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Evaluating patient and stakeholder engagement in research: moving from theory to practice

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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.

Keywords: comparative effectiveness research • evaluation • patient engagement • patient-centered outcomes research • PCOR • review • stakeholder engagement

Background

Engagement of patients and other healthcare stakeholders (herein, stakeholder partners) is increasingly recognized as essential to patient-centered comparative effectiveness research (CER), which is intended to answer questions of importance to patients and their caregivers [1]. Often described as researchers doing research with patients, rather than for, at or to them [2–4], patient-engaged research implies a level of involvement that extends beyond the role of research subject [5]. This shift has been fueled in part by the 2010 creation of the Patient-Centered Outcomes Research Institute (PCORI) by Congress with the passage of the Patient Protection and Affordable Care Act. PCORI is committed to producing and promoting high-integrity CER that is 'guided by patients, caregivers, and the broader healthcare community.' [6].

The PCORI Methodology Report states that patient engagement can include: defining topics and formulating study questions, identifying a study population and choosing interventions, comparators and outcomes, developing optimal strategies for recruitment and retention of study participants, conducting a study and analyzing results and disseminating research findings into clinical practice [7]. Generally, the value of engaging stakeholder partners in research is that it can help reorient and improve the research enterprise, reduce clinical uncertainty and speed adoption of meaningful findings that hold great promise with the ultimate goal of improving patients' care experience, decision-making and health outcomes [6].

Despite the growing interest in and demand for research that engages stakeholder partners – or, 'research done differently,' [8] there is limited evidence in the published literature to demonstrate the value – or return on investment – of this engagement. This evidence gap is reflective of a general lack of evaluation of research engagement activities. In fact, the majority of published research with a stakeholder partner engagement dimension does not include an evaluation component [9–11]. To adequately inform and support engagement activities, we need to know more about the dividends of engaged research, and how to evaluate these effects.

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The purpose of this paper is to synthesize what the literature proposes as the hypothesized impacts of engagement (i.e., the benefits), share what has actually been evaluated and assessed and propose the steps needed to reduce the gap between research engagement's promises and the underlying evidence base supporting its practice. By mapping the hypothesized impacts of research engagement to what has actually been assessed, we build upon Workman's call to action for greater evaluation of engagement processes [12]. Our assessment provides guidance to researchers for future evaluation metrics, and calls for the field to plan in advance their purposes of engagement and move beyond surface level analyses of stakeholder partner/researcher experiences and satisfaction.

Methods

This manuscript is directly informed by a scan of the peer-reviewed literature using PubMed and PsychInfo to identify articles published from January 2005 to May 2013 focusing on patient, public and stakeholder engagement in the healthcare field. We selected search terms through an iterative review and revision process with PCORI staff. We searched article titles for a combination of terms covering 'who' (e.g., patient, consumer, stakeholder, etc.), 'action' (engagement, participation, involvement, etc.) and 'purpose' (research, prioritization, resource allocation, etc.) (Supplementary Material; see online at: www.futuremedicine.com/doi/suppl/10.2217/cer.14.79).

Five research team members selected articles for abstraction by reviewing titles and abstracts and applying inclusion and exclusion criteria (after calibration amongst team members). Inclusion criteria were as follows: research studies that involved or described the engagement of patients or others stakeholders in the planning and/or conduct of research (i.e., beyond the role of research subjects); or articles that presented an engagement framework with an evaluation component; or articles that synthesized relevant aspects of the literature (e.g., review articles) or seminal articles prior to 2005 that were frequently referenced. Articles were excluded if they did not provide enough level of detail to ascertain whether patients or other healthcare stakeholders were engaged beyond the role of research subjects, or if they did not provide any information on possible evaluation measures or outcomes associated with engagement.

Expert advisors and staff at PCORI provided guidance throughout the design and implementation of the work. In addition, members of the Consumer Patient Researcher Roundtable suggested relevant articles to include in the scan. The Consumer Patient Researcher Roundtable is a convening activity of AcademyHealth that recognizes the shared interests of both patients and researchers (i.e., the desire for better health and healthcare), and facilitates dialogue on topics of mutual interest and collaborative work.

To supplement our scan, we retrospectively incorporated a selection of articles from a bibliography of papers published between 1995 and 2011 focused on patient and public involvement in research [13]. We selected articles from this scan meeting the inclusion criteria based upon our review of the titles, as well as a determination of whether they would add new information to our scan – specifically regarding evaluation of engagement. A selection of gray literature products was also included, though not identified through an exhaustive search. In total, the literature scan considered over 1000 articles from various sources. After the application of our criteria, we selected 108 for abstraction, most of which were reviews and case studies published in peer-reviewed journals.

We assigned the articles amongst five researchers who abstracted information from each article into an MSExcel format. Abstracted fields included information such as author, date, primary objective, methods, group being engaged, main intent behind engaging the specified group, methods of evaluation for engagement in research and suggested or measured outcomes of engagement. As we proceeded with article abstraction, we eliminated those that (upon scanning the full manuscript) did not present new information compared with what we already captured. After abstraction was complete, two researchers divided the data and conducted a content analysis of the abstracted information using NVivo software looking for common themes and then summarized the data.

Hypothesized impacts of engagement

The literature proposes several hypothesized impacts of stakeholder partner engagement. Identifying and understanding the intended purposes of engagement is key to structuring the activity of stakeholder partner engagement, and also provides a goal post against which engagement can be assessed. The following purported reasons are identified by the literature, some of which may only apply to patients (as indicated below).

Better quality research

One of the major hypothesized reasons for engaging stakeholder partners in research is that they provide a unique perspective, sometimes with direct knowledge and experience, which has the potential to promote more useful evidence that is more relevant and responsive to patients' and stakeholders' needs [7,14–19].

Expanded applicability of research, particularly in 'hard-to-reach' populations

Some literature, particularly in the area of community-based participatory research (CBPR), argues that patient engagement in research is key to reaching hard-to-reach or otherwise marginalized populations [20,21]. By more actively engaging these community members as partners in the research process, these authors argue that it improves a population's participation, and ultimate 'ownership' of the research process and outcomes. These authors also suggest that engagement may address disparities in inclusiveness in medical research study samples, and consequently facilitate research findings that are more applicable and acceptable to a wider range of patients.

Empowering patients

Many authors argue that research engagement is essential to empowering patients in their healthcare, which is a fundamental premise of the CBPR approach [20–22]. While the precise relationship of CBPR to PCOR has yet to be determined, incorporating patients into the research process is also a central component of PCOR. Empowering patients is also perceived as having valuable downstream effects. By taking greater ownership of research, authors hypothesize that engaged patients may play a more active role in their healthcare [21].

Increased translation, dissemination & uptake of results

Authors also argue that stakeholder partner engagement in early stages of the research process aids in the translation and interpretation of the findings, which ultimately increases the 'actionability' of research results [3,19]. Authors also argue that by incorporating patients and other stakeholders as partners throughout the research process, they can effectively serve as early ambassadors of research efforts and subsequent findings, which may help to expand to audiences beyond peer-reviewed journals, and may facilitate increased uptake of results into the community and healthcare setting thereby accelerating its adoption into practice [15,23–25].

Democracy & accountability

From a political perspective, engaging patients serves the democratic ideals of accountability and transparency [26]. It can increase the likelihood that individual researchers, research organizations and funders of research (public or private) are accountable and responsive to users of medical knowledge and the broader community, providing some assurance that resources are being allocated in ways that serve the public interest [27]. In this way, engaging patients in research can contribute to the legitimacy and credibility of research [19,26].

Moral obligation

The moral argument underlying patient engagement in research is that patients and other stakeholders have a fundamental right to be involved in the process. Related to the notion of social justice, the idea is that, as ultimate end-users of the research results, they should have the opportunity to be involved in shaping its conduct [17,28,29]. This premise is embodied in the well-known quote 'nothing about us, without us.' [30]. Given these arguments, researchers would have a moral obligation to involve patients in research beyond the role of subjects.

Measurement & evaluation of engagement

The research literature also proposes and applies a range of measures to evaluate stakeholder partner engagement, which we categorize according to three key dimensions: context evaluation (the environment and conditions that underpin and support engagement); process evaluation (how engagement is implemented) and impact evaluation (the intended effects of engagement) [31,32]. Context refers to the conditions required for engagement to have an impact while process refers more to how the involvement is done [31]. Examples of each are listed below.

Context & process

With respect to evaluating engagement context and process, the literature theorized several suggested measures; however, many authors recognize a lack of clarity of these concepts and how to effectively measure them [31–33].

In our scan of the literature, we did not identify any research reporting findings of these concepts or dimensions (Table 1).

Evaluation of the impacts of engagement

While many papers theorize or propose intended impacts, very few empirical studies have applied or tested hypothesized impacts. Tables 2 & 3 map the intended purposes of engagement (hypothesized impacts) against those indicators that have actually been developed and measured (suggested and assessed measures). We also have distinguished between assessments that are primarily qualitative versus quantitative. It is worth noting that the categorization presented here assumes that 'hypothesized impacts' of engagement are the 'end goals' of patient and stakeholder engagement in research; it is possible, however, that many of the indicators listed preceding the longer-term measures could reasonably serve as intermediate outcomes of these intents.

As depicted in Tables 2 & 3, the limited evaluation measures that we found in the literature primarily measured the near-term effects of engagement (e.g., better

Table 1. Context and process measures.

Category	Suggested dimensions to measure	Assessed dimensions
Context	Appropriate funding, budget and/or resources available for engagement (e.g., remuneration, travel subsidies, staff time and honoraria) [5,31,32,34]	None reported
	Attributes of the sponsoring organization (e.g., level of commitment to, attitudes toward, and/or values about engagement) [31,32]	
	Attributes of the engaged community/individuals (e.g., organizational attributes and attitudes toward engagement) [32]	
	Availability of training to patients/other stakeholders and researchers [5,19,31,35,36]	
	Characteristics of the issue being deliberated (e.g., degree of scientific uncertainty, type of decision, decision timeline [32]	
	Researcher–decision-maker relationships [32]	
	Appropriate time allocation [31]	
Process	Diversity and representativeness of patients engaged; inclusivity, participation rate [37]	None reported
	Access to sufficient/appropriate resources to facilitate engagement [37]	
	Patient/stakeholder satisfaction [32,37]	
	Timing, frequency and/or stages of engagement [31,32,37–40]	
	Process fairness, flexibility and transparency [32,37]	
	Use of an explicit process [26], task/role definition and structured decision-making [5,32,37]	
	The extent to which the mechanisms for patient engagement are adequate and appropriate (continuum from less engaged (i.e., passive, tokenistic) to more engaged (i.e., active, collaborative) [31,35,41,42]	

quality research, patient empowerment). We did not identify any suggested or assessed measures that evaluate the longer-term, downstream effects of engagement, such as improved decision-making or health outcomes.

Discussion

The most striking observation taken from this exercise and reflected in both tables is how few studies actually assess or formally evaluate any measures of engagement. Of the studies that formally evaluated impact, most were qualitative, involving retrospective accounts of engagement experience and relying on self-report through focus groups, one-on-one semistructured interviews, informal observation and/or written surveys with open-ended text responses. This finding is in line with other authors' conclusions [9,38,51,52,69]. We identified only two studies with quantitative results, one of which used an unvalidated Likert-scale survey to assess patient and researcher perceptions about engagement and one systematic review that reported the results of 19 CBPR clinical trials [46]. Of the assessed measures, the literature most often reported the impact of engagement on those patients engaged, and on the research itself. Of the research impacts evaluated, there appeared to be more evidence on engagement in the following stages of the research process: topic solicitation, agenda setting, research question selection, study design and methods development, a finding in line with other authors' assessments [9,69]. This is not surprising because engagement in these stages is more often reported in the literature generally (in comparison to other stages of research); with more research in these stages overall, it is natural that there is more evaluation and/or reported impact found by our scan.

The level of detail reported on the assessed outcomes also varied greatly. Research whose primary objective was to measure patient engagement in research often included more detailed results; case studies including patient engagement measures reported them as a subsection of their results. However, even in studies focused on reporting the impact of research engagement exclusively, the level of detail provided regard-

ing the evaluation design, strategy and results was very limited, and generally inadequate for our purposes. For example, in many studies it was not clear whether the evaluation was planned in advance of study execution, or conducted as an informal post hoc exercise. Furthermore, authors often did not explicitly report the extent to which the engagement exercise made a demonstrable impact on the measures reported.

Collectively these findings support other researchers' accounts of the lack of rigorous evidence underpinning patient and stakeholder engagement efforts internationally, as well as the lack of robust tools available for evaluation of engaged research [9,51,70]. What this exercise contributes is a mapping of the hypothesized impacts of engagement with what has actually been evaluated and assessed in the literature.

In the absence of a rigorous evidence base to guide engagement and subsequent evaluation efforts, qualitative findings and empirical reviews point toward some key considerations that may prove useful to those involved in or contemplating PCOR studies. To evaluate stakeholder partner engagement in PCOR, researchers should consider:

- The need to establish or select an evaluative framework or set of criteria for patient or stakeholder engagement in research prior to the execution of any research activity (in conjunction with the patients or other stakeholders engaged for collaborative and user-led types of engagement) [26,50,61];
- To the extent possible, using predefined, validated tools [9,51,61];
- Conducting evaluations at continuous or regularly scheduled intervals throughout the engagement process and, if possible, involving external evaluators [9,61]; and
- Documenting the context and process of engagement as fundamental components of the evaluation (i.e., context refers to funding, policy, physical environment or attitudes of those involved; process refers to the level of involvement of users, how they are involved, when, and what procedures are in place to improve likelihood of success) [51].

To our knowledge, this paper is the first to compare the intended purposes of engagement (hypothesized impacts) with actual applied measures (suggested and assessed measures). By mapping the intended outcomes to the evaluation measures, a clearer picture of whether engagement has fulfilled its intended purposes should emerge. However, our effort reveals a fundamental lack of evidence underlying much of the impetus behind the practice of stakeholder partner engagement in research. Conceptually, there appears to be little clarity or consensus on the major purpose(s) of engagement and, empirically, there is little evidence to support its potential impact. Only a few studies have conducted any kind of formal evaluation, and the quality of these studies is highly variable. Given the state of the evidence base, research engagement appears to be primarily driven by the promise that – if done well, it will improve research generally, and moral and political grounds [10]. While these are important and justifiable aims, more research is needed to truly understand how to pursue engagement strategies under specific conditions.

The lack of congruence between the stated aims for patient engagement (hypothesized impacts) and suggested measures should guide future evaluation efforts. In fact, studies often did not make clear their goals for engaging stakeholder partners at all. In a recently published Delphi study, Snape *et al.* found significant disagreement between stakeholders on the purpose of engagement in research as well as its justification on ethical and patient empowerment grounds [71]. Without agreement and clarity on the purposes for stakeholder partner engagement in research, it is virtually impossible to assess the extent to which its objectives have been met, if at all.

To build an evidence base that is coherent, generalizable and facilitates comparison across studies and jurisdictions, the field needs to develop more conceptual guidance and consensus to drive evaluation efforts. While we may never be able to adequately control for every contextual factor, a more solid understanding of the goals of patient engagement, some level of consensus on measurable impacts and development and validation of measures is clearly needed. Furthermore, we suggest that future evaluations of engagement research be designed *a priori* as an embedded component of the research process.

Of the existing guidance on evaluation, the literature tended to emphasize the process side of engagement as opposed to its impact. And, of the evaluations conducted, studies focused primarily on immediate or near-term outcomes as opposed to longer-term health outcomes. These findings are in line with those of Workman, who found that the near-term effects of research were most explored and included impact on patients and researchers (e.g., satisfaction, increased skills or knowledge) [12]. These two observations point to the challenges associated with developing indicators that are considered feasible to measure [72]. Longer-term outcomes typically have complex causes that are difficult to trace back to one research study, let alone the engagement of patients or other stakeholders in the research enterprise [27]. Beyond clarifying the goals for

Table 2. Mapping hypothesized impacts to suggested and assessed measures of engagement. Part 1: better quality research.

Suggested dimensions to measure	Qualitative assessments	Quantitative assessments
Research quality and research process [28,43,44]	Improved quality and validity from engaging patients [45] Enhanced credibility and improved the research [46]	85% of patients and researchers (n = 59) agreed that the quality of research improved [41]
New funding and funding opportunities [41,47]	Patients' contributions on research proposal, lay language summary and encouragement for reapplying [48]	None reported
Research topic, priorities and/or resource allocation become more appropriate/relevant to patients [38,49–52]	Patients suggested research ideas and provided feedback on usefulness of research to the benefit of the research process [48] Improved relevance of research ideas and topics [45] Identification of study topics by patients was an impetus for research [53]	None reported
Research questions, hypotheses, interventions and medical technologies become more relevant/usable for patients [1,54,55]	Patients' experiential knowledge helped shape research question [23]	None reported
Research design, methods and study procedures become more appropriate, sensitive and ethically acceptable [9,17,21,34,38,41,51,55–57]	Patient research partners provided insight/access into social networks, patient organizations and the healthcare field [23] Patients helped translate scientific jargon into plain language materials [23] Patients provided feedback on intervention design and data collection instrument [48]	None reported
Recruitment, accrual rates and retention improves [9,28,34,38,54] Representativeness/diversity of research subjects (i.e., inclusion of more hard-to-reach patients) [34,36,41]	Patients contributed ideas to increase recruitment (e.g., feedback on patient advertisements) and modifications to interview schedules [48]	Majority of clinical trials using CBPR from systematic review demonstrated effective recruitment of minority populations and high retention rates [20]
Data collection procedures and data quality changes [34,36,38,51,57,58]	None reported	None reported
Intervention and/or survey implementation by patients [17]	Data collected from peer interviewers (i.e., patients engaged) increased 'frankness' of responses [45] Research respondents appreciated presence of a patient research partner in interviews or focus groups [23]	None reported
Data analysis and/or results interpretation by patients [34,38,41,51]	Patients co-analyzed qualitative data and suggested additional themes [48] Joint data analysis helped acknowledge patient perspective and minimized risks of misinterpretation [23]	None reported
Researchers' knowledge and capacity increases [38,44,59]	Researchers reported increased learning [38]	None reported

†Long-term outcomes.
CBPR: Community-based participatory research.

Table 2. Mapping hypothesized impacts to suggested and assessed measures of engagement. Part 1: better quality research (cont.).

Suggested dimensions to measure	Qualitative assessments	Quantitative assessments
Changes in researchers' attitudes about the value of patient perspective [5]	Perception of value added from patient engagement and allaying of researcher concerns [60] Researchers perceived improved research and value added from engaging patients [45]	None reported
More useful evidence for clinical and health policy decision making [26]†	None reported	None reported
More relevant evidence for patients [61] Results more applicable to entire spectrum of Americans (including minorities) [21] and changes to health disparities [41]†	None reported	None reported
Changes to health outcomes, including overall population health, morbidity and mortality [26,36,44,59]†	None reported	None reported

†Long-term outcomes.
CBPR: Community-based participatory research.

engagement, the field would benefit from the development of corresponding indicators to facilitate and promote a stronger, more coherent evidence base behind engagement efforts.

While process measures of engagement were emphasized more than outcomes, there is still a need to further understand who should be engaged, when should this engagement occur (i.e., at what points in the research process), and how this engagement should be done (i.e., what are the approaches to engagement that yield the desired results). Further research in these areas has been called for by others in the field, notably by Workman, who suggested the development of measurable impacts and tools beyond those focused on changes in attitudes and satisfaction among those involved in the research [12].

Numerous research teams, many supported by the PCORI are devising, developing, applying and testing strategies for engaging stakeholder partners in the research process [73]. To understand the value of these processes, and also drive toward improvement of engagement process (and theoretically improve the results of the engagement), context and process measures need to be further developed and validated.

Despite these challenges, our review surfaced promising efforts in reporting and evaluating outcomes. Researchers in the field of CBPR have established measures for the evaluation of some aspects of engagement, which can help inform the development of this effort in PCOR [74]. Furthermore, researchers are beginning to develop evaluative frameworks for public participation in research, which may help provide more guidance to those looking to integrate evaluation into their engagement activities [75–77]. Based upon engagement efforts in the UK, researchers have developed a checklist to improve the quality, content, detail, consistency, transparency and completeness of reporting of engagement activities [31]. Though it has not been widely used by the research community since its publication, increased uptake of this tool and subsequent improved reporting could help strengthen the evidence base and allow comparisons across similar studies [31]. Building on these efforts, CONSORT-style guidance will be released to assist researchers in their reporting [51]. While traditional peer-reviewed journals should encourage the reporting of the evaluation in their methodology and results, researchers should also look to other dissemination mechanisms for sharing lessons learned in engagement, as well as evaluation methodology and results.

The current evidence base may also be a product of research incentives and existing infrastructure. A commitment from research institutions and funders to support stakeholder partner engaged research is needed to adequately resource and support rigorous evaluation of research engagement activities. While there are increased political and funding imperatives to conduct PCOR in the United States, most significantly in the establishment of PCORI, other funders and institutions should assist to support and fund the development of measures and methods for such evaluation.

Limitations of this paper

This paper was informed by a literature scan that draws upon multiple sources of relevant evidence. It

Table 3. Mapping hypothesized impacts to suggested and assessed measures of engagement. Part 2: other hypothesized impacts.

Hypothesized impacts	Suggested dimensions to measure	Qualitative assessments	Quantitative assessments
Patient empowerment	Knowledge of community needs (empathy), services available, motivation to help community (citizenship literacy) [28]	Patients motivated to take interest in community, developed greater empathy and understanding of others in community [62] Improved 'citizenship' literacy [45]	None reported
	Patient or community research knowledge, skills and capacity [10,18,41,44,47,49,59]	Increased learning of new skills (including research skills) and knowledge on topic area [18] Increased learning by patients [38] Increased knowledge and skills, putting learning/training into practice and raised awareness of issues and services [25] Enhanced teamwork skills [45]	None reported
	Self-empowerment, increased self-confidence, feeling of being valued and making a contribution [10,18,21,24,31,34,35,38,39,44,51,54,55,63,64]	Increased confidence/sense of personal achievement [45] Equal status on project team, ownership of services being received, social support, increased confidence and self-esteem [25]	None reported
	Impact on mental health of patients [62]	Improved emotional health feel valued and involved and having activities to look forward to [25] Enhanced outlook on life [45] Development of patients' pride and ownership of their work [62]	None reported
	Patient and public satisfaction (as indicated by continued willingness to participate, buy-in, attitudes and perceptions) [44,49,60,63]†	Future engagement in research by patients previously engaged [45] Participation in new research and educational activities [48] Patients' increased recognition of research as legitimate and useful [62]	None reported
	Future opportunities for patients to participate in research or in job market, etc [34]†	Forming links with professionals and increased employment skills [25] Employability increased as patient-researchers were sought after for their experience [45]	None reported
Increased translation, dissemination, and uptake of results	Highlighting findings most relevant to patients [38,41,51]	None reported	None reported
	Changes in translation and dissemination of research into practice and community [7,25,34,38,41,44,55]	Patient partners attended events and presented at conferences and served as champions for the research [48] Improved dissemination (including presentations at community events and conferences and authorship on papers) [45]	None reported
	Improved dissemination to patients and the community [5,51]†	None reported	None reported

†Long-term outcomes.

Table 3. Mapping hypothesized impacts to suggested and assessed measures of engagement. Part 2: other hypothesized impacts (cont.).

Hypothesized impacts	Suggested dimensions to measure	Qualitative assessments	Quantitative assessments
Increased translation, dissemination, and uptake of results (cont.)	Faster uptake of new evidence [38]† Changes healthcare practice [44]† Changes in health regulation and policy [28,36,44,49]† Shifted priorities and changes in use of healthcare resources [26]† Changes in the cost of healthcare [65]†	None reported	None reported
Democracy and accountability	Transparency [3,26,38,61,66,67] Legitimacy [26,27] and credibility [27] Accountability [26,27,38,61,66] Public trust in public institutions [26,27]	Majority of patients and researchers felt that involvement improved credibility [46]	None reported
Moral obligation	Fairness [26–28,50,66] Respect and trust between researchers and engaged stakeholders [9,26,27,68]	Development of trust between researchers and service users [38]	None reported
	More ethically acceptable research [52]†	None reported	None reported

†Long-term outcomes.

is not a systematic review, therefore we may not have captured all of the potential studies that evaluated engagement activities. Still, the findings in this paper are in line with others' findings in the field who implemented systematic reviews [9,51]. Furthermore, we triangulated multiple data sources to ensure the inclusion of seminal papers and provide a snapshot of the field, which is quickly evolving. Our review is also different in that it emphasized literature that focused on more active, collaborative approaches to patient and stakeholder engagement. Articles solely focused on engaging patients as research subjects were not included. While other recent reviews in the field included articles assuming a broader definition of engagement [19], therefore covering a larger number of articles, our paper builds upon the state of the evidence suggested by these reviews with a deeper and more thorough assessment of various approaches to patient and stakeholder engagement. Furthermore, this is the only assessment of the literature known to date that attempts to consider both suggested/intended impact as well as evaluated measures. This paper demonstrates the distance the field needs to travel in order to substantiate claims and provide evidence-based guidance for the practice of stakeholder partner engaged research.

Conclusion

This paper maps and compares the intended purposes of engagement with actual applied measures to determine whether engagement has fulfilled its promised goals. Our assessment confirms the lack of evidence underlying much of the impetus behind the practice of patient and stakeholder engagement in research. Conceptually, there appears to be little clarity or consensus on what the major purpose(s) of engagement is and, empirically, there is little evidence to support its potential impact. Only a few studies have conducted any kind of formal evaluation, and the quality of these studies is highly variable. Given the state of the evidence base, research engagement appears to be primarily driven by the promise that – if done well, it will improve research generally, and moral and political grounds. This paper 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 of engagement processes.

Future perspective

To build an evidence base that is coherent, generalizable and allows comparison across studies and jurisdictions, the field needs to develop more conceptual and practical guidance to drive toward rigorous evaluation of research engagement. While we may never be able to adequately control for every contextual nuance, a more solid understanding of the goals of patient engagement, some level of consensus on measurable impacts and development and validation of measures

is clearly needed. We suggest that future evaluations of engagement research be designed *a priori* as an embedded component of the research process. While traditional peer-reviewed journals should encourage the reporting of the evaluation in their methodology and results, researchers should also look to other dissemination mechanisms for sharing lessons learned in engagement, as well as evaluation methodology and results. There should also be a commitment from institutions and funders to support patient-centered research by building adequate resources into their funding opportunities to support rigorous evaluation of research engagement activities.

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Executive summary

Background

- The literature proposes several benefits and hypothesized impacts of patient and stakeholder engagement in research yet there is an absence of evidence underlying these claims.
- This paper is the first to our knowledge to compare the hypothesized impacts of engagement with what has actually been evaluated and assessed.

Hypothesized impacts

- The proposed benefits of research engagement are: better quality research (includes expanded applicability of research), empowering patients, increased translation, dissemination and uptake of results, democracy and accountability, and moral obligation.

Measurement & evaluation of engagement

- With respect to evaluating the context and process of engagement (who, when and how to engage), the literature theorizes several suggested measures but we did not identify any research reporting findings along these dimensions.
- The limited number of studies that evaluate the impacts of engagement focus exclusively on the near-term effects of engagement.
- Of the studies that formally evaluated impact, most were qualitative, involving retrospective accounts and relied on self-report, informal observation or surveys.

Discussion

- This assessment confirms the lack of evidence underlying much of the impetus behind the practice of patient and stakeholder engagement in research.
- Conceptually, there appears to be little clarity or consensus on what the major purpose(s) of engagement is and, empirically, there is little evidence to support its potential impact.
- Given the state of the evidence base, research engagement appears to be primarily driven by the promise that – if done well, it will improve research generally, and moral and political grounds.
- This assessment provides explicit guidance for better alignment of engagement's promised benefits with evaluation efforts.
- It also identifies specific areas for development of evaluative measures and better reporting of engagement processes.
- This culture shift will require investment and dedication from both researchers and funding institutions.

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