

Benefits of Patient Engagement in Health Research



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Outline for this session

What is
Patient
Engaged
Research



Why PE matters

- Overall impact of PE in health research

What do we know

- What evidence exists on benefits of PE

PaCER - Across the Research Lifecycle

- Characteristics of PE with positive effects

How to demonstrate impact

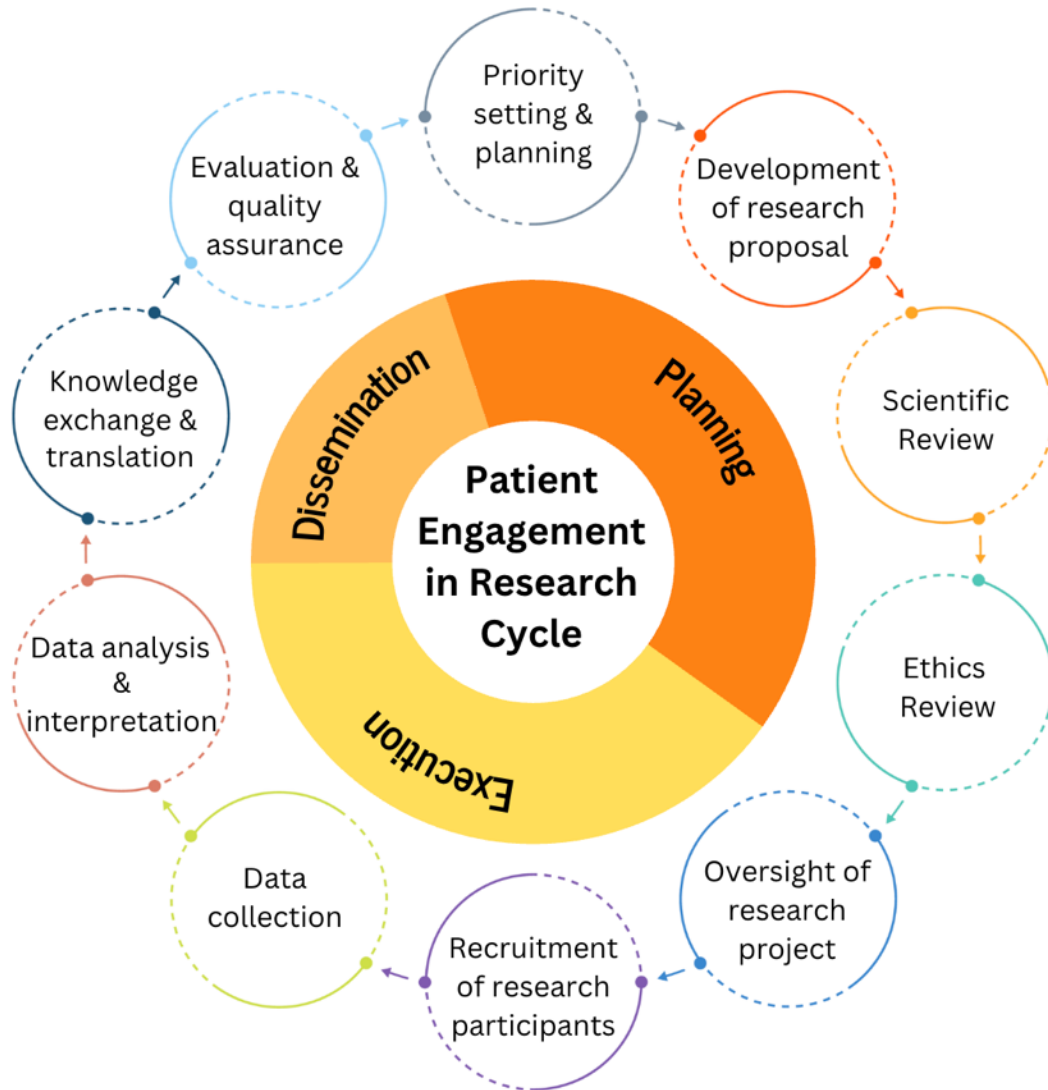
- Tools/frameworks for evaluating impact

Example from CIHR IMAGINE SPOR



Future
Directions

What is Patient Engaged Research?



Meaningful and active involvement of individuals with lived experiences, including patients, families, and communities, as equal and active partners in the research team throughout the **entire research cycle**.

Why Patient Engagement Matters?



- Patient engagement in health research helps ensure that priorities, processes, and outcomes are relevant and impactful for the individuals and communities the research is intended to serve - namely patients, families, and caregivers
- **Benefits of Patient Engagement:**
 - Improved Research Quality & Relevance
 - Increased Feasibility & Recruitment
 - Enhanced Trust & Transparency
 - Empowerment & Learning
 - Improved Translation into Practice
 - Stronger Health Systems



What evidence exists?

Scoping Review on Benefits of patient engagement on healthcare quality (n = 17 articles)

CATEGORY	MAIN BENEFIT OF PATIENT ENGAGEMENT	EXAMPLES OF IMPACT
01 Health Outcomes / Effectiveness	Improves quality and outcomes of care	Better quality of care, improved treatment success, higher patient satisfaction, reduced anxiety and depression
02 Patient Compliance	Increases adherence to treatment	Better medication adherence, stronger commitment to care plans, improved follow-through with treatment
03 Resources	Encourages patients to take an active role in their care	Greater self-management, healthier behaviors, improved blood pressure and diabetes control
04 Self-Efficacy	Improve efficiency and productivity, but difficult to measure	Potential cost savings, reduced hospital use, increased productivity, though time and resources remain barriers

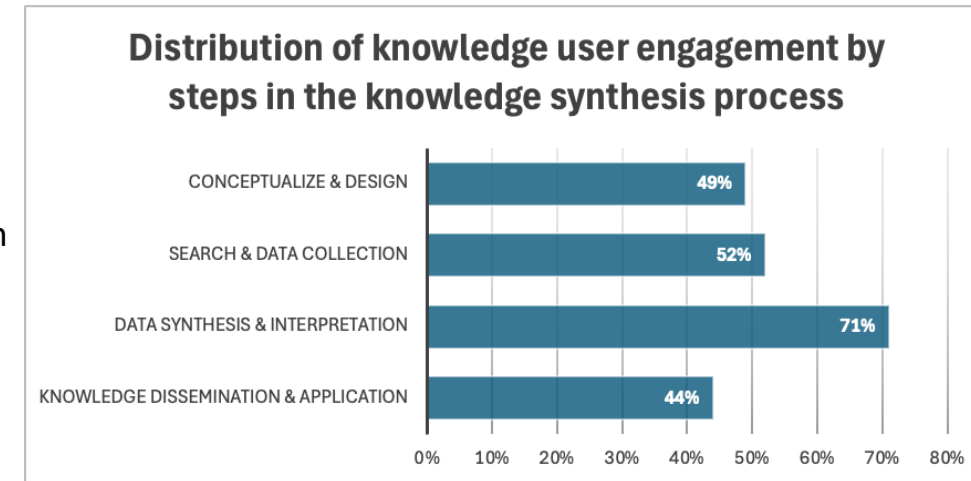
Value of Patient and stakeholder engagement in systematic reviews?



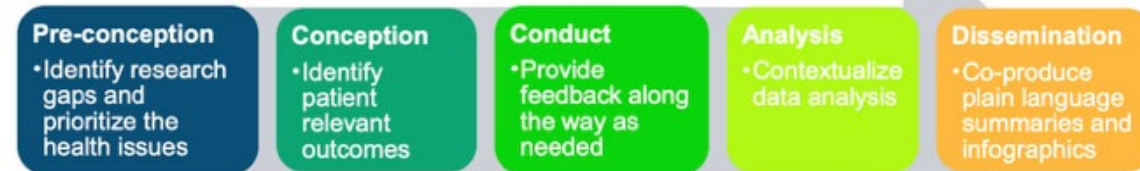
*Note: One eligibility criterion for this review was that the article must mention engagement with either policymakers or health system level decision-makers. Each individual knowledge user can represent multiple categories.

Key Findings

1. Engagement in systematic reviews is often concentrated at the beginning (topic consultation) and end of the process (interpret data synthesis)
2. Stakeholders in systematic reviews often includes policy-makers, health system managers, policy analysts, healthcare organizations, government agencies in addition to patients and caregivers



What stages of a knowledge synthesis can you engage patient and public partners?



Tricco, A.C., Zarin, W., Rios, P. *et al.* Engaging policy-makers, health system managers, and policy analysts in the knowledge synthesis process: a scoping review. *Implementation Sci* 2018; 13, 31. doi.org/10.1186/s13012-018-0717-x

Domecq, J. P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., Brito, J. P., Boehmer, K., Hasan, R., Firwana, B., Erwin, P., Eton, D., Sloan, J., Montori, V., Asi, N., Abu Dabrh, A. M., & Murad, M. H. (2014). Patient engagement in research: a systematic review. *BMC Health Services Research*, 14(1), Article 89

How to Measure and Report Patient Engagement?



Category	Framework / Tool	Purpose
Reporting & Documentation	GRIPP2 (Guidance for Reporting Involvement of Patients and Public)	Standardized reporting checklist used to improve transparency and consistency in reporting patient/public involvement in research.
	CORE Framework (Critical Outcomes of Research Engagement)	Framework used to identify and evaluate short- and long-term outcomes of engagement, including patient-centeredness, collaboration, rigor, legitimacy, transparency, feasibility, and sustainability.
Evaluation of Engagement Outcomes	Multi-Stakeholder Framework with Metrics	Framework developed to evaluate patient engagement in medicine development using measurable stakeholder-focused metrics.
	Seven-Item Questionnaire	Evaluates engagement outcomes such as representativeness, diversity, transparency, dissemination, and research relevance.
	PEIRS-22 (Patient Engagement in Research Scale)	Measures the quality and meaningfulness of patient engagement experiences in research projects.
	PPEET (Public and Patient Engagement Evaluation Tool)	Evaluates participant experiences and key features of engagement initiatives such as trust, support, satisfaction, and collaboration.
	WE-ENACT (Ways of Engaging- ENGagement Activity Tool)	Measures stakeholder roles, activities, and perceived influence throughout the research process.
Engagement Process & Research Phases	ACTIVE / Analytical Framework	Organizes engagement across research phases (preparatory, execution, translation) and examines methods, barriers, and outcomes of engagement.
Participation & Partnership Models	IAP2 Spectrum of Public Participation	Describes levels of engagement and partnership between researchers, patients, and the public.
Psychosocial / Conceptual Models	Patient Health Engagement (PHE) Model	Psychosocial framework focused on emotional, cognitive, and behavioral dimensions of engagement.



IMAGINE's Patient Research Partners (PRPs) and Patient And Community Engagement Research (PaCER)



- Patient Research Partners (PRPs) roles in IMAGINE:
 - Members of Governance Committees
 - Theme Working Group members
 - Patient Research Partners on Research Projects
- Building capacity by training individuals with lived experience in qualitative research through PaCER program
- PRP's conduct and publish research, for example:

Rines, J., Daley, K., Loo, S., Safari, K., Walsh, D., Gill, M., Moayyedi, P., Fernandes, A., Marlett, N., and Marshall, D. (2022). A patient-led, peer-to-peer qualitative study on the psychosocial relationship between young adults with inflammatory bowel disease and food. *Health Expectations : An International Journal of Public Participation in Health Care and Health Policy*, 25(4), 1486–1497.

Zelinsky, S., Daley, K., Neary, E., Mason, K., Bellissimo, G., DeNino, A., MacKean, G., Fernandes, A., Moayyedi, P., and Marshall, D. (2021). Improving patient participation in longitudinal research: An innovative patient-led patient-oriented qualitative research project to understand the motivations and barriers to getting and staying involved in the IMAGINE SPOR study. *Gastroenterology*, 160(3), S68–S69.



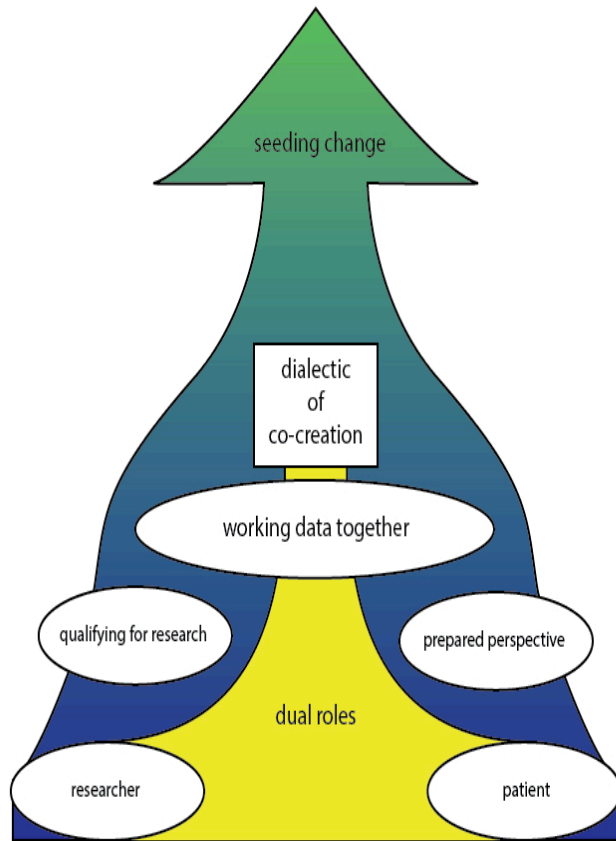
IBD National Team: The Mob: A peer-to-peer study on the psychosocial relationship between individuals with IBD and food



IBD Alberta Team: We've Got Guts: Exploring what resources IBD patients need after diagnosis

What is PaCER?

“Part of the Team”: Building New Patient Roles and Relationships in Health Research and Planning



Co-creation of PaCER role as ‘Twin Innovation’

3 major areas of impact:

- 1) increased capacity of patients to engage in healthcare research and planning
- 2) New roles for patients in health care planning – impacting attitudes and practices
- 3) New, collaborative roles for patients in research

Fundamental cultural change, and a way to embed and value patient role in research.

Shklarov S, Marshall DA, Wasylak T, Marlett NJ. “Part of the Team”: Mapping the outcomes of training patients for new roles in health research and planning. *Health Expectations* 2017;20:1428-36

Marlett N, Shklarov S, Marshall DA, Santana MJ, Wasylak T. Building New Relationships in Research: A Model of Patient Engagement Research. *Qual Life Res* 2015;24(5):1057-67.

PaCER Training



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- ~12-month, virtual certificate program offered by University of Calgary Continuing Education
- Patients/caregivers/community members learn about patient-engaged research and then develop, design and conduct a highly collaborative qualitative health research project



Practicum in research and consultation skills in patient and community engagement research

CPE
219 | 40 Hours | Online

Theoretical foundations in patient and community engagement research

CPE
221 | 40 Hours | Online

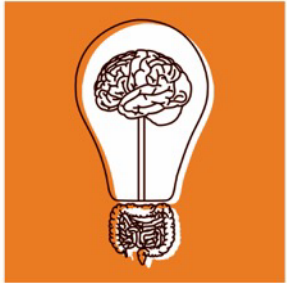
Internship in conducting patient and community engagement research

CPE 220 | 80 Hours | Online and field work



“Knowing what works in health care is of highest importance for patients, healthcare providers, and other decision makers.”

- Harvey V. Fineberg, M.D., Ph.D. President, Institute of Medicine February 2011 in Forward, Institute of Medicine. 2011. Finding What Works in Health Care: Standards for Systematic Reviews. Washington, DC: The National Academies Press



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Gastro-Intestinal & Neuropsychiatric Effects

Exploratory Study: Engaging patient partners in designing research on patient preferences (EP4)



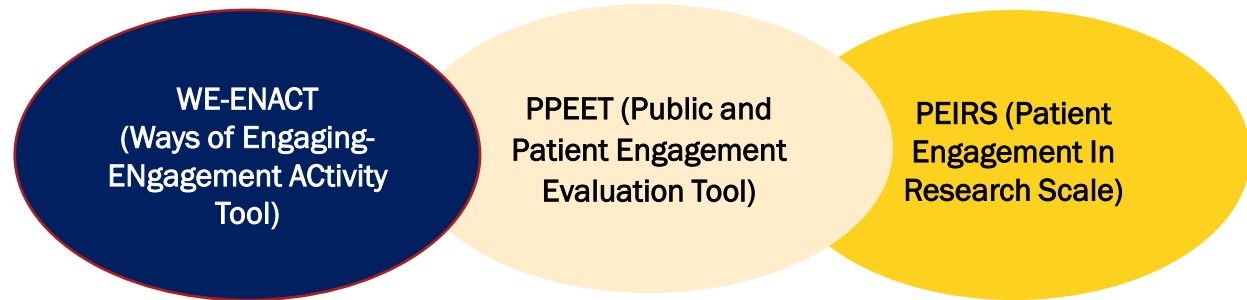
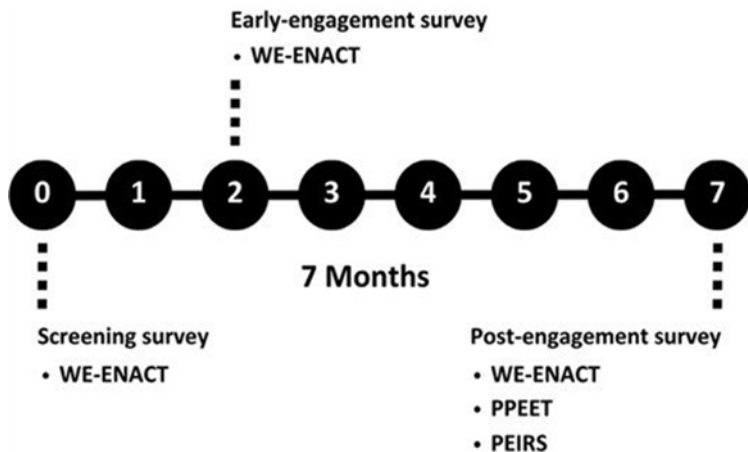
Objectives: Assess relationship between patient engagement and research outputs guided by patient vs researcher

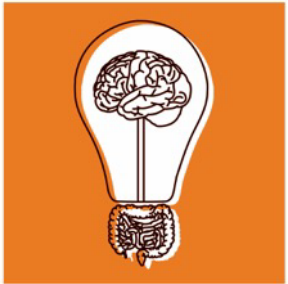
Study Design: Mixed methods observational comparative prospective study with two groups who independently conducted qualitative research

Measures:

- Compared the process, engagement and research outputs using direct observation, journey mapping and assessment of 11 Critical Outcomes of Research Engagement (COREs)
- Measured patient and researcher engagement using 3 PE survey instruments pre and post

	<i>Patient-Researcher-Led Group (n=7) PLG</i>	<i>Academic-Researcher-Led Group (n=7) RLG</i>
Patient research partners (PRPs)		
Clinicians		
Researchers		





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EP4 Assessment Critical Outcomes of Research Engagement (COREs)



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11 core outcomes and their measures

Measures impact of patient engagement on the research conduct and outcomes

Addresses short- and long-term outcomes of collaboration

Patient-centered

Meaningful

Team collaboration

Understandable

Rigorous

Integrity/
Adaptable

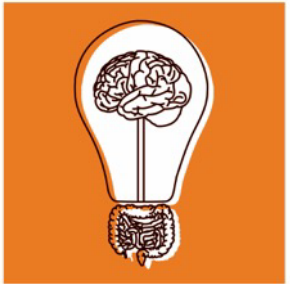
Legitimate

Feasible

Ethical and
Transparent

Timely

Sustainable



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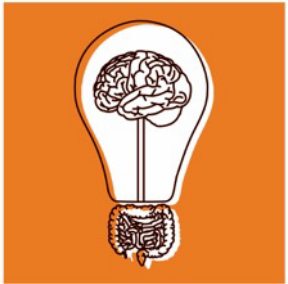
EP4: Impact of PE on Project Outputs



Patient research partners impacted the outcomes of the project

PLG/RLG	Patient Led Group (PLG)	Research Led Group (RLG)
Some overlaps, some unique Identified process and outcome attributes	<ul style="list-style-type: none">• 11 candidate attributes from patient interviews• More outcome attributes• Presented in patient-friendly language	<ul style="list-style-type: none">• 21 candidate attributes- (8 patient and 13 clinician interviews)• More process attributes• Presented in clinical/research terms

Marshall, D.A., Suryaprakash, N., Lavalley, D.C. *et al.* Studying How Patient Engagement Influences Research: A Mixed Methods Study. *Patient* 17, 379–395 (2024); Marshall, D. A., Suryaprakash, N., Lavalley, D. C., et al. (2023). Exploring the outcomes of research engagement using the observation method in an online setting. *BMJ Open*, 13(11), e073953



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EP4: PEIRS-22 Quality of Engagement



Based on meaningful experience -scores > cut-off points for deficiency for each of 7 domains

- PEIRS-22 total score for both groups was above cut-off point
- Mean domain scores above cut-off points on all domains for PLG group and deficient for 2 domains (team interaction and benefits) for RLG

	PEIRS 22 Total Score (100)	Procedural Requirements (31.8)	Convenience (13.6)	Contributions (13.6)	Team Environment & Interaction (9.1)	Support (9.1)	Feel Valued (9.1)	Benefits (13.6)
Patient Led Group (PLG)	89	30	12	12	8	8	8	11
Researcher Led Group (RLG)	73.2	24	10.6	9.6	6	6.6	7.4	9.2
Deficiency in meaningfulness Cut-off	70.1	22.3	9.6	9.6	6.4	6.4	6.4	9.6

Marshall, D. A., Suryaprakash, N., Bryan, S., et al. (2024). Measuring the Impact of Patient Engagement in Health Research: An Exploratory Study Using Multiple Survey Tools. *J Canadian Assoc Gastro*, 7(2), 177–187

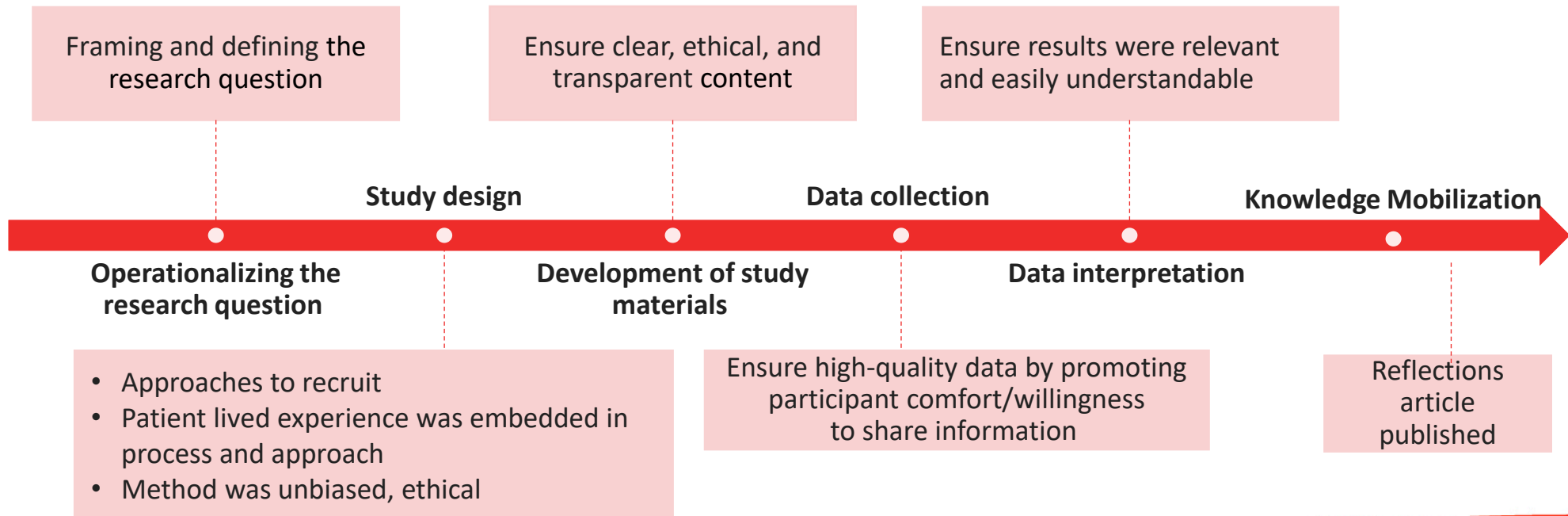
Hamilton Clayton B, Hoens Alison M, McKinnon Annette M et al. Shortening and Validation of the Patient Engagement In Research Scale (PEIRS) for Measuring Meaningful Patient and Family Caregiver Engagement." *Health Expectations* 24, no. 3 (2021): 863–79.



EP4 Overall Study Findings



- PRPs performed and/or provided insights that shaped the direction, methods, analysis, and/or outcomes across the research continuum
- Meaningful PE can influence every stage of health research leading to more patient-centered, understandable, ethical, relevant, and impactful research





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EP4: Does PE Matter?

YES – probably – it seems that patient-led engagement matters!

- 1) PRPs performed and/or provided insights that shaped the direction, methods, analysis, and/or outcomes across the research continuum
- 2) PE as measured by 3 PE instruments: PE for both groups was high, but PLG > RLG

...need further research

Future Directions

Although benefits from patient engagement are widely reported, future directions for research that would improve the evidence base and impact of engagement include:

- Generating high quality data to measure the impact of patient engagement
- Standardized evaluation methods
- Metrics for good patient engagement
- Consistent reporting
- Long-term measurement of impact

References Selected General Patient Engagement

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Thank you !

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