# Creative approaches to reimagining PPI in cancer research

Report
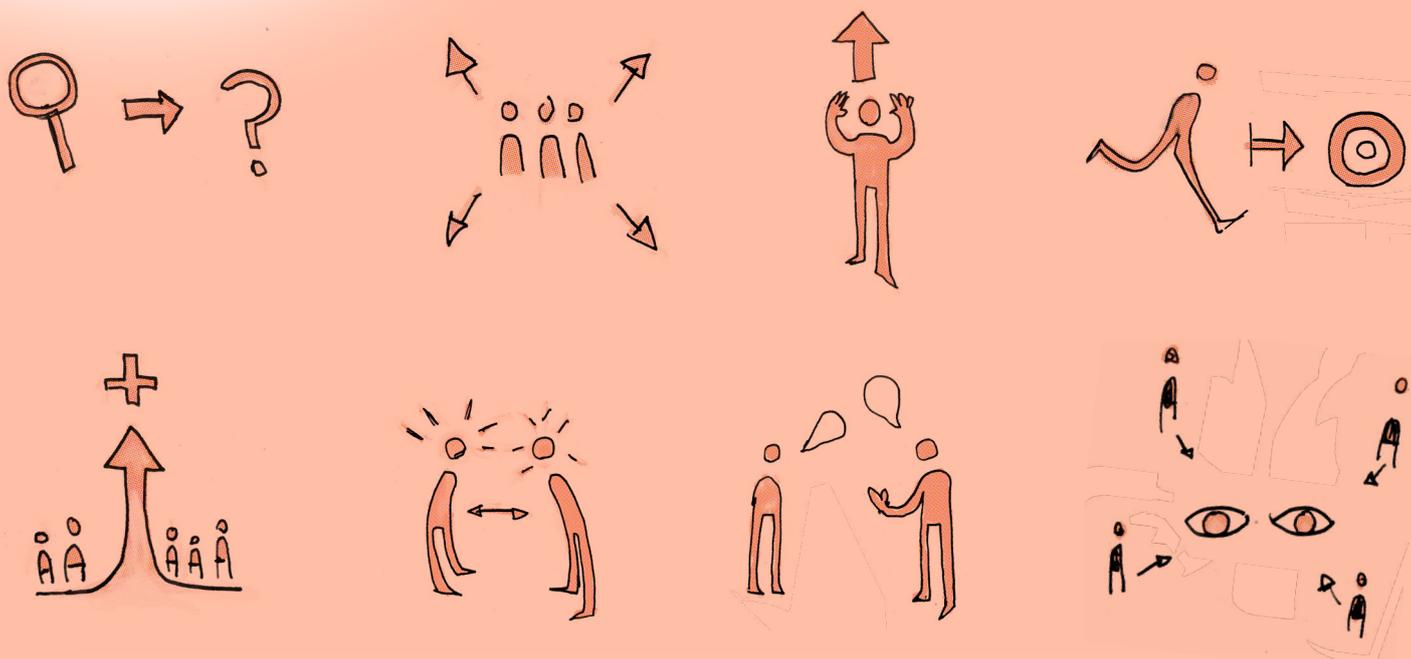
Patient and Public Involvement (PPI) is the integration of patient and public perspectives into health research, ensuring those affected by research outcomes shape its direction and implementation.

This study dives into the realms of PPI within cancer research. Through in-depth interviews with a diverse range of voices (patient representatives, research professionals and research professionals with lived experience of cancer), the research aims to provide a more personal understanding of the current PPI landscape. It recognises both its inherent value and the challenges it faces, such as the risk of superficial involvement or the potential dilution of the patient voice. Key themes emerged, including the importance of harmonious communication, the motivations driving PPI, the challenges and opportunities surrounding accessibility and diversity, and the power of a co-creative and human-centric approach.

The insights gained provide practical suggestions for refining PPI's role in cancer research. This work delves not only into the 'how' but also the 'why', offering recommendations that hope to contribute to ongoing discussions and practices.

Introduction

Patient and Public Involvement (PPI) emphasises the importance of integrating the perspectives and experiences of patients and the public into research planning, design, and dissemination. The belief behind PPI is that those affected by research outcomes should have a say in how research is conducted. In the realm of cancer research, this becomes especially pertinent, given the life-altering nature of the disease and the profound impact research can have on patient outcomes and quality of life.

However, while the essence and importance of PPI are widely recognised, its actual implementation presents numerous challenges. These range from tokenistic involvement to the potential of over-professionalising patients, thereby diluting the unique patient voice that PPI seeks to capture. The current landscape is dotted with toolkits, many of which are practical in nature, designed to help researchers and patients in their PPI tasks. Yet, there remains a gap in tools that truly foster meaningful communication, mutual understanding, and co-design between patients and researchers.

The actions delineated in each chapter are forward-looking suggestions, conceived based on the insights accrued during the study. These proposals aim to address identified challenges and gaps, offering potential pathways for the evolution of PPI. While these actions stem from the broader findings, they are not verbatim recommendations from participants but rather conceptual provocations for future initiatives.

This project aims to envision the future of PPI in cancer research, outlining not just the 'how' of PPI, but trying to capture its underlying culture, aims, and values.

Table of contents

0) Processes
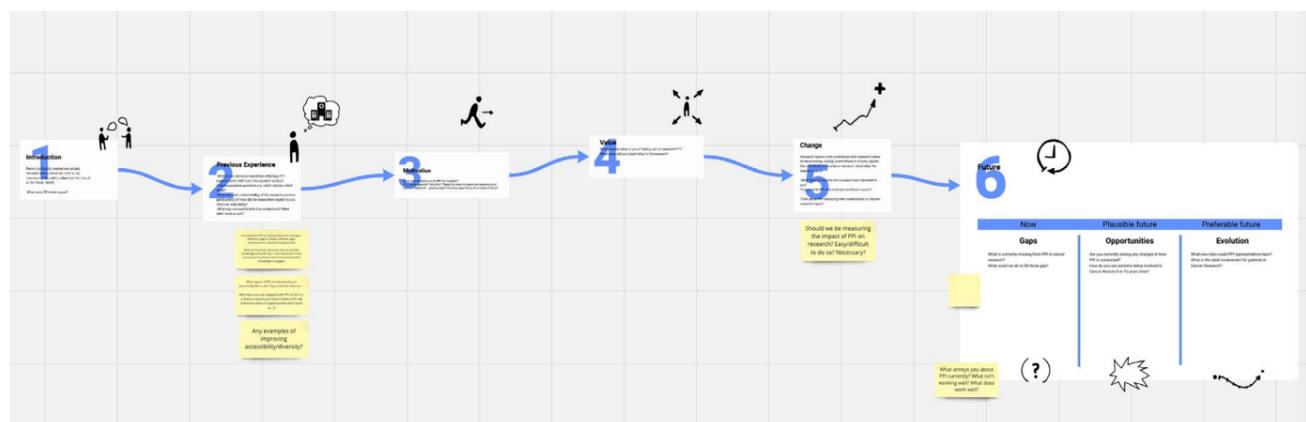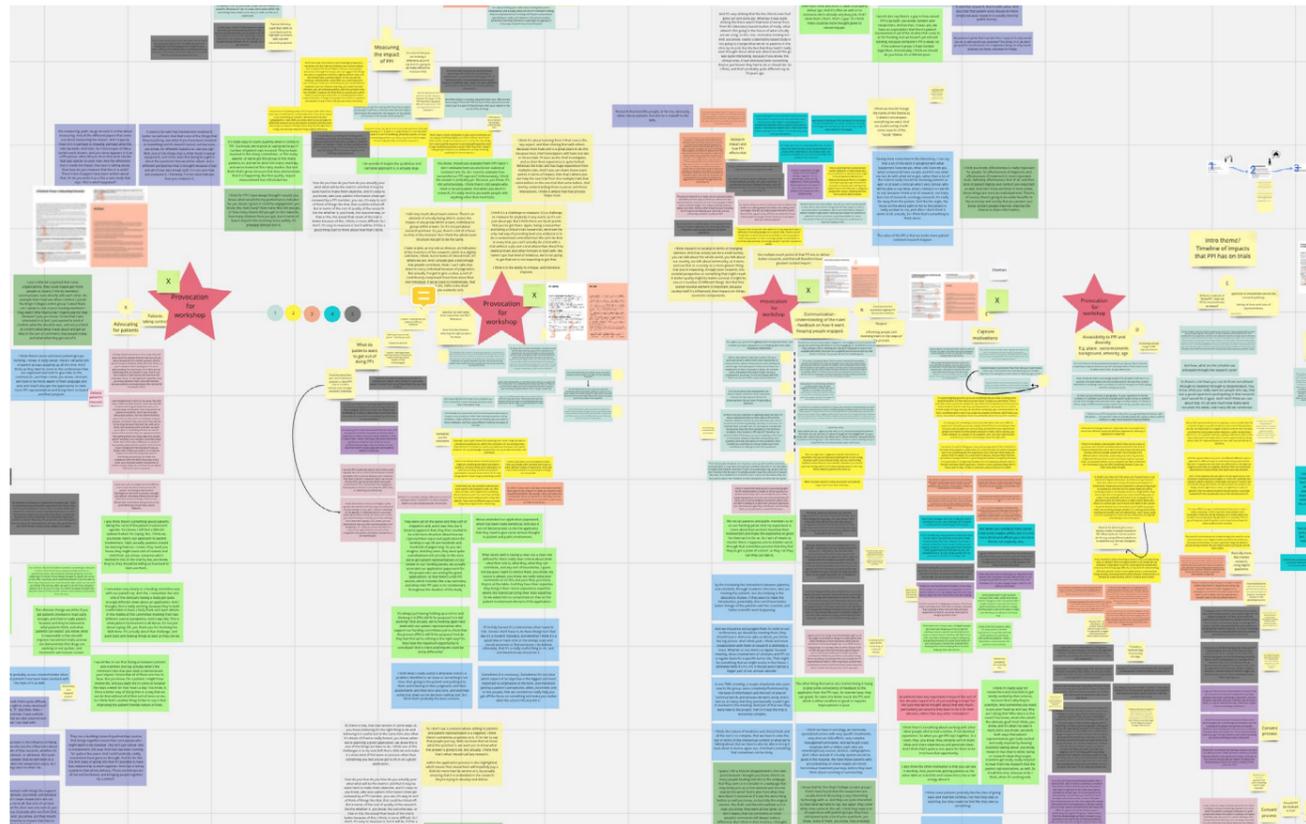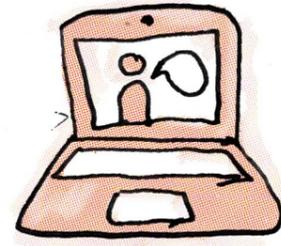
Phase 1: Background Desk Research
A literature review was conducted to understand existing frameworks, toolkits, and methods related to PPI in research. For example, works by INVOLVE, CRUK, NCRI, and others were examined. This phase provided an understanding of what exists and where gaps might lie.

Phase 2: Gathering Perspectives / Recruiting Participants
Fifteen semi-structured interviews were conducted, each lasting approximately one hour. Participants were purposively sampled to ensure a diverse range of perspectives. This included:

5 PPI representatives (either with direct lived experience or loved ones of people who had cancer)
5 cancer research professionals
5 cancer research professionals with lived experience of cancer

The interview guide focused on the participants':

-Understanding of PPI
-Previous experiences with PPI
-Motivations around PPI
-Value derived from and contributed to research
-Views on the impact of research and the role of PPI in influencing these impacts
-Future vision for PPI

Interviews were recorded, transcribed, and subjected by the two researchers to thematic analysis, a method that identifies, analyses, and reports patterns (themes) within data.

Phase 3: Theme Development
Emerging themes from the interviews were collated and categorised. These themes were treated as lenses through which the future vision for PPI in cancer research was further explored.
In the next part of the report, our findings are presented through the lens of these themes.

Phase 4: Brainstorming Workshops
Two group workshops were organised, attended by participants from the interviews. These workshops provided an interactive platform for participants to reflect on the themes derived from the interviews and brainstorm potential interventions. Given the diverse backgrounds of participants, these sessions were enriched by the multifaceted perspectives they brought to the table. These workshops were recorded and also subjected to thematic analysis.

All interactions, both interviews and workshops, were conducted remotely using Zoom, ensuring wide accessibility.

Phase 5: Report Writing
Based on insights from the interviews and workshops, recommendations and actions were developed. These are presented through this report and meant for further discussion and dissemination to stakeholders.

0.2) Insights from Involving Researchers with Lived Experience of Cancer

The specificity of our research is the involvement of a distinct group: professionals in cancer research who are also cancer survivors. This dual perspective was invaluable, offering a rare understanding of cancer care and research from both a professional and personal standpoint. This group's insights bridge the gap between empirical knowledge and lived experience, offering a more holistic view of patient needs, fears, and aspirations. Their experiences challenge and enrich the discourse on patient-centric care, research ethics, and the role of empathy in medicine. These unique perspectives can contribute to developing more effective, compassionate, and patient-focused research practices.

Personal Experience Shaping Professional Approach
"when I was sitting on the other side of the desk, I thought, I don't want why I don't want my treatment decided by a flip of a coin. And it's interesting that because I've never really thought about it like that when I was when I was the professional. But when I was the patient, I was thinking, I I want the information to see what this trial is for what question it's asking. (...) I want every bit of treatment that's on offer."
This quote shows the internal conflict faced by a professional when transitioning into a patient's role. The firsthand experience of making tough decisions regarding clinical trials illuminates the emotional and psychological complexity inherent in these choices. This highlights the gap between a theoretical understanding of clinical trials and the lived reality of making such decisions under the duress of a cancer diagnosis.

Ethical Considerations and Transparency in Patient Recruitment for Trials
"I am so keen to make sure they understand what is being offered and what the downsides are."
Leading from the prvious point, this statement reflects a heightened sense of ethical responsibility, influenced by the interviewee's personal journey as a cancer patient. The emphasis on transparency and thorough understanding for patients during the recruitment process for clinical trials underscores the need for ethical and honest communication.

Enhanced Empathy and sense of purpose
"I think it's probably just understanding, just empathy. And seeing the problem from both sides. . Because it's it's fairly easy to sit and research and (researchers) forget quite why they're doing it"
Here, the interviewee reflects on the of their personal cancer experience on their professional role. This dual perspective fosters a deeper empathy and a more nuanced understanding of patient needs and concerns, guiding a more patient-centered approach in research and treatment.

Balancing Professional Knowledge with Personal Experience in Research
"My professional knowledge is a strength, my personal experience makes me biased."
"I think, to be a good patient representative, you don't need to be medically qualified, you need to have that non scientific, non medical perspective to fulfill the role properly. I think it's easy as medical researchers to get to have to have a very narrow field of view and send up digging down a rabbit hole and following small questions when you possibly lose sight of the bigger picture and what's important to the general population."
This insight speaks to the delicate balance between leveraging professional expertise and acknowledging the influence of personal biases shaped by one's experience with cancer. It underscores the complexity of integrating personal experiences into professional roles without compromising the objectivity necessary in scientific research. On the other hand, some of the researchers dismissed their lived experience as not representative of the general population because of their medical qualifications.

1) Themes
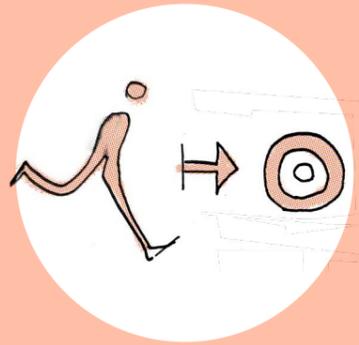
A) Purpose
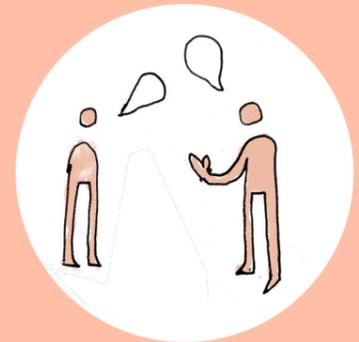
B) Harmonious Communication
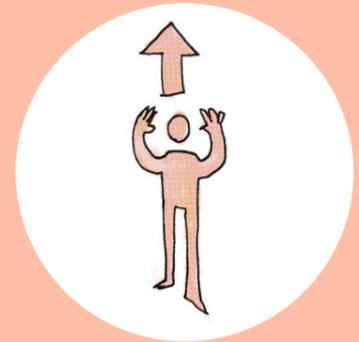
C) Motivational Mosaics
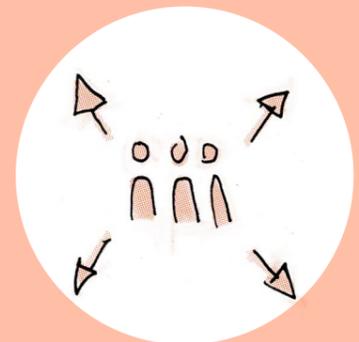
D) Navigating Accessibility and Diversity
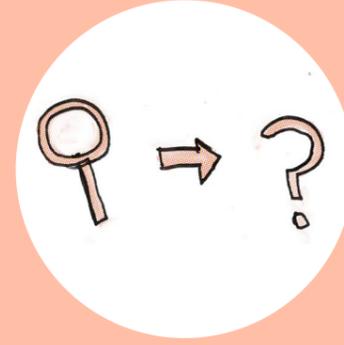
E) Amplifying Impact, and Fostering Co-creation

F) Empathetic Bridges: a Human-Centric PPI
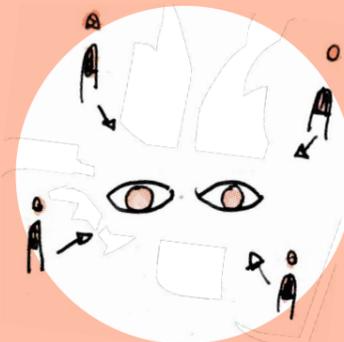
G) Relevance: Diverse Perspectives
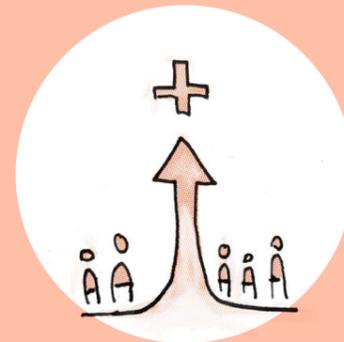
H) Patient Power: Unleashing Potential

A) Purpose

1
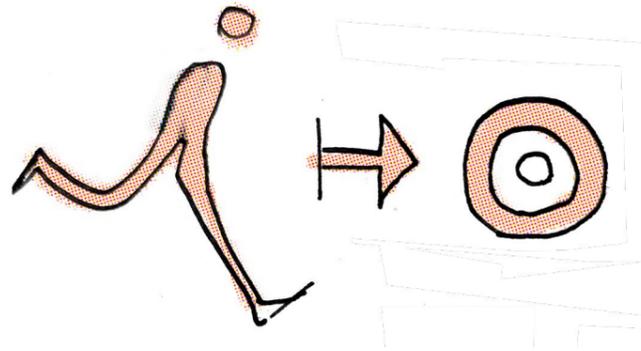
Bridging Expectations
"It starts with understanding, as I mentioned earlier, what is it you want from PPI. Is it tokenistic? Or is it something more substantial? What is it? What do you think the PPI might want from the opportunity? Because I'm going to want something completely different. And it's trying to compromise."
Recognising the different expectations that researchers and PPI contributors have is crucial in ensuring their collaboration is productive and meaningful. The key is to find a common ground where both parties can contribute effectively and feel valued in the research process.

A Two-Way Street of Collaboration
"So I feel it's very much a two-way street where we want their input on our research to make our research more impactful and better. But equally, I like to be open and transparent about our research so that they can see what we do and why we do it, and what it could mean for them in the future."
A successful PPI initiative relies on a mutually beneficial relationship between researchers and patients. Both parties can learn from each other and create a more impactful research project.

Defining Clear Roles
"What works well is having a clear role defined for them, really clear criteria about what their role is, what they can contribute, and any sort of boundaries... So we ask them to concentrate on the patient involvement element of the application."
Establishing clear roles and responsibilities for PPI contributors from the outset of the project helps to prevent misunderstandings and ensures that patients can make a significant impact in areas where their input is most valuable.

Genuine Patient Representation
"So I don't see a scenario where adding in patients and patient representation is a negative. I think there's sometimes a laziness to it... [PPI is being emphasized as an important part of the research funding application process], which means that researchers will hopefully pay a little bit more than lip service to it, by actually ensuring that it is embedded in the research they're trying to develop and deliver."
Researchers should move beyond tokenistic PPI and genuinely embed patient representation in the research process. This commitment to authentic collaboration leads to more patient-centered and impactful research outcomes.

Shared Vision
"It's a bit like researchers' expectations, PPI expectations, but if they're never voiced to each other, then they might never match. And then you give researchers a bad experience of PPI, and they'll never want to do it again."
Open communication between researchers and patients is vital for aligning expectations and fostering a shared sense of purpose. By voicing their goals and desires, both parties can work together more effectively and avoid negative experiences that could deter future involvement.

Proposed Actions:

Clarification for the Proposed actions:
These are potential project ideas that reflect future visions of PPI, designed to adress the issues identified in the interviews. They are not fully formed proposals and may be combined, overlapped, mixed.... These proposed actions are envisioned as adaptable frameworks.

1. Storytelling with Purpose
Storytelling has the ability to foster connection by relating shared experiences. This can build a shared language between researchers and PPI contributors, leveraging narrative templates, prompts, and visualisation. These would aid in creating a compelling and engaging platform to share experiences, expectations, and goals for PPI in cancer research.
For example, a series of short documentary videos or podcasts would share real patient stories, highlighting their experiences with cancer treatment and research. These narratives would humanise the data for researchers and serve as a reminder of the real-world impact of research.

2. Buddy System: Peer-to-Peer Support for PPI Contributors
Both patient representatives and cancer researchers directly recommended a 'buddy' system for PPI representatives, which would allow for more in-depth explanations and learning experiences. Drawing inspiration from mentorship programs in professional settings, the Buddy System would pair PPI contributors with experienced participants or researchers. This model would facilitate knowledge sharing and foster a supportive community, promoting PPI contributors' confidence and engagement. The pairing process should consider individual needs, personalities, and experiences to ensure the formation of strong, productive relationships.

3. Showcases and Celebrations: Recognising Achievements and Inspiring Participation
This would serve to acknowledge the collective successes and progress made in PPI initiatives. These events create an atmosphere of accomplishment and recognition, fostering a sense of pride and achievement among all participants. Regularly celebrating milestones encourages continued involvement and can inspire others to incorporate PPI in their research initiatives.
A platform designed to celebrate the value of PPI in medical research. Regular features would highlight impactful PPI contributions, the people behind them, and their transformative influence on research projects. This would serve multiple purposes—providing recognition for existing representatives, inspiring potential contributors, and keeping a record of these successful PPI contributions, helping to track the impact of PPI on research.

4. Onboarding Workshop: Setting the Stage for Collaborative Research
The Onboarding Workshop would aim to create a shared understanding of the PPI principles and expectations right at the start of a project. This interactive workshop should include an overview of the research process, a discussion of the roles and responsibilities of PPI contributors, and activities designed to foster rapport and open communication among all parties. Such a proactive approach can help to avoid misunderstandings and conflicts.

5. Role Specification: Clear Expectations for PPI Contributors
Role specification is a critical aspect of successful PPI implementation. A clear 'Patient Representative Job Spec' would help potential PPI contributors understand their roles, responsibilities, and expectations, contributing to a more purposeful and effective collaboration. It should be drafted in collaboration with past and present PPI contributors to ensure its relevance and clarity, and would be specific to each project.

B) Harmonious Communication

Proposed Actions:
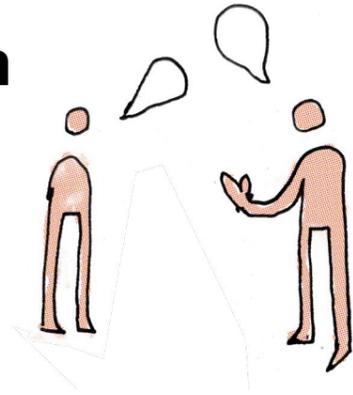
Dance of Communication
Effective communication is crucial in creating successful ongoing relationships between PPI representatives and researchers. An interviewee likened this to joining a club, explaining that without engagement:
"you just wander off and go do something else where it is more engaging"
"Poor communication leads to an unhappy PPI experience. It's not the sort of PPI I want to be involved in"
Dialogue is an exchange of ideas between PPI representatives, researchers, and patients. To foster effective collaboration, the conversational floor must be open, and maintained through continuous engagement and feedback.

Beyond Generic Appreciation
The desire to feel valued as part of the research team was a recurring theme in interviews. Generic thanks, while pleasant, do not satisfy the craving for meaningful recognition. As one interviewee noted:
"If that praise is more specific, you value it a lot more"

Navigating Feedback
I may have come up with a brilliant idea that's very workable, or may have come up with a brilliant idea that it's not workable, or maybe total rubbish. And then it's part of my learning to say, project next on, don't mention that because it's probably going to have the same set of reasons why they can't implement it.
Patients' input, however brilliant or impractical, requires feedback for both learning and adjustment. One participant pointed out that without such feedback, their contributions could be "total rubbish" and they would have no way of knowing or adjusting. Participants expressed a pressing need for prompt feedback following their contributions.
The desire for involvement in wider research discussions, as well as for more transparent knowledge on how their contributions impacted outcomes, was a common sentiment.

No Empowerment without Delivery
There was agreement that empowerment without delivery does a disservice to the PPI concept
"If you're going to be empowered, you have to deliver. That's important because being empowered but not delivering does PPI generally a disservice,"
Empowerment in PPI must be coupled with tangible outcomes. Simply involving PPI participants without acting on their input can lead to a static, ineffective process. In contrast, ongoing engagement, incorporating regular updates and follow-ups, offers tangible progress, ensuring that empowerment leads to concrete changes in research practices.

Balancing Complexity and Simplicity
"The nature of medicine and clinical trials is so complex. But we also have to bring it back down to basics again"
A researcher explained. Navigating through complex jargon can be overwhelming for non-experts. A balance must be struck between complex technicalities and accessible communication.

'PPIing' in the Time of Zoom
"With Zoom, you can't have one-to-ones either. So it's group or nothing."
Participants noted that the increased use of digital platforms during COVID-19 has eroded the social aspect of PPI interactions and caused a feeling of isolation. This calls for a deliberate strategy to foster a sense of belonging and integration in the digital PPI landscape.

1. Conversational Catalysts: Nurturing the Art of Dialogue
"Conversational Catalysts," proposes a context-sensitive resource for enhancing dialogic capabilities. The learning resource would comprise modules tailored to PPI representatives, researchers, and patients, addressing challenges in conveying complex ideas and fostering mutual understanding. The Catalysts would not only demystify medical jargon but also incorporate the principles of effective listening, assertiveness, and constructive feedback.

2. Feedback Now! Amplifying Voices
A platform for PPI feedback. This would provide an outlet for timely, constructive feedback and would facilitate a cyclic process of giving, receiving, and implementing suggestions.
It would address the need for visible impact, underscoring the value of PPI contributions. As a feedback hub, it would host a transparent record of feedback history, implementation timelines, and outcome documentation.

3. Progress Dashboard for Projects
A digital dashboard that tracks a given PPI projects' progress and fosters a sense of shared journey and collective achievement. It would provide updates, serving as a digital compass for all stakeholders. It would foster transparency and help keep engagement high by allowing participants to see how their contributions influence research outcomes. This transparency can enhance the accountability and credibility of PPI processes.

4. Mapping the PPI Landscape
To aid newcomers in navigating the often-complex PPI terrain, we propose a user-friendly guide would offer navigational support to representatives while demystifying PPI processes and terms. This would serve as a living document, containing background resources, reflecting current best practices and the evolving nature of PPI. Its goal is to reduce the learning curve for PPI engagement and to empower representatives, enhancing their participation quality and confidence.

C) Motivational Mosaics:
The Drives Behind Participation

The Giving Guardians

"I think they tend to be patients who have been through difficult times or are going through difficult times. And I think their motivation is to try and change things for the better in the future."

Characterised by a sense of gratitude, these participants engage driven by altruism. Their experiences in overcoming or enduring cancer inspire them to contribute to research, not just as a token of thanks to the medical community, but with a desire to enhance future patient care. Here, the focus is on a broader, forward-looking impact, rooted in thankfulness. As one interviewee stated, *"if I can do anything to help the next generation of patients, then I would be happy to."*

The Knowledge Navigators

"Just knowing what advances are being made, but that's possibly more from a curiosity point of view rather than a PPI."

Another motivation identified was a thirst for knowledge about cancer research and the progress being made. Participants expressed that their involvement in PPI allowed them to stay informed and up-to-date on advancements in the field. This curiosity-driven engagement helps to ensure that research remains relevant to patients and addresses their concerns.

The Empathy Explorers

"I think in the first instance, often it's, they want to use their experience in a way that will help other patients or, you know, other potential patients."

Here, the motivation is a deep understanding of the patient's journey. The participants' involvement in PPI stems from a desire to leverage their personal experiences to support and guide current and prospective patients through similar challenges. This group's aim is to directly apply their individual stories to shape and inform research, ensuring it resonates with and is relevant to those undergoing treatment now or in the future.

The Mindful Mentors

"There were a lot of very smart, intelligent people who had had a diagnosis of cancer and for whatever reason, weren't necessarily back at work or they'd retired. And they still had a lot to offer."

PPI representatives often possess valuable skills, knowledge from their work or life experience before their diagnosis of cancer. Participating in PPI allows them to contribute their expertise and wisdom, while also keeping their minds active and engaged.

The Change Champions

"Some people want to get involved because they really, really think things need to change as well."

A strong desire to create meaningful change in the healthcare system was also evident among PPI participants. These individuals were often vocal advocates for improvements in patient care and research approaches, seeking a seat at the table to influence and steer the direction of cancer research. *"Some people want to get involved because they really, really think things need to change as well... they want a seat at the table to make sure that they can influence and steer that."*

The Resilient Reclaimers

For some, PPI served as an opportunity to regain a sense of control after experiencing the powerlessness that often accompanies a cancer diagnosis. By engaging in research projects and contributing their unique perspectives, these individuals found a renewed sense of purpose and agency. *"Cancer makes you pretty powerless... So this is something where even if you make the smallest increment, which helps one patient somewhere, then it's worthwhile doing because it's a positive use."*

The Social Synergists

Lastly, some participants highlighted the social aspects of PPI as a motivating factor. By engaging with other patients and sharing experiences, individuals found a sense of camaraderie and support. This collaborative environment allowed them to learn from each other and generate new ideas, fostering a sense of community. *"I think there's something about working with other people who've had a similar, if not identical experience... they certainly (...) share experiences and generate ideas."*

Proposed Actions:

1. The PPI Motivations Matrix
Create an interactive tool that allows PPI representatives to map their unique motivations for participation. This matrix can help researchers better understand and cater to the diverse motivational drivers of their PPI contributors, fostering stronger connections and more meaningful collaborations.

2. The Curiosity Capsule
Design a digital platform where PPI representatives can access up-to-date research findings and engage in thought-provoking discussions with cancer researchers. This platform will help satisfy the curiosity of PPI representatives while encouraging knowledge exchange and fostering a community of shared learning.

3. Empathy Enrichment Workshops
Hold co-creation workshops that bring together PPI representatives, cancer researchers, and other stakeholders to share their experiences and insights. These workshops can help cultivate empathy and understanding among participants, ultimately leading to more patient-centered research practices.

4 The Change Lab
Develop a collaborative space where PPI representatives, researchers, and other stakeholders can come together to brainstorm, prototype, and test innovative solutions to pressing challenges in cancer research. By involving PPI representatives in the change-making process, we can foster a sense of agency and empowerment, ultimately leading to more effective and impactful research outcomes.

D) Navigating Accessibility and Diversity
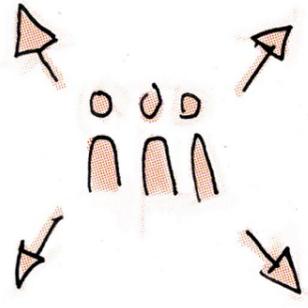
Bridging Ambition and Realisation
The journey towards inclusivity and diversity in PPI is layered with a tension between aspiration and implementation.
"we're quite rapidly getting to a point where… we have to have a more organised way about how you get access to patients"
This underlines the need for a strategic, structured approach that balances the heightened expectations set by funders and the reality of engaging patients who can actively participate.

Expansion's Double-edged Sword
Expansion in PPI has been simultaneously promising and complicated.
"It's adding burden, and it's adding quite a lot of effort to specific individuals, obviously".
The extension of PPI, although beneficial, has led to an over-reliance on a narrow patient demographic. This necessitates a more strategic, structured approach allowing for a balanced participation.

Language, Literacy and Accessibility
Inclusivity in PPI extends beyond representation to encompassing language and literacy.
"we would all love to have our information sheets in every possible language. But the reality is we don't have funding or capability to do that".
There is a challenge to find innovative, cost-effective solutions that promote linguistic diversity and inclusivity.

Representation Across Ages
The representation of diverse age groups is a significant challenge in PPI, often resulting in a skewed representation. This observation was echoed by an interviewee who noted a trend of retired individuals forming the bulk of PPI members This disproportionate representation may distort the focus of research, underscoring the need for strategies that promote diversity of age in PPI.

The 'Professional Patient' Challenge
Interviews revealed a growing concern of PPI being dominated by 'professional patients' - those who may over-represent certain patient perspectives, potentially skewing the research.
"The disadvantage we have at the moment is you sometimes have almost like professional patients… And you need to make that more broad".
This poses a hurdle in achieving representative PPI. To address this, it's important to diversify involvement, encouraging a broader spectrum of patients to participate, balancing deep contributions with a wider representation of patient experiences. Introducing varied levels of participation could be the way to expanding scope while maintaining quality input.

Inclusion of the Unseen
Interviews also highlighted that lower socio-economic cancer patients, those with comorbidities or poor prognosis, often remain unheard in PPI activities.
"How do you ensure that you're getting patient involvement… that is broadly representative of the population… rather than the skewed patient and involvement population?"
This highlights the urgency of developing strategic initiatives to ensure these overlooked voices are heard.

Proposed Actions:

1. Structured Patient Access System
This system would utilise data analytics to curate patient groups, prioritising diversity in medical conditions, backgrounds, and socio-economic statuses. The design of this system should be guided by ethical considerations to manage the burden on individual participants effectively. The system should also include a comprehensive feedback mechanism to continually evaluate and improve the quality of interactions.

2. Cross-Demographic PPI Engagement Platforms
Interactive online platforms offer an accessible avenue for diversified PPI. This should aim to create a platform that caters to different schedules and levels of digital literacy. To ensure maximum engagement, the platform should utilise interfaces tailored for all accessibility needs. For instance, the use of voice-assisted services can increase engagement among participants with literacy challenges.

3. Linguistic and Literacy Considerations
To address linguistic and literacy barriers in PPI, it is recommended to integrate translation services into the research process. For visual learners, infographics and pictorial guides could be utilised, while podcasts or audiobooks can aid auditory learners. To ensure the feasibility of these strategies, partnerships with language service providers and educational institutions would be sought.

4. Diversified PPI Advisory Panels
Curating a patient advisory group comprising individuals from different demographics, health conditions, and socio-economic backgrounds. Creating diverse advisory panels is critical to avoid polarised viewpoints. Training programs could be implemented to empower these individuals with the necessary skills to communicate their experiences effectively and contribute to the research discourse.

5. Ethnic and Socio-economic Sensitivity
Engaging directly with community groups is key to developing sensitive research questions. This project involves creating a cultural sensitivity training module for researchers, coupled with a community outreach program. The training module should incorporate the principles of cross-cultural communication, while the outreach program should focus on building strong relationships with community leaders to facilitate dialogue and collaboration.

6. Patient Profiles
A resource for creating patient personas could inform inclusive research designs. This project would entail the development of a tool to generate representative patient profiles based on real-world data. The tool should include demographic factors, medical histories, and socio-economic information to reflect the diversity of patient experiences.

E) Amplifying Impact, and Fostering Co-creation
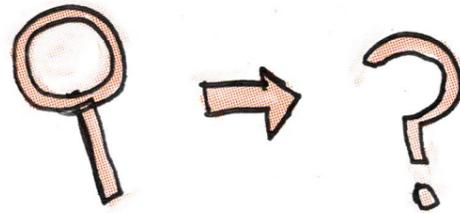
Aligning Research Goals

As one PPI representative remarked, patient groups ought to actively scrutinise research prospects and tailor them to their needs. This was echoed by a former cancer patient who envisioned a scenario where a group of mesothelioma patients outline their expectations for a clinical trial, in essence, defining research priorities.

"We're often less structured about getting them to think about the practicalities of the trial," lamented a cancer researcher. Co-shaping research questions is a potential arena of rich dialogue.

The Continuum of Patient Involvement

While one researcher envisioned PPI representatives involved in every step of a study—from design to dissemination—another pinpointed ongoing governance and research dissemination as two areas needing improvement. "A genuine partnership in research would be the ultimate evolution," they concluded. Patient involvement can extend beyond research context, potentially serving a more direct role in clinical service, thus making the dance of research more balanced and harmonious.

Connecting Funding Process and Patient Journey

An issue surfaced was the disconnect between the funding of research projects and the actual patient journey.

"I think if researchers knew a bit more about the patient journey...and what the actual common problems are in the clinic, that that would drastically affect what work goes on in the laboratory."

Patient involvement could complete the picture, benefiting research design and patient experience.

From PPI Participation to Co-leadership

Beyond involvement, patients co-leading research is a potential next step. They can bring a more patient-focused approach to the outputs of research. As a former cancer patient stated, "I'd like to see them like properly co-leading research," highlighting the potential shift from PPI representatives being just contributors to becoming co-leaders of the research process.

From Tokenistic Involvement to Authentic Partnerships: Unmasking the Spectrum of PPI

"It's surface deep, what you do...That for me is not real PPI." One participant drew a stark contrast between 'traditional PPI,' characterised by quarterly meetings and brief interactions, and the 'PIRRIST' model that fostered stronger relationships with PPI representatives. This highlights the need for a spectrum of PPI involvement, moving from mere superficial engagement to genuinely meaningful partnerships.

Proposed Actions:

1. PPI Involvement Spectrum Guide:
This guide would aim to address the lack of understanding of the different levels of PPI participation. It would involve the creation of an illustrative "PPI Involvement Spectrum Guide", providing a clear and accessible representation of different PPI models. It would range from traditional involvement models to more progressive ones such as the PIRRIST model, serving as a roadmap for meaningful PPI engagement. The guide will also address the potential barriers at each level and propose possible solutions, facilitating a smooth transition from a more passive to an active, leadership-driven PPI involvement.

2. Researcher-Patient Exchange Programs:
Recognising the potential of direct interaction between researchers and patients, this initiative would promote a bi-directional knowledge transfer where researchers share their work with patients in an accessible manner, while also gaining patient-focused insights from firsthand accounts. This approach will help align the aims of research more closely with patient needs and experiences. Events could include seminars where researchers present their work in a lay-friendly way and informal meet-and-greets that allow for open conversations. An interviewee's suggestion about having patients define their expectations from clinical trials could be incorporated into these sessions.

3. PPI Advisory for Clinical Services:
Composed of PPI representatives, this advisory board would have an influence on the design and improvement of clinical services. From refining patient communication strategies to contributing to the hospital environment design, the advisory board will be instrumental in making services more patient-centric. This project underscores the concept of patients as experts in their care and treatment.

4. PPI Flex Roles:
The proposed "PPI Flex Roles" project is designed to address the often rigid role assignment in PPI. Instead of predefined roles, PPI representatives would have the liberty to choose their involvement based on their skills and interests. This flexible approach could encompass technical contributions, creating patient information leaflets, or even serving as PPI ambassadors. Such flexibility would allow for more diverse and meaningful contributions, reflecting the realities and capacities of PPI representative.

5. Co-creation Workshops for Lay Summaries:
To enhance the accessibility of research findings, these workshops would bring together researchers and PPI representatives to create easily understandable summaries of complex research findings. This project not only helps to demystify scientific jargon but also strengthens the role of PPI representatives in the research process, fostering a culture of shared understanding.

6. Empowering Patient Leaders
Foster patient leadership within research spaces. This move towards co-leadership aims to eradicate the notion of patients as passive recipients of research outcomes. Building on the transformative model, we propose the development of "Patient Leadership tools". This program empowers patients to step into leadership roles, providing resources, and training necessary to work with or as associate Principal Investigators (PIs), steering committees, and governance bodies. This would consist of leadership training modules, best practices for co-leading research, and resources to develop skills in research methods and ethics.

F) Empathetic Bridges: a Human-Centric PPI

Social Presence in Virtual Spaces
"...the chit chat before, the chit chat after, which I think is so important..."
In the era of remote meetings and virtual conferences, the social aspect of PPI has diminished significantly. Participants yearn for in-person interactions, recognising the value of informal conversations before and after meetings. These seemingly trivial exchanges often lead to the development of trust, empathy, and understanding between patients, researchers, and PPI representatives.

Perspectives: Clinicians and Patients
"...we're just coming at it from completely different places..."
The interviews revealed a distinct gap in perspective between career clinicians and patients. While clinicians strive to maintain emotional stability and professional detachment, patients are fully invested in their own outcomes. Clinicians often seek broad, representative perspectives from patient representatives, focusing on generalised experiences rather than individual stories. This contrasts with patients' inclination to share their personal, detailed accounts of their health journey. Both parties have the same goal—improving healthcare and research—yet approach it with contrasting lenses. PPI initiatives should facilitate empathetic understanding and bridge these differing viewpoints.

Humanising the Data
"...it's not just patient number six, you know, 365, whatever, it is a person..."
Researchers sometimes forget the ultimate purpose of their work: to improve the lives of real people. PPI helps remind them that their research isn't just an academic exercise, but a vital endeavor to serve patients in need. By humanising the data, PPI encourages researchers to treat patients as unique individuals, rather than statistics.

The Language of Empathy
"...consider the person first and not to make it about, you know, because that person has done something (that has caused) this condition..."
The interviews emphasised the importance of language in shaping attitudes and perceptions around PPI. Language that blames or stigmatises patients for their conditions can be detrimental to the PPI process. Promoting empathy through careful language selection is crucial to fostering productive dialogue between patients, researchers, and PPI representatives.

Unreported Toxicity and the Fear of Consequences
"...they tend not to report toxicity..."
Many patients in clinical trials choose not to report toxic side effects of treatments, often fearing that such admissions could lead to changes or discontinuation of their treatment, and thereby affecting its effectiveness. This trend underscores a critical gap in patient-clinician communication, one that needs addressing in the PPI development phase. By involving patient representatives who understand these concerns, PPI initiatives can be more finely tuned to encourage open dialogue about treatment side effects, ensuring that patient feedback is genuinely heard and acted upon.

Proposed Actions:

1. The Social Catalyst: A Virtual Platform for Unstructured Conversations
To address the lack of informal interaction in virtual meetings, we propose a virtual platform that simulates in-person socialising. This platform would offer "breakout rooms" for casual conversation before and after PPI meetings, encouraging the development of personal connections and facilitating empathy between participants.

2. Empathy Workshops: Bridging the Gap Between Clinicians and Patients
Initiate workshops that unite clinicians, researchers, and PPI representatives for empathy enhancement exercises, with the inclusion of personal narratives. Each PPI representative should either commence their role with a brief personal story or provide a written synopsis of their experience. This ensures researchers grasp the specific experiences of their PPI counterparts. Encourage PPI representatives to reflect on the broader patient community they represent, beyond their individual experiences. This dual focus—on personal narratives and representative diversity—will enrich the understanding between participants.

4. A Language Guide for PPI Communication
Develop a language guide that offers alternative phrasing and terminology to avoid blaming or stigmatising patients during PPI discussions. This guide would be a valuable resource for researchers, clinicians, and PPI representatives, ensuring that conversations remain empathetic, respectful, and productive.

5. The Toxicity Transparency Initiative: Encouraging Open Dialogue on Side Effects
Initiate a focused campaign to encourage open discussions about treatment side effects, aimed at both patients and PPI representatives. This initiative will involve educational materials and targeted workshops. These resources will empower PPI representatives to confidently facilitate dialogues about side effects, ensuring patients can share experiences without fear or repercussions. The outcome: healthcare professionals receive clearer insights, leading to enhanced patient care.

G) Relevance: Diverse Perspectives
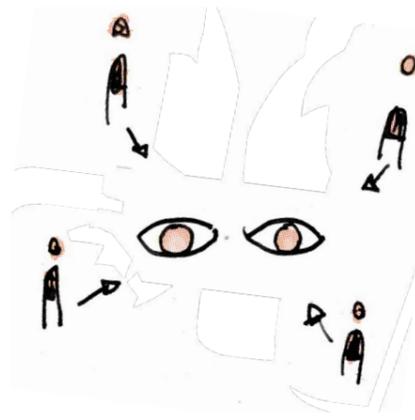
The Symphony of Experiences
"Making use of people's expertises and experience beyond cancer... for me, PPI means all bringing my entire life experience and skills to the table."
Participants in the PPI process come from a diverse array of backgrounds, each bringing their unique set of skills, experiences, and perspectives to the table. This wealth of expertise goes beyond their cancer-related experiences, shaping the way they approach research and problem-solving. By tapping into this symphony of experiences, the PPI process can yield innovative and creative solutions, addressing the multifaceted nature of the patient experience. Embracing this diversity leads to richer discussions and a more holistic understanding of the challenges faced by cancer patients and their carers.

The Art of Balance
"I am a very small cog in a very massive organisation... I just think it increases the potential for ideas."
The delicate dance of PPI relies on the recognition and appreciation of each participant's individual strengths and backgrounds. Every person plays a vital role, contributing their own unique voice to the larger conversation. Fostering an environment where these diverse strengths can be leveraged creates a collaborative atmosphere, encouraging the exchange of ideas and ultimately leading to more effective research outcomes. Striking the right balance between participants with different skills and expertise is key to maximising the potential of the PPI process.

The Science of Communication
Although scientific knowledge can be helpful, it is not a prerequisite for effective PPI participation. In fact, a lack of scientific background can be an advantage, as it allows participants to approach research with a fresh, unbiased perspective. The true value of a PPI representative lies in their ability to communicate effectively, empathise with others, and understand different perspectives. By focusing on these skills, rather than scientific expertise, the PPI process can create a more inclusive and accessible environment for all stakeholders.

The Dance of Lived Experience
"I think lived experience needs to be better defined... for me, it's just people who have had a particular illness themselves, they've been a carer, or they are a healthcare worker."
The concept of "lived experience" is often narrowly defined, limiting the pool of potential PPI participants. To better harness the full potential of PPI, the definition of lived experience must be broadened to include individuals with a range of experiences, such as carers, healthcare workers, and those with experience in various health conditions. This expanded definition ensures that a more diverse group of individuals can contribute to the PPI process, ultimately enriching the research and leading to better patient outcomes.

The Serendipity of Naivety
"I think one of the main things is that the understanding of what it means that you are bringing... I simply bring a patient voice. I bring that experience, and it's a lived experience."
In the world of PPI, naivety can be a valuable asset. Individuals with little knowledge of clinical trials or medical research often bring fresh perspectives and unbiased insights to the table. This serendipitous naivety can lead to innovative ideas, challenging established norms and preconceptions within the research community. By embracing the unique viewpoints of these "naive" participants, PPI can break through barriers and drive transformative change in the field of cancer research.

Proposed Actions:

1. Expertise Swap Shop
This digital hub facilitates connections between PPI representatives and researchers, allowing them to find the perfect blend of skills needed for each project. By enabling PPI representatives to share their unique skillsets, it promotes a collaborative environment that values and utilises the diverse expertise within the PPI community. An "Expertise Exchange Tracker" can be integrated to measure the level of skill exchange and collaboration, indicating the active involvement of PPI representatives in research processes.

2. The Science Simplifier:
An educational series which aims to make complex scientific concepts comprehensible to PPI representatives. This multimedia series, featuring interactive modules and 'jargon busters', empowers PPI representatives to engage more effectively in research conversations. Simultaneously, it preserves the uniqueness of their non-scientific perspectives, strengthening the diversity of viewpoints in PPI.

3. The Bias Balancer:
A workshop program that helps patients and researchers recognise and constructively navigate their biases. By promoting open dialogue and collaboration, these workshops encourage balanced decision-making and prevent the marginalisation of diverse perspectives. An accompanying "Bias Reduction Score" can provide quantitative feedback on the effectiveness of the workshops, contributing to continuous improvement.

4. The Lived Experience framework
A framework that clearly defines and evaluates the representation of lived experience in PPI. This set of measuring tools aids researchers in understanding and incorporating diverse patient perspectives, ensuring their inclusion in research. An attached "Representation Monitor" can quantitatively assess the diversity of patient experiences in PPI, driving a more equitable research environment.

H) Patient Power: Unleashing Potential

Networking and Collaboration Opportunities for Patients and Researchers

"They run a building research partnerships course that brings together researchers and people who might want to be involved."

Creating opportunities for patients and researchers to come together and learn from one another is crucial for fostering a strong, collaborative PPI culture. Workshops, conferences, and other events led by patients can provide a forum for open dialogue and shared learning. Researchers should also be encouraged to attend patient-led events to gain a better understanding of the potential of PPI.

Challenges in Patient and Researcher Collaboration

Several issues were identified, including barriers to researcher involvement, the importance of patients taking the reins of the PPI agenda, and the need for trials to be designed with patients in mind.

"I would like to see that trials are designed with patients in mind rather than the science in mind, which I know sounds really mad."

Successful practices, such as the Building Research Partnerships course, were also highlighted. This course, led by a patient, fosters collaboration between researchers and potential research participants. The value of patients' networks in disseminating research results was also underscored: "I have networks that perhaps researchers don't have. And so that's a working together on that."

Breaking Down Barriers: Patient-Centric Trial Design

"We can't just deliver this and say, right, we want to do this trial, and we're going to do it on you or to you."

Early-phase clinical trial protocols often place a significant burden on patients, with demanding sampling requirements and frequent hospital visits. To improve the patient-friendly nature of trials, researchers and patients should collaborate to identify the minimum necessary assessments and develop innovative ways to reduce the impact on patients' lives. This collaborative approach will not only make trials more appealing to potential participants but also demonstrate that the research is truly patient-centered.

When I was sitting on the other side of the desk, I thought, I don't want my treatment decided by a flip of a coin. And it's interesting that because I've never really thought about it like that when I was when I was the professional. But when I was the patient, I was thinking, I I want the information to see what this trial is for what question it's asking.

From the Choir to the Lab: Harnessing Patient Networks

"I sing in a choir of 100 patients who have been impacted by cancer, I can share what those results are."

Patients often have access to extensive networks of support groups, community organisations, and other patient communities that researchers may not be aware of. By involving patients in the dissemination of research findings, researchers can ensure that the results reach a wider audience and have a greater impact on the lives of those affected by cancer. Encouraging patients to share their experiences and insights at conferences, workshops, and other events can also help to bridge the gap between researchers and patients, fostering a more collaborative research environment.

Shifting the Balance of Power: Patient-Led PPI

"Patients should be steering that too."

Despite the growing recognition of the importance of PPI in cancer research, patients often feel they lack the authority to make decisions or challenge researchers' views. By placing patients in leadership positions within PPI initiatives, organisations can empower patients to take the reins and guide the direction of the patient involvement agenda. This will not only help to ensure that patients' voices are heard but also create a more equitable partnership between researchers and patients.

Proposed Actions:

1. "PPI Pioneers": Establish a network of PPI ambassadors
Create a network of PPI ambassadors made up of patients, survivors, caregivers, and healthcare professionals. These ambassadors would help bridge the gap between researchers and the public, engaging with support groups and community organisations, and co-presenting at conferences. This would involve the creation of a structured training program for potential ambassadors. This initiative can be scaled up via collaborations with community centers, hospitals, and educational institutions, establishing a bridge between researchers and diverse communities.

2. "Empathy Expeditions": Embed researchers in patient communities
Empathy forms the bedrock for genuine collaboration and understanding. Empathy Expeditions provide immersive experiences where researchers and PPI contributors can gain insight into each other's worlds. By allowing researchers to shadow patient consultations and enabling PPI contributors to participate in the research process, a shared understanding emerges. This would necessitate clear planning, respect for the privacy and personal boundaries of all participants, and an open mind for the potential revelations and learning opportunities that may occur.

3. Involve patients in trial design from day one
Involve patients in the design of clinical trials from the earliest stages. Patients should be engaged in the development of research questions, outcome measures, and recruitment strategies to ensure trials are more patient-friendly and relatable.

4. PPI Masterclass
Develop comprehensive PPI guidance for researchers, providing practical help on how to involve patients in their research. This should draw inspiration and include previous PPI toolkits and include case studies, best practices, and resources to help researchers navigate PPI.

5. "PPI Café": Host regular PPI-focused events and workshops
Organise regular events and workshops to bring together patients, researchers, and PPI representatives. These gatherings could include panel discussions, interactive workshops, and networking opportunities, fostering an environment of open dialogue and collaboration.

6. "Patient-Powered Conferences": Encourage patient-led presentations at research conferences
Promote the inclusion of patient-led presentations at research conferences, giving patients the opportunity to share their insights and experiences with a wider audience.

Workshops Process

The brainstorming workshops were designed to facilitate discussions between participants and generate actionable interventions. Participants, who had also been part of the initial interviews, were convened remotely via Zoom.

Structure
The session commenced with an overview of the research's aims and objectives. Additionally, participants were introduced to one another.

Themes Discussion
The core portion of the workshop was dedicated to dissecting the primary themes identified from the interviews. These encompassed:

-Purpose: Examining the fundamental goals and objectives of PPI in cancer research.
-Accessibility and Diversity: Discussing the challenges and opportunities in ensuring PPI is inclusive and representative.
-Communication: Evaluating the efficacy and challenges of current communication channels and methods.
-Patients Taking Control: Reflecting on the empowerment of patients in shaping research. To spur discussions, select quotes from the interviews were presented, serving as empirical evidence and prompts.

Proposal Development
Participants collaboratively devised potential solutions or interventions for the challenges identified. This segment focused on:

-Problem Identification: Clearly defining the specific challenge or issue to be addressed.
-Intervention Proposal: Proposing tangible solutions, be it in the form of services, campaigns, or organisational strategies.
-Implementation Pathway: Outlining the steps or measures required to transform the proposal into a reality.

The workshops' structured approach ensured that discussions were focused and oriented towards devising practical solutions. The diverse backgrounds of participants enriched the sessions, ensuring a multifaceted exploration of the themes and challenges in PPI in cancer research.

Workshops Summary

Nurturing a Unified Vision through Clear Expectations

Navigating the intricate landscapes of medical research can be both enlightening and challenging, with potential for divergence and misunderstanding. Setting clear expectations from the outset is an important first step.

"The early bit of communication is about expectation and training."

For effective Patient and Public Involvement (PPI) in medical research, aligning all stakeholders to a shared purpose becomes paramount, ensuring that everyone begins with a clear understanding of their roles and expectations.

Simplifying Language: From Barriers to Bridges

Language plays an instrumental role in PPI, acting both as a facilitator and a hurdle. It serves as the medium through which ideas, findings, and concerns flow between researchers and PPI representatives. However, *"the jargon of trials,"* as one respondent described, poses accessibility challenges. A comment from the workshop underpins the issue:

"Even for people who might have a degree, but who know nothing about research is exactly the same as somebody who left school at 14 and doesn't understand research."

Building Trust through Constructive Feedback

Trust-building, in any collaborative setting, necessitates open communication. In PPI, the requirement for genuine feedback becomes even more pronounced. One respondent shared that a mere *"'That's very helpful, thank you' is not helpful."* This underscores the importance of feedback loops that foster both learning and mutual respect. As one PPI representative noted, to build trust,

"you need to be able to debate with somebody."

Redefining Power Dynamics and Amplifying Diversity

The inherent power dynamics in PPI, stemming from perceived hierarchies and socio-economic disparities, play a crucial role in the nature of collaboration.

"The research environment can be quite intimidating...you need to have that mutual respect,"

In reshaping these dynamics, all stakeholders, irrespective of their background, should actively contribute to shaping the research process.

"It really is about defining a purpose. And agreeing a purpose."

By recognising expertise and experiences across the board, PPI can become more inclusive.

Embracing Co-creation for Holistic Research

PPI has considerable potential for co-creation. PPI representatives aspire to be involved deeply in each phase, not just as passive participants. One representative's wish to *"work with you"* and stand at the *"forefront"* of research decisions encapsulates this sentiment. This co-creation focuses on shared control and decision-making.

"When you're a patient, you don't have control... I could gain some control back over what involvement I'm having in what happened to me"

Actions:

1. Multi-dimensional Patient Partnerships
Workshop participants emphasised the pressing need to transition from a "uni-dimensional model" to one that effectively captures the essence of inclusivity. A suggested response is the development of a toolkit, ensuring a rich and diverse perspective, steering clear of exhaustive details while embracing simplicity.
"...we need to create a toolkit...that would actually help facilitate researchers and patients... to take the whole trial concept forward."
There was an acknowledged tension between keeping the toolkit concise and yet comprehensive.
"The toolkit structure still has to have brevity at its heart."

2. Guiding Researcher Approaches with Resource Repositories
Patient involvement can become overwhelming, and there is a real need to help researchers navigate these waters. The second proposal revolves around a repository that leads those involved in research to pertinent resources and possible research partners.
"...background resources, which people using the toolkit could dip into... using some of the channels that we've mentioned already in this meeting."
Embracing existing tools and signposting them appropriately ensures researchers don't start from scratch, enriching the PPI journey.

3. Crafting Shared Expectations through Training and Alignment
To negate superficial PPI, it's imperative that both researchers and PPI representatives initiate their partnership with aligned expectations. Consideration was given to mandatory workshops, functioning as a space for dialogue and mutual understanding, as well as a proposed common checklist, to guide researchers and facilitate alignment.
"Expectations...so that both align otherwise you'll have rubbish PPI that nobody likes or of no value to the study..."

4. Embracing Simplicity: Plain English Workshops
The fourth proposal hinges on the adoption of plain English, making complex research comprehensible to bridge patient understanding and researcher communication. Role-playing exercises were highlighted as a practical solution, where feedback could be exchanged.
"Trying to be practical with it rather than just theory and frameworks."
There was a discernible importance in ensuring that a "summary is a summary." Additionally, it was proposed that such methodologies be introduced to early career researchers, fostering a culture that prioritises patient perspective from the get-go.

Acknowledgements & Credits

Contributor Roles(CRediT - Contributor Roles Taxonomy)

Gaston Welisch: Conceptualization, Methodology, Formal analysis, Investigation, Resources, Data curation, Writing – original draft, Writing – review & editing, Visualization, Project administration, Funding acquisition

Catherine Hanna: Conceptualization, Methodology, Formal analysis, Investigation, Resources, Data curation, Writing – original draft, Writing – review & editing, Visualization, Supervision, Project administration, Funding acquisition

Rob Jones: Conceptualization, Resources, Writing – review & editing, Supervision, Project administration, Funding acquisition

Nicol Keith: Conceptualization, Resources, Writing – review & editing, Supervision, Project administration, Funding acquisition

Report Design and Layout: Gaston Welisch