Worksheet 3. Planning Engagement Activities

This worksheet takes you through four queries. At the conclusion of this worksheet, consider writing a one paragraph summary of your responses. This summary may suffice to address the engagement requirements of a variety of funders.

Query 1: What is the rationale for engaging with stakeholders?

Query 2: Who are your partners (from Worksheet 1)?

Query 3: How extensively will stakeholders be involved (from Worksheet 2)?

Query 4: What are the appropriate roles by which stakeholders may be engaged in your research?

Query 1: What is the rationale for engaging with stakeholders?

Pre-specifying the rationale – or desired outcomes – of engagement is a critical factor in developing an engagement plan. By establishing the desired outcomes in advance, the study team can later evaluate the extent to which expectations have been met. This section points at ways to characterize the expected value of stakeholder engagement.

To articulate the rationale for engagement, the team might consider both its intrinsic and instrumental imperatives.

- Intrinsic imperatives suggest that engagement is an end in itself. In other words, involving stakeholders may simply be the right thing to do, especially if public dollars are used. The principles of engagement call researchers and stakeholders to pursue intrinsic goods like autonomy, dignity, equity, inclusiveness, partnership, and participation; in contrast, superficial involvement can be insulting to stakeholders.
- Instrumental imperatives suggest that engagement produces some other good worth having. For instance, involving stakeholders may make study questions more relevant, methods and approaches more transparent, findings more useful, and evidence more likely to be used in practice. If researchers wish our work to have detectable impact on health-related decisions, we should involve decision makers as we carry the work out.

<u>To complete this section, answer the following questions:</u>

1. What are the intrinsic reasons for engaging with stakeholders
2. What are the instrumental reasons?
    a. How might the engagements improve the quality of your research? Consider how the research questions may become more relevant to decision-makers. Consider how the work you do in carrying out the research may become more

    understandable to decision-makers. Consider whether and how engagement might improve the uptake, use, and evaluation of the evidence you produce.
   b. How might the engagements improve the quality or efficiency of health care?
   c. How might the engagements improve patient or public health?

3. Summarize your response in a few sentences.

Query 2: Who are your partners (Worksheet I)?

Previous frameworks have sought to help researchers identify stakeholders in their work. Concannon *et al* identified seven types of stakeholders in the Tufts-RAND 7Ps taxonomy for engagement; Deverka *et al* identified eight types in the Center for Medical Technology Policy framework for engagement; PCORI identified nine types in its engagement "rubric". Cochrane identified four audiences in its recent knowledge translation strategy. Tugwell *et al* named six types in a WHO Bulletin on knowledge translation for systematic reviews. By putting the first three of these models in a single table (see next page), it is possible to see that differences in the *number of* stakeholder types are largely a matter of classification, not a disagreement about who should be included. At least two of the approaches were developed and published simultaneously, suggesting independent agreement about which stakeholders are key to improving health research.

Each of these frameworks recognizes that identifying the right individuals to represent stakeholder perspectives is a challenge, as stakeholders within a single group may hold different views. Choosing a multi-stakeholder approach is even more complex given the need to consider how to assure that under-represented voices are heard, to ensure that the financial or academic interests of one group don't dominate the discussion, to manage group interactions and potential power imbalances, and to synthesize the views of different groups. It is important to be transparent about who was involved and why.

<u>To complete this section, answer the following questions:</u>

1. What model will you use to identify stakeholders?
2. What is the research for?
   a. Which communities make decisions the research is meant to inform?
   b. Which communities are affected by decisions the research is meant to inform?
3. How do the communities wish to be engaged? Any insight you have on the preferences, concerns, and resources of different stakeholders groups will be helpful.
4. Summarize your response in a few sentences.

7Ps Model[1]		PCORI Model[2]		CMPT Model[3]	
Type	**Description**	**Type**	**Description**	**Type**	**Description**
Patients and the Public	Current and potential consumers of patient-centered health care and population-focused public health, their caregivers, families and patient and consumer advocacy organizations.	Patients	Persons with current or past experience of illness or injury, family members or other unpaid caregivers of patients, or members of advocacy organizations that represent patients or caregivers	Patients and Consumers	Persons or organizations that represent the patient or consumer perspective generally, or within specific disease states, such as individuals with particular conditions, caregivers, patient advocates and advocacy organizations
Providers	Individuals (e.g. nurses, physicians, mental health counselors, pharmacists, and other providers of care and support services) and organizations (e.g. hospitals, clinics, community health centers, community based organizations, pharmacies, EMS agencies, skilled nursing facilities, schools) that provide care to patients and populations.	Clinicians	Providers of health care in a clinical setting, including physicians, nurses, physician assistants, rehabilitative professionals, pharmacists, mental healthcare providers, complementary and alternative healthcare providers, and professional societies serving clinicians	Clinicians	Individuals who provide healthcare services, such as physicians, nurses, pharmacists, nurse practitioners, physician assistants and mental health providers
		Hospitals and Health Systems	Organizations where care is delivered, including public and private hospitals and health systems, urgent care centers, retail health clinics, and community health centers, and organizations representing these facilities	Healthcare providers	Institutions that deliver healthcare services, such as hospitals, nursing homes, outpatient clinics, clinical laboratories and accountable healthcare organizations
Payers	Insurers, Medicare and Medicaid, state insurance exchanges, individuals with deductibles, and others responsible for reimbursement for interventions and episodes of care.	Payers	Those who function as financial intermediaries in the health system, including private insurers and public insurers, and organizations representing insurers, such as America's Health Insurance Plans	Payers and purchasers	Organizations that pay for healthcare goods and services, such as public and private insurers, health plans and employers
Purchasers	Employers, the self-insured, government and other entities responsible for underwriting the costs of health care.	Purchasers	Those who purchase health benefits for employees and their dependents, including individual businesses as well as local, state, regional, and national business groups, coalitions that represent businesses, and health coalitions		
Product Makers	Drug and device manufacturers	Industry	Companies that design, invest in, or manufacture diagnostics, devices, pharmaceuticals, electronic records systems, and mobile apps, and organizations representing the life sciences industry, such as the Advanced Medical Technologies Association	Life sciences industry	Entities that develop and market medical technologies, such as pharmaceutical, medical device, diagnostic, biotechnology companies and organizations that represent life science company interests
Policy Makers	The White House, Department of Health and Human Services, Congress, states, professional associations, intermediaries, and other policy-making entities.	Policy Makers	Those who help craft public policy at any level of government, including federal, state, and local government officials; federal, state, and local units of government; and organizations that represent policy makers	Policy-makers and regulators	Individuals and organizations that create, monitor and oversee policies or regulations of healthcare-related issues, such as federal, state and local government agencies, medical and professional organizations and clinical guideline developers
Groups described in PCORI's definition of Training Institutions are distributed in 3Ps: Principal Investigators, Providers and Policy Makers		Training Institutions	Those that deliver health professional education include public and private universities and colleges, individuals affiliated with the delivery or administration of health professional education, and trade or professional associations representing these institutions, organizations, and individuals	Groups described in PCORI's definition of Training Institutions are distributed in 3 CMTP types: researchers, policy makers and regulators, and healthcare providers	
Principal Investigators	Other researchers and their funders	Researchers	Those who conduct clinical research, including investigators or funders of research and organizations or associations representing the research community	Researchers	Individuals and their related organizations that develop scientific and clinical evidence, such as clinical researchers, health services researchers, social scientists and basic scientists
				Research Funders	Entities that provide monetary support for research efforts, such as government, foundations and for-profit organizations

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[1] Concannon TW, Meissner P, Grunbaum JA, McElwee N, Guise JM, Santa J, Conway PH, Daudelin D, Morrato EH, Leslie LK. A new taxonomy for stakeholder engagement in patient centered outcomes research. Journal of General Internal Medicine, 2012 Aug; 27 (8):985-991. PMCID: PMC3403141.

[2] PCORI's Stakeholders, http://www.pcori.org/funding-opportunities/what-we-mean-engagement/pcoris-stakeholders. Accessed February 2017.

[3] Deverka PA, Lavallee D, Desai PJ, Tunis SR. Journal of Comparative Effectiveness Research, 2012 Mar; 1(2):181-194.

Query 3: How extensively will stakeholders be involved (Worksheet II)?

Researchers might consider how extensive the engagement of stakeholders should be. Some partner with stakeholders as co-investigators, sharing full control over the direction, management, and budget of a study. Others may arrange for stakeholder involvement at the level of technical advice. Thus, stakeholders may be empowered with differing levels of control over a study, from providing direction, to collaborating, consulting, and providing information. It is possible, however, to mix approaches over the course of one or more studies and across different stakeholder groups.

<u>To complete this section, answer the following questions:</u>

1. How extensively will stakeholders be engaged
    - in preparing for the research project?
    - in conducting the research project?
    - in using the research project?
2. How intensively can stakeholders be involved in each activity?
3. What resources and time will be devoted to engagement activities?
4. Summarize your responses in a few sentences.

Query 4: What are the appropriate roles and modes by which stakeholders may be engaged in your research?

All study teams—even those in basic and clinical sciences—have experience working with independent peers who review study protocols and manuscripts. This is a form of stakeholder engagement, in which external researchers with an interest in safeguarding the ethical conduct and rigor of research use commonly held standards to review the proposed or completed work.

Engagement with non-research stakeholders is similar. This might involve assembling a panel of individuals who have an interest in the outcomes of the research and can potentially use it to support decisions. Expert panels can review documents, run practice tests of survey instruments, vote on the relevance or importance of evidence for decisions they make, or work together to identify the implications of study results for their communities. They can develop study inclusion criteria, discuss and revise study protocols and materials, and identify outcomes that are most important to them.

Distinct from the roles stakeholders play are the modes of interaction. While roles refer to the activities of stakeholders as they become involved in the work, modes have to do with the format and structure of interactions between researchers and stakeholders. Working from the most intensive styles of engagement to the least intensive:

- routine communication channels and interaction opportunities of the research workplace, such as in-person meetings, chance meetings, telephone calls, e-mails, and web-enabled communications.
- specialized communications in person, by telephone, by e-mail, or over the web.
- group communications such as town meetings, or group discussions, and these can also be held in-person or virtually
- public comment periods for research prioritizations or plans, and comments may be collected in writing, electronically, or by telephone.

To complete this section, carry out the following steps:

1. Fill out the matrix on the next page to summarize a stakeholder engagement approach for your research program or study. The rows describe stages and illustrative activities in a research project (add activities we haven't thought of). The columns describe stakeholder groups. Please note:
    - It is not necessary to fill in every cell. Choose cells where engagement can improve the relevance, transparency, and usefulness of the research.
    - In many cases, the roles and modes of involvement will be identical for stakeholders representing different communities.
2. Summarize the activities and stakeholders in a written paragraph.

Research Stage	Research Activity	Stakeholder Group						
		Patients & the public	Providers	Payers	Purchasers	Product Makers	Policy Makers	Principal Investigators
Preparing for research	Building research capacity of patients and other stakeholders							
	Training researchers to work with stakeholders							
	Prioritizing evidence gaps							
	Choosing research topics							
Conducting research	Defining the research question							
	Choosing relevant outcomes							
	Designing a research protocol							
	Defining participant inclusion & exclusion criteria							
	Drafting or revising study materials & protocols							
	Recruiting participants							
	Monitoring patient data and safety							
	Collecting data							
	Analyzing data							
	Identifying findings							
	Interpreting findings							
	Disseminating results							
Using research	Implementing evidence in practice							
	Evaluating research							
	Evaluating engagement							
	Identifying topics for future research							