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MCH Innovations Database Practice Summary & Implementation Guidance

Standard of Compensation for Youth and Family Partners on Research Teams

Youth, families, and patients who work on research studies as co-investigators or research partners should be paid for their work and lived experience. The Standard of Compensation for Youth & Family Partners outlines standards for fairly compensating research partners and includes a comprehensive glossary of research terms. There is a second guide for researchers.



		
Location	Topic Area	Setting
Colorado	Family/Youth Engagement	Community
		
Population Focus	NPM	Date Added
CYSHCN	N/A.	March 2020

Section 1: Practice Summary

Charlene Shelton, CYSHCNet, (303) 724-4359, charlene.shelton@cuanschutz.edu

PRACTICE DESCRIPTION

Youth and families who work as partners on research projects should be compensated for their work and lived experience in more than pizza or parking fees. The Standard of Compensation for Youth and Family Research Partners (SoC) helps Principal Investigators (PIs) budget for including youth and families as full members of a research team and ensuring compensation is fair and takes into account the rich lived experience of partners and outlines for youth and families what they should expect as partners.

Up to now there has not been a guide to compensating youth, family, and patient leaders (YFP) who are co-investigators on research projects. While funders are beginning to suggest or require that YFP be included as full partners on research projects, none have guidance about compensation outside of a suggestion that YFP be paid and/or their expenses be covered. Therefore, YFP are often offered a token amount of compensation such as a gift card or lunch, or they are considered volunteers. Yet YFP are expected to contribute the same type of expertise as any other member of the research team to a project. There is a body of literature that suggests engaging families in research at the level of co-Principal Investigator (co-PI) makes research more relevant to the needs of patients and families. The literature spells out myriad ways in which research is more impactful such as tackling questions that are important to patients and families vs. to a researcher. This guide provides concrete information, recommendations, and examples for research teams, including specific dollar amounts that YFP should be paid, yet it allows for flexibility in the project budget. It even speaks to how to pay YFP if the PI is a student with little or no funding for YFP partners. There is a separate guide for youth and families that gives them.

The Standard of Compensation features a guide for research teams and another for families. While the basic information is the same, the family guide includes a comprehensive glossary of research terms to help those who are new to the research process understand the jargon that they will commonly find in the literature and in meetings. In both guides we include sample budgets and recommendations for how much youth and families should be paid. We researched average salaries for research assistants at various levels of expertise in different parts of the U.S. and included an increase for lived experience. Thus, our recommendation is that youth and family partners be paid a minimum of \$25 per hour with a \$100 minimum.

CORE COMPONENTS & PRACTICE ACTIVITIES

The research cycle was used as a framework to have researchers and YFP begin to think about how YFP engagement could begin at any stage of the research process. We looked to models from the UK for inspiration and took some of their recommendations to guide the Standard of Compensation. During several calls with NHS Patient and Public Involvement group in the UK, we worked to adapt the portions of their standards to research in the U.S. with their help. We also did an extensive literature review to look for any type of compensation model. The result was that we found very little in the way of specific recommendations, outside of the notion that YFP should be paid. We also had interviews with others working on family engagement equity in areas where family and patient



engagement as research partners is more normative, particularly in the UK and Canada. We took what we considered to be the best ideas from all our contacts and adapted them for the U.S. along with lessons-learned from our research network’s experience in engaging youth and family leaders as research partners.

The primary goals of this practice are:

1. Normalize fair compensation of youth and family partners on research teams;
2. Increase the number of partnerships of youth and families on research teams;
3. Standardize rates of compensation of youth and family partners across domains;
4. Make it easy for research teams to engage youth and families as full partners on projects by providing guidance that can inform budgets when applying for grants.

Research teams should think about the roles and responsibilities of youth and family partners as they are considering a project. They should consider the amount of time that partners will spend on the project and include those costs in their grant proposals. Beside compensation, teams should consider expenses that might be incurred by partners such as childcare, transportation, and others that are outlined in the Standard.

Core Components & Practice Activities		
Core Component	Activities	Operational Details
Roles of youth/family partners (YFP)	List roles that will be assigned to YFP	What roles do you expect YFP to have on the project? Include attending meetings, reviewing documents, brainstorming, crafting surveys or interview questions, administering surveys, data analysis, authorship, etc.
Budgeting	Assess project budget	Calculate the number of hours that YFP will likely spend on the project. Based on their level of expertise, multiply the number of hours by the rate you are paying, being mindful that the minimum rate should be \$25/hour. A partner with experience in research or advanced degrees should be paid commensurate with their expertise. For example, a partner with several years of experience working on research projects and a masters or JD degree should receive at least \$75 to \$100 per hour plus expenses. -Expenses should be included after speaking with the partner and determining his/her needs. Expenses may include childcare, transportation, interpreters, or personal assistants. If you are budgeting before securing a partner, you should build in a cushion for these potential expenses.



		-Include the budget in your grant proposal.
Contract	Create a contract or written agreement	Creating a written agreement with YFP is a best practice and may be required by your grants office.
Type of payment	Determine what type of payment YFP can accept	Some partners may not be able to accept cash payments due to receiving means-tested benefits. You should check with the YFP before initiating payments to them

HEALTH EQUITY

Health equity requires that all relevant voices be at the table and that those who are most affected by research findings play a substantial role in crafting the research. Engaging YFP in the research process at a level that values their lived experiences and honors their commitment requires that they be treated the same as all other members of the team; that is, they are paid commensurate with their expertise, time, and commitment to the project. Researchers often question how much to pay and in what form (cash, gift card, lunch). Having a straightforward guide to compensating YFP takes the guesswork out of how to engage them into any project, at any point in the project. When YFP are involved in the research process, they bring their lived experiences to the table, which are often experiences that researchers have not addressed. Individuals from varying populations are more apt to participate in research because the universe of families and patients spans all races, ethnicities, linguistic populations, and other markers of diversity. The experiences of individuals from vulnerable populations are important to ensuring that research reflects the full spectrum of the population being targeted. Ensuring compensation for youth and families makes it easier for YFP from populations that are often silenced in the research arena to participate because their expenses can be met.

EVIDENCE OF EFFECTIVENESS

We send a short survey to everyone who downloads the guides to find out if they have used the guides and, if so, how. We ask for comments about how to improve them and keep a count of the number downloaded as well as the institutions to which downloaders belong.

Section 2: Implementation Guidance



STAKEHOLDER EMPOWERMENT & COLLABORATION

Family Voices and CYSHCNet have an on-going partnership that directly contributed to the development of the Standard of Compensation. We worked together through all phases of its creation including dissemination. We consulted with our advisory committee that consists of youth, families, researchers, clinicians, foundation executives, Medicaid executives, insurance executives, MCHB personnel, and patients. Once the Standard was complete, we sent it to organizations with an interest in family partnerships such as PCORI, the AAP, and others and discussed the draft to get feedback on whether they felt the documents would be appropriate for their use.

REPLICATION

The Standard is being used by at least one funder to help potential grantees budget for their youth and family partnerships.

INTERNAL CAPACITY

The Standard of Compensation was created through a partnership with Family Voices. Together, we assessed the problem (family partners were not necessarily being compensated fairly for their time and expertise), reviewed the literature, communicated with organizations that have a history of partnerships with families (the NHS, INVOLVE, etc.), and received feedback from an advisory group composed of youth, families, and investigators.

We have promoted the adoption of the Standard through our partner organizations including the AAP, PCORI, MCHB, and others. Individual investigators and research teams have begun reaching out for advice on compensation and have begun using the Standard to inform their grant proposal budgets and budget justifications.

PRACTICE TIMELINE

Phase: Planning/Pre-Implementation



Activity Description	Time Needed	Responsible Party
Begin to develop the research idea	As project conceptualization begins	Principal investigator
Identify youth and/or family partner (YFP)	As early as possible in the planning process	Principal investigator
Discuss compensation with YFP, including method of payment, expenses (childcare, transportation, etc.)	As soon as YFP are identified	Principal investigator
Create a scope of work that outlines roles and responsibilities	As soon as YFP agree to work on the project	Principal investigator
Include compensation and scope of work in the grant proposal budget	During grant writing	Principal investigator

Phase: Implementation

Activity Description	Time Needed	Responsible Party
Create a contract with YFP	Once compensation is agreed upon	Principal investigator or Project Manager
Pay YFP on the agreed schedule	As outlined in the contract	Payroll or other financial personnel



Phase: Sustainability

Activity Description	Time Needed	Responsible Party
Consistently implement terms of the contract such as orientation, scope of work, and payment schedule	On-going	Research team

PRACTICE COST

This practice does not have a cost of implementation. The cost for compensating youth and family partners working on a research project is dependent on the project, its scope of work, timeline, and the role and responsibility of the youth or family partner.

LESSONS LEARNED

Assets:

There are no other current standards for compensating youth, family, or patient partners. This guide gives research teams concrete recommendations for equitably compensating YFP and helps in budgeting and writing YFP into grant proposals. The guide allows for adapting compensation for meet the circumstances of both the YFP and the research team. It provides resources for further assistance in working with YFP such as consulting family-led organizations. The guide makes recommendations based on current payment structures for research assistants.

Challenges:

The primary challenge that we face is getting the guide adopted by organizations so that there is consistency in compensation of YFP. To date, the Lucile Packard for Children's Health has adopted it and has added it to their proposal protocol. While the Standard has been downloaded over 200 times, we do not know whether any other organizations have adopted it as a resource for their research teams. A second challenge is getting downloaders to complete the survey. Typically, the response rate has been very low.

Lessons learned:



We have changed the form on our website to get some of the survey information up front. We have followed up on the dissemination by presenting the Standard through posters (due to the cancellation of conferences due to COVID-19) at various virtual conferences.

NEXT STEPS

We are working on a comprehensive guide to best practices in partnering with youth and families that will include much of the general information in the Standard. We may include the SoC as part of the guide in its entirety, while also continuing to offer it as a stand-alone product.

RESOURCES PROVIDED

- [Standard of Compensation for Youth and Family Partners](#)

APPENDIX

- N/A.

