The Patient Partner Roadmap: Fostering Meaningful Partnerships in Continuing Education

A product of the
Meaningful Engagement of Patient Partners in CE
Working Group at Learn to Thrive 2023

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Glossary of Terms

CE	Continuing Education
CME	Continuing Medical Education
CPD	Continuing Professional Development
IPCE	Interprofessional Continuing Education
HCP	Healthcare Provider
HIPAA	Health Insurance Portability and Accountability Act
IRB	Institutional Review Board
JAC	Joint Accreditation Criteria
Patient Partner	Patients, caregivers, advocates and families
PFCCP	Patient and Family Center Care Partners
PFAC	Patient and Family Advisory Council
PCORI	Patient-Centered Outcomes Research Institute
PWLE	People with Lived Experience
PDSA	Plan-Do-Study-Act

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Introduction

We have developed this Patient Partner Roadmap to help continuing education (CE) professionals foster meaningful and effective patient, family, and caregiver engagement in the planning and delivery of accredited continuing education for health professionals. This resource is a flexible tool that can guide CE programs to improve educational partnership through specific, step-wise approaches. The authors intend that the Patient Partner Roadmap be an essential tool for engaging patients and enhancing the standard of care through CE.

As you progress through the Roadmap, you will encounter a **Battle Scale**. The Battle Scale has eight components and provides a flexible framework allowing individuals or a team to expand their patient partner involvement in continuing education (CE) from simple CE activity such as grand round sessions to more complex ones, like an advisory committee, as they gain experience. The scale is named after **Aaron Battle**, our patient advisor. It serves as a reference tool to help you determine how far you want to level-up your engagement. As you strive to enhance your interactions with patient partners, you should aim to increase your level of engagement. The spectrum of your needs may encompass all scales; note that it is only guidance. We encourage you to try as many scales as possible as it will increase patient partner engagement and opportunities and improve patient outcomes.

Continuing Education

Continuing Professional Development (CPD), Continuing Medical Education (CME), and Continuing Education (CE) are used interchangeably. While CME is commonly used in many of our offices, we are also transitioning towards interprofessional CE activities. As a result, it would be more suitable to use the term CE.

Patient Partners

We define patients as the people with lived experience (PWLE). PWLE are outpatients, in-patients being cared for in their homes or through community programs, and residents of long-term care homes who are not terminally ill.[1] PWLE also includes family members, caregivers, and the organizations that are representative of the populations you may be working with.

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Introduction

A patient partner can be defined as someone who has or can communicate a patient's lived experience. That could be a parent or caregiver of a pediatric patient, an actor or representative who is communicating something a patient doesn't feel comfortable portraying, or the family of an incapacitated or deceased patient. Having input from patient communities that cannot communicate or portray their lived experience is crucial in improving the patient experience and outcomes. Without that input, learning to improve would be missing a vital aspect. Not everyone is comfortable sharing their healthcare experiences, linking themselves to their experiences, especially sensitive ones. This gives us an opportunity as educators to make sure that their voices are heard, but in a way that creates safety for the patient and the learner.

A few examples include:

- a patient who was a victim of domestic violence. If they don't feel comfortable sharing or re-living that trauma while sharing their care experience, it could be done by someone else who has an accurate way of communicating that patient's experience
- a parent or guardian of a pediatric patient who cannot speak for themselves. Parents/guardians can be the best advocates for their children who cannot or do not understand how to communicate for themselves
- a simulation in which an actor depicts a patient case informed by a documented experience

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Getting Ready

To get the most out of the Patient Partner Toolkit, it will be helpful to have a good understanding of the accreditation requirements that reward engaging patients as partners in the planning and teaching of accredited CE. Both the Accreditation Council for Continuing Medical Education (ACCME®) and Joint Accreditation™ have optional requirements for organizations seeking *Accreditation with Commendation* that address this topic.

ACCME Menu of Criteria for Accreditation with Commendation

Engages Patients

Patient/public representatives are engaged in the planning and delivery of CME.

https://www.accme.org/accreditation-rules/accreditation-criteria/engages-patientspublic

Rationale:
Accredited continuing medical education (CME) is enhanced when it incorporates the interests of the people who are served by the healthcare system. This can be achieved when patients and/or public representatives are engaged in the planning and delivery of CME. This criterion recognizes providers that incorporate patient and/or public representatives as planners and faculty in the accredited program.

Critical Elements:

- Includes planners who are patients and/or public representatives **AND**
- Includes faculty who are patients and/or public representatives

The Standard:

- Attest to meeting this criterion in at least 10% of activities (but no less than two) during the accreditation term.
- At review, submit evidence for this number of activities: *
    - S: 2; M: 4; L: 6; XL: 8
      **Program Size by Activities per Term: S (small): <39; M (medium): 40 -100; L (large): 101-250; XL (extra-large): >250.*

Getting Ready

Criteria for Joint Accreditation with Commendation

JAC 13: The provider engages patients as planners and teachers in accredited IPCE and/or CE.

Guidance:

- Describe how the provider incorporates patients and/or public representatives as planners and teachers. Attest to meeting this criterion in at least 10% of activities during the accreditation term.
- Submit evidence for the required number of activities: S: 2; M: 4; L: 6, XL: 8.
- The size of a CE program is determined by a provider's total number of activities (CE and IPCE) for the current accreditation term based on the best available information at the point of submission: S (small): less than 39; M (medium): 40-100; L (large): 101-250; XL (extra-large): > 250

https://jointaccreditation.org/accreditation-process/requirements/commendation/

Learn More!

Watch Dr. Graham McMahon, ACCME President and CEO, provide a brief overview of the "Engages Patients" Commendation criterion.

https://vimeo.com/250137033

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What is Patient Partner Engagement in CE?

Accrediting bodies—ACCME and Joint Accreditation—support patient partner engagement in CE. We have seen in the previous section how accreditation requirements provide guidance for meeting minimum expectations. Certainly, pursuing and achieving Accreditation with Commendation is a laudable goal for CE providers. But this toolkit is intended to provide CE providers (and their patient partners) with strategies that enable them to go beyond accreditation requirements to strive for the most impactful engagement.

Patient voices in CE can broaden perspectives and provide clarity for both patients and clinicians. Patients bring valuable insights to the table, helping to identify practice gaps in education. Their involvement in CE planning processes can lead to greater sensitivity to patient needs, improved patient care, and a demonstration of an organization's commitment to inclusivity.[2,3]

Healthcare providers are accustomed to hearing patient case studies in their continuing education programs but rarely hear from actual patients. That is changing as accreditation organizations recognize patient experiences' impact on educational outcomes. While clinical data is undoubtedly important, the patient voice adds a human element to the information, making it more relatable and easier to apply in practice.

By involving patients as part of the team, health providers gain valuable insights that can be immediately applied in their practices.[4] This not only enhances the quality of care but also reinforces the reasons why healthcare professionals do what they do. Patient experiences bring data to life meaningfully and can have more staying power. Patient stories have more staying power than clinical data because they are relatable. Hearing from patients can make the content more memorable.[5,6] Furthermore, patients can become part of the CE team by planning, teaching, and advising for the CE activity.

There are a variety of ways that patient partners can be engaged in CE. Let us take a look at the **Strategies to Engage Patients Battle Scale**.

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Strategies to Engage Patients Battle Scale

The **Strategies to Engage Patients Battle Scale** is an exciting tool that helps categorize a patient partner's different roles in CE. Seeing efforts made to involve patients in designing, implementing, and evaluating CPD programs is a positive development, moving away from the passive role of demonstration. This approach will help patients better understand their healthcare needs and ultimately lead to improved public health outcomes.[6] After reviewing the scale, identify where your program fits and consider where and how to shift your engagement.

Learn More!

Hear perspectives from patients, advocates, physicians, and educators about how to involve patients in CE.

https://vimeo.com/243710707

Battle Scale: Strategies to Engage Patients

	What You Can Do
Beginner *Passive engagement scale* *Patient partner new to experience* *CE staff new to experience*	• Patient partners can demonstrate a technique (using a device or in a study). • Patient partners can be used as standardized patients to teach and give feedback. • Patient partners tell their stories. • Plan an activity with patient partners to do role-playing to assess clinical skills.
Intermediate *Mixed engagement scale* *Patient partner is experienced in CE engagement* *CE staff wants to increase opportunities to engage patient partners*	• Patient and family give their perspective in relation to a condition/disease. • Patients contribute to the development of needs assessment. • Patients contribute to curriculum design and teaching materials such as case-based learning. Live or videos. • Participate in a case discussion or bedside teaching.
Advanced *Fully active engagement scale* *Patient partner is fully committed and has experience* *CE staff & institutional leaders want a full partnership with patient partners*	• Use patient partners as program directors in a CE activity; patients are equal partners in developing education programs and as educators. • Patient partners may train/onboard others. • Strategic planning. Leadership role in decision-making and strategic planning. • Engage in scholarship/research to study and disseminate effective CE approaches that include patients.

*Patient Partners are inclusive of people with lived experience (PWLE), formal or informal caregivers, and family members. A patient partner can also be defined as someone who has or can communicate a patient's lived experience.

Why is Patient/Family/Caregiver Experience Important to CE?

Research shows that learners tend to retain more information when it is constructed as a story than if it is presented as a series of facts.[7,8] Incorporating patient perspectives into continuing education can be incredibly valuable for healthcare providers. By including the voice of patients and their lived experiences, clinicians can gain a deeper understanding of the impact of various conditions and treatments. These personal accounts can help humanize the experience of illness and treatment, which is often missing from clinical data and statistics. Ultimately, incorporating patient perspectives may lead to more personalized and empathetic care for all patients.[9]

Incorporating Patient Perspectives into CE Acts as a Vehicle for Breaking Down Barriers

Sharing patient voices in provider education is an effective way to overcome patient/provider gaps and to help providers retain what they have learned. One reason patient voice is so powerful is because it affords healthcare providers (HCPs) insight into the considerations that patients and their families have during their journey.[10] These insights may open the door to consideration of treatment approaches that can be successfully adhered to in order to gain a better understanding of the patient’s lifestyle. For example, an HCP might have two patients with similar clinical experiences but vastly different perspectives, goals, and family and financial situations that may affect their treatment decision-making.[9]

Fostering Shared Decision-Making

There is much discussion in healthcare about the concept of shared decision-making. That starts with understanding the journey that patients go through. When HCPs leave a CE program after hearing these firsthand stories, they are more confident in communicating with patients and initiating discussions important to patients/caregivers. Often, the patient’s voice is not heard, leading to poor adherence and poor outcomes. Amplifying patient voices helps find a treatment that works well, provides good outcomes, and is manageable for the patient/caregiver.[6]

Why is Patient/Family/Caregiver Experience Important to CE?

Overcoming Disparities in Care

Healthcare disparities are well documented and have become a growing part of the national conversation. These can occur due to a patient's age, location, income, gender, race, ethnicity, sexual identity, or other factors. These are highly complex issues that will not be solved overnight. Giving patients from diverse backgrounds a voice is a first step. Including a representative set of patients in educational activities can aid providers in addressing disparities in care. By listening and learning from a wide range of patients, providers can begin to consider factors that influence each patient's well-being. This awareness can benefit providers seeking to improve their cultural competencies.[10]

Patients' voices can help healthcare providers (HCPs) understand the patient's actual experience, not just the disease. Sharing insights from patients about their struggles through diagnosis, treatment navigation, communication, and more drives home the real experiences of the people they treat each day. In an era when providers have less and less face time with individual patients, these insights are even more crucial.[6]

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Why is Patient/Family/Caregiver Experience Important to CE?

Case Study: ACT UP and the FDA

The US Food and Drug Administration (FDA) initiated patient involvement in the year 1988 amidst the AIDS epidemic as a measure to ensure patient-centered care. In 1988, ACT UP, the Aids Coalition to Unleash Power, wanted the FDA's help. The group protested and was heard loud and clear. As the AIDS epidemic was ravaging the country, patients helped the FDA look at the disease in a different way: acknowledging that patients and their caregivers were experts in their disease. They knew about aspects of their diseases and experiences that the FDA experts and scientists did not know but needed to so they could find the best ways to treat them. Ever since, the US FDA has convened multiple forums on specific topics and diseases where patients, caregivers, and advocates share their experiences of living with the condition and burden of treatment while scientists, experts and companies can listen and learn. (US Food and Drug Administration, n.d.) [10,11]

Learn More!

Patients Matter: Giving Patients a Seat at the Table. Watch this five-minute video from the FDA as an example of why patients matter and what we can learn by partnering with patients.

https://www.youtube.com/watch?v=IKOPEMQYdkI

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Know Why You Engage

Using the **Readiness Battle Scale** can help your team clarify your goals, objectives, and overall readiness for successful engagement with patient partners. You can have multiple reasons for wanting to engage patient partners in CE activities. Be aware that the more complex and multi-faceted the decisions are to involve patient partners, the more ambitious and resource-intensive your engagement plan may need to be.[13]

Before you begin, discuss these questions in the Battle Scale as a team.

Battle Scale: Team Readiness

	Questions to Think About
Beginner *Passive engagement scale* *Patient partner new to experience* *CE staff new to experience*	• Does your organization allow the use of patients in CE? • What is your reason for wanting to engage? • Does your CE team see the value and benefit of partnering with patient partners?
Intermediate *Mixed engagement scale* *Patient partner is experienced in CE engagement* *CE staff wants to increase opportunities to engage patient partners*	• Are we clear on what issues or concerns we are trying to address on this CE activity? • What other stakeholders will need to be engaged in this CE activity?
Advanced *Fully active engagement scale* *Patient partner is fully committed and has experience* *CE staff & institutional leaders want a full partnership with patient partners*	• Have the CE activities involved patients and families in the past? If so, what have been the implications of this? • Does the budget allow for compensation for patient partners? • What support do we have from our leadership to ensure this is successful for the duration of the initiative?

*Patient Partners are inclusive of people with lived experience (PWLE), formal or informal caregivers, and family members. A patient partner can also be defined as someone who has or can communicate a patient's lived experience.

What Are Your Partnership Goals?

Does it Fit the CE Activity?

Ensure that your engagement goals benefit patients and families! Knowing why you partner with a patient or caregiver is the start of the process. Asking the questions in the **Reflection of Engagement Battle Scale** helps to ensure the readiness of the team to engage patients in CE.

If you cannot say “yes” to any of these broad goals, you might want to reconsider your current plan for engaging patients and caregivers.

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Battle Scale: Reflection of Engagement

	Will Engagement of Patient Partners* Help Your CE Program to:
Beginner *Passive engagement scale* *Patient partner new to experience* *CE staff new to experience*	• Improve health outcomes? • Improve patient experience? • Ensure access to treatment? • Help PWLE share their stories?
Intermediate *Mixed engagement scale* *Patient partner is experienced in CE engagement* *CE staff wants to increase opportunities to engage patient partners*	• Ensure appropriate treatment and care? • Improve safety? • Reduce risk factors and prevent ill health?
Advanced *Fully active engagement scale* *Patient partner is fully committed and has experience* *CE staff & institutional leaders want a full partnership with patient partners*	• Strengthen accountability? • Improve transitions between services? • Set priorities for action? • Improve service design and/or the process of receiving care?

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What Are the Best Ways to Engage?

Does it Benefit the Patient Partner?

Can partnering with patients help planners develop more meaningful programs? Compelling reasons to incorporate lived experience stories into healthcare improve outcomes. Patient memories are a foundation for medical learning. The stories of individual patients interlaced with scientific knowledge, evidence, and hands-on experience offer great insights; bringing them together serves as a bridge to help anchor these memories. Additionally, patient stories highlight the frustrations and successes that can often be overlooked.[7] Engagement can also benefit patients by providing them strength and empowerment as they share their healthcare journey.

Research shows that patient engagement enhances knowledge retention when used appropriately, and we have witnessed how it bridges the gap between what HCPs observe in practice versus what patients experience in their daily lives. Although it may require time and effort, it is worthwhile for CE providers to elevate the role of patients in educating our healthcare providers.[7]

How Do You Want to Engage?

The "patient voice" is the presence of patients' lived experiences, values, and preferences as an integral part of medical education, often in the form of video testimonials. It can be incorporated into programs in any number of ways. These may be live or pre-recorded videos of a patient or family member embedded in a panel discussion. Another established and practical approach has been to include a patient or caregiver on a panel with clinical faculty, where they can bring the unique perspective of their care journey to the discussion.[11] The patient partners can share their story in a TED-talk style format. The **Activity Type Battle Scale** offers some optional engagement that CE providers can use.

Battle Scale: Activity Types

	Activity Type
Beginner *Passive engagement scale* *Patient partner new to experience* *CE staff new to experience*	• Symposia lecture and/or direct care-level perspectives where patient partner* can share “My Story” • Grand Rounds (i.e., Regularly Scheduled Series), webinars, recorded interviews or presentations from patient partners
Intermediate *Mixed engagement scale* *Patient partner is experienced in CE engagement* *CE staff wants to increase opportunities to engage patient partners*	• Convening patient partners to obtain feedback, identify professional practice gaps, support needs assessment, conduct focus groups for CE planning, content, teaching, or assessment • Including patient partners in shared decision-making • Collaborating with patient partners in short-term working groups or program and service planning engagements • Engaging patient partners in quality improvement and/or safety activities.
Advanced *Fully active engagement scale* *Patient partner is fully committed and has experience* *CE staff & institutional leaders want a full partnership with patient partners*	• Engaging patient partners in research and scholarship to study the effectiveness of CE approaches (including patient engagement!). • Patient partners as members of advisory committees, system-level leadership.

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Engagement in Practice

Learn More!

Watch a short video prepared by **Dr. Cynthia Pineda** where she describes her experience including patients as partners in the design and developmental process of creating simulation-based patient education videos on bladder self-care management using aspects of human-centered design. The patient education videos were created for the **DISCOVER SCI/D** program to help persons with spinal cord injuries and their caregivers understand more about the patient's body after a spinal cord injury or disease (SCI/D) diagnosis.

https://www.youtube.com/watch?v=cmeRZ_c0yPc

Creating an Approach

Once you have decided to include patient partners in your CE activity, how do you build support with your CE planning team and faculty?

Making the Case to CE Planners and Activity Directors

First, is important to gather evidence and research on the subject to effectively demonstrate the value of involving patients in CE. One recommendation is to speak to researchers who have worked with patients in their studies and have them discuss the benefits of such partnerships with planning faculty members. Identify a physician or other health care provider who shares a passion for patient partnerships and can help build enthusiasm and address concerns from committee members, researchers, institutional leaders, and other stakeholders.[15]

In addition to personal testimonials, it is essential to present data and research that supports patient-centered care. One resource to explore is the Patient-Centered Outcomes Research Institute (PCORI), which has funded numerous studies on the benefits of patient engagement.[14] Other institutions prioritizing patient-centered research include the non-profit Institute for Patient and Family Centered Care (IPFCC) and (for profit) Patient and Family Centered Care Partners. By sharing this information, you can help decision-makers understand the importance of involving patients in your CE programs.[15,17]

It is critical to gain buy-in from leadership. Educators should communicate their plans and goals for patient engagement with leadership, explaining how this engagement will support strategic goals for quality and safety, foster trust and connections with patients and communities, and help clinicians counter burnout, build resilience, and rediscover meaning and joy in their work. Engaging patient partners in CE may also help your organization achieve Accreditation with Commendation. By getting leadership on board, you can ensure that patient engagement is prioritized throughout the organization.[18]

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Creating an Approach

Finally, emphasis should be placed on the benefits of having more meaningful engagement of lived experience perspectives to inform improvement in processes of care and overall system performance. Collaboration and leadership with the patient voice is an opportunity for the organization to increase patient and community health outcomes. Additionally, it can reduce errors and adverse events, increase patient loyalty, reduce malpractice risk, increase employee satisfaction, and improve financial performance for the positive image it brings to the organization.[15,18]

Building Support and Closing the Deal

As you plan for your next CE activity, it is essential to consider the professional practice gaps that you aim to address. Upon reviewing the practice gaps, you can ask the Activity Director and planning committee: Have you considered involving patients? Advise them that patients are often experts in their own conditions. Their disease state allowed them to have close relationships with their care providers. It also allows for insights and experiences regarding the disease, treatment, and interactions with healthcare professionals that HCP learners may not be fully aware of. Engaging patient partners as planners and teachers of CE can have a significant impact on addressing gaps in communication, public health, cultural competencies, health equity, and health disparities. For example, it is important to help CE planners understand that patients' real-world insights and experiences can be particularly valuable for CE activities addressing health disparities and systemic biases.[17]

Learn More!

Explore the difference between patient participation and patient engagement in this short video from PCORI.

https://youtu.be/KnVaMHwWFFE?si=oYRHcHQuGKVzPqIy

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Creating an Approach

Researchers recommend delineating the why, who, how, and what of lived experience engagement in CE initiatives to develop a feasible strategy. This approach can help ensure that the engagement is effective and meaningful for all parties involved. One creates a well-planned and successful CE initiative by clearly defining the engagement's purpose, target audience, methods, and expected outcomes.[17] The CE team should take a proactive approach when engaging with patient partners. All of the concerns may not be resolved in one meeting; however, it is important to discuss and assess that the planning team members have the self-efficacy to ensure that the patient partner can be integrated into the CE environment to ensure a successful outcome.[14]

Address any resistance and build support among the planning committee before moving forward with the CE initiative. Emphasize the importance of the role and voice of the patient as a member of the CE committee and the patient's involvement in developing meaningful content for the activity. Many times, patients are often outnumbered by expert faculty member planners; participating and speaking up can be intimidating.

Establishing ground rules also ensures everyone is on the same page and clearly understands their role in the CE activity. This can address potential barriers or challenges, such as time commitments or required expertise, and help establish meaningful engagement.[18,19]

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Identifying Patient Partners (Recruiting, Vetting, and Inviting)

Now that you have the buy-in and your key questions have been answered, the next step is to recruit patient partners. Finding and recruiting patient partners is a common challenge. Recruiting patients can be a formal or informal process. The **Tactics for Recruitment Battle Scale** provides some ways that patient partners can be approached.

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Battle Scale: Tactics for Recruitment

	Tactics
Beginner *Passive engagement scale* *Patient partner new to experience* *CE staff new to experience*	• Ask physicians, nurses, and other providers in the planning committee to assist. • Ask hospital support group leaders. • Ask CE peers and other networking groups. • Attend patient group meetings.
Intermediate *Mixed engagement scale* *Patient partner is experienced in CE engagement* *CE staff wants to increase opportunities to engage patient partners*	• Ask your organization's volunteer office • Ask known patients, families, and friends • Ask patient and/or disease advocacy groups
Advanced *Fully active engagement scale* *Patient partner is fully committed and has experience* *CE staff & institutional leaders want a full partnership with patient partners*	• Ask community service leaders, patient family advisory councils (PFACs), and other advisory committees. • Create and post a notice (with appropriate language) in clinics or hospital units.

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Identifying Patient Partners (Recruiting, Vetting, and Inviting)

Creating a rapport and asking the right questions to foster a meaningful partnership is vital in establishing effective engagement opportunities.

Questions to start a conversation with prospective patient partners…

- Tell me a bit about yourself. (i.e., what do you like to do in your free time, what things are you interested in, where are you from?)
- Do you feel able to share your experiences in ways that others can learn from? Can you provide an example?
- Do you have any concerns about the emotional experiences you may have in sharing your story?
- Is there any other information that you think might be important for us to know about you?
- Do you have a recent healthcare experience or a past healthcare experience that was important to you?[12]

When interacting with potential patient or caregiver partners, it is important to consider a diverse range of people. This includes individuals from different backgrounds, genders, and socio-economic levels. You may need to provide an interpreter if they do not speak English. It's also important to consider those with mobility issues. If the patient is a minor, involve their parent(s) or guardian(s). For seniors, consider a caregiver. By embracing diversity, you can provide better care and ensure everyone feels welcome and included.

Take the opportunity to explore and define the patient partner's role in the CE activity during the recruiting process. For instance, help patient partners to understand what might be different about having a role in CE planning versus teaching. Clear and open communication is helpful.[20] Regardless of the person, the partnership must be clear on goals and objectives in order to have a strong and successful partnership. Avoid tokenistic modes of participation and commit to a shared decision-making process.[22]

The patient partner needs to have an equal voice. Establishing it at the onset sets the tone. What usually happens is the planning team talks with the patient at the initial meeting, and then the rest falls on the CE staff to do all the other work. They never talk to the patient again and the CE staff is left holding the basket. You have to consider early on how much of a partnership the CE activity requires and how much leadership in co-creating the CE activity the team is able and willing to provide. — **Edeline Mitton**

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Fostering Meaningful Patient Partner Relationships

Identify a Committee Member/CE Staff Liaison

After the decision is made to engage with patient partners, select a member of the team to engage with them as a staff liaison. Having 1-2 people closely involved with communication lessens the chance of confusion. This person's role is to prepare and debrief the patient partner throughout the CE activity, help navigate challenges, foster connections, and ensure potential barriers are addressed. Because this person will be the primary contact, it is important that they can provide administrative and communication support to the patient partner. It is helpful for the staff liaison to be someone who has, or can build, a strong rapport with organizational leadership, clinicians, staff, patients, and family members.[22]

Patient/Caregiver Orientation

The orientation process should provide the patient partner with a broad overview of your institution and an understanding of your CE planning process. Review goals, mission, and responsibilities. This is an opportunity to orient the patient partners about the CE activity and address their concerns. Key areas to focus on include:

- Duration of the collaboration
- Meeting schedule
- Specific roles and responsibilities
- Time commitment
- Expectations for attendance at meetings
- Reimbursement for expenses

Reflect on and continually reassess the process with the patient partner to ensure reliability. Moreover, be sure to be flexible, open, and humble. If any issues arise, discuss the effort with your team and others; seek guidance as needed.

> *As a patient, speaker, and advocate, my experience working with organizations continues to grow. When I began my advocacy journey, I was fortunate enough to work with a group that prepared me through education. The most important thing I've found is when patients feel prepared and comfortable, they will flourish and become an integral part of the team.*
>
> — **Aaron Battle**

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Communication

When communicating with the patient partner, it is important to consider how best to create a welcoming environment.

a. Assess the patient partner's learning style, needs, and preferences.
b. Use clear, simple, and respectful language to communicate with patient partners.
c. Use visual aids, technology, and other resources to enhance the patient partner's education.
d. Check the patient partner's understanding and address any questions or concerns.
e. Motivate and empower patient partners to take an active role in the CE activity (e.g., planning, teaching).
f. Recognize that communications with planning committees and/or faculty may need to be modified to ensure they are effective with patient partners.

Some jargon and acronyms are hard to avoid in CE. Provide an explanation or definition of any terms they may not understand or be familiar with. It may be helpful to encourage committee members who are beginning to work with patient partners, including family members or caregivers, to develop a list of any acronyms and jargon associated with CE. Advisors and staff members can collaboratively develop and add to this list as necessary. Also, when referencing research data, use plain English, not scientific jargon.[18]

> *I'm in all these different committees now, and I noticed that I'm a terrible person with acronyms. There's so many of them, but I do find that on the work groups that I've been working with, I've learned a great deal more, and I think we need to let patient partners understand that there it's a learning experience and that they're not going to know a lot of this stuff but the learning will come.* — **Aaron Battle**

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Fostering Meaningful Patient Partner Relationships

Challenges of Getting Patient Partners to Come to Meetings

- COVID-19 is still active, and some patients are at high risk. Planners should consider this when asking patient partners and caregivers to participate. Always prepare for virtual options and virtual support when possible.
- Planners should consider a recorded option for the patient partner if the program is in-person.
- Consider transportation and logistical arrangements that need to be coordinated. Does the program cover mileage for the person to attend? Provide car service if possible.
- Is the location accessible to the patient partner? Time and place of the meeting can be a factor. If it is around mealtime, provide a meal or snack.
- Patient partners can feel reluctant to participate if unsure of their role in the program. Acknowledge their reluctance and provide guidance.

> *Since the pandemic, it has been challenging working with patient partners. Whereas before, the main question that was asked was for directions to the meeting, or, "Do you have parking?" Now the patient partner is asking, how many people will be at the meeting? They are worried if it is a large gathering. So, your next question is—Are you home? Is there someone home with you? Can you access Zoom? Do you have a PC or laptop? All of this is an added challenge.* — **Edeline Mitton**

Confidentiality

- Ask the patient partner not to disclose any personal identifiers or locations of medical facilities where they have been or are currently being treated.
- Ask if they prefer to use a different name instead of their real name.
- Maintain confidentially when disclosing lived experiences.
- Ask permission. Respect culture and safety issues.

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Fostering Meaningful Patient Partner Relationships

Comfort Level for Speaking

- Have the patient partner rehearse in advance to increase their comfort level (e.g., give them specifics on the audience that will be attending, setting for the meeting, whether a microphone will be used, how many people will be attending, etc.)
- Consider a panel with other persons sharing lived experiences so that the focus is not just on one patient partner.
- Prepare questions and share them in advance with the patient partner.
- Use an interview format.

Ethical Considerations

- Asking patients how they would like to be addressed, including their pronouns.
- It's important always to consider and respect the lived experience of patients. When they share their experiences, listening attentively and avoiding interruptions or comments that might invalidate their feelings is crucial. Everyone's experiences are unique and valid. It is essential to create a safe and supportive environment where patients feel heard and understood.
- Consider an interpreter as needed if the patient partner is not English-speaking. Ensure other accommodations for vision or hearing impairments (e.g., sign language, live captioning, audio/visual availability, and/or other accommodation assistance if necessary.) Ask patient partners what will be helpful to ensure they are comfortable and able to participate fully.
- Keep in mind that some patient partners may have experienced traumatic events. Trauma can affect anyone regardless of age, gender, or socioeconomic status. For example, individuals living in impoverished neighborhoods are often exposed to community-level violence and the stresses of poverty, which can lead to trauma. It is crucial to establish trust with patient partners and have access to a trauma-informed healthcare provider who can provide support and care.[21]

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Resources

- When addressing the technological needs of patients, it is crucial to prioritize their comfort level. For instance, some individuals may feel uneasy about public speaking or being in the spotlight. Moreover, due to the pandemic, some patients may prefer virtual engagement over in-person interactions. If an in-person meeting is preferred, it is essential to inquire about any dietary restrictions and accessibility requirements to ensure a seamless experience. Considering these factors, we can create a supportive and comfortable environment for the patient throughout the engagement process.
- Assure that seating is available on stage or in the presenting area, especially for elderly patient partners.
- Consider the lighting being used.
- Have audiovisual personnel available for assistance.

Equity, Diversity, and Inclusion

- Some health professionals and policymakers may believe that patients do not have enough medical knowledge to be involved in health policy decision making or in planning/delivering accredited CE activities. They may not consider them "experts by experience." Similarly, some may not believe that certain topics—like gender issues—are not important. In defense of equity, diversity, and inclusion in practice, be an advocate for the lived experience perspectives of your patient partners to ensure that their voices are recognized and valued.[24]
- Patient partners may see their involvement as an opportunity to address this potential marginalization. When they become involved in healthcare-related education, their motivation might include a desire to improve healthcare and reduce inequalities in available treatments/care for all patients and for special populations. Keep in mind that patient partners want their involvement to result in change.[24]
- It is crucial to avoid any discrimination in patient partner participation. Examples are the patients' sex, racial or ethnic origin, religion or belief, disability, age, or sexual orientation.

Fostering Meaningful Patient Partner Relationships

- Gender should definitely be considered in relation to health. Women and men should be treated equally wherever they have common needs. At the same time, their differences should be addressed in an equitable manner.[24]
- Patient partners should come from a broad range of backgrounds and represent diverse genders, expertise, socio-economic levels and cultural demographics. In addition, materials that you develop, provide, or circulate to the patient partner should be written in clear, plain language.[24,25]

Things to keep in mind: good communication, emotional support, respect, empathy, involvement in decisions, and provide clear information about CE processes.

Consider these helpful engagement principles from the Patient-Centered Outcomes Research Institute (PCORI)[25] as tenets of your collaboration with patient partners.

- **Reciprocal relationships** through collaboratively defining roles and decision-making responsibilities of all partners
- **Co-learning** through establishing a plan and budget for the education of all partners about the CE activity process, patient-centeredness, and engagement strategies
- **Partnership** through valuing the time and contributions by making realistic requests for participation and compensating the patient partner appropriately
- **Trust, Transparency, and Honesty** through promoting inclusive and transparent decision-making and open and honest communication

Battle Scale: Effective Communication

	Be sure to:
Beginner *Passive engagement scale* *Patient partner new to experience* *CE staff new to experience*	• Orient patient partners* on how to collaborate effectively. • Establish trust. • Provide the patient partner with a direct contact. • Have parking passes and expense forms ready.
Intermediate *Mixed engagement scale* *Patient partner is experienced in CE engagement* *CE staff wants to increase opportunities to engage patient partners*	• Offer a mentor for new patient partners: an experienced or past patient partner and/ or an existing committee member. • Designate one staff member to be responsible for reimbursement and all logistics for patient partners.
Advanced *Fully active engagement scale* *Patient partner is fully committed and has experience* *CE staff & institutional leaders want a full partnership with patient partners*	• Balance power relationships between committee members. Make it welcoming. • Create a list of all committee members with a brief description of each person's role/photo to increase patient partner's confidence.

*Patient Partners are inclusive of people with lived experience (PWLE), formal or informal caregivers, and family members. A patient partner can also be defined as someone who has or can communicate a patient's lived experience.

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Considering the CE Team

The CE team's role is to build relationships with all stakeholders involved in creating effective education—including the patient partner. It is important to create a culture of inclusion that makes it clear that all are welcome and valued. Integrate CE processes seamlessly into meetings, taking time to explain expectations and verify understanding. Setting up for success starts with great communication.

> "Just as you create a safe space for clinicians to learn, you can create a safe space for patient partners to participate as members of the education team.
>
> Be explicit with patients and faculty about expectations. Explain that patient partners are in charge of their own participation, are under no obligation to answer questions or participate in any way that they are uncomfortable with, and can stop at any time.
>
> Explain how time and audience questions will be managed. Faculty/planners should avoid creating a misperception that participation is obligatory, and they should check in regularly to gauge the patient's comfort level. At the same time, faculty need to share control by allowing and encouraging patients to participate."

12 Tips for Engaging Patients in CME

https://www.accme.org/publications/12-tips-for-engaging-patients-cme

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Considering the CE Team

As described earlier, the staff liaison for the patient partner has a very important role. This person should be closely involved with both the CE staff and patient partner(s) throughout the processes of their collaboration—be it planning the education, teaching or facilitation, review of curricula, or assessing impact of the education. The liaison must clearly communicate expectations and scope of the patient partner's involvement, timeline(s) for the CE activity, nature of the patient partner's role, and desired outcomes. It is important for the liaison—along with the rest of the team—to create a safe space for the patient partner that is built on trust and authenticity.

Many of our patient partners have never contributed to the planning or delivery of CE content and often have no idea what to expect. While our organization does not allow patient partners to serve as members on our CE planning committees, we invite them to engage as content experts. Patient partners are invited to our faculty planning calls. Over the years, we have recognized the importance of tailoring our communication with patient partners with a softer and more personalized tone. We want to ensure our patient partners feel part of the planning team and that their voice and experience matters. We make sure we clearly communicate the timeline, expectations, and deliverables through every step of the planning process and are mindful of regular check-ins in case any questions or concerns arise along the way. Fostering a relationship with patient partners has certainly helped in the planning process. — **Cristina Graham**

CE Activity Timeline

Plan in advance when considering involving patients as partners in the CE activity. Advise them of the schedule so it does not conflict with their medical appointments or other personal/professional commitments they may have. Map out their role and timeline of meetings, deliverables, and presentations. Explore with them the possibility of how the lived experience can complement evidence-based education.[26]

Many discharged patients we have asked to partner with us cannot make our planning committee time, so we have accommodated their input using other approaches. Together with our Patient Advocate—our patient partner liaison—a group of us met separately with the patient partner. We discussed program goals, objectives, and their role in the small meeting. We let them know that their voice needed to be heard.

We accommodated the patient partner because they could not attend an 8:00 AM planning meeting. The subset of planning meetings was the best way. We took the patient's voice back to the planning committee; in that way, we were still able to capture and share their views. We shared what piece of the planning was needed, understanding their role, and made them feel more comfortable. This can also be a way to make that patient's voice heard without them feeling intimidated, even recording the smaller meeting and taking it to the larger planning group. — **Sandie Coleman**

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Considering the CE Team

Administrative Challenges

Legal/Disclosure

In some institutions, the decision to include patient partners does not need legal approval. However, that may not be the case for all organizations. Ensure the protection of the patient partner and your institution by identifying any legal or disclosure requirements that exist within your organization. Once a policy has been identified, the CE team should outline any terms and expectations to ensure adherence to their organization's policies. For example, your institution may require that an application for exemption be submitted to its Institutional Review Board (IRB) that oversees (and protects) the role of patients as research subjects.

All accredited CE requires that information regarding financial relationships with industry (i.e., ineligible companies) is disclosed by anyone—including patient partners—who may have a role in controlling the content of education. The CE staff members who are responsible for obtaining this information should clearly communicate with patient partners the purpose of this disclosure and explain how the information will be used. It would also be helpful for CE staff to help patient partners understand other expectations of the *Standards for Integrity and Independence of Accredited CE*™ to ensure they can be partners in creating a safe space for health professional learners.

For More Information:

Educate patient partners about the Standards by using tools like the Planning Guide for Independence in Accredited Continuing Education.

Considering the CE Team

Speaker Agreement/Compensation

Recruitment, remuneration, and recognition of patient partners is essential. How your organization chooses to address compensation is part of the recruitment process. Some issues may arise depending on the CE activity and the role expectations for the patient partner. For example, some patient partners may see payment as a source of "employment" that would restrict their role in other endeavors, or freedom of opinion; others may feel that their time needs to be compensated. It is up to your organization to develop guidelines and address this issue at the forefront.[20, 28]

Patient partners bring invaluable perspectives, unique insights, and lived experiences that significantly enhance the quality and relevance of continuing education programs. The patient partner recruitment process is designed to identify individuals who are willing to share their experience, are interested in improving patient care, and reflect the diversity of patient population in your community. The CE provider should also assess the patient partner's skills and experiences to ensure the role aligns with their strengths and interests.

Recognizing patient partners' time commitment and expertise in our education initiatives by providing fair remuneration for their efforts and contributions is important. In addition to financial compensation, you should recognize and appreciate patient partners. This may include public acknowledgment, certificates of appreciation, or other forms of recognition.

The motivations of recruited patient partners as teachers and planners can vary widely between programs. Some patients can receive remuneration as a course-based fee whereas others can receive an hourly rate.[21] Remuneration can also be a matter of reimbursing transportation and other expenses incurred during their engagement.

Considering the CE Team

Obtain Appropriate Permission

Once the patient partner has agreed to engage in the educational initiative, consider developing a written agreement with the patient partner. Seek appropriate guidance from institutional policies and practices concerning the protection of confidential and private information when including patient partners in accredited CE. For example, the Health Insurance and Portability and Accountability Act (HIPAA) does not prohibit the use of patients as faculty, planners, or learners in CE if they have given their permission. Consider how to ensure that patient partners understand—and agree to participate—if the education will broadcast the patient's identifiable images or information beyond the institution and/or engage learners who are not healthcare professionals.[28]

Furthermore, it should be noted that the Joint Commission is supportive of both patient and family engagement and of partnering with patients and families in health care redesign and improvement (e.g., patient and family advisory councils) to achieve quality and safety goals.[28]

Before patient engagement, all CE staff should:

- Check with their institution or organization's marketing, risk management, and/or research (i.e., IRB) department policies.
- Request the patient partner's permission to include them in the CE activity.
- Obtain their consent to use the patient partner's unique insights and lived experiences in the CE activity.
- Have a conversation with the patient partner to ask their preference regarding using their actual name versus an alias (both first and last name).
- Have a conversation with the patient partner about not disclosing information such as their healthcare provider's name, location of treatment and other information that might be confidential.

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Considering the CE Team

Participation in Governance

Witnessing patients and their families actively participating in quality improvement workgroups, continuing education activities, patient safety task forces, and patient and family advisory councils (PFACs) is very strategic. Such inclusive practices promote positive patient outcomes and excellent patient- and family-centered care delivery. Insights from these interactions can also help hospital systems in reducing readmission rates, addressing medical errors, and enhancing overall quality and safety standards. Healthcare providers benefit by involving patients and families in decision-making to achieve optimal healthcare outcomes. As discussed previously, privacy issues should always be taken into consideration when including patient partners.[28] The **Governance/Administrative Battle Scale** illustrates some of the issues that CE providers can take into consideration when involving patient partners in these roles.

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Battle Scale: Governance/Administrative

Beginner *Passive engagement scale* *Patient partner new to experience* *CE staff new to experience*	• Advise patient partners* of basic rights to privacy (e.g., Health Insurance Portability and Accountability Act [HIPPA]). • Provide guidelines to establish clear expectations. • Set boundaries regarding the handling of confidential information and how it can be shared. • Educate patient parners on Conflict of Interest policies.
Intermediate *Mixed engagement scale* *Patient partner is experienced in CE engagement* *CE staff wants to increase opportunities to engage patient partners*	• De-identify sensitive data by complying with HIPAA's "minimum necessary" standard for specific activities like quality improvement. • Consider using an abridged HIPAA training to teach patient partners.
Advanced *Fully active engagement scale* *Patient partner is fully committed and has experience* *CE staff & institutional leaders want a full partnership with patient partners*	• Consider vetting the backgrounds of patient partners to mitigate risks when involved in a full scale level. • Demonstrate a commitment to transparency and accountability, which can help build trust and confidence among patient partners.

*Patient Partners are inclusive of people with lived experience (PWLE), formal or informal caregivers, and family members. A patient partner can also be defined as someone who has or can communicate a patient's lived experience.

Considering the CE Team

Governance in CE is an opportunity to engage patient partners in educational leadership beyond the planning and delivery of education activities. The CE team should consider conducting basic HIPAA training for patient partners to provide an overview of the privacy and security of sensitive patient healthcare information. By educating patient partners on the HIPAA privacy and security rules, they can better understand their role in ensuring adherence to these rules and protecting private information. With proper training, patient partners can be powerful allies in maintaining HIPAA compliance and safeguarding patient privacy.

Additionally, if an organization intends to involve patient partners in ongoing task forces, committees, councils, and boards, their competence with these issues may be required. Consult with one's organization to identify any potential red flags, such as criminal background, professional licensure issues, or conflicts of interest that could compromise the integrity of the patient partners' roles in governance or administrative work. Your organization's legal department should be consulted and able to provide guidance.

Consider requiring all patient partners to sign a confidentiality agreement, or other non-disclosure agreement, as a critical step in protecting patient privacy and other proprietary information. This statement should outline the advisor's responsibilities regarding confidentiality, including what information is considered confidential and how it should be handled. It should also include consequences for violating confidentiality, including termination of their advisory role.[28]

Sample wording: *"As a non-employed committee member, you may have access to protected health information. It is important that you recognize that any protected health information can only be used and disclosed as permitted by law. This information cannot be shared by written, verbal, or e-mail communication at school or home; with friends or family; or outside the hospital, clinic, or other health care facility unless specifically permitted by law."*

National Partnership for Women & Families Fact Sheet: HIPAA Privacy And Security Rules. https://www.ipfcc.org/bestpractices/HIPAA-Factsheet.pdf

Lessons Learned/Challenges

At the partnership's end, closing the loop is an important part of managing relationships with patient partners. Articulating and sharing appreciation of the relationship, summative and formative evaluation of the impact of the engagement, and providing feedback to stakeholders is a good approach bring the CE collaboration to closure.[31]

Exploring the outcomes of the collaboration allows communication of the value of engaging with patient partners.[32] Gathering this type data is essential and can be accomplished in several ways.

Reflection/Formative Evaluation

Foster a culture where patient voices are not only heard but also shape the educational landscape in CE. The insights gained through patient partner evaluations will inform adjustments or improvements to future CE activities, ultimately leading to more impactful patient-centered educational experiences.

Coming from the pediatric world, we do talk to the parents and caregivers as well as the patient, if age appropriate, ahead of time on what they are planning to talk about and what questions could come up during the meeting. We have 2 or 3 questions that go into our evaluation. If we have a patient panel or patient partners involved, we say, "The course you took or the course you engaged with incorporated patients with lived experience perspectives. Please answer the following questions. "How did the incorporation of the patient's experience impact your learning experience?" "Would like to see more patient/lived experience involvement in future educational activities?" And then we ask our learners for open-ended feedback regarding the patient partner, as well. We find these questions very helpful. — **Victoria Cunningham**

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Lessons Learned/Challenges

Sample Questions to Ask Patient Partners

- Do you feel prepared to partner with the CE Team?
- Do you feel supported by the team to speak up?
- Did the team listen to and take your perspective and ideas seriously?
- Do you feel your contributions were valued by the team?
- Was the team willing to make changes based on your input?
- Do you believe the CE activity was improved because of your participation?
- Do you feel that you participated in this CE activity to the best of your ability?
- Would you partner with the team in the future?
- How detailed, complete, and easy to understand was the background information provided to you?
- Do you feel you had enough of the right information to take part in the discussion?
- Overall, how is your experience as a patient partner?
- How could your experience as a patient partner be improved?
- What would you do differently next time?
- Overall, how satisfied are you that your opinions were heard and understood?
- Overall, how confident are you that your contributions will influence the final educational activity or initiative?
- How satisfied are you with the outcome?
- Overall, how satisfied are you about your role in planning and decision making for the activity/initiative?
- How satisfied are you with the way in which the CE staff recognized your role and contributions? To what degree do you feel you were fairly compensated for your effort as a patient partner?
- Any additional comments?

Lessons Learned/Challenges

Sample Questions to Ask Stakeholders and Other Participants

- How many patient partners participated in the engagement activity?
- Were the right patients and family members/caregivers, including hard-to-reach populations, at the table?
- Did you use any incentives to encourage participation? If so, what incentives did you use?
- Was staff time within estimates?
- Were engagement costs within budget?
- Did patient partner engagement contribute to the CE activity? If so, explain how. If not, explain why.
- Were planning decisions and their rationale(s) communicated to patient partners?
- Was input from the patient partner(s) included in the planning decision-making processes?
- Were organizational goals for engaging patients, families, and care givers achieved? If not, why not?
- What would you do differently next time?
- Did patient partners' perspectives align with learning objectives and contribute to the overall learning experience? If not, why not?

Adapted from: Capital Health. Engagement Framework and Toolkit. Capital Health. 2011.

Lessons Learned/Challenges

Use Videos, Observation Notes, and Debrief Meetings to Gather Data and Perspectives on the Partnership Collaboration

> *You know, sometimes the patient partner's experiences are traumatic or for other reasons they are not comfortable sharing. They can also share written experiences. The department sometimes hires actors to act it out or have one of our providers do it even. We have some courses where we use actors to portray child maltreatment and neglect cases.*
>
> *In our case conferences, we typically use an actor as the caregiver in those scenarios, and they are given a script from an actual patient or caregiver that they are acting out. There needs to be a dialogue with the patient ahead of time about their experiences. We discuss their reflection of their experience, and then the paid actor or actress is enacting the situation during the lecture. After the presentation, the patient partner will then explain what would have been helpful if they had more guidance on this or that. It's a little bit different with kids, but that has been our experience so far.*
>
> *The actor is giving you reflective feedback based on what the patient said and their experience while the healthcare providers in the room are the learners. If the learners ask a question that the actor does not know how to answer, that can take them out of the experience a little bit. But, getting continuous feedback from actors and patients on what information would be helpful to know is one way of doing a reflective debriefing.*
>
> — Victoria Cunningham

Avoiding Pitfalls

Engaging patient partners requires careful consideration to avoid potential pitfalls. Here are a few strategies to help minimize challenges:

- Communication - Listen to them; use proper language.
- Provide opportunities for skill-building and development; do they need Zoom lessons or have stage fright? Do they speak a foreign language?
- Support them with briefings and information.
- Respond to their contributions (you may need to do this before and after each meeting).
- Avoid too much bureaucracy and administrative burden. Assist with forms and other necessary documents.
- Be willing to learn from others' experiences.
- Be willing to change—and make changes—in response to what you have learned.

Take a look at the **Success Battle Scale** to ensure a wonderful experience for all.

Battle Scale: Your Patient Partnering Success

Beginner *Passive engagement scale* *Patient partner new to experience* *CE staff new to experience*	• Prepare patient partners* on how to collaborate effectively. • Solicit, process, integrate, and apply patient partners input. • Emphasize the value and contributions of patient partners on the team – share examples!
Intermediate *Mixed engagement scale* *Patient partner is experienced in CE engagement* *CE staff wants to increase opportunities to engage patient partners*	• Identify a liaison to support patient partners and answer questions. • Teach patient partners basic CE concepts such as Institutional Review Board (IRB), consent, conflict of interest policies, and Plan-Do-Study-Act (PDSA) cycles. • Celebrate your collaboration and the improved processes and results with patient partners.
Advanced *Fully active engagement scale* *Patient partner is fully committed and has experience* *CE staff & institutional leaders want a full partnership with patient partners*	• Welcome patient partner input in all phases of the activity, including planning, meeting other faculties, data analysis, presentation, and outcome processes. • After completing the CE activity, include patient partners in the debriefing and evaluation summation.[8]

*Patient Partners are inclusive of people with lived experience (PWLE), formal or informal caregivers, and family members. A patient partner can also be defined as someone who has or can communicate a patient's lived experience.

Your Patient Partnering Success Battle Scale

> *At our institution, we do not have many patients on our CE planning committee, but we do have them at our most important meeting, which is a breast cancer symposium. And it is one of the biggest in the world. We have two patient partners on the committee. I have come to learn that there's a little bit of reluctance from the patient partners to speak up because they are sitting in a group of 50 experts from all over the world. It is like CME staff, these patients, and then all the experts. I do not think we really have a debrief with any of them, but we probably should. In all these years that we've done this, there is always the one patient advocate that is very experienced with the science. That person is usually the more vocal one. However, the other patients lack that insight and they do not speak up.*
>
> *It takes a lot for someone to speak up, and I get it. I am intimidated, too, as the CME Director. I think we need debriefing… really sitting with them to see how they feel, and that is one of our pitfalls. We have not given them clear direction; therefore, the stronger personality is usually the one that will speak up or get more engaged in the science.*
>
> —Leticia Bresnahan

We hope you find this Roadmap useful. Regardless of whom you are engaging, patient partners, caregivers, communities, or public representatives, for engagement to succeed, remember to:

● **STOP**

Ask and consider questions before you proceed; Consult your institution/organization's policies.

● **LOOK**

Check out best practices/tips/guidelines.

● **LISTEN**

Hear about examples of lived experience from others.

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Resources

- Agency for Healthcare Research and Quality (AHRQ) - Working with Patients as Advisors - Working with Patients & Families as Advisors (Implementation Handbook) (ahrq.gov)
- Patient and Family Centered Care – www.pfccpartners.com
- Patient-Centered Outcomes Research Institute - https://www.pcori.org/engagement/value-engagement
- Ontario Patient Engagement Framework - https://www.hqontario.ca/Portals/0/documents/pe/ontario-patient-engagement-framework-en.pdf
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- Patient and Family Engaged Care: An Essential Element of Health Equity - https://nam.edu/patient-and-family-engaged-care-an-essential-element-of-health-equity/
- Evaluating Research Partnerships: Key Questions to Ask - https://ipfcc.org/bestpractices/sustainable-partnerships/tools/IPFCC_Evaluating_Research_Partnerships.pdf
- Closing-the-Loop-Template-Example.pdf - https://patientvoicesbc.ca/wp-content/uploads/2022/02/Closing-the-Loop-Template-Example.pdf

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