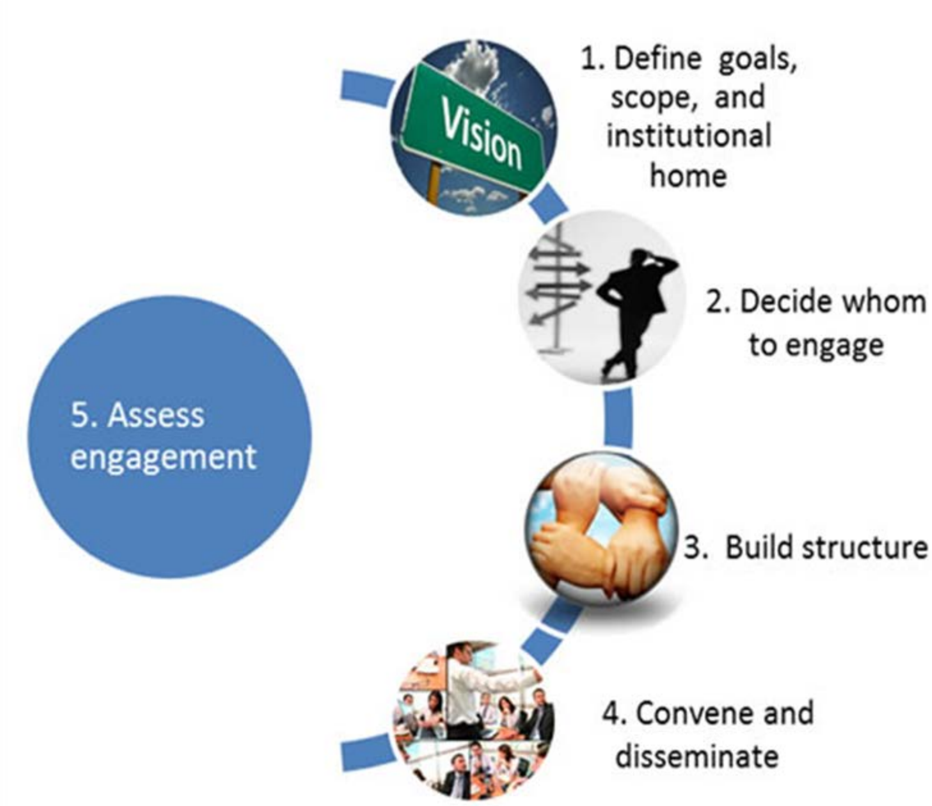
UNIVERSITY OF PITTSBURGH AND UPMC STAKEHOLDER ENGAGEMENT RESOURCE GUIDE



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THE COMPARATIVE EFFECTIVENESS RESEARCH CENTER (CERC; SALLY C. MORTON, PHD, DIRECTOR) AT THE UNIVERSITY OF PITTSBURGH HEALTH POLICY INSTITUTE COMPILED THE FOLLOWING RESOURCES THAT SERVE AS PRACTICAL GUIDELINES AND HELPFUL EXAMPLES OF EFFECTIVE STAKEHOLDER ENGAGEMENT.

PLEASE DIRECT QUESTIONS TO MS. MONICA COSTLOW, JD, COSTLOW@PITT.EDU

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STAKEHOLDER ENGAGEMENT RESOURCE GUIDE

INTRODUCTION

The rising interest and funding in patient-centered outcomes research (PCOR) and comparative effectiveness research (CER) at the national level provides an opportunity for the University of Pittsburgh and UPMC to become a leader in the provision of evidence-based, individualized care for our patients. The non-profit Patient-Centered Outcomes Research Institute (PCORI) is a premier PCOR/CER funding agency, but Agency for Healthcare Research and Quality (AHRQ) and other agencies have also featured PCOR/CER and stakeholder engagement funding announcements.

The Comparative Effectiveness Research Center (CERC) created this resource guide to serve as a roadmap for University of Pittsburgh and UPMC researchers to address stakeholder engagement in preparation for funding proposals. It is sequentially organized by guiding questions that cover the following topics:

WHO IS A STAKEHOLDER?

Each funding agency develops their own stakeholder definition. In general, patients, providers, caregivers, families, advocacy groups, consumers, institutions, organizations, programs and employers are identified as having a vested interest in or are likely to be impacted by the proposed research. Specifically, Concannon et al.[1] outlined stakeholders using the "7 P's Framework": Patients and the Public, Providers, Purchasers, Payers, Policy Makers, Product Makers, and Principal Investigators.

[1] Concannon T et al. J Gen Int Med 2012

Table One displays the most recent (January 2015) stakeholder definition for various funding agencies.

TABLE ONE: Stakeholder definition by funding agency

Funding Agency	Stakeholder Definition
Patient Centered Outcomes Research Institute (PCORI) (PCORI Funding Announcement. (2011). Accessed January 21, 2015, from http://www.pcori.org/assets/PCORI-Pilot-Projects-Funding-Announcement-Amendment-1-_v2_-09302011.pdf)	• Patients or patient-advocacy groups • Caregivers or caregiver-advocacy groups • Community groups • Health care providers • Relevant professional associations • Others with insights on the patient perspective
Agency for Healthcare Research and Quality (AHRQ) (The Effective Health Care Program Stakeholder Guide. (2011). Accessed January 21, 2015, from http://www.ahrq.gov/research/findings/evidence-based-reports/stakeholderguide/chapter3.html	• Consumers, patients, caregivers, and patient advocacy organizations • Clinicians and their professional societies • Health care institutions, such as hospital systems and medical clinics, and their associations • Purchasers and payers, such as employers and public and private insurers • Health care industry and industry associations • Health care policymakers at the Federal, State and local levels • Health care researchers and research institutions • *Stakeholders may be patients, caregivers, clinicians, researchers, advocacy groups, professional societies, businesses, policymakers, or others. Each group has a unique and valuable perspective.*
Centers for Disease Control and Prevention (CDC) (Get Smart: Know When Antibiotics Work Evaluation Manual. (2006) Accessed January 21, 2015, from http://www.cdc.gov/getsmart/program-planner/Step1.html)	• Those involved in program operations: management, program staff, partners, funding agencies, and coalition members. • Those served or affected by the program: patients or clients, advocacy groups, community members, and elected officials. • Those who are intended users of the evaluation findings: persons in a position to make decisions about the program, such as partners, funding agencies, coalition members, and the general public or taxpayers.
Centers for Medicare and Medicaid Services (CMS) (The Center for Consumer Information & Insurance Oversight. Accessed January 21, 2015, from http://www.cms.gov/CCIIO/Stakeholder-Engagement/index.html)	States, issuers, and consumers in State Partnership and consumers in Federally-facilitated Health Insurance Marketplace States.
National Institutes of Health (NIH) (National Institutes of Health, National Center for Biotechnology Information, Accessed January 21, 2015, from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3371639/figure/F1/)	Patients and consumers, clinicians, healthcare providers, payers and purchasers, policymakers and regulators, life sciences industry, researchers, research funders.

HOW ARE STAKEHOLDERS IDENTIFIED AND INVOLVED IN THE RESEARCH?

There are numerous sources for finding consumer and family stakeholders. Advocacy and community organizations have been trained on how to participate in these types of meetings and processes. The UPMC Research Participant Registry may serve as a means of identifying and recruiting stakeholders, primarily patients and family members, concerned with specific types of health conditions. Additional information on this free UPMC service is listed in the resource section below.

Many funders, including PCORI, do not require specific ways that a stakeholder may be involved in a project. However, the essence of stakeholder engagement must be a meaningful and valuable partnership that is continuous throughout the project. Here are some example stakeholder engagement methods:

Step in CER Process	Purpose of Patient Engagement
Topic Solicitation	• Identify topics that are important to patients, caregivers, and the community • Propose topics to be investigated
Prioritization	• Solicit feedback on relevance and priority of topics • Discuss the urgency of addressing topics
Framing the Question	• Ascertain questions' relevance and usefulness • Assess "real-world" applicability
Selection of Comparators and Outcomes	• Identify comparator treatments of interest • Identify outcomes of interest • Incorporate other aspects of treatment
Creation of Conceptual Framework	• Provide a "reality check" • Verify logic of conceptual framework • Supplement with additional factors not documented in the literature
Analysis Plan	• Verify importance of factors and variables • Ascertain whether there is a good proxy for a specific concept • Inquire about potential confounding factors
Data Collection	• Determine best approaches for data collection (e.g. trial, registry, medical charts) • Assist with selection of data sources
Translation	• Interpret results to be meaningful • Document which results are easy or difficult to understand • Indicate which results are counterintuitive
Dissemination	• Facilitate engagement of other patients • Help other patients to understand findings

(Mullins, C. D. et al. "Continuous Patient Engagement in Comparative Effectiveness Research" JAMA 2012;307:1587-1588

HOW ARE STAKEHOLDERS DOCUMENTED IN THE RESEARCH PROPOSAL?

Table Two outlines the six possible levels of stakeholder inclusion in research. Associated roles and responsibilities to the project are described, in addition to specific proposal requirements.

TABLE TWO: Stakeholder Project Involvement and Proposal Requirements

Level of Involvement	Roles and Responsibilities	Proposal Requirements
Shared-Principal Investigator (PI)	• Shared authority and responsibility for leading and directing the project intellectually and logistically. • Involved in all phases of the research process.	• NIH biosketch that includes an NIH eRA Commons ID • Personal statement reflecting leadership role in the project. • *Recommended:* Individual Investigator Agreement
Co-Investigator (Co-I)	• Works with the PI in the scientific development or execution of a project during a specific percentage of time. • May be employed by or affiliated with the applicant/grantee organization or another organization participating in the project under a consortium agreement.	• NIH biosketch that includes an NIH eRA Commons ID • Personal statement reflecting leadership role in the project. • Research ethics training required if the consultant will be 'engaged in research'. • *Recommended*: Individual Investigator Agreement
Individual Consultant	• Provides professional advice or services for a fee, but typically not as an employee of the engaging party.	• Letter of support from stakeholder indicating clear expectations of consulting, time and reimbursement. • Research ethics training required if the consultant will be 'engaged in research'. • *Recommended*: NIH biosketch.
Advisory Board Member	• Provides consultative and expert advice to PIs. • May include assistance the following: -Development of surveys -Suggestions regarding recruitment -Interpretation of findings -Dissemination activities	• Letter of support indicating purpose of the advisory board; how often they will meet; what kind of input they will provide; and their specific expertise that they bring to the board.*
Non-profit/ Community Organization Support	• Support the project work. • May help with recruitment. • May assist with interpretation of findings and dissemination.	• Letter of support indicating history of the community organization and their future role in the project.
Other Stakeholder Engagement	• Other methods for engaging stakeholders include, but are not limited to: -Identifying a group of patients through the research participant registry to provide specific individual feedback related to the project. -Focus group discussions with community members or health care providers. -Open community forum to discuss aspects of the project.	• Other methods for engaging stakeholders should be included in the Research Strategy portion of the proposal, where recruitment strategies should be addressed.

(Burke, J et al. "PCOR, CER, and CBPR: Alphabet Soup of Complementary Fields of Health Research?" Clin Trans Sci 2013; Volume 6: 493-496)

* Most advisory boards do not participate in the data collection process, thus are not considered "engaged in research".

For example, in a PCORI application, researchers are asked to demonstrate the commitment to patient and stakeholder engagement in criterion 5. This includes the following information: identification of stakeholders, description of engagement frequency and type, and a barriers assessment.

We compiled examples of proposal items related to stakeholder involvement as traditional forms may not be applicable or practical. The following examples are located in the identified appendices:

- Example Family Member Letter of Agreement *(Appendix A)*
- Example Youth Letter of Agreement (*Appendix B*)
- Childcare Policy for Participants (*Appendix C*)
- Advisory Board Meeting Attendance Policy (*Appendix D*)
- Advisory Board Selection Process/Responsibilities (*Appendix E*)
- Sample Application Kit for Family Members (*Appendix F*)

Please contact the Community PARTners Core (http://www.ctsi.pitt.edu/partners.html) to discuss stakeholder biosketches and letters of support.

HOW ARE STAKEHOLDERS INCLUDED IN THE IRB PROCESS?

If stakeholder advice is being solicited to only submit an application, the information will only be used for personal knowledge and to write the grant. This is not considered research and, therefore, does not require IRB approval. If, however, a researcher wants to publish results or distribute findings of any sort at any time, IRB approval is needed.

NIH Commons ID: Institution of Organization Stakeholder

Only if the stakeholder organization is listed as a Co-PI do they need a NIH commons ID. Otherwise, the stakeholder organization needs a Federalwide Assurance to participate in the research project and receive federal funds.

Federalwide Assurance: Institution or Organization Stakeholder

If a stakeholder *institution* is "engaged in research", they need a Federalwide Assurance (FWA). The FWA is the only type of assurance currently accepted and approved by the United States Department of Health and Human Services (HHS) Office for Human Research Protections (OHRP). Through the FWA, an institution commits to HHS that it will comply with the requirements in the HHS Protection of Human Subjects regulations at 45 CFR part 46. The documents in *Appendix K* provide guidance on what is defined as "engaged in research" and how to file or renew a FWA. Please contact the University of Pittsburgh IRB for further information.

Individual Investigator Agreement: Individual Stakeholder

There may be instances when a stakeholder is "engaged in research", but is not affiliated with an institution or the affiliated institution is not involved with the research. The individual stakeholder "engaged in research" must 1) complete human subject research training and 2) receive an individual human subject research certification. The Community PARTners Core offers human research subject training. Please contact the Core and the University of Pittsburgh IRB for further information.

University of Pittsburgh Institutional Review Board (IRB) (www.irb.pitt.edu)
IRB Consultation Services are available.

HOW ARE STAKEHOLDERS INCLUDED IN THE BUDGET?

Table Three outlines the budget requirements for each level of stakeholder involvement.

TABLE THREE: Stakeholder involvement and budget requirements

Level of Involvement	Budget Requirements
Shared-Principal Investigator (PI)	• Subcontract with specific budget line items for salary, fringe, travel costs, indirects, etc. • If PI is working on behalf of a community agency, budget justification should include intention to obtain a FWA as part of the subcontract.
Co-Investigator (Co-I)	• Subcontract with specific budget line items for salary, fringe, travel costs, indirects, etc. • If Co-I is working on behalf of a community agency, budget justification should include intention to obtain a FWA as part of the subcontract.
Individual Consultant	• Specific budget line item included under consultants. • Budget justification should include clear statement about what the consultant will be doing, how often and for how much. • If this individual is working on behalf of a community agency, budget justification should include intention to obtain a FWA as part of the subcontract.
Advisory Board Member	• Budget justification should include payment to advisory board members as a specific research expense.
Non-profit/ Community Organization Support	• In some instances, PIs may wish to formally include stipends for the community organization in the budget as a specific research expense. (These would include childcare, travel expenses, and food provided at meetings.)
Other Stakeholder Engagement	• Include in budget justification as a research expense.

* Information in Table 3 was provided by the University of Pittsburgh Community PARTners Core and the Qualitative, Evaluation And Stakeholder Engagement (Qual EASE) Research Services (http://www.crhc.pitt.edu/DataCenter/qualitativeServices.html).

Appendix H provides an example of youth and family stipends policy.

If you have payment questions, please contact the University of Pittsburgh Office of Research (412-624-7400). They will guide you through a Subcontract/Contracted Services Agreement.

WHAT STAKEHOLDER RESOURCES ARE AVAILABLE AT THE UNIVERSITY OF PITTSBURGH?

We encourage all researchers to contact the following Centers and cores directly.

Comparative Effectiveness Research Center (CERC), Health Policy Institute

CERC was established in 2011 to support Comparative Effectiveness Research/Patient Centered Outcomes Research (CER/PCOR) research, facilitate the securing of external funding, enhance the science of comparative effectiveness, connect researchers and institutions, provide guidance on stakeholder involvement and train University of Pittsburgh and UPMC investigators in CER/PCOR methods. Please contact Monica Costlow, JD, MPH (costlow@pitt.edu) to inquire about the CERC.

Community PARTners Core

Community PARTners facilitates relationships between community organizations and clinical and translational researchers to enhance collaborative research, foster public trust in clinical and translational research, and ultimately increase activities that promote health. The core can assist researchers in being paired with local organizations to conduct research. Community PARTners can also help researchers develop projects relevant to Western Pennsylvania residents and improve diversity in recruitment and retention in research trials. Please see (http://www.ctsi.pitt.edu/partners.html) for additional information.

Regulatory Knowledge and Support Core

The Clinical and Translational Science Institute's (CTSI's) Regulatory Knowledge and Support Core (RKSC) promotes good clinical practice and facilitates regulatory compliance in clinical and translational research by providing education, training, services, and resources for researchers, health professionals, and research participants from the community. The core provides Regulatory Compliance Facilitators who will directly support you as you address compliance regulations (e.g., IRB, IND, IDE, HIPAA) for your project. Please see (http://www.ctsi.pitt.edu/regulatory.shtml) for additional information.

Qualitative, Evaluation And Stakeholder Engagement (Qual EASE) Research Services Data Center, Center for Research on Health Care (CRHC)

The Qualitative and Stakeholder Engagement Core works individually with investigators on study design and conceptualization; grant development, interview conduction, data collection, data analysis, stakeholder engagement and final reports/manuscripts. The core offers the full range of expertise and staff needed for grants and projects: PhD collaborators, trained interviewers/focus group moderators, skilled note takers and transcriptionists and experienced coding staff. For more information, please see (http://www.crhc.pitt.edu/DataCenter/qualitativeServices.html) and contact Dr. Susan Zickmund (slz9@pitt.edu).

UPMC Research Participant Registry

The Research Participant Registry connects community members and UPMC patients with researchers conducting studies at the University of Pittsburgh and UPMC. It is a voluntary database of people who are willing to consideration participation in research studies on a variety of topics. There is no fee for this service.

However, IRB approval is needed. Please contact the UPMC Research Patient Registry at 1-866-438-8230 or researchregistry@hs.pitt.edu for information.

Office of Research, Health Sciences

The Office of Research, Health Sciences (OORHS) reviews grant applications prepared by faculty members from all six schools of the Health Sciences. Services include: scientific review of specific aims and study design, grantsmanship advice, editorial review for language and clarity, and review for consistency with funding announcement focus and funding agency priorities. For more information or to request assistance with a grant application, please visit www.oorhs.edu, or contact Dr. Jeremy Somers at somersj@pitt.edu.

WEBSITE RESOURCES

Federalwide Assurance (FWA)
FWAs are formal written commitments submitted to a federal agency where an institution promises to comply with applicable regulations governing research with human subjects and stipulates the procedures to be used to achieve compliance.

To learn more about FWAs, please visit the hhs.gov website at any of the links listed here. (See Appendix E)

HHS Websites
http://www.hhs.gov/ohrp/assurances/

Flow Chart - Guidelines
Pdf doc: http://www.hhs.gov/ohrp/assurances/irbfwasequence.pdf.
What is an FWA?
http://www.hhs.gov/ohrp/assurances/assurances/filasurt.html

How to file a NEW FWA?
http://www.hhs.gov/ohrp/assurances/assurances/file/index.html
Step by Step Instructions
Pdf doc: http://www.hhs.gov/ohrp/assurances/forms/fwainstructions.html

Status check of IRB and FWA?
http://www.hhs.gov/ohrp/assurances/status/index.html

Who to Contact?
http://www.hhs.gov/ohrp/assurances/contact/index.html

FORMS
http://www.hhs.gov/ohrp/assurances/forms/index.html

USCF – GUIDE FOR RESEARCHERS
http://accelerate.ucsf.edu/files/CE/guide_for_researchers.pdf

OTHER RESOURCES
LEARN MORE ABOUT PCORI FUNDING OPPORTUNITIES

FAQs for Applicants
http://www.pcori.org/funding-opportunities/funding-center/faqs-for-applicants/

APPENDICES

Examples provided by the Youth and Family Training Institute (www.yftipa.org) by Laurie Jones, unless otherwise noted.

APPENDIX A: Family Member Letter of Agreement

Family Member
Letter of Agreement

I, ______________________________, representing the interests of parents/guardians and family members throughout Pennsylvania, have been selected to participate as an Advisory Board member for the Youth and Family Training Institute. I understand that there will be monthly meetings starting in June 2008 that will be held in the Mechanicsburg/Harrisburg area.

I understand that I have been selected to participate in this process because of my experience in raising a child or children with behavioral health issues; my ability to advocate for children and families; and my interest in assuring that future parents/guardians and family members get the information and support they need.

I understand that my voice, expertise, and life skill experience is valued and respected.

I understand that I will keep all information that I receive during these meetings as confidential unless the Advisory Board agrees that the information should be shared. I especially understand that any personal information that I learn about other participants will not be shared outside of the group.

I understand that I will treat all members of the Advisory Board with respect. I acknowledge that there are no "bad ideas," and I will work hard to develop recommendations and plans that are strengths-based, culturally competent, and in the best interest of future families and their children.

I understand that a stipend of $___ will be provided to me at the end of each approved meeting and that my travel (and any other) expenses will be reimbursed several weeks after I submit the appropriate paperwork. I also understand that childcare will be provided for my child(ren) if I need it and give advanced notice.

I understand that I will not seek any additional financial reimbursement for my participation on this Advisory Board.

I understand that I will make every effort to attend all meetings. If, for any reason, I cannot attend a meeting, I will notify ____________________ at ____________________.

I understand that failure to follow the agreed-upon terms of this agreement may limit or eliminate my participation on this Advisory Board.

__________________________ (Signature of family member)	__________________________ (Signature of ____________________)
_______________ (Date)	________________ (Date)

APPENDIX B: Youth Letter of Agreement

Youth
Letter of Agreement

I, ____________________________, representing the interests of youth throughout Pennsylvania, have been selected to participate as an Advisory Board member for the Youth and Family Training Institute. I understand that there will be monthly meetings starting in June 2008 that will be held in the Mechanicsburg/Harrisburg area.

I understand that I have been selected to participate in this process because of my experience in dealing with my own behavioral health issues; my ability to advocate for youth; and my interest in assuring that youth get the information and support they need.

I understand that my voice, expertise, and life skill experience is valued and respected.

I understand that I will keep all information that I receive during these meetings as confidential unless the Advisory Board agrees that the information should be shared. I especially understand that any personal information that I learn about other participants will not be shared outside of the group.

I understand that I will treat all members of the Advisory Board with respect. I acknowledge that there are no "bad ideas," and I will work hard to develop recommendations and plans that are strengths-based, culturally competent, and in the best interest of future youth and their families.

I understand that a stipend of $___ will be provided to me at the end of each approved meeting and that my travel (and any other) expenses will be reimbursed several weeks after I submit the appropriate paperwork. I also understand that childcare will be provided for my child(ren) if I need it and give advanced notice.

I understand that I will not seek any additional financial reimbursement for my participation on this Advisory Board.

I understand that I will make every effort to attend all meetings. If, for any reason, I cannot attend a meeting, I will notify ___________________ at ___________________.

I understand that failure to follow the agreed-upon terms of this agreement may limit or eliminate my participation on this Advisory Board.

________________________	________________________
(Signature of family member)	(Signature of ___________________)
______________	_______________
(Date)	(Date)

APPENDIX C: Childcare Policy for Participants (sample)

Child Care
Policy #002

Purpose

The Youth and Family Training Institute recognizes that some family and youth members may have child care issues that would prohibit their participation in Youth and Family Training Institute activities. This policy outlines when and how child care reimbursement will be provided to youth and family members.

Objective

The Youth and Family Training Institute encourages youth and family members to be active participants in the development of the Institute regardless of child care needs.

A youth/family member, who participates in select committees or processes, may be eligible to receive reimbursement towards child care costs based on the information below.

Definition

Child Care includes costs incurred by a youth and or family member for assuring the care of their child/children while they participate in a related Youth and Family Training Institute activity.

Child Care reimbursement is a set amount of money that will be paid to eligible youth and family members towards costs incurred for child care.

Authority

The Youth and Family Training Institute has sole responsibility for the implementation of this policy. Reimbursement towards Child Care costs is dependent on the availability of funds.

Approved Youth and Family Involvement Activities

Youth and family members who participate on the following committee(s) may be eligible to receive reimbursement for child care:

- Advisory Board
- Evaluation committee(s)
- Training committee(s)
- Conference committee(s)
- Implementation committee(s)
- Other committee(s) at the discretion of the Institute

In addition, youth and family members may be asked to present information or to train others about the Institute or may be asked to attend trainings on behalf of the Institute. Participation in these activities may also result in reimbursement towards child care costs.

Procedures

The Youth and Family Training Institute will identify and select youth and family members to participate as needed, based on developed criteria, interest and qualifications. The need for child care reimbursement will be considered and discussed with youth and family members prior to final selection.

The Institute will make sure that youth and family members are made aware of this policy prior to their participation.

Youth and family members will complete a letter of agreement (prior to participation) which will outline the expectations and requirements for participation on any committee or for any approved activity that will result in the payment of child care reimbursement.

The process and necessary paperwork for receiving child care reimbursement will be explained to eligible participants.

The Institute will pay the allocated amount to the youth or family member once participation is completed.

The Director of the Youth and Family Training Institute has the authority to approve the payment of child care reimbursement.

Child Care Reimbursement Requirements

Child care reimbursement shall be provided if the following criteria are met:

1. The dependent/s are under the age of 18 and are not in school.

2. The youth/family member is responsible for finding the child care provider.

3. Hours that the child is in school will not be paid for, but hours before and after school may be paid for depending on the travel time required.

4. They youth or family member makes the requests for child care reimbursement to the Director of the Youth and Family Training Institute two weeks prior to any event in which dependent care may be needed.

Participation by youth and family members in Institute events that require out-of-town, out-of-state or overnight participation will be handled on a case by case basis and will be fully explained to the participant(s) prior to their agreement to participate.

Reimbursement Rate for Child Care Costs

The Institute will reimburse the following amount for Child Care if all the above requirements are met:

$10.00 per hour with a maximum of $40.00 dollars a day per family (not per individual child)

Exclusions

The Institute will not reimburse for child care for the following:

- Attendance at any meeting, educational event or support group relating to the family members own child(ren) or to the youth's own care/treatment.
- Any meeting or event not pre-approved by the Institute's director.
- Travel time
- Meal time (unless a working lunch is part of the agenda)
- Overnight time (if applicable)
- Meetings with legislative representatives

Interpretation

The Youth and Family Training Institute is responsible for the official interpretation of this policy. Questions regarding the application of this policy should be addressed to the Institute's Director.

Signed: ____

Director, Youth and Family Training Institute

Effective Date: ________________

Updated: August 2011

APPENDIX D: Advisory Board Meeting Attendance Policy (sample)

Advisory Board Meeting Attendance
Policy #003

Purpose:

The Youth and Family Training Institute recognizes the value and expertise that youth, family and system partner collaboration and participation can bring to program development, implementation, evaluation and governance. This policy outlines attendance expectations for the Youth and Family Training Institute Advisory Board meetings.

Objective

The Youth and Family Training Institute encourages youth, family members and system partners to be active contributors in the development of the Institute through participation on the Advisory Board. Youth, family member and system partner involvement is valued because:

- Family Members provide relevant expertise about the realities of raising a child with behavioral health issues.
- Youth Members provide expertise about living with and managing behavioral health issues.
- System Partners provide expertise about available assessment, treatment, services and systems.
- Mutual sharing and learning among youth, family members and system partners create a unique and worthwhile partnership that will enhance the development of the Institute.

It is known that situations come up for everyone that could prevent attendance at scheduled meetings. However, it is in the best interest of the Institute to develop a core team of youth, family members and system partners that will guide the Institute.

In order for team building, mutual sharing and learning to occur, regular attendance and participation in advisory board meetings are necessary.

Definition:

Regular attendance is defined as attendance at 75% of the Advisory Board's scheduled meetings. As of July 2008, meetings are scheduled monthly. This means that advisory board members must attend nine (9) meeting per year.

Authority:

The Youth and Family Training Institute has sole responsibility for the implementation of this policy.

Procedures

The Youth and Family Training Institute staff will take attendance at each Advisory Board meeting.

If a member knows ahead of time that he/she will not be able to attend a scheduled meeting, they will contact Patricia Turley at 412-856-8781 or via email at turleype@upmc.edu to let her know.

If a member misses three meetings during a year (defined as July 1-June 30), they will be asked to resign from the Advisory Board, but may be encouraged to continue their involvement with the Institute in some other (less frequent) capacity.

Open slots will be filled according to policy 005 (Recruitment process for advisory board members).

Interpretation

The Youth and Family Training Institute is responsible for the official interpretation of this policy. Questions regarding the application of this policy should be addressed to the Institute's Director.

Signed: ____

Director, Youth and Family Training Institute

Effective Date: ________________

Updated: August 2011

APPENDIX E: Advisory Board Selection Process/Responsibilities Policy (sample)

Advisory Board Tri-Chair Selection Process and Responsibilities
Policy # 006

Advisory Board Tri-Chairs
Three tri-chairs will be elected by the Advisory Board Members to include a youth, a family member and a systems partner. This configuration mirrors the composition of the Advisory Board and models a true partnership.

Tri-Chair positions can only be held by a member of the committee who has served at least one year as a regular member and has fulfilled meeting attendance requirements for the past year (attended 8 out of the last 12 meetings annually). OMHSAS and YFTI Staff employees are not eligible to serve in Tri-Chair positions.

Selection and Terms
Advisory Board members elect Tri-Chairs of each committee for two calendar year terms, and chairs will serve until a successor has been duly elected. There must be a minimum of a two-year hiatus before being considered again for the position of Tri-Chair.

In September of each year, current tri-chairs, supported by the YFTI staff, will be responsible for soliciting nominations/approaching individuals who are qualified and willing to serve as a Tri-Chair. Beginning in January 2012, Tri-chair position vacancies will alternate with one being open one year, and two the next.

Election of Tri-Chairs shall be conducted by the October/November meeting, with the term as tri-chair to begin at the January meeting. Election shall be by a simple majority vote of those present and voting, providing a quorum has been reached.

For the initial year of implementation in 2011
Elections in September 2010 to support planning and preparation of tri-chairs for newly defined roles.

Tri-chairs to move into leadership roles as of January 2011. To begin staggering terms to ensure continuity on leadership:

- One tri-chair serves a one (1) year term ending as of December 2011 and is eligible for one more two (2) year term.
- Two tri-chairs serve a two (2) year term then rotate off as of December 2012 and are not eligible for re-election.

Responsibility of Tri-Chairs:

- Work to jointly develop meeting agendas
- Chair committee meetings
- Provide timely review and necessary response to correspondence.
- Provide liaison with the YFTI, UPMC and OMHSAS staff
- Determine, in conjunction with YFTI staff, the need for workgroups/ad hoc groups.
- Assure correspondence necessary to the function of the advisory committee is completed.
- Participate in additional activities as requested by YFTI, UPMC and OMHSAS
- Prepare an annual summary of activity of the Committee

Tri-Chair Vacancy

In the event of a vacancy of a Tri-Chair position, the unexpired portion of the term will be filled by an appropriate youth/family/systems partner person selected by Special Election.

- The current tri-chairs, supported by the YFTI staff will solicit nominations of individuals qualified and willing to serve as a Tri-Chair.
- A ballot of nominees will be presented to the committee
- Election shall be by a simple majority of those present and voting, providing a quorum has been reached.

Committee Workgroups

A. Committee Structure and Membership

   The formation and purpose of Committee Workgroups will be the determination of Committee Tri-Chairs in conjunction with YFTI Staff to assist in issue-focused, task oriented, time-limited work of the committees. Advisory Committee may be appointed to participate in workgroups to assure the necessary representation and expertise needed to meet the goals of the workgroup. When establishing workgroups, attention will be given to workgroup membership composition, with the goal to achieve appropriate representation of stakeholders as well as geographical and cultural representation of members.

   Ad Hoc workgroups may also be convened as needed with volunteer or appointed participation as deemed appropriate by the Committee Tri-Chairs in conjunction with YFTI Staff.

B. Committee Process
   - Committee establishes need for workgroup.
   - Workgroup develops draft timeline and “work product.”
   - Timeline and draft work product are distributed to the committee for comment via email or at regularly scheduled meeting of the committee.
   - Comments considered in final product, and final product distributed to the committee.

IV. Conduct of Business

A. The business and affairs of the Advisory Committees and workgroups shall be managed by the chairpersons. Administrative support and technical assistance will be provided by YFTI Staff.

B. Notice of meetings, including the agenda for the meeting, shall be distributed to the membership not less than five working days if written, or not less than 48 hours if electronically, prior to the meeting.

C. A volunteer will be solicited from the Committee membership to take and transcribe minutes of each Advisory Committee meeting using a preformatted template. Final editing will remain the responsibility of YFTI staff.

D. Voting – Only voting committee members may vote on committee issues. Any action before committees will be presented by motion, seconded, and voted on by members. For voting purposes, a simple majority of the quorum will constitute approval of any motion.

Staff Support

A. YFTI will provide adequate staff to ensure effective committee and subcommittee activity

B. YFTI will provide, at a minimum, the following support functions:
   - Meeting arrangements and set-up
   - Final editing and distribution of meeting minutes and mailings
   - Confirmation of attendance at committee meetings and compilation of attendance records.
   - Maintain records of expenses and travel reimbursement
   - Inter-office distribution of committee business
   - Liaison with Committee Tri-Chairs
   - Travel and overnight arrangements
   - Sunshine notification of meetings

YFTI staff will support committee and workgroup functions and business as required. This includes responding to committee requests for information on any pertinent issues. Appropriate YFTI staff are expected to attend committee meetings.

Signed: ____

Director, Youth and Family Training Institute

Initial Effective Date: December 2010

Updated: August 2011

Updated: October 2012

APPENDIX F: Sample Application Kit for Family Members

Pennsylvania System of Care Partnership
State Leadership Team
Application Kit for Family Members (Please note that there is a separate application kit for youth)
This packet includes an overview of the Pennsylvania System of Care Partnership, an application form for family members, and complete instructions for applying to become a member of the State Leadership Team. (January 2010)

Pennsylvania System of Care Partnership (Partnership)

The Pennsylvania Department of Public Welfare (DPW), Office of Mental Health and Substance Abuse Services (OMHSAS) along with its partners in Child Welfare, Juvenile Justice and the Governor's Commission on Youth and Families are seeking applications from family members who are raising a child or children with behavioral health issues that have also been involved in the child welfare and/or juvenile justice systems to serve on a State Leadership Team. The purpose of the State Leadership Team will be to provide direction and leadership to the Pennsylvania System of Care Partnership.

The State Leadership Team will be comprised of twelve total members. Three of these members will be young adults, ages 18-26, with behavioral health issues that are /have been involved with child welfare and/or juvenile justice. (A separate application form is being used to recruit these young adults) Three members will be family members who are raising a child or children with behavioral health issues that have also been involved with child welfare and/or juvenile justice and six members will be professionals from the behavioral health, child welfare, juvenile justice and the Governor's office.

Pennsylvania System of Care Partnership - Overview

Pennsylvania has been awarded a major grant to develop a System of Care to serve youth ages 8-18 that have serious mental health needs, and their families. These youth are also involved with child welfare or juvenile justice, and are in or at risk of out of home placement. The $9 million grant from the federal Substance Abuse and Mental Health Services Administration (SAMHSA) covers 6 years and will be implemented in fifteen Pennsylvania counties. Through this Grant, Pennsylvania becomes part of the national movement to utilize organized multi-level systems to more effectively serve youth with serious behavioral health challenges, and their families. The Pennsylvania System of Care Partnership will transform the current categorical and fragmented service delivery approach into a comprehensive community-oriented delivery system.

A State Leadership Team comprised equally of youth and family representatives and top officials from Mental Health, Child Welfare, Juvenile Justice, and the Governor's Commission on Youth and Families, will be responsible for the Pennsylvania System of Care Partnership. Comparable youth, family and professional governance structures will also be established in the Partner Counties.

The Youth and Family Training Institute, a division of the University of Pittsburgh and Western Psychiatric Institute and Clinic of UPMC, will support the implementation, monitor, and evaluate the System of Care development in the counties. 15 counties, identified during the planning year on the basis of need, commitment, and readiness will establish the infrastructure to build systems that work together with the youth and family, integrate professional services, and utilize the natural supports that exist in the families and communities throughout Pennsylvania.

The System of Care Partnership will build on and enhance efforts that have been underway in Pennsylvania for several years to integrate and more effectively provide services to youth. Each participating county will utilize the practice model defined by the National Wraparound Initiative to serve at least 50 youth annually, with over 1,000 youth and families to be served during the course of the SAMHSA grant. The ultimate vision is that Pennsylvania will eventually expand the structured approach to System of Care development to all Pennsylvania counties.

1

State Leadership Team

The State leadership Team will be a significant part of making the Pennsylvania System of Care Partnership successful. The purpose of the State Leadership Team will be to provide direction and leadership to the Pennsylvania System of Care Partnership by overseeing the policy development, planning, financing and monitoring. The State Leadership Team will also work closely with the Youth and Family Training Institute Advisory Board to assure coordination between policy development and implementation.

Our goal is to assure that the State leadership Team reflects the diversity of Pennsylvania. We are seeking members of different ages, gender, ethnicity, socioeconomic background and geographic location.

If selected as a member of the Pennsylvania System of Care Partnership State Leadership Team, you will need to attend monthly meetings held in the Harrisburg area. Childcare will be provided if needed, and food expenses as well as travel expenses (tolls and mileage) will be reimbursed. In addition, under certain circumstances, if an overnight stay is necessary, hotel accommodations will be available and paid for by the Partnership. All family member Leadership Team members will be offered a stipend for approved meetings. This stipend is a token of our appreciation for your time and expertise. The amount of the stipend has been determined by the Youth and Family Training Institute Advisory Board, and is based on the length of the meeting and is dependent on available funds.

State Leadership Team Questions and Answers:

How do I become a member of the State Leadership Team?

The first step is to fill out the attached application and send it to:

Laurie Jones
c/o Youth and Family Training Institute
Corporate One Office Park
Building 2, Suite 106
4075 Monroeville Blvd.

Monroeville, PA 15146

Joneslh@upmc.edu
412-802-6639 (W)
412-246-6820 (fax)

Applications will be reviewed by family members who are members of the Youth and Family Training Institute Advisory Board (who will keep all information contained in the application confidential and will not share it with anyone except the selection committee). They will evaluate each applicant based on pre-established criteria, and make their recommendations to the Partnership's Principal Investigator, who will make the final decisions.   It is important that we select State Leadership Team members who represent the diversity of Pennsylvania as well as those who have a significant and extensive understanding of the behavioral health, child welfare and/or juvenile justice systems. Once the final decisions have been made, someone will contact you to let you know if you have been selected.

Please note that there is a separate application kit for young adults who are interested in being on the State Leadership Team.

Professional representation on the State Leadership Team will include:

- Stan Mrozowski (Director, OMHSAS Children's Bureau)
- Richard Gold (Deputy Secretary, Office of Children, Youth and Families)
- Keith Snyder (Deputy Director, Juvenile Court Judges Commission)
- Angie Logan (Children's Policy Specialist, DPW Secretary's Office)
- Ellen DiDomenico (Executive Director, Governor's Commission on Children and Families)
- Mike Pennington Director, Office of Juvenile Justice, Pennsylvania Commission on Crime and Delinquency

Who can become a family member of the State Leadership Team?

Anyone who is raising a child or children (ages 8-26) with mental health issues **and** past/current experience with the child welfare and/or juvenile justice systems can apply to be on the State Leadership Team. Preference will be given to family members with experience participating on other state or local advisory boards. It is important that the State Leadership Team represents the diversity of Pennsylvania.

How many people will be selected to be on the State Leadership Team?

There are three positions for family members on the State Leadership Team (and three for youth/young adults). There will be twelve total members.

How does the selection process work?

The current Youth and Family Training Institute Advisory Board family members will review all applications and make recommendations to the Pennsylvania System of Care Partnership Principal Investigator based on selection criteria. We are seeking members of different ages, gender, ethnicity, socioeconomic background and geographic location. In addition, we are seeking members with a variety of experiences in navigating the behavioral health system in combination with the child welfare and/or juvenile justice systems on behalf of their child.

An advisory board family member may call you during the selection process if there are any questions about your application.

How often will the State Leadership Team meetings be held?

Meetings will be held once a month on a day and time to be determined. Please indicate on the application if there are days or times that you would be unable to attend scheduled meetings. State Leadership Team members are expected to attend all meetings. Occasionally, an additional meeting, training or committee meeting may occur, but you will be notified in advance.

Where will the meetings be held?

The meetings will be held at a location (yet to be determined) in the Harrisburg area.

How much will I be paid?

You will be offered a stipend for each approved meeting that you attend. This stipend is a small way of showing how much we value your input into our discussions. The stipend amount is dependent on the length of the meeting. For a four hour meeting, you will receive $50, as long as funding is available.

When are the applications due?

The application deadline is Tuesday, January 19, 2010.

When will I know if I have been selected as a board member?

Someone from the Pennsylvania System of Care Partnership will contact you to let you know if you have or have not been selected. The notification date is expected to be on or before Friday, January 29, 2010.

If I am selected to be a member of the State Leadership Team, what will I have to do?

You will be expected to:

- Work with other youth, family members and professionals to oversee the development of the Pennsylvania System of Care Partnership.
- Represent the views and voices of family members who are raising a child or children with behavioral health issues with involvement in the child welfare and/or juvenile justice systems to help shape the vision and goals of the Partnership.
- Attend and actively participate in the monthly meetings.
- Attend and participate in all training/education related to the Partnership.
- Attend two out-of-state trainings per year (all expenses will be paid).

My child has a primary diagnosis of Autism Spectrum Disorder. Am I eligible to apply for the State leadership Team?

The Pennsylvania System of Care Partnership is being established to transform the child/adolescent mental health, child welfare and juvenile justice systems. The Bureau of Autism Services is working on developing the system for children with autism. At this time, we are seeking family members who are raising child/children with complex mental health issues who have also been involved with the child welfare and/or juvenile justice systems. While this does not preclude working with children who are on the autism spectrum and their families, it is not a major emphasis.

Pennsylvania System of Care Partnership
State Leadership Team Application Form for Family Members
(*Please continue on a separate piece of paper if more space is needed*)

Personal Information

Name: ____ E-Mail:_______________________

Day phone: ____________________ Evening phone: ___________________ Best time to call: ________________

Address: ____

County and Community where you live: ____

Ethnicity: ☐ African/American/Black ☐ American Indian/Native Alaskan ☐ Asian ☐ Caucasian/White ☐ Hispanic ☐ Other, please describe_____________________

Gender: Male ☐ Female ☐

Work - School - Volunteer Information

Are you currently employed outside of the home? No ☐ Yes ☐

If yes, where do you work and what do you do? ____

Are you now, or have you ever been a member of an advisory board or a board of directors?
No ☐ Yes ☐ If yes, please explain:
____

Are you now, or have you ever been involved in any community/county organizations or on any committees? No ☐ Yes ☐ If yes, please describe: _____________________________________

Availability

Do you have a reliable means of transportation to attend meetings in Harrisburg? No ☐ Yes ☐

Is there anything that will prevent you from attending or participating in the meetings?
No ☐ Yes ☐ If yes, please explain: ____________________________

What days/times are best for you to attend Leadership Team Meetings? Check all that apply.

Mon ☐ Tues ☐ Wed ☐ Thur ☐ Fri ☐

Mornings ☐ Afternoons ☐ Late afternoons ☐ Evenings ☐

Life Experience

How old is your child with mental health issues, and what is his/her current diagnosis?

Please tell us about some of your experiences in dealing with the behavioral health system and the child welfare and/or juvenile justice systems. Again, this information will be kept very confidential:

Have you ever been involved with any behavioral health, child/welfare, and/or juvenile justice youth leadership groups or organizations? No ☐ Yes ☐ If yes, please describe:

State Leadership Team Interest

Please let us know why you want to be a member of the Pennsylvania System of Care Partnership State Leadership Team?

Briefly describe any unique experiences or skills that you have that would benefit this Leadership Team:

References

Please provide one personal and one professional written letter of reference. These letters should not come from a family member or from anyone who is related to you. The reference letters should be brief and should include:

1) Name of the person and their contact information, 2) How they know you and how long they have known you; and 3) Why they think you would be a good addition to our State Leadership Team. The selection committee may want to contact these people by phone. Be sure to include the person's daytime phone number.

Your references may send their letter of reference directly to Laurie Jones (address or e-mail or fax on page 2 above) or you can send them with your application.

Thank you again for your interest in the Pennsylvania System of Care Partnership State Leadership Team.

How did you hear about this opportunity? ____

APPENDIX G: ***Draft*** Guidance on "Engaged in Research" and FWA

Citation: Community PARTners Core and Regulatory Knowledge and Support Core

IRB GUIDANCE FOR INVESTIGATORS
ENGAGING IN RESEARCH WITH THE COMMUNITY

INTRODUCTION

As a growing number of researchers are participating in community-based and community-partnered studies, the be Community PARTners (i.e. the community engagement core) of the Clinical & Translational Science Institute (CTSI) has developed this brief guidance to introduce investigators to some IRB-related regulations to help facilitate implementation of their research in the community.

The United State Department of Health and Human Services (HHS) Office for Human Research Protections (OHRP) is the area of the federal government that applies the rules of research to any federally-funded research or to any research being done at an institution or location which receives federal funding.

This guidance is a synthesis of some of the basic principles involved in conducting research in the community. Every research study has unique situations and characteristics that require consideration by the IRB. Please always work with the University of Pittsburgh IRB to work through specific questions and concerns.

What is an FWA?

The **Federalwide Assurance (FWA)** is a way for an institution such as a University, or research taking place in the community, such as church, school or non-profit agency, to say that they will comply with the rules the government has set up for research.

Why is an FWA important?

When a community-based organization applies for an FWA, they are certifying that they are complying with OHRP regulations. The reason for obtaining an FWA is **for the protection of human research participants**.

Who needs an FWA?

An FWA is necessary whenever an institution or community agency/organization is "engaged in research". An institution is "engaged in research" if they meet the following criteria:

1. Institutions that receive money directly from HHS for human subjects research. [Translation: If your federal research funds are going to a community partner to help with your study, it is likely that they will need an FWA.]

2. Institutions whose employees or agents intervene for research purposes with any human subjects of the research.
   [Translation: If your community partners are doing more than posting flyers about the study, such as being involved in the delivery of an intervention that is part of the study, it is possible that they will need an FWA.]

3. Institutions whose employees or agents obtain the informed consent of human subjects for the research.
   [Translation: If your community partners are obtaining the informed consent of participants, they definitely need an FWA. Note, if a community member (individual) and not an agency is involved, they will

be asked to complete human subjects research ethics training and obtain an individual investigator agreement (see below).]

4. Institutions whose employees or agents obtain for research purposes identifiable private information or identifiable biological specimens from any source for the research. In general, obtaining identifiable private information or identifiable specimens includes, but is not limited to:

    a. observing or recording private behavior;
    b. using, studying, or analyzing for research purposes identifiable private information or identifiable specimens provided by another institution; and
    c. using, studying, or analyzing for research purposes identifiable private information or identifiable specimens already in the possession of the investigators.

    [Translation: If your community partner is participating in data collection and data analysis, unless all the information is de-identified, it is likely they need an FWA.]

References
http://www.hhs.gov/ohrp/assurances/assurances/filasurt.html
http://www.hhs.gov/ohrp/assurances/forms/fwainstructions.html
http://www.hhs.gov/ohrp/policy/engage08.html

Individual Investigator Agreement

As noted above, in some instances, a study may involve community members who are involved in delivery of an intervention or data collection where they are not affiliated with any specific agency. An example might be a community member who is a church volunteer who is able to secure space at one of the local churches, but the church is not engaged in the study. This community member is a research collaborator (i.e., 'engaged in research' as discussed above). In this instance, the community member (the individual) must complete human subjects research training (a series of modules described below) and receive an individual human subjects research certification. **This individual may then be added to your study protocol as a Co-Investigator, if desired by the Principal Investigator or required by the funding agency.**

The Community Engagement Core of the CTSI offers an easy-to-understand human subjects research training intended specifically to help community partners learn about the research process and ethics involved in engaging in research.

Step by Step Checklist:

1. Does the project I am proposing constitute research?
   --check with our University of Pittsburgh IRB if you are not sure.

2. Does the community member I am working with function as an individual or as part of a community/agency organization?
   --if an individual, then follow the Individual Investigator Agreement section above

3. Does the community agency/organization I am working with already have a research ethics board or Institutional Review Board (IRB) to review the study protocol?
   - If no internal IRB exists and you are a University of Pittsburgh/UPMC researcher, contact the University of Pittsburgh IRB for guidance on whether they can be considered the IRB of record for the agency/organization before the agency/organization submits an FWA.

The agency/organization may be required to provide proof of insurance/liability coverage.

4. Does the community agency/organization need an FWA?
   - Is your community partner consenting human subjects?
   - Is your community partner observing and recording behaviors of human subjects
   - Is your community partner collecting identifiable private information on human subjects?
   - Is your community partner using, studying, or analyzing for research purposes identifiable private information or specimens provided by another institution OR already in the possession of you, the investigator?

****Once the community agency/organization has an FWA and they do not have their own IRB, they must work with you to complete an Inter-Institutional agreement with the University of Pittsburgh IRB. PLEASE NOTE: This applies only to studies involving University of Pittsburgh investigators.****

How to file a NEW FWA online?

Electronic submission is required through the OHRP website at http://ohrp.cit.nih.gov/efile/

1. Need to get submission number to file a new FWA
   - Electronic Submission
     http://ohrp.cit.nih.gov/efile/FwaStart.aspx

2. Once you have the submission number return to website and begin filling in the application
   - Electronic Submission
     http://ohrp.cit.nih.gov/efile/FwaStart.aspx

The University of Pittsburgh IRB FWA number is 00006790.

How to update changes to a FWA?

The FWA must be updated within 90 days if changes occur with the following:

Legal name of the institution
The Human Protections Administrator
The Signatory Official

How to file a RENEWAL for an FWA (every 5 years)

- Electronic Submission

http://ohrp.cit.nih.gov/efile/FwaRenew.aspx

- The FWA is effective for 5 years; must be renewed every 5 years, regardless if changes have occurred.

APPENDIX H: Youth and Family Stipends Policy (sample)

Youth and Family Stipends
Policy #001

Purpose:

The Youth and Family Training Institute recognizes the value and expertise that youth and family collaboration and participation can bring to program development, implementation, evaluation and governance. This policy outlines when stipends will be provided to youth and family members.

Objective

The Youth and Family Training Institute encourages youth and family members to be active participants in the development of the Institute. Youth and family involvement is valued because:

- Family members can provide expertise about the realities of raising a child with behavioral health issues
- Youth can provide expertise about living with and managing their behavioral health issues
- Mutual sharing and learning among professionals, family members and youth creates a unique and worthwhile partnership that will enhance the development of the Institute

A youth/family member, who participates in select committees or processes, is eligible to receive a stipend for his/her time spent in this activity.

Definition:

A stipend is a payment provided to a family member and/or youth as an acknowledgement of the value of their time and expertise.

Authority:

The Youth and Family Training Institute has sole responsibility for the implementation of this policy. Payment of a stipend is dependent on the availability of funds.

Approved Youth and Family Involvement Activities

Youth and family members who participate on the following committee(s) may be eligible to receive a stipend:

- Advisory Board
- Evaluation committee(s)
- Training committee(s)
- Conference committee(s)
- Implementation committee(s)
- Other committee(s) at the discretion of the Institute

In addition, youth and family members may be asked to present information or to train others about the Institute or may be asked to attend trainings on behalf of the Institute. Participation in these activities may also result in the payment of a stipend.

Youth and Family Member Qualifications

In order to be eligible to receive a stipend for their time and expertise, youth and family members must have the following:

- Personal knowledge and expertise in managing one's own behavioral health issues OR experience raising a child with behavioral health issues
- Ability to share thoughts and opinions in a group setting
- Ability to attend applicable meetings
- Ability to be respectful of diverse opinions
- Willingness to partner with other youth, family members and professionals to improve the system

Procedures

The Youth and Family Training Institute will identify and select youth and family members to participate as needed, based on developed criteria, interest and qualifications.

The Institute will make sure that youth and family members are made aware of this policy prior to their participation.

Youth and family members will complete a letter of agreement (prior to participation) which will outline the expectations and requirements for participation on any committee or for any approved activity that will result in the payment of a stipend.

The process and necessary paperwork for receiving a stipend will be explained to eligible participants.

The Institute will pay the stipend amount to the youth or family member once participation is completed.

The Director of the Youth and Family Training Institute has the authority to approve the payment of stipends

Stipend Amounts

Stipends shall be provided in the following increments:

- 1-3 hours shall receive $25 (twenty-five dollars)
- 4-6 hours shall receive $50 (fifty dollars)
- 7+ hours shall receive $75 (seventy-five dollars)

Participation by youth and family members in Institute events that require out-of-town, out-of-state or overnight participation will be handled on a case by case basis and will be fully explained to the participant(s) prior to their agreement to participate.

Taxes

Youth and family members who accrue more than $600 per year in stipends will have a 1099 form dispersed to them automatically by UPMC/University of Pittsburgh by January 31 of the year following the delivery of service.

It is the responsibility of the youth and family member to report this income on their applicable tax filings (federal, state, and local).

Youth and family members who do not wish to receive a 1099 form can elect to stop receiving stipends at any point during the year before they have accrued a total of $600 (six hundred dollars) in reportable compensation. Youth and family members who elect to not receive compensation for a meeting will still be reimbursed for travel, lodging, and child care per the Youth and Family Training Institute Policy and Procedures.

Exclusions

The Institute will not pay a stipend for the following:

- Attendance at any meeting, educational event or support group relating to the family members own child(ren) or to the youth's own care/treatment.
- Any meeting or event not pre-approved by the Institute's director.
- Travel time
- Meal time (unless a working lunch is part of the agenda)
- Overnight time (if applicable)
- Meetings with legislative representatives
- Travel, lodging (if applicable), and child care costs will be addressed separately, per the UPMC policy and procedure manual regarding travel.

Interpretation

The Youth and Family Training Institute is responsible for the official interpretation of this policy. Questions regarding the application of this policy should be addressed to the Institute's Director.

Signed: ____
Director, Youth and Family Training Institute

Effective Date: ________________

Updated: August 2011