

**PROPOSAL FOR OUR NEW
INSIGHT AND INVOLVEMENT
COMMUNITY**

Introduction

- This is the proposal for our new insight and involvement community
- Breast Cancer Voices and Insight & Experience Panel will be replaced by a single, but multi-layered, community
- The community exists:
 - to serve the organisation in helping to shape its work through the views and perspectives of those affected by breast cancer
 - to provide a route for those affected to have a voice within the charity and wider breast cancer community

Basis for the proposal

The proposal was co-developed through:

- Involvement of community members via focus group, survey and co-creation workshop
- Staff working group and consultation
- External research with other charities



Basis for the proposal

Our research and consultation showed:

What members want:

- Personal
- Two-way relationship
- Sense of community
- Updates and achievements

What colleagues want:

- Diversity and representation
- Ability to connect with the right people
- Ability to contact people quickly

Summary of proposal:

We develop a large, inclusive, diverse community

- Easy to sign up to with key criteria asked for
- Monthly digest bulletin via email or post
- Signposting to webpages
- Ad hoc emails targeted by criteria for quick response
- New email design and brand
- Longer-term work done to diversify and grow

We offer opportunities to engage and connect

- For members to better understand/connect with the charity and feel part of a wider community
- Share stories from members and the team
- Share achievements and updates
- Monthly volunteer event series
- Annual insight & involvement event/webinar

We provide a “higher level/tier of involvement” option

- New members offered welcome call during sign-up
- Call will develop relationship and explore skills/interests
- Agree to receive warm approaches + invites
- Further opportunities to move up to this level of involvement will be offered during the welcome journey

Specialist panels to support a specific project or insight area

- Usually short-term membership for specific projects
- May be focus groups, patient representatives or steering committees – user involvement
- A framework to champion and integrate involvement into the fabric of the organisation
- Providing guidance and best practice to colleagues

Monthly digest email – everyone receives

What members want to see in these emails

- Stories and case studies, hearing more from other members
- Updates, achievements and outcomes, as well as research studies and other opportunities to get involved
- Not limiting the variety of different things you get to hear about
- Those that want more personalisation can follow the higher level of involvement route
- A clear identity and personal style
- More cross-over and cross-promotion with campaigns, volunteering, case studies
- Bear in mind the top five things members want to hear about, and the top three things members want to feel when they open the emails ([from survey/workshop summary](#))
- More understanding of who is emailing them

Targeted ad hoc emails – for fast turnaround

Content

- Only one opportunity per email (usually) – sent as and when needed (for quick turnaround or when we want to give it priority)
- Notification style – fairly simple, but personal (include, this is why we're sending it to you)
- Linked to the post on the website

Sent to

- Filter relevant members, based on key demographics and criteria:
 - Personal diagnosis of breast cancer OR affected in another way
 - Diagnosis of secondary OR primary breast cancer
 - Gender
 - Ethnicity
 - Younger women
 - Location
- Need to be aware this may be a much smaller number of people than the main network

Higher level of involvement – optional welcome call

Welcome call purpose	<ul style="list-style-type: none">• Hear a bit more about your experience• Understand wider relationship with the charity, or kind of relationship you want to have• Explore skills and interests to find out more, such as: interest in writing, patient expert speaker roles, volunteering/campaigning, case studies• Talk through other Breast Cancer Now involvement opportunities as relevant
What the welcome call will cover	<ul style="list-style-type: none">• Connection to the charity – what else have you been involved in or interested in?• What are you hoping to get out of your participation?• Details of breast cancer experience (if want to share)• What areas of our work are you interested in?• What skills do you feel they have and would be interested in using more?• Experience working in the health sector or in a scientific field?• How far are you willing to travel or do you prefer at home opportunities?

Higher level of involvement – warm approaches

Purpose	<ul style="list-style-type: none"> • Meets the need for fast contact of specific, relevant people for a particular task • Enables us to reach out to people we know and meet the criteria, and won't mind additional contact 	
Sent to	<ul style="list-style-type: none"> • People we know well from previous contact and relationship-building • People we can identify as relevant and interested via the welcome call skills and interests audit 	
Examples	Conference panelist We may be holding a session at a conference where we would like a community member to sit on the panel and co-host the Q&A	Social media We may be looking for specific experiences or quotes via a blog post, podcast, video or Twitter
	Patient advocate speaker Research centres contact us for a speaker to share their personal experience with researchers and students to humanise the science	Award or fundraising bids Co-presenting to the award or grant panel or sharing experiences and perspectives in the applications

Specialist panels

Specialist panels	<ul style="list-style-type: none"> • Support the larger strategic goal of using lived experience to meet organisational needs • Normally fixed-term, and established around a particular issue topic, or area • A template of involvement and terms of reference is created, outlining best practice for the supporter journey and effective involvement to enhance the project outcomes • Set up around a teams' need or a topic, e.g. fundraising, digital, men, equality/inclusion • External panels set up for e.g. research involvement requests 	
Examples	Health information review <p>Pool of members for team to call on for lay review of our health info. Terms of reference created for length of time on panel and kinds of requests, best practice guidance for getting useful feedback and managing relationship.</p>	Website development <p>Project group to support website development project through regular meetings during fixed period. A private online forum may be set up to share ideas and updates in between meetings. Template terms of reference and guidance used.</p>
	New marketing campaign <p>Sound boarding panel to support development of new campaign, from idea generation to message testing. Template terms of reference and guidance used.</p>	Review researcher PPI proposal <p>Review group to support development and implementation of PPI proposal. Template terms of reference and best practice for running meetings and reviewing proposal together</p>

Opportunities to engage and connect

- Welcome webinars to meet new members and answer questions
- Volunteer events series to meet others, upskill, and connect with the charity's work
- Annual involvement and insight event to showcase achievements and co-create the agenda for the next year
- Possibility of future regional volunteer networks



What about a new name?

Name

- We're looking at a name for our new network
- It will capture our sense of community, of using our voice and experience in a powerful way to create change and to connect us, to show others that they're not alone, that different voices and experiences come together to embrace our difference for the benefit of everyone

Tagline

- The tagline will sit with the name – in the same way that “The research and care charity” sits with “Breast Cancer Now”
- To give it fuller expression, to inspire and connect with our purpose and vision as a community

Narrative

- A full description of who we are and what we do
- It will capture the essence of what you have told us about your motivations and interests and experiences throughout the development and co-creation process
- It will explain what we're here for and give us a guide for all our other communications, helping us to talk powerfully about the impact you have on our charity and for others affected by breast cancer and why your contribution makes all the difference in helping us achieve our aim that by 2050, everyone who develops breast cancer will live, and be supported to live well
- Thank you for helping make this happen