Phase II Stakeholder Engagement Research

Katherine Kim, University of California Davis
Bethany Kwan, University of Colorado Denver

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Progression in Stakeholder Engagement Research
Progress to date in Phase II
Stakeholder Engagement Research Conceptual Model
Progression

- SCANNER (2010-2013)
- pSCANNER phase I (2014-2016)
- pSCANNER phase II (2016-2019)
Progression

SCANNER (2010-2013)

- Develop stakeholder-informed governance framework
- Understand perspectives on data sharing
  - Policy expert council (10)
  - Patient focus groups (6)
  - Health system interviews (15)
  - Consumer survey (n=800, n=1200)
pSCANNER phase I (2014-2016)

- Demonstrate scalable stakeholder decision-making approaches
- Develop priorities for patient-centered outcomes research (PCOR) topics
  - Stakeholder advisory boards (46 stakeholders)
  - Online Delphi study (349 stakeholders: patients, caregivers, clinicians, researchers) resulting in approved PCOR priorities for KD, HF, WMO
- Patient research willingness survey (n=2444)
Formalize stakeholder engagement in and governance of research process
Evaluate stakeholder engagement in research design
- Stakeholders in governance committees and advisory board (24)
- Research co-design teams to design PCOR priority studies for KD, HF, WMO
Visualizations of research data
Engagement Framework
Patient Research Willingness Survey

- HF/WMO (n=2,444)
  - 10.2% response rate
  - 70% overweight or obese
  - 38% diagnosed with diabetes
  - 33% previously participated in research

- KD (n=65)
  - 37% previously participated in research
# Phase II Progress to Date

## Willingness to Participate in Research (n=2,440)

<table>
<thead>
<tr>
<th>#</th>
<th>Interest in Research Activity</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Completing a one-time survey or list of questions</td>
<td>2.42</td>
<td>0.6</td>
</tr>
<tr>
<td>2</td>
<td>Giving a blood sample one time</td>
<td>2.32</td>
<td>0.68</td>
</tr>
<tr>
<td>4</td>
<td>Testing a treatment given by phone or over the internet (like getting advice about your health)</td>
<td>2.28</td>
<td>0.71</td>
</tr>
<tr>
<td>3</td>
<td>Completing a survey two or more times</td>
<td>2.27</td>
<td>0.68</td>
</tr>
<tr>
<td>14</td>
<td>Giving a blood sample that is used to study your DNA.</td>
<td>2.27</td>
<td>0.72</td>
</tr>
<tr>
<td>10</td>
<td>Taking part in a project in which you would stay in the hospital for 1 or more days</td>
<td>1.79</td>
<td>0.76</td>
</tr>
<tr>
<td>11</td>
<td>Taking part in a project which involves a procedure such as a special x-ray or new type of surgery</td>
<td>1.79</td>
<td>0.73</td>
</tr>
<tr>
<td>9</td>
<td>Taking part in a project that involves you and other people in your family</td>
<td>1.78</td>
<td>0.76</td>
</tr>
<tr>
<td>19</td>
<td>A study about weight control that required surgery</td>
<td>1.43</td>
<td>0.7</td>
</tr>
</tbody>
</table>

*a Each activity rated 1 = not interested to 3 = very interested*
# Phase II Progress to Date

HF/WMO

## Mode of Contact

<table>
<thead>
<tr>
<th>Interest in Research Contact by Mode&lt;sup&gt;a&lt;/sup&gt; (N=2,381)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 Personal phone call from research staff or my doctor</td>
<td>1,221</td>
<td>51.28</td>
</tr>
<tr>
<td>1 E-mail</td>
<td>858</td>
<td>36.04</td>
</tr>
<tr>
<td>3 Letter or post card in the mail</td>
<td>712</td>
<td>29.9</td>
</tr>
<tr>
<td>2 Cell phone text messaging</td>
<td>379</td>
<td>15.92</td>
</tr>
<tr>
<td>7 Talking face-to-face with research staff or my doctor when I am visiting the clinic</td>
<td>361</td>
<td>15.16</td>
</tr>
<tr>
<td>8 Other</td>
<td>150</td>
<td>6.3</td>
</tr>
<tr>
<td>6 A computer created phone message</td>
<td>102</td>
<td>4.28</td>
</tr>
<tr>
<td>5 Social media (such as Facebook, Twitter, or Pinterest)</td>
<td>18</td>
<td>0.76</td>
</tr>
</tbody>
</table>

<sup>a</sup> Percentages do not add up to 100% as multiple responses were allowed.
Phase II Progress to Date

- KD Research Co-design Team
  - Convened: 1 KD patient and 1 KD parent (co-investigators), 2 KD SAB members, pSCANNER (Burns, Tremoulet, Kim, Haynes, Marie)
  - PCORI application submitted: A stakeholder-driven comparative effectiveness study of treatments to prevent coronary artery damage in patients with resistant Kawasaki disease.
    » Includes exploratory aim to evaluate patient reported outcomes (PROs) and use of a parent observation tool to record discomfort, psychosocial concerns, and other experiences of treatment during the child’s in-hospital stay.
Phase II Progress to Date

Conceptual Framework for Characterizing Methods of Stakeholder Engagement in Research Design

- Objective: To develop a conceptual framework to guide systematic evaluation of stakeholder engagement methods
Research Question(s)

- What are effective and efficient strategies for conducting multi-stakeholder engaged research?
- Under what circumstances are different strategies most appropriate?

PCORI Principles of Stakeholder Engagement

- Reciprocal relationships—clear roles and decision making
- Co-learning—understanding by researchers and stakeholders of research process and patient-centeredness
- Trust, transparency, and honesty—inclusive and honest communication
- Partnership—valued time and contributions
| **Who?** | The types of stakeholders (perspectives, expertise and experience with the research topic /health concern) participating, and the size of the group (how many of each type); characteristics of those who choose to participate |
| **What?** | The stated objective(s) of the engagement effort (what will be produced); to what aspects of study design do stakeholders contribute |
| **Why?** | The stated motivations for engagement (the reasons for bringing together the particular stakeholder group and why each wants to participate; what problem they want to solve) |
| **When?** | How often, for how long, and over what period of time do stakeholders work together? |
| **Where?** | In what settings do stakeholders convene? Is the work synchronous or asynchronous? |
| **How?** | The process of engagement, including methods for gathering input (co-learning), identifying paths of action, and decision making; how stakeholder representatives elicit from the broader community their own perspectives and needs |
For each element...

- Terminology (how do we label and describe the characteristics of the method used)
  - What are the variables?
  - Rely upon relevant existing theories, models and frameworks
    - E.g., what is the ideal group size for stakeholder engagement? → Psychology literature on group behavior and “group composition effects”

- Goal (how do we know if it was effective?)
Application of the Engagement Framework

- **PLAN**
  - Have we considered all important elements?
  - Does the engagement approach optimally reflect engagement principles?

- **DESCRIBE**
  - Have we provided enough details on the engagement approach so others may replicate?

- **EVALUATE**
  - Which approaches work best under which circumstances?
Stakeholder Engage Team

- University of California Davis
  - Katherine Kim, Kate Marie
  - Patient Co-investigator Hugo Campos
- University of California San Diego
  - Howard Taras, Elizabeth Bell
- University of Colorado Denver
  - Bethany Kwan, Kristen Curcija
- University of Washington
  - Kari Stephens, Brenda Mollis, Gina Keppel