



Cystic Fibrosis Reproductive and Sexual Health Collaborative

<http://cfreshc.org/>

Patient-Centered Outcomes Research in the Cystic Fibrosis Community

- Resources for Researchers and Providers -

10/7/2019

Why Engage Patients and Caregivers in Research?	
Better Research Through Engagement	https://www.pcori.org/sites/default/files/PCORI-Better-Research-Through-Engagement.pdf
Research Done Differently	https://www.pcori.org/sites/default/files/PCORI-Research-Done-Differently.pdf
Impact of Engagement in Research	Forsythe, L., Heckert, A., Margolis, M.K. et al. Qual Life Res (2018) 27: 17. https://doi.org/10.1007/s11136-017-1581-x
Research Letter: Improving Structural Research by Involving Stakeholders	Minnecci PC, Nacion KM, Lodwick DL, Cooper JN, Deans KJ. <i>Improving Surgical Research by Involving Stakeholders. JAMA Surgery. June 2016</i> https://jamanetwork.com/journals/jamasurgery/fullarticle/2486918
Engaging Patients and Caregivers as Partners in Research	
Initiating Partnerships for PCOR	https://www.pcori.org/sites/default/files/PCORI-Engagement-Strategies-for-Initiating-Research-Partnerships-Info-Sheet-71917.pdf
Developing Research Partnerships	Adams A, Williamson A, Sorkness C, Hatfield P, Eggen A, Esmond S. The Steps Model: A Practical Tool for Engaging Communities to Improve Health Outcomes. <i>Acad Med.</i> 2017 Jun;92(6):890. doi: 10.1097/ACM.0000000000001677. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5449250/ Anyanwu C, Hemphill R. Finding and Recruiting Research Partners: Lessons from PCORI Awardees. PCORI Engagement Blogs. Sep 1, 2017. https://www.pcori.org/blog/finding-and-recruiting-research-partners-lessons-pcori-awardees
True Partner Engagement	http://trailhead.institute/wp-content/uploads/2017/04/truepatientpartnerengagement_final.pdf
Roles of Patient and Caregiver Partners in Research	https://www.pcori.org/sites/default/files/PCORI-Engagement-in-Research-Making-a-Difference-Webinar-Info-Sheet-091917.pdf

Effective Partnerships	https://www.becertain.org/sites/default/files/INSPIRE%20PCOR%20Workshop%20Summary%20FINAL%202016.10.05.pdf
Stakeholder Engagement Challenges, Strategies, and Resources	https://www.pcori.org/sites/default/files/PCORI-Patient-Stakeholder-Engagement-Challenges-Strategies-Resources-Handout-120517.pdf
PCOR in Grant Applications	
<i>PCORI Engagement Rubric</i>	https://www.pcori.org/sites/default/files/Engagement-Rubric.pdf
<i>PCORI Engagement Plan Template</i>	https://www.pcori.org/sites/default/files/PCORI-Updated-Engagement-Plan-Template.pdf
<i>PCORI Engagement Rubric for Applicants</i>	https://www.pcori.org/sites/default/files/Engagement-Rubric.pdf
<i>PCORI Compensation Framework</i>	https://www.pcori.org/sites/default/files/PCORI-Compensation-Framework-for-Engaged-Research-Partners.pdf
<i>PCORI In-Practice Webinars</i>	https://www.pcori.org/events/past?type=110
<i>Budget for Engagement Activities</i>	https://www.pcori.org/sites/default/files/PCORI-Budgeting-for-Engagement-Activities.pdf
<i>Engagement in Health Research Literature Explorer</i>	https://www.pcori.org/literature/engagement-literature
<i>PCOR and IRB Points to Consider</i>	https://www.partners.org/Assets/Documents/Medical-Research/Clinical-Research/PCOR-and-IRB-Points-to-Consider.pdf
PCOR 101	
<i>Potential PCOR Barriers</i>	Homes B, McGavin C. Patient Engagement in Research: How we're trying to get it right. Institute for Patient & Family- Centered Care International Conference. New York, July 26, 2016. https://www.ipfcc.org/bestpractices/sustainable-partnerships/tools/SPOR_PCRResearch.pdf
<i>Traditional Research vs. Community-Engaged Research</i>	http://trailhead.institute/wp-content/uploads/2017/04/316043919-community-engaged-research-final.pdf
PCOR Team Dynamics	
<i>SWOG Field Guide</i>	https://www.pcori.org/sites/default/files/TeamScience-SWOG-Field-Guide.pdf
<i>Collaboration and Team Science</i>	Bennett LM, Gadlin H. Collaboration and team science: from theory to practice. J Investig Med. 2012 Jun;60(5):768-75. https://www.ncbi.nlm.nih.gov/pubmed/22525233

<p><i>TeamSTEPPS</i></p>	<p>https://www.ahrq.gov/teamstepps/about-teamstepps/index.html</p> <p>TeamSTEPPS 2.0 Leadership Briefing: https://www.ahrq.gov/teamstepps/about-teamstepps/leadershipbriefing.html</p>
<p>Online Collaboration</p>	
<p><i>Overcoming Challenges in Collaborating Online</i></p>	<p>https://www.extension.harvard.edu/professional-development/blog/challenges-managing-virtual-teams-and-how-overcome-them</p> <p>https://hbr.org/2012/10/how-to-collaborate-in-a-virtua</p>
<p>Evaluating Partnerships</p>	
<p><i>Measuring Trust in Partnerships</i></p>	<p>http://trailhead.institute/wp-content/uploads/2017/04/health_promot_int_2011-jones-484-91.pdf</p>
<p><i>SWOG Field Guide</i></p>	<p>https://www.pcori.org/sites/default/files/TeamScience-SWOG-Field-Guide.pdf</p>
<p>PCOR in the Literature</p>	
<p><i>CF Example</i></p>	<p>Kazmerski T.M., Miller E, Sawicki GS, Thomas P, Prushinskaya O, Nelson E, Hill K, Miller A, Emans SJ. Developing Sexual and Reproductive Health Educational Resources for Young Women with Cystic Fibrosis: A Structured Approach to Stakeholder Engagement. <i>Patient</i>. 2019 Apr;12(2):267-276. https://www.ncbi.nlm.nih.gov/pubmed/30361885</p>
<p><i>Health Affairs</i></p>	<p>Forsythe LP, Carman KL, Szydlowski V, Fayish L, Davidson L, Hickam DH, Hall C, Bhat G, Neu D, Stewart L, Jalowsky M, Aronson N, Anyanwu CU. Patient Engagement in Research: Early Findings From The Patient-Centered Outcomes Research Institute. <i>Health Aff</i>. 2019 Mar;38(3):359-36. https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2018.05067</p>
<p><i>Health Expectations</i></p>	<p>Shippee ND, Domecq Garces JP, Prutsky Lopez GJ, Wang Z, Elraiyah TA, Nabhan M, Brito JP, Boehmer K, Hasan R, Firwana B, Erwin PJ, Montori VM, Murad MH. Patient and service user engagement in research: a systematic review and synthesized framework. <i>Health Expect</i>. 2015 Oct;18(5):1151-66. doi: 10.1111/hex.12090. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5060820/</p>
<p><i>BioMed Central</i></p>	<p>Staley K. 'Is it worth doing?' Measuring the impact of patient and public involvement in research. <i>BMC Research Involvement and Engagement</i>. 1(6);2015. https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-015-0008-5</p>
<p><i>Implementation Science</i></p>	<p>Bombard, Y., Baker, G.R., Orlando, E. et al. <i>Implementation Sci</i> (2018) 13: 98. https://link.springer.com/article/10.1186/s13012-018-0784-z</p>