

Achieving excellence in clinical governance

Service User Involvement

your service
your say

CONTENTS	PAGE
FOREWORD	3
DEFINITIONS OF KEY TERMS AND ABBREVIATIONS	4
PURPOSE OF THE GUIDANCE DOCUMENT	5
2.1 Scope of the document	
2.2 Relationship with other Codes and documents	
2.3 Frequency of revision	
2.4 Working group members	
APPLYING THE GUIDANCE DOCUMENT	7
SERVICE USER INVOLVEMENT	10
4.1 Service user involvement	
4.2 Why involve?	
4.3 How to involve?	
4.4 Types of involvement	
4.5 Principles for involvement	
SERVICE USER FOCUSED INTERVENTIONS	16
ACCOUNTABILITY	21
REFERENCES	22
APPENDICES	
Appendix 1 Producing Effective Service User Health Information	24
Appendix 2 Useful Web-links and Resources	25
Appendix 3 HSE, Office of Consumer Affairs, Publications	27
FIGURES	
Figure 1 Framework for Integrated Quality, Safety & Risk Management	
Figure 2 Continuous Quality Improvement Cycle	
Figure 3 Arstein’s Ladder of Participation	
Figure 4 Using the evidence in your organisation to improve the safety and quality of healthcare services	
Figure 5 Service User Focused Interventions	

FOREWORD

Placing service users at the centre of health and social care delivery is one of the key objectives of the Irish Health Strategy, 'Quality and Fairness; a Health System for You' (HSE 2001).

To achieve this objective, the following seven goals have been outlined in the 'National Strategy for Service User Involvement in the Irish Health Services'

1. Commitment and leadership
2. A systematic approach to effective service user involvement
3. Patient involvement in their own care
4. National guidelines
5. Specific work to ensure the involvement of children, young people and socially excluded groups
6. Develop existing service user structures
7. Performance and development (DoHC & HSE 2008).

Within each goal there are a number of actions which will be delivered upon within the given timeframe of one to five years (2008-2013).

Healthcare organisations are responsible and accountable for delivering safe, high quality, cost-effective care that achieves the best possible health outcomes for people in Ireland. To this end, the HSE has embraced the concept of 'clinical governance' which is operationalised through its 'Framework for Integrated Quality, Safety and Risk Management' (HSE 2009a). The Framework requires healthcare organisations, amongst other things, **to involve patients/service users and the public/communities in the planning, development, delivery and evaluation of healthcare services.**

This document supports the Framework and the National Strategy by providing healthcare organisations with further guidance on patient/service user and public/community involvement.

We look forward to working with you in continually improving and ensuring that high quality healthcare is accessible to the people of Ireland.

Mary Culliton,
Director of Advocacy, HSE

Dr Joe Devlin
Quality and Clinical Care Directorate, HSE

February 2010

DEFINITIONS OF KEY TERMS AND ABBREVIATIONS

Service user

The term 'service user' is used to include:

- People who use health and social care services as patients
- Carers, parents and guardians
- Organisations and communities that represent the interests of people who use health and social care services
- Members of the public and communities who are potential users of health services and social care interventions.

The term service user also takes account of the rich diversity of people in our society whether defined by age, colour, race, ethnicity or nationality, religion, disability, gender or sexual orientation, and may have different needs and concerns' (DoHC & HSE 2008, p.6).

Involvement

The term 'involvement' is used to mean:

'A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change...' (DoHC & HSE p.6).

Framework

The 'Framework for Integrated Quality, Safety and Risk Management' (HSE 2009a) comprises thirteen core elements, each with its own supporting principles or requirements, which healthcare organisations must have in place in order to achieve excellence in clinical governance. The Framework requires healthcare organisations to involve service users in the planning, development, delivery and evaluation of healthcare services.

Abbreviations

DoHC	Department of Health and Children
HSE	Health Service Executive
PCT	Primary Care Teams
QCCD	Quality & Clinical Care Directorate
QIPs	Quality Improvement Plans

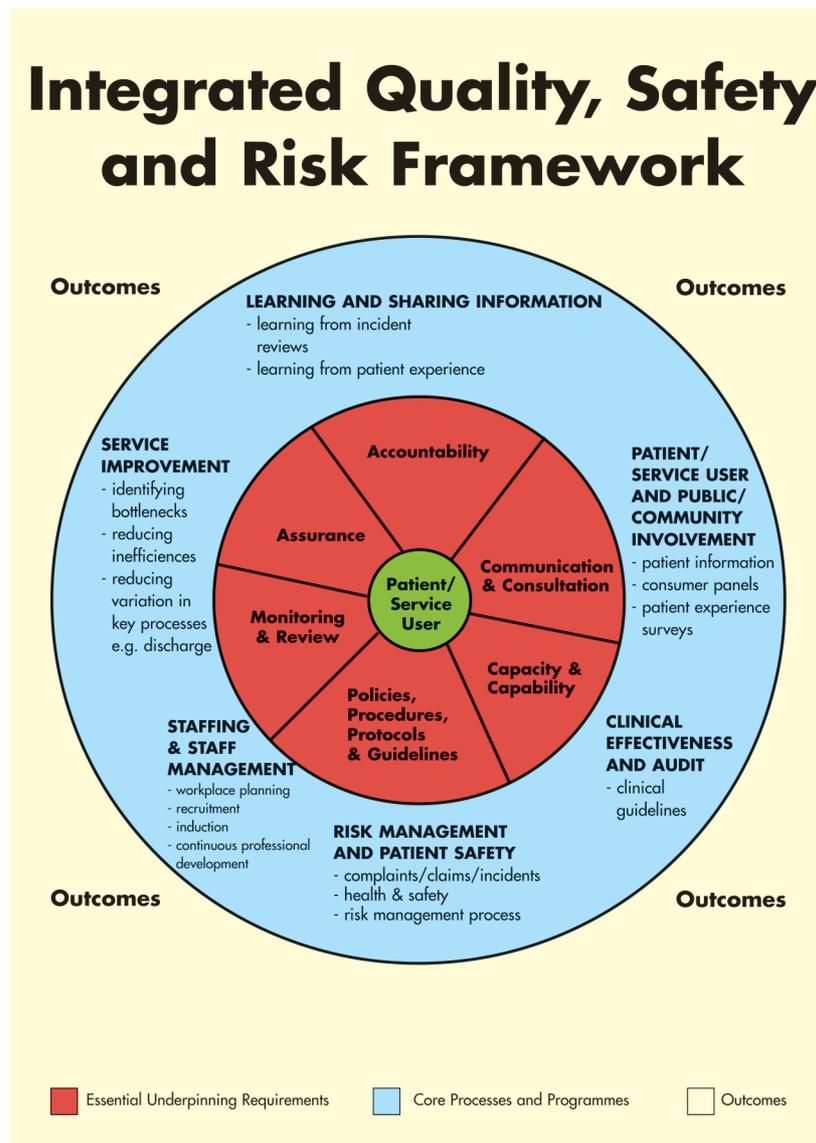
PURPOSE OF THE GUIDANCE DOCUMENT

The 'Framework for Integrated Quality, Safety and Risk Management' (HSE 2009a) comprises thirteen core elements, each with its own supporting principles or requirements, which healthcare organisations must have in place in order to achieve excellence in clinical governance. This document is one of a series of guidance documents for HSE funded service providers which will cover the various elements of the Framework.

This particular document has been drafted as a guide to help those concerned with the element of **patient/service users and public/community involvement to:**

- Understand and apply the principles of service user involvement
- Assess the strengths of current service user involvement arrangements in their own organisation
- Improve current arrangements where necessary.

Figure 1: Framework for Integrated Quality, Safety and Risk Management



2.1 Scope of the document

The document is intended for use by all organisations that provide healthcare services using public funds. This includes acute and continuing care services, primary care, community care and voluntary providers. Non-public sector organisations also use public funds to provide healthcare services and this document is designed to help them too.

2.2 Relationship with other Codes and guidance documents

This document was produced by Quality and Clinical Care Directorate. It provides advice, information and practical examples to help healthcare professionals engage service users in the design, development and delivery of healthcare services.

It aims to complement, rather than duplicate, the extensive Codes, guidance and documents that already exist in the HSE and in other organisations in relation to the involvement of service users in healthcare services. The document therefore includes links to other documents and websites where readers can find more information.

Where Codes and guidance do not exist, we hope that this document will provide a shared understanding of service user involvement for healthcare services.

2.3 Frequency of Revision

This guidance document will be reviewed in 2011.

2.4 Working Group Members

Ms. June Boulger, Advocacy Services, HSE

Dr Paul Kavanagh, Quality & Clinical Care Directorate, HSE

Dr. Philip Crowley, Deputy Chief Medical Officer, DoHC

Ms. Mary Culliton, Director of Advocacy, HSE

Ms Rachel McEvoy, Advocacy Services, HSE

Ms. Winifred Ryan, Quality & Clinical Care Directorate, HSE

APPLYING THE GUIDANCE DOCUMENT

The principles of service user involvement as outlined in the Draft National Guidelines - “What Service Users can expect of the HSE and what the HSE can expect from Service Users”, 2009 form part of the service user involvement element of the ‘Framework for Integrated Quality, Safety and Risk Management’ (HSE 2009a). Different healthcare organisations have different requirements and therefore will use different methods for implementing the Framework and National Strategy for Service User Involvement.

Whilst recognising and acknowledging such differences, the HSE expects healthcare organisations to show how they are putting these principles into practice in a way that reflects their requirements. The guidance can be implemented through the following five steps:

1. Establish the current position
2. Identify areas for improvement
3. Develop plans for continuous quality improvement
4. Implement
5. Evaluate

1. Establish the current position (See section four, page 10)

Healthcare organisations are required on an annual basis to **self-assess** against the thirteen elements of the Framework. The self-assessment results will help organisations to identify their current position with regard to service user involvement and will indicate examples of good practice where lessons can be learnt, and areas of concern where improvements can be made. Healthcare organisations can **gather service user feedback** in a variety of ways including service user surveys, comments and complaints (i.e. ‘Your Service, Your Say’: The HSE Complaints Process) service user panels, advocates and other methods such as focus groups. In addition, reliable **evidence can be gathered** using a range of techniques, including framework self-assessment and review of incidents. Examining self-assessment results, feedback and evidence will give a direct insight into what is working well – and not so well – in the way your organisation delivers care.

2. Identify areas for improvement

Careful examination of self-assessment results, patient feedback and evidence will highlight the areas that need improvement to provide a better service for service users, and supply the evidence for change. Key to success is the involvement of staff and service users in identifying areas for improvement and developing quality improvement plans. It is important to prioritise areas for improvement. It is better not to tackle everything at once, but stick to a few main priorities for action. Choose areas that show clear potential for improvement. If plans are too ambitious they may fail so it is important to be realistic and choose approaches that are likely to succeed. Small successes will help to keep the momentum going and encourage continuous improvement.

3. Develop plans for continuous quality improvement (see Sections four and five, pages 10 to 21)

Review the areas for improvement and **agree the priorities** for your organisation for the current year. Consider the **appropriate interventions** to encourage continuous improvement. Service user focused interventions are generally grouped across 3 levels - individual care and patient/department/ward level and healthcare organisation. Write your **quality improvement plans** to include the 3 levels. Divide your quality improvement plans into manageable **actions** and achievable targets. Identify **responsible persons** and **reasonable timescales** for completing each of the actions along with details of how and when **progress** will be measured and reported.

4. Implement (see Sections four and five, pages 10 to 21)

Each healthcare organisation must implement the service user focused interventions identified in their quality improvement plans. Priority actions for service user involvement will also be identified by the Quality and Clinical Care Directorate on an annual basis for healthcare organisations to implement.

5. Evaluate

To identify if the priority actions are being implemented, an evaluation and monitoring process is required. This includes incorporating the 'Continuous Quality Improvement Cycle' outlined in Figure 2 (HSE 2009a). The Cycle is a four-step model for carrying out change and just as a circle has no end, the Cycle should be repeated again and again for continuous improvement. Evaluations should reflect the priority actions and the continuous quality improvement cycle described in Figure 2.

Progress against deadlines and milestones should be monitored on a regular basis. Meetings should be arranged to update everyone and assess how effective the changes are. This will help to maintain enthusiasm and interest. You need to know when you have achieved your objectives. Build mechanisms into your plan that will enable you to evaluate the impact of changes you make. Gathering further feedback will enable you to assess the impact of your work.

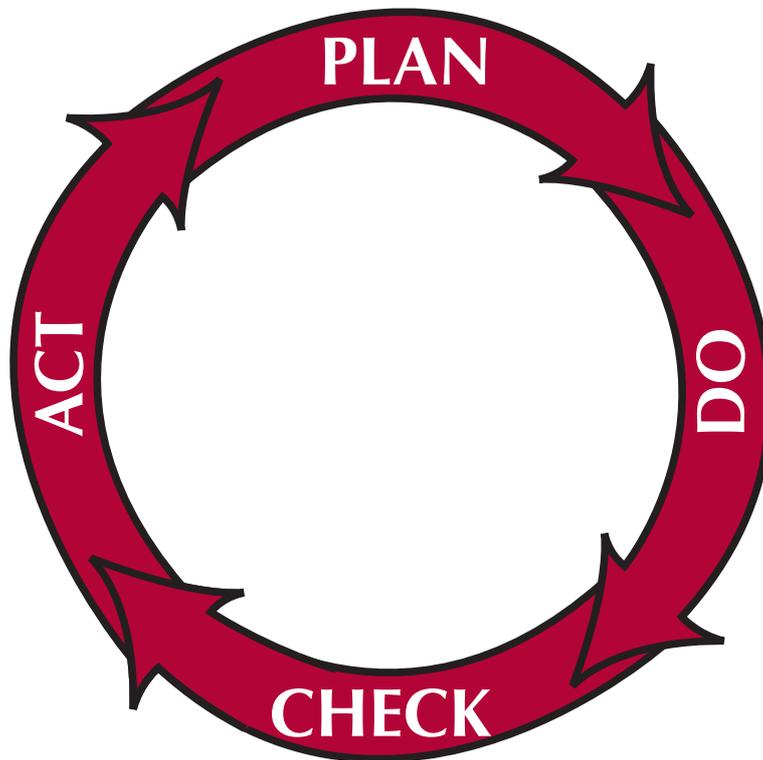


Figure 2: Continuous Quality Improvement Cycle

i. When to use the Continuous Quality Improvement Cycle

- As a model for continuous improvement
- When starting a new improvement project
- When developing a new or improved design of a process, product or service
- When defining a repetitive work process
- When planning data collection and analysis in order to verify and prioritise problems or root causes
- When implementing any change
- The service user should be involved at all stages of the cycle.

ii. Procedure

1. **Plan.** Recognise an opportunity and plan a change
2. **Do.** Test the change. Carry out a small-scale study
3. **Check.** Analyse the results and identify what you have learned
4. **Act.** Take action based on what you learned in the check step: If the change did not work, go through the cycle again with a different plan. If you were successful, incorporate what you learned from the test into wider changes. Use what you learned to plan new improvements, beginning the cycle again (ASQ Quality Tools 2010).

SERVICE USER INVOLVEMENT

4.1 Service user involvement

Engagement, consultation and participation are all words that can be used to describe different types of involvement activity. Involvement occurs when service users are meaningfully involved in decision making regarding their health and social care and treatment and in the planning and delivery of healthcare services.

4.2 Why involve?

There are a range of benefits from involvement at both an individual, organisational and community level. These include better health and treatment outcomes, more appropriate and relevant services, increased legitimacy and credibility of decision-making, increased sense of dignity and self-worth and improved service user satisfaction (McEvoy, Keenaghan & Murray 2008).

Involvement should be undertaken to discuss with service users:

- their ideas
- their experiences
- their health and social care treatment plans
- why services need to change
- what they want from health and social services.

Involvement practice needs to consider the diversity of people within Ireland today, such as:

- Children and young people
- Women and men
- People living with a disability
- Different sexual orientations
- Culturally and linguistically diverse communities
- Different socio-economic status
- Diverse health and illness conditions
- Travellers
- Different social circumstances.

Some of these people do not live in groups or communities and thus are harder to reach, easy to overlook and may require more time, money and effort to involve. Use feedback received from service users to inform / capture all perspectives of your service. Local community groups have a wide breadth of knowledge and many community groups will be skilled in various consultation techniques as will many social inclusion, community development workers and health promotion staff in the HSE.

4.3 How to involve?

Service Users do not necessarily want to be engaged extensively over every healthcare issue. Instead they want to be engaged appropriately; hence different types of involvement are appropriate at different times. There are many different ways of listening to people and involving them. Arstein's model of participation for example is one of several that identifies the spectrum of involvement from 'power-holders' to the people or communities (See Figure 3). These models suggest that more genuine involvement occurs at the higher levels (levels 6 to 8) of the ladder of participation.

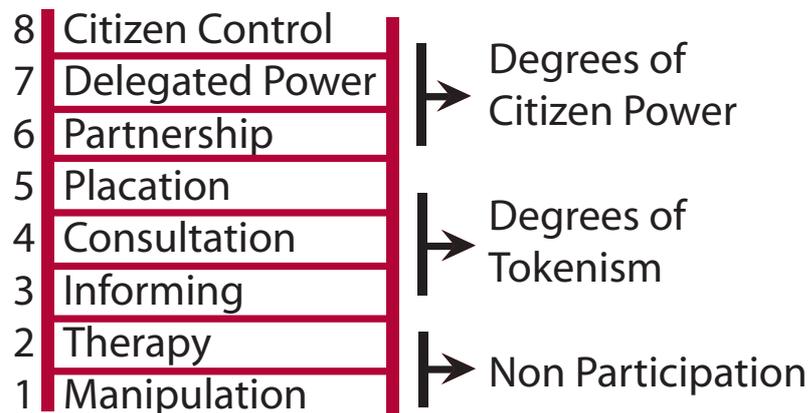


Figure 3: Arstein's Ladder of Participation (1969).

Drawing on Arstein's approach, the methods of service user involvement have been commonly grouped under the following 5 headings:

1 Information

- To support involvement
- To convey facts
- To educate

2. Consultation

To gauge reaction to a proposal or plan and invite feedback. Feedback must influence meetings subsequent policy, care and treatment choices.

3. Partnership

To work directly with the service user to ensure that service user concerns and aspirations are understood and considered in decision making around healthcare service planning, configuration and delivery.

4. Delegation

To hand control to the service user in each aspect of the decision, including the development of alternatives and the identification of the preferred solution.

5. Control

To place final decision-making the hands of the service user.

No one method of involvement is better than another. Each method of involvement will have its own strengths and weaknesses. **It is important to understand the type of service user involvement that you require and select the right method for the particular purpose and context in question.** Avoid choosing one method as a favourite and using it all the time. To explore each method in greater detail is beyond the scope of this document however, for further information on service user involvement visit (<http://www.peopleandparticipation.net/display/Methods/browse+methods>).

4.4 Principles for involvement:

Guiding the way in which the HSE, patients, service users, the public and community work together to make involvement successful are nine principles for service user involvement.

1. **Access:** Equity of access to public healthcare
2. **Respect:** Respect, dignity and consideration
3. **Safety:** Promoting safe and competent care
4. **Communication:** Communicating clearly throughout the period of care
5. **Information:** Being informed about services, treatment and care
6. **Participation:** Informed decision making and informed choices
7. **Privacy:** Ensuring personal information is secure
8. **Redress:** Commenting on care and having concerns addressed
9. **Prevention:** Provision of information and services to protect health.

The principles apply wherever and whenever care is provided. They recognise the important role that families and communities play in receiving and delivering care, and that entitlements and expectations also apply to families, carers and other nominated support people where appropriate. (Draft National Guidelines - "What Service Users can expect of the HSE and what the HSE can expect from Service Users", 2009).

4.5 Using the evidence in your organisation to improve the safety and quality of healthcare services

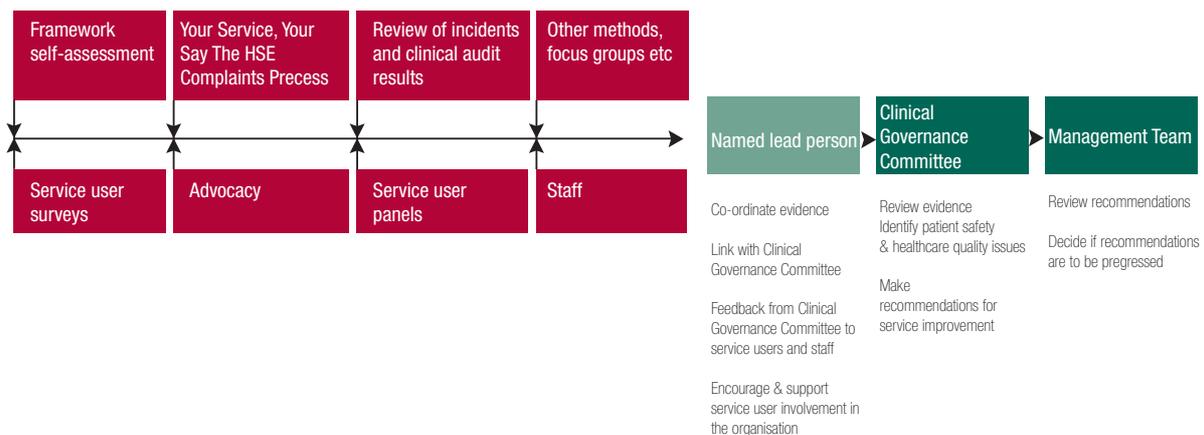


Figure 4: Using the evidence in your organisation to improve the quality and safety of healthcare services

Framework self-assessment

Self assessment is a process whereby the healthcare organisation measures its conformance against the requirements for service user involvement as outlined in the Framework for Integrated Quality, Safety and Risk management. An electronic self-assessment tool is available that allows service providers to 'score' themselves in relation to the following check questions.

- Is patient/service user and public feedback, including feedback on actual patient experience, regularly sought and integrated into quality, safety and risk management improvement activities?
- Is sufficient information and opportunity provided for patients/service users to meaningfully participate in their own care?
- Are patients/service users and the public involved in the development of patient information?
- Are arrangements in place to train and support patients/service users, staff and the public involved in the patient and public involvement process?
- Are patients/service users and the public invited to assist in planning new services?

On completion of the self assessment process, where improvements are required, these areas for improvement should be reported to the named lead person in the organisation.

Your Service, Your Say – The HSE Complaints Process

There is a feedback policy in place in all HSE services. The policy is provided for in law under the Health Act 2007 (Part 9). It ensures that everyone has a right to make comments about the services they have received. The legislation also requires the healthcare services to ensure that people are made aware of this right by adequately publicising the policy.

Any comment, compliment or complaint is an opportunity to improve the quality of our services and to learn lessons from any mistakes made. Sometimes an adverse event is reported by a service user as a complaint.

Each healthcare organisation has literature (soon to be updated when out of stock) all of which should be on display and easily accessible in all public areas.

- Guide to the HSE Feedback Policy
- Leaflets
- Posters

The promotion and accessibility of this literature gives the message that this is an organisation which wants to hear from the people who use its services

The complaints officer will ensure that all comments, compliments and complaints are collected, collated and reported to the named lead person in the organisation. He /she will also ensure that feedback is given to service users on quality improvements which have been put in place as a result of service user feedback.

Review of incidents and clinical audit results

Recording, analysing and learning from all types of incidents and claims are key components of a successful 'reactive' approach to improving quality and safety of services. All incidents and claims should be properly recorded, reported to the named lead person in the organisation and subjected to periodic aggregate reviews to identify trends and further opportunities for learning, risk reduction and quality improvement.

A structured programme, or programmes, should be in place to systematically monitor and improve the quality of clinical care provided across all services. This should include, systems to monitor clinical effectiveness activity (including clinical audit); mechanisms to assess and implement relevant clinical guidelines; systems to disseminate relevant information; and use of supporting information systems. Results from clinical audit activity that may have implications for service user safety and healthcare quality should be reported to the named lead person in the organisation.

Service user experience surveys

Service user experience surveys are the best method of gathering feedback when you want to know the views of a large number of people. They allow you to study patterns and trends and to see how common certain experiences are. They show if a problem is occurring more or less frequently over time and the types of people who seem most likely to experience it. Questions should be developed with patients before they are used to ensure they are appropriate. Surveys can be carried out by post, telephone, online or electronically with hand-held and other devices. The results of these surveys should be reported to the named lead person in the organisation.

Advocacy

A service user advocate acts as a liaison between the service user and the healthcare provider to help improve or maintain a high quality of healthcare. The advocate may be an individual (the service user, carer, friend, family member or a healthcare professional) or an organisation. There are 4 levels of advocacy:

1. **Individual:** service users own efforts to educate and orientate themselves and other efforts that seek to bolster service users' knowledge and confidence so that they can more fully participate in their own care.
2. **Interpersonal:** advice giving, emotional support and the provision of resources and other help. The most relevant interpersonal relationships may be those between service users and their family members and friends and between their healthcare providers and their family members and friends.
3. **Organisational:** Organisations include hospitals, local health offices, professional associations, medical and other health science schools, etc. Staff develop and implement models of service user centred care that engage service users by increasing the accessibility of medical information, improving the navigability and appearance of healthcare buildings, etc
4. **Policy:** service user advocates work to influence policy making through activism, ombuds programs and political lobbying so that lay people have a voice in a healthcare system otherwise dominated by the beliefs and practices of health professionals and business interests.

Mechanisms should be in place to ensure, where appropriate that this feedback is reported to the named lead person in the organisation.

Service user panels

Recruiting a panel of people from the local community provides a sounding board for new ideas and an opportunity to debate and test opinion on an ongoing basis. Views can be sought using online, postal or face-to-face methods. Feedback from service user panels should be reported to the named lead person in the organisation.

Staff

Staff who work directly with service users will also receive feedback from service users can also offer a useful perspective. Mechanisms should be in place to ensure, where appropriate that this feedback is reported to the named lead person in the organisation.

Other methods (focus groups, etc)

Service user feedback consists of the views and opinions of service users on the care they have experienced. Healthcare organisations can gather patient feedback in a variety of ways including focus groups, public consultation, etc. It is important to select the most appropriate method for your task.

SERVICE USER FOCUSED INTERVENTIONS

Service user focused interventions aim to promote active involvement of service users at all levels of the health care system and improve the quality of healthcare services.

Individuals or family members/carers can play a central role in their own care by:

- diagnosing and treating minor, self-limiting conditions
- preventing occurrence or recurrence of disease or harm
- selecting the most appropriate form of treatment in partnership with healthcare professionals for more serious illness
- actively managing long term conditions.

Service user focused interventions are generally aimed at one or more of the following quality improvement goals (see figure 5, page 20):

- Health literacy
- Shared decision-making
- Self-care
- Safety
- Access
- Care experience
- Service development

These interventions have been grouped across three levels

1. Individual care level
2. Programme/department/ward level
3. Healthcare organisation level

The 'Application' section in each level explains what should be done to put it into practice. Good practice examples in relation to each level are also outlined.

1. Individual care level

Description

This level is about the service user and, if appropriate, their carer(s), being actively involved in their own care and treatment.

This level maps to:

National Strategy

Goal 3:

Patient involvement in their own care

Goal 4:

Patients charter/national guidelines

Goal 5:

Specific work to ensure the involvement of children, young people and socially excluded groups

Framework

Questions 2 and 3

Application (see performance targets for service user involvement for the current year)

Health literacy

1. Clear and respectful communication with service users
2. Service users involved in the development of service user information
3. Accessible information to service users about health and social care and treatment

Shared decision making

4. Listen and act on the decisions the service user and, where appropriate, their carer(s) make about their care and treatment

Self-care

5. Encourage and support service users to look after themselves safely and confidently to live as normally as possible.

Access

6. Promote the rights, entitlements, expectations and health responsibilities of service users to the community, service users and carers.

Note: See sample service user focused interventions - Figure 4, page 20

Good Practice Examples

- Appropriate, timely, relevant, personalised and accessible information for the service user
- Written information works best when service users are involved in its preparation and when used as an adjunct to professional consultation and advice
- Interactive TV, audiotape and web based information work can improve service users confidence and involvement, leading to better clinical outcomes and health behaviours
- Communication skills training for healthcare professionals can lead to improvements in knowledge, involvement and adherence to treatment choices
- Coaching and question prompts for service users. Encouraging service users to ask questions can help to improve their knowledge and recall of information
- Self-management education programmes for specific diseases which are well-designed, intensive and reinforced in regular consultations with healthcare professionals
- Self-help groups help service users cope with the effects of disease, giving them a better sense of social support
- Telephone support can reduce social isolation and improve service users confidence
- Walk-in centres
- 24 hour advice and information phone service
- Telephone reminders and telephone consultations are popular; effective and safe.
- Service user access to their healthcare records enables them to find and correct mistakes, reducing the risks caused by inaccurate records.

2. Programme/Department/Ward Level

Description

This level is about staff working in healthcare organisations developing and providing information, care and treatment with service users at programme/department and/or ward level.

This level maps to:

National Strategy

Goal 2:

A systematic approach to service user involvement

Goal 6:

Develop existing service user structures

Framework

Questions 1, 4 and 5

Application *(see performance targets for service user involvement for the current year)*

Shared Decision making

1. Provide training to staff in communication skills and how to involve service users and carers in decision making.

Safety

2. Involve service users in service user safety initiatives

Access

3. Create welcoming and accessible services for the diverse members of your community.

Care experience

4. Promote the importance of service users and carers providing feedback to improve services.

Service Development

5. Establish links with community organisations to provide emotional support and ongoing information to service users and carers.
6. Involve service users, carers and community members in the development of clinical guidelines and research.

Note: See sample service user focused interventions - Figure 4, page 20

Good Practice Examples

- Service user involvement in infection campaigns
- Simplifying dosing regimes
- More user-friendly information about medicines
- Service users reporting adverse drug side effects to drug safety agencies
- Complaints, choice and service user feedback together make a considerable volume of 'service user' focused information available to service providers

3. Healthcare Organisation Level

Description

This level targets the organisational decision makers in healthcare organisations. It focuses on how involvement can be promoted and increased at the organisational level at each health care service. As outlined in the National Strategy for Service User Involvement. "Commitment of management at all levels is essential to ensure leadership and delivery on this strategy" (2008. p 11).

This level maps to:

National Strategy

Goal 1:

Commitment and leadership

Goal 7:

Performance and development

Framework

Questions 1, 4 and 5

Application *(see performance targets for service user involvement for the current year)*

Shared decision making

1. Provide staff training and education on how to use the different types of involvement
2. Ensure that job descriptions include service user involvement as an integral component of all work

Care experience

3. Evaluate, monitor and report on results of involvement to service users and communities
4. Support service users to work in partnership with health and social care services

Service development

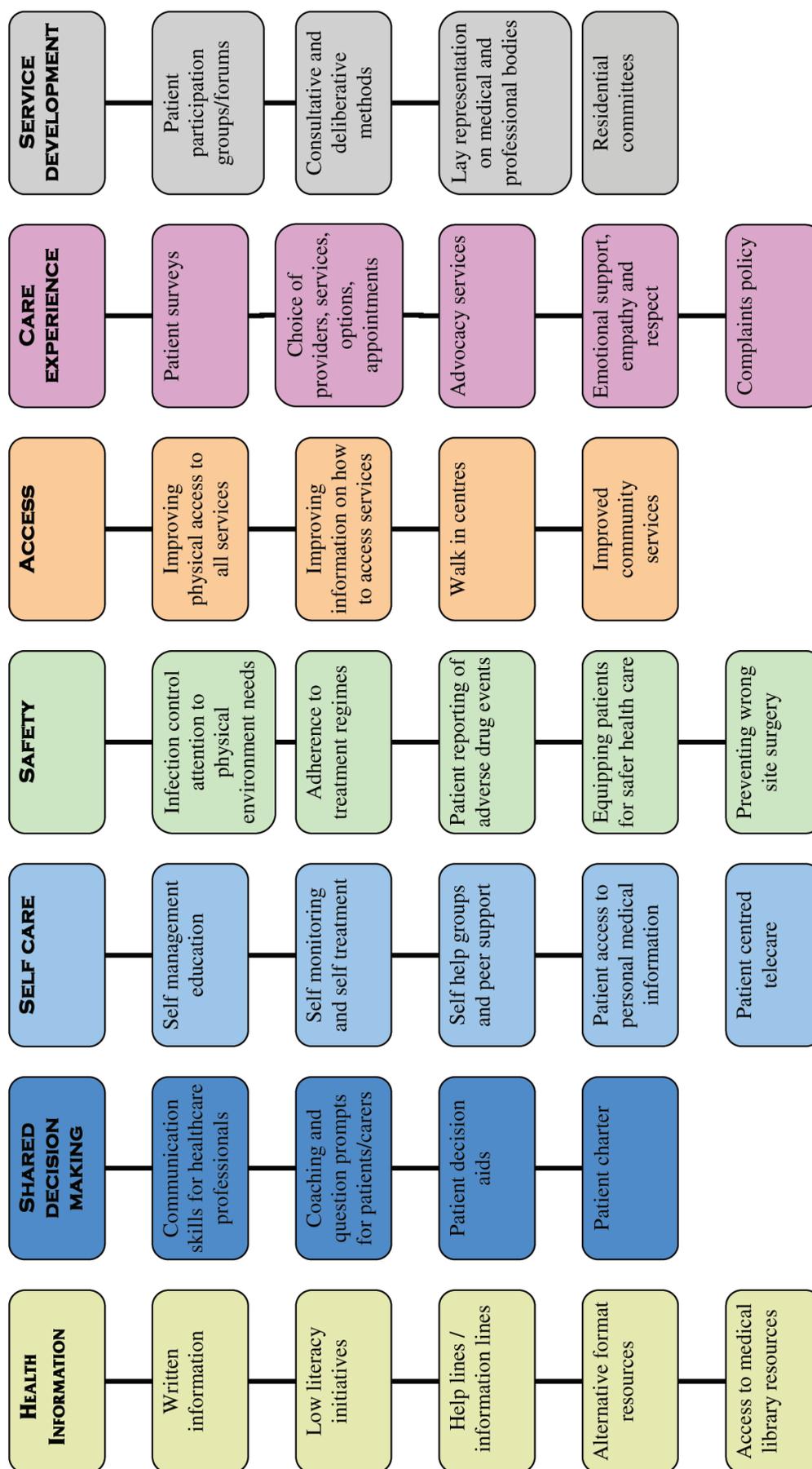
5. Ensure service users are involved in the organisations clinical governance structure at all appropriate levels.
6. Ensure service users are involved in the review of system level issues regarding service user and carer feedback and complaints
7. Ensure service users are involved in all aspects of the organisation's planning and development through to evaluation and monitoring.

Note: See sample service user focused interventions - Figure 4, page 20

Good Practice Examples

- Service user experience surveys - can be used to prompt service improvement and measure its progress over time
- National surveys results can trigger national action. Surveys can benchmark progress against national policies or targets
- Advocacy services are proven to help marginalised groups
- Promotion of patient feedback through 'Your Service, Your Say'
- Making healthcare organisation performance data publicly available can encourage healthcare providers to implement quality improvements
- Community advisory committees can be an effective method of involvement – gives the public a clear role, time and support to make considered decisions. These decisions must have a clear impact on services.

Figure 5: Service User Focused Interventions (Coulter & Ellins 2006)



ACCOUNTABILITY

Structures and processes should be in place to ensure that senior staff who are responsible for managing the organisation are made aware of feedback from service user involvement activities. The healthcare organisation should respond to and learn from all forms of service user involvement on an ongoing basis. The results of this involvement should be used to improve the manner in which services are planned, configured and delivered. This should include the following:

A **named lead person** in the organisation who will liaise with service users and work with staff in the organisation to co-ordinate service user involvement activities and feedback. This person should work at a high level and be in a position to influence management and clinical leaders in the organisation. The feedback and evidence from service user involvement activities should be channelled to the management team through the named lead person and the clinical governance committee (see Figure 4, page 13).

The **clinical governance committee** is responsible for agreeing and recommending a strategic approach to clinical governance whilst ensuring that high quality systems and safe services are in place for the benefit of service users, staff and visitors. This committee is chaired by the clinical director who is a member of the management team. The committee will also have links to the national director of quality and clinical care and the risk committee of the HSE Board. A minimum of **two service user representatives** should sit on the clinical governance committee.

The clinical governance committee on behalf of the management team should develop and monitor implementation of a clear policy on the following on an ongoing basis.

- The types of issues on which the organisation will consult or engage with service users
- How the organisation will use this input in decision making (the input must have a real impact and service users must be made aware of how their ideas and involvement have influenced healthcare services)
- How it will feed these decisions back to service users
- How the organisation will ensure that it hears the views and experiences of people of all backgrounds.

Each year, the **management team** should publish information about the organisation's outcomes, achievements and the satisfaction of service users in the previous period.

REFERENCES

ASQ Quality Tools 2010. Project Planning and Implementation Tools. Retrieved from the World Wide Web: <http://www.asq.org/learn-about-quality/project-planning-tools/overview/pdca-cycle.html>

Appraisal of Guidelines Research and Evaluation (2009). As cited in HSE Quality Systems, Policies, Procedures & Guidelines (2010)
[http://hsenet.hse.ie/Hospital_Staff_Hub/mullingar/Policies - Procedures and Guidelines.html](http://hsenet.hse.ie/Hospital_Staff_Hub/mullingar/Policies_-_Procedures_and_Guidelines.html)

Arnstein, A. (1969). A Ladder of Citizen Participation, *Journal of the American Institute of Planners*, Vol. 35, No. 4, July 1969.

Bishops, P. and Davis, G. (2002), Mapping public participation in policy choices, *Australian Journal of Public Administration*, 61(1) pp 14-29, as quoted in Brackertz, N. *et al.* (2005). *Community Consultation and the Hard to Reach: Concepts and Practice in Victorian Local Government*. Victoria: Institute for Social Research.

Coulter, A. & Ellins, J. (2006). *Patient Focused Interventions: A Review of the Evidence*. Picker Institute Europe. Retrieved from the World Wide Web:
http://www.health.org.uk/publications/research_reports/patientfocused.html

Community Development and Health Network (2008). *Engagement Toolkit for Commissioners*. Retrieved from the World Wide Web www.cdhn.org

Department of Health (2009). *Understanding what matters: A guide to using patient feedback to transform services*. Retrieved from the World Wide Web www.nhs.co.uk.

Dept of Health & Children (2001). *Quality and Fairness: A Health System for You*.

Draper, M (1997). *Involving service users in improving hospital care: Lessons from Australian Hospitals*, Canberra. Department of Health and Family Services.

DoHC & HSE (2008). *National Strategy for Service User Involvement in the Irish Health Service 2008-2013*. Retrieved from the World Wide Web
http://www.hse.ie/eng/Your_Service_Your_Say/Your_Service_Your_Say_Publications.html

HSE (2009a). *Towards Excellence in Clinical Governance – A Framework for Integrated Quality, Safety and Risk Management across HSE Service Providers*. Available at
http://hsenet.hse.ie/HSE_Central/Office_of_the_CEO/Quality_and_Risk/Documents/HSE_quality_safety_and_risk_framework_V1_Jan_2009.pdf

HSE (2009). Best Practice Guidelines for establishing and developing service user Panels. Office of Consumer Affairs. Available at http://www.hse.ie/eng/Your_Service_Your_Say/Your_Service_Your_Say_Publications.html

McEvoy, R., Keenaghan, C. & Murray, A. (2008). Service User Involvement in the Irish Health Service: A Review of the Evidence. Available on the World Wide Web http://www.hse.ie/eng/services/Publications/Your_Service,_Your_Say_Consumer_Affairs/Reports/Literature_Review.html

Ministry of Consumer Affairs (2004). *Service user Representation; Recruiting Effective Service user Representatives*. Retrieved from the World Wide Web <http://www.consumeraffairs.govt.nz/aboutus/consumer-rep/Recruit.pdf>

National Standards for Community Engagement. *Indicators for the working together standard*. Communities Scotland. Retrieved from the World Wide Web <http://www.scdc.org.uk/national-standards-community-engagement/>

NHS (2009). Understanding what matters: A guide to using patient feedback to transform services. Retrieved from the World Wide Web www.dh.gov.uk/publications.

People and Participation.net (2009). Your gateway to better participation. Retrieved from the World Wide Web www.peopleandparticipation.net

Picker Institute Europe (2009). *Using Patient Feedback*. Useful Tools. Retrieved from the World Wide Web <http://www.pickereurope.org/usingpatientfeedback>

Appendix 1

PRODUCING EFFECTIVE SERVICE USER HEALTH INFORMATION

Good practice guidelines for producing service user health information recommend the following principles:

1. Actively involve service users in the development and evaluation of information materials
2. Before preparing the materials, consider the information needs of the target population. Where possible, information should be tailored to the individual service users circumstances and concerns
3. Written information should be presented in plain English and be at a reading level which is suitable for the target population
4. Materials should reflect cultural diversity and be made available in non-English languages
5. Information should be accurate, non-biased and include a clearly stated evidence-base
6. Language should be non-alarmist, non-patronising and in the active voice
7. Avoid the use of unnecessarily long words, technical jargon and acronyms
8. Where possible, make use of illustrative diagrams and other appropriate visual aids
9. Present information clearly and in short blocks of text. Question and answer formats, sub-headings and bullet points are helpful to divide long sections of text
10. Include a publication date so that readers can gauge whether the information is up-to-date
11. Provide a list of contacts where patients can obtain further information if required
12. Make information available in a variety of mediums and from a range of sources
13. The timing of information dissemination is crucial to its effectiveness. Bear in mind that service users' information needs are likely to change over the course of their illness.

(Ref: Victoria Health 2009)

Appendix 2

USEFUL WEB LINKS AND RESOURCES

WEB LINKS

<http://www.hse.ie/eng/services/ysys/SUI/>:

Site users can access the **Library** function which contains useful websites, publications and practical guides to service user involvement. It also contains monthly evaluation bulletins of the community participation and primary care joint funding initiative, and progress updates relating to the implementation of the National Strategy for Service User Involvement in the Health Services.

www.peopleandparticipation.net

www.involve.org.uk

www.pickereurope.org/index.php

www.library.nhs.uk/ppi/

RESOURCES

The HSE Intercultural Guide

The guide provides important information on the approach to intercultural healthcare and profiles the needs of twenty-five diverse groups who are cared for in our healthcare settings. It is a resource and practical tool for staff from all backgrounds and includes communities with a longer history in Ireland as well as newer communities”.

Multilingual Aid

A resource book titled *Emergency Multilingual Aid: A multilingual and illustrated communication phrasebook for use by patients and staff* has been developed and will be disseminated in early 2009.

The *Emergency Multilingual Aid* is intended to assist staff in communicating more effectively with patients with limited English proficiency who present in acute/emergency situations, prior to requesting the services of an interpreter or while awaiting the interpreter’s arrival.

The resource covers 160 common questions and statements to help front line hospital staff to communicate with patients with limited English proficiency. It also contains some patient-led questions to assist communication in the absence of an interpreter. These questions are translated into twenty languages.

The resource is a partnership project between the *National Intercultural Health Strategy* (Social Inclusion Unit) and the Health Promoting Hospitals Network. For further information contact socialinclusion@hse.ie

Accessible health information

Equality, social inclusion and health promotion initiatives across the health services have increased our awareness of English language proficiency issues for some recently arrived migrants as well as *health literacy* issues among the general population. In response to this, efforts are in place to produce essential health information in easily understood terms and in some cases in the mother tongue of the person. At present particular initiatives are in place to address the need to produce and make available health information in an accessible and user-friendly manner.

A resource document, *HSE Plain language style Guide for documents*, outlining the process to be used for developing effective and user-friendly health information, including writing in plain English, is currently being finalised. This Guide is available on www.healthpromotion.ie.

Under the implementation plan for the National Intercultural Health Strategy the Social Inclusion Unit is developing processes to ensure that essential information is available in a number of key languages. Some essential information has been translated into key languages and is available at a language hub on the HSE website at http://www.hse.ie/eng/services/find_a_service/languages

The Social Inclusion Unit is leading an initiative to develop guidelines and a business process that will ensure consistent standards for translated materials across healthcare settings. For further information contact socialinclusion@hse.ie

Process for Community Participation and Primary Care Teams

In the context of the rollout of the Primary Health Care Strategy and the National Strategy for Service User Involvement, the 'Joint Community Participation in Primary Care Funding Initiative' was initiated in 2008 by the Combat Poverty Agency and the Office of Consumer Affairs (HSE) in collaboration with the Directorate for Primary Community and Continuing Care (HSE).

The Joint Funding initiative is an exciting opportunity for community based projects to demonstrate in partnership with the HSE how methods of community participation can be of benefit to the ongoing development of Primary Care Teams (PCT).

The initiative is currently being evaluated by Dr. Jane Pillinger. An important objective of the formation evaluation is to identify and recommend to the HSE methods and practices and processes for community participation in the development and ongoing work for PCT. In addition resource documents are currently being devised to support the process of ensuring community participation.

<http://www.hse.ie/eng/services/ysys/SUI/Library/participation/>

Appendix 3

OFFICE OF CONSUMER AFFAIRS, PUBLICATIONS AVAILABLE

[‘Your Service, Your Say’ The Policy and Procedures for the Management of Consumer Feedback to include Comments, Compliments and Complaints in the HSE’.](#)

This booklet outlines the policy and procedures for *‘The Management of Consumer Feedback to include Comments, Compliments and Complaints in the Health Service Executive’*.

[‘Your Service, Your Say’ Guide to the Health Service Executive’s Feedback Policy’.](#)

This guide outlines how the HSE will listen to and act on the feedback received from those using its services. It explains how service users can make a comment, pay a compliment or make a complaint.

[‘Your Service, Your Say’ Customer Service Strategy.](#)

The Customer Service Strategy Statement sets out the actions that the HSE will take over the coming years to give effect to quality customer service principles. It also further develops the HSE’s capabilities in delivering the highest quality service to its customers.

[Your Service Your Say, Information on how to make Comments, Compliments and Complaints Leaflets.](#)

‘Your Service Your Say’. Information on how to make comments, compliments and complaints about health and social services received within the HSE. The leaflet is available in English, Irish, Polish, French, Russian and Chinese.

[Insight O7: Health and Social Services in Ireland – a survey of consumer satisfaction.](#)

Insight O7 is the first independent large scale study undertaken among people who have used hospitals and community based health services in Ireland. The study identified for the first time what proportion of the population is using which service.

[National Strategy for Service User Involvement in the Irish Health Service 2008-2013.](#)

This strategy will build on the existing work undertaken and documented on service user involvement in health. This strategy has been developed to ensure a systematic and consistent approach to service user involvement across the health and social services in Ireland.

[Literature Review: Service User Involvement in the Irish Health Service.](#)

A review of the evidence. 2008.