

# Breast cancer voices engagement guidance and terms

**People affected by breast cancer are at the heart of everything we do.**

Breast Cancer Voices is made up of people whose lives have been changed by breast cancer, and who use their diverse experiences to shape breast cancer research, policy and support.

**Please read through our guidance and terms to understand how we can support you to involve Breast Cancer Voices in your work, our expectation, and standards of involvement.**

This document covers:

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## 1. What we can and can't help with

Voices can use their lived experience to help in a variety of ways, such as:

- Taking part in research
- Surveys and focus groups
- Patient representatives or committee/panel members
- Speaking at conferences or events
- Reviewing materials and data

Although there are lots of things we could support, we need to be mindful of how many opportunities we are able to send to Voices. For this reason, we normally don't support:

- commercially driven market research, that isn't in partnership with Breast Cancer Now
- Projects with life science or private sector companies
- Research projects below master's level
- Projects originating outside the UK (exceptions may apply)

However, please [\*\*contact the Breast Cancer Voices team\*\*](#) if you'd like to discuss possible exceptions.

## 2. How we contact our Voices

There are 2 main ways we can contact our Voices, depending on what you need and who you want to connect with:

- **Monthly Voices bulletin**

This goes out to the whole community on the fourth Tuesday of the month and is the main way we circulate opportunities for Voices to get involved.

The bulletin is received by over 1,500 Voices, and we often share up to 10 projects in each bulletin.

- **Ad hoc louder Voices mailouts**

Over half the community have signed up to be a 'louder Voice', meaning we can contact them as

and when we need to with priority or targeted requests. Depending on the nature of the request, we can sometimes select a small number of Voices to approach directly.

### 3. Deadlines and lead times

The Voices bulletin with all the latest opportunities is sent on the **fourth Tuesday of each month**.

You'll need to [complete our engagement request form](#) **two or three weeks ahead of this date**, depending on the type of request:

- Research studies (requiring due diligence by our research team): **3 weeks before the bulletin**
- All other requests, including research PPI: **2 weeks before the bulletin**

If you need to discuss your deadlines and any flexibility, please email [voices@breastcancernow.org](mailto:voices@breastcancernow.org) and we'll do our best to accommodate your request.

When setting deadlines or event dates, we recommend at least one week after the bulletin date for survey responses and at least four weeks for meetings or events.

### 4. Completing our engagement request form

In order for us to share your project, you need to complete an [engagement request form](#). This form asks you for all the relevant details of your project so that we can share it with our Voices. It should take you less than 10 minutes to complete. In the form, we'll ask you for the following:

- **Details of your project:** a summary of your project aims and description, criteria for taking part, deadlines and contact details
- **Documentation and weblinks:** a copy of any questions and any other information for participants, survey links, webpage addresses or forms to be completed

For research studies, we also require:

- Research summary and participant information sheet
- Confirmation of the ethics approval for the project

We use this form to create the ad for your opportunity. This will be shared on the Voices notice board, or the research studies page. In order for us to write the ad, please ensure that the information you provide

- Is written in plain English, with any technical terms or jargon explained
- Has enough information so that Voices will understand what the project is about and what's being asked about them
- Clearly states how the Voices can sign up or take part, and how they can find out more information if needed.

We recommend you look at some examples of previously published [research studies](#) and [involvement projects](#).

### 5. Support and signposting

When sharing their lived experience or taking part in projects, we ask that you consider any potential for upset or distress and put appropriate measures in place.

This could include:

- Ensuring there is a key contact in place to answer any questions
- Providing adequate information ahead of any activity
- Signposting to [Breast Cancer Now's support services or helpline](#)
- Providing opportunities for feedback

## 6. Accessibility and inclusion

When everyone is included and enabled to contribute, the outcomes are improved for everyone. We ask that you:

- Proactively ask people about their access requirements, and accommodate them where possible
- Ensure that all members of the project team are informed of any access needs and how to accommodate to them
- Remove jargon and unnecessary complexity from written documents or discussion
- Provide a telephone or paper alternative to online participation or contribution (for example surveys) where possible
- Offer technical support in any online meetings where possible, and clear instruction or training on online platforms or software
- Ensure that any written information or opportunities, such as documents or surveys can be read by a screen reader
- Where possible, provide translators (including sign language) if necessary
- Consider any other barriers to full participation

## 7. Thanking and updating

After an activity, it's important to appropriately thank your Voice participants, and update them on the progress of the project to show them their value, and impact of their contribution. You are expected to:

- **Thank them**

Send a thank you email to Voices who took part in your project. Tell them what impact the Voices has by being involved and what the next steps in the project are. You can adapt our [thank you email template](#) for this.

When you send people a thank you email, we ask that you copy in the Voices inbox

- **Ask them to complete our feedback form**

Unless participation was anonymous, send Voices a [link to our feedback form](#) so we can understand their experience. There's a link to the feedback form in the thank you email template.

- **Reimburse them**

In line with our **payment for involvement policy**, we require that you reimburse Voices for any expenses incurred, including

- Travel
- Subsistence

In some circumstances, we provide payments or incentives to take part in activities. Please [contact the involvement manager](#) for advice on our payment for involvement policy.

- **Update them**

It's very important that you provide an update on the outcomes of your project to Voices who took part. If your outcomes won't be available for a long time, send interim updates to the Voices so they understand the next steps of the project.

- **Putting an update in the bulletin**

In some instances we will approach you to arrange for a project update from you to appear in subsequent Voices bulletins.

## 8. Impact evaluation

After your project, we'll ask you for feedback on how you found the process of engaging Voices and how their involvement impacted your project. We'll ask in the engagement request form when is best for us to send you this form.

This is an important part of our monitoring and reporting, so please complete the form when we send it.

We may also be in touch to ask you to share an update with our Voices community in our bulletin. You'll be able to indicate in the feedback form when we'll be able to approach you about this.

## Ready to get started?

[Complete our engagement request form](#)

If you have any questions or want to discuss your project further, please email us at [voices@breastcancer.org](mailto:voices@breastcancer.org), using the name of your project as the subject.