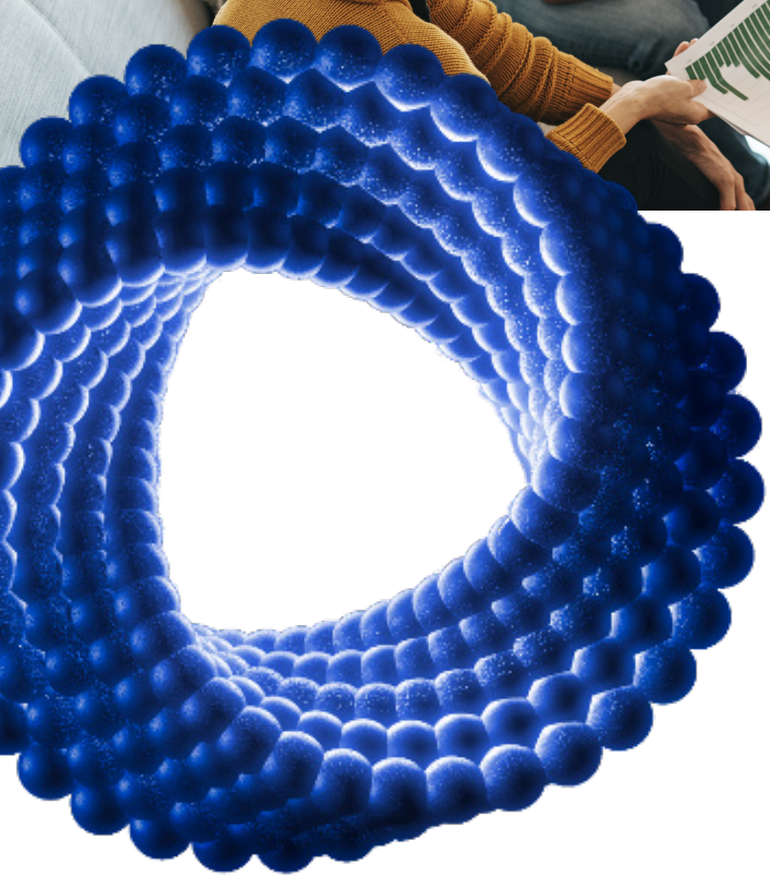
MediPaCe®
Making Patient Engagement a Reality

Voices That Matter:

A Journey of Co-Creation with Patients

How ZEISS listened to the patient community in the design of patient information





ZEISS Educational Partner

Introduction

Culture is changing. The spirit of the term ‘nothing about us without us’ - a phrase originally used in European political movements and later adopted by disability advocates - has, over the last several decades, permeated all branches of society. The legitimacy of institutional orthodoxy is now in the spotlight, with those affected by the actions of corporations and policy makers demanding a greater say in decisions that impact their lives.



Experience matters

This reinvigorated mood extends to healthcare, too. The first mention of the ‘expert patient’ appeared in the UK in a 1999 government white paper entitled ‘Saving Lives: Our Healthier Nation’ in which the then-Secretary of State for Health asserted that those living with chronic diseases and disabilities are experts in their own lived experience, and therefore should be listened to by medical professionals when it comes to making decisions about their own care. As a result of the paper, the UK’s National Health Service went on to develop ‘The NHS Expert Patients Programme’ (NHS EPP), based on a model developed by Stanford University in the United States. The Stanford Center for Patient Education’s programmes have been adopted in many countries across Europe, including Germany, and according to an article by the Centre for Empowering Patients and Communities (CEmPaC), are ‘...an ideal vehicle for patients to feel more in control of their health and wellbeing and actively engage in changing how health care is provided.’

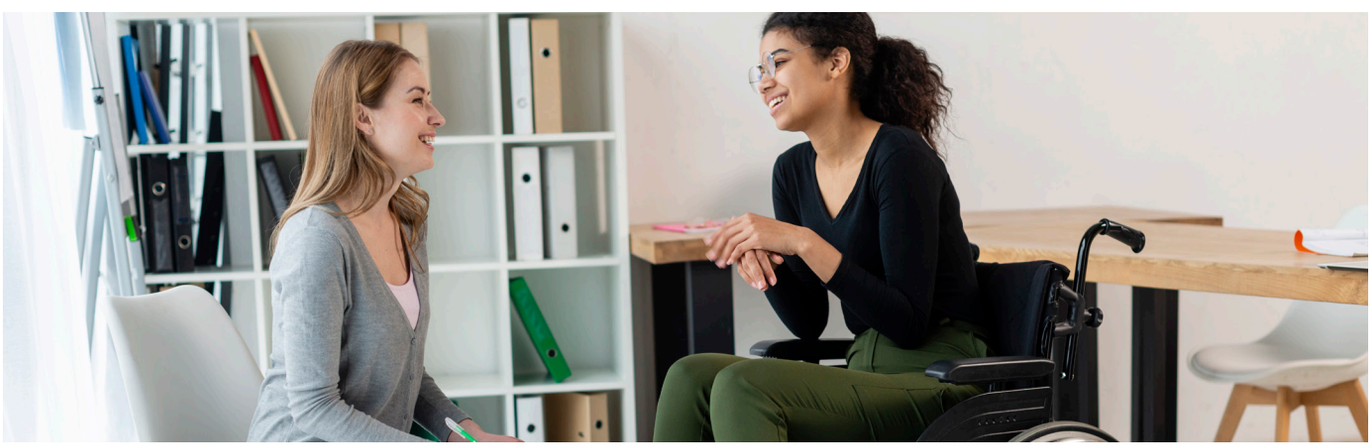
The changing role of patients

Germany has a decades-long history of educating patients on their conditions and ensuring they are involved in decisions about their treatment. Since their introduction in 2003, the country’s Disease Management Programmes (DMPs), which currently cater to twelve chronic conditions, have proven essential in creating a collaborative working relationship between healthcare practitioners and patients, so that patients are adequately educated in their own conditions, receive relevant and clinically-approved information, and are supported in strengthening their own self-care practices to help them manage their conditions. And in the twenty-five years since the UK’s ‘Saving Lives’ white paper was published, both the term and its definition have evolved: ‘patient experts’ not only have expertise in their own specific conditions accrued through lived experience, but often self-educate on the full range of treatments and medical developments around their illnesses and build connections with those in decision-making roles within the healthcare system. Other patients who may not necessarily consider themselves ‘experts’ have equal value; they too research their conditions, ask questions of healthcare professionals, and are keen to know as much about their conditions as possible. This seeking out and absorption of so much information in an over-saturated data landscape develops - in both patients and patient experts - a keen sense of discernment: precisely the skill that makes them excellent consultants and collaborators in offering advice on how best to present information to people who have gone through similar health experiences to themselves.

Introduction

Expanding patient engagement

It is no longer only public sector health bodies that recognise the value of patient experts: medical technology and pharmaceutical companies also understand the benefits of working with people with lived experience. Patient organisations, patients and patient experts are in the unique position of being able to advise medical technology and pharmaceutical companies on how best to communicate new treatments and tech effectively; they can advise on how to set the right tone, use language and graphics that are clear and informative without condescension, and guide companies in how to express difficult information sensitively so that, even if what they are reading is uncomfortable to digest, patients can still be fully informed.



Building trust

While new patients navigate the emotional and psychological impact of diagnosis, it can be reassuring to know that they can access information that has been developed in collaboration with fellow patients and has passed a patient ‘stress-test’ for quality. It also suggests a level of transparency by the company who commissioned the patient expert-centred consultation and illustrates a willingness by those in the healthcare industries to take constructive criticism from people with personal experience.

Working together

Taking this into consideration, ZEISS made the decision to collaborate with MediPaCe, a patient expert, and a select group of patients to create a document that would offer a full explanation of the radiotherapy options currently available to breast cancer patients, including its specially developed INTRABEAM® intraoperative radiation therapy (IORT). ZEISS and MediPaCe would combine their own respected professional credentials, and the wisdom and expertise that only lived experience can provide would be supplied in abundance by patient consultants.

Working together with patients with personal experience vastly improves the relevance, accuracy and appropriateness of information for patients. It’s a no-brainer! It is also such a rewarding way to work for everyone! We really enjoy collaborating with new people, finding out about their lives and delving into their experiences. It’s especially rewarding to know that we are working together to make things better for others. - MediPaCe

Patient experience survey - Part I: Sharing Information

Those in health communications will be familiar with standards such as the Patient Education Materials Assessment Tool (PEMAT), which is used to “evaluate and compare the understandability and actionability of patient education materials”, and DISCERN, an instrument developed by the University of Oxford to “enable consumers and information providers to judge the quality of written consumer health information on treatment choices”. The purpose of these tools is to ensure that information about healthcare treatments is readable, clear and uses language that is suited to people who might not necessarily have medical expertise. The benefits of providing scientifically-supported but easily digestible information to patients are many: as well as empowering patients to take part in their own care journeys, studies have shown that patients who are actively involved in learning about their conditions and who can, based on this learning, participate in choosing their own care, enjoy positive psychological outcomes that make coping with their diagnosis less burdensome.



Exploring patient journeys

ZEISS recognises the many benefits of patient involvement; they respect the expertise that patients can provide and acknowledge that consideration of their experience can be hugely empowering for patients. ZEISS asked MediPaCe to assist them in learning more about how patients were first informed about radiation treatment, and how that information was presented to them. They wanted to understand the initial stages of a patient’s path through breast cancer - from diagnosis to selecting treatment - so they could better centre the patient experience in the information they planned to present.

Networks of trust

MediPaCe responded to this request by calling upon the vast network of patient organisations with expert patient members, ready to generously offer insight into living with a health condition. For this project, patient organisations with members who had experienced breast cancer and had undergone radiation as part of their treatment plan were sought. Patients’ insights on how best to deliver disease education are invaluable, particularly around care options that might be perceived as extreme or intimidating, such as radiation treatments. Having been through the experience themselves, the patients that MediPaCe worked with knew the intricacies of radiation treatment from an experiential vantage point, and so were able to highlight what information they found valuable in their own journeys and - importantly - what they wish had been thoroughly explained.

Gathering information

To begin to delve into these insights, MediPaCe captured anonymously-contributed insights from patients around two areas of focus: their experience of first being told about radiation as a treatment option, and the details of how that information – and subsequent educational materials - was presented.

The value of lived experience

The comments offered by patients were revealing, and proved just how invaluable lived experience really is. Participants were so open: they described their personal experiences in great detail and explained various aspects of their own very specific journeys. Their comments on the information presented were also extremely useful: some patients wrote that they would have liked more of the information to have been written in lay language; others wanted to see statistics and graphics that would round out the text and provide a more substantive overview of the stages of treatment. Though age played a significant factor in how patients generally responded, the consensus across all groups was that they preferred information to be primarily rational and scientific - though explained in plain language – but written in a warm tone.

Brochure - Part II: Creating the Brochure



ZEISS studied this abundance of information thoroughly and took its time in examining patients' responses, making sure they fully understood what had been expressed. They knew that the greatest show of respect to participants who had so carefully considered the information they had been presented with was to try and truly reflect what they had asked for.

Getting to work

ZEISS's science writers and designers set to work on the first draft of the brochure, using information provided by patients and weaving it into their own work. This was a natural continuation of the collaborative nature of this project: melding the skills and ideas of all parties to create a document that incorporated patients' views while meeting ZEISS's high design and production standards.

Creating a 'live' document

It was understood by all parties that this document would be 'live': it would be reviewed and refined by patient feedback over the course of several drafts, until each party in the collaboration was happy. This ongoing refinement was important to ZEISS: it truly believed in the collaborative process and knew how important it was to create a document that met the specifications of the patients who had so freely given their time and experience to the project. ZEISS was happy to receive multiple rounds of feedback until all concerned were satisfied.

Content review - Part III: Reviewing the Brochure

So, who were the reviewers asked to assess ZEISS's draft brochure and provide feedback? MediPaCe coordinated a group that consisted of lay patients and patient experts, as well as a Patient Expert Consultant, Susanna van Tonder. Susanna is an expert in her field: she is a trained psychologist and a patient expert specialising in chronic illness management – an element that was vital to her involvement in this project. Susanna is also active in the field of research across Europe and the rest of the world, and is Vice President of the Luxembourgish MS Society, as well as being an Executive Committee Member of the European Multiple Sclerosis Platform.

Calling upon expertise

Susanna's contribution to this project was central. Not only did she represent a degree of independence within the collaboration – being, as she was, primarily concerned with ensuring that patients and patient experts felt comfortable with the requirements of the project – but she was also able to ensure that participants had a safe, anonymous space in which to share their very personal stories. In Susanna's experience, the security of knowing one's identity will be kept private is essential:

> **Patient anonymity...is key to ensure that all valuable information of the patient experience can be captured. A lot of times, patients also do not wish to share their personal experience with direct outsiders but offering a security net of anonymity allows them to open up.**

That sense of safety was borne out in how open patients were able to be. They discussed all aspects of the draft brochure with Susanna and were able to talk about how they felt the first draft was clear, undaunting and well-designed, while offering honest thoughts about the photographs and graphics that had been chosen. While some requested that additional elements of the radiation experience be included, others felt that this would obfuscate the main purpose of the brochure, proving that no two patients – or patient journeys – are the same, and that the need for individual patient involvement in this kind of work is imperative.

MediPaCe sees Susanna's participation as invaluable:

It's been great working so closely with patient expert Susanna. She comes with such a wealth of experience and passion and has really driven all the direct communications with breast cancer patients in Germany. It's thanks to her that the insights we gained were so in-depth.

When it comes to explaining treatment to patients that might be perceived as frightening or off-putting, Susanna feels that one word should always be central to any kind of communication:

Empathy. Difficult information to process in terms of the side effects of medication, or more invasive medical procedures such as surgery is unfortunately still a reality for many treatments. Nevertheless, patients need and want clear, concise and objective information in relation to their treatment choices. Informed-Decision Making is one of the key priorities.

Though it may be challenging to explain difficult treatment options with sensitivity, there are ways to go about it that centre empathy and compassion, and can also encourage patients to ask questions of their health care provider (HCP) if they have concerns:

Having easily digestible - as well as reliable - information is crucial. As these topics carry heavy weight, it often is a balancing act in knowing how detailed the patients would like their information to be. Focus groups and interviewing individual patients has proven to be very effective to know more and to address the latter efficiently and kindly. Another key aspect is to inform patients that should they have any questions, that their provider whether a specialist or their primary HCP is a good starting point to initiate conversations.

Distilling the message

After incorporating the initial round of feedback, a second draft was provided to the same groups for further comment so that ZEISS could continue to refine the brochure. ZEISS was happy – but how did the patients and patient experts feel about the process?



Assessment of the collaboration

Collaborative Working: How Did We Do?
Partnering with patient organisations was an essential part of this project. The trust that such organisations have developed with their membership over time means that patient members are happy to participate in studies like these, because they know that their contribution will help other patients in their own decision-making, if they can be sure their private information is in safe hands and will be used responsibly. Susanna van Tonder agrees:

> **Patients…want to support their co-patients and are generally open and willing to share their personal experiences and expertise when they trust and believe in the good use of their data.**

Susanna describes how empowering it was for patients to be asked their thoughts and opinions as part of this collaboration, and how important it is to them to be recognised for their valuable contributions to this type of work:

> **Patients enjoyed the fact of working with a patient-focused project…They appreciated the personalised approach and being seen as full human being – not just as patients…Patients have a different lens when it comes to their health. Oftentimes, clinicians speak "clinician talk" whilst patients bring the human and existential experience to the table.**

Susanna suggests that patients feel a great amount of fulfilment in being helpful to others who are going through similar health situations:

> **I do think this is one of the most rewarding experiences – knowing that experiences that cause pain can be a source of support and a path towards wellbeing for others.**

MediPaCe's team on this project - Natalie Swiderska, Patient Engagement Lead; Charlotte Hooker, Research Executive; and Sandeep Bagga, Research Lead – also know the importance of working with patients and patient experts, and how fulfilling it can be. The team goes on to say that this project has been no exception:

> **The collaboration between ZEISS, patients and MediPaCe has worked so beautifully and produced something which will meet the needs of breast cancer patients to better inform them about their treatment options.**



Assessment of the collaboration

Susanna expressed gratification at witnessing the various stages of changes to the brochure based on the feedback of the patients she worked with, and how the alterations she saw in each round faithfully reflected patients' suggestions:

> **I feel that an excellent achievement has been made – when having seen the final output, it was clear how the patients' input has been evaluated and immense changes have been made to the final brochure. I can definitely see how delicately the different viewpoints have made a great product even better.**

Conclusion/next steps - Stepping Forward

When we talk about success in the context of this collaboration, what exactly do we mean? Perhaps we must go back to the beginning: to look at what ZEISS initially set out to do and assess whether it was achieved.

ZEISS wanted to create literature that would provide information to patients about the various types of radiation treatments that are currently available; to describe what embarking on a radiation path might look like; and to explain to patients - with as much clarity as possible – elements of these treatments that might not always be communicated in a transparent way.

But they did not want to create this information in isolation. They knew it would be elevated and enhanced by involving patients who have direct understanding of these treatments, and asked them sensitively: will you share your experience with us? What can we do to make this easier for those who might find themselves in your position in the future? Will you tell us what will help?

They understood that this project would need care, compassion and professionalism, and MediPaCe provided those elements with plenitude. MediPaCe reached out to hardworking patient organisations that respected its values, and from that, a group of smart, generous and learned patients and patient experts was formed, led by a highly skilled, experienced independent specialist. Each of these collaborators had one thing in common: they wanted to use their own unique skills to help others.

This is how true communities are built: by recognising the value of every kind of voice, and creating space for each to thrive, with patience, understanding and a strong desire to not only listen, but to act on what those voices say.



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