Keeping patients at our heart

Insight and Experience Panel impact report 2018-19
Foreword

by Dr Anna Sarphie

“I am delighted to be writing this foreword for the annual report for what I believe to be an invaluable, unique resource” – Breast Cancer Now’s Insight and Experience Panel.

Having worked as a Patient Advocate in Breast Cancer Now’s Service Pledge programme, and having secondary breast cancer myself, I know only too well how important it is for patients to have their voices heard.

The Insight and Experience Panel enables those closely affected by breast cancer to give their opinions on a wide variety of subjects, as well as having the opportunity to be patient representatives or to engage in relevant research. By doing this, not only do we enrich the knowledge and understanding of the charity, making their work as relevant as possible, but patients personally gain a sense of control and purpose.

I have been a member of the Insight Panel since its inception and have been involved in a variety of projects. In this report, you will read about what we as panellists do. From information-gathering surveys, to reviewing campaign material, focus groups and more, the Insight Panel touches on a wide range of breast cancer-related subjects. You will learn about how we are developing and improving so that our impact is maximised.

Statistics and demographic data have been gathered through member surveys and are detailed here – revealing a wide range of voices with a breadth of skills, interests, and experience of breast cancer.

There is also data on how the Insight Panel benefitted a wide range of teams within the charity, with an impressive 100% recommending this unique resource. You will read about some of the highlights of this year’s work, which include giving opinions on campaigns, messaging and breast cancer services. Finally, there is a section on how the Panel might grow and contribute in the future.

Given how much has already been achieved in its first two years, it is clear that there is huge potential for the Panel. This can only increase with the exciting merger with Breast Cancer Care, opening up new opportunities where patients can offer valuable insight. Keeping patients at the heart of Breast Cancer Now’s work means that the focus on what is truly relevant to patients won’t be lost – and that starts with letting our voices be heard.

Thank you,

Dr Anna Sarphie

Anna is a single parent of two. She has a BSc in Biochemistry and in Psychology, an MSc in Forensic Psychology, and a DPhil (PhD) in Biochemistry. Anna is the Patient Representative on Breast Cancer Now’s Science Strategy Committee, and a member of our Insight and Experience Panel. She also sits on the committee for her local breast cancer charity, the Oxford Breast Buddy Group. What she’d like to communicate to everyone is that there is life after a secondary diagnosis. It is possible to live, and live well.
Introduction

Breast Cancer Now’s Insight and Experience Panel started life as a way of bringing the voices of those affected by the disease into our policy and campaigning work, to ensure that we were pushing for changes that would most benefit them.

At the end of its second year, we were proud of the growth and strength the Panel had shown, reaching over 90 members. Its membership continues to grow at the time of writing, continuing to shape and improve our work not only on policies, but communications, campaigns, partnerships and more. It is helping us to put the needs of people affected by breast cancer at the front and centre of everything we do.

While the Insight and Experience Panel is obviously hugely beneficial to Breast Cancer Now, we can’t downplay its benefits to the members that sit on it too. On the next page you will see quotes from some of our Panel members, on how they feel their part in the Panel has helped them, and the wider breast cancer community.

In April this year, Breast Cancer Now and Breast Cancer Care merged to create the UK’s first comprehensive breast cancer charity, united around the aim that by 2050 everyone who develops breast cancer will live – and receive the support they need to live well. From research to care, our new charity continues to have people affected by breast cancer at its heart.

So, the Insight and Experience Panel has never been more important – whether a member has been diagnosed, or somebody close to them has, their views, insights and feedback will be vital in ensuring that our new charity’s aims and offerings are truly relevant to everybody whose life has been touched by breast cancer in the UK.
Why our Panel gets involved

“Meeting a variety of individuals, hearing their stories and mentoring or advising in the light of my own experience has been such a positive use of time for me. Through the Insight Panel I have been able to help spread the message that with the right support it is possible to live well with breast cancer. It’s an opportunity to turn a negative experience into something positive that has value.”

Flora

“Meeting a variety of individuals, hearing their stories and mentoring or advising in the light of my own experience has been such a positive use of time for me. Through the Insight Panel I have been able to help spread the message that with the right support it is possible to live well with breast cancer. It’s an opportunity to turn a negative experience into something positive that has value.”

Penny

“The chance to “give something back” by sharing my story for the benefit of others, the opportunity to be part of efforts to improve access to care for others and toward research is invaluable. On a personal level, I also value meeting other breast cancer survivors and advocates.”

Rachael

“Being part of the Insight Panel has given me the opportunity to empower myself as a person, act on behalf of other patients, and join a great charity working to improve things for people with breast cancer. It has transformed my difficult experience into something of value.”

Clover

“I have felt it gave me a sense of purpose. I feel that being involved helps me deal with my own issues to do with breast cancer, such as losing my mum to it the year before I was diagnosed, and what it could mean to my wider family in the future.”

Janine

“I love being involved in the Service Pledge and improving the patient experience. I love representing the charity and being able to meet people who are fundraisers or who are interested in the work of the charity and how it can save lives. I am proud to represent the voice of women and men affected by breast cancer and help be part of a future without breast cancer.”

Karen
What we do

Many teams from Breast Cancer Now have collaborated with the Insight and Experience Panel this year. The requirements of the Panel have been vastly wide-ranging, and our Panel members have taken action in the following ways, to help us ensure our work is appropriate and sensitive to their views:

Completed surveys
This helps us to gather input on many aspects of our work, including messaging and campaign directions. It also allows us to get more in-depth answers about our members’ thoughts, gather evidence on how people affected by breast cancer feel about our work, answer any outstanding questions we may have, and give us the data needed to back up and strengthen our external influence.

Attended focus groups
This gathers much the same information as above, but allows us to delve into conversation about a subject and really get to the root of any issues, or ideas that people may have about our work.

Became patient representatives
Many of our Panel members have joined committees and panels on behalf of Breast Cancer Now. This collaboration means our members can use their experiences to provide expertise from a unique angle, to those who would not normally hear it. This enables the committees and projects to keep focus in the right place, and guides them into the right decisions.

Reviewed materials and data
Our Panel is often asked to feed back on our information, letting us know if it is readable and accessible to different audiences. They also help to provide a patient perspective on data and what it means.

Shared stories
The views and stories of our Panel have been told with great detail and emotion when we have needed to provide consultation responses, or support media queries. They’ve also given us quotes and personal experiences to add to our reports, so we can connect influencers and decision-makers with the realities of what it’s like living with, or loving somebody with breast cancer.

10 different teams across Breast Cancer Now have been helped by the Panel in 2018
Amount of opportunities or updates from each team in 2018:
- Public Health and Information: 6
- Insight and Experience Panel: 5
- Policy: 5
- Health Advocacy: 3
- Campaigns: 3
- Public Affairs: 2
- Corporate Partnerships: 1
- Fundraising Campaigns: 1
- Fundraising Products: 1
- Research: 1

There isn’t a team in this organisation that doesn’t benefit from the existence of the Insight and Experience Panel. Having people affected by breast cancer feel about our work is paramount to making it a success. There are so many opportunities to improve and enhance our offering as a charity by asking the Panel for their contributions.

100% of those that utilised the Panel have said:
- They feel that Panel involvement added value to their project or activity
- The number of respondents met their requirements, with over a third saying numbers exceeded expectations
- They would definitely recommend using the Insight Panel to others

We’re developing and improving Panel opportunities
Over the last year, we have introduced new processes and ideas to try and maximise the impact the Panel can have, and the benefit for members:
- Introduced feedback forms for each opportunity
- Introduced staff member feedback forms
- Introduced 6-month round-ups to share impact
- Completed a skills and interests audit
- Introduced an anonymous demographics survey
- Working closely with teams across the organisation

We wanted to see what was working well and what members were getting out of taking part – it’s very important to us that members are being sent work that they care about, and want to continue getting involved with. We also wanted to know where we had gaps in representation, particularly in terms of regions, backgrounds, ethnicity and variety of experiences, so we could look at doing some promotion to fill those gaps, making the Panel even more effective in the future.
The Panel made a difference:

90 Panel members

Helped 10 different teams across Breast Cancer Now

21 different opportunities

7 involved attending a focus group or becoming a patient representative, requiring travel

14 could be done anywhere

All opportunities had someone take part.

"I wanted to make a difference and my voice to be heard."

28 members responded to the end of year evaluation

93% say the Panel is achieving their expectations at least to some extent.

96% had taken part in one or more of the opportunities

63% have gone on, or plan to become involved in our work.

88% feel they have made a positive difference to our work.

"I wanted to be part of a team which the Insight and Experience Panel has given me."

"I like to feel that I am contributing to improving breast cancer services for future breast cancer patients."
Who does our Panel represent?

Our Insight and Experience Panel brings a vast range of experience and perspectives to our work. We introduced a demographics survey in 2018 to help us understand more about who the Panel are, find out where we might be missing representation, and what we can do to fix this.

We had 46 responses to our first survey request (52% response rate). Since then, we have requested that everybody who joins the Panel completes this anonymous survey.

The results show that we have representation across gender, ethnicity, age and sexual orientation, although more could be done to improve membership from less well-represented groups.

It is also worth noting that a range of educational levels are also represented across our Panel. This is important as we ask members to ensure the accessibility of our communications.

Members are mainly England-based at the moment, with some representation in Scotland. We are working to improve representation on the Panel across the four nations, working closely with our colleagues to build links. However, there is still work to be done in having equal representation across all nations.

Each of our Panel members gets involved for different reasons, but one common experience ties them together – the devastating impact of breast cancer. We are grateful to each and every one of them for using their experiences to help us to improve things for others affected by this devastating disease.

Panel members’ commitment to Breast Cancer Now and the amount of priority they give to helping others is particularly impressive when considering the range of responsibilities that members have, both in work and at home. They are all quite time poor, but make the time to help us. We couldn’t be more grateful.

These results show the importance of being sensitive to members’ other commitments and not asking for too much. Equally, it’s important to thank and recognise members’ contributions and ensure that they know just how valued they are, that their contribution is having an impact and that their efforts are worthwhile.

Research holds the key to a world where everyone who develops breast cancer lives.
What makes our Panel tick

There is a vast range of skills, experiences and potential within the Panel, not just from people’s experience of breast cancer, but their wider interests and life outside of breast cancer.

Members have proved themselves to be keen to use their particular skills and experiences to contribute to our work, and want to do more than we ask of them.

We decided to do a skills and interests audit to find out what else people were doing across the charity, what they felt passionately about, the areas of our work that most resonated with them, and the sort of activities they were most interested in doing or felt most confident in.

This information is now being used to target certain opportunities to particular members, so we aren’t overloading the whole Panel with things that aren’t appropriate for them.

e.g Some opportunities are only relevant for those with secondary breast cancer. We also wanted to develop new opportunities or see where there was potential to maximise the wealth of experience within the Panel.

Our skills and interests audit results:

• 46 respondents
• 74% involved in other work of the charity as well
• Interested in variety of our work, in particular: living well with and after breast cancer, treatment and care, patient experience, Government policy, breast cancer research, prevention of breast cancer
• Confident in a variety of skills, in particular: Reviewing and analysing information, Written communications e.g blogs, articles or reports, mentoring/supportive relationships, advocacy

Skills members feel confident in and/or enjoy

<table>
<thead>
<tr>
<th>Skill</th>
<th>% Confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reviewing and analysing information</td>
<td>53%</td>
</tr>
<tr>
<td>Written communications</td>
<td>52%</td>
</tr>
<tr>
<td>Mentoring/ supportive relationships</td>
<td>49%</td>
</tr>
<tr>
<td>Advocacy</td>
<td>47%</td>
</tr>
<tr>
<td>Campaigning</td>
<td>33%</td>
</tr>
<tr>
<td>Public speaking</td>
<td>32%</td>
</tr>
<tr>
<td>Negotiating and debating</td>
<td>32%</td>
</tr>
<tr>
<td>Delivering training / running discussions</td>
<td>30%</td>
</tr>
<tr>
<td>IT and using a computer</td>
<td>26%</td>
</tr>
<tr>
<td>Maths, budgeting or accounting</td>
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Number “very interested” in topic

<table>
<thead>
<tr>
<th>Topic</th>
<th>% Interested</th>
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<tbody>
<tr>
<td>Living well with and after breast cancer</td>
<td>84%</td>
</tr>
<tr>
<td>Treatment and care</td>
<td>80%</td>
</tr>
<tr>
<td>Patient experience</td>
<td>78%</td>
</tr>
<tr>
<td>Government policy</td>
<td>77%</td>
</tr>
<tr>
<td>Breast cancer research</td>
<td>73%</td>
</tr>
<tr>
<td>Prevention of breast cancer</td>
<td>72%</td>
</tr>
<tr>
<td>Screening and early diagnosis</td>
<td>67%</td>
</tr>
<tr>
<td>New treatments/drugs</td>
<td>63%</td>
</tr>
<tr>
<td>Guidelines for delivery of care</td>
<td>58%</td>
</tr>
<tr>
<td>Secondary breast cancer</td>
<td>57%</td>
</tr>
<tr>
<td>Physical activity</td>
<td>54%</td>
</tr>
<tr>
<td>Workforce issues</td>
<td>43%</td>
</tr>
</tbody>
</table>
This year’s highlights

We crafted new approaches to fundraising

The Panel helped us create innovative ways to recruit and retain new regular financial givers – people who give a monthly donation via Direct Debit – to Breast Cancer Now. Our fundraising team interviewed seven people who added to our understanding of our supporters, and the reasons they would have for donating regularly to our cause.

"After a great response from the Panel, we ended up interviewing seven people. They really helped add to our understanding of our supporters and we often refer back to this information to assess whether options feel right for people like our supporters. Now our next step is to do some creative testing which will take us to the next stage in this project."

- Owen Collier, Direct Marketing Manager

A name was decided on for our breast reconstruction report

We asked what the Panel thought we should name our report into restrictions in access to breast reconstruction and balancing surgery. Lots of helpful insight was given into what’s important to the members, and the messages that resonate with their experiences, finally coming up with ‘Rebuilding my body; Breast reconstruction in England’.

"It was useful to see the difference in opinions on the suggested titles. For every participant who said that a particular title spoke to them, another said that they hated it. That helped us realise the strength of feeling on this issue. It also gave us some valuable insight into men and breast reconstruction."

- Sally Greenbrook, Policy Manager

We found out what information breast cancer patients need

When NICE wanted to update their clinical guideline on early and locally advanced breast cancer, we asked the Panel to let us know the information they felt patients need, when making decisions about treatment and care. These views were included in our submission to NICE during their consultation on updates to the guideline, and we were delighted to see that our suggestions had been taken on when the guideline was published. Read the updated NICE clinical guideline here.

“"We got a good response, and had constructive conversations with Panel members that we were able to reflect in our response to the NICE guideline. As a result, NICE has included a number of tables in the guideline which set out the topics that should be included in discussions with patients to help them make decisions on various treatment options. They are now exploring existing information on topics covered by the guideline to help ensure patients get access to the information they need.”

- Melanie Sturtevant, Policy Manager
Meet Anna,
Patient Representative for the Science Strategy Committee

“In August 2018 I was, unfortunately, re-diagnosed with breast cancer. But this time it is secondary and therefore incurable. So I have had more chemotherapy and will be on aromatase inhibitors and Herceptin every three weeks for as long as they keep working – which they thankfully are so far.

I joined Breast Cancer Now’s Insight and Experience Panel as part of its pilot in 2016. This presented the opportunity to be a patient representative on the Science Strategy Committee (SSC). Since I also have a PhD in Biochemistry, this seemed an ideal fit for me so I was delighted when my application was accepted.

Working with the SSC brings that patient voice from the treatment programmes to the cutting edge of science. I think it’s invaluable to have a patient voice in this particular arena because sometimes scientists (and I speak as one!) can get so focussed on their area that they forget the wider picture - that they are working to help prevent people like me from dying. From my own point of view, it was exciting to hear what research was going on, the breadth of the topics, what was planned for the future and what had already made strides in scientific understanding.

I had worried that my opinion might not be entirely welcome or relevant but this seemed to be far from the case and I felt that my points were taken on board. My voice was heard. And it made a difference.”

The patient voice was brought to our Science Strategy Committee

We asked our Panel for applications to be the patient representative on our Science Strategy Committee (SSC). The SSC was established to provide expert scientific advice directly to the Board of Trustees. Members include leading international scientists and the Committee meets three times a year.

The main purpose of the SSC is to oversee Breast Cancer Now’s research portfolio and funding mechanisms, ensuring the strategic aims of the charity are delivered effectively. Six of our Panel members applied for the role, out of 23 total applications from breast cancer patients and those affected by the disease. Those that were unsuccessful in their applications were referred to our Panel, leading to five new sign-ups.

How the Panel helped

“Advertising this opportunity with the Insight and Experience Panel was a driving factor to successful recruitment. It helped us reach an engaged group of people with personal experience of breast cancer. Approximately one-quarter of applications ended up being from Panel members, and the selected Patient Representative was also a Panel member! Even better than expected, many of those that weren’t selected for this particular role ended up joining the Insight and Experience Panel afterwards.”

- Nicole Lyons, Senior Research Officer

You can read more about the process by reading Nicole’s blog on appointing a Patient Representative on our website.

After in-depth interviews and assessments, the appointed person is a member of our very own Panel, Dr Anna F Sarphie.
How the Panel helped

“Over the last two years we have made a concerted effort to further develop the Service Pledge. Not only to ensure maximum effectiveness of the programme, but also to ensure it is communicated properly at all levels. This means it has to resonate as effectively with healthcare professionals as patients – not an easy task. We have worked to create core messaging and a look and feel for the Service Pledge, and our Panel has been on hand the whole time to ensure that they are all fit for purpose.

Panel members were included remotely by reviewing surveys, messaging and different visual styles for us, as well as looking at letters to patients and posters to display in services. This not only ensures that Service Pledge communications are sensitive and appropriate to everybody who goes through the breast cancer services we work with, but reinforces the collaborative nature of the programme.

Panel member Juliet kindly volunteered to sit on the Service Pledge working group and attend meetings with The Clearing, to give her perspective as a patient and someone who had seen the Service Pledge in her hospital. Juliet was also involved in reviewing and feeding back on the development of the Service Pledge as a whole. Patient involvement at all stages is paramount to the success of the Service Pledge and I couldn’t be more grateful to every Panel member that has helped us to grow the programme.”

- Susanna Glover, Senior Services Improvement Officer

Meet Juliet,
Patient Representative for the Service Pledge improvements

“This was a great piece of work to be involved with. The staff went out of their way to ensure that I felt very much part of the team, to the extent that they arranged for me to contribute through a video link so that I could participate remotely. My opinions as a patient representative were respected and listened to and it was wonderful to be part of the policy decision making.”

- Juliet, Patient Representative for the Service Pledge improvements

The Service Pledge was improved

The Service Pledge is an innovative programme dedicated to delivering lasting positive change to everyone’s experience of breast cancer. It brings patients, healthcare professionals and Cancer Alliances together to work in partnership to design and deliver improvements in a concrete action plan.

By sharing best practice at a regional and national level, we’re working to support the NHS to deliver consistently high quality services for both breast cancer patients and the professionals dedicated to giving their support.

This year we have been working to improve staff engagement and ways of developing and implementing improvements, as well as encouraging cross-service communication. To do this, we have developed a set of key messaging, designed new materials and a look and feel, and more widely overhauled the programme.
Breast Cancer Now staff met Panel member Bal

In December, one of our regular Lunch and Learn sessions for Breast Cancer Now staff was dedicated to helping us all to learn more about the Insight Panel, who it represents and how the Panel can help with their work.

Panel member Bal came along to share her experience of why she got involved.

“I was humbled to share my story with such an amazing audience, who made me feel that life is worth living and not to let breast cancer define me. It matters to me to make a real difference, thank you for the opportunity.”

“The session really helped staff understand the wealth of experience on the Panel and get excited about how they might be able to help.

We shared with them the new Insight Panel webpage and sign-up form, where they can direct their supporters who might be interested in signing up. This is a really exciting new step for us, as it means people with experience of breast cancer can find out more via the website and can also share the link with their contacts – hopefully driving up the membership.

It’s really important for staff to hear experiences first-hand and we got lots of really positive feedback about the session, particularly the opportunity to meet and hear from Bal.”

- Susanna Glover, Senior Services Improvement Officer

This should mean that more staff will want to use the Panel’s expertise and insights next time they’re working on a project, so we can look forward to lots more interesting opportunities in the future.
We learned about physical activity after a diagnosis

We asked Panel members for their experiences of physical activity following a breast cancer diagnosis, as part of a new partnership with Sport England. Two of our Panel members were recruited to the advisory panel for this project, aimed at addressing women’s barriers to physical activity following a breast cancer diagnosis. Panel members were requested to complete a survey, take part in interviews and attend an intervention development workshop to feed into the project.

How the Panel helped

This insight project, funded by Sport England, sought to build on research and work already undertaken to fill a gap in our current knowledge – specifically how to engage breast cancer patients aged 55+ to become more physically active. Breast Cancer Now partnered with Women in Sport to carry this out.

The first phase included completion of a survey, interviews, and an intervention development workshop in Birmingham, so that the Panel could feed in from their own personal perspective and share their direct experience as patient representatives. Phase two of this work, starting late 2019, is to put forward a funding proposal to develop and pilot an intervention to encourage breast cancer patients aged 55+ to become more physically active.

The Panel were able to feed into this project from the outset, providing their own valued experiences and perspectives, helping to guide conversations and sharing ideas to feed into this project throughout its life course. Their ideas will help to shape the next phase of this important piece of work.

- Manveet Basra, Head of Public Health and Wellbeing

Meet Penny, a key contributor towards our Sport England work

“Although I wouldn’t call myself a sportswoman, exercise was hugely important to me before my diagnosis, throughout my treatment and beyond. But it was difficult to access helpful advice about what types of exercise were appropriate, how hard to push myself and how to manage re-building strength and stamina after surgery. I am also certain that physical activity was beneficial in terms of managing my mental wellbeing and gaining a sense of taking back some control over my own body.

The surgery and side effects of treatment were a blow to my body confidence so I was keen to regain some fitness. However, I didn’t feel that sufficient guidance was available to me from my medical team or at gyms or classes to determine what exercise regime would be appropriate for me at different stages during and after treatment. And leaflets in hospital waiting rooms look like they are aimed at retirees who just want to take things easy!

This is why I was keen to get involved in the Sport England and Breast Cancer Now project to talk about how people can better be supported and motivated to become more active - I felt really positive about how the project was gathering information from people like me who might benefit from a campaign to better support us in increasing our physical activity to help our recovery.”

Meet Penny,
a key contributor towards our Sport England work

From the insight work, workshop and feedback from the advisory group, there is a clear gap in encouraging and supporting women in mainstream activities, either from the start, or transitioning from hospital-based classes. Breast Cancer Now can take this insight and use it to form appropriate campaigns to help those returning to exercise after a breast cancer diagnosis.
The Government and NHS made commitments on breast cancer

Last year, we gathered the opinions of our Panel members and people that were involved in our campaigning work, on what they thought the priorities should be for the NHS Long Term Plan. It was so important to us that our recommendations to NHS England came directly from those affected by the disease. The Panel was invaluable in helping us understand what we needed to ask of the Health Secretary, Matt Hancock – and we handed him our ten recommendations in November 2018.

There was also a social media campaign at the same time as our campaigns team addressing the Health Secretary directly, helping our wider support base to share their own stories and reasons that these suggestions were so important.

Thanks to the help of everybody that contributed, the NHS Long Term Plan, now published, includes commitments to:

- Review the breast screening service to look at how to increase screening uptake and introduce new technologies
- The use of personalised and risk stratified screening for the earlier diagnosis of cancers
- Access to the right expertise and support, for all patients, including those with secondary cancers, including a Clinical Nurse Specialist (CNS) or other support worker
- Potentially offer patients more personalised treatment options.

It’s fantastic to see that the Government has listened to what Breast Cancer Now, the Insight Panel and others affected by breast cancer think should be done. We’re very proud of this achievement.

How the Panel helped

“The feedback given by the Insight and Experience Panel really helped add to our understanding of the experiences of people affected by breast cancer, so that we could influence on the things that matter most. In particular, it was useful to have quotes from patients to support our call for evidence. When the Plan was published and many of the priorities we had highlighted were referenced, it was brilliant to know that these commitments were what people affected by breast cancer wanted to see improve. Having people affected by breast cancer feeding into this project from the very beginning through the Insight Panel means that we know the impact of the project will make a difference to them.”

- Jenny Steele, Senior Policy Officer

Meet Johnny,

one of the voices that helped breast cancer become a priority for the NHS long term plan.

“I love fundraising for the charity and the research they fund, inspired by my sister Geraldine who sadly is living with incurable secondary breast cancer, and have put myself through so many challenges for them.

But the immediacy of helping with their campaigning work and the Insight Panel really is fantastic. I only heard about the Insight Panel off the back of campaigning with them; the opportunity to be more involved with their work and to feed into more aspects of what they do was something I couldn’t turn down.

With so many of us coming together to help the charity, it really gives a sense of community, or even family! There’s such a close link between everyone involved, fellow supporters, staff and scientists. We all have a common goal of trying to make things better for everyone with breast cancer. And with the NHS long term plan taking on so many of our suggestions, it really feels like we’re achieving that.”

- Johnny, Supporter
We were very pleased with the level of engagement – uptake and completion of the survey were both really good and we had 21 respondents. We used this feedback to improve our core health messages, which we use across our communications. Once we had established these they were fed back into our Panel, to make sure that any amends we had made were still fit for purpose. Their review of materials was invaluable in ensuring our sensitivity and suitability to everybody that may be affected by breast cancer.

All this input and feedback will help us have as much impact as possible in helping women reduce their risk of breast cancer and making sure breast cancer is diagnosed early.

- Tom Beattie, Health Information Officer

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Thanks to the work of our Panel, we have now started to integrate all the new messaging into our health information, marketing campaigns, social media posts, and supporter emails.

While we updated our online materials to include this messaging, we decided to update our imagery too. As the Panel had been so instrumental in the development of this, we asked them to step in again, to take part in a photoshoot for more real and representative imagery in our materials. Two members of our Panel took part in the first photoshoot, which was so successful that we progressed to do another, alongside healthcare professionals at a London hospital, reflecting real experience of the pathway through breast cancer services.

“It was great to have two patient representatives modelling in our first hospital photoshoot, who both approached the shoot with a lovely and positive attitude, enthusiasm and humour. Having images of real people alongside our health information will be really helpful, as we know being diagnosed and going through treatment can be a worrying and anxious time. We want the images to reflect – as far as possible – what people really experience when in hospital so they can feel fully informed and prepared.”

- Faiza Peeran, Health Information Officer
What next for the Insight and Experience Panel?

What the merger means for the Panel

On 1 April 2019, Breast Cancer Care and Breast Cancer Now merged to create one charity for everybody affected by breast cancer. This is exciting for the Panel as it means that we can integrate its growth and development in with building our new charity. It will be depended on to give real insight into what our supporters need from the new charity, and new opportunities that arise from us uniting with Breast Cancer Care will keep the Panel fresh and involved. The importance of the Panel cannot be downplayed, it keeps the views of those affected by breast cancer front and centre of our work, and it will remain a part of the organisation as it grows. As we know from our statistics and demographic surveys, there are still gaps to be filled, as well as perspectives and views that need to be taken on board. Growth among the four nations of the UK is something we must focus on and with Breast Cancer Care’s office bases in Cardiff, Glasgow and Sheffield, in addition to the existing Breast Cancer Now office base in Edinburgh, this feels even more achievable than ever before. It is essential that the Panel is built upon to become fully representative, and utilised as much as possible.

We will be working hard to ensure that every Panel member is kept well informed as we develop, and that we maintain our strong relationship with them.

Our relationship with Panel members

There’s such a range of experiences and enthusiasm on the Panel, not only through experience of breast cancer, but the other life and work experiences and skills that they can bring to the table, including working in healthcare and sciences. We’ve built strong relationships with many of them through the different opportunities they’ve been involved in, and we know many of them are keen to write for us about their experiences, give us strong, clear and detailed feedback on our work, and contribute their insights and experiences in many different ways.

It’s vital to maintain and grow these relationships and ensure we keep giving them what they need and want from being a supporter. It’s a reciprocal relationship. The core of what the Panel is about for them is an opportunity to take what they’ve experienced and turn it into something of use to others and to the charity.

They are experts by experience, and we need to tap into it at every opportunity.

They keep us in touch with what people affected by breast cancer really think, and are willing to provide hard evidence of that, where we need it for making a case.

We’ve been expanding the Panel over the past year, to try and build a wider base of knowledge, experience and expertise, by promoting it with staff to share with their supporters, and via members’ blogs online which share the link to the sign-up page. It’s also easier to find on the website now if people are looking to get involved. This means we now need to do more to connect with new joiners, ensure we get to know them, and find out what their strengths and interests are.
Summary of recommendations

1. **Dedicate time to building and taking the Panel forward** in the new merged charity to ensure we’re representing a range of experiences and expertise. To do this we must: promote the Panel more heavily, while staying clear about the remit of the Panel and maintaining its integrity.

2. **Ensure that we maintain our strong relationship with our Panel members** and that they are kept well informed. To do this we must: continue to give them a range of opportunities that we know tap into their own experiences, as well as regularly communicating and involving them in other developments in the charity.

3. **Ensure we’re collecting useful feedback from those using the Panel** to see what’s working for them and how we can improve. To do this we must: constantly review and improve the feedback process to ensure we’re getting the answers we need.

4. **Use feedback to evaluate and communicate impact with members.** To do this we must: continue our regular impact reporting. This can then be used to encourage and inspire other Panel members through round-ups and blog posts.

5. **Tap into the Panel’s expertise at every opportunity.** To do this we must: keep promoting the Panel internally so that teams are aware of the opportunity for those affected by breast cancer to feed into their work and the significant impact this can have.

6. **Do more to connect with new members,** get to know them and find out their strengths and interests, and make sure we keep focussed on their needs. To do this we must: continue to find out about our Panel members’ experience and expertise, as well as giving more opportunities for our Panel members to contribute their personal stories through blogs, features in our round-ups and more.

7. **Connect more deeply with different teams,** especially new colleagues in the merged charity to promote use of the Panel. To do this we must: educate our new colleagues on just how helpful the Panel can be, meet and connect with colleagues who may benefit from the Panel’s input, and use internal communications to share stories and feedback from the Panel.

8. **Set expectations for both Panel members and staff** to ensure everyone involved understands what is expected of them, and particularly what Panel members can expect from the staff offering opportunities. To do this we must: update our briefing processes and terms of reference, and clearly communicate these.

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Thank you

Whether you are an existing Panel member, thinking about joining, a member of staff interested in making use of the Panel, or otherwise – thank you so much for being a part of what makes this initiative so special. It is only through the collaboration of teams within the charity, and our incredible supporters, that we can continue to keep those affected by breast cancer at the heart of everything we do.

We are here to build a better future for everybody affected by this devastating disease. A future where everybody who develops breast cancer lives – and receives the support they need to live well. The growth of the Panel over the last year, and the encouraging enthusiasm of every team to get involved and build their work with them shows us that this shared vision is something so powerful. Together, we can make this vision a reality.

Thank you.
A special thank you to our Panel case studies:

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