

PATIENT-CENTERED COMPARATIVE EFFECTIVENESS RESEARCH CENTER (PCERC)
Research Dissemination Best Practices Resource Document

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Overview

This document was compiled by the [Patient-centered Comparative Effectiveness Research Center \(PCERC\)](#) as a guide to research dissemination for BWH researchers interested in comparative effectiveness research (CER) or patient-centered outcomes research (PCOR). For more information on the dissemination of research results, please [contact PCERC](#).

What do we mean by dissemination?

Dissemination in this document refers to the communication of research results to specific audiences (e.g. patients, care providers, hospital leadership, policy makers, etc.) in order for these stakeholders to make more informed decisions that ultimately lead to improved patient outcomes.

Why is dissemination important?

Creating a sound dissemination strategy for a research project will lead to increased awareness of the research and, therefore, maximize the impact that the research can have in improving the health outcomes of the patients that will benefit from it. Regardless of how innovative or transformational research is, it will not make an impact unless it is communicated in a timely manner to the audiences that can directly benefit from it. While scientific journals may help CER/PCOR reach the academic community, this dissemination avenue alone will not reach other important stakeholders. Policy makers, hospital administrators, and patients—especially those in hard to reach communities such as the elderly, disabled, and impoverished—directly impacted by a research project could use the information to make more informed decisions that lead to improved patient outcomes. However, in order to effectively reach these stakeholders, researchers need to create a well-thought-out dissemination strategy that targets all relevant stakeholders.

Dissemination and the evaluation of the dissemination strategies utilized can also provide a better understanding of the barriers to dissemination and lead to greater utilization of the most effective dissemination strategies in future research projects. Additionally, the agencies that fund CER/PCOR (i.e. PCORI, AHRQ, etc.) consider giving something back to be a major component of this research and want to ensure that the research projects that they fund remain centered on patients and continue to engage the research participants even after these projects are

completed. It is important for CER/PCOR research projects to positively impact the research participants involved in order to promote meaningful participation in the future¹. Furthermore, as many subpopulations of patients are hesitant to trust researchers, dissemination of research within these communities can create lasting relationships that enable more effective engagement with individuals in these communities¹. As there are significant health disparities within many of these communities, a comprehensive dissemination strategy that targets these subpopulations can also help reduce these disparities.

How does PCERC support the dissemination of research results?

The Biomedical Research Institute's Patient-centered Comparative Effectiveness Research Center (PCERC) supports CER/PCOR researchers with 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 PCERC focus on ensuring that the results BWH's research projects reach all relevant stakeholders. To that end, the Center has a dissemination working group, which includes researchers as well as the BWH Vice President of Marketing and Planning, the BWH Director of Public Affairs, and the BWH CCHHE Director of Health Equity Research and Intervention. This working group helps shape PCERC's dissemination initiatives and facilitate more effective communication between the BWH CER/PCOR research community, BWH Marketing and Planning, BWH Communication and Public Affairs, and the BWH CCHHE to create many dissemination avenues and reach broad audiences—including hard to reach communities such as the elderly, disabled, racial/ethnic minorities, and individuals of low socioeconomic status—in order to ensure that the research of BWH-affiliated investigators makes a maximum impact on the health outcomes of patients. The avenues and strategies for effective dissemination in this area developed by PCERC and its' collaborators will be communicated broadly.

PCERC's resources and collaborators across BWH create a broad network for dissemination that utilizes a variety of avenues to reach all healthcare stakeholders:

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 PCERC's dissemination working group 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 working group with a focus on communicating with the community and public.

c. BWH Center for Community Health and Health Equity (CCHHE): The BWH Center for Community Health and Health Equity is committed to “advancing systems of care, research, and community programs that elevate the health status of the communities [they] serve”. These neighboring communities include Mission Hill, Roxbury, Jamaica Plain, Mattapan, and Dorchester. The CCHHE has partnered with these communities to

address real life issues including health disparities, access to care for vulnerable populations, and health awareness. PCERC has formed a collaboration with the CCHHE which has numerous relationships within the local community in order that the BWH research community can more effectively engage these communities and the hard-to-reach subpopulations within them. The CCHHE Director of Health Equity Research and Intervention additionally sits on PCERC's dissemination working group to help the working group members identify the most effective strategies for dissemination of research results within these communities.

d. 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.

e. PCERC Website: The [Center website](#) serves as a hub for all researchers at BWH participating in CER/PCOR. As soon as BWH CER/PCOR community's research results are available they will be posted to a Research Highlights link on the PCERC website. The website additionally advertises the Center events, which often involve BWH researchers presenting on their research, in addition to events hosted by PCERC's collaborators and events focused on CER/PCOR in the greater Boston area. Furthermore, the greater community including patients and any non-hospital-affiliated individuals are invited to all PCERC sponsored events. The PCERC website 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.

f. Patient-centered Outcomes Seminar Series: PCERC's Patient-centered Outcomes Seminar Series brings together CER/PCOR researchers across BWH for the purposes of discussing research findings, methods, and policy. This series provides CER/PCOR researchers with a platform to both share their research and learn from colleagues. The audience of the seminars is typically physicians, researchers, patients, hospital administrators, and hospital staff.

g. PCERC Newsletter: The Center distributes a monthly newsletter to the BWH CER/PCOR community that highlights the research results of BWH investigators, provides announcements/news regarding important developments and publications within CER/PCOR globally, and advertises the events of the Center and our collaborators (CCHHE, Harvard Disparities Research Program, Harvard Community Health Innovation and Research Program, etc.).

What are the specific resources and avenues available to facilitate the dissemination of research? Internal avenues at BWH

- Email updates/online publications
 - ThisWeek
 - HealthHub blog
 - Research Connection
 - Center for Clinical Investigation updates
 - BWPO news
 - PCERC newsletter/updates
 - Specific Harvard Department email lists
 - Harvard Catalyst
 - CRN/Safety Matters
 - BWH Award and Honors
 - BWH Bulletin
 - BWH Clinical and Research News
 - BWH nurse
- Additional event advertising avenues
 - BWH Carousel (TV screens located throughout BWH)
 - BWH/BRI Calendar
 - MD Educational Video Center
 - BWH press releases
 - BWH waiting rooms

- Websites
 - PCERC website
 - BRI website
 - Center for Community Health and Health Equity (CCHHE) website
 - Individual department/lab website
- Social Media
 - BWH Facebook page
 - BWH Twitter account
 - BRI Twitter account
- BWH sponsored events/seminars
 - PCERC Seminar
 - PCERC Workshops
 - CCHHE Community Events
 - Poster sessions
 - Professional meetings (e.g. grand rounds)
- Collaborative efforts with specific CCHHE Programs

Avenues for following up with study participants

- Study newsletters
- Email updates
- Letter of thanks to study participants (can include research findings)
- Have a party/celebration with the participants at the completion of the study
- Create Facebook page or Twitter account for your study

Avenues within the local community

- Partners Healthcare Hospitals
- Community Health Centers
- Cambridge Health Alliance
- Local churches, schools
- Local events, seminars, conferences
- Local organizations (e.g. MassBio)
- Longwood area calendars (Harvard, DFCL, MGH, Boston Children's, etc.)
- Local media publications
- Local community agency publications and websites
- Billboards
- Radio/TV commercials
- [Community Connect to Research*](#)
- Fact sheets/information sheets
- Training workshops
- [Science Cafes](#)
- Partnering with local high school students for disseminating research results into their communities

National avenues

- Clinicaltrials.gov
- Scientific journals
- Research summaries
- Poster sessions at professional conferences
- Presentations at professional conferences
- Partnerships with specialty organizations
- Partnerships with health systems/hospitals in collaborative dissemination efforts (possible hospitals/systems with patient populations that is not well represented in Boston)
- Relationships with health plans
- Presentations/talks for specific groups

- Policy Briefs (*if applicable*)
- Patient advocacy organizations (*see Appendix A*)
- Media organizations (lay articles, interviews, etc.)
- Web services, social media, apps, etc.

**Note: If you are interested in using the [Community Connect to Research](#) as part of your research dissemination strategy, please contact [Dr. Alexa McCray](#) in advance of your grant application.*

How do we better disseminate information to the local community, including hard to reach populations?

CCHHE Community Network

The Center for Community Health and Health Equity (CCHHE) sponsors many programs within the local community that focus on health equity, violence intervention and development, and youth education and professional development. Through this extensive network, the CCHHE has affiliations and relationships with many community stakeholders.

The CCHHE has:

- Affiliations with community health centers
- Youth Programs
- Health Equity Programs
- Violence Intervention and Prevention Programs
- Community based participatory research and dissemination

If you are interested in collaborating with the CCHHE on dissemination of health research, please contact [Dr. Cheryl Clark](#), the CCHHE Director of Health Equity Research and Intervention.

Informational talks/workshops

The BWH Community Learning Network, which is a joint effort between BWH's CCHHE and the Biomedical Research Institute (BRI), puts on a series of events that are free, open to the public and designed to encourage dialogue between BWH researchers and community members about research findings and health news that can be applied to daily life. BWH researchers can contact PCERC (as part of the BRI) or the CCHHE about providing content for one of these events. However, the content of these informational talks needs to be relevant to the local community. For example, a recent event held at the Whittier Street Health Center in Roxbury focused on prostate cancer awareness for middle-aged or older men.

Some possible venues for these talks/workshops:

- Brookside/Southern Jamaica Plain Community Centers
- Whittier Street Health Center, Roxbury, MA
- Local YMCAs
- Local churches, temples, mosques, youth groups

Local Media Publications

PCERC in collaboration with Public Affairs will help facilitate getting relevant health articles from BWH researches into local media publications.

Possible print avenues:

- Jamaica Plain Gazette
- Boston Metro
- Dorchester Reporter
- Dorchester News
- East Boston Sun Transcript
- Hyde Park Tribune
- Mattapan Reporter
- Mission Hill Gazette
- West Roxbury Transcript

Is there dissemination expertise available?

Yes, PCERC will not only provide guidance as you shape your dissemination plan, but we will also support the dissemination of your research results later on to maximize the impact. We can additionally put you in touch with dissemination experts at BWH and Harvard that can provide consultative services to help you create and implement an effective dissemination strategy. If you are interested in being connected to these dissemination experts, please [contact us](#) as early as possible.

Important considerations when developing a dissemination strategy

- **Goal:** Consider your dissemination goals and the impact that you would like your research project to have.
- **Barriers to dissemination:** In order to develop an effective dissemination strategy, it is important to understand the barriers to dissemination for your particular project. Potential barriers to dissemination may be related to knowledge translation and exchange, knowledge to action, translating research into policy and practice, research utilization, knowledge utilization, technology transfer, and knowing-doing gap, etc.
- **Audience:** Consider the stakeholders affected by this research project and which dissemination methods will be most effective in reaching each of these stakeholders.
- **Budget:** Be sure to budget adequate resources within the grant proposal for the dissemination component of your project.
- **Resources:** When developing a dissemination strategy, it is important to leverage the existing resources in place at BWH as well as your relationships/partners and networks
- **Evaluation:** It is important to evaluate the effectiveness of your dissemination plan so that future researchers can learn from your experiences

What are the different audiences that I am disseminating the results of my research to?

Although the stakeholders will likely vary for each CER/PCOR research project, the below image identifies many of the stakeholders that are often impacted by this research.

Patients & Consumers	• Persons or organizations that represent the patient or consumer perspective generally, or within specific disease states, such as: individuals with particular conditions, caregivers, patient advocates, and advocacy organizations
Clinicians	• Individuals that provide health care services, such as: physicians, nurses, pharmacists, nurse practitioners, physician assistants and mental health providers
Health Care Providers	• Institutions that deliver health care services, such as: hospitals, nursing homes, outpatient clinics, clinical laboratories and accountable health care organizations
Payers & Purchasers	• Organizations that pay for health care goods and services, such as: public and private insurers, health plans and employers
Polymakers & Regulators	• Individuals and organizations that create, monitor and oversee policies or regulations concerning health care-related issues, such as: federal, state and local government agencies, medical and professional organizations and clinical guideline developers
Life Sciences Industry	• Entities that develop and market medical technologies, such as: pharmaceutical, medical device, diagnostic, biotechnology companies and organizations which represent life science company interests
Researchers	• Individuals and their related organizations that develop scientific and clinical evidence, such as: clinical researchers, health services researchers, social scientists and basic scientists
Research Funders	• Entities that provide monetary support for research efforts, such as: government, foundations and for-profit organizations

When writing a dissemination strategy, it is important for researchers to specifically address how they will disseminate research findings to each of the stakeholders affected by the research project. For instance, the researchers will likely need to use different dissemination avenues to reach patients than they would to reach clinicians or policy makers. It is also important that the results are conveyed to each individual audience in a manner that is understandable to them, using appropriate language/information. Researchers should determine which medium of dissemination is the most effective way to reach each audience/stakeholder group³.

Dissemination checklist

- Does my grant proposal have an effective dissemination strategy?
- What behavior am I looking to change and what impact am I looking to make with my dissemination strategy?
- Am I reaching the audiences that will directly benefit from this research, including hard to reach populations?
- Have I used appropriate language/dissemination avenues for each target audience (patients, clinicians, policy makers, etc.)?
- Am I utilizing all the available resources at BWH to disseminate my research both internally and externally?
- Am I leveraging my existing networks and relationships?
- Am I effectively reaching the local community?
- Am I reaching the relevant stakeholders nationally?
- Am I budgeting adequate resources for dissemination?
- Have I considered the barriers that I may face in disseminating my research results? Do I have strategies for how to overcome those barriers?
- Did I describe how the patient participants of my research project will be involved in the dissemination of the research results?
- Am I returning the results to the study participants?
- Am I committing to follow up with the patients that have participated in my research study in the future? Have I clearly delineated my follow up plan?
- Does my grant proposal have a plan to evaluate my dissemination strategy? Have I included clear criteria for this evaluation?
- Did I inform PCERC and the BWH Department of Communication and Public Affairs of my results, major publications/articles, and media attention?
- Did I reference PCERC in my grant proposal? :)

External Dissemination and Implementation Resources

- [Beyond Scientific Publication: Strategies for Disseminating Research Findings](#)
- [AHRQ Development of a Planning Tool to Guide Dissemination of Research Results](#)
- [AHRQ Dissemination Planning Tool: Exhibit A](#)
- [University of Connecticut Dissemination and Implementation Resources and Information](#)
- [Center for Health Education Dissemination and Implementation Research](#)
- [RE-AIM \(Reach Effectiveness Adoption Implementation Maintenance\)](#)
- [An Introduction to Effectiveness, Dissemination, and Implementation Research](#)
- [Developing an Effective Dissemination Plan, RUSH](#)
- [General Characteristics of Effective Dissemination and Utilization, RUSH](#)
- [Communicating and Disseminating Research, Research Information Network](#)
- [PCORI Dissemination and Implementation Roundtable Slides](#)

Questions

If you have any questions about this document, the communication and dissemination resources in place at BWH, or how PCERC can help you effectively disseminate your research results, please contact [Joshua Di Frances](#), BWH Biomedical Research Institute Project Manager.

Appendix A: Major Patient Advocacy/Non-Profit Organizations with an interest in health

Alpha-1 Foundation	Lupus Foundation of America
Alzheimer's Association	March of Dimes
American Association of Retired People	Michael J. Fox Foundation
American Autoimmune Related Diseases Association	Myasthenia Gravis Foundation of America
American Cancer Society	National Alopecia Areata Foundation
American Diabetes Association	National Down Syndrome Society
American Foundation for Suicide Prevention	National Eczema Association
American Heart Association	National Foundation for Ectodermal Dysplasias
American Kidney Fund	National Hemophilia Foundation
American Liver Foundation	National Marfan Foundation
Amputee Coalition	National Multiple Sclerosis Society
Arthritis Foundation	National Osteoporosis Foundation
Asthma and Allergy Foundation of America	National Patient Advocate Foundation
Barth Syndrome Foundation	National Psoriasis Foundation
Center for Medical Consumers	National Venture Capital Association
Colorado Citizens for Accountability	Osteogenesis Imperfecta Foundation
Consumers Advancing Patient Safety (CAPS)	Parkinson's Action Network
Consumer's Union	Patient Advocate Foundation
DiagKNOWsis	Patient Services Inc.
Easter Seals	PKD Foundation
Epilepsy Foundation	Prevent Blindness America
Every Patient's Advocate	PULSE: Persons United Limiting Substandards and Errors
Everyday Health	Reduce Infection Deaths (RID)
FasterCures - The Center for Accelerating Medical Solutions	RESOLVE: The National Infertility Association
Global Healthy Living Foundation	Sjogren's Syndrome Foundation
Guide Dog Foundation for the Blind, Inc.	Spina Bifida Association
HealthHIV	The ALS Association
Huntington's Disease Society of America	The Empowered Patient Coalition
Hydrocephalus Association	The Institute for Healthcare Improvement
Immune Deficiency Foundation	The LAM Foundation
Kanter Family Foundation	The National Patient Safety Foundation
LIVESTRONG Foundation	

Appendix B: References

¹ *Integrating Patients' Voices in Study Design Elements with a Focus on Hard-to-reach Populations*. Rep. Patient-Centered Outcomes Research Institute, n.d. Web. 22 May 2013.

<http://pcori.org/assets/pdfs/Integrating%20Patients%20Voices.pdf>

² Key stakeholder groups for CER. Digital image. *CMPT Better Evidence. Better Decisions. Better Health*. Center for Medical Technology Policy, n.d. Web. 21 Apr. 2013. <http://www.cmtynet.org/stakeholder-engagement/>

³ *Beyond Scientific Publication: Strategies for Disseminating Research Findings*. Rep. Yale Center for Clinical Investigation, n.d. Web. 29 May 2013.

http://www.yale.edu/bioethics/contribute_documents/CARE_Dissemination_Strategies_FINAL_eversion.pdf

This document will be continually updated as BWH investigators perform more projects and evaluate the effectiveness of their dissemination strategies.