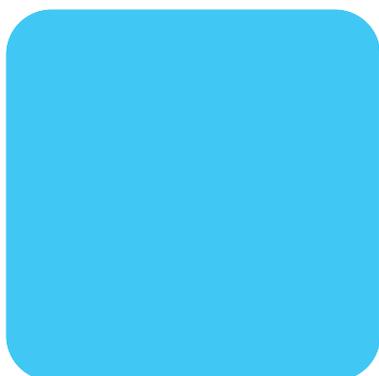
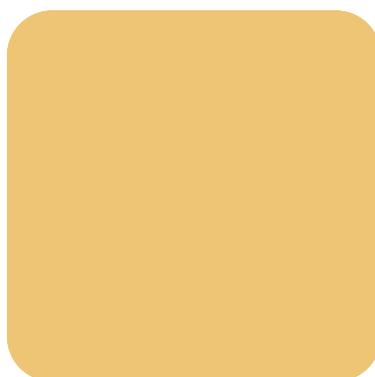


Service User Involvement Methods A Guidance Document





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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 working to involve service users in the design, development and evaluation of health services. 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. This is clearly illustrated in the formative evaluation of the Joint Community Participation in Primary Care Initiative (Pillinger 2010).

I would like to acknowledge all who contributed to the development of this guidance document, and a sincere thanks to those who submitted case studies applying the various methods outlined in the document. There are also other many excellent examples of service user involvement initiatives happening around the country and the HSE Achievement Awards for 2010 is testament to that.

We should always welcome the involvement of those who use our health services and are willing to give up their time to do so. I would encourage all staff therefore to promote, practice and support service user involvement at all levels (i.e. individual levels, ward/programme/departments and organisational) and continue to endorse and support the National Strategy for Service User Involvement.

If you have further case studies that you consider provide valuable learning for service user involvement please let us know; we look forward to hearing from you.

Mary Culliton
Director of Advocacy
Health Service Executive



1.0 BACKGROUND

The empowerment and participation of service users has become a key element of government policy, and the need to listen and act on the views of service users, is an increasingly integral part of the planning and delivery of healthcare (HSE & DoHC 2008).

Different levels of service user empowerment, participation and involvement exist on a continuum of participation including information, consultation, partnership, delegation and control (see McEvoy, Keenghan & Murray 2008).

Before you embark on the process of involving service users there are four stages of thinking and preparation to be considered:

1. Take stock: be sure why you should do it all.
2. Map out the skills and strengths of your team to assess the baseline to build on.
3. Assess the extent to which user involvement and public engagement are welcomed as a meaningful exercise by your colleagues at work. How much practical supports will there be from others?
4. Before you start; define the purpose; be realistic about the magnitude of the planned exercise; select an appropriate method or several methods depending on the target population and your resources; get the commitment of everyone who will be affected by the exercise; frame the method in accordance with your perspective; write the protocol (Chambers et al. 2003, p.89).



2.0 SCOPE

The scope of this document is applicable to all service users and all professionals within health and social care services.

2.1 DEFINITIONS

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).

2.2 PURPOSE

The following document presents a methods planning tool and provides readers with an overview of the range of different methods available for service user involvement.

The following list of methods is not exhaustive; there are numerous tools and techniques available some of which ensure maximum participation in decision making whilst some to a lesser extent. The following methods, however, are ones that you may be more familiar with:

- Consultations: written and online
- Complaints handling
- Deliberative workshops and conferences
- Journey mapping
- Focus groups
- Mystery shopper
- Service user panels
- Online notice-boards and online forums
- Surveys

For a more comprehensive list of methods see www.peopleandparticipation.net

Please note that the methods outlined above are not a choice between one or another as any involvement of opinion exercise will be more valid if you obtain views and input from more than one source to minimise bias. If you are considering an important topic and want wide-ranging views, choose two or three methods, put the results together and compare your findings.



Don't cut corners because you do not have sufficient resources to undertake a user involvement exercise properly, so that you leave out essential stages for example piloting questionnaires. If you sacrifice best practice for expediency, you will devalue your exercise and the outcome will be meaningless.

If you do not have enough resources or skills, either wait until you have rectified the deficiency or select another method that you can afford or have the ability to undertake (Chamber *et al.* 2003).

The document also presents guiding principles when engaging in service user involvement processes and also when:

- Working together
- Communicating with 'The Deaf Irish Sign Language Community'
- Communicating with Children and Young People

METHODS PLANNING TOOL

METHODS PLANNING TOOL

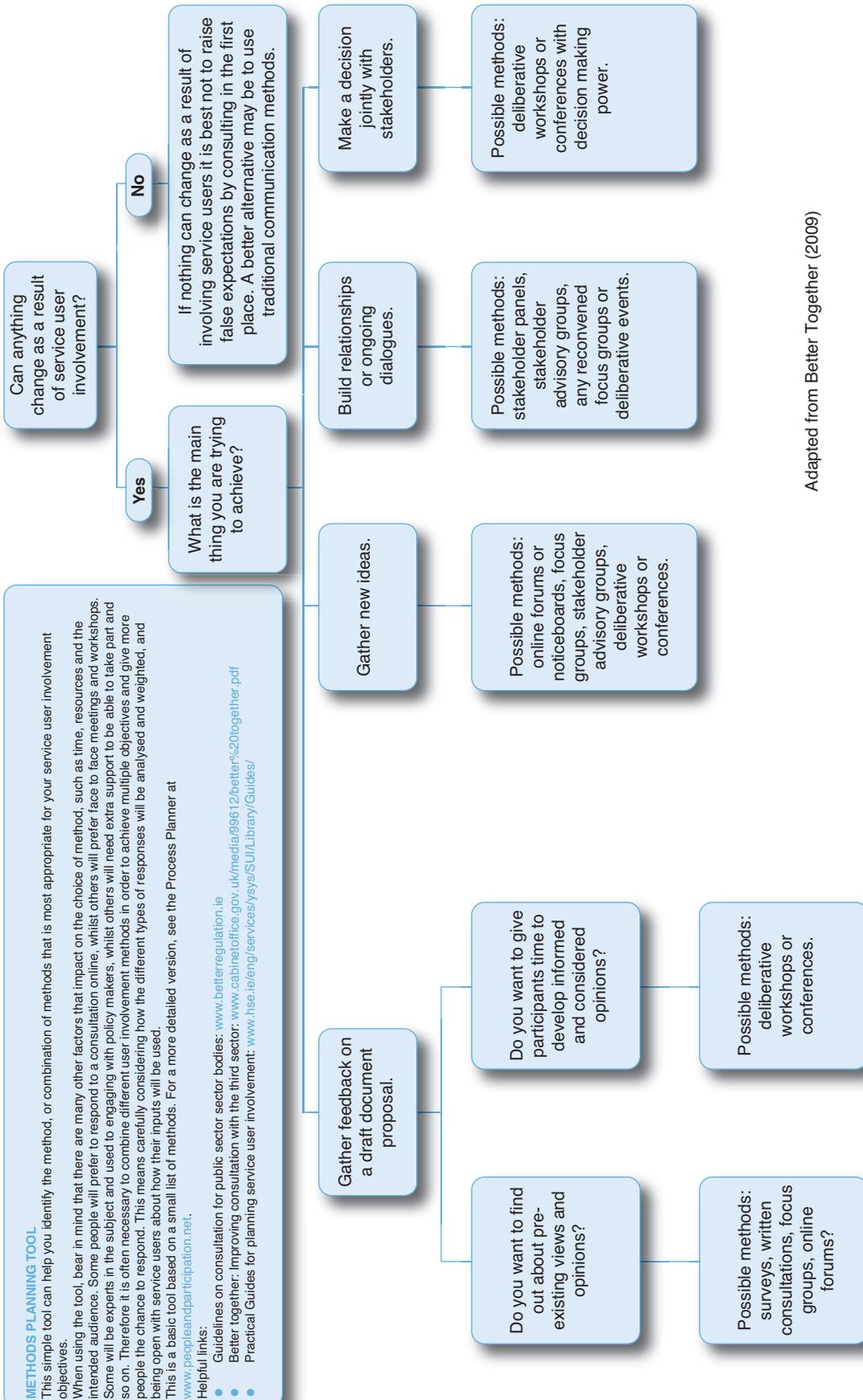
This simple tool can help you identify the method, or combination of methods that is most appropriate for your service user involvement objectives.

When using the tool, bear in mind that there are many other factors that impact on the choice of method, such as time, resources and the intended audience. Some people will prefer to respond to a consultation online, whilst others will prefer face to face meetings and workshops. Some will be experts in the subject and used to engaging with policy makers, whilst others will need extra support to be able to take part and so on. Therefore it is often necessary to combine different user involvement methods in order to achieve multiple objectives and give more people the chance to respond. This means carefully considering how the different types of responses will be analysed and weighted, and being open with service users about how their inputs will be used.

This is a basic tool based on a small list of methods. For a more detailed version, see the Process Planner at www.peopleandparticipation.net.

Helpful links:

- Guidelines on consultation for public sector, sector bodies: www.betterregulation.ie
- Better together: Improving consultation with the third sector: www.cabinetoffice.gov.uk/media/99612/better%20together.pdf
- Practical Guides for planning service user involvement: www.hse.ie/eng/services/sys/SUI/Library/Guides/



Adapted from Better Together (2009)



2.3 ACCESS AND RETAINING PARTICIPANTS

Before you embark on any research or involvement exercise, you will need to think about who you want to participate in it and how you will access that group of people, get them involved and keep them interested. Some question to ask yourself and top tips on improving access are outlined below:

Questions to ask yourself:

- Who do you want to research/consult?
- Will race, class and gender influence people's involvement?
- Can you identify any potential problems with regard to accessing this group?
- Who are the key service users, carers, individuals, groups or gate keepers, who can help you to access this group?
- What is the role of your initial contact, or gatekeepers, in ensuring your continuing access?
- Who do you need to get permission from about involvement?
- How much commitment will you require from the participants in terms of hours, days, weeks or months? Is this reasonable? Would you give up this amount of time for someone else?

How to increase your chances of gaining access to people?

- Ask for advice on the most appropriate way to access the intended subjects.
- Be modest in your requests of people, but be open too about any further involvement they might incur after the initial contact.
- Make full use of your established contacts and those of your colleagues, supervisor, manager etc.
- Consider offering something back to your subjects.
- Ask people to help or participate at the right time, be aware of busy periods.
- Be as clear as possible for doing your involvement exercises, why it will be helpful and what the outcomes might be.
- Minimise non-response – people who refuse to participate in your involvement activity, or who initially agree, but later withdraw. Non-response is not easy to address, but if you think carefully about why people might refuse before you start out, then you can make changes to make it more attractive.



3.0 METHODS FOR SERVICE USER INVOLVEMENT

3.1 CONSULTATION

Consultation is about seeking the views of those outside the decision-making process in order to better inform that process.

Consultation is not intended to be a substitute for decision-making, but reflects the fact that the decision-making process benefits from having the widest range of views and fullest information on a particular issue. Different methods of consultation suit different situations, two of the main methods however include written consultations and online consultations.

3.1.1 WRITTEN CONSULTATIONS

Description:

Written consultations engage with other parties to gather intelligence, ideas and viewpoints on any type of issue. A written consultation asks that a report be made on an issue focusing on certain details, emphasising a key area and exploring possible actions on them (Better Government 2005).

Used for:

They are typically used by organisations to engage the public in current issues.

Suitable Participants:

Non-profit organisations and charities are suitable as outside bodies for consultation on public issues.

Cost:

Costs will depend on whether the exercise is carried out inhouse or by an external consultancy firm.

Time Requirements:

This depends on the nature of the consultation. Any thorough written consultation process can take months and plenty of time should be given to allow a complete report to be produced.

When to use:

- To generate new or different ideas to help decision makers.
- To get a better understanding on issues.
- To encourage greater debate.
- Helps to monitor existing policy and assess whether changes are needed.

When not to use:

- For quick, easy or cheap engagement.

Strengths:

- Generates sophisticated and lengthy responses.
- Can involve a wide range of groups and individuals who have specific interests/expertise.

Weaknesses:

- Can be expensive.
- Will only access certain sectors of the public.



3.1.2 ONLINE CONSULTATIONS

Description:

Online consultations can take different forms. At its simplest, consultation documents can be made available online together with an email address to send responses to.

Online consultation using structured templates is more complex and uses software that is designed to emulate the face-to-face methods used in facilitated workshops. Different templates can be used, for example, to allow participants to brainstorm ideas, identify issues, prioritise solutions, or comment on consultation documents.

The relatively informal nature of online communication can foster both deliberation and build a sense of community. Online consultation enables participants to comment in detail and those commissioning the process to collate responses and present the results back to participants quickly, comprehensively and transparently.

The fact that the participant comments do not need to be transcribed adds real benefit and speeds up analysis.

Used for:

- Online consultation can be used to give a large number of people the opportunity to comment on an issue (e.g. a new policy development).
- It allows information gathering and giving without the constraints that group size or travel can place on face to face events.

Structured Templates allow very large volumes of feedback to be collated, analysed and presented back to participants swiftly and transparently.

Suitable Participants:

- Electronic processes are very flexible when it comes to the number and location of participants, but do not presume that everyone has easy access to the Internet or that everyone can navigate it with ease.
- Organisers must ensure that literacy and/or the 'digital divide' does not prevent participation, usually by organising alternative methods of participation.

Cost:

Hosting an online consultation cuts costs for venues and postage, but has costs of its own. These can include process design, technology set up, or the cost and effort of getting people to participate in online processes. It is still necessary to find and recruit participants in advance of the process.

Time Requirements:

- Most online consultations are only in existence for a few months to discuss a current event or situation.
- Shorter than two months doesn't really leave enough time for participants to contribute while letting the consultation become a permanent feature tends to transform it into an online forum.



When to use:

- When you have a clear idea of what you want to achieve.
- When you are dealing with a large and/or widely dispersed group of participants.
- When you have a well planned strategy of recruitment.
- When your participants are more comfortable participating online than in other ways.
- When general input to decisions; informal sharing of ideas between participants are required.
- When you can offer options for participants to prioritise.

When not to use:

- When you cannot ensure that everyone has the opportunity to join in the process or provide an acceptable alternative means of participating.
- If your primary aim is to build strong relationships.
- When you need intensive deliberation, empowered participants, direct decisions or strong relationships between participants.

Strengths:

- Allows a large number of people to contribute.
- Gives all participants an 'equal voice'.
- Can reach people who are unlikely to respond to traditional engagement methods.
- A quick and accessible mode of engagement from the participants' perspective.
- Allows participants to discuss an issue at their convenience (regardless of location or time).
- Anonymity of online processes can encourage open discussion.

Weaknesses:

- If not carefully planned, online consultations can generate unmanageable amounts of material.
- Excludes people who do not or cannot access/navigate the internet.
- The technology can shape the process rather than vice-versa.
- Written communication can be a barrier for some already marginalised groups.
- Any perceived complexity, such as registration, can be a barrier to participation.



CHECKLIST FOR BETTER CONSULTATION

- Are you clear on the purpose and objectives of your consultation?
- Are you clear on the questions you want to ask in your consultation?
- Have you identified all of the stakeholder groups and individuals that should be consulted?
- Have you chosen the most appropriate and inclusive methods of consultation, including those that meet the needs of 'non-traditional' stakeholders?
- Have you allowed for sufficient resources for the consultation?
- Have you considered all of your legal obligations?
- Have you publicised your consultation in online and offline media?
- Have you allowed sufficient time to give stakeholders an opportunity to consider the issues fully?
- Have you planned how you will analyse the submissions received during your consultation?
- Have you planned to evaluate your consultation process and to ensure any lessons learned are taken into account for the future?

(Better Government 2005)



3.2 COMPLAINTS HANDLING

Description:

This is a management-led user involvement system. The HSE's Feedback Policy to include comments, compliments and complaints is 'Your service Your say'. The policy is provided for in Irish law and ensures that everyone has a right to give feedback about the services they have received (HSE 2009a).

Comments or complaints can be made in the following ways:

- Submission of the 'Your Service Your Say' leaflets that are in each HSE service.
- Telephone the HSE infoline on 1850 24 1850.
- Email yoursay@hse.ie
- Speak directly to a complaints officer
- Talk to any member of staff.
- Comment directly on www.hse.ie

Used for:

Typically feedback from service users is used to help improve the quality of services and to learn lessons from any mistakes made.

When to use:

- To generate new or different ideas to help decision makers.
- To get a better understanding of issues important to service users.
- To encourage greater debate.

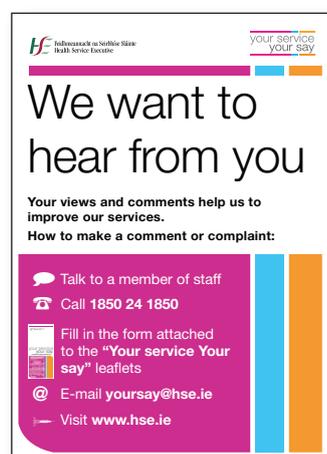
- Helps to monitor existing services and identify where changes may be needed.

Strengths:

- Is a structured system of response to user feedback and complaints.
- Valuable resource because it is restricted to users who have identified possible areas for service improvement, or replication elsewhere.
- Allows a large number of people to contribute to the improvement of services.
- Gives all participants an 'equal voice'.

Weakness:

- Requires staff understanding of the value of feedback.
- Not representative of the complete patient experience, or necessarily the worst or best service experience.
- Service users if vulnerable may not feel confident in commenting on the service.
- Management led.





3.3 JOURNEY MAPPING

Description:

Journey mapping is the process of tracking and describing all the experiences that service users have as they encounter a service or set of services, taking into account not only what happens to them, but also their responses to their experiences. Used well, it can reveal opportunities for improvement and innovation in that experience, acting as a strategic tool to ensure every interaction with the service user is as positive as it can be (NHS 2010).

Journey mapping can challenge preconceptions and help change perceptions, acting as a call to action and contributing to culture change.

Journey Mapping Approaches:

There are three types of journey mapping approaches:

1. Service user experience mapping is a qualitative approach, focused on emotional insights about a service, in order to tell his or her story with passion and narrative. It's a powerful way of engaging both staff and service users.
2. Mapping the system, or process mapping, maps the steps in a process and identifies where to act to make the experience as easy, pleasant and efficient as possible.

3. Measuring the experience is a form of mapping that allows you to determine how well an experience is delivered. It can quantify the effect of changes and contribute to business cases.

The approaches work best of all in combination. Mapping the experience brings the story to life and engages the audience. Comparing this with current processes helps identify priority actions. Adding quantification to this tells how many people are affected and at what cost.

Used for:

- How prospective and current service users use a service and when they interact with staff and the system.
- How service users perceive the organisation at each interaction and how they would really like the service user experience to be.
- How departments and functions need to work together.
- The potential barriers and obstacles that service users encounter.
- How to use this knowledge to design an optimal experience that meets the expectations of major service user groups and achieves competitive advantage.



Diagnostic questions:

Responding positively to any of the following questions signifies the potential in engaging in journey mapping processes:

- Do you have gaps in your understanding of the experience that service users undergo at the moment?
- Would it help you to have high impact feedback to challenge conventional thinking?
- Do you have intractable policy challenges – where you keep trying things but without getting anywhere?
- Do you need to convince colleagues in other functions about the importance of a patient centred approach?

Cost:

- Medium cost depending on whether the mapping is done in-house or by an external consultant.

When to use:

- To improve efficiency within an organisation or service.
- To gain an understanding from the perspective of the service user.
- To identify the interdependencies of processes that interact with the service user.
- To identify the different perspectives and priorities of different user groups.
- To encourage a flexible approach to working to ensure that the process remains aligned with service user needs.

When not to use:

- It cannot deliver an understanding of the wider community as only service users will be consulted.

Strengths:

- It can encourage a more participatory approach to service design and improvement.

Weaknesses:

- Only works for specific services and it may not be seen externally as engagement.



Journey Mapping within the Irish Mental Health Services

The aim of this project is to develop and implement individual care and treatment plans to support recovery in accordance with Standard 1.1 of Quality Framework for Mental Health Services in Ireland (MHC, 2007).

Eleven teams are part of this project, working across a variety of clinical settings including community mental health teams, day hospitals and inpatient units. A team consists of service users, carers and mental health professionals. Key to the project is the active inclusion of service users and carers in all aspects of the collaborative.

The process mapping exercise had two distinct steps and was completed during the pre planning phase. In **step 1** each team mapped the service users' journey from admission to discharge from treatment. Each team was provided with a guidance note on how to complete the process. Results were recorded using a standard template. In **step 2** Service users' opinions on care planning were collected using a questionnaire, developed for the project. This process was facilitated by the local team project facilitators in partnership with the Irish Advocacy Network (IAN). A copy of each process map and service user questionnaires were sent to the project manager and national results collated. At a team level each team was asked to reflect on the process map, service user questionnaires results and to identify key goals for the action period. During a national learning event in May 2010, each team presented their process map and the key findings to each other.

The exercise highlighted a number of common themes across teams including process duplications and complex access routes to the team for service users. One community mental health team noted after the exercise that the "*Processes for ensuring smooth movement through the Service from the first point of contact is unclear*". A number of teams have also used the mapping exercise to develop partnerships with clinicians in other areas including accident and emergency staff to improve the process for service users.

For further details contact Rhona Jennings [Rhona.Jennings@mhcirl.ie]



3.4 DELIBERATIVE WORKSHOPS

Description:

Deliberative workshops are a form of facilitated group discussion that provide participants with the opportunity to consider an issue in depth, challenge each other's opinions and develop their views/arguments to reach an informed end position.

Deliberative workshops are similar to focus groups although there tends to be more focus on deliberation. They can take anything from a few hours to several days to conduct. They are also useful in bringing service users and providers together. Many of the methods suggest a "them and us" involvement, this particular method however is one that provides an opportunity for developing insight and understanding.

Used for:

Deliberative workshops allow for an in depth discussion on a specific topic with a few people over a couple of hours or days.

It allows the organisation conducting the event to have a greater understanding of what may lie behind an opinion or how people's views change as they are given new information or deliberate on an issue.

Suitable Participants:

Deliberative workshops typically involve between 8 and 16 participants. Who is involved will depend on the issue at stake; participants could be selected on the basis of demographics, interest group, or random selection.

Cost:

- Generally, the cost of deliberative workshops is not high, unless you need to recruit participants through truly random selection, which can be costly.
- An incentive may have to be offered in order to get people to participate in the workshop.
- Additional costs include venue hire (choose an informal setting where possible), catering and supporting arrangements, such as childcare.
- Sometimes a deliberative workshop reconvenes on several occasions; which will add to the cost and time requirement.

Time Requirements:

- Low, unless the workshop takes place on several occasions.

When to use:

- To access the informed opinion of a small group of people.
- To observe and track how people's views and perspectives change through deliberation or as they receive information.

When not to use:

- Deliberative workshops only involve small numbers of people and therefore cannot be used to gather statistically significant data to accurately measure public opinion.



- The fact that participants' views are developed through deliberation may also mean that they can be criticised for not being representative of the views of the wider public.

Strengths:

- Allows participants the time and resources to consider an issue in depth, including costs, benefits and long-term consequences.
- Discussing with others gives participants an insight into other perspectives, allowing their own views to be developed and challenged.
- Can build and improve relationships between participants.
- Can give participants new knowledge and skills.

Weaknesses:

- Like all forms of qualitative research, deliberative workshops are open to manipulation: how the discussions/ activities are framed, how the participants are introduced to the topic, and what questions are asked will all influence the results.
- Needs work to overcome any power inequalities and to ensure that participants are comfortable with each other and feel safe.



Conducting a deliberation workshop to assess the implementation of the policy and procedures for the management of complaints in the HSE

The technique of deliberative workshop was used to explore the implementation of the policy and procedures for the management of complaints in the HSE. Two objectives were outlined and discussed through a day long workshop with key stakeholders. For each objective three key challenges were identified

OBJECTIVE 1:

To ascertain what elements are proving to be most challenging in relation to legislation/regulation?"

Top three key challenges identified:

1. Review officer report sent at the same time to the complainant, the complaints officer who investigated the complaint, the Executive and or service provider (as per Section 14.8 of the Regulations).
2. Clinical judgement:
 - Definition of clinical or professional judgement in legislation, what is included;
 - Dealing with complaints regarding clinical judgement internally. Authority of complaints/review officers to deal with clinical judgement issues.
3. Timeframes for reviews are too short:
 - Appointing a review officer within 5 working days;
 - Completing a review within 20 working days.
 - Two or more parts to a complaint and 30 days and 20 day extension (Joint 3rd).

OBJECTIVE 2

To ascertain the challenges encountered while managing complaints/reviews?

Top three key challenges identified:

1. Actions from reviews – are the recommendations implemented. Sharing of learning from complaints.
2. Methodology of complaint investigation.
3. Legal advice in reviews/complaint investigations.

The findings from the deliberation workshop formed part of an overall evaluation of the HSE 'Your Service Your Say' complaints process. For further details contact Rachel.mcevoy@hse.ie



3.5 FOCUS GROUPS

Description:

A facilitator leads a guided discussion of 6-12 people on a specific topic. A typical focus group normally lasts one or two hours and is normally recorded and a report is produced of the process and results. This is then distributed to all the participants. The focus group may be watched by the client or other interested parties.

Focus groups provide useful information on how people respond to particular questions or issues, but the short amount of time limits the depth of discussion that can be had.

Used for:

Focus groups allow for:

- In depth discussion on a specific topic with a few people over a couple of hours.
- A greater understanding to be shared with the service users of what may lie behind an opinion or how people approach an issue.

Suitable Participants:

- Members of the focus group can be selected to be representative of the population at large or of a specific group of the population. It can be a good way of engaging marginalised groups.
- The group needs to be small (6-12) for participants to feel comfortable in voicing their views.

Cost:

- Medium-Low. The cost of focus groups is generally not very high, unless you need to recruit participants through truly random selection, which can be costly.
- An incentive may have to be offered to citizens in order to get them to participate in the focus group.
- Additional costs include venue hire (choose an informal setting where possible), catering and supporting arrangements, such as childcare.

Time Requirements:

- Low. The focus group event itself is relatively short but do not overlook the time required to plan the event, recruit the participants and write up and respond to the results of the focus group.
- If the topic for discussion is complex or largely unknown to the participants you may need to provide reading in advance.

When to use:

Use focus groups when:

- You want participants to interact in a small group.
- You are looking to explore the views of the wider population or specific groups.
- You need to understand the views of groups that would not normally respond to written questionnaires or consultations.



- You want to get the views of people who are not native English speakers (through the use of translators).

When not to use:

Do not use focus groups if:

- You are looking for a detailed exploration of an issue, as some people feel that focus group discussions do not allow enough time to discuss things in depth.
- You are looking for quantitative or fully representative results.
- The participants you want to involve are not comfortable in a group discussion environment.

Strengths:

- High level of participant interaction due to the small size of the group.
- Can lead to a greater understanding of how people think about issues.
- Members can be specially recruited to fit (demographic) profiles.
- Good for getting opinions from people who would not be prepared to give written answers. Focus groups can be useful for getting opinions from non-native speakers, using translators.
- Provides understanding of how people think about issues.

Weaknesses:

- The group may be dominated by one or two strong opinions and who may imbalance the discussion. Some participants may feel inhibited to speak.
- Responses are not quantitative and so cannot be used to gauge wider opinion.
- The term 'focus group' has been used widely and may describe any small meeting of people.
- Excludes participation of people with specific communication difficulties.



Hearing through Focus Groups

In 2010, the National Director of Primary Community and Continuing Care (PCCC) requested a national review of audiology services in Ireland. A key focus of the review is the integration between PCCC, acute services and external agencies involved in the provision of audiology services.

Whilst invitations for written submissions to the national review process were advertised through a number of communication channels (i.e. national newspaper, internet, intranet, social networks etc.), service users were also invited to attend facilitated workshops, and share their experiences of accessing audiology services in Ireland, and to help make appropriate recommendations for the future design, development and delivery of audiology services.

Workshops were held in each of the four HSE regions, targeting adult users, parents of children accessing audiology services and with children and young people themselves. Workshops in Dublin and Galway were facilitated by members of the Health Services National Partnership Forum (HSNPF), and an in-house facilitator was arranged for the workshops in Cork. A local audiology staff member and a parent representative from the steering group were also in attendance at each workshop event.

Three key questions were explored at each of the workshop events:

1. What are the challenges you have experienced since you started to use the service?
2. What aspects of the service do you think work well?
3. What suggestions do you have that would help improve the service?

For further details contact Shirley Keane [Shirley.keane@hse.ie]



3.6 MYSTERY SHOPPER

Description:

A mystery shopping exercise is conducted using volunteers who are trained and pose as service users in typical interactions with staff. The mystery shoppers then record their experience. By compiling the results from multiple mystery shopper sessions you can get a clearer idea of how service users experience a particular service.

Mystery shopping was developed in the private sector but is increasingly used in the public sector. It is recommended to train the mystery shoppers well, preferably over two separate occasions, with the first looking at general skills and the latter dedicated to the specific task that the shoppers will be attempting to carry out (e.g. get advice on a topic).

The task or scenario that the mystery shopper will be working under needs to be well developed so that the shoppers feel comfortable in their role. You should also provide the mystery shoppers with false names and addresses, and provide them with a number they can call in case they are 'caught out' and need to prove that they are legitimate mystery shoppers.

Following the visit the mystery shopper fill in forms recording their experience. These are then gathered and collated. In some cases a follow up event is held with all mystery shoppers to explore common experiences.

Used for:

Auditing the quality of a service using undercover volunteers.

Suitable Participants:

- Participants should be current or potential users of the service in question. They should be adequately compensated for their time and effort. This can be in the form of cash, gift vouchers or other rewards, depending on the circumstances.
- It is important to ensure that the involvement of service users as mystery shoppers is ethically appropriate. For example when the service users are vulnerable groups, young people or people with learning disabilities you need to pay extra attention to the ethical implications of involving them as mystery shoppers.

Cost:

- Varies, depending on the number of mystery shoppers, amount of training needed and what kind of reimbursement they will get.

Time Requirements:

- The recruitment and training of mystery shoppers can be quite labour intensive. There are firms that do this for organisations, but this obviously has cost implications.



When to use:

You should use mystery shoppers when:

- You want to gain an understanding of a service from the service users' perspective.
- You want to create a more service user/user centred culture within your organisation.
- Your users are willing and able to perform the task of mystery shopping.
- Mystery shopping can deliver a better understanding of the service user perspective.
- You have specific criteria/standards that you want to check out/measure.

When not to use:

You should not use Mystery Shoppers when:

- You don't have resources to reward or recognise participants.

- You don't have time to adequately support and train the mystery shopper.
- The mystery shopping role has the potential to be dangerous or unethical.
- You are looking to involve service users over a longer term.
- Mystery Shoppers cannot deliver long term involvement.

Strengths:

- Powerful way of gathering service user perspective.

Weaknesses:

- Limited to assessing services, cannot advise on what needs to change.
- Limited short term involvement.

Making a comment, compliment and or complaint within the acute hospital setting investigated:

In 2008, a mystery shopper study was carried out to critically assess the process service users go through in order to find the necessary information on how to make a comment, compliment and or complaint (CCC) about services received within the Health Service Executive (HSE) Acute hospital sector. It explored the extent to which local 'Your Service Your Say' information resources are accessible and well signposted so that service users can find the necessary information for themselves. The research for this study was collected from mystery shopping assessments; onsite hospital audits, and questionnaire surveys. The study is available to view in the HSE Lenus Library.

For further details contact Rachel McEvoy [Rachel.mcevoy@hse.ie]



3.8 SERVICE USER PANELS

Description:

Whilst more commonly referred to in the literature as a 'consumer panel' or 'consumer forum', 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.

Service user panels usually take the form of a workshop and it is important to outline a clear purpose and the time required for participants' involvement right from the beginning (HSE 2009).

There also needs to be very clear lines of feedback between the panel members and the decision-makers.

Used for:

- Getting users' views on their experiences and expectations of services and testing their reaction to changes and proposals.
- It can also be used to find and generate ideas for improvements.

Suitable Participants:

- A user panel should be relatively small to allow quality interaction between participants.
- Some organisations recruit a large pool of users so that they can draw out smaller groups to be consulted on a particular issue.

- These groups can be targeted to reflect certain subgroups of users, such as people with disabilities, or ethnic minorities.
- It is best to include a diverse range of users in the panel, being mindful of the Equal Status Acts 2000 and 2004.

Panel members should not remain on the panel indefinitely, after a while participants tend to become too knowledgeable about the service delivery organisation and may come to identify with it and so lose credibility with other users.

Cost:

- The panel needs to be facilitated in a neutral way and panel members should at least receive their expenses.
- Arranging free transport to and from meetings can be appropriate, especially if the service users are the elderly or health care users.
- It is hard to assess the costs of running a panel as it depends greatly on whether or not you have in-house facilitation skills, where the groups meets, how large it is and how often it meets.

Time Requirements:

- User panels are usually ongoing (with participants being replaced as time goes on). A member of staff will need to provide support for the panel.



- The accountability and credibility of the panel can be increased if you allow time for representatives to refer back to wider user groups.

When to use:

- You should use user panels when you are working with people who are not usually heard, for example those with learning disabilities, children, and the elderly.
- When you want to establish a two-way dialogue between service providers and users.
- When you want to set up a sounding board for new approaches or proposals relating to services.
- As a way of identifying emerging problems.
- As a sounding board on which to test plans and ideas, relatively quick feedback and continuing dialogue with service users.

When not to use:

- When service providers and planners do not support the work and are unwilling to respond to recommendations and consider implementing change.
- When service providers and planners see user panels as the only way of getting user feedback.

- When you want to gather statistical information.

Strengths:

- Changes can be tracked over time.
- Most people can participate with the help of an interpreter, advocate, carer.
- Solution focused.
- The panel members are well informed on the issues.

Weaknesses:

- Time consuming/long-term commitment.
- The panel is not necessarily representative.
- A small number of people may dominate the group.
- May not take into account relevant needs of non-users of services.

A document highlighting 'Best Practice Guidelines for Establishing and Developing Service User Panels in the Irish Health Services' (2008) is available for download at www.lenus.ie or at www.hse.ie



A service user panel established and delivering results in Luke's Hospital, Co Kilkenny

The service user panel in St. Luke's Hospital, Kilkenny has achieved many tangible outcomes since its inception. The most highlighted outcome from both data collection methods was the appointment of a Patient Liaison Officer, and the sense of pride in this particular outcome was highly evident during both focus groups.

Other outcomes highlighted include:

- The appointment of a complaints officer;
- The acknowledgement of the group as a force for change;
- The development of a Care of the Dying Hospital Initiative;
- The incorporation of patient views at various levels in developments and strategy initiatives in the hospital;
- Development of a Patient Information Booklet;
- Patient representation on a number of sub-groups and committees in the hospital, for example, maternity;
- Involvement in the development of the new Out-Patients Block
- Change in visiting hours;
- Improved communication between the hospital and its service users.

Hospital forum promoting greater service user involvement

A 10-person forum made up of service users and heads of different sections of Ennis Hospital is working behind the scenes at the hospital to promote and encourage service user involvement in all aspects of their care.

As a result of the forum the hospital has developed service user folders for all wards and departments within the hospital and are currently in the process of information sessions for staff towards improving the service user experiences.

Councillor Considine explained that earlier this year the hospital sought service users of the hospital to join an advisory committee. *"I was anxious to join this. I had personal experience of Ennis hospital's service last year and my life was saved there. I knew for certain that I wanted to be involved in this forum. While my experience in the hospital had been good, obviously during my stay there I made certain observations, which are informing my contribution and discussion on this forum"*.

The Forum has one main committee, on which all members sit, and a number of sub-committees, including hygiene, which focus on certain aspects of the hospital. For further details contact.



3.9 ONLINE FORUMS

Description:

Online forums, are sometimes referred to as message boards, web forums or chat rooms provide a space for online debate and discussion. The discussions on forums are usually organised by 'threads', that is responses to an initial message are displayed sequentially.

Used for:

Discussions on online forums can fill a variety of roles. They can be hosted by decision making organisations or independent organisations.

Decision makers might for example present the various options they are considering for a decision and solicit comments about people's preferences. Alternatively an online forum can be used to discuss an issue before concrete options have been developed to inform thinking. Discussion forums can also be used for more general conversations or as a tool for community self-organising.

Suitable Participants:

Online forums can be open to all who wish to take part or limited to specific groups.

A key challenge can be to get enough activity on the forums. In general it can take some time before people begin to post messages as opposed to just reading what others have written. If the forum is under-used chances are that people will not spend much time on it.

Solutions to this include identifying and encouraging active users to post, providing options for registering agreement with existing posts for those visitors who do not feel comfortable posting their own message and choosing topics which are likely to engage participants.

Cost:

The cost of running an online forum varies. However, it does not have to be high, so it can be a quick and easy way of gathering public feedback on an issue. However maintaining an online presence so that people are aware of the forum's existence can have costs attached to it, as can staff time to set up and moderate the forum (see below).

Time Requirements:

The time required varies. If a forum becomes successful it can be highly intensive to manage. Forums require moderation, which is someone to maintain control over what is posted on the site to ensure that nothing inappropriate or illegal is posted.

When to use:

- When you want to explore people's perceptions of specific options.
- When you want to have an open discussion about an issue.
- When your intended participants are willing to engage online.



When not to use:

- When some of your intended participants are unable or unwilling to use the internet.
- When you do not have the time or resources to moderate the forum.
- When you are looking for in-depth deliberation.

Strengths:

- Participants can access it at any time.
- Anonymity of internet can help people feel comfortable stating their views.
- Feedback can be gathered quickly.
- Online forums combine the spontaneity of verbal communication with the clear records of written communication.

Weaknesses:

- Limited deliberation on online forums, many people just post their comments and do not engage with what others have said.
- Limited to those with internet access.
- Can be difficult to get people to post.
- Requires moderation – un-moderated Online Forums are often chaotic but anonymous and unaccountable moderators can also frustrate participants.



SpunOut.ie has become a major force in effectively reaching, engaging and supporting young people when it comes to their health and wellbeing. **SpunOut.ie** provides information, support and opportunities to over 500,000 users per year and is now being recognised internationally, with interest from health services abroad.

The **SpunOut.ie** Online Forum is a friendly and non-judgmental space where young people can anonymously vent, seek peer-to-peer support, and get further information about their particular issues from well trained Forum Moderators. Sub-sections of the SpunOut.ie Forum include: Activism, Politics, Protest; Sex & Relationships; Alcohol & Drugs; Everything Goes!; Mind Matters.



Forum traffic shows an interest in interacting about a wide variety of topics, some weeks presenting more heavy hitting issues, while others touch on more fun and light-hearted topics.

Strongest Forum Benefits:

- Safe space for anonymous discussion and support.
- Guaranteed 24 hour response time from Moderators; realistically much quicker.
- Clear evidence of young people being signposted to support.

Sample of User Feedback:

- *I'd like to thank you all so much for the replies, advice and support on here, this site and forum is amazing!!*
- *It feels like yesterday when I stumbled across this site and was debating with myself for days on end whether or not to post something. I'm glad I did though, it's just so easy to talk here and even though sometimes I feel like I'm whining or even looking back on some of the don't know how you's made sense of them. But I really have to thank you's all. You've been brilliant really and if I didn't have here to just let it out a bit, I don't know what I do. So thanks guys.*
- *cheers alllllll 4 ur advice feel so much more confident in wat 2 do.*

In order to be clear that the [SpunOut.ie](https://www.spunout.ie) Forum is NOT a support service, it is clearly state that:

"This forum does not provide counselling or online professional support. [SpunOut.ie](https://www.spunout.ie) staff and volunteers cannot offer advice, support or counselling."

[SpunOut.ie](https://www.spunout.ie) recently sharpened this disclaimer in order to prevent young people in grave crisis coming to us for more interactive, immediate and direct support, as we are not equipped to address this level of service. The new disclaimer is viewable clearly throughout the Forum.



3.10 SURVEYS

Description:

The word survey is used most often to describe a method of gathering information from a sample of individuals. The sample is usually just a fraction of the population being studied. Surveys can be classified by their method of data collection. Postal, Electronic, telephone interview, and in-person interview surveys are the most common.

Used for:

Surveys should be seen as part of a quality improvement process, which includes evaluation and dissemination of results to key players, consultation and development of plans for improvement, implementation of plans, and re-evaluation to measure gains and identify new priorities for improvement. However, all too often this does not occur as surveys are carried out in isolation and consequently they are frequently seen as irrelevant. The ability to continuously monitor patient satisfaction would represent a step forward in the measurement of patient's experience.

Cost:

The cost of running a survey varies according to:

- Method of delivery (i.e. postal/telephone/email).
- Size of population being surveyed.

Online survey present a relatively inexpensive survey option, particularly for larger samples. The turnaround of results is quick and the interactive element of this methodology offers the opportunity to explore issues more creatively.

Time Requirements:

- Will be determined by the size and complexity of the survey.

When to use:

- When you wish to reach a large number of respondents with relatively minimal expenditure.
- When you want to explore people's perceptions of specific options.

When not to use:

- When you are looking for in-depth deliberation.

Strengths:

- Anonymity of surveys can help people feel comfortable stating their views.
- Feedback can be gathered quickly.



Weaknesses:

- Can be difficult to get people to complete and return surveys.
- Limited room to explore people's experiences or clarify questions if required.
- Complex data collection and interpretation require good organisation and can be quite timely.
- No explanation as to why respondents think in a particular way.

The following websites are particularly useful if exploring the use of surveys:

www.surveymonkey.com

SurveyMonkey is one of the leading providers of web-based survey solutions

www.pickereurope.org/surveys

Picker Institute Europe has expertise in measuring experiences of healthcare - those of patients, staff and the public.

INSIGHT 07

Following on from the Health Service Executives (HSE) national survey of Emergency Departments, the HSE published 'INSIGHT 07', a national survey of consumer satisfaction with the health and social care services in Ireland

Commissioned by the HSE and carried out by the School of Public Health and Population Science in University College Dublin in partnership with Landsdowne Market Research, this was the first time that a study of this scale has been undertaken among a nationally representative sample of people who have used the HSE's hospitals and community services.

The survey involved detailed face-to-face interviews with 3,517 people across the country who were asked about their experience of the public health and social care services during the 12 months preceding the survey. The results clearly show that there is strong satisfaction with health services and a high degree of confidence and trust in health professionals.

For further details contact June Boulger [june.boulger2@hse.ie]



4.0 WHEN ENGAGING IN SERVICE USER INVOLVEMENT PROCESSES

4.1 DO:

- ✓ Remember, improving service user involvement involves changing minds – positive attitudes and behaviours make a difference.
- ✓ Ensure senior leadership and commitment.
- ✓ Ensure effective channels of communication. Communication will not just happen, it must be planned, and actively encouraged and promoted.
- ✓ Select the method of involvement that matches the purpose you have identified and the needs of the service users.
- ✓ Employ a range of different communication methods to include those for whom English is not their preferred language of communication and for service users with sensory disabilities.
- ✓ Ensure that participants, particularly those whose voices are seldom heard, are given an opportunity to participate in inclusive and diverse ways. Remember there should be no discrimination of membership, or recommendations to service providers, on the nine grounds outlined in the Equal Status Acts 2000 and 2004.
- ✓ Ensure that resources, including staff time, are factored into the plan at the outset.
- ✓ Establish terms of reference (ToR), as these will 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.
- ✓ Use feedback to identify what is working well – recognise, reward and promote good practice (Picker Institute Europe 2009).
- ✓ Ensure a 'process' and 'outcome evaluation' of the respective service user involvement process 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.
- ✓ Build ongoing opportunities for dialogue with organisations/groups representing service users.



4.2 DON'T:

- ☒ Expect a 'quick fix', changing minds takes time, and by creating a structured approach you will be able to monitor success.
- ☒ Decide upon a method of engaging and collating feedback without understanding the context, business case and ongoing costs.
- ☒ Ignore the need to invest in capability and capacity to implement a sound approach.
- ☒ Use technical jargon. Plain language must always be used. It should be jargon free and without abbreviations to ensure understanding. Jargon has the potential to intimidate service users and subsequently can prevent members from engaging with the person using it.
- ☒ 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.
- ☒ Ignore previous relevant service user involvement processes/outcomes. There is a high risk of contributing to "consultation fatigue" among many individuals and groups of service users who have offered their views before but haven't seen any resultant change.



4.3 10 GUIDING PRINCIPLES FOR WORKING TOGETHER

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. Recognise existing agency and community obligations, including statutory requirements.
5. Encourage openness and the ability for everyone to take part.
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. Effectively manage change 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 (National Standards for Community Engagement 2008).



4.4 10 GUIDING PRINCIPLES FOR COMMUNICATING WITH THE DEAF IRISH SIGN LANGUAGE COMMUNITY

1. Always ask the Deaf person how they want to communicate, never assume.
2. Make good eye contact. Look directly at the Deaf person. Don't look away, cover your face, chew gum or have a pen in your mouth etc. when communicating with a Deaf person.
3. Ensure the Deaf person is looking at you before you attempt to communicate.
4. Don't stand with a light or a window behind you. The light needs to be on your face.
5. Be responsive: nod rather than saying 'hmmm'. Use gestures, body language and facial expressions to communicate the emotion of a message where appropriate.
6. Speak clearly and at a slightly slower pace, but don't shout or over-enunciate mouth movements as this will distort your lip patterns. Keep your head fairly still.
7. Relax and be patient. If you're really stuck, you can write something down.
8. Be prepared to repeat and rephrase information.
9. Refer to visual information during conversations.
10. Best of all: learn some Irish Sign Language (CPA & Deaf Society 2005).



4.5 10 COMMANDMENTS WHEN COMMUNICATING WITH CHILDREN AND YOUNG PEOPLE

1. Question your own beliefs about children and young people.
2. In all communication use clear and simple (not patronising but jargon free) language.
3. Welcome their views and reassure them that being critical of a service will not mean that they will be refused a service.
4. Let them know that they can ask their parent or another responsible adult to ask questions or make comments on their behalf.
5. Be mindful of the needs, rights and responsibilities of parents/guardians who influence and are impacted by your interaction with the child or young person. For information on consent, confidentiality and specific methodologies: www.hse.ie/go/workingwithchildren
6. Be clear about the limits of your relationship. It is important to build up trust but do not offer anything that cannot be delivered or maintained. Remember, the child/young person may have mixed experiences of relationships developed with service providers and other adults.
7. Always demonstrate evidence that changes have been brought about through children and young people's involvement.
8. Only put in place participation structures that can be supported and maintained. Children and young people should only be invited to participate in such structures if they are given a clear mandate and opportunity for direct impact/change.
9. Children and young people are diverse. Ensure that your approaches give due consideration to age, gender, ethnicity, culture and ability.
10. Avail of training where possible. Useful resources on best practice and specific guidelines can be found on: www.hse.ie/go/workingwithchildren

The above commandments are sourced from the HSE Working with Children and Young People a Quick Guide for Frontline Staff. The Guide aims to raise awareness of the responsibilities of all frontline staff in relation to your work with children and young people. More details are available from www.hse.ie/go/workingwithchildren

For further details contact Celia Keenaghan [celia.keenaghan@hse.ie]



5.0 ADDITIONAL RESOURCES

Weblinks:

<http://www.hse.ie/eng/services/ysys/SUI/Library/>
www.peopleandparticipation.net
www.involve.org.uk
www.pickereurope.org/index.php
www.library.nhs.uk/ppi/

Contacts:

June Boulger
National Lead for Service User Involvement
Consumer Affairs Corporate Office
HSE
june.boulger2@hse.ie

Rachel McEvoy
Research Officer
Consumer Affairs
HSE
Rachel.mcevoy@hse.ie

Dr. Celia Keenaghan
Lead for Child and Youth Participation
Children and Families Social Services
HSE
Celia.Keenaghan@hse.ie

Ann Breen*
Senior Medical Scientist
HSE
Ann.breen@hse.ie

Brid Boyce**
Hospital Accreditation Manager
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 thesis 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.

Additional Resources.



There are further local resources within Change & Process (HSE Change Hub), Health Services Partnership Forum (HSNPF) or Performance and Development that might be of help when engaging in service user involvement processes, processes which for many will require organisational change (see below for relevant contact details).

The HSE **Change Hub** is an on-line resource offering practical assistance and advice on managing change in the Health & Social

Care Services. In addition to a complete set of tools and templates required in managing any change project, the **Change Hub** enables collaborative working through secure on-line sharing of documents and project material as well as engagement and feedback opportunities on all aspects of change and service improvement in the Health and Social Care Services. First time users to the **Change Hub** will need to register on www.hseland.ie and then click on the blue **Change Hub** icon.

Name	Address	Phone	Email
Sé O'Connor Asst. National Director of Organisation Development & Design	Corporate Change & Process Unit, Health Services Executive, Room 228 Dr. Steevens' Hospital, Dublin 8.	(01) 635 2372	se.oconnor@hse.ie
Patricia Blunden Project Manager HSE Change Management Resources	Change & Process Health Services Executive, 2nd Floor, Block B, Civic Centre, Bray, Co. Wicklow.	(01) 274 4202	patricia.blunden@hse.ie
HSE Dublin Mid Leinster			
Mary Sheehan Area Head Organisation Development & Design - HSE DML	ODD Unit, HSE Dublin Mid Leinster, Oak House, Limetree Avenue, Millenium Park, Naas, Co. Kildare.	(045) 880 410/ 446	mary.sheehan2@hse.ie
Denise Keoghan Organisation Development & Design, HSE DML	ODD Unit, HSE DML Unit 4, Central Business Park, Clonminch, Tullamore, Co. Offaly.	(057) 935 7835	
Jennifer Garry, Organisation Development & Design, HSE DML		(057) 935 7891 086 381 1513	



Name	Address	Phone	Email
Oliver Smith Partnership Facilitator	C/O Dermot Hehir's Private Rooms, Arden Road, Tullamore, Co. Offaly.	(057) 932 7177	osmith@hsnpf.ie
Teresa Hanley Partnership Facilitator	Adelaide & Meath Hospital (incorp. NCH), Tallaght, Dublin 24.	(01) 414 5925	thanley@hsnpf.ie
Karen Lodge Partnership Facilitator	Human Resources Department, Oak House, Limetree Avenue, Millennium Park, Naas, Co. Kildare.	(045) 880 400	klodge@hsnpf.ie
Liz White Partnership Facilitator	Block B, Civic Centre, Main Street, Bray, Co. Wicklow.	(01) 274 4329	lwhite@hsnpf.ie
Seosamh Ó Maolalaí Partnership Facilitator	3rd Floor, Block 2, Phoenix House, Conyngham Road, Dublin 8.	(01) 616 7407	somaolalai@hsnpf.ie
HSE Dublin North East			
Caitriona Heslin Area Head Organisation Development & Design - HSE DNE	ODD Unit, Dublin North East, Dublin Road, Kells, Co. Meath.	(046) 928 0533	caitriona.heslin@hse.ie
Michael Kelly Partnership Facilitator	3rd Floor, Block 2, Phoenix House, Conyngham Road, Dublin 8.	(01) 616 7409	mkelly@hsnpf.ie
Rosaleen Kelly Partnership Facilitator	Partnership Office, 25A/B Rosary House, Mater Misericordiae Hospital, Eccles Street, Dublin 7.	(01) 803 4174	rkelly@hsnpf.ie
Carol O'Reilly Partnership Facilitator	3rd Floor, Block 2, Phoenix House, Conyngham Road, Dublin 8.	(01) 616 7408	coreilly@hsnpf.ie



Name	Address	Phone	Email
Eilish McKeown Partnership Facilitator	3rd Floor, Block 2, Phoenix House, Conyngham Road, Dublin 8.	01 616 7400	emckeown@hsnfp.ie
Jo Hardwick Partnership Facilitator	Admin Block, St. Mary's Hospital, Phoenix Park, Dublin 2.	01 6234679	jhardwick@hsnfp.ie
Mai Kearns McAdam Partnership Facilitator	2nd Floor, St. Theresa's Nurses Home, Our Lady of Lourdes Hospital, Drogheda, Co. Louth.	041 9875207	mkearnsmcadam@hsnfp.ie
HSE South			
Judy Foley Area Head Organisation Development & Design - HSE South	ODD Unit, HSE South, Aras Slainte, Wilton Road, Cork.	021 492 3719	judy.foley@mailp.hse.ie
Lesley Hewson Partnership Facilitator	C/O Administration Office, Kilcreen Orthopaedic, Hospital, Kilkenny.	087 6471087	
Anne Nee Partnership Facilitator	Partnership Office, Front Block, St. Patrick's Hospital, John's Hill, Waterford.	051 848791	anee@hsnfp.ie
Dolores Geary Partnership Facilitator	Partnership Office, HSE South, Floor 3, Áras Sláinte, Wilton Road, Cork.	021 4923753 021 4923724	partnershipcuh@hse.ie
HSE West			
Libby Kinneen Area Head Organisation Development & Design- HSE West	ODD Unit, HSE West, Nurses Home, Merlin Park, Regional Hospital, Galway.	091 775 953	libby.kinneen@hse.ie
Brendan Murphy National Organisation Development & Design Manager - HSE West	ODD Unit, HSE West, Partry House, Parnell St., Limerick.	061 312 700	brendanm.murphy@hse.ie



Name	Address	Phone	Email
Vera Kelly Organisation Development and Design Consultant – HSE West	ODD Unit, HSE West, Nurses Home, Merlin Park, Regional Hospital, Galway.	(091) 775 953	Vera.kelly@hse.ie
Marie O'Haire Partnership Facilitator	31-33 Catherine St., Limerick Limerick, North Tipperary, Partnership Office, Mayo General Hospital, Castlebar, Co. Mayo.	(094) 904 2338	mohaire@hsnpf.ie
Michele McGirl Trainer/Facilitator	Performance & Development Saimer Court, Ballyshannon Co. Donegal.	(071) 982 2100	Michele.mcgirl@hse.ie
Billy Gallagher Partnership Facilitator	Training Centre, Kilmacrennan Road, Letterkenny, Co. Donegal.	(074) 912 2033 / (074) 912 9371	bgallagher@hsnpf.ie
Eamon Naughton Partnership Facilitator	National Federation of Voluntary Bodies, Oranmore Business Park, Oranmore, Co. Galway.	(091) 792 316	enaughton@hsnpf.ie
Esther-Mary D'Arcy Partnership Facilitator	HSE Western Area Partnership Office, West City Centre, Seamus Quirke Road, Galway.	(091) 548 391	emdarcy@hsnpf.ie
Marian Doran Partnership Facilitator	HSE West, C/O Health Promotion, Saimer Court, Ballyshannon, Co. Donegal.	(071) 985 2000 087 997 9280	marian.doran@hse.ie
Siobhan Patten Area Performance & Development Manager, HSE West	Performance & Development HR Building, Merlin Park, Galway.	(091) 775 489	Siobhan.patten@hse.ie
Karen Crawford Training Officer	Performance & Development, Saimer Court, Ballyshannon Co. Donegal.	(071) 982 2100	Karen.crawford@hse.ie
Anne Broderick Senior Executive Officer	Performance & Development HR Building, Merlin Park, Galway.	(091) 775 865	Anne.broderick@hse.ie

**SERVICE USER INVOLVEMENT METHODS
A GUIDANCE DOCUMENT**



Name	Address	Phone	Email
Mona Eames Senior Executive Officer	Performance & Development HR Building, Merlin Park, Galway.	(091) 775 866	Mona.eames@hse.ie
Elaine O'Doherty Training Co-Ordinator/Facilitator	Performance & Development, Millenium Court, Pearse Road, Letterkenny, Co. Donegal.	(074) 912 3653	Elaine.odoherty@hse.ie
Marie Liston Support Services Training & Development Co-ordinator	Performance & Development, Saimer Court, Ballyshannon Co. Donegal.	(071) 982 2100	Marie.liston@hse.ie
Anne Hargadon Trainer	Performance & Development Saimer Court, Ballyshannon Co. Donegal.	(071) 982 2100	Anne.hargadon@hse.ie
Head Office Based			
John McAdam National Coordinator, HSNPF	3rd Floor, Block 2, Phoenix House, Conyngham Road, Dublin 8.	(01) 616 7405	jmcadam@hsnpi.ie



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