuring that staff have received sufficient education and training is essential for effective PPI. Staff should be trained to conduct patient involvement activities and also have good interpersonal, communication and team skills.

**Quantitative Rating:**

- **Agree Strongly** = 5
- **Agree** = 4
- **Neither** = 3
- **Disagree** = 2
- **Disagree Strongly** = 1

**Qualitative Comments:**

**Agree / Agree Strongly** = Organisations with sufficiently and appropriately trained and educated staff will find it easier to implement their PPI programmes. Additionally, the presence of trained and educated staff gives confidence to the public and patient representatives and maximises the information to be gained from the involvement process.

**Disagree / Disagree Strongly** = Insufficient training and education for staff will
lead to reduced confidence in the involvement process by the public and patients, and reduced confidence in the staff member(s). Organisations should determine the level of education required to conduct the involvement process, and then devise a plan on how to meet these training requirements.

**Question 2.9**

**What public and patient involvement activities are currently in use in your organisation?**

- Information Booklets – Organisational General
- Information Booklets – Care Specific
- Telephone Helpline
- Staff Communication – Education
- Website Information
- Patient Videos – Organisational General
- Patient Videos – Care Specific
- Audio Information – CD/Tapes
- In-House Education
- Surveys – Organisational General
- Surveys – Care Specific
- Complaints System
- Feedback System
- Comment Cards
- Patient Charter
- Focus Groups
- In-depth one-to-one Interviews
- Patient Councils
- Patient Residents’ Committees
- Patient Representation (Care Groups)
- Patient Representation (Service Planning)
- Advocacy Officer
- Community Meetings
Health Promotion Campaigns
Defined Involvement in Care Plans
Other (Please Specify)

(Score one point for every activity selected)

Section 3.0 “Check” & “Act”

Question 3.1
What public and patient involvement activities (in your organisation or elsewhere) seem to be the most beneficial?

Rationale
This question is somewhat subjective, and may be open to the interpretation and opinion of the individual/group that is completing the questionnaire. However, it is a useful start at attempting to identify the areas of PPI which appear to be working in the organisation. Indications that particular activity/activities may be beneficial include observation of objectives achieved; feedback (formal or informal) from patients or staff; utilisation of information received from involvement; observed enthusiasm from patients, staff or management; associated improvements in the organisation’s culture regarding patient involvement etc.

Question 3.2 (related to Question 2.9)
Of the public and patient involvement activities currently being conducted by your organisation, how may have undergone evaluation?
(please give details)

Rationale
Evaluation of a process or activity enables an organisation to see what is being done right and what could be improved upon. The organisation should have clearly identified in Question 2.9 what PPI activities currently exist. This list should now be used to identify if any of these activities have been evaluated. An example of this
might be if an organisation has conducted Focus Groups, and has evaluated the sessions afterwards with the participants and the staff involved.

The organisation should score one point for each public and patient activity which has undergone evaluation.

**Question 3.3.**

*Have any improvements arisen and been implemented as a result of evaluation of the public and patient involvement activities* (please give details)

**Rationale**

Evaluation conducted on PPI activities will have been highlighted in Question 3.2. It is imperative that information collected from an evaluation is utilised to make further improvements. As per the example given in the previous question, an organisation may have conducted Focus Groups and may have evaluated the sessions with the participants and staff. The information gathered from these evaluations should then be used to make improvements to subsequent Focus Groups conducted by the organisation.

The organisation should score one point for each improvement which has arisen from evaluation of PPI activities.

**Qualitative Analysis**

When Stage One of the evaluation form is completed, add up the total scores achieved for each question which has a numeric scoring attached to it. This will give you one overall numerical value. The bands below provide an indication of where your organisation currently lies in terms of PPI. Organisations should aspire to continually improve their services, and a result of this continual improvement, there should be a corresponding increase in the band within which the organisation lies.
**Band 1: Score between 0 – 20**

Scoring within this category suggests that a good deal of work is needed in the organisation in terms of PPI. This should commence with a thorough analysis of the activities that the organisation is currently conducting, what objectives the organisation would like to achieve in terms of PPI and creation of a plan to achieve these objectives.

**Band 2: Score between 21 – 40**

For organisations in this category, it can be assumed that there is a general recognition of the benefits of PPI. It indicates that some initial work has commenced in the area. Such organisations may find it beneficial to review the current activities in terms of PPI, particularly in relation to the Leadership and Partnership aspects to encourage further improvement (*Levels 3 and 4 of Section 3*).

**Band 3: Score between 41 – 60**

Organisations that fall into this category are showing some success in their PPI activities, and are recognising the importance of strategic planning for the involvement process. The next step for consideration is a review of the areas of evaluation and improvement, to ensure continuous improvement in the process.

**Band 4: Score 61 +**

Organisations that score in this top band are successfully involving public and patients in a number of involvement activities. They are likely to have a positive attitude from staff and management in terms of the involvement process, and this should be demonstrated from a strategic perspective. Additionally, the activities and the involvement process are evaluated and the evaluation is used for continuous improvement. Such organisations should focus on continuously reviewing the process to ensure that maximum benefits from PPI are achieved.
4.3.2 Stage Two - Reflection and Opportunities for Improvement

**Question 4.0**

Summarise your organisation’s areas of excellence in public and patient involvement activities:

*Rationale:*

This question is designed to enable organisations to reflect on their existing PPI activities identified in Question 2.9, and discuss which of these activities are conducted really well.

**Question 5.0**

Outline any opportunities for improvement in the area of public and patient involvement for your organisation

*Rationale*

Regardless of the extent of PPI currently in existence in an organisation, there is always room for improvement. This question is designed to focus the organisation’s attention towards areas related to PPI which require further improvement. Organisations are encouraged to utilise all of the questions addressed in Stage One to help them to identify the key areas for improvement. A quick initial guide can be provided by looking at the quantitative ratings achieved for each question – those with the lowest scores (e.g. 1 or 2) will require initial attention.

**Question 6.0**

Outline any existing plans (including determined timeframes and responsibilities) proposed to address these opportunities for improvement

*Rationale*

Comprehensive and definite plans are necessary to ensure that objectives regarding PPI are achieved. Once the opportunities for improvement have been identified in
Question 5.0, it is necessary to consider how they are to be achieved. Specific plans including timeframes and responsibilities should be created. Remember to take on manageable goals – if you have identified a large number of opportunities for improvement, begin with a small number of the most pertinent ones. You can always return to the list at a later date and complete the remaining ones. By outlining the existing plans proposed to address the opportunities for improvements here, organisations will be enabled to focus on what plans are outstanding.

**Question 7.0**

What public and patient involvement activities do you hope to see implemented in the next two years

- Information Booklets – Organisational General
- Information Booklets – Care Specific
- Telephone Helpline
- Staff Communication – Education
- Website Information
- Patient Videos – Organisational General
- Patient Videos – Care Specific
- Audio Information – CD/Tapes
- In-House Education
- Surveys – Organisational General
- Surveys – Care Specific
- Complaints System
- Feedback System
- Comment Cards
- Patient Charter
- Focus Groups
- In-depth one-to-one Interviews
- Patient Councils
- Patient Residents’ Committees
- Patient Representation (Care Groups)
- Patient Representation (Service Planning)
• Advocacy Officer
• Community Meetings
• Health Promotion Campaigns
• Defined Involvement in Care Plans
• Other (Please Specify)

**Rationale**

This allows organisations to complete a final summary of the activities which they aspire to have in place over the next two years. This should be considered in the context of the already defined opportunities for improvement and improvement plans.
Section 5: Making Improvements

(“Act” of the Plan, Do, Check Act Cycle)

An organisation that has completed a self-assessment will have a list of areas of excellence and opportunities for improvement in the area of public and patient involvement. To be of benefit to the public and patient representatives and to the healthcare organisation, this information must be utilized to continuously improve the involvement process and to add benefit to it.

Opportunities for improvement identified in the evaluation phase should be reviewed by those involved in the implementation of the involvement programme. It will not always be possible to introduce all improvements, or at the same time. The improvement opportunities should be evaluated and prioritised, and those with the highest priority should have the initial focus. Once these have been implemented, the subsequent improvements can be addressed.

Continual improvement of the process is beneficial for healthcare organisations as it ensures that effective and efficient processes are being conducted, that there are maximum usages of resources and that the maximum benefit from the involvement processes is gained. Additionally, continuous improvement is of benefit for the patient representative. If a patient has made an evaluation or review of the process and suggested improvements, and these improvements are not conducted, there is a reduction in confidence regarding the entire process.
# Appendix 1- Evaluation Form

## Stage One: Assessment of current level of public and patient involvement

### 1.0 PLAN

<table>
<thead>
<tr>
<th>Question</th>
<th>Disagree</th>
<th>Disagree</th>
<th>Neither</th>
<th>Agree</th>
<th>Agree Strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1.1</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

There is an identified need for increased public and patient involvement in my organisation.

<table>
<thead>
<tr>
<th>Question</th>
<th>Disagree</th>
<th>Disagree</th>
<th>Neither</th>
<th>Agree</th>
<th>Agree Strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1.2</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

There is a specific planning process for public and patient involvement in my organisation.

<table>
<thead>
<tr>
<th>Question</th>
<th>Disagree</th>
<th>Disagree</th>
<th>Neither</th>
<th>Agree</th>
<th>Agree Strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1.3</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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</tbody>
</table>

There are defined objectives regarding public and patient involvement in my organisation.

<table>
<thead>
<tr>
<th>Question</th>
<th>Disagree</th>
<th>Disagree</th>
<th>Neither</th>
<th>Agree</th>
<th>Agree Strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1.4</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Stakeholders are consulted when objectives are being defined.

### 2.0 DO

<table>
<thead>
<tr>
<th>Question</th>
<th>Disagree</th>
<th>Disagree</th>
<th>Neither</th>
<th>Agree</th>
<th>Agree Strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q2.1</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Public and patient involvement has been specifically incorporated into my organisation’s vision, mission and values.

<table>
<thead>
<tr>
<th>Question</th>
<th>Disagree</th>
<th>Disagree</th>
<th>Neither</th>
<th>Agree</th>
<th>Agree Strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q2.2</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Public and patient involvement has been utilised in the development of my organisation’s strategic plan.

<table>
<thead>
<tr>
<th>Question</th>
<th>Disagree</th>
<th>Disagree</th>
<th>Neither</th>
<th>Agree</th>
<th>Agree Strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q2.3</td>
<td>1</td>
<td>2</td>
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</tbody>
</table>

There is a defined strategy for maximising public and patient involvement in the delivery of the organisation’s services.
<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
<th>Disagree</th>
<th>Disagree</th>
<th>Neither</th>
<th>Agree</th>
<th>Agree Strongly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q2.4</td>
<td>There are clearly defined communication channels to disseminate information regarding public and patient involvement.</td>
<td>1</td>
<td>2</td>
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<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Q2.5</td>
<td>Activities are being conducted to promote a public and patient involvement culture.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Q2.6</td>
<td>The management and governance of the organisation are supportive of the public and patient involvement process.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Q2.7</td>
<td>There are specifically designated staff with responsibility for promotion of public and patient involvement.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Q2.8</td>
<td>Staff have received training and education regarding participation in public and patient involvement.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<td>5</td>
</tr>
<tr>
<td>Q2.9</td>
<td>What public and patient involvement activities are currently in use in your organisation? (circle each activity currently in use):</td>
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<td></td>
<td>• Information Booklets – Care Specific</td>
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<td>• Telephone Helpline</td>
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<td>• Staff Communication – Education</td>
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<td>• Website Information</td>
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<td>• Patient Videos – Organisational General</td>
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<td>• Patient Videos – Care Specific</td>
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<td>• Audio Information – CD/Tapes</td>
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<td>• In-House Education</td>
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<td>• Surveys – Organisational General</td>
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<td>• Surveys – Care Specific</td>
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<td>• Complaints System</td>
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<td>• Feedback System</td>
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<td>• Comment Cards</td>
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<td>• Patient Charter</td>
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<td>• Patient Councils</td>
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<td>• Patient Representation (Care Groups)</td>
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<td>• Patient Representation (Service Planning)</td>
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<td>• Advocacy Officer</td>
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<td>• Community Meetings</td>
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<td></td>
<td>• Health Promotion Campaigns</td>
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<td>• Defined Involvement in Care Plans</td>
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<td>• Other (Please Specify)</td>
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</table>
### 3.0 CHECK & ACT

#### Q3.1
What public and patient involvement activities (in your organisation or elsewhere) seem to be the most beneficial?

_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________

#### Q3.2
Of the public and patient involvement activities currently being conducted by your organisation, how many have undergone evaluation? (please give details)

_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________

Total number of public and patient involvement activities which have undergone evaluation:

#### Q3.3
Have any improvements arisen and been implemented as a result of evaluation of the public and patient involvement activities (please give details)

_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________

Total number of improvements implemented as a result of evaluation:

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*Total Numerical Score for Stage One Quantitative Analysis:*
### Stage Two: Reflection and Opportunities for Improvement

#### Q 4.0
Summarise your organisation’s areas of excellence in public and patient involvement activities.

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#### Q 5.0
Outline any opportunities for improvement in the area of public and patient involvement for your organisation.

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#### Q 6.0
Outline any existing plans (including determined timeframes and responsibilities) proposed to address these opportunities for improvement.

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#### Q 7.0
What public and patient involvement activities do you hope to see implemented in the next two years?

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Glossary

Accreditation  A self-assessment and external review process used by healthcare organisations to accurately assess their level of performance in relation to established standards and to implement ways to continuously improve the healthcare system.

Advocacy  Promoting and/or supporting a cause, such as patient rights to services, information and basic human rights.

Advocate  A person who actively supports another person’s cause.

Audio/Visual Multimedia  The provision of patient information using various media such as audio and video. It includes the use of:
- Audio: CDs, Tapes, Audio downloads
- Audiovisual: Video DVD
- Interactive: Web, Interactive Kiosks

Barriers  Issues that can prevent people from taking a certain course of action. In terms of public and patient involvement, barriers to implementation of involvement can exist for both the public/patient and the healthcare organisation/professional.

Baseline Study  The collection and analysis of data regarding an intended audience or situation prior to intervention.

Benchmark  The continuous process of measuring and comparing services and processes with similar systems within and outside the organisation to promote continuous improvement.
Case Study

A detailed study of individuals or organisations. This can involve a range of methods including interviews, questionnaires, and focus groups. The information collected is analysed in a systematic way to address the research questions being asked.

Channel

The route of message delivery (e.g., mass media channels include television, radio, newspapers, magazines; interpersonal channels include health professional to patient; community channels include community events, such as health fairs or sporting events).

Clinical Audit

A quality improvement process that seeks to improve patient care and outcomes through systematic review of care against explicit standards and the implementation of change.

Clinical Governance

A framework through which health service organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish. Clinical governance activities include clinical audit and review, monitoring and evaluation of service quality, service development and improvement, staff training and risk management.

Closed-ended Questions

Questions that provide respondents with a list of possible answers from which to choose; also called multiple choice, forced-choice, or fixed-choice questions.
**Comment Cards**

Tool for public and patient involvement which provides service users with a 'sounding board' where information can be provided if the service users so choose. Often designed in the format of some basic questions followed by asking for general input or comments. Can be electronic or paper based.

**Communication Strategy**

A formalised plan which describes how information will be communicated to the various stakeholders. For the purpose of public and patient involvement, the communications strategy would be designed to ensure all relevant stakeholders receive information regarding the aspects of the public and patient involvement process. It can be an independent strategy for public or patient involvement only or it can be a part of the organisation’s overall communications strategy.

**Community Forums**

Involvement of a large group of service users with a small number of staff with the aim of educating people, sharing information about a specific issue or developing an appreciation of different viewpoints.

**Community Partnerships**

Structured cyclical planning processes with a specified role for the community in shared decision-making with healthcare providers. They often involve the coming together of various community groups and organisations to implement or develop a specific initiative, and aim to combine resources to help tackle specific problems.
Consumer
People who either directly or indirectly use the health services. Consumers are as diverse as the full range of people living in contemporary society.

Convenience Samples
Samples that consist of respondents who are typical of the intended audience and who are easily accessible; results cannot be projected to the entire population being studied.

Co-production
The idea that citizen partnership is involved in the provision of any services. Used by Donabedian (1992) as a way to conceptualise the relationship between patients and the health services.

Environmental Factors
Factors that are external to an individual but can influence the individual’s behaviour (e.g., policies, access to services, geography, physical features such as sidewalks and parks).

Ethics
A set of moral principles or values. With regard to professions, a code of professional standards, containing aspects of fairness and duty to the profession and the general public.

Evidence Based Approaches based upon empirical evidence that have been shown to produce superior results which are then adapted to fit a particular organisation.

Evaluation
Assessment, appraisal, examination and judgement of the worth of an activity or process. Allows the organisation to reflect on what works and what doesn’t. It should be linked to the objectives of the activity or
process, and provides information that should be used for continuous improvement.

**Expert Patients**

People who have an experience of a condition or illness and who are prepared to share their experience with others living with the condition in order to convey knowledge about it. It aims for people with a condition to train others with similar long-term condition to develop skills in managing their own illness.

**Feedback and Complaint Systems**

A mechanism which allows structured and recorded input for the public and patients. It should allow for the provision of positive feedback in addition to negative feedback (complaints).

**Focus Group**

A qualitative research technique in which an experienced moderator guides about 8 to 10 selected participants through a discussion of a selected topic, allowing them to talk freely and spontaneously. Focus groups are often used to identify previously unknown issues or concerns or to explore reactions to potential actions. The group should have a focused and defined purpose which reflects the size and composition of the group.

**Formative Evaluation**

Evaluative research conducted during process development. May include state-of-the art reviews, pretesting messages and materials, and pilot testing a program on a small scale before full implementation.
Gatekeeper

An organisation or individual you must work with before you can reach an intended audience (e.g., an organisation, a schoolteacher, a television public service director).

Goal

The overall health improvement an organisation or agency strives to create as a result of public and patient involvement.

Healthcare Outcomes

That which happens following treatment or care. Documented changes in patients' performance and conditions in relation to the interventions employed, and related to the costs of provision of service.

Healthcare Organisation/Staff

Inclusive of all staff members who work in a healthcare setting. This includes clinical and non-clinical, direct- and non-direct-care and volunteers.

Health Professionals

A consultant, doctor, nurse or other specially trained individual having certain responsibilities regarding the health of individuals or groups. A person who helps in identifying or preventing or treating illness or disability.

Impact Evaluation

A type of research designed to identify whether and to what extent a programme contributed to accomplishing its stated goals (here, more global than outcome evaluation).

In-depth Interviews

A type of qualitative research in which a trained interviewer guides an individual through a discussion of a selected topic, allowing the person to talk freely and
spontaneously. This technique is often used to identify previously unknown issues or concerns, or to explore reactions to potential actions, benefits, or concepts during the planning and development stages.

**Intended Audience**
The audience selected for programme messages and materials.

**Internet**
A global network connecting millions of computers all over the world, allowing for the exchange of information.

**Leadership**
Influencing and directing the performance of group members towards the achievement of organisational goals.

**Low Literacy**
A limited ability to use printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential.

**Outcomes**
The consequence of the project. Outcomes can be negative or positive. Projects should have a positive outcome i.e. provide benefits e.g. increased public and patient involvement.

**One-to-one Patient Interaction**
Interaction and communication that occurs between a patient and a healthcare professional on a one-to-one basis.
Open-ended questions Questions that allow an individual to respond freely in his or her own words, in contrast to closed-ended or fixed-choice questions.

Organisational Culture A shared system of values, beliefs and behaviours within an organisation known to all who work in the organisation. The organisational culture can impact significantly on the attitude towards and the success of public and patient involvement programmes.

Outcome Evaluation Research designed to assess the extent to which a programme achieved its objectives.

Partnerships Collaborative relationship that features reciprocity and mutual exchange.

Patient & Public Representative An individual who acts as a representative of a larger group of service users. These individuals provide a consumer perspective.

Patient-centred care A philosophy of care that encourages (a) shared control of the consultation, decisions about interventions or management of health problems with the patient and/or, (b) a focus in the consultation on the patient as a whole person who has individual preferences within social contexts.
Patient Commitment Statement  
Published standards which are defined by the organisation against which patients can measure the care and services that are provided. They can play an important role in empowering patients by making them aware of their entitlements as individuals. They are written patient rights and guarantees which are provided to specify service conditions and identify mechanisms for complaint where they are not met.

Patient Councils  
A group of patients who advise the organisation on service developments and aspects relating specifically to patient care. Its aim is to work closely with the organisation and its staff to improve services for all patients who use the services.

Patient Diaries  
Mechanism by which patients record events that occur and their personal thoughts during their healthcare journey. It is a structured framework that allows the patient to maintain an active record of their perceptions of the care that they receive.

Patient Shadowing  
Occurs when another patient, volunteer or member of staff accompanies a service user through the health system. It aims to provide objective, observational feedback.

Pretesting  
Testing or piloting the planned involvement process with a number of representatives. It is a type of formative evaluation that involves systematically gathering intended audience reactions to messages and materials before the messages and materials are produced in final form.
Primary Health Care

The first level of health service delivery that is preventative in orientation.

Principles

The basis upon which public and patient involvement processes should be conducted. They act as a set of guidelines for consideration: key themes and concepts for both the public/patient and the healthcare professionals/organisations to consider.

Printed Media

Printed information on the services or specific aspects of a service provided by a healthcare organisation. It is easily transferable and allows patients to take their time in reviewing the information provided.

Process Evaluation

Research conducted to document and study the functioning of different components of programme implementation; includes assessments of whether materials are being distributed to the right people and in what quantities, whether and to what extent programme activities are occurring, and other measures of how and how well the programme is working.

Programme Objectives

The specific outcomes that you expect your entire programme to achieve. These will be broader than communication objectives, but must also specify outcomes.
**Promotion Campaigns**  
An organised campaign to increase people's awareness and understanding of a particular topic or set of issues. Healthcare promotion campaigns usually have a particular health issue focus.

**Public and Patient Involvement (PPI) / Participation**  
The participation of patients, their carers or representatives in their own care and treatment. This may also be at the level of service delivery and quality monitoring.

**Public Relations**  
Marketing activities designed to raise the public's awareness about a product, service, individual, or issue; management of an organisation's public image that helps the public understand the organisation and its products.

**Qualitative Research**  
Research that aims to understand the experience of individuals in context in order to explore why people and/or organisations act the way they do. Qualitative methods, including in-depth interviews and/or focus groups are used, to explore in detail, selected areas appropriate to the research questions being asked. The information collected from these sources is analysed in a systematic way to uncover patterns of behaviour or systems for a group of individuals or organisations. The information gathered should not be described in numerical terms, and generalisations about the intended audience cannot be made. Qualitative research is useful for exploring reactions and uncovering additional ideas, issues, or concerns.
Quantitative Research

Research designed to gather objective information by asking a large number of people identical (and predominantly closed-ended) questions. Results are expressed in numerical terms (e.g., 35 percent are aware of X and 65 percent are not), and, if the respondents are a representative random sample, quantitative data can be used to draw conclusions about the intended audience as a whole. Quantitative research is useful for measuring the extent to which knowledge, attitudes, or behaviours are prevalent in an intended audience.

Quantitative Surveys

Large scale surveys, usually by questionnaire, of structured or random sample groups. The information gathered is then systematically analysed and subjected to statistical tests of significance. The results of the survey are then shown to be, or not to be, representative of similar populations.

Random sample.

A sample of respondents selected from an intended population in which every member of the population had an equal chance of being included.

Readability testing.

Using a formula to predict the approximate reading level (usually expressed in grades) a person must have achieved in order to understand written material.
Resources

Inputs that are required for a project to be successful. Adequate resources are essential for the success of public and patient involvement processes, and include time, personnel, administrative, physical etc.

Search engine

A mechanism for finding Web sites or documents contained on Web sites. To make sure others can find your site, you can register it with popular search engines (e.g., Yahoo!) by providing a description of your site and a few keywords.

Segmentation.

Subdividing an overall population into homogeneous subsets in order to better describe and understand a group, predict behaviour, and tailor messages and programmes to match specific interests, needs, or other group characteristics. Segments may be demographic, geographic, psychographic or they may be based on a combination of these factors.

Self-Assessment

An organisation examines its public and patient involvement activities and processes and assesses them against established standards. It enables organisations to determine their areas of excellence in a particular field and highlights opportunities for improvement.

Self-administered Questionnaires

Questionnaires that are filled out by respondents themselves (rather than by an interviewer).
Service Users

All people who use the service. A general term which encompasses patients, families, carers, residents, the public, etc.

Shared (medical) decision-making.

Usually refers to clinical consultations where the ethos is one where health care professionals work with patients to define their problems. Patients are given full information about the range of treatment/management options available for a condition and any uncertainties about outcomes where they exist. Patients are encouraged to participate fully in the decision(s) made about which option(s) to pursue. See Patient-centred care above.

Stakeholders

The different groups that are affected by decisions, consultations and policies.

Strategy

The overall approaches a programme takes.

Surveys

The collection of information by means of questionnaires. They can be administered by a number of methods including face-to-face or telephone interview, or self-administered (e.g. postal or internet survey).

Systematic reviews.

A review of existing research evidence/literature based on clearly defined rules regarding study identification, study quality appraisal and strict criteria for inclusion of studies in the review. The outcomes and methods of the selected studies are then analysed for comparability and the weight of the evidence assessed.

Telephone Hotline

Dedicated phone line manned by a dedicated health care organisation employee/volunteer which is specifically designed to accommodate patients/public who wish to
call regarding a topic relating to the healthcare organisation. They allow patients to provide feedback on aspects of the healthcare service in a simple manner.

**Telephone Phone-In’s**  Short term strategies which use the telephone hotline to receive information from service users regarding specific aspects of the service or particular health related topics. Informing service users of their existence, and of the particular issue being addressed, is essential for their success.

**Website**  A location on the World Wide Web containing documents or files. Each site is owned and managed by an individual, company, or organisation.

**World Wide Web**  A part of the Internet designed to facilitate navigation of the network through graphic user interfaces and hypertext links.
Further Resources:

- Better Practice Guidelines on Complaints, Management for Health Care Services, Australian Council for Safety and Quality in Health Care, 2004

- Community Participation And Primary Care: Learning From The Building Healthy Communities Programme (2005)

- Consumers’ Health Forum 1999, Guidelines for consumer representatives, 4th edn, Lyons, ACT.


- Expert Patients Example
  www.expertpatients.nhs.uk

- Institute of Customer Service
  www.instituteofcustomerservice.com

- Irish & EU Patient Provider Commitment


National Adult Literacy Agency
http://www.nala.ie/

Patient Advice and Liaison Service (PALS) NHS UK
http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/PatientAndPublicInvolvement/PatientAdviceAndLiaisonServices/fs/en

Patient Advice and Liaison Service (PALS) Gloucestershire
http://www.palsglos.org.uk

Patient Councils Example – Airedale Primary care Trust NHS
A Guide to Patient Councils in Airedale 2004

Patient Diary Example
http://www.teamworkfile.org.uk/teamfile.html

People Matter – Complaints Matter, Draft Guidelines for Handling of Complaints, Health Services Executive, 2005

Readability Test: Simplified Measure of Gobbledygook
http://www.literacytrust.org.uk/campaign/SMOG.html

Readability Test: Flesch Reading Ease score

St James’s Hospital Community Consultation Forum
http://www.stjames.ie/CommunityLiaison/CommunityConsultation/#d.en.9595

Telephone Helplines Association – Guidelines for Good Practice 2004

The Measurement of Patient Satisfaction with Acute Services in Ireland;
Irish Patient Satisfaction Literature Review and Scoping Exercise;

- Usability Testing
  [www.usability.gov](http://www.usability.gov)

- W3C Accessibility Guidelines
  [http://www.w3.org](http://www.w3.org)