

# BREAST CANCER VOICES ENGAGEMENT GUIDANCE AND TERMS

Real lives. Real experiences. Real change.



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 our work – so we can keep accelerating research and providing vital support, every way we can.

[Get in touch](#) if you'd like to know more about our current membership.

## What we can and can't help with

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

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

We generally don't support:

- Market research projects
- Projects with life science or private sector companies
- Research projects below master's level
- Projects originating outside the UK

However, please [contact the Breast Cancer Voices team](#) if you need to discuss this further.

## How we contact our Voices

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

1. 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.
2. 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 urgent and priority requests. We can also segment this list, so we can target communication.
3. Warm approaches  
Many of the louder Voices complete our 'getting to know you' survey, which means we can often filter through the personal experiences and interests they've shared, to find people we can approach directly.

## 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](#) – providing all your details and documentation – with around two or three weeks' notice ahead of this date, depending on the type of request:

Research studies (requiring due diligence by our research team): 3 weeks

All other requests, including research PPI: 2 weeks

	Mon	Tue	Wed	Thu	Fri
			1	2	3
<b>Deadline: Research study</b>	6	7	8	9	10
<b>Deadline: Other requests</b>	13	14	15	16	17
	20	21	22	23	24
<b>Bulletin mailout date</b>	27	28	29	30	

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

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

## The documents you'll need to provide

If you have all your project information to hand, this form should take less than 10 minutes to complete. It can be completed in more than one sitting if need be, but you'll need to request your unique editing link.

We'll ask you for:

- 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
- Confirmation: adherence to data protection regulations and best practice, support and signposting for any participants, consideration of accessibility and inclusion

Researchers and students may also require:

- Confirmation letter from the principal investigator on this project (if someone other than yourself), that this is a legitimate study and that this work has their support
- Confirmation of the ethics approval for the project

Supported file types: PDF, DOC, DOCX, PNG, JPG, JPEG

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

## What we expect from you

We take our relationship with our Breast Cancer Voices very seriously and we expect people who work with them to value them as much as we do.

### 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

### Accessibility and inclusion

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

- Removing jargon and unnecessary complexity
- Providing a telephone or paper alternative to online participation/contribution
- Offering technical support
- Clearly demonstrating appreciation and valuing each contribution
- Considering any other barriers to full participation

## After the activity

We request that – where possible and relevant – you:

- Thank them  
Where possible, send a thank you email to Voices who took part in your project. We can also arrange for a thank you message from you to appear in subsequent Voices bulletins.
- Ask them to complete our feedback form  
Unless participation was anonymous, we'll provide a feedback form for you to send to Voices after the activity.
- Reimburse them  
Pay reasonable expenses where relevant. Breast Cancer Now staff should do this in line with our [Volunteer Expense Policy](#). Where appropriate, consider recompensing Voices for their time, in line with the [NIHR guidance on payment and recognition for public involvement](#).
- Update them  
It's very important that you provide an update on the outcomes of your project to Voices who took part. We can also arrange for any updates to appear in subsequent Voices bulletins.

## 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 – you can let us know in the engagement request form when is best for us to send you this form.

We may also be able to help to share and disseminate your project outcomes – you can let us know about this in the form.

## Ready to get started?

[Complete our engagement request form](#)

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