

# Make your voice heard

Your guide to how patients, carers and the public can influence the services they receive.





Across the UK, there is a strong policy emphasis on patient and public involvement. The government has set out a series of responsibilities for the NHS to involve patients, carers and the public in decisions about local healthcare.

A competent and viable bid needs to reflect dialogue with patients/service users and the public at every stage. Gathering service users' views and experiences is critical to improve outcomes.

#### **Follow these steps:**

1

Before you do anything, ensure you have buy-in from all those involved in the process and sufficient resources allocated to it. 2.

Consider who will be affected by the changes you are hoping to implement as a result of your bid – it may be a very specific group of patients, or it may be the public at large. 3.

Consider how you will communicate with them. It's crucial to allow sufficient time to make the dialogue meaningful.

4.

Identify how to reach them, for instance:

- the Patient Advice and Liaison Services
- your local patient and public involvement forums such as Healthwatch
- local support, community or faith groups
- local or national patient organisations
- local press.

**5.** 

Decide how to involve them. This could include:

- questionnaires/surveys
- focus groups
- community engagement events
- setting up a cardiac reference group specific to your service
- inviting an experienced patient or user representative on to the stakeholders' group
- one-to-one interviews
- informal conversations with patients
- the National Voices website.

6.

Be clear about what is expected from the start. Let those who are getting involved know:

- why they are being involved
- in what capacity they are being involved
- what is expected of them in terms of time commitment
- what support they can expect to receive (including expenses, a named contact, any training if relevant)
- how they will receive information
- when and how they can expect to get feedback on how their views are used
- a clear end date/point (if there is one)
- what has happened as a result of what they said
- what is still to happen
  and when
- what cannot happen – and why
- the decisions made and the rationale for them.

## **Engagement** approaches

#### **Explanation**

# An event based in the local community with 15-30 participants. Participants tend to work in small groups on set discussion topics, although whole group discussions can also be used. An excellent way to generate broad discussions with a wide range of people.

1 or 2 lead facilitators required, with extra support for facilitating table discussions.

#### **Benefits**

- You will hear from a wide range of people, which will generate lots of discussion and lots of ideas.
- You can use a range of activities within this including individual reflection, pair work, small group work, whole group discussions. Where appropriate, you can also use techniques such as a world café.

#### **Pitfalls**

- Some people are less comfortable speaking out in large groups.
- Whoever shouts the loudest gets heard!
- Reliant on good facilitation otherwise subgroups may appear and individuals dominate.
- Can be difficult to capture really detailed notes. Often reliant on participants to capture discussions.

### Focus groups

**Engagement** 

events

Small groups of 8-12 people, focusing on a specific issue or topic.

Can be helpful for speaking to hard-to-reach groups if you are struggling to engage with them at wider community events.

1 lead facilitator and a note taker required.

- Can generate very detailed discussions and allows for detailed note capturing.
- Allows everyone the chance to have their say and be heard.
- Opportunity to hear from a range of individuals with diverse experiences.
- Dominant characters can take over if not managed well.
- Allows people to be influenced by the opinions of others.

#### **Interviews**

A one-to-one meeting (or a very small group discussion) designed for a specific objective.

- Good for building rapport.
- Easier to obtain individual perspectives and ensure everyone gets a chance to have their say.
- Some people are more comfortable sharing their opinions in a one-to-one setting than a group setting.
- Can generate very detailed feedback.

 Time intensive to capture the views of lots of different people.

## **Engagement** approaches

#### User/ Reference Groups

#### **Explanation**

User or Reference Groups are ongoing advisory groups of a selected small group that meet over a period of time for the purpose of achieving specific objectives – and should link into decision making groups. A relatively formal recruitment process is usually used and the membership is selected to represent different elements of the local population.

Requires ongoing staff commitment to support, facilitate and administer the group. Good facilitation is important.

#### **Benefits**

- Helps build a sense of partnership and gives people a sense of ownership.
- Creates the opportunity for ongoing, meaningful involvement.

#### **Pitfalls**

- The role suits a certain type of person.
- Involves a high level of commitment and time from both participants and staff managing the group.

#### Patient Representatives

Two or three service users are selected to be representatives of the larger population. They sit on decision-making groups alongside professionals.

Requires ongoing support and training, if necessary.

- Adds a service user perspective right where decisions are made.
- Encourages partnership working.
- The role suits a certain type of person. They will need some familiarity of attending formal meetings and have the confidence to share their views.
- Can be seen as tokenistic by both professionals and service users.

### Online networks

A network of people who are willing to be engaged with in an ad-hoc way, mainly via email. These people can also be invited along to focus groups etc. as appropriate.

- An efficient and cost-free way of keeping in regular contact with people and maintaining relationships with those who want to be engaged in an ongoing way.
- Excludes those who are not comfortable using computers.
- Can be tokenistic, should not be used as the only approach to engaging service users.



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