



## Role Opportunities for PWLE on Research Projects

When we talk about involving people with lived experience (PWLE) in research, it's important to move beyond just asking them to "review". There are a wide range of roles PWLE can play across the research cycle, and the more diverse and flexible these roles are, the more meaningful the involvement becomes.

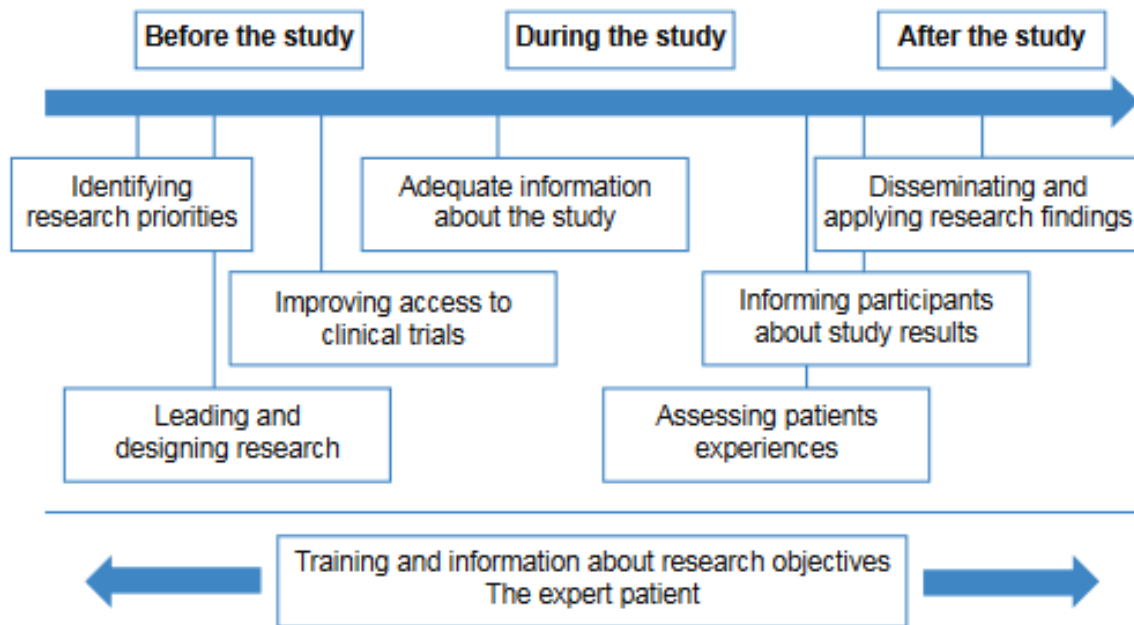
Here are just a few examples:

- **Co-designers of the research process** – This might involve collaborating from the very beginning: shaping the research question, choosing methods, and determining how findings will be used. This kind of partnership aligns with approaches like community-based participatory research (CBPR), which centers equity and shared ownership.
- **Program evaluators** – PWLE can offer critical insight into whether interventions are working in real-world settings, and why. Their perspectives can identify blind spots and generate more practical, people-centered evaluation criteria.
- **Consultants** – In this role, PWLE may provide feedback or guidance at different stages of a project, drawing from personal or community experience to help refine approaches or anticipate ethical and practical concerns.
- **Service and program delivery** – In applied research settings, PWLE might be directly involved in implementing interventions or programs, which allows for rich feedback loops and real-time adaptation.
- **Feedback providers** – This could mean reviewing recruitment materials, consent forms, or data collection tools to ensure they're accessible, respectful, and relevant.
- **Co-authors of manuscripts** – Lived experience perspectives are increasingly being recognized as essential contributions to academic publications. Co-authoring is a tangible way to value this expertise.
- **Advocacy or advisory group members** – Whether through formal boards or informal networks, PWLE can support decision-making, offer accountability, and help ensure that projects are grounded in the realities of the communities they aim to serve. WE-SPARK is proud to have a group of PWLE serving on a lived experience advisory board for exactly these reasons.

The ideal scenario is to create diverse opportunities for involvement, offering different levels of responsibility and time commitment, so people can engage in ways that are meaningful to them. The key is flexibility, clarity, and a shared understanding of what each role involves. Ultimately, integrating PWLE across multiple roles enhances research relevance, credibility, and impact.

## When to Involve PWLE

This diagram outlines the involvement of PWLE throughout the research process, emphasizing the value of their contributions before, during, and after a study. Patient involvement should start early, shaping the research from the ground up. Furthermore, by providing education, PWLE become research partners rather than passive subjects, equipped to engage meaningfully at every stage.



## How to Involve PWLE

The following diagram is a continuum of engagement with PWLE, ranging from the least desirable form of involvement to the most meaningful and impactful. Aim for involving the members of the database assigned to your project on the green side of the continuum!

