

Building Meaningful Patient Engagement within a Clinical Data Research Network

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WE ARE **OCHIN**



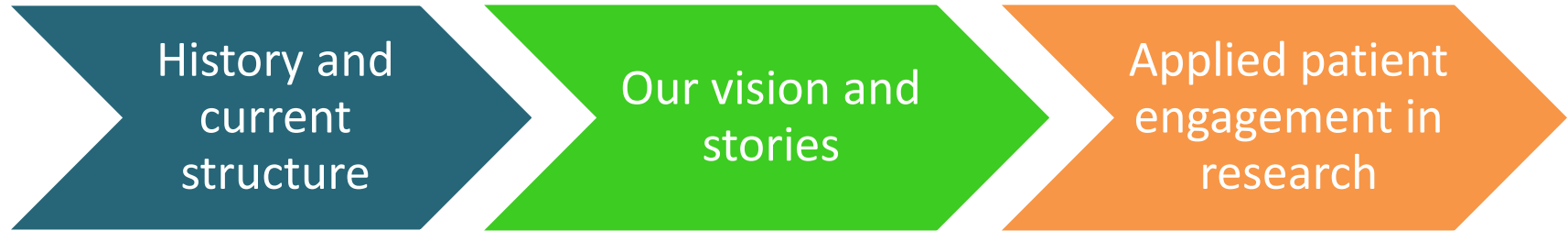
The Patient Voice

“We are all patients – you have the whole community to draw from for your patient advisors. Look to the people who you respect. Reach out to those who inspire you personally to find individuals willing to meaningfully give back from their life experience, because these patients have important opinions on this work. Involve community leaders, scientists, nurses, doctors, clinic managers, educators. Ask for their recommendations. The individuals you find will be a joy to work with and will drive great improvements.”

“Having a small voice in the world of medical research enables me to participate where benefit will eventually be brought to the greatest number of people.”

- Lynn Robbins, Patient Investigator

What we'll talk about today





OCHIN's Vision

Quality, affordable
health care for all

Our Strategy

Provide innovative
technology, research,
and professional
services to our
members

Innovation

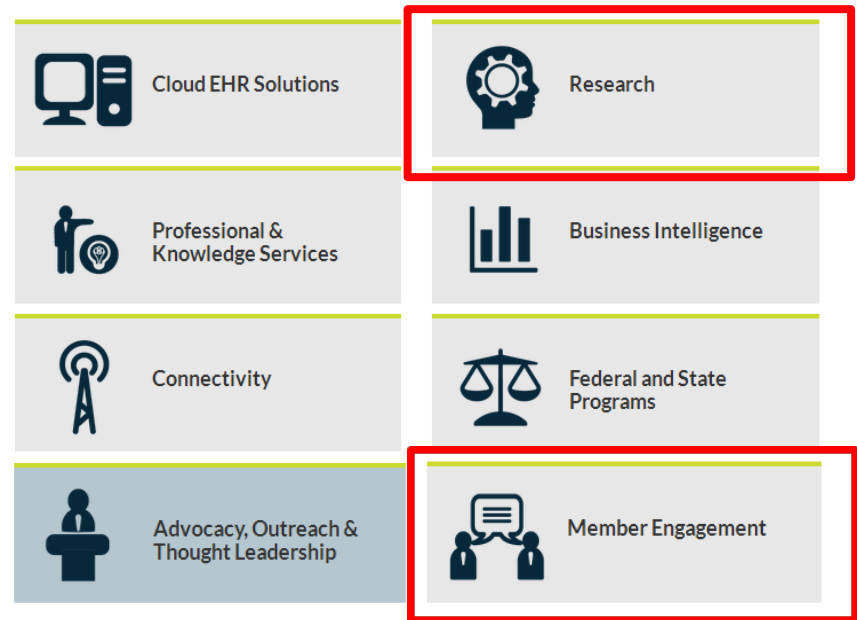
Excellence


Collaboration

Leadership

OCHIN – Research and Engagement in Context

- Founded in 2001, OCHIN is a nonprofit, community-based health information technology collaborative.
- OCHIN serves 94 health systems (FQHCs, community health centers, critical access hospitals, and rural hospitals) in 17 states across the nation, linking >487 community health centers (CHCs) with 4,000 providers serving >2,400,000 patients in one, common electronic health record.





OCHIN is committed to building the nation's foremost community laboratory for health outcomes, policy, and primary care research with vulnerable and underserved populations.

We prioritize studies that examine effective interventions and delivery system improvements...

Understanding

and addressing health conditions with known health disparities common in safety net populations



Improving

health outcomes in safety net populations



Evaluating

interventions that have potential to improve safety net practice



Testing

health IT interventions to improve population health



Implementing

evidence-based practices within the clinic network



OCHIN Research is Unique

One of just a few organizations currently capturing aggregate health care data and statistics of low income and uninsured populations

Most diverse patient databases of Medicaid-insured and uninsured individuals

Centralized expertise and large group of innovative organizations

“Community laboratory” for conducting research at the clinic level

With our partners, we have the largest clinical data set on the safety net in the Nation

	OCHIN Data Set	OCHIN Total with Partners
Number of Unique Patients	1.7 Million	3 Million
% Female	56%	57%
Race		
White	70%	68%
Black	16%	19%
Asian	4%	3%
American Indian/Alaska Native	1%	1%
Not Collected/Unknown	9%	8%
Spanish as Primary Language	18%	20%
At or Below 100% of Poverty Level	48%	51%
Federally Insured	52%	45%

- Partner data has resulted in greater diversification, particularly around Black and Hispanic patients.
- More patients in Florida (non-Medicaid expansion state) has dramatically reduced average federally insured rates in our population.



Engagement Structure and Opportunities

Background

- Patient engagement is now recognized as an essential characteristic of transformed health care systems and patient-centered research.
- Strategies to meaningfully engage patients to improve and enhance research and clinical care are increasingly being implemented.
- Before ADVANCE funding, OCHIN began creating a “patient-centered medical village” among its member clinics serving low-income, vulnerable patients.
- Practice-based research typically engages stakeholders (e.g., clinicians, patients, members) on a project-by-project basis.
- We identified the need for a meaningful patient voice in:
 - Overall research strategy
 - Current projects
 - Research in development

Makings of a Practice-Based Research Network

2011

OCHIN Board approves policy for secondary use of health data for research

2012

OCHIN Patient Engagement Panel created

2013

OCHIN is awarded the first PCORI research grant to Oregon

2014

OCHIN awarded ADVANCE Clinical Data Research Network (CDRN) and built nation's most comprehensive clinical datasets on safety net patients

2014

Jen DeVoe, MD, DPhil, OCHIN Chief Research Officer, elected to the Institute of Medicine

2015

ADVANCE CDRN refunded

2011

Formal OCHIN Research Department formed

2010

OCHIN receives grant from HRSA for research infrastructure (CHARN)

2007

OCHIN's Practice-Based Research Network (PBRN) is created

2005

Kaiser Permanente NW Community Benefit Initiative Fund funds several research projects

2005

OCHIN makes Epic EHR available to Community Health Organizations

2002

OCHIN began providing Epic Practice Management to Community Health Organizations

2000
OCHIN founded

Patient Engagement Panel (PEP)

- The PEP helps to shape the vision of the OCHIN Practice-Based Research Network (PBRN) and ensures that patient voices are heard.
- PEP members are asked to guide research design and implementation, to think about the impact of changes in health care delivery, and to share research findings with stakeholders.
- The PEP includes 18 members from diverse backgrounds and experiences (urban/rural, race, age, gender, clinic board members, peer health educators).



Patient Engagement Panel



18 members (remote and local)

How Did We Do It? 2010-2014

Initial Planning

1. Determined the role of the PEP with input from PBRN leadership
2. Identified eligible patients to serve on the PEP
3. Patient Co-Founders recruited

Development

1. Collaboratively developed a member manual and agreed on PEP member compensation
2. Held strategic planning meetings to set vision
3. Developed strategy to raise awareness about the PEP
4. Patient co-presenters for NWRPCA, CCPH, IPFCC, etc.
5. Further recruitment

Sustainability

1. Hired full time Patient Engagement Coordinator
2. Incorporated patient engagement into institutional strategies and leadership structures
3. Budget for patient engagement activities
4. Training and ambassador model initiatives kicked off
4. Further recruitment

The Patient Voice

Why is it important to you to have a patient voice in health care?

“My focus is doing all I can to bring affordable health care to all poor and underserved people. As a Hurricane Katrina survivor, I have personally known too many people who passed away due to inadequate health care. More people are now eligible for health care, but waiting for an open appointment is still too long. I've heard many people on the bus and in other public areas talk about lack of affordability. They don't understand words and/or procedures and have many, many frustrations. Culturally appropriate health care would be a good place to start. Traditional health care workers need more recognition.”

- Kay Dickerson, PEP Founding Member, Patient Investigator and PCORI Ambassador

The Patient Voice

Why is it important to you to have a patient voice in health care?

“I have been interested in understanding more about health care systems ever since I was wounded by shrapnel in Vietnam. I spent six months recovering from my injuries—half of the time in Vietnam and half in Okinawa. During that time, I learned how hospital systems worked and how to interact with doctors. Since then, I cared for my aging parents, which led to a deeper interest in the medical field. I really wanted to understand how I could do more for them and help them. Most recently, I lost a girlfriend who passed away from a pulmonary embolism. Her loss stirred me to be more passionate about patient advocacy, and I began to explore patient advocate groups. In 2014, I joined OCHIN’s Patient Engagement Panel and the VA’s Civic Veterans Advisory Council.”

- John Lind, ADVANCE Advisory Council Representative and Patient Investigator

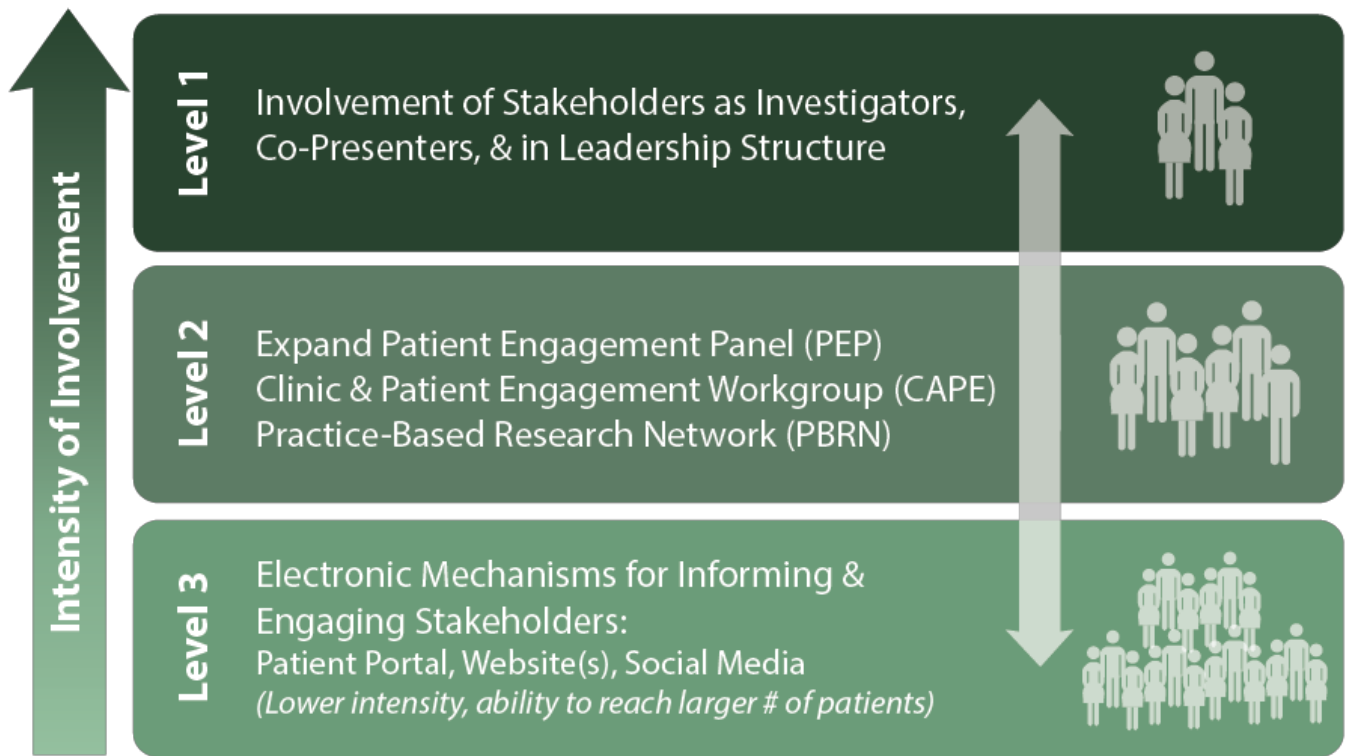
The Patient Voice

Why is it important to you to have a patient voice in health care?

“During my schooling and work history as a CNA, scrub technician, and patient transporter, I’ve realized that our system does not truly hear what patients are trying to say. I live with type 2 diabetes and my sister was recently diagnosed with type 1 diabetes. We know all too well the risks and dangers of health problems getting out of control. My sister and I often say that ‘we want to manage our diabetes instead of letting our diabetes manage us.’ This begins by helping clinic staff and doctors so they can help their patients. As an African-American woman representing patients whose voice has not been heard often enough, I’m very interested in advocating for more effective care that can reach patients who represent diversity of race, ethnicity, socioeconomic status, language, geography, gender, and education.”

- Sele D’Amato, Patient Investigator

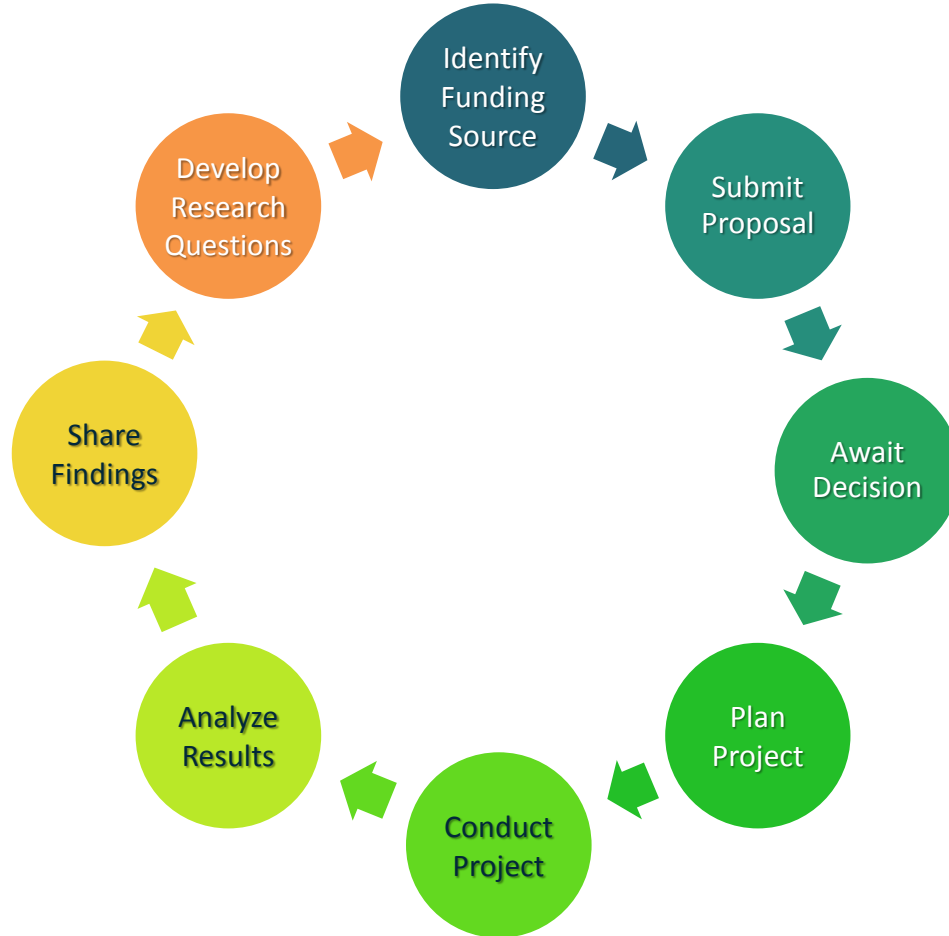
Our Approaches to Engagement



Patient Engagement on a Research Proposal



Research Lifecycle (More Engagement Needed!)





Applied Patient Engagement in Research

Real-world Applications in Research

- How do researchers and patients collaborate on research projects?
 - IMPACCT Kids' Care
 - CATCH-UP
 - MyPreventiveCare
 - ADVANCE



IMPACCT Kids' Care

- Innovative Methods for Parents And Clinics to Create Tools for Kids' Care (IMPACCT Kids' Care)
- Funded by the Patient-Centered Outcomes Research Institute (PCORI)
- Background:
 - Stable health insurance facilitates access to health care for children
 - Coverage gaps are associated with unmet health care needs and poor health outcomes
 - Despite federal initiatives to increase coverage, millions of US children remain uninsured or experience frequent gaps
 - Patients on public insurance must regularly reapply to maintain coverage, often leading to coverage gaps
 - Primary care practices benefit when insurance gaps are minimized and patients remain consistently insured



IMPACCT Kids' Care: Key Questions

1. How can patients' families, medical informaticists, and FQHC staff be engaged in the development of HIT tools to support health insurance outreach?
2. How can HIT resources be used, within the FQHC setting, to reach uninsured children and those at risk for losing coverage?



IMPACCT Kids' Care: Family Interviews

- Health insurance is important to families
- Family challenges included:
 - Different coverage end-dates for different children in the family
 - Re-application letters sent to old addresses
 - Paperwork volume
 - Language and literacy barriers
- Families want clinics to assist them
- Families were comfortable with clinics keeping track of insurance information
- Communication strategies families approved of were:
 - Telephone
 - Text messages
 - Letter or email
 - Personal health record

CATCH-UP

- Community-based HIT Tools for Cancer Screening and Health Insurance Promotion (CATCH-UP)
- Funded by National Cancer Institute
 - Spread the IMPACCT project tools to 12 clinics, targeting adults with public insurance
- Patient engagement:
 - Project design
 - Refining qualitative tools
 - Interpreting results
 - Dissemination

MyPreventiveCare

- Funded by National Cancer Institute
- Hypothesizes: adding higher levels of functionality (*MyPreventiveCare*) to patient portals will better inform and activate patients
- Outcomes measured:
 - Shared decision-making
 - Delivery of preventive and chronic care
 - Percent of patients who use patient portals
- Patient engagement:
 - Learning collaboratives with clinic and research staff
 - Refining tool design and layout
 - Dissemination



ADVANCE Clinical Data Research Network

- OCHIN leads the Accelerating Data Value Across a National Community Health Center Network (ADVANCE) Clinical Data Research Network (CDRN), in partnership with Health Choice Network and Fenway Health.
- Funded by the Patient-Centered Outcomes Research Institute (PCORI)
- The CDRN reaches 22 states, achieving a truly national footprint in its robust engagement of patients, clinicians, health systems, and researchers.
- Partners
 - American Academy of Family Physicians, Robert Graham Center
 - Care Oregon
 - Fenway Health
 - Health Choice Network
 - Kaiser Permanente NW Center for Health Research
 - Legacy Health
 - Oregon Health & Science University

ADVANCE Patient Engagement: Cohort Survey

- ADVANCE patient advisors co-developed a clinical health survey (also assessing research interest) conducted across OCHIN clinics via patient portal.
- Survey data including over 13,280 patient respondents and a response rate of over 20% of the denominator of patients active on the portal.
- Patient advisors conducted rigorous usability testing, resulting in recommendations to make the survey more visible and purpose more relevant for patients.



ADVANCE Patient Engagement

ADVANCE patient advisors provide ongoing guidance to improve research recruitment, retention and transparency. Some examples include:

- The PEP founding member was a featured patient ambassador author on the PCORI national blog, where she described the influence that PCORI has had on the work of ADVANCE and her perspectives on clinical research.
- Patient co-authors have advised and guided accepted manuscripts, including key reviews and contributions from PEP members and co-authors with lived experience of the condition of study.

ADVANCE Patient Engagement

- ADVANCE patient investigator guidance resulted in changes to proposal methodology for patient-reported outcome (PRO) measures, based on the level of burden patients with the condition of study might be willing to accept.
- Patient advisor and PEP guidance resulted in a change of a proposal's primary outcome measure following stakeholder investigator calls and proposal reviews.
- Of 29 active research projects at OCHIN (as of April 2016), PEP members have increased their involvement as patient co-investigators, with nine PEP members affiliated with more than 22 proposals and awarded projects.
- Research Operations staff and PEP members have co-developed our engagement structure to maximize and streamline patient impact from project kickoff.

PCORI Pipeline to Proposal Award

- An OCHIN PEP member successfully received a PCORI Pipeline to Proposals (P2P) award in April 2015: “Setting the Stage for Patient Involvement: Connecting Patients with Periodontal Disease.”
- Project has moved from successful PCORI P2P Tier I funding to successful Tier II funding in April 2016.
- PEP members provided guidance on P2P project development, review of potential recruitment materials and processes.
- More project information at PCORI P2P Award website under [“Setting the Stage for Patient Involvement: Connecting Patients with Periodontal Disease.”](#)



More Information

- DeVoe JE, Angier H, Likumahuwa-Ackman S, Hall J, Nelson C, Dickerson K, Keller S, Burdick T, Cohen DJ. (2014) Use of Qualitative Methods and User-Centered Design to Develop Customized Health Information Technology Tools within Federally-Qualified Health Centers to Keep Children Insured. *Journal of Ambulatory Care Management*. 2014 Apr-Jun;37(2):148-54. <http://pbrn.ahrq.gov/events/harnessing-health-information-technology-assist-individuals-and-teams-practical-insights>
- Arkind J, Likumahuwa-Ackman S, Warren N, Dickerson K, Robbins L, Norman K, DeVoe JE. (2015) Lessons Learned from Developing a Patient Engagement Panel: An OCHIN Report. *The Journal of the American Board of Family Medicine*. 2015 Sep 1;28(5):632-8. <http://www.jabfm.org/content/28/5/632.full>

Expanding the Patient Engagement Panel

Membership Sources

- Collaborate with existing contacts at member clinics (e.g., Patient Advocates)
- Recruit outside OCHIN clinic membership
 - Research project networks
 - Community groups

Recruitment Tools

- Borrow from existing strategies of:
 - Member clinics
 - Patient advisory groups
 - Legislative councils
- Materials co-created by Engagement Coordinator and PEP members

PEP Recruitment Materials

It's time for **patients** to have a voice
in national healthcare conversations.



Join a Patient Engagement Panel

WE ARE **OCHIN**

You bring a valuable perspective to the national conversation surrounding healthcare delivery and research.

Share that perspective and help shape future programs by joining OCHIN's Patient Engagement Panel, and contribute your thoughts on:

- Research questions
- Changes to healthcare processes and their Impact on patients
- Project communication to the general public
- Patient recruitment for studies
- Health technology

OCHIN is a nonprofit healthcare innovation center designed to provide knowledge solutions that promote quality, affordable healthcare to all.

www.ochin.org

Details:

- You will receive gift cards for time spent during PEP meetings.
- The Patient Engagement Panel meets monthly for one hour and focuses on primary care research and the patient perspective.

Interested?

Email or call Nate Warren, OCHIN Patient Engagement Coordinator, for more information about getting involved today: warren@ochin.org or 503.943.2568.

Measuring Patient Engagement

- Assessment of engagement work has included an external evaluation conducted throughout Phase I of the ADVANCE clinical data research network.
- Engagement is evaluated through both process measures (e.g., attendance, number of co-investigators) as well as outcome measures, such as documenting patient testimonials on the value of research engagement; tracking patient guidance provided to network activities; and in what capacity feedback has impacted projects throughout the research lifecycle.
- We continually look to refine our metrics on what constitutes "successful engagement" and how we approach this process differently based on the audience.

Evaluation: Lessons Learned and Future Priorities

- “Overall, the findings show that the ADVANCE team has a working governance process in place, partners have been meaningfully engaged, and the core leadership is perceived as effective.”
- “Key considerations for engagement for Phase II included providing patients with ongoing training opportunities related to medical terminology, computer terminology, and health literacy and working with partners to understand the diversity of the patient population they serve and tailor messages in a culturally competent manner.”



ADVANCE Phase II Engagement Priorities:

Training:

- This priority includes training resources for all stakeholders (e.g. patients, clinicians, health systems leaders). In response, ADVANCE has purchased the CITI Program Training for Responsible Conduct of Research for utilization by all stakeholder groups.
- Research engagement staff are working with PEP to facilitate completion of the CITI training module and certification.
- PEP patient leaders are also co-developing training resources (from Level 3 to 1, including investigator training) in partnership with OCHIN's training subject matter experts and partner PCORnet CDRNs to be provided via web (websites, videos) and in person.

ADVANCE Phase II Engagement Priorities:

Ambassador Model:

- Our PEP and PBRN engagement structures are expanding their reach through utilization of an ambassador model.
- Working with the Oregon Clinical and Translational Research Institute (OCTRI), we are using their model for advocacy within community advisory boards to recruit more PEP/PBRN members, co-investigators and broaden our reach to the larger communities in which OCHIN member sites serve.
- We recently used this peer-to-peer model to engage a non-ADVANCE affiliated patient with a specific opioid-treatment background into an ADVANCE research proposal as a new patient co-investigator. An established ADVANCE patient investigator co-led the successful recruitment effort for this role in collaboration with the network's Engagement Coordinator.

ADVANCE Phase II Engagement Priorities:

Dissemination:

- Beyond traditional scholarly dissemination approaches (e.g. conferences, manuscripts), we are focused on efficient and effective ways to widely disseminate PBRN research findings as a critical component of accelerating the translation of research into practice.
- Social media strategies, including podcasts and blogging, have the potential to augment the reach of research beyond traditional publication venues.
- We are committed to enhancing public trustworthiness both as an organizational and ADVANCE-specific priority. This requires thoughtful approaches towards dissemination via blogs and podcasts that complement scholarly publications being written and using posts to communicate findings about recently published papers to broad community and patient audiences.

Discussion and Recommendations

1. *What are the best ways to identify patient representatives?*
2. *How to engage patients in designing and conducting research?*
3. *What are the observed benefits of patient engagement?*
4. *What are the harms and barriers of patient engagement?*



Thank you!

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Share that perspective and help shape future programs by joining OCHIN's Patient Engagement Panel, and contribute your thoughts on:

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- Health technology

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Details:

- You will have the opportunity to receive gift cards in recognition of time participating in Patient Engagement meetings.
- The Patient Engagement Panel meets monthly for one and a half (1.5) hours and focuses on primary care research and the patient perspective.

Interested?

Email or call Nate Warren, OCHIN Patient Engagement Coordinator, for more information about getting involved *today*: warrenn@ochin.org or 503.943.2568.

By-Laws: OCHIN Patient Engagement Panel (PEP)

OCHIN Mission Statement and Work

OCHIN is a nonprofit healthcare innovation center designed to provide knowledge solutions that promote quality, affordable healthcare to all. Transforming healthcare to improve outcomes and reduce costs demands both innovation and collaboration. It takes individuals and communities working side-by-side to design relevant and reasonably priced information technology and data solutions that can be shared across the healthcare continuum.

Patient Engagement Panel (PEP) Vision Statement

Patients offer important opinions and suggestions regarding healthcare, as well as experience and information from the patient perspective. The Patient Engagement Panel (PEP) will ensure that patient voices are heard. PEP members will work with policy makers, providers, and researchers to improve patients' healthcare experiences. PEP members will also help to shape the vision of the OCHIN Practice-Based Research Network (PBRN).

Patient Engagement Panel Purpose

PEP members will be asked to share their thoughts on their experiences with the healthcare system as regards:

- Research questions
- Changes to healthcare delivery and how it impacts patients
- How to best share information with the general public
- How to best recruit patients for studies
- Health technology

A member of the Patient Engagement Panel can expect to:

- Attend monthly meetings to share their thoughts, opinions and experiences about different healthcare topics.
- Provide input, as requested, on a variety of topics, such as patient communication materials, research proposals, recruitment models, changes to how clinics work, and sharing project findings.

Why Join the Patient Engagement Panel?

- **Work together with healthcare information technology and researchers** to build better research studies and help people live healthier lives.
- **Gain insight and understanding of how medical research** is done and what sort of research is taking place in doctor's offices.
- **Help OCHIN present research findings to patients, caregivers and patient communities** in an accessible, understandable and available manner by shaping the way people find out about these results.

Recognition for participation:

PEP members have the opportunity to receive gift cards in recognition of participating. You will receive gift cards based on the time you spend with us:

Hours Spent Working with Us	Gift Card Amount <i>(To a Department Store of Your Choice)</i>
1-3 hours	\$25
4-6 hours	\$50
7-9 hours	\$75
10-12 hours	\$100
13-15 hours	\$150

Patient Engagement Panel Structure

The PEP strives to include patients from all walks of life. PEP members may represent OCHIN member sites, other healthcare organizations, and/or community groups locally and nationally. The OCHIN Patient Engagement Coordinator will work with members to set agendas and schedule meetings. The PEP meets once a month for one and a half (1.5) hours at OCHIN headquarters in Portland, Oregon. Some members will participate via toll-free calls and screen-sharing technology.

Norms and Expectations

- Treat each other with dignity and respect
- Make every effort to come to meetings and events on time, either in person or through participation via screen-sharing technology
- No interrupting or “cross-talk”
- Refrain from cursing, swearing, or using derogatory language

How Do I Become Involved?

For more information, please contact Nate Warren, Patient Engagement Coordinator at OCHIN, at warrenn@ochin.org, or by phone at 503.943.2568.

Signature of Member

I have read and agree with the Patient Engagement Panel by-laws and have signed and printed below.

Signature of patient, or legal representative

___/___/___
Date

Printed name of patient, or patient’s legal representative

Legal representative’s relationship to the patient

Messaging Template for Patient Engagement Panel Recruitment

Thank you for being part of OCHIN's Patient Engagement Panel (PEP) initiative. The materials provided will help you reach out to your community, and include:

- Suggested email content (below), please feel free to personalize to your patient's needs.
- A poster (provided with this document).
- PEP By-Laws (provided with this document).

Patients have an important perspective as recipients of care and community members. The panel strives to be representative of all patients, including (for example): persons coping with chronic disease; a mix of ages, genders, race, and ethnicities; and those with any and all insurance statuses. The PEP gives patients a way to actively advise and guide decision makers, providers and researchers in work to improve patients' healthcare experiences and treatment options. Patient PEP members are sought out to share their insights and suggestions on issues such as:

- Research questions
- Changes to healthcare delivery and how it impacts patients
- How to best share information with the general public
- How to best recruit patients for studies
- Health technology

We ask that you coordinate your outreach and any questions you may have with OCHIN's Patient Engagement Coordinator, Nate Warren, warrenn@ochin.org, 503-943-2568.

Thank you in advance for your help in building these patient engagement panels, and allowing patients to contribute to these important conversations being held across the nation.

Email Template:

SUBJECT LINE: Lend your voice to the national healthcare conversation- Join a Patient Engagement Panel.

SUGGESTED COPY:

Dear _____,

You bring a valuable perspective to issues surrounding healthcare delivery. We are writing to encourage you to share that perspective with other patients and community members. By joining OCHIN's Patient Engagement Panel you can help shape the future.

What Will I Do as a Member of this Panel?

This panel (or "group") includes patients like you who have an important point of view to offer. The Patient Engagement Panel gives patients a way to actively advise and guide decision makers, providers and researchers in work to improve patients' healthcare experiences and treatment options. Patients are sought out to share their insights and suggestions on issues such as:

- Research questions
- Changes to healthcare delivery and how it impacts patients
- How to best share information with the general public
- How to best recruit patients for studies
- Health technology

What Else Do I Need to Know?

- Patients will meet once a month for one and a half (1.5) hours. Meetings will be in person at OCHIN Headquarters in Portland, Oregon, or via conference call and screen-sharing solutions.
- Patients may choose to be "on-call" to answer questions about research studies. If you do this, you will be contacted no more than 4 times per year.
- Patients have the opportunity to receive gift cards in recognition of participating.

For more information, please contact Nate Warren, Patient Engagement Coordinator at OCHIN, at warrenn@ochin.org, or by phone at 503.943.2568.