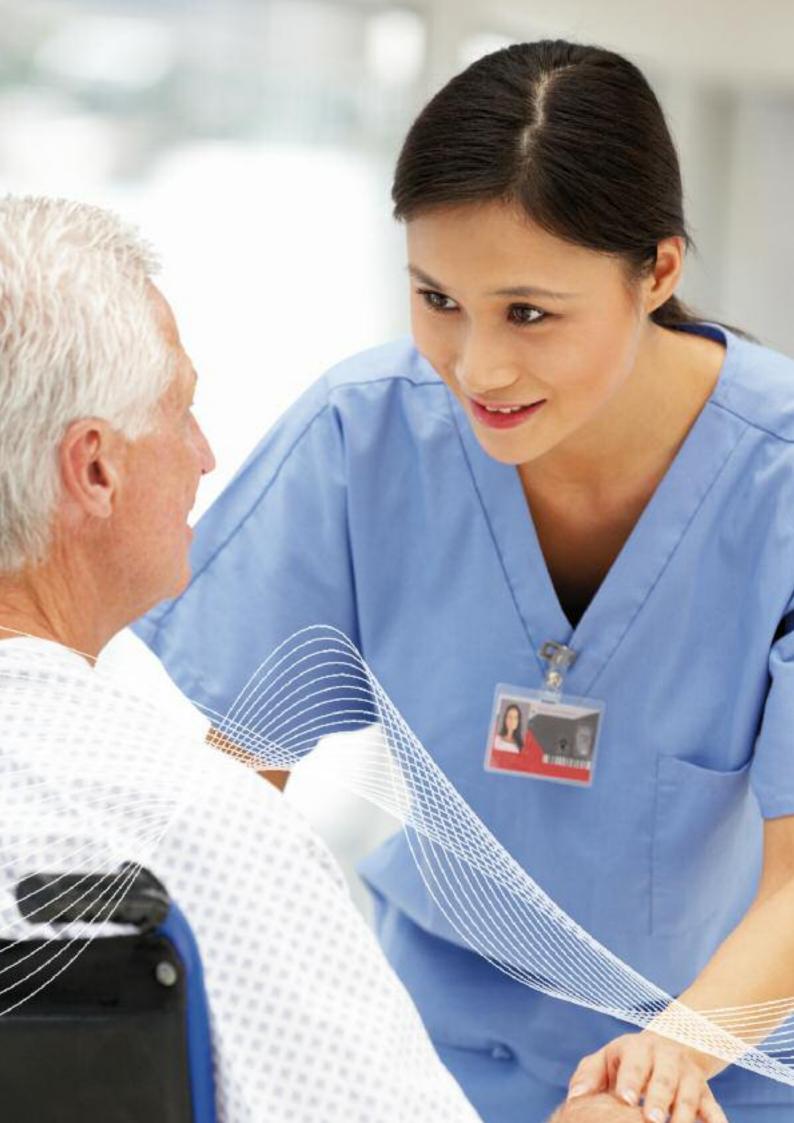
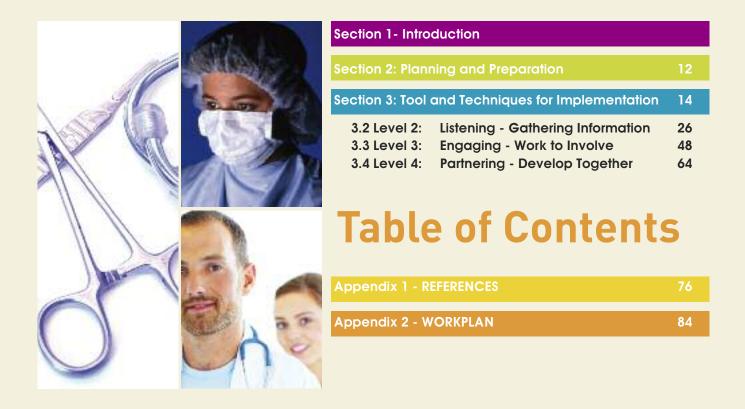
Galway and Roscommon University Hospitals Group

Strategic Plan for Public and Patient Involvement 2013-2015





FOREWORD



As Group Director of Nursing and Midwifery at Galway Group, I am delighted to be involved firstly as a Nurse and secondly as an Executive Board member in the development and enhancement of a "Patient First" culture in our organisation.

This is at the heart of all we do in developing our structures and patient experience is the key differentiator in assuring all staff from "Bed to Board"

The Group is invested in delivering a service to our public and patients that is underpinned by compassion and kindness. We value the unique experiences that people have when they enter their hospitals and need their feedback to

continuously improve.

Patients First is our guiding principle, we strive to provide outstanding and compassionate care every step along the way. This requires care that addresses every aspect of a patients encounter. We aim to exceed the expectations of patients and families and the launch of this strategy will underpin our plans to create the environment and culture of Patient First always.

We are committed at every level of the organisation to the implementation of this plan. Please take the time to read this plan, own it and guide you in everything you do

Colette Cowan Group Director of Nursing and Midwifery Galway Group.

1.2 Rationale

The importance of public and patient participation in the planning and implementation of health care 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 health care, which stated unequivocally that 'people have the right and duty to participate individually and collectively in the planning and implementation of their health care'. The National Strategy for Service User Involvement in the Irish Health Services 2008-2013, and the National Healthcare Charter You and Your Health Service 2012, have been developed with input from many interested parties, including patient advocacy groups, patients and staff in Galway and Roscommon. The National Healthcare Charter outlines supporting arrangements for a partnership of care between everyone in healthcare, patients, familes, carers and healthcare providers. It aims to inform and empower individuals, families and communities to look after their own health and to influence the quality of healthcare in Ireland.

There is increasing evidence that public and patient participation in the provision of health care leads to better health outcomes and better quality of care, including:

- 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 on the Irish health system. We have seen this concept as a central pillar to the National Health Strategy, Quality and Fairness, A Health System for You. Action points 48-52 have their primary objective defined as "The patient is at the centre in the delivery of care". In particular Action Point 50 aims to ensure "Individuals and families will be supported and encouraged to be involved in the management of their own health care."

This Public and Patient Involvement (PPI) Strategy shall provide the Group with a framework and practical methodologies to develop patient partnerships, thus increasing communication and involvement, which will ultimately lead to better health outcomes and better quality of care.

This Public and Patient Involvement Strategy shall increase patient/client participation in the planning, management, evaluation and review of the Group health services. The Strategy is fundamentally founded on evidence based best practice and learning from current international initiatives.

1.3 What is Public and Patient Involvement (PPI)

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. They are in their infancy and considerable work still needs to be done in relation to 'buy in' – hence the need for a Strategy such as this to assist in accelerating the necessary change.

Avedis 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 entails the idea that citizen partnership is involved in the provision of any services (Brudney and 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. This takes place at many levels from the contribution that the public 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 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 which is so widespread at present. Suggested descriptions include that by Saunders (1995) which 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 acknowledges that public and patient participation has also been seen to focus on other aspects of care, such as patient compliance with treatment plans (Craig, 1985,) self-medication (Webb et al 1990), self-monitoring (Nelson 1977), patient education (Wilson-Barnett and Osbourne, 1983), goal setting (Janz et al, 1984) and sharing information and taking part in physical care (Macleod-Clark and Latter, 1990). The literature appears to suggest that patient participation is a very amorphous and ill-described concept.

Operational documents regarding public and patient involvement have useful working definitions to describe public and patient involvement, such as that utilised in the Lambeth NHS Tool-Kit:

'Public and patient involvement is the active participation of patients, users, careers, 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 which are very useful when considering the concept of public and patient partnership within the Group:

- 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 Strategy to 'public and patient' is intended to be inclusive of patients, service users, families, carers and the public.



Nursing Leadership Programme Launch



1.4 Why is Public and Patient Involvement (PPI) Important?

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)

There are numerous reasons why public and patient involvement in healthcare is important, not least due to the potential benefits for both the public and patient, and the healthcare provider. These benefits include:

- 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 will be
 viewed as the ethical and democratic right of the public and patients.
- 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 between the patient and staff. This enhances the relationship between the two parties, and shall inspire confidence in the patient with respect to the Group.
- 3. Public and patient participation in healthcare delivery improves their health outcomes Involvement of the public and patients in healthcare delivery enables patients to have a better understanding of their conditions and treatment plans to 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).
- 4. Public and patient participation in healthcare delivery makes services more responsive to the needs of its public and patients By involving patients and the public in healthcare delivery there will be a large impact on service delivery levels such as the development of new services and improving interactions and understanding between health professionals and service users. Involvement shall impact on policy and strategy through the utilisation of better information for organisations and providers of health services; this will result in measurable changes in policy and strategy, and community-generated proposals will be enhanced.
- 5. Public and patient participation in healthcare delivery progresses service quality and safety Involvement of the public and patients in healthcare delivery will influence the Irish healthcare quality improvement agenda and provide an opportunity for organisational learning and development. It shall provide crucial information on what patients'/clients' expectations are and how they perceive the quality of care which they receive. The National Health Strategy, 2001, confirmed this belief when it stated that:

'the 'people-centred' health care 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'.

There are also a range of theoretical frameworks for addressing the issue of consumer involvement in health care. These have been summarized recently by Entwistle (1997) and her colleagues as having an ethical, rights-based or consequentialist basis. These include:

- The ethical framework emphasises the concept of respect for patient autonomy and self determination. Consumer research continually receives from patients the statement that they want 'to be treated with respect, like a person'
- The rights-based approach addresses the rights that patients have, for example, to information, choice, safety, fair treatment and redress. This finds expression in the various charters which specify consumer rights
- The consequentialist approach judges the rightness of the approach from the point of view of the consequences. This approach is the foundation for the attempts to provide evidence, based on research, that outcomes are improved by involving patients in their treatment.
- Wilson, (1999), states that involvement by individuals in their care increases the effectiveness of their treatment. This can also be strongly linked with the continuing escalation of the cost of healthcare and the increasing need to make links to effectiveness.

In summary, effective public and patient involvement strategies will influence the following:

- Lead to more accessible and effective health services (Draper and Hill, 1995)
- Facilitate participation by those traditionally marginalized by mainstream health services
 (Alexader 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)
- Can increase consumer confidence (Chambers, 2003

1.5 What Public and Patient Involvement (PPI) Can and Cannot Do

It is of no doubt that public and patient involvement in healthcare delivery is of enormous benefit to both the service user and to the healthcare provider. However, it must be recognised that this benefit is not limitless, and shall be utilised within specific areas and to achieve specific objectives.

Patient and Public Involvement shall:

- 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 benefit 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.

Public and Public Involvement shall not:

- Compensate for inadequate healthcare or access to healthcare services.
- Produce sustained change in complex health behaviours and situations independently, i.e. public and patient involvement shall require additional support to achieve on-going change and improvements.
- Be equally effective in addressing all issues between the healthcare organisation and the public/patient. This may occur because the topic or suggested behaviour change may be 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.)

1.6 Integration with Other Systems

Public and patient involvement is potentially of huge benefit to many aspects of the healthcare services. Information gathered from involvement shall be utilised in a number of different areas within the Group, and will be of benefit to areas outside of which it was originally conducted for. Therefore it is essential for the Group to ensure that there is an integrated, functioning patient involvement and subsequent communications system which the relevant information will be disseminated.

It is essential to integrate public and patient involvement within healthcare governance. Public and patient involvement is an important factor in continuously improving service quality and utilising patient feedback in this improvement. Linking public and patient involvement to governance also demonstrates a commitment to the process from the top down. Being able to measure accurately, and respond to patient views, is a central aspect of healthcare governance, encouraging improvements in the quality of care and verifying that these have taken place. Public and patient involvement will 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. By forming substantial links between public and patient involvement and these (amongst other) governance activities, this will keep the Group's system connected to the needs, expectations and experiences of the public and patients.

Clinical audit is one such area where public and patient involvement shall be incorporated. Clinical audit involves improving the quality of clinical services given to patients, thus it shall be focused on what matters most to patients. For example, if the Group is auditing outcomes, consultation with the public and patients will suggest which outcome measures actually matter to them.

Ideally public and patient involvement shall be a main priority for the Group in both strategic and operational terms. The Group shall aspire to setting specific goals and objectives regarding public and patient involvement on a routine basis. Thus once the overall goals have been set, the existing practice will be assessed against the goals to determine the achievement of the goals and the level of continuous quality improvement.

One of the predominant aims of public and patient involvement is to provide opportunities for the public and patients to influence decision-making by the Group. Information collected from public and patient participation will 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, public and patient involvement will assist in assessing whether the health and personal social services are managed and delivered to ensure the best possible outcomes within available resources.

Section 2: Planning and Preparation

2.1 Key Principles for Public and Patient Involvement (PPI)

Principles are the basis upon which public and patient involvement programmes will 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 shall be beneficial to utilise the principles which were identified in the Department of Health (UK) Bristol Inquiry (2001) as a guide when considering policy development for, and practical implementation of, public and patient involvement activities. These include:

Patients and the public are entitled to be involved in decisions about care

- The involvement of patients and the public shall be embedded in the structures of the health system and permeate all aspects of healthcare
- The public and patients shall have access to relevant information
- Healthcare professionals shall be partners in the process of involving the public
- There will be honesty about the scope of the public's involvement, since some decisions cannot be made by the public
- There shall be transparency and openness in the procedures for involving the public and patients
- The mechanisms for involvement shall be evaluated for their effectiveness
- The public and patients shall have access to training and funding to allow them fully to participate
- The public shall be represented by a wide range of individuals and groups and not by particular `patients' groups'

Successful public and patient involvement requires the Group and professionals to establish partnerships, and this requires accepting uncertainly. By its very nature, feedback and outcomes from public and patient involvement are uncertain – if we knew what the outcomes were going to be, we wouldn't need to do the consultation in the first place. The Group shall 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 public and patient involvement can have. Public and patient participation shall be a bottom up approach, but requires strong support from the top of an organisation to effectively and efficiently occur and to utilise the information provided. Strong emphasis on training, education, and communication, listening and people skills are fundamentally required, and these shall be supported. Finally, public and patient involvement requires an organisational culture that is supportive of it to ensure trust and commitment by both parties.

2.2 Levels of Involvement

The public and patient involvement Strategy outlines a number of tools and techniques which will be used in patient involvement.

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 public and patient involvement process for the first time may be at the first level, where their principal involvement is through education and communication. Organisations who's public and patient involvement programmes are more developed, may be at a higher level, where they are actively involving their patients in service delivery. The Group shall aim to move up through the levels, by increasing public and patient involvement, and utilising different tools and techniques for the involvement process.

The four different levels are outlined:

- Level 1: Communicating- Inform and Educate
- Level 2: Listening- Gathering Information
- Level 3: Engaging- Work to Involve
- Level 4: Pattering- Develop Together



Senior Nurse Management & Paeds SN pictured at the opening of refurbished paeds.

Section 3: Tool and Techniques for Implementation

3.1 Level 1: Communication- Inform and Educate

The Group shall communicate with the public and patients through various forms. These tools and techniques will concentrate on relaying messages to the public and patient, providing information and education on various issues. Printed media and audio/visual multimedia shall be well incorporated to deliver the message efficiently. Websites shall be used to convey information, as is the educational possibilities of promotions campaigns and public meetings to convey specific messages.

| | Deliverables | Outcomes | Year |
|-------|-----------------------------|--|------|
| 3.1.1 | Printed Media | The Group booklets and information leaflets shall provide the patients with information on the services available within the organisation. The printed information shall be easy to read and allows the user to take their time in reviewing the information provided. | 1 |
| 3.1.2 | Audio/ Visual Multimedia | The CD's, audio downloads, DVD's, web, interactive kiosks shall provide users with easy accessible information on the services provided by the Group The information shall be reliable, accurate, easy to understand | 2 |
| 3.1.3 | Website | The Group website shall provide information about the services available. The website shall be easy to read and easy to navigate. The website will provide patient feedback mechanisms for patient input. | 1 |
| 3.1.4 | Promotions Campaigns | The Promotions Campaigns shall highlight particular health issues through advertising in the media, distribution of pamphlets, appearances on radio, talks The Promotions Campaigns shall attempt to inform, persuade or motivate behaviour change of the public or patients. | 3 |

3.1.1 Printed Media (Year 1)

The Group shall provide the patients with printed information on services available within the organisation. This information shall be easily transferable and will allow the patients to take their time reviewing the information. It is important to consider over half of the general public in Ireland find written health information difficult to read and understand (IALS 1997). This is especially true today with the everchanging demographics of Ireland. Consideration shall be given to those who do not have English as their primary language as well as those who may have low literacy skills.

The Group shall consider that quantity often relates to quality when it comes to printed information. The Group is aware of the need for printed information and are conscious that 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.

The development of printed information shall 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. The Group shall develop information leaflets and attempt to involve the end user at the earliest stage. This is a critical requirement and shall occur prior to publishing. It is practically impossible for an individual who reads well and has good vocabulary to be able to guess what people will understand. In this regard the Group shall consider not just 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 assure that the information being provided to patients is up-to date and reflects best practice, is also essential. Printed media which has no visible date of publication is often an indicator for poor patient information. Printed patient information shall be developed as part of an overall strategy emanating from a primary overarching information document on the organisation. This will provide the basis for more specific areas to develop, circulate, review and use to assist the patient.

The Group shall use the printed media to provide information regarding specific areas of treatment or treatment choices. In these occurrences, the printed media will be provided to supplement personal communications, and not as the primary channel for giving information. These publications shall be considered as part of a wider spectrum of information-giving strategies that in turn will initiate dialogue with the patients.

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

The Group shall ensure that the information leaflets:

- Are easy to read, free of jargon and use simple text
- Capture the readers interest
- Are focused for the relevant population, age group, reading ability
- Are up to date
- Are 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. The pre-testing may be linked to other public and patient involvement methodologies such as Focus Groups and Project Teams.

Some key points the Group shall consider when developing patient and public printed media include:

- 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. The Group will keep the piece short and focused on the objective of the information document. Any additional information which may be of interest to others or may promote the organisations work shall be avoided. A common mistake is attempting to utilise an information leaflet to educate both patient 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.
 - Put the most important points first and last
 - Information presented at the beginning and end of an information leaflet have been shown to
 be remembered best
 - Respect the intended audience

The Group shall ensure that no matter how good the intention, not to talk down the reader. This will be a difficult balancing act in relation to assuring clarity and simplicity of information. It is important to remember that individuals with low-literacy skills encompasses people of different ages, genders, cultures and socioeconomic status, including highly intelligent adults with significant life experience who just cannot read very skilfully.

The Group shall test the 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. The Group shall utilise readability scores to assess the level of the documents. The two primary readability tests are:

- Flesch Reading Ease score
- Simplified Measure of Gobbledygook (SMOG)

Key Points

- The printed information shall be easily transferable and allows patients to take their time reviewing the information provided
- Over half of the general public find written health information difficult to read and understand
- Effectiveness 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
- Appropriate document control systems will ensure that the information being provided to patients is up-to-date.
- The Group shall present the information clearly and simply.
- The Group shall Pre-test all material prior to its publication.



Pictured at the launch of Brachytherapy Programme

3.1.2 Audio/ Visual Multimedia (Year 2)

Audio/ Visual Multimedia information refers to the provision of patient information using various media such as audio and video. The Group is aware that the provision of patient information through audio and visual multimedia is necessary to ensure the needs of all individuals, including those with special needs, are met. This included the use of:

- Audio CD's, Tape, Audio downloads.
- Audio-visual Video DVD
- 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 will also be beneficial where dealing with multiple demographics. By utilising the web this will be made more easily accessible. Information will be recorded in digital format and downloaded without any additional production costs, from the healthcare organisations website.

The utilisation of patient information videos and DVDs will make use of both audio and visual senses. The use of audio and visual multimedia will help patients within the Group to understand about the services provided, increasing patient knowledge and greatly reducing anxiety and increase patient knowledge and understanding. By seeing the organisation from their television or have streaming video information available on the website, patients will become more familiar with the organisation prior to arrival. The Group patient information videos shall deliver reliable, accurate and easy to understand information. This information shall be made available while patients are still in hospital, at the time patients are most interested in learning more about their medical condition.

The utilisation of audio/visual technology within the organisation will not be limited to patients rooms, a Touch-screen kiosk-based health information system will be installed to provide the opportunity to present a user enticing methodology to the organisation. These information kiosks shall provide the public, and patients, with information and education utilising a multitude of methods including video, audio and text. The information kiosks shall also be used to administer patient feedback similar to utilising Comment Cards.

Implementation:

The development of audio/visual materials for patient communication shall follow simple rules that will increase their benefit to the patient. These include:

Ensure the message is accurate

The accuracy of the message in any format is vital to producing desired outcomes. This is particularly important because of the rapid changes that occur in healthcare. The Group shall consult with an expert to check the contents of the topic are accurate. The information shall remain simple enough for the intend audience.

Be consistent

All messages in all materials and activities shall reinforce one another. The Group shall ensure that the same logo is used on all materials.

Be clear

As with printed media, audio/visual material will contain as few technical /scientific/bureaucratic terms as possible and eliminate information that the audience does not need in order to make necessary decisions or take desired action (such as over detailed background about disease, treatment etc.).

• Be relevant

The Group will ensure that the audience will relate to what they are watching or listing to by means of using an appropriate presentation style. A humorous approach shall be used if appropriate.

Be appealing

The Group shall ensure that the message is noticed and received by the intended audience. Concept testing and message testing shall be used to help ensure to use the correct approach. The Group will produce high quality materials to simply present information remembering to entertain while educating.



Staff Midwives and members of the Maternity Department attending the Baby Friendly Hospital presentation for Galway University Hospitals on Monday 14 May from left: Mary Reidy, Carmel Connolly, Fidelma Kenny, Teresa Hughes, Marian Warden and Margaret Coohill.

Key Points:

- Audio/ Visual Multimedia information refers to the provision of patient information using various media such as audio and video.
- The Group shall ensure that the needs of all individuals, including those with special needs are met.
- Information in audio format will be beneficial when dealing with difficult demographics.
- Video's and DVD's shall utilise both audio and visual (including txt) senses to help patients' understanding.
- Streaming video information shall be available on websites.
- Information shall be made available while patients are still in hospital, at the time patients are most interested in learning more about their medical condition.
- Touch-screen kiosk-based health information system shall provide the opportunity for hospitals to present a user methodology to the Group.
- Accuracy of the message is vital to producing desired outcomes.
- Information shall contain as few technical /scientific/bureaucratic terms as possible.
- The Group shall choose a presentation style appropriate to the intended audience.
- Shall entertain while educating.

3.1.3 Website (Year 1)

A website is often the first point of contact for patients wishing to find information on the services provided by the Group. This is increasing the case as a result of the number of people in Ireland who now have access to the internet. A recent survey identified that 78% of the population in Ireland have internet access. The Group will consider its websites usability, the amount of information available and basic information functionality. The technology used by the Group will allow for the inclusion of interactive solutions to provide patient education through video, practical tools and feedback mechanisms. The Group website shall graphically appeal and provide information about the organisation and related issued in a simple and informative manner. Consideration will be given to the ease of navigation ensuring to keep a logical sequence, grouping similar themes. The Group will keep visitors interested in the site by making it easy to navigate and shall be more accessible to a wider audience. The Group shall consider the creation of specific sections that relate to health promotions or patient feedback.

The Group shall ensure that the website content is easy to read and similar rules to those defined in Printed Media will be followed. The website shall be compliant to the World Wide Web Consortium (W3C) accessibility guidelines. The primary goal of these guidelines is to promote accessibility to help people find information on the site more quickly.

Benefits of Websites include:

- Ease of access.
- Ease of use- particularly where W3C guidelines are used.
- Dynamic- information shall be changed regularly and inexpensively.
- High amount of content.
- 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 tools, the inclusion of pretesting is essential to maximising the benefits of the website. The testing shall begin while developing the site and the feedback from the testers shall allow improvements to be made before it is used. The Group will ensure that the information is logically grouped and in plain and simple language, considering the targeting audience.

The use of multimedia will greatly increase the functionality of the Group website keeping the interest of the user and thus the uptake. The website is an invaluable tool to receive information as well as provide it. The Group shall provide simple mechanisms for user input, such as patient feedback forms allowing the patients and the public to provide feedback in a structured manner. These will be monitored carefully ensuring that they are being used appropriately.

In order to help people easily find the website the Group will register with the main search engines such as Goggle and Yahoo. All publications will clearly identify the web address. The Group shall ask relevant organisations to put a web link on their sites. Characteristics of a well-designed site include:

- W3C accessibility guidelines complaint 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 the site so people can find information easily.
- Structured and understandable menus.
- Multimedia to keep the interest of the user and thus the uptake.
- Short concise pages.
- Compatibility with major browsers.
- Track site usage and facilitate patient and public response.

Key Points:

- The website is the first point of contact for patients.
- 78% of the population in Ireland have Internet access.
- Graphically appealing sites with good information shall keep the users interest.
- Use of multimedia will greatly increase the functionality of the site.
- Ensure to keep it clean, simple and uncluttered.
- Provide a mechanism for user input.
- Publicise the site.

3.1.4 Promotions Campaigns (Year 2)

Promotion Campaigns generally consist of an organised campaign to increase people's awareness and understanding of a particular health topic or set of issues. A campaign includes a number of different methods, such as advertising in the media; distribution of pamphlets; appearances on radio, talks and workshops etc.

Promotional campaigns designed for healthcare usually have the objective of highlighting a particular health issue. The objective of the Group involves changing the behaviour of the public or patients, in an attempt to influence health outcomes in some way.

The Group shall implement well designed campaigns which will operate on a number of levels simultaneously, distributing information by a range of methods, aiming to reach a large population size. In conjunction with providing information the Group will identify potential allies, consult with them and if possible, develop partnerships. This will help increase the impact of the campaigns, and increase the chances of reaching the objectives. It is likely that some of these allies will be consumer groups.

Comprehensive promotion campaigns shall be:

Goal-oriented attempts to inform, persuade or motivate behaviour change in the target audience. Aimed at the 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:

The Group will systematically plan promotional campaigns prior to the implementation to increase the likelihood of success. Key areas that shall be considered for the process include the following:

Manage the Project

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

Analyse the Audience

Promotional campaigns will have the greatest impact when they are directed at a specific audience. Prior to commencing the campaigns, information regarding the demographic, behavioural and psychographic (e.g., values and beliefs) of the chosen audience shall be collected. This will enable an audience profile to be established. From this it will be possible for the Group to review the characteristics of the audience to determine whether or not they can be divided or segmented into smaller, more homogeneous groups (audience segmentation).

Develop an Inventory of Communication Resources

Communication resources include media outlets, community spokespersons, etc. within the community. These resources shall be assessed to determine the strengths, weaknesses and possibilities of getting our message delivered through these resources.

Select Objectives

Identification of clear objectives prior to commencing campaigns will assist in maximising benefits. This will include identification of the 'bottom-line' changes that the campaigns aim to achieve.

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 shall be identified and chosen.

Develop the Message

The key message, or messages, communicated by the campaigns shall be carefully chosen. These will relate to the defined objectives for the campaigns.

Develop a Project Identity

Create an identity that will clearly communicate your image and your intended relationship with your audience (i.e., the purpose of your communications campaign and why it's important).

Develop Materials (Production)

Develop specifications for each desired product (vehicle). This will include documentation, printed media and other vehicles which will transport the message. This will incorporate the need to select suppliers and manage the production process.

• Implement your Campaign Make it all happen in a co-ordinated way to assure maximum impact.

Evaluate your Campaign

Collect and interpret information on the planning, implementation and results of the campaigns in order to identify effective aspects of the campaign and areas where improvement is required.

Key Points:

- The Group shall take undertake 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 will operate on a number of levels simultaneously.
- Identify the 'bottom-line' changes.
- The Group shall ensure the key message is carefully chosen.

3.2 Level: 2 Listening-Gathering Information

The Group shall concentrate on obtaining information from both the public and patients using various mechanisms. These methods shall assist in effectively gathering information to help improve the health service being provided by the Group. These include feedback and complaint systems, both formal and informal. Telephone hotlines and comment cards, which shall act as 'sounding boards' for service users are discussed, as is the issue of patient shadowing and patient diaries and surveys.

| | Deliverables | Outcomes | Year |
|-------|---|---|------|
| 3.2.1 | Feedback and Complaint Systems | The Feedback and Complaint Management System shall provide a structured input mechanism for patients and public Feedback and Complaint System shall improve service quality which in turn leads to a positive image with service users. Feedback and Complaint System will provide a friendly approach to resolving complaints. The feedback system should demonstate how patient feedback is being used to inform quality improvement, needs assessment and improved outcomes for patients | 1 |
| 3.2.2 | Telephone Hotline | The Telephone Hotline will allow patients to provide feedback on aspects of the service. The Hotline shall be easily accessible- free phone number. Telephone Hotline will provide a clear procedure for complaint calls. | 2 |
| 3.2.3 | Comment Cards | The Comment Cards shall enable patients to input their views on the services provided. The questions shall be simple, clear and few in number. | 1 |
| 3.2.4 | Patient Shadowing | Patient Shadowing will monitor and measure performances of the service provided, as well as identify training needs. Patient Shadowing will oversee specific points mentioned by patients and staff. | 3 |
| 3.2.5 | Patient Diaries | Patients Diaries shall record the patient's event and personal thoughts. Patient Diaries will instil a sense of being listened to and their views acknowledged. | 3 |
| 3.2.6 | Surveys | Surveys shall be administered by a face-to-face or telephone interview, mail or provided online via web. Questions will focus on patient's actual experience or on their evaluation of results. The survey carried out will provide a true measure of patient experience, measuring what actually happened during the course of their care or encounter with healthservices Surveys should measure what's important to patients including, access, being treated with dignity and respect, safe and effective services, communication and information, involvement in decision making, privacy, health promotion and giving feedback about patient experience. | 1 |
| 3.2.7 | Patient Reported Outcome Measures (PROMs) | PROMs shall consist of both pre-operative and post-operative patient surveys to assess the health gain attained by the patient through treatment. PROMs will measure the effectiveness of care from the patient's own perspective. | 1 |

Nursing and Midwifery Strategy 2013 - 2018 - Gathering Information



3.2.1 Feedback and Complaint Systems (Year 1)

A feedback and complaint system shall provide structured and recorded input and feedback to the Group health services by the public and patients. The intention of the Group system shall be to encourage public and patient involvement, to capture both positive and negative feedback. To provide a more comprehensive system, the Group shall work in conjunction with other involvement tools for example, implementing a Patient Advice and Liaison Service (PALS). This system shall be well advertised throughout the organisation. This system shall be well advertised throughout the organisation. The complaints process shall be the responsibility of the Quality and Safety Department. Analysis of patient feedback, through complaints, surveys and other methods will be triangulated to gain a better understanding of patient's experience.

Complaints are a source of public and patient involvement that shall be utilised to its full potential by GRUGH. The Group shall ensure that the patient complaints policies and procedures in place within the organisation are consumer friendly and non-bureaucratic.

The Group shall provide a speedy and personal response from an individual who is trained and authorised to solve the problem. The staff shall identify and follow-up with patients who are dissatisfied, but have not formally complained. The Group will handle complaints in ways that are culturally appropriate and in ways that make it as easy as possible for the person making the complaint.

The Group recognise that becoming more patient involved and encouraging their patients to complain will increase the level of complaints. The rise of complaints shall be a sign of success, demonstrating that the feedback system is being used. This information will convey what the organisation is doing wrong and enable them to make appropriate adjustments. Complaints are essential to improve service quality which in turn leads to a positive image with service users.

A well-handled complaint shall:

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

To maximise the benefits of a Feedback and Complaint System:

- The Group shall adopt the right culture of accepting all feedback, including complaints, as positive.
- There shall be a clear and concise complaints process, which is publicly and easily available.
- Staff will be well trained in the management of complaints.
- The process of handling complaints will be culturally sensitive.
- Handling of personal feedback and complaints will not be neglected.
- / The Group shall aim to become `complaints friendly' and learn to seek out and welcome complaints
- The group will demonstrate how patient feedback is being used to inform quality improvement

Implementation:

The Group shall consider the guidelines provided by the Australian Council for Safety and Quality in Health Care to support the development or improvement of the feedback and complaints management system.

1. Commitment to consumers and quality improvement

Leaders in the health care service promote a consumer-focused approach to complaints as part of a continuous quality improvement programme.

• 2. Accessible

The service encourages consumers to provide feedback about the service, including concerns and complaints, and makes it easy to do so.

• 3. Responsive

The service acknowledges all complaints and concerns and responds promptly and sensitively.

• 4. Effective assessment

The service assesses complaints to determine appropriate responses by considering risk factors, the wishes of the complainant and accountability.

• 5. Appropriate resolution

The service deals with complaints in a manner that is complete, fair to all parties and provides just outcomes.

• 6. Privacy and open disclosure

The service manages 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 records 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 uses complaints to improve the service, and regularly evaluates the complaints management policy and practices.

These guidelines also reflect the core principles identified in Your Service, Your Say and People Matter – Complaints Matter, Guidelines for Handling of Complaints, both published by the Health Services Executive, which are:

Simple to understand and use

A complaints system should make it easy for people to make complaints. A simple explanation of how to make a complaint and the procedures that will be followed in dealing with the complaint forms the basic component of an effective complaints system.

• Speedy

Complaints are often exacerbated by long and complicated responses to the complainant. It is important that complaints are dealt with in a timely manner and that there is an immediate response to the complainant

Keeping people informed of progress

Long periods where there is no communication from the organisation to the complainant, and the organisation makes it difficult for the complainant to find out what is happening, can be very frustrating for the complainant. Hence there is a need for regular communication to keep the complainant informed of progress.

Listening to people

Complainants on the whole do not find it easy to make a complaint about their care and treatment. It is important that their perspectives are valued and their complaints are taken seriously.

Confidential

Confidentiality is a primary consideration both for the complainant and where relevant for the member of staff against whom a complaint is made.

Informative

A good complaints system should:

- Provide the complainant with accurate information about what happened, a clear explanation for why this happened and measures that will be taken to prevent it from reoccurring;
- Provide staff with clear guidelines on how to improve the service.

• Fair

The complaints handling process should be implemented without fear, favour or prejudice towards the complainant, the person who is the subject of the complaint or the service. Procedures and outcome should be fair and be perceived as fair by both the complainant and, where relevant, staff who are the subject of a complaint.

Effective

The complaints procedure should be capable of thoroughly investigating complaints to the satisfaction of the complainant and should result in the resolution of the majority of complaints received.

• Regularly monitored and audited to make sure it is effective and improved.

Complaints provide opportunities for improvement. The system for handling complaints should also be subject to regular review and improvement and the feedback should improve the quality

Key Points:

- A feedback and complaints system is a mechanism that shall provide a structured and recorded input for patients and public.
- The right of patients wishing to make a complaint was identified as part of the Health Act 2004. Part 9, Section 45 to 55.
- The Group shall encourage a user friendly approach to complaints and provide a speedy and personal response.
- Complaints shall be handled in a culturally appropriate manner.
- The Group shall encourage all feedback, including complaints.
- Increased level of complaints is a sign of success.
- The Group aim to become 'complaints friendly' and learn to seek out and welcome complaints.

3.2.2 Telephone Hotline (Year 2)

The Telephone Hotline provided by the Group shall allow the public and patients to provide feedback on the service in a simple manner. It will be one of the simpler public and patient involvement tools to implement. The Group shall appoint skilled staff and volunteers to maximise the effectiveness of this service.

The Group shall provide a Telephone Hotline to invite general public and patient comments, suggestions and complaints on their role and activities. This involvement shall be accommodated by publicising the provision of a free hotline that will be a permanent feature of the organisation's public and patient involvement.

Benefits to a Telephone Hotline:

- It shall be a very accessible way for the public and patient to address ideas or issues
 - It will be particularly beneficial for those with limited mobility
 - The Group shall ensure that people know about it
- It will be a cheap and on-going means of feedback on the service provided.
 - The calls will be categorised to show trends
- It shall provide an opportunity to resolve patient dissatisfaction at an early stage

In order for the Telephone Hotline to be a success, the Group will ensure that the public and patients are aware of the service. This shall include knowledge on the purpose of the hotline, the kind of topics that can be addressed on the hotline, when it is available (e.g. hours when it is manned) and how to access it (i.e. the number to dial).

This service shall obtain information about specific issues and will provide an opportunity to resolve patient dissatisfaction at an early stage. The Group intends to make this process a very accessible and cheap way for the public and patient to address ideas.

The Group will consider the characteristics of the people who will use the hotline facilities. The callers will not be expected to represent the views of the wider population. They shall, however, provide with some insights into why people who hold those views do so. This shall provide a source of people who can be referred into other avenues of public and patient involvement such as focus groups, committees or patient support groups.

Implementation:

The Telephone Hotline shall be one of the simpler patient and public involvement tools to implement within the Group. The creation of a free phone number shall be easily facilitated by any telephone service provider. The Group shall consider these areas to establish the hotline:

- Define the purpose of the proposed hotline.
- Who are 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.

The Group shall guarantee effective implementation of the Telephone Hotlines ensuring the individuals taking the calls will be provided with training in such areas 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.
- Top tips for giving information and signposting.
- When and how to end a call.

Some simple standards which will be adhered to during the operation of line Hotline includes:

• 1. Finding out about the Hotline

There will 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 will be staffed, open and accessible as advertised. Provisions will be made for out-ofhours callers and busy times.

• 3. The Call - Establishing and maintaining interaction.

The Group hotline workers shall respond to callers with courtesy. They will 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 offered to callers shall be up-to-date, accurate and appropriate to their enquiry, and signposting and referral to an appropriate agency.

• 5. Complaints about the service

The Group will introduce a clear procedure for callers to the hotline to be able to make complaints about the service.

Key Points:

- The Telephone Hotline shall allow patients to provide feedback on the aspect of the service in a simple manner.
- The service will rely on publicity and on the phone being attended.
- Cheap and on-going means of feedback.

States and States

3.2.3 Comment Cards (Year 1)

Comment Cards provide an easy to use mechanism to receive patient and public input. The Group shall design these in the format of some basic questions followed by asking for general input or comments. This method shall provide a sounding board for patients.

The Group shall create well designed and focused Comment Cards. The Comment Cards shall be based on the type of people who shall use the Comment Cards. These people will predominately be:

- 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).

As part of an overall public and patient involvement strategy, Comment Cards shall form an effective yet simple starting point for encouraging public and patient involvement.



In relation to the questions asked these shall be simple, clear and few in number. Examples of existing cards such as resource developed by the National patient forum will be considered. This leaflet includes three simple questions, which were identified by patients:

The Group shall ensure that the questions are indicators to issues and as a result will be broad in nature. To maximise benefit the Group shall consider Comment Cards with a specific focus,

e.g. questions only relating to hygiene or staff communication. The staff will allow patients and visitor's time to consider completing a Comment Card. The more Comment Cards completed the more useful information the Group will receive.

The Comment Cards utilised by the Group shall be as user friendly as possible. Questions shall not overshadow the amount of space available for leaving general comments. The Group will consider the simpler the system and the better positioned the greater the likelihood of its uptake. This method shall form a part of a greater overall patient involvement strategy.

YOU SAID WE DID



Patients will feel more confident about giving feedback about their experience if they know that their feedback is taken seriously. The Group website will profile how patient feedback has informed quality improvement. You said..... we did, a page on the we-site will profile examples of how patient feedback about their experience will be used to inform quality improvement.

The Group shall consider that Comment Cards have the advantages of low cost and require little staff time once in place. For patients, they are fairly anonymous which will add to the attraction of use, certainly where the users feel extremely happy or extremely unhappy.

Points for consideration include:

- 1. Comment Cards provide a simple starting point for patient feedback, the Group staff shall allow the time for patients and the public to complete them.
- 2. The Comment Cards shall be located in a highly visible area.
- 3. The card design shall be simple and straight forward.
- 4. The questions will be broad enough to be cues for the patient to give additional information. The Comment Cards shall be focused on any particular area. There will be plenty of room left for patient's comments.
- 5. The patients/public shall be asked to leave contact details so that they will followed up about their concerns if they wish.
- The Group shall define the process for maintenance, collection and analysis of feedback. Each area shall be responsible for its own information or it shall be implemented centrally.
- 7. The Group shall be aware that negative feedback from individuals may be symbolic of a bigger issue in the organisation.



- The Comment Cards created by the Group shall be an easy to use mechanism to receive public and patient input.
- The Comment Cards will provide a sounding board for patients.
- Success of the Comment Cards is dependent on the type of service provided.
- Comment Cards with a specific focus will be helpful.
- Comment Cards will form a part of a greater overall strategy.

3.2.4 Patient Shadowing (Year 3)

Patient shadowing occurs when another patient, volunteer or member of staff accompanies a patient or carer through the health system. Preferably the Group will select an individual who shall not have knowledge of the service and will be comfortable asking questions.

Patient shadowing shall provide objective, observational feedback that will be balanced by other approaches (for example by obtaining the views of the staff providing the service). Physical details, such as environment and waiting times will be recorded as well as perceptions of the service.

This provision will establish a comprehensive picture of an individual patient's flow and movement throughout the system. This shall be combined with a flow diagram of actions and a qualitative perception of the process or whichever aspect relevant to improvement. This information will be invaluable when trying to map what happens within the service.

The Group will use the Patient Shadowing technique to monitor and measure performance as well as to identify training needs. It shall be used to help staff realise what is important to patients. The Group shall ensure that the 'shadower' fully understands and is comfortable with their role. Support and feedback shall be provided to the patient and the 'shadower' that participate in the provision. Practice in the use of patient shadowing will increase the creativity with which it can be used. Patient Shadowing shall be used:

- To map a patient process to find out what really happens on the patients' journey.
- To monitor and measure the performance of the health service being provided.
- To identify training needs. It shall be used as a training and development tool to help staff understand what is important to patients as they progress through the healthcare service(s).

Patient Shadowing will be an effective yet simple mechanism for obtaining information from patients. Some simple points the Group shall consider:

- Clearly identify what the Group is trying to achieve and how shadowing will help to reach a goal.
- Ensure the 'shadower' fully understands and is comfortable with their role.
- Provide support for the patient and 'shadower' and respect the contribution of time and effort from both.
- Feedback to the patient and the 'shadower' regarding how their work will help with service improvement.
- Practice will increase the creativity with which patient shadowing shall be used.

Patient Shadowing will assist in gathering information to help improve the service. These are a number of points which the Group shall consider and develop briefly discussed below:

- 1. The Aim
 - What information shall the Group collect? For example:
 - What is the actual time spent waiting or being seen.
 - What is the standard of verbal, printed and signposted information given.
 - How do staff respond to questions and specific needs, e.g. disability.
 - What is the ambience of each area visited.
 - Any specific points mentioned by patients and staff.

• 2. What will be carried out?

- Time
 - The Group shall select a period for shadowing patients. This will vary between one to three weeks.
- Recruitment
 - The Group shall identify who will recruit staff, volunteers and patients, and how. Recruitment
 of patients shall be carried out by the receptionist staff / nurse. They will provide information
 on the process and introduce them to their shadower. The shadower will introduce themselves
 and ensure the patient understands what will happen. It shall be made clear that at any
 time they can ask the shadower to stop. The shadower will follow the patient for the duration
 of their stay.
 - During the consultation or procedure the shadower shall remain 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 will ask the patient for their reactions to what had happened. Information shall be collected in a concise way. The patient will be able to see what the shadower is writing if they wish.
 - When the appointment is finished, the shadower will ask general questions on what could be done better and what was particularly good. They shall also provide an opportunity for the patient to add anything they chose. After the patient leaves, the shadower will add his or her own comments in the box provided. Comments from staff shall also be recorded.

3. What outcomes shall the Group expect?

- 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.

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

3.2.5 Patient Diaries (Year 3)

Patient Diaries are a mechanism by which patients record both events that occur, and their personal thoughts, during their healthcare journey. The Group shall implement Patient Diaries to allow patients to maintain an active record of their perceptions of the care they receive. A written document shall be provided to the patients during their stay, also there will be consideration given to the use of electronic diaries, as well as video recording equipment.

The Patient Diary will assist the Group by providing information on the service provided and specific aspects of care, information from the diary shall be shared with the organisation. The aim is to help get a better understanding of the patient's journey, as well as difficulties encountered and the level of anxiety relating to them. The amount of information shared is dependent on the patient. Patient Diaries shall be developed to either focus on the entire journey, or part of it, depending on the objectives. Patients Diaries will be used where it is not possible to carryout Patient Shadowing.

The Patient Diary will provide a therapeutic basis for patients as it shall be designed to include the patient's personal emotions in relation to their disease. In the provision of certain care services the diary shall log treatment changes which will be completed in conjunction with members of staff. In this case the treatment details shall be kept separate from the patient commentary. This method shall look at the detail of the patient's view of a service. It will identify issues that the patient may not remember to talk about later.

The individual events of a patient's illness as well as the overall patterns of care will provide useful insight into the way a service is delivered and used over time. Such a retrospective overview is a valuable aid to the Group. It will also serve as a beneficial, reflective medium for a person who may have had a traumatic experience during their care. Equally, a positive encounter will provide an individual with a good source of reference should they need to use another or similar service in the future. This simple methodology of collecting diary-based experiences will provide a comprehensive picture, over time, of a specific service and provide important information.

The Group shall ensure that the patient will understand their role in the diaries use. A common problem is that many may 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. As a result staff shall assist patients in keeping up-to-date with their entries.

Benefits of Patient Diaries Include:

- Patients will get a sense of being listened to and their views acknowledged.
- Patients will get an opportunity to reflect on issues that occurred and provide suggestions on possible solutions.
- The Diaries will provide information in virtual real time that will assist in speedier rectification of issues
- They shall determine issues identified from a patients viewpoint
- It will allow for a deeper examination of issues that were previously flagged.

A Patient Diary initiative can be implemented with varying degrees of detail and, as a result, cost. The Group will use Patient Diaries in the form of a small booklet that shall be designed for ease of use. Where patients have been identified with poor literacy skills other mediums will be considered.

Questions shall be developed to reflect the concerns and language of the patient. There will also be the facility for the patient to incorporate information outside of the guide questions as they so choose.

Education will be provided to patients who have agreed to participate. This will not just be limited to the beginning of its use. Patients shall be encouraged and supported on an ongoing basis. It is essential that the patients have a clear understanding of what is required and how it benefits. Upon completion of their care the confidentiality of the patient will be observed.

- Patient Diaries are a mechanism by which patients record events and their personal thoughts.
- Patient Diaries will be in written form or digital equipment.
- Information shall be shared with the organisation to get a better understanding of the patient's journey.
- Patient Diaries will instil a sense of being listened to and their views acknowledged.
- Guide questions shall be developed for ease of use.
- Education and support will be provided to patients continuously.
- Patient confidentiality will always be observed.

3.2.6 Surveys (Year 1)

Surveys gather information for organisations by means of questionnaires. The Group shall implement surveys by means of questionnaires ensuring public and patient involvement within the organisation. This is the most common method used to receive feedback on healthcare services and shall be administrated by an interviewer face-to-face or by the telephone, or they shall be sent through the mail. The Group will provide the surveys online via the web, to be completed (Self-administered) by the respondent. The Irish Society for Quality and Safety in Healthcare administer the Patient Perception of Acute In-Patient Care in Ireland, the largest patient survey in the Irish health system.

The Group shall introduce a sample survey providing information relevant to the wider population following a few basic rules. This will reduce the cost and time involved in surveying the whole population (a census), by taking a sample from which can infer information about the wider population.

The Group shall take into consideration the variety of patient experience questionnaires which vary in size detail and focus. Some will be detailed, multidimensional scales designed to assess the overall concept of satisfaction and tested for reliability and validity. Others shall be simpler one-off questionnaires designed for specific settings, which do not aspire to such sophistication. These less sophisticated surveys will provide valuable information from a simple tool if the right steps are followed.

The Group shall consider a number of important criteria for choosing a patient satisfaction instrument:

Generic or specific measures

Patient experience will be expressed around a number of aspects of healthcare (specific) and also in a global sense. An overall satisfaction score will be supplement by information on the more specific aspects of the service.

Question focus

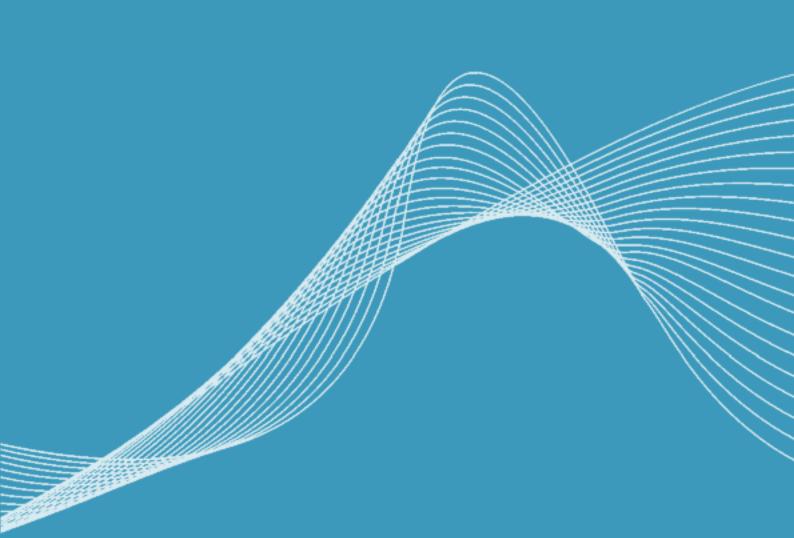
The wording and presentation of questions will greatly influence responses. Questions shall focus on patient's actual experience or on their evaluation of results. Short, clear questions are best. Asking patients what actually happened during the course of their care or encounter with health services provides services with real and meaningful information about what they can improve. The question "were you satisfied with the length of time you had to wait for your appointment" gives a service provider very little information about what needs to improve, the question "how long did you wait", measures experience and yields a more meaningful response and providing information that can help to improve services for all.

Psychometric properties

Structured measures of patient experiences shall adhere to the principles of psychometric measurement. Questionnaire reliability and validity will be important as survey results shall be frequently used as measurement data in assessing quality improvement interventions.

Validity

The measure shall be a 'true' measure of patient satisfaction and not, for example, be a measure of general life satisfaction. Qualitative methods will ensure that those aspects of health services most salient to the patients are included in the survey. Every effort shall be made to ensure views remain anonymous or confidential.



Reliability

It shall be consistent, such that, given similar experiences, patients would return similar ratings on the scales.

Implementation:

Before undertaking the development and administration of the survey, the Group will ensure that the survey is designed the right way to find out the adequate information. At the beginning the Group shall look at the area of interest and decide if it is a suitable topic for a sample survey.

To assist in the decision, as well as helping identify steps in the development process, the Group shall consider a number of key questions:

- Questions to consider before identifying patients who shall be invited to participate in the evaluation.
- Questions to consider when ready to begin involving patients.
- Evaluation questions.
- 1. Questions that GRUGH shall consider before identifying patients who shall be invited to participate in the evaluation
 - Why is experience being measured?
 - What dimensions of quality are to be measured?
 - Principles of the National Healthcare Charter and the Standards for Safer, Better Healthcare
 - 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 we 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?
- 2. Questions the Group shall consider when ready to begin involving patients.
 - Do we know who our patients are?
 - Do we know how patients would like to participate in our organisation?
 - What dimensions of quality / aspects of experience 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 to support those patients who provide their time and expertise to theorganisation?

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?

Regardless of which methodology utilised to administer the patient survey, the Group will remember it will be seen as part of an overall quality improvement process. This shall 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 will not happen in isolation but rather as part of your overall patient and public involvement strategy.

- Surveys collect information by means of questionnaires.
- Surveys will be administered by a face-to-face or telephone interview, or sent through the mail, or provided online via the web.
- The most common form of survey is a sample survey.
- Less sophisticated surveys will provide valuable information if the right steps are followed.
- An overall picture of patient experience shall be supplemented by information on more specific aspects of their care.
- The wording and presentation of questions greatly influences responses.
- Post and telephone response rates will be significantly increased by telephone follow-up.
- Surveys are part of the overall quality improvement process.



SN pictured at the opening of refurbished paeds.

3.2.7 Patient Reported Outcome Measures (PROMs) (Year 1)

Patient Reported Outcome Measures (PROM)s consists of both pre-operative and post-operative patient survey to assess the health gain attained by the patient though treatment. PROMs measure the effectiveness of care from the patient's own perspective. The Group shall ask patients about their health and quality of life before they have an operation, and about their health and the effectiveness of the operation after it. This will help the Group measure and improve the quality of its care.

Objectives include:

- Provide timely patient reported outcome data to a hospital and clinicians
- To inform the effectiveness of care, and highlight any variation in patient outcome
- To alert of any correlations in data collected relating to significantly high or low patient outcomes (identify best practice and highlight any outliers).
- All relevant GRUHG patients will be asked to fill in a short questionnaire before their operation. Once they have filled in the consent form and completed the questionnaire, answers will be held by the Group.
- A few months later, depending on the type of operation, a follow-up questionnaire will be sent. The information will help the Group to measure and improve the quality of health services.

Implementation:

A well-designed PROM questionnaire will assess either a single underlying characteristic or, where it addresses multiple characteristics, should be a number of scales that each address a single characteristic. These measurement "characteristics" are termed constructs and the questionnaires used to collect them, termed instruments, measures, scales or tools.

Questionnaires may be generic (designed to be used in any disease population and cover a broad aspect of the construct measured) or condition-targeted (developed specifically to measure those aspects of outcome that are of importance for a people with a particular medical condition).

The most commonly used PROM questionnaires assess one of the following constructs:

- Symptoms (impairments) and other aspects of well-being
- Functioning (disability)
- Health status
- General health perceptions
- Quality of life (QoL)
- Health related quality of life (HRQoL)
- Reports and Ratings of health care.
- Support for self-management-opportunities to get involved in expert patient programme

Measures of symptoms may focus on a range of impairments or on a specific impairment such as depression or pain. Measures of functioning assess activities such as personal care, activities of daily living and locomotor activities. Health-related quality of life instruments are generally multi-dimensional questionnaires assessing a combination of aspects of impairments and/or disability and reflect a patient's health status. In contrast, QoL goes beyond impairment and disability by asking about the patient's ability to fulfill their needs and also about their emotional response to their restrictions and needs for self-management support.



3.3 Level 3: Engaging- Work to Involve

The Group will ensure that the professionals interact with the public and patients. This public and patient involvement process will be done on an individual basis (i.e. one-to-one with patients,) or through, for example, focus groups. The Group shall consider incorporating methods such as Patient Advocacy and Liaison Services, patient commitment statements and Patient Councils in the involvement process.

| | Deliverables | Outcomes | Year |
|-------|---------------------------------------|---|------|
| 3.3.1 | One to One Interaction | One to One Interaction will provide information about patient problems and the outcome, side effects of treatment and advice. The One to One Interaction patient involvement process will greatly influence compliance, patient education and health outcomes. Patients shall be offered support to take part in decision making and raise questions about quality. | 1 |
| 3.3.2 | Focus Groups | The Focus Groups shall engage with patients and the public to listen and learn from them. Participants can state their views and explain the reason why. | 2 |
| 3.3.3 | Patient Advice and Liaison Service | The PALS shall provide general information to patients, their carers and families and will help them resolve problems and concerns quickly. The PALS shall help ensure that the patient's voice is heard. | 1 |
| 3.3.4 | Patient Commitment Statements | Patient Commitment Statements will empower patients by making them aware of their entitlements as individuals and consumers. Patient Commitment Statements identify the patients and publics responsibilities. | 1 |
| 3.3.5 | Patient Councils | Patient Councils will consist of patients who advise the organisation service development and patient care. Patient Councils shall work closely with the Group and staff to improve services for the patients. | 3 |

3.3.1 One-to-One Patient Interaction (Year 1)

One to One Patient Interaction with healthcare professionals is the most basic form of patient involvement, and is central to its effectiveness.



The professionals within the organisation will discuss with patients the side effects of treatment and offer advice on what they can do for themselves. The Group shall encourage good one to one interaction within the organisation to greatly influence compliance, patient education, and health outcomes. The priniciples of the National Healthcare Charter and accompanying suite of resources support both staff and patients to promote and sustain a culture of shared decision making and working in partnership.

Good one to one patient provider communication offers many tangible benefits. Many studies show significant positive associations between healthcare professionals' communication skills and patients' 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.

The Group is aware that communication is not a one-way system. The patients within the organisation shall be supported 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 "Lets Talk. A guide to becoming more actively involved in your healthcare". This document aimed to provide the patient 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. In 2012 the HSE launched a leaflet entitled "its safer to ask" is is the first of a series of leaflets which encourage patients to become involved in the decision making about their healthcare and care plan.



The Group understand that learning communication skills is dependent on an openness to change. The Group shall utilise effective listening skills and elicit and provide information using effective nonverbal, explanatory, questioning, and writing skills. The Group will encourage patients to work in partnership with the them to become more actively involved in their treatment. This change will not happen overnight but will be supported, through the provision of information, education and support structures, by the Group.

The implementation of one to one patient communication is a patient involvement mechanism. The aim of the Group will be to maximise 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

The Group will provide patients with information, education and support to assist them in becoming involved with their care. The Group shall explain that good healthcare is best achieved through an active and positive partnership between the patient and the healthcare team. The Group shall encourage the patients to take part in decision making about their treatment in order for them to get the best possible care for their needs and to help prevent things from going wrong.

Patients will be encouraged to ask the healthcare staff questions, and shall be given answers that they can understand. The Group will advise patients to write their questions down before their appointment and to take notes or to have a family member or carer with them. Patients will be reminded to pay attention to the care they are receiving. This will help ensure such things as receiving the right treatments and medications by the right members of staff.

The Group shall support patients to become more involved and 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 for staff regarding patient interaction will assist in the overall care of the patient. Education on patient interactions will encourage the Group staff to:

- Build a personal yet professional rapport with the patient.
- Use non-directed 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 concern is or
- / what are their expectations.
- Be aware of the impact of non-verbal communication.
- Resources developed to support staff to implement the principles of the Ntaional Healthcare Charter, have been developed with both patients and staff and will be made available as part of staff training:



NOTE: analysis of feedback received from patients suggests that staff attitude is an area for improvement, training in personnel excellence is recommended in addition to communications skills

training, it is currently being piloted.

The skill levels of staff will 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 will 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.

- 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 outcome.
- Good one to one interaction greatly influence such aspects as compliance, patient education, and health outcomes.
- There are significant positive associations between healthcare professionals' communication skills and patients' 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.
- The Group staff will communicate with patients to maximise interaction to assist in the overall patient outcome.

Strategic Plan for Public and Patient Involvement 2013-2015 - Focus Groups

3.3.2 Focus Groups (Year 2)

Focus Groups will offer the Group with a simple method of gathering information from patients and the public on specific topics. Focus Groups are one of the most common ways of gathering qualitative information from patients and the public. The Group shall use the Focus Groups to receive input on proposals or plans currently being developed in the organisation.

The Focus Groups will enable the Group to systematically establish the issues, concerns and opinions of patients. These will play an important role in drilling down information which otherwise may not be accessible. Information from focus Groups will assist in areas such 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 the range of people's experiences in order to prepare a survey questionnaire on these matters.

The Group will ensure that the group have a focused and defined purpose which reflects the size and composition of the group. There shall be a minimum of 6 and not exceeding 16 contributors in this group. The participants will be selected because they have characteristics in common, for example, all are expatients of a hospital, or all are carers of someone with the same or related conditions.

The key 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. The Group shall introduce Focus Groups to allow participants state their views about a particular topic and explain to the group members the reason why they hold these views. The Group shall expect the participants to expose the reasoning behind their opinions to allow the researcher to consider.

The Group shall consider the marginalised groups who are often difficult to get to participate. By identifying these limitations it shall be possible to maximise the benefits of the Focus Groups. Fundamentally, Focus Groups are a way of listening to people and learning from them. Within the group itself there shall be continual communication between the moderator and the participants. The moderators will be motivated to listen and learn from the participants. The facilitation of Focus Groups will by no means be a passive process.

Benefits of Focus Groups include:

- Gains insights into public and patient perceptions.
- Detailed information will be found quickly.
- Relatively Low Cost.
- Supports other public and patient involvement methodologies.
- Is not dependent on literacy skills.
- Shall accommodate cultural diversity.

Implementation:

1. Purpose

Prior to the issuing of invitations to a Focus Groups the Group will clearly define the topics they wish to focus the discussion on and what they wish to learn. This shall be provided to the participants in advance and, where relevant, background information on the topics will be provided. The Group will ensure that the patients express their thoughts and ideas and will make sure these are acknowledged.

• 2. Participants

The Group shall ensure that the people selected to participate in Focus Groups are fairly open. Consideration will be given to a simple document that outlines peoples expected competencies. The people involved will be able to express their feelings in front of a small group of people and be prepared to interact with them.

• 3. The Moderator

Focus Group discussions shall involve the participants and the moderator in a highly interactive process. The moderator shall be skilled in group working to ensure the group operates in an orderly and meaningful manner. They shall be skilled at establishing a non-threatening and supportive atmosphere for patients where everyone feels their contributions are valued. The moderator will not be involved in providing any of the services under discussion.

4. Key Issues

- Some key issues the Group shall consider when facilitating a Focus Group:
- Keep the focus at all times to ensure not to 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 be devils advocated 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 are understanding what is being said.
- Provided feedback to the group on completion of the session and formally at a letter stage.
- Thank them! This may be in the form of refreshment after the session, honoraria, or simply verbally.

- Focus Groups are a simple method of engaging patients and the public.
- Number of participants can range from 6 to 16.
- Participants shall state their views and explain the reason why.
- Benefits are largely dependent on the moderator.
- Moderators shall be motivated to listen and learn.
- Participants must not only by knowledgeable but open.



3.3.3 Patient Advice and Liaison Service (PALS) (Year 1)

A Patient Advice and Liaison Service (PALS) is a method for addressing patient and public issues and concerns at a local level. The Group shall implement a PALS to provide general information to patients, their carers and families and to help them resolve problems and concerns quickly before they become more serious. First introduced in the UK, the PALS concept arose out of growing concerns from practitioners, managers, patients, carers, voluntary organisations and many others about the increasing numbers of complaints being made about all aspects of health care. Although they will inform people of the complaints procedure and support available, they will not administer complaints. The complaints process shall be administered by the Quality and Safety Department.

The PALS will be predominately provided by trained volunteers. These volunteers shall be trained, supported and co-ordinated by the Group PALS Co-ordinator. The Patient Advice and Liaison Service (PALS) will help engage with the public and the patients at the earliest point of contact. Building from the existing concepts of Patient Advocacy Officers, the creation of such a service will troubleshoot a range of problems and hopefully form a great engagement with the patient.

The Patient Advice and Liaison Service (PALS) will form part of the overall public and patient involvement strategy within the Group. They shall interact with Patient Councils, Focus Groups, etc., as well as other Patient Advice and Liaison Service (PALS) developed in partner and support organisations. The primary role of the PALS shall be to provide information to patients, carers and families, about health and health services locally and put patients in contact with relevant voluntary organisations and support groups. Where possible, the PALS will attempt to resolve problems and concerns quickly, before they become more serious. Although they will inform people of the complaints procedure and support available, they will not administer complaints.

The Patient Advice and Liaison Service (PALS) shall act as an early warning system for the Group by identifying trends of problems arising and issues discussed with patients. This information will assist in highlighting gaps in services and staff training. The PALS shall operate in a network, ensuring a seamless service for patients who move between different parts of the care system, which will assist in benchmarking.

Benefits of Patient Advice and Liaison Service (PALS) shall include:

- A confidential service for patients, family and carers.
- A visible focal point for patients in the provision of information on services.
- A place where patients shall turn to if they have a problem, but do not want to complain.
- Assistance in resolving patients' concerns quickly and efficiently and shall improve the outcome of the care process.
- Listening to concerns, suggestions or queries.
- A gateway to enable patients and the public to become involved in the provision of health services.

The development of a Patient Advice and Liaison Service (PALS) will be a significant undertaking by the Group. Members of the Patient Advice and Liaison Service (PALS) will work to ensure that every patient is supported and encouraged to maintain their level of autonomy and self direction. The Patient Advice and Liaison Service (PALS) will facilitate patients in the task of taking personal responsibility by focusing on their needs, concerns and issues relating directly to their treatment and care.

In order to ensure patient choice, the Patient Advice and Liaison Service (PALS) shall assist the patient in accessing all information on which the patient can base an informed choice. The Patient Advice and Liaison Service (PALS) shall provide this information in an appropriate manner, i.e. couched in plain language.

The Patient Advice and Liaison Service (PALS) shall ensure that the patient's voice is heard by those professionals with direct responsibility for the patient's treatment and care. If the patient shall voice any doubt that their needs, concerns or wishes have not been heard or considered, the Patient Advice and Liaison Service (PALS) will work to highlight this with the appropriate health care professional and ensure that the patient is provided with a response.

- A Patient Advice and Liaison Service (PALS) is a method for addressing patient and public issues and concerns at a local level.
- PALS shall provide general information to patients, their carers and families and shall help them resolve problems and concerns quickly.
- PALS shall inform people of the complaints procedure and support available, they will not administer complaints.
- PALS shall act as early warning system for the healthcare organisation.
- Visible focal point for patients in the provision of information on services.
- Facilitates patients in the task of taking personal responsibility by focusing on their needs, concerns and issues relating directly to their treatment and care.
- PALS shall help to ensure that the patient's voice is heard.

3.3.4 Patient Commitment Statements (Year1)

Patient Commitment Statements shall be published standards, defined by the Group, against which patients will measure the care and services provided. Patient Commitment Statements shall play an important role in empowering patients by making them aware of their entitlements as individuals. These written patient rights and guarantees provided by the Group will specify service conditions and identify mechanism for complaint where they are not met.

The Group shall ensure success of the Patient Commitment Statement by creating realistic expectations and goals. Organisational specific Patient Commitment Statements will be a beneficial mechanism between the Group and the patient where it will be used to identify mutual responsibilities. The Patient Commitment will publicise patients' responsibilities in maximising the efficiency of their health service.

In 2012 the Health Services Executive (HSE) developed a National Healthcare Charter. The Charter aims to create a Patient Commitment in relation to access, dignity, accountability, religion and information.

Implementation:

The Group shall use the Patient Commitment Statements to empower patients by making them aware of their entitlements as individuals and consumers. Patient provider commitments will in all cases be realistic with regards to expectations.

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

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

The Patient Commitment Statement will identify the patients and public's responsibilities. Patients and public shall be involved at the development stage to help focus their responsibilities. These shall include:

- Dignity to Staff
- Provision of Information
- Involvement In Education
- Understanding in Limitations
- Adherence to Instructions

The Group will consider how each point in the Patient Commitment Statement shall be measured for success. There is little point in developing an ideological wish list that cannot be achieved! Where the commitments are not being met the Group will clearly identify what methods of redress are available, e.g. Complaints Process, Patient Advocacy, etc.

The Patient Commitment Statements shall be focused at the wider population. The Group shall draw up guarantees taking into consideration the whole community level and to whom they shall ultimately be accountable. These will be prominently displayed in public areas and on the website. The Patient Commitment Statements shall be of benefit to both patients and staff.

- Patient Commitment Statements will empower patients by making them aware of their entitlements as individuals and consumers.
- The success of organisational specific Patient Commitment Statement shall depend on the creation of realistic expectations and goals.
- The Patient Commitment Statement shall publicise patient's responsibilities.
- Consideration shall be given to defined national and international rights.
- A balance between the individual requirements and that of the community shall exist.
- All points of a Patient Commitment Statement shall be measurable with identified actions for redress.
- The Group shall publicise Patient Commitment Statement.

3.3.5 Patient Councils (Year 3)

The Patient Council shall consist of a group of patients who will advise the Group on service development and aspects relating specifically to patient care. The overall aim of the Group Patient Council will be to work closely with the organisation and its staff to improve services for all patients who use its services.

Patient Councils have been established by some organisations as a mechanism for bringing together representatives of several consumer groups. Other organisations use the Patient Council as a central tenet to their overall public and patient involvement programme.

The Group shall introduce the Patient Councils 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 differ from organisational committees representation (see also Patient and Public Representation) by the fact that Patient Councils are comprised entirely, or at least predominantly, of patients and carers. The Patient Council is established for the specific purpose of providing patient involvement.

The Group will implement the Patient Council to work closely with the patients to improve the services. Each Council shall be unique in its own right, addressing issues specific to the organisation. The structure of the council shall be carefully considered, representatives will need to have tenure long enough to learn to be useful, but not so long they become part of the organisation. The Group will carefully recruit members, utilising representation from other patient bodies and associations or running recruitment campaigns in their organisation. The Group shall have a clear Terms of Reference for the Council as well as defined selection criteria defining commitments and responsibilities.

Benefits of Patient Councils will include:

- Assistance in the creation of service developments that shall be more responsive to patients' needs.
- Allows for a central structure to oversee public and patient involvement strategies.
- Provides an ongoing review of initiatives due to the duration of its membership.
- Publicly highlights the organisation's commitment to patient involvement.
- Increases local ownership of care services.

The development of the Patient Council within the Group will be a significant undertaking. There shall be a need for clarity with regard to all issues including:

• The role of the Patient Council.

Defined Terms of Reference must be developed. What will be the scope of the Council? How will it interact with the rest of the organisation.

• The membership.

How many representatives and who they are expected to represent. This can vary from 8 to 20.

Reporting.

Who will the Council report to and who will they be accountable to?

• Appointments.

How will they be recruited and appointed and by whom?

• Duration.

What is the life expectancy of the Council? Will there be rolling membership? Under what circumstances can members be dismissed?

Resources.

What supports will be available to the committee? Will members have access to research resources, administrative assistance, photocopying, etc?

Costs.

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

The Group shall think strategically about how the Councils findings or advice will be used by the organisation. The Group will consider is the organisation currently open enough to hear what the Council may come up with? How shall the links between the Council and the organisation be maximised? Patient Councils will drive patient and public involvement in the organisation. The Group will ensure that the organisation has the capacity and the commitment to patient involvement to support the Council and to see it through for the long run.

- Patient Councils comprise of groups of patient who advise the organisation on improving the service.
- It will act as a central tenet to all public and patient involvement.
- Patient Councils shall comprise entirely, or at least predominantly, of patients and carers.
- Patient Councils will not become places of negativity.
- Each Council will be unique in its own right, address issues specific to each organisation.
- Representatives shall have tenure long enough to learn to be useful, but not so long they become part of the organisation.



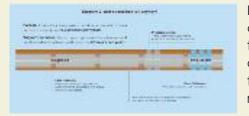
3.4 Level 4: Partnering – Develop Together

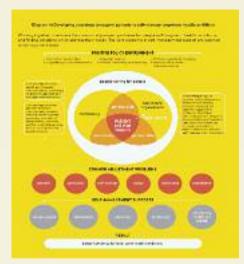
The Group shall concentrate on how the public and patients can work together to maximise the mutual benefits. Methods for achieving this shall include the "Expert Patient" and public and patient representation on groups. Also community forums and community partnerships shall be used.

| | Deliverables | Outcomes | Year |
|-------|--------------------------------------|---|------|
| 3.4.1 | Expert Patient | The Expert Patient will share their experience of a condition or illness to convey knowledge about living with it to others. Patients shall 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. | 3 |
| 3.4.2 | Patient and Public Representation | Patient andPublic Representatives shall act as representative of a larger group of services users. Patient andPublic Representatives shall act as The use of Representatives on committees will show commitment to partnering with patients to help develop a more patient centred process. | 3 |
| 3.4.3 | Community Forums | The Community Forums shall be used to hear the experiences and ideas of the community. The Community Forums shall be easy for service users to attend. The Community Forums shall provide information, the opportunity to ask questions and the opportunity to participate in the development of further ideas or action plans. | 3 |
| 3.4.4 | Community Partnerships | The Community Partnerships will involve the coming together of various community groups and the Group to implement or develop a specific initiative. The Community Partnerships will combine resources to help tackle specific problems | 3 |

3.4.1 Expert Patients (Year 3)

An Expert Patient is a term used to refer to people who have an experience of a condition or illness and who is prepared to share it in order to convey knowledge about living with it to others. The term was first used in the UK National Health Service's white paper, entitled Saving Lives: Our Healthier Nation, acknowledges the role of patients in manageing their own conditions, as outlined in diagram 2 below, who's condition is it anyway?.







Research from the US and UK over the last two decades demonstrates that people living with chronic illnesses are often in the best position to know what they need in managing their own condition. Provided with the necessary 'self-management' skills, they will make a tangible impact on their disease and quality of life more generally.

The Group will develop self-management programmes in the form of Expert Patients, to enable people with a condition to train others with a similar long-term condition to develop skills in managing their own illness. This shall help create a new generation of patients who are empowered to work with the health service to enhance their overall quality of life. The National Framework –Support for Self Management –Long-term Health Conditions will be used to inform this work. Developing a plan for self management support requires a wholes systems approach (depicted in diagram 4, below) which require a partnership between patients and professionals, patients and their communities and health services and voluntary agencies/ communities.

Under an Expert Patient Programme, patients shall receive support to help them to 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 shall be placed on developing local patient led, generic chronic disease self management course (the core of an Expert Patient Programme) in partnership with voluntary organisations who have the ability to deliver these courses.

The Group self-management programme will ensure that a person's 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 this shall be the use of other patients, the Expert Patient, to assist others with similar conditions to themselves. These programmes will go beyond the purely medical view, to look at how chronic disease affects daily life. These courses shall impart information and also facilitate the development of self management skills, such as problem solving and goal setting over six weekly sessions.

The Group Expert Patient programme shall motivate and assure the patient to use their own skills, information and professional services to take effective control over life with a chronic condition. The Group will involve voluntary organisations in the development of the Expert Patients Programme. These organisations shall assist the Group in determining which chronic conditions to focus upon and how to tackle it. To date in the UK there has been creation of Expert Patients Programmes in such areas as:

- Arthritis
- Diabetes
- Asthma
- Substance Abuse
- Disabilities

These voluntary organisations will be a key resource to identifying content, structure and resources in the development of the self management training courses which shall be central to the development of Expert Patients.

Programmes shall be based on developing the confidence and motivation of the patient to use their own skills, information and professional services to take effective control over life with a chronic condition. With adequate support, patients will take a lead in managing their own conditions, which will help to improve health, quality of life and reduce incapacity.

The Group shall develop a sustainable model to support a plan for self management support, this is depicted in the diagram 4 above. Introduce self-management courses to help people manage their long-term condition, and to adopt approaches that will prevent their condition from getting worse and reduce the risk of getting further conditions.

The course tutors shall be patients who have a long term health condition themselves and will be either paid tutors or volunteer tutors who previously undergone the programme. These shall be known as the Expert Patients. At the commencement of the course this will not be possible to have access to such experienced people, however the Group will carefully consider the appropriate people.

The content of the courses will be reflective of the aims of the overall Expert Patient programme as well as that which is specific to the chronic illness. Elements shall 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.

The five core self management skills have been identified as:

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

- The Expert Patient shall have experience of a condition or illness and shall be prepared to share it to convey knowledge about living with it to others.
- First referred to in the NHS Saving Lives: Our Healthier Nation.
- Provided with the necessary 'self-management' skills, patients will make a tangible impact on their disease and quality of life.
- Expert Patients will enable other people to develop skills.
- Patients shall 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 will be the principal route for creating Expert Patients.
- Expert Patients shall work in partnership with health and social care staff.
- Verlag with by debiated over the difference in the control of the intervention of the interve

3.4.2 Patient and Public Representatives (Year 3)

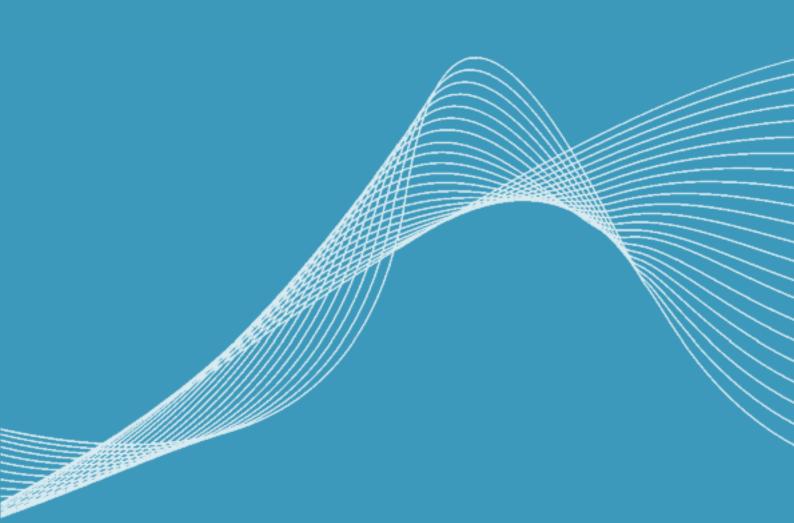
The Patient or Public Representative shall act as a representative of a larger group of service users and will provide a consumer perspective. The decision to involve a Patient/Public Representative in the Group's committees is a significant one and will not be taken lightly.

The implementation of a consumer on the Group health service committee shall be a long-term strategy. As part of an overall involvement strategy the use of Patient/Public Representatives on committees such as Management Committees and Quality and Safety Committees, will show a commitment to partnering with patients to help develop a more patient centred process. Using representatives on these committees will require a significant commitment from the Group in terms of time, communication, support and often training.

The Group shall have clear terms of reference for the committee(s) prior to the investigation of any recruitment of Patient/Public Representatives. The Group will clearly state to potential representatives the kind of role and power the committee has. For example, can the committee make decisions? If not what other decision making structures must be involved?

The Group shall choose the most appropriate individuals to maximise the benefit of Patient/Public Representatives. The skills will vary however, the Group shall consider their ability:

- To analyse information and identify its potential effects in relation to the patient.
- To see the possibilities of both short and long term outcomes.
- To negotiate on issues
- To work as a team member to achieve the desired outcomes
- To articulate their opinions



Fundamentally, successful recruiting of Patient/Public Representatives for committees will require clarity 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 the Group is clear on these three areas the recruitment will be guided by the role identified for the representative. This will help identify which route to take. The Group shall recruit a representative by contacting a relevant patient advocacy body and requesting a nomination from there. This will be appropriate if the committee has a particular care focus, e.g. cancer care. The Group shall provide the advocacy body with both plenty of information about the committee and the role, and plenty of time for them to consider who would be most suitable.

If this will not be appropriate, the Group shall advertise through local newspapers, radio, or even internally in the organisation to yield the type of individual required to fulfil the criteria. The Group shall provide a central contact to handle inquires. This member of staff will help explain the process to those who express an interest in becoming representatives. The Group will consider organising an opening evening to provide more information.

The Group shall require that those interested provide a written explanation, based on the 'job description', as to why they feel they would be suitable. The 'job description' shall be used as a checklist for essential characteristics that will allow the Group to reduce the number of applicants who do not meet the basic requirements. From here interviews shall be carried out. The Group shall organise that a Patient/Public Representatives is on the interview panel (perhaps 'borrowed' from another organisation).

The Group shall remember to contact and thank those applicants who have been unsuccessful. If possible, they will advise them on the outcome.

Following the selection of a Patient/Public Representative the Group shall spend time educating them on the activities of the organisation, the role of the committee and the expectations of the organisation. The Group shall understand the expectations of the representatives in order to get good results and avoid disappointment and conflict later down the track. The Group shall consider the following questions when discussing expectations with the newly appointed Patient/Public Representative:

- 1. What are your overall goals for your family, community and yourself?
- 2. How do you feel your involvement in the committee can help you to achieve this?

3. 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

4. What on-going support would you like to receive?

Key Points:

- Patient or Public Representatives shall act as a representative of a larger group of service users.
- Involving Patient/Public Representative in committees shall require significant investment by the organisation.
- Patient / Public Representatives shall be a long term strategy.
- Clarity will be provided as to the role of the representative.
- A detailed selection criteria shall be required.
- Clarity will be provided on:
 - the role of the committee in question
 - the role of the Patient/Public Representatives
 - the recruitment and selection process to be used

Note definition of representative / nominee; Representative is a consumer, carer or community member who is nominated by and accountable to an organisation of consumers, carers or community members. The term 'representative' is linked to living in a democracy. Hence, they are there to represent the formal views of a particular group and report back to that group. (hence the importance of evidence based feedback, re: needs, experience and outcomes of care).

Nominee is the term used to describe somebody who is representative or has links with a particular group(s). They are not accountable in the way that a representative is but are participating because of their links with a group(s).

3.4.3 Community Forums (Year 3)

Community Forums shall be a useful way for the Group to hear the experiences and ideas of the community. In this regard, they are somewhat similar to Focus Groups. However, the forum shall involve a large group of patients and will include a small number of staff.

The Community Forums shall educate people, share information about a specific issue and develop an appreciation of different viewpoints. The Group will organise a series of meetings at which the public and staff discuss matters of shared concern. The Forums shall provide feedback about the care or service patients have received, these will also enable the patient and public to achieve wider input into organisational decision-making and planning.

In implementing a Community Forum the Group will 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, and
- A sense of involvement in making decisions and the actions which follow the decisions. This means that all members should participate.

A Community Forum's aim shall be classified as:

- Visible community involvement in the development of healthcare services.
- Provides the community with the mechanism to:
- receive information
 - provide input
 - discuss ideas
 - enhance partnership.
 - Provides information on services and developments.

The Group will converse with the Community Forums to discuss alternative policies or programmes, to get feedback and to refine proposals. For example, a Community Forum shall consult with community members about the location of a new health care facility; or to consult people from different ethnic groups about their perceived barriers to using your health service.

The Group shall require staff members attending the Forum to be flexible, prepared to listen and able to express themselves clearly and concisely. The Group will understand the purpose of the Forum shall be to provide recommendations and not make final decisions. Consideration shall be given regarding the use of an external facilitator.

The effectiveness of Community Forums will be enhanced by using such facilitators. These shall provide non-directive guidance in assisting the Forum to come to decisions. Facilitators will ideally have a neutral role in relation to the matters being discussed. The facilitators shall work with the Group to design the process beforehand, including formulating the agenda and suggesting forms of participation.

Implementation:

The introduction of Community Forums shall be a significant undertaking by the Group and will signify a major step towards enhancing public and patient involvement. To maximise the involvement in, and thus the benefits of, the Community Forum, the following areas shall be considered:

• 1. Highlight Awareness

Ensure to provide sufficient notice, using a range of methods to let the intended audience know about the meeting.

• 2. Accommodate 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, begin with 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

The process will 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 discussion.

5. Facilitator

An experienced facilitator will be used. There will also be enough people with group experience to act as facilitators for the small group discussions.

• 6. Forum Conclusion

The conclusion of the forum will include a clear summary of the outcomes of the forum. Ensure participants are kept up to date.

Key Points:

- Community Forums shall hear the experiences and ideas of the community.
- Forums shall be effective as a series of meetings.
- Community Forums shall gain wider input into organisational decision-making and planning.
- Staff members attending the Forum will be flexible, prepared to listen and able to express themselves.
- Consideration shall be given to the use of an external facilitator.
- Community Forums will signify a major step towards enhancing public and patient involvement.

3.4.4 Community Partnership (Year 3)

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 participation and a strong community focus and culture in the organisation.

Community Partnerships can take many forms. The Group shall come together with various community groups to implement or develop a specific initiative, for example, a substance abuse initiative. Joint planning partnerships between the community and the Group shall be a significant form of public and patient involvement. These partnerships will aim to combine resources to help tackle specific problems. These resources will not limit to financial but shall also include staff members and their expertise.

Partnerships will bring together organisations with differing histories, priorities and cultures. They will involve groups with different agendas and individuals with differing goals and needs relating to their involvement in the partnership. On occasions they shall be established very quickly; to respond to local demands or to meet the criteria for, or timetable of, a new urban regeneration funding initiative. 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 Group and the community partners are clear about how the partnership will work.

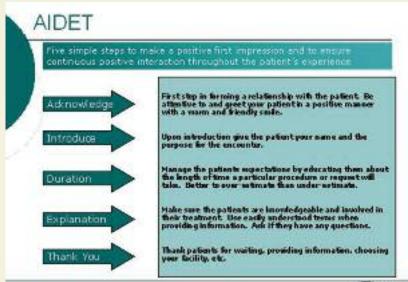
Implementation:

Points the Group shall consider to establish Community Partnerships include:

- Clarify the aims and objectives in forming a partnership. What will the Group try to achieve, and how shall community partners assist?
- Identify the stakeholders in the project or programme.
- Consider who the Group will need as partners, and who will want to be a partner.
- Before approaching potential partners, the Group shall ensure that the organisation will support and agree working with others.
- The Group shall communicate with the partners in language they will understand, focusing on what they may want to achieve.
- Plan the partnership process over time. Successful partnerships will take time to formally establish.
- The Group shall use a range of methods to involve people workshop sessions as well as formal meetings.
- Encourage ideas from the partners. Ownership leads to commitment.
- Be open and honest.

Key Points:

- Community Partnerships are structured cyclical planning process 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.
- The Group and the community partners shall be clear at the outset about how the partnership will work.
- The Group shall plan the partnership process over time. Successful partnerships will take time to formally establish.



Galway Group is committed to this collaboration with our patients and families and look forward to improving on our care and involvement every day. We will flourish at this work through

тепет

"making the status quo uncomfortable and making the Future attractive" Strategic Plan for Public and Patient Involvement 2013-2015 - Appendix 1

Appendix 1 - REFERENCES

Alexander, M., and Hegarty, J.R., 2001. Measuring client participation in individual programme planning meetings. British Journal of Learning Disabilities. 29:17-21.

Alexander, K., and Hicks, N., 1998. Sailing without radar: an excursion in resource allocation. Australian Health Review, 2:76-99.

Al-Assaf, A.F., 1993. Introduction and historical background. In A.F. Al-Assaf and J.E. Schmele (Eds.). The Textbook of Total Quality in Healthcare. Florida: St Lucie Press.

Batchelor, C., Ownes, D., Read, M., and Bloor, M., 1994. Patient Satisfaction Studies: Methodology, Management and Consumer Evaluation. International Journal Healthcare Quality Assurance 7(7):22-30.

Baum, F., Cooke, R. and Murray, C.,1998. Community Based Health Promotion – Evaluation and Development SA Community Health Research Unit, Adelaide

Bisset, A.F. and Chesson, R., 2000. Is this Satisfaction Survey Satisfactory? Some points to consider in their planning and assessment. Health Bulletin 58(1):45-52.

Bowling, A., 1992. Assessing health needs and measuring patient satisfaction. Nursing Times 88(31):31-34.

Brundley, J, and England, R., 1983. Towards a definition of the Co-Production Concept. Public Administration Review p59-65

Bruster, S., Jarman, B., and Bosanquet, N., 1994. National Survey of Hospital Patients. British Medical Journal 309:1542-1549.

Bubela, N., Galloway, S., McCay, E., 1990. Factors influencing patients' information needs at time of hospital discharge. Patient Education and Counselling. 17:441-445.

Cahill, J., 1998. Patient participation – a review of the literature. J Clin Nurs. 7:119-128.

Chambers, R., Drinkwater, C., and Boath E., 2003. Involving Patients and the Public, How to do it Better. Radcliff Medical Press.

Charles, C., and De Maio, S., 1992. Lay participation in health care decision-making: a conceptual framework. CHEPA working paper series No. 92-16. Ontario: McMaster University.

Charles, C., Whelan, T. and Gafni, A., 1999. What do we mean by partnership in making decisions about treatment? British Medical Journal. 319:780-782.

Cleary, P.D., Edgeman-Levitan, S., and McMullen, W.. 1992. The relationship between reported problems and patient summary evaluations of care. QRB 2:53-59.

Cohen, G., Forbes, J., and Garraway, M., 1996. Can Different patient satisfaction survey methods yield consistent results? Comparison of three surveys. British Medical Journal 313:841-844.

Consumer Focus Collaboration, 2000. Education and training for consumer participation in health care. Canberra, Australia: Consumer Focus Collaboration.

Consumer Focus Collaboration, 2001. The evidence supporting consumer participation in healthcare. Commonwealth Department of Health and Aged Care.

Consumer Focus Collaboration, 2001. Review of existing models of reporting to consumers on health service quality: summary report and guidelines. Canberra, Australia: Consumer Focus Collaboration.

Coulter, A. and Fitzpatrick, R., 2000. The Patients Perspective Regarding Appropriate Healthcare. In: Handbook of Social Studies in Health and Medicine, Anonymous London:Sage, p. 454-464.

Craig, H., 1985. Accuracy of indirect measures of medication compliance in hypertension. Research in Nursing and Health. 8:61-66.

Crawford, M., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., and Tyrer, P., 2002. Systematic review of involving patients in the planning and development of health care. British Medical Journal, 325: (7375) 1263-65.

Delbanco, T., 1996. Quality of care through the patient's eyes. Satisfaction surveys are just the start of an emerging science. British Medical Journal 313:832-833.

Department of Health and Children, 1994. Shaping a Healthier Future. Dublin: Stationary Office

Department of Health and Children, 2001. Quality and Fairness: A Health System for You. Dublin: Stationary Office

Department of Health, 2001. Learning from Bristol: the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995. London: Department of Health.

Department of Health, 2001. The Expert Patient: a new approach to chronic disease management for the 21st century. London: Department of Health.

Department of Health, 2001. Involving Patients and the Public in Healthcare: Response to the Listening Exercise. London: Department of Health

Department of Health UK, 2004. Patient and public involvement in health: The evidence for policy implementation. London, HMSO.

Donabedian, A., 1992. Quality assurance in health care: consumers' role. Quality in Health Care 1;4:247-251.

Draper M., 1997. Involving consumers in improving hospital care: lessons from Australian hospitals. Commonwealth Department of Health and Family Services

Draper, M., Cohen, P., and Buchan, H., 2001. Seeking consumer views: what use are results of hospital satisfaction surveys? International Journal for Quality in Healthcare 13(6):463-468.

Draper, M., and Hills, S., 1995. The role of patient satisfaction in surveys in a national approach to hospital quality management. Commonwealth Department of Health and Family Services, Canberra.

Enehaug, I. H., 2000. Patient participation requires a change of attitude in healthcare. International Journal of Healthcare Quality Assurance. 13(4):178-181.

England, S., and Evans, J., 1992. Patients' choices and perceptions after an invitation to participation in treatment decisions. Social Science Medicine. 34:1217-1225.

Entwistle, V et al., 1997. Supporting Consumer Involvement in Decision Making: What Constitutes Quality in Consumer Health Information? International Journal for Quality in Healthcare. 8;5;425-437.

Fallowfield, L., Hall, A., Maguire, G., and Baum, M., 1990. Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. British Medical Journal. 301:575-580.

Fitzpatrick, R., 1991. Survey of patient satisfaction: 1 - Important general considerations. British Medical Journal 302:887-891.

Fitzpatrick, R., 1991. Surveys of Patient Satisfaction: II - Designing a Questionnaire and Conducting a Survey. British Medical Journal 302:1129-1132.

Fitzpatrick, R., Hopkin, A., and Havard-Watts, O., 1983. Social dimensions of healing. Soc. Sci.Med. 17:501-510.

Florin, D.; Dixon, J., 2004. Public involvement in health care. British Medical Journal, 328: (7432), 159-161

Grant, L., 1998. Remind me who I am, again. Granta Books, London.

Hall, J.A., and Milburn, M.A., 1998. Why are sicker patients less satisfied with their medical care? Tests for two explanatory models. Health Psychology 17(1):70-75.

Hardy, G.E., West, M.A., and Hill, F., 1996. Components and Predictors of Patient Satisfaction. British Journal Of Health Psychology 1:65-85.

Health Services Executive, 2008. Your Service, Your Say.

Health Services Executive, 2008. National Strategy for Service User Involvement in the Irish Health Service

Irish Health Services Accreditation Board, 2004. Acute Care Accreditation Scheme. Irish Health Services Accreditation Board.

Irish Society for Quality & Safety in Healthcare, 2005. National Patient Perception of Care Survey 2004/2005. Irish Society for Quality & Safety in Healthcare.

Janz, N. K., Becker, M.H., and Hartman, P.E., 1984. Contingency contracting to enhance patient compliance: a review. Patient Education and Counselling. 5(4):165-178.

JCAHO Joint Commission on the Accreditation of Healthcare Organisations, 1994 Manual for the Accreditation of Hospitals, Illinois: Oak Brooks, 1993.

Jenkinson, C., Coulter, A., and Bruster, S., 2002. The Picker Patient Experience Questionnaire:

development and validation using data from in-patient surveys in five countries. International Journal, for Quality in Healthcare 14(5):353-358.

Kohn, L.T., Corrigan, J. M. and Donaldson, M.S., 2000. To Err Is Human: Building a Safer Health System. Washington, DC: Institute of Medicine.

Lasek, R.J., Barkely, W.M., and Harper, D., 1997. An evaluation of the impact of non-response bias on patient satisfaction surveys. Medical Care 35(6):646-652.

Lin, B., and Kelly, E, 1995. Methodological issues in patient satisfaction surveys. International Journal of Healthcare Quality Assurance 8(6):32-37.

Little, P., Everitt, H., Williamson, I., Warner, G., Moore, M., Gould, C., Ferrier, K., and Payne, S., 2001. Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. British Medical Journal. 323:908-911.

Lutz, B., and Bowers, B., 2000. Patient-Centred care: Understanding its interpretation and implementation in health care. Scholarly inquiry for nursing practice. 14(2), 165.

Macleod-Clarke, J., and Latter, S., 1990. Working Together. Nursing Times. 86(48):28-30

McCartan, D., McAleer, E., and Naqvi, I., 1996. Service Quality: a satisfaction survey of the elderly. International Journal of Healthcare Quality Assurance 9(3):4-10.

McColl, E., Jacoby, A., Thomas, L., Soutter, J., and Bamford, C., 2001. Design and use of questionnaires: a review of best practice applicable to surveys of health service staff and patients. Health Technology Assessment 5(31).

McGee, H., 1998. Patient Satisfaction Surveys: Are they useful as indicators of quality of care? Journal of Health Gain p5-7.

McIvor, S. and Carr-Hill, R., 1989. The NHS and its Customers - A survey of the current practices of customer relations, University of York: Centre of health Economics.

Meredith J and Wood, N., 1995. The development of the Royal College of Surgeons of England's patient satisfaction audit service. Journal Quality in Clinical Practice 15:67-74.

Meyer, J., 2000. Qualitative research in health care: Using qualitative methods in health related action research. British Medical Journal, 320:178-181

Morgan, D., Krueger, R. A., 1998. The Focus Group Kit. Sage Publications

National Expert Advisory Group on Safety and Quality in Australian Health Care, 1999. Implementing Safety and Quality Enhancement in Health Care; National Actions to Support Quality and Safety Improvement in Australian Health Care. AGPS, Canberra. Chapter five, p54

Nelson, R. O., 1977. Assessment and therapeutic functions of self-monitoring. In Progress in Behaviour Modification (Herson M., ed) Vol. 5. Academic Press, New York.

NHS Lambeth Primary Care Trust, 2004. Tool-Kit for involving patients and the public in Lambeth PCT.

NHS Lambeth Primary Care Trust.

NHS Wales, 2001. Improving health in Wales: a plan for the NHS with its partners. Cardiff: The National Assembly for Wales.

NHS Wales, 2001. Signposts – a practical guide to public and patient involvement in Wales. Cardiff: The National Assembly for Wales.

NHS Wales, 2003. Signposts Two – putting public and patient involvement into practice. Cardiff: The National Assembly for Wales.

Office of Health Management, 2002. Patient Satisfaction Surveys - Issues to Consider. Dublin: Office of Health Management.

Office of Health Management, 2002. Public & Patient Participation in Health Care: A Discussion paper for the Irish health Services. Dublin, Office of Health Management.

Organisation for Economic Cooperation and Development; International Adult Literacy Survey (IALS) 1997

Ong, L.M., de Haes, J.C., Hoos, A.M., and Lammes, F.B., 1995. Doctor-patients communication: a review of the literature. Soc Sci Med 40: 903-918

Ovretveit, J., 1993. Co-ordinating Community Care. Multidisciplinary Teams and Care Management. Buckingham, UK: Open University Press.

Øvretveit, J., 1998. Evaluating health interventions: an introduction to evaluation of health treatments, services policies and organisational interventions. Buckingham: Open University Press.

Ownes, D., and Batchelor, C., 1996. Patient Satisfaction and the Elderly. Soc. Sci.Med. 42(11):1483-1491.

Pascoe, G.C., 1983. Patient satisfaction in primary health care. Evaluation and Programme Planning 6:185-203.

Roberts, P., 1999. Testing user satisfaction tools. Nurse Researcher 6(3):67-75.

Scott, A., and Smith, R.D., 1994. Keeping the customer satisfied. International Journal for Quality Assurance in Healthcare 6(4):353-359.

Saltman, R. B., 1994. Patient choice and patient empowerment in Northern European health systems: a conceptual framework. International Journal of Health Services. 24(2):201-229.

Saunders, P., 1995. Encouraging patients to take part in their own care. Nursing Times. 91(9):43-43

Scottish Executive Health Department, 2000. Our National Health: A plan for action, a plan for change. Edinburgh: The Stationery Office.

Sherman, S., 1999. 18 Commandments of Customer Satisfaction Management. Anonymous Press, Ganey 10th Annual Client Conference, Nashville, Tennessee.

Sitzia, J., 1999. How valid and reliable are patient satisfaction data? An analysis of 195 studies. International Journal for Quality in Healthcare 11(4):319-328.

Sitzia, J., and Wood, N., 1997. Patient satisfaction: a review of issues and concepts. Soc. Sci.Med. 45(12):1829-1843.

Smith, R., 2002. The discomfort of patient power: medical authorities will have to learn to live with 'irrational' decisions by the public. British Medical Journal. 324:497-8.

Stuart, G., 1999. Government wants patient partnership to be integral part of NHS. British Medical Journal. 319: 788.

Thomas, S., 1996. On the Right Track. Health Service Journal. 31

Tower, B.A., 1999. Seeking the user perspective in palliative care. International Journal of Palliative Nursing. 5(5):240-243.

US Department of Health and Human Services, 2004. Making Health Communications Work. US Department of Health and Human Services.

Ware, J.E. and Hays, R.D., 1988. Methods for measuring patient satisfaction with specific medical encounters. Medical Care 26(4):393-402.

Webb, C., Addison, C., Holman, H., Sakdaki, B., and Wagner, A., 1990. Self medication for elderly patients. Nursing Times. 86(4):46-49.

Weiss, B., and Serf, J., 1990. Patient satisfaction survey instrument for use in healthcare organisations. Medical Care 28:434-445.

Williams, B., 1994. Patient satisfaction: a valid concept? Soc Sci Med 38(4):509-516.

Williams, S.J. and Calnan, M., 1991. Convergence and divergence: assessing criteria of consumer satisfaction across general practice, dental and hospital care settings. Soc. Sci.Med. 33(6):707-716.

Wilson, J., 1999. Acknowledging the expertise of patients and their organisations. British Medical Journal. 319:771-4.

Wilson, M.R., Runciman, W.B., Gibberd, R.W., Harrison, B.T., Newby, L., and Hamilton, J. D., 1995. The Quality in Australian Health Care Study. Medical Journal of Australia. 163, 458-471.

Wilson-Barnett, J., and Obourne, J., 1983. Studies evaluating patient teaching. Implications for practice. International Journal of Nursing Studies. 20(1): 33-34

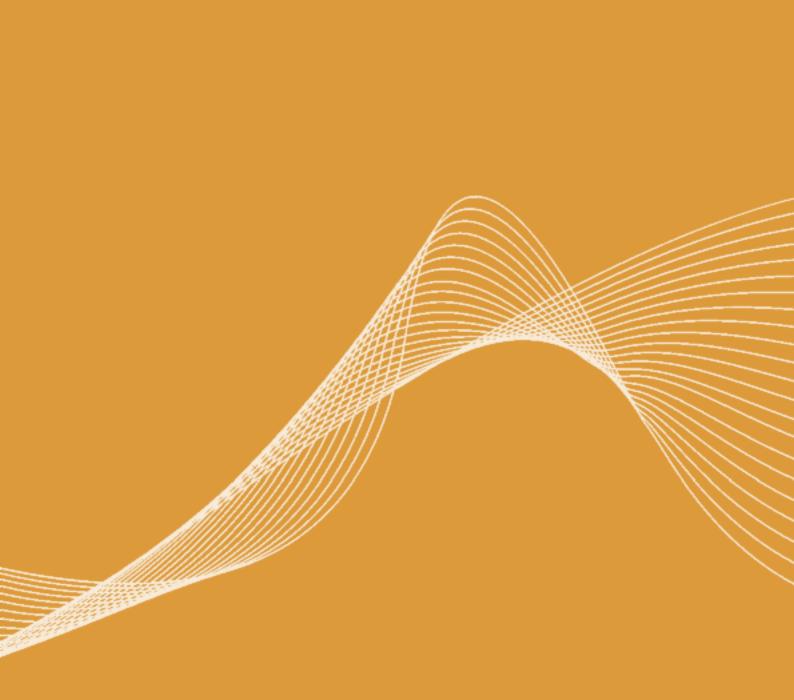
World Health Organisation, 1998. Health21: the health for all policy framework for the WHO European Region. European Health for all series, no. 6.

World Health Organisation, 1978. Declaration of Alma-Ata. World Health Organisation.

Young-Mahon, P., 1996. An analysis of the concept 'patient satisfaction' as it relates to contemporary nursing care. Journal of Advanced Nursing 24:1241-1248.

Appendix 2 – WORKPLAN

| Year 1 | Deliverables | Outcomes | Initiative Lead |
|---------|-----------------------------------|---|--|
| Level 1 | Printed Media | The Group booklets and information leaflets shall provide the patients with information on the services available within the organisation. The printed information shall be easy to read and allows the user to take their time in reviewing the information provided. | Patient advise and liaison Coordinator (PALS) |
| Level 1 | Website | The Group website shall provide information about the services available. The website shall be easy to read and easy to navigate. The website will provide patient feedback mechanisms for patient input. | Maurice Power Chair of ICT |
| Level 2 | Feedback and Complaint Systems | The Feedback and Complaint Management System shall provide a structured input mechanism for patients and public Feedback and Complaint System shall improve service quality which in turn leads to a positive image with service users. Feedback and Complaint System will provide a friendly approach to resolving complaints. | Pat Nash Group Clinical Director |
| Level 2 | Comment Cards | The Comment Cards shall enable patients to input their views on the services provided. The questions shall be simple, clear and few in number. | Colette Cowan Group Director of Nursing |
| Level 2 | Surveys | Surveys shall be administered by a face- to-face or telephone interview, mail or provided online via the web. Questions will focus on patient's actual experience or on their evaluation of results. The survey carried out will provide a true measure of patient satisfaction. | Colette Cowan Group Director of Nursing |
| Level 3 | One to One Interaction | • One to One Interaction will provide information about patient problems and the outcome, side effects of treatment and advice. | Colette Cowan Group Director of Nursing |



| Year 1 | Deliverables | Outcomes | Initiative Lead |
|---------|---------------------------------------|--|--|
| | | The One to One Interaction patient involvement process will greatly influence compliance, patient education and health outcomes. Patients shall be offered support to take part in decision making and raise questions about quality. | |
| Level 3 | Patient Advice and Liaison Service | The PALS shall provide general information to patients, their carers and families and will help them resolve problems and concerns quickly. The PALS shall help ensure that the patient's voice is heard. | PALS coordinator |
| Level 3 | Patient Commitment Statements | Patient Commitment Statements will empower patients by making them aware of their entitlements as individuals and consumers. Patient Commitment Statements identify the patients and publics responsibilities. | Bill Maher CEO |
| Level 3 | Patient Councils | Patient Councils will consist of patients who advise the organisation service development and patient care. Patient Councils shall work closely with the Group and staff to improve services for the patients. | Colette Cowan Group Director of Nursing & Non executive Board member |

| Year 2 | Deliverables | Outcomes | Initiative Lead |
|---------|-----------------------------|---|----------------------------|
| Level 1 | Audio/ Visual Multimedia | The CD's, audio downloads, DVD's, web, interactive kiosks shall provide users with easy accessible information on the services provided by the Group The information shall be reliable, accurate, easy to understand | Maurice Power ICT Chair |
| Level 2 | Telephone Hotline | The Telephone Hotline will allow patients to provide feedback on aspects of the service. The Hotline shall be easily accessible- free phone number. Telephone Hotline will provide a clear procedure for complaint calls. | Maurice Power ICT Chair |

| Year 2 | Deliverables | Outcomes | Initiative Lead |
|---------|--------------|---|-----------------------------|
| Level 3 | Focus Groups | The Focus Groups shall engage with patients and the public to listen and learn from them. Participants can state their views and explain the reason why. | Colette Cowan Group DONM |

| Year 3 | Deliverables | Outcomes | Initiative Lead |
|---------|-------------------------|---|--|
| Level 1 | Promotions Campaigns | The Promotions Campaigns shall highlight particular health issues through advertising in the media, distribution of pamphlets, appearances on radio, talks The Promotions Campaigns shall attempt to inform, persuade or motivate behaviour change of the public or patients. | Tony Canavan Chief Operations Officer |
| Level 2 | Patient Shadowing | Patient Shadowing will monitor and measure performances of the service provided, as well as identify training needs. Patient Shadowing will oversee specific points mentioned by patients and staff. | Colette Cowan Group Director of Nursing |
| Level 2 | Patient Diaries | Patients Diaries shall record the patient's event and personal thoughts. Patient Diaries will instil a sense of being listened to and their views acknowledged. | Colette Cowan Group Director of Nursing & Non executive Board member |
| Level 4 | Expert Patient | The Expert Patient will share their experience of a condition or illness to convey knowledge about living with it to others. Patients shall 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. | Board through GDoNM Colette Cowan Group Director of Nursing |

| Year 3 | Deliverables | Outcomes | Initiative Lead |
|---------|--------------------------------------|---|---|
| Level 4 | Patient and Public Representation | Patient and Public Representatives shall act as representative of a larger group of services users. The use of Representatives on committees will show commitment to partnering with patients to help develop a more patient centred process. | PALS coordinator |
| Level 4 | Community Forums | The Community Forums shall be used to hear the experiences and ideas of the community. The Community Forums shall be easy for service users to attend. The Community Forums shall provide information, the opportunity to ask questions and the opportunity to participate in the development of further ideas or action plans. | Colette Cowan Group Director of Nursing |
| Level 4 | Community Partnerships | The Community Partnerships will involve the coming together of various community groups and the Group to implement or develop a specific initiative. The Community Partnerships will combine resources to help tackle specific problems | Bill Maher CEO |

































Strategic Plan for Public and Patient Involvement 2013-2015