



Partnering with People with Lived Experience in Research

A Standard of Compensation

for Investigators
2024

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Portions of this document are adapted from "Budgeting for Involvement," Simons, L., Kabir, T., & Cartwright, J. (2013) with permission from the United Kingdom National Institute for Health Research.



About this Resource

Engaging youth, families, and patients as full partners in the research process makes research better. The recommendations outlined in this document are designed to provide guidance to investigators in how to identify, orient, and support youth, family, and patient partners on a research team. This guide provides advice on budgeting and compensating youth, family, and patient partners who work on research studies. Using this standard as a guide will help you create a realistic budget for potential funders and for your research team. This guide will also help you justify your costs and decide when costs will be incurred.

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Background: The role of Youth, Families, and Patients in Research

The role of people with lived experience in research has been expanding but defining strategies for compensating for this role has lagged behind their degree of participation.¹ Building on the philosophy of patient- and family-centered care, research teams and funders are recognizing the pivotal role of youth, families, patients, and community leaders in making medical decisions. Through partnering with people with lived experience, research teams acknowledge their expertise as valuable resources in the program and system design, policy, evaluation, and implementation of research.²⁻⁴

Involving people with lived experience as partners in research studies is a concept that has been promoted by family and community organizations, funders like the Patient-Centered Outcomes Research Institute (PCORI), and federal agencies like the Health Resources and Services Administration's Maternal and Child Health Bureau.⁵ Organizations such as these have determined that involving youth, families, and patients in research studies as partners makes the research more meaningful to all

stakeholders and improves the quality of the end product⁶. Furthermore, many funders now require that youth, families, and patients participate in the planning and execution of research projects.^{7,8}

“Making patients and their families truly the force that drives everything else in health care is perhaps the most revolutionary tool of all.”^{9(pxxii)}

Youth, families, and patients bring their own lived experience, which is invaluable for designing health-related research that is meaningful for them, contributing interpretation of the results, and putting the findings of such research into practice. Youth, families, and patients can bring a perspective that health care providers may not have; the perspective of someone very close to the health care system, but not constrained by the traditions of the system. They are experts in navigating a complex health care delivery system: they know how the system works versus how it was designed to work

This Guide

Recognizing that people with lived experience bring different skill sets and interests to a project,¹⁰ this guide provides assistance to investigators who work with youth, families, and patients on research initiatives and outlines fair compensation for their work. Whether working as co-Principal Investigators (co-PIs), in an advisory capacity, or at a research assistant level, youth, family, and patient partners should be compensated commensurate with their roles, responsibilities, and expertise.

Many funders are prioritizing projects that include lived experience partners in various roles including advisory boards, consultants, partners, co-investigators, and even staff.⁵ While more researchers are recognizing the value of working with people with lived experience, little concrete guidance indicates strategies for compensating them^{11,12}.

We recommend that all research projects employ two or more lived-experience partners.

People with lived experience play many roles in research and need to be compensated appropriately for their time and expertise. Rather than a “one size fits all” payment of gift cards or bus fare, lived experience partners should be compensated commensurate with their level of responsibility, time spent on the project, and contribution to the project.^{10,13,14} Unique circumstances for each research partner requires the Principal Investigator (PI) be thoughtful about the method and timing of compensation.¹³

For example, additional income may hurt a family’s eligibility for Medicaid or other financial programs that provide critical supports and services to the patient and family. *It is important to have a discussion with lived-experience partners about any financial constraints prior to the beginning of a project so that these circumstances can be addressed.*

In this guide we address specifics of compensation and include recommendations in Section 3.

1. Introduction: The Compensation Guide

1.1 Who Is This Compensation Guide For?

This guide is of particular use for

- Researchers
- Youth, family, patients, and community partners
- Funders
- Evaluators
- Grant Reviewers

1.2 Aims of the Compensation Guide

This guide provides practical advice on budgeting and payment for lived experience partners who work on research projects in any capacity and assists in budgeting at any stage of a research project. This guide does not include recommendations on compensation for study participants such as interviewees.

This Guide:

Explains levels of participation of youth, family, and patient partners in research projects	Suggests ways to work with outside organizations such as community-based groups who can be effective partners in recruiting and supporting youth, family, and patient partners (see Appendix A for a list of some community-based organizations).	Presents a sample budget
Presents a process for planning, identifying costs, and considering where in the research process costs might be incurred		Outlines some specific costs associated with engagement in research projects, including payments to youth, family, and patient partners and caregivers for their skills, time, and expertise as research personnel;

1.3 What is “Active Engagement” in Research?

Active engagement by people with lived experience is defined as “research being carried out *with* or *by* people with lived experience rather than *to, for, or about* them – “nothing about us without us”.¹⁵ This includes, for example, people with lived experience working with funders to prioritize and design research projects, providing advice about or actively recruiting participants, helping to develop materials, carrying out aspects of research such as conducting interviews with study participants, among other activities.

Lived experience partners can include:

- Patients and potential patients;
- People who provide care or support to patients on an informal basis;
- Parents or guardians of patients;
- Adults with health conditions beginning in childhood;
- Individuals who may be targeted by public health or health promotion initiatives;
- Community-based organizations and advocacy groups led and staffed by patients and their families.



Taking part in a research study as a study participant is not “active engagement”. It is important to separate costs for these kinds of research activities, such as participating in focus groups or completing surveys, from costs for actively involving people with lived experience in the research process. This guide does not describe costs associated with carrying out the research protocol or compensating research study participants, but only remuneration for people with lived experience who work on the research team as active partners.

Active Engagement means a partnership between people with lived experience and researchers in every aspect of the research process, rather than just participation of people as subjects of research. Active engagement may include:

- Partnering in the designing, writing, and reviewing of a research proposal;
- Participating in meetings about research at every stage;
- Preparing for meetings and other activities by reading relevant documents;
- Participating in training events, receiving support and mentoring around research terms and processes;
- Interviewing participants or leading a focus group;
- Co-production of reports, articles, and other dissemination materials;
- Presenting research findings at a conference;
- Sharing findings with patients and their families.

1.4 Increasing Engagement of Diverse People with Lived Experience

It is important that lived experience partners are representative of the populations being studied. Diversity does not mean only racial and ethnic diversity, but also diversity in socioeconomic status, education, geography, rural/urban, culture, nationality, language, religion, and other aspects of the human condition.¹⁶ Reaching out to individuals from diverse backgrounds will bring a richness of perspectives to your study. Working with a community organization can be helpful in recruiting diverse people with lived experience.

1.5 Levels of Lived Experience Partners' Participation and Compensation in Research

The chart on the following page provides guidance on the levels of participation for youth, family, and patient partners in research. Compensation should be flexible enough to consider each lived experience partner's circumstances, the amount of money available within a budget, expertise of youth, family, and patient partners, and the specific roles requested of the youth, family, and patient partners. Youth, family, and patient partners serving in identical roles (for example, serving on a committee) should receive identical compensation.

Variations required by a particular individual's circumstances should be discussed with and approved by the research team, both to promote transparency and to consider any extenuating circumstances that may deter people with lived experience from partnering fully in the study.



EXAMPLE LEVELS OF PARTICIPATION IN RESEARCH		
Category of Participation	Expectations	Type/Method of Compensation
On-going and consistent team member	<ul style="list-style-type: none"> • Lived experience partners have an on-going relationship with the project, but are not employees of the organization. • Having an “on-going relationship” means that s/he is participating on a regular basis, which may include attending regular meetings, engaging in scheduled tasks such as survey development, data collection, participant recruitment, and others. • Partners may work on an hourly basis or on contract and may require a 1099 form, scope of work, or other documentation for the organization. 	A contract is appropriate, based on an hourly rate or on a per-job basis.
Advisor	<ul style="list-style-type: none"> • Lived experience partner has time-limited contact with the project, for example, reviewing survey questions, wording of documents, transcribing or translating a document, conducting key informant interviews, participating in one-time or periodic Advisory Committee meetings. • Partner acts as a facilitator or co-facilitator of a focus group. • Partners may be part of a group of individuals serving in similar roles, such as on an Advisory Committee. In this case, compensation should be consistent for all members of the group doing the same job. 	A stipend is appropriate.
Speaker	<ul style="list-style-type: none"> • People with lived experience invited to speak at a national or local conference or meeting and assist with dissemination of material related to the research project. 	A stipend or honorarium is appropriate
Staff	<ul style="list-style-type: none"> • Lived experience partner who is hired to work on tasks that are a core function of a project and is a regular employee of the organization, even if the employment is temporary in nature. • Role may focus on family outreach (recruiting, interviewing, direct family contact). • Performs functions commensurate with expertise, but brings the perspective of lived experience – this could be at any level from research assistant to PI. • Can facilitate relationships with external lived experience partners, but does not replace the role of external lived experience partners. • Expect this role to be on-going throughout the project. 	A paycheck is appropriate.

2. Budgeting

Planning the budget for engaging people with lived experience in a research project involves estimating study costs to create a realistic budget. Many funders such as the Patient-Centered Outcomes Research Institute (PCORI), Health Resources and Services Administration's Maternal and Child Health Bureau (MCHB), and others will encourage or require stakeholder engagement as members of the research team.



The importance of planning a budget that includes people with lived experience early in budget development cannot be overstated because it demonstrates your commitment to the principles of engagement, and ensures that funds will be available to compensate your partners. Once a grant has been approved, it is difficult to obtain further funding for lived experience partners if funding was not built into the original application.

2.1 Costs Incurred Prior to Funding your Study

If you need to cover costs that are incurred before your study is funded, your university department or community-based organizations may be able to allocate funds for this. You should think about what funds are necessary prior to funding and try to plan to either have funds available or minimize expenses that your lived experience partners will incur ahead of funding. You should also check with your funding agency to make sure that you understand any restrictions on expenses incurred prior to funding.

2.2 Getting Started with Budgeting

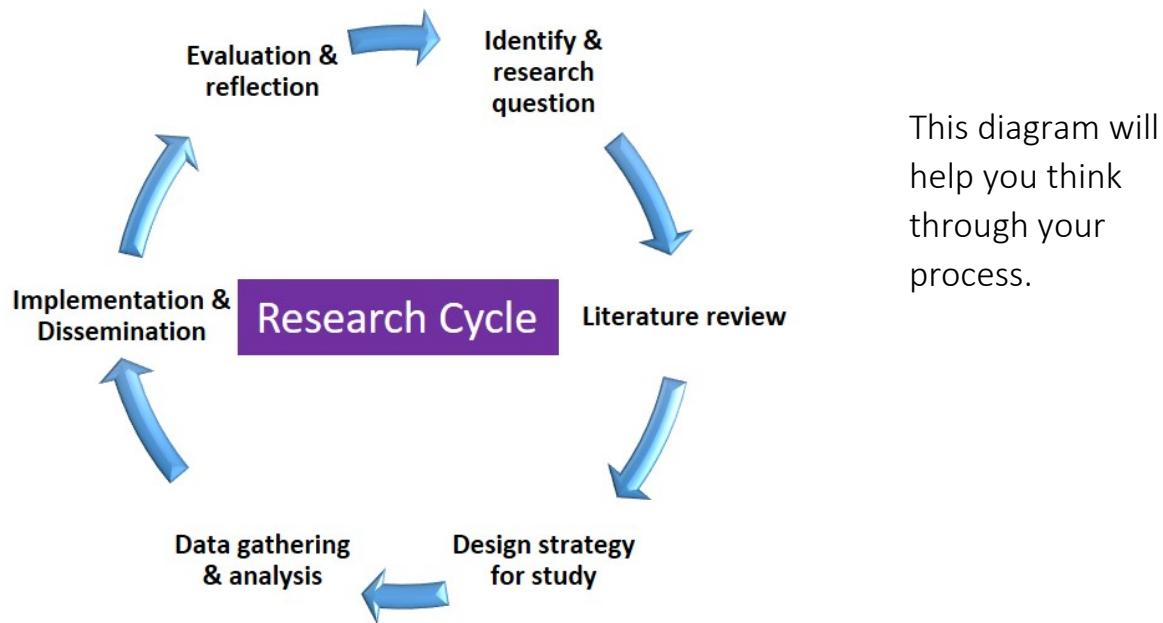
Included in this guide are step-by-step processes that will help you determine costs for each stage of your project. The table below is a summary of the process. Section 3 has an example of a budget.

GETTING STARTED WITH BUDGETING	
Step	Activity
Step 1: Framework selection	Select a framework for mapping costs for people with lived experience engagement, such as the research project cycle (See Section 3) or a project timeline.
Step 2: Planning activities	Plan the partner roles and activities you intend to incorporate in your project.
Step 3: Determine your costs	For each activity identify the specific costs that you need to budget for.
Step 4: Determine total costs	Estimate the cost or range of costs for each activity. See the sample budget in Section 3.
Step 5: Mapping	Map the activities onto your project framework so that you will know when the costs will be allocated.
Step 6: Develop a contract with your youth, family, and patient partners	A contract should be established with the lived experience partners that is based on Step 4 above. The contract may be based on an hourly basis or on a monthly/periodic retainer. Such a contract might specify: Total compensation anticipated Projected/ approximate number of hours Specific tasks expected Support available Deliverables Timelines for project activities, meetings, deliverables Other engagement requirements Process and expectations of documentation needed for compensation payments

3. How to Budget for your Study

This section presents a step-by-step process to help you plan and budget for engagement of lived experience partners. While you can begin at any point in your study, we suggest that you start planning your budget before applying for funding.

STEP 1: Where in the Research Cycle will you Likely Need to Engage with Lived Experience Partners?



This diagram is adapted from the INVOLVE Briefing notes for researchers (2012)
www.involve.nihr.ac.uk/posttyperesource/where-and-how-to-involve-in-the-research-cycle

STEP 2: How will you Engage your Lived Experience Partners?

Since how you engage lived experience partners in your study will vary based on the scope of your project, we provide more detailed information to help you plan the types of activities that are pertinent to your study.

STEP 3: How Much will it Cost?

Below is a sample table to help you estimate your costs for a single youth or family partner. The actual cost will depend on the individual cost of each item as outlined in the example below.

SAMPLE BUDGET			
Expense Type	Quantity	Estimated cost each	Total
Payment and incentives			
Salary or stipend (Six 1-hour meetings (2 in-person), 3 hours prep time, 6 hours follow-up time, one half-day local conference)	19 hours	\$25 - \$50	\$475 - \$950
Expenses for youth, family, and patient partners			
Travel from home to meeting (for 2 meetings + 1 local conference)	45 miles	\$.54/mile	\$25
Childcare or caregiver based on child needs and local costs (\$20 per meeting lasting 1 hour each + 1 hour travel time X 2 meetings)	8	\$20	\$160
Food	n/a		
Personal assistants	n/a		
Overnight accommodations	n/a		
Engagement activities			
Finding lived experience partners collaborators	n/a		
Training costs for partners – Fyreworks, PORCCH or PCORI training modules to be done at partners' own pace, but completed within 60 days	5 hours	\$25	\$125
Conference registration for local conference	1	\$150	\$150
Staffing	n/a		
Other costs			
Background checks and medical checkups or vaccinations (background check required by hospital)	1	\$160	\$160
Translation or interpretation	n/a		
TOTAL			\$1,095 - \$1,570

STEP 4: Mapping Lived experience Partners' Activities to your Project Framework

You can estimate when you will incur costs by mapping lived experience partners' activities to your project timeline. Using the above example, you can schedule the six meetings over the 3-month period and budget for each month's expenses.

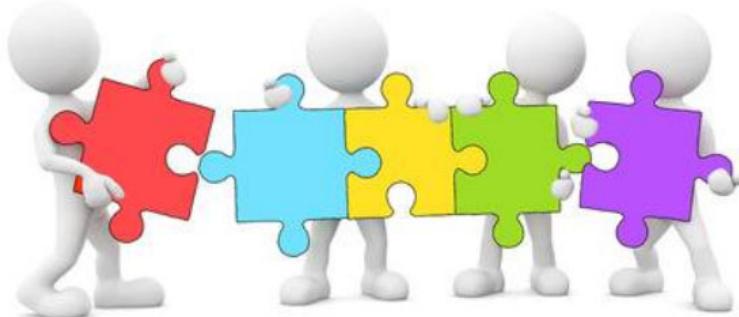
STEP 6: Develop a Contract with your Youth and Family Partners

STEP 5: Orienting lived experience Partners to your Project

Use the template below to list the basic engagement activities that lived experience partner should be aware of. This template will help guide you in orienting your entire research team.

SAMPLE ENGAGEMENT TEMPLATE	
Study Title	Involving Youth, Patients, and Families as Research Participants
Planned timeline	September 2021 to August 2023
Study Aims	<ol style="list-style-type: none">1. Develop strategies for recruiting people with lived experience as research partners2. Evaluate strategies that appeal to youth vs. that appeal to adults
Methods	<ol style="list-style-type: none">1. Survey people with lived experience who currently participate in research studies
Role of PWLE	<ol style="list-style-type: none">1. Participate in the design, protocol, analysis, and presentation2. Help recruit study participants and administer surveys3. Participate in writing the manuscript
Support for PWLE	<ol style="list-style-type: none">1. Research project orientation2. Research methods training (if necessary)3. Research team member assigned to support PWLE4. Bi-monthly meetings with research team5. Meeting minutes sent to PWLE6. Remuneration and expense reimbursement
Budget	Costs for recruitment, reimbursement, and remuneration are built into the budget and grant proposal
Research Team	<ol style="list-style-type: none">1. Dr. Lupe Gonzales, PI2. Greg Williams, Research Assistant3. PWLE #1 (to be determined)4. PWLE #2 (to be determined)

It is a best practice to develop a contract or scope of work (SOW) that outlines the lived experience partners' duties and compensation. Lived experience partners can be paid by a set fee based on a contract, by the hour, or by the task. See Section 4 below for suggested items to include in your contract or SOW.



4. What do you need to Budget For?

In this section we provide a list of the common costs associated with active engagement in research. You should budget for items that are relevant to your study. For each item we explain why this cost might be incurred. Depending on your study protocols, there may be other costs not listed here. For any costs you should check your institution's standard rates, such as for mileage, or for preferred suppliers who can help you calculate estimated costs.

Costs are organized into five categories:

- Payment and Incentives
- Expenses
- Activities
- Staffing
- Other Costs

We recommend that payments for begin at a rate of \$25 per hour with a \$100 minimum payment.

4.1 Payment and Incentives: Fees to Individuals

Payments to lived experience partners recognize their time, skills, and expertise. These payments may be in the form of cash or check, gift cards, or in-kind; the type of payment will depend on what is best for each partner, given their individual circumstances. The rate you offer will depend on a number of factors including expertise, expected time commitment, and level of responsibility.

We recommend that payments begin at a rate of \$25 per hour with a \$100 minimum payment. This rate is commensurate with the average hourly rate for an entry-level research assistant¹⁷⁻¹⁹ in the United States and includes an increase for lived experience. This rate would not include incidental expenses for child care, transportation, or other expenses that partners might incur. It is helpful to establish a contract with partners that is based on the hourly rate or on a monthly/periodic retainer.



The following questions may be helpful in determining what rate to offer lived experience partners.

- What level of skills, expertise, and experience is required for your project?
- What are the time commitments involved in the role (including preparation, reading, travel, meetings, etc.)?
- What is the level of responsibility required?
- What training outside of specific project training is required?
- When providing reimbursement, time should be compensated under a separate payment category from expenses (such as transportation or mileage), such that reimbursement for expenses is not included as income for tax or benefits purposes (see the categories below).

Understand your organization's policies or practices for paying consultants on a one-time or on-going basis. If you find institutional complexities or barriers to making these types of payments, consider contracting with a community-based or advocacy organization in your state or community to administer payments to lived-experience participants, as well as assist in other aspects of effective partnership such as recruiting and mentoring youth, family, and patient leaders in these roles. Contracting with a community-based organization should include indirect or overhead costs for their role, but may save time for research staff in areas of recruitment and support.

4.2 Expenses for Lived experience Partners

Travel

Travel by lived experience partners for the project should always be covered by the research group. Costs may include public transit fares, mileage, or air fare as appropriate. Most organizations have a rate for mileage reimbursement and may also have travel agencies that they use for air travel. Also include parking fees and additional expenses that occur as a result of travel. If your partner requires a personal assistant, the cost for travel for that person will need to be included. Occasionally, state benefit programs will help cover the cost of a personal assistant.

Overnight Accommodations

If partners are travelling a long distance, participating in a conference or attending another project-related meeting over several days, they may need overnight accommodations. Your institution may have a special rate for hotels and a preferred travel agent. You should anticipate the need

for accommodations so that you can book hotels early and get the best rates.



Childcare and Caregiving

Partners may need someone to care for a child, youth, or adult during the time they are working on the project. The cost for caregiving will vary depending on the type of care needed. You should ask your partners what types of caregiving they need.

Food

Meals during travel or long meetings should be covered at your institution's per diem rate.

Accommodations and Personal Assistants

You may need to provide support for impairments such as hearing or mobility. Such support may include sign language interpretation, a personal assistant, or mobility equipment. If your partners require the support of a personal assistant to get involved in your research project, you should ask them what types of costs they anticipate. Occasionally, state benefit programs will help cover the cost of a personal assistant. See Appendix for some organizations that can provide information about paying for personal assistants. You may also want to hire partners from communities who do not speak English. In that case, a translator maybe required.

Training Costs

Training and orientation will usually be required for partners. They will need to understand the project, their role, and the roles of others, including the PI, research assistants, and other

members of the research team as well as basic information about teams and processes.

They will also need training that is specific to their role. Even though the partners may have worked on other studies, your study will be new to them and have specific requirements that the entire research team will need to know about, including partners. If the partners will take on the role of co-PI, there may be more intensive training required, possibly including research methods, data analysis, and manuscript writing.

The research team may also need training and orientation or guidance in working with people with lived experience. Connecting with a family, advocacy, or community organization can assist with orienting the research team to working with people with lived experience partners as active partners.

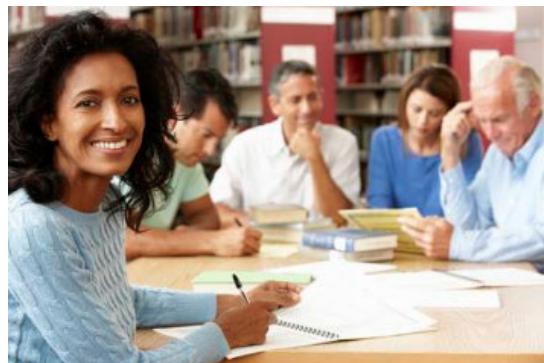
Conference and Meeting Fees

You might want to include partners in conferences as presenters or as attendees. Costs will include travel,

hotel, conference fees, and food.

Other costs may be incurred, depending on the activities in which the partners participate.

4.3 Engagement Activities: Recruiting People with Lived Experience



Identifying people with lived experience to participate as researchers can be challenging. It is important to think about who on the research team will do the recruiting and through what means. Funding for a staff member such as a research assistant who will work on recruitment should be incorporated into the budget. It can be a wise investment to work with family- or

community-based organizations that can provide recruitment, training, and support for people with lived experience.

4.4 People with Lived Experience as Staff

If continuous engagement is required of your partners, you might think about employing them as staff members. They should receive the same compensation as any other staff member in the capacity in which they are employed, considering their expertise and lived experience. Another option is to contract with a community-based organization to be in charge of this kind of continuous engagement.

4.5 Other Costs

- Background Checks
- Medical Checkups or Vaccinations
- Institution-required Trainings

Depending on the role of the lived experience partners, you may be required to do background checks, pay for vaccinations, or other services that ensure the safety of your study participants. If partners are working in a hospital setting, for example, the hospital may require certain vaccines, background checks, and specific institutional training such as HIPPA certification.

4.6 The Budget Justification

When writing your budget justification, remember to emphasize that people with lived experience are being paid for their work and expertise. Use action words (oversee, design, develop, assess) and terms of respect (honoraria, mentor, advisor, authority). Avoid words that cast people with lived experience in a passive role (suggest, help, incentives, participant, consumer, member).

Use a distinctive term for lived experience partners, such as community partner, so that they are not confused with research participants. You may encounter individuals who don't recognize the difference between lived experience partners and research participants; careful word choice in your budget

justification (and proposal) will help them understand the distinction.

In your budget justification, and in your payments to partners, keep payments for work distinct from reimbursement for expenses. Payments for work are taxable income, and will count against those who depend on means-tested programs. You can reduce your own administrative burden and the reporting burden partners by using flat rates or standardized calculations for costs. For example, pay \$25 per participant to cover childcare costs for a one-hour meeting, and calculate mileage based on what town each partner lives in. Use institutional, state, or federal standards to support your cost estimates when available.

5. Partnering with Community-based Organizations

If a research team has little funding to conduct their project and therefore would be unable to pay people with lived experience as members of their research team, for example, a doctoral student conducting a research project, we recommend connecting with advocacy organizations in your state such.



Advocacy organizations or community-based organizations may be able to provide recruitment, training, and support for partners and specialized expertise and experience that can be helpful to a researcher with little funding. Such organizations

may also have more flexibility in strategies to compensate partners in case organization policies present barriers, for example, prohibiting the purchase of gift cards. They may also have limited funds available to help pay people with lived experience in the case of a project that does not have sufficient funding.

Subcontracts with community-based organizations are similar to other kinds of subcontracts, and will need to cover organizational expenses in the form of indirect costs, an increased hourly rate, or a deliverable-based payment structure.

Note that non-profit organizations can lose non-profit status if they are suspected of violating tax laws; confirm that your compensation plans are accepted practice before asking family or community-based organizations to undertake them.

Conclusion

Working with people with lived experience as partners on research projects is a rewarding experience that pays dividends in terms of the quality and applicability of the research findings. People with lived experience should be an integral part of research teams because studies show that engaging them makes research better and more meaningful to all stakeholders. Compensating lived experience partners fairly for their expertise, lived experience, and work on a project shows a commitment to excellence in research and helps ensure that findings are representative of the population. We hope that this guide will help investigators and research teams effectively plan for engagement. For questions or more information, please visit our web site at www.LivedHealthExperience.org.

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Appendix A

Family & Community Organizations	
FAMILY ORGANIZATIONS	<u>PERSONAL ASSISTANTS INFORMATION</u>
Family Voices www.FamilyVoices.org	<u>Special Needs Answers</u> https://specialneedsanswers.com/personal-care-assistants-can-offer-much-needed-help-to-families-with-special-needs-children-15859
The ARC www.thearc.org	<u>Funding Options for Personal Assistance Services</u> https://www.dol.gov/odep/research/FundingOptionsPersonalAssistanceServices(PAS).pdf
Institute for Patient- and Family-Centered Care www.ipfcc.org	
Hands and Voices www.handsandvoices.org	
Parent to Parent www.p2pusa.org	
National Alliance on Mental Illness (NAMI) www.nami.org/Find-Support/NAMI-Programs/Nami-Family-Support-Group	
Genetic Alliance www.geneticalliance.org	
Families USA http://www.FamiliesUSA.org	