

Measuring patient engagement: The importance of a framework

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Background

- Adoption of patient engagement activities is growing within health economics and outcomes research.
- Measuring the quality, outcomes, and impact of patient engagement is necessary to enhance the patient advisor experience, prove relevance and provide data for return on investment.
- The Patient-Centered Outcomes Research Institute (PCORI) developed an Engagement in Research Framework with 27 concepts across 5 domains that support positive patient and research outcomes. There is little evidence indicating this framework has been formally applied in the context of a research study and compared to other commonly used engagement evaluation tools.

Objective

- To develop and assess an evaluation strategy that measures quality, outcomes, and impact of patient engagement activities.

Methods

- This evaluation study utilized the PCORI Engagement in Research Framework to inform the design, conduct, and analysis and the Public and Patient Engagement Evaluation Tool (PPEET) \* to measure the quality of the engagement activities.
- We administered the PPEET at the end of a 6-month engagement with patient advisors who were part of an atopic dermatitis study team. The PPEET consists of 3 validated evaluation instruments used to standardize the measurement of patient engagement activities.
- Advisors (n=2) completed the PPEET Participant Questionnaire and study team members (n=4) completed the PPEET Project Questionnaire.
- Average scores were calculated for each item with Likert scale response options (1 Strongly Disagree to 5 Strongly Agree).
- Additional data collection was conducted to supplement the PPEET results including qualitative interviews with advisors and study team members pre- and post-engagement, a review of budget costs, timesheets and personnel resource investments.

\*Abelson, J., K. Li, G. Wilson, K. Shields, C. Schneider, and S. Boesveldt. 2016. Supporting quality public and patient engagement in health system organizations: development and usability testing of the Public and Patient Engagement Evaluation Tool. Health Expectations 19(4):817-827. <https://doi.org/10.1111/hex.12378>.

Figure 1: The Public and Patient Engagement Evaluation Tool (PPEET)




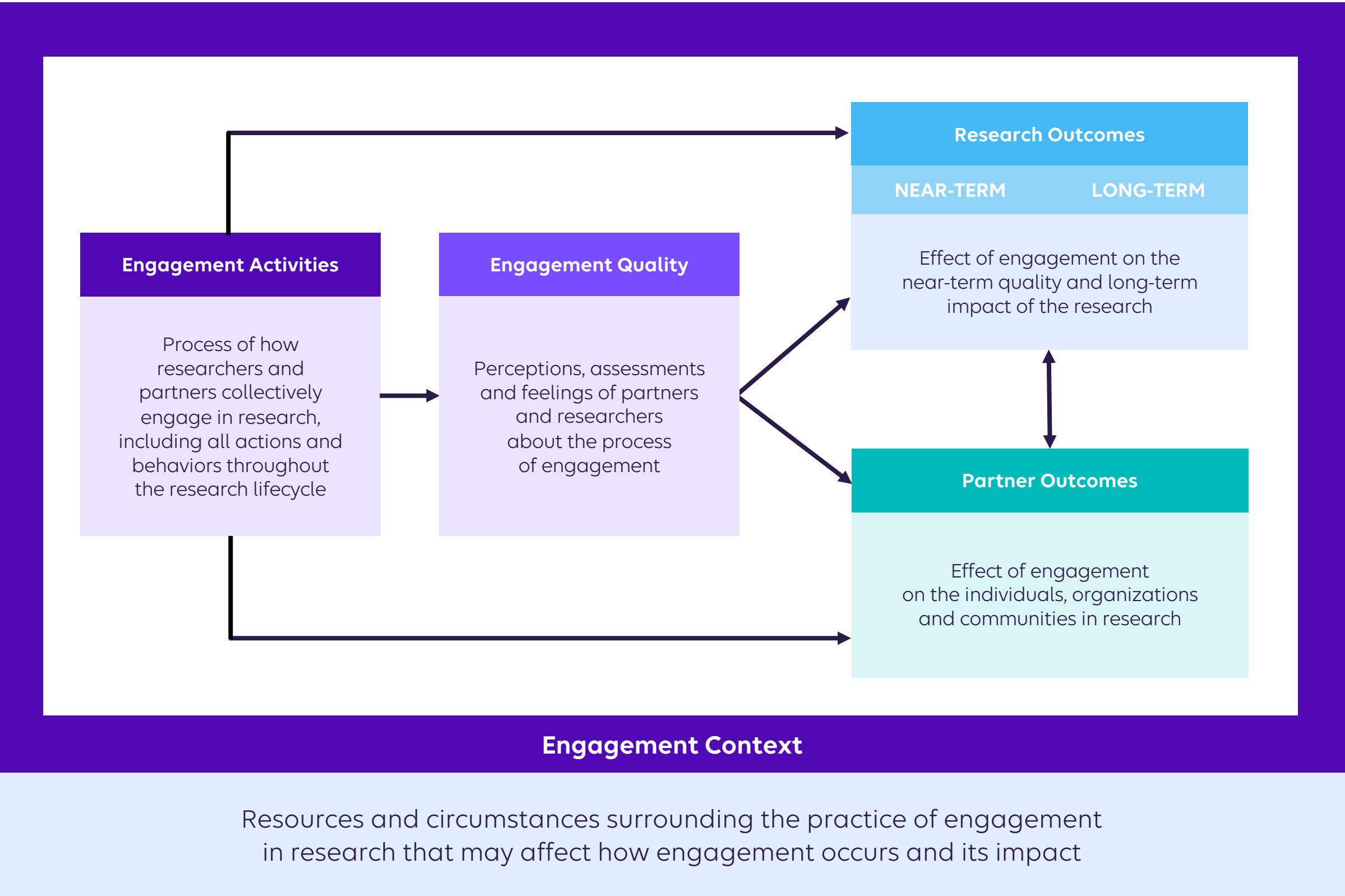
		
Participant Questionnaire	Project Questionnaire	Organization Questionnaire

Figure 2: PCORI Engagement in Research Framework: Theory of Action\*



\*Measuring What Matters for Advancing the Science and Practice of Engagement. <https://www.pcori.org/sites/default/files/PCORI-Measuring-What-Matters-for-Advancing-the-Science-and-Practice-of-Engagement.pdf>

Table 1: Crosswalk Between PCORI Engagement in Research Framework and PPEET Participant Questionnaire Abbreviated Items\*\*

PCORI Framework Domain	PCORI Framework Concept	PPEET Participant Questions Abbreviated
Engagement Context	Partner representativeness	Represented a broad range of perspectives
Engagement Activities	Planning and supporting engagement	Clear understanding of the purpose
	Planning and supporting engagement	Supports needed to participate were available
	Facilitating participation	Enough information to contribute
	Engagement experience	Express views freely
Engagement Quality	Partnership functioning and group dynamics	Views were heard
	Engagement experience	Initiative achieved its objectives
	Engagement experience	Confident input will be used
	Partnership functioning and group dynamics	A wide range of views shared
	Engagement experience	Satisfied with engagement
Partner Outcomes	Post-engagement capacity and readiness	Better informed
	Other partner effects	Input will make a difference to the work
	Other partner effects	Engagement was a good use of time

\*\*Author interpretation of crosswalk between PCORI Framework and thematic concepts evaluated in PPEET

Results

- PPEET Participant and Project Questionnaire items spanned 4 of 5 PCORI Engagement Framework domains, with the Research Outcomes domain not assessed.
- The PPEET Participant and Project Questionnaires evaluated the fewest number of concepts in the PCORI Engagement Context and Partner Outcome domains.

Table 2: Additional PCORI Concepts That Support Evaluation of Return on Investment

PCORI Concept	Modifying Factors	Output
Pre-engagement capacity and readiness for engagement	Advisor experience participating on Boards or Councils and familiarity with survey research	Efficient start up and onboarding
	Researcher leveraged publicly available resources	Pre-planned advisor compensation included in budget
	Fair Market Value Calculator PCORI training modules and engagement plan template	Clarity in advisor role and responsibilities along with an activity timeline set purpose and expectations
Pre engagement trust	Researcher had previous facilitation experience	Advisors ranked partnership functioning and group dynamics high
	Patient advocacy organization had established positive relationships with advisors	Credibility and enthusiasm for initiative was reinforced by PAO
Resources for engagement	Established and trusted research study team relationships	Open bi-directional communication supported uptake of patient input
Sustainability of engagement	Client conceptually and financially support engagement activities	A clear budget was established
Resource use	Patient advocacy organization reinforced accountability, consistent bi-directional engagement made advisors feel heard	High retention of advisors
	Total cost of engagement evaluated, including time and personnel	Forecasts investment for future projects

- Contextual concepts such as pre-engagement capacity and readiness for project engagement, pre-engagement trust, and planned resources modified the total investments needed to ensure high quality engagement and sustainability.
- Contextual concepts and total resource use supported the evaluation of return on investment and informed future engagement planning.

Figure 3: Contextual Concepts That Modify Engagement Quality and Partner Outcomes

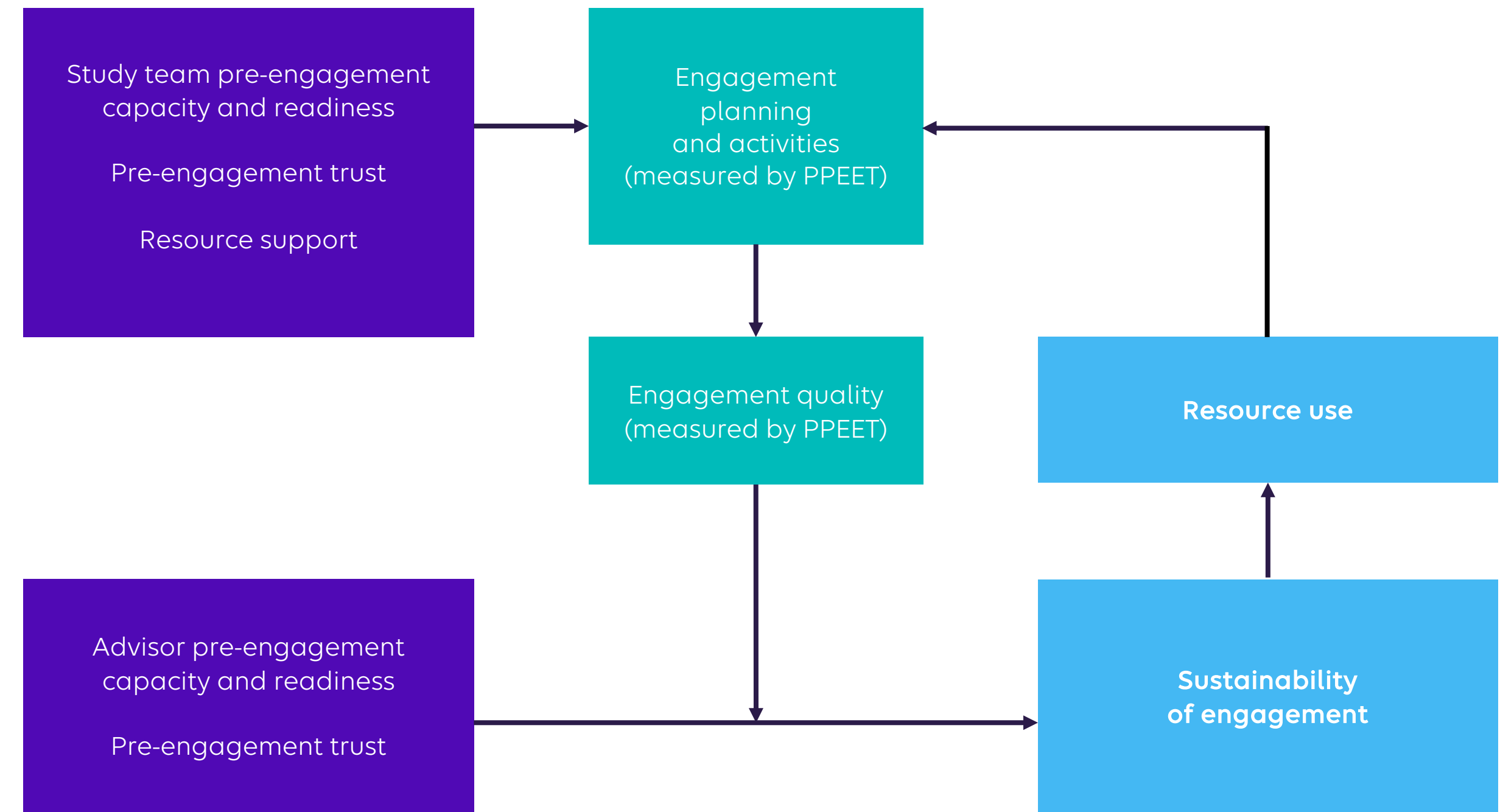


Table 3: Quantitative Results from the PPEET Participant and Project Questionnaires

	Average Score
PPEET Participant Questionnaire Patient Advisor (n=2)	
Support needed to participate was available	3.50
Input will make a difference to the work	4.00
Represented a broad range of perspectives	4.00
A wide range of views shared	4.00

Table 3: Alignment of Quantitative Results From the PPEET Participant and Project Questionnaires (cont'd.)

	Average Score
Satisfied with engagement	4.00
Engagement good use of my time	4.00
Initiative achieved its objectives	4.00
Confident input will be used	4.50
Enough information to contribute	4.50
Better informed	4.50
Express views freely	5.00
Views were heard	5.00
Clear understanding of the purpose	5.00
PPEET Project Questionnaire Research Study Team (n=4)	
Adequate time was planned and allocated for engagement	3.25
Output from engagement influenced project outcomes	3.67
Perspectives of those most affected by outputs reflected through advisors	3.67
Satisfied with engagement	4.00
Engagement was a good use of program resources	4.00
Engagement added value to project	4.25
Goals were shared with advisors	4.33
Output considered by those who could act on it	4.50

- The PPEET Participant and Project Questionnaire items align conceptually and provide a quantitative way to measure advisor and researcher perspectives.
- Process features such as partnership functioning, engagement experience, and communication ranked highest among advisors and researchers.
- Engagement support and adequate time were ranked lowest by advisors and researchers, respectively.

Conclusions

- The PPEET provided necessary information on the management and quality of the engagement process but was not sufficient to capture all key project elements needed to justify future investments.
- The PCORI Engagement in Research Framework expanded the scope of the evaluation by identifying key contextual and resource supports that modify the efficiency and effectiveness of the engagement.
- Future engagement evaluations would benefit from the use of the PCORI Engagement in Research Framework to comprehensively guide data collection and generate evidence that supports future data-driven investments in patient engagement activities.

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