

Compensating People with Lived Experience: Co-designing options that work



An organizational guide to respectful,
flexible compensation practices



People with lived experience (PWLE) contribute critical insight to the work of transforming healthcare systems. They know what works, what’s not working, what’s missing, and what really makes a difference because they’ve lived it. When organizations invite PWLE to participate as co-designers, advisors, reviewers, storytellers, or co-designers, they’re investing in better care, access, equity, and outcomes.

Like other professionals working to improve organizations’ processes, policies, products and services, **PWLE should be compensated for their expertise and time.**

Fair, flexible compensation goes beyond paying people. Compensation acknowledges the value of PWLE contributions and makes the work of system change more respectful and authentic.

CACP’s Approach: Grounded in practice, informed by community

The Center to Advance Consumer Partnership (CACP) team has had the privilege of partnering with PWLE, co-designing engagement practices and building health care infrastructures for more than two decades. This guide reflects the insights we have gained through ongoing consultation with our national PWLE Advisory Council and our experience in authentic consumer partnership with clients and project partners across states, health plans, and systems of care.

Drawing on insights from CACP’s PWLE Advisory Council, this guide provides a framework for designing compensation practices that are respectful, flexible, and rooted in equity and is intended for health care organizations who seek to engage PWLE in co-design, decision-making, and systems improvement work.

Navigating Complexities for Real Impact

Conventional payment practices can unintentionally limit participation from PWLE, particularly those navigating public benefits systems or other logistical barriers such as transportation, mobility, or childcare. These individuals bring highly relevant, firsthand expertise that enhance organizational planning and outcomes. Thoughtful, flexible compensation practices that keep these complexities from becoming prohibitive will make it possible to include the full range of perspectives needed to design solutions that truly work for the people your mission serves.

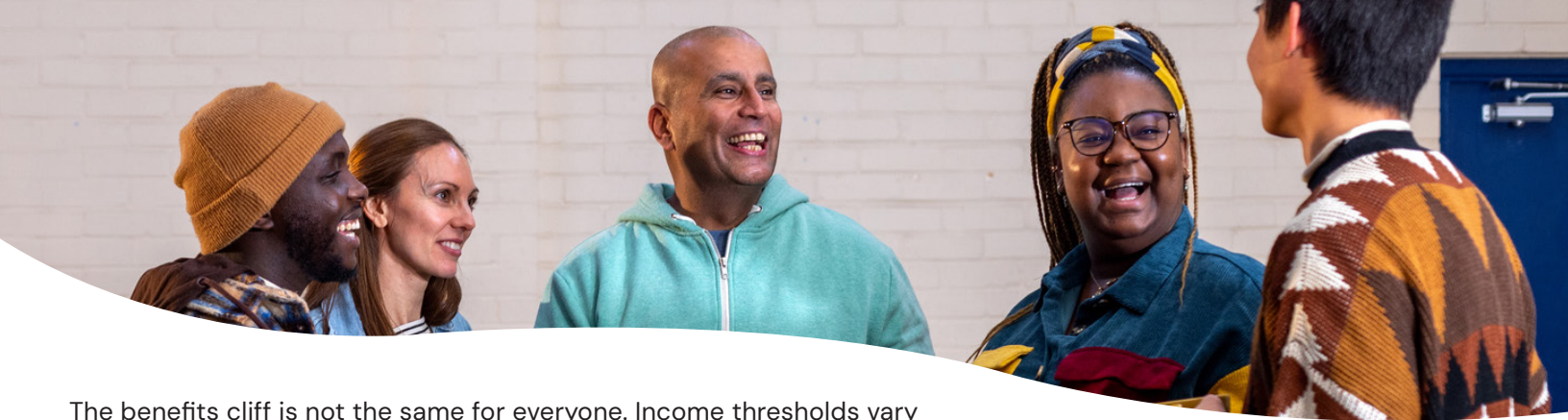
The Benefits Cliff

Many PWLE who contribute their expertise to health care improvement efforts may rely on federal and/or state benefit programs to manage complex health, caregiving, or financial needs. These benefits are tied to strict income and asset limits. Even modest additional income from participation can unintentionally reduce monthly support or result in a loss of eligibility; a situation known as the *benefits cliff*.



Examples of federal or state benefits tied to income thresholds:

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| • Medicaid | • Childcare subsidies |
| • Supplemental Security Income (SSI) | • Public housing support |
| • SNAP (food stamps) | • Health insurance subsidies |
| • TANF (cash assistance) | |



The benefits cliff is not the same for everyone. Income thresholds vary by state, by program, and by an individual's family and financial circumstances. This makes it challenging for participants to assess the impact of compensation on their benefits.

Offering a range of flexible compensation options and, when possible, guidance or referrals to resources that can help participants understand their specific situation, can make it safer and more feasible for PWLE to share their expertise without risking essential support.

Accessibility Matters

Just as compensation requires thoughtful flexibility, organizations must also anticipate and plan for a wide range of accessibility needs participants may have. From mobility supports like wheelchair-accessible meeting spaces, to assistive technologies for low vision or hearing, to options that make participation possible for those who cannot easily leave their homes, thoughtful planning ensures every contributor can fully participate.

The simplest way to get it right is to ask in advance about accommodations and then follow through. Doing so signals respect, and makes it possible for all voices to be heard.

- For in-person sessions, ensure meeting spaces are ADA compliant and fully accessible
- For virtual engagement, provide online tools (e.g., transcripts, closed captions, recordings, screen readers, translators) and other accommodation needed to support participation

"No one's time is free."

– CACP PWLE Advisory Council Member

Remove the Cost Barrier

Organizations should ensure that PWLE never have to spend their own resources to participate. Cover all reasonable out-of-pocket expenses directly, such as transportation, mileage, lodging, meals, or childcare, so that cost doesn't get in the way of including the people you need to listen to most. These reimbursements make participation possible for many and should be treated as covered expenses, not income, and therefore never reported as such.

KEY ACTION:

Consider consulting with outside experts on accessibility and public benefit eligibility requirements when developing your compensation practices. They can be a resource for you and the PWLE you seek to engage.

Compensating PWLE with Purpose and Fairness

Flexibility Matters

Flexibility and co-design must be part of your compensation model before you begin. Respectful engagement means respecting how people can and want to receive value for their expertise and time.

Rigid compensation models overlook the day-to-day realities of disability, caregiving, trauma recovery, public benefit programs, and income insecurity. When compensation isn't designed with these realities in mind, participation can become untenable, unsafe or impossible.

Compensation Can Take Different Forms

Financial payment for an individual's time, expertise, and lived experience can come in the form of stipends, wages, honoraria, or gift cards.

Tangible, non-financial items that an individual finds valuable or helpful, may include:

- Training or skill development, e.g., public speaking, conflict resolution, facilitation skills
- Access to computer, phone, printer, headset, or other hardware that facilitates participation
- Business cards or professional digital headshots
- Broadband subsidies, Wi-Fi, personal hotspot, Zoom account, other software platforms, cellular phone minutes
- Journal subscriptions or online articles, event registration fees, or membership dues to professional associations
- Wellness services for individual goals, (e.g., Headspace or Calm app membership, art classes, or fitness membership)

"Swag is nice, but it's not compensation. It's advertising for your organization."

– CACP PWLE Advisory Council Member

KEY ACTION:

Work together with PWLE to create a menu of compensation options. This ensures compensation that avoids assumptions, meets the needs of PWLE, and can be consistently implemented by the organization.



Steps Your Organization Can Take

Whether your organization is just beginning to compensate PWLE or looking to evolve your current approach, here's what we recommend:

- 1 | Start with respect and ask first.**
Don't assume what's helpful. Invite PWLE to co-design compensation approaches that reflect their needs, goals, and circumstances. Respect is the baseline and **choice is the goal**.
- 2 | Offer a flexible menu of options.**
Compensation isn't always about money, and it's never one-size-fits-all. Offer a range of financial and non-financial options and allow flexibility month to month, knowing that a person's capacity to contribute may shift based on income thresholds, health, or life events.
- 3 | Communicate clearly and early.**
Be upfront about what your organization can offer. Explain the process, payment timing, and any constraints. Be open to exploring options you may not have considered. Transparent communication builds trust and supports informed decision-making.
- 4 | Be mindful and trauma-sensitive.**
Conversations about income, benefits, or personal circumstances can stir up emotions, especially when tied to pride, privacy, or past experiences with systems. Approach these discussions with care and never require disclosure of public benefit status.
- 5 | Support informed choices.**
Maintain a list of local community organizations, advocacy organizations, navigators, benefits counselors, case managers, social workers, etc. who can help PWLE ascertain the potential impact of compensation and make the decision that's right for them.
- 6 | Close the Loop**
When organizations share back how PWLE input has shaped decisions, improved services, or led to new initiatives, it reinforces trust and demonstrates respect. Closing the loop isn't just good practice, it's a powerful way to show PWLE that their expertise made a difference. This helps people see the value of their participation, strengthens relationships, and builds momentum for future collaboration.

KEY ACTION:

Clearly communicate your compensation practices with PWLE when asking for their participation to answer questions such as:

- Will I be paid hourly or a stipend, and how often?
- What form will payment take (e.g., check, gift card, direct deposit)?
- What non-financial compensation options are available?
- What resources or reimbursement do you offer for participation (e.g. transportation, translation services, childcare)?

In Closing

Considerate compensation makes your engagement with PWLE stronger while reinforcing trust and partnership. When compensation is flexible, thoughtful, and co-designed, more voices can be heard, trust can grow, and your work is better aligned with the communities you serve.

We hope you have found this guide useful and as you consider your compensation practices, remember to consider every aspect of the engagement carefully.

This guide was co-designed with CACP's PWLE Advisory Council and reflects their lived experience navigating compensation and engagement. We are grateful for their decades of insight, leadership, and commitment to improving health care systems for everyone.

About CACP

CACP is a nonprofit working to improve the health care system by working directly with health sector organizations around the country, helping them realize the value of every voice and put the voices of people with lived experience at the heart of strategy and operations.

We know people with lived experience belong where decisions are made. We envision a health care system that recognizes and values the lived experiences of individuals with complex health and social needs, fosters deep collaboration between experts by experience and experts by training, and builds trust while sharing power to co-design solutions that improve outcomes, enhance experiences, and manage costs.

CACP is here to help your team co-design compensation strategies that are effective, compliant, and rooted in respect.

Contact us to learn more or to schedule a consultation. www.consumerpartnership.org

