

PATIENT ENGAGEMENT CONSULTING

by the HCSRN Patient Engagement in Research SIG*

The increasing desire and need to include patient and other stakeholder partners in research have highlighted a gap in generalized knowledge of engagement best practices.

The HCSRN Patient Engagement in Research Scientific Interest Group (PER SIG) has evolved to identify and create best practices for engaging patients in the research process. The PER SIG seeks to address the knowledge gap by providing consulting to individual research teams on engagement best practices.

Purpose:

To provide research teams throughout the HCSRN with the knowledge, methods, and tools to meaningfully engage patients as partners on their research teams. **There is no charge for this service, and requests for consultation will be scheduled on a first come first served basis.**

Method:

The PER SIG will provide these services as follows:

1. **Disseminate** the availability of the consulting services through the HCSRN via listserv, website, and email from site Governing Board members to their respective research shops.
2. **Schedule** 1-2 requests from research teams per month for consultation during the monthly SIG call, and spend no more than 30 minutes total on the consultation(s). [beginning June 2015]
3. **Pre-screen** each request to ensure applicability and obtain the consultation question(s) from the requestor(s). This information will be shared with the PER SIG prior to each call.
4. **Address** each request on the call by referring to the specific consultation question(s) and asking for suggestions from SIG members attending the call.
5. **Write up** the question(s) and responding suggestions as a continuing archive of engagement practice.
6. **Evaluate** consultations by following up with each requester to determine extent of their implementation, and effectiveness of engagement. Improve practice iteratively.

Examples of Questions:

- How do we decide what roles patient partners should play on our research team?
- How much should we pay our patient partners, and what kind(s) of contracts should we use?
- When do we evaluate how our patient partners are doing, and how?
- What kind of training does our research team need before we bring in patient partners?
- Where can we find the patients we think we need for our research team?
- How should we train our new patient partners?

FOR MORE INFORMATION OR TO REQUEST A CONSULT:

Contact the PER SIG Co-chairs, Sarah Madrid (sarah.madrid@kp.org) or Leslie Wright (leslie.a.wright@kp.org) at KPCO.

*New members welcome!