Engaging Patients in Research: Using Multiple Participatory Approaches to Achieve Results

A Comic Primer to a Free Training: HIPXCHANGE.ORG/DEEPLYENGAGINGPATIENTS
The Engagement Roadmap

Ten steps to effective stakeholder engagement...

A stakeholder is any person or entity with a declared or conceivable interest in a project.

1. Discernment: Understanding the purpose of engagement and getting the research team on the same page regarding its value.

2. Stakeholder mapping: Identifying the best stakeholders for the project.

3. Engagement tools selection: Selecting the best tools for the project.

4. Matching tools with project stages: Determining the best engagement tools for each research stage.

5. Addressing legal considerations and logistics: Institutional review boards and budgeting.


7. Patient orientation about the engagement process.

8. Team building to effectively work together.

9. Engagement: Engaging stakeholders in all phases of research projects, from planning through dissemination.

10. Celebration and honoring stakeholder contributions!
**Principles of Engagement**

**What is Stakeholder Engagement in Research?**

“The meaningful engagement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the research process – from topic selection through design and conduct of research to dissemination of results.”

**Patient-Centered Outcomes Research...**

- Focuses on outcomes valued by patients
- Assesses benefits and harms
- Accounts for different contexts and experiences
- Investigates optimizing outcomes
- Helps people and caregivers communicate and make informed health care decisions

*Identify valued outcomes through patient engagement!*

**Build partnerships that lead to relevant research, implementation of results, and optimal health!**

**Create a culture of patient-centeredness in research!**

**Philosophy**

Patient-Centered Research

**Outcome**

Improved Health and Patient Experiences

**Approach**

Stakeholder Engagement
The Value of Stakeholder Engagement

“NO MATTER HOW COMPLICATED THE RESEARCH, OR HOW BRILLIANT THE RESEARCHER, PATIENTS AND THE PUBLIC ALWAYS OFFER UNIQUE, INVALUABLE INSIGHTS.”

Chief Medical Officer of Britain, akin to the U.S. Surgeon General

“THEIR ADVICE WHEN DESIGNING, IMPLEMENTING, AND EVALUATING RESEARCH INEVARIABLY MAKES STUDIES MORE EFFECTIVE, MORE CREDIBLE, AND OFTEN MORE COST EFFICIENT…”

Practical and Philosophical Values

- Generate new research ideas
- Improve dissemination by making information more understandable
- Improve acceptance of research
- Improve study retention
- Increase study efficiency
- Boost project relevance
- Increase transparency and public confidence

- Avoid pointless research
- Improve recruitment and informed consent materials
- Design better inventions
- Show respect and foster trust for participants
- Increase patient-centered data collection and outcomes
- Enrich data analysis
- Avoid pointless research

Other observed benefits

- Improve dissemination by making information more understandable
- Improve acceptance of research
  - Improve study retention
  - Increase study efficiency
  - Boost project relevance
- Increase transparency and public confidence
**Engagement Best Practices**

**Best Practices Include…**

- Taking time to build trust…
  *Compassion and humility foster inclusiveness and integration of community perspectives*

- Supporting integration of local cultural knowledge

- Adapting engagement approaches within cultural and local contexts

- Training research team members from communities experiencing health inequities

- Communicating realistic expectations for research outcomes and sharing all findings with the community

- Restoring, not taking from, communities

**Ensure meaningful stakeholder influence on research!**

**Stakeholders Include…**

- Patients and consumers including caregivers and advocacy organizations

- Community representatives

- Policymakers + regulators

- Training institutions

- Healthcare providers like hospitals, clinics, and clinicians

- Payers and purchasers public and private insurers, health plans and employers

- Life sciences industry entities that develop and market medical technologies

- Researchers + funders including government, foundations, and for-profit organizations

**Value the patient perspective!**
We recommend the following four step process to identify stakeholders for a research project:

1. **Identify Potential Stakeholders Through Brainstorming…**
   - Begin with those familiar with the research
   - Ask them to suggest others who should be engaged to reach outsider perspectives

2. **Categorize Possible Stakeholders…**
   - Who affects or is affected by the topic?
   - What is their level of interest?
   - What resources and power do they bring to the table?
   - Who is necessary to achieve dissemination + implementation of findings?

3. **Evaluate Possible Stakeholders To Determine The Intensity Of Their Involvement…**
   - Consider interests, knowledge, expectations, influence, and requirements
   - Consider and plan for possible conflicts and negative reactions

4. **Finalize Potential Stakeholder List And Levels Of Involvement**

“A common concern for researchers, especially those with less experience of involvement, was how to go about finding people to involve and how formal the process should be.”

Avoid using representatives on advisory boards wearing two hats… i.e. the nurse who had cancer.
The Engagement Framework shows categories of patient engagement along a spectrum of engagement.

<table>
<thead>
<tr>
<th>Engagement Categories</th>
<th>INFORM &amp; EDUCATE</th>
<th>LISTEN &amp; GATHER</th>
<th>DISCUSS</th>
<th>INVOLVE</th>
<th>PARTNER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direction &amp; Strength of Engagement</td>
<td>From Health System to Stakeholders</td>
<td>From Stakeholders to Health System</td>
<td>Bidirectional</td>
<td>Bidirectional and ongoing</td>
<td>Joint venture</td>
</tr>
<tr>
<td>Definition</td>
<td>Stakeholders benefit from information and education</td>
<td>Stakeholders give voice to experiences</td>
<td>Stakeholders provide valuable input and receive feedback</td>
<td>Stakeholders are ongoing advisors</td>
<td>Stakeholders are full participants</td>
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<tr>
<td>Methods</td>
<td>Websites, social media, newsletters</td>
<td>Surveys, cycle time, suggestion boxes, gathering narratives/stories</td>
<td>One-time focus group, town-hall style meetings, community gatherings, interactive interviews</td>
<td>Ongoing feedback panels, advisory boards</td>
<td>Voting members of governance boards, members of QI/research teams</td>
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</tbody>
</table>

- **WHAT INPUT DO I NEED AT EACH STAGE OF MY RESEARCH PROJECT?**

Using this framework you can:

- Identify which tools and approaches will work for your project
- Consider using a mix of tools and approaches to reach your particular stakeholders
- Implement different phases of your project
- Identify anticipated effects of each tool and approach
CELEBRATE SUCCESS!

HONOR YOUR STAKEHOLDERS AND THEIR CONTRIBUTIONS!

REASONS TO CELEBRATE IN A PARTNERSHIP—
- WHEN PARTNERSHIP GOALS ARE ACHIEVED
- WHEN FUNDING IS OBTAINED
- WHEN NEW STAFF OR PARTNERS JOIN OR MOVE ON FROM THE PARTNERSHIP
- TO RECONNECT WITH OR SHOW APPRECIATION FOR PARTNERS, STAFF AND VOLUNTEERS

CAPTURE EXPERIENCES ALONG THE WAY—
- TAKE PHOTOS AT MEETINGS
- CAPTURE NOTABLE QUOTES
- ASK PATIENTS TO SHARE A REFLECTION OF THEIR EXPERIENCE
- TRACK HOW YOUR RESEARCH CHANGES FOR THE BETTER BASED UPON STAKEHOLDER INPUT

TELL YOUR STORY IN ORDER TO INSPIRE OTHERS!

HIGHLIGHT HOW PATIENT ENGAGEMENT IMPROVED THE RESEARCH PROCESS!

DISCUSS CHALLENGES AND HOW THEY WERE OVERCOME!

FREE TRAINING ON STAKEHOLDER ENGAGEMENT AT WWW.HIPXCHANGE.ORG/DEEPLYENGAGINGPATIENTS

REFERENCES AVAILABLE AT HTTPS://WWW.PATIENTPARTNERSHIPS.ORG/RESEARCH/COMICS/