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Recounting the untold stories of breast cancer patient experiences: lessons learned from a patient–public involvement and engagement storytelling event

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Abstract

Objectives: Breast cancer remains a prevalent disease in women worldwide. Though advancements in breast cancer care have improved patient survival, a breast cancer diagnosis, and subsequent interventions have a lasting impact on patients' lived experiences during the pandemic.

Methods: We present the collaborative learning process from this patient engagement workshop series as a community-academic partnership. Narrative medicine tools were used to recount patients' lived experiences following diagnosis, where both patients and researchers shared their cancer research activities in each workshop, and the role of the multidisciplinary healthcare team was discussed.

Key findings: We used an iterative approach to cohort building, narrative development, and the use of multiple media formats to capture stories. Over 20 patients with breast cancer shared their stories for the first time since their diagnosis with a wider audience. Here, we present the learning process and considerations from this event.

Conclusions: Understanding patients' lived experiences can support researchers and healthcare professionals in developing an empathetic approach to shared healthcare decision making. Moreover, understanding the lived experiences of patients is critical to addressing disparities in healthcare.

Keywords: PPIE; breast cancer; narrative medicine; storytelling; breast cancer research

Background

Breast cancer remains a leading cause of female cancer-related diagnoses in the UK, with up to 4200 new cases in Scotland per annum [1]. Advancements in early screening campaigns, standard of care, and patient education have seen significant improvements in patient prognosis beyond a breast cancer diagnosis [2, 3]. The term 'breast cancer' represents a heterogenous collection of diseases, with classification occurring based on molecular subphenotypes and hormone receptor expression, each dictating different intervention pathways for patients often requiring multiple therapeutic interventions associated with long-term effects impacting patient quality of life years beyond their care [4–6].

While recent technological advancements have revolutionized the diagnosis and treatment of breast cancer, these advances alone cannot be relied on to support a patient in their journey of illness. Patients become entangled in the confusion of scientific jargon, fear of the unknown, and lack of effective communication with healthcare professionals about their perceptions, emotions, and lived experiences [7]. Increased pressures on healthcare systems have created an environment focussing on symptom management where the provision of lifestyle advice can be adversely impacted [8]. Clinical care leads to the co-creation of a narrative formed by an encounter between the patient and healthcare professional, which evolves during the different stages of their illness. Healthcare professionals are trained in the art of history taking to efficiently extract relevant information, without spending time on unnecessary detail.

Patient and public involvement and engagement (PPIE) has come into focus from research funding bodies and healthcare-based research institutions to drive patient input

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into research [7]. The value of PPIE is recognized as an integral part of research, not only at the mid-end stage of project development but also at the point of project design. While PPI has proven benefits in the inclusion of the patient voice in research, it can be heavily influenced by the research team narrative or those patients with extensive prior involvement with researchers [9]. PPIE provides researchers with the opportunity to share their research with citizens and enables a two-way dialogue between the audiences and researchers. This model allows for a flexible approach to patient involvement, enabling feedback on current efforts and inspiration for research prioritization[10]. Though extensive guidelines and training resources exist on PPIE, there is a paucity of publications or case studies providing detailed exemplars of such activities [11].

Storytelling is increasingly used as a pedagogical tool for public engagement [12], however, it can often be poorly designed in a way that leads to one-way communication and a lack of participatory input. Therefore, the design of activities that promote interaction, reflection, and authentic story development within a patient cohort setting is critical. The approaches used in the current study to promote engagement included object-based storytelling using mementos brought by each participant. This is a common storytelling approach used to foster positive conversation between people during group activities by displaying visual mementos later used as focal points for discussion [9]. Narratives were visualized to promote reflective practice [13], provide source material and evoke memories from which stories could develop and be reconstructed for oral communication.

While storytelling has been demonstrated as a beneficial tool for promoting patient-centred care [14] and can provide a narrative of the patients' lived experiences in advancing patient care, its implementation in cancer research PPI and informing the design of healthcare interventions including the provision of pharmaceutical care services remains limited in scope.

Healthcare professionals are trained to listen to patient stories and recognize the cultural and social elements shaping those stories. This enables self-reflection on their prior lived experiences and biases, however, there have been growing concerns over the communicative competence of newly qualified health care professionals [15]. Through engaging with patient narratives *via* storytelling, healthcare providers and researchers can gain a deeper insight into patient perspectives and needs, informing clinical decision-making, improved communication, and fostering a more compassionate approach to patient-centred care [16]. Beyond the improvement of healthcare provision, narrative medicine encourages patients to actively participate in decisions around their healthcare by actively participating in dialogue and sharing their stories with healthcare providers. Through this reflective process, patients can find meaning in their experiences and perceptions, while simultaneously gaining a voice and a sense of empowerment [17]. Healthcare concepts of narrative medicine are predominantly used in medical education to examine the patient-doctor relationships, while also accounting for contributions from other health professionals including pharmacists, nurses, and allied health professionals. Narrative medicine has been increasingly recognized as a valuable approach in pharmacy practice, allowing pharmacists to enhance their understanding of the patient experience and improve their communication and consultation skills.

As a discipline, narrative medicine and the use of storytelling have been applied across many areas of pharmacy practice, including patient-centred care by emphasizing the importance of understanding the patient voices, perceptions, and values. Pharmacists can actively engage with patients in dialogue, to learn more about patient experiences, and their concerns and stories surrounding their medication [18]. Through active listening, pharmacists can gain an insight into the patient's perspective and develop more tailored pharmacological and non-pharmacological interventions in the provision of personalized care [19, 20]. Non-adherence to prescribed medication is another area in which narrative medicine has been implemented in pharmacy practice, where pharmacists have encouraged patients to recount their narratives surrounding barriers, misconceptions, and challenges they face in taking their medication [21]. Using these narratives, pharmacists can collaborate with patients to develop personalized counselling and support, while simultaneously addressing the root causes of non-adherence. Beyond the delivery of patient-centred care, patient narratives can be used to improve health literacy as a public health measure [22]. By replacing jargon, pharmacists can use storytelling techniques as an aide to explain how medicines work, their side effects, and potential outcomes in patient populations. Relatable stories can be used to enhance the public comprehension, engagement, and interaction with the concepts presented to improve the management of medicines [23]. Beyond patient-centred care, other reported applications of narrative medicine have been as a resource in interprofessional collaboration [24] and continued professional development activities [17].

A key consideration underpinning the implementation of storytelling is providing adequate guidance and coaching to patients on how best to enable the sharing of stories across all stakeholders involved in patient care [25].

We present the collaborative learning process and key findings from a workshop series in a breast cancer survivor storytelling project (Fig. 1). This project aimed to break barriers between researchers, patients, and clinicians, facilitating the development of new relationships, while simultaneously learning about patient concerns and perceptions of breast cancer that can be applied to improving the provision of patient care locally. We used the patient stories to develop research questions, as well as considering how the role of the multidisciplinary healthcare team, shared decision making can be better communicated with patients during the initial stages of their breast cancer diagnosis. To achieve these aims, we developed an environment in which patients can rationalize their lived experiences of breast cancer with peers.

Methodology

Participant recruitment

Two formats were employed to recruit patient participants, including promotion on social media with an Eventbrite registration link (see Supplementary Information) and recruitment of participants *via* a breast cancer clinic in NHS Lanarkshire. All workshop participants were women diagnosed and treated by NHS Lanarkshire for breast cancer after 2020. Workshop participants (>30) were identified by the consultant involved in their care and issued an invitation letter to participate in a storytelling workshop series, the event promotional leaflet, and a participant information leaflet informing patients of

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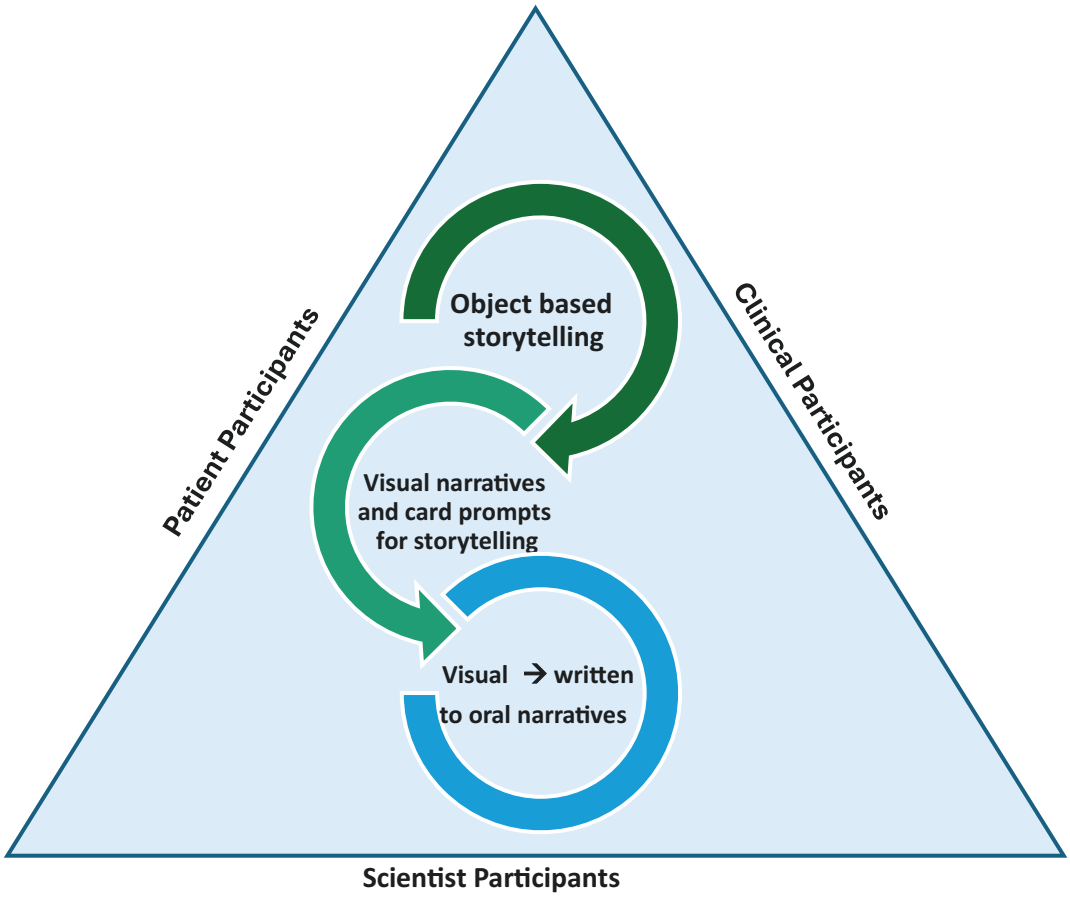

Figure 1. Using storytelling tools to establish meaningful communication across patient, clinical, and scientist workshop participants.

the workshop goals, and a media written consent form (see Supplementary Information).

Workshop format

A three-part workshop series was held with patients and researchers, and the breast surgeon being the connect between both with prior engagement with all participants. The timing and structure of each workshop is detailed below (Fig. 2).

Workshop 1—'Show and tell'

The aim of workshop 1 was for patient and scientist participants to meet and develop a cohort. Feedback from workshop 1 participants, informed the design of workshop 2.

During workshop 1 all participants networked, followed by an interactive ground rule setting for terms of engagement between participants and training on storytelling. We partnered with a storytelling professional to help all participants identify, share, and structure stories of their personal lived experiences in a personalized manner.

All participants were prompted by email to bring an object of personal significance, which was used to capture the role of object memory in the lived experience, and shared their stories within small focus groups of 5–7 participants (Fig. 3).

All participants brought an object and in instances where they had no objects available, a table of objects was provided to enable inclusion of all participants in object-aided storytelling. Stories captured from object memory discussions shared by patient participants were captured and converted to visuals. Recurring objects selected from the object-aided storytelling were patient wigs, books that played a central role in coping during treatment, and pictures recalling memories from their breast cancer journeys. Additional objects included a camisole to signify dignity during the tattooing process experienced during radiation therapy, and a bell to signify the end of cancer treatment.

Researchers presented objects (component of a mass spectrometer, a cell culture flask labelled with a breast cancer cell line) and the clinician presented an object from a memorable patient encounter (Fig. 3).

Following object-based narrative development within smaller focussed groups, all participants placed their objects in a central table and shared their narratives with the rest of the participants. As everyone recalled their object memories, a facilitator simultaneously visualized stories (Fig. 4). Visual narratives are a powerful way to promote reflective practice in group settings and develop confidence when interacting with peers.

Workshop 1 concluded with a reflection of all activities, followed by a discussion engaging patients on their feelings about workshop 1 and recommendations for the format of activities and running order for workshop 2. A feedback notebook was provided for all participants to reflect and feedback on the sessions, which was used as an additional tool to design subsequent workshops.

Workshop 2—'Bringing your story to life'

In workshop 2, breast cancer researchers and the clinician presented their work in story format, starting with the

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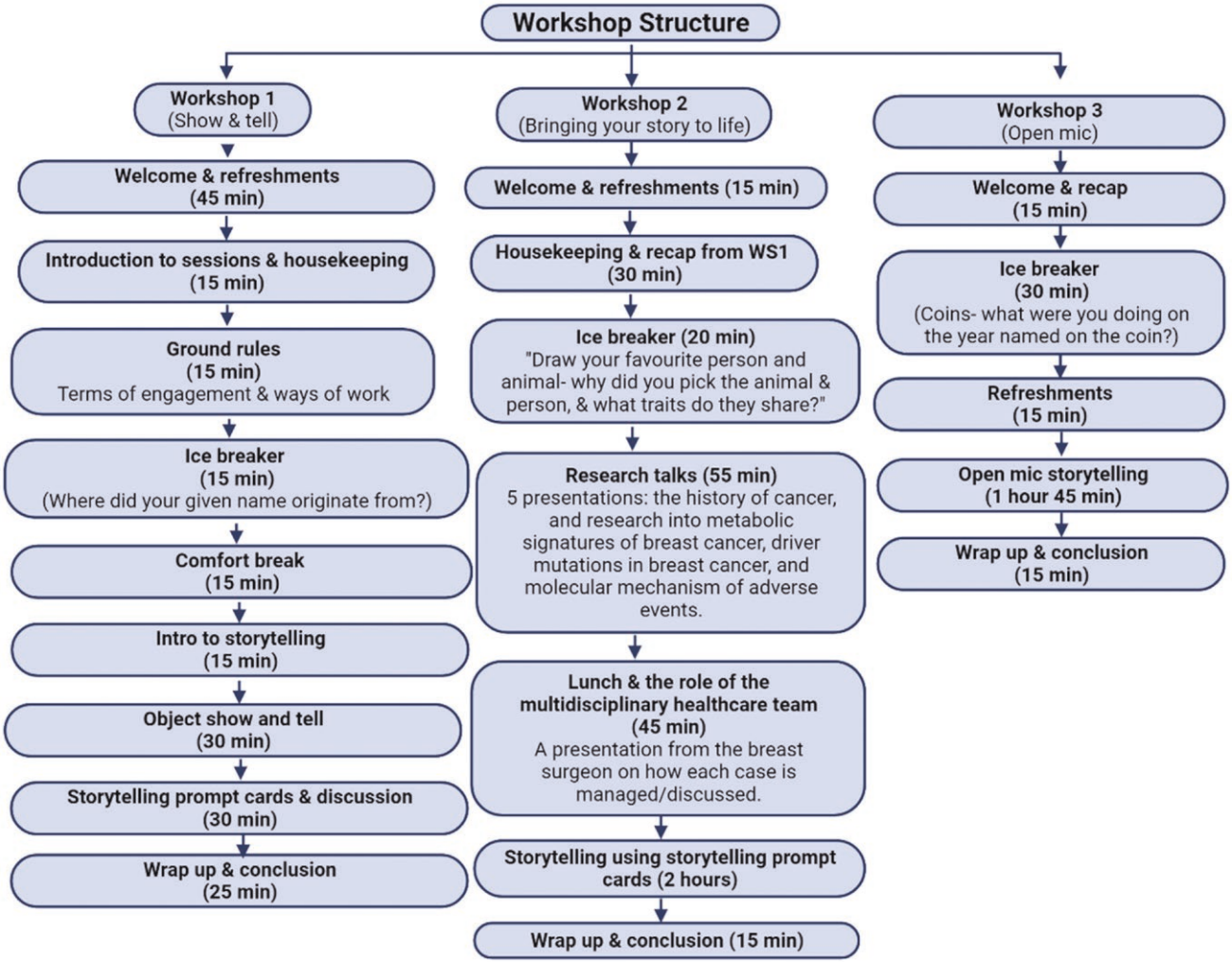

Figure 2. Workshop schedule and format used to build trust and participant narratives.

history of breast cancer diagnosis and treatment. This was followed by researcher facilitators sharing their research in story format covering various topics such as the role of driver mutations in breast cancer prognosis [26], response to chemotherapy, and the discovery of novel treatments against breast cancer [27], mass spectrometry-based metabolomics fingerprinting of tumours, and the drivers of chemotherapy-induced cardiotoxicity [28] as exemplars. These talks were designed to be interactive, where participants could ask questions during the PowerPoint presentation-aided storytelling.

The research talks were followed by a demonstration from the clinician who described the role of multidisciplinary teams (MDTs) in healthcare decision making and the selection of treatment interventions. This component covered how physicians, nurses, pharmacists, and allied health professionals work together in the pharmacological and non-pharmacological management of breast cancer. In the latter half of the workshop, patients were given storytelling prompt cards (Supplementary Information) to consider the beginning, middle, and end of their breast cancer story.

Used within small breakout groups, the purpose of storytelling prompt cards was to support the development of patient narratives and ensure equal and representative engagement from all participants. Facilitators within breakout groups were responsible for capturing timelines of patient stories and all breakout groups shared their relative experiences with all participants attending the workshop. During this session, participant stories were captured using multiple media formats (quotes, timelines, drawings, and an essay).

In workshop 3, patient participants were invited to share their lived experiences of breast cancer in an open-mic format.

Workshop 3—'Open-mic'

In workshop 3, there was an exhibition of photographs from past workshops, including patient quotes, and imagery from story arcs. All participants were invited to present their stories in open mic format while seated, and the microphone passed between participant volunteers throughout the session. All stories were captured in audio format with participant consent. The aim of this final session was for patients to voice their lived experiences, sharing their breast cancer diagnosis and treatment experiences with their peers. Following the completion of open-mic storytelling, key emerging themes and concepts from the patient stories were discussed within the group. The workshop concluded with feedback on the delivery of the workshop, and how it benefited all participants in different ways.

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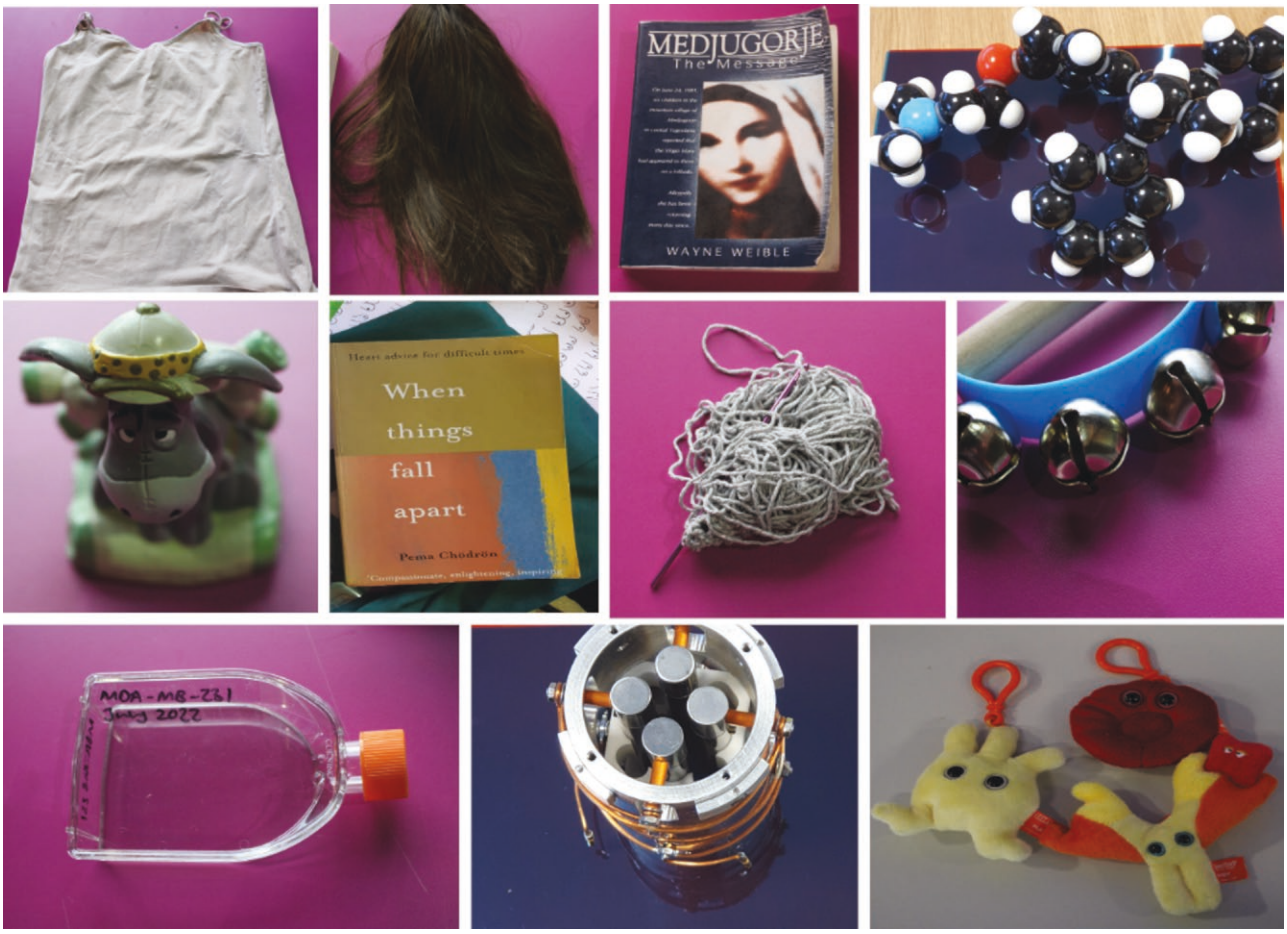

Figure 3. Exemplar objects that patient participants and researchers presented at workshop 1.

Logistical considerations

Patients invited for participation were geographically based in Lanarkshire, which is situated outside the borders of Greater Glasgow in Scotland. This community representing a population of 665,000 individuals across rural and urban communities [29], is often underrepresented in University PPIE and outreach activities, due to challenges in encouraging participants to travel into the city to participate in such events. We also perceived that meeting patient participants within a University campus could provide an additional barrier for those concerned about sharing their emotions, which we later found through patient perspectives to not impact patient willingness to participate. Accounting for these considerations, we selected a public venue within the local community that would be accessible for all participants and provide an environment in which a safe space and place of trust can be created. Through our engagements with North Lanarkshire Council, we hosted all three workshops at the SummerLee Museum of Scottish Industrial Life. An advantage of this venue was convenience in accessibility, the availability of appropriate facilities (accessible toilets, lifts), and accessibility to public transport.

Discussion

Communication between patients, healthcare professionals, and researchers is increasingly being considered in cancer research, an area that has seen ever-increasing emphasis on PPIE in the design and dissemination of research activities to stakeholders. To date, many participatory approaches have been implemented in PPI for cancer research, to enable communication between researchers and patients within the confines of a predefined project remit or subject area [30]. This is in part a consequence of the rapid growth in clinical and translational research, and the need to ensure that technological advancements made in diagnostics and therapeutics are directly aligned with the needs of the target patient population. A major challenge that remains with existing approaches to PPI is the lack of critical reflection of process. Various models of PPIE have been proposed, that are defined based on the scope of patient involvement and can be broadly categorized as a ladder with the rungs of engagement ranging from informational (passive participation) to controlled (defining the direction and priorities in research) interactions depending on the nature of PPIE activity or the body involved in its design [31]. Reflective practice in the PPIE process was factored into the design of the approaches used in the current study in a way that each workshop was informed by the experiences captured in the preceding event.

PPIE activities may take place during various stages of research and concept design including research focus, research design, recruitment, data generation and analysis, and dissemination activities [30]. Several systematic reviews have highlighted that PPI activities may take place across one or multiple stages of research project conceptualization and delivery, with most reviews of participation in cancer research

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Figure 4. Exemplar visual narratives created from patient object memory stories.

indicating more PPIE occurs during the initial stages of research design for defining research priorities. This often means that the impact of such activities is often lost through a lack of patient engagement at the later stages of the research project. The long-term loss of which can give the impression that PPIE activities are tokenistic in scope [32]. Here, all participants were provided with an equal opportunity to contribute towards projects emerging from the discussions, feedback and stories shared, including the analysis of qualitative data generated from patient stories.

A key aspect identified from the systematic analysis of cancer PPI initiatives is the lack of reporting on challenges and recommendations, nor sharing of processes that were followed during the PPI activity. Therefore, the longer-term legacy and impact on subsequent PPI activities are often lost [30]. Moreover, an element that remains unaddressed in many PPIE activities, is 'how do we empower patients to have a real voice?' and 'what is the best approach?', to ensure that the patient voice is heard during PPIE initiatives, and that they also directly benefit from such activities in a more active capacity. As part of the workshop series findings, we report both the positive and negative impact of the experiences shared as part of the workshop series. Many of the patient participants cited that they had been in denial of having cancer and that they had not really visualized themselves as being a cancer survivor until the workshop experience. One participant even acknowledged that the realization of their survivorship status had prompted them to seek additional support from their local cancer charity. This will be a perennial challenge with PPIE as it may evoke situations that may lead to patients re-living negative experiences or coming to terms with the illnesses that they have endured therefore post-workshop engagement and follow-up are essential.

The rise of widespread PPIE activities and emphasis on their implementation in research, has seen the development of a range of educational resources and toolkits to researchers, through public partnerships, UK-based charities, and trusts (e.g. the Cancer Research UK patient involvement toolkit) [33]. While these resources are informative for engaging patients, they are often written by researchers and healthcare professionals, and do not provide a direct template for the successful design and delivery of a PPIE event. Moreover, in the scope of pharmacy practice, as frontline health professionals pharmacists are not routinely involved in discussing non-pharmacological elements of patient cancer care though they are best positioned to signpost to local care services and charities.

In the design of these workshops, we aimed to overcome some of the limitations described above by engaging an audience who had not previously served as expert patients or advocates. All participants were provided with the same training on storytelling. Storytelling facilitated meaningful communication of participant lived experience narratives

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and successfully led to the step-wise development of rich stories of patient experiences. All patient participants were diagnosed during the COVID-19 pandemic, which further limited their access to peer support or the opportunity to meet other patients. Overall, the workshop provided participants with the opportunity to connect not only with researchers, but those with a similar lived experience throughout the course of their diagnosis and treatment for breast cancer.

Here, we discuss the lessons learned from the design and delivery of this PPIE event, where we have grouped these according to key concepts.

Design of workshop series

The team

The concept of the workshop was initiated by the clinician and first and last author(s) and the need for additional skillsets (i.e. storytelling, oral history, and live sketching, volunteer gender balance, and intergenerational facilitators) was discussed to ensure the formation of an optimal team structure aligning to workshop objectives. We identified the storyteller by contacting the Scottish Storytelling Centre, and our primary criteria for selecting the storyteller was prior experience of storytelling with patients or in a healthcare setting.

Number and timing of workshops

Through engagement with the facilitator design group and patient participants, the workshops were hosted over three events to maximize benefit to patients and build trust. Timings were selected to accommodate those with caring responsibilities, those in employment, and accounting for travel, at low-demand times (August-September). Two 3.5-hour sessions (workshops 1 and 3), and one 6-hour (workshop 2) session were developed.

Facilitators

Several researcher participants were involved in workshops 1–3 to ensure representation and streamlined delivery of activities, who are all included as authors in this manuscript. The balanced representation of the researcher's characteristics (i.e. age, gender, ethnicity) served as a good opportunity to promote dialogue and networking with patient participants during icebreakers and refreshment intervals. In terms of researcher demographics, there were three PhD researchers and four academic investigators active across different areas, including chemoresistance development to standard-of-care cancer chemotherapies, development of novel nanomedicine-based therapies for cancer, developing multiomics-based approaches for precision medicine, understanding drivers of off-target cardiotoxicity with cancer chemotherapies, and women's health history.

Overall, these interactions created a safe space and levels of trust throughout the cross-section of all workshop participants.

Participant recruitment and cohort development

Two approaches were used to recruit participants: Firstly, an open invitation was promoted on social media with a QR code for the Eventbrite webpage. Secondly, an invitation letter and participant information sheet were issued to breast cancer patients attending the NHS Lanarkshire breast clinic. All participants had been diagnosed and treated for their breast cancer in NHS Lanarkshire under the care of the same surgeon. The second approach was most successful in attracting participants. Overall, 20 patients participated across the three workshops, with eight attending all three workshops, 12 attending two workshops, and 10 attending workshop 3. Each workshop was designed to be sufficiently standalone so that patient participants could recount their stories in workshops 1 and 2 if they were unable to attend workshop 3.

The composition of participant (patients, researchers, facilitators) breakout groups was varied across every activity and session, to promote networking and overcome any issues arising from participants feeling uncomfortable in each other's presence.

Activities

We iteratively implemented a combination of discussion- and task-based activities. During Workshop 1 and following discussions with participants, we identified activities for subsequent workshops (workshops 2 and 3). We found the sequential combination of tasks followed by discussion allowed for every participant to feel confident in contributing to wider discussions. For example, patients were asked to capture key timelines in their breast cancer stories as a task using storytelling prompt cards and were provided with transparent acetate sheets. Each participant described their sketch and timelines, sharing relatable aspects of their stories, and unexpected differences in their experiences.

Feedback

All participants were provided with a book to reflect or add suggestions for future workshops, which were used for designing subsequent workshops. We also collated feedback from patients during the last 15 minutes of each workshop to inform the design and format of subsequent workshops. This took place *via* open discussion and discussing the proposed format of the workshop between facilitators and participants (Supplementary Information).

Strengths and limitations

Feedback from all participants was overwhelmingly positive, with most patients wishing for the workshop series to never end, and a lasting positive impact on their mental health and wellbeing. The event series was informative in identifying patient health education needs and creating a peer community. However, with the workshops concluding, patients felt isolated. Future events would consider inviting participants to the University campus or support patient groups through community centres as additional follow-up events following the workshop series to ensure continued participant access to peer support. We also plan to signpost all workshop participants to patient support services (e.g. https://www.maggies.org/)

Another limitation associated with our approach is the transferability of the event to other nations and patient demographics, since the patient participants were predominantly Caucasian. To address this limitation, we are developing a bespoke storytelling workshop series with male patients with breast cancer and patients from Black and Minority Ethnic origins. Our insights from delivering these workshops will

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inform the applicability of our approach to other participant demographics and audiences.

The goal of this manuscript is to disseminate the process involved, which incorporates community-researcher dialogue around patient engagement and best practices. No findings from the analysis of the stories are presented as this is ongoing and a report on the overall results from this study will be published separately.

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Supplementary Material

Supplementary data are available at *International Journal of Pharmacy Practice* online.

Author contributions

Design, conceptualization: Z.R., M.R.C., A.L., N.J.W.R., S.C., Y.Mc., A.G.; Initial drafting: M.R.C., Z.R.; Review, editing, and feedback: S.C., I.L., L.M., Y.S., D.B., N.J.W.R., S.C., P.K., K.D., A.L.; Funding: Z.R., N.J.W.R., M.R.C., A.L.

Conflict of interest

The authors declare no competing interests.

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Ethical approval

This study was a patient experience workshop to develop local breast cancer services and as such was deemed by the West of Scotland Research Ethics Committee to not require ethics approval. All participants were provided with a participant information leaflet explaining the workshop format, and the potential for their stories to be anonymized, captured, and published (see Supplementary Information). All patients consented to participate in the workshop and for their stories to be shared.

Consent for publication

All authors have read and reviewed the content, and consent to the publication of this manuscript.

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