PORTAL Patient Engagement Council (PEC)
Member Application Packet

Developed by:
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On behalf of the PORTAL Patient Engagement Council (PEC) Leadership Council
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This toolkit was developed in full partnership with the PORTAL Patient Engagement Council (PEC) patient stakeholders. These materials may be used to help engage patients as research partners. The PEC is no longer a funded or active group. If you would like to reach out to one of the PEC members to engage them in a future project, please email Carmit McMullen, PhD, Senior Investigator, Kaiser Permanente Center for Health Research: Carmit.McMullen@kpchr.org.
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INTRODUCTION

Application
All applicants to the PORTAL PEC will receive information about PORTAL, the role of the PEC in PORTAL, and the core responsibilities of PEC members (job description), including time commitment and compensation. Applicants will complete an application form and any other supporting materials (e.g., a resume; documents, resources, or links that demonstrate related work).

Interview
A small panel composed of the PEC team leads and one representative PEC member will interview all qualified applicants to the PEC. The interview will include questions about related work in personal or professional health advocacy or research, experience working on a team, and flexibility (see Appendix for draft interview questions). Qualified candidates will move on to the selection process.

Selection Process
The 3-member interview team will present qualified candidates for PEC membership to the entire PEC for final review and approval.

ONBOARDING

New PEC members will participate in an onboarding process. Upon joining, each new member will receive a welcome letter, conflict of interest statement, and set of orientation materials describing PORTAL and the mission and vision for the PEC; PEC role and responsibilities, including time commitment; and core trainings for patient and caregiver research partners. New members will meet with the Co-Leads in a 2-hour webinar to review their skill level and experience related to the PEC role, and receive core training. Additional training resources will also be suggested for another 5 hours of self-study.

Orientation of new members will also include an introduction to the team and pairing up with a current PEC member mentor that will serve as a partner to support the new member in adjusting to the Council. Orientation will include how to be an effective member of the Council, how to communicate issues and concerns effectively, and how to work in a collaborative environment with individuals with diverse skills and interests.

EXPERIENCE ASSESSMENT

Assessment of the skill level, experience and expertise of the PEC will provide us with the opportunity to engage individual members in task areas where they are most qualified, have the desire to enhance their learning or feel comfortable working on the team. The framework used for this assessment is Patricia Benner’s model, from Novice to Expert (see pages 11-12 for more information).
WHAT IS PORTAL?

Patient Outcomes Research to Advance Learning (PORTAL) is a collaboration of four healthcare delivery systems—Kaiser Permanente, Group Health Cooperative, HealthPartners, and Denver Health—and their 11 research centers. These partners are conducting research comparing the effectiveness and safety of preventive, diagnostic, and treatment options for:

- Patients with a diagnosis of colorectal cancer
- Adolescents and adults with severe congenital heart disease (CHD)
- Adults who are overweight or obese

The PORTAL network represents nearly 11 million members in nine states and the District of Columbia. The network is new. During 2014 and 2015 it will identify high-priority research questions for each of these patient groups. This work will help us develop a system for conducting research about other health conditions in the future.

Patients, families, and healthcare providers frequently make healthcare decisions without information about which approach would be best, given their particular situation and goals. To address this issue, we will produce evidence that is useful for patients, caregivers, and their healthcare providers so they can make more informed healthcare decisions.

How will we make sure that our research addresses the needs of patients and providers?

We are bringing together patients, healthcare providers, and health system leaders to participate in key decisions. We have created three councils to advise us: a Patient Engagement Council, a Clinician Engagement Council, and an Operational Engagement Council. We are also partnering with two national patient advocacy groups (Fight Colorectal Cancer and the Adult Congenital Heart Disease Association), an online patient community organization (Smart Patients), and our health system members to ensure our research meets the needs of those we serve.

Who is funding PORTAL?

The Patient-Centered Outcomes Research Institute (PCORI) recognizes that the nation does not have the capacity to conduct research quickly and efficiently. PCORI invested more than $100 million to create a national infrastructure (PCORnet) for conducting research that will significantly increase the information available to healthcare decision makers and speed up delivery of that information to people who need it the most. PORTAL is one of the clinical data research networks in PCORnet helping to fulfill this mission.
WE ARE LOOKING FOR PATIENT ADVISORS
FOR A NEW KIND OF HEALTH RESEARCH

PORTAL is a research network of health plans that is conducting research that focuses on improving care based on the needs and experiences of patients with three important health conditions:

- Colorectal Cancer
- Severe Congenital Heart Disease
- Overweight/Obesity

PORTAL 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 these conditions and their priorities for health research. We are looking for patients to help us as:

- Members of our Patient Engagement Council who will participate in formal meetings in person and by conference call (paid position)

If you are interested in becoming a member of our Patient Engagement team, please call XXXXX XXXXX to learn more:

Phone: (XXX) XXX-XXXX
Email: XXXX@XXXX.XXX
PATIENT ENGAGEMENT COUNCIL POSITION DESCRIPTION

What is the PORTAL Patient Engagement Council?

- The Patient Engagement Council (PEC) will help our collaborative health research network conduct research that is important to patients with the three health conditions we will study: colorectal cancer, congenital heart disease, and overweight/obesity.
- The PEC will include a total of 12 members, four patients with each of the health conditions we will study.
- To represent each health condition, we will recruit three patients from a PORTAL health system and one representative from a patient advocacy organization.

What is the purpose of the PORTAL Patient Engagement Council?

The PEC will help to set up the PORTAL network and shape its future development by:

- Identifying outcomes and research questions that are important to patients.
- Providing feedback on important aspects of governing the network, such as privacy and confidentiality, informed consent for the collection of tissue or blood samples and returning research results to participants.
- Collaborating with PORTAL staff to include larger communities of patients in key discussions.
- Facilitating communication between PORTAL and broader patient/community audiences.

Who is an ideal PEC Member?

PEC members will be patients or caregivers who have experience with colorectal cancer, congenital heart disease, or overweight/obesity. We are looking for people who have:

- The ability to provide input on how communities think and feel about a variety of research issues.
- An aptitude for making decisions and reaching consensus as part of a group process.
- An ability to advocate for the patient perspective as well as compromise and collaborate.

Other valuable skills include:

- Familiarity with health research.
- Experience representing a patient constituency at the community level or higher, as part of multi-stakeholder groups, or as an advisor to a health system.
- Experience facilitating communication between researchers and a patient community.
- Position in your community that allows you to communicate with others.
What do PEC Members do?

- Commit to participating on the PEC on an annual basis.
- Attend a bi-annual in-person meeting in Oakland, California.
- Participate in orientation and training sessions to gain the required skills and knowledge to most effectively serve on the PEC.
- Participate in webinars with the full PEC and with PORTAL-affiliated groups.
  - Review materials and gather feedback from others in your community in preparation for the webinars (if applicable).
  - Provide guidance and work to build consensus about decisions during the webinars.
  - After webinars, review summaries of discussions and decisions from webinars.

Will PEC members be paid?

- PEC members are paid collaborators.
- Each member will be paid $40.00/hour for their work on the Council.
- All travel costs are paid by the PORTAL grant.
PATIENT ENGAGEMENT COUNCIL (PEC) MEMBERSHIP APPLICATION

Date: ______________

Name: __________________________________________

Address: __________________________________________________________________________

Email Address: _____________________________________________________________________

Day-Time Phone ______________ Home Phone _______________ Cell Phone ________________

If you are a patient, what is your diagnosis? ____________________________________________

If you are a family member, what is your loved one’s diagnosis? ____________________________

Tell us more about yourself and your experience (attach a resume if relevant). Use a separate sheet of paper if needed.

__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

Why do you want to be involved in the Patient Engagement Council (PEC)?

__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

Area(s) of expertise/contribution you feel you can make. If you have participated in any other organizations or committees, please share some examples. These may be from work, community or church.

__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

Other volunteer commitments _________________________________________________________
Is there anything else you would like us to know?

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

Thank you for taking the time to complete this application! Please return this completed form to:

PEC
Name: XXXXXXXX
Phone: XXXXXXXX
Email: XXXXXXX

Prior to participating in the PEC you will be asked to sign a confidentiality statement and complete an orientation program.

Date                               Signature

=================================================================================================

For Council Use

__ Nominee has had a personal interview with XXXXXXXX Date: _____________

__ Nominee reviewed by the committee. Date: _________________________

__ Nominee attended a Council meeting. Date: _________________________

__ Nominee interviewed by the Council. Date: _________________________

Action taken by the Council ____________________________________________
CONFLICT OF INTEREST STATEMENT

PEC members must avoid potential conflicts of interest, or the appearance of conflicts of interest, as a consequence of involvement in commercial, private, or government entities that compete with or might appear to benefit from the research program.
SKILL LEVEL ASSESSMENT FOR CANDIDATES FOR THE PORTAL PATIENT ENGAGEMENT COUNCIL (PEC)

Patricia Benner is a nurse researcher and theorist who developed this model using the Dreyfus Model of Skill Acquisition (Benner, 1982). Benner uses five levels to describe the skills necessary to gain proficiency among nurses. This model is transferable to other disciplines (Dreyfus, 1981; Baltimore, 2004). The levels are Novice, Advanced Beginner, Competent, Proficient, and Expert. Using this model to assess new members will provide the team with knowledge of the members’ skills and experience level; more importantly, it will provide new members with an opportunity to acknowledge where they are along the continuum and may reduce the stress level associated with feeling underqualified or not feeling valued. Each individual will know their comfort zone and be able to work in areas or on projects and tasks where they feel they can make the best contributions based on the goals of the Council. A comprehensive orientation is another opportunity to promote success and retention for new members.

<table>
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<th>LEVEL</th>
<th>PEC MEMBER CHARACTERISTICS</th>
<th>TRAINING IMPLICATIONS</th>
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| NOVICE             | Has transferable skills but has not been involved in research activities (e.g., has not read a research article, conducted a literature review, presented on research publicly, critiqued a research proposal or paper); is not familiar with group process or with discussing own healthcare issues. | Conducting a literature search  
Writing research articles or proposals  
Writing a research critique  
Engaging in group process  
Basics of public speaking  
Understanding healthcare advocacy & patient engagement |
| ADVANCED BEGINNER  | Has minimal experience: speaking/presenting information publicly, has none/some exposure engaging in group process, has read at least one and/or been exposed to an article critique related to research material, has none to minimal experience with conducting a literature search, is minimally comfortable discussing or advocating for own healthcare issues. | All of the above, plus related advanced learning opportunities. |
| COMPETENT          | Has presented publicly, has read and critiqued a research article, can conduct a literature search, has presented information publicly, is comfortable discussing or advocating for own healthcare issues, and those of related groups. Needs more opportunities to gain experience and proficiency | Updated training where needed to improve existing skills and competencies |
| PROFICIENT         | Is a competent public speaker, reads and understands research material, conducts literature searches, has provided written critiques for research articles, frequently discusses healthcare issues/topics in a public forum, has facilitated group discussions on a regular basis. Advocates for self and others related to healthcare issues. | Updated training as needed to improve and enhance existing skills and competences. |
| EXPERT             | Is an expert in the field, frequently reviews, writes, presents, conducts literature searches, critiques research articles, speaks publicly to groups, engaged and advocates for health related policy issues. | Updated training as needed, engage in teaching and mentoring others. |
## NOVICE TO EXPERT ASSESSMENT SCALE FOR PEC

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<tr>
<th>SKILL AREA</th>
<th>NOVICE</th>
<th>ADVANCED BEGINNER</th>
<th>COMPETENT</th>
<th>PROFICIENT</th>
<th>EXPERT</th>
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<tr>
<td>Involvement in research</td>
<td>⃝</td>
<td>⃝</td>
<td>⃝</td>
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<td>⃝</td>
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<tr>
<td>Familiarity with research articles, literature searches</td>
<td>⃝</td>
<td>⃝</td>
<td>⃝</td>
<td>⃝</td>
<td>⃝</td>
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<tr>
<td>Critiquing/reviewing research articles and grant proposals</td>
<td>⃝</td>
<td>⃝</td>
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<td>Group process</td>
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<td>Health advocacy</td>
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Assessment level:

List attributes and provide examples that support this level:
REFERENCES

