

TOOLS FOR STAKEHOLDER ENGAGEMENT IN RESEARCH

Hard-to-Reach Patient Stakeholders: An Engagement Guide

<https://www.hipxchange.org/HARPS>

HARPS is a set of planning materials for researchers and others who want to engage hard-to-reach stakeholders as advisors on patient-centered projects. It contains the following materials:

- The **roadmap**, a fillable workbook that uses 10 guiding questions and supplemental Appendices to help develop ideas and plans for successful engagement of stakeholders
- An 80-minute **workshop video** that discusses the 10 guiding questions in the roadmap and addresses key considerations for patient stakeholder engagement
- 22 **supplemental videos** (approximately 20-60 seconds each) that feature patient stakeholders, community partners, and researchers discussing key topics related to engagement

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Toolkit on Patient Partner Engagement in Research (TOPPER)

<https://www.hipxchange.org/TOPPER>

TOPPER is a comprehensive set of orientation materials created for patient partners on a research study—i.e., people who advise researchers throughout a research project. TOPPER contains the complete set of materials used in a three-hour orientation program for patient partners, including:

- A session **agenda**
- A detailed **manual for two facilitators** to use during the orientation
- 20 supplementary worksheets, exercises, forms, and examples

The toolkit includes activities that interest adult learners, provide opportunities for self-expression, and build group norms for respectful, focused interactions.

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Sustaining Engagement of Blended Stakeholder Boards

<https://www.hipxchange.org/SustainingEngagement>

This toolkit was developed for researchers by researchers to guide you through the process of drafting a compelling plan for meaningfully engaging blended stakeholder boards across the lifecycle of a research or quality improvement project. The materials in this toolkit were originally created as part of a two-part workshop series led by researchers at the University of Wisconsin - Madison, and include:

- **Videos** from the interactive workshop sessions, including expert PCOR speakers
- Corresponding **templates and materials** to the workshops for planning successful stakeholder engagement

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Deeply Engaging Patients with a Mix & Match of Methods

<https://www.hipxchange.org/DeeplyEngagingPatients>

This online training is designed to equip researchers to deeply engage patient stakeholders in research. Beyond advisory boards, this training explores multiple ways to engage patient stakeholders, including expanding roles of patients on the research team. The training is a portal to existing resources and an independent source for high quality, vetted information that has been synthesized from peer-reviewed articles on engagement, stakeholder mapping, marketing, and ethical issues in research. It offers practical and actionable materials to clear barriers to engagement, including **templates to download, videos, resources, and literature references.**

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HealthExperiencesUSA

<http://www.healthexperiencesusa.org>

HealthExperiencesUSA.org brings patients' voices to American health care and seeks to describe the widest possible range of individual experiences from the patient's point of view. The first module provides insight into young adults' experiences with depression, with videos on how depression feels, living with depression, coming to terms with depression, self-care strategies, seeking help, and messages to others. Modules on other conditions are planned for the future. The Experiences Research Network is committed to implementing the [DIPEX methodology](#) for collecting and producing patient narratives so that the qualitative work is interpretive, deeply descriptive, and holistic. Because dialogue, diverse viewpoints and collaborative inquiry are essential to these dimensions of quality in qualitative research, we are committed to using team-based approaches, and multidisciplinary teams in our studies.

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Engaging Research Participants in Disseminating Health Experiences Research

<https://www.hipxchange.org/HealthExperiencesResearch>

This action-oriented toolkit shares lessons learned from collaborating with former research participants to disseminate health experiences research through a "**Patient Experiences Ambassador Program**," It is based upon our experience disseminating about the first HealthExperiencesUSA module (see above) featuring Young Adults' Experiences of Depression in the U.S. We believe most lessons learned can be generalized to health experiences research, and note where this may not be the case. It is intended for researchers, clinicians, policymakers, or health advocates who are interested in engaging patients in dissemination efforts for a research or quality improvement project.

The toolkit includes four main sections:

- Creating a patient experiences **ambassador program** that invites and trains ambassadors, matches them with activities, and incorporates logistical and IRB considerations
- Planning **dissemination activities** with ambassadors, such as presentations, poster sessions, and exhibits, as well as using social media and traditional earned media
- **Evaluation** of ambassadors' role in dissemination and their overall experience as dissemination partner
- **Worksheets, resources, and tools** that support the creation, execution, and evaluation of your program

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Engaging Veterans in Research

<https://www.hipxchange.org/EngagingVeterans>

This toolkit contains guidance and resources for investigators and research team members who wish to engage Veterans as stakeholders in the design, implementation, and/or dissemination of their research. Veterans can provide valuable feedback that is based on personal experience relevant to the research topic being studied. Their experiences in the military, with a specific health condition, or with receiving Veterans Administration (VA) services gives them a unique perspective and expertise that can serve to improve the quality and impact of research. Several tools and materials are included in this toolkit to help researchers:

- Develop the skills and knowledge necessary to cultivate strong relationships with Veteran stakeholders
- Find Veterans with expertise relevant to a specific research topic and the skills necessary to effectively provide feedback on research projects
- Write a well-designed and feasible Veteran engagement plan
- Guide effective Veteran engagement throughout the research process

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