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Involving patients by virtue of their experiential knowledge in health research: lessons from the onboarding process in a transdisciplinary project at Belgian universities

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Transdisciplinary (TD) research is increasingly recognized as essential for addressing complex challenges in healthcare and research. Similarly, in recent decades, patient participation in health research has grown, and patients' experiential knowledge helps shed light on their perspectives and preferences. In the context of cancer, challenges they face extend beyond pathology and treatment to encompass physical, psychological, social, and spiritual needs. We set out to take the very first step in our TD exploration together with patients as co-researchers in the Belgian TD project, "Symphony of Us" (aimed at better understanding and implementing the concept of "Patient Value" in oncology research). In this perspective paper, we reflect on building the team of co-researchers (academic scientists and patient-researchers), with a focus on the onboarding of the patient-researchers. We share our experience of the two key onboarding moments - a dedicated workshop and training - and outline the most important lessons learned and the challenges faced during this process, with emphasis on the gaps and research needs for research teams, funders, and universities. TD research offers new perspectives by combining expert and experiential knowledge, which requires specific modes of organization. Co-research can present many challenges and require a constant questioning of one's practices and personal posture. There are practical, ethical, and emotional issues involved in patient participation. It is therefore necessary to build a solid, committed, and mutually trusting team by promoting a reflexive capacity that enables adjustment of the scientific approach and project design. We believe our trajectory could inspire and help other transdisciplinary teams aiming to collaborate with patients in meaningful ways, as well as universities and funders who wish to support similar collaborations.

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Introduction

Transdisciplinary (TD) research is increasingly recognized as essential for addressing complex challenges in healthcare and research (Archibald et al., 2023; Bergmann et al., 2012). We—the authors of this perspective piece—are part of the “Symphony of Us” (SoU), a 2-year TD project that aims to better understand and implement the concept of “Patient value” in oncology research.¹ The project is a collaboration of three Belgian higher education institutions (Ghent University, AP Hogeschool Antwerpen, and Université Libre de Bruxelles), and it is initiated and supported by the King Baudouin Foundation. The SoU project builds on a strategic reflection initiated by the King Baudouin Foundation in 2020, which brought together a broad coalition of stakeholders in Belgian oncology research, complemented by international experts. This reflection revealed systemic challenges that hinder the generation of patient value, including institutional fragmentation, limited patient involvement, and misaligned incentives across the research ecosystem. From this process emerged a shared vision for a more inclusive and patient-centered oncology research system, emphasizing the need to define and assess “Patient value” as a guiding principle.² The SoU project operationalizes this vision by fostering TD collaboration and integrating patient perspectives into research design and decision-making, with the ultimate goal of aligning research efforts more closely with what truly matters to patients.

Many definitions of TD research exist,³ but for the purposes of our project, we consider TD as the co-creation of a research project with different academic disciplines and multiple non-academic stakeholders, by means of both reflection-oriented and action-oriented research, and with the purpose of knowledge collection and generation. By non-academic actors, we specifically mean individuals with lay knowledge in a certain area, i.e., experts by experience. In healthcare and research, these would include patients and caregivers. Other non-academic actors include professionals in fields such as healthcare, the pharmaceutical industry, and regulatory and policymaking. In a TD process, the involvement of such non-academic stakeholders is more significant than the researchers merely collecting data from other stakeholders or informing them about the results through publications or conferences. Instead, TD aims to co-produce knowledge together in ways that enable the non-academic actors to shape the research and to have their knowledge valued.

The project is already established on interdisciplinary grounds, as four academic researchers with diverse backgrounds (law, biomedical sciences, nursing sciences, and social sciences) are involved. However, to be truly TD, we need to actively seek out and ensure collaboration with other stakeholders in the oncology research field, including patients, physicians, nurses, pharmaceutical companies, academic institutions, policymakers, law-makers, and others.

While the role, experience, and input of all stakeholders are equally important, we believe the patients’ voice should be at the heart of a project focused on patient value. To lay the foundations for this, we opted to take the very first step of our TD exploration together with patients. Namely, to partner with patients in every aspect of the research project. Such a partnership implies involving patients in the research team as co-researchers and co-authors. Inspired by work done in France with the association “Seintinelles” (Baillat et al., 2023), the SoU sought to involve patient-researchers in the project. Co-research recognizes patients’ unique experiences and expertise related to their disease and ensures research is relevant and meaningful to them (Ivany et al. 2023).

This paper provides a reflection on building a team of co-researchers (academic scientists and patient-researchers), the lessons drawn from the ongoing learning process, the challenges encountered, and our recommendations for addressing them.

Building the team: symphony of Us and patient-researchers

The process of selecting and involving patient-researchers in the project took approximately 3 months (from March to June 2024), and had three main objectives:

1. Building a TD research team and ensuring its members’ authentic engagement;
2. Building a common language and rudiments for shared knowledge;
3. Launching a participatory approach based on a relationship of mutual trust.

In March 2024, we began with a widely disseminated call for oncology patients’ participation (via emails to patient organizations and posts on social media, such as LinkedIn and Facebook). We specifically looked for people who are experts only by virtue of their experience as patients. No formal previous training in research methodology and practice was required, but curiosity about research and willingness to contribute to the project were a must. Moreover, as the SoU project is based in Belgium, a country with several official languages,⁴ the studies need to be conducted in French or Dutch. As the team’s working language is English, we sought patients who spoke either one of the official languages and English fluently. At the time of recruitment, no formal partnership with a healthcare organization was established but the invitation was sent to several healthcare professionals. This decision was primarily influenced by the aim to reach a diverse group of individuals with lived experience in oncology, with no regard for the status of current and former patients, and without being limited to the patient pool of a healthcare institution.

An online meeting was organized with candidates to provide more information and details on the expected collaboration with patient-researchers. 22 candidates registered and 9 participated in the online meeting.

Between the online meeting and the start of the collaboration, there were two key events which we describe in more detail below: (1) a workshop in person and (2) a training of the selected patient-researchers. For each event, we also include a dedicated section describing the patient-researchers’ experience in their own words, developed during a moment of collective reflection.

The patient-researchers workshop. We organized a two-day workshop (April 2024) with interested participants, with two main goals: (1) organizational, i.e., to offer an opportunity to candidates to assess for themselves whether becoming part of the SoU project fits with their interests, expectations and availability and to lay a solid ground for building the future collaboration and (2) research (i.e., to gather insights and reflect on how TD processes can be organized and to start the exploration on what patient value could mean for different people and in different contexts). Five oncology patients with diverse backgrounds and native languages (Dutch and French) took part in the workshop.

The workshop preparation and execution were guided by the appreciative inquiry method (AIM). AIM focuses on identifying and leveraging a team, an organization, or a community’s strengths to drive positive change. It involves engaging stakeholders in discovering what works well, envisioning desired futures, designing pathways to achieve those futures, and sustaining the momentum for continuous improvement. Created initially by Cooperrider in the 1980s (Cooperrider, 1986), for the purposes of the patient-researchers workshop, the SoU team organized a two-day program so that the sessions followed the stages of the AIM cycle as described by Bushe (Bushe, 2011), namely: discovery, dream, design, and delivery/destiny. Through a carefully selected and prepared mix of educational sessions and



Fig. 1 Discussions at the patient-researchers' workshop. Photo credits: Florence Horicks.

practical exercises such as “Values and research”, “Value in life protocol”, “Speed-analysis of patient’s account” and “Your research dream”, the academic scientists and the potential patient-researchers got to know each other. They got to delve into the basics of research. Most importantly, the patients were given the opportunity to experience their unique power as both patients and (future) patient-researchers. To further ensure the creation of a safe space, the SoU team collaborated with an experienced facilitator with a background in psychology (Fig. 1). The AIM approach enabled us to co-construct the foundations of shared aspirations for the SoU project. The ideas exchanged during this process have inspired and infused the subsequent studies we conducted, ensuring that the expectations and perspectives of patient-researchers were incorporated into the research.

The workshop through the eyes of the SoU patient-researchers (Lyzette, Bernard, Willy, and Ine). The workshop was a warm welcome to the essence of the Symphony of Us. It was clear from the get-go that the team was there to provide a safe and supportive place for us.

What stood out to us were the patients’ different perspectives and how all the voices found a place in the program. We were carefully introduced to the basics of transdisciplinary research and the different possible responsibilities of joining the program. Knowing we will be taught to use our experience to create change for others was empowering.

We were invited to reflect on our own values in life, and the workshop ended with an exercise to dream about our ideal role in the project.

The workshop met a threefold objective for us:

First, we were able to speak freely about our individual situations and views on patient experiences. It was comforting and a relief to finally talk about what we value as cancer patients, in an exchange of views with other patients, some of whom had entirely different perspectives on what is valuable to others. As a cancer patient, you have gone through a process of research, diagnosis, and care individually, and forming an opinion about patient experience as a lonely exercise. During the workshop, it was liberating to hear different and/or like-minded views. This first step was mandatory to allow us to take distance and adopt a broader vision.

Second, we developed our skills in active listening, respect, and non-judgment of others’ experiences. Initially, it was not easy to

define values and feelings together. Mutual respect and willingness to listen gave us a lot of confidence in the project.

Third, the workshop also provided us with a sense of purpose, to be engaged in a project that may change something in cancer care practices. The dynamic of the workshop gave us a sense of being part of a community and the hope of helping other patients, which subsequently motivated and gave us purpose to continue participating in this project.

All in all, the workshop gave us the trust to dive into co-designing the research project, knowing we will be trained and included along the way.

The patient-researchers training. Through a facilitated self-selection process, all participants in the workshop committed to becoming patient-researchers in the SoU-project. The researchers were in line with this selection and therefore did not make further distinctions. After the constitution of the patient-researcher team, the SoU academic researchers organized a two-day in-depth training on qualitative research methodologies (May 2024). The aim was to lay the foundations for research and to prepare patient-researchers for their roles in the project, from both theoretical and practical perspectives. The training covered the nature of research, the key stages of a study, and the specificities of qualitative research relative to clinical and quantitative approaches. We also provided practical tools, such as understanding what a focus group or a semi-structured interview entails, and offered guidance on how to conduct oneself during interviews. We also introduced essential aspects of research ethics, including confidentiality. Moreover, the practical exercises provided the patient-researchers with the opportunity to join the SoU team in the design of planned studies within the project.

The training had an additional goal: to co-create a collaboration chart that provides, inter alia, a mutual framework of values and behaviors and helps manage expectations. Time was specifically allotted to discuss topics such as the roles and responsibilities within the blended team of academic and patient-researchers, the structure of the collaboration, the types of meetings, and the importance of confidentiality as a guiding principle for scientific research.

The training through the eyes of the SoU patient-researchers (Lyzette, Bernard, Willy, and Ine). The training took place over two highly interesting days, during which we were informed about the different steps of research and why they are needed. We were trained on how to conduct research, and talked about the various roles of research we could join in, and what our responsibilities would be.

We were asked to share our perspective and input on the research project as a whole.

There were many interesting debates as we refined the research structure to better reflect the voices and needs of patients.

Among the patient researchers, there were often different values, but we were always able to reach an inclusive understanding of how to shape the research to address all patients’ needs.

The team was there to guide us along these discussions, always valuing our opinions equally, modeling respectful and inclusive communication.

Perhaps the most extended discussions among us were about finding the right words: cancer patients experience intense, year-long treatments and after-effects that are challenging to varying degrees, and euphemisms cannot express what one is going through. Having those discussions was an essential part of the research process, shaping the methodological approaches.

We practiced interviewing together using existing cases to feel prepared for actual interviews.

Table 1 Team members demographics.

Academic researchers	4
Expert by experience	4
Age range (years old)	[28-66]
Gender	
Female	5
Male	3

As non-researchers, it was a very educational experience for us. Putting ourselves out of our comfort zone was not easy but the team brought us closer together. These two days were essential for the project.

Lessons, challenges and recommendations

Although the selection and onboarding of patient-researchers were finalized in the period March-June 2024, the collaboration process is still ongoing. In this perspective paper, we aim to share the lessons learned during the set-up and operationalization of the patient-researchers' involvement and share our collective recommendations on addressing such challenges.

Team composition. Of the 22 registrations for the online info-session, only 9 actually attended the meeting. From the 9 participants, 6 were patients, 1 was a patient advocate and 1 was working for a patient association.

We observed a progressive attrition of the group—from 22 initial registrants to 9 participants in the online meeting to 5 who participated to the onboarding events, and eventually to 4 who remained engaged throughout the project. We attribute this attrition primarily to self-selection, as participants gradually assessed their interest, availability, and alignment with the project's goals. While this reduction in numbers was not ideal, it resulted in a committed core group who were genuinely motivated by the research purpose and willing to contribute meaningfully. Curiosity about research emerged as a key factor through this self-selection process. The initial call for participation clearly emphasized the project's research-oriented nature, helping potential participants understand that their involvement would go beyond sharing personal experiences—it would also include contributing to the research process itself. This framing naturally attracted individuals interested in engaging with research, even those with no prior experience.

The final team composition evolved to 4 academic researchers and 4 patient-researchers, of whom one has an academic background (see Table 1). The 4 patient-researchers are cancer survivors, no longer under acute anti-cancer treatment. Despite our efforts to balance language-speaking members, they are all Dutch-speaking.

Lessons. The selected methodological approach and exercises allowed us to build trust between the SoU academic researchers and the patient-researchers. The workshop proved to be a valuable step, allowing the patient-researchers to assess whether becoming part of the project meets their interests, expectations, and availability. Recognizing and discussing values—individual and collective—was central to both the workshop and the training, and allowed us to establish a shared language. A spirit of openness, enthusiasm, and trust was built and maintained throughout the two events and beyond; such a spirit is key to collaboration within the SoU team. In connection with the SoU project's objectives, this initiative also facilitated the development of a shared vision for transforming the oncology research system.

As researchers who work closely with patients in a transdisciplinary approach, this way of working profoundly transforms our research experience. It is no longer just a question of answering theoretical questions or producing knowledge, but of entering a living dialog with those who live the realities we study. This proximity to patient-researchers brings a much more tangible and human meaning to our work: we do not only seek “on” or “about” something, but “with” people, in a dynamic where their knowledge and experiences enrich and guide our reflections.⁵

This direct interaction gives our work moral weight and emotional impulse. Instead of being simple observers, we engage as actors in a process of co-creation, which pushes us to question the purpose of what we do and remain anchored in a sense of responsibility and social utility, moving us away from the sometimes dehumanizing logics of traditional academic production.

As recently described by researchers at the Centre for Unusual Collaborations (CUCo, 2024), there is “collateral joy” in inter- and transdisciplinarity and in working closely with people from diverse backgrounds. Each meeting is an opportunity to learn and see a problem from a new perspective. The creative approaches used in transdisciplinarity promote collective exploration and provide space for everyone, regardless of their perspective, to contribute meaningfully. This creates a sense of shared accomplishment that is both challenging and deeply rewarding.

This transdisciplinary approach also invites us to constantly reflect on our research practices. Working with patients means accepting that one must get out of one's comfort zone, listen actively, and question theoretical or methodological frameworks that one thought were fixed and well-established. This requires intellectual humility and a sincere commitment not to instrumentalize others, but to value their expertise. This reflexivity is both demanding and enriching. It allows us to evolve as researchers and to be more attentive to our personal and professional values.

Lessons through the eyes of the SoU patient-researchers (Lyzette, Bernard, Willy, and Ine). We learned that seemingly opposing opinions and needs can co-exist in transdisciplinary research, as long as you speak the same language, and that that in itself is like a 'micro cosmos' of our vision of the oncology system - that every voice of every individual counts. All too often, we encountered assumptions and misconceptions about what 'the patient' wants or needs. In reality, there is a pluriformity of patient wants, needs and desires, as our discussions in the project showed, but it is entirely possible to have a uniform approach that allows for pluriformity, a shared vision on how people differ. Important values within that vision are autonomy and agency.

Regarding working in a sensitive field, we learned that we are happy to have joined this project in the phase of our lives that we are in, one of healing from our stories. In our work as patient-researchers, we inevitably encounter triggering situations similar to ours and stories of people going through experiences similar to ours. For us, the professional research lens enabled us to examine people's stories and current challenges within the system without becoming emotionally overwhelmed. We remind ourselves that we are here observing in order to create change. It's been very healing and highly empowering. At the same time, going through the process so far has made some of us realize that sticking to a purely scientific approach may not be sufficient to achieve the project's objectives. Because of scientific constraints (time and costs), the timeline of research is too long to come to concrete action and to make a change. By the time a study reaches its end and results are disseminated, the environment and the actors have already changed.

Table 2 Recommendations on working in a sensitive and vulnerable field.

Recommendations

Research teams Establish clear, flexible boundaries and maintain open communication.
 Provide patient-researchers with autonomy in deciding their level of involvement.
 Regularly check in on their capacity and comfort, and create a supportive environment where they feel empowered to step back if needed without guilt.
 Prioritize care and compassion to ensure that collaboration remains both meaningful and sustainable

Table 3 Recommendations on managing different points of view.

Recommendations

Research teams Strive to find a careful balance to integrate each one’s perspective and knowledge
 In the first stages of the collaboration, ensure to provide a presentation to the patient-researchers on the problem field; not on research in general or on methodologies, but on approaches to the problem.

Table 4 Recommendations on the lack of tailored training materials and curricula to support such collaborations.

Recommendations

Research teams Reach out to experts and patients with experience in TD collaborations
 Openness and empathy are key, as is allocating sufficient time during project planning to carefully research and prepare the training.
 Preferably, the training subjects should already be added to the project itself to enhance project engagement.
 Funders When constituting a new transdisciplinary team, selection bodies should strive for team compositions in which at least one member has prior experience collaborating with patients and providing patient training.
 Universities Strive to offer a course (providing both theory and practice in collaborating and training patients) dedicated to researchers from all faculties.
 Learn from the experience of not-for-profit organizations in providing tailored training to patients^{vi}
 Provide available basic materials that TD teams could adapt for their projects’ needs (e.g., presentations, handouts and videos covering the basics of research, as well as sample agenda’s, tips and tricks for training of patient-researchers).

Table 5 Recommendations on lack of funding.

Recommendations

Funders Foresee budget for experiential knowledge recognition in transdisciplinary projects.
 Universities Establish a framework to recognize and value participatory research in researchers’ career evaluations, particularly for early-career academics.

Transdisciplinary research can only work if the scientists (initiators) themselves are convinced of this method. Afterwards, added value can be created by involving patient researchers in the story. But this requires a lot of time and energy.

Challenges and recommendations. During the onboarding and training process, the SoU team and the patient-researchers collectively identified several challenges. We also share our recommendations for solutions addressed to research teams, universities, and funders (see Tables 2–8 below, under challenges 1–7, respectively).

It is important to highlight that, to address multiple of the identified challenges, it would be beneficial to involve patient-researchers on an equal footing and with shared responsibility before the start of a research project. Such an approach follows the best practices of transdisciplinary research.⁶

While some challenges and recommendations discussed below extend well beyond initial onboarding and training phases, they are integral to the entire trajectory of patient involvement in research. Recognizing these broader dynamics from the outset is essential, as they shape the conditions for meaningful collaboration and long-term impact. Therefore, these insights should be considered foundational elements to be

addressed from the very beginning of involving patients in research projects.

Challenge 1: Working in a sensitive and vulnerable field. Involving patient-researchers requires careful navigation between the value of their involvement and the ethical imperative to protect their well-being. Having this dual role can make patient-researchers more susceptible to emotional or physical strain. This challenge already presented itself at the very beginning of the onboarding during the online information session. A total of 22 participants registered for this meeting; however, only 9 ultimately attended. The main reasons for cancellation included fatigue, concurrent medical appointments, or treatment-related side effects, reflecting the vulnerability of this population. The emotional component of experiential knowledge can be challenging for those invited to share it (Liabo et al., 2024). The SoU team strives to establish clear, flexible boundaries and to maintain open communication. This includes providing patient-researchers with autonomy to decide their level of involvement, regularly checking in on their capacity and comfort, and creating a supportive environment where they feel empowered to step back if needed, without guilt. One of the committed patient-researchers, for example, withdrew from the project because interacting with other patients and immersing in their experiences brought back emotions and stress

Table 6 Recommendations on voluntary involvement as patient-researcher.**Recommendations**

Research teams	Each team needs to evaluate and apply an approach based on the specific project's objectives, available budget and time. Irrespective of the choice made, it is of utmost importance to consider in all cases the vulnerable and sensitive field in which such collaborations occur (cf. Challenge 1), and to establish clear boundaries, empathy, and trust. Opt to contact patient (advocate) organizations, they could have a potential role in identifying and 'matching' patients to limit drop-out or enhance engagement. Tackle the loss of engagement or enthusiasm throughout the project by maintaining good contact not only through research data, but also through moments of genuine human connection.
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Table 7 Recommendations on time and organizational aspects.**Recommendations**

Research teams	During the conception and design of new TD projects, and where relevant, allocate time specifically to involve patient-researchers. Discuss and make an informed choice on how to balance the conduct of studies and the involvement of patient-researchers. For instance, an option could be to do fewer studies than a classical project, but to involve patient-researchers meaningfully.
Funders and Universities	Recognize and support additional time spent on involving patient-researchers in research projects. Foresee incentives for junior researchers who collaborate with patient-researchers (e.g., positive consideration of such partnerships in their career evaluations).

Table 8 Recommendations on the onboarding of new applicants after the final team constitution.**Recommendations**

Research teams	Create a relationship of trust among all patient-researchers (established and new members) to promote a warm, clear, and structured welcome and to recognize each new member's unique contribution and added value. This can be addressed by developing an accelerated onboarding process for new members, prioritizing trust-building between existing and incoming members, and fostering a sense of belonging before focusing on content-specific onboarding. To improve recruitment efficiency, tight collaboration with healthcare institutions and patient organizations could enhance visibility and recruitment and support the sustainability of patient involvement initiatives. Allocate a dedicated team member responsible for communication, visibility, and recruitment. This person serves as a consistent point of contact, ensuring continuous recruitment efforts, sustained outreach, responsiveness, and relationship-building.
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that were not yet healed. It's essential to find a balance between utilizing patient's contributions and respecting their limits, particularly when their enthusiasm to help might lead them to take on more than they can comfortably manage.

Challenge 2: Managing different points of view. Any TD team needs to manage sometimes diverse perspectives and sensitivities amongst members. Researchers must navigate varying viewpoints, disciplinary frameworks, and individual perceptions while ensuring alignment with the research agenda. The SoU-team experiences similar challenges in this regard. Research rules can sometimes be difficult to coincide with patients' expectations. Also, academic researchers involved in TD research can experience a certain tension between the needs of academic research and the field transformation. We thus need to find a careful balance to integrate each one's perspective and knowledge. To tackle this upfront, the research team presented the patient-researchers the problem field; not on research in general or methodologies, but on approaches to the problem that have been tried in the past and why they were not satisfactory. In nursing and psychology, researchers have demonstrated that shared mental models, whether task- or team-related, positively influence team processes and performance (Mathieu et al., 2000; McComb & Simpson, 2014).

Challenge 3: Lack of tailored training materials and curricula designed to support such collaborations. While initiatives have focused on empowering patient involvement⁷ and a rich literature

identifies challenges associated with transdisciplinary team research (Gaziulusoy et al., 2016; Pohl, 2008), there is a striking gap in training designed specifically for university researchers, especially in Belgium. This lack of preparation extends to both patient-researchers and academic researchers, creating a critical knowledge and skills gap (Mosconi et al., 2023). The problem is particularly acute for young researchers who may lack exposure to frameworks for engaging with patients ethically and effectively. Without structured guidance, young researchers are left to navigate complex dynamics on their own, risking ineffective collaborations and potential harm to people involved in the transdisciplinary team.

In the SoU team, this challenge was mitigated by the previous professional experience of the involved academic researchers in collaborating with patients and by the opportunity within the scope of the project to dedicate time and resources to creating a dedicated training for patient-researchers.

Challenge 4: Lack of funding. Despite growing interest in transdisciplinarity for studying complex problems, a gap persists in funding frameworks for participatory research (Smith-Carrier and Van Tuyl, 2024). The lack of dedicated funding for citizen remuneration is a major obstacle to transdisciplinary and participatory research. While some European countries provide more successful models (De Simoni et al., 2023; Staniszewska et al., 2017; Aas et al., 2023), this challenge is shared by several researchers worldwide (Mosconi et al., 2023). In the SoU project, patient-researchers received the official Belgian volunteer rate, but

few research funders offer the option to add a budget line for experiential knowledge recognition. These lived experience experts, often from vulnerable or marginalized contexts, bring a unique and essential perspective to co-construct knowledge adapted to the realities on the ground. However, their involvement is often voluntary, raising ethical questions about the recognition of their contributions and limiting the transformative potential of participatory research.

Additionally, TD research presents extra challenges for researchers and requires deep engagement. The additional time spent involving lived experience experts, building, and maintaining the trust relationship is often difficult to quantify and therefore difficult to gain recognition from funders and academic authorities.

Challenge 5: Voluntary involvement as patient-researcher. By volunteering in the SoU project, patient-researchers may gain skills, expand their networks, and experience a sense of purpose from their experience of cancer to help others. However, volunteering can also present challenges, such as balancing enthusiasm for contributing with personal limits, which is crucial to ensuring a positive experience. A lack of formal compensation may lead to the undervaluation of their time and expertise, particularly in collaborations that require sustained effort. Additionally, the absence of clear expectations can lead to feeling overburdened or taken for granted. On the other hand, being a volunteer allows patient-researchers to set their own boundaries more freely regarding the time they spend on the project, the tasks they are willing to do, and the energy they invest in the research. It didn't happen in this specific collaboration, but a pitfall could be a loss of engagement or enthusiasm with time, risking leaving the project prematurely. Ultimately, regarding the type of involvement in a TD project as a patient-researcher (i.e., voluntary or full-time), there is no one-size-fits-all solution.

Challenge 6: Time and organizational aspects. Research projects are often bound by time and human resources constraints. In our case, the SoU project has a 2-year duration and is conducted by a relatively small number of researchers (4 in total). Throughout the onboarding process, we found that it is of utmost importance to strike the right balance between providing sufficient information and research tools to empower patients in their new role as patient-researchers, without overburdening them with academic material. Moreover, there is a fine balance to be struck between time spent equipping patients from a research perspective and time spent with them to gain their commitment and trust. Finally, the trajectory of the patient-researchers is one of the multiple initiatives conducted within the project – it is crucial to allocate time well between all strands of the project.

Challenge 7: Approaching the onboarding of new applicants after the final team constitution. Integrating a new member into an already formed team can be a challenge, as the group has often established dynamics, implicit roles, and work habits. In the specific context of the SoU project, the transdisciplinary approach adds an additional difficulty and requires the creation of a relationship, particularly based on mutual trust and commitment. It is obviously impossible to reproduce the workshop and the training for a new member who would join the team. This situation could lead to resistance to this person's involvement in the team. More generally, recruitment of a sufficient number of patient-researchers has proven to be a persistent challenge. Maintaining a continuous recruitment process also requires sustained communication efforts and administrative support, which is demanding in terms of time and resources. Without dedicated support, teams may struggle to maintain momentum and inclusivity, mainly when operating with limited resources.

Conclusion

In this perspective piece, we shared an open reflection on building a blended team of academic scientists and patient-researchers within the scope of a Belgian transdisciplinary oncology research project (the Symphony of Us). Two key moments in onboarding patient-researchers—a workshop and training—are outlined, with emphasis on the patient-researchers' experiences in their own words. Furthermore, the paper summarized the most important lessons drawn and challenges faced during this initial process and outlined suggestions for solutions based on the research team's experience. Building a strong foundation of mutual trust is one of the cornerstones of TD research, and everything that happens in the process builds on it. We believe our trajectory could inspire other TD teams aiming to collaborate with patients in meaningful ways.

Data availability

Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

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Notes

- 1 For more information about the project: <https://www.symphonyofus.be/en/?lang=en>
- 2 Strategic Reflection, available at: <https://kbs-frb.be/en/oncology-research-optimal-patient-value-systems-approach>
- 3 See Utrecht University, Interdisciplinary Field Guide, available at: <https://www.uu.nl/en/research/transdisciplinary-field-guide/get-started/what-is-transdisciplinary-research>
- 4 Dutch, French, and German
- 5 See also the definition of patient and public involvement, the National Institute for Health and Care Research Glossary, available at: <https://www.nihr.ac.uk/glossary#letter-p>
- 6 See e.g., Utrecht University, Transdisciplinary Field Guild, available at: <https://www.uu.nl/en/research/transdisciplinary-field-guide/get-started/what-is-transdisciplinary-research#engaging>
- 7 See e.g., the European Patients Academy on Therapeutic Innovation: <https://eupati.eu/>, the Patient Expert Center: <https://patientexpertcenter.be/fr/patient-expert-center/>, the EURORDIS Open Academy: <https://openacademy.eurordis.org/>, the WECAN Academy: <https://wecanadvocate.eu/academy/>

References

- Aas SN, Distefano MB, Pettersen I et al. (2023) Patient and public involvement in health research in Norway: a survey among researchers and patient organisations. *Res Involv Engagem* 9:48. <https://doi.org/10.1186/s40900-023-00458-x>
- Archibald MM, Lawless MT, de Plaza MAP et al. (2023) How transdisciplinary research teams learn to do knowledge translation (KT), and how KT in turn impacts transdisciplinary research: a realist evaluation and longitudinal case study. *Health Res Policy Syst* 21:20
- Baillat L, Bauquier C, Pannard M, Piton M, Denieul C, Sevenne M, Gerard A, Mouline M, Jean-Daubias S, Jacob G, Préau M (2023) Co-construire un projet de recherche en oncologie avec les personnes concernées : retour d'expérience et leçons apprises. *Sté Publique* 35(HS2):15–19
- Bergmann M, Jahn T, Knobloch T, Krohn W, Pohl C, Schramm E (2012) *Methods for transdisciplinary research: a primer for practice*. Campus Verlag, Frankfurt
- Bushe GR (2011) 'Appreciative inquiry: theory and critique'. In: Boje D, Burnes B, Hassard J (eds) *The Routledge companion to organizational change*. Oxford, Routledge, p 87–103
- Cooperrider DL (1986) *Appreciative Inquiry: toward a methodology for understanding and enhancing organizational innovation*. Unpublished doctoral dissertation. Department of Organizational Behavior, Case Western Reserve University, Cleveland, Ohio
- CUCo (2024) 'Finding joy, creativity and meaning through unusual interdisciplinary collaborations'. *Humanit Soc Sci Commun* 11:1159
- De Simoni A, Jackson T, Inglis Humphrey W et al (2023) Patient and public involvement in research: the need for budgeting PPI staff costs in funding applications. *Res Involv Engagem* 9:16. <https://doi.org/10.1186/s40900-023-00424-7>

- Gaziulusoy AI, Ryan C, McGrail S, Chandler P, Twomey P (2016) Identifying and addressing challenges faced by transdisciplinary research teams in climate change research. *J Clean Prod* 123:55–64
- Ivany C, Hudson T, Schneider P, Farrukh H, Ghert M (2023) Patient engagement in research; benefits, challenges, importance, and implications [Preprint]. medRxiv. <https://doi.org/10.1101/2023.03.28.23287870v1>
- Liabo K, Asare L, Ruthen P, Burton J, Staunton P, Day J (2024) Emotion in public involvement: a conceptual review. *Health Expect* 27(2):e14020
- Mathieu JE, Heffner TS, Goodwin GF, Salas E, Cannon-Bowers JA (2000) The influence of shared mental models on team process and performance. *J Appl Psychol* 85(2):273–283. <https://doi.org/10.1037/0021-9010.85.2.273>
- McComb S, Simpson V (2014) The concept of shared mental models in healthcare collaboration. *J Adv Nurs* 70:1479–1488. <https://doi.org/10.1111/jan.12307>
- Mosconi P, Colombo C, Paletta P et al. (2023) Public and patient involvement: a survey on knowledge, experience and opinions among researchers within a precision oncology European project. *BMC Cancer* 23:814. <https://doi.org/10.1186/s12885-023-11262-x>
- Pohl C, Hirsch Hadorn G (2008) Methodological challenges of transdisciplinary research. *Nat Sci Soc* 16(2):111–121
- Smith-Carrier T, Van Tuyl R (2024) ‘The Merits and Pitfalls of Participatory Action Research: Navigating Tokenism and Inclusion with Lived Experience Members’. *Int Rev Public Policy* 6(1):46–62. <https://doi.org/10.4000/11whj>
- Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S et al. (2017) GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *BMJ* 358:j3453. <https://doi.org/10.1136/bmj.j3453>

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Author contributions

Shared first co-authors: TLS and FH. Conceptualization: TLS, FH, and SL. First draft manuscript: TLS and FH. Review and revision: SL, LB, BC, WD, and IVZ. All authors have reviewed and agreed with the article.

Competing interests

The authors declare no competing interests.

Ethical approval

No ethical approval was needed for establishing the collaboration with patient-researchers.

Informed consent

This comment is a reflection co-authored by the scientists and patient-researchers involved in the project. Hence, informed consent was not required.

Additional information

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