



**Patient  
Information  
Forum**

# **Co-production: Involving users in developing health information**

*Revised October 2021*

# Involving users in co-production

This guide provides practical support for co-production, including planning user engagement and involving users in the production of health information. Put simply, co-production means working together with users to develop health information.

### Why this matters

Patients have a different perspective to those working in healthcare. Co-production and involving users in the production of your health information will ensure it is relevant, easy to understand and accessible. Involving users in development can help ensure the insight you gather is fully reflected in the final product.

### Co-producing

- At the outset, define how users will be involved and how involved they will be in decision-making.
- User testing is an iterative process – after initial testing, test again at a stage where you can still make changes.
- Invite feedback once projects are live to ensure a continuous cycle of improvement.

### Planning engagement

- Plan how users will be involved throughout your project.
- Tell users what their roles and responsibilities will be and what financial support you can offer.
- Consider the types of users you are recruiting. How many do you need, are they from your target audience, do they reflect a broad range of users?

### Methods for involving users

- Use a range of different techniques, for example online surveys and focus groups, at different stages of production.
- Whichever method you use, make sure you have a clear idea of what you want to achieve from each engagement.
- Always give feedback to users and thank them for their involvement.

### **This guide supports the PIF TICK assessment process for criteria:**

**3.0 Identifying need** – Resources are produced to meet a genuine need

**5.0 Involving users** – Users have been involved in the development of information resources

**6.0 Content** – Resources are written to meet the health literacy needs of the target audience and use appropriate language and tone

**7.0 Layout and design** – Resources are easy to access and navigate



## Best Practice

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### Co-production: Involving users in developing health information

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Patients, carers and those who use services are essential partners in the production of health information. Without them there is no guarantee the health information you provide will be relevant, accessible or useful.

Patients see things from a different viewpoint, often placing emphasis on things that are overlooked by those working in healthcare. Understanding the signs and symptoms of an illness is very different to knowing what it is like to live with that illness. Both types of knowledge are crucial when producing high-quality health information.

#### **Working in partnership with users will help ensure your information:**

- is clear and easy to understand.
- contains the information that is relevant and useful to users.
- is accessible to the audience it is aimed at.
- enables users to act upon the information appropriately.

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People want to know about the experience of the procedures, treatments, medicines and care they will need – what it actually feels like – as well as the technical details of what will happen. They want it explained in a way they can understand, without medical jargon, so they can make an informed decision. A [report](#)<sup>1</sup> published by Public Health England and UCL Institute of Health Equity found '42% of adults in England are unable to understand or make use of everyday health information, rising to 61% when numeracy skills are also required'.

The provision of information is fundamental to informed consent. The law on informed consent changed in 2015. Doctors must ensure that patients are aware of any 'material risks' involved in a proposed treatment, and of reasonable alternatives, following the judgment in the case [Montgomery v Lanarkshire Health Board](#)<sup>2</sup>. It is therefore essential that users are involved in the production process from start to finish. This change is reflected in [GMC Guidance](#)<sup>3</sup> on decision making and consent which came into effect on 9 November 2020.

User involvement can range from gathering feedback to full co-production. Some simple definitions are provided below.

### **Co-production**

Co-production (working together) means users and decision makers are working together in an active way to plan, design and review information and services. It is an equal relationship between people who use services and the people who run them. They share strategic decision-making.

### **Co-design**

People who use services are a part of planning them, based on their experiences and ideas. They are a real part of planning resources, but they are not a part of seeing it through to the end.

### **Engagement**

Here, people who use information and other services are given more opportunities to give their views. They may be able to have an effect on some decisions, but this depends on those running a project.

Full co-production is the gold standard, but not all organisations have the capacity to implement this process.

This guide is designed to provide practical support to people who want to involve users in the production of health information. [The ladder of co-production](#)<sup>4</sup> describes a series of steps towards full co-production in health and social care.

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### **This resource covers the following topics:**

- Planning engagement
  - Dealing with expenses and payment
  - Methods for involving users
  - Benefits and barriers to involvement
  - Working together on production and dissemination
  - Useful resources
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# 1. Plan engagement to involve a diverse range of users

## Plan how users will be involved throughout your project

The most impactful health information involves users at the beginning, and at every stage in the development process. The earlier you involve your target audience, the sooner you will identify if your information resource will work in practice.

### Users need to be involved when:

- considering what new information might be useful.
- revising existing material.
- designing and writing new resources.
- testing the final version.
- creating a plan for dissemination.
- evaluating how the impact is measured.

Decide at the beginning how to involve users throughout your project. Discuss which aspects of the project users are best placed to influence and how much influence they will be able to have.

From the outset you need to consider how you will manage the personal data of users you engage with. Check your organisation's data protection policy and look at the [Information Commissioner's Office website](#). Remember rules on data protection change over time as case law develops, so check your policy/process is up to date.

Factor in lots of time for user engagement. User involvement should not be a single, one-off exercise. It requires time and commitment to involve the right people in the right way.

Money and time spent on understanding your audience at the planning stage will be returned many times over in the effectiveness of the final product.

Find out the needs and requirements of your service users. What is important to them? What questions would they like answers to? Do existing information resources meet some/all of their needs? Fundamentally, where are the gaps from their perspective?

## Share expectations with users involved in your project

It is important at the outset of any engagement with users to establish their roles and responsibilities. This could even involve a role description. Where appropriate, develop terms of reference for any type of advisory group, steering group or committee they may be involved in.

There may be times when users will require induction, training or other support to enable them to fulfil their role. Some people may need specific provisions for accessibility or digital technology.

### Ensure your users:

- understand the aims of the project and your expectations.
- are clear what they are being asked to do and why.
- know how much influence they will have.
- understand how much time they are required to give.

- have the opportunity to share their requirements and expectations of being involved.
- know what they will receive from you e.g. expenses and payment (and when these will be paid), training, induction, etc.
- understand the length of term of office, if appropriate.
- know what they might gain from being involved in your project.
- feel valued.

### Expenses and payments

It is important to think about what financial support you are able to offer users to help them engage and participate properly.

Pay your participants' travel expenses and compensate them for their time or offer a thank you (e.g. store voucher) to encourage them to take part.

Best practice would be for an organisation to book travel for the participant so they do not need to make the payment. Be sure to reimburse expenses as quickly as possible after the event.

Particular care should be taken when paying users who receive financial help from the Government, as this may impact on their financial welfare. [NICE](#) has useful resources and sample letters for benefits agencies.

Consider all the likely costs of user participation throughout your project and budget appropriately.

### Involve an appropriate number of users

Get the right balance of how many users to involve. Avoid relying on one or two regular users.

If you involve too few users you won't gather enough feedback. If you involve too many you may be overwhelmed with conflicting comments. When communicating about the involvement of users be transparent about the number of people you have worked with.

### Recruit users from your target audience

When identifying the need for a new or updated information resource you will have also identified the potential groups of users the information resource is for.

It is crucial to engage with representative users. Ensure that your methods for involvement and engagement are relevant for your target group, and actively enable people to participate.

The most successful way to engage with truly representative users is to find out where your audience is and go to them.

People are much more likely to share their views if they are in an environment in which they feel comfortable. Individuals often feel more able to open up if they are in the company of their peers. Being in familiar settings helps build confidence and trust.

Be mindful of users' physical and psychological needs. Make involvement accessible for people with disabilities, and taking into account energy/fatigue levels and the pacing of meetings.

A series of short meetings might be better for some groups. If users are talking about things that are distressing or where they felt stigmatised, they may need support.

Think about the language you use when engaging with people. Use plain language, aim for a reading age of 9-11<sup>5,6</sup> and avoid medical terms and NHS jargon. Explain unfamiliar words if they cannot be avoided. Some groups have specific terminology that they prefer or dislike, for example, around gender or ethnicity. If you are unsure, be honest and check directly with users.

### **There are many ways of finding and recruiting users**

- Asking the health professionals that you know to introduce you to relevant patients.
- Partnering with clinics and patient organisations to recruit your target group.
- Tapping into existing community or faith organisations or activity groups.
- Using trusted community intermediaries and influencers – this is particularly useful if your target audience are an excluded group who may be distrustful of cold contacts.
- Through older people's lunch clubs.
- Via parent and toddler groups.
- Using online video chat gatherings and online communities.
- Attending festivals to engage with younger audiences.

### **Think about how you can engage a broad range of users**

Be inclusive in your user involvement recruitment. It is important to consider how you will involve people with communication difficulties,

disabled people, individuals with poor reading skills and those from seldom heard groups.

Young people will have different requirements to older people and someone newly diagnosed with a condition will have different needs to someone who has lived with a condition for 10 years.

Consider what barriers might prevent users being involved, such as digital skills and access, location of activities and timing of meetings. Hold face-to-face meetings in the evening or at weekends for those who work or look after children during the day.

Use familiar and easy to use digital tools that are free for participants to use. If you are planning a physical event make sure the venue is easy to get to, with parking and good public transport links. Use local venues, such as libraries and church halls. Check accessibility for wheelchair users and ensure adequate seating is provided for those less able to stand.

Think about whether you can offer services such as childcare or an interpreter. Ask users what will make it easier for them to become involved.

### **Users may include:**

- Those with limited literacy skills.
- Those who don't regularly use resources, documents or websites.
- Those who don't currently access the current information resource or project.
- Experienced users who have valuable insights as to what did or didn't work for them.
- People with quite recent experiences because treatments and services change.

Experiences from five or more years ago (and sometimes less) might not reflect current medical practice.

- Particular age groups, such as older or younger people – especially if the information is particularly relevant to their age group.
- People who have no experience of the subject of the information – such as the disease or treatment involved – as these people are most similar to newly-diagnosed patients.

#### **Seldom heard groups could include:**

- Black, Asian and minority ethnic communities
- people with a range of disabilities
- younger people
- LGBTQ+ communities
- religious communities
- those living in rural areas
- people from vulnerable groups, such as homeless people, drug users, vulnerable migrants, sex workers, traveller communities.

#### **Preparing to engage**

It is common to worry about 'getting it right' when it comes to cultural diversity. What matters is intent, along with an effort to understand.

At every stage of your project check out your own perspective. Write down your personal views on issues like gender, sexual orientation, race, social class, age, addiction, even politics. Recognise we view the world through our own experiences, perceptions and assumptions.

Even people with similar backgrounds might see a subject very differently.

Having someone to challenge your approach is one of the benefits of working in a team and overcoming unconscious bias.

Consider using a co-facilitator from the community or training members of the community to gather insight with you, this will help overcome unconscious bias and help build trust.

#### **Keep users informed as the project develops**

Let users know what will happen at each stage of the project and what the ultimate outcome is, even if they have only been involved in a small part of the process.

#### **Have a clear decision-making process**

It is helpful to explain at the start of the project how any suggestions will be managed, and have a clear process for making decisions about what is used/not used in the final version. This will help avoid disputes and difficult conversations.

People are more likely to want to be involved in the future if they receive feedback on how their involvement has influenced the project.

#### **Don't take criticism personally**

As a writer or resource producer it can sometimes be hard to hear criticism of your work. Ask for feedback in a positive and constructive way and make it clear it will not be taken personally.



## Say thank you

It sounds obvious, but always thank people for giving their time to help. Send users a copy of the final resource and ensure they are acknowledged in the resource, where appropriate.

## Feedback

Feeding back and thanking people for their contributions is an essential part of

user involvement. Take the time to evaluate the experience users have had of being involved in your project.

This could be via an evaluation form or through discussion. By finding out what worked well and less well, you can improve your user involvement activities in the future.

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## 2. Methods for involving users

### The most common ways to involve users

- Online surveys
- Informal feedback
- Online communities and support groups
- Virtual or face-to-face focus groups
- Informal engagement events
- Individual interviews
- Readers panels.

Using a range of different techniques, at different stages, is the best way to get feedback from a wide variety of users at different points within your project. You might like to start with online surveys and informal feedback and then move on to focus groups and individual interviews.

### Online surveys

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

Surveys are an invaluable tool to get feedback from a large number of people quickly and cheaply.

### Online surveys tend to be used to:

- Gather demographic or behavioural details – such as who is using a website and why.
- Gain insight into a specific product or service – such as customer satisfaction, product evaluation or to test new concepts.
- Develop insight into what people think and feel about living with a condition, for example, how pain affects them, what it stops them doing in day-to-day life.

Questionnaires can range from being short and snappy to complex and in-depth. Online tools make surveys very straightforward to conduct and take part in.

### Benefits of online surveys

- Relatively cheap because they can be set up without using an external research agency.
- Quick because people tend to respond within a few days.

- Responses are processed and available automatically.
- Respondents can take part in the survey when and where they choose.
- People are sometimes more honest with their opinions because they are not face to face with a researcher.

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

Care must be taken to recruit representative participants and avoid tokenism. It is important to understand the demographics of who has taken part and who has not. Develop a methodology, so you know who you have targeted and how.

### Points to consider

- Some groups of people won't or can't take part in online surveys, such as those with poor reading or I.T. skills and those who do not have access to the internet or suitable technology.
  - 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.
  - A group of your audience may not take part because they are, for example, too busy or not engaged with your organisation.
  - Some people may only respond because they want to complain or because they are familiar with your service.
- One major obstacle for any survey is how to get accurate representative feedback, whether it is from the general public, current customers, or a specific sub-group.

There are many companies that offer online survey functions. Some basic options are free of charge, others you will have to pay for.

A survey questionnaire must be designed carefully to get the data you need. Writing surveys is a skill, and it is easy to gather meaningless feedback if you aren't careful. Shorter surveys are likely to be more successful.

### Writing survey questions

- Write questions carefully. Use clear language participants will understand, and ask simple questions.
- Avoid any potentially leading questions.
- Keep your survey focused. Ask yourself what you are going to do with the answer each 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.
- Choose the question type to best suit your needs. These include multiple choice, drop down lists, open-ended text questions or comment boxes, star rating, matrix or table grids.
- Think about how you will analyse the feedback. If you offer open text questions then you can get some really valuable in-depth feedback, but you need to have the time, skills and resources to analyse and use it properly.

## Engaging with respondents

- Test your survey with a small group of target responders before sharing it more widely. They will be in a position to highlight any questions that are difficult to understand or potentially misleading.
- Consider how you will contact respondents and be aware of current GDPR regulations.
- If you want to involve current known users 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 through news groups, web communities, QR codes, newsletters, social media and via key opinion leaders and influencers.
- It is usual to give respondents a few weeks to take part in a survey and always give a specific deadline.
- To [maximise response rates](#), send reminders and make the survey short and simple.
- To encourage respondents to take part think about what the benefits might be to them. For example, they will be able to influence your health information so that it addresses their questions. An incentive can be used, such as a voucher. This can also be something you question in the testing phase of your project, by asking respondents what would make them complete your survey.
- It is a good idea to give respondents an honest idea of the length of time the survey may take to complete, and/or show their progress within the survey itself.

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 detailed report can then be downloaded.

The companies listed below are not endorsed by PIF, but they do offer advice on how to design and set up surveys.

### [Mentimeter](#)

Polling [software](#) which enables visual responses in real-time to create a fun and interactive experience.

### [Smart Survey](#)

Lists six steps for conducting an [online survey](#).

### [Survey Monkey](#)

Examples of [customer satisfaction surveys](#) and [patient surveys](#).

### [QuestionPro](#)

Offers a free downloadable [book](#) and [tutorials](#) on how to produce online surveys.

## Informal feedback

Informal feedback can come from anyone, via any route, at any time. It may come from current users of your health information or non-users, the public or professionals. It can be via conversation, letter, helpline calls, email, websites, online communities and social media and even the search terms people use to find your website.

Complaints can be a valuable form of feedback. Users can also take part in their own discussions, such as within public forums, support groups and online communities, and

you can 'listen in'.

### **Benefits of informal feedback**

- It is an easy, low-cost way of developing relationships and maintaining on-going dialogues with users, which is a great way to understand their needs.
- 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.
- It allows you to constantly listen to users and actively respond and engage with them. Many users will appreciate an informal, friendly way of doing this.

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

The nature of informal feedback means that participants are most likely to be current users of your health information 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.

Informal feedback is unlikely to be representative of all users. If you get informal feedback, you must view these comments within the context of the whole user group. For example, a few people with concerns don't necessarily represent the views of many

satisfied users.

Often, informal feedback is the trigger for more formal research to get a clearer understanding of all users' opinions.

### **Common questions that are used to ask for informal feedback**

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

### **There are simple, traditional ways you can gather informal feedback**

- A suggestion box
- Monitoring written correspondence and helpline data
- Feedback form slips or tear off page provided in resources you have produced
- Asking for feedback by advertising in newsletters and local networks
- Informal engagement events.

### **Online tools**

- Online content rating – happy or sad face, thumbs up or down, scale of 1-10
- 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 community-hosted customer feedback forums.

## Online communities and support groups

The number of condition-specific support group [online communities](#) is growing. These groups allow people with a particular health condition to connect with others who might be going through a similar experience, and provide peer support and practical information.

One of the biggest benefits of such communities is that people can participate from anywhere in the world. This is particularly important when some conditions can make people feel isolated, if they live in more rural or remote locations, or if their condition limits their mobility.

### Points to consider

Online support groups often develop group guidelines to ensure discussions are appropriate and respectful. These can include:

- who the group is for (e.g. patients, carers)
- behavioural guidelines (being respectful of other members)
- no advertising or promotional content rules.

When considering joining an online support group, it is important to read a group's guidelines and note their privacy settings. Look to see if the group has a good sense of community and that posts are positive and supportive.

A community feedback forum that you host, as the provider of health information, is another way for users to post their comments publicly – this time on your website or Facebook page for example. Users get to share thoughts, while you can keep up to date with what users are saying.

## Examples of online customer communities

### Directly created by support organisations:

- [Diabetes UK](#)
- [Macmillan Cancer Support](#)
- [Mind](#)
- [MND Association](#)
- [MS Society](#)

### Indirectly supported or independent communities:

- [HealthUnlocked](#)
- [IBD Relief](#)
- [Patients Like Me](#)
- [Shift MS](#)
- [Shine Cancer Support](#)
- [talkhealth Partnership](#)

A successful community thrives on open conversation, honesty and trust. Providers of health information 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.

### Focus groups

A focus group involves a facilitator guiding a small group of people through a discussion. The aim is to get a clear insight into their behaviours, attitudes and preferences. The group environment stimulates people's thoughts and opinions and encourages sharing and debate.

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

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. This will ensure your resource/service is what users want and how they want it.

However, some information providers are reluctant to use focus groups. Reasons for this include:

- Costs
- Time constraints
- Difficulty recruiting representative users
- Availability of facilitators with the appropriate skills.

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 not been effective.

Focus groups tend to be made up of 6-10 people. The number of participants needs to be large enough to allow a useful discussion, but small enough to manage and to allow everyone to contribute. Less confident and talkative participants may prefer one-to-one discussions or smaller groups.

### Things to consider

- Participants should reflect the target audience and may or may not be representative of the general population.
- If participants are amongst people of similar background and experience, they are more likely to relax and contribute openly.

- 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.
- Groups can be divided by, for example, gender, age, experience, or background.
- To increase the likelihood of people taking part, make it easy for them.

Focus groups can be held in person or online depending on the needs of the participants. This can make logistics easier for some people, and sensitive issues may be easier to discuss without being face to face. However, ensure the conferencing software is free and easy to use. People can easily be put off if there are IT issues using the software selected.

*See comparison of online platforms on page 16. You can find further guidance on recruiting users in section 1.*

Any focus group needs careful planning to ensure it yields the information you are looking for.

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

A clear discussion guide is crucial, focusing on key questions or topics. Focus groups tend to be 45–90 minutes long. Any longer and people start to tire and the discussion is less productive. As in all consumer research, participants must be able to understand and respond to questions.



### As a rule, good questions:

- sound conversational
- use words participants are familiar with
- are easy to understand
- are clear
- are short.

Good questions are open-ended – for example, 'What information were you given when diagnosed?' as opposed to 'Were you given information when diagnosed?'

They are also 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.

You should include helpful instructions – are you asking them to rank something, write something down, answer verbally?

### Briefing participants

Participants should be asked to sign a consent form in advance, which includes an explanation of the involvement and may include a confidentiality agreement.

For online focus groups you should get participant's consent to record the meeting and let people know when you start recording.

Often a fee is paid to participants. Be specific about when payment will be made. *You can find further guidance on budgeting in section 1.*

### During the event

The group facilitator should have skills and experience in conducting consumer-focused research, and ideally experience of communicating with the target group, particularly if it involves people with learning difficulties or from seldom heard groups.

Ideally an assistant facilitator also attends the focus group, to welcome and help organise participants when they arrive and take notes.

Consider people's previous experience with services, for example even a simple lanyard can carry negative associations for children and young people who have had previous negative experience with social workers, police or teachers. Make sure you create the right environment to encourage participation.

The facilitator starts the focus group using a prepared script to welcome everyone, explain the purpose of the group, and set ground rules.

The topic can be introduced and opening questions used to engage participants and make them feel at ease. The facilitator can then start to explore opinions, behaviour and attitudes.

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

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

The facilitator should be able to respond to the group's thoughts and ideas in a non-judgemental way and ensure everyone is able to contribute. The chat function on virtual platforms can be a useful way for quieter participants to contribute and for the facilitator to include their views in discussion.

Consider using poll functions on virtual platforms and use [dot democracy](#) at

face-to-face events, so the group can decide on priority issues democratically to avoid dominance by strong personalities.

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

	Ease of use for participant	Devices	Functions and features	Accessibility features
<b>Zoom</b>	No account needed, just click a link. May need to download the app.	- Desktop - Mobile - Tablet	- Record meetings - Poll functions - Breakout rooms - Chat function	- Background audio suppression - Closed captioning - Keyboard shortcuts - Screen reader support - Auto transcripts - Third party captioning - Multi-spotlight and multi-pinning + more
<b>Microsoft Teams</b>	No account needed, just click a link from an email. Access from app or browser (Edge or Chrome only).	- Desktop - Mobile - Tablet	- Record meetings - Poll functions - Breakout rooms - Chat function	- Screen reader support - Live closed captioning - Background audio suppression - Language translation - Audio messaging - Customise reading and viewing experience - Keyboard shortcuts - Compatible with dictation software, voice control and screen magnifiers + more
<b>Skype</b>	No account needed, just click a link from an email. Access from app or browser (Edge or Chrome only).	- Desktop - Mobile - Tablet	- Record meetings - Poll functions - Chat function	- Screen reader - High contrast view settings - Screen magnifier



## Informal engagement events

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.

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.

There are some innovative, informal engagement events such as [bread making](#), that can bring seldom heard groups together for an activity. This can lead to informal discussions about a particular topic which can help inform your project.

## Individual interviews

Interviews can be used to collect valuable qualitative feedback. They can be conducted face-to-face, by telephone or by video call, and can be as structured or in-depth as necessary. This type of engagement allows detailed questions to be asked 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

- They do not require participants to have literacy or computer skills.

- Interpreters can be employed if necessary.
- Non-verbal data can be collected through observation.
- Interviews can be carried out at all stages of user testing.

Telephone interviews can be a 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.

However, interviews 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.

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.

If you plan to make an audio recording of the interview then ensure you ask for written permission first.

## Readers Panel

A Readers Panel is a group of people who have volunteered and been recruited to read and review new and newly-revised information.

Members on the panel are sent resources to review, which may be accompanied by a short questionnaire about the resource, or people may be encouraged to provide general comment.

The information resource is usually sent to the panel by post, email or online, whichever is preferable to the reader. If by post a pre-paid envelope should be provided.

Individuals on the Readers Panel are given between 1-2 weeks to provide feedback.

## Feedback

Whatever method you use to involve users make sure you share your findings with those

involved. In the case of focus groups and interviews this is essential to ensure you haven't misinterpreted anything and to check people are comfortable with what has been reported.

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## 3. Working together on production and dissemination

After gathering insight into the needs of users, involve them to help guide the development of your resource. This can help ensure the insight you have gathered is fully reflected in the development of the resource.

You can hold workshops to scope your resource and then involve users at key development points to make sure development stays on track and decisions are taken together.

Make sure the technique is appropriate to the users and their abilities. For example you can use visual tools to support people with communication difficulties or learning disabilities. [Talking Mats](#) can provide a very simple framework for conversations.

Involving users during the development can set the right tone and embed the 'user voice' in the resource, before you release for wider user testing.

### Use the voices of real people in your resources

Including experiences, stories and comments from users in your information resource can be beneficial.

Reading or hearing what other patients say can be comforting, and can offer valuable tips on coping with treatments and side effects.

Ensure you include user voices from a range of perspectives and experiences. Patient experiences can sometimes be quite negative and some very positive. It is important to reflect both where possible.

Seek permission to use any quotes from the individuals involved before publication. Consent is also required for data protection purposes, even if you don't name participants. Health information is considered sensitive, personal data.

### Design your approach to dissemination and promotion with users

Involve your target users in developing your plans for dissemination or promotion. Ask where they would expect to hear about resources and look to find information. They can often be your best advocates.

If you are planning to disseminate resources via healthcare professionals, or for the resource to be used in consultations, it is important to seek views on how the resource can be used in practice.

## Evaluate your resources with users

For involvement to be meaningful, it must make a difference. Identify at the start of the project how you will evaluate and measure the impact of the resource you are developing with users.

This enables you to identify how effective your information has been, what has worked – or not worked – and will improve future health information projects.

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## 4. Test your information with your target audience

User testing is a specific method of finding out whether a piece of health information works effectively, and improving it, before publication. Essentially it determines how well – or how badly – potential users can find, understand and use your health information.

### User testing is designed to test the near-finished information product

It is important that the version you are testing reflects, for example, final fonts, colours and paper weight or, in the case of a web-based resource, navigation and layout.

### Decide who to test the information with

Write a clear protocol at the outset for selecting your user testing participants, and choose people who represent the target audience for your information. You may want to specify a mix of participants.

For example, if the information is about a particular illness or treatment, you may wish to select people with experience of that condition – though you should avoid 'expert patients' who know much more than is typical.

### Recruit participants

How many people you are able to test the information with depends on the budget and time you have available – but you will need to allow at least half an hour for each user test.

The time needed for each person to test the resource will depend on its nature and size.

Two rounds of tests with five people each time is a reasonable minimum. If you test with less than five people, you are less likely to find all the problems in the product.

Recruiting user testers of the right demographic can be difficult and time consuming.

If budget allows, you may wish to consider using a professional agency to find people to test the information.

These sites are not endorsed by PIF, but are used by some members:

- [whatusersdo.com](https://www.whatusersdo.com)
- [takepartinresearch.co.uk](https://takepartinresearch.co.uk)
- [researchopinions.co.uk](https://researchopinions.co.uk)
- [peopleforresearch.co.uk](https://peopleforresearch.co.uk)

You can find further guidance on recruiting users in section 1 and 2 above.

Advice from the [Herschel S. Horowitz Center for Health Literacy at the University of Maryland](#)<sup>7</sup>:

- Screen for participants with limited health literacy skills using proxy measures, such as low household income.
- Develop consent forms, and facilitator guides in plain language.
- Limit the number of questions and tasks.
- Pre-test your protocol with at least one participant with limited literacy skills, from your target audience.
- Help participants feel comfortable during testing.
- Choose a facilitator with experience of conducting research with your target participants.
- Conduct testing sessions in a setting that is familiar and accessible to participants.
- Use cash incentives when possible.
- Conduct user research throughout the project lifespan using multiple methods.

### Find a suitable location

Choose a location for your user testing that people can find easily and which takes into consideration any accessibility needs.

Ensure participants will have somewhere they can sit comfortably.

You may want to consider carrying out a test alongside a local community event or meeting that is already taking place, to make it easier for participants to attend.

Offer refreshments and explain how expenses can be claimed.

If you are testing a web-based resource you will need to arrange for people to have access to a computer and internet connection during the test. Consider whether you can conduct the user testing remotely.

### Develop your test questions

Before carrying out your test, identify the information that you most want people to be able to find and act on in your resource.

Take the top 10-15 issues, and turn these into action-orientated questions, together with a confidential list of what you think the actions/ answers might be. If you are testing a symptom tracker or diary, ask people to fill it in.

You may want to ask some open questions to find out what participants thought of the information overall, and how they would improve it.

### Observe people using the information in situations as close as possible to real life

It is not just about asking people what they think of the information but about setting them specific challenges to find certain pieces of information, and observing whether and how they succeed in doing this.

### At the start of each session it helps to:

- Welcome people and put them at ease.
- Explain what the test will involve and how long it will take.
- Reassure participants that it is the information that is being tested, not them.

- Let participants know that their participation is voluntary and that all information they give will be treated anonymously and confidentially.

The aim of user testing is to watch how participants use the information in real time – watch how they react to it, how they try to search and navigate through it.

It is helpful to have support available if any of the user testing process raises questions or concerns for participants.

Depending on the content this might be more/less of a concern, but it is an important part of valuing participants.

Observe and write down both what participants do (how they search through the document or website) as well as what they say.

Keep notes as you analyse responses so you have a clear record of how participants have engaged with your resource. This will aid future decision-making.

Receive feedback gratefully. Thank participants and at a later date, feedback how the prototype has changed based on their input and provide participants with a copy of the final version.

### **Decide on your recommendations and implement them**

After user testing consider carefully how you might change your information to respond to the feedback given and to solve issues that have been identified.

Once you have decided on changes to try, implement them and create a new prototype.

### **User testing is an iterative process**

Making improvements to your information and conducting a further round of user testing enables you to see whether the improvements have worked and to check that you haven't added any new problems in the process. So, it makes sense to test at a stage where you can still make changes to your product.

At the end of the process, you should feel confident that users really can use your product to become more informed.

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## **Summary**

The involvement of users in your information project should be meaningful, not tokenistic.

It may not always be possible, due to financial and other constraints to follow all the steps above, but don't be put off. If you need to, start your patient involvement activities small and build them up over time. This is preferable to not involving users at all.

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## Useful resources

10 ways to get user feedback

[www.blog.theteamw.com/2010/01/17/10-ways-to-get-user-feedback](http://www.blog.theteamw.com/2010/01/17/10-ways-to-get-user-feedback)

Blog on different approaches to usability testing.

Asking for patient feedback in sensitive situations

[www.england.nhs.uk/publication/bite-size-guides-to-patient-insight](http://www.england.nhs.uk/publication/bite-size-guides-to-patient-insight)

NHS England Insight bite-size guide to seeking feedback in sensitive situations, giving useful advice on when and how this can be done and why it's important.

Beyond the usual suspects: towards inclusive user engagement

[www.shapingourlives.org.uk/resources/our-resources/all-publications/beyond-the-usual-suspects](http://www.shapingourlives.org.uk/resources/our-resources/all-publications/beyond-the-usual-suspects)

The focus of this report is making it possible for everyone who wants to, to be more involved in and have more say over their lives and the services they use.

Community engagement: improving health and wellbeing and reducing health inequalities

[www.nice.org.uk/guidance/ng44](http://www.nice.org.uk/guidance/ng44)

This guideline covers community engagement approaches to reduce health inequalities, ensure health and wellbeing initiatives are effective and help local authorities and health bodies meet their statutory obligations.

Co-production from proposal to paper

[www.nature.com/articles/d41586-018-06861-9](http://www.nature.com/articles/d41586-018-06861-9)

Three examples show how public participation in research can

be extended at every step of the process to generate useful knowledge.

Co-production is more than consultation

[www.alliance-scotland.org.uk/blog/opinion/co-production-is-more-than-consultation/](http://www.alliance-scotland.org.uk/blog/opinion/co-production-is-more-than-consultation/)

COPE Scotland uses the concept of Jigsaw lids to facilitate co-production.

Co-production model

[coalitionforpersonalisedcare.org.uk/resources/a-co-production-model](http://coalitionforpersonalisedcare.org.uk/resources/a-co-production-model)

Coalition for Collaborative Care's five values and seven steps to making this happen

Evidence-based user experience research, training and consulting

[www.nngroup.com/reports](http://www.nngroup.com/reports)

Research reports including user experience guidelines for creating and improving your web, mobile, and intranet sites.

Experience-based co-design toolkit

[www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit](http://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit)

As well as step-by-step guidance to experience-based co-design (EBCD), the toolkit includes videos of people who have taken part in EBCD projects.

#### Framework for public participation

[www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/framwrk-public-partcptn-prim-care.pdf](http://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/framwrk-public-partcptn-prim-care.pdf)

NHS England framework for patient and public participation in primary care commissioning.

#### Guide to age-friendly and inclusive volunteering

[www.ageing-better.org.uk/sites/default/files/2019-05/Age-friendlyandinclusivevolunteeringfinalprint.pdf](http://www.ageing-better.org.uk/sites/default/files/2019-05/Age-friendlyandinclusivevolunteeringfinalprint.pdf)

Guide from the Centre for Ageing Better which introduces six principles organisations working with volunteers can adopt to address barriers to inclusion and widen participation.

#### Health Literacy Toolkit

[www.hee.nhs.uk/our-work/population-health/training-educational-resources](http://www.hee.nhs.uk/our-work/population-health/training-educational-resources)

Guide sharing practical tools and techniques for communicating with and supporting people with low levels of health literacy. Includes sections on spoken and written communication, using images, and the design and layout of information.

#### How lay member payments affect benefits

[www.nice.org.uk/get-involved/our-committees/what-lay-members-do/lay-member-payments-and-expenses/how-lay-member-payments-affect-benefits](http://www.nice.org.uk/get-involved/our-committees/what-lay-members-do/lay-member-payments-and-expenses/how-lay-member-payments-affect-benefits) Lay member information and vacancies.

#### How to co-produce a project

[www.mssociety.org.uk/what-we-do/our-work/our-strategy/working-together](http://www.mssociety.org.uk/what-we-do/our-work/our-strategy/working-together)

Co-production toolkit from the MS Society.

#### Market Research Society (MRS) Guidelines

[www.mrs.org.uk/standards/guidance](http://www.mrs.org.uk/standards/guidance)

Guides and codes of conduct for market research, includes a guide to qualitative research, guidelines on recruitment, online research and designing a questionnaire.

#### Patient and public participation in commissioning health and care: statutory guidance for CCGs and NHS England

[www.england.nhs.uk/publication/patient-and-public-participation-in-commissioning-health-and-care-statutory-guidance-for-ccgs-and-nhs-england/](http://www.england.nhs.uk/publication/patient-and-public-participation-in-commissioning-health-and-care-statutory-guidance-for-ccgs-and-nhs-england/)

This guidance is for clinical commissioning groups (CCGs) and NHS England. It supports staff to involve patients and the public in their work in a meaningful way to improve services, including giving clear advice on the legal duty to involve.

#### Paying people who receive benefits – Co-production and participation

[www.scie.org.uk/co-production/supporting/paying-people-who-receive-benefits](http://www.scie.org.uk/co-production/supporting/paying-people-who-receive-benefits)

This briefing looks at benefit changes that can make it easier for people who use services and carers to get involved in paid co-production/participation in health and social care.

#### Public engagement: a practical guide

[senseaboutscience.org/wp-content/uploads/2017/11/Public-engagement-a-practical-guide.pdf](http://senseaboutscience.org/wp-content/uploads/2017/11/Public-engagement-a-practical-guide.pdf)

This is a practical guide on involving the public in how to communicate research findings.

#### Rethinking engagement

[www.patientlibrary.net/cgi-bin/library.cgi?page=Blog;prevref=;top=76](http://www.patientlibrary.net/cgi-bin/library.cgi?page=Blog;prevref=;top=76)

David Gilbert, writes from his experiences as both professional and patient, and calls for a fresh approach to patient engagement.

#### Service user involvement in the delivery of mental health services

[www.together-uk.org/wp-content/uploads/downloads/2014/06/Service-User-Involvement-briefing.pdf](http://www.together-uk.org/wp-content/uploads/downloads/2014/06/Service-User-Involvement-briefing.pdf)

Includes a 'service user leadership spectrum' to measure how well organisations involve users.

#### Statutory guidance on involving people in health and care

[www.england.nhs.uk/publication/involving-people-in-their-own-health-and-care-statutory-guidance-for-clinical-commissioning-groups-and-nhs-england/](http://www.england.nhs.uk/publication/involving-people-in-their-own-health-and-care-statutory-guidance-for-clinical-commissioning-groups-and-nhs-england/)

NHS England statutory guidance on the benefits of involving people in their own health and care and involving communities in commissioning decisions.

#### Tools for co-production in mental health commissioning

[www.rcpsych.ac.uk/improving-care/nccmh/other-work/coproduction](http://www.rcpsych.ac.uk/improving-care/nccmh/other-work/coproduction)

Document published by the Royal College of Psychiatrists covers co-production with people in at-risk populations.

#### User involvement in regulation: A qualitative study of service user involvement in Care Quality Commission inspections of health and social care providers in England

[onlinelibrary.wiley.com/doi/10.1111/hex.12849](http://onlinelibrary.wiley.com/doi/10.1111/hex.12849)

This study explores the role of service users and citizens in health and social care regulation, including how the CQC involved people in inspecting and rating health and social care providers.

#### Working with seldom heard groups

[www.england.nhs.uk/participation/resources/involveseldom-heard/](http://www.england.nhs.uk/participation/resources/involveseldom-heard/)

Bite size guides to diverse and inclusive participation.

#### Working together

[www.plymouth.ac.uk/uploads/production/document/path/11/11116/working-together-guide.pdf](http://www.plymouth.ac.uk/uploads/production/document/path/11/11116/working-together-guide.pdf)

An essential guide for healthcare practitioners, researchers, educators and regulators looking to work with services users, patients, carers and members of the public.



## About the Patient Information Forum

PIF is the independent UK membership body for people working in health information and support. We also run the only UK-wide quality mark for health information – the PIF TICK.

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

The PIF membership body come from across all sectors, representing every kind of information and support producer and provider, from the NHS to large international companies, health charities to national health departments, researchers to freelance medical writers.

PIF is committed to improving the healthcare experience for patients and the public by helping individuals and organisations to deliver high-quality, evidence-based, accessible information and support so that everyone can understand their care, and make informed decisions about their health and wellbeing choices.

### You can find out more:

Web: [www.pifonline.org.uk](http://www.pifonline.org.uk)

LinkedIn: [www.linkedin.com/in/patientinformationforum](https://www.linkedin.com/in/patientinformationforum)

Twitter: [www.twitter.com/PIFonline](https://www.twitter.com/PIFonline)

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