



Patient Information Forum

For everyone involved in health information and support

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Methods for involving users: an introduction

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Best practice has identified that involving users at every stage of information development results in more effective health information materials.

This means involving users from identifying the need for and purpose of your resource, through developing the format and content, to disseminating and evaluating your materials.

Listening to, and engaging with, users are both core parts of information provision. User feedback helps you:

- Get to know who the users are
- Better understand their information needs
- Assess what they think of your health information
- Understand the impact of your health information
- Correct problems and make improvements

This guide provides an introduction to the most common methods for involving users:

- [Focus groups](#)
- [Online surveys](#)
- [Individual interviews](#)
- [Informal Feedback](#)

A [further resources](#) section at the end of the guide contains links to more detailed information and support.

An approach that uses a range of different involvement techniques at different stages, is the best way of getting feedback from wide variety of users at different levels and points within your project.

Planning when and how you will involve users at the start of the project is important. It is also key to agree beforehand the purpose of your user involvement – what questions you want to answer. For example, do you want to co-produce your resource with your users; test understanding of a particular health message; or identify gaps in the current provision of information support?

1. Focus groups

What is a focus group?

A focus group involves a moderator guiding a small group of people through a discussion. The aim is to get a clear insight into their behaviours, attitudes and often preferences. The group

environment stimulates people's thoughts and opinions and encourages sharing and debate.

Why?

Focus groups are a powerful way of exploring beyond yes/no or one-line answers. The aim is to glean as many ideas and opinions as possible, and get a clear understanding of what participants think.

In the world of health information, focus groups are a very useful way of asking potential users what they want. At the start of an information project or service development, you can ask users what they think of current provisions and new proposals. Participants can then help brainstorm new ideas and prioritise options. Without this process, you cannot be sure that your service is what users want or how they want it.

Some information providers are reluctant to use focus groups. Reasons for this include:

- Costs
- Time constraints
- Difficulty recruiting representative users
- Assumption that they already know what users think

These may be valid concerns. Nevertheless, anyone who has witnessed a focus group will be impressed by the insight it gives them and the value it adds to a project. It is far better to spend the time and money getting a project correct at the start, rather than to discover later on that it has missed the mark.

Who?

Focus groups tend to be made up of 6 – 10 people who do not know each other. The number of participants needs to be enough to allow a useful discussion, but small enough to manage and to allow everyone to contribute.

The choice of participants should reflect the target audience and may or may not be representative of the general population.

Ideally, more than one focus group is needed to get valid results, particularly if the target audience consists of disparate groups. It is better to conduct separate sessions with each audience group. If participants are amongst people of similar background and experience they are more likely to relax and contribute openly.

How?

Any focus group needs careful planning to ensure it yields the information you are looking for. The resources section below lists some very helpful guides explaining more about setting up this type of research.

A clear discussion guide is crucial, focussing on key questions or topics. Groups tend to be 45–90 minutes long. Any more than that and people start to droop and the discussion is less productive.

Groups can be divided into, for example, gender, age, experience, or background. However, care must be taken to recruit representative participants.

To increase the likelihood of people taking part, make it easy for them. This is particularly important if you are to recruit beyond the same old engaged, eager and familiar faces.

Consider holding groups in the evenings for those that work or look after children during the day. Make the venue easy to get to, with parking or good public transport links. Try to find local venues, such as libraries and community centres. Consider offering services such as childcare or an interpreter.

As in all consumer research, participants must be able to understand and respond to the questions. As a rule, good questions:

- Sound conversational
- Use words participants would use
- Are easy to understand
- Are clear

- Are short
- Are open-ended (*For example 'What sort of information were you given when diagnosed' as opposed to 'Were you given information when diagnosed'.*)
- Are one-dimensional (*The question asks one thing only and it doesn't group things that may be perceived as different. For example, asking if something is "useful and practical" might be confusing as some people interpret these things as different.*)
- Include good directions. (*Are you asking them to rank something, write something down, answer verbally.*)

The group moderator should have skills and experience in conducting consumer-focused research.

It is also crucial that they have a clear understanding of the purpose of the research, and the nuances of what is needed. It is best to involve the moderator closely when developing the discussion guide.

Ideally an assistant moderator also attends the focus group, to help organise participants when they arrive and take notes and run the recording during the group.

When they arrive, participants should be asked to sign a consent form that includes an explanation of the research and a confidentiality agreement. Often a fee is paid to participants,

typically ranging from £30 – £50. The moderator starts the group using a prepared script to welcome everyone, explain the purpose of the group, and set ground rules.

The topic can then be introduced and opening questions used to engage participants and make them feel comfortable. Then the moderator can start to explore opinions, behaviour and attitudes.

The discussion can end with a summary of headline messages, and questions to check if anything was missed in the discussion.

The skill of the moderator is to steer the discussion through the planned questions within the allotted time. He or she must also put participants at ease and create an accepting environment where people feel able to be open and honest.

The moderator should be able to respond to the group's thoughts and ideas in a non-judgemental way and ensure everyone is able to contribute.

Soon after the focus group, the moderator should complete a detailed report of the session. This will usually include headline findings, detailed discussions and direct quotes from participants.

Focus groups can also be held online, using conferencing software. This can make logistics easier for some people, and sensitive issues may be easier to discuss without being face to face.

2. Online survey

What is an online survey?

Online surveys are questionnaires that can be sent out and completed over the internet. They can be used to collect quantitative and qualitative data.

Why?

Online surveys are valuable for collecting information about people's attributes and attitudes. They tend to be used to either:

- Gather demographic or behavioural details – such as who or why people are using a website
- Gain insight into a specific product or service – such as customer satisfaction, product evaluation or to test new concepts.

Surveys are an invaluable tool to get feedback from potentially a large number of people quickly and cheaply. Questionnaires can range from being short and snappy to complex and in-depth. These days, online tools make surveys very straightforward to conduct and take part in.

Information producers may be concerned that such surveys will be expensive, time consuming or not worthwhile. However, online surveys are relatively cheap because you can set them up without using an external research agency.

They are quick because people tend to respond within a few days, and the responses are processed and available automatically. Respondents can take part in the survey when and where they choose.

Some sites also claim that respondents are more honest with their opinions because they are not face to face with a researcher.

Who?

When setting up an online survey, decide who you want to hear from. You can aim for a large audience or you can hone in on smaller defined groups.

For example, you might want current users or those that have not used your service before.

Bear in mind there will always be certain groups of people who won't or can't take part in online surveys: those with poor reading or IT skills; those who do not have access to the internet.

One major obstacle for any survey is how to get accurate representative feedback, whether it's from the general public, current customers, or a specific sub-group.

How?

There are many companies that offer online survey functions, either on an external survey site or embedded within your own site. Some basic options are free of charge; others you will have to pay for.

You may also need to establish if there is a response bias: those 'visible' online may not be representative of the needs and views of the 'less visible' users. Indeed, some large, open and free websites find that users remain silent despite requests for feedback.

Is a group of your audience too busy to take part, or not engaged with your organisation? Or are people only responding because they want to complain or because they are familiar with your service?

Care must be taken to recruit representative participants and avoid tokenism. Also, it is important to understand the demographics of who have taken part and, hopefully, who has not. The number of responses you need will depend on the heterogeneity of the users.

The companies listed in the resources section are not endorsed by PiF, but they do offer lots of advice on how to design and set up surveys.

A survey questionnaire must be designed very carefully to get the data you need. Decide what the aims of the study are and phrase these as clear direct unbiased questions or measurements.

Write the questions carefully. Use clear language the participants will understand, and ask clear questions.

In order to keep your survey focused and to the point ask yourself what you are going to do with information that question gives you. If you are not sure then the question may be unnecessary, or need to be re worded so that it provides you with information you can use.

It can be useful to test your survey with a group of target responders before sharing it more widely. This will help you check that the questions make sense to your target audience and that the responses you get will provide information and feedback that you can use.

Choose the question type to best suite your needs. These include:

- Multiple choice
- Drop down lists
- Open ended text questions or comments boxes
- Star rating
- Drag to order list ranking
- Matrix or table grids.

Consider how you will contact respondents. If you want to involve current known customers you may be able to contact them directly, by email, text, social media or even by post.

You can also advertise a survey more generally by posts on news groups, web communities, QR codes, newsletters and social media.

It's usual to give respondents a few weeks to take part in a survey. To maximise response rates, experts recommend personalising survey invitations, sending reminders and making the survey short and simple. Also promote the survey on social media and member forums.

To encourage respondents to take part think about what the benefits to them might be. For example they will be able to influence your health information to make sure it addresses their questions. An incentive can be used, such as a prize.

This can also be something you cover in the testing phase of your survey, asking your test respondents what would be the key things that make them want to complete your survey.

Many online surveys can be set up to provide instant data, as and when respondents complete a questionnaire. When the survey has been closed, a detail report is then provided.

It is a good idea to give respondents an honest idea of the length of time the survey may take them to complete, and/or show their progress within the survey itself.

3. Individual interviews

Interviews can be used to collect valuable qualitative feedback. They can be conducted face-to-face or by telephone, and can be as structured or in-depth as necessary.

This type of engagement allows detailed questions to be asked, while further probing and the freedom to let the discussion evolve can provide rich data. Complex and unknown issues can be explored, although sensitive issues maybe challenging.

Key benefits of face-to-face interviews are that they do not require participants to have literacy or computer skills, and interpreters can be employed if necessary. Also, non-verbal data can be collected through observation.

However, they can be expensive and time consuming. Care must be taken to reduce interviewer and interpreter bias and to ensure they are administered in a standardised way.

User-testing health information can be carried out during face-to-face individual interviews. It is a powerful way of watching a resource being used and gathering in-depth feedback

Telephone interviews can yield just as accurate data as face-to-face interviews, and are cheaper and faster.

However, interviewers may need to make repeated calls to get through. There is also a bias towards those who are at home. This method is only suitable for short surveys and those with access to a telephone.

Telephone interviews can be a very productive way of engaging with stakeholders who perhaps do not have the time or inclination to take part in questionnaires or face-to-face meetings.

A discussion guide can help ensure each interview addresses the key topics. It is important to ensure an accurate record is kept of each interview.

As with all user involvement, care must be taken to recruit representative participants.

4. Informal feedback, such as forums, user groups

What?

Informal feedback can come from anyone, via any route. This may be current users or non-users, the public or professionals. It can be via conversation, letter, telephone, email, websites, online communities and social media.

Why?

Developing relationships and maintaining on-going dialogues with users is a great way of understanding their needs. Informal feedback routes can be an easy, low-cost way of doing this.

They allow you to constantly listen to users and actively respond and engage with them. Also, many users will appreciate an informal friendly way of doing this.

Of course, the nature of informal feedback means that participants are, in general, contributing because they have chosen to make contact; they have easy access to a feedback route; and/or they have a specific reason to want a discussion.

Feedback can arise when users choose to communicate with you, such as those that make a complaint or respond to feedback requests. Or users can take part in their own discussions, such as within public forums, support groups and online communities, and you can 'listen in'.

Information producers may find it easy to offer informal feedback routes, especially simple cheap options such as an email address.

However, some producers admit to not always paying much attention to it. This may be because they think it is an isolated comment and, without the credibility and weight of mass feedback, it is easy to ignore. Or perhaps too many different comments are tricky to assimilate into a coherent approach.

Whilst almost all websites include simple feedback mechanisms, there are many organisations that are still reluctant to engage or support more sophisticated options such as online communities and social media.

Who?

The nature of informal feedback means that participants are most likely to be current users or customers engaged with your product or service. Such users have a reason to be giving feedback – often because they are happy or unhappy about a service.

By definition, informal feedback is unlikely to be representative of all users.

For example, online forums only represent online users; anyone contacting a helpline or filling in an online feedback form has already found and, to some extent, engaged with that provider;

How?

There are simple, traditional ways you can gather informal feedback, such as:

- Suggestion box
- Monitoring written correspondence and phone line data
- Asking for feedback by advertising in newsletters and local networks
- Informal engagement events.

those using social media are likely to represent a younger demographic; those filling in a form have sufficient reading and writing skills to do so.

If you get informal feedback, you must view these comments within the context of the whole user group. For example, a few people grumbling don't necessarily represent the views of many satisfied users. And vice versa!

Care must be taken to analyse the demographics of participants. Often, informal feedback is the trigger for more formal research to get a clearer understanding of all users' opinions.

Online tools include:

- Online feedback forms – something that either pops up on a website, or a link to a feedback form or email
- Feedback requests via email, websites and social media, such as Facebook and Twitter
- Online communities
- Hosted customer feedback forums.

Common questions that are used to ask for informal feedback include:

- Did you find what you were looking for?
- Was it helpful?
- Do you have any suggestions?

Online customer communities are becoming a valuable tool. Users can go online to share ideas, complain and support each other.

A successful community thrives on open conversation, honesty and trust. Such communities may or may not be affiliated with the service that they are focused on. Providers can choose to stay at arm's length or to be closely involved. Either way, they are a great place for you to go for feedback and to invite engagement.

A hosted customer feedback forum is another way for users to post their comments publicly – this time on a provider's website or

Facebook site for example. Users get to share thoughts, while you can keep up to date with what users are saying.

An informal engagement event is a way of going out into the community to meet the public or a specific user group.

By meeting people, you can explore what they think, develop ideas, and discuss options and priorities.

This can help you engage with those that would not feel able to contribute to more formal processes, such as meetings or filling in forms.

This is particularly the case for involving vulnerable and marginalised people.

Engagement events are also an opportunity to work in partnership with other organisations, such as carers groups, the NHS, local charities and community groups.

5. Further resources

Focus Groups

- Professor Richard Krueger, Focus Groups: A Practical Guide for Applied Research
- Market Research Society's [Guidelines for Qualitative Research](#) includes guidelines on recruitment, as well as conduct during research.
- The Focus Group Tips website gives plenty of examples of how to plan focus groups and define questions.

Online Surveys

- The Market Research Society run an [online training course](#) on questionnaire design.
- SmartSurvey lists [6 steps to conducting an online survey](#).
- SurveyGizmo includes [tutorials](#) on how to set it all up.
- SurveyMonkey has examples of [customer satisfaction surveys](#) and [patient surveys](#) .
- QuestionPro offers a free downloadable [book](#) and [tutorials](#) on how to do online surveys.

Online customer communities:

Directly created by support organisations:

- [Macmillan](#)
- [British Heart Foundation](#)
- [Mind](#)
- [MS Society](#)

Indirectly supported or independent communities:

- [talkhealth Partnership](#), in partnership with NHS Choices
- [Patients Like Me](#)
- [Great Britain diabetes online community \(GBdoc\)](#)
- [HealthUnlocked](#)

About the author

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About PiF

PiF is a non-profit organisations working to improve the quality and accessibility of health information for patients and public across the UK.

Our work involves: delivering resources and events for information producers; influencing to raise the profile of health information; and bringing together those interested in the field of health information via the PiF network.

You can find out more at www.pifonline.org.uk.