Measurement Matters
Literature Scan Findings

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Contents

Introduction

Background

Some funders require engagement of people most impacted by research in the design and implementation of research. However, researchers and practitioners often lack the tools to measure engagement activities, making it hard to assess the effect of engagement on research outcomes. **Measurement Matters** was chosen by the Patient Centered Outcomes Research Institute (PCORI) to develop and validate a tool that measures effective engagement in research. Measurement Matters is guided by a group of Technical Advisors with experience using engagement methods and by a Steering Committee composed of researchers and community partners with unique interest in diversity, equity, and engagement principles.

Project Aims

The Measurement Matters project aims to 1) develop a comprehensive PCOR Engagement Measure (PCOR-EM) and 2) assess content validity and reliability of the PCOR-EM in partnership with the National Patient-Centered Clinical Research Network (PCORnet®) (specifically with PCOR projects conducting research relevant to and including older adults).

Purpose

The Literature Scan is the first of four qualitative research activities conducted in year one of the Measurement Matters project to inform tool development. The goal of this literature scan is two-fold:

1) To help refine the conceptual definition of patient engagement in research.
2) To source a "bank" of potential PCOR-EM domains, measurable outcomes, and measurement concepts.

The Literature Scan employed a three phase Article Search, Selection, and Analysis process, described below, to build on (not duplicate) previous literature reviews and scans. Literature Scan findings established a foundation for PCOR-EM tool development and informed content for Measurement Matters' subsequent qualitative research activities: consensus methods, focus groups, and cognitive testing. Due to the short timeline of the Measurement Matters project, a rapid Literature Scan (vs. a traditional Literature Review) was utilized to refine the conceptual definition of engagement in research and source a "bank" of potential PCOR-EM elements. As such, decisions regarding the scope of Literature Scan activities were modified to accommodate project timeline and resource allocation. Reviewers are advised not to compare this rapid Literature Scan to traditional Literature Review protocols.

Literature Scan Methods

Led by the Qualitative Research Lead, the project leadership developed a Literature Scan protocol, which was informed by an examination of articles and best practices for systematic reviews. For instance, elements from the [Preferred Reporting Items for Systematic and Meta-Analyses (PRISMA) Framework](#) informed development of the Article Selection Quality Checklist and Inclusion and Exclusion Criteria.[i] Technical Advisor feedback, obtained through 1:1 discussions and a Literature Scan Survey, also influenced Research Team decisions regarding search terms, database selection, article inclusion and exclusion criteria, and the addition of key articles recommended by **Other Sources** (e.g. Technical Advisors, the PMT, the Steering Committee, and those cited in the systematic reviews featured in the Science of Engagement PFA).

Article Search

Research assistants searched for **Database Articles** including academic journal articles and "grey" literature (e.g. non-peer reviewed reports, working papers, documents, and other sources) related to engagement and measurement published *after* the November 2022 [Science of Engagement PCORI Funding Announcement (PFA)](#), which was informed by previous literature reviews and cited key texts relevant to the

science of engagement. Research assistants searched for relevant literature across nine databases, including:

- EBSCOhost
- Elsevier
- Google Scholar
- INVOLVE Publications Database
- PCORI Portfolio

- PCORI Engagement in Health Research Literature Explorer
- PsychINFO
- PubMed
- Web of Science

Research assistants used eight key search term combinations within each database and used advanced search filter options (**Table 1**). They then documented search results by key term combination in a Database Search Metrics Tracking file.

Table 1. Measurement Matters Database Key Search Terms and Advanced Search Filters

Key Search Terms
1) ("patient engagement" OR "patient participation" OR "patient involvement") and ("evaluate" OR "assess" OR "measure" or "framework") and ("research")
2) ("user engagement" OR "user participation" OR "user involvement" OR "user-led") and "research" and ("evaluate OR "assess" OR "measure" OR "framework")
3) ("community engagement" OR "community action" OR "community involvement") and ("research") and ("evaluate" or "assess" or "measure" or "framework")   a. **WITHOUT "FRAMEWORK"**: ("community engagement" OR "community action" OR "community involvement") and ("research") and ("evaluate" or "assess" or "measure")
4) ("stakeholder engagement" or "stakeholder involvement") and ("research") and ("evaluate" or "assess" or "measure" or "framework")   a. **WITHOUT "FRAMEWORK":** ("stakeholder engagement" or "stakeholder involvement") and ("research") and ("evaluate" or "assess" or "measure")

5) ("public engagement" or "public involvement") and ("research") and ("evaluate" OR "assess" OR "measure" OR "framework")
    a. **WITHOUT "FRAMEWORK":** ("public engagement" or "public involvement") and ("research") and ("evaluate" OR "assess" OR "measure")
    b. **WITHOUT "FRAMEWORK" AND ONLY MEASUREMENT IN 3RD BUCKET:** ("public engagement" or "public involvement") and ("research") and (measure)

6) ("collaborative engagement" and "research") and ("evaluate" or "assess" or "measure" or "framework")
7) "engagement measurement" and "scale"
8) "science of engagement measurement"

Advanced Search Filters (for academic database and grey literature searches)	
✓ Key Terms "In Title"	✓ English Language
✓ Peer Reviewed	✓ View Title and Abstract
✓ Published between November 2022-January 2024	

Advanced Search Filters (for PCORI Portfolio)	
Award Type	**Status**
✓ Research	✓ Completed
○ Research Conducted Using PCORnet®	✓ PCORI Peer Review (in PCORI peer-review process)
✓ Engagement in Research	

o Engagement Award Project	
✓ Dissemination and Implementation	**Year Completed**
✓ Research Infrastructure	✓ 2022
✓ Other Evidence Products	✓ 2023

Article Selection

Research assistants first conducted an **Initial Title and Abstract Screening** of key search term results and rejected any article not immediately related to engagement measurement and articles published prior to November 2022. The research assistants then tracked the number of irrelevant and relevant articles in the Database Search Metrics spreadsheet. As a result, 1,470 articles were identified through database searches, 1,396 records were excluded, and 73 articles were selected for full-text review. Duplicate articles identified through multiple database searches were eliminated.

Research assistants then conducted two rounds of **full text reviews** of the 73 database articles using the Measurement Matter's **9-item Quality Checklist** (**Table 2**) and **Inclusion and Exclusion Criteria** PRISMA Framework (**Table 3**) and documented article Checklist and Criteria adherence in the Inclusion and Exclusion Criteria and Quality Checklist Tracking file. Project leadership then reviewed this file to assess the strength, quality, and relevancy of articles identified through database searches and selected 24 eligible articles for full-text qualitative analysis.

Research Assistants also reviewed and tracked 65 key **Other Source** articles sourced from the Science of Engagement PFA or contributed by Steering Committee members, Technical Advisors, and Research Team members. No additional review of these files for appropriateness was required. Once duplicates were removed, 61 eligible Other Source articles moved forward for full-text qualitative analysis.

Results. 24 **Database Articles** and 61 **Other Sources** articles (N=85) met Quality and Inclusion Criteria and were included in full-text qualitative analysis.

Table 2. Measurement Matters Quality Checklist Items

Introduction	• Does it have a rationale? • Does it mention aims/objectives of the study? • Does it include a conceptual definition of engagement?
Methods	• Does it describe information or data sources used? • Does it describe measurable engagement domains, elements, or items? • Does it describe a measurement type (e.g. binary, scale, checklist, open or closed ended questions, etc.) OR a framework?
Results	• Does it describe findings?
Discussion	• Does it describe limitations? • Does it include conclusions?

Table 3. Measurement Matters Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
✓ Peer reviewed articles and/or grey literature resources ✓ English language OR translated publications ✓ Published after November 2022 ✓ Primary or Secondary Studies	× Articles measuring engagement of patient/user/community/stakeholders as subjects of research (e.g. data collected for a topic OTHER THAN

Inclusion Criteria	Exclusion Criteria

✓ Includes or aligns with definition of patient/user/community/stakeholder engaged research
✓ Measurement Tool/Framework Description Present (if a tool or framework exists). Examples:
   o Number of questions or domains explored by the tool
   o What was asked or evaluated through the tool/questions
   o How were things asked or evaluated (binary e.g. yes/no questions, checklist, open-ended questions, Likert scales, etc.)
   o Methods for completing the tool/questions, such as in-person, web-based, survey, focus groups, etc.
   o Who (lens) implemented the tool/questions
   o Who responded to the tool/questions
   o Who funded the tool/framework
✓ Engagement process present (if no tool exists). Examples:
   o List of topics addressed through engagement
   o Process used to conduct engagement
   o Who (type of lens) conducted engagement
   o Who (types of lenses) was engaged
   o Who funded engagement
   o If the engagement was measured or evaluated
   o What were their findings or lessons learned from the engagement process, if any
	engagement, such as focus groups or interviews to learn about diabetes)
	
	× Articles related to engagement in clinical environments (e.g. involvement in treatment, decision-making, care planning, data-collection, etc.)
	
	× Articles employing engaged research methods that do not feature the engaged research process, outcomes, or lessons learned (e.g., we did engagement, but we are not going to tell you anything about that process)

Article Analysis

Five members of the Research Team used NVivo qualitative data analysis software to complete theme-based full-text analysis of the 24 Database Articles and 61 Other Source Articles. Given the density of the sources and the time allocated to this project, some coders did not code all sources. PDF copies of all 85 articles were uploaded to NVivo for coding. The Qualitative Research Lead developed a high-level codebook for analysis and assisted with piloting of the coding process. The Research Team conducted thematic coding of the literature to capture conceptual definitions of engagement, measurement tools or frameworks present, or engagement processes present if no tool or framework was referenced (**Table 4).** The Research Team analyzed codes and identified primary themes and subthemes, which are fully documented in the Literature Scan Findings section below.

Literature Scan Findings

Terminology Used When Describing Engagement

Our literature scan found that most authors' work was formed in the context of geography, funding, and disciplines, leading to various terms used to describe patient engagement and broader community involvement in research.[ii] We noticed this play out in what authors named their engagement process (e.g., Community Based Participatory Research, Participatory Action Research, Patient and Public Involvement, and User-Involved Research). Also, terms describing the act of engagement, such as Involvement, Collaboration, and Participation, were used interchangeably by some authors to describe engagement while other authors used these terms to describe levels or types of engagement. For example, participation was used broadly to mean people taking part in a study; whereas others used participation to imply a level of shared ownership within the research process.

COMMONLY USED TERMS
• Patient Engagement
• Public Engagement
• Stakeholder Engagement
• Citizen Engagement
• Community-Led Activities
• Patient and Public Involvement
• Stakeholder Engagement
• Citizen Engaged Research
• User Led Research

Authors also used various terms to describe the individuals who are engaged, such as patient, stakeholder, and citizen.[iii] Some expressed a dislike for certain terminology, such as "stakeholder" (due to its roots in colonial violence) and "patient" (due to its medical connotation). Authors outside of the US referenced lenses such as Carer, Peers, and Contributors when discussing who is engaged in the research process. "Public" was often used to describe a specific group of people with a particular experience or to describe the range of people who may be engaged in research (patients, carers, peers...).

Conceptual Definitions of Engagement

When defining engagement, the most consistently referenced concepts were **partnership and collaboration**.[iv][v][OBJ] When using these terms, most authors emphasized the importance of engaging individuals as partners in research rather than as research subjects. According to the authors, individuals engaged should have some level of experiential knowledge or lived experience with the matter being studied and should be engaged through all stages of research. For instance, authors noted the importance of engaging partners with lived experience to identify priority topics for research; contribute to the design and conduct the research; and participate in the dissemination of the results.

ENGAGEMENT CONCEPTS
• Partnership
• Collaboration
• Shared Decision-Making
• Knowledge Sharing
• Two-way Learning
• Sharing Power
• Diversity, Equity, Inclusion
• Involvement

Authors also identified **shared decision-making** as key to engagement. Authors who described "Public Involvement" commonly recognized the importance of sharing ideas and knowledge and creating pathways for two-way learning between the researcher and those being engaged. Authors also recognized a sensitivity to power relations and the ability to share power as important to building trust and meaningfully engaging partners.

Authors also identified **diversity, equity, or inclusion** as key to engagement.[vi][vii] Authors stressed that engagement should ethically include groups who are known to be underrepresented, typically excluded, and/or experience inequities. Authors frequently addressed concepts of transparency, building trust, and managing power relations when referencing the importance of diversity, equity, and inclusion. Authors also

stressed the importance of diversity of experiences, not just demographics, among the people they involve. Other than different preferences for terminology, the literature did not contradict the Patient-Centered Outcomes Research Institute's (PCORI's) definition of engagement, which is:

> *"The meaningful involvement and partnership of patients and stakeholders throughout the research process, from planning and conducting research to disseminating research results."* [viii]

Expectations for Engagement

Authors consistently suggested the importance and demonstrated the value of implementing engaged research methods.[ix] [x] Authors frequently referenced an increased push for researchers to engage those being impacted by the topics they seek to study. Some authors noted an expectation from funders that patients and community members be involved in the actual design, conduct, and dissemination of research. Authors point to government institutions that have established policies that mandate or support engagement models within policy and/or research, including in the United States, the United Kingdom, and Canada. Organizations, such as the World Health Organization (WHO) and the National Institute for Health and Care Excellence (NICE), as well as patient advocacy groups are cited as promoting the engagement of patients in health research with the goal of improving health outcomes. Authors also noted growing expectations for engagement from ethics committees as well as academic and research institutes.

Reasons for Engagement

Authors point to the value and impact of effective engagement and how engagement could potentially enhance the quality of research activities. Specific reasons for implementing engaged research, according to this analysis, are described below.

Improve Research Methods. Authors suggest engaging patients, community members, and others leads to improved research methods across all phases of research.[xi] [xii] Through mutual learning, engagement reportedly increases researchers' understanding of issues that are relevant to what is being studied. This reportedly can then inform the prioritization of research topics that are reflective of and relevant to communities. Authors also report that engagement can challenge researchers' assumptions, revealing and potentially combating possible researcher bias and gaps in evidence the researcher may not have considered. Authors also noted that engagement led to better recruitment, including more effective messaging for better access to certain populations and reduced attrition rates. Some authors also suggested that engagement increases the dissemination and application of findings.

> **SUGGESTED OUTCOMES OF ENGAGEMENT**
> - Research Aligns with Community Priorities
> - Increased Knowledge and Informed Decision Making
> - Improved Trust of Researchers and Research
> - More Participant Involvement in Research
> - Improved Health Outcomes

Build Trust. According to the literature, when researchers engage community members, they improve relationships between researchers and the communities they study and build trust in the research findings.[xiii] [xiv] Researchers reportedly build trust through the clear delineation of roles, shared decision-making activities, and demonstrating mutual respect. If engaged effectively, authors report that

participants' improved trust in the research process and findings can guide positive individual or community action as well as increase likeliness of future participation in research.

Improve Clinical Outcomes. Authors propose that engagement in healthcare, including at the systems level where policies, programs, and services are designed, improves systems and health outcomes.[xv][xvi] Healthcare interventions may align better with patient's perspectives and patients' experiences of care improve.[xvii] Authors also suggested that engagement with health care professionals improves care coordination and health outcomes. Authors note when patients are engaged in health research, they better understand the evidence relating to treatment and care, which may lead to increased public trust and motivation to participate in their health care.

Barriers to Engagement

In the scan of the literature, authors referenced barriers to engagement more than one hundred times. By barriers we mean any factor, as reported by the author, that may challenge or prevent the effective engagement of patients, partners, community members, or the public. The most prevalent barrier noted was the assumption that researchers and community partners have **different priorities,** which may impede the progress or quality of a project.[xviii] For example, some authors discuss how individuals may prioritize their own needs over participating in a research project; a researcher's aim may conflict with a community's needs or priorities; and individuals may challenge researchers' ideas or methodologies. Authors also referenced how some researchers and communities prioritize professional knowledge over patient experience. Authors also noted that some researchers see engaged research as bias or partisan and thus inferior to traditional research.

The second barrier to engagement, according to the literature, is **insufficient funding for engagement**.[xix][xx] Authors report insufficient financial resources to fund effective engagement, which often includes compensation for partner's time and commitment; accessibility expenses, such as language translations and interpreter services; the cost of meeting spaces, equipment, and materials; and the cost of the facilitator's time managing and coordinating the engagement process. Some authors discuss how funds are needed even before a project is awarded to support proper community engagement in project design.

Authors also point to **difficulties reaching diverse communities**, the third most prevalent barrier noted in the literature.[xxi][xxii] Authors note challenges associated with engaging unique populations, such as minority ethnic groups, people with disabilities, older people, and other hard-to-reach groups. Authors commonly note that that this often leads to the exclusion of important perspectives. Even when these unique communities are reached, authors note facilitators can lack the knowledge and skills required to engage the communities effectively. For example, individuals from certain cultures may find it inappropriate to talk about their personal health; this requires a researcher in a health-related study to be aware of and sensitive to the partner's cultural norms. Authors also point to similar obstacles, including researchers' use of unfamiliar terminology and jargon; not providing training and support to those who may lack knowledge of the topic; and not considering accommodation needs of those engaged.

Another significant barrier to engagement, according to the literature, is **time**.[xxiii][xxiv] The literature points to a disconnect between the time it takes to conduct engagement and the time allowed to complete a project for which engagement is important. According to the literature, those implementing engagement often underestimate the time it takes to recruit, train, engage, and collaborate with partners. Authors recognize that both facilitators and community partners can experience time constraints in their personal and professional lives that make engagement, especially engagement that influences decisions, difficult. Project timelines and funding requirements (e.g. deliverable due dates) reportedly also affect the ability for researchers to methodically engage community partners.

Authors noted **tokenism** as a considerable barrier to meaningful engagement.[xxv][xxvi] Tokenism reportedly occurs when there is an appearance of inclusion, but community partners' contributions are not actually impacting the design of the research, policy, or program. This occurs when the facilitator of engagement lacks the skills to effectively engage and/or does not value the importance of engagement. Authors also noted that some researchers may go through the engagement 'motions' to satisfy reporting requirements of funders and ethics committees, but that failure to compensate and prepare partners to actively participate in the process leads to engagement falling short.

The literature also identifies the difficulty of **recruiting and retaining partners** as a barrier to engagement.[xxvii][xxviii] This is largely associated with many of the barriers above, including the inability to engage underserved populations; identify people with relevant skills and experience; access resources to provide an accessible and accommodating experience; and manage time constraints. Authors noted that setting clear expectations and defining roles could help with recruitment and retention. The literature showed that when the roles of the partner were clearly defined early in the process, and the level of commitment was communicated, there was more trust, better attitudes, and partners stayed engaged.

Ethical Considerations for Engagement

Many of the sources[xxix] described growing debates on the ethics of engagement and unique topics that must be considered when measuring engagement to ensure ethical practice. For one, there is an overarching theoretical debate within the literature about whether engagement is a 'democratic right,' and if so, whether this right takes priority over measurement and outcomes. Even if engagement is seen as a right, the literature[xxx] also recognizes potential 'deficits" within our democratic process given most people who engage are "white, middle class, retired people." The International Collaboration of Participatory Health Research[xxxi] developed seven "Ethical Principles" which should be considered when implementing engagement. These are:

1. Mutual Respect
2. Equality and Inclusion
3. Democratic Participation
4. Active Learning
5. Making a Difference
6. Collective Action
7. Personal Integrity

Through this Literature Scan, additional ethical topics cited by researchers for future research and exploration included: confidentiality and data sharing practices; conflicts of Interest; fair compensation; power differentials; tokenism, and virtue signaling.

Engagement Frameworks

A total of 24 frameworks were referenced within this Literature Scan. Arnstein's Ladder of Citizen Participation was referenced the most,[xxxii] followed by the Public Involvement Impact Assessment Framework (PiiAF),[xxxiii] and the Critical Outcomes of Research Engagement (CORE) Framework.[xxxiv] Our analysis categorized these frameworks in three classifications:

Type 1: Continuum of Engagement Frameworks: Frameworks that address the continuum of engagement (e.g., ladders delineating level of decision making or power of patients in engagement)

Type 2: Factor Frameworks: Frameworks that address the factors influencing engagement (e.g., personal characteristics, process, and society influences)

Type 3: Impact Frameworks: Frameworks that address the impact or outcomes of engagement (e.g., trust and improved research design).

Below, we review sample frameworks found within the literature.

Continuum Frameworks

Continuum of Engagement Frameworks present hierarchical structures, such as a ladder or continuum, to delineate various levels of engagement. **Table 6** outlines specific frameworks' purposes and uses. While these frameworks share similarities, they also exhibit notable differences in target population and application. Arnstein's[i] and Hart's[xxxv] Ladders and the TYPE pyramid[xxxvi] primarily center citizen participation in community development and various contexts of public engagement. On the other hand, the Multidimensional Framework for Patient and Family Engagement in Health and Health Care[xxxvii] framework focuses explicitly on patient and family engagement within healthcare settings. The domains considered in these frameworks are multidimensional and context dependent. Considerations such as trust and communication are featured across multiple frameworks. Power dynamics, citizen control, and partner empowerment emerge as central factors in Arnstein's Ladder[i], Spectrum of Public Participation[xxxviii], and the TYPE Pyramid[xiv]. The Multidimensional Framework for Patient and Family Engagement in Health and Health Care[xxxix] includes dimensions like decision-making involvement and collaboration with healthcare providers.

Table 6. Continuum Frameworks Found in the Literature Scan

Continuum of Engagement Frameworks	
Name	**Purpose/Use (Summarized Directly from Source Documents)**
Arnstein's Ladder of Participation [i]	Describes eight 'rungs' to represent progressive degrees of less or more meaningful citizen participation, ranging from nonparticipation to degrees of tokenism and degrees of citizen power.
Hart's Ladder of Children's Participation [xx]	Distinguishes different approaches of engaging youth in research based on the degree of decision-making power held by youth at various stages of the research cycle.
Spectrum of Public Participation [xxiv]	Helps determine the level of participation that defines the public's role in a public participation process. This describes five general modes of public participation in democratic decision-making
Typology of Youth Participation and Empowerment (TYPE) Pyramid [xiv]	Categorizes and conceptualizes different levels of youth participation and empowerment in research, decision-making, and advocacy processes. It helps partners identify the level of youth participation appropriate for a given project or activity.
A Multidimensional Framework for Patient and Family Engagement in Health and Health Care [xxii]	Illustrates the different levels of patient and family engagement across the health care system via three categories of engagement activities: consultation, partnership, and shared leadership.
Treseder's Degrees of Participation [xxiii]	Reconstructed Hart's five levels of participation, shifting them out of a ladder, and into a non- hierarchical frame. The Degrees of Participation imagined different forms of engaging youth in research based on the degree of decision-making power held by youth at various stages of the research cycle.
Rowe and Frewer Framework[xl]	Describes different dimensions of public engagement in science and technology decision-making, including information provision, consultation, and deliberation. It is used to assess the effectiveness and legitimacy of public engagement processes.

Factor Frameworks

Factor frameworks emphasize various aspects that can, in theory, influence the success of engagement. These frameworks generally emphasize strategies that support meaningful and sustainable engagement while ensuring the inclusion of diverse perspectives and challenging power or hierarchal imbalances. **Table 7** details specific factor frameworks' use and purpose. Factor frameworks, collectively, aim to enhance patient and partner engagement across various stages of research, healthcare delivery, and policy development. However, the frameworks vary in terms of their scope, focus, and practical application. The Center for Medical Technology Policy (SMTP) framework[xli] for engagement and the Armstrong Framework for Continuous Patient Engagement[xlii] offer approaches to foster continuous decision-making processes. Similarly, the Integrated Knowledge Translation (IKT) model[xliii], the CIHR SPOR Patient Engagement Framework[xliv], Nabobo-Baba's (2008) Vanua Framework,[xlv] the Facilitate, Identify, Respect, Support, Trust (FIRST) model[xlvi], and the Patients Active in Research and Dialogues for an Improved Generation of Medicines (PARADIGM)[xlvii] outline the importance of and guidance for integrating diverse perspectives into research and healthcare practices.

Table 7. The Factors of Engagement Frameworks Found in the Literature Scan

Factors of Engagement Frameworks	
Name	**Purpose/Use (Summarized Directly from Source Documents)**
Center for Medical Technology Policy (SMTP) framework for engagement (10-Step Framework for Continuous Engagement)[iv]	Illustrates the inputs, methods, and outputs relevant to community engaged research; differentiates methods at each stage of the project; depicts the relationship between components; and identifies outcome measures for evaluation of the process.
Armstrong Framework for Continuous Patient Engagement[i]	Provides an approach for incorporating patient perspectives and experiences into healthcare research and decision-making processes to improve the relevance (and impact) of healthcare initiatives.
Integrated Knowledge Translation (IKT) Model[vi]	Facilitates the collaboration between researchers and knowledge users (e.g., policymakers, healthcare providers, patients) throughout the research process to ensure that research findings are relevant, accessible, and effectively applied in practice.
PAE Attention Framework[xlviii]	Provides a strong foundation for understanding and implementing meaningful and effective engagement across a broad range of program, policy, and research activities.
Patients Active in Research and Dialogues for an Improved Generation of Medicines (PARADIGM)[x]	Enhances patient involvement in drug development processes, improving research methodologies by ensuring that patient perspectives are integrated into decision-making.
Tufts-RAND 7Ps Taxonomy for Engagement[xlix]	Categorizes and organizes partner engagement activities in healthcare research across seven domains: planning, partnering, protocol development, project conduct, presentation, policy and practice change, and public and patient engagement.
PROGRESS-Plus Framework[l]	Guides researchers in considering social determinants of health (e.g., place of residence, race/ethnicity, occupation, gender, religion, education, socioeconomic status) and other relevant

Factors of Engagement Frameworks	
Name	**Purpose/Use (Summarized Directly from Source Documents)**
	factors when designing and analyzing health research. This framework is used to ensure that health interventions and research studies are *equitable, inclusive,* and *address the needs of diverse populations*.
Conceptual Framework Guiding Proposed Design and Methodology[li]	Provides a conceptual basis for understanding the potential impact of engagement activities on research processes and outcomes. Framework can be used by researchers to plan and implement engagement strategies.
CIHR SPOR Patient Engagement Framework[vii]	Guides the meaningful involvement of patients in health research through the Strategy for Patient-Oriented Research (SPOR) initiative in Canada. Framework emphasizes partnership, collaboration, and capacity-building.
Nabobo-Baba's (2008) Vanua Framework[viii]	Conceptualizes community engagement and empowerment within the context of Pacific Island societies, emphasizing indigenous knowledge, cultural values, and community participation.
Facilitate, Identify, Respect, Support, Trust (FIRST)[x]	Helps to guide and foster structural partnerships between patients and professionals in health research projects.
Tritter's Conceptual Framework[lii]	Used to inform the design of patient engagement strategies that promote transparency, accountability, and inclusivity in decision-making which would enhance the relevance and impact of health policies and programs.

Impact Frameworks

Impact Frameworks address the measurement of the impact or outcomes of engagement (e.g., trust, partner satisfaction, and improved research design). The impact frameworks recognize the importance of evaluating the outcomes and effectiveness of engagement activities to understand their value and contribution to research processes. The frameworks provide guidance on the evaluation and improvement of patient and partner engagement, but can differ in their specific approach, setting, domains of assessment, and methodologies of assessing engagement. **Table 8** describes each framework's use and purpose. Many of the frameworks take a comprehensive approach to impact assessment, considering multiple dimensions or domains. These may include changes in research priorities, methodologies, outcomes, policies, practices, and the experiences of partners involved in the research process. The frameworks prioritize capturing the perspectives and experiences of diverse partners, including patients, caregivers, researchers, policymakers, and community members. Four of the seven frameworks (PCOR engagement Rubric[liii], Public Involvement Impact Log[liv], CORE[iii], and PiiAF[ii]) recognize impact across more than one level, such as individual, project, organization, system, community, or society level.

Table 8. Impacts Frameworks Found in the Literature Scan

Impacts of Engagement Frameworks	
Name	**Purpose/Use (Summarized Directly from Source Documents)**
Critical Outcomes of Research Engagement (CORE) Framework by Dillon et al., 2017[iii]	Provides guidance on the measurement of impact of patient and lay person involvement in research.
Patient Engagement Monitoring and Evaluation Framework[lv]	Provides guidance to healthcare organizations, research institutions, and patient advocacy groups on the measurement of effectiveness and outcomes of patient engagement activities in healthcare research and decision-making over time.
The Public Involvement Impact Assessment Framework (PiiAF)[ii]	Provides guidance in the design and assessment of the impact of public involvement in health research.
The Public Involvement Impact Log[xvi]	Provides guidance on how to track the outcomes of involvement activities at different levels and their cumulative effects on research quality, relevance, and uptake.
Youth Engagement Framework by Pancer and colleagues[lvi]	Conceptualizes the potential impacts of youth engagement in research across multiple levels.
Engaging Youth in Bullying Prevention Through Community-based Participatory Research (EIPARS) Model[lvii]	Provides guidance to assess the impact of youth engagement on research processes, intervention outcomes, and community change in youth bullying.
PCOR Engagement Rubric[xv]	Outlines criteria for assessing the quality and effectiveness of engagement activities.

Tools and Measures to Evaluate Engagement

There are numerous tools available for use by researchers to approach evaluating engaged research. This literature scan (not exhaustive) identified fourteen. These tools share a common goal of assessing an element of engagement in research, but differ across their scope, specific focus, and methodology. **Table 9** outlines Measures and Tools used to evaluate engaged research found across the literature scan. Measures developed by organizations like PCORI (PCORI Engagement Activity Inventory, PCORI Engagement Awards Evaluation Reporting Tool) may be tailored to the context of patient-centered research, whereas others, such as PEIRS/PEIRS-22, are designed to assess the impact of public engagement in research projects, capturing the broader outcomes and effects of engagement efforts. Despite differences in scope and application, all measures contribute insights into understanding engagement in research endeavors.

Table 9. Measures and Tools used to evaluate Engaged Research found across the literature scan.

Sample Tools and Purpose	
Tool Name	**Purpose/Use (Summarized Directly from Source Documents)**
Community Engagement Research Index (CERI)[lviii]	CERI measures are designed to measure and evaluate community engagement in research activities. The CERI assesses the extent and quality of collaboration between researchers and community members throughout the research process, measures engagement in research by tracking and quantifying community involvement, and monitors changes in engagement levels over time.

Sample Tools and Purpose	
Tool Name	**Purpose/Use (Summarized Directly from Source Documents)**
Evaluation Involvement Scale (EIS)[lix]	EIS measures the construct of partner involvement use within multi-site evaluation settings in which local project level evaluators are partners in larger program-level oversight evaluations.
Measurement Approaches to Partnership Success (MAPS)[lx]	MAPS measures the effectiveness of partnerships in various projects or initiatives. MAPS evaluates the dynamics, strengths, weaknesses, and outcomes of partnerships, providing insights into the level of engagement and collaboration within these partnerships.
Partnership Assessment in Community-based Research (PAIR)[lxi]	PAIR measures partnerships between community members and researchers. The PAIR measure encourages partners to assess the fundamental characteristics of a strong partnership, including open and honest communication, equitable collaboration, shared partnership values, and a plan for sustaining the partnership.
Patient Engagement in Research Scale (PEIRS)[lxii]	PEIRS measures the impact of public engagement activities in research, including what patient partners value as the essential elements of meaningful engagement in research.
Patient Engagement in Research Scale-22 (PEIRS-22)[lxiii]	PEIRS-22 is an extension of PEIRS, offering a more comprehensive measurement of public engagement impact. PIERs-22 enables standardized assessment of engagement in research across various contexts and provides a structured approach to evaluate the meaningfulness of engagement as well as the broader impact of public engagement on partners and society as a whole.
Participatory Evaluation Measurement Instrument (PEM)[lxiv]	PEM measuresparticipation based on 3 fundamental dimensions: diversity of participants, extent of involvement, and control of the evaluation process.
PCORI Engagement Awards Evaluation Reporting Tool[lxv]	PCORI Engagement Awards Evaluation Reporting Tool assesses outcomes for Reach, Engagement, Adoption, and Implementation to learn best practices and innovative ways to ensure that patients, communities, and other partners' voices are represented in research.
PCORI Engagement Activity Inventory[lxvi]	PCORI Engagement Activity Inventory captures researchers' experiences with patient and other partners engagement in research and the role of patients and other health care partners in research projects and overall process from the researcher's point of view.
Public Involvement Impact (PPI) Log[lxvii]	PPI log enables both patients and researchers to report and reflect on learnings, immediate outcomes and longer-term impacts following any given public activity. It can be used longitudinally throughout the research cycle as a space for both public and researchers to consider their own role and learning. This tool is used to track and evaluate the impact of public involvement in research projects. It measures the influence of public involvement activities on various aspects of research, such as study design, participant recruitment, and dissemination, thereby assessing the level of engagement and contribution of the public.
Public and Patient Engagement	PPEET measures the engagement of partners in public health research. PPEET consists of three questionnaires -participant, project, and organization questionnaires - developed to measure the processes, outputs, and perceived

Sample Tools and Purpose	
Tool Name	**Purpose/Use (Summarized Directly from Source Documents)**
Evaluation Tool (PPEET)[lxviii]	impacts of engagement activities in health system organizations from the perspectives of patient partners/advisors, staff, and organizational leaders.
Research Engagement Survey Tool (REST)[lxix]	REST measures community perspectives about the quality of activities (how well) and their frequency using a five-point Likert scale across eight principles: 1) focus on community perspectives and determinants of health, 2) partnership is vital, 3) partnership sustainability to meet goals and objectives, 4) foster co-learning, capacity building, and co-benefit for all partners, 5) build on strengths and resources within the community, 6) facilitate collaborative, equitable partnerships, 7) involve all partners in the dissemination process, and 8) build and maintain trust in the partnership.
Ways of Engaging-ENgagement ACtivity Tool (WEENACT)[lxx]	WEENACT measures researchers' experience with patients' and other partners' engagement in research by documenting the role of patients and other health care partners in research projects.

Source Bank of Domains, Measurement Concepts, Outputs and Outcomes

Numerous factors relevant to engagement were identified in the literature when authors presented frameworks and described their findings. We used McGaffigan's PAE Attention Framework (2011) to categorize these concepts into sample domains, measurement concepts, and outcomes as described below (**Table 10**).

Table 10. Sample Domains, Measurement Concepts, Outputs and Outcomes

Sample Domains and Measurement Concepts			
PEOPLE Values, Skills, Knowledge, Experience	• Aligned Interests • Authentic/ Genuine • Collaborative • Confidence • Diversity • Experience/ Expertise	• Good Will Flexibility • Health Literacy • Health Status/Functioning • Integrity • Knowledge • Language Literacy	• Leadership • Motivation • Power Resources • Skills • Time • Values & Beliefs
APPROACH Purpose, Preparation, Methods, Support	• Accessible/ Accommodations • Budgets • Building/ Maintaining Relationships • Capacity Building • Clear Purpose • Clear Roles • Aligned Interests • Communication • Compensation • Conflict	• Decision Making • Documentation/ Accountability • Facilitation • Feedback Loop • Financial Resources • Follow-Up • Heard/ Listen • Information Shared • Impact • Meeting Frequency	• Mode of Engagement • Needs Identified • Outreach • Plain Language • Power • Preparation • Representation • Time & Resources • Training • Support

ENVIRONMENT Buy-In, Readiness, Funding, Demand	• Buy-In/ Readiness • Culture of Expertise • External Policies and Regulations	• External Push for Change Funders/ Funding • Internal Push for Change	• Leadership Style • Decision Making Style • Social Norms • Transparency
Sample Outputs and Outcomes			
Outputs/ Indicators of Change	• Active/Mutual Learning • Collective Action • Democratic Participation	• Empowerment • Equity and Inclusion • Making a Difference	• Mutual Respect • Synergy • Trust
Mid or Long-Term Outcomes	• Buy-In for Change • Civic Productivity • Cost Savings • Improved Recruitment • Enhanced Relevance and Usefulness of the Research	• Improved Data Collection • Informed Decision Making • More Involvement	• Network Building • New Knowledge • Personal Growth

Key Takeaways

The Literature Scan identified several key takeaways. For instance, despite differences in language due to authors' geographic origin, funding source, and discipline, we found some consistency across sources in definitions of engagement, levels of engagement, and phases of engagement. Also, very few authors focused on unique or 'best' methods of engagement. Instead, most authors described the factors that influenced engagement rather than how these factors were implemented. This aligns with feedback from our partners, who consistently indicated that a focus on 'best' methodology is misguided. We also identified an abundance of frameworks within the literature, but little consensus is found among authors on the 'best' frameworks. When frameworks were presented, the majority focused on a continuum of engagement of the factors influencing engagement as opposed to the impact of engagement. Notably, there is debate within the literature whether engagement can or should be measured given its complexity of variables and the importance of democratic participation. Even so, most authors called for advancement in engagement measurement to help improve practices and demonstrate impact. Finally, the Measurement Matters project has adopted the PAE Attention Framework[lxxi] as the foundation for conceptual measurement; the literature scanned does not contradict this framework as a meaningful lens in which to organize engagement concepts for measurement.

Technical Advisor Input and Review

The Measurement Matters Research Team engaged seven Technical Advisors (TAs), which include experts with experience as engaged researchers, engagement facilitators, and community partners, throughout the Literature Scan design, implementation, and interpretation of findings. TAs informed the Literature Scan search term bundles and inclusion and exclusion criteria through a planning survey. TAs also suggested

articles, frameworks, and other literature foundational to engagement. This indicated a limitation in our Literature Scan as work deemed vital by engagement experts was not present in academic database searches. To account for this gap, we included TA suggestions among the **Other Sources** analyzed. The need for the **Other Source** category may indicate a gap in the literature, preventing researchers from accessing essential engagement literature, including literature about engagement measurement.

Additionally, TAs reviewed our preliminary Literature Scan Findings Report and discussed findings with our Research Team to provide clarity and organizational suggestions, challenge and expand upon our interpretation, and inform next steps for future project activities. For instance, TAs extensively reviewed the sample domains and measurement concepts that resulted from the Literature Scan and provided clarifications, such as calling out 'Capacity Building' and 'Training' as separate approach concepts and specifically identifying 'Enhanced Relevance and Usefulness of the Research' as an outcome.

This report highlights the findings from the literature scan; however, due to our engagement process, our team captured additional feedback from TAs not incorporated in this report. TAs provided suggestions to the sample domain and measurement concepts, which were not corroborated by the Literature Scan findings. These are:

- 'Researcher and community reputation' as a potential people factor that may influence engagement success
- 'Opportunity for reward, recognition, or other career benefits due to conducting engagement' as a potential environmental factor that may influence engagement success
- 'Competing priorities' as a potential environmental factor that may influence engagement success

The lack of corroboration in the findings may indicate gaps in the literature. The Measurement Matters Research Team captured these suggestions for further investigation throughout project activities. Additionally, TAs offered challenges and alternatives to our conceptualization of 'outputs/indicators for change.' For instance, TAs noted that 'Democratic Participation' may relate to a decision-making process distinct from engagement, rather than an output, adding an additional layer to the debate within the literature. Some TAs suggested that concepts such as 'Mutual Respect' and 'Trust' may be prerequisites for successful engagement; however, suggestions from other TAs supported findings from the literature, indicating that these concepts emerge from effective engagement approaches. The Measurement Matters Research team captured this feedback to ensure future activities dive deeper into the relationship between effective engagement approaches and these indicators for change.

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