PROTOCOL FOR ACCESSING PORTAL PATIENT ENGAGEMENT RESOURCES

As a PCORI funded network, PORTAL is committed to engaging patients in all aspects of our work. During Phase I, we developed a Patient Engagement Core group including Carmit McMullen, Carolyn Taylor, Roni Zeiger, Suzanne Gillespie, and Chalinya Ingphakorn. We invited 8 patients and 1 caregiver with deep experience in our three areas of focus – colorectal cancer, congenital heart defects, and obesity – to join the PORTAL Patient Engagement Council (PEC). In Phase II, we will bring on new patient partners with experience in additional areas.

PORTAL provides some support for patient involvement and patient engagement resources. We are also happy to work more closely with investigators on studies where funds exist for more in-depth planning and implementation, including work with patient partners and their direct participation.

Patient Engagement Council (PEC) Capabilities

During Phase II, the PORTAL PEC is available to partner with investigators within each cohort on research activities including:

- **Study conceptualization and design**
  Identify issues that are important to patients; identify patient reported outcomes [PROs].

- **Proposal review**
  Review proposals and prepare feedback, with a special focus on adequacy of patient engagement; join meetings to share feedback and brainstorm ideas.

- **Implementation and data collection plans**
  Develop survey questions; pilot-test survey questions.

- **Manuscript review**
  Review papers and prepare feedback; join meetings to share feedback and brainstorm ideas.

- **Dissemination**
  Identify other methods of dissemination in addition to manuscripts and presentations.

Smart Patients Capabilities

PORTAL is partnering with Smart Patients, an online community of over 10,000 members where patients and caregivers learn from each other. Smart Patients is available to partner with investigators within each cohort on research activities including:

- **Smart Patients hosts communities of patients with many health conditions, including cancer, heart failure, and diabetes, to name a few (https://www.smartpatients.com/communities).** PORTAL health plans and research sites can invite their patients to these high quality online communities for peer support and can obtain updates about the topics of online discussions.
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- **#1day program experiences** Smart Patients brings together teachers (persons with lived experience of an illness or disease) and learners (researchers and others who want to understand this experience) for one day to gain perspective on what it’s like to live with various illnesses. Learners receive an empathy kit to enhance the real-life perspective. Teachers and learners communicate all day long using email, phone, and text.

- **Brief surveys and online discussions** The Smart Patients team will work with investigators to design brief surveys (5-10 questions) and/or discussion prompts and invite members of Smart Patients to participate in them. Surveys will typically be viewed by 500-1000 patients and 50 – 200 (on average) will complete a survey. Data returned to the researcher might help refine a research idea or serve as prep-to-research data.

Resources for Patient Engagement in Research

The Patient Engagement Core group develops, obtains, and maintains resources related to patient and caregiver involvement in research that may benefit PORTAL-affiliated investigators. The Patient Engagement Core group will share these resources with investigators as well as search out resources that we may not currently have. In addition, any of the members are available to brainstorm how to most fully engage patients in the research we do. Specific resources include:

- Patient engagement recruitment materials
- Patient engagement training documents including in-person and webinar presentations (e.g., developing surveys and reviewing results, informed consent, privacy training, reviewing research proposals, accessing research literature, writing manuscripts)
- Patient engagement data library

How Can Researchers Access Patient Engagement Resources?

The process for engaging members of the Patient Engagement Core group, the PEC, or Smart Patients is simple:

- An investigator affiliated with PORTAL contacts the Patient Engagement Core with an idea to brainstorm or a specific request.
- The Patient Engagement Core works with the investigator to understand the request and invite Smart Patients and/or the most appropriate PEC members to participate.
- Depending on the research activity, participation may be via email, phone, conference call, webinar, or in-person.
- We ask investigators to give as much advance notice as possible and to send related materials (e.g., proposal draft, manuscript draft) as early as possible with a clear request (e.g., provide feedback on the entire proposal, provide feedback on the proposal rationale and stakeholder engagement sections) and timeline.
- The Patient Engagement Core has a budget to compensate PEC members for their time and expertise and Smart Patients has a subcontract with PORTAL.

Consider working with us to learn more about what matters most to patients and caregivers as you plan, implement, and disseminate your research. For more information, please contact XXXXX XXXXXXX with the PORTAL Patient Engagement Core team (email@email.com).