

## Engagement dans les activités de recherche et d'enseignement

Suggestions de lecture des professionnels de l'information du CIUSSS Centre-Sud-de-l'Île-de-Montréal



Abdool, P. S., Nirula, L., Bonato, S., Rajji, T. K., & Silver, I. L. (2016). **Simulation in Undergraduate Psychiatry: Exploring the Depth of Learner Engagement.** *Acad Psychiatry*. <http://dx.doi.org/10.1007/s40596-016-0633-9>

**OBJECTIVES:** Simulation-based methodologies are increasingly used in undergraduate medical education to expand students' exposure to complex clinical scenarios. Engagement of students in these simulation-based methodologies is a key determinant of their success in learning. Thus, the authors conducted a systematic review to (1) identify simulation methods in use within the undergraduate psychiatry curriculum and (2) assess learner engagement using these methods. **METHODS:** Following a PRISMA methodology, the authors searched MEDLINE, ERIC, and PsychINFO databases from 1977 to 2015. Studies applying simulation in undergraduate psychiatric education were reviewed. The depth of learner engagement was assessed using Kolb's four-stage learning cycle. **RESULTS:** Of 371 publications identified, 63 met all the inclusion criteria: 48 used standardized patients and 16 used online or virtual learning case modules. Only one study used high fidelity mannequins. Three studies satisfied multiple stages in Kolb's Learning Cycle, including a single study that addressed all four domains. **CONCLUSIONS:** Despite the varied uses of simulation across other health disciplines, there were few novel or innovative uses of simulation in undergraduate psychiatric education since the last review in 2008. Expanding on the use of simulation to improve communication, build empathy, and decrease stigma in psychiatry is essential given the relevance to all facets of medical practice. Given the complexity of psychiatry, simulation interventions should extend beyond communication scenarios. Medical students need more opportunities to reflect and debrief on simulation experiences and integrate learning into new contexts. Faculty development should focus on these novel approaches to simulation to deeply engage learners and enhance outcomes.



Anderson, J., Williams, L., Karmali, A., Beesley, L., Tanel, N., Doyle-Thomas, K., . . . Chau, T. (2017). **Client and family engagement in rehabilitation research: a framework for health care organizations.** *Disabil Rehabil*, 1-8. <http://dx.doi.org/10.1080/09638288.2016.1276973>

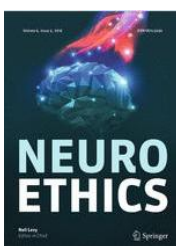
**PURPOSE:** To describe the development and implementation of an organizational framework for client and family-centered research. **METHOD:** Case report. **RESULTS:** While patient-centered care is now well established, patient-centered research remains underdeveloped. This is particularly true at the organizational level (e.g., hospital based research institutes). In this paper we describe the development of an organizational framework for client and family centered research at Holland Bloorview Kids Rehabilitation Hospital in Toronto, Canada. **CONCLUSION:** It is our hope that, by sharing our framework other research institutions can learn from our experience and develop their own research patient/client/family engagement programs. Implications for rehabilitation Family engagement in rehabilitation research \*Rehabilitation research is crucial to the development and improvement of rehabilitative care. \*The relevance, appropriateness, and accountability of research to patients, clients and families could be improved. \*Engaging clients and families as partners in all aspects of the research process is one way to address this problem. \*In this paper, we describe a framework for engaging clients and families in research at the organizational level.

**BMJ Open**

Boaz, A., Hanney, S., Jones, T., & Soper, B. (2015). **Does the engagement of clinicians and organisations in research improve healthcare performance: a three-stage review.** *BMJ Open*, 5(12), e009415. <http://dx.doi.org/10.1136/bmjopen-2015-009415>

**OBJECTIVE:** There is a widely held assumption that engagement by clinicians and healthcare organisations in research improves healthcare performance at various levels, but little direct empirical evidence has previously been collated. The objective of this study was to address the question: Does research engagement (by clinicians and organisations) improve healthcare performance? **METHODS:** An hourglass-shaped review was developed, consisting of three stages: (1) a planning and mapping stage; (2) a focused review concentrating on the core question of whether or not research engagement improves healthcare performance; and (3) a wider (but less systematic) review of papers identified during the two earlier stages, focusing on mechanisms. **RESULTS:** Of the 33 papers included in the focused review, 28 identified improvements in health services performance. Seven out of these papers reported some improvement in health outcomes, with others reporting improved processes of care. The wider review demonstrated that mechanisms such as collaborative and action research can encourage some progress along the pathway from research engagement towards improved healthcare performance. Organisations that have deliberately integrated the research function into organisational structures demonstrate how research engagement can, among other factors, contribute to improved healthcare performance. **CONCLUSIONS:** Current evidence suggests that there is an association between the engagement of individuals and healthcare organisations in research and improvements in healthcare performance. The mechanisms through which research engagement might improve healthcare performance overlap and rarely act in isolation, and their effectiveness often depends on the context in which they operate.

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Broer, T., Pickersgill, M., & Deary, I. J. (2016). **The Movement of Research from the Laboratory to the Living Room: a Case Study of Public Engagement with Cognitive Science.** *Neuroethics*, 9, 159-171. <http://dx.doi.org/10.1007/s12152-016-9259-6>

Media reporting of science has consequences for public debates on the ethics of research. Accordingly, it is crucial to understand how the sciences of the brain and the mind are covered in the media, and how coverage is received and negotiated. The authors report here their sociological findings from a case study of media coverage and associated reader comments of an article ('Does bilingualism influence cognitive aging?') from *Annals of Neurology*. The media attention attracted by the article was high for cognitive science; further, as associates/members of the Centre where it was produced, the authors of the research reported here had rare insight into how the scientists responsible for the *Annals of Neurology* article interacted with the media. The data corpus included 37 news items and 228 readers' comments, examined via qualitative thematic analysis. Media coverage of the article was largely accurate, without merely copying the press release. Analysis of reader comments showed these to be an important resource for considering issues of import to neuroethics scholars, as well as to scientists themselves (including how science communication shapes and is shaped by ethical, epistemic, and popular discourse). In particular, the findings demonstrate how personal experiences were vital in shaping readers' accounts of their (dis)agreements with the scientific article. Furthermore, the data show how scientific research can catalyse political discussions in ways likely unanticipated by scientists. The analysis indicates the importance of dialogue between journalists, laboratory scientists and social scientists in order to support the communication of the messages researchers intend.

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Revue canadienne de soins  
infirmiers en oncologie

Bryant-Lukosius, D. (2015). **Réflexions sur la recherche : Première partie : Le cybermentorat : une stratégie destinée à promouvoir la participation des infirmières en oncologie à la recherche.** *Revue canadienne de soins infirmiers en oncologie*, 25(4), 472-475. <http://canadianoncologynursingjournal.com/index.php/conj/article/view/618/611>

Le processus de recherche ressemble à un long chemin sinueux comportant une série d'arrêts et de destinations. Les arrêts le long de la route peuvent aller de la détection des lacunes en matière de connaissances sur les pratiques infirmières en oncologie, à la mise en œuvre d'une étude ou à la promotion de l'application des résultats à la pratique. Souvent, il faut faire des détours par rapport à la feuille de route ou au plan de recherche initial afin d'améliorer les méthodes et de résoudre les problèmes imprévus. La destination finale ou le but qui incite à poursuivre la recherche consiste à générer des connaissances fondées sur des données probantes et à les appliquer afin d'améliorer les soins infirmiers.

Revue canadienne de soins  
infirmiers en oncologie

Zanchetta, M., & Maheu, C. (2015). **Réflexions sur la recherche : Deuxième partie : Le mentorat en recherche pour les infirmières en oncologie en milieu clinique : pour qui, pourquoi et comment?** *Revue canadienne de soins infirmiers en oncologie*, 25(4), 478-479. <http://canadianoncologynursingjournal.com/index.php/conj/article/view/620/613>

À titre de mentors en recherche sur les soins infirmiers en cancérologie et dans d'autres domaines, dans le présent article, nous abordons le mentorat des étudiants, des infirmières en oncologie et d'autres professionnels de la santé. Nous expliquons qu'il s'agit d'une expérience extrêmement enrichissante à la fois pour le mentor et pour le mentoré.



Careyva, B., Shaak, K., Mills, G., Johnson, M., Goodrich, S., Stello, B., & Wallace, L. S. (2016). **Implementation of Technology-based Patient Engagement Strategies within Practice-based Research Networks.** *J Am Board Fam Med*, 29(5), 581-591. <http://dx.doi.org/10.3122/jabfm.2016.05.160044>

**BACKGROUND:** Technology-based patient engagement strategies (such as patient portals) are increasingly available, yet little is known about current use and barriers within practice-based research networks (PBRNs). PBRN directors have unique opportunities to inform the implementation of patient-facing technology and to translate these findings into practice. **METHODS:** PBRN directors were queried regarding technology-based patient engagement strategies as part of the 2015 CAFM Educational Research Alliance (CERA) survey of PBRN directors. A total of 102 PBRN directors were identified via the Agency for Healthcare Research and Quality's registry; 54 of 96 eligible PBRN directors completed the survey, for a response rate of 56%. **RESULTS:** Use of technology-based patient engagement strategies within PBRNs was limited, with less than half of respondents reporting experience with the most frequently named tools (risk assessments/decision aids). Information technology (IT) support was the top barrier, followed by low rates of portal enrollment. For engaging participant practices, workload and practice leadership were cited as most important, with fewer respondents noting concerns about patient privacy. **DISCUSSION:** Given limited use of patient-facing technologies, PBRNs have an opportunity to clarify the optimal use of these strategies. Providing IT support and addressing clinician concerns regarding workload may facilitate the inclusion of innovative technologies in PBRNs.



Carman, K. L., & Workman, T. A. (2017). **Engaging patients and consumers in research evidence: Applying the conceptual model of patient and family engagement.** *Patient Educ Couns*, 100(1), 25-29. <http://dx.doi.org/10.1016/j.pec.2016.07.009>

**OBJECTIVE:** This essay discusses applying the Conceptual Framework for Patient and Family Engagement to partnerships with patients and consumers to increase their use of research evidence in healthcare decisions. The framework's foundational principles hold that engagement occurs on a continuum across all levels of healthcare—from direct care to policymaking—with patients and healthcare professionals working in full partnership and sharing responsibility for achieving a safe, high-quality, efficient, and patient-centered healthcare system. **DISCUSSION:** Research evidence can serve as a critical decision-making tool in partnerships between patients and health professionals. However, as the framework suggests, without patient and consumer engagement in the design, planning, interpretation, and dissemination of research findings, it is unlikely that the broader consumer population will find research evidence useful, much less use it, to guide their healthcare decisions. Understanding what factors influence patient and consumer engagement can lead to effective strategies that enable meaningful partnerships between patients and researchers. **CONCLUSION:** Understanding patient and consumer perspectives of research evidence is critical to engaging them in meaningful partnerships that produce actionable research findings that they can in turn use in partnership with health professionals to improve their own health and the healthcare system as a whole.

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Concannon, T. W., Fuster, M., Saunders, T., Patel, K., Wong, J. B., Leslie, L. K., & Lau, J. (2014). **A systematic review of stakeholder engagement in comparative effectiveness and patient-centered outcomes research.**

*J Gen Intern Med*, 29(12), 1692-1701. <http://dx.doi.org/10.1007/s11606-014-2878-x>

**OBJECTIVES:** We conducted a review of the peer-reviewed literature since 2003 to catalogue reported methods of stakeholder engagement in comparative effectiveness research and patient-centered outcomes research. **METHODS AND RESULTS:** We worked with stakeholders before, during and after the review was conducted to: define the primary and key research questions; conduct the literature search; screen titles, abstracts and articles; abstract data from the articles; and analyze the data. The literature search yielded 2,062 abstracts. The review was conducted on 70 articles that reported on stakeholder engagement in individual research projects or programs. **FINDINGS:** Reports of stakeholder engagement are highly variable in content and quality. We found frequent engagement with patients, modestly frequent engagement with clinicians, and infrequent engagement with stakeholders in other key decision-making groups across the healthcare system. Stakeholder engagement was more common in earlier (prioritization) than in later (implementation and dissemination) stages of research. The roles and activities of stakeholders were highly variable across research and program reports. **RECOMMENDATIONS:** To improve on the quality and content of reporting, we developed a 7-Item Stakeholder Engagement Reporting Questionnaire. We recommend three directions for future research: 1) descriptive research on stakeholder-engagement in research; 2) evaluative research on the impact of stakeholder engagement on the relevance, transparency and adoption of research; and 3) development and validation of tools that can be used to support stakeholder engagement in future work.

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Health Services Research

Domecq, J. P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., . . . Murad, M. H. (2014). **Patient engagement in research: a systematic review.** *BMC Health Serv Res*, 14, 89.

<http://dx.doi.org/10.1186/1472-6963-14-89>

**BACKGROUND:** A compelling ethical rationale supports patient engagement in healthcare research. It is also assumed that patient engagement will lead to research findings that are more pertinent to patients' concerns and dilemmas. However; it is unclear how to best conduct this process. In this systematic review we aimed to answer 4 key questions: what are the best ways to identify patient representatives? How to engage them in designing and conducting research? What are the observed benefits of patient engagement? What are the harms and barriers of patient engagement? **METHODS:** We searched MEDLINE, EMBASE, PsycInfo, Cochrane, EBSCO, CINAHL, SCOPUS, Web of Science, Business Search Premier, Academic Search Premier and Google Scholar. Included studies were published in English, of any size or design that described engaging patients or their surrogates in research design. We conducted an environmental scan of the grey literature and consulted with experts and patients. Data were analyzed using a non-quantitative, meta-narrative approach. **RESULTS:** We included 142 studies that described a spectrum of engagement. In general, engagement was feasible in most settings and most commonly done in the beginning of research (agenda setting and protocol development) and less commonly during the execution and translation of research. We found no comparative analytic studies to recommend a particular method. Patient engagement increased study enrollment rates and aided researchers in securing funding, designing study protocols and choosing relevant outcomes. The most commonly cited challenges were related to logistics (extra time and funding needed for engagement) and to an overarching worry of a tokenistic engagement. **CONCLUSIONS:** Patient engagement in healthcare research is likely feasible in many settings. However, this engagement comes at a cost and can become tokenistic. Research dedicated to identifying the best methods to achieve engagement is lacking and clearly needed.

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Duffett, L. (2017). **Patient engagement: What partnering with patient in research is all about.** *Thromb Res*, 150, 113-120.  
<http://dx.doi.org/10.1016/j.thromres.2016.10.029>

The inclusion of patients on important decision related to healthcare has marked a significant 'patient revolution' during the last several decades. Patients now played active roles in personal health decisions, healthcare delivery and policy making, and the development of clinical practice guidelines. Such inclusion of patients' values has resulted in largely positive effects. The next wave of this 'patient revolution' is active and meaningful engagement with patients in health related research. Similar to other aspects of healthcare, it is increasingly recognized that experienced patients, their families, and caregivers, have a wealth of knowledge that comes from living and experiencing a medical condition. By understanding and valuing this experience-based knowledge, research priority setting, research study design, trial conduct, analysis of results and knowledge dissemination can be positively influenced. Patients can challenge our assumptions, align research with the needs of patients, increase transparency and trust in research, and lead to research that has a greater impact on the ultimate care of patients. This new approach to research is timed well with a larger movement towards simple, pragmatic clinical trials better reflecting realistic patient care. While there is still much to be learned about the best methods and exact impacts of patient engagement in research, preliminary results are promising and future venous thromboembolism research will likely benefit from the adoption of patient engagement in research.

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Journal of  
Comparative  
Effectiveness  
Research

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. <http://dx.doi.org/10.2217/cer.14.79>

Despite the growing demand for research that engages stakeholders, there is limited evidence in the literature to demonstrate its value - or return on investment. This gap indicates a general lack of evaluation of engagement activities. To adequately inform engagement activities, we need to further investigate the dividends of engaged research, and how to evaluate these effects. This paper synthesizes the literature on hypothesized impacts of engagement, shares what has been evaluated and identifies steps needed to reduce the gap between engagement's promises and the underlying evidence supporting its practice. This assessment provides explicit guidance for better alignment of engagement's promised benefits with evaluation efforts and identifies specific areas for development of evaluative measures and better reporting processes.

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Fernandez, A., Sadownik, L., Lisonkova, S., Cundiff, G., & Joseph, K. S. (2016). **Determinants of research engagement in academic obstetrics and gynaecology.** *BMC Med Educ*, 16, 111. <http://dx.doi.org/10.1186/s12909-016-0640-2>

**BACKGROUND:** To identify the determinants of research engagement among faculty in an academic department of Obstetrics and Gynaecology. **METHODS:** All members of the Department of Obstetrics and Gynaecology at the University of British Columbia were mailed an online version of the Edmonton Research Orientation Survey (EROS) in 2011 and in 2014. High scores on overall research engagement and on each of the 4 subscales, namely, value of research, value of innovation, research involvement and research utilization/evidence-based practice were quantified. Analyses were carried out on both surveys combined and on the 2014 survey separately. Logistic regression was used to identify determinants of high levels of research engagement. **RESULTS:** The overall response rate was 37% (130 responses; 54 respondents in 2011 and 76 respondents in 2014). The average EROS score was 140 (range 54 to 184) and 35% of respondents had a score  $\geq 150$ . Significant determinants of positive research engagement based on the overall EROS scale included being paid for research work (adjusted odds ratio [AOR] 22.1, 95% confidence interval [CI] 2.47-197.7) and carrying out research during unpaid hours (AOR 6.41, 95% CI 1.97-20.9). Age  $< 50$  years (AOR 11.0, 95% CI 1.35-89.9) and clinical experience  $< 20$  years (AOR 19.7, 95% CI 2.18-178.8) were positively associated, while journal reading during unpaid hours (AOR 0.21, 95% CI 0.07-0.62) was negatively associated with specific EROS subscales. **CONCLUSIONS:** In a setting with a positive research orientation, research engagement among the faculty was associated with paid research time, research work and journal reading during unpaid hours and more recent entry into clinical practice.

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Journal of  
Comparative  
Effectiveness  
Research

Forsythe, L. P., Frank, L. B., Workman, T. A., Borsky, A., Hilliard, T., Harwell, D., & Fayish, L. (2017). **Health researcher views on comparative effectiveness research and research engagement.** *J Comp Eff Res*. <http://dx.doi.org/10.2217/cer-2016-0063>

**AIM:** To understand researcher capability for and interest in patient-centered comparative effectiveness research (PC-CER), particularly related to engaging with patients/caregivers. **MATERIALS & METHODS:** Web-based survey of 508 health researchers recruited via professional health research organizations. **RESULTS:** Most respondents (94%) were familiar with CER and many (69%) reported having previously conducting some form of CER. Most respondents were familiar with (81%) and interested in (87%) partnering with patients and/or caregivers in research. Resources to assist in training, coordination of partners, guidance in apply for funding and improved infrastructure were commonly cited factors that would help researchers conduct PC-CER. **CONCLUSION:** There is a

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significant opportunity for researchers to engage patients and caregivers as partners in CER. Researchers recognize the need for additional training and expertise to leverage those opportunities.

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Journal of  
Comparative  
Effectiveness  
Research

Forsythe, L. P., Frank, L. B., Workman, T. A., Hilliard, T., Harwell, D., & Fayish, L. (2017). **Patient, caregiver and clinician views on engagement in comparative effectiveness research.** *J Comp Eff Res.* <http://dx.doi.org/10.2217/cer-2016-0062>

**AIM:** Describe patient, caregiver and clinician views toward engagement as partners in health research. **MATERIALS & METHODS:** Online surveys of patients and caregivers managing rare (n = 560 patients, n = 609 caregivers) or chronic conditions (n = 762 patients, n = 776 caregivers) and practicing clinicians (n = 638). **RESULTS:** Over half of respondents were unfamiliar with the concept of partnering with researchers but most expressed interest in working in a research partnership. Potential facilitators endorsed were ensuring research is meaningful, applying results in an understandable way, and sharing results. Lack of time is a potential barrier. Clinicians were most interested in helping researchers decide on intervention comparisons and identifying implications for clinical practice. **CONCLUSION:** Patients, caregivers and clinicians are interested in research roles that emphasize usefulness and understandability of research.

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George, A. S., Mehra, V., Scott, K., & Sriram, V. (2015). **Community Participation in Health Systems Research: A Systematic Review Assessing the State of Research, the Nature of Interventions Involved and the Features of Engagement with Communities.** *PLoS One*, 10(10), e0141091. <http://dx.doi.org/10.1371/journal.pone.0141091>

**BACKGROUND:** Community participation is a major principle of people centered health systems, with considerable research highlighting its intrinsic value and strategic importance. Existing reviews largely focus on the effectiveness of community participation with less attention to how community participation is supported in health systems intervention research. **OBJECTIVE:** To explore the extent, nature and quality of community participation in health systems intervention research in low- and middle-income countries. **METHODOLOGY:** We searched for peer-reviewed, English language literature published between January 2000 and May 2012 through four electronic databases. Search terms combined the concepts of community, capability/participation, health systems research and low- and middle-income countries. The initial search yielded 3,092 articles, of which 260 articles with more than nominal community participation were identified and included. We further excluded 104 articles due to lower levels of community participation across the research cycle and poor description of the process of community participation. Out of the remaining 160 articles with rich community participation, we further examined 64 articles focused on service delivery and governance within health systems research. **RESULTS:** Most articles were led by authors in high income countries and many did not consistently list critical aspects of study quality. Articles were most likely to describe community participation in health promotion interventions (78%, 202/260), even though they were less participatory than other health systems areas. Community involvement in governance and supply chain management was less common (12%, 30/260 and 9%, 24/260 respectively), but more participatory. Articles cut across all health conditions and varied by scale and duration, with those that were implemented at national scale or over more than five years being mainstreamed by government. Most articles detailed improvements in service availability, accessibility and acceptability, with fewer efforts focused on quality, and few designs able to measure impact on health outcomes. With regards to participation, most articles supported community's in implementing interventions (95%, n = 247/260), in contrast to involving communities in identifying and defining problems (18%, n = 46/260). Many articles did not discuss who in communities participated, with just over a half of the articles

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disaggregating any information by sex. Articles were largely under theorized, and only five mentioned power or control. Majority of the articles (57/64) described community participation processes as being collaborative with fewer describing either community mobilization or community empowerment. Intrinsic individual motivations, community-level trust, strong external linkages, and supportive institutional processes facilitated community participation, while lack of training, interest and information, along with weak financial sustainability were challenges. Supportive contextual factors included decentralization reforms and engagement with social movements. CONCLUSION: Despite positive examples, community participation in health systems interventions was variable, with few being truly community directed. Future research should more thoroughly engage with community participation theory, recognize the power relations inherent in community participation, and be more realistic as to how much communities can participate and cognizant of who decides that.

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Hanney, S., Boaz, A., Jones, T., & Soper, B. (2013). **Engagement in research : an innovative three-stage review of the benefits for health-care performance.** *Health Services and Delivery Research*, 1(8), 1 - 151. <http://dx.doi.org/10.3310/hsdr01080>

There is a widely held assumption that research engagement improves health-care performance at various levels, but little direct empirical evidence. To conduct a theoretically and empirically grounded synthesis to map and explore plausible mechanisms through which research engagement might improve health services performance. A review of the effects on patients of their health-care practitioner's or institution's participation in clinical trials was published after submission of the proposal for this review. It identified only 13 relevant papers and, overall, suggested that the evidence that research engagement improves health-care performance was less strong than some thought. We aimed to meet the need for a wider review. An hourglass review was developed, consisting of three stages: (1) a planning and mapping stage; (2) a focused review concentrating on the core question of whether or not research engagement improves health care; and (3) a wider (but less systematic) review of papers identified during the two earlier stages. (...)

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Harrison, J., & Frampton, S. (2016). **Patient and Family Engagement in Research in Era 3.** *J Am Coll Radiol*, 13(12 Pt B), 1622-1624. <http://dx.doi.org/10.1016/j.jacr.2016.09.009>

Embracing Era 3 will require a new belief system supportive of engaging patients and families in the full research process, including topic selection, conducting the research, dissemination, and evaluation. This new belief system will require that organizations and publishers support access to research. (...)The slogan "nothing about me without me," characteristic of patient-centered culture change models, can serve as a guiding principle, reminding us that patient and family engagement in research cannot be an afterthought but must be a part of the foundation in the new era.

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Harrison, S. L., & Brooks, D. (2015). **Active Patient Engagement: Long Overdue in Rehabilitation Research.** *Physiother Can*, 67(4), 305-310. <http://dx.doi.org/10.3138/ptc.67.4.GEE>

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## Genetics in Medicine

Hartz, S. M., Quan, T., Ibiebele, A., Fisher, S. L., Olfson, E., Salyer, P., & Bierut, L. J. (2017). **The significant impact of education, poverty, and race on Internet-based research participant engagement.** *Genet Med*, 19(2), 240-243. <http://dx.doi.org/10.1038/gim.2016.91>

**PURPOSE:** Internet-based technologies are increasingly being used for research studies. However, it is not known whether Internet-based approaches will effectively engage participants from diverse racial and socioeconomic backgrounds. **METHODS:** A total of 967 participants were recruited and offered genetic ancestry results. We evaluated viewing Internet-based genetic ancestry results among participants who expressed high interest in obtaining the results. **RESULTS:** Of the participants, 64% stated that they were very or extremely interested in their genetic ancestry results. Among interested participants, individuals with a high school diploma ( $n = 473$ ) viewed their results 19% of the time relative to 4% of the 145 participants without a diploma ( $P < 0.0001$ ). Similarly, 22% of participants with household income above the federal poverty level ( $n = 286$ ) viewed their results relative to 10% of the 314 participants living below the federal poverty level ( $P < 0.0001$ ). Among interested participants both with a high school degree and living above the poverty level, self-identified Caucasians were more likely to view results than self-identified African Americans ( $P < 0.0001$ ), and females were more likely to view results than males ( $P = 0.0007$ ). **CONCLUSION:** In an underserved population, engagement in Internet-based research was low despite high reported interest. This suggests that explicit strategies should be developed to increase diversity in Internet-based research. *Genet Med* 19 2, 240-243.

## SAGE Open Medicine

Hearld, K. R., Hearld, L. R., & Hall, A. G. (2017). **Engaging patients as partners in research: Factors associated with awareness, interest, and engagement as research partners.** *SAGE Open Med*, 5, 2050312116686709. <http://dx.doi.org/10.1177/2050312116686709>

**OBJECTIVES:** There is growing interest in engaging patients in healthcare research, which raises important questions about the factors that may promote such engagement. The purpose of this study was to examine the association between patient characteristics and three aspects of patient engagement in the medical research process: awareness, interest, and actual participation. **METHODS:** Cross-sectional, bivariate analyses were employed using the 2014 Health Information National Trends Survey. **RESULTS:** Analyses suggest modest levels of interest among respondents engaging as patient partners in the research process (37.7% of respondents), low level of awareness of what patient engagement in research was (15.3% of respondents), and a very low level of actual participation (2.7% of respondents). Respondents of higher socioeconomic status and with more positive patient attitudes regarding their health and healthcare were more likely to be interested in research. In comparison, relatively few patient characteristics were significantly associated with patient awareness and actual participation in research. **CONCLUSION:** Although it is promising that people are interested in being engaged in research, the results suggest that there is work to be done to raise awareness of these engagement opportunities. Likewise, the gap between awareness and participation highlights opportunities to identify why patients may be reluctant to participate even when they are aware of research opportunities.

## Journal of Investigative Medicine

Holzer, J. K., Ellis, L., & Merritt, M. W. (2014). **Why we need community engagement in medical research.** *J Investig Med*, 62(6), 851-855. <http://dx.doi.org/10.1097/jim.0000000000000097>

**BACKGROUND:** The medical research enterprise depends on public recognition of its societal value. In light of evidence indicating public mistrust, especially among minorities, inadequate enrollment as well

as diversity of research participants, and poor uptake of findings, medical research seems to fall short of sufficient public regard. Community engagement in medical research, with special attention to minority communities, may help to remedy this shortfall by demonstrating respect for the communities in practical ways. **APPROACH:** We provided 3 case examples that illustrate how specific approaches to community-engaged research can build trust between researchers and communities, encourage participation among underrepresented groups, and enhance the relevance as well as the uptake of research findings. **DISCUSSION:** A common attribute of the specific approaches discussed here is that they enable the researchers to demonstrate respect by recognizing community values and interests. The demonstration of respect for the communities has intrinsic ethical importance. **CONCLUSIONS:** The 2 potential outgrowths of demonstrating respect specifically through community engagement are (1) the production of research that is more relevant to the community and (2) the mitigation of asymmetry in the researcher-community relationship. We summarized practical resources available to researchers who seek to incorporate community engagement in their research.



## Health Research Policy and Systems

Miller, C. L., Mott, K., Cousins, M., Miller, S., Johnson, A., Lawson, T., & Wesselingh, S. (2017). **Integrating consumer engagement in health and medical research - an Australian framework.** *Health Res Policy Syst*, 15(1), 9. <http://dx.doi.org/10.1186/s12961-017-0171-2>

**BACKGROUND:** Quality practice of consumer engagement is still in its infancy in many sectors of medical research. The South Australian Health and Medical Research Institute (SAHMRI) identified, early in its development, the opportunity to integrate evidence-driven consumer and community engagement into its operations. **PROCESS:** SAHMRI partnered with Health Consumers Alliance and consumers in evidence generation. A Partnership Steering Committee of researchers and consumers was formed for the project. An iterative mixed-method qualitative process was used to generate a framework for consumer engagement. This process included a literature review followed by semi-structured interviews with experts in consumer engagement and lead medical researchers, group discussions and a consensus workshop with the Partnership Steering Committee, facilitated by Health Consumer Alliance. **OUTCOMES:** The literature revealed a dearth of evidence about effective consumer engagement methodologies. Four organisational dimensions are reported to contribute to success, namely governance, infrastructure, capacity and advocacy. Key themes identified through the stakeholder interviews included sustained leadership, tangible benefits, engagement strategies should be varied, resourcing, a moral dimension, and challenges. The consensus workshop produced a framework and tangible strategies. **CONCLUSION:** Comprehensive examples of consumer participation in health and medical research are limited. There are few documented studies of what techniques are effective. This evidence-driven framework, developed in collaboration with consumers, is being integrated in a health and medical research institute with diverse programs of research. This framework is offered as a contribution to the evidence base around meaningful consumer engagement and as a template for other research institutions to utilise.



Naing, C., Wai, V. N., Durham, J., Whittaker, M. A., Win, N. N., Aung, K., & Mak, J. W. (2015). **A Systematic Review and Meta-Analysis of Medical Students' Perspectives on the Engagement in Research.** *Medicine (Baltimore)*, 94(28), e1089. <http://dx.doi.org/10.1097/md.0000000000001089>

Engaging students in active learning lies at the center of effective higher education. In medical schools, students' engagement in learning and research has come under increasing attention. The objective of this study was to synthesize evidence on medical students' perspectives on the engagement in

research. We performed a systematic review and meta-analysis. Relevant studies were searched in electronic databases. The methodological quality of the included studies was assessed. Overall, 14 observational studies (with 17 data sets) were included. In general, many studies did not use the same questionnaires and the outcome measurements were not consistently reported; these presented some difficulties in pooling the results. Whenever data permitted, we performed pooled analysis for the 4 education outcomes. A Bayesian meta-analytical approach was supplemented as a measure of uncertainty. A pooled analysis showed that 74% (95% confidence interval [CI]: 1.57%-11.07%; I<sup>2</sup>: 95.2%) of those students who engaged in research (while at the medical school) had positive attitudes toward their research experiences, whereas 49.5% (95% CI: 36.4%-62.7%; I<sup>2</sup>: 93.4%) had positive attitudes toward the study of medical sciences, 62.3% (95% CI: 46.7%-77.9%; I<sup>2</sup>: 96.3%) had self-reported changes in their practices, and 64% (95% CI: 30.8%-96.6%; I<sup>2</sup>: 98.5%) could have published their work. There was substantial heterogeneity among studies. We acknowledged the caveats and the merit of the current review. Findings showed that engagement in research resulted in favorable reactions toward research and academic learning. Future well-designed studies using standardized research tools on how to engage students in research are recommended.

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Oyler, D. R., Romanelli, F., Piascik, P., & Cain, J. (2016). **Practical Insights for the Pharmacist Educator on Student Engagement.** *Am J Pharm Educ*, 80(8), 143. <http://pubmedcentralcanada.ca/pmcc/articles/PMC5116795/pdf/ajpe808143.pdf>

Student engagement continues to be a point of emphasis in pharmacy education, yet there remains little data on tangible means to increase organic student engagement. This review attempts to better define student engagement, draws from educational theorists to emphasize the importance of student engagement, and provides the reader with practice philosophies that can be used across a variety of teaching settings to help develop an engaging learning environment.

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Patino, C. M., Kubicek, K., Robles, M., Kiger, H., & Dzekov, J. (2017). **The Community Mentorship Program: Providing Community-Engagement Opportunities for Early-Stage Clinical and Translational Scientists to Facilitate Research Translation.** *Acad Med*, 92(2), 209-213. <http://dx.doi.org/10.1097/acm.0000000000001332>

**PROBLEM:** A goal of the Southern California Clinical and Translational Science Institute (SC-CTSI) at the University of Southern California and Children's Hospital Los Angeles is to train early-stage clinical and translational scientists (CTSs) to conduct research that improves the health of diverse communities. This goal aligns well with the Institute of Medicine's recommendations emphasizing community engagement in biomedical research that facilitates research translation. The Community Mentorship Program (CMP), created to complement community-engaged research didactics, matches CTSs with community mentors who help them identify and complete community-engaged experiences that inform their research. **APPROACH:** The CMP was piloted in 2013-2015 by the SC-CTSI Workforce Development and Community Engagement cores. The CMP team matched three CTSs (assistant professors pursuing mentored career development awards) with mentors at community-based organizations (CBOs) aligned with their research interests. Each mentor-mentee pair signed a memorandum of understanding. The CMP team checked in regularly, monitoring progress and addressing challenges in CTSs' completion of their community-engaged experience. **OUTCOMES:** Each pair completed at least one community-engaged activity informing the CTS's research. In exit interviews, the CTSs and CBO mentors expressed satisfaction with the program and stated that they would continue to work together. The CTSs reported that the program provided opportunities to develop networks outside academia, build trust within the community, and receive feedback and learn

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from individuals in communities affected by their research. NEXT STEPS: The CMP will be expanded to include all eligible early-career CTSs and promoted for use in similar settings outside the SC-CTSI.



Ramsden, V. R., Salsberg, J., Herbert, C. P., Westfall, J. M., LeMaster, J., & Macaulay, A. C. (2017). **Patient- and community-oriented research: How is authentic engagement identified in grant applications?** *Can Fam Physician*, 63(1), 74-76. <http://www.cfp.ca/content/cfp/63/1/74.full.pdf>



Shippee, N. D., Domecq Garces, J. P., Prutsky Lopez, G. J., Wang, Z., Elraiyah, T. A., Nabhan, M., . . . Murad, M. H. (2015). **Patient and service user engagement in research: a systematic review and synthesized framework.** *Health Expect*, 18(5), 1151-1166.

<http://dx.doi.org/10.1111/hex.12090>

**BACKGROUND:** There is growing attention towards increasing patient and service user engagement (PSUE) in biomedical and health services research. Existing variations in language and design inhibit reporting and indexing, which are crucial to comparative effectiveness in determining best practices. **OBJECTIVE:** This paper utilizes a systematic review and environmental scan to derive an evidence-based framework for PSUE. **DESIGN:** A metanarrative systematic review and environmental scan/manual search using scientific databases and other search engines, along with feedback from a patient advisory group (PAG). **ELIGIBLE SOURCES:** English-language studies, commentaries, grey literature and other sources (including systematic and non-systematic reviews) pertaining to patient and public involvement in biomedical and health services research. **DATA EXTRACTED:** Study description (e.g. participant demographics, research setting) and design, if applicable; frameworks, conceptualizations or planning schemes for PSUE-related endeavours; and methods for PSUE initiation and gathering patients'/service users' input or contributions. **RESULTS:** Overall, 202 sources were included and met eligibility criteria; 41 of these presented some framework or conceptualization of PSUE. Sources were synthesized into a two-part framework for PSUE: (i) integral PSUE components include patient and service user initiation, reciprocal relationships, colearning and re-assessment and feedback, (ii) sources describe PSUE at several research stages, within three larger phases: preparatory, execution and translational. **DISCUSSION AND CONCLUSIONS:** Efforts at developing a solid evidence base on PSUE are limited by the non-standard and non-empirical nature of much of the literature. Our proposed two-part framework provides a standard structure and language for reporting and indexing to support comparative effectiveness and optimize PSUE.

- Vous souhaitez obtenir un de ces documents? Communiquez avec votre bibliothèque ou centre de documentation de proximité. La liste des coordonnées est disponible dans l'Intranet, section Enseignement et recherche.
- Plus de références ainsi que les résumés sont disponibles dans l'Intranet des cadres.