



Phase II Stakeholder Engagement Research

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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)

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)

SCANNER (2010-2013)

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)

SCANNER (2010-2013)

pSCANNER phase I (2014-2016)

pSCANNER phase II (2016-2019)

- 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)

HF/WMO

Top four

Bottom four

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

^a Each activity rated 1 = not interested to 3 = very interested

HF/WMO

Mode of Contact

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

^a Percentages do not add up to 100% as multiple responses were allc

- 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.

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

- 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

Stakeholder Engagement Framework Elements

	Definition
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

- 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?)

- 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?

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