PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

PCORI Evaluation Framework 3.0

Evaluation Framework

Background on Framework

The purpose of the PCORI Evaluation Framework is to capture all of the questions that our stakeholders and we at PCORI have about our work and about PCOR in general and convey how we plan to answer those questions.

Initially, our focus for the PCORI Evaluation Framework was on making sure that we understood and captured everyone's *questions* about PCORI's approach and its impact on Comparative Effectiveness Research (CER), on attainment of our strategic goals, and ultimately on health decisions, health care, and health outcomes.

In this revised version, we re-organized our Evaluation Framework and laid out how we are (or will soon be) *answering the questions* about PCORI. For each question, we specify what we will measure to answer the question (metrics), how we will use that data (methods), and where we will find the information we need (sources).

Each section comes with a figure that depicts our theory about how our approach is supposed to work (If we do A, it will result in B), followed by a table that outlines the questions about that theory (Is A resulting in B?). It is not necessary to understand the figures in order to understand the questions in the tables. We anticipate a wide variety of readers for this document, and the figures are provided for those who find this kind of display of information helpful.

The first section of the framework covers the "Overall Impact of PCORI." The subsequent sections "zoom in" on six key ingredients in the PCORI recipe (zooming in is represented with a red circle on a key ingredient, followed by a more detailed model of the circled section). The detailed theory underlying how each ingredient contributes to PCORI's success is indicated with dashed arrows in the figure, and the evaluation questions these dashed arrows represent are detailed in the corresponding table.

We recognize that this framework is lengthy and packed full of information. That's simply a reflection of our attempt to capture how we will answer all of the questions our stakeholders have about our work. We're striving to keep the evaluation framework as straightforward and understandable as possible, and we welcome your continued review, comments, and thoughts on how to best do that. Please feel free to tackle the entire draft or focus on one or two sections that interest you the most.

What is the overall impact of PCORI?

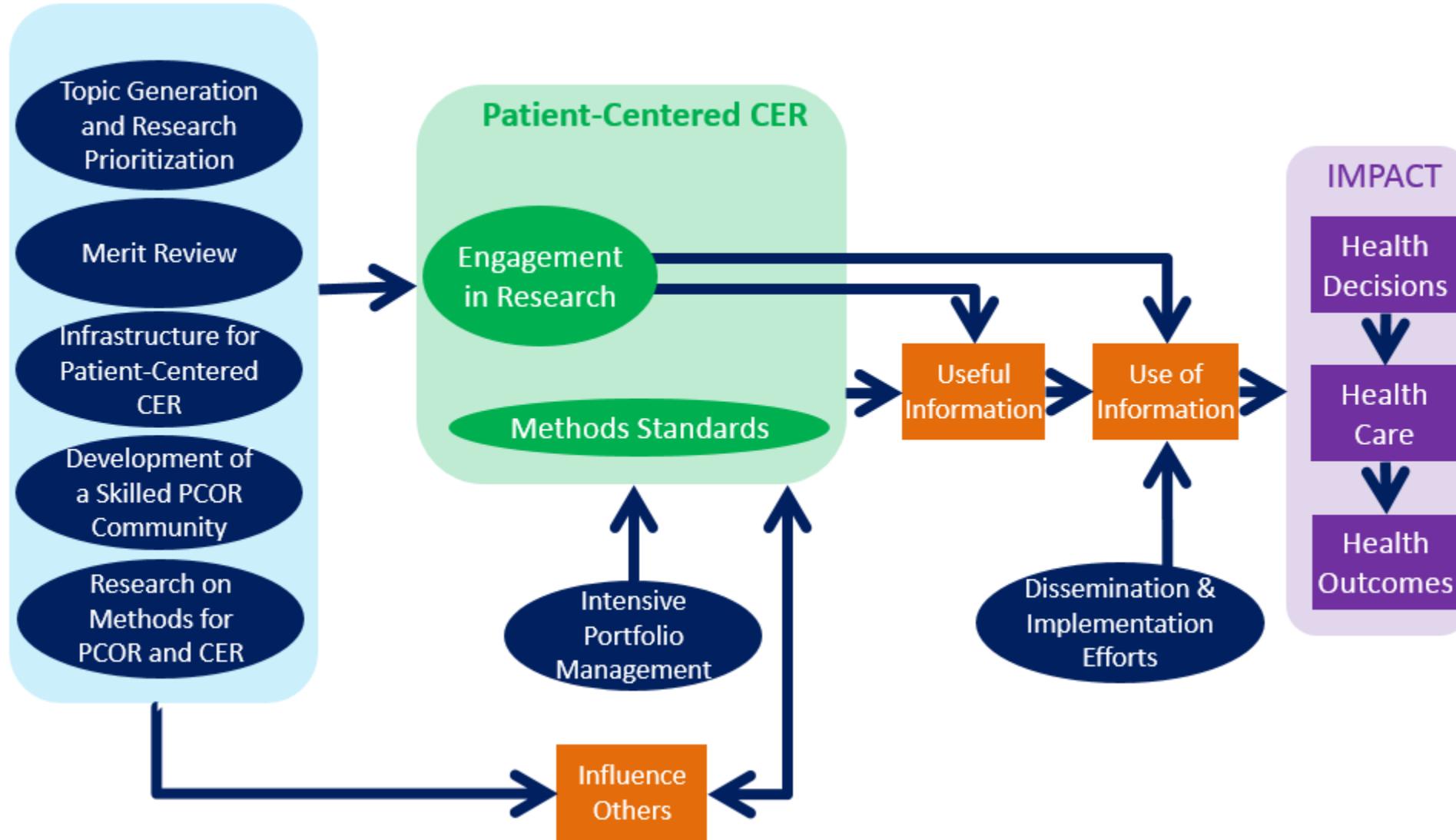## Figure 1. Model for Evaluating the Overall Impact of PCORI

Table 1. Evaluation Questions for the Overall Impact of PCORI

Question	Metrics/indicators	Methods	Sources
1.1 Does the creation of a dedicated entity (PCORI) and funding stream (PCORTF) result in:			
a. *increased total funding for CER,*	• total dollars spent on CER • proportion of dollars spent on CER by PCORI • proportion of CER by other funders	• comparisons over time of funding data sources	• publicly and possibly privately (i.e. pharma funding for CER) available funding information

b. *increased availability of CER data for research,*	• amount of data available
	• accessibility of data
		• comparisons over time of:
		  o peer-reviewed literature,
		  o registries, and
		  o study-databases
		    o PCORI administrative data
		    o PCORnet data
			• peer-reviewed and gray biomedical literature and registries like: clinicaltrials.gov, HSRProj, etc.
			• Available data sets from completed studies
			•

c. *increased number of CER studies,*	• number of manuscripts based on CER
	• number of CER studies in clinicaltrials.gov, HSRProj, and other registries
		• comparisons over time of:
		  o peer-reviewed literature,
		  o registries, and
		  o study-databases
		• PCORI administrative data
			• peer-reviewed and gray biomedical literature and registries like: clinicaltrials.gov, HSRProj, etc.

d. *increased availability of CE information for decision-makers,*	• amount of CE findings and products, such as decision-making aids and tools	• comparisons over time based on:
		  o literature,
		  o registries,
		  o study-databases,
		  o Surveys, and
		  o focus groups and structured interviews with stakeholder communities
			• peer-reviewed and gray biomedical literature and registries like: clinicaltrials.gov, HSRProj
			• surveys, focus-groups, and structured interviews with stakeholder communities

Question	Metrics/indicators	Methods	Sources
e. higher quality of CER, and	• adherence to the PCORI Methodology Standards • adherence to other widely agreed upon standards	• comparisons over time (before and after PCORI Methodology Standards) of CER studies on quality indicators • comparisons over time (before and after PCORI Methods Studies) of CER studies on quality indicators	• peer-reviewed and gray biomedical literature and registries like: clinicaltrials.gov, HSRProj, etc. • IPR data • Research reports • PCORI administrative data
f. higher Impact of CER?	• degree of impact of CER on health decisions, quality of health care, and health outcomes	• comparisons over time (before and after PCORI) of a variety of health indicators for selected CER topics	• health system databases and other databases and registries as relevant to the selected CER topic
1.2 How does information resulting from PCORI's approach to CER (patient-centered CER) compare with that from others in terms of:			
Core Measures **a. the usefulness of information,**	• end-user assessment of usefulness • extent of use (see the metrics/ indicators for 1.2.b. "use of information" below)	• focus groups and structured interviews with stakeholder communities • case studies of sub-portfolios with the relevant end-user community – expert ratings	• dissemination activities with stakeholder communities • roundtables & workshops
b. uptake and use of information,	• for all PCORI Studies: o whether results are reported back to study participants	• focus groups and structured interviews with stakeholder communities	• stakeholder communities • peer-reviewed and gray biomedical literature and registries like: clinicaltrials.gov, HSRproj

Question	Metrics/indicators	Methods	Sources
	o access to PCORI study report	• comparisons over time of:	• PCORI interim progress reports
	o presentations: ▪ scientific/professional audiences ▪ lay audiences	o peer-reviewed literature, o registries, and o study-databases	
	o bibliometrics: ▪ number of publications ▪ time to publication ▪ impact factor ▪ citations		
	o alternative metrics for key groups: ▪ number of manuscript downloads ▪ number of manuscript bookmarks ▪ media coverage ▪ social media coverage		
	• for a subset of PCORI studies: o adoption of study findings into the study setting		
	o incorporation into: ▪ systematic reviews ▪ patient and consumer education materials ▪ graduate medical education or continuing medical education ▪ practice guidelines ▪ decision making infrastructure ▪ payer policies ▪ institutional, local, state, and national policy		
	• speed of uptake		

Question	Metrics/indicators	Methods	Sources
c. *cost of research, and*	• total costs (including dollars, person-time, etc.) of PCORI studies including direct costs, indirect costs and administrative oversight • costs per dissemination product (publication, other communications, etc.) • cost for PCORI to fund studies	• comparisons of cost for PCORI-funded research with that of other funders	• PCORI administrative data • publicly and possibly privately (i.e. pharma funding for CER) available funding information • Altmetrics

d. *higher impact of CER:*
• *better informed health decisions,*
• *better health care, and*
• *better health outcomes?*
	• decisional quality
	• information density
	• usability
	• for a small set of exemplar studies, changes in:
	  o health decisions:
	    ▪ information available to support decisions
	    ▪ shared decision-making
	    ▪ decision quality
	  o health care:
	    ▪ quality of care
	    ▪ practice patterns
	    ▪ practice variation
	    ▪ disparities in care
	  o health outcomes:
	    ▪ functional status
	    ▪ morbidity
	    ▪ health-related quality of life
	    ▪ mortality
		• comparisons over time (before and after PCORI studies) of a variety of health indicators for a subset of PCORI studies	• depending on the subset of PCORI studies, the sources may include: population indicators of health, claims databases, etc.

1.3 What is the impact of PCORI's work			
a. *among a variety of key stakeholder*	• attitudes towards CER among key stakeholder groups	• focus groups and structured interviews with stakeholder communities	• stakeholder communities • surveys: o PCORI Stakeholder surveys

Question	Metrics/indicators	Methods	Sources
groups (patients, clinicians, researchers, payers, caregivers, policy makers, etc.)?	• use of CER in health decisions among key stakeholder groups (difficult because CER isn't the only piece of information used in decision making) • attitudes towards engagement of patients and other stakeholders in CER among key stakeholder groups • practices in engagement among key stakeholder groups	• surveys of stakeholder communities	o national association of state health policy makers (NASHP) o primary care clinician professional associations o health information national trends survey (HINTS) • Knowledge Awards funded through the Eugene Washington Engagement Award Program
1.4 How does PCORI's work influence others, including:			

a. *adoption of CER and PCOR concepts,*	• use of CER and PCOR terminology in:
	  o funding announcements
	  o publications
	  o abstracts
	  o blogs
	  o workshops
	• endorsement, promotion, and dissemination of PCORI work
		• tracking over time	• peer-reviewed and gray biomedical literature and registries like: clinicaltrials.gov, HSRproj, etc.

b. *use of PCORI guidance regarding patient-centered CER,*	• number of publications, scientific presentations, webinars by PCORI to provide guidance on Patient-Centered CER • bibliometric indicators of use of PCORI guidance • endorsement, promotion, and dissemination of PCORI work by others	• tracking over time • outreach to other funders and organizations	• peer-reviewed and gray biomedical literature and registries like: clinicaltrials.gov, HSRProj, etc. • publicly and possibly privately available funding information

Question	Metrics/indicators	Methods	Sources

c. use of PCORI stakeholder-engaged approaches to research topic generation and prioritization, merit review, and peer review,	• other funders use of the following criteria in proposal review:
	  o patient-centeredness
	  o engagement in research
	  o potential speed of uptake of findings in clinical practice
	• use of non-scientists in proposal review
	• use of non-scientists in communication and dissemination of research results
	• endorsement, promotion, and dissemination of PCORI work
		• review of procedures of other funding agencies
		• outreach to other funders regarding changes in review processes and factors influencing change
			• publicly and possibly privately available funding information

d. use of PCORI-supported curricula or training,	• number and nature of training or curricula developed or funded by PCORI • use of training or curricula developed or funded by PCORI (attendance, use, downloads, etc.) • endorsement, promotion, and dissemination of PCORI work	• tracking over time	• PCORI administrative data • publicly and possibly privately available training or curricula databases
e. collaborations/ co-funding with other funders,	• number and nature of projects co-funded by PCORI and others • amount of funding and resources involved in collaborations	• count projects, events, and other initiatives co-funded by PCORI and other agencies	• PCORI administrative data
f. use and support of PCORnet for the conduct of CER,	• number and proportion of studies conducted using PCORnet by investigators external to PCORnet • number and proportion of studies conducted using PCORnet funded by groups other than PCORI • amount of non-PCORI funding for studies using PCORnet • endorsement, promotion, and dissemination of PCORnet by others	• tracking over time	• PCORnet administrative data • peer-reviewed and gray biomedical literature and registries like: clinicaltrials.gov, HSRProj, etc. • Patient-Centered Research Foundation (PCRF)

Question	Metrics/indicators	Methods	Sources
g. *use of PCORI Methodology Standards,*	• use of PCORI methodology standards on patient-centeredness in non-PCORI research • endorsement, promotion, and dissemination of PCORI work	• tracking over time • survey	• peer-reviewed and gray biomedical literature and registries like: clinicaltrials.gov, HSRProj, etc. • PCORI CER researcher survey
h. *use of PCORI methods research,*	• # of publications, scientific presentations, webinars by PCORI funded methods projects • bibliometric indicators of use of PCORI funded methods projects • endorsement, promotion, and dissemination of PCORI work • # and nature of curricula and training materials incorporating PCORI methods evidence	• tracking over time	• peer-reviewed and gray biomedical literature and registries like: clinicaltrials.gov, HSRProj, etc. • PCORI administrative data
i. *use of PCORI evaluation work,*	• number of publications, scientific presentations, webinars on PCORI evaluation work • bibliometric indicators of use of PCORI evaluation work • endorsement, promotion, and dissemination of PCORI evaluation work	• tracking over time	• peer-reviewed and gray biomedical literature and registries like: clinicaltrials.gov, HSRProj, etc.
j. *secondary use of data from PCORI funded studies, and*	• number of secondary analysis studies using PCORI funded project data • amount of external funding for secondary data analysis studies using PCORI funded project data	• tracking over time	• PCORI administrative data • peer-reviewed and gray biomedical literature and registries like: clinicaltrials.gov, HSRProj, etc.
k. *funding investments in PCOR?*	• amount and proportion of total PCOR funding that comes from funders other than PCORI	• tracking over time	• publicly and possibly privately (i.e. pharma funding for CER) available funding information

Question	Metrics/indicators	Methods	Sources
1.5 What is PCORI's Return on Investment (ROI)?	• Placeholder: cost & impact	• Placeholder: cost & impact	• Placeholder: cost & impact

What is the Impact of PCORI's Approach to Topic Generation and Research Prioritization (TGRP)?

Figure 2a. Model for Evaluating the Impact of PCORI: Where does PCORI's Approach to Topic Generation and Research Prioritization (TGRP) fit?
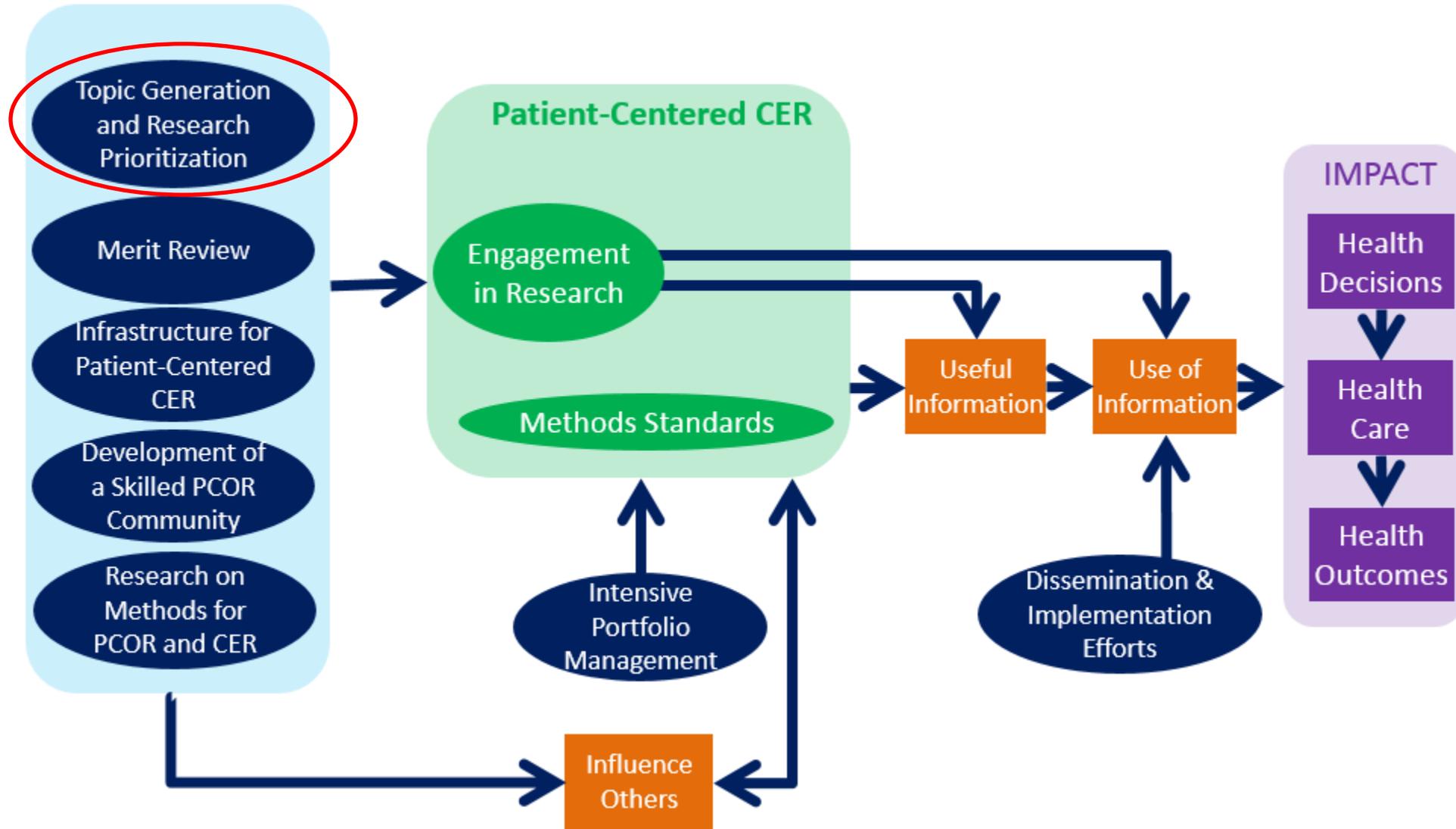
Figure 2b. Model for Evaluating PCORI's Approach to Topic Generation and Research Prioritization (TGRP)
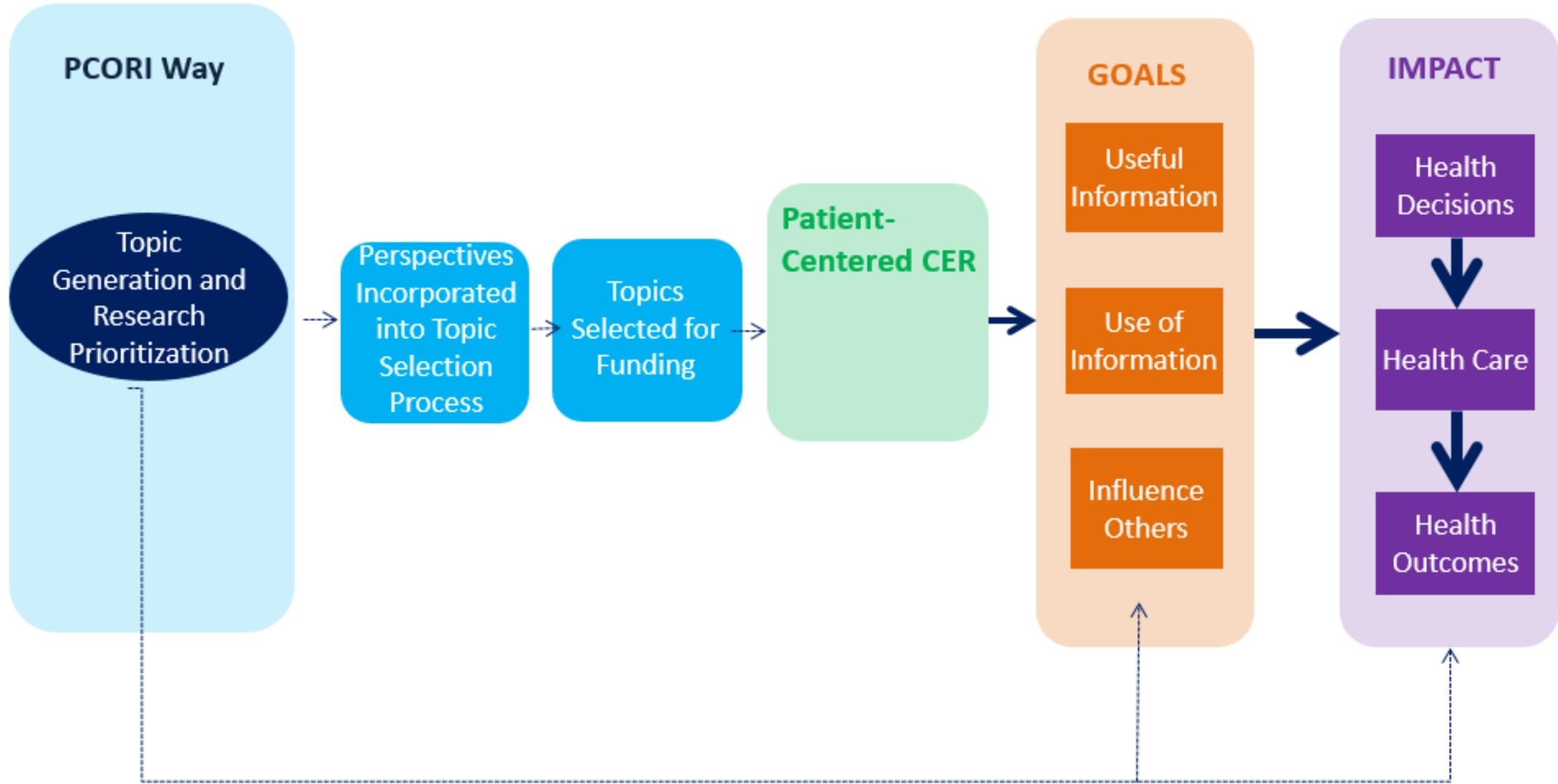
Table 2. Evaluation Questions for PCORI's Approach to Topic Generation and Research Prioritization (TGRP)

Question	Metrics/indicators	Methods	Sources
2.1 What is the impact of PCORI's approach to *Topic Generation, Prioritization, and Selection* (inclusion of patients and other stakeholders, methods for ranking and selection) on:			
a. perspectives incorporated into topic selection process,	• stakeholder perceptions of TCRP process, such as, perceived influence on the content of the topic database • relative contributions of the patients and stakeholders in ranking submitted topics • panelist perceptions of the TCRP process • indicators of dynamics in the panel discussion • number and type of stakeholders submitting topics to PCORI	• focus groups • surveys • database review	• stakeholder communities • PCORI advisory panel survey data • PCORI topic database
b. the topics selected for funding, and	• PCORI projects filling identified research gaps, such as IOM and AHRQ identified research gaps	• database review	• PCORI topic database
c. identifying new research gaps?	• types of gaps documented as important to patients and other stakeholders that were not previously identified • how many submitted topics score well on the topic selection patient-centeredness criterion	• database review • document review	• PCORI topic database • PCORI administrative data

Question	Metrics/indicators	Methods	Sources
2.2 Compared to broad funding announcements, what is the effect of targeted funding announcements on the:			
a. *impact of information, and*	• degree of impact on health decisions, quality of health care, and health outcomes	• comparison of PCORI projects funded through broad funding announcements to projects funded through targeted funding announcements	• PCORI Administrative Data
b. *core measures: usefulness, use, and cost of information?*	• (core metrics, see 1.2a,b&c)	• test associations between systematic data for TCRP and usefulness, use, and cost	• (core sources, see 2a,b&c)
2.3 Compared to funding opportunities developed with input from scientists only, what is the effect of funding opportunities developed based on multi-stakeholder input on the			
a. *impact of information?*	• degree of impact on health decisions, quality of health care, and health outcomes	• comparison of PCORI funding announcements developed with multi-stakeholder input to funding announcements from other organizations that incorporate scientist-input only	• PCORI administrative data • publicly and possibly privately (i.e. pharma funding for CER) available funding information

What is the Impact of PCORI's Approach to Merit Review?

Figure 3a. Model for Evaluating the Impact of PCORI: Where does PCORI's Approach to Merit Review fit?
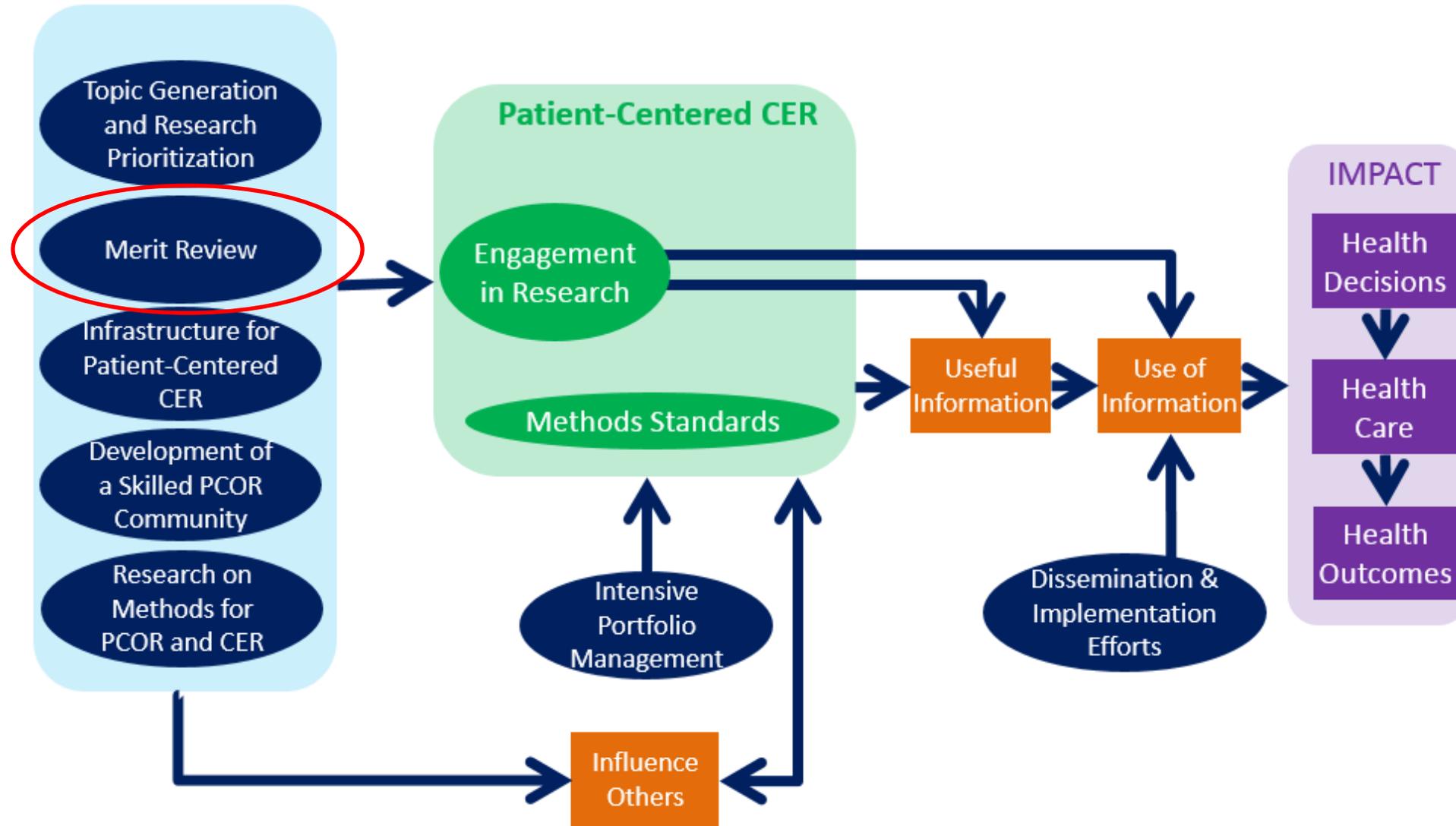
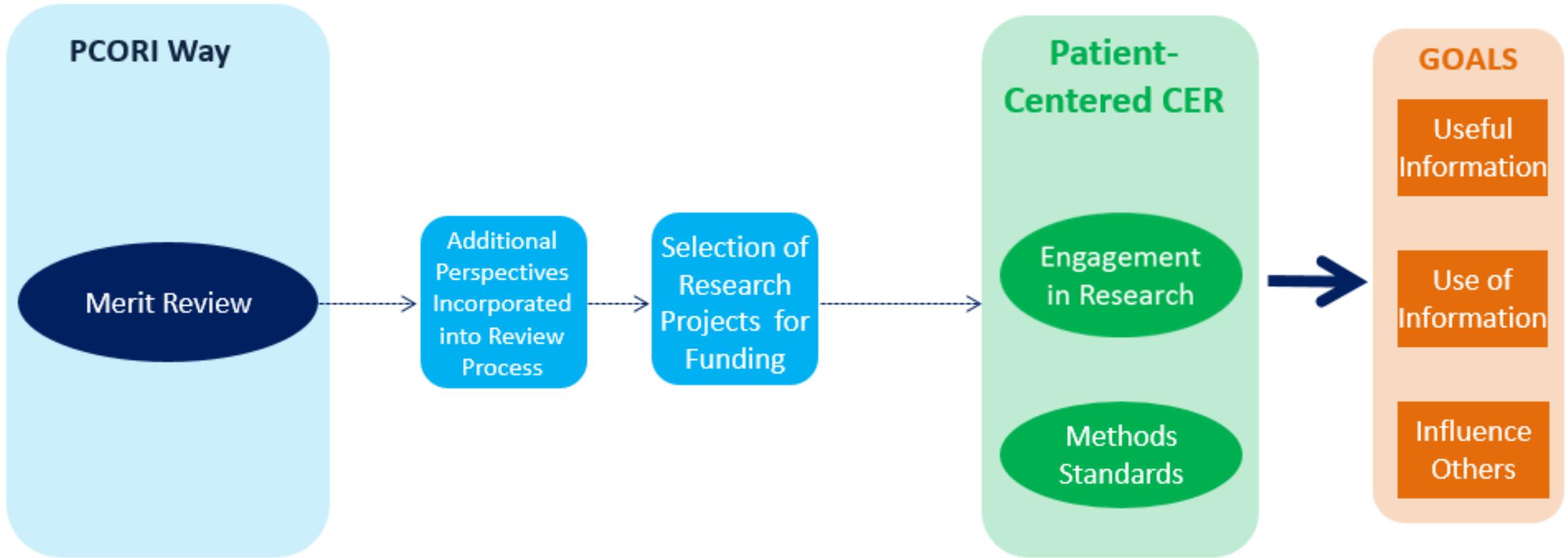**Figure 3b. Model for Evaluating PCORI's Approach to Merit Review**

Table 3. Evaluation Questions for PCORI's Approach to Merit Review

Question	Metrics/indicators	Methods	Sources
3.1 What is the impact of PCORI's approach to *Merit Review* (inclusion of patients and other stakeholders, unique criteria, and application of these criteria) on:			

a. perspectives incorporated in the review, and	• reviewer perceptions of PCORI Merit Review
	   o the value of input of each reviewer type
	   o receptivity to input from each reviewer type
	   o importance of each PCORI criteria for evaluating applications
	
	• dynamics in the panel discussion
	
	• change in review scores among different reviewer types (scientist, patient, stakeholder) from pre- to post discussion
	• convergence of review scores across different reviewer types pre- to post-discussion
		• Surveys
		• focus groups
		• analysis of merit review scores
		• document review
		• observation of merit review process
			• PCORI merit review documents
			• PCORI merit reviewer survey data
			• PCORI applicant survey data
			• PCORI merit reviewer focus group data
			• PCORI administrative data on:
			   o merit review scores
			   o applications reviewed, discussed, and funded

	• unique feedback from each reviewer type in written application critiques • adoption of feedback from each reviewer type in resubmitted proposals • likelihood of PCORI funding based on responsiveness to feedback from different reviewer type		

b. **selection of research projects for funding?**	• the relationship between PCORI criteria scores and overall scores for each reviewer type	• analysis of merit review scores
		• document Review
		• comparisons within PCORI applications and portfolio and with the portfolios of other funders
		• experimental panels
			• PCORI merit review documents
			• PCORI funding applications
			• PCORI administrative data on:
			  o merit review scores
			  o applications reviewed, discussed, and funded
			• administrative data from other funders

	• the relationship between PCORI criteria scores, by reviewer type, and funding decisions		
	• characteristics of projects selected for funding, such as: methodological quality, study design, intervention, disease/ condition, population		
	• characteristics of applicants		
	• characteristics of projects selected for funding compared to un-funded projects		
	• characteristics of PCORI's portfolio compared to other funders		
	• concordance between merit review results and expert review	• focus groups and structured interviews with experts	• experts

What is the Impact of PCORI's Approach to Developing a Skilled PCOR Community?

Figure 4a. Model for Evaluating the Impact of PCORI: Where does PCORI's Approach to Developing a Skilled PCOR Community fit?
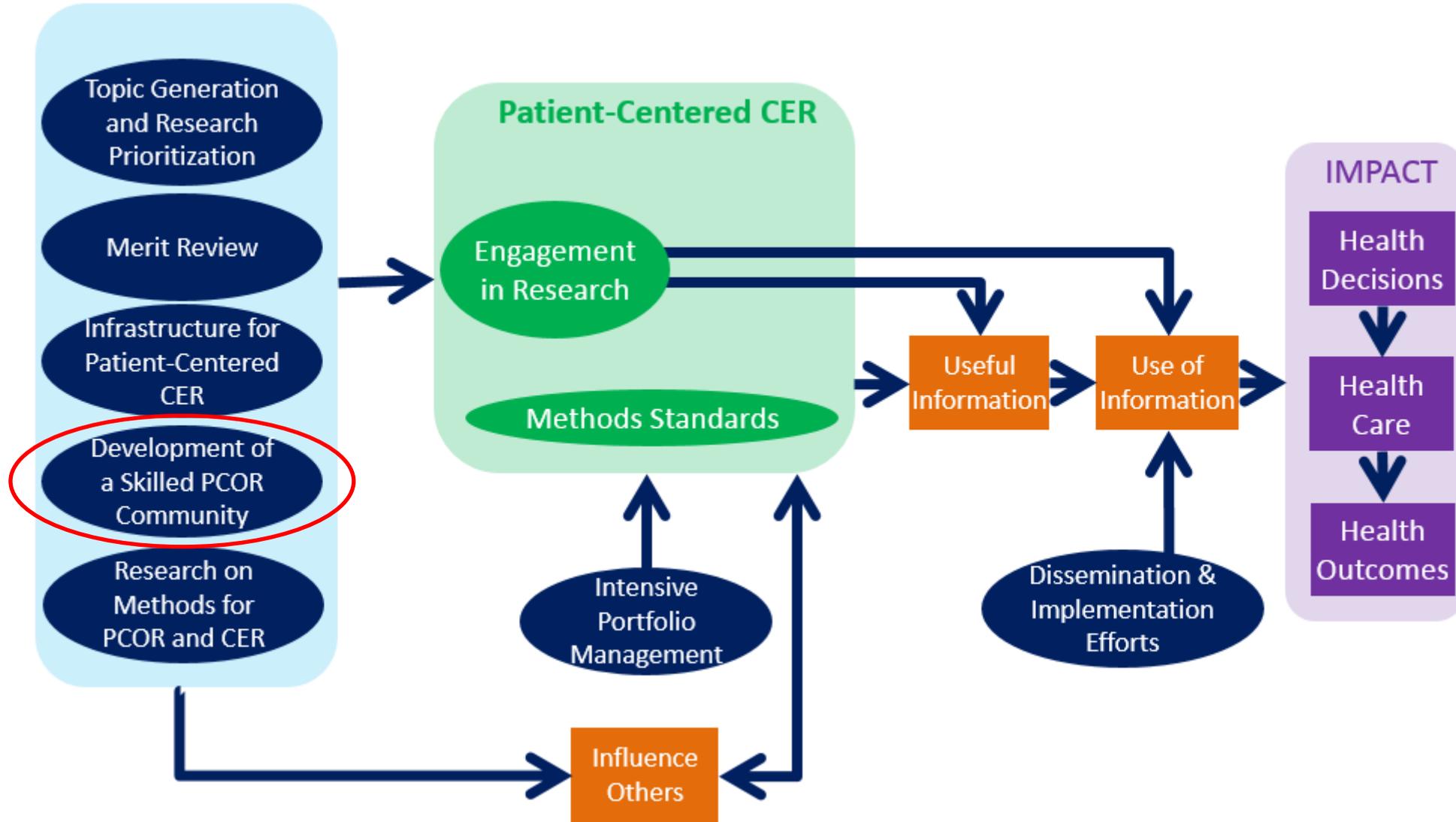
Figure 4b. Model for Evaluating PCORI's Approach to Developing a Skilled PCOR Community
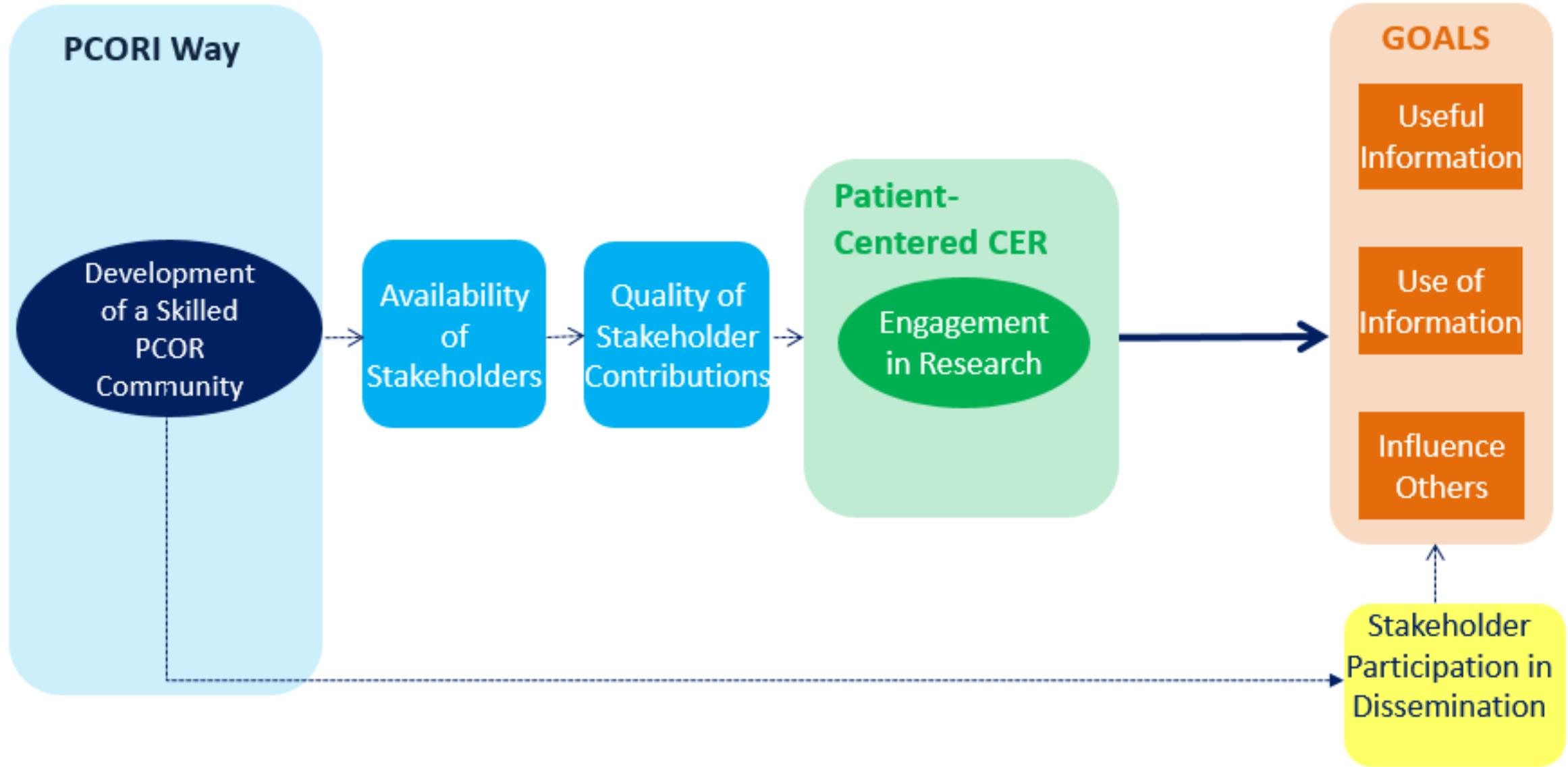
Table 4. Evaluation Questions for PCORI's Approach to Developing a Skilled PCOR Community

Question	Metrics/indicators	Methods	Sources
4.1 What is the effect of PCORI's unique approach to developing a skilled PCOR community on:			
a. the availability of people to conduct, promote, and partner on or participate in Patient-Centered CER,	• number of trained merit reviewers, ambassadors, pipeline to proposal awardees	• document review	• PCORI administrative data
	• number of people attending PCORI events: roundtables, working groups, workshops, and webinars • feedback from event attendees regarding their learnings from the event and their planned next steps to facilitate PCOR	• surveys • document review	• PCORI survey data • PCORI administrative data
	• number of people (researchers versus patient and/or stakeholders) accessing PCORI training materials	• document review	• PCORI administrative data
	• number of applications to PCORI that come from the Pipeline to Proposal Awards • number of Pipeline to Proposal awardees that go on to receive funding elsewhere that builds on their Pipeline award • number and quality of partnerships formed through the Pipeline Award program	• document review • survey	• PCORI administrative data • PCORI survey data
	• number of patients and/or stakeholders in PCORI projects (total and average per project)	• document review • self-report data from PCORI funded researchers • Social network analysis	• PCORI administrative data • Interim Progress Reports (IPRs)
	• researcher perceptions of the ease of finding partners	• survey	• PCORI survey data

	• patients and/or stakeholder perceptions of the ease of finding opportunities for partnering in research	• survey	• PCORI survey data

	• researcher, patient and stakeholder, and public:
	   o interest in Patient-Centered CER,
	   o valuing of patient perspective in research, and
	   o awareness of methods for Patient-Centered CER
		• survey
		• monitor the work of others
			• PCORI surveys:
			   o PCORI Stakeholder surveys
			   o Health Information National Trends Survey (HINTS)

	• use of PCORI Compensation Framework • Use of PCORI Engagement Rubric	• TBD •	• TBD

	• # of publications and presentations from PCORI awardees specifically about engagement methods and experiences	• comparisons over time of:
		   o peer-reviewed literature,
		   o registries, and
		   o study-databases
			• peer-reviewed and gray biomedical literature and registries like: clinicaltrials.gov, HSRProj, etc.

	• number of engagement awards • use of products or tools from engagement awards	• document review	• PCORI administrative data

b. quality of contributions of engaged partners, and	• Input from patients and stakeholder partners perceived as influential, valuable by researchers
	• Patients and stakeholder partners feel that their input was viewed as influential, valuable
		• self-report data from PCORI funded researchers and their patient and stakeholder partners
		• case study
			• IPRs
			• WE-ENACT
			• PCORI funded projects:
			   o primary investigator
			   o engaged partner

c. patient and/or stakeholder participation in dissemination of findings?	• Patient and/or stakeholder involvement in:
	   o plans for dissemination,
	   o writing manuscripts or other communications,
	   o giving presentations, and
	   o other approaches to dissemination
		• self-report data from PCORI funded researchers and their patient and stakeholder partners
		• case study
		• comparisons over time of:
		   o peer-reviewed literature,
		   o registries, and
		   o study-databases
			• IPRs
			• WE-ENACT
			• PCORI funded project:
			   o primary investigator
			   o engaged partner
			• peer-reviewed and gray biomedical literature and registries like: clinicaltrials.gov, HSRProj, etc.

What is the impact of Engagement in Research?

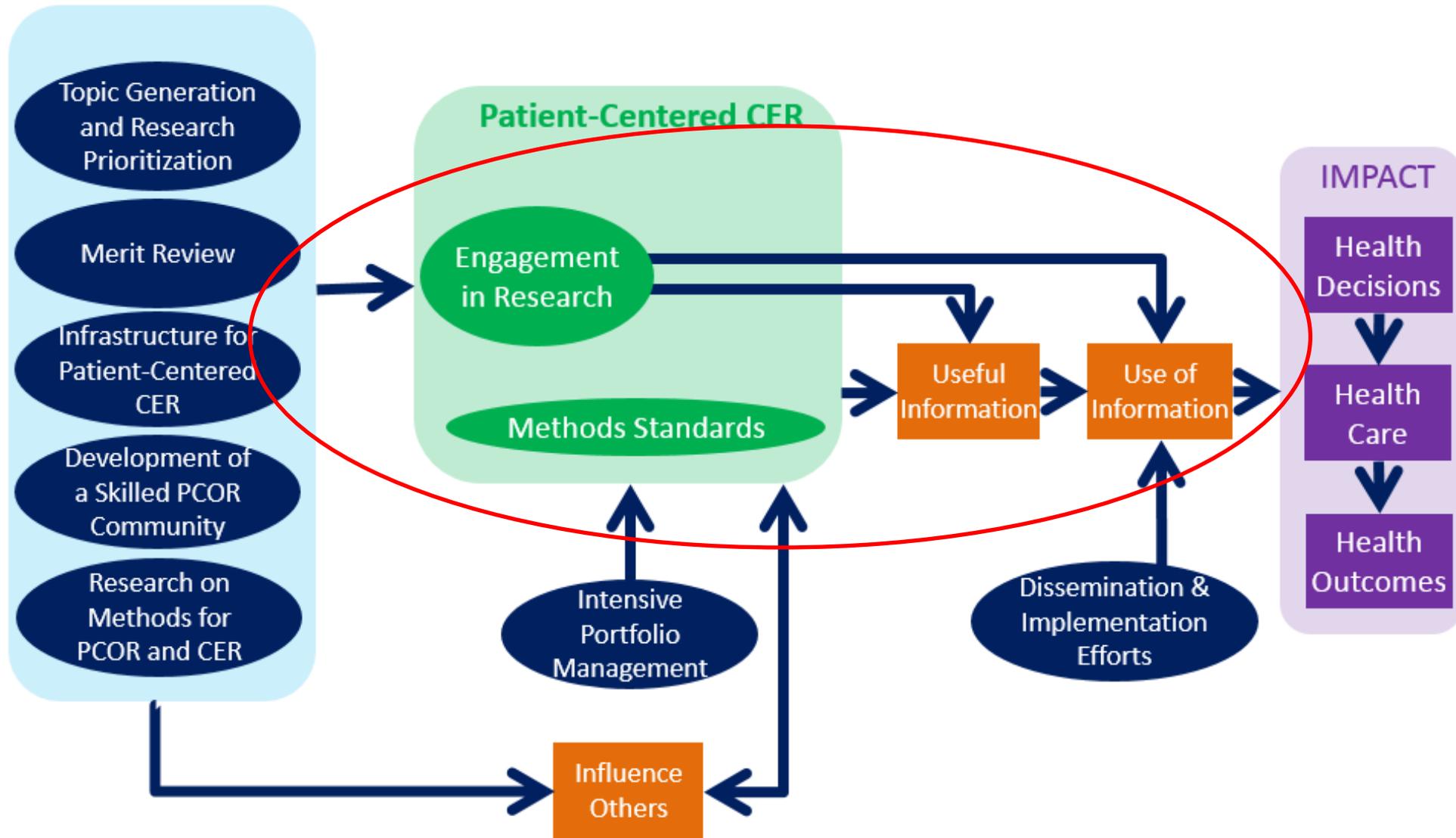**Figure 5a. Model for Evaluating the Impact of PCORI: Where does Engagement in Research fit?**

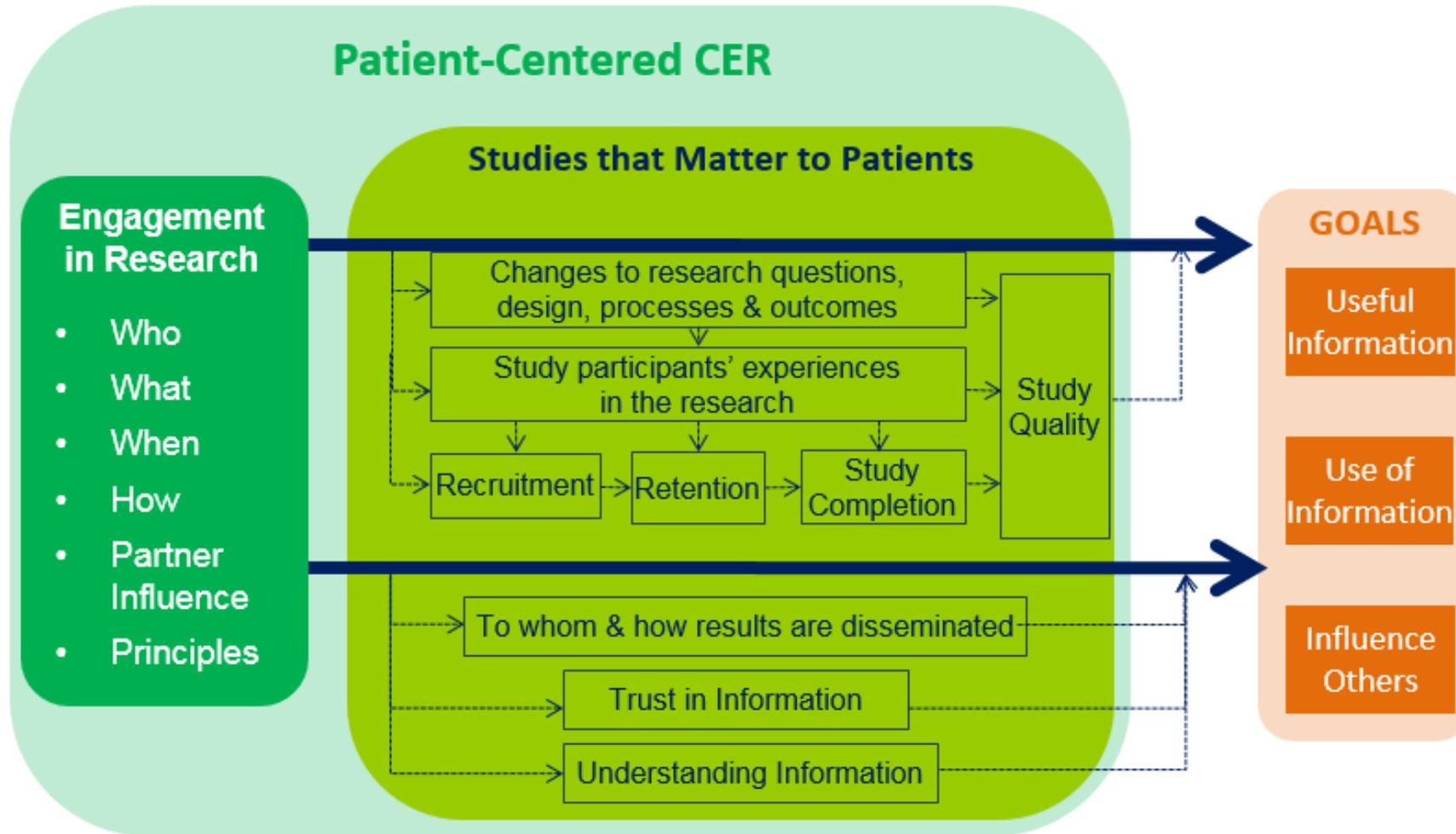**Figure 5b. Model for Evaluating Engagement in Research**

Patient-Centered CER

Studies that Matter to Patients

Engagement in Research
- Who
- What
- When
- How
- Partner Influence
- Principles

Changes to research questions, design, processes & outcomes

Study participants' experiences in the research

Recruitment → Retention → Study Completion

Study Quality

To whom & how results are disseminated

Trust in Information

Understanding Information

GOALS
- Useful Information
- Use of Information
- Influence Others

Table 5. Evaluation Questions for Evaluating the Impact of Engagement in Research

Question	Metrics/indicators	Methods	Sources
5.1 What is the impact of *Engagement in Research,* particularly, • **Who (Types of stakeholders) is involved** • **When engagement occurs (stages of research)** • **How much (the nature of engagement- information, consultation, collaboration, patient/stakeholder direction)** • **Level of influence of patients and stakeholders** • **Patient and/or Stakeholder experiences as engaged partners (satisfaction, empowerment)** • **Principles of engagement (trust, co-learning, etc.)** **on:**			

a. *research processes and characteristics in studies that matter to patients and/or stakeholders, and*	• changes to research questions resulting from engagement	• self-report data from PCORI funded researchers and their patient and stakeholder partners
		• focus groups and key informant interviews
			• Ways of Engaging- ENgagement ACtivity Tool (WE-ENACT)
			• Interim Progress Reports (IPRs)
			• PCORI funded projects:
			  o primary investigator
			  o engaged partner

Question	Metrics/indicators	Methods	Sources
		• case studies/ testimonials about engagement in PCORI funded projects • comparisons over time of: o peer-reviewed literature, o registries, and o study-databases • comparisons of PCORI studies to studies funded by other funding agencies that do not require engagement • PCORI document review	• literature databases (i.e. Medline, Embase, etc.) and databases of CER studies (i.e. clinicaltrials.gov and HSRProj) • PCORI study participant survey data
	• changes to study design resulting from engagement • number and type of patient reported outcomes (PROS) • changes to outcomes resulting from engagement • recruitment and retention rates	• self-report data from PCORI funded researchers and their patient and stakeholder partners	• IPRs • WE-ENACT
	• recruitment and retention rates among hard to reach populations	• self-report data from PCORI funded researchers	• IPRs
	• study participants' experiences in the research	• PCORI to monitor work of others	N/A

Question	Metrics/indicators	Methods	Sources
	• proportion of studies that complete data collection • time to study completion	• PCORI document review • self-report data from PCORI funded researchers • comparisons of PCORI studies to studies funded by other funding agencies that do not require engagement	• PCORI administrative data • IPRs • publicly and possibly privately (i.e. pharma funding for CER) available funding information
b. Dissemination of PCORI studies	• to whom and how research is disseminated	• tracking of dissemination outputs	• *TBD* • W
	• proportion of studies in the portfolio where the participants receive the study findings	• self-report data from PCORI funded researchers	• IPRs
	• end-user understanding of findings • end-user trust in findings	• case studies	• stakeholder communities
c. core measures: usefulness, use, and cost of information?	• (core metrics, see 2a,b&c)	• test associations between systematic data for	• (core sources, see 2a,b&c)

Question	Metrics/indicators	Methods	Sources
		engagement and usefulness, use, and cost	
5.2 How much does the impact of engagement (see question 11.a., above) depend on:			

a. *contextual factors?*	• study population
	• study setting
		• PCORI document review
		• self-report data from PCORI funded researchers and their patient and stakeholder partners
		• focus groups and key informant interviews
			• PCORI administrative data
			• WE-ENACT
			• PCORI funded projects:
			   o primary investigator
			   o engaged partner

What is the Impact of PCORI's Approach to Infrastructure Development?

Figure 6a. Model for Evaluating the Impact of PCORI: Where does PCORI's Approach to Infrastructure Development fit?
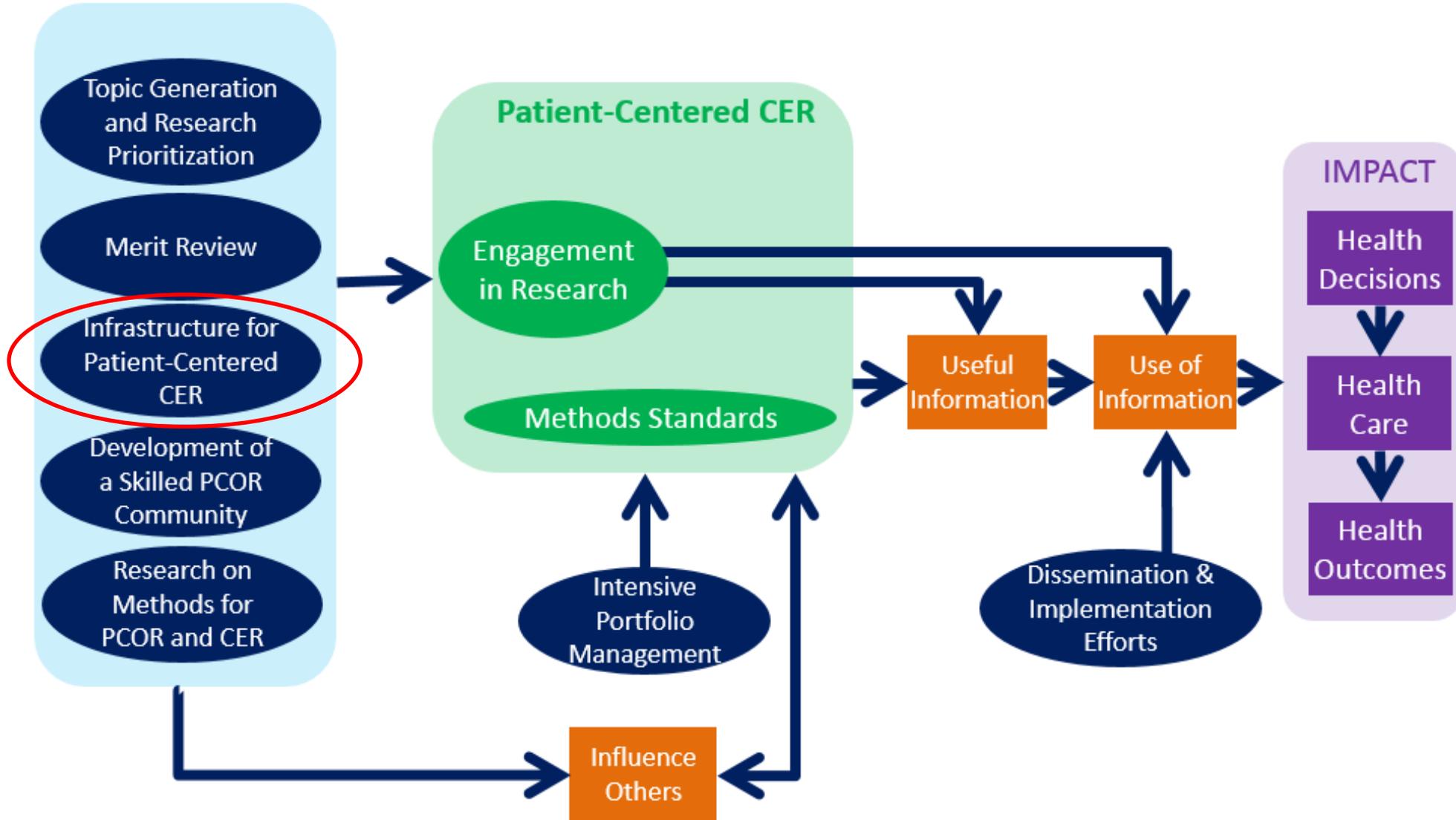
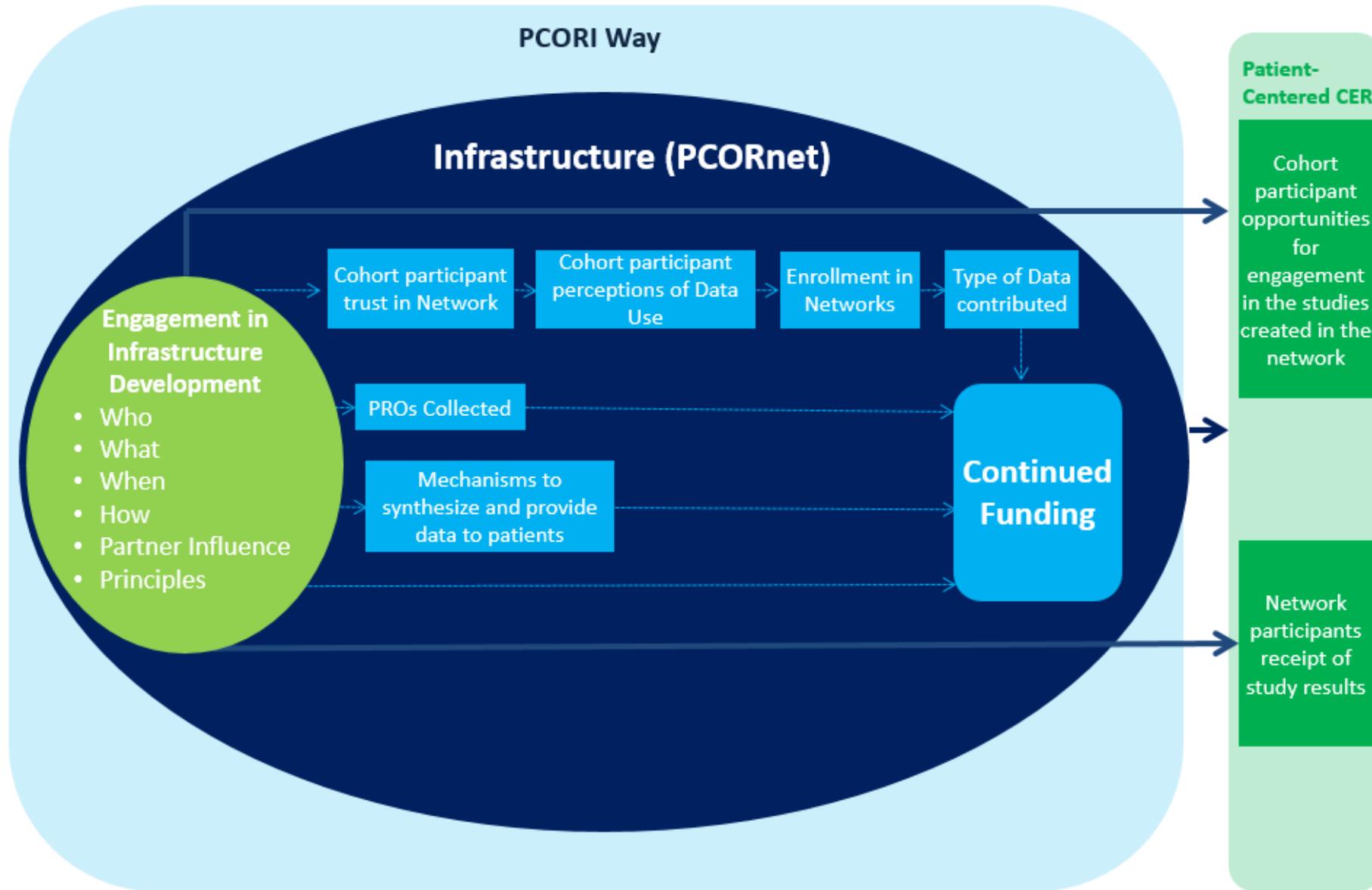**Figure 6b. Model for Evaluating PCORI's Approach to Infrastructure Development**

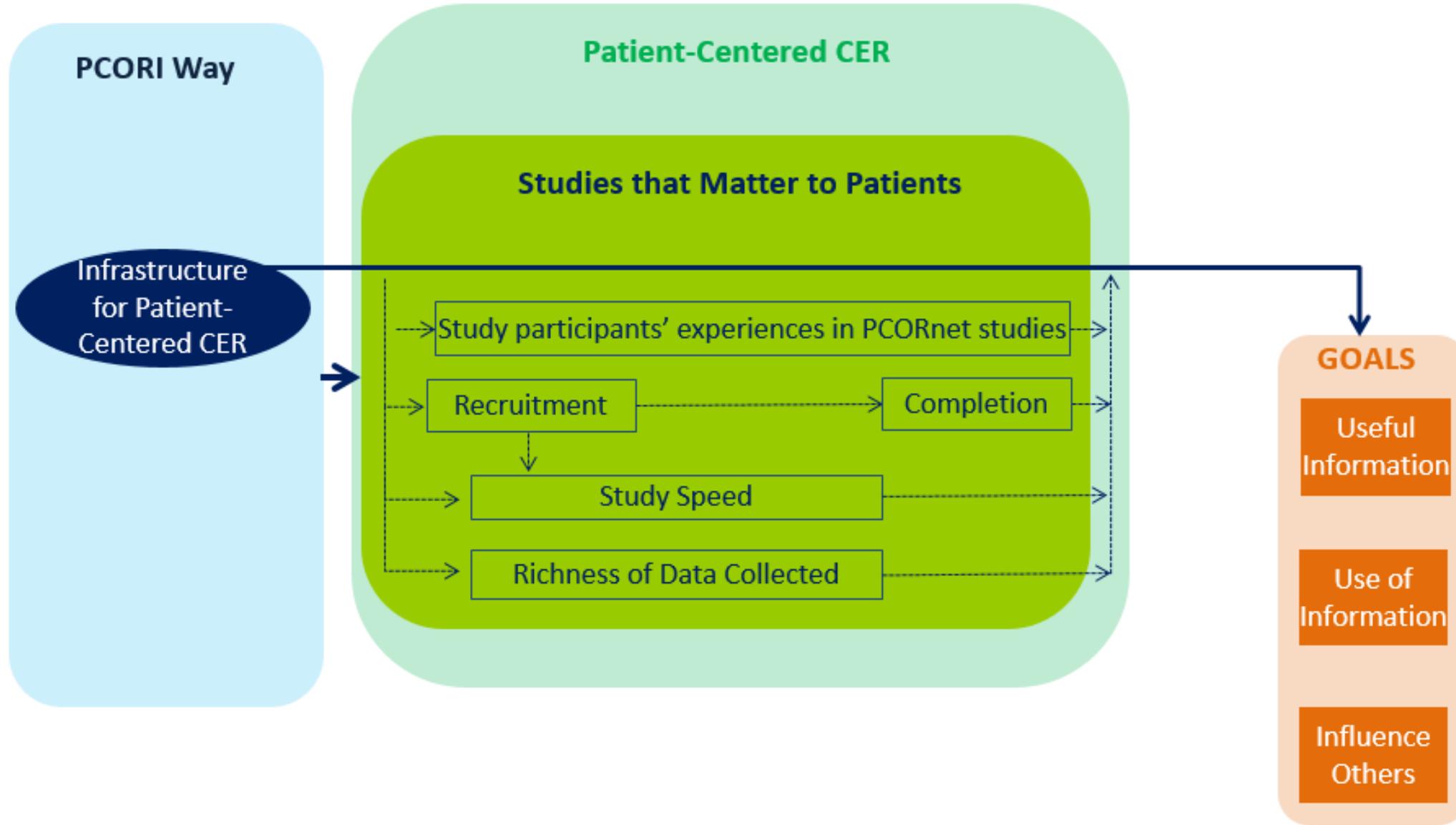**Figure 6c. Model for Evaluating PCORI's Approach to Infrastructure Development**

Table 6. Evaluation Questions for PCORI's Approach to Infrastructure Development

Question	Metrics/indicators	Methods	Sources
6.1 What is the effect of Engagement of patients and other stakeholders in the development of research networks on:			

a. enrollment in the networks,	• percent of members consented and enrolled in the network or in specific cohort
	• time to desired enrollment numbers
		• self-report data from PCORI funded researchers and their patient and stakeholder partners
		• PCORI document review
			• PCORI PCORnet projects:
			  ○ primary investigators
			  ○ patient participants
			• bi-annual data collection from researchers and patient and stakeholder partners (PCORnet Ways of Engaging- ENgagement ACtivity Tool: netENACT)
			• bi-annual reporting via interim progress reports

b. outcomes collected,	• number and type of patient-reported outcomes (PROs) and patient-generated information (PGI) collected as part of the network
	• proportion of PROs and PGIs collected that were new or modified after patient involvement
		• self-report data from PCORI funded researchers and their patient and stakeholder partners
		• PCORI document review
			• PCORI PCORnet projects:
			  ○ primary investigators
			  ○ patient participants
			• bi-annual data collection from researchers and patient and stakeholder partners (PCORnet Ways of Engaging- ENgagement ACtivity Tool: netENACT)
			• bi-annual reporting via interim progress reports

Question	Metrics/indicators	Methods	Sources
c. feedback mechanisms to provide data and study findings to patient participants in the Network,	• types of personal data shared with patient participants • whether or not relevant study findings are shared with patient participants • what types of findings are shared (i.e. lay summary as opposed to link to PDF of article) • number of mechanisms to share with patient participants • proportion of study participants that receive a summary of study findings	• self-report data from PCORI funded researchers and their patient and stakeholder partners • PCORI document review	• PCORI PCORnet projects: • primary investigators • patient participants • bi-annual data collection from researchers and patient and stakeholder partners (PCORnet Ways of Engaging- ENgagement ACtivity Tool: netENACT) • bi-annual reporting via interim progress reports
d. patient participant perceptions of the Network,	• patient participant trust in network • patient participant awareness of the ways in which their data is used • patient participant's perceived ability to contribute data as desired • patient participant satisfaction with opportunities to contribute to the research process (e.g., topic capture) • patient participant perceptions of the influence of network members on the research process	• surveys of network enrollees	• network enrollees

Question	Metrics/indicators	Methods	Sources

e. opportunities for engagement in the studies conducted in the Network, and	• number and nature of opportunities for patient participant for research engagement (pre-existing vs. new opportunities)	• self-report data from PCORI funded researchers and their patient and stakeholder partners	• PCORI PCORnet projects:
			  o primary investigators
			  o patient participants
			• bi-annual data collection from researchers and patient and stakeholder partners (PCORnet Ways of Engaging- ENgagement ACtivity Tool: netENACT)

f. productivity and sustainability of the network?	• attainment of PCORI funding	• PCORI document review	• PCORI administrative data • bi-annual reporting via interim progress reports
	• attainment of non-PCORI funding • number of studies conducted through PCORnet networks • number of studies conducted through PCORnet by people external to the networks		
6.2 Compared to other CER studies, for studies conducted in the PCORnet, what is the impact of PCORnet on:			
a. experiences of participants in PCORnet studies,	• study participants trust in the research process - proxies may include recruitment, retention, decisions to share data, etc.	• PCORI document review • Survey of PCORnet study participants	• PCORI administrative data • PCORnet participant survey data
b. recruitment for CER studies,	• time to recruitment • recruitment rates for hard-to-reach populations • retention of hard to reach-populations	• PCORI document review	• bi-annual reporting via interim progress reports

Question	Metrics/indicators	Methods	Sources
c. *completion of CER studies,*	• proportion of completed studies • time to completion for IRB approval • time to completion for recruitment • time to completion of data collection • total time for study completion (all phases of the research process)	• PCORI document review	• bi-annual reporting via interim progress reports
d. *richness of data collected,*	• number of PROs and PGIs used • type of PROs and PGIs used • information on confounders available and used	• PCORI document review	• PCORI administrative data
e. *patient-reported outcomes (PROs), and*	• PRO harmonization: percentage of networks that adopted the PRO common measures	• PCORI document review	• PCORI administrative data
f. *core measures: usefulness, use, and cost of information?*	• (core metrics, see 2a,b&c)	• test associations between systematic data for PCORnet studies and usefulness, use, and cost	• (core sources, see 2a,b&c)

What is the Impact of PCORI's Approach to Communication, Dissemination, and Implementation?

Figure 7a. Model for Evaluating the Impact of PCORI: Where does PCORI's Approach to Communication, Dissemination, and Implementation fit?
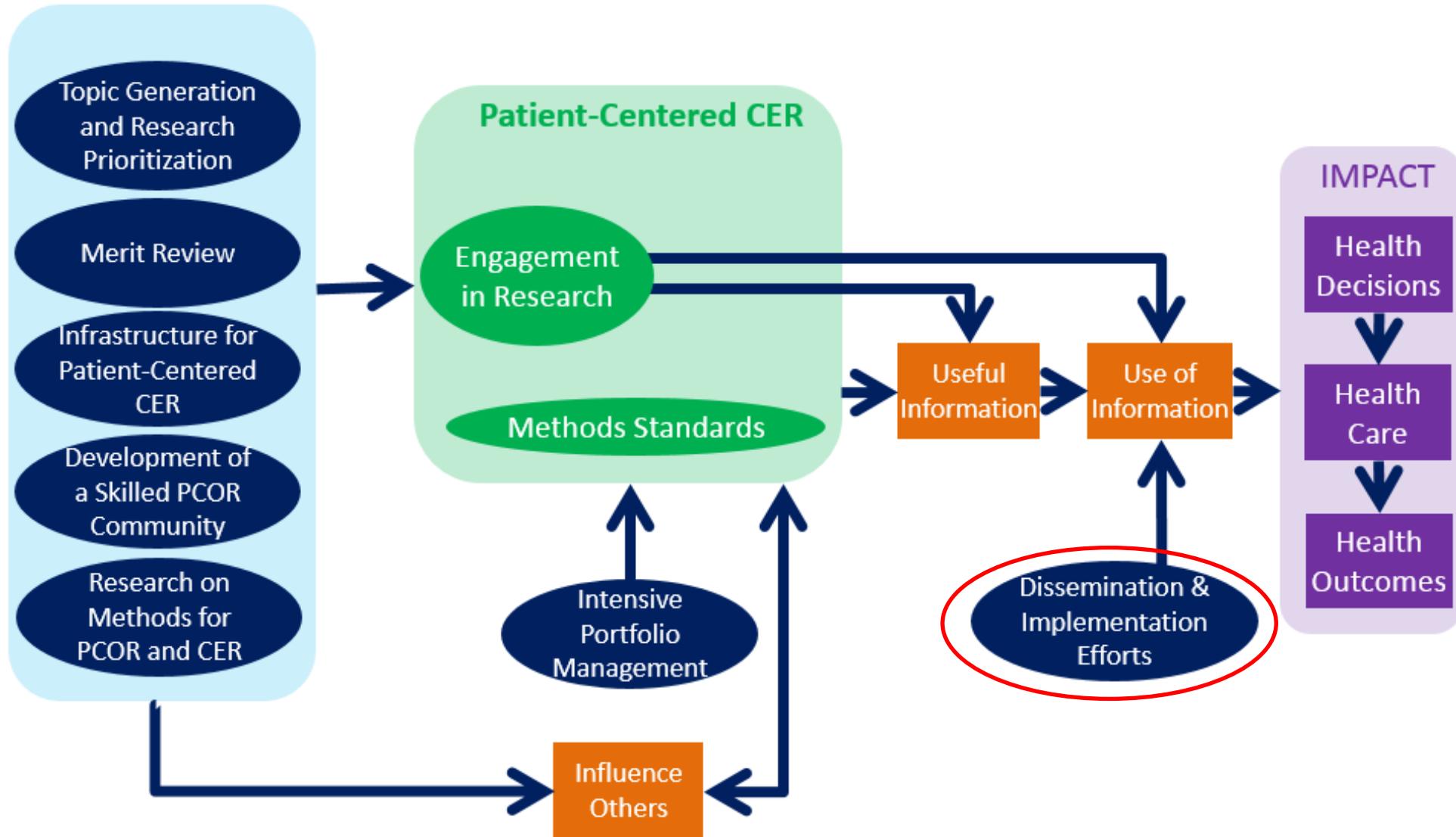
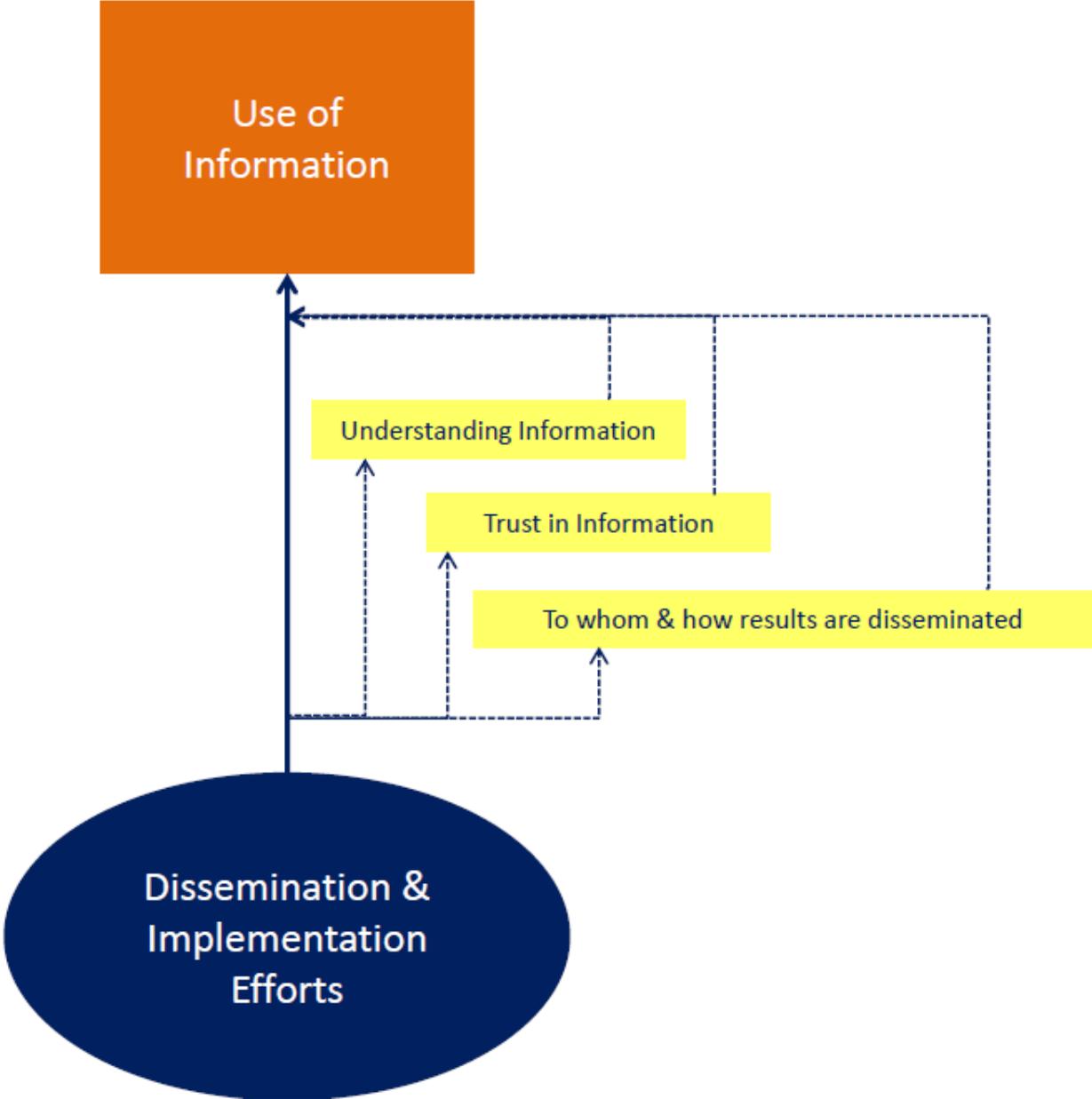**Figure 7b. Model for Evaluating PCORI's Approach to Communication, Dissemination, and Implementation**

Table 7. Evaluation Questions for PCORI's Approach to Communication, Dissemination, and Implementation

Question	Metrics/indicators	Methods	Sources
7 **What is the effect of including patients and other stakeholders in planning dissemination on:**			

a. *dissemination of findings, and*	• increased direct-communication to patients from PCORI projects vs projects funded by others
	
	• to whom the findings are disseminated
	• end-understanding of findings
	• end-user trust in findings
		• surveys
		• PCORI document review
		• self-report data from PCORI funded researchers and their patient and stakeholder partners
			• PCORI Stakeholder surveys
			• PCORI administrative data
			• PCORI PCORnet projects:
			  ○ primary investigators
			  ○ patient participants
			• bi-annual data collection from researchers and patient and stakeholder partners (PCORnet Ways of Engaging- ENgagement ACtivity Tool: netENACT)

b. <u>*core measures: usefulness, use, and cost of information?*</u>	• (core metrics, see 2a,b&c)	• test associations between systematic data for PCORI's approach to communication, dissemination, and implementation and usefulness, use, and cost	• (core sources, see 2a,b&c)