

Brigham and Women's Hospital Biomedical Research Institute – Patient-centered Comparative Effectiveness Research Center

The mission of the BWH Biomedical Research Institute (BRI) Patient-centered Comparative Effectiveness Research Center (PCERC) is to improve the health of patients through population management, comparative effectiveness research and system redesign. In support of this mission, the PCERC has developed and continues to develop critical initiatives including: 1. Patient/Stakeholder Engagement, 2. Dissemination Strategies, and 3. Database Management.

1. Patient/Stakeholder Engagement:

a. Patient-Family Advisory Councils: BWH has established eight Patient and Family Advisory Councils (PFAC) and six additional councils are in development. These councils work in partnership with the leadership and clinical staff at BWH to foster patient and family-centered care across the entire institution, and provide feedback regarding patient and family-centered care activities. The PFACs oversee the BWH Patient and Family-Centered Care Philosophy and the way it is interpreted and implemented throughout the institution. Through this partnership, discussions and decisions about patient and family-centered care occur in various meetings and forums. The BRI PCERC is establishing a research-specific PFAC - the Brigham and Women's Informed Health Options Program (BIHOP) - which will provide a conduit to forming partnerships between researchers and individual patients throughout the lifespan of a research project. Patients/caregivers in the BIHOP may be invited to partner with investigators who may engage them as collaborators on research grants; those participating in this capacity will typically be paid \$50/hour for their time spent doing advisory activities such as meetings, specific assigned tasks, surveys and more.

b. Online patient forums: [PatientsLikeMe](#) (PLM) is an online health data sharing platform that allows more than 150,000 patients to engage with other patients like them across more than 1000 conditions. PLM works with trusted nonprofit, research and industry partners who access de-identified health data from its members to improve products, services and care for patients. BWH researchers can work with PLM to attain input on the grant writing process and request various research services once the grant has been funded

c. Communications through Patient Gateway: BWH has an online tool that allows patients to communicate with their doctors, schedule appointments, request prescription renewals, receive test results, request insurance referrals, view health record information and update mailing address and other demographic data. There are currently 300,000 Partners HealthCare patients now using PG. Working with the BWH-longitudinal medical record (LMR) team, PCERC researchers can distribute or broadcast a survey link to BWH patients. An example of one of these studies is "Prepare for Care" with Blackford Middleton MD, Jeffrey Schnipper MD, MPH, Tejal Gandhi MD, MPH, Adam Wright PhD, Eric Poon MD, MPH. The Prepare for Care study was a trial of interactive tools added to the Partners electronic patient portal (Patient Gateway - PG) to improve communication, documentation, and patient care regarding medications, family history, health maintenance, and diabetes. Prior to an upcoming visit, patients were given the opportunity to view and interact with components of their electronic medical record and create "eJournals" of information to be updated and topics to be addressed with their primary care doctors. Results of the study showed improvements in documentation, patient-provider communication, and in some cases appropriate actions taken more often. Another study completed in Spring 2012 included a survey of PG users who had viewed their problem list in PG. They were sent a secure message with a link to take the survey (which was hosted on REDCap). If they didn't respond, they were sent one reminder. There was a great response rate of 40%, possibly because of the

reminders, or because it was a secure message. Other possible reasons for the high response rate; patients were targeted shortly after they'd used PG and the survey was left open for several months. One downside of this approach is that the link was not tied to the patient record, so the response wasn't tied to clinical information. Additional surveys, communications, and information models as well as online consulting are being developed using PG.

d. Population and Epidemiologic Studies: BWH has a long history of unparalleled commitment to population health, including patient-engaged epidemiological studies. For instance, [The Nurses' Health Study](#) (NHS) is considered the "grandmother" of women's health studies and represents the single largest cohort study of women, which has resulted in more than 265 published scientific papers. The NHS was established in 1976 to study the relationship between the use of oral contraceptives and cigarette smoking and the risk of major illnesses. For a variety of reasons, including the dedication and commitment of the participants, the scope and range of the study has broadened over time to evaluate the implications of various lifestyle factors such as exercise and diet on women's health. The study includes data from 127,000 nurses between the ages of 30 and 55. Participants receive detailed questionnaires every 2 years in which they report medical histories, daily diet habits and major life events that have occurred in the past 24 months; the response rate averages 90 percent.

BWH researchers may access the NHS and other existing cohort study populations to obtain needed information by adding questions to existing questionnaires or proposing ancillary procedures, rather than starting a new population/patient group. Researchers can also add structured patient assessments within ongoing studies or clinical services in an efficient and timely way.

e. PCERC Stakeholder Engagement Board: The PCERC has begun to develop relationships across relevant stakeholders, including patients, patient advocates, providers, insurers, and regulators – relationships that will continue to broaden. A Stakeholder Engagement Methodology has been developed within the PCERC that includes: expert moderation, meeting format and schedule, reimbursement for time, meeting principles and stakeholder evaluations. As our Center Investigators engage with more Stakeholder boards, the methodology will be updated, expanded and made generally available over time.

f. Center for Community Health and Health Equity: It is essential to the PCERC that all BWH patient communities are included in both engagement as well as dissemination. [The Center for Community Health and Health Equity](#) (CCHHE) focuses on addressing and reducing health care disparities, improving knowledge of healthy habits and behaviors, and general outreach to underserved populations – this partnership is key to the PCERC's mission. A member of CCHHE sits on each PCERC committee including the Patient/Stakeholder Engagement committee.

2. Dissemination:

The PCERC supports the dissemination of research results so as to maximize impact. BWH has a strong infrastructure in place for dissemination that individuals engaged with PCERC can leverage for outreach in this area. The dissemination goals of the BRI PCERC focus on ensuring that results reach all relevant stakeholders. To that end, the Center has a Dissemination Committee, which includes researchers as well as the Vice President of Marketing and Planning and the Director of Public Affairs for BWH. Strategy developed in this area will be communicated broadly. We have begun to develop a set of best practices for dissemination which will be updated as the PCERC Investigators perform more projects.

a. BWH Communication and Public Affairs: The Communication and Public Affairs office focuses on communications with both internal and external audiences. The Director of Communication and Public

Affairs sits on the PCER dissemination committee and is committed to ensuring successful dissemination of results. The weekly [BWH Bulletin](#) is an online and print publication that is distributed across the campus and shares news about our employees – research, awards, organizational changes and more. Pike Notes is the hospital's Intranet and serves as a hub for any and all information employees might need. This Week @BWH is a bi-weekly email that reaches BWH's entire 15,000+ employee base. To communicate with stakeholders such as patients, payers, regulators, and the community at large Public Affairs utilizes social media sites Twitter ([General](#) and [Research](#)) and [Facebook](#) as well as [press releases](#) and local press. Community members are advising us on new ways of communicating and engaging local and global communities.

b. BWH Marketing and Planning: Marketing is responsible for communicating with BWH patients, faculty, and referring physicians. The [BWH Health Hub blog](#) and our [Health eNewsletter](#) are online tools that allow BWH to connect with patients regularly. Additionally, marketing distributes several referring physician publications that serve as an ongoing way to connect with many of the physicians across New England that send their patients to BWH. Marketing continues to add new tools for communication; most recently the [MD Video Education Center](#) was launched in 2011 as a way to share information with BWH physicians and scientists as well as those from outside institutions. Collectively, these activities form a key means of sharing information across a large network of physicians, scientists and other stakeholders. The Vice President of Marketing sits on the PCERC dissemination committee with a focus on communicating with the community and public.

c. BWH Departments and Divisions: BWH structure includes extensive hospital services and departments that connect with patients on a daily basis – from admitting to ambulatory services and clinical departments. These interfaces provide yet another conduit for sharing information with BWH patients and employees.

d. PCER Website: The [Center website](#) will serve as a hub for all researchers at BWH participating in PCER. As soon as BWH researchers PCER papers are available they will be posted to a Research Highlights link on the PCER website. This page will be routinely updated and promoted through all of the Center's dissemination efforts; social media and other online dissemination tools will be utilized to push out updates.

3. Methods and Database Management: Members of the PCERC have access to databases and expertise around data management that can be leveraged by members of the BWH community. These include expertise related to: major commercial health insurers, Medicaid and Medicare claims, i2b2, the Medicare Current Beneficiary Survey, the National Inpatient Survey, Partners' Healthcare's Electronic Medical Records (EMR) and more. Local EMR cohorts are now being linked with insurance claims databases; these linked cohorts will be available through the PCERC. The Center is acting as a hub of resources for the development of methods for researchers working in this area. In addition to the database access and management, there is strong expertise in the methods for large database analyses. PCERC investigators have begun to develop a "catalogue" of analytic methods that different research groups in our community can access. Many state of the art CER methods have been developed here at BWH or at the Harvard School of Public Health, facilitating access to this expertise for members of the PCERC.

4. Other PCER Activities: The PCERC also provides support in terms of Biomedical Research Institute staff to field inquiries, help connect researchers with appropriate resources and collaborators, as well as guidance with respect to IRB submission and other administrative hurdles.