



HealthPartners® Institute

**Partnering with Patients, Families and Members
to Conduct Patient-Centered Research within a
Learning Health Organization**

Institute for Patient-and Family-Centered Care
July 27, 2016

- ❖ Overview, Tools & Processes
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Director, Research Strategy &
Administration
HealthPartners Institute
- ❖ Experience & Best Practices
Christine Norton, MA
Patient Co-Investigator

Largest Consumer-Governed Non-Profit Healthcare Organization in the Country

- » **22,500**
employees
- » **1.5 million**
members
- » **1 million**
patients



HealthPartners®



Learning Health Care Organization

Medical Group & Clinics

Hospitals

Pharmacy

Medical & Dental Health Plan

**HealthPartners Institute
(Research and Education)**

DENTAL GROUP

HealthPartners Institute

- 200+ clinician and staff researchers
- 300+ staff
- 450 active research studies at any time
- Clinical Trials and Health Services Research

Cancer
Chronic Disease
Health Economics
Maternal & Child Health
Mental Health

Neuroscience
Oral Health
Research Methodology
Critical Care
Center for Memory & Aging



Patient, Family, Member Engagement in Research



HealthPartners®

Mission

“We Seek to Improve Health and Well-being
in Partnership with our
Members, Patients and Community”



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PFM Engagement in Research Experience

Study / Initiative	Patient Engagement
❖ PIONEER Study (Solberg - PCORI)	Christine Norton – Patient Co-Investigator Patient Advisory Council
❖ Hypertension & Thiazides Study (Margolis – NHLBI)	Two Patient Advisors
❖ Hyperlink Study (Margolis - PCORI)	Christine Norton – Patient Co-Investigator Additional Patient Investigator TBD Patient Advisory Council TBD
❖ Patient Reported Outcomes - Organizational Initiative	Patient Partners in Development
❖ Research Strategy and Planning Council (Institute)	Patient Member



Patient, Family, Member Engagement in Research

Resources for Building Infrastructure:

- HealthPartners Patient Engagement Team
 - > 30 Active Patient Partnerships
- HealthCare Services Research Network - Special Interest Group
- Institute Stakeholder Group
 - 3 Senior Investigators (Margolis, Solberg, O'Connor)
 - 2 Senior Project Managers (Tillema, Bergdall)
- HealthPartners Legal, Compliance & IRB Teams
- Institute for Patient-and Family-Centered Care
- Patient Centered Outcomes Research Institute (PCORI)
- Patient Advisory Group: PCORI-funded Project (PIONEER – Solberg)



Patient, Family, Member (PFM) Engagement in Research – Toolkit

- ✓ Planning Checklist with Available Resources
- ✓ Templates:
 - Job Descriptions
 - Recruiting Materials
 - Standard Contracts
- ✓ Sample Interview Questions
- ✓ Best Practices for Meetings
- ✓ Compliance Guide
- ✓ IRB Quick Reference
- ✓ myLearning Online Training & Onboarding



PFM Engagement - Checklist

Process Step	Resources/Templates Available
Determine Need for Study	
Define Role for PFM Engagement	✓ Job Description Templates
Structure the Engagement	✓ Contract Agreement (Consultant Agreement) ✓ Finance: Budget & Payment Mechanism
Determine Privacy / Compliance Training Level	✓ Compliance protocol
Define Requirements for Recruitment	
Review & Select Venues for Recruitment; Review with IRB if Necessary	✓ IRB protocol ✓ Recruitment materials (study summary; flyers, letters, 1-page study summary) ✓ HP/PN PFM Inventory
Complete Application Process & Screen Volunteers using study appropriate questions. Customize screening questions based on method:	✓ Application Form ✓ Job Description ✓ Interview/Screening Questions ✓ Guidelines to Screening (avoid bias)
Select Participants & Finalize Paperwork	✓ Compliance Protocol ✓ Contract Templates
Onboard Selected Participants & Complete Paperwork	✓ Compliance Protocol ✓ myLearning PFM page
Train in Privacy & Security	✓ Compliance Protocol ✓ myLearning PFM page ✓ Checklist for Meeting conduct
Conduct Study	✓ Meeting best practices
Monitor and Evaluate Participation	○ Feedback Form – Patient to PI ○ Feedback Form – PI to Patient
Project End	
Dissemination / Papers / Authors	



PFM Engagement – Job Description

PATIENT ENGAGEMENT COUNCIL POSITION DESCRIPTION

What is the [Study Name] Patient Engagement Council?

What is the purpose of the [Study] Patient Engagement Council?

Who is an ideal PEC Member?

Other valuable skills include:

What do PEC Members do?

Will PEC members be paid?

Additional Benefits of Participating:

Funding information:



PFM Engagement – Recruiting Tools

WE ARE LOOKING FOR PATIENT ADVISORS FOR A NEW KIND OF HEALTH RESEARCH

[STUDY NAME] is a research project being conducted by HealthPartners Research Institute. Our research will focus on improving patient care based on information we receive from patients like you who have **[specific condition or experience in something]**. This is an opportunity for you to help us understand your experience and improve healthcare.

The **[Study Name]** project is working to help patients, caregivers, and their healthcare providers make informed decisions. To do this, we need patients to share their perspectives about living with this condition and their priorities for health research. We are looking for patients to help us by:

[Describe the position(s) briefly]

Participating as a member of our Patient Engagement Council who will participate in formal meetings with other patients and researchers in person and by conference call (paid position).

If you are interested in becoming a member of our Patient Engagement team, please contact **Project Manager** to learn more:

Phone:
Email:



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PFM Engagement – Interviews

- Prior Volunteer Experiences?
- Any experience in the health field? In other Boards or community groups?
- Do you have any prior experience with research?
- Do you have any particular concerns or special interests about health care? (Probe: Such as?)
- Do you feel have experience or feel comfortable speaking in meetings (sharing your story)?
- Please share an experience when you had a different view point or opinion on an issue in a professional or public setting. How did you handle that situation?
- What is your availability for these specific meeting times/frequency?
- Are you comfortable with email / conference calls /computers?
- Do you have any transportation restrictions or issues?
- Additional Study-specific Questions: Topic, Interests, etc.



Patient, Family, Member Engagement in Research - Compliance

Role of PFM in Research	Duties	Compliance Considerations
Advisory Panel	Grant Development Activities Project Meetings No PHI (Confirm) Potential Co-Author (?)	<ul style="list-style-type: none"> • Practices tied to Federal Funding? • Volunteer Orientation / Onboarding practices? • Organizational employee legal requirements (codes, confidentiality, etc.) • Signed volunteer or employment agreement required?
Co-Investigator	Grant Development Activities Project Meetings Data Review or Discussions Co-Author	<ul style="list-style-type: none"> • HR requirements for screening new employees? • Practices tied to Federal Funding? • Volunteer Orientation / Onboarding practices? • Organizational employee legal requirements (codes, confidentiality, etc.) • Signed volunteer or employment agreement required? • Research Privacy & Security / Code of Conduct Training(s) required?
Consultant	Grant Development Activities Project Meetings Data Review or Discussions (Confirm) Co-Author	<ul style="list-style-type: none"> • Practices tied to Federal Funding? • Volunteer Orientation / Onboarding practices? • Organizational employee legal requirements (codes, confidentiality, etc.) • Signed agreement required? • Research Privacy & Security / Code of Conduct Training(s) required?
Focus Group Member	Occasional Meetings to provide feedback No PHI	<ul style="list-style-type: none"> • Practices tied to Federal Funding? • Volunteer Orientation / Onboarding practices? • Organizational employee legal requirements (codes, confidentiality, etc.) • Signed volunteer or employment agreement required?

Patient, Family, Member Engagement in Research – IRB Guidance

Role of PFM in Research	Recruitment Methods (examples)	IRB Requirements
All Roles	EXAMPLE: Investigators aware of a specific patient advisory group supported by the organization can approach the group staff/contact to determine the best way to engage with prospective individuals to inform about the need for a patient advisor on the study team.	<ul style="list-style-type: none"> • Check with your IRB officials
All Roles	EXAMPLE: Investigator or PM approaches a provider(s) at a clinic to suggest appropriate patients to serve in an advisory capacity on a specific study. Provider supplies names of suggested patients and recruitment materials are passed along.	<ul style="list-style-type: none"> • Check with your IRB officials
All Roles	EXAMPLE: Subjects currently active in an approved study are approached by the investigator to inquire as to whether the subject might agree to serve in an advisory capacity for a new study.	<ul style="list-style-type: none"> • Check with your IRB officials
All Roles	EXAMPLE: Lacking specific patient advisory resources, there may be a need to engage a programmer to evaluate patient medical records to find an individual or individuals that may meet the criteria sought for a patient advisor on the study team. Access to charts for this purpose may need IRB review to grant at minimum a partial waiver of consent according to HIPAA to allow access to their chart, and develop a method of contact to make connection with the patient requesting consideration in joining the study team. .	<ul style="list-style-type: none"> • Check with your IRB officials • Do you need to run opt out lists?

Patient, Family, Member Engagement in Research – Onboarding Partners



- Home
- Learning
- Connect
- Custom Pages



Suggested Learning

test video



Check Out



Browse for Training



My Transcript



Calendar



Watch eLearning Video



Contact Us
952-883-5249

Patient, Family, Member Engagement in Research - Communication



Patient Partner Perspective

The PIONEER Study

Measuring Patient Outcomes from High Tech Diagnostic
Imaging Studies

Funded by PCORI (Patient Centered Outcomes Research Institute)

Investigator: Leif Solberg, MD
Co-Investigator: Christine Norton, MA



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Patient Partner Perspective

- ❖ Selecting a Patient Partner
- ❖ Preparing Your Patient Partner
- ❖ Supporting Through the Project
- ❖ General Tips



Selecting Your Patient Partner

Sources for recruiting patient partners

- Existing Patient Advisory Councils
- Healthcare related nonprofit organizations
- College classes for Adults
- Clinicians – by Specialty
- Researchers – prior studies; outside committees

Selecting Your Patient Partner

Helpful Qualities in a Patient Partner:

- Ability to go beyond anecdotal experience and see the big picture
- Curiosity & willingness to learn
- Ability to work well in a group of diverse stakeholders
- Available for research team meetings – often in person
- Available for the duration of the research project
- Confidence to speak out during meetings
- Comfortable with computers: email, webinars, & editing documents
- Phone access

Preparing Your Patient Partner

Partner with Compliance and HR to Determine Agreements & Training Requirements

Meet with the PI & Project Manager & other appropriate co-investigators

Communicate logistics:

- Primary point of contact

- Team member names

- Contact information

- Affiliations

- Roles in the project / Duties of PP

- Financial Compensation

Educate on Specific Research Study:

- Basic explanation of how this type of research works

- Time commitment to participate

- Understandable background articles

- Glossary with acronyms & terminology – this should be a dynamic document



Supporting Through the Process

- Remember the PP is NEW to this process !
- Have pre-meetings to prepare if necessary.
- Pair a new PP with an experienced PP who can mentor.
- Provide ongoing education.
- Be responsive to emails & calls.
- Send printed materials in advance of the meeting.
- Encourage communication/questions/observations .
- Draw the PP into research team discussions.
- Genuine praise & appreciation are wonderful & powerful motivators.
- Gently offer help if it's not going well.
- Hold periodic check-ins:
 - ✓ What is going well & what can be improved?
 - ✓ Is your time being appropriately used?
 - ✓ Any suggestions going forward?



Summary - General Tips

- ❖ Involve the PP from the beginning.
- ❖ Be sure their involvement is meaningful & not window dressing or “box ticking”.
- ❖ Set clear expectations for the PP.
- ❖ Prepare the other team members for working with a PP since this may be new for them.
- ❖ Remember - PPs don't have “institutional history” about research like the rest of the team.
- ❖ Be gentle/tactful when commenting on their ideas & suggestions.
- ❖ If appropriate, ask the PP to present information at a meeting, and offer time to help them prepare in advance.
- ❖ During in person meetings, observe the PP's body language. Be aware of any non-verbal communication.

My Cool & Meaningful Experience



By being involved from the beginning, I felt an integral part of the proposal development and the actual research itself from survey development to editing articles submitted for publication.

I'd done peer reviews for DoD, NCI & Avon Foundation for 20 years but now saw research from the other side. I have a new appreciation as I review proposals!

It was terrific & important to feel accepted from the beginning by the research team.

I learned a lot about Patient Reported Outcomes & interpreting statistics.

I collaborated with two others to write a paper. It was SO cool to be part of my first published paper!!

Research group also has a published paper & another submitted.

More Fun!!

The Hyperlink-3 Study

Pragmatic Trial Comparing Telehealth Care and Clinic-based Care for
Uncontrolled High Blood Pressure

Funded by: PCORI

Investigator: Karen Margolis, MD
Co-Investigator: Christine Norton, MA

Beginning Soon!



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Questions and Comments



Patient, Family, Member Engagement in Research

Thank You!

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