

PEDSnet Collaboration Request Engagement Guidelines

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Table of Contents

PEDSnet policy for Patient/Parent Engagement.....	2
Engagement in Research - Background.....	2
<i>WHY – why is engagement in research important? What is the purpose of engagement?.....</i>	<i>2</i>
<i>HOW – how can engagement in research be done? What is feasible, related to variables like timelines and project funding?</i>	<i>2</i>
<i>WHO – who can be involved in patient-centered outcomes research engagement?</i>	<i>3</i>
PEDSnet Engagement in Research – Engagement Tiers	3
Beginner Partnership Co-production	3
Intermediate Partnership Co-production.....	3
Advanced Partnership Co-production	4
PEDSnet Engagement in Research – Engagement in Different Study Types	5
Database-only studies	5
Randomized-control trial.....	5
Qualitative studies	5
Additional Engagement Resources	6
PEDSnet Engagement in Research - Patient Partner Compensation	6
PEDSnet Engagement in Research – Collaboration Request Process and Timeline.....	7
PEDSnet Engagement in Research – Engagement Template.....	8

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PEDSnet policy for Patient/Parent Engagement

In general, PEDSnet studies engage parents and/or pediatric patients in the research process, including: formulating research questions; defining essential characteristics of study participants, comparators, and outcomes; identifying and selecting outcomes for the population of interest, conducting and monitoring the research and disseminating and implementing the results. Patients and parents/caregivers who participate in PEDSnet studies or governance are compensated for their time.

Engagement in Research - Background

WHY – why is engagement in research important? What is the purpose of engagement?

PEDSnet believes that patient and caregiver engagement in research can help increase the impact of the study. Through community input and patient co-production in each step of the research process – study design, implementation, analysis, and dissemination – researchers can better come to understand the needs of the community they are serving.

Both PEDSnet and PCORnet® engage in patient-centered outcomes research. Patient-centered outcomes research, as defined by [PCORI](#)®, “helps people and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options” by answering patient and caregiver centered questions about their health and healthcare.

HOW – how can engagement in research be done? What is feasible, related to variables like timelines and project funding?

There are many different ways to incorporate patient and caregiver engagement in research. The level of engagement will vary based on a number of factors, including the timeline of the project, amount of funding allocated, bandwidth of the study team, and study team experience with patient engagement.

Here are some questions we encourage investigators to consider when thinking about engagement in a research study:

- Does your institution have a compensation policy for Patient and Family Partners? Does your research award (if applicable) include funding for partner compensation? If not, are there other mechanisms available to you to compensate patient and family partners for their time and expertise?
- What is the timeline of the research study?
- Does the research team have any previous experience working with patient engagement? If not, does anyone on the team have knowledge of what resources exist within their institution (e.g. group facilitation, engagement lead, etc.)
- Is patient engagement feasible during each phase of the study, or just during specific phases? What is the justification for the feasibility?

The PEDSnet Family and Youth Advisory Councils created two Best Practices in Research guides for engaging youth and families in research. These documents are [available to download on the PEDSnet website](#). We strongly encourage you to download and review those documents if you have not already.

WHO – who can be involved in patient-centered outcomes research engagement?

Engagement in research can include but is not limited to:

- Patients or Caregivers/Family Members
- Community Members, Advocacy Organizations
- Clinicians, clinical staff, researchers
- Policymakers, Industry, Hospital and Health Systems, Payers

PEDSnet Engagement in Research – Engagement Tiers

Engagement in research will vary from study to study, based on the questions outlined above. To help investigators, we have created three tiers of engagement ranging from beginning partnership to advanced partnership. The tiers include examples of potential engagement methods at that tier.

Beginner Partnership Co-production

A beginner level co-production partnership approach to engagement is best suited for investigators whose studies have a very short timeline or limited funding, and have a study team with little to no prior experience working with patient partners.

Beginner partnerships will not require substantial time from the patient partners and the activities have the potential to be completed asynchronously.

Examples of beginner partnership activities:

- Patient partner is consulted or reviews study design, grant application, methods, etc.
- Patient partner provides feedback on recruitment materials and processes such as flyers, interview questions, cognitive interviewing, methods, etc.
- Patient partners are given an opportunity to tell their stories
- Patient partners can test a data collection instrument

Intermediate Partnership Co-production

An intermediate co-production partnership approach to engagement is for investigators with more bandwidth and funding for engagement activities related to their study. While prior experience with patient partner engagement can be beneficial, it is not necessary for intermediate partnership approaches.

Intermediate partnerships often require a time commitment from patient partners typically on a monthly or quarterly basis.

Examples of intermediate partnership activities:

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- Study has community partners/advisory boards/etc.
- Patient communities are updated monthly/quarterly with study updates
- Patient communities/partners are consulted regularly for study improvements, data validation, etc.
- Patient partners contribute to the development of a needs assessment
- Patient partners contribute to curriculum design and teaching materials

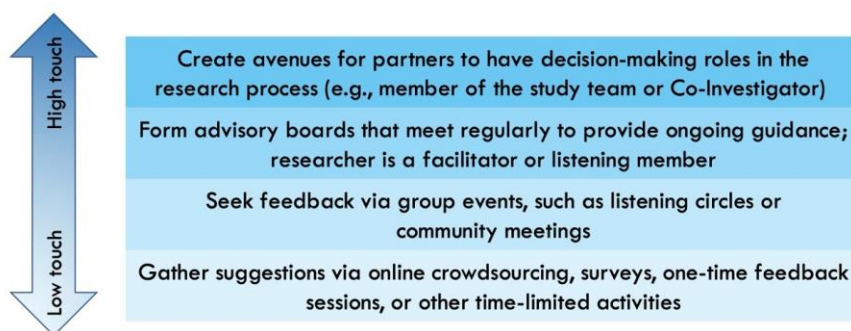
Advanced Partnership Co-production

Advanced co-production partnership approach is what PEDSnet encourages all investigators to aim for. Engagement activities at this tier require ample funding and bandwidth. Advanced partnership engagement plans allow patient partners to serve in a decision-making role throughout the study. Plans at this tier require a substantial time commitment from both the patient partner and the study team.

Examples of advanced partnership activities:

- Patient partner as Co-Investigator
- Patient partner helps create study design, is involved in weekly meetings, is a part of the study from conception to close out
- Study hires a patient partner champion to work exclusively with patient partners/communities to ensure voices are heard and connected
- Patient partners train and/or onboard other patient partners
- Patient partners assume a leadership role related to strategic planning or other decision-making processes

This graphic from the University of North Carolina provides a visual example of beginner co-production (low touch) to advanced co-production (high touch) engagement methods:



Graphic Source: *The North Carolina Translational and Clinical Sciences Institute. Engagement in Research Training Series. Unc.edu. Published 2025.* <https://tracs.unc.edu/index.php/services/engagement/training>

PCORI also provides the [Methods of Patient & Public Engagement Guide](#) from the George & Faye Yee Centre for Healthcare Innovation as an engagement resource.

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The PEDSnet Family and Youth Advisory Councils created [Best Practices in Research](#) documents for researchers who are partnering with families and youth.

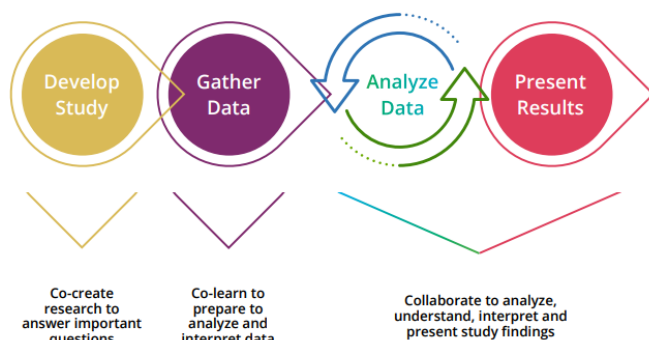
PEDSnet Engagement in Research – Engagement in Different Study Types

In addition to outlining the types of co-production engagement, we wanted to provide examples of what engagement could look like for different study types that are common within PEDSnet.

Database-only studies

- Patient Partners could serve in a consulting role for the study team throughout the study, offering guidance and input as questions or concerns arise (intermediate to advanced touch partnership)
- Surveys could be administered to patient partners, community groups, and/or clinicians about the study topic or to fill information gaps where needed (beginner to intermediate partnership)
- Data Party could be held following the data collection and analysis for dissemination ideas (beginner to intermediate partnership)
- You can learn more about how to utilize patient partners in database or data analysis only studies from this PCORI created resource [here](#). This document offers a variety of ideas on how to incorporate patient partners throughout a data only study. In short, work to involve patients at multiple stages as seen in Figure 1 below:

Figure 1. Data Informs Every Step in the Research Process



Randomized-control trial

- Patient Partners serve on advisory council for duration of the study (intermediate partnership)

Qualitative studies

- Patient partners consult during study start-up, which could include providing feedback on recruitment materials, questions for a survey or focus group, etc. (beginner to intermediate partnership)

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- Patient partners consult during the data collection phase, which could include reviewing participant responses, being a part of the research team during focus group interviews, etc. (beginner to advanced partnership)
- Patient partners consult during the analysis phase, which could include a participatory group analysis process or coding responses (intermediate to advanced partnership)

Additional Engagement Resources

- Connect with the PEDSnet Engagement Core and join a FAC/YAC Meeting for feedback, ideas, and suggestions for your proposal or research study. Go to this link to [Utilize the PEDSnet advisory councils](#) and someone from PEDSnet will get in contact with you.
- [STAR CRN Engagement Guidelines and Resources for Patient Centered "Data Only" Studies](#) provides guidance on engagement, compensation of partners, and dissemination of results
- [The Continuum of Community \(Stakeholder\) Engagement in Research](#) exemplifies a multilevel approach to engagement in research
- PCORI provides [Project Snapshot: Early and Ongoing Engagement](#) which includes examples of engagement throughout the entire research process that can be applied to a variety of studies

PEDSnet Engagement in Research - Patient Partner Compensation

Providing compensation to patient partners engaged in research is a key activity in making research more equitable and diverse by helping to break down barriers to research participation. Compensation for patient partners involved in PEDSnet studies is **required**. Compensation will vary study to study.

Here are some common questions to consider when thinking about appropriate compensation for patient partners:

- Are patient partners engaging on a recurring basis throughout the study (e.g. attending monthly meetings or reviewing materials on an ongoing basis) or is their participation a one-time ask (e.g. complete one survey)?
 - If participation is a one-time ask, you may consider providing gift cards for participation rather than paying via check. There are no tax implications for gift card payments for patient partners, but any payment received via check is taxable.
- Is any travel required for patient partners participation in this study?
 - PEDSnet recommends pursuing a virtual option for study meetings whenever possible
 - In addition to receiving compensation for their work on a study, if patient partners are required to travel to a conference or meeting for a study, they should be compensated for their time at the meeting and have their travel expenses covered.

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- Are any of the patient partners I am working with employees at a participating institution?
 - If patient partners are employees at a participating institution, their compensation may look different than other patient partners.

The current rate for paying patient partners that work with PEDSnet is \$60 an hour. For particularly time intensive or laborious studies, you may think about increasing the hourly rate to closer to \$75 an hour. Compensation for completion of a survey or another one-off ask is typically around \$15-25 but may be more depending on what the survey or ask entails for the parent partners.

Below we have linked 3 guides that will help walk you through how to determine appropriate compensation for your patient partners:

- [PCORI's Dedicated Funds for Engagement & Partner Compensation](#)
- [National Health Council Fair Market Value Calculator](#)
- [PEDSnet Patient and Family Compensation Guidelines](#)

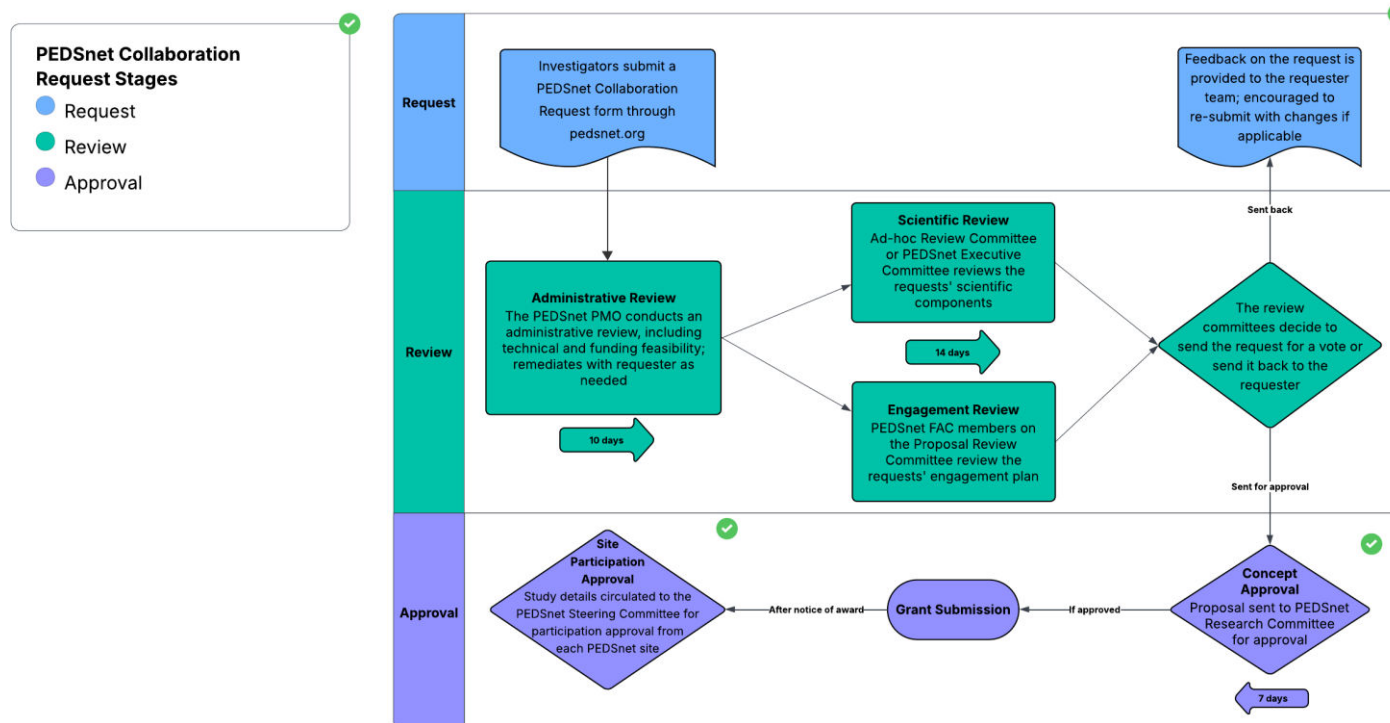
PEDSnet Engagement in Research – Collaboration Request Process and Timeline

Engagement is core to any collaboration request for PEDSnet research. Any researcher who works with PEDSnet has to follow the network's Collaboration Request Process. This process involves reviewing a project proposal for technical and funding feasibility, as well as for inclusion of an engagement component. The workflow below demonstrates the typical timeline for a collaboration request for a grant proposal.

Researchers who do not come to PEDSnet with an engagement plan and require assistance in formulating an engagement plan can refer to this document. If further assistance is needed, PEDSnet recommends first connecting with your home institution. The list of institutions that participate in PEDSnet can be found on our [website](#).

If additional questions arise or support is needed, please contact the PEDSnet Collaboration Request Team at pedsnet@chop.edu.

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PEDSnet Engagement in Research – Engagement Template

PCORI has a downloadable template for engagement plans that has space for researchers to outline how patient partners will be involved at each stage of the research project. It can be [downloaded on the PCORI website](#).

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