

Best Practice Guidelines for Establishing and Developing a Service User Panel within a Health Setting







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FOREWORD

Critical to the successful implementation of the National Strategy for Service User Involvement (HSE & DoHC 2008) is how health services involve and encourage service users to drive quality improvement at a national, local and individual level. Health care services need to be organised in the future to maximise the role of service users in:

1. The co-operation of healthcare – i.e. needs assessment, design, delivery and evaluation
2. The promotion of patient centred care
3. Quality improvement.

It is the aim of the HSE that this document will be of value to all of those involved in the development and running of service user panels and in the promotion of service user involvement. It is intended to be both theoretically informative and practically applicable. And whilst this document provides guidelines for the setting up and running of a service user panel, it is important to emphasise that service user panels are but one of a range of involvement methods that can be chosen from (see

appendix 8). All methods have certain strengths and weaknesses. The key, however, is to select the right method for the particular purpose and context in question, rather than choosing one method as a favourite and using it all the time.

Involvement processes usually combine several methods to achieve an aim. The shape, use and results of methods are usually determined by who is using them as well as by the nature of the methods themselves and the context, purpose etc.

Finally, I would like to acknowledge all who contributed to the development of these guidelines and the members of the steering group for sharing their knowledge and experience during its preparation.

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1.0 PURPOSE

The purpose of this document is to provide a framework for the establishment and development of a service user panel within a health setting.

The guidelines can be easily adapted to meet the particular needs of specific groups. The guiding principles are the same, but in reality implementing meaningful involvement for some groups will require additional creativity. Without such creativity membership may not be as inclusive as one would wish. By acknowledging this and forging ahead with plans while actively seeking to address the imbalance can contribute to new learning.

2.0 SCOPE

The scope of this document is applicable to all service users and providers within the HSE.

3.0 DEFINITIONS AND ABBREVIATIONS

Service users

'We use the term 'service user' 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' (HSE & DoHC 2008, p.6).

Community participation

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 (HeBE 2002).

Service user panel

Whilst more commonly referred to in the literature as a 'consumer panel', a service user panel is a method of involvement that enables a range of stakeholders to come together to discuss an issue(s) and reach consensus on ways to improve delivery and quality of services.



4.0 RESPONSIBILITY

The HSE has overall responsibility to provide opportunities for service users to voice their opinions about the services it provides (HSE & DoHC 2008).

If deemed the most appropriate method of involvement (see scoping exercise, appendix 1), the decision to implement service user panels is the responsibility of the relevant local health manager (LHM) and hospital network manager (HNM) who may designate responsibility to a general manager or head of department.

The annual business plan for each service must clearly define processes for service user involvement and, if applicable, responsibility for each service user panel.

It is vital that the LHM and HNM of the relevant service be fully committed to any service user involvement process and be one of the named person(s) to whom the issues raised are brought to.

The name of the LHM and NHM, and any other individuals, to whom issues are brought to must be made known to the panel members. Comprehensive feedback to the panel members should also be guaranteed outlining what has changed, what was not accepted and what was unable to be carried out.

Accountability, open channels of communication and feedback are essential components to the overall success of any service user involvement process.



5.0 BEST PRACTICE GUIDELINES

This document outlines guidance for establishing and developing a service user panel under the following headings:

- 5.1 Necessary criteria**
- 5.2 Functions**
- 5.3 Terms of reference (ToR)**
- 5.4 Membership**
- 5.5 Operation**
- 5.6 Evaluation**
- 5.7 Freedom of information**
- 5.8 Support**
- 5.9 Expenses**
- 5.10 Communication with service managers**

5.1 Necessary criteria

If a panel is deemed by the relevant HSE service management team to be the most suitable process for involving service users within their respective setting (see scoping exercise, appendix 1), it is essential that the following criteria are in place:

- Clear leadership
- Clear aims and goals that can be monitored and measured
- Organisational and management support and commitment to the process

- Resources to support the organisation and development of the panel
- Support and capacity development to ensure that the voices of those who are seldom heard are listened to and responded to throughout the process
- Diversity of participation and that the panel is a just, open, non-discriminatory equality proofed forum as per section 5.4.6 of this document
- A structure for clear lines of communication between the service user panel and relevant service management to help ensure appropriate actions are put in place.

It is recommended that other methods of involvement, along side service user panels, should be considered for people who have difficulty communicating in a group due to language barriers, illness etc. A summary of over 20 methods of involvement is available in appendix 8. For further information about how to use these methods of involving people log on to:

www.hse.ie/eng/Your_Service_Your_Say/SUI/



5.2 Functions

The main functions of a service user panel are to:

- Encourage service user involvement at frontline level and provide an opportunity to reflect, listen and learn from the experiences of service users
- Provide an opportunity to involve service users, particularly for those whose voices are seldom heard
- Provide advice and guidance to HSE management on a particular issue(s) and subsequently help improve delivery and quality of services
- Ensure responsiveness to the needs and concerns of the public and contribute to developments such as integrated care
- Establish potential networking opportunities within the organisation.

5.3 Establishing terms of reference

Terms of reference (ToR) should document how the scope of the service user panel will be defined, developed, and verified. ToR should also provide a documented basis for making future decisions and for confirming or developing a common understanding of the scope among stakeholders.

Creating detailed ToR is critical as they define the:

- Vision, objectives, scope and deliverables (i.e. what has to be achieved)
- Stakeholders, roles and responsibilities (i.e. who will take part in it)
- Resource, financial and quality plans (i.e. how it will be achieved)
- Work breakdown structure and schedule (i.e. when it will be achieved)

They should also include:

- Success factors, risks and restraints.

The ToR set out a road map. They give a clear path for the progression, by stating what needs to be achieved, by whom and when. There must then be a suite of deliverables which conform to the requirements, scope and constraints set out in the ToR.

Proposed ToR should be outlined by the HSE management team and reviewed annually. The terms should be presented by the chairperson to the panel members at the first meeting for consideration, and then again at the second meeting for joint agreement. Once the ToR have been approved, the panel members will have a clear definition of the scope of the project and process.



5.4 Membership

A service user panel should be composed of the following members:

- Chairperson (section 5.4.1)
- Co-ordinator (section 5.4.2)
- Panel members (section 5.4.3).

5.4.1 Chairperson

The chairperson of a service user panel has the vital role of ensuring that meetings are run in an efficient, fair, transparent and supportive way, and that all members of the panel have an opportunity to express their views in a safe and non-threatening environment. They must also ensure that the panel co-ordinator supports the meetings in a manner that is non-biased and without influence.

It is recommended that the position of chairperson be reviewed annually. A chairperson may be re-elected by the panel members, but should only serve a maximum of three years. If, however, a chairperson wishes to stand down and return to the group as a panel member he/she may do so at any time. A new chairperson must then be proposed and seconded by the panel.

5.4.1.1 Who may become a chairperson?

The chairperson should be someone of good standing and is independent of the particular health service for which the panel has been established.

A chairperson can be:

- Proposed by the relevant general manager/head of department from a list of possible chairpersons and approved by panel members
- Proposed by the panel members from a list of possible chairpersons and approved by the relevant general manager/head of department.

A chairperson should not:

- Be currently receiving a salary from the HSE other than remuneration of expenses as a panel member
- Have any personal conflicting interest in the development of services in the HSE
- Demonstrate any bias towards the health service.



5.4.1.2 Role of the chairperson

- Fosters an air of co-operation between all members of the panel
- Maintains a balance between the interests and demands of service users and evidence of best practice
- Ensures that the panel members adhere to the ToR and to ensure that the panel have realistic expectations as to what the panel can or cannot achieve
- Conducts meetings in an orderly fashion
- Liaises between the panel co-ordinator and panel members to achieve progress in discussions
- Follows-up on matters arising with the panel co-ordinator
- Provides evaluation feedback to the relevant service providers on the operation of the panel as requested.

5.4.1.3 Qualities of an effective chairperson

- Is fair, open minded and non-judgemental with a capacity for clear thinking and an ability to identify issues
- Demonstrates leadership and team building abilities
- Has a capacity to manage and administer the service panel process within the ToR
- An ability to work confidentially and with integrity
- Is reliable and has a capacity for loyalty to the process.

5.4.1.4 Interim chairperson

An interim chairperson from within the membership of the panel may be nominated to the service user panel until a permanent chairperson is appointed. Upon the election of a permanent chairperson, the interim chairperson must step down from their post and rejoin the panel as a member, ensuring that all relevant information is passed on to the incoming chairperson.

5.4.1.5 Vice-chair

Each panel is advised to nominate a person from the group to be the vice-chair. The role of this person is to act on behalf of the chairperson where required, to chair the panel meeting in the absence of the chairperson and to communicate details of missed meetings to the chairperson.

5.4.2 Service user panel co-ordinator

The panel co-ordinator makes a key contribution to the running and development of a service user panel. This person should be selected carefully and should be made fully aware of the significance of their role and what will be expected from them. This role should not be taken or given lightly.



5.4.2.1 Who may become a co-ordinator?

- The co-ordinator may be assigned by the relevant LHM, HNM, and/or service manager
- Ideally the co-ordinator should be appointed from the service relevant to the panel. However, if there are people in other parts of the organisation that have the necessary skills/knowledge, and most importantly the interest and time to be involved in projects that have a defined life span, they should also be considered for the role
- The co-ordinator must be allocated adequate protected time to prepare and commit to this important role
- The co-ordinator is to be a silent member of the panel and must not express any opinions about the service at panel meetings. However, he/she may clarify issues and/or arrange for relevant personnel/management to attend specific meetings to clarify issues or to give information etc.
- The co-ordinator must have strong links with the service so that issues identified by the panel may be confidently brought to the attention of the relevant service managers
- The co-ordinator must ensure fair and equitable representation and that the panel is equality proofed as per section 5.4.6 of this document.

5.4.2.2: The role of the service user panel co-ordinator

The role of the panel co-ordinator is two fold. Firstly the co-ordinator must:

- Identify and select service user panel members in consultation with relevant managers and service providers (see section 5.4.4.1)
- Support the chairperson of the panel and to jointly draft agendas, reports and evaluations etc.
- Liaise with the chairperson, panel members, service management and staff as deemed necessary
- Liaise with advocacy groups to ensure that there is representation of service users by the advocacy groups where required
- Contribute to the evaluation of the process and to the development of annual reports and ad-hoc reports where requested.

Secondly, whilst the co-ordinator may delegate the following duties to other service personnel, he/she still has ultimate responsibility for ensuring that:

- Meetings are organised and that associated arrangements are put in place
- All administrative support, including correspondence, minute taking and distribution is provided



- Feedback from panel meetings reach the relevant personnel within the service area, and vice versa
- Organise relevant persons to attend service user panel meetings as deemed necessary by the panel members for information or educational purposes
- Ensure panel members are appropriately trained and supported in carrying out their functions
- Register the establishment of the panel with the HSE, Office of Consumer Affairs (see appendix 4).

5.4.2.3 Qualities and skills of an effective co-ordinator

- Strong administration and organisational skills
- Reliability and a capacity for loyalty to the process
- Capacity to take appropriate initiatives and delegate tasks
- Excellent communication, diplomacy, reporting and evaluation skills
- Ability to work on one's own and as part of a team
- Ability to work confidentially and with integrity.

5.4.3 General panel members

5.4.3.1 Selection of panel members

An effective panel member is someone who brings the service user perspective to the consultation process and is open to constructive dialogue. Together service users bring the knowledge and experience that enables health service providers to develop a clear understanding of the elements of a successful solution and a clear understanding of the consequences of particular decisions for those groups represented.

5.4.3.2 Qualities of an effective panel member

- An ability to appreciate the common good
- Understands the need to work as a team
- Addresses issues from the perspective of the service user
- Has strong communication skills and will be assertive and persistent if necessary
- An ability to listen and respect the views of others as well as putting their own opinions forward
- Communicates effectively and finds solutions and common ground with others
- Exercises good judgement



- Respects cultural differences
- Has an openness to engage in constructive dialogue
- Demonstrates a comprehensive understanding of confidentiality.

To achieve true representation in the early stages of establishing a panel it will be necessary to provide training and capacity building. This will help enable potential panel members to fully contribute to the process, particularly members who may not possess all of the above qualities.

5.4.4 Recruitment process

The various methods that may be used for the recruitment of service users to a service user panel include:

- Random selection from a list of potential service users
- Purposive selection (i.e. selection of those likely to be able to provide relevant information)
- Representatives from advocacy groups, support groups and/or chronic illness groups which may have a working history with the service
- Voluntary membership arising from public advertisement, for example a public notice within the hospital waiting area.

The selection of panel members should take into account any specific needs of the population from which the panel is selected. For example, a group might consist of six members selected at random from a list of service users of the relevant service, two members purposively selected for their in-depth knowledge of the area (e.g. nominated by the general manager, community groups), and four members who represent advocacy groups (nominated by the groups). Panel selection, however, where possible, should reflect the geographical, social, gender and age profile of the population.

Service users may be members of more than one panel at any given time. However, they must ensure that the issues brought to the table are relevant to each particular panel and that the confidentiality and privacy rights of other panel members are respected at all times.

Health professionals, public representatives and HSE staff who are selected as members of a panel may do so as expert advisers and/or on the basis of their own personal experience. Their role, however, should be determined at the first meeting and recorded within the minutes of the meeting and ToR.



5.4.4.1 Selection criteria and process

Panel members should be selected with the necessary skills/expertise in mind. This may be done by simply applying the description of the qualities of a panel member and adding it as an appendix (as per section 5.4.3.2), and/or indicating that certain attributes are particularly important.

The selection process should be sensitive to the ability of individuals to participate effectively and assistance should be available if required. People with disabilities, for example, should be facilitated to take as full a part as possible and assistance should be available if required. Carers should be included for their detailed experience of services available or provided to service users.

Where required, a person selected to a service user panel may bring a 'personal support' to facilitate the articulation of their views at the meeting. However, the 'personal support' must only articulate the views of the person they are assisting and not their own views.

Service user panels should be made up of approximately twelve members of the public (minimum eight members). Fifteen members, however, should be appointed initially. This is to allow for some members 'dropping out' in the initial start-up period.

All selected panel members should be requested to sign the appropriate consent forms prior to the groups first meeting (see

appendix 3) and given a copy of the guideline for establishing and developing a service user panel within a health setting.

5.4.5 Dealing with personal conflict within the service user panel

If a service user panel should experience difficulties with a panel member(s) or an appointed chairperson, such difficulties should be brought to the attention of the panel co-ordinator.

When such difficulties arise the service user panel should be requested to formulate the difficulties clearly and explain its reasons for considering them to be counterproductive to the groups stated ToR, aims and objectives. The co-ordinator and relevant health service management must then make every reasonable effort to resolve any conflict or issues prior to the next service user panel meeting.

If the issue cannot be addressed satisfactorily prior to the panel's next meeting, the co-ordinator must inform the HSE, Office of Consumer Affairs who may decide to call an extraordinary meeting with the relevant parties to identify the issues and provide possible solutions. If the panel should experience difficulties with the panel co-ordinator the same procedure outlined above would apply. However, the chairperson would be required to approach the named LHM or HNM as opposed to the panel co-ordinator.



5.4.6 Equality proofing

All service users must be fairly represented by the panel members, and there should be no discrimination of membership, or recommendations to service providers, on the following nine grounds:

1. Gender
2. Age
3. Disability
4. Marital status
5. Family status
6. Sexual orientation
7. Religion
8. Race
9. Membership of the travelling community. (Equal Status Acts 2000 and 2004 and Provision of Health Service).

5.5 The operation of a service user panel

5.5.1 Life span

In general, the proposed life span of a panel will be determined by the longevity of the issue(s) for which the panel was convened to advise and guide service management upon.

For example:

...in some services, for example cancer we have used a shorter time period of 3 meetings over 3- 6 month periods arranging meetings and giving the dates to the participants before the panels commence. This format is particularly beneficial if information is required that will directly influence the service and that information is required quickly, as was the case in development of a leaflet for the symptomatic breast clinic and development of a new breast unit at our site. The longer time frame would not have suited the purpose of this panel... (Excerpt from Breen & Boyce 2007).

Ideally, the existence and role of a panel should be reviewed annually. However, if a panel is convened for a long period of time consideration should be given to disbanding or reforming any existing panel after three years to prevent the development of 'group think' and to ensure that other service users have an opportunity to participate in the process.

Note however, that panel members need to have tenure long enough to learn to be useful, but not so long that they become part of organisation.



5.5.2 Ground rules

The ground rules should be prepared at the first meeting of the panel by the chairperson, co-ordinator and panel members. Rules should include:

- Signed consent and agreement to confidentiality (see appendix 3)
- Roles and responsibilities
- Set dates and timing of meetings
- Protocol for non-attendance
- Proposed terms of reference and the lifespan of the panel
- Freedom of information.

Best practice would suggest that there should be a minimum of 50% of the panel in attendance at each meeting. If 50% or more of panel members fail to confirm their attendance forty eight hours in advance of the meeting then the co-ordinator must cancel the meeting until the next proposed date, or if deemed more appropriate given the length of time between meetings arrange for a new date.

The ground rules, along side the agreed ToR, should be reviewed annually and should be signed/initialled by each panel member, and each new panel member thereafter.

5.5.3 Organisation

Venue and locations of meetings should be organised by the co-ordinator to suit panel members and should be accessible for those with physical or sensory disabilities.

The panel co-ordinators must ensure that venue locations meet basic requirements such as:

- Adequate space
- Heat and ventilation
- Meets fire and safety requirements
- Tea and coffee facilities
- Parking facilities
- Ease of access
- The panel co-ordinator must organise for refreshments to be provided at each meeting.

These ground rules should be recorded on the minutes of the first meeting of the service user panel.



5.5.4 Agenda

The agenda of each panel meeting should be developed by the chairperson and co-ordinator. All panel members should be given sufficient time and opportunity to place items on the agenda as required. The agenda should be circulated by the co-ordinator at least one week before the scheduled meeting. The general content of the agenda should include the following:

- Minutes of last meeting
- Matters arising
- Correspondence
- Review of action plan (see appendix 7)
- Feedback from service managers, HSE
- Issues for discussion
- Date of the next meeting.

5.5.4.1 Issues for discussion and action planning

Issues for discussion will vary according to the context upon which each panel is established. Some examples however include:

- General topics such as hygiene and cleanliness, information provision, communication etc.
- Discussion on policies and new information leaflets

- Service provision and maintenance issues
- Issues of concern such as MRSA
- Issues of concern as highlighted by document analysis, for example comments, compliments and complaints
- Topics of concern as agreed by the consumer panel (Breen & Boyce 2007).

Issues open for discussion should be outlined within the agreed ToR. An action plan template is provided in appendix 7.

5.5.5 Minutes

5.5.5.1 Control of meeting minutes: circulation and approval

- With permission from all panel members, minutes may be recorded using a Dictaphone and a designated note taker. Transcribing tapes is somewhat time consuming but has the advantage of accurately reflecting the words of panel members.
- Minutes should specify each issue discussed, document the main points (anonymously), decisions taken and actions specified. Only the names of those who have agreed to carry out the actions should be specified.



- The 'draft' minutes should be circulated by the co-ordinator to the panel members within two weeks of the panel meeting. The draft minutes should then be approved at the next panel meeting, and signed by the chairperson and co-ordinator and sent out to all relevant panel members and service managers.
- After each meeting any issues raised should be forwarded directly to the relevant service manager without delay to be addressed (as per section 5.5.4).
- Minutes for public attention must not identify panel members who are service users.

Jargon has the potential to intimidate panel members and subsequently can prevent members from engaging with the person using it.

Any issues that are not addressed must be highlighted at subsequent panel meetings, recorded in the minutes and attempts to follow-up should continue. Where there is persistent non-response by the relevant service manager to the issues and recommendations raised by the panel, the matter may be taken by the chairperson of the relevant service user panel to the next appropriate level of management authority.

5.5.6 Following up on issues raised

The follow up of issues raised by the panel with relevant service managers and personnel will be the responsibility of the co-ordinator, liaising with the chairperson as necessary. This process should be done in writing. Refer to section 5.10 for 'communication with service managers'.

The co-ordinator will also be required to ensure that adequate feedback is made available to all panel members, and that relevant HSE personnel attend the meeting where and when requested by the panel members. The responsibility of service managers and/or co-ordinators to respond to and/or address panel members in a clear, jargon-free manner cannot be over emphasised enough.

5.5.7 Non-attendance

While it is recognised that panel members cannot be expected to attend all meetings, there is a need to ensure a level of consistency between the meetings. Protocol for non-attendance at panel meetings can be tailored to suit each panel; however, this should be agreed upon by all panel members at the first meeting and recorded within the ToR and minutes of the meeting.

If a panel member should miss two consecutive panel meetings, the co-ordinator must contact the member to identify if there are any issues that may be restricting their attendance at the meetings. If this should be the case, the co-ordinator should identify if any of the issues can be resolved to facilitate the attendance of the member at the meeting.



If issues cannot be resolved, the agreed upon protocol should be enacted.

5.6 Evaluation

It is the responsibility of the service manager to ensure that a process and outcome evaluation of their respective service user panel is carried out.

The process evaluation will help improve upon involvement practices, whilst the outcome evaluation will help determine the degree to which engaging with service users has impacted on service delivery. For example:

Process evaluation:

- Were we able to involve 'hard to reach groups'?
- Did panel members feel the process enabled them to get their views across?
- Did panel members receive the information they needed to make a relevant response?
- Did panel members effectively engage in the process?
- Did we get good quality responses and commitment to the process?

Outcome evaluation:

- What information or knowledge emerged from the process that service management had not previously been aware of?
- What impact did the feedback from the panel members have on the final commissioning decision?
- Would you describe their contribution and impact as minor, intermediate or substantial?

It is important to think about how best to evaluate process and outcomes from the very beginning so that the necessary steps are taken throughout the process.

Whilst the panel co-ordinator and chairperson will have a key role in supporting the service manager in the evaluation process, it is also essential that the panel members are given the opportunity to contribute, review and comment on the final report.

Evaluation methods should also examine the following:

- Selection process
- Training provided for panel members, facilitators and staff



- Analysis of attendance at meetings
- Details of the issues raised
- Details of actions arising and actions delivered
- Details of actions outstanding
- Survey of perspectives of panel members on process and outcomes
- Methods may include:
 - Documentary analysis (see Breen & Boyce 2007)
 - Post-meeting surveys
 - Periodic interviews/focus groups with relevant panel members, chairpersons, co-ordinators, service providers etc.
 - Questionnaires (see appendices 4-5 for example questionnaires).

The final report should be issued by the panel chairperson and co-ordinator, and endorsed by the panel members. A copy of the report must then be submitted to the relevant service manager and to the HSE, Office of Consumer Affairs.

5.7 Freedom of information

All panel members must be made aware that all information generated by the service user panels, for example agendas, minutes, etc. may be obtained by others through the freedom of information procedure. Hence, all personal information must be protected, including identity of panel members etc.

5.8 Support

5.8.1 HSE, Office of Consumer Affairs

The HSE, Office of Consumer Affairs will support the development of service user panels in terms of:

- Developing criteria for the development of service user panels
- Developing and keeping abreast of best practice in the area of service user involvement and making available such developments on the 'Your Service Your Say' webpage
- Encouraging and supporting the development and functioning of service user panels
- Establishing, monitoring and reviewing policies, procedures and guidelines to support the service user panels
- The provision of an online forum for the sharing of information, queries, difficulties arising from the functions of the service user panels
- Revisiting the service user panel guidelines every two years
- Monitoring and evaluating the process nationally; ensuring guidelines are being followed and that change is happening as a result (see appendix 5)
- Establishing a database of all service user panels through a national registration programme (see appendix 4).



Once registered with the HSE, Office of Consumer Affairs, both the panel chairperson and co-ordinator will also be given access to an online discussion forum. This support will be provided through www.Hseland.ie which is the HSE's online resource for learning, development and managing change.

5.8.2 Service areas

Business plans for each service area will outline the commitment of the service to the development and support of service user involvement processes.

Should a service area select a service user panel as an appropriate involvement mechanism, it is the responsibility of that service to support the implementation of the service user panel(s) within their area by providing administrative support, co-ordination support and access to relevant service personnel as is recommended by HeBE (2002).

Services will also be required to allocate a budget to support service user involvement by paying relevant expenses incurred as a result of participation in panels/forums/committees etc. as per section 5.9. In addition, service managers must be

committed to attending service user panel meetings on a mutually satisfactory date to address issues raised by the panel.

If a representative is sent on behalf of the service manager, he/she must be sufficiently informed and empowered to adequately discuss issues and to agree on actions that may be taken to resolve issues. There needs to be open and transparent dialogue arising out of the participatory process.

5.9 Expenses

The business plan for each service must clearly define who is responsible for service user panels relevant to that service so that the responsibility for the payment of expenses is clearly defined. Best practice dictates that:

- Expenses will be paid at the current agreed rate in line with national HSE guidelines
- Expenses will be paid regularly on the basis of the official expenses claim form which should be filled out at the end of each service user panel meeting (see appendix 2)
- The expenses sheet must be signed by the co-ordinator of that panel and then forwarded to the relevant service manager for approval.



5.10 Communication with service managers

Direct communication should be facilitated between the panel and relevant HSE management.

Communication is a multi-layered process; it is as much about listening and encouraging dialogue and feedback as it is about providing information. Communication will not just happen, it must be planned, and actively encouraged and promoted.

The vital element is that before setting up a panel the CEO, director or manager of the relevant service must be fully committed and be one of the named persons to whom the issues raised are brought to.

To ensure effective communication the following elements are critical:

- Feedback is an essential part of communication and therefore must be actively sought
- Relevance, openness, honesty and consistency are vital; all communication should be shared and expressed in a manner which meets the needs of the panel members and should occur at appropriate times

- Plain language must always be used. It should be jargon free and without abbreviations to ensure understanding
- Ranges of different communication methods should be used to include those for whom English is not their preferred language of communication and for panel members with disabilities
- Communications should be prepared and sensitively delivered in a professional manner which instils confidence and understanding
- Methods and channels of communication should be reviewed regularly to ascertain effectiveness and to ensure that a correct message has been conveyed and is understood by those who receive it.

6.0 FREQUENCY OF REVISION

These guidelines will be reviewed at least every two years.

7.0 AUDIT TOOLS FOR THE IMPLEMENTATION OF THIS GUIDELINE

- Process and outcome evaluation of service user panels by relevant service managers and service users (see appendix 5)
- Service user panel checklist (see appendix 6)
- Minutes of meetings
- Attendance at meetings.



8.0 TOP TEN TIPS MOVING FORWARD

Do:

- ✓ Remember, improving service user involvement involves changing minds – positive attitudes and behaviours make a difference
- ✓ Ensure senior leadership and commitment when starting to plan involvement processes
- ✓ Select the method of involvement that matches the purpose you have identified and the needs of the service users
- ✓ Ensure that resources, including staff time, are factored into the plan at the outset
- ✓ Use feedback to identify what is working well – recognise, reward and promote good practice.

Don't:

- ✗ Expect a 'quick fix', changing minds takes time, and by creating a structured approach you will be able to monitor success
- ✗ Ignore the need to invest in capability and capacity to implement a sound approach
- ✗ Decide upon a method of engaging and collating feedback without understanding the context, business case and ongoing costs
- ✗ Proceed with service user involvement processes before you are clear about who is responsible and accountable for using the feedback to improve patient experience and quality of services
- ✗ Forget to feedback to staff and to tell service users how you have used their feedback to improve services (NHS 2009).



9.0 REFERENCES

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9.0 APPENDICES

Appendix 1: Scope checklist

1. Can anything change as a result of involvement?

If nothing can change as a result of involvement it is often better to rely on traditional communication methods. The experience of taking part in a process without any potential impact is often frustrating and can damage the image of the sponsoring organisation. It is very important to be honest about what is open to change through involvement and which decisions are already made so that potential participants can make an informed decision whether or not they want to take part.

2. Do you have at least three months to set up and run the process?

While it is sometimes possible to set up and run good involvement processes in a very short period of time this is very challenging and should be avoided. Short time scales can make it difficult to recruit the participants and leave less time for planning and adaptation to local circumstances.

3. Do you have enough resources for your intended process?

There are many examples of where insufficient resources have led to bad practice. Involving service users can be surprisingly time-consuming and staff need to be properly supported and trained. If the allocated budget is insufficient to run a suitable involvement process it is often better to opt for a less ambitious option rather than risk failure.

4. Is the decision maker/problem holder supportive of wider participation?

It is challenging to run an involvement process when those who hold the power are unwilling to listen. Many participants may choose not to get involved in a process with very slim chances of making an impact and it is important not to give participants false hopes about potential outcomes. In cases where decision makers are unsupportive of involvement a more traditional approach may be more appropriate.



5. Is the issue one which is of interest to your intended participants?

Often the agenda for involvement events are set solely based on the interests of the sponsoring organisation. If consideration is not given to what potential participants might get out of the process, failure is inevitable

6. Have previous attempts at involving service users (if any) been successful?

The fact that previous processes have failed should not deter the sponsoring organisation from trying. However, take cognisance of the reasons why previous processes failed and the potential need to reconsider previous approaches taken. It is also worth keeping in mind that past failures often breed apathy and cynicism amongst participants and that working relations may need to be rebuilt.

7. Is your process the only attempt to involve these participants around this issue?

The number of engagement processes has increased markedly over the past decade. Unfortunately many processes duplicate each other, either in terms of what they are trying to engage around or whom they are trying to reach. By joining forces with other service areas that are also trying to engage with the same groups better use can be made of both your resources and the time of your participants.

Appendix 2: Expenses claim form for panel members

Service: _____

CLAIM FOR TRAVELLING EXPENSES

NAME: _____ DATE: _____

OFFICIAL ADDRESS: _____

Engine cc: _____

| Location & Date of Meeting | Time of departure from residence | Time of return to residence | Number of Hours | Distance of Meeting (miles/kilometres) Please specify | Amount claimed for Travelling Expenses € |
|----------------------------|----------------------------------|-----------------------------|-----------------|---|--|
| | | | | | |
| | | | | | |
| | | | | | |

Total Travelling Allowance: _____

Overall Total: _____

Signature: _____

I certify that the claimant attended the meeting(s) on the date(s) shown and that the account is correct.

Managers Name: _____ Signature: _____ Date: _____

Please Note: If you wish to claim public transport or accommodation expenses please include receipts for same with the completed form.





Appendix 3: Consent Form

Consent form for service user panel members

The purpose of the service user panel for _____ (panel name/area) has been explained to me.

I understand that we will be discussing areas relating to health services for service users at _____, that minutes will be taken of these meetings and that issues raised will be reported to the general manager _____ (name).

Whilst such issues are not of themselves confidential, I agree not to discuss what other panel members say outside of the meetings in order to respect the privacy of all concerned.

I understand that panel members must never discuss with anybody any private or privileged matters that may inadvertently arise during the course of these discussions.

I understand that all records relating to the service user panel are subject to freedom of information and data protection legislation.

I consent to take part in the service user panel and abide by the above conditions.

Signed/initialled: _____

Date: _____



Appendix 4: National Registration

National registration of service user panels

Name of panel

Address of panel

Date of establishment: _____

Number of panel members: _____

Name of key contact:

Chairperson _____

Email _____

Telephone _____

Co-ordinator _____

Email _____

Telephone _____

Please submit completed from to:

Deirdre McKeown

Office of Consumer Affairs,

Room 1.25, First Floor,

Dr Steevens Hospital,

Dublin 8

Deirdre.mckeown@hse.ie



Appendix 5: Evaluation questionnaire survey

Name of panel:

Address of panel:

Date of establishment: _____

Number of panel members: _____

Name of key contact:

Chairperson _____

Email _____

Telephone _____

Co-ordinator _____

Email _____

Telephone _____

Establishing a service user panel

Was a scoping exercise (see appendix 1) completed to ensure that a service user panel was the most appropriate method of involvement? Yes ☐ No ☐

If no, what prompted the service to establish a service user panel as a method of involving service users?



Please rate your level of agreement with the following statements in respect to the service user panel established within your area:

| Our service user panel has | Strongly Agree | Agree | Disagree | Strongly Disagree |
|---|----------------|-------|----------|-------------------|
| Encouraged service user participation at frontline level and provides an opportunity to reflect, listen and learn from the experiences of service users. | | | | |
| Helped improve delivery and quality of services through feedback | | | | |
| Examined potential partnership arrangements in the provision of health services. | | | | |
| Helped to improve communication channels between service users and the HSE. | | | | |
| A structure in place for clear lines of communication between the service user panel and the service managers and appropriate actions have been put in place as a result. | | | | |

If you disagree with any of the above statements please specify why?



What resources were put in place to support the service user panel?

Did any training or capacity building take place prior to setting up the panel or during its life span?

Yes ☐ No ☐ If yes, please specify.

Were any difficulties experienced during the life span of the panel?

Yes ☐ No ☐ If yes, please specify.

What changes were made within the service as a result of the work of the service user panel?



Are there any issues outstanding?

Yes ☐ No ☐ If yes, please specify.

Was there anything that should have been done differently in terms of the setting up and running of the service user panel?

If you have any other comments you would like to make about the setting up and running of the panel, please give details below.

If you experienced difficulties in adhering to the guidelines set out in the document, please give details below.



Is there any additional material which would help to make the guidelines more useful, comprehensive or understandable?

Please attach results from the service user panel member's evaluation survey.

Signed by:

Chairperson _____

Co-ordinator _____

Local Health Manager _____

Panel Representative _____

**This form can be photocopied, alternatively a copy may be downloaded from the
'Your Service Your Say' web page at www.hse.ie**



Service user panel member evaluation form

Name of the panel?

Length of time on the panel? _____ **months**

Please place a tick (✓) in the appropriate space, and include comments in the comment section if you wish

Do you feel that during your membership on the panel you were...

| | Always | Sometimes | Never |
|----------------------|---------------|------------------|--------------|
| Treated with respect | | | |
| Listed to | | | |
| Supported | | | |
| Welcomed | | | |

Any additional comments on your feelings above?

Please state your level of agreement with the following statements.

| The panel... | Always | Sometimes | Never |
|---|---------------|------------------|--------------|
| Was a fair and open forum of discussion | | | |
| Resulted in changes within the service | | | |
| Was operated in an organised manner | | | |
| Members had an opportunity to place items on the agenda as required | | | |
| Meetings were held in a suitable venue and location | | | |
| Terms of reference were adhered to throughout the process | | | |



Any further comments in relation to your response to these statements:

Please rate your level of agreement with the following statements in respect to the service panel of which you were a member:

| Our service user panel has... | Strongly Agree | Agree | Disagree | Strongly Disagree |
|--|----------------|-------|----------|-------------------|
| Encouraged service user participation at frontline level and provided an opportunity to reflect, listen and learn from the experiences of service users. | | | | |
| Helped improve delivery and quality of services through feedback. | | | | |
| Helped to improve communication channels between service users and the HSE. | | | | |
| A structure in place for clear lines of communication between the service user panel and the relevant service management and appropriate actions have been put in place as a result. | | | | |

If you disagree or strongly disagree with any of the above statements please specify why?



Was there anything that you felt should have been done differently in terms of the setting up and running of the service user panel?

What changes were made within the service as a result of the work of the service user panel?

Are there any issues outstanding?

Yes ☐ No ☐ If yes, please specify.

If changes proposed by the panel were not carried out was this clearly communicated to you by management?

Yes ☐ No ☐ If no, please specify why not.

Are there any other comments or suggestions that you would like to make in relation to the service user panel and the overall process?

Thank you for taking the time to complete this form



Appendix 6: A quick checklist

Gather feedback regularly and systematically

- ☐ Are you clear about what you want to find out?
- ☐ Do you know who you need feedback from?
- ☐ Have you made use of existing data e.g. national survey findings?
- ☐ What other patient feedback do you need and how will you gather it?

Understand your findings

- ☐ Have you examined your feedback to identify priorities for improvement?
- ☐ Have you decided how to analyse your results?

Consider:

- ☐ aspects of the patient journey
- ☐ changes over time
- ☐ how you compare to other organisations
- ☐ comparing differences within your organisation, possibly by specialty or department
- ☐ issues reported by large numbers of patients
- ☐ existing organisational priorities.

Share results widely throughout your organisation and with the local community

- ☐ Have you developed a practical communication strategy which identifies:
 - ☐ your key audiences and main messages?
 - ☐ ways to reach out to as many people as possible?

Action plan with service users and staff

- ☐ Have you devised an action plan with clear priorities and timelines?
- ☐ Have you identified some project champions?
- ☐ Are clinical and support staff across the organisation involved?
- ☐ How are you involving service users in action planning?

Get stakeholders involved

- ☐ Have you identified all your stakeholders and how to involve them?
- ☐ Have you set up a working group?

Maintaining progress

- ☐ Are you implementing some short term 'quick wins' as well as longer term improvements?
- ☐ How will you measure the impact of your changes?
- ☐ Are you confident that stakeholder involvement can be sustained throughout?
- ☐ What are your plans for reporting and monitoring?

Appendix 7: Service user panel action plan

Action Plan

| Identified Issue | Objective/Goal | Work Needed | Timescale | Responsibility | Monitoring | Link with each other work |
|---|--|---------------------------------|--|---|---|---|
| What issue has the survey identified? e.g. 25% of patients were not given enough privacy when discussing their condition or treatment | What do you hope to achieve? What measurable difference will you make? | How will you achieve this goal? | When will this be done by? Are there any major milestones along the way? | Who will take the lead on this initiative? Who else will be involved in making it happen? | How and when will progress be measured? e.g. audit, repeat questionnaire, comment box | Are there any other initiatives that this overlaps with? Are there any groups or teams working on similar/related issues? |
| | | | | | | |
| | | | | | | |
| | | | | | | |



Appendix 8: Methods of involving service users

| Method | Description |
|---|---|
| Nominal group techniques | Small group process for clarifying priorities. May be useful for service user involvement in identifying priority issues, allocating scarce resources etc. However, does not allow for much in depth exploration of the issues. |
| Suggestion boxes | Easy to implement, but may be limited in obtaining useful feedback. May attract negative and unhelpful comment. Only for use in conjunction with other strategies. Responses limited to those with time and literacy skills. |
| Hotlines and phone ins | Information gathering. Relies on publicity and the phone being attended. Works best with skilled staff or volunteers to answer. Attracts respondents fairly indiscriminately. |
| Text messaging | Information gathering. Useful for getting feedback from young people. |
| Complaints handling | Response to user feedback and complaints. Valuable resource because restricted to users who have identified possible area for service improvement. Requires staff understanding of value of complaints. Not representative of patient experience or necessarily the worst service experience. |
| Responding to service user initiatives | How your organisation/team responds to enquiries or requests initiated by consumers. Developing clear policies, processes and skills to be 'response-able'. |
| Workshops | Working meeting usually of 8-12 service users, possibly with providers, to share information and to develop a shared approach to a specified issue. Participants usually have been selected on the basis of particular skills, knowledge or experience, requires informed participants. |
| Patient advocates | Healthcare organisation employs person to consult with service users and advocate on their behalf for service improvement. |
| Promotions and campaigns | Ways to get information out. Can be innovative and creative and can involve service users, possibly through consultation in planning and partnerships in implementation. |
| Search conferences | Meeting of 30-50 invited people. Investigates a subject/issue in a planned manner. May use discussion paper as starter. Asks specific search question. Wide range of views canvassed. Answer(s) expected as outcome. |
| Public inquiries and hearing | Instigated by organisations. Formally set terms of reference. Receive public submissions, oral and written. Formal and possibly intimidating. Likely to exclude views of socially disadvantaged service users. |
| Distributing discussion papers | Written presentation of information for discussion. No dialogue involved unless structured. May, however, be used as precursor to public meetings or other discussion. |
| Public meetings and forums | Audiences usually over 20 people. Meeting structured to canvass views and/or debate an issue. Representatives, nominated by community/voluntary groups. Open to public. |



| Method | Description |
|---|--|
| Seminars and conferences | Instigated by organisations to explore ideas/issues. May be expensive and, therefore, be restricted to those who can pay. Audiences over 20 people. Format structured, informal or spontaneous input may be restricted, tending to give providers/professional more 'air time' than service users. |
| User councils, panels and reference groups | Structure and role prescribed by organisation but should be negotiated and written down. Input to whole organisation based on advice from service users. Need to ensure and support user representative links with appropriate constituency. Representatives need to have tenure long enough to learn to be useful, but not so long that they become part of organisation. |
| Policy round tables | Invitations to discuss policy items. Structured. Convened to advise on the development of specific policy and implications. |
| Stakeholder representatives on committees | Informing, training and supporting, stakeholder representatives. Negotiated and recorded roles and terms of reference for all members of the committees they sit on. A medium to long term investment. |
| Patient panels | Patients invited to focus on an area/issue. Usually structured. |
| Facilitating mutual support groups | Support to assist people, on their terms, about their issues. Groups can be consulted about service improvement. Clinicians can enter into partnership with groups as expert advisers. |
| Networking | Informal relationship building with people who have common interests or goals. Will include building links to community/voluntary groups, advocacy groups etc. |
| Partnership of providers & service users | Structured cyclical planning process with specified role for service users in shared decision making with providers. Process and outcomes are a shared responsibility. Usually the result of years of development of service user involvement and a strong service user focus and culture in the organisation. |
| Myspace | Service users can provide feedback in an anonymous form. Useful to receive feedback about sensitive areas of service provision or where patients do not want to be identified because of the nature of their attendance (e.g. sexual health and pregnancy conditions). |
| Electronic logs | Service users provide ongoing continuous dialogue through a website. May be consumer initiated. Informal relationship building with people with common interests or goals. |

(Source: People and Participation.net 2009)



Appendix 9: Indicators for the working together standard

1. Behave openly and honestly – there are no hidden agendas, but participants also respect confidentiality.
2. Behave towards one another in a positive, respectful and non-discriminatory manner.
3. Recognise participant's time is valuable and that they have other commitments.
4. Recognising existing agency and community obligations, including statutory requirements.
5. Encourage openness and the ability for everyone to take part by:
 - Communicating with one another using plain language
 - Ensuring that all participants are given equal opportunity to engage and have their knowledge and views taken into account when taking decisions
 - Seeking, listening to and reflecting on the views of different individuals and organisations, taking account of minority views.
 - Removing barriers to participation.
6. Take decisions on the basis of agreed procedures and shared knowledge
7. Identify and discuss opportunities and strategies for achieving change, ensuring that:
 - Key points are summarised, agreed and progressed
 - Conflicts are recognised and addressed.



8. Manage change effectively by:
 - Focusing on agreed purpose
 - Clarifying roles and who is responsible for agreed actions
 - Delegating actions to those best equipped to carry them out
 - Ensuring participants are clear about the decisions that need to be made
 - Ensuring that, where necessary, all parties have time to consult with those they represent
 - Co-ordinating skills
 - Enhancing skills where necessary
 - Agreeing schedules
 - Assessing risks
 - Addressing conflicts
 - Monitoring and evaluating progress
 - Learning from one another
 - Seeking continuous improvement in how things are done.
9. Use resources efficiently, effectively and fairly.
10. Support the process with the administrative arrangements that enable it to work.

(Source: National Standards for Community Engagement 2008)



Appendix 10: Useful weblinks and contacts

Weblinks:

http://www.hse.ie/portal/eng/Your_Service_Your_Say/

www.peopleandparticipation.net

www.involve.org.uk

www.pickereurope.org/index.php

www.library.nhs.uk/ppi/

www.publichealth.ie

Contacts:

June Boulger, National lead for service user involvement
Consumer Affairs Corporate Office,
Health Service Executive,
Oak House,
Lime Tree Avenue,
Millenium Park, Naas, Co. Kildare.
June.boulger2@hse.ie

Rachel McEvoy, Research officer, Consumer Affairs, HSE
Rachel.mcevoy@hse.ie

Ann Breen*, Senior Medical Scientist.
Biochemistry Department, Midwestern Regional Hospital, HSE
Ann.breen@hse.ie

Brid Boyce*, Hospital Accreditation Manager, Midwestern Regional Hospital, HSE
Brid.boyce@hse.ie

*Both Ann and Brid have considerable expertise in the establishment and running of service user panels within the HSE. They have also recently submitted a masters in this area of study in part fulfilment of the Degree of MSc in Quality in Healthcare, School of Healthcare Management, Royal College of Surgeons in Ireland, Dublin.

Breen, A and Boyce, B (2007). *Establishing best practice generic guidelines for setting up and conducting a service user panel within an acute hospital setting using action research.*



Appendix 11: Submissions and steering group membership

Submissions

- Brain Nesson, Functional Manager Research & Development, Health Promotion
- Caoimhe Gleeson, Equality Officer, HSE West
- Catherine Murphy, Assistant National Director, Health Promotion, HSE
- Dr Celia Keenaghan, Population Health, HSE
- Dr. Hilary Dunne, CEO, ISQSH
- Dr. Philip Crowley, Deputy Chief Medical Officer, DoHC
- Diane Nurse, Social Inclusion, HSE
- Elaine Houlihan, Projects Officer, Combat Poverty Agency
- Jim Reilly, Patient Focus
- Local Health Managers, HSE
- Office of Consumer Affairs, HSE
- Patient Forum, St Luke's Hospital, Kilkenny
- Patient Forum, Waterford Regional Hospital
- Rosemary O'Callaghan, Development Officer for Women's Health, HSE
- Service User Involvement Strategy, Oversight Implementation Group
- Sheila Reaper Reynolds, Health Promotion, HSE
- Transformation Development Officers, HSE.
- William Ebbitt, Functional Manager, Health Promotion Policy & Strategy, HSE.

Members of the service user panel steering group May 2009

- Samantha Hughs Team Lead for Clinical Audit and Quality
- Debbie Keyes General Manager, Consumer Affairs
- Rachel McEvoy Research Officer, Consumer Affairs
- June Boulger National Lead for Service User Involvement
- Brid Boyce Mid Western Regional Hospital's Accreditation Manager
- Ann Breen Senior Medical Scientist
- Annmarie Kearns Member of the National Service User
Involvement Implementation Oversight Group and Springfield
Service user Panel
- Antoinette Carberry Member of the Patient Forum, Waterford Regional Hospital.



Appendix 12: 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 07: Health and Social Services in Ireland – a survey of consumer satisfaction](#). Insight 07 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 builds 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.



Notes

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Notes

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