

 Center on Society and Health
The SEED Method Toolkit:
Overview and Summary

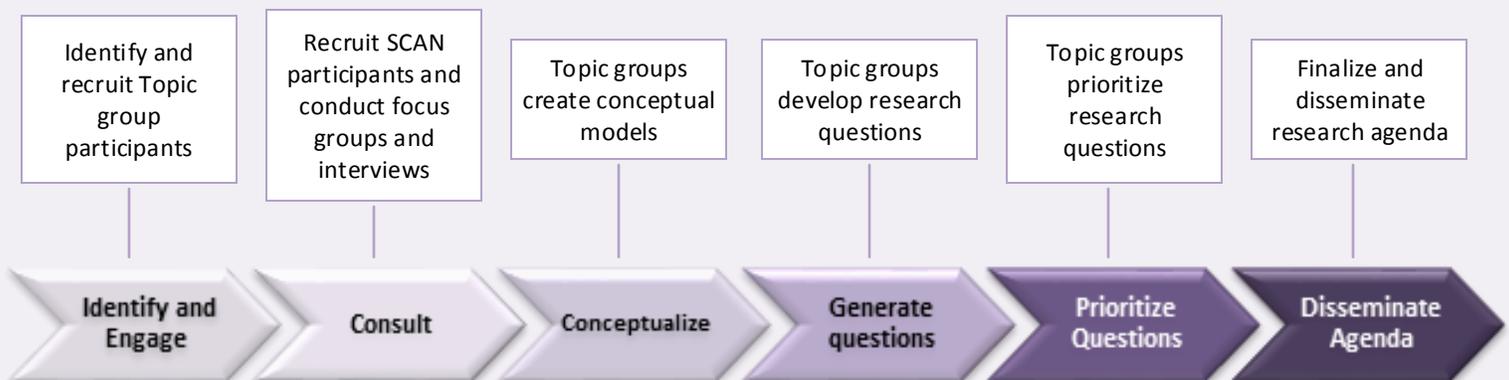


What is the SEED Method and how can it be used?

The Stakeholder Engagement in quEstion Development and prioritization (SEED) Method is a stakeholder engagement methodology that combines participatory modeling and question development with a review of available evidence. The SEED Method uses a multilevel stakeholder engagement model that is led within a participatory framework to develop stakeholder priorities, such as research topics or questions. Engagement encompasses three levels of participation:

1. A community-based participatory **Research Team** that collaboratively leads the project from beginning to end
2. Participatory **Topic Groups** of stakeholders brought together based on their experience and knowledge of the health-related topic that develop research questions
3. Consultative stakeholder participation through focus groups and interviews (**SCAN** participants)

The SEED Method was designed to take place in six steps over the course of nine months, however the method was designed to be flexible and scalable to fit with alternative timelines and objectives.



Although specifically created for the development of research questions, we encourage users to consider alternative uses of the method, such as identifying research priorities or intervention ideas, or developing participatory models as part of planning process for research projects.

Who can use the SEED Method?

- Researchers
- Organizations – including community-based and health systems
- Decision-makers
- Project teams – including coalitions

Those who wish to plan stakeholder-engaged research, involving people in multiple levels of participation, and who seek to create research priorities or agendas around a health topic would benefit the most from using the SEED method.

Customizable tools for:

- Engaging in participatory research
- Creating conceptual models diagramming causal pathways
- Developing stakeholder-generated priorities
- Using the scientific literature to refine research questions and priorities

SEED Method evaluation findings from two demonstration projects

- The SEED Method resulted in **unique conceptual models and research questions** across diverse stakeholder groups
- The final research agendas were understandable, informative, and impactful – with external stakeholders noting research questions were of interest to them/their organization and that agendas make an important contribution to research in the field
- The SEED Method process enhanced community and stakeholder capacity, including **personal growth, skill development**, and increase in **knowledge and skills** of participants
- Participants report high satisfaction with their participation in the SEED Method

What are participants saying about the SEED Method?

“I had never did anything like [this project], I’ve done things similar but not to this extent where my voice actually mattered and my opinions and what I said was taken in consideration...” - Research Team participant

“The process of developing research that’s really relevant to the kind of challenges that people are having is so important...research in general is far off base compared to what I learned from patients...” - Research Team participant

“[I liked] the group interaction, in terms of how we all assisted each other in clarifying our questions for the exercise given.” - Topic group participant

What does the toolkit provide?

An overview of the SEED Method, instructions, example documents – including timelines, meeting agendas, and powerpoint slides – and customizable templates – including organizational documents, facilitation guides, and training materials. An optional evaluation module is also included as part of the toolkit for users who would like to assess SEED Method processes or outcomes.

Who developed the toolkit?

The SEED Method was funded through a Patient-Centered Outcomes Research Institute (PCORI) Award (#1310-07664) to Emily Zimmerman (Principal Investigator), Center on Society and Health at Virginia Commonwealth University.

The toolkit was developed by members of the SEED method team - Emily Zimmerman and Sarah Cook.

Where can I can get the toolkit?

All materials are free and available for download at: go.vcu.edu/SEED

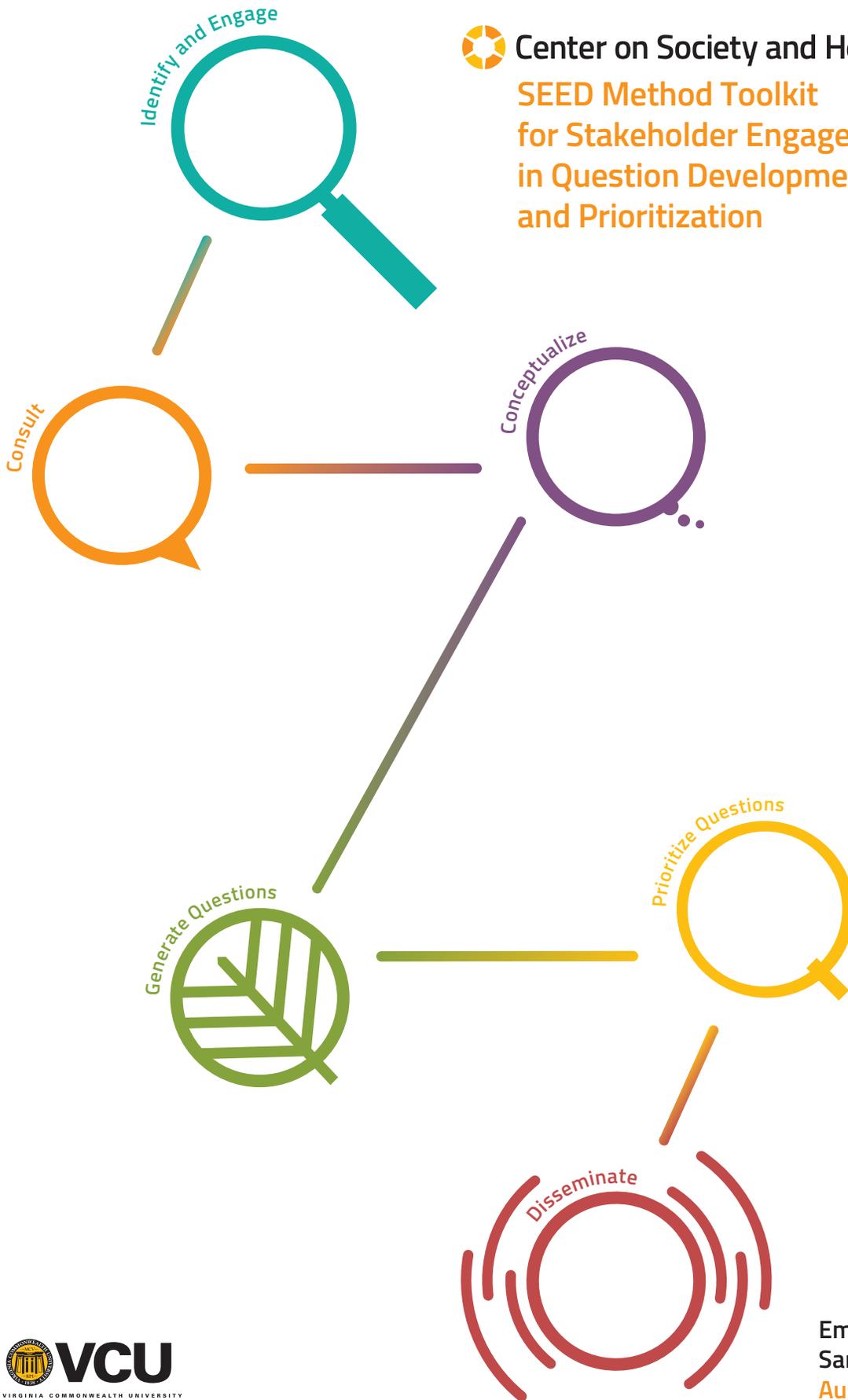
Need additional information about the toolkit or SEED Method? Contact us at:

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 Center on Society and Health
SEED Method Toolkit
for Stakeholder Engagement
in Question Development
and Prioritization



Acknowledgements

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We'd like to thank Ms. Sarah Blackburn and Ms. Cassandra Ellison for their graphic design work, and extend our deepest gratitude to the community-based participatory research teams *Engaging Richmond* and *Engaging Martinsville* for their efforts in leading the two demonstrations.

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Toolkit Assistance and Contact Information

Please direct questions to Emily Zimmerman at emily.zimmerman@vcuhealth.org.

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V. Question Refinement/Literature Review

a. Introduction/instructions – Guide for SEED Method Step 6

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- Question refinement template, Question summary template,

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- Question refinement example, Research agenda example

SEED Methodology – Instructions and Introduction to Toolkit

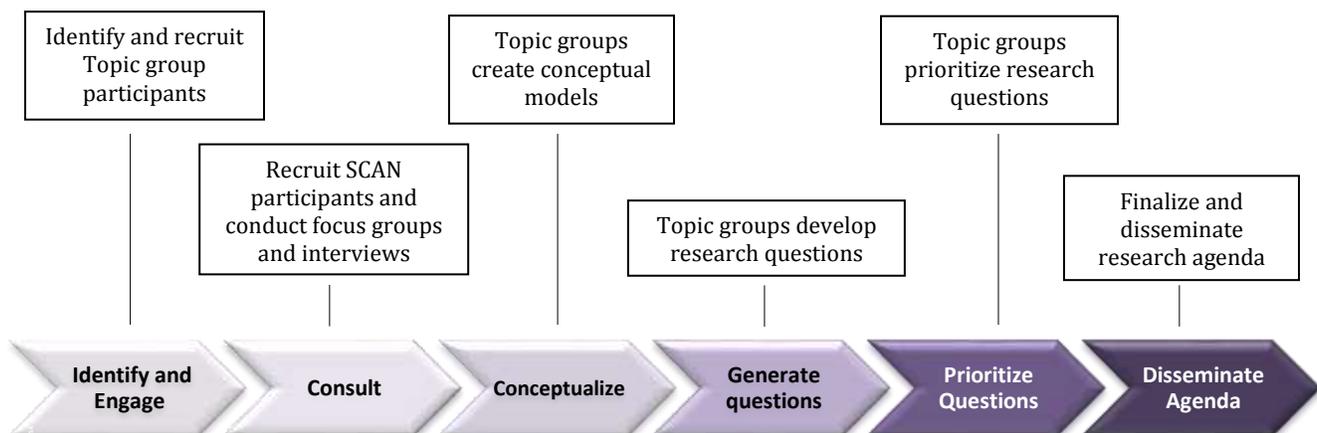
BACKGROUND: The SEED (Stakeholder Engagement in Question Development and Prioritization) Method provides a framework for PCOR (Patient Centered Outcomes Research) researchers to develop more robust stakeholder engagement and to collaboratively generate research questions. Research reported in this Toolkit 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 Principal Investigator was Emily Zimmerman at Virginia Commonwealth University.

INTRODUCTION TO THE SEED METHOD: The SEED Method is a stakeholder engagement methodology that combines participatory modeling and question development with a review of available evidence. The SEED Method employs a multilevel stakeholder model that is led within a participatory framework. Engagement encompasses three levels of participation:

1. Community-based participatory **Research Team** who collaboratively lead the project from beginning to end
2. Participatory **Topic Groups** of stakeholders brought together based on their experience and knowledge of the health-related topic that develop research questions
3. Consultative stakeholder participation through focus groups and interviews (**SCAN** participants)

The SEED method was 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 (see Figure). In step 2 the Research Team collaborates with the Topic groups to gather further data and gain the perspective of a broad range of stakeholders (SCAN participants) 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 they are patient centered. In step 6 the research agenda is finalized and disseminated. The proposed process is not about seeking consensus but instead tapping into stakeholders' experiences to generate new insights and ideas, and then letting all stakeholders contribute to prioritizing those ideas. Unlike stakeholder involvement methods that simply query stakeholders to rank or rate issues, the proposed process engages stakeholders to place their lived experience -- and their understanding of the cultural and social context -- into an analytical framework. It increases patient-centeredness and validity by broadening and deepening stakeholder involvement.

SEED Method Process:



SEED Methodology – Instructions and Introduction to Toolkit

Table 1. Summary of SEED Method Steps

Step 1: Identify and Engage
The Community Research Team meets weekly to finalize the topic, review relevant data on the target population, conduct individual informational interviews and review data, complete the stakeholder matrices, and recruit Topic group participants. Fieldwork includes informational interviewing and recruitment of Topic group participants. The Topic groups have their kickoff meetings.
Step 2: Consult
The Topic groups meet to plan focus groups and interviews and to review results together with the Research Team. The Research Team meets weekly, conducts focus groups and interviews, prepares summaries, and develops logistics for step 3.
Step 3: Conceptualize
Each Topic group meets once to undergo training on building conceptual models. Topic groups meet a second time for a facilitated exercise in creating conceptual models, and the Research Team reconciles/finalizes the models. The Research Team prepares logistics for the next step.
Step 4: Generate Questions
Each Topic group reconvenes to review the full set of models (from all Topic groups) and participates in a facilitated exercise to prioritize pathways and relationships of interest and generate research questions. The Research Team prepares logistics for the next step.
Step 5: Prioritize Questions
Each Topic group reconvenes to prioritize research questions. The Research Team prepares logistics for the next step.
Step 6: Disseminate Agenda
The Research Team reviews related literature and/or conducts systematic reviews and finalizes the list of research questions. The Research Team finalizes and implements the dissemination plan and conducts presentations to stakeholders.

RESEARCH TEAM ACTIVITIES: The Research Team engages in the following activities throughout the SEED Method:

- Review of health statistics and demographic data of health topic
- Conduct informational interviews with local health care system representatives to learn about at-risk populations and where they receive services in the community
- Completion of Stakeholder Identification and Recruitment Matrices to identify and recruit Topic Group participants
- Facilitation of Topic Groups
- Data collection from SCAN participants

TOPIC GROUP ACTIVITIES: Topic Group participants are brought together based on their personal or professional experience with the health topic. They engage in a series of meetings throughout the project to build conceptual models that explore potential causal factors leading to the health topic, and develop and prioritize research questions

SCAN ACTIVITIES: Focus group and key informant interviews are conducted with additional stakeholders with personal or professional experiences with the health topic. These are meant to broaden Topic Group and Research Team members’ understanding of the experiences of a diverse set of stakeholders.

SEED Methodology – Instructions and Introduction to Toolkit

PREVIOUS DEMONSTRATIONS: Two demonstration of the SEED Method were conducted and focused on the following health topics:

- Richmond, VA: Dietary compliance for diabetes/hypertension¹
- Martinsville, VA: Lung cancer outcomes

Research agendas were developed at each of these sites and were disseminated to a wide audience, including academic researchers and funding organizations.

HOW TO USE THE TOOLKIT: We encourage Toolkit users to familiarize themselves with all the materials in the toolkit, and to adapt documents, tools, templates, and timelines to fit the specifics of your project. As such, many of the Toolkit items are presented as templates to be customized by users, including areas that require project-specific details such as the [health topic] of choice and [Research Team name]. These are presented in red font. In addition, throughout this Toolkit, you will find examples from the two SEED Method demonstration projects, including meeting agendas, presentation slides, timelines, and organizational documents. These are provided to orient users and illustrate final versions of project materials. Evaluation materials are provided for those who want to evaluate SEED Method processes or outcomes.

ADAPTING THE SEED METHOD: The SEED Method can be adapted for projects of varying scope in a variety of ways to fit the specifics of your project, including timeline and budget constraints:

Timeline: Here are the four recommended scenarios for scaling down the current SEED Method process and timeline, ranging from longest to shortest implementation time:

Scenarios	Stakeholder groups involved	Estimated Time required
Full SEED Method (as presented in toolkit)	Research team, Topic groups, SCAN participants	9-12 months
Abbreviated SEED Method	Research team, Topic groups	4 months
Topic group facilitated activities only, including conceptual modeling (#1), question development (#2), and question prioritization (#3)	Topic groups	6 weeks
Conceptual model training and conceptual modeling facilitated activity (#1) only	--	1 meeting

Stakeholders: Users can customize the stakeholders involved in the SEED method, including number of Topic groups and whether or not focus groups and interviews (SCAN) are conducted. In addition, composition of the Research Team may vary across sites and may include a CBPR team, existing research team, or expert panel to lead the process.

Deliverables: Although specifically created for the development of research questions, we also encourage users to consider alternative uses of the method, such as identifying research priorities

¹ Zimmerman EB, Cook SK, Haley AD, Woolf SH, Price SK, and The Engaging Richmond Team. A patient and provider research agenda on diabetes and hypertension management. Am J Prev Med. 2017; 53(1): 123-129.

SEED Methodology – Instructions and Introduction to Toolkit

or intervention ideas, policy decisions, or developing participatory models as part of a planning process for research projects.

Setting: The SEED Method does not need to be used and implemented by an academic research group – other researchers, organizations (community based, health systems), decision-makers, and project teams (coalitions) would be well suited for implementing the SEED Method.

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V. Question Refinement/Literature Review

a. Introduction/instructions – Guide for SEED Method Step 6

b. Templates

- Question refinement template, Question summary template,

c. Examples

- Question refinement example, Research agenda example

Research Team and Other Project Documents

INSTRUCTIONS: The following section contains materials for recruiting, organizing, and facilitating Research Team meetings and activities in the SEED Method. The Research Team is a multidisciplinary partnership composed of stakeholders and researchers, such as a community-based participatory research (CBPR) team, to collaboratively lead the research process. The Research Team will be responsible for choosing the project's health topic, conducting informational interviews with local service providers, identifying Topic Group members and SCAN participants, facilitating stakeholder meetings, conducting data collection, and assisting with project dissemination activities.

We recommend working with Research Team members with the following attributes: well-connected to the target population; ability to commit to regular meetings and outside work throughout the duration of the project; an interest in developing or utilizing research skills; comfortable talking to groups of people and facilitating meetings; and a willingness to share and contribute to the project. Team members may bring expertise in areas such as knowledge of the community or target population, expertise on the health issue, or research experience. The Lead Investigator and Project Coordinator may or may not be included as members of the Research Team.

MATERIALS: You'll find the following Research Team and project coordination materials included in this section of the Toolkit:

Templates

- Meeting materials:
 - Research team project overview
 - Research team agenda items
- Research Team activities:
 - Informational interview script template
 - Stakeholder matrix facilitation guide template
 - Stakeholder Matrix 1, 2, 3 templates

Example documents

- SEED one page summary
- Timeline example
- Research Team kickoff presentation example
- Meeting agenda example

Research Team Member Overview

[Community Research Team Name]

SEED Project Description

Purpose:

[Organization name] is conducting a study in [city/location] to actively engage diverse stakeholders – such as patients, caregivers, advocates, and health professionals - in developing research questions around [health topic].

Project Goals:

- To actively engage community stakeholders in identifying and prioritizing research questions surrounding [health topic]
- To generate a relevant research agenda that addresses the concerns, needs, and values of diverse stakeholder groups
- To disseminate the research agenda to the community, researchers, policymakers, funding organizations and those in power to affect change

SEED Project Roles and Responsibilities

Project Participants:

- We are hiring community researchers to be members of the [Community Research team name] team. [Community Research team name] is a [description of team and mission]. [Community Research team name] will lead the [timeframe] project throughout all phases of the project.

Role of Community Researchers ([Community Research team name]) on this project:

Responsibilities include: identifying and recruiting stakeholders, planning and conducting focus groups and interviews, reviewing data, and analyzing and disseminating results.

Time commitment:

Project participation lasts from [date range], with weekly meetings occurring on [day and time of meeting]. There are flexible additional fieldwork hours outside of regular weekly meetings available. These activities include:

- Conducting informational interviews with community organizations
- Recruiting research participants
- Conducting focus groups
- Conducting interviews
- Attending stakeholder meetings

The official Kickoff meeting is on [date and time].

Compensation

Team members will be compensated [amount or hourly rate] for their involvement.

Contact

To learn more about the SEED study or to get involved, please contact [Project Coordinator name and contact information; Principal Investigator name and contact information].

Research Team Agenda Items – SEED Method

STEP 1: IDENTIFY AND ENGAGE

- Choose/reconfirm health topic
- Kickoff meeting:
 - Orientation to project
 - Consent
 - Review timeline
 - Roles/responsibilities
 - Project logistics
- Human Subjects Research Training and certification
- Review health topic/demographic information
- Informational interviews:
 - Planning/signing up for informational interviews
 - Conducting informational interviews
 - Reporting back to group on findings
- Complete stakeholder matrices:
 - Identify Topic group participants, SCAN participants
 - Recruitment planning for Topic groups, SCAN participants

STEP 2: CONSULT

- SCAN planning and facilitation:
 - Focus Groups (FGs)
 - Design Focus Group recruitment flyers
 - Recruitment plan
 - Focus Group facilitation training
 - Logistics
 - Create Focus Group guides, consent forms, etc.
 - Conduct focus groups
 - Key Informant Interviews (KIIs)
 - Design Key Informant Interview recruitment flyers
 - Recruitment plan
 - Training on conducting one-on-one interviews
 - Create Key Informant interview guides, consent forms, etc.
 - Conduct interviews
 - Compile findings – prepare summary for Topic groups
 - Conduct additional FGs/KIIs based on Topic group’s feedback (OPTIONAL); compile findings
- Topic group planning and facilitation:
 - Design Topic group recruitment flyers
 - Topic group recruitment plan
 - Recruitment practice
 - Roles/responsibilities
 - Additional trainings: facilitating meeting, notetaking, etc.
 - Develop meeting schedule and agendas
 - Coordination and logistics of all Topic group meetings (includes securing building space for meetings,
 - Logistics for Facilitated Activity #1

Research Team Agenda Items – SEED Method

STEP 3: CONCEPTUALIZE

- Training on conceptual models/path diagrams
- Review 'Domains worksheet' and make edits, deletions, additions (this will be used in Facilitated Activity #1 with Topic groups)
- Provide feedback on Topic groups' conceptual models (after Topic group facilitated exercise #1) and prepare models for next facilitated exercise
- Logistics for Facilitated Activity #2

STEP 4: GENERATE QUESTIONS

- Training on Creating Research Questions
- Review Topic groups' research questions and add to list
- Logistics for Facilitated Activity #3

STEP 5: PRIORITIZE QUESTIONS

- Review Topic groups' prioritized research questions; feedback and refinement of final questions ahead of literature review step

STEP 6: DISSEMINATE

- Plan for dissemination events
- Question refinement/Literature review

SEED Informational Interview Template: Identifying Affected Populations and Service Providers

TOOL INSTRUCTIONS: Please modify this tool to fit the goals of your project. Where noted, fill in the specific **health topic** of focus and details about the **Community Research Team**. We also recommend adapting the interview questions used in this guide to best suit your needs.

Purpose of interview:

The purpose of conducting these informational interviews is to get a sense of where to find potential stakeholders to recruit for participation in the SEED Topic groups and to identify subgroups of people at risk of or affected by **[health topic]**. Topic group members will undergo a series of facilitated exercises to develop and prioritize research questions related to **[health topic]**.

Participants:

People in local organizations who can provide information about the health topic, population at risk, and the services the organization provides will be interviewed by members of the Community Research Team.

Interview instructions:

As a group, you will identify service providers and organizations in the community that you are familiar with that serve people with **[health topic]**. On your own, please contact your assigned person/organization to schedule a brief informational interview to be conducted over the phone or in person. This interview should last no more than 30 minutes.

Please follow the attached interview script, and make sure to take thorough notes throughout the interview. It is best to take notes during the interview, rather than wait until after the interview is finished.

Interview Information	
Name of Interviewer (Community Research Team Member):	
Organization name:	
Name of person being interviewed:	
Interview Focus (circle one)	[health topic 1] [health topic 2]
Date of interview:	
Interview START time:	
Interview END time:	

Introduction:

“Thank you for taking the time to speak with me today. My name is [name] and I’m a member of [Community Research team name], a [mission of Community Research team]. Currently, we are working on a project that seeks to develop research questions surrounding [health topic]. I’m interested in knowing more about your organization and the people it serves, in order to get a better sense of who is affected by these health conditions, and the resources available to them.”

Interview Questions:

IQ1: “Among the people your organization serves, who is most affected by [health topic]?”

Probe: “Do you see important differences by age, sex, race-ethnicity, socioeconomic status, place, health status, or something else?”

IQ1a: “Which groups are most at risk? Are there any sub-populations particularly at risk for getting the disease?”

IQ1b: “Are there any sub-populations particularly at risk for poor outcomes?”

IQ2: “What types of support or information do patients receive from your organization for [health topic]?”

IQ3: “Where else do patients receive support or services?”

IQ4: “What types of local advocacy organizations exist?”

IQ5: “Are there other local leaders/policymakers/etc. involved in this issue?”

Stakeholder Identification and Recruitment Matrices Facilitation Guide - Template

The research team completes a set of Stakeholder Identification Matrices to develop a comprehensive sampling plan for stakeholder engagement. The matrices are designed to be adaptable to different types of projects by customizing each template based on the study population and topic. This step may be used to select Topic group participants and/or SCAN participants.

The matrices include:

- A detailed *Matrix 1: Patient Stakeholder Identification matrix*, which identifies potential patients/caregiver subgroups by demographic, social, and health-related characteristics. To complete this matrix, the team used preliminary data to rank subgroups based on a variety of criteria to determine which subgroups are most relevant to include as stakeholders for the particular topic and geographic area being studied.
- *Matrix 2: Service Provider and Other Stakeholder Identification matrix*, which identifies subgroups of health care professionals in clinical, ancillary, and non-clinical settings, and other stakeholder such as payers, policymakers, and researchers.
- *Matrix 3: Stakeholder recruitment matrix*, which identifies specific places to recruit each patient, health care professional, and other stakeholder subgroup by source type (e.g., clinics, community organizations, churches, support groups, etc.).

The set of matrices can be found in the excel file '*Stakeholder Matrices_templates*'.

Stakeholder Identification and Recruitment Matrices Facilitation Guide - Template

Matrix 1: Patient Stakeholder Identification Facilitation Guide

Purpose: This matrix will be used to identify patient stakeholder participants by demographic, social, and other health-related criteria. This step may be used to select Topic group participants and/or SCAN participants.

What you will need:

- *Matrix 1: Patient Stakeholder Identification* (projected)
- *Demographics Information* handout
- Information from Informational Interviews conducted by Research Team members
- Flip charts/white board
- Markers
- Pens (1 per person)
- Sticky notes or index cards (voting)
- Rank cards (1 pack per person; each pack contains three notecards with the following written: 'Low', 'Medium', 'High' (one word per card))

Instructions and Facilitation Questions (FQ):

Before starting this step, the research team should decide the number of Topic groups to recruit for this project. The number of groups selected may be influenced by factors such as the diversity of the target population, available time and resources, and goals of the project. Similarly, if this step will be used to select SCAN participants, it will be useful to decide beforehand how many focus groups and interviews will be conducted.

Introduction:

There are many ways in which stakeholders, patients, and caregivers impacted by [health condition] can be involved in this project. There are three different participant groups, and each type of participation has a different role.

Topic groups: This is the most involved group of stakeholders we will be working with throughout the project. They will be involved in all Topic group meetings, and will talk at length about their experience with [health condition]. Each Topic group will develop a conceptual model diagramming the factors that influence the health outcome based on their own experience, and will create research questions that are important to them. It's important to remember that each Topic group will bring their own unique perspective of the health topic to the table, and both their conceptual models and research questions will reflect this unique perspective and experience. Therefore we want to consider who would be the best people to serve in this role throughout the project.

Stakeholder Identification and Recruitment Matrices Facilitation Guide - Template

Today we will work through an activity to help us determine who we'd like to be a part of the Topic groups in this project. Patients, caregivers, providers and other stakeholders can also be involved in this project as SCAN participants:

Focus groups: Focus groups are interactive group meetings that allow participants to share their experiences, perceptions, and opinions about our health topic. People involved in this type of participant group will be involved in a one-time only focus group lasting approximately 90 minutes. This is a great way for people to participate who may not be able to commit to a more involved, long-term commitment like the Topic groups.

Key informant interviews: One-on-one interviews, lasting between 30 and 60 minutes, will be conducted over the phone or face-to-face. This allows us to include people in our study that might not be able to meet for longer periods of times (Topic groups) or are not able to attend a focus group. Rather, this allows us to include people who have busy schedules or who might prefer to meet privately (i.e., health care providers (MDs), policymakers, etc.).

Step 1: Choosing patient sub-groups:

Purpose: This step will help the research team brainstorm different patient sub-groups affected by the health topic. There is flexibility in choosing which patient categories and subgroups to use (far left-hand side of the matrix) – add/delete categories as necessary.

Stakeholder Identification and Recruitment Matrices Facilitation Guide - Template

Matrix 1: Patient Stakeholder Identification

Identifying Priority Patient Subgroups

Purpose: This matrix will be used to identify potential patients and caregiver subgroups by demographic, social, and health-related characteristics. Please use the 'Health and Demographic' data document to rank subgroups based on a variety of criteria to determine which subgroups are most relevant to include as stakeholder participants in the Topic groups.

Instructions (Please refer to Facilitation Guide for more detailed instructions):

1. Edit the 'Who is Affected' in the first column according to the data on diabetes and hypertension (ADD/DELETE as necessary).
2. As a group, decide on a set of decision criteria (remaining columns).
3. As a group, gather data and fill in the criteria for each identified patient subgroup by ranking.
4. As a group, weight responses to each criteria and determine whether to specifically recruit within each subgroup. Place recruitment decision in 'Decision' column.

Who is affected? (Patient Stakeholders)	Criteria 1: e.g. risk level (low, med, high)	Criteria 2: e.g. presence in study area	Criteria 3: e.g. vulnerable population	Decision
Sex				
Females				
Males				
Age				
School-age				
Adolescents				
Young adults				
Adults				
Seniors				
Military/veteran status				
Veterans				

Brainstorm activity: Begin this brainstorm without looking at or projecting the matrix. Facilitator should lead the Research Team in an activity to identify all potential patient groups that should be involved in the project. Facilitator prompts discussion through the following questions and writes down all groups identified on a board or flip-chart. After completing brainstorming, edit the categories in the matrix document and project the final matrix for the group to see.

FQ 1: *“Who is affected by [health condition]?”* [without looking at matrix – facilitator writes list on board]

- *“What did we discover about who is affected by [health condition] from the demographics information handout?”*
- *“In our informational interviews, what were some of the local organizations and resources we learned about? What people/patients do they serve? Do they target any specific groups of people?”*
- *“Which patients in this community are at high risk? Are there certain people at risk because of the type of work they do? Because of age, gender, behavior, other medical conditions, etc?”*
- *“Which patients in this community have trouble accessing care or services?”*
- *“Which patients in this community might provide a unique perspective?”*

Stakeholder Identification and Recruitment Matrices Facilitation Guide - Template

Edit the matrix: After completing brainstorming, edit the categories in the matrix (rows on left).

Step 2: Choosing decision criteria:

Purpose: To help reduce the size of the initial brainstormed list of patient subgroups, the research team will decide upon which groups of patients should be prioritized and included as participants in Topic groups. This will be accomplished by having them decide upon a set of decision criteria. These criteria will be used to rank each patient subgroup, and should be filled in across the top (columns) of Matrix 1.

Matrix 1: Patient Stakeholder Identification

Identifying Priority Patient Subgroups

Purpose: This matrix will be used to identify potential patients and caregiver subgroups by demographic, social, and health-related characteristics. Please use the 'Health and Demographic' data document to rank subgroups based on a variety of criteria to determine which subgroups are most relevant to include as stakeholder participants in the Topic groups.

Instructions (Please refer to Facilitation Guide for more detailed instructions):

1. Edit the 'Who is Affected' in the first column according to the data on diabetes and hypertension (ADD/DELETE as necessary).
2. As a group, decide on a set of decision criteria (remaining columns).
3. As a group, gather data and fill in the criteria for each identified patient subgroup by ranking.
4. As a group, weight responses to each criteria and determine whether to specifically recruit within each subgroup. Place recruitment decision in 'Decision' column.

Who is affected? (Patient Stakeholders)	Criteria 1: e.g. risk level (low, med, high)	Criteria 2: e.g. presence in study area	Criteria 3: e.g. vulnerable population	Decision
Sex				
Females				
Males				
Age				
School-age				
Adolescents				
Young adults				
Adults				
Seniors				
Military/veteran status				
Veterans				

Choosing decision criteria: Prompt a discussion on potential decision criteria using the following question. Write all of the recommended criteria on a board or flip chart.

FQ1: "How should we decide which groups of patients we want to include as part of our patient Topic groups?"

- **"What are some decision criteria we should use?"**
 - **"Is prevalence of this disease (how common it is) in a particular group important?"**
 - **"Is the presence of this group in our community important?"**
 - **"Should we specifically prioritize vulnerable groups of people?"**
 - **"What about a groups risk level - risk of complications, death, poor health outcomes?"**

Stakeholder Identification and Recruitment Matrices Facilitation Guide - Template

- “Any other decision criteria?”

Voting: Have the group vote on the top three criteria they want to use. This can be done by passing out notecards (three cards per person) and having Research Team members write ONE criteria per notecard. Pass notecards to facilitator to count. The three criteria with the most votes will be used in the next step.

Edit matrix: After completing criteria selection, edit the categories (columns) in the matrix with the top three criteria.

Step 3: Ranking each patient subgroup according to criteria:

Purpose: Rank each patient subgroup according to the decision criteria decided on in the last step.

Matrix 1: Patient Stakeholder Identification

Identifying Priority Patient Subgroups				
<p>Purpose: This matrix will be used to identify potential patients and caregiver subgroups by demographic, social, and health-related characteristics. Please use the 'Health and Demographic' data document to rank subgroups based on a variety of criteria to determine which subgroups are most relevant to include as stakeholder participants in the Topic groups.</p>				
<p>Instructions (Please refer to Facilitation Guide for more detailed instructions):</p> <ol style="list-style-type: none"> Edit the 'Who is Affected' in the first column according to the data on diabetes and hypertension (ADD/DELETE as necessary). As a group, decide on a set of decision criteria (remaining columns). As a group, gather data and fill in the criteria for each identified patient subgroup by ranking. As a group, weight responses to each criteria and determine whether to specifically recruit within each subgroup. Place recruitment decision in 'Decision' column. 				
Who is affected? (Patient Stakeholders)	Criteria 1: e.g. risk level (low, med, high)	Criteria 2: e.g. presence in study area	Criteria 3: e.g. vulnerable population	Decision
Sex				
Females				
Males				
Age				
School-age				
Adolescents				
Young adults				
Adults				
Seniors				
Military/veteran status				
Veterans				

Ranking process: Each person will get a set of rank cards (Low, Medium, High) to use for ranking each patient subgroup on each of the three decision criteria. The project coordinator will have the research team indicate a rank (low, medium, high) for each decision criteria for each patient subgroup using the rank cards. The coordinator will count the number of votes for each ranking. The ranking with the greatest number of votes is converted to a number according to the following number system:

Low = 1 point

Stakeholder Identification and Recruitment Matrices

Facilitation Guide - Template

Medium = 2 points

High = 3 points

This number is recorded in the appropriate box in Matrix 1.

Facilitator: *“Now we are going to look at each of the patient subgroups we brainstormed and rank them based on the decision criteria we just set. For example, based on what we’ve learned so far in this project, for [SUBGROUP 1], do you think this group is low, medium, or high [DECISION CRITERIA 1] for having [health condition]? What about [DECISION CRITERIA 2] – do you think [SUBGROUP 1] is low, medium, or high?”* (See below for example script from Richmond demonstration.)

[Richmond demonstration example: **“Now we are going to look at each of the patient subgroups we brainstormed and rank them based on the decision criteria we just set. Based on what we’ve learned so far in this project, do you think FEMALES have low, medium, or high rates (Criteria 1: PREVALENCE) of diabetes or hypertension?** (Group responds: High). *“Okay, so diabetes and hypertension has a high PREVALENCE in FEMALES.”* [Notetaker/coordinator places “3” in corresponding box]. **“Looking at our next decision criteria, do you think FEMALES have a low, medium, or high risk for having POOR OUTCOMES (Criteria 2) associated with diabetes and hypertension?”** (Group responds: High). *“Okay, so FEMALES have a HIGH risk of POOR OUTCOMES.”* [Notetaker/coordinator places “3” in corresponding box]. **“And lastly, how prevalent are females within our community (the East End of Richmond) – is there a low, medium, or high PRESENCE (Criteria 3: PRESENCE IN COMMUNITY) of FEMALES here?”** (Group responds: High). *“Okay, so FEMALES have a HIGH PRESENCE within our community.”* [Notetaker/coordinator places “3” in corresponding box].

Step 4: Weight responses, prioritization of patient subgroup and Final Decision:

Purpose: Select patient subgroups that will be carried over for use in Matrix 3.

Example: Completed Matrix 1

Who is affected? (Patient Stakeholders)	Criteria 1: Prevalence <small>(high, medium, low)</small>	Criteria 2: Poor outcomes <small>(high, medium, low)</small>	Criteria 3: Presence in community <small>(high, medium, low)</small>	Decision
Females	3	3	3	9
Males	2	2	2	6

Subgroup selection: Add up the three criteria rankings for each of the patient subgroups. Record this number in the ‘Decision’ column. (Can create an equation within

Stakeholder Identification and Recruitment Matrices Facilitation Guide - Template

excel to automatically populate this score.) The subgroups with scores of 8 points or more* are carried over to the next step as prioritized patient subgroups for Topic groups. Highlight all groups that were carried-over in yellow.

*This number can be adjusted and reduced if this eliminates too many patient subgroups

MOVE ONTO MATRIX 2: SERVICE PROVIDER/OTHER STAKEHOLDER IDENTIFICATION

Stakeholder Identification and Recruitment Matrices Facilitation Guide - Template

Matrix 2: Service Provider/Other Stakeholder Identification Facilitation Guide

Purpose: This matrix will be used to identify all Health Care, Service provider and Policymaker stakeholders to participate as Topic group members.

What you will need:

- Matrix 2: Service Provider/Other Stakeholder Identification (projected)
- Information from Informational Interviews
- Sticky notes or index cards (voting)
- Flip charts/white board
- Markers
- Rank cards (1 pack per person; each pack contains three notecards with the following written: 'Low', 'Medium', 'High' (one word per card)

Step 1: Choosing Service Provider/Other Stakeholder sub-groups:

Purpose: This step is meant to help the research team brainstorm different service provider subgroups or other stakeholders involved with the health topic. There is flexibility in choosing which provider categories and subgroups to use (far left-hand side of the matrix) – add/delete categories as necessary.

Brainstorm activity: Begin this brainstorm without looking at or projecting the matrix. Facilitator should lead the Research Team in an activity to identify all potential provider groups that should be involved in the project. Facilitator prompts discussion through the following questions and writes down all groups identified on a board or flip-chart. After completing brainstorming, edit the categories in the matrix document and project the final matrix for the group to see.

FQ 1: “Who is involved with **[health condition]?**” (without looking at matrix – facilitator writes list on board)

- “In our informational interviews, what were some of the local organizations and resources we learned about? What types of professionals are serving in these organizations?”
- “What types of health care professionals serve people with **[health condition]?**”
 - “What types of service providers are important for people with **[health condition]?** (e.g., social services, health education, etc.)”
- “What other types of professionals may work in the area of **[health condition]?**” (research, policy, insurance, advocacy)

Stakeholder Identification and Recruitment Matrices Facilitation Guide - Template

- *“What other type of stakeholder might bring a unique and important perspective about [health condition]?”*

Edit the matrix: After completing brainstorming, edit the categories in the matrix.

Step 2: Choosing decision criteria:

Purpose: To help reduce the size of the initial brainstormed list of service providers/other stakeholders, the research team will decide upon which groups of stakeholders should be prioritized and included as participants (either as Topic group members, Focus Group participants, or Key Informant Interviews). This will be accomplished by having them decide upon a set of decision criteria. These criteria will be used to rate each service provider subgroup, and should be filled in across the top (columns) of Matrix 1.

Choosing decision criteria: Prompt a discussion on potential decision criteria using the following question. Write all of the recommended criteria on a board or flip chart.

FQ1: *“How should we decide which groups of service providers/other stakeholders we want to include in this project?” (Topic groups, Focus groups, and Key Informant Interviews)*

- *“What are some decision criteria we should use?”*
 - *“Is the amount or type of professional experience, expertise, and knowledge important to consider?”*
 - *“What about how much contact they have with patients with lung cancer?”*
 - *“Ability to affect the services that patients receive?”*
 - *“Ability to affect the policy environment?”*
 - *“A unique perspective on [health condition] outcomes?”*
 - *“Anything else?”*

Step 3: Ranking each service provider subgroup according to criteria:

Purpose: Rank each service provider/other stakeholder subgroup according to the decision criteria decided on in the last step.

Ranking process: Each person will get a set of rank cards (Low, Medium, High) to use for ranking each patient subgroup on each of the three decision criteria. The project coordinator will have the research team indicate a rank (low, medium, high) for each decision criteria for each patient subgroup using the rank cards. The coordinator will count the number of votes for each ranking. The ranking with the greatest number of votes is converted to a number according to the following number system:

Low = 1 point

Stakeholder Identification and Recruitment Matrices Facilitation Guide - Template

Medium = 2 points

High = 3 points

This number is recorded in the appropriate box in Matrix 2.

Step 4: Weight responses, prioritization of service provider subgroup and Final Decision:

Purpose: Select service provider/other stakeholder subgroup that will be carried over to the next step as prioritized service provider/other stakeholder subgroup.

Subgroup selection: Add up the three criteria rankings for each service provider/other stakeholder subgroup. Place this number in the 'Decision' column. (Can create an equation within excel to automatically populate this score.) The subgroups with scores of 8 points or more* will be carried over to the next step as prioritized service provider/other stakeholder subgroup for Topic groups. Highlight all groups that were carried-over in yellow.

*This number can be adjusted and reduced if this eliminates too many subgroups

NEXT STEP: CHOOSING COMPOSITION OF TOPIC GROUPS

Stakeholder Identification and Recruitment Matrices Facilitation Guide - Template

Choosing composition of Topic Groups

What you'll need:

- Flip chart/whiteboard
- Markers
- Sticky notes or index cards (voting)

Step 1: Choosing composition of Topic groups:

Purpose: As part of this study, the research team is limited to having a certain number of different stakeholder Topic groups.

****Throughout this process, the Research Coordinator/Group Facilitator should coach the group to not go so narrow that it makes finding participants difficult, but also not to rule out groups because of issues such as age, literacy, or how busy they are (e.g., MDs)****

Step 1a: Brainstorming Patient Stakeholder Topic Groups:

[On a piece of paper (or projected), list out all the highlighted prioritized patient subgroups from Matrix 1.]

FQ1: “Looking at our final list of patient subgroups (those that were retained with the highest scores), who should we include as participants in our TOPIC groups? It’s important to understand that each group of people will bring a unique perspective to this project that will be reflected in their conceptual models and research questions. This may be helpful in thinking about who we want to include in these patient groups, as well as the feasibility of engaging them throughout the project.”

“First let’s look at all of the groups and see if we should modify, clarify, or combine any of them:”

- ***“Does it make sense to include any of these groups together?”***
- ***“What ‘combination of specific characteristics should participants have in order to be eligible for the group? (i.e., African American over 65 years of age?)”***

“Now let’s think about each group and why it might be important to include them:”

FQ2: “Why is it important to include these groups?”

FQ3: “What information are we wanting to learn from them? What unique perspective would they provide? What might we expect to hear from them?”

Stakeholder Identification and Recruitment Matrices Facilitation Guide - Template

FQ4: “How feasible would these groups be to recruit for and retain throughout the Topic group meetings?”

Step 1b: Brainstorming Service Provider Stakeholder Topic Group:

[On a piece of paper (or projected), list out all the highlighted prioritized provider/other stakeholder subgroups from Matrix 2.]

FQ1: “Looking at our final list of provider subgroups (those that were retained with the highest scores), who should we include as participants in our Topic groups? It’s important to understand that each group of people will bring a unique perspective to this project that will be reflected in their conceptual models and research questions. This may be helpful in thinking about who we want to include in this Topic group, as well as the feasibility of engaging them throughout the project.”

- *“Does it make sense to include any of these groups together?”*
- *“What criteria would you like participants to meet in order to be eligible for the group? (i.e. Must be an African American over 65 years of age?)”*

FQ2: “Why is it important to include these groups?”

FQ3: “What information are we wanting to learn from them? What unique perspective would they provide? What might we expect to hear from them?”

FQ4: “How feasible would these groups be to recruit for and retain throughout the Topic group meetings?”

Step 1c: Voting on Patient Stakeholder and Service Provider/Other Stakeholder Topic Groups:

[On a piece of paper (or project), list out all the highlighted prioritized patient and provider/other stakeholder subgroups from Matrix 1 and Matrix 2.]

1. Each member of the research team should propose a specific Topic group of their choosing (see below for example groups). Go around the circle and write down each Topic group that is suggested.
2. Prior to voting, the research coordinator/facilitator should work to combine and eliminate redundancies and overlaps among the brainstormed list of Topic groups.
3. In order to narrow down groups, each research team member should be given ballots to cast their vote (sticky notes). The number of ballots each person receives should be equal to 1/3 of the number of Topic groups listed. (For example, if there are 9 Topic groups listed, each research team member will receive 3 ballots.)
4. Research team members should vote on their top Topic groups.

Stakeholder Identification and Recruitment Matrices Facilitation Guide - Template

5. Repeat this voting process (if necessary) until there are the desired number of Topic groups remaining.

(**Example Patient Stakeholder Groups** from Richmond demonstration that were brainstormed during this step include: African American females, Senior Citizens with heart disease or obesity, Veterans with history of substance abuse, and Unemployed adults without health insurance.)

NEXT STEP: DECIDING WHERE TO RECRUIT TOPIC GROUP PARTICIPANTS FROM.
Please complete Matrix 3 (facilitation guides are not included)

Matrix 1: Patient Stakeholder Identification

Identifying Priority Patient Subgroups

Purpose: This matrix will be used to identify potential patients and caregiver subgroups by demographic, social, and health-related characteristics. Please use the 'Health and Demographic' data document to rank subgroups based on a variety of criteria to determine which subgroups are most relevant to include as stakeholder participants in the Topic groups.

Instructions (Please refer to Facilitation Guide for more detailed instructions):

1. Edit the 'Who is Affected' in the first column according to the data on diabetes and hypertension (ADD/DELETE as necessary).
2. As a group, decide on a set of decision criteria (remaining columns).
3. As a group, gather data and fill in the criteria for each identified patient subgroup by ranking.
4. As a group, weight responses to each criteria and determine whether to specifically recruit within each subgroup. Place recruitment decision in 'Decision' column.

Who is affected? (Patient Stakeholders)	Criteria 1: e.g. risk level (low, med, high)	Criteria 2: e.g., presence in study area	Criteria 3: e.g., vulnerable population	Decision
Sex				
Females				
Males				
Age				
School-age				
Adolescents				
Young adults				
Adults				
Seniors				
Military/veteran status				
Veterans				
Race (break down further if relevant)				
Black/African American				
White				
Asian				
Ethnicity (custom list for study)				
Hispanic				

Disability				
Mobility impaired				
Other				
Co-morbid conditions (list relevant conditions)				
Insurance status				
Uninsured				
Medicaid/Medicare				
Private Insurance				
Reproductive				
Pregnant				
Hi-risk populations				
Substance abusers				
Homeless				
Other high risk occupations				
Other hard-to-reach populations				
Employment				
Employed				
Unemployed				
Day/temporary labor				
Military				
Medical home				
No medical home				
Regular medical home				
ER as medical home				

Matrix 2: Service Provider/Other Stakeholder Identification

Identifying Priority Service Provider/Other Stakeholder groups

Purpose: This matrix will be used to identify potential service providers, health care providers, and policymakers to include as stakeholders in this project. Stakeholder subgroups will be ranked based on a variety of criteria to determine which groups are most relevant to include as participants in the Topic groups.

Instructions (Please refer to Facilitation Guide for more detailed instructions):

1. Edit the 'Who is Involved' in the first column (ADD/DELETE as necessary).
2. As a group, decide on a set of decision criteria (remaining columns).
3. As a group, gather data and fill in the criteria for each identified service provider/other stakeholder subgroup by ranking.
4. As a group, weight responses to each criteria and tally up scores. Place each subgroup total score in 'Decision' column.

Who is involved? (Health care providers, Service Providers, Policymakers)	Criteria 1: e.g., Knowledge/Expertise	Criteria 2: e.g., Contact with Patients	Criteria 3:	Decision
Primary Care				
Doctors				
Nurses/PA's				
Specialists				
Ancillary Care Providers				
Non-Service Providers				
Social Work				
Advocacy				
Support Services				
Support Groups				
Other:				

Payers				
Private Insurance				
Public Insurance				
Employers				
Researchers				
Biomedical researchers				
Behaviors/Social Science researchers				
Research Funders				
Other:				
Public Policy				
Health Department				
Social Services				
Other:				
Other Stakeholders				

Matrix 3: Stakeholder Recruitment Matrix (Patient, Service Provider, and Other Stakeholders)
Recruitment sources

Purpose: This matrix will be used to identify specific places to recruit all patient and provider stakeholders from for participation in Topic groups.

Instructions:

1. Fill in the list of 'Patient Subgroups' in the first column based on the results of Matrix 1 (Part 1).
2. Fill in the list of 'Provider/ Policymaker/ Other Stakeholder Subgroups' in the first column based on the results of Matrix 2 (Part 2 and Part 3).
3. Fill in 'Sources' to recruit all stakeholders from in the remaining column headers. These can be edited and adapted. Use as many columns as needed.
4. Fill in the boxes with names of specific organizations, places, etc. to recruit stakeholders from.

Stakeholders	<u>Source 1</u> Clinics and doctors offices	<u>Source 2</u> Hospitals, nursing homes, etc.	<u>Source 3</u> Churches	<u>Source 4</u> Support groups	<u>Source 5</u> Membership/Advocacy organizations	<u>Source 6</u> Community Organizations	<u>Source 7</u> Professional Organizations	<u>Source 8</u> Other
Part 1: PATIENT STAKEHOLDERS								
[INSERT PATIENT SUBGROUP FROM MATRIX 1]								
[INSERT PATIENT SUBGROUP FROM MATRIX 1]								
[INSERT PATIENT SUBGROUP FROM MATRIX 1]								
[INSERT PATIENT SUBGROUP FROM MATRIX 1]								
[INSERT PATIENT SUBGROUP FROM MATRIX 1]								
[INSERT PATIENT SUBGROUP FROM MATRIX 1]								

Part 2: SERVICE PROVIDER STAKEHOLDERS

Primary Care

Doctors								
Nurses/PA's								

Specialists

[Specialty 1]								
[Specialty 2]								
[Specialty 3]								

Ancillary Care Providers

[Provider Type 1]								
[Provider Type 2]								
[Provider Type 3]								

Non-Clinical Providers

Social Work								
Advocacy								
Support Services								
Support Groups								
Other Types								

Part 3: OTHER STAKEHOLDERS

Payers

Private Insurance								
Public Insurance								
Employers								

Researchers

Biomedical Researchers								
Behavioral/Social Science Researchers								
Research Funders								

Other								
Public Policy								
Health Department								
Social Services								
Other								
Other Stakeholders								
Types								



The SEED Method for Stakeholder Engagement in Question Development and Prioritization

Funded by the Patient Centered Outcomes Research Institute
(November 2014 – October 2017)

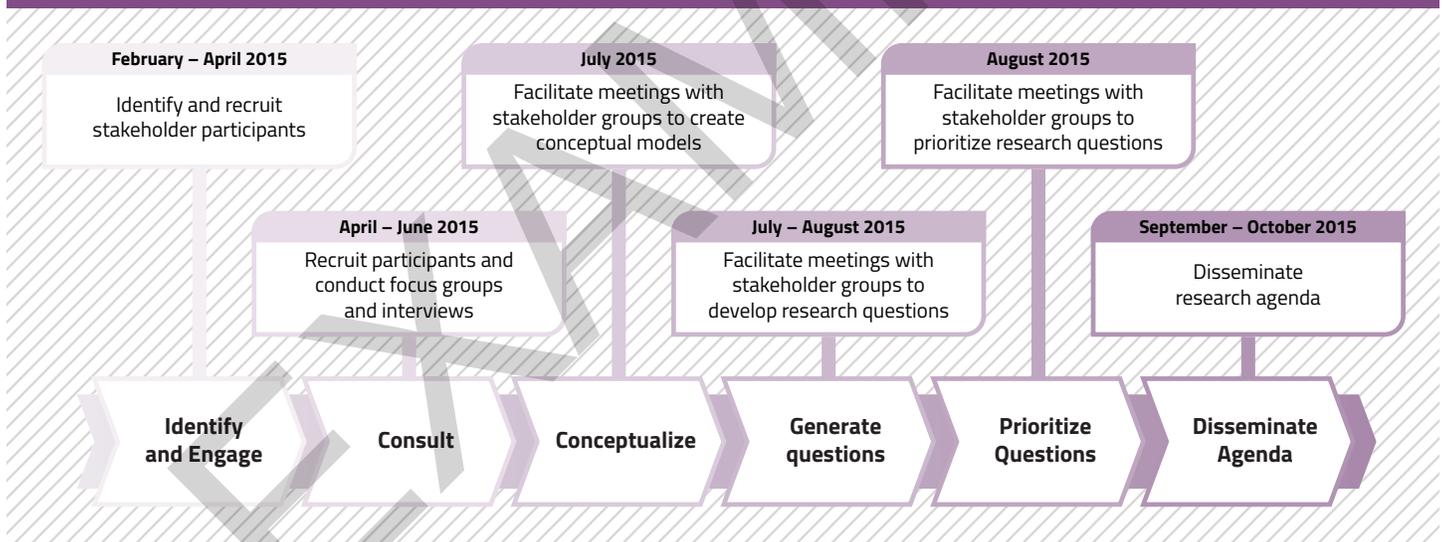
Purpose

VCU's Center on Society and Health is conducting a study in Richmond City of a new methodology for actively engaging diverse stakeholders—such as patients, caregivers, advocates, and health professionals—in identifying important factors surrounding diet compliance for those with diabetes, hypertension, and other chronic, diet-sensitive conditions.

Project Goals

- To generate a relevant research agenda of prioritized research questions that addresses the concerns, needs, and values of diverse stakeholder groups
- To disseminate the research agenda to the community, researchers, policymakers, funding organizations and those in power to affect change

Study Steps and Processes



To learn more about the SEED study or to get involved, please visit go.vcu.edu/seed or contact:

Emily Zimmerman
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ABOUT THE CENTER

The Center on Society and Health is an academic research center that studies the connections between social factors and health.

FOR MORE INFORMATION

☎ 804-628-2462
🌐 societyhealth.vcu.edu
✉ societyhealth@vcu.edu

Example Timeline

Week	Meeting Date	Research Team (Engaging Richmond - ER) Weekly Agenda	ER outside work	Topic Group Agenda	SCAN Agenda
Step 1: Identify and Engage (February - April 2015)					
1	2/9/2015	Kickoff Meeting: ER Orientation, describe project, schedule, roles/finalize research topic			
2	2/16/2015	Review of health (diabetes/hypertension) and demographic data for target population			
3	2/23/2015	Plan for informational interviews/training	Conduct Informational interviews		
4	3/2/2015	Conduct and discuss informational interviews (total of 8); Will use already developed script	Conduct Informational interviews		
5	3/9/2015	Conduct and discuss informational interviews, complete 'Patient Subgroup Identification' matrix			
6	3/16/2015	Complete 'Patient Recruitment' matrix; Decide on number and type of patient Topic groups			
7	3/23/2015	Complete 'Service Provider Stakeholder' and 'Other Stakeholder Recruitment' matrices; Decide on number and type of provider/other stakeholder Topic group			
8	3/30/2015	Begin recruitment planning for Topic groups and logistics			
9	4/6/2015	Recruitment of Topic groups and logistics; Begin working on key informant interview/focus group guide for SCAN participants			
10	4/13/2015	Recruitment of Topic groups/planning Topic group meetings and logistics	Recruitment for Topic groups		
11	4/20/2015	Recruitment of Topic groups/complete Topic group 'schedule of activities'/planning Topic group meetings and logistics	Recruitment for Topic groups		
12	4/27/2015	Focus group planning and key informant interview Planning and recruitment	Recruitment for Interviews; Recruitment for Topic groups		
Step 2: Consult (April - June 2015)					
13	5/4/2015	Undergo Interview Training; Organize interviews, logistics; Create key informant interview guide	Recruitment for Interviews; Recruitment for Topic groups; Interview preparation		
14	5/11/2015	Practice Interviewing, key informant interview logistics (planning and scheduling)	Conduct key informant interviews with SCAN participants		Participate in interviews
15	5/18/2015	Debrief on interviews, Undergo Focus Group Training, Create Focus Group Guides, Focus Group Recruitment sign-up	Conduct key informant interviews with SCAN participants		Participate in interviews
	5/20/2015	ER co-facilitators meet to plan out Topic group meeting #1			
16	5/25/2015 (HOLIDAY)	**No meeting due to holiday**	Conduct key informant interviews with SCAN participants; Recruitment for Focus groups	Introductory meeting: purpose, goals, methods, schedule of activities; (Meeting 1) (1.5 hours)	Participate in interviews
17	6/1/2015	Debrief and updates on interviews; Debrief on Topic Meeting #1; Focus group roles and responsibilities; Practice focus group facilitation using FG guides	Recruitment for Focus groups; Conduct Key Informant Interviews	Participate in key informant interviews (OPTIONAL)	Participate in interviews
	6/1/2015	ER co-facilitators meet to plan out Topic group meeting #2			
18	6/8/2015	Debrief on interviews, Topic groups; Focus Group logistics; Focus Group facilitation practice	Conduct focus groups with SCAN participants	Review health/demographic information, Resources document; discuss FG/Interview planning; (Meeting 2)* (1.5 hours)	Participate in focus groups; Interviews
19	6/15/2015	Debrief on focus groups; Discuss and summarize focus group and interview findings; Discuss dissemination of findings to community; Prepare presentation of findings to give to Topic groups	Conduct focus groups with SCAN participants	Participate in focus groups (OPTIONAL)	Participate in interviews
20	6/22/2015	Discuss and summarize focus group and interview findings; Discuss dissemination of findings to community; SEED Debrief	Present SCAN findings to TOPIC groups	Review and discuss interview/FG findings (Meeting 3)* (1.5 hours)	
21	6/29/2015	Topic group debrief; SEED debrief; Conceptual Model training and debrief			
22	7/6/2015	Conceptual Model training and debrief; Discuss dissemination of findings to community (health education event)	Present SCAN findings to TOPIC groups	Review and discuss interview/FG findings; Conceptual Model training; (Meeting 4) (1.5 hours)	

Step 3: Conceptualize (July 2015)					
23	7/13/2015	Topic group debrief; Logistics for Topic group conceptual modeling exercise (procedures, meeting logistics); INTERIM GROUP DYNAMICS QUESTIONNAIRE; Review Observation Logs for facilitated activities			Facilitated Exercise #1: Conceptual modeling (Meeting 5)* (3.5 hours)
24	7/20/2015	Review process and conceptual models from Topic groups and discuss; Prepare models for use in next Topic group step; Logistics for next Topic group meeting; Dissemination activities (National Night Out and Community Field Day)			
Step 4: Generate Questions (July 2015)					
25	7/27/2015	**No Meeting**			Facilitated Exercise #2: Generate research questions (Meeting 6)* (3.5 hours)
26	8/3/2015	Debrief on Topic groups; Review research questions and add to list; Dissemination activities (National Night Out and Community Field Day)	**National Night Out**		
Step 5: Prioritize Questions (August - September 2015)					
27	8/10/2015	Research Question Training and Improvement; Refine research questions; Logistics for prioritization; Dissemination Activities			Facilitated Exercise #3: Prioritize research questions (Meeting 7)* (3.5 hours)
28	8/17/2015	Finalize research agenda (based on Topic groups prioritized questions and Admin's literature reviews); SEED debrief on facilitated activities with Topic groups; Dissemination Activities	**Community Field Event**		
29	8/24/2015	Refine Research Questions; Dissemination planning			
30	8/31/2015	Dissemination Planning - continue discussion on Dissemination events			
31	9/7/2015	**No Meeting - Labor Day!**			
Step 6: Disseminate (September - November 2015)					
32	9/14/2015	Dissemination Planning (i.e. Topic group celebration event); Research Team presents back on process of literature review/questions			
33	9/21/2015	**No Meeting**			
34	9/28/2015	Prepare presentations/publications; Research Team presents back on process of literature review/questions			
35	10/5/2015	**No meeting			
36	10/12/2015	**No meeting			
37	10/19/2015	**No meeting			
38	10/26/2015	Update on Literature Review; Topic group celebration event planning			
39	11/2/2015	Topic Group celebration event planning			
40	11/9/2015	**No meeting	**Topic Group Celebration Event**		Topic group celebration event (11/13/2017)

Kickoff Meeting

The SEED Method for Stakeholder
Engagement in Question Development



What is the SEED Method?

A new method to develop
**stakeholder-driven
health research !**

Today's goals

- Learn about health research in the U.S.
- Learn about stakeholders
- Learn about patient-centered research
- Learn about the SEED Method
- Review details of this project

Health research in the U.S.

- Basic medical research
- Epidemiological studies
- Prevention
- Disease detection, screening and diagnosis
- Disease treatment and intervention
- Health services and policy



Examples of health research topics

- Specific diseases
- Treatments and therapies
- Genetics and biological factors
- Environmental and social factors
- Health services delivery & financing
- Health policy
- Health disparities
- Maternal/child health
- Aging
- Mental health/behavioral health
- Health promotion/education
- Health information technology
- Occupational health



Who funds health research?¹

- Private industry
- Federal agencies
- Private philanthropy/foundations
- State and local institutions
- Health associations
- Universities/research institutes



National Institutes
of Health



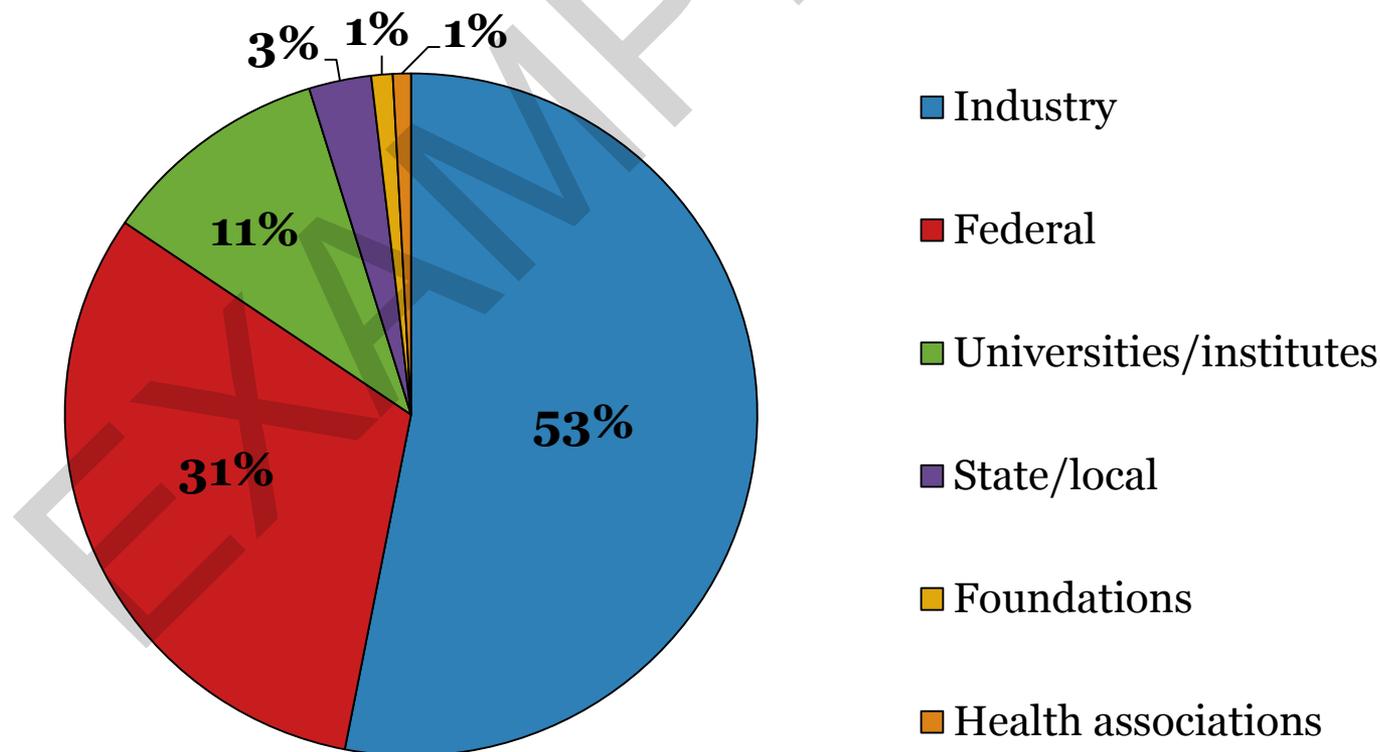
CENTERS FOR DISEASE
CONTROL AND PREVENTION



VCU

How much is spent on health research in the U.S.?

An estimated **\$130 billion** was spent in the U.S. on medical and health research in 2012.¹



How do research topics get picked now?

For publicly funded research, agencies solicit input from a range of stakeholders.

- Advisory board, councils, and committees
- Agency staff
- Research scientists and professional societies;
- Patient organizations and voluntary health associations;
- Institute and Center Advisory Councils;
- Political bodies (e.g., Congress);

Many research proposals to NIH are “investigator-initiated research” in which the researcher submits the research question and a research plan.



Stakeholder input

While there may be some areas for stakeholder input for research priorities, without systematic opportunities for engagement stakeholders like patients and health care workers are **unlikely to have much say in what gets funded.**



What is a stakeholder?

Stakeholders have **an interest** in what happens in any project, initiative, policy, organization, etc.

- That is, what happens, how it happens, and the results *matter* to them.

Who do you think has an interest in health research?



Patients and their caregivers

What interests do patients have in health research?

- Causes of the disease
- Behaviors and their effects on disease
- Diagnosis
- Treatments
- Services
- Barriers to diagnosis, services, treatment
- Access to information and education
- Participation in decision making and advocacy



Community

What interests does the community have in health research?

- Advocacy
- Informed decision making
- Providing information and education
- Understanding and addressing causes and risk factors
- Reducing risk
- Improving screening and detection
- Eliminating disparities



Health care providers

What interests do health care providers have in health research?

- Understand causes of disease
- Understand risk factors and preventive measures
- Access to and dissemination of preventive measures
- Provide treatments and services
- Improve care delivery
- Improve patient outcomes
- Access to information and educational tools
- Improve technology
- Decision making and advocacy



Health care systems/funders

What interests do health care systems and funders have in health research?

- Identify populations at risk
- Prevention
- Planning
- Improve treatments and services
- Improve care delivery
- Improve patient outcomes
- Information and education
- Improve technology
- Cost effectiveness and reducing total costs
- Financing and regulation



Policymakers

What interests do policymakers have in health research?

- Understand extent of risk in population
- Assess needs and allocate resources
- Implement programs and policies to prevent spread and consequences of disease
- Support cost effective interventions
- Improve population outcomes
- Financing and regulation
- Ethics
- Respond to community/stakeholder concerns and values



Practice

List 10 areas in which YOU are a stakeholder

- Hints:
 - Are you a patient?
 - Do you have kids in school?
 - Do you own or rent a home?

EXAMPLE

Practice

List 5 different approaches you can take as a stakeholder to represent or advance your interests.

EXAMPLE



Stakeholder involvement

Level of engagement	Type of engagement	Examples
Low 	Information	Read newspaper; Attend informational meetings; Go to websites
	Consultation	Go to a community forum and provide opinions; Participate in a survey or focus group
	Involvement	Join an advisory board; Become an advocate
	Collaboration/partnership	Work together to develop and implement a program
	High	Control/decision making



A New Model: Patient-Centered Research

*“PCORI helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information **that comes from research guided by patients, caregivers, and the broader healthcare community.**”*



Improving Methods for Conducting Patient-Centered Outcomes Research²

- Research that identifies optimal methods for **engaging patients in the research process**, and methods for evaluating the impact on research outcomes of patient engagement in the research process
- Research that determines methods for assuring study questions, outcomes, and interventions are **meaningful to patients and other stakeholders**
- Research in generating, selecting and prioritizing **topics** for research



What is Patient-Centered Outcomes Research (PCOR)?²

PCOR helps people and their caregivers communicate and make informed health care decisions, allowing their voices to be heard in assessing the value of health care options. This research:

- **Assesses the benefits and harms** of health care services and delivery features to inform decision making
- Focuses on **outcomes that people notice and care about**
- **Addresses individual differences and barriers to implementation and dissemination**
- May investigate optimizing outcomes while addressing stakeholder perspectives.



Question development and prioritization

*A **priority problem**—When it comes to health and healthcare interventions, **there are so many important questions!***

- With limited research dollars we need to prioritize
- We need a set of methods to guide which questions the system should tackle first and a way to keep patients central in that prioritization process
- Too often this ranking has been done out of public view through a process subject to political and economic forces that lacks a coherent strategy. ^{3 (page 7)}



Stakeholder engagement in question development

“Including patients in topic generation is **unconventional... patients should be engaged in all phases** of patient centered outcomes research...

...Topic selection is usually done by researchers or sponsors, and while they may believe they know what patients want, their choices may be influenced by their training and by their professional or commercial interests. **Without adequate input from patients, research priorities may not fully reflect patient perspectives on potential benefits or risks**, ultimately impeding the uptake of research discoveries.

Some empirical research, mostly conducted outside the United States, has shown that **patient involvement can produce more relevant research questions and results that are more useful for making decisions.**” ³ (page 35).



Phases of PCOR

- **“What should we study?”**
- “What study designs should we use?”
- “How do we carry out and govern the study?”
- “How do we enable people to apply the study results?”

Generating research questions³

Phase of PCOR	Details of phase
1. What should we study?	
Identify and define important research questions	<ul style="list-style-type: none"> Identify topics, decisions, and questions that are important to patients, caregivers, and other stakeholders Specify the research questions in a manner highlighting patient-centered outcomes and information needs
Prioritize research questions	<ul style="list-style-type: none"> Decide on the importance and priority of topics and questions, taking into account evidence gaps and the value of information
Refine and specify details of research questions	<ul style="list-style-type: none"> Specify the population, interventions, comparators, outcomes, timing, and setting (PICOTS) to accurately capture each research question
Develop funding announcements	<ul style="list-style-type: none"> Develop and release funding announcements for high-priority questions Incorporate guidance and standards to ensure alignment with the resulting projects
Conduct peer review and funding decisions	<ul style="list-style-type: none"> Incorporate guidance to reviewers to facilitate assessment of investigator responsiveness to patient-centeredness aspects of studies

Why test a new method?

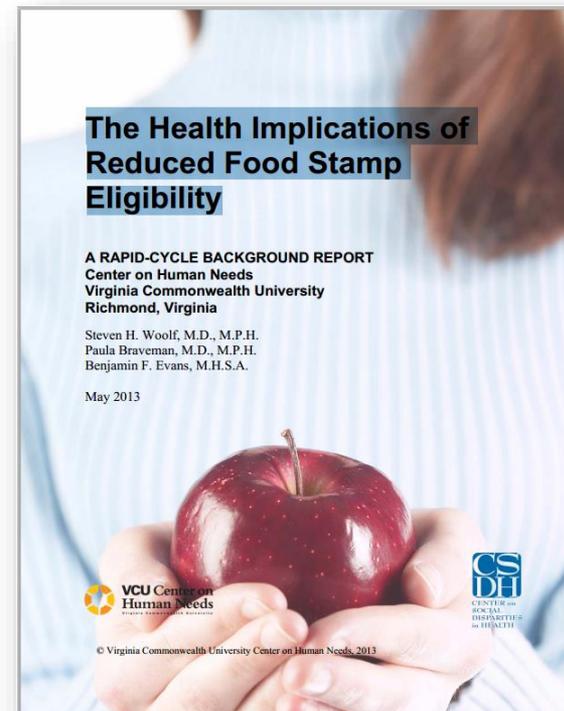
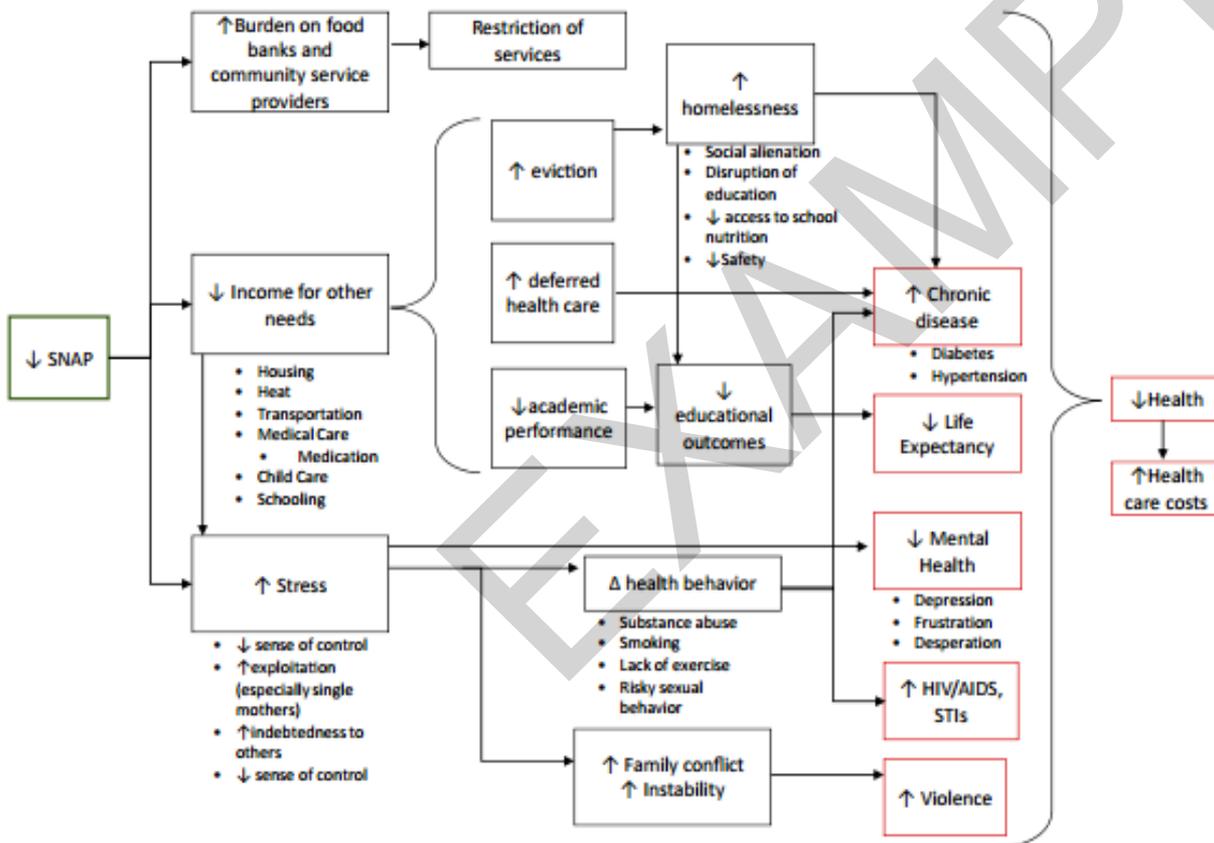
*“Particularly in methods to engage patients in prioritizing and refining research topics, it is not possible to identify evidence-based standards. We believe that standards for engaging patients in each phase of the research process are essential, but lack the evidence to specify which methods for doing so are best.”*³ (page 21).



The SEED Method: Background

Engaging Richmond and The Health Implications of Reduced Food Stamp Eligibility

Health Effects of Reducing Food Stamp Eligibility (Income)



SEED Method: Background

The SEED Method was developed in response to PCORI's Improving Methods program

Participatory causal modeling as a starting point, then:

- Focused the process on question development and prioritization
- Created a number of new steps and participant types
- Developed instruments and procedures



SEED METHOD: Local Aims (Richmond)

- Develop a research agenda on **diet compliance for hypertension (high blood pressure), diabetes, and other diet-sensitive conditions** with stakeholders in Richmond, VA
- What is a stakeholder-driven research agenda?
 - A set of recommended research questions developed by patients, caregivers, health care providers and other stakeholders.

SEED Method: Local Aims (South Hill)

- Develop a research agenda on **respiratory cancer outcomes** with stakeholders in South Hill, VA

EXAMPLE

SEED Method: Intermediate Aims

Conduct a **demonstration** of the SEED Method

- A demonstration project tests the value and feasibility of a new method or program

Ensure **replicability** and **scalability** through project documentation, **evaluation** and preparation of tools for future research

Disseminate final research agenda



SEED Method: Long-term Aims

Provide a framework for future PCOR researchers to develop more robust causal models and to collaboratively generate research questions relevant to stakeholders



SEED METHOD: Who Participates?

Three levels of stakeholder engagement

1. The Research Team

- Community-based participatory research (CBPR) team
- Collaboratively leads the research!

2. Topic groups

- Groups of stakeholders brought together based on their **experience and knowledge of the health-related topic**
- The demonstration projects will have three TOPIC groups organized by type (e.g., patients, health professionals, funders, etc.)

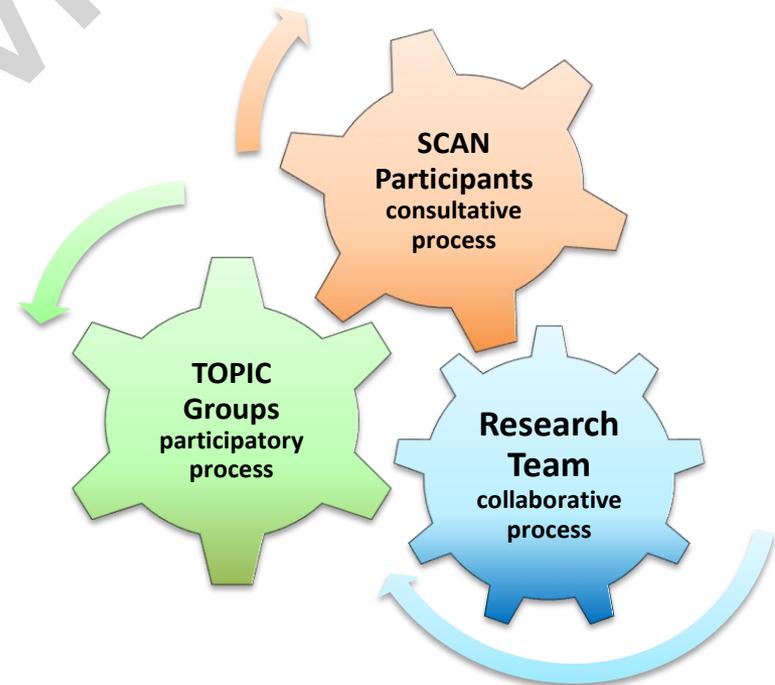
3. SCAN participants

- Participate in focus groups and interviews

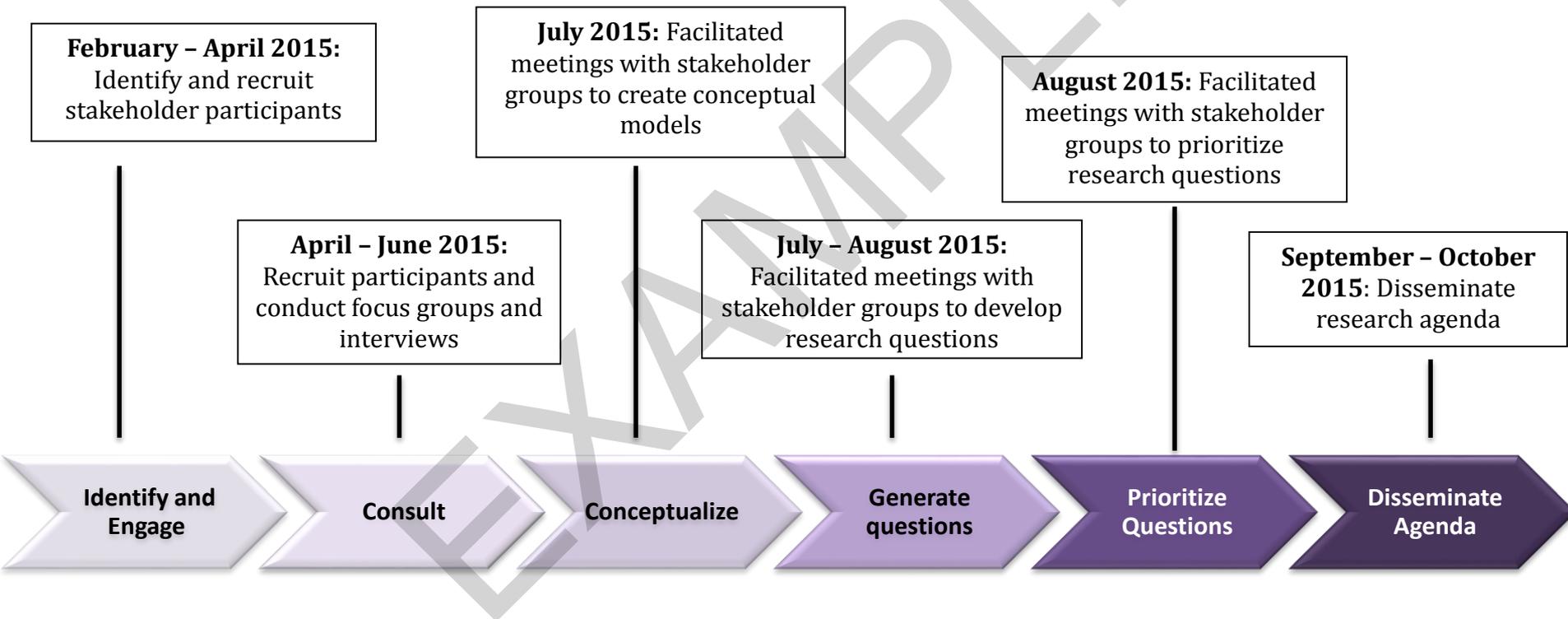


Three levels of engagement

1. **Research Team: COLLABORATIVE**
2. **Topic Groups: PARTICIPATORY**
3. **SCAN Participants: CONSULTATIVE**



Summary of SEED Method Process



Summary of SEED Method Process

Research Team Members (examples):

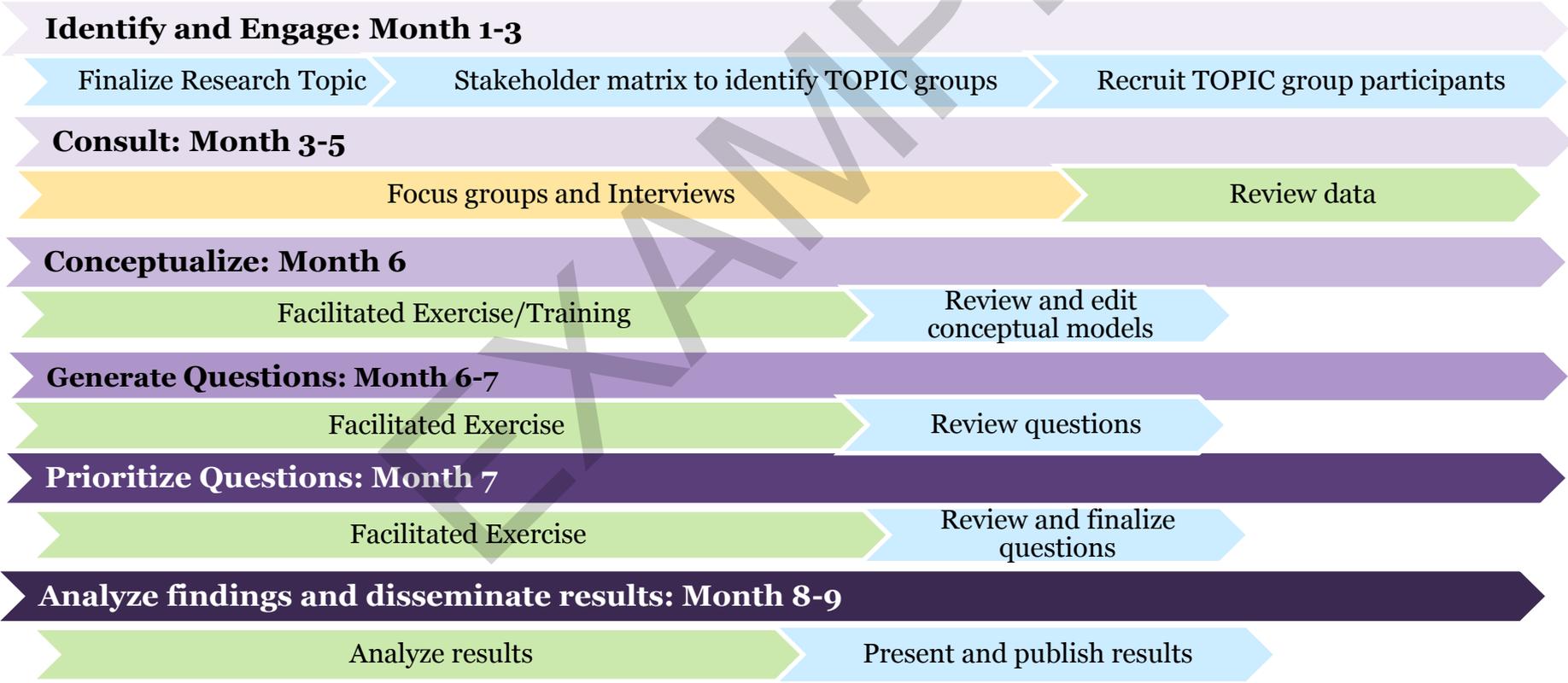
- Patients/Community Members
- Service Providers
- University faculty/staff
- Community organizations

Topic Group (examples):

- Patients/Caregivers
- Non-clinical service providers
- Clinical service providers
- Policymakers
- Community members
- Funders/payers

SCAN Participant (examples):

- Patients/Caregivers
- Non-clinical service providers
- Clinical service providers
- Policymakers
- Community members
- Funders/payers



Research Team Roles



1. Finalize Research Topic

- Identify the broad research area or topic
- Choose a topic that comes from the community or is generated in a collaborative process
- We achieved this ideal in this demonstration by focusing on health-related topics that were prioritized by a participatory process in both demonstration sites:
 - **Richmond City:** Engaging Richmond and ACORN
 - **South Hill:** Cancer resource and gap community assessment



Research Team Roles



2. Identify Topic groups (3-step process)

- Review health statistics and demography
- Conduct informational interviews with representatives of health care systems
- Complete 'Stakeholder Identification Matrices' to develop a comprehensive plan for stakeholder engagement

3. Recruit TOPIC Group participants

- Establish inclusion criteria for recruitment, such as personal or professional experience with the topic, diversity, ability to commit to participation in research activities, etc.
- Recruit from local organizations identified in the 'Stakeholder Identification Matrix'



Research Team Roles



4. Gather data from SCAN participants

- Plan focus groups and interviews
- Recruit participants
- Conduct focus groups and interviews
- Summarize data to share with TOPIC groups

5. Logistics and planning for Topic groups

- Schedule of activities: meeting dates, locations, logistics
- Group Exercises: Conceptual modeling, Question development, Question prioritization



Research Team Roles



6. Review and edit conceptual models

- Review causal models create by each TOPIC group, reconciling overlaps and highlighting differences

7. Review and finalize questions

- Refine the list of research questions utilizing a scoring process based on availability of current research evidence and relevance to PCOR

8. Present and disseminate results

- Finalize and implement the dissemination plan
- Conduct presentations to stakeholders



Topic Group Roles

1. Review SCAN Data

- Engage in group discussions of the issues that emerged, review and reflect on the themes, issues and concerns of others
- Reflect on their experiences in the context of others stakeholders' experiences
 - Did other people experience what I experienced?
 - What else do others in this situation have to deal with?



Topic Group Roles

2. Conceptualize (Activity #1)

- Each Topic Group will work as a team through a facilitated process to develop a conceptual model of the factors that influence the health outcome
 - **Part 1: Identification of factors:** brainstorm, discuss and agree on list of factors related to the health outcome
 - **Part II: Training in conceptual modeling**
 - **Part III: Sketching the causal model**



Topic Group Roles

3. Question Development (Activity #2)

- Compare the conceptual models they created with the models presented by other TOPIC Groups
- Brief training in developing research questions
- Facilitated process to propose research questions

4. Prioritize questions (Activity #3)

- Engage in facilitated process to prioritize research questions based on the needs and interests of stakeholders



SCAN Participants

One-time participation in:

- **Focus Groups**
- **Individual Interviews**

EXAMPLE



SEED Evaluation

Goals of Evaluation

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

What this means....



Dissemination Plan

Goals of Dissemination

- Disseminating final research agenda to relevant stakeholders
- Utilizing appropriate dissemination channels and formats

EXAMPLE



Community Partners

- Richmond City Health District
- 7th District Health and Wellness Initiative
- East End Ministers Alliance
- Bon Secours Health System
- American Heart Association
- VCU School of Nursing
- Virginia ACORN
- VCU CCTR
- VCU Health System - VCC



Next Steps....

Next meeting: Monday February 16th

- Review health and demographic data to identify target population and help prepare for individual interviews with community organizations

February – April 2015:
Identify and recruit
stakeholder participants

Identify and Engage

Consult

Conceptual
ize

Generate
questions

Prioritize
Questions

Disseminat
e Agenda



Questions?

EXAMPLE

References

1. Research!America. U.S. Investment in Health Research: 2012. <http://www.researchamerica.org/uploads/healthdollar12.pdf>
2. Patient-Centered Outcomes Research Institute. Funding Announcement: Improving Methods for Conducting Patient-Centered Outcomes Research. Published November 16, 2012, Updated January 15, 2013
3. Helfand M, Berg A, Flum D, Gabriel S, Normand S, eds. Draft Methodology Report: Our Questions, Our Decisions: Standards for Patient-Centered Outcomes Research. Patient-Centered Outcomes Research Institute. July 23, 2012.



SEED Contact Information

EXAMPLE

Our mission is to explore and investigate social determinants of health through mixed methods research in order to find and propose effective community-based solutions



Engaging Richmond: Team Meeting (#2)

AGENDA

Monday February 16, 2015

10:00 a.m. - 1:00 p.m.

10:00-10:30 Team Check-in ☺

- Sign-in
- Weather Report

10:30-10:40 Ground Rules: TMI principles and confidentiality

10:40-11:30 Diabetes/Hypertension Information

- Review Fact Sheet
- Q/A with Wendy

11:30-11:40 Break

11:40-12:50 Health/Demographic information

- Group exercise
- Facilitation/Brainstorming session
- Review Health/Demographic document

12:50-1:00 Logistics

- Resources document - Homework

Homework for this week:

- Review Resources Document at home and add to list based on places and organizations that you know of in the community that serve people with diabetes and/or high blood pressure. Expected completion time 1 hour or less.

Upcoming SEED Events:

- Meeting 3: Monday February 23 from 10am – 1pm (Planning for Informational Interviews)

Other Upcoming Events:

- CAPSTONE Retreat, Kingsmill Resort, February 20-22, 2015
- Community Engagement Institute, May 13-15 2015, TBD

Topic Groups

INSTRUCTIONS: The following section contains materials for recruiting, organizing, and facilitating meetings with Topic group participants in the SEED Method. Stakeholders are selected for participation in the Topic groups by the Research Team using the *Stakeholder Identification Matrices* (see **Community Research Team Templates** part of the Toolkit) based on their personal or professional experience with the health topic. Topic groups are the most involved group of stakeholders, and members are engaged through a series of meetings throughout the course of the project. Topic group participants will be involved in all Topic group meetings and will talk at length about their experience with the health condition. Each Topic group will develop a conceptual model diagramming the factors that influence the health outcomes based on their own experience, and will create research questions that are important to them. Each Topic group will bring their own unique perspective of the health topic to the table, and both their conceptual models and research questions will reflect this.

MATERIALS: You'll find the following Topic Group materials included in this section of the Toolkit:

Templates

- Meeting Materials:
 - Stakeholder participant overview
 - List of agenda items
- Topic Group Facilitated Activities:
 - Topic Group Facilitation Scripts
 - Facilitated activity objectives
 - Facilitated Activity Script – Conceptual Model Training
 - Facilitated Activity #1 Script – Building Conceptual Models
 - Facilitated Activity #2 Script – Creating Research Questions
 - Facilitated Activity #3 Script – Prioritizing Research Questions

Topic Group Stakeholder Participant Overview

SEED Project Description

Purpose:

[Organization name] is conducting a study in [city/location] to actively engage diverse stakeholders – such as patients, caregivers, advocates, and health professionals - in developing research questions around [health topic].

Project Goals:

- To actively engage community stakeholders in identifying and prioritizing research questions surrounding [health topic]
- To generate a relevant research agenda that addresses the concerns, needs, and values of diverse stakeholder groups
- To disseminate the research agenda to the community, researchers, policymakers, funding organizations and those in power to affect change

SEED Project Roles and Responsibilities

Project Participants:

We are seeking persons with personal or professional experience managing [health topic]. These stakeholder participants will take part in a series of meetings and facilitated exercises to develop and prioritize research questions, meeting [number of meetings] times over a [time frame].

Role of Stakeholder participants:

Responsibilities include: planning focus groups and individual interviews, analyzing and discussing findings, and participating in facilitated meetings to develop research questions. Additional activities are available outside of regular meetings, for those interested in participating. These include: undergoing research training, participating in focus groups and interviews, helping with final presentations and other dissemination activities towards the end of the project.

Time commitment:

Project participation lasts from [date range], with a total of [number] meetings.

The official Kickoff meeting is on [date, time].

Compensation

Stakeholder participants will be compensated a total of [dollar amount] for their involvement, which will be paid out in [number] installments of [dollar amount].

Topic Groups

List of Agenda Items

- Kickoff – orientation to project
- Review health topic and demographic information
- Review focus group and interview (SCAN) data
- Decide on additional focus group and interview participants (optional)
- Conceptual model training
- Conceptual model activity
- Research question training
- Research question development
- Research question prioritization
- Team celebration – reconvening to thank participants and review findings (optional)

List of Evaluation items (if using Evaluation module)

- Personal Information (Demographics) questionnaire
- Group Readiness questionnaire
- Group Dynamics questionnaire
- Training Satisfaction questionnaires (x3)
- After Action Reviews (x3)
- Observation Logs (x3)
- Activity Logs (x3)

Topic Group Facilitated Activity Objectives

INTRODUCTION: This document lists out the goals of each Topic group facilitated activity and should be used when completing the corresponding Activity Logs and Observation Logs to assess whether or not activity objectives were met.

Conceptual Model Training Objectives

- Train Topic group members in terminology and use of path diagrams
 - Participants understand use of path diagrams
 - Participants understand components of path diagrams
 - Participants feel comfortable drafting simple path diagrams

Facilitated Activity #1 Objectives: Building Conceptual Models

Part I: Identifying factors affecting the health outcome

- Topic groups brainstorm a range of potential factors
- Topic groups discuss potential factors and provide examples
- Topic groups agree on a final list of factors related to the health outcome

Part II: Modeling the health outcome

- Topic group add factors to model, while considering whether they are exogenous or mediating factors and whether there are links between factors
- Topic groups sketch diagrammatic model of how determinates are interrelated
- Topic groups include factors in model that reflect group's personal experience or knowledge, data collected with SCAN participants

Facilitated Activity #2 Objectives: Creating Research Questions

Part I: Review of models

- Topic groups review their model and those of other groups; discuss new factors; highlight important factors

Part II: Training on research question development

- Train Topic groups on research questions and how to develop them

Part III: Question development

- Topic groups prioritize pathways and relationships of interest to generate research questions
- Topic groups propose research questions based on prompts from facilitator

Part IV: Listing questions

- Topic group participants share research questions

Topic Group Facilitated Activity Objectives

Facilitated Activity #3 Objectives: Prioritizing Research Questions

Part I: Prioritization

- Topic groups make use of multi-voting to prioritize research questions

Part II: Making question patient-centered

- Topic groups vote and prioritize remaining research questions according to patient-centeredness criteria:
 - Population
 - Treatment option
 - Study outcomes
 - Timeframe
 - Setting

Conceptual Model Training

TOOLKIT INSTRUCTIONS: The included documents provide the instructions, list of materials, and scripts for conducting the following facilitated Topic group activities:

1. Conceptual Model Training
2. Developing Conceptual Models (Activity #1)
3. Creating Research Questions (Activity #2)
4. Prioritizing Research Questions (Activity #3)

All of these activities will take place with each of the Topic groups. A facilitator, along with members of the Research Team, are needed to help facilitate and assist with each exercise. Additional supports may be needed for Topic group participants with vision problems or literacy challenges, therefore additional Research Team members should attend these meetings to provide one-on-one assistance to Topic group participants in need of assistance.

Facilitators should be well-versed in all the facilitated activities, therefore it is recommended that facilitators read through the following scripts and training materials several weeks in advance of leading the Topic group meetings. We recommend scheduling each of these activities one week apart – with the exception of ‘Creating Research Questions’ Activity #2 – this should be held TWO WEEKS after ‘Developing Conceptual Models’ Activity #1 in order to allow sufficient time for editing the models in between meetings.

The ‘Conceptual Model Training’ will take approximately 40 minutes to facilitate, while the subsequent three activities will take 3.5 hours. This includes a short break and time for a snack/meal break. We recommend holding these meetings in a space large enough to accommodate the Topic Groups and additional facilitator(s) and Research Team members, along with plenty of space for the group to move about. Ideally, rooms would be equipped with audio/visual equipment to allow for projecting presentations, and a large empty wall to accommodate building each conceptual model. We also recommend providing refreshments for Topic Group members during these long meetings – such as sandwiches, salads, cookies, coffee, etc.

We recommend adapting these tools to fit the goals of your project. Where noted, fill in the [health topic] of focus.

If evaluating these activities, please consult the Evaluation Module for the appropriate tools and instruments to administer, including:

1. Facilitated Activity Satisfaction Questionnaire
2. Activity Log
3. Observation Log
4. Meeting Notes template
5. After Action Review



Conceptual Model Training (60 minutes)

Facilitator Preparation: We recommend the following resources to familiarize the facilitator and other members of the Research Team with conceptual modeling and how to build path diagrams ahead of leading the Topic Groups through this training:

- <https://www.youtube.com/watch?v=200gudOnayo>
- Zimmerman EB, Woolf SH, Haley A. Understanding the Relationship Between Education and Health: A Review of the Evidence and an Examination of Community Perspectives. In Kaplan R, Spittel M, David D. *Population Health: Behavioral and Social Science Insights*. AHRQ Publication No. 15-0002. Rockville, MD: Agency for Healthcare Research and Quality and Office of Behavioral and Social Sciences Research, National Institutes of Health; July 2015: 347-384.
- Joffe M, Mindell J. Complex causal process diagrams for analyzing the health impacts of policy interventions. *Am J Public Health*. 2006;96 (3):473-479. <http://dx.doi.org/10.2105/AJPH.2005.063693>.
- Paradies Y, Stevens M. Conceptual diagrams in public health research. *J Epidemiol Community Health*. 2005;59(12):1012-1013. <http://dx.doi.org/10.1136/jech.2005.036913>.

Materials Needed:

- White board or large wall
- Large Sticky notes
- Dry Erase Markers

Facilitator	20-40 minutes	[Facilitator draws on white board or other large area to illustrate examples.]
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Step 1: Introduction to path diagrams:

“Today we are going to be learning how to develop diagrams called ‘conceptual models’ or ‘path diagrams’. These diagrams are pictures we can use to help us organize information and show cause and effect relationships.”

Step 2: Developing a path diagram using ‘Car’ example:

*“Let’s say we are interested in predicting whether someone will buy a new car. We’ll call ‘buying a car’ the **OUTCOME**. Let’s draw a circle at the right and label it ‘buy car’”*

[On white board, write ‘Buy a car’ on the far RIGHT side.]

Buy a car

“We use a process called a ‘path diagram’ to map out relationships. We are going to map out the reasons people generally make decisions, or generally do something, such as buy a car. We understand that there are always exceptions to any rule, but today we want to focus on these ideas generally.”

Step 2a: Brainstorming factors

“What are some important reasons someone might buy or not buy a car?” [Facilitator or group member should write each reason on a large sticky note and place on the far LEFT side of board.]

Probe for the following variables :

- Savings/credit
- Condition of old car
- Commuting
- New baby

Probing questions:

- **“What else influences whether or not someone will buy a car?”**
- **“Why might someone choose to buy a car?”**
- **“Who might be in the market to buy a new car?”**

[**The example conceptual model on the last page does not include all the possible factors that predict buying a car. Please adjust as needed and be sure to include the factors your group brainstorms during this step.**]

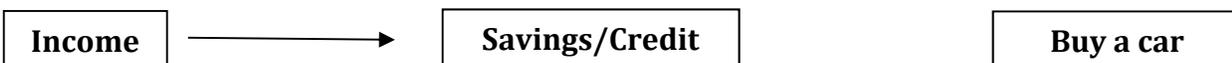
Step 2b: Developing first path

“Let’s think a little more about SAVINGS/CREDIT... does anything important affect whether someone has good savings/credit to buy a car?”

Probe for:

- **Employment or income**

“Let’s call Income a PREDICTOR, because it helps predict the OUTCOME (‘BUY A CAR’) and put it all the way on the left side of the model. [Place ‘INCOME’ on left side of board.] Now if income usually causes someone to have better savings/credit, we can draw an arrow from ‘INCOME’ to ‘SAVINGS/CREDIT’. [Draw one-way arrow from ‘INCOME’ to ‘SAVINGS/CREDIT’.] The one-way arrow means that it has some type of impact on where the arrow points. So we call ‘INCOME’ a PREDICTOR and ‘SAVINGS/CREDIT’ a MEDIATOR, because it mediates or comes between the relationship ‘INCOME’ and ‘BUYING A CAR’. This arrow only means probability, not a rule.”



[Example of exception – probe for recognition of exception.] **“Can you have a good income and bad credit/no savings? Yes. Can you have low income and good credit/good savings? Yes. However, in most cases you will see that as income rises, credit and savings rise too. Now let’s draw an arrow from ‘SAVINGS/CREDIT’ to ‘BUY A CAR’.** [Draw one-way

arrow from 'savings/credit' to 'buy a car'.] *Again, this arrow means probability not a certainty. Can you have good credit and savings, yet still not buy the car? Yes, but chances are, the better your credit and income, the higher the probability that you will buy the car.*"

"We now have one path in our diagram."



Step 2c: Incorporating other factors into path diagram:

"Now the diagram becomes more complicated. Let's think more about each of the other factors we brainstormed.

What about CONDITION OF OLD CAR? Does something important come first, meaning, what predicts the condition of your old car?" [Facilitator or group member should write each factor on a sticky note and place in diagram.]

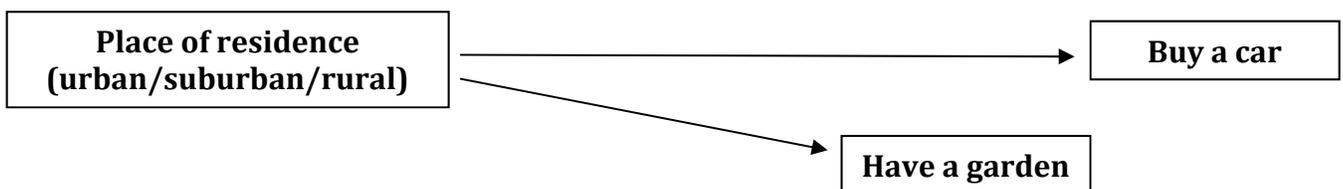
- Probe for income/employment

"What about COMMUTING? Does anything important come first? Is everyone equally likely to commute?"

- Probe for age, rural/urban
- Probe for bidirectional relationships like income and age – *"How does age affect a person's income?"*

"When there is no relationship we leave an arrow out. If 'COMMUTING' and 'SAVINGS/CREDIT' are not related to each other, meaning one doesn't cause a change in the other, then we don't need an arrow there."

"Sometimes we find that variables look related to the outcome we are interested in, but they are really not important at all. Here is an example: a gardening club finds data that people with gardens were more likely to buy cars than people without gardens. Does having a garden cause people to buy cars? Probably not. Another explanation is that people in rural and suburban areas are more likely to have gardens, and are also more likely to buy cars. Where you live (rural, suburban, urban) causes both items to change, but there is no real relationship between having a garden and buying a car. That is called CONFOUNDING. It looks like there is a relationship because both items tend to change (more gardens = more car buying), but that is only because both items are affected by the same thing (where you live)."



Step 3: Review the model

“Let’s review all of the paths in the model. Do they make sense? Are the arrows in the right place? Is anything important missing?”

Step 4: Using model to predict who will buy a car:

“Now we have a path diagram. We can use it to make predictions about who would be most likely to buy a car. We can gather data on who buys cars and test which of the paths in the model are strongest (or the most likely to happen), and maybe find that some don’t matter very much after all.”

Discussion questions:

- *“What do you think makes this model useful?”*
- *“If you were selling cars, how would this model affect who you will try to sell a car to? How about where you build a car dealership?”*
- *“If you were selling cars, would this model help you? Why?”*
- *“If you were buying a car, would this model help you? Why or why not?”*

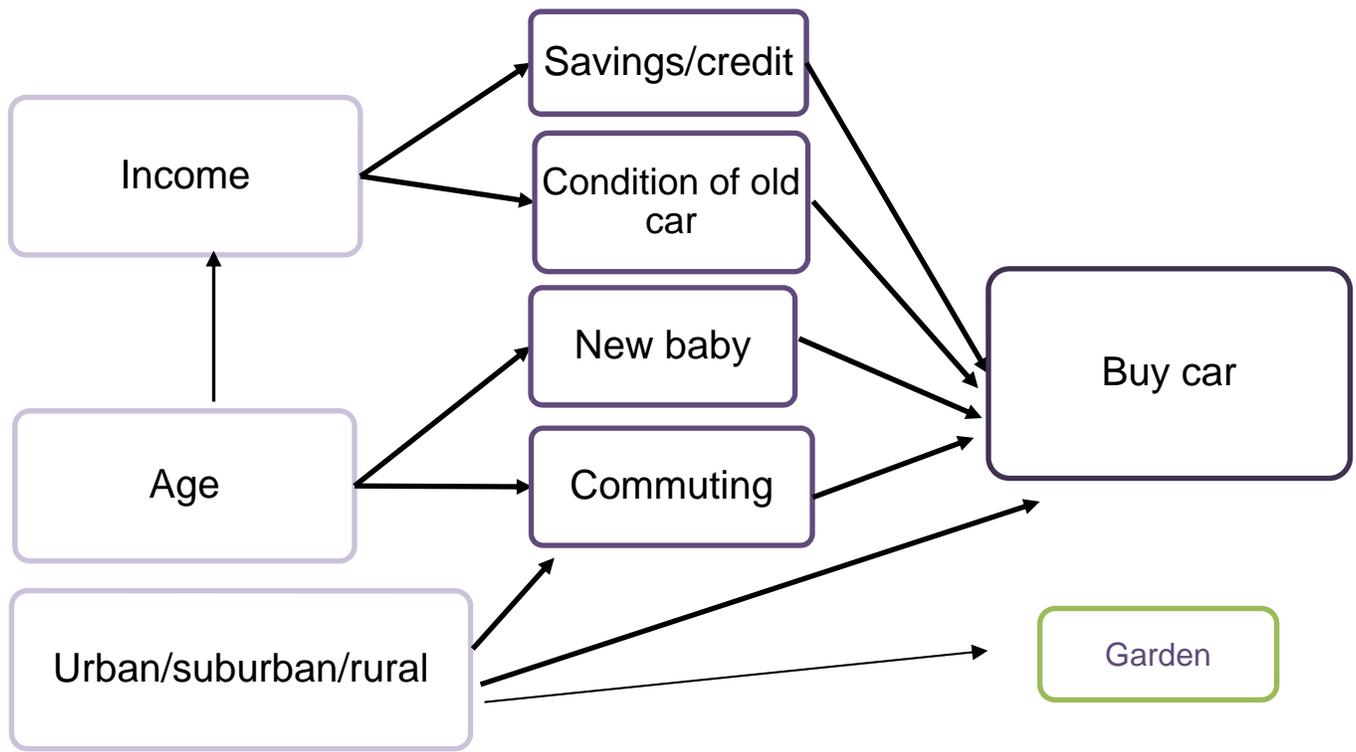
Facilitator [Display sample path diagram in powerpoint. See below for sample diagrams.]

Facilitator and Topic group Discuss path diagram and answer questions

Wrap-up.

Facilitator [[Optional]: If completing evaluation module, please complete ‘Activity Log’ for Conceptual Model Training. Other evaluation activities include Observation Log, and Facilitated Activity Satisfaction questionnaire.

Sample Path Diagram for Training – Car Example



Path diagram example #2 – Flu vaccination

Instructions: [Using the same process as outlined above, create a conceptual model where ‘decision to receive/not receive a flu vaccine’ is the health outcome of interest. Use the facilitation questions below to guide the Topic group conversation and generate factors/relationship within the model.]

Facilitation questions to ask for creating conceptual model:

- *“What influences whether or not someone will get a flu vaccine? Why might someone choose to get a vaccine or not?”*
 - *“What influences these factors?”*
- *“How are all these factors related to each other? What relationships exist between these factors?”*

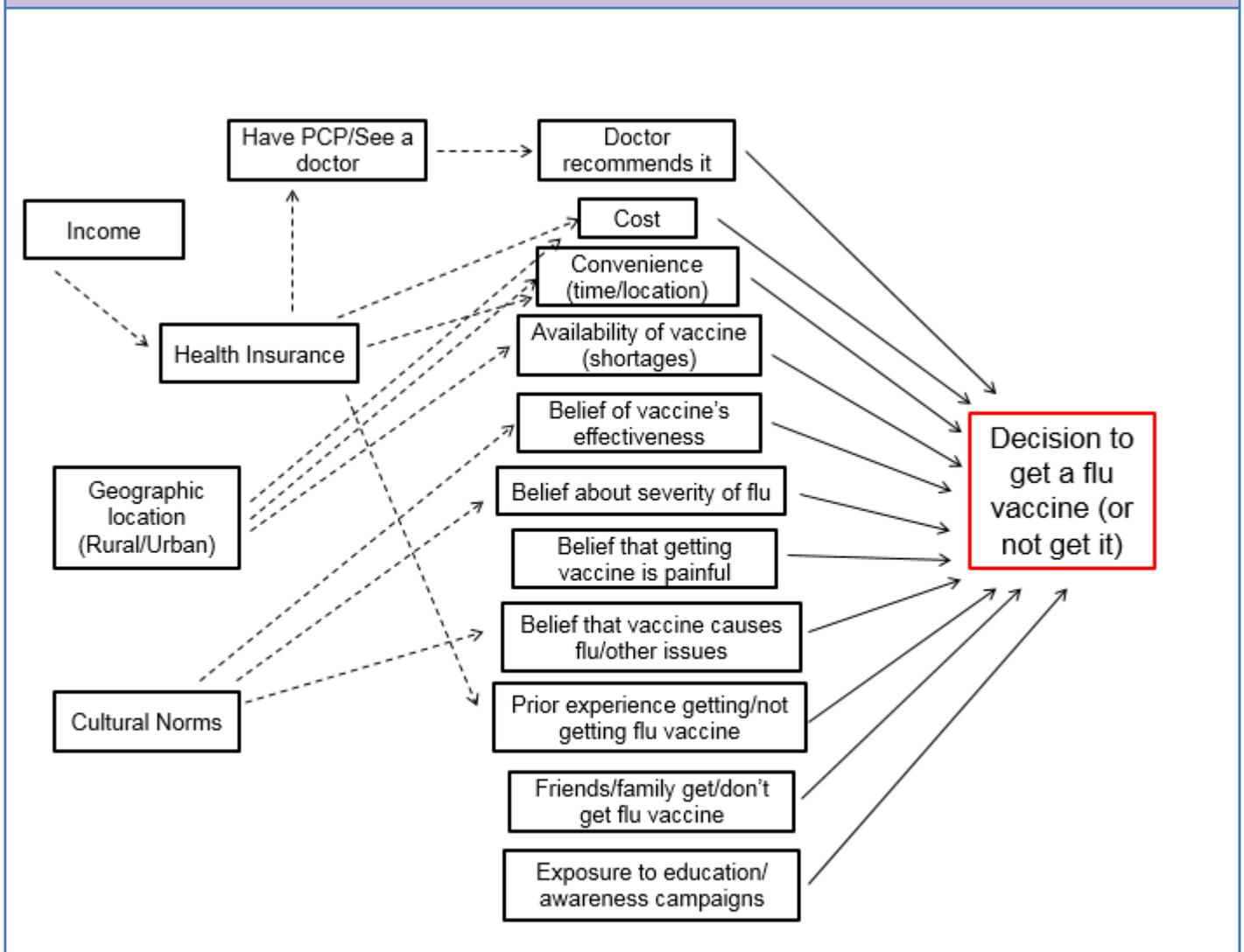
[Once path diagram is completed, display sample conceptual model in powerpoint.]

[Use the questions below to generation discussion about the model among the Topic group participants.]

Discussion questions:

- *“What do you think makes this model useful?”*
- *“If you were a public health official trying to encourage more people to get the flu vaccine, would this model help you? How so?”*

Sample path diagram - Flu vaccination example



Preparation for Facilitated Activity #1:

1. Have the Research Team review the 'Domain worksheet' ahead of Facilitated Activity #1 (Building conceptual models) making edits, additions, and deletions as they see fit. This portion of the powerpoint should be updated prior to the next meeting.

Building Conceptual Models (Activity #1)

TOOLKIT INSTRUCTIONS: The included documents provide the instructions, list of materials, and scripts for conducting the following facilitated Topic group activities:

1. Conceptual Model Training
2. Building Conceptual Models (Activity #1)
3. Creating Research Questions (Activity #2)
4. Prioritizing Research Questions (Activity #3)

All of these activities will take place with each of the Topic groups. A facilitator, along with members of the Research Team, are needed to help facilitate and assist with each exercise. Additional supports may be needed for Topic group participants with vision problems or literacy challenges, therefore additional Research Team members should attend these meetings to provide one-on-one assistance to Topic group participants in need of assistance.

Facilitators should be well-versed in all the facilitated activities, therefore it is recommended that facilitators read through the following scripts and training materials several weeks in advance of leading the Topic group meetings. We recommend scheduling each of these activities one week apart – with the exception of ‘Creating Research Questions’ Activity #2 – this should be held TWO WEEKS after ‘Developing Conceptual Models’ Activity #1 in order to allow sufficient time for editing the models in between meetings.

The ‘Conceptual Model Training’ will take approximately 60 minutes to facilitate, while the subsequent three activities will take 3.5 hours. This includes a short break and time for a snack/meal break. We recommend holding these meetings in a space large enough to accommodate the Topic Groups and additional facilitator(s) and Research Team members, along with plenty of space for the group to move about. Ideally, rooms would be equipped with audio/visual equipment to allow for projecting presentations, and a large empty wall to accommodate building each conceptual model. We also recommend providing refreshments for Topic Group members during these long meetings – such as sandwiches, salads, cookies, coffee, etc.

We recommend adapting these tools to fit the goals of your project. Where noted, fill in the [health topic] of focus.

If evaluating these activities, please consult the Evaluation Module for the appropriate tools and instruments to administer, including:

1. Facilitated Activity Satisfaction Questionnaire
2. Activity Log
3. Observation Log
4. Meeting Notes template
5. After Action Review



Facilitated Exercise 1: Developing Conceptual Models (Total Time = 3.5 hours – Includes 1 break, meal)

IMPORTANT! Prior to activity: Have the Research Team review the ‘Domain worksheet’ ahead of this activity, making edits, additions, and deletions as they see fit. This portion of the powerpoint should be updated prior to this activity.

Materials needed for this activity:

- Large wall or whiteboard
- Large sticky notes
- Large white flip charts – labeled with Domains at top
- Pre-cut sticky ‘arrows’ (if not using whiteboard)
- Pens (1 per person)
- Markers
- ‘Brainstorming factors’ worksheet (1 per person) – see appendix
- Facilitated Activity #1 Powerpoint (includes ‘Domain worksheet’ which will be projected – see appendix)

Introduction

Facilitator 5 minutes [See script below and use powerpoint presentation as prompt]

“We are here to talk about [health topic]. Everyone here has some experience in this area, and we are interested in learning from your experiences. The purpose of this exercise is to find new ways of looking at what affects [health topic] based on the experiences or knowledge of people like you. Today we will focus on the various factors that you might think affect [health topic]. At a later time, we will get together again to work on developing a list of research questions that you think are most important to study in order to help people with [health topic].

Here are some ground rules for today’s work. First, be aware that there are no right or wrong answers today. Don’t be afraid to speak up or think outside the box. Second, everyone gets a chance to contribute. Third, if people talk about their personal experiences, please respect their right to privacy and do not repeat this information outside this room.

Before we start, I want to thank everyone for participating in this process. As you think about [health topic] today, I want you to think about what you have learned about it personally in your own life or profession. I also want you to think about any data you might have seen regarding [health topic], and finally, please think about the research you did with other people like yourself who have experience with [health topic] and what you learned from them. I’ll give some more instructions in a minute, but does anyone have any questions before we start?”

Topic group 5 minutes Question/answer

Part I: Identifying factors affecting the health outcome (90 minutes)

Step 1: Brainstorm

Facilitator [Hand out 'Brainstorming Factors' worksheet and pens. See script below.]

"Take a few minutes and write down five to ten things you believe contribute to improve or worsen [health outcome]. These could be anything, from physical health to behaviors to the environment." (Corresponds to Part 1 on 'Brainstorming Factors' worksheet.)

Topic group 5 minutes Stakeholders brainstorm factors with potential causal relationship to [health outcome].

Step 2: Domains: Display domains and order factors

Facilitator 5 minutes [Using a projector, project the 'Domain' slide and discuss each of the domains. Next, have stakeholders organize their factors from Part 1 on their worksheet into domains (Part 3 of worksheet). See script below.]

"For this step, go ahead and organize your list into these domains which you'll see in Part 3 of your worksheet. Domains are categories that group related factors together. In our sessions we sometimes referred to them as 'buckets'. For example, the domain 'Health' may contain factors such as physical health, mental health, diseases, symptoms, etc. The 'Environment' domain may contain factors such as the built environment, the natural environment, pollution, climate, etc. You can also create new domains. If you need help placing something into a domain, just let me know and we can figure that out together."

Topic group 5 minutes [Stakeholders add their ideas from the brainstorming Part 1 to the domains in Part 3 on worksheet.]

Step 3: Adding factors

Facilitator [Project the slides with domains and additional factors, briefly talking over each factor. See script below.]

"These next slides cover a lot of different domains and things that might affect [health outcome]. Some of these you might have already written down in the previous step. For example, the environment domain may include factors in the environment we live in that might affect our health, from pollutants to the built environment. For this step, read through each of the factors under each domain, and write on your worksheet anything that you'd like to include that you didn't initially think of when brainstorming."

Topic group 10 minutes Stakeholders write down items on the worksheet.

Step 4: Fill in domain charts

Facilitator and Topic group [Ask the group to read out all the factors they listed in Part 3 of the worksheet. These will include both the factors they brainstormed in Part 1, and additional factors they added from the 'Domains' powerpoint slides. Have the person who suggested the factor describe briefly why it is important. It should also be emphasized that only the factors that are mentioned in the step will be included in the conceptual model.]

Facilitator and Topic group 5 minutes [For each factor added, ask if there is agreement from the group. If not, have the group discuss and come to an agreement about whether it stays or goes. The criteria should be that it may be a predictive factor for at least some persons facing [health outcome], not

necessarily all persons. Once agreement is made, write this factor down on a large sticky note and place onto corresponding Domain flipchart page.]



“Does anybody else have anything to add about why this factor is important as a cause of [health topic]?”

60 minutes *REPEAT* across all factors



Facilitator

[Once all factors are shared, the group can take a break.]

Part II: Modeling the health outcome (110 minutes)

Introduction

Facilitator 2 minutes [See script below]

“Last time we met, we learned how to create path diagrams, which are used to show the cause and effect relationships between two things. We used the example of someone buying a car, and brainstormed ideas for all the reasons why someone might buy a car or might not buy a car, and other factors that might influence this decision. Then we placed them on a diagram and created a path using arrows.

Does anyone have any questions about this activity from last week?”

Step 1: Solicit factors from Topic group

Facilitator [Set up a place for interactive modeling, such as a bare wall, large table, or white board. This will be a hands-on activity for all group members, and will involve moving the large sticky notes from the ‘Domain’ flip charts onto the wall/table/whiteboard where the model is being built]

****Tip! Start with the health outcome all the way to the right of the model.****

“Let’s first draw our dependent variable (the health outcome) on the right, just like in the example. Now, let’s take turns noting the items on our pages that you have highlighted.”

Facilitator [Have someone from the group select one of the factors.]

“OK, now, do we think that goes all the way on the left of our diagram, or does something come first?”

Topic group 2.5 minutes Discussion about whether factor is external (not affected by other factors in the model) or is impacted by some factor already in the model.

Facilitator **“Does this factor affect something else – is there any other mediating factor between this one and the health outcome?”**

Topic group 2.5 minutes Discussion about whether factor is a mediator.

Facilitator [Place the factor in the correct spot on the model. This may be to the far left for exogenous factors, somewhere in the middle for mediating factors, or just left of the health outcome if it has a direct effect on the health outcome.]

30 minutes Continue this process with other factors until all important factors are added to the model. Make sure each participant adds at least one new factor.



Facilitator

“Is there anything missing from the model? Is everything that affects [health outcome] included?”

Topic group

15 minutes

Discussion and decision about any additional factors.

Step 2: Building the paths

Facilitator

“In this next part, we’re going to decide how all these things affect each other. We’ll be placing arrows in the diagram to show how these factors relate to one other. We’re going to start on the far left side.”

[Starting with factor on the far left side of model]: “What factor does this directly affect? Can [factor] affect [factors to right]?”

[Place arrows on wall/board/table in between factors as the group discusses the relationship between factors in the model.]

*****Example: “Can AGE affect INHERITED CONDITIONS? No, it doesn’t affect the conditions you’re born with. Can AGE affect the kind of JOB you have? Yes, so we’ll put our first arrow from AGE to JOB. What else can AGE affect? The availability of health care? Yes, so we’ll put our second arrow from AGE to HEALTH CARE AVAILABILITY.”*****



[Make sure to probe group for each factor. Continue this process until all factors and relationships have been discussed.]

Topic group	30 minutes	[Continue adding arrows to model and discussing relationships among factors.]
Step 3: Reviewing the path diagram		
Facilitator		<i>“Let’s see where we stand with this model. Does anything look like it shouldn’t really be here?”</i>
Topic group	15 minutes	Discuss final diagram and come to a decision
Facilitator		<i>“Have we added all of the arrows we need to add? Let’s look at each item and see if it has a causal relationship with anything else in the diagram.”</i>
Facilitator and Topic group	15 minutes	Review arrows coming to/from each causal factor and discuss potential additions and subtractions.
Facilitator		[GROUP WRAP UP: Review final path diagram with group]

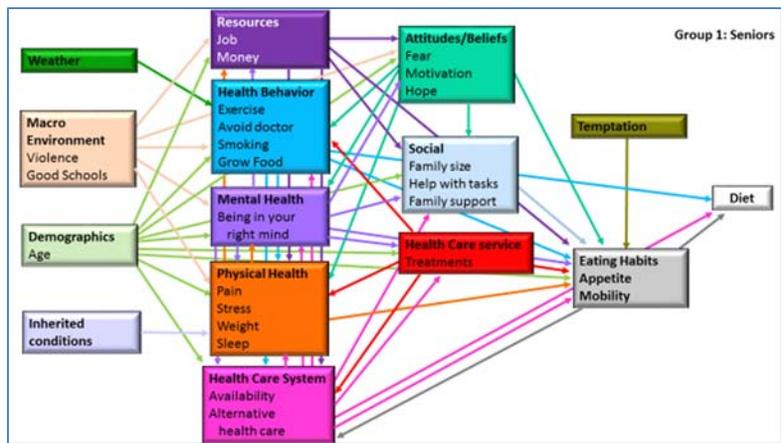


[Carefully document the final path diagram and record the name of the stakeholder group, the facilitator, date and place. (Make sure to take several pictures of the model.) Staple the pages together from each participant and collect those as well.]

[Optional]: If completing evaluation module, please complete 'Activity Log #1' for Facilitated Activity 1. Other evaluation activities include Observation Log #1, Facilitated Activity Satisfaction questionnaire, and After Action Review.

Preparation for Facilitated Activity #2:

1. Using meeting notes and the photos taken of the conceptual model, create an electronic version of the conceptual models using powerpoint. Factors can be consolidated and groups back into Domains in order to help readability of the model.



2. Create worksheet documenting common and unique factors across all Topic group models.

Creating Research Questions (Activity #2)

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1. Conceptual Model Training
2. Developing Conceptual Models (Activity #1)
3. Creating Research Questions (Activity #2)
4. Prioritizing Research Questions (Activity #3)

All of these activities will take place with each of the Topic groups. A facilitator, along with members of the Research Team, are needed to help facilitate and assist with each exercise. Additional supports may be needed for Topic group participants with vision problems or literacy challenges, therefore additional Research Team members should attend these meetings to provide one-on-one assistance to Topic group participants in need of assistance.

Facilitators should be well-versed in all the facilitated activities, therefore it is recommended that facilitators read through the following scripts and training materials several weeks in advance of leading the Topic group meetings. We recommend scheduling each of these activities one week apart – with the exception of ‘Creating Research Questions’ Activity #2 – this should be held TWO WEEKS after ‘Developing Conceptual Models’ Activity #1 in order to allow sufficient time for editing the models in between meetings.

The ‘Conceptual Model Training’ will take approximately 60 minutes to facilitate, while the subsequent three activities will take 3.5 hours. This includes a short break and time for a snack/meal break. We recommend holding these meetings in a space large enough to accommodate the Topic Groups and additional facilitator(s) and Research Team members, along with plenty of space for the group to move about. Ideally, rooms would be equipped with audio/visual equipment to allow for projecting presentations, and a large empty wall to accommodate building each conceptual model. We also recommend providing refreshments for Topic Group members during these long meetings – such as sandwiches, salads, cookies, coffee, etc.

We recommend adapting these tools to fit the goals of your project. Where noted, fill in the [health topic] of focus.

If evaluating these activities, please consult the Evaluation Module for the appropriate tools and instruments to administer, including:

1. Facilitated Activity Satisfaction Questionnaire
2. Activity Log
3. Observation Log
4. Meeting Notes template
5. After Action Review



Facilitated Exercise 2: Question Development Guide (3.5 hours – Includes meal and 1 break)

Introduction

Instructions: In this meeting, stakeholders will be developing research questions related to the health topic. We recommend that additional Research Team members are on hand to help Topic group members who may have literacy challenges, vision problems, or difficulty writing – one-on-one may be needed for these participants.

Materials needed for Exercise #2:

- Electronic version of all conceptual models from Facilitated Activity #1 (powerpoint to project)
- Paper copies of all conceptual models (1 per person)
- Conceptual model factor summary handout (1 per person) – see appendix for template
- “Creating Research Questions Training” powerpoint
- Facilitated Activity #2 facilitation powerpoint
- Writing Research Questions document (1 per person) - see appendix for template (this should be adapted)
- Pens (1 per person)
- Highlighters (1 per person)
- Flip Charts
- Markers

Evaluation materials needed (if using Evaluation module):

- Facilitated Activity Satisfaction Questionnaire
- After Action Review Agenda and materials
- Activity Log #2
- Observation Log #1

Facilitator 5 minutes

“Last time we met we identified factors related to [health topic] and diagrammed them in a path model.”

[Display group’s final (edited) path model and hand out copies.]

“Today, we are going to do a few additional steps. We will look back at the path diagram you created along with the path diagrams created by other Topic groups. We will create possible research questions from those models, and choose the most important ones. The selected questions will then be combined with questions selected by the other Topic groups and distributed and published as a research agenda on [health topic]. That will help guide researchers and funders in choosing research projects.”

[Leave time for Questions/Answers from group]

Part I: Review of models (55 minutes)

Materials: Enough copies of all conceptual models; projector with group's model on slide or powerpoint, highlighters

“Let’s review the model this group created last meeting.”

[Facilitator points out the factors that were identified and how they are related in the model.]

“Now, let’s review the model created by [name of stakeholder group].”

Facilitator 30 minutes

[Hand out copies of this model.]

[Facilitator points out any factor or relationship on the other stakeholder group model that was not present in this group’s model. Also, facilitator points out any differences in the way that relationships were diagrammed.]

Hold off on discussion until all alternative models have been presented.

Facilitator

Repeat previous step for each additional stakeholder model. Each Topic group will have created one conceptual model.

Topic Group

20 minutes

Discussion of new factors.

[Facilitator hands out a summary sheet that lists all factors identified across the stakeholder groups and their hypothesized relationships.]

Facilitator

Conceptual Models

Factors unique to Topic Group 1:

1. Fear
2. Alternative health care
3. Being in your right mind
4. Help with tasks
5. Growing own food

Factors unique to Topic Group 2:

1. Illnesses
2. Medication side effects
3. Mood
4. Lack of resources
5. Social skills
6. Learned behavior
7. Community involvement
8. Relationship closeness
9. Regular doctor
10. Health care access
11. Hobbies
12. Drugs/alcohol
13. Meal programs
14. Trust
15. Willpower
16. Awareness
17. Urgency
18. Health care beliefs
19. Risky environment
20. Family values

Factors unique to Topic Group 3:

1. Sex
2. Risk factors
3. Dental health

"I want you to take time to review this sheet, which summarizes the factors and relationships that this group and the other stakeholder groups identified. As you read it over, highlight those factors and relationships that you think we need to know more about."

Topic group 5 minutes Individually review the summary sheet.

Part II. Training on research question development (45 minutes w/break)

Instructions: This powerpoint was developed to train Topic group members on research questions and is meant to preface the Question Development activity where stakeholders create their own research questions. This powerpoint can be adapted to fit the needs and experience of your Topic groups, and we encourage the Research Team to seek out any additional training materials that may be of use to the Topic groups during this step.

Materials Needed:

- **"Creating Research Questions Training" Powerpoint**

[Use the powerpoint to present information about developing good research questions – 30 minutes]

"Research is difficult and expensive and often time consuming and there are limited funds available. A competitive research question has to address an important issue and it must be feasible to design a study to get a clear answer."

Step 1. Identify a focus area

Step 2: Identify a topic

Step 3: Begin to ask questions about a topic

- Who, what, when, where, why
- Hypothesis, related factors, and testing a hypothesis
- Making questions more specific with when, where, and who

Step 4: Creating research questions

15 minutes Break

Part III: Question development (32 minutes)

Instructions: This next part will walk Topic group participants through a series of prompts to create research questions that are of interest and importance to them. The following prompts were used in each of the demonstration sites, however we recommend adapting these to fit the goals of your project, as needed.

Materials Needed:

- **'Writing Research Questions' document (1 per person)**
- **Pens (1 per person)**
- **Highlighters (1 per person)**
- **Projector with "Facilitated Activity #2" powerpoint slides.**

Introduction

Facilitator 2 minutes *"We are going to start drafting research questions. As you think about the questions you would ask, you can look at the models created by all of the groups. You can also think about*

the data you are familiar with, such as which people are most at risk, the theories you are familiar with, and your own personal experiences and those of the other people you heard from.

I am going to provide a series of cues or prompts, and for each prompt I want you to write down at least one research question. You can write as many as you have time for."

Step 1: Prompt #1 - Causes

Facilitator Prompt

5 minutes

"Looking at the models and thinking about what you know about the subject, which pathways are critical to understanding the outcome? Stated another way, "If we really want to know how to improve [health topic], we need to better understand the relationship between X and Y." Now, you have to decide what X and Y are, and remember, they can be anywhere on the model, not just factors that lead directly to [health topic]."

[Display the prompt question.]

"Remember to write at least one question, and you can write as many as you have time for."

Topic Group

[Write down their questions.]

Step 2: Prompt #2 - Impact

Facilitator Prompt

5 minutes

"Looking at the models and thinking about what you know about the subject, which pathways are most likely to respond to intervention? Stated another way, if we could change factor X it would likely have a strong effect on [health topic]. Remember, the strong effect you are thinking of might directly affect [health topic], or it might affect another factor in the path."

[Display the prompt question.]

"Remember to write at least one question, and you can write as many as you have time for."

Topic Group

[Write down their questions.]

Step 3: Prompt #3 - Patient-Centeredness

Facilitator Prompt

5 minutes

"Looking at the models and thinking about what you know about the subject, what questions if we answered them would help patients with [health topic] make more informed decisions? Stated another way, if we could answer this question, patients would have better information for choosing treatments or for making other types of decisions."

[Display the prompt question.]

"Remember to write at least one question, and you can write as many as you have time for."

Topic Group	[Write down their questions.]
Step 4: Prompt #4 - Verification	
Facilitator Prompt	5 minutes
	<p><i>“Looking at the models and thinking about what you know about the subject, are there relationships in the model that are promising but we need to know more about? Stated another way, is there something you believe that needs to be proven for a fact? Do we need more evidence to show that a particular cause is important or that a promising treatment is effective?”</i></p> <p>[Display the prompt question.]</p> <p><i>“Remember to write at least one question, and you can write as many as you have time for.”</i></p>
Topic Group	[Write down their questions.]
Step 5: Prompt #5 - New Directions	
Facilitator Prompt	5 minutes
	<p><i>“Looking at the models and thinking about what you know about the subject, what is a new way of thinking about [health topic]? This is the time to think outside the box. Is there something important as a cause or solution that is missing or misunderstood in these diagrams? If stated another way, is there something here we know very little about right now?”</i></p> <p>[Display the prompt question.]</p> <p><i>“Remember to write at least one question, and you can write as many as you have time for.”</i></p>
Topic Group	[Write down their questions.]
Step 6: Highlight questions	
Facilitator	5 minutes
	<i>“Take a few minutes to read over all of the questions you have written down, highlighting the ones you think are most important.”</i>
Topic Group	Highlight questions.

Part IV: Listing Questions (50 minutes)

Instructions: In this next steps, participants will share the research questions they created that they feel are most important. They will be asked to share that question and provide an explanation about why they feel the question should be included. As each stakeholder shares a question – write this on a large flip chart, along with the name of the participant that developed the question. This is also a time when facilitators can probe for additional information to help stakeholders think through their terms and clarify the meaning of their question. It is important to keep detailed records of these steps and the questions that are generated in this meeting, therefore we recommend taking notes during the meeting as well as photographing each of the flip charts containing the questions. Participant’s worksheets should also be collected.

[We recommend the Project Coordinator types up each question into a word document/meeting notes as each question is being added to a sticky note. Each question should include the Topic group member's name that proposed the question, and their explanation for including the question. This information will help provide context to the final question in the Literature Review/Question Refinement step.]

Step 1: Listing questions

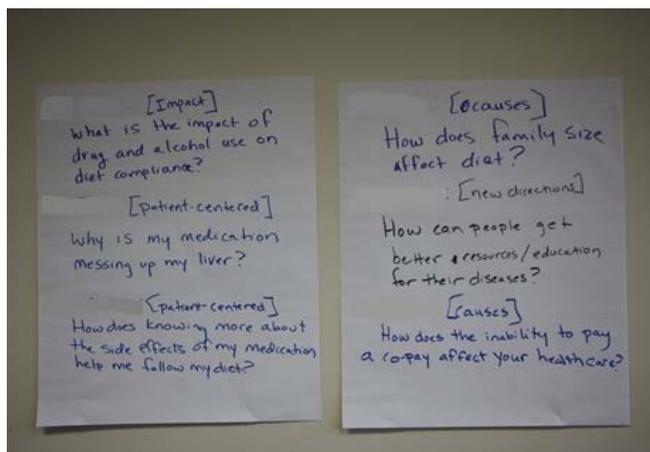
Facilitator 2 minutes

"We are going to go around the room and take turns reading off our research questions we highlighted. When it is your turn, read a question from your list that you think is most important and give a brief explanation of why you think it is important. We'll come back around until everyone has had a chance to read out all their questions or we run out of time".

Topic group 45 minutes

[Have group take turns reading off their research questions and providing an explanation. Each person can give one question in each round, but the group can add as many questions to the list as there is time for. Each person will have time at the next meeting to review their questions and provide a brief explanation for why they included it. Make sure to probe for additional information as needed, to clarify the nature of the question and the terms used. This can be a first step to 'wordsmithing' each question.]

[Write each of these questions on white flip chart with name of Topic group member who provided the question. ****Tip! Bring these flip charts back next week!****]



Step 2: Wrap Up

Facilitator 3 minutes

"Great! When we meet during our next meeting, we'll take turns reading off our research questions again, but will also allow time for you to provide a brief explanation for why you included it as a question. We will also walk through some steps on deciding which are the most important questions to include. Please pass forward the worksheets you wrote your questions on as we will be collecting these."

[Optional]: If completing Evaluation Module, please complete 'Activity Log #2' for Facilitated Activity 2. Other evaluation activities include Observation Log #2, Facilitated Activity Satisfaction questionnaire, and After Action Review.

Preparation for Facilitated Activity #3:

1. Using meeting notes and the photos taken of the research questions, number and transfer these questions to a Word document. The research questions should be categorized by Topic group. Topic groups will only be working with their own set of research questions, not the questions generated by other Topic groups.
2. Modify powerpoint to include Topic group questions.
3. Decide on the final number of research questions desired (per Topic group) – this will be the number of questions prioritized in Facilitated Activity #3.

Prioritizing Research Questions (Activity #3)

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We recommend adapting these tools to fit the goals of your project. Where noted, fill in the [health topic] of focus.

If evaluating these activities, please consult the Evaluation Module for the appropriate tools and instruments to administer, including:

1. Facilitated Activity Satisfaction Questionnaire
2. Activity Log
3. Observation Log
4. Meeting Notes template
5. After Action Review



Facilitated Exercise 3: Question Prioritization Guide (3.5 hours – includes 1 break and meal)

Materials Needed:

- Facilitated Activity #3 powerpoint slides
- Whiteboard or flipchart to record and display prioritized questions
- Large supply of pre-cut paper ballots (small sticky notes or note cards)
- Pens or pencils (1 per person)
- Copies of Topic Group questions (1 per person)
- Flip charts from last meeting (Facilitated Activity #2) with Topic group’s question

Introduction

Instructions: In this step (Part I, Step 1), Topic groups will be reviewing the questions their group created and shared during the last facilitated activity (#2). We recommend displaying their questions on the flip charts used in the last meeting. We also suggest numbering and typing up these questions in a word document to pass out to the Topic group, as well as projecting these questions in the powerpoint slides). Topic group members will be given a chance to read through each question and provide an explanation to the questions they proposed during the last meeting, as well as add any additional questions they’d like to the list. The next step (Part I, Step 2) will involve stakeholders voting on their top favorite questions (prioritization) through a multi-voting method. ***Facilitators should decide ahead of this meeting how many final research questions they’d like to end up with at the end of this meeting.*** There may be multiple rounds of voting to get to this final number of questions – this depends on the number and quality of questions at the start of the voting, and how strongly favored they are by the group. Continue voting until the Topic group has reached the final desired number of questions. The last step (Part II) will involve making the prioritized set of research questions more specific and patient-centered.

[In Part II, we recommend the Project Coordinator types up each prioritized question into a word document/meeting notes as each question is made more specific and patient-centered. Each question should include the original wording and the group’s discussion around making it more specific. This information will help provide context to the final question in the Literature Review/Question Refinement step.]

“When we met last time, we went around the group and read off research questions we had developed during our meeting. Today, we’ll have a chance to re-visit those same questions and again provide an explanation for why you included it as a question.”

Part I: Prioritization (70-80 minutes)

Step 1: Listing questions

Topic group	45 minutes	[Group should take turns with each person reading off their research questions and giving brief explanations. Each person can give one question in each round, but the group can add as many questions to the list as there is time for.]
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Step 2: Multi-voting		
Facilitator	3 minutes	<p>[Hand out paper ballots to each stakeholder. The number of ballots should equal one-third of the number of questions on the list.]</p> <p>[**For example, if there are 18 questions on the list, each participant should receive 6 ballots. They will cast a total of 6 votes (1 ballot = 1 vote) for their top favorite questions they'd like to carry over to the final step. Continue distributing ballots (one-third of the number of questions on the list) until the group has reached the final desired number of questions.**]</p> <p><i>“Now I want you to use these ballots to vote on the questions in the list. You must use all of your ballots and you may only vote for a question one time. Write the number of each question you are voting for on one of these ballots. Vote for the questions you think are most important.”</i></p>
Topic Group	5 minutes	Vote and turn in their ballots (Round 1 of voting).
Facilitator	7 minutes	<p>[Tally the votes. Cross out items that have:</p> <ul style="list-style-type: none"> • Two or fewer votes if the group has 5 or fewer members • Three or fewer votes if the group has 5 to 15 members • Four or fewer votes if the group has more than 15 members] <p>[Count the number of questions remaining. Each person again gets the number of ballots equal to one-third of the number of items remaining on the list.]</p>
Topic Group	5 minutes	Vote and turn in their ballots.
Facilitator / Topic Group	10-25 minutes	Repeat voting procedure until there are about [desired number] questions remaining.
Facilitator		Document complete list of questions that were selected after voting. If using Evaluation Module, can document on 'Activity Log 3'.

Part II: Making research questions patient-centered (70 minutes)		
Facilitator		<p><i>“We are going to focus our questions a bit more on defining the populations and outcomes that should be address in the research questions. Let’s go through our final list of questions to narrow down some of the needed elements.”</i></p> <p>POPULATION:</p> <p><i>“Let’s start with question one. First is the population. Who should be included as research participants? If you were designing a study to answer this question, are there people you would almost certainly want to be part of that study? Are there people you think should not be part of that study, at least not yet?”</i></p>
Topic Group		Discussion – group comes to a consensus about most popular options

Facilitator	<p>OUTCOMES:</p> <p><i>“Patient centered research requires the use of study outcomes that matter to patients, outcomes that they notice and find meaningful. Examples might be measures of symptoms, such as pain or nausea, or measures of function, such as mobility or continence. What outcomes would be most meaningful to patients? What should researchers measure?”</i></p>
Topic Group	Discussion – group comes to a consensus about most popular options
<p>[Optional prompts: We recommend using the following additional prompts with more experienced Research Teams only.]</p>	
Facilitator	<p>[If the question is about a treatment option or intervention].</p> <p>TREATMENT:</p> <p><i>“What should we compare the treatment we are interested in to? For example, if we were looking at treatment for arthritis, we might compare one type of pain medication to another type of pain medication.”</i></p>
Topic Group	Discussion – group comes to a consensus about most popular options
Facilitator	<p>TIMEFRAME:</p> <p><i>“What timeframe would be best for patients to look at outcomes? What about follow up?</i></p> <p><i>For example, should we follow people in this study for a month? A year? How long does it take to get meaningful answers?”</i></p>
Topic Group	Discussion – group comes to a consensus about most popular options
Facilitator	<p>SETTING:</p> <p><i>“What settings should this research take place in? For example, should we look at treatment as outpatients, in hospitals, somewhere else?</i></p> <p><i>For example, if the study tests a new exercise program, should the study take place with hospitalized patients, patients attending a clinic, at a community center, or should people do the exercise program at home?”</i></p>
Topic Group	Discussion – group comes to a consensus about most popular options
<p>***Repeat steps for the rest of the research questions, spending 10-20 minutes on each research question; Adjust time as needed depending on the number of final research questions in list***</p>	

Wrap-up

Facilitator [Review final set of questions that were voted on.]

[Re-cap the project and each facilitated exercise, and what the next steps are with these research questions. Make sure to thank stakeholder for their time and participation.]

Facilitator [Make sure to document the final set of research questions. It is also recommended that photos are taken of each of the flipcharts that questions were written down on.]

[Optional]: If using Evaluation Module, please complete 'Activity Log #3' for Facilitated Activity 3. Other evaluation materials include Observation Log #3, Facilitated Activity Satisfaction Questionnaire, and After Action Review.

SCAN: Focus Groups and Key Informant Interviews

INSTRUCTIONS: The following section contains materials for recruiting, organizing, and facilitating data collection with consulting stakeholders in the SEED Method who participate in focus groups and interviews – referred to as SCAN (Stakeholder ConsultANT) participants. SCAN participants are engaged through a one-time participation in a focus group or key informant interview. The purpose of this consultative engagement is to gain additional perspectives and experiences with the health topic beyond those of the Topic groups.

Focus groups: Focus groups are interactive group meetings that allow participants to share their experiences, perceptions, and opinions about the health topic. People involved in this type of participant group will be involved in a one-time only focus group lasting approximately 90 minutes. This is a great way for people to participate who may not be able to commit to a more involved, long-term commitment like the Topic groups.

Key informant interviews: One-on-one interviews, lasting between 30 and 60 minutes, will be conducted over the phone or face-to-face. This allows for people to be included in the study that might not be able to meet for longer periods of times (Topic groups) or are not able to attend a focus group. Rather, this includes people who have busy schedules or who might prefer to meet privately (i.e., health care providers (MDs), policymakers, etc.).

Research Team and Topic groups should work together to decide the composition of focus groups and interviews. We recommend revisiting the completed *Stakeholder Identification Matrices (Matrix 1 and 2)* (see **Community Research Team Templates** part of the Toolkit) to consider including groups of stakeholders that may not be represented in Topic groups. All focus groups and interviews should be conducted and analyzed prior to Topic groups beginning Facilitated Activity #1 (Creating Conceptual Models).

Focus group and key informant interview guides should be developed collaboratively with the Research Team. We recommend brainstorming a list of open-ended questions that tap into the types of information one is interested in learning from SCAN participants. These questions should then be tailored to each focus group and interview that is conducted.

MATERIALS: You'll find the following SCAN materials included in this section of the Toolkit:

Templates

- Focus group cover sheet template
- Focus group guide template
- Key informant interview cover sheet template
- Key informant interview guide template

Focus Group Cover Sheet

Focus Group Information	
Focus group:	
Location:	
Research Team Information	
Name of person(s) facilitating focus group:	
Name of person taking notes:	
Focus Group Information	
Date of focus group:	_____/_____/_____ (mm/dd/yyyy)
Focus group START time:	_____:_____ (AM/PM)
Focus group END time:	_____:_____ (AM/PM)

Date consent forms were signed: _____ (mm/dd/yyyy)

Was this focus group's audio recorded?

Yes

No

Were all focus group participants paid a \$25 participant stipend?

Yes

No

Focus Group Cover Sheet

Top 3 observations/points of interest from focus group:

1.

2.

3.

Focus Group Guide Template

Introduction

[Moderator: introduce self and any co-moderators or other project members present]

Patients with these chronic conditions are often told to [insert text/information about health topic]. In this interview, we want to hear your opinions and experiences regarding the factors that [insert goal of interview].

This conversation is part of a larger project funded by [funding organization]. We are trying to learn more about [health topic]. We also want to learn more about how to involve patients, caregivers and other stakeholders in the process of developing questions that drive the research studies that get funded and conducted.

Before we begin discussing today's topic, I want to go over some basic information. The first part is to make sure that everyone wants to participate today and to give you information about what that means. When we gather information from people as part of research, we ask them to understand and sign a consent form which serves of the purpose of making sure that you are informed about the project and about your rights. Let's go over that now... [GO OVER CONSENT FORM WITH GROUP]

Any questions so far?

Okay, next we will go over a few ground rules for today's discussion. Stop me if you have any questions.

1. This is a conversation. There are no right or wrong answers and we are not here to judge each other's responses. Once someone is finished speaking, the next person will have a chance and it doesn't matter if people agree or disagree with each other.
2. Everyone gets a chance to talk.
3. In order for people to feel free to speak, we need to respect each others' rights. What you hear people talk about here should stay in this room – please do not share what other people said with others outside this group.
4. Please speak up and speak clearly so that we can be sure to hear your responses.

We have prepared some information for those of you who feel you have questions about dietary restrictions or where you can get help. After the session, please stop and get the information or talk to us if you feel it would be helpful.

OK. Let's go around the room and quickly tell us your first name. You might want to mention something else about yourself, like [insert ice breaker question].

Focus Group Guide Template

FOCUS GROUP QUESTIONS:

[insert questions]

CONCLUSION:

[insert wrap-up text]

Key Informant Interview Cover Sheet

Key Informant Information	
Name of Key Informant:	
Organization:	
Position/Job title:	
Contact Information (phone/email):	
Engaging Richmond Information	
Name of person conducting interview:	
Name of person taking notes:	
Interview Information	
Date of interview:	_____/_____/_____ (mm/dd/yyyy)
Interview START time:	_____:_____ (AM/PM)
Interview END time:	_____:_____ (AM/PM)

Date consent form was signed: _____ (mm/dd/yyyy)

Was this interview done over the phone or in-person?

- Over the phone In-person

Was this interview's audio recorded?

- Yes No

Will this Key Informant be paid a \$20 participant stipend?

- Yes No

Top 3 observations/points of interest from interview:
1.
2.
3.

Key Informant Interview Guide Template

INTRODUCTION:

Thank you for taking the time to speak with me today. My name is [_____] and I'm a member of [research team name], a [description of research team and mission statement]. Currently, we are working on a project that seeks to develop research questions surrounding [health topic].

Patients with these chronic conditions are often told to [insert text/information about health topic]. In this interview, we want to hear your opinions and experiences regarding the factors that [insert goal of interview].

This conversation is part of a larger project funded by [funding organization]. We are trying to learn more about [health topic]. We also want to learn more about how to involve patients, caregivers and other stakeholders in the process of developing questions that drive the research studies that get funded and conducted.

Before we begin discussing today's topic, I want to go over some basic information. The first part is to make sure that you want to participate today and to give you information about what that means. When we gather information from people as part of research, we ask them to understand and sign a consent form which serves the purpose of making sure that you are informed about the project and about your rights. Let's go over that now...

[GO OVER CONSENT FORM WITH KEY INFORMANT]

Any questions so far?

We have prepared some information in case you have questions about dietary restrictions or where you can get help. After the interview, please let us know if you'd like a copy of this information.

INTERVIEW QUESTIONS:

[insert questions]

CONCLUSION:

[insert wrap-up text]

Guide for SEED Method Step 6: Literature, refining the research questions and completing *Question Refinement Template* (Review of the literature)

OVERVIEW: During this step the research team will review related academic literature in order to uncover gaps in knowledge and finalize the list of research questions. The time needed for this method will depend on the number of questions being reviewed, the size and experience of the review team, and the time allotted for this task by individual reviewers.

I. Guidelines for completing literature review

The need to complete a thorough literature review will largely depend on the goals of the project. We recommend this type of review be completed if the aim is to publish the research agenda in the scientific literature or disseminate it to professional audiences. For goals such as prioritizing funding decisions or identifying research topics for internal use, a less intensive level of review may be needed.

Recommendations:

1. **Limit the number of final research questions** each Topic group prioritizes! This will in turn expedite the literature review process.
2. **Create a literature review team** of no less than three people. Each question can take up to 40 hours to thoroughly research depending on the experience and expertise of team members conducting the review. Make sure your team is large enough to adequately handle the number of questions that are being refined and researched.
3. Make sure literature review **team members have appropriate experience and skill set**. It is recommended that people helping with the literature review are well versed in interpreting academic literature, literature reviews, and how to search large academic databases. Expertise in the content of the questions is helpful.
4. **Meet regularly** as a large team throughout the literature review phase in order to discuss search strategies, talk through refinement process of each question, and troubleshoot issues as they arise.

II. Literature Review Training – Q/A

What is a literature review?

A literature review asks: **What do we know - or not know - about this particular issue/ topic/ subject?** How well you answer this question depends upon:

1. The effectiveness of your search for information
2. The quality & reliability of the sources you choose
3. Your ability to synthesize the sources you select

(from <http://guides.library.vcu.edu/lit-review>)

What is the purpose of the literature review in the SEED Method?

The SEED Method uses a review of the literature to investigate which aspects of each question have been answered by prior studies in order to make recommendations targeting research gaps. The literature review also helps utilize appropriate wording in revising each question. The research questions generated by the Topic groups that represent gaps in current knowledge and are relevant to patient centered outcomes research will be incorporated into a *Research Agenda*.

How do I start?

The first step to beginning the literature review is to understand the question that is being posed! Please see Section III A2 below for additional details regarding review of the Topic group audio and transcripts to better understand how the question originated, the context and meaning behind the question, and the direction of the question being asked. The context of the discussion may be very helpful if the question itself was not precisely worded.

A second important step is to review the recommended process and materials, such as the *Refinement Template*.

How do I search for articles?

We recommend using a search engine such as PubMed, Web of Science, or an academic library system in order to search for academic articles. If you are unfamiliar with searching these databases we recommend meeting with a librarian before beginning.

How do I organize my search?

There are several ways to organize your search, however we recommend using a citations manager such as Refworks or another system that suits your team's needs. Citations can be saved under sub-folders linking them to each research question, and can be easily uploaded through search engines such as PubMed.

How do I know I'm on track?

We found that group meetings to review work in progress are a great way to stay on track.

How do I know if and when I've thoroughly researched a question enough?

It is helpful to keep in mind that your goal is to re-word the question posed by the stakeholders instead of changing direction. If the question is out-of-step with the current research, then completing the 'Summary of the Literature' table (Part III) in the *Question Refinement Template* is a good guide.

I've done the literature review, now what? How do I use this to refine the research questions and inform the gaps in knowledge?

Use Part III (Summary of the Literature) and Part IV (Research Gaps) tables in the *Question Refinement Template* to synthesize what was learned from the literature and revise the final questions based on the findings.

III. Completing *Question Refinement Template*

A. Reviewing the prioritized research questions:

1. Review Topic Group notes and audio recordings to make sure questions reflect the groups' discussions and revisions. This includes:
 - Question wording
 - Population, outcomes, and special concerns
 - Rationale for the question
 - Context of the question
2. Understand the direction of the relationship specified in each question (What impacts what? What is the predictor variable? What is the outcome of interest?).
 - **Tip: Only review studies that focus on correct direction of relationship! That is, make sure the articles you use in your literature review are getting at the outcomes of interest in each research question!**
3. Check-in with the Lit. Review team to develop keywords together and discuss your search strategy and direction you're heading in.
4. Narrow down population or outcomes (if necessary) to get to the "right" question.

B. Reviewing the scientific literature:

1. Review the professional literature on the topic – use PubMed or other databases.
 - a. Start by searching "keywords" that were developed.
 - Review articles that seem the most relevant to finding out whether the question has been answered as posed.
 - **Systematic reviews are a great resource!**
 - b. As you review the most relevant articles pay attention to the citation trail. This helps to focus your search in the right direction.
 - In recent articles that have cited your article of interest, go through their reference list and look for other relevant citations.
 - In older articles, look 'forward' to papers that have cited this article and look for other relevant citations.
 - c. Only summarize and document the relevant articles in the *Question Refinement Template* (see next section below).

Tip: When reviewing articles, start with the abstract and conclusion sections to see if the article is relevant and adds anything to your search! Also make sure that it is trying to answer the research question you're investigating! If so, pull out the important points.

2. How to move from "reviewing the literature" to "uncovering the knowledge gaps":
 - a. Ask yourself:
 - Did the studies answer the main question being asked?
 - Did the studies answer the question for the special populations, outcomes, and specific concerns?
 - What are the research gaps identified in those articles?

- Look for author comments about where evidence is lacking, as well as specific recommendations for future research.

C. Filling out the Question Refinement Template:

1. Begin filling out the *Question Refinement Template* with the most relevant, “on-point” articles.
 - **Tip: Save time by cutting and pasting key points from the article!**
 - **Tip: Start with basic literature and systematic reviews. After that, you can look for articles about special populations, innovative interventions, and dissemination and implementation.**
 - **Tip: Assess the strength of the evidence. This will provide a framework for recommending further research on the topic (if evidence is preliminary) or moving on to more targeted issues.**
 - **Tip: Focus attention on the limitations as well as the recommendations for further research in each article.**
 - Periodically check-in with your Lit. Review team.
2. Check-in with team after filling in five articles to make sure your search is going in the right direction.
3. Fill in the rest of the template and do another check-in around 10-12 articles. Bring suggestions for the final re-worded questions.
4. The Lit. Review team provides feedback and works together to come up with the final, refined research questions.

Tip: Continuously fill out Lit Review Tracking document to update question status!

D. Identifying and reaching out to content experts

1. Use the *Question Summary Template* to create a summary for each research question.
2. Reach out to content experts and send the completed *Question Summary* for the question of interest to them to review. Be clear that you are looking for feedback on the question itself and that you are not looking for them to provide answers to the question. The request should be for a small amount of their time via a short interview (15 minutes).
3. Speak with a topic/content expert on each research question to:
 - Ensure that topic was fully explored and that the review captures the relevant scientific literature.
 - Discuss their feedback and thoughts on the final research question(s), including question wording, or suggestions for different directions.
4. Incorporate experts’ suggestions into final research questions (as you and your team see fit).
5. Final research questions should be asking questions that get at the gaps in the scientific knowledge base, while reflecting as closely as possible the questions suggested by Topic groups!

E. Documenting final, refined research questions

1. Once a question is finalized, transfer the final, refined research question to *Final Refined Research Questions Template*.

Necessary documents – see templates

- *Question Refinement Template* (one per research question)
- *Question Summary Template* (one per research question)
- *Final Refined Research Questions Template* – this becomes the Research Agenda (not attached – please see example documents)
- *Lit Review Tracking document*

Question Refinement Template

Question topic area:	
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Part I: Topic Group Data	
Question(s) as posed:	
Outcomes of interest:	
Populations of interest:	
Other special concerns:	
Research team input:	
Quotes that help illustrate rationale and context of question:	
Key words:	

Part II: Literature Review	
Studies that address the main question:	
Citation:	
Population studied:	
Methodology:	
Results/findings:	
Research gaps:	
Main take-away:	
Citation:	
Population studied:	
Methodology:	
Results/findings:	
Research gaps:	
Main take-away:	

add additional sections as needed

Studies that address outcomes of interest:	
Citation:	
Population studied:	
Methodology:	
Results/findings:	
Research gaps:	
Main take-away:	
Citation:	
Population studied:	
Methodology:	
Results/findings:	
Research gaps:	
Main take-away:	

add additional sections as needed

Question Refinement Template

Studies that address specific populations of interest:	
Citation:	
Population studied:	
Methodology:	
Results/findings:	
Research gaps:	
Main take-away:	
Citation:	
Population studied:	
Methodology:	
Results/findings:	
Research gaps:	
Main take-away:	

add additional sections as needed

Studies that address patients with/at risk for [Health Issue] .	
Citation:	
Population studied:	
Methodology:	
Results/findings:	
Research gaps:	
Main take-away:	
Citation:	
Population studied:	
Methodology:	
Results/findings:	
Research gaps:	
Main take-away:	

add additional sections as needed

Studies that address any other special concerns:	
Citation:	
Population studied:	
Methodology:	
Results/findings:	
Main take-away:	
Citation:	
Population studied:	
Methodology:	
Results/findings:	
Research gaps:	
Main take-away:	

add additional sections as needed

Question Refinement Template

Part III: Summary of the Literature	
What we know	What we need to know more about
Research on the main question	
Research on outcomes of interest	
Research on populations of interest	
Research on patients with/at risk of [Health Issue]	
Research on any other specific concerns	

Part IV: Research gaps? (Fill in where relevant)	
Substantive (e.g., Patient perceptions/knowledge, clinical care, interventions, outcomes (including long-term outcomes), comparative effectiveness, communication, education, policy)	
Methodological (e.g., study design and methods)	
Population (e.g., Race, socioeconomic status, health status, geography, age, vulnerable populations, workers)	

Part V: Refining original research question
Suggested re-wording of research question(s)
Final research question(s) (after group's feedback)

Question Refinement Example

Question topic area:	Support Systems/Coping Mechanism
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Part I: TOPIC GROUP Data	
Question(s) as posed by Topic Group: (Question 3)	What are the factors of patient's faith (for example, knowing what happens when you die, feeling of peace or seeing family members again) and knowing family and community are praying for them; how does this affect lung cancer outcomes? Does it reduce stress and does it change your outlook?
Outcomes of interest:	<ul style="list-style-type: none"> • Measurement for research: • Stress – the ability to handle challenges and physical manifestations of stress (BP, muscle tension, biomarkers) • Measure of reliance on faith vs self-reliance • Length of hospitalization • Grief and family and patient
Populations of interest:	<ul style="list-style-type: none"> • Pastors • Congregants of faith communities • African Americans • People of Faith
Other special concerns:	Measurement of faith and support from a faith community.
Engaging Martinsville input:	<p>Initial thoughts about this questions were :</p> <ul style="list-style-type: none"> • Multiple questions in one. • Would be hard to research. • How do you measure faith? • Comparing different faiths, denominations, and their approach to activities supporting parishioners who are ill.
Quotes that help illustrate rationale and context of question:	<p>“Knowing where you are going when you die and knowing that you are going to see family again and that they are going to see you, takes that awful grieving away. You still grieve but it’s like the grieving of those that don’t have that assurance, and it definitely reduces stress even though being a Christian or not when you were told you first told you had cancer, it’s like, but then you, you pray and get peace.”</p> <p>“And um, it definitely does reduces stress and it changes your outlook, because you know that whether you live or you die, you are in God’s hand.”</p> <p>“names some things that are related to faith and then wants to measure how that impacts stress and 13 is trying to hash out more of those factors of faith and how it affects lung cancer outcomes”</p>
Key words:	<p>Religiosity – broadest sense, is a comprehensive sociological term used to the numerous aspects of religious activity, dedication and belief.</p> <p>Intrinsic religiousness – religion that is an end to itself, a master motive, a framework of one’s life.</p> <p>Religious coping – a means of dealing with stress that are religious. These include prayer, congregational support, pastoral care, religious faith.</p>

Question Refinement Example

	<p>Prayer – a request for help to God or other object of worship.</p> <p>Key words for research used: religiosity, intrinsic religiousness, religious coping, prayer, faith, outcomes, spirituality, religion, hope health outcomes, quality of life, longevity, mortality, stress, attitudes, perceptions.</p>
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Part II: Literature Review	
Studies that address the main question:	
Citation:	Haghighi, Fatemeh. "Correlation between Religious Coping and Depression in Cancer Patients." <i>Psychiatra Danubina</i> 25, no. 3 (September 2013): 236–40. (1)
Population studied:	Descriptive-correlational study was conducted on 150 consequent cancer patients in three centers. All patients with a confirmed diagnoses of cancer.
Methodology:	Two questionnaires including Pargament’s questionnaire for evaluation of religious coping and the Beck depression inventory (BDI) were used. The Religious Coping Questionnaire (RCOPE) included 20 items on a 5-point Likert scale rating which evaluated religious belief and practice including relationships with God, avoidant relationship with God and an alternately fearful and hopeful relationship.
Results/findings:	The study was carried out on 150 cancer patients and it was determined there was no significant difference between men and women in the mean score of avoidant relationship with God and alternate fearfulness and hopefulness (ambivalence coping style). The mean score of relationship with God in women was higher than men. The rate of depression was higher among patients who had an avoidant strategy. The religious coping method of relationship with God was effective in reducing depression. The rate of depression was lower among patients whose families had a better attitude to religion.
Research gaps:	Many studies have been done on religiosity and its impacts but few show definite/particular quality of life impacts. “Although, there was no relationship between positive religious coping and psychological distress, religious coping was correlated with multidimensional aspects of quality of life” (Ramirez et al. 2012)
Main take-away:	Psychotherapy, individual/familiar counseling, and especially increasing of religious beliefs such as praying and trust in God, as well as increasing the knowledge of patient and his/her family cause better acceptance of the disease and better confrontation of psychological problems.
Citation:	Pérez, John E., and Amy Rex Smith. "Intrinsic Religiousness and Well-Being among Cancer Patients: The Mediating Role of Control-Related Religious Coping and Self-Efficacy for Coping with Cancer." <i>Journal of Behavioral Medicine</i> 38, no. 2 (August 29, 2014): 183–93. doi:10.1007/s10865-014-9593-2. (2)

Question Refinement Example

Population studied:	Cross sectional design of 179 ambulatory cancer patients. Participants were predominately white, Christian, and female with an average of 16 years of education.
Methodology:	179 adult cancer outpatients at three northeaster U.S. hospitals. Patients with stage II – stage IV cancer as well as advanced cancers. Patients had to be 18 years or older and in active outpatient treatment. Measures used: Demographic questionnaire, Medical chart review, Intrinsic religious motivation scale, Religious coping (RCOPE), Cancer Behavior Inventory-brief version, Functional Assessment of cancer therapy (FACT-G)
Results/findings:	“The relationship between intrinsic religiousness and well-being is fully mediated by control-related religious coping and self-efficacy for coping with cancer.” Active religious surrender positively predicts self-efficacy for coping with cancer. Higher levels of self-efficacy for coping with cancer predict higher levels of the four different types of well-being. The four types of wellbeing include: physical, functional, emotional and social. “Intrinsic religiousness is the internalization of faith as the primary motive for people’s lives.” Several authors have fond that intrinsic religiousness is associate with better health and wellbeing. Among cancer patients, intrinsic religiousness has been positively associated with hope, meaning, and peace.
Research gaps:	There were some limitations to the study to include: non-random, clinical sample was comprised of predominately white, Christian females. They are unable to generalize the results of the study to populations that differ by race, gender, socioeconomic status and religious affiliation.
Main take-away:	The findings suggest pathways by which intrinsic religiousness and control-related religious coping are linked to various dimensions of well-being among cancer patients.
Citation:	Gene Meraviglia, Martha. “The Effects of Spirituality on Well-Being of People With Lung Cancer.” <i>Oncology Nursing Forum</i> 31, no. 1 (January 1, 2004): 89–94. doi:10.1188/04.ONF.89-94. (5)
Population studied:	60 adults ranging from 33-83 years of age. Most participants had non-small cell lung cancer and were female, Caucasian and older than 50.
Methodology:	Participants completed a questionnaire composed of six survey instruments: Life Attitude Profile, Adapted Prayer Scale, Index of well-being, Symptom distress scale and background information sheet, cancer characteristic questionnaire.
Results/findings:	Higher meaning in life scores were associated with higher psychological well-being and lower symptom distress scores. Higher prayer scores were associated with higher well-being.
Research gaps:	More research is needed on the spiritual concepts to refine framework.
Main take-away:	Spirituality and prayer have a positive effect and positive physical response which may impact lung cancer outcomes. A higher level of meaning in life showed a lower symptom distress. “Higher prayer scores are related to better well-being. Meaning in life and prayer lessen the impact of lung cancer on well-being”

Question Refinement Example

	The study finds that people with lung cancer are unique in their response to the impact for cancer. For example, people who were unmarried, in need of income to meet their daily needs, experiencing poor physical health or functional status, or currently receiving cancer treatment reported more symptom distress. The findings emphasize the importance of an individualized approach to care based on ongoing circumstances.
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Studies that address outcomes of interest:	
Citation:	Silvestri, Gerard A., Sommer Knittig, James S. Zoller, and Paul J. Nietert. "Importance of Faith on Medical Decisions Regarding Cancer Care." <i>Journal of Clinical Oncology</i> 21, no. 7 (April 1, 2003): 1379–82. doi:10.1200/JCO.2003.08.036. (4)
Population studied:	One hundred patients with advanced lung cancer, their caregivers, and 257 medical oncologist were interviewed.
Methodology:	One hundred patients with advanced lung cancer, their caregivers, and 257 medical oncologist were interviewed. Participants were asked to rank importance of the following factors that might influence treatments decisions: cancer doctor's recommendation, faith in God, ability of treatment to cure disease, side effects, family doctor's recommendations, spouse's recommendations and children's recommendations.
Results/findings:	All three groups ranked the oncologist recommendation as most important. Patients and caregivers ranked faith in God second, whereas physicians placed it last.
Research gaps:	Future studies need to clarify HOW faith influences decision making. One major limitation is that all patients and interviews were from participants that were from the bible belt. This could potentially affect the results by not including a diverse religious group.
Main take-away:	"Patients and caregivers agree on the factors that are important in deciding treatment for advanced lung cancer but differ substantially from doctors. All agree that the oncologist's recommendation is most important. This if the first study to demonstrate that, for some, faith is an important factor in medical decision making, more so than even the efficacy of treatment. In faith plays an important role in how some patients decide treatment, and physicians do not account for it, the decision making process may be unsatisfactory to all involved." Medical decision making can certainly affect outcomes for the patient, therefore making a correlation between faith – decision making – outcomes. The authors feel this is the report regarding the difference of how physicians, caregivers and patients view influences of medical decision making.
Citation:	Juliana, Franceschini, José R. Jardim, Ana Luisa Godoy Fernandes, Sérgio Jamnik, and Ilka Lopes Santoro. "Reliability of the Brazilian Version of the Functional Assessment of Cancer Therapy-Lung (FACT-L) and the FACT-Lung Symptom Index (FLSI)." <i>Clinics (Sao Paulo, Brazil)</i> 65, no. 12 (2010): 1247–51. (6)

Question Refinement Example

Population studied:	30 patients with lung cancer were recruited from an outpatient lung cancer clinic.
Methodology:	The FACT-L with the FLSI questionnaire was prospectively administered to 30 consecutive, stable, lung cancer patients.
Results/findings:	The FACT-L with FLSI questionnaire is reliable, quick and simple to apply. The instrument can be used to evaluate the quality of life of Brazilian lung cancer patients.
Research gaps:	Translation of the FACT to other languages
Main take-away:	The primary purpose of the study was to review the reliability of the FACT-L assessment in conjunction with the FACT-Lung Symptom Index questionnaire to prove quality of life. This assessment could potentially be used with the spiritual assessments to evaluate lung symptoms and prove quality of life either being better or worse. Quality of life has become an important aspect for <i>clinical trials</i> and important research agenda to prove or not that spirituality does improve the quality of life.

Citation:	Monod, Stéfanie, Mark Brennan, Etienne Rochat, Estelle Martin, Stéphane Rochat, and Christophe J. Büla. "Instruments Measuring Spirituality in Clinical Research: A Systematic Review." <i>Journal of General Internal Medicine</i> 26, no. 11 (November 2011): 1345–57. doi:10.1007/s11606-011-1769-7. (7)
Population studied:	35 instruments were used to measure spirituality in clinical research. The literature search initially began with 1575 citation and were narrowed down to 35 instruments. The instrument was validated in the largest and most diverse population by using 5087 participants in 18 countries through the World Health Organization.
Methodology:	A systematic search in MEDLINE, CINHAI, psycINFO, ATLA and EMBASE databases using terms such as "spirituality"
Results/findings:	Thirty five instruments were classified into measure of spirituality (22), spiritual well-being (4), spiritual coping (4), and spiritual needs (4). The instruments that are most frequently used are the FACIT-SP and Spiritual Well-being scale.
Research gaps:	The study also highlights the absence of instruments to measure poor spiritual well-being
Main take-away:	This review provides details on instruments that assess spirituality and the relationship between spirituality and health. The first reaction of the research team members and the topic group members was that no one could imagine there would be measurement tools for spirituality. The research question is one that one would think was open ended and did not have the ability to connect with other assessments to prove or disprove the connection of spirituality (prayer) and outcomes. After the literature review, it is clear that many have interest in the relationship between spirituality and well-being – therefore resulting in good outcomes but have had some challenges to try to use the appropriate/effective tools to create a constructive and concrete way of evaluating the two to prove results. Much research is still to be done

Question Refinement Example

	regarding this relationship. More research is needed on the relationship of spirituality and wellbeing.
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Citation:	Smith, Amy Rex, Susan DeSanto-Madeya, John E. Pérez, Elizabeth F. Tracey, Susan DeCristofaro, Rebecca L. Norris, and Shruti L. Mukkamala. "How Women with Advanced Cancer Pray: A Report from Two Focus Groups." <i>Oncology Nursing Forum</i> 39, no. 3 (May 1, 2012): E310-316. doi:10.1188/12.ONF.E310-E316. (8)
Population studied:	13 adult females outpatients receiving active treatment for ovarian or lung cancer.
Methodology:	Two focus groups were conducted with data coding and analysis using standard procedures.
Results/findings:	"Four themes emerged: finding one's own way, renewed appreciation for life, provision of strength and courage, and gaining a stronger spiritual connection. In addition, praying for others, conversational prayer, petition prayer, ritual prayer and thanksgiving prayer were used most often by participants to cope.
Research gaps:	There is research on hope and wellbeing with many types of cancer; however there is limited research on spirituality and lung cancer.
Main take-away:	The findings support that prayer is a positive coping mechanism. The goal was to look at the meaning of prayer and identify the effects that it has. In conclusion of the focus groups, it was identified that prayer was an important factor for coping in cancer diagnosis.

Citation:	Lissoni, P., G. Messina, D. Parolini, A. Balestra, F. Brivio, L. Fumagalli, L. Vigore, and F. Rovelli. "A Spiritual Approach in the Treatment of Cancer: Relation between Faith Score and Response to Chemotherapy in Advanced Non-Small Cell Lung Cancer Patients." <i>In Vivo (Athens, Greece)</i> 22, no. 5 (October 2008): 577-81. (12)
Population studied:	50 consecutive patients who were suffering from metastatic non-small cell lung cancer.
Methodology:	A clinical approach to investigate spiritual faith.
Results/findings:	The study suggest that there is evidence of a "high degree of faith as an expression of an active spiritual life was associated with a greater efficacy of cancer chemotherapy and may predict a longer survival in metastatic cancer patients." The study suggest that the positive influence of spiritual faith in patients who were receiving chemotherapy vs those without faith.
Research gaps:	This study was specific to non-small cell lung cancer with metastatic disease.
Main take-away:	The preliminary study suggest that evidence of a high degree of faith as an expression of an active spiritual life was associated with great efficacy of cancer treatment and may predict a longer survival rate. This study was directly focused on lung cancer and could possibly be used for other types of cancer. The study did emphasis the importance faith has and the influencing factors on neoplastic disease. Further

Question Refinement Example

	research will be needed in a greater number of patients to confirm the data.
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Studies that address specific populations of interest:	
Citation:	Achour, Meguellati, Fadila Grine, Mohd Roslan Mohd Nor, and Mohd Yakub Zulkifli MohdYusoff. "Measuring Religiosity and Its Effects on Personal Well-Being: A Case Study of Muslim Female Academicians in Malaysia." <i>Journal of Religion and Health</i> 54, no. 3 (April 27, 2014): 984–97. doi:10.1007/s10943-014-9852-0. (3)
Population studied:	315 Muslim female of academic staff as respondents working in Research Universities.
Methodology:	Data was completed by 450 female academic staff working in Research University in Klang Valley. A total of 315 questionnaires were returned with a response rate of approximately 70%. The ages of the respondents ranged from 30-60 years.
Results/findings:	A positive and significant correlation between personal well-being and religiosity. Well-being shows significant positive correlations with beliefs and worship.
Research gaps:	The article does not address lung cancer impacts/outcomes. The emphasis is primarily on correlation of faith and well-being. Many research projects have been done regarding faith and well-being but more research needs to be done in different religious sectors and correlation of impacts on patients with cancer.
Main take-away:	A positive correlation of faith, prayer and religiosity affecting overall well-being of women in the Muslim faith. If it creates a positive correlation in life overall, would it continue in tragedies of life, cancer diagnosis and other challenges faced in life.
Citation:	Rawdin, Blake, Carrie Evans, and Michael W. Rabow. "The Relationships among Hope, Pain, Psychological Distress, and Spiritual Well-Being in Oncology Outpatients." <i>Journal of Palliative Medicine</i> 16, no. 2 (February 2013): 167. doi:10.1089/jpm.2012.0223. (9)
Population studied:	78 patients who were care in a comprehensive oncology center.
Methodology:	Patients were recruited from a Symptom Management Service (SMS) who were 18 years of age or older who had a diagnosis of cancer.
Results/findings:	95 patients were approached and 78 agreed to participate. The sample consisted of 64% women and 36% men with a mean age of 57.6 years. Levels of hope were not associated with age, gender or the presence of metastatic disease. This study was performed due to the lack of research on the relationship between hope and pain among cancer patients. The findings suggest that hope is related most closely to psychosocial elements of the pain experience, rather than pain intensity. "hope is a key clinical and perhaps therapeutic variable, affecting cancer patients"
Research gaps:	Lack of causal relationships between hope and pain. The limitations were that the study was cross sectional and it would be ideal if there

Question Refinement Example

	was a longitudinal study between causal links between hope, pain, and psycho-spiritual factors.
Main take-away:	The study suggest “that when confronted with a patient who seems to have “lost hope,” the physician should look beyond pain measures and explore psychological adjustment and spiritual concerns.

Studies that address patients with/at risk for lung cancer.	
Citation:	Clay, Kimberly S., Costellia Talley, and Karen B. Young. “EXPLORING SPIRITUAL WELL-BEING AMONG SURVIVORS OF COLORECTAL AND LUNG CANCER.” <i>Journal of Religion & Spirituality in Social Work</i> 29, no. 1 (January 1, 2010): 14–32. doi:10.1080/15426430903479247. (10)
Population studied:	800 survivors was drawn from the Alabama CanCORS cohort, who had a diagnosis of cancer, less than one year post treatment, 18 years or older, able to read and write English, had completed the CanCORS baseline questionnaire.
Methodology:	The survey was mailed to potential participants. Of the 800 surveys, 343 (43%) were completed and returned. Spiritual well-being was measured using an expanded version of the FACIT-SP.
Results/findings:	The purpose of the study was to characterize spiritual well-being in newly-diagnosed survivors of colorectal and lung cancer. The study found that spiritual well-being scores were high across both colorectal and lung cancer survivors. There is some question of defining a lung cancer survivor regarding survivorship as “the period extending from the time of diagnosis throughout the balance of life”
Research gaps:	Limitation included a cross-sectional descriptive, correlation design which only identifies asocial of a specific point in time. The study did not attempt to address or control potential self-selection bias, where differences may exist between those who volunteered and those who refused participation in the study. There are some studies that have been done to link spiritual well-being and breast cancer survivorship, there are no published studies of the examination among colorectal and lung cancer. The lack of adequate and accurate data on colorectal and lung cancer survivors and quality of outcomes must be addressed because of the significant incidence they both account for.
Main take-away:	Future research is needed on survivors of colorectal or lung cancer and spiritual-based therapeutic and lifestyle interventions must be developed to potentially treat or ameliorate the physiologic and psychosocial late effects of cancer in general. The overall finding states a significant need for oncology and social workers to assess spiritual well-being in cancer survivors to strengthen treatment plans, which can change outcomes.
Citation:	
Citation:	Steinhauser, Karen E., Stewart C. Alexander, Ira R. Byock, Linda K. George, Maren K. Olsen, and James A. Tulsky. “Do Preparation and Life Completion Discussions Improve Functioning and Quality of Life in Seriously Ill Patients? Pilot Randomized Control Trial.”

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	<i>Journal of Palliative Medicine</i> 11, no. 9 (November 2008): 1234-40. doi:10.1089/jpm.2008.0078. (11)
Population studied:	82 hospice eligible patients enrolled in the study: 38 were women and 35 were African American.
Methodology:	Baseline measurement assessed pain and symptoms, functional status, anxiety, depression, quality of life at the end of life, and daily spiritual experience.
Results/findings:	Participants in the active discussion showed improvements in functional status, anxiety, depression and preparation for end of life. The study concluded that patient emotional and spiritual well-being were identified as part of two larger domains: end of life preparation and completion.
Research gaps:	50% of the participants were not able to complete the study due to functional decline or death. Sample size was not large enough to show statistical significance.
Main take-away:	A concept model was created and show that patients living with advanced serious illnesses face challenges associated with physical, psychosocial, spiritual, and emotional concerns. Attention to these is required to reduce suffering and increase quality of life.

Studies that address any other special concerns:	
Citation:	Granero-Molina, J., M.m. Díaz Cortés, J. Márquez Membrive, A.m. Castro-Sánchez, O.m. López Entrambasaguas, and C. Fernández-Sola. "Religious Faith in Coping with Terminal Cancer: What Is the Nursing Experience?" <i>European Journal of Cancer Care</i> 23, no. 3 (May 1, 2014): 300-309. doi:10.1111/ecc.12150. (13)
Population studied:	23 nurses who had cared for people with terminal cancer for at least six months.
Methodology:	A qualitative approach. The participants were nurses, Masters in Nursing.
Results/findings:	The statements in the students were that faith in relation to end-of-life was apparent. Traditional faith and religious beliefs continue to be an important aspect in relation to end-of-life. The goal of the study was to understand how significant faith is during the end-of-life process.
Research gaps:	Research shows that faith in coping is essential but is individualized and changeable. "Some studies have found a correlation between faith and finding peace and a meaning to life for cancer patients" The need for a larger review of nurses who were unaware of the study and also include a better selection of nurses who's age ranges will give a better source of information towards the study.
Main take-away:	Knowledge by the nursing staff of knowing how important spirituality is can help to improve the quality of life for individuals with a terminal cancer diagnosis. Three main themes: Faith facilitates the coping process – "faith can help to give meaning to the dying process, giving answer in the search for reason of existence." Faith hinders the coping process – some participants will reflect on divine punishment; therefore hindering the coping process. The

Question Refinement Example

	<p>patients feel they are being punished by God for certain habits or life situations. Guild can cause some spiritual suffering for patients. Terminal illness impacts faith – Terminal illness can affect patients and families differently to include doubting faith, strengthening faith and even abandoning faith. Anger can take over and cause abandonment in their faith and family due to overwhelming feelings of resentment and abandonment from God.</p>
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Part III: Summary of the Literature	
What we know	What we need to know more about
Research on the main question	
<p>There are spiritual tools to assist with measuring spirituality. These tools are also taken with other tools such as FACT-L tools to evaluate quality of life. In conjunction we are able to assess spirituality and increase/decrease of quality of life. This tool is reliable, quick and simply to apply. There are so many measurement tools that it is difficult to address which one is the most affective and accurate.</p>	<p>Little is known about the outcomes specifically regarding lung cancer. How does early/late detection factor into the connection of spirituality and quality of life/outcomes.</p>
<p>Religious coping is effective with reducing depression and that depression was lower among patients whose family members had a better attitude and connection with faith.</p>	<p>What aspects of family members connection with faith directly impacts patients with lung cancer. What attributes to the lowering of depression?</p>
<p>Active religious surrender affects coping with cancer</p>	<p>What coping skills are directly affected? What types of cancer are going to reflect this statement due to the fact that different cancers offer different responses from their patients? Lung cancer is typically found in late stage and the coping mechanism may not be the same as one diagnosed with a cancer that is early and considered non-life threatening.</p>
<p>Higher prayer is associated with higher well being</p>	<p>Does well being differ in patients with different cancer diagnosis? For example, breast vs lung or colon vs lung or bladder vs lung?</p>
Research on outcomes of interest	
<p>Quality of life indicators can be vastly different per individuals. Lung Cancer offers a different set of issues because of the expected high mortality rate; therefore causing individuals to experience fear and apprehension immediately in the initial diagnosis stage.</p>	<p>More research regarding standards that outline quality of life indicators for lung cancer patients. Lung cancer patients present with different barriers that most cancer diagnosis due to breathing issues causing anxiety and stress. Also, lung cancer patients are typically diagnosed at a later stage; therefore creating more anxiety facing the terminal disease and prognosis.</p>

Question Refinement Example

Research on populations of interest	
Cancer in general has been researched in connection with spirituality/quality of life/outcomes	Which populations are most impacted? Are their particular religious sectors that provide more/less quality of life outcomes?
Research on patients with/at risk of lung cancer	
Specific studies for lung cancer are limited. This is due to some studies being incomplete due to lack of interest, length of study,	Does a lung cancer diagnosis fall within the realms of other cancer diagnosis due to the fact that it does have a high mortality rate and also physical complications create more barriers for patients with coping and wellbeing?
Research on any other specific concerns	
Studies on religious coping, religiosity, effects of spirituality, measurement tools (numerous), well-being, end of life with lung cancer.	Are there any particular tools that are more effective when measuring these?
	How can increasing focus on spirituality increase patients to choose care at facilities who provide this service – spirituality, counseling, support groups. (The increase of patients choosing facilities who offer these services may cause facilities to focus on providing these to increase revenue – this could be a winning situation for patients who are in rural areas that are going outside of the area because of perceived “better services”)
	Typically there are differences of how physicians assess spirituality and its importance. Continued education of support of patients from a spiritual aspect to cross over to providers, nursing, social workers and others who are providing caregivers to lung cancer patients.
	How do you measure poor spiritual wellbeing?
	How would clinical investigations on spiritual faith affect the concept and application of these tools affect lung cancer patients wellbeing? If clinical providers acknowledged and accepted spiritual effects on patient outcomes, would they be more willing to adopt these practices in their daily treatment plans.

Part IV: Where are the research gaps? (Fill in where relevant)	
Substantive (e.g., Patient perceptions/knowledge, clinical care, interventions, outcomes (including long term outcomes), comparative effectiveness, communication/education, policy)	Long term studies are typically not available. Many participants are unable to finish studies due to declining health or death.
Methodological (e.g., study design and methods)	Most studies include questionnaires.

Question Refinement Example

<p>Population (e.g., Race, socioeconomic status, health status, geography, age, vulnerable populations, workers)</p>	<p>Available participants that cover a multi-cultural group. Age gaps and inconsistent age gaps. Typically more female participants than male.</p>
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Suggested Re-wording of research questions:
Research Questions :
1. How does faith affect a lung cancer patient's decisions about their clinical care?
2. How does faith affect a lung cancer patients outcomes vs a lung cancer patient without faith?
3. What specific lung cancer outcomes are affected by Faith?
4. Does faith reduce stress and improve survival of lung cancer patients?
Research Questions (after groups feedback)
1. How does faith affect a lung cancer patient's decisions about their clinical care?
2. How does faith affect a lung cancer patients outcomes vs a lung cancer patient without faith?
3. What specific lung cancer outcomes are affected by faith?
4. Does faith reduce stress and improve survival of lung cancer patients?
Final Research Questions (after VCU feedback)
1. How does religious faith affect lung cancer patients' decision making about their treatment options and health care?
2. How do patient lung cancer outcomes differ between people with and without faith?
3. What health and quality of life outcomes are impacted by religious faith among patients with lung cancer, including stress and survivorship?

EXAM

Patient and Stakeholder Developed Research Agenda – Diabetes/Hypertension Management

The **SEED** (Stakeholder Engagement in quEstion Development and prioritization) **Method** is a new stakeholder engagement methodology that combines engagement with a review of available evidence to generate research questions that address current research gaps that are important to patients and other stakeholders.

The first demonstration of the SEED Method took place during 2015 in Richmond, VA in a primarily low-income, urban, African American community. The health topic of focus was diet and behavioral management for diabetes and hypertension.

Stakeholder engagement: The SEED Method allowed stakeholders to participate through three different modes of engagement: collaborative, participatory, and consultative.

Collaborative engagement: This level of engagement consisted of a research team derived from an existing community-university partnership made up of academic faculty, staff, and community residents. The Research Team was engaged throughout the project and were responsible for selecting and recruiting participants, data collection and analysis, and facilitation of Topic group meetings and activities.

Participatory engagement: This level consisted of groups of stakeholders (Topic groups) selected by the research team based on their experience with and knowledge of diet and behavioral challenges in diabetes and hypertension management. Three groups of stakeholders were convened to participate in a series of meetings that resulted in the development and prioritization of research questions. The groups included: 1) seniors with diabetes or hypertension who were overweight or had cardiovascular disease (n=8), 2) adults with diabetes or hypertension with limited health care access or other specific challenges (e.g. history of homelessness or substance use) (n=7), and 3) nurses, health educators, and other local services providers (n=8).

Consultative engagement: To broaden the Topic groups' understanding of the experiences of different stakeholders, this level of engagement consisted of focus groups and one-on-one interviews. Five focus groups were conducted, composed of: African American females, seniors, food pantry clients, Supplemental Nutrition Assistant Program (SNAP) recipients, and people taking medications for diabetes and hypertension. Eleven interviews were conducted with health care workers, service providers, and parents of children with diabetes.

SEED Methodology: The SEED Method followed a six-step process that included 1) identifying the health topic and recruiting participants, 2) conducting focus groups and interviews, 3) developing conceptual models, 4) developing research questions, 5) prioritizing research questions, and 6) creating a dissemination plan and distributing the final research agenda.



Patient and Stakeholder Developed Research Agenda – Diabetes/Hypertension Management

Development of Research Agenda: In total 18 research questions were prioritized by the Topic groups. Each question was researched and finalized by a review team of VCU researchers through a review of the scientific literature. The review explored what parts of each question had already been answered by prior studies and made recommendations to get at issues that remain unanswered empirically. Based on the review conducted for each question, the review team made recommendations to address relevant gaps in the peer reviewed literature. As a final step, research and subject matter experts were consulted on each finalized questions for feedback on the wording of the recommendations and to ensure their relevance to their respective fields of study.

Patient and Stakeholder Developed Research Topics Related to Diet and Behavioral Management for Diabetes and Hypertension (Reprinted with permission from the American Journal of Preventive Medicine)

Risk factors and health behaviors

1. Does a person's **functional capacity** (physical and cognitive) influence their ability to follow their diet?
 - ❖ Among people with diabetes or hypertension, how do functional capacity (physical and cognitive) and geriatric conditions (such as visual impairment, mobility) impact the ability to follow dietary recommendations?
 - ❖ How and why does a person's functional capacity influence their ability to follow the recommended diet for diabetes and hypertension?
 - ❖ What are the long-term diabetes and hypertension-related health outcomes for people with limited functional capacity or geriatric conditions?
2. What is the impact of **drug and alcohol use** on diet compliance?
 - ❖ What are optimal and practical ways to screen for co-morbid substance abuse disorder in patients with diabetes or hypertension?
 - ❖ Can health care providers use information on type and frequency of substance use to inform dietary recommendations?
 - ❖ What is the efficacy and cost-effectiveness of substance abuse screening, brief intervention, and referral to treatment (SBIRT) in improving outcomes for individuals with coexisting substance use disorder and diabetes?
 - ❖ What is the comparative effectiveness of different interventions that integrating SBIRT for alcohol and other drug use problems into diabetes care models?
3. Do **cognitive impairment and dementia** impact self-care behaviors and health outcomes in people with diabetes and hypertension?
 - ❖ At what levels and domains of cognitive impairment are patients most likely to become at risk of non-adherence to diabetes self-care management?

Patient and Stakeholder Developed Research Agenda – Diabetes/Hypertension Management

- ❖ What are the healthcare needs and goals of patients with cognitive impairment and diabetes and what are the needs of their caregivers? How are these different from the needs of patients without cognitive impairment?
- ❖ What are the most effective strategies for successfully managing both cognitive impairment and diabetes?

4. Does not having enough **sleep** affect diet for people with diabetes and hypertension, and how do specific sleep patterns affect diet?

- ❖ What are the current levels of patients' knowledge, perceptions and understanding of the relationship between sleep and health outcomes related to diabetes and hypertension?
- ❖ Are health care providers regularly and effectively communicating with patients about the impact of sleep duration on weight, glucose control, diabetes risk and hypertension?
- ❖ Which interventions can improve sleep duration among patients with diabetes or hypertension? What is the effectiveness among at risk populations, including African Americans, shift workers, younger, and low-income groups?
- ❖ What communication strategies or tools can improve patient-centered information about the risk of insomnia and changes in sleep patterns related to anti-hypertensive agents and other drugs for hypertension or diabetes?

Health care communication/knowledge and perceptions

5. What strategies are available to identify and enhance patients' **sense of control** related to following the recommended diet?

- ❖ What is the comparative effectiveness of interventions for increasing patients' empowerment and improving dietary compliance over time? (Strategies include empowerment-based diabetes self-management education programs; web-based tools and social media)
- ❖ How can interventions for empowering patients be incorporated into different clinical settings?

6. If mental health patients were given **nutrition guidelines and information**, would it affect overall health?

- ❖ What strategies and interventions are most effective in improving the diet and nutrition of people with severe mental illnesses, particularly those who continue to have uncontrolled diabetes or hypertension?
- ❖ What strategies and interventions are most effective in improving the diet and nutrition for elderly patients with severe mental illnesses?
- ❖ Which health professionals or service providers are best able to assist patients with severe mental illness, especially those navigating multiple systems and medication routines?

7. Will controlling diabetes and hypertension **prevent other diseases** or more serious illness?

- ❖ What are the most effective strategies for communicating risk of complications to patients with diabetes or hypertension?

Patient and Stakeholder Developed Research Agenda – Diabetes/Hypertension Management

- ❖ What are the most effective strategies for communicating risk information among special populations, such as patients with low health literacy, low income, and elderly patients and are they being used in care settings?
- ❖ How do patients' understanding of risk information and related health beliefs predict clinical outcomes and development of complications?
- ❖ What is the effect of diabetes combined self-management education and training (DSME/T) on clinical outcomes and development of complications?

8. How does **knowing about your diet and risks** help with understanding diabetes?

- ❖ What are the strongest influences on patient perception (knowledge, understanding, attitudes) of diabetes, and what are the best practices for altering perceptions that prevent effective disease management?
- ❖ What are the most effective strategies for integrating nutrition education into regular diabetes care administered by health professionals to improve diet?
- ❖ How does patient perception of diabetes differ by age and health literacy?

9. How could provider/patient communication about the **science of nutrition and exercise** be simplified and made more interactive?

- ❖ How can nutrition and physical activity counseling in primary care be improved and made more understandable for patients?
- ❖ What strategies and messages are being utilized during a primary care visit or over a course of visits? How can messages be tailored to the health literacy, cultural context, and motivation of individual patients?
- ❖ What is the comparative effectiveness of different nutrition counseling strategies in patient uptake and outcomes? What about physical activity counseling?
- ❖ What are effective strategies for combining primary-care based counseling with follow up interventions and access to information (e.g., telephone, web and text-based delivery) and getting those services reimbursed?

Health care delivery and quality

10. Will having a **regular doctor** improve diabetes and hypertension self-management?

- ❖ What factors affect the relationship between having a regular doctor and patient-centered health outcomes among patients with diabetes and hypertension? What is the role of race/ethnicity, mental health conditions, and low socioeconomic status?
- ❖ What are the most effective strategies for arranging a regular doctor for patients with diabetes/hypertension, including patients with mental health challenges, with a regular care provider or medical home?

11. How are healthcare quality and **trust in one's doctor** related, and how does that impact diabetes and hypertension management?

Patient and Stakeholder Developed Research Agenda – Diabetes/Hypertension Management

- ❖ How does continuity of care impact patient trust in patients with diabetes/hypertension who are uninsured or have limited access to care? What are the best strategies for increasing continuity of care in this population?
- ❖ What aspects of care continuity predict patient trust and improved health outcomes?
- ❖ What are the most effective interventions for increasing patient trust, especially among vulnerable populations?

12. Would communicating with your primary care provider for **longer periods of time** during a given visit lead to better prioritizing and self-management behavior for diabetes and hypertension?

- ❖ How does the length of consultation with primary care physicians impact self-management behaviors and clinical outcomes in patients with diabetes and hypertension? Does an increase in appointment length lead to improved clinical outcomes and patient self-management behaviors?

Health economics

13. How does the inability to pay an **insurance co-payment** affect your health care?

- ❖ How does cost sharing affect health care utilization for patients with diabetes or hypertension who have low- and very low incomes, including those who are food insecure?
- ❖ Among people with diabetes or hypertension, what types of health care services are reduced as a result of cost sharing?
- ❖ How do long-term health outcomes of people with diabetes or hypertension differ with cost sharing versus those not subject to cost sharing?
- ❖ What is the impact on health care utilization and health outcomes of programs that reduce or cap cost sharing among vulnerable low-income groups? What is the impact by race/ethnicity?
- ❖ How do co-payments affect health care utilization decisions, including patient perceptions, knowledge, preferences, strategies and the impact of competing needs? How do patients describe the impact of co-payments on these decisions and strategies?

Policy

14. How is the amount of **Supplemental Nutrition Assistance Program (SNAP) benefits** determined for those who qualify and how does that match up with need?

- ❖ How can SNAP qualifications and benefit levels be adjusted to reflect the needs of individuals with chronic, diet-sensitive conditions?
- ❖ How can the SNAP program work with individuals with diet-sensitive conditions to improve diet quality and diabetes self-management?
- ❖ What is the risk, based on longitudinal data, for negative health outcomes among food insecure individuals with (or at risk of) diabetes or hypertension? What role do SNAP benefits play in mitigating negative outcomes?

15. How could we encourage communities to focus on **economic development** in high risk areas to have the highest impact on dietary compliance?

Patient and Stakeholder Developed Research Agenda – Diabetes/Hypertension Management

- ❖ What is the impact of local food initiatives (urban agriculture, community supported agriculture (CSA's), farmers markets, community gardens, farm to school/institution) on local economies, jobs, income supplementation, workforce integration, and social capital development?
- ❖ Do local food initiatives improve food security, diet quality and long-term health outcomes of individuals with diabetes or hypertension?
- ❖ How effective are incentive programs such as farmers market vouchers and other interventions (e.g., food demonstrations and educational initiatives) at increasing the impact of local food initiatives on diet quality for individuals with diabetes or hypertension in low-income or food insecure households?

Physical and social environment

16. What role does **food** play in one's family and upbringing, and how does that affect individuals' relationship with food as adults?

- ❖ What culturally-sensitive strategies are effective in changing social norms around eating and in achieving long-term behavior change and healthy eating?
- ❖ Can programs that adapt culturally preferred foods into healthy eating plans affect diet compliance for people with diabetes or hypertension?
- ❖ Is healthy eating affected more by personal preferences and social norms or by the availability of household/community resources on healthy eating? How does knowledge of healthy eating mediate those relationships?

17. How does the local **environment**, such as access to stores, affect the diet of people with diabetes or hypertension?

- ❖ For those with diet-restricting conditions (ex. hypertension and diabetes), what role does the food environment play in individual's ability to adhere to diet? How do individuals adapt to or navigate their existing food environment to meet their dietary needs or goals?
- ❖ How can small food retailers and others in adverse food environments be better engaged to carry and promote healthier food options?
- ❖ What role can community organizations and businesses play in promoting healthier food choices or change in the local food environment?

18. How does lack of **transportation** affect the likelihood of seeking medical treatment, resources, and services among individuals with diabetes and hypertension?

- ❖ What interventions by communities, health service providers, and health systems to reduce transportation barriers positively impact service usage those living with chronic conditions?
- ❖ Are telemedicine and internet enabled home-based care viable (in terms of cost, feasibility, and effectiveness) alternatives to regular outpatient diabetes or hypertensive care among those who lack transportation?
- ❖ For patients with chronic diseases, how do transportation barriers vary across urban, suburban, or rural areas?
- ❖ Do transportation-only interventions improve treatment compliance among patients with multiple challenges or needs?

Appendix – Full list of Toolkit files available for download

Those interested in using the SEED Method Toolkit can download individual files or a zip file containing all items (listed below) at go.vcu.edu/SEED

SEED Method

- SEED Method Brochure
- Introduction to SEED Method and Toolkit
- Community Research Team - Introduction/instructions
- Community Research Team – Templates
 - Timeline (excel)
 - Trainings (all): Focus Group facilitation, Conducting Key Informant Interview, and Notetaking (ppt)
 - Meeting materials:
 - Research team project overview, Research team agenda items, Research team meeting agenda template
 - Research Team kickoff presentation template, Roadmap template
 - Research Team activities:
 - Informational interview script template, Informational interview sign-up sheet, Stakeholder matrix facilitation guide template, Topic group planning templates
 - Stakeholder Matrices - Matrix 1, 2, 3 templates (excel)
- Community Research Team - Examples
 - SEED one page summary, Timeline example, Research Team kickoff presentation example, Topic group planning examples, Stakeholder Matrix 3 example, Selected meeting agendas and materials (including: Health demographics handout, Diabetes/hypertension information sheet, and Local health resources handout)
- Topic Group Introduction/instructions
- Topic Group – Templates
 - Meeting Materials:
 - Stakeholder participant overview, List of agenda items, Topic group full schedule template, Topic group meeting agenda template
 - Topic Group Facilitated Activities:
 - Topic Group Facilitation Scripts
 - Facilitated activity objectives
 - Facilitated Activity Script – Conceptual Model Training
 - Facilitated Activity #1 Script – Building Conceptual Models
 - i. Brainstorming factors worksheet
 - ii. Domain worksheet
 - Facilitated Activity #2 Script – Creating Research Questions
 - i. Conceptual models – unique and similar factors Worksheet
 - ii. Writing research questions document
 - Facilitated Activity #3 Script – Prioritizing Research Questions

- Facilitated activity powerpoint presentations, including:
 - Conceptual model training presentation
 - Facilitated activity #1 presentation
 - Facilitated activity #2 presentation
 - Creating research questions training presentation
 - Facilitated Activity #3 presentation
- Topic Group Examples
 - Topic group recruitment flyer, Topic group meeting schedule example, Topic group example meeting agendas and materials, including Kickoff presentation example, Facilitation questions for discussing focus group and key informant interview findings
- SCAN Introduction/instructions
- SCAN – Templates
 - Focus group cover sheet template, focus group guide template, key informant interview cover sheet template, key informant interview guide template
- SCAN – Examples
 - Focus group guide example, key informant interview guide example, focus group recruitment flyer example
- Literature Review Introduction/instructions – Guide for SEED Method Step 6
- Literature Review – Templates
 - Question refinement template, Question summary template, Final refined research questions template, Literature review tracking template
- Literature Review – Examples
 - Question refinement example, Question summary example, Final refined research questions example, Research agenda example

Evaluation Module

- Introduction/instructions
- Evaluation matrix and constructs
- Instruments and Questionnaires
 - SEED ID document
 - Group Readiness questionnaire
 - Group Dynamics questionnaires – Research Team, Group Dynamics questionnaires – Topic Groups
 - Training Satisfaction questionnaire
 - Stakeholder Matrix document, Stakeholder Matrix QQ – Administrative Team, Stakeholder Matrix QQ – Research Team
 - Observation logs – Topic group facilitated activities: Conceptual model training observation log, Facilitated Activity #1 observation log, Facilitated Activity #2 observation log, Facilitated Activity #3 observation log
 - Activity log – Topic group facilitated activities: Conceptual model training activity log, Facilitated Activity #1 activity log, Facilitated Activity #2 activity log, Facilitated Activity #3 activity log
 - Facilitated Activity Satisfaction questionnaire

- Personal information questionnaire
- After Action Review guide
- End of project interview guide
- Research Agenda Evaluation questionnaire
- Conference Evaluation questionnaire
- Meeting notes template
- Example – Observation log example