

**BROADLY ENGAGED TEAM SCIENCE IN CLINICAL & TRANSLATIONAL RESEARCH
RESOURCE GUIDE**

This bibliography is intended to offer sources for further information. As a curated, abbreviated list, it is not comprehensive. Because broadly engaged team science is a new topic, we have drawn upon publications addressing stakeholder-engaged research, team science, comparative effectiveness research, and implementation research, among others. The publications address concepts and theories, implementation strategies and practices, methodological considerations, and evaluation. Several publications offer tools and practical guidance.

Methods and Organization

Relevant literature was identified by searching bibliographic indices, supplemented by informal recommendations. Citation databases (the National Library of Medicine PubMed; Elsevier Scopus; Clarivate Analytics Web of Science) were searched for articles published since 2010 addressing interdisciplinary research collaboration and the engagement of stakeholders and communities in academic research. The Engagement in Health Research Literature Explorer, a sortable bibliography maintained by the Patient-Centered Outcomes Research Institute, was an important source of citations, as were a number of reviews of patient and stakeholder engagement (Concannon, 2014; Domecq, 2014; Shippee, 2013), the science of team science (Cooke, 2015; Hall, 2019), and academic and community engagement (Perkmann, 2019; Salsberg, 2015).

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CONCEPTUALIZATIONS AND THEORY

Fransman J (2018) Charting a course to an emerging field of 'research engagement studies': a conceptual meta-synthesis. Research for All 2:185-229. doi:10.18546/RFA.02.2.02

This article provides a broad overview of how participatory research has been conceptualized in a range of academic fields and sectors of policy and practice (higher education; science and technology; public policy (health, social care, and education); international development; and community development). The author reviews the themes and approaches characterizing engagement in these specific contexts before proposing a framework to identify commonalities and enable comparative studies of the diverse purposes, participants, processes, practices, and products that have evolved.

Frank L, Forsythe L, Ellis L, Schrandt S, Sheridan S, Gerson J, Konopka K, Daugherty S (2015) Conceptual and practical foundations of patient engagement in research at the patient-centered outcomes research institute. Qual Life Res 24 (5):1033-1041. doi:10.1007/s11136-014-0893-3

This paper describes the concept of “meaningful engagement” adopted by the Patient-Centered Outcomes Research Institute to guide many aspects of its work, including how it sets research

priorities, structures funding programs, and reviews the proposals it receives. A set of principles considered foundational to patient-centered outcomes research are identified and discussed in relation to the goals and processes of engagement.

Tebes JK, Thai ND (2018) Interdisciplinary team science and the public: steps toward a participatory team science. *Am Psychol* 73 (4):549-562. doi:10.1037/amp0000281

This paper presents a concept of participatory team science, which emphasizes the inclusion of public stakeholders on science teams as co-producers of knowledge. Active and meaningful engagement of the public can enhance research on complex problems and promote justice but achieving these goals requires a different organizing framework for team science. The article summarizes work on public engagement in science, describes opportunities for various types of engagement, and provides an example of participatory team science carried out across research phases.

Ray KN, Miller E (2017) Strengthening stakeholder-engaged research and research on stakeholder engagement. *J Comp Eff Res* 6 (4):375-389. doi:10.2217/cer-2016-0096

This article summarizes current literature describing the underlying values, processes, and potential impacts of stakeholder engagement undertaken in comparative effectiveness and health outcomes research. Key concepts are synthesized to form a conceptual model of the hypothesized impacts of engagement activities that relates a given project's context, the practices employed, and outcomes over time. The authors drawn on the model to formulate guidance for planning, reporting, and evaluating projects. They also include an explanatory grid mapping such values onto the processes where they might be most clearly reflected.

Israel BA, Schulz AJ, Parker EA, Becker AB (1998) Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health* 19:173-202. doi:10.1146/annurev.publhealth.19.1.173

This review provides a synthesis of key principles of community-based research, discusses rationales for its use, and explores major challenges and facilitating factors and their implications for conducting effective community-based research aimed at improving the public's health. Eight key principles of community-based research are identified: community is recognized as a unit of identity; research builds on strengths and resources within the community; research involves a collaborative partnership in which control is shared over all phases of a process; knowledge and action are integrated for mutual benefit of all partners; co-learning facilitates the reciprocal transfer of knowledge, skills, and capacity; the research process is cyclical and iterative; health is addressed from both positive and ecological perspectives; and the research seeks to disseminate the findings and knowledge gained to all partners involved.

Stokols D, Hall KL, Taylor BK, Moser RP (2008) The science of team science: overview of the field and introduction to the supplement. *Am J Prev Med* 35 (2 Suppl):S77-89. doi:10.1016/j.amepre.2008.05.002

The science of team science draws on diverse disciplinary perspectives to better understand and enhance the processes and outcomes of scientific collaboration. This article summarizes the major theoretical models that have been advanced to account for the circumstances under which team science initiatives are more or less effective. Key themes and promising directions for future research are organized around the following broad challenges: (1) operationalizing cross-disciplinary team science and training more clearly; (2) conceptualizing the multiple dimensions of readiness for team science; (3) ensuring the sustainability of transdisciplinary team science; (4) developing more effective models and strategies for training transdisciplinary

scientists; (5) creating and validating improved models, methods, and measures for evaluating team science; and (6) fostering transdisciplinary cross-sector partnerships.

Concannon TW, Meissner P, Grunbaum JA, McElwee N, Guise J-M, Santa J, Conway PH, Daudelin D, Morrato EH, Leslie LK (2012) A new taxonomy for stakeholder engagement in patient-centered outcomes research. J Gen Intern Med 27 (8):985-991.

doi:10.1007/s11606-012-2037-1

This article provides a framework for identifying relevant patient-centered outcomes research stakeholders. The framework distinguishes seven categories of possible stakeholders: patients and the public (including current and potential consumers of health care and population-focused public health, their caregivers, families, and patient and consumer advocacy organizations); providers (including individual care providers and healthcare organizations and systems); purchasers; payers; policy makers; product makers; principal investigators (including researchers and their funders).

Deverka PA, Lavalley DC, Desai PJ, Esmail LC, Ramsey SD, Veenstra DL, Tunis SR (2012) Stakeholder participation in comparative effectiveness research: defining a framework for effective engagement. J Comp Eff Res 1 (2):181-194. doi:10.2217/ce.12.7

This article presents a conceptual model for involving stakeholders in comparative effectiveness research. The definitions and model were developed from a literature search, expert input, and the experience of the Center for Comparative Effectiveness Research in Cancer Genomics. The proposed engagement methods will reflect individual project requirements but center on bidirectional communication and deliberation facilitated by the use of consensus and opinion synthesis methods such as nominal group technique and Delphi processes.

Falk-Krzesinski HJ, Börner K, Contractor N, Fiore SM, Hall KL, Keyton J, Spring B, Stokols D, Trochim W, Uzzi B (2010) Advancing the science of team science. Clin Transl Sci 3 (5):263-266. doi:10.1111/j.1752-8062.2010.00223.x

This paper presents the results of a concept mapping project done as part of the First Annual International Science of Team Science Conference, held in 2010. The exercise was aimed at setting a programmatic foundation for future research in the science of team science by generating a comprehensive taxonomy of relevant issues. The resulting concept map categorizes concerns into eight thematic clusters: definitions and models; measurement and evaluation; disciplinary dynamics; structure and context for teams; institutional support and professional development for teams; management and organization for teams; and characteristics and dynamics of teams.

Boaz A, Hanney S, Borst R, O'Shea A, Kok M (2018) How to engage stakeholders in research: design principles to support improvement. Health Res Policy Syst 16 (1):1-9. doi:10.1186/s12961-018-0337-6

This paper discusses stakeholder engagement, focusing on design principles drawn from existing literature and empirical insights from the authors' longitudinal study of stakeholder engagement. The design principles presented relate to organizational practices; principles that foster shared commitment; and principles to guide the practical aspects of planning and implementing a program of work.

STRATEGIES AND PRACTICES

Morain SR, Whicher DM, Kass NE, Faden RR (2017) Deliberative engagement methods for patient-centered outcomes research. *Patient* 10 (5):545-552. doi:10.1007/s40271-017-0238-8

This article provides practical guidance on deliberative engagement, a method to elicit preferences from patients and other stakeholders that the authors consider particularly useful for patient-centered outcomes research and other projects focused on complex health policy issues. The method is intended to generate qualitative and quantitative data on participant preferences informed by interactive deliberation between stakeholders and experts. Advantages and challenges of the approach are considered together with a description of its application.

Bennett LM, Gadlin H (2012) Collaboration and team science: from theory to practice. *J Investig Med* 60 (5):768-775. doi:10.231/JIM.0b013e318250871d

This article delineates characteristics and processes the authors consider essential to effective cross-disciplinary research collaboration. The authors summarize findings from their research and practical experience as well as literature in psychology, management, and organizational studies concerning team dynamics and group behavior. They also point to specific strategies teams can employ to avoid miscommunication and productively manage conflict.

Horowitz CR, Robinson M, Seifer S (2009) Community-based participatory research from the margin to the mainstream: are researchers prepared? *Circulation* 119 (19):2633-2642. doi:10.1161/CIRCULATIONAHA.107.729863

This paper discusses the increasing recognition that prevention and control of complex conditions require addressing an array of non-clinical issues that impact health. Using hypertension as an example, the authors discuss community-based participatory research and its benefits and challenges, before outlining ways investigators can integrate participatory approaches into research. Approaches are described for building partnerships and developing rules of operation and decision-making to guide study selection and design, funding and ethics review, research conduct and analysis, and the translation of findings into policy and practice.

Hobin JA, Deschamps AM, Bockman R, Cohen S, Dechow P, Eng C, Galey W, Morris M, Prabhakar S, Raj U, Rubenstein P, Smith JA, Stover P, Sung N, Talman W, Galbraith R (2012) Engaging basic scientists in translational research: identifying opportunities, overcoming obstacles. *J Transl Med* 10:72. doi:10.1186/1479-5876-10-72

This paper includes guidance to facilitate the participation of basic scientists in translational research. The authors give recommendations and examples of training and support systems that could facilitate a favorable environment for collaboration.

Salazar MR, Lant TK, Fiore SM, Salas E (2012) Facilitating innovation in diverse science teams through integrative capacity. *Small group research* 43 (5):527-558. doi:10.1177/1046496412453622

This paper addresses the challenge of integrating knowledge in teams composed of different stakeholders and the roles that social and cognitive processes play. The authors focus specifically on the unique challenges facing science hoping to generate novel knowledge.

Greenhalgh T, Hinton L, Finlay T, Macfarlane A, Fahy N, Clyde B, Chant A (2019) Frameworks for supporting patient and public involvement in research: systematic review and co-design pilot. *Health Expect* 22 (4):785-801. doi:10.1111/hex.12888

This article presents a comprehensive review of published frameworks for patient and public involvement in research. The 65 frameworks identified were critically examined, including

through a series of a workshops with patients and other nonacademic partners who considered the utility and usability of the tools. The authors consider such co-design workshops as particularly useful and often a necessary step to fitting pre-established frameworks to particular use cases and local circumstances.

Majchrzak A, More P, Faraj S (2012) Transcending knowledge differences in cross-functional teams. *Organization Science* 23 (4):951-970.

doi:doi.org/10.1287/orsc.1110.0677

Teams that bring together people from different disciplines or backgrounds often find that knowledge sharing can slow progress towards achieving a common goal. This article review approaches in the literature for overcoming these difficulties. Suggested approaches to sharing knowledge emphasize deep dialogue and require significant resources and time.

Drahota A, Meza RD, Brikho B, Naaf M, Estabillo JA, Gomez ED, Vejnaska SF, Dufek S, Stahmer AC, Aarons GA (2016) Community-academic partnerships: a systematic review of the state of the literature and recommendations for future research. *Milbank Q* 94 (1):163-214. doi:10.1111/1468-0009.12184

Community-academic research partnerships span disciplines, involve a variety of community stakeholders and focus on a large range of study topics. This paper reviews 54 unique partnerships to explore common influences on collaborative processes and outcomes. Twenty-three factors affecting interpersonal and operational processes were identified as either facilitating or hindering the formation of these community partnerships. The quality of relationships or communication among partners accounted for the majority of positive influences.

Fiore SM (2008) Interdisciplinarity as teamwork: how the science of teams can inform team science. *Small Group Research* 39 (3):251-277. doi:10.1177/1046496408317797

This paper discusses the implementation of principles from teamwork and team training to improve interdisciplinary research and the practice of team science. The author compares multiple levels of research, ways of translating theory into practice, and ways of improving interdisciplinary research and theory in team science.

Hoffman A, Montgomery R, Aubry W, Tunis SR (2010) How best to engage patients, doctors, and other stakeholders in designing comparative effectiveness studies. *Health Aff (Millwood)* 29 (10):1834-1841. doi:10.1377/hlthaff.2010.0675

The authors review a number of case studies on stakeholder involvement in comparative effectiveness research in order to illuminate key principles for engagement. They highlight the importance of employing skilled and neutral facilitators who can foster a safe environment for information sharing. The role of facilitators in eliciting productive conversations is identified as particularly important in situations where interests may be perceived as incompatible or when consensus among stakeholders must be achieved.

Madden M, Morley R (2016) Exploring the challenge of health research priority setting in partnership: reflections on the methodology used by the James Lind Alliance Pressure Ulcer Priority Setting Partnership. *Res Involv Engagem* 2 (1):12-12. doi:10.1186/s40900-016-0026-y

The James Lind Alliance (JLA) is a group based in the United Kingdom that brings patients, caregivers, and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritize shared uncertainties about the effects of treatment. The JLA uses a sequence of steps to focus the research agenda on outcomes patients prioritize. This article explores the

challenges of putting co-production methods into practice by reflecting on the methods used by the JLA Pressure Ulcer PSP (JLAPUP).

Hall KL, Vogel AL, Stipelman B, Stokols D, Morgan G, Gehlert S (2012) A four-phase model of transdisciplinary team-based research: goals, team processes, and strategies. *Transl Behav Med* 2 (4):415-430. doi:10.1007/s13142-012-0167-y

This paper discusses scientific skills and team processes required for cross-disciplinary collaboration. Drawing on the science of team science, as well as findings from research on group dynamics and organizational behavior, the authors identify scientific goals and the team routines, processes, and norms critical to success in each phase of a team-science project: development, conceptualization, implementation, and translation.

Stokols D, Misra S, Moser RP, Hall KL, Taylor BK (2008) The ecology of team science: understanding contextual influences on transdisciplinary collaboration. *Am J Prev Med* 35 (2 Suppl):S96-115. doi:10.1016/j.amepre.2008.05.003

The authors present a typology of contextual circumstances that influence the process and outcomes of team science. Derived from a systematic review of team performance and collaboration, their model encompasses six categories of factors that can jointly determine the effectiveness of transdisciplinary science and training: intrapersonal, interpersonal, organizational, physical environmental, societal/political, and technological. The proposed typology is intended to offer a basis for designing, managing, and evaluating team science initiatives.

National Research Council (2015) Enhancing the effectiveness of team science. The National Academies Press, Washington, DC. doi:10.17226/19007

A National Academy of Sciences committee produced this report in response to dramatic increases in the scale and complexity of scientific research and an accompanying shift toward collaborative research. Responding to a charge of understanding how team-based approaches work and how they can be supported, the report synthesizes and integrates the available research to provide guidance on assembling teams and specific aspects of leadership, education, and professional development they require. It also examines institutional and organizational structures and policies to support science teams and identifies areas where further research is needed.

Bozeman B, Boardman C (2014) Research collaboration and team science: A state-of-the-art review and agenda. Springer

This review identifies gaps in theory and research on collaboration and proposes ways to improve public policy for scientific collaboration and project-level management of collaborations. In addition to proposing a framework for collaboration, the book explores factors affecting collaboration outcomes, with particular attention on institutional factors such as industry-university relations and the rise of large-scale university research centers.

ENGAGING INDIVIDUALS AND COMMUNITIES

Forsythe LP, Szydowski V, Murad MH, Ip S, Wang Z, Elraiyah TA, Fleurence R, Hickam DH (2014) A systematic review of approaches for engaging patients for research on rare diseases. J Gen Intern Med 29 Suppl 3:S788-800. doi:10.1007/s11606-014-2895-9

This systematic review was conducted by a team of Patient Centered Outcomes Research Institute staff and academic researchers to synthesize evidence about engagement of patients and other stakeholders in research on rare diseases. The authors assessed 35 studies reporting on involvement of patients with rare diseases, their caregivers, and relevant organizations in research initiatives. Findings from the review highlight an increasing importance of rare disease organizations in advancing research. Although none of the studies included empirical evaluations, engagement was perceived to benefit the design, conduct, dissemination, or relevance of the research.

Ehlers AP, Davidson GH, Deeney K, Talan DA, Flum DR, Lavalley DC (2017) Methods for incorporating stakeholder engagement into clinical trial design. EGEMS (Wash DC) 5 (1):4. doi:10.13063/2327-9214.1274

and

Ehlers AP, Davidson GH, Bizzell BJ, Guiden MK, Skopin E, Flum DR, Lavalley DC (2016) Engaging stakeholders in surgical research: the design of a pragmatic clinical trial to study management of acute appendicitis. JAMA Surg 151 (6):580-582. doi:10.1001/jamasurg.2015.5531

These two articles describe the stakeholder engagement component developed for a large, multi-site comparative effectiveness clinical trial funded by the Patient Centered Outcomes Research Institute. The study included a central unit dedicated to coordinating engagement activities, which sought to involve patients and other stakeholders in all aspects of trial design and research conduct. In addition, the diverse group of stakeholders included surgeons and other medical personnel; leaders from professional societies; representatives from accountable care organizations, insurers, and payers; and other researchers.

Boote J, Baird W, Sutton A (2011) Public involvement in the design and conduct of clinical trials: a narrative review of case examples. Trials 12 (S1):A82-A82. doi:10.1186/1745-6215-12-S1-A82

This study examined the engagement of patients and other stakeholders in the design and conduct of a group of nine individual US, UK and Australian trials in a variety of health areas. The authors identified examples of involvement across the life of a study, from planning to dissemination of results. The roles and activities undertaken are described and considered in relation to both strategies that were employed to facilitate engagement and the challenges encountered.

Wilson H, Dashiell-Aje E, Anatchkova M, Coyne K, Hareendran A, Leidy NK, McHorney CA, Wyrwich K (2018) Beyond study participants: a framework for engaging patients in the selection or development of clinical outcome assessments for evaluating the benefits of treatment in medical product development. Qual Life Res 27 (1):5-16. doi:10.1007/s11136-017-1577-6

This paper presents a methodological framework for engaging patients at varying levels in the selection and development of outcome assessments for medical product evaluations. In drug and device trials, it is important to focus on endpoints that reflect a patient's perceptions of how they feel and function, in addition to objective biomarkers. Patient groups have been at the center of most engagement efforts related to product development, and these groups continue

to play increasingly important roles throughout the medical product development process, including in the selection and design of clinical outcome assessments.

Shippee ND, Domecq Garces JP, Prutsky Lopez GJ, Wang Z, Elraiyah TA, Nabhan M, Brito JP, Boehmer K, Hasan R, Firwana B, Erwin PJ, Montori VM, Murad MH (2015) Patient and service user engagement in research: a systematic review and synthesized framework. Health Expect 18 (5):1151-1166. doi:10.1111/hex.12090

This paper presents a systematic review of the peer-reviewed literature on patient and service user engagement in biomedical and health services research. The review assessed 202 papers with the primary aim of synthesizing a standardized framework and language for understanding, reporting, and assessing engagement practices. The authors develop a two-part framework specifying the research stages at which engagement occurs and its key components. Engagement was determined to have four components: patient and service user initiation, building reciprocal relationships, co-learning and re-assessment and feedback.

Spoth RL, Greenberg MT (2005) Toward a comprehensive strategy for effective practitioner–scientist partnerships and larger-scale community health and well-being. Am J Community Psychol 35 (3):107-126. doi:10.1007/s10464-005-3388-0

This article articulates two priorities to address tensions between community practitioners and scientist. The first priority is to expand the knowledge base on practitioner–scientist partnerships, particularly on factors associated with positive outcomes within communities. The second priority is future capacity-building for diffusion of effective partnership-based interventions to achieve larger-scale health and well-being across communities. It outlines two salient tasks: clarification of a conceptual framework and the formulation of a comprehensive capacity-building strategy for diffusion.

Gesell SB, Klein KP, Halladay J, Bettger JP, Freburger J, Cummings DM, Lutz BJ, Coleman S, Bushnell C, Rosamond W, Duncan PW (2017) Methods guiding stakeholder engagement in planning a pragmatic study on changing stroke systems of care. J Clin Transl Sci 1 (2):121-128. doi:10.1017/cts.2016.26

This paper reports on the engagement work undertaken as part of the COMPASS Study, a large, pragmatic trial. The considerations which shaped the engagement plan are described. Among these are the identification of appropriate partners among the diverse group of stakeholders that was identified as relevant to the study, which involves a combination of services delivered by a broad range of community-based care providers; and the determination of appropriate roles for each stakeholder, a process informed by their self-reported interests, expertise, time, and communication requirements informed.

Harris J, Croot L, Thompson J, Springett J (2016) How stakeholder participation can contribute to systematic reviews of complex interventions. J Epidemiol Community Health 70 (2):207-214. doi:10.1136/jech-2015-205701

This article discusses a review of community-based peer support interventions carried out with the active involvement of stakeholders, including service users and patients. The authors used participatory methods to develop a model of successful interventions that guided the identification of relevant data from published studies. The authors also captured primary data relating to interpersonal relationships and contextual condition. This helped to (1) identify active components of the studied interventions; (2) describe feedback loops where interactions influenced success of the intervention; (3) identify instances of tailoring the intervention in the literature; (4) identify proximal outcomes and (5) analyze the ways in which context affects the intervention at different levels.

Pinsoneault LT, Connors ER, Jacobs EA, Broeckling J (2019) Go slow to go fast: successful engagement strategies for patient-centered, multi-site research, involving academic and community-based organizations. J Gen Intern Med 34 (1):125-131. doi:10.1007/s11606-018-4701-6

This paper describes the findings from an evaluation of stakeholder engagement practices used as part of peer-based support for aging in place. The study was planned and conducted with an intentional focus on meaningful community and stakeholder engagement and the involvement of recipients of peer support services, children of older adults receiving peer support services, peer support volunteers, and representatives of aging services organizations on the study team. The paper's authors used interviews to identify a number of practices they feel helped sustain meaningful engagement over the research project's life. The authors also describe the role of a national association of community-based organizations as a cultural broker, mediating the relationship between the academic researchers and local community groups in ways that contributed to sustaining a positive team culture.

Burke JG, Jones J, Yonas M, Guizzetti L, Virata MC, Costlow M, Morton SC, Elizabeth M (2013) PCOR, CER, and CBPR: alphabet soup or complementary fields of health research? Clin Transl Sci 6 (6):493-496. doi:10.1111/cts.12064

This commentary addresses the potential role of stakeholders in research done to compare the effectiveness, benefits, and harms of different treatment options. The authors assert broader aspects of healthcare delivery need to be considered and it is necessary to involve nontraditional partners in the research process. The paper suggests community-based participatory research provides a lens through which stakeholders and communities can be involved to enhance comparative effectiveness research.

Wandersman A (2003) Community science: bridging the gap between science and practice with community-centered models. Am J Community Psychol 31 (3-4):227-242. doi:10.1023/a:1023954503247

This article uses the theme of bridging the gap between science and practice in prevention efforts to outline priorities for an interdisciplinary community science. It suggests that a predominant "prevention science" model of bringing science to practice is necessary but not sufficient for influencing the quality of interventions. The development of a community science will require a participatory process of many fields and participants but will lay the groundwork for developing interventions that (1) explicitly emphasize integrating research and practice and (2) take the community and the world of practice as an active stimulus and participant in research.

Bammer G (2019) Key issues in co-creating with stakeholders when research problems are complex. Evidence & Policy 15 (3):423-435. doi:10.1332/174426419X15532579188099

This paper introduces the Integration and Implementation Sciences framework as a way to systematically take into account multiple stakeholders with multiple relevant inputs. The framework is relevant to addressing research problems that are difficult to delimit, have contested definitions, multiple uncertainties, and unresolvable unknowns. Such "complex problems" can require different ways of including stakeholders and deciding on appropriate forms of engagement.

Seifer SD, Michaels M, Collins S (2010) Applying community-based participatory research principles and approaches in clinical trials: forging a new model for cancer clinical research. Prog Community Health Partners 4 (1):37-46. doi:10.1353/cpr.0.0103

Community-based participatory research (CBPR) approaches have been recommended as a key strategy for increasing and diversifying cancer clinical trial participation and enhancing the trial's relevance and quality. This paper discusses an effort to develop the first set of national

recommendations to employ CBPR approaches in multisite, Phase III cancer clinical trials. The report provides specific guidance as to how and why clinical trials should involve communities affected by cancer. The background and rationale for the initiative, the process used to develop and disseminate the report, and the challenges and opportunities for implementing the report's community-based approaches to cancer clinical research are presented.

Adler NE, Stewart J (2010) Using team science to address health disparities: MacArthur network as case example. *Annals of the New York Academy of Sciences* 1186(1):252-60.

This article relates insights from the Science of Team Science to the history of the MacArthur Network on Socioeconomic Status and Health. The network is intended to examine the complex social problems underlying health disparities through transdisciplinary approaches. The forging of a group agenda and the development of a productive group working style among network members are treated as a case study of team science processes.

Minkler M (2010) Linking science and policy through community-based participatory research to study and address health disparities. *Am J Public Health* 100 Suppl 1:S81-87. doi:10.2105/AJPH.2009.165720

The author examines the potential of Community-Based Participatory Research as a strategy at the intersections of research, practice, and policy to study and address health disparities. Two case examples from a national multisite case study analysis illustrate the utility of this approach for linking place-based research and action with broader policy change. The author highlights factors that appeared to support or impede partnership efforts at the policy level.

Nowell B (2009) Profiling capacity for coordination and systems change: the relative contribution of stakeholder relationships in interorganizational collaboratives. *Am J Community Psychol* 44 (3):196-212. doi:10.1007/s10464-009-9276-2

This work describes a rigorous methodology to assess impacts of stakeholder activities. The researchers used survey and social network data to assess the impacts of collaborative groups (roughly described as community-based groups with various stakeholders). Cooperative stakeholder relationships were found to be a strong predictor of systems change outcomes.

Stahmer AC, Aranbarri A, Drahota A, Rieth S (2017) Toward a more collaborative research culture: extending translational science from research to community and back again. *Autism* 21 (3):259-261. doi:10.1177/1362361317692950

This article discusses the emerging use of community-based participatory research strategies in studies investigating treatments in autism spectrum disorder. Examples of this type of research can be seen in early intervention, schools, and community mental and behavioral health settings. These projects have relied on bi-directional collaboration between applied researchers and community stakeholders to adapt intervention and training methods to facilitate the implementation of treatment strategies. The authors find that these community-academic collaborations resulted in improved community capacity for effective services.

EVALUATION AND ASSESSMENT OF ENGAGEMENT PRACTICES AND THEIR HEALTH OUTCOMES

Staniszewska S, Brett J, Simeria I, Seers K, Mockford C, Goodlad S, Altman DG, Moher D, Barber R, Denegri S, Entwistle A, Littlejohns P, Morris C, Suleman R, Thomas V, Tysall C (2017) GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *BMJ* 358:j3453-j3453. doi:10.1136/bmj.j3453

This paper describes the development of the Guidance for Reporting Involvement of Patients and the Public (GRIPP2), an initiative to improve the quality, consistency, and transparency of reporting on engagement activities in health research. The guidance is based on systematic review evidence and the consensus opinions of an international group of researchers and others familiar with the goals and methods of patient and public involvement. It is available in two versions, a five-item short form, and a 34-item long form.

Goodman MS, Sanders Thompson VL (2017) The science of stakeholder engagement in research: classification, implementation, and evaluation. *Behav Med Pract Policy Res* 7 (3):486-491. doi:10.1007/s13142-017-0495-z

This commentary proposes a system for classifying stakeholder engagement as an essential step in developing empirical evidence on the association between engagement and research outcomes. The authors suggest a number of questions that should guide the implementation and evaluation of engagement.

Esmail L, Moore E, Rein A (2015) Evaluating patient and stakeholder engagement in research: moving from theory to practice. *J Comp Eff Res* 4 (2):133-145. doi:10.2217/cer.14.79

In this paper, the authors synthesize the motivations for patient and stakeholder engagement in health research. They review the literature published between 2005 and 2013 and identify engagement impacts, including improvements to the quality, applicability, and translation of research; the empowerment of patients; and the advancement of public accountability and moral goals. The authors provide steps that individual researchers and engagement research community should undertake to strengthen assessment practices and develop an evidence base.

Boivin A, L'Espérance A, Gauvin FP, Dumez V, Macaulay AC, Lehoux P, Abelson J (2018) Patient and public engagement in research and health system decision making: A systematic review of evaluation tools. *Health Expect* 21 (6):1075-1084. doi:10.1111/hex.12804

This paper presents a systematic review of tools for evaluating patient and public engagement in research and health system transformation. Twenty-seven patient and public engagement evaluation tools are included in the review and systematically assessed using criteria co-developed with key stakeholders. A presentation of the main strengths, weaknesses and characteristics of each is offered to guide user's selection of tools to fit particular evaluation needs.

Bowen DJ, Hyams T, Goodman M, West KM, Harris-Wai J, Yu JH (2017) Systematic review of quantitative measures of stakeholder engagement. *Clin Transl Sci* 10 (5):314-336. doi:10.1111/cts.12474

This paper presents the results of a systematic review of the existing quantitative measures of stakeholder engagement in published research. Fifty observational measures and a slightly higher number of participant-reported measurements were identified for the review. Variability in

the measures selected and the broad range of concepts they seek to capture makes comparison difficult.

Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, Suleman R (2014) Mapping the impact of patient and public involvement on health and social care research: a systematic review. Health Expect 17 (5):637-650. doi:10.1111/j.1369-7625.2012.00795.x

This systematic review examines the conceptualization, definition, measurement, impact, and outcomes of patient and public involvement in health and social care research. A total of 66 papers and reports describing involvement in research in these domains were included in the review. The authors considered impacts that could be attributed to involvement at each stage of research and highlight the importance of involvement in the initial stages of research.

Dukhanin V, Topazian R, Decamp M (2018) Metrics and evaluation tools for patient engagement in healthcare organization-and system-level decision-making: a systematic review. Int J Health Policy Manag 7 (10):889-903. doi:10.15171/ijhpm.2018.43

This systematic review focuses on metrics used to evaluate patient, public, consumer and community engagement in efforts to design and implement health care services. Published and gray literature were reviewed to create a taxonomy of possible evaluation metrics relevant to healthcare decision-making by organizations, communities, and health systems. Twenty-three evaluation tools were identified, most employing mixed methods.

Oliver K, Kothari A, Mays N (2019) The dark side of coproduction: do the costs outweigh the benefits for health research? Health Res Policy Syst 17 (1):33-33. doi:10.1186/s12961-019-0432-3

This commentary addresses the evidence for what works in collaborative models that include stakeholders in the research process. The authors point to potential costs and risks associated with the use of participatory approaches that should be weighed against the specific objectives for particular research projects. The article identifies key questions that researchers, funders, and others can use in deciding when and where coproduction is warranted and to choose appropriate modes of engagement.

Goodman MS, Thompson VLS, Arroyo Johnson C, Gennarelli R, Drake BF, Bajwa P, Witherspoon M, Bowen D (2017) Evaluating community engagement in research: quantitative measure development. J Community Psychol 45 (1):17-32. doi:10.1002/jcop.21828

and

Goodman MS, Ackermann N, Bowen DJ, Thompson V (2019) Content validation of a quantitative stakeholder engagement measure. J Community Psychol 47(8): 1937-1951

The authors describe the development and content validation of a quantitative measure to assess the extent to which stakeholders in research partnerships feel engaged. The measure uses 32 items to assess the quantity and quality of adherence to eight principles that define community engagement. The engagement principles were arrived at through a content validation study to identify a consensus view across a multi-stakeholder panel.

TOOLS AND GUIDES

Hamilton CB, Hoens AM, Backman CL, McKinnon AM, McQuitty S, English K, Li LC (2018) An empirically based conceptual framework for fostering meaningful patient engagement in research. Health Expect 21 (1):396-406. doi:10.1111/hex.12635

and

Hamilton CB, Hoens AM, McQuitty S, McKinnon AM, English K, Backman CL, Azimi T, Khodarahmi N, Li LC (2018) Development and pre-testing of the Patient Engagement in Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. PLoS One 13 (11):e0206588-e0206588. doi:10.1371/journal.pone.0206588

and

Hamilton CB, Hoens AM, McKinnon AM, McQuitty S, English K, Hawke LD, Li LC (2021) Shortening and validation of the Patient Engagement In Research Scale (PEIRS) for measuring meaningful patient and family caregiver engagement. Health Expect. doi:10.1111/hex.13227

These papers report the development of the Patient Engagement In Research Scale (PEIRS), a tool designed to measure patient engagement in research. The PEIRS is a self-administered questionnaire completed by patient partners (including family caregiver partners) to determine their degree of meaningful engagement in research. The tool, which has been assessed for internal consistency, structural and construct validity, reliability and interpretability, is intended to be used for comparative effectiveness research.

Boote J (2011) Patient and public involvement in health and social care research: a bibliography. NIHR Research Design Service for Yorkshire and the Humber. National Institutes for Health Research.

This bibliography was prepared as a technical report of the research support service of the United Kingdom's National Institutes for Health Research and contains an extensive list of peer-reviewed papers, books, policy documents, and guidance materials on patient and public involvement in health and social care research.

PCORI Engagement in Health Research Literature Explorer.

<https://www.pcori.org/engagement/engagement-literature>

The Patient-Centered Outcomes Research Institute maintains a curated compendium of literature on engagement in health research. The resource is sortable by article topic type, types of stakeholders engaged, and phase(s) of research in which engagement occurred.

The Science of Team Science (SciTS) Library.

[https://www.mendeley.com/community/science-of-team-science-\(scits\)/](https://www.mendeley.com/community/science-of-team-science-(scits)/)

The Science of Team Science Mendeley Group Forum maintains an extensive reference library of empirical literature on team science and scientific collaboration as a free, community resource.

Boote J, Wong R, Booth A (2015) 'Talking the talk or walking the walk?' A bibliometric review of the literature on public involvement in health research published between 1995 and 2009. Health Expect 18 (1):44-57. doi:10.1111/hex.12007

This paper reviews international literature on public involvement in health research that developed over a 15-year period beginning in the early-to-mid-1900s, when government funding bodies and professional associations in the US, UK, Canada, and Australia began promoting research engagement. Bibliometric analyses identify trends in categories of publications and areas of study that are associated with the development of public involvement as a discrete field of enquiry.

Concannon TW, Grant S, Welch V, Petkovic J, Selby J, Crowe S, Synnot A, Greer-Smith R, Mayo-Wilson E, Tambor E, Tugwell P, Multi-stakeholder Engagement (MuSE) Consortium (2019). Practical guidance for involving stakeholders in health research. J Gen Intern Med 34 (3):458-463. doi:10.1007/s11606-018-4738-6

This paper seeks to help teams developing stakeholder-engaged research projects systematically consider the appropriate roles for stakeholders and how their interactions with the team should be structured. A set of guiding questions synthesize expert opinion and research literature on engagement in research and are intended to be applicable to a broad range of health-related studies. The authors provide a matrix that teams can use to summarize the roles and modes of engagement expected for each stakeholder group, across a study's stages and component activities.

Sheridan S, Schrandt S, Forsythe L, Hilliard TS, Paez KA, Advisory Panel on Patient Engagement (2017) The PCORI engagement rubric: promising practices for partnering in research. Ann Fam Med 15 (2):165-170. doi:10.1370/afm.2042

and

PCORI engagement rubric <https://www.pcori.org/sites/default/files/Engagement-Rubric.pdf>

To address the need for guidance on creating meaningful stakeholder partnerships in patient-centered clinical comparative effectiveness research, the Patient-Centered Outcomes Research Institute (PCORI) developed the PCORI Engagement Rubric. The Rubric provides a framework for operationalizing engagement to incorporate patients and other stakeholders in all phases of research. It includes: principles of engagement; definitions of stakeholder types; key considerations for planning, conducting, and disseminating engaged research; potential engagement activities; and examples of promising practices from PCORI-funded projects.

Principles of Community Engagement Second Edition (2011). National Institutes of Health. Center for Disease Control and Prevention

Developed by a taskforce of the Clinical and Translational Science Awards (CTSA) Consortium as an update to the 1997 publication *Principles of Community Engagement*, this report is a primer that sets out a framework for engagement and reviews a number of case studies as a structure for practical guidance.

INVOLVE. National Institute for Health Research (2012) Briefing notes for researchers: public involvement in NHS, public health and social care research

http://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf

The United Kingdom's National Institute for Health Research provides this guidance document for researchers interested in involving members of the public, and people who use services, as active partners in research. A series of ten briefing notes provide instructional overviews and links to in-depth information on planning, conducting, disseminating, and evaluating involvement activities.

Salas E (2015) Team training essentials: research-based guide. Routledge/Taylor & Francis Group, New York, NY, US. doi:10.4324/9781315747644

This is a guidebook to team training based on knowledge developed primarily in organizational psychology and outlining research-based best practices. Multiple aspects of team training are covered, from design and delivery to evaluation, transfer, and sustainment methods.

Glandon D, Paina L, Alonge O, Peters DH, Bennett S (2017) 10 Best resources for community engagement in implementation research. Health Policy Plan 32 (10):1457-1465. doi:10.1093/heapol/czx123

This review identifies resources for engaging stakeholders in research projects aimed at understanding contextual factors affecting the implementation of health-related interventions. The resources, drawn from the peer-reviewed and gray literature, were selected based on comprehensiveness of guidance, presence of a robust conceptual framework, ease of application, and evidence of successful use in relevant contexts.

Examining Community-Institutional Partnerships for Prevention Research Group (2006) Developing and sustaining community-based participatory research partnerships: a skill-building curriculum. www.cbprcurriculum.info

This curriculum is aimed at researchers who are using or planning to use a Community-Based Participatory Research (CBPR) approach to improving health. It covers the basic principles of CBPR and strategies for applying them; the key steps involved in developing and sustaining CBPR partnerships; and common challenges faced by CBPR partnerships.

Patient engagement in health research: a how-to guide for researchers (2018). Alberta SPOR SUPPORT Unit <https://albertainnovates.ca/app/uploads/2018/06/How-To-Guide-Researcher-Version-8.0-May-2018.pdf>

This guide was developed to help academic investigators and others engage patients throughout research projects. It outlines a range of strategies organized in five into five key stages: Why, Who, How, Engage, and Evaluate. Each stage includes an overview of current evidence, methods of engagement, patient and researcher competencies, tips for engagement, key examples, and engagement tools that can be used to optimize the process.

Campus Community Partnership for Health (CCPH) (2021). <https://www.ccphealth.org>

The Community-Campus Partnerships for Health is a nonprofit membership organization that promotes health equity and social justice through partnerships between communities and academic institutions. As part of its mission of training and technical assistance, the group provides a set of useful guidelines on communication and decision-making processes for collaborations between academic researchers and community partners.

Clinical Trials Transformation Initiative (2016) CTTI recommendations: effective engagement with patient groups around clinical trials. <https://ctti-clinicaltrials.org/>

The Clinical Trials Transformation Initiative's (CTTI) report on patient engagement in translational research is part of a multi-stakeholder project that brought together patient groups, industry sponsors, and academic researchers to delineate the roles patients can play in clinical research and develop consensus views on the elements of successful collaboration around clinical trials. The report presents best practices to guide engagement activities, together with tools to support practical implementation.

Engagement Tool and Resource Repository (2021) Patient-Centered Outcomes Research Institute. <https://www.pcori.org/engagement/engagement-resources/Engagement-Tool-Resource-Repository>

The Patient-Centered Outcomes Research Institute (PCORI) maintains an online repository of over 300 engagement-related tools and resources developed and used by its awardees. The materials are organized by focus, health condition, stakeholder audience, targeted population, and applicable phase of research. Included items were vetted by PCORI staff on a number of criteria, including completeness, adaptability to different settings, and development on the basis of best practices.

Mallery C, Ganachari, D, Fernandez, J, Smeeding, L, Robinson, S, Moon, M, Lavalley, D, Siegel, J (2012) Innovative methods in stakeholder engagement: an environmental scan. Agency for Healthcare Research and Quality US Department of Health and Human Services

This Agency for Healthcare Research and Quality-funded report identifies five priority methods that researchers working with stakeholders may wish to consider for enhancing the process of engaging stakeholders. These methods are relevant for stakeholder recruitment and preparation, involvement in topic identification and prioritization, product development, and dissemination of research findings and products.

Methods and tools for co-producing knowledge (2020) <https://naturalsciences.ch/co-producing-knowledge-explained>

This resource is a toolbox for joint research between scientists, practitioners, and stakeholders on societal challenges. The portal organizes resources by process phases and key issues. It provides overviews, details on use, and links to a selection of widely used methods and tools for co-producing knowledge.

Switzer S, Adams, M, Community-Based Research Team at Access Alliance (2012) Community-based research toolkit: resources and tools for doing research with community for social change [https://accessalliance.ca/wp-content/uploads/2020/07/CBR Toolkit 1 -Jan2012.pdf](https://accessalliance.ca/wp-content/uploads/2020/07/CBR_Toolkit_1_-Jan2012.pdf)

This toolkit developed by Access Alliance, a Canadian health services agency, contains hundreds of resources and tools for making the research process more inclusive and collaborative, and for training and engaging non-academic partners to design and conduct studies. It includes information handouts, templates, worksheets, and checklists for developing effective “principles of collaboration”, designing research collaboratively, training community members in research, collaborative data analysis, project management and budget considerations for community-based research.

Bagley HJ, Short H, Harman NL, Hickey HR, Gamble CL, Woolfall K, Young B, Williamson PR (2016) A patient and public involvement (PPI) toolkit for meaningful and flexible involvement in clinical trials - a work in progress. Res Involv Engagem 2:15. doi:10.1186/s40900-016-0029-8

This paper describes a web-based toolkit designed for use by investigators and study teams to facilitate effective patient and public involvement at all stages of a clinical trial. The authors reviewed existing resources corresponding to four activities necessary to patient and public involvement in trials: (i) developing an engagement plan; (ii) identifying contributors with appropriate experience and skills; (iii) allocating appropriate costs; and (iv) managing the expectations of patient and public partners. Tools and guidance materials are provided in appendices together with a links to a variety of additional resources.

Bennett M, Gadlin, H, Marchand, C (2010) Collaboration team science: field guide. U.S Department of Health & Human Services National Institutes of Health

This Field Guide is a multi-level resource providing practical guidance on collaboration in research teams. It is divided into 13 chapters addressing different phases of research and covering topics from individual readiness and team dynamics to overviews organizational structures. Concepts are illustrated with supportive case studies and supplemented with additional materials such as templates.

Cancer Research UK. Patient involvement toolkit for researchers.

<https://www.cancerresearchuk.org/funding-for-researchers/patient-involvement-toolkit-for-researchers>

The large, London-based cancer research charity, Cancer Research UK, provides an online toolkit with extensive guidance, tips, and templates for involving patients in research. Among the resources is a series of case studies illustrating patient involvement in diverse research projects. Each case study summarizes how patients were involved, what support was provided, and what challenges were encountered.

Effective engagement: building relationships with community and other stakeholders: the engagement toolkit Book 3 (2014). State Government Victoria Department of Environment, Land, Water & Planning

This Engagement Toolkit is an extensive collection of tools and techniques that can assist in planning and conducting community engagement. The 68 approaches include all types of engagement, from information sharing to full participation. For each, a brief overview is followed by a detailed description of the technique's objectives, contexts of use, and the time, skills, and resources required. It also provides guidance on the selection or adaptation of tools suited to specific purposes and settings.

Patient Protocol Engagement Tool (2012-2021).

<https://www.transceleratebiopharmainc.com/ppet/planning-for-patient-engagement/>

TransCelerate, an alliance of biopharmaceutical companies formed to improve clinical trial processes, provides tools and resources to help clinical trial sponsors and other stakeholders engage patients in study design and conduct. This includes questions for consideration during engagement with patients, aids to facilitate clear communication of concepts, templates and planning tools, and case studies illustrating various types of engagement.

Budget Item recommendations from CCPH CBPR listserv members. Northwestern University

<https://www.feinberg.northwestern.edu/sites/cch/docs/ccphgrantwritingresources.pdf>

Community-Campus Partnerships for Health (CCPH) provides a checklist of items that should be considered when planning budgets for community-engaged research.