

**SEED Method Evaluation Report:  
Executive Summary**



# Executive Summary

## Introduction

Research reported in this report was funded through a Patient-Centered Outcomes Research Institute (PCORI) Award (#1310-07664) in the Improving Methods for Conducting Patient-Centered Outcomes Research program. The statements presented in this work are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors, or Methodology Committee.

The SEED Method for Stakeholder Engagement in Question Development and Prioritization was funded by PCORI's Improving Methods for Conducting PCOR program. The specific aims were to:

1. Conduct a demonstration of the SEED method for participatory generation of causal models and research questions,
2. Ensure replicability and scalability through project documentation, evaluation and preparation of tools for future research.

The long-term objective is to provide a framework for future PCOR researchers to develop more robust causal models and to collaboratively generate research questions relevant to stakeholders. The anticipated impact of the method is that stakeholders will have the opportunity to generate research that is consistent with the concerns, needs, and values of stakeholders.

## Program Background

The SEED method is a stakeholder engagement strategy that combines collaborative, participatory, and consultative engagement to provide meaningful participation from patients and other stakeholders. In this methodology, stakeholders participate through three different modes of engagement:

1. **Research team** – a multidisciplinary partnership composed of stakeholders and researchers, such as a community-based participatory research (CBPR) team, that collaboratively lead the project
2. **Topic groups** - groups of stakeholders brought together based on their experience and knowledge of the health-related topic being investigated
3. **SCAN participants** - consulting stakeholders who participate in focus groups and interviews.

Each of these three modes of engagement make unique contributions to the project, but work together iteratively.

The SEED method is designed to take place in six steps. In step 1 the research team identifies a focus area and conducts preliminary research to identify stakeholders and organize Topic groups. In step 2 the research team collaborates with the Topic groups to gather additional data and gain the perspective of a broad range of stakeholders through focus groups and interviews. In step 3 the Topic groups take part in a facilitated concept mapping exercise designed to tap into stakeholders' experiences of why and how these factors are interrelated. In step 4 the Topic groups participate in a facilitated process to develop research questions. In step 5 they prioritize the questions and focus on ensuring that the questions are patient centered. In step 6 the research agenda is finalized and disseminated.

Two demonstrations of the SEED method were conducted: an urban site (Richmond, VA) focusing on diet and behavioral management of diabetes and hypertension, and a rural site (Martinsville, VA) focusing lung cancer outcomes.

## Overview of Process and Outcome Evaluation

The evaluation addresses the potential for the SEED Method to improve PCOR methods. It seeks to answer the following broad questions:

- 1) Is the SEED Method approach feasible?
- 2) Does the SEED Method result in new standards or improvements of existing standards for engaging stakeholders in generating, selecting, and prioritizing topics for research?

The **process evaluation** focuses on the activities that occurred to identify, engage and train stakeholders, and implement procedures. The goal was to refine constructs, procedures, and instruments, and to measure whether the SEED Method was implemented as intended. The process evaluation addresses the following questions:

1. Were appropriate research team members identified and recruited?
2. Were the research teams effective at managing the process?
3. Were appropriate stakeholders identified and recruited?
4. Were stakeholders meaningfully engaged in the process?
5. Were tools and instruments effective?
6. What improvements have been identified to increase feasibility of the method?

The **outcome evaluation** assesses whether the SEED Method produced changes in the desired short- and medium-term outcomes. The outcome evaluation addresses the following questions:

1. Were unique conceptual models of causal relationships developed by different stakeholder groups?
2. Did causal modeling impact question development?
3. Were unique research questions developed by stakeholder groups?
4. Were the final research agendas understandable and informative?
5. Was the dissemination plan effective in reaching target audiences?
6. Are the research agendas impactful?
7. Did the SEED Method process enhance community and stakeholder capacity?

## Evaluation Approach and Methods

Data were collected using a set of instruments designed for this study, including questionnaires to assess group readiness, group dynamics, and participant satisfaction, project documentation, and analysis of research products. Qualitative assessments were conducted using interviews and After-Action Reviews. Observations were recorded using observation logs and activity logs.

Quantitative data were entered into SPSS and analyzed via descriptive statistics and bivariate inferential tests of significance (where appropriate). We also used open-ended responses from the questionnaires in the qualitative analysis. Qualitative data were transcribed and coded to identify key themes. We also directly analyzed the content of products produced by the stakeholders (e.g., conceptual models and questions) to assess key outcomes questions.

## Summary of Process Evaluation Findings

### ❖ **Appropriate research team members were identified and recruited, and were effective at managing and leading the SEED method process:**

Data on the experiences, openness, diversity, and belief in the benefits of this project appear to confirm that appropriate research team members were recruited to lead this project. Research team members completed a self-administered Group Readiness and Group Dynamics questionnaires throughout the project. In both demonstration sites, the majority of research team members strongly agreed that the demonstration would benefit themselves, patients and stakeholders, and the community; that they were willing to mentor/be mentored, learn new skills, and share their opinions and experiences; that they understood their role in the project; and that the group reflected the diversity of the community. The majority of team members agreed that members are networked to the community and understand its history, politics and needs; that they could communicate a compelling case for working together on this project; and that they were willing to participate in leading the project.

One-on-one interviews with team members also yielded a variety of insights about the ability and readiness of team members to lead the project. They endorsed positive qualities such as trust, respect, ability to relate to one another, commitment, participation, getting along with one another, and preparation.

Team members generally expressed satisfaction with group dynamics, decision-making processes, and logistics. In general, more conflicts arose in a site where new team members and veteran team members had to collaborate quickly, but these seemed to diminish over time as trust and group processes improved.

Overall, research team members tended to strongly agree that they were made to feel welcome, everyone has a voice in decisions, team members respect each other's view, team members could talk honestly at meetings, and that their opinions were listened to. Most disagreed or strongly disagreed that it takes too much time to reach decisions or that team members hold onto ideas too tightly. Regarding group decision-making processes, the majority of team members were very satisfied or satisfied with meeting facilitation, how the team works, the decision-making process, and how the team deals with problems. Team members responded that they understood their role on the project.

Overall, team members were satisfied with meeting frequency, location, and times as well as compensation and their personal contributions.

Team members liked various aspects of the project. They mentioned personal growth, learning about the health topic, working with a diverse group, team dynamics, engaging with the community, providing health information to the community, sharing opinions, learning about research, learning new skills, being part of something important, and learning about the views of others. Dislikes included issues with team dynamics, difficulty learning the process, scheduling, compensation, and timeline. One member expressed dissatisfaction with the aim of producing research questions rather than an intervention

Project milestones that were in the scope of work of the research teams were completed on time and results met expectations.

❖ **Appropriate stakeholders were identified and recruited, and were meaningfully engaged in the process:**

A diverse group of stakeholders participated in Topic groups, focus groups, and interviews. Topic group members in both demonstration sites were administered a Group Dynamics questionnaire and responded that they were open to learning new skills, and sharing opinions, and believed the project would benefit them and their communities.

A variety of data were collected on project activities to assess whether Topic group participants were meaningfully engaged, satisfied with facilitated activities, processes, and outcomes, and what they liked or would change about the process. The majority of Topic group members strongly agreed that they were willing to learn new skills, and share their opinions and experiences; the demonstration would benefit themselves, patients and stakeholders, and the community; that they understood their role in the project and the time involved; and that the group reflected the diversity of the community. They also agreed that group members are networked to the community and understand its history, politics and need; and that they could communicate a compelling case for working together on this project.

Responses to the Group Dynamics Questionnaire by Topic Group members showed that most participants strongly agreed and the rest agreed that they could talk openly and honestly at meetings, respected each other's point of view, felt listened to and welcome, and felt the team was successful in completing project tasks. Most were either very satisfied or satisfied with group processes and personal experiences. Respondents strongly agreed most often with statements that they could talk openly and honestly at team meetings, were made to feel welcome, and that teams were successful in completing project tasks. Topic group members expressed the most satisfaction about how their teams worked. They expressed less satisfaction with their own contributions, team meeting times, and understanding their role.

In open-ended responses Topic group members described many aspects of the process that they liked: working with and meeting others, learning the process, the process itself, learning about the health issues, and helping the community. Some participants noted dislikes such as meeting times, room comfort, transportation, and the perception that the process moved slowly in some parts.

Each Topic group completed a training on conceptual modeling and a series of facilitated exercises. Satisfaction questionnaires and After Action Reviews found that Topic group members were satisfied with each facilitated activity, with 63% to 96% saying they strongly agreed that goals were clearly defined, goals were met, the activity was organized and easy to understand, the facilitator was well prepared, and that the activity is an important step in creating stakeholder driven research questions. In open-ended responses they mentioned a wide variety of aspects of the project that they found effective, such as interactivity, visuals, brainstorming, the process itself, facilitation, and discussions. Barriers such as people arriving late or getting off topic were observed. Suggestions for improvements were implemented between demonstrations including modes of presenting information and adding in additional time to Topic group facilitated activities.

❖ **Tools and instruments developed for the SEED Method were effective:**

The process used a variety of tools and instruments developed specifically for the SEED Method. Recruitment of Topic group members and SCAN participants began with the Stakeholder Identification Matrices and the Stakeholder Recruitment matrices. The stakeholder matrices – developed to help the research team identify and recruit stakeholder participants – appeared to be

useful and effective. Satisfaction questionnaires were completed by the research teams. For most questions, research team members agreed or strongly agreed that the matrices were easy to use, instructions were clear and helpful, and that the matrices helped with decisions about where to recruit stakeholders. They also agreed or strongly agreed that they had enough data and information to fill out the matrices and that they would recommend them as tools for other projects. The majority found the matrices very helpful or mostly helpful in identifying where to recruit stakeholders, deciding on which stakeholders to recruit, and staying organized. However, 52% agreed or strongly agreed that the matrices were complicated to fill out.

Based on feedback from the teams, the matrices were improved between demonstrations. These improvements included creating an instruction document and guide for facilitators to use while facilitating the Stakeholder Matrix activity. The matrices were further refined after the second demonstration.

- **Several changes and improvements were made to increase the feasibility of the SEED Method:**

These improvements included:

- Building in more flexibility in who selects SCAN participants and when the focus groups and interviews are conducted.
- Improvements to tools and instructions for activities such as use of the Stakeholder Identification and Recruitment Matrices.
- Refinement of the Topic group facilitated activity scripts.
- More focus on visual information sharing and talking points during activities.
- Development of the literature review templates and instructions.
- Inclusion of examples from the demonstration sites -- such as completed models, research agendas, and detailed timelines.

## **Summary of Outcome Evaluation Findings**

Data for the outcome evaluation were collected using various instruments, including questionnaires and interviews. Quantitative data were entered into SPSS and analyzed via descriptive statistics and bivariate inferential tests of significance (where appropriate). Qualitative data were transcribed and coded to identify key themes. We also directly analyzed the content of products produced by the stakeholders (e.g., conceptual models and questions) to assess key outcomes questions.

- **The SEED Method resulted in unique conceptual models across diverse stakeholder Topic groups:**

Each Topic group developed its own conceptual model based on its list of identified factors and group discussions about the meaning, importance, and potential relationships between those factors. We reviewed the factors listed by the Topic groups in each site to assess the extent to which different stakeholder groups added unique versus common factors to their models.

In the Richmond demonstration, six unique factors were provided by Topic group 1, 23 by group 2, and 25 by group 3. Forty factors were identified by two or more Topic groups. In Martinsville, 18 unique factors were provided by Topic group 1, 31 by Topic group 2, and 16 by group 3. Twenty-six factors were identified by two or more Topic groups.

Although there were some fundamental (and expected) overlap between the concepts and

relationships in the conceptual models created by the different stakeholder groups, each group presented from 6 to 31 unique factors. In addition, there were some major differences between models in that almost all stakeholder models had at least one category of interest that was not present in the models created by other groups.

- **Causal modeling impacted question development:**

To assess whether causal modeling impacted question development, we reviewed each question discussed or prioritized by the Topic groups to see if they were based on unique factors identified by that group during the modeling exercise. We found that 4 to 12 questions per Topic group were based on factors unique to that group. A total of five prioritized questions were based on unique factors in Richmond and three in Martinsville. The data consider only factors named by a single group in each site, however there were also multiple factors name by two out of three of the groups which could also be considered as providing a unique perspective. These results link unique factors added to the conceptual model by stakeholders to the development of specific research questions that reflect their concerns and perspectives. These findings support the hypothesis that the causal modeling exercise impacted question development.

- **The SEED Method resulted in research questions that reflect the unique perspectives of different participating stakeholder groups:**

In order to ascertain whether unique research questions were developed by different stakeholder groups, we coded the questions to show the distinct contributions of the groups according to the focus (domain) of each question. In Richmond, 18 questions were prioritized. Based on our coding, we found that each Topic group provided one to three questions addressing a domain that was not addressed by the other groups. In addition, seven domains were addressed by two Topic groups but not all three, and three domains were addressed by all groups.

In Martinsville, 12 questions were prioritized. Each group provided two to four questions addressing a domain that was not addressed by the other groups. In addition, five domains were addressed by two Topic groups but not all three, and one of the domains was addressed by all groups.

Comparison of the question domains and topics, combined with the results shown in the previous sections, provide support to the hypothesis that involving unique stakeholder will help in the development of research questions that reflect the unique perspectives of different participating stakeholder groups.

- **The final research agendas were understandable, informative, and impactful:**

A number of stakeholders provided feedback on the research questions created by the stakeholders in the form of questionnaires and one-on-one interviews. Most respondents agreed or strongly agreed to questions about satisfaction with and utility of the research agenda. The statements most strongly endorsed were that the agenda is of interest for generating awareness of patient/stakeholder interests and meeting the needs of patients/stakeholders through changes in education, practice, etc., and that stakeholder generated research questions can be useful to the respondent's organization. Forty percent of respondents strongly agreed that the research agenda makes an important contribution to research in the field. Respondents were most likely to disagree with the statement that 'incorporating these research questions into my/my organization's work would be easy'.

Conference and workshop participants also had the opportunity to weigh in on the SEED Methodology. Respondents most often strongly agreed that participants provided unique insights that are worth paying attention to (64%) and that the research agenda is important because it was generated by patients and stakeholders (58%).

- **The SEED Method process enhanced community and stakeholder capacity:**

Members of the research team were asked questions on capacity building on the Group Dynamics questionnaire approximately 10 weeks into their site's project. Most respondents strongly agreed or agreed that the project provided personal growth, increased skills and knowledge, and helped develop skills.

In interviews with research team members, themes emerged around: 1) increasing the factual health knowledge of team members and community; 2) being a part of a new or novel approach to conducting research; and 3) heightening the sense of authentic community engagement. Participants reported personal and professional growth resulting from their involvement in the project, and named specific contributions they felt they had made to the team. These included growth and contribution in specific project skills (e.g., using data, interviewing), as well as an awareness of increased application of general skills such as public speaking, active listening, and time management which had been strengthened through their participation.

The demonstration projects also impacted community capacity by providing information on the health topics to project participants and the community

## Lessons Learned

The evaluation report describes lessons learned during the demonstrations in the following areas:

- Institutional review board approval of participatory research components that are developed during the project.
- Difficulty recruiting stakeholders when very specific selection criteria are used.
- Challenges communicating with participants about complex research designs.
- Working through conflicts.
- Recruiting stakeholders with tight deadlines.
- Keeping stakeholders engaged.
- Planning ways to give back to the community.
- Longer than expected time needed for the literature reviews.
- Challenges with the project timeline.

## Next Steps

Next steps include:

- Continued dissemination of demonstration site findings and the SEED Methodology. The SEED Method Toolkit and the Evaluation Report Executive Summary are available on the VCU Center on Society and Health website. Additional publications are planned.
- Follow-up studies are being planned, including testing a rapid version of the SEED Method.

## **Strengths and Limitations**

This project evaluation used numerous questionnaires, interviews, and documentation to track team member, participant, and stakeholder satisfaction with the process and products of the SEED Method. We are encouraged by the favorable responses and mindful of the project challenges. The SEED Method, if implemented in its complete form, requires significant time (at least nine months), resources, and commitment. The results, however, can have transformative potential in terms of integrating stakeholders into the research process, improving stakeholder relations, generating new research topics and approaches, and developing community action plans for stakeholders to participate in and contribute services to the community.

Despite the large number of measures utilized in this evaluation, the number of responses is small. Hopefully more data will be gathered in future studies. While these demonstrations were the first and not without their challenges, they were guided by a PI and team who understood the methodology and were familiar with the ups and downs of community engagement. We hope to see how other teams manage the process and to learn from their insights.