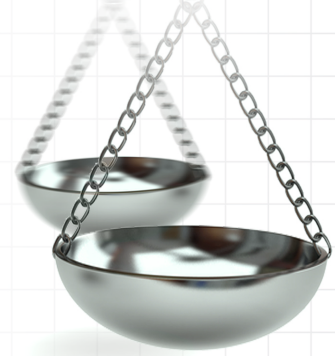
Research Article



Journal of Comparative Effectiveness Research

Health researcher views on comparative effectiveness research and research engagement

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 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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For nearly two decades, there has been growing interest in and funding for comparative effectiveness research (CER) [1–3]. CER compares the effectiveness and safety of preventive, diagnostic and treatment options to produce evidence that is useful for making informed decisions in real-world clinical settings [4]. In the USA, the US$1.1 billion for CER provided by the American Recovery and Reinvestment Act of 2009, which also mandated prioritization of CER topics by the Institute of Medicine, reinforced an already growing interest for CER to help improve decision-making about medical interventions for both patients and clinicians [5–11].

At the same time, interest has grown in greater patient and other stakeholder involvement in healthcare decision-making and research. Patient-centeredness, a concept that orients healthcare around the preferences and needs of patients through active and respectful partnerships between clinicians, patients and families, has become a central approach to healthcare delivery in the USA [12]. Both American Recovery and Reinvestment Act, and the Patient Protection and Affordable Care Act of 2010, which established the Patient-Centered Outcomes Research Institute (PCORI), emphasized the active role of patients and other stakeholders, such as caregivers in the planning, conduct and dissemination of research studies, which extended the concept of patient-centeredness from healthcare delivery to research [13]. Growing evidence suggests that this approach, known as patient-centered CER (PC-CER), fosters comparative studies that more closely align to the outcomes of greatest interest to patients and clinicians [9,14–16]. Engaging patients/caregivers is a critical component of PC-CER, as it can help to ensure that the research conducted is meaningful, relevant and useful to patients and their families in making health decisions [13]. Evaluations of

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PC-CER both in the USA and the UK indicate that involving patients and caregivers in the research process can increase study-enrollment rates; help researchers choose relevant and patient-focused research questions, objectives and outcomes; and provide patient perspectives on data interpretation [17–19].

Despite increased interest in PC-CER, little is known about health researchers' experiences, attitudes and needs related to conducting CER and engaging patients and caregivers as research partners. Surveys assessing stakeholder's attitudes toward CER and research engagement have primarily focused on patients, clinicians, Medicaid directors and other groups of CER stakeholders, rather than researchers [9,14,20–24]. Qualitative research with a limited number of researchers suggests that health researchers recognize the value of engaging patients, but face challenges in doing so [25,26]. With clear gaps in the evidence, additional quantitative and qualitative research is needed to better understand health researchers' perceptions on the value of engagement, as well as facilitators and barriers to engagement of patients and caregivers. Expanding the knowledge base in this area can help promote researcher collaboration with patients, caregivers and others interested in encouraging more informed and evidence-based clinical decisions [14], and can inform PCORI and other funders on increasing the quality and impact of CER.

In 2014, PCORI commissioned the current survey study to: understand healthcare researchers' attitudes toward and experiences with, conducting PC-CER; assess facilitators and barriers to conducting CER and partnering with patients and caregivers for this research; and understand the influence of PCORI on the conduct of PC-CER from a broad set of researchers. This study was part of a larger PCORI effort to understand the beliefs, values and attitudes of various audiences, including patients with rare and chronic diseases, caregivers, clinicians and researchers about CER and PC-CER; the engagement of patients in the research process; and the use of evidence-based information in clinical decision-making.

Materials & methods

Stakeholder input

The project was guided by an Advisory Group comprised of 11 representatives of patient advocacy organizations, medical societies, researchers with expertise in patient engagement and comparative effectiveness researchers. A Working Group of eight health researchers also guided the project. These groups assisted in the development of the final set of survey domains, guided revisions based on cognitive testing, provided suggestions for sampling, provided input into interpretation of the results, and contributed to the determination of key findings and their implications for PCORI.

Survey development

Survey development was guided by an environmental scan of the literature (n = 33 relevant articles), key informant interviews (n = 4) to assess general knowledge and lessons learned from existing surveys on researcher involvement with or use of CER, and input from the Advisory Group and Researcher Working Group. The survey was tested through cognitive interviews (n = 12) with researchers.

Measures

The survey included 40 individual survey items exploring: the type of research the respondent conducted and the setting; respondent knowledge and attitudes regarding the conduct of CER; respondent knowledge, experience and attitudes about engaging patients/caregivers as partners in research; respondent knowledge and perceived impact of PCORI; and general respondent demographics. In addition, we sought to understand whether there were significant differences in attitudes, beliefs, and perceptions of CER and interest in patient engagement among researchers based on specific demographic characteristics (e.g., years of research experience and clinician vs nonclinician researchers). Response options included: 3- and 4-point Likert scales (e.g., from very important to not important at all), mark all that apply and binary yes/no options (see Supplementary Material for the full survey instrument).

Sampling & population

We defined healthcare researchers as clinical, health services and health outcomes researchers. Since a comprehensive list of healthcare researchers does not exist, we used a convenience sample of members of professional research organizations or groups. The final list of 24 organizations was developed with the goal of ensuring representation of clinical, health services and health outcome researchers who currently conduct CER, or who are likely to conduct CER given that the field of CER research is relatively new to some (see Supplementary Material for a full list of the organizations). The target number of completed surveys was 500–1000 to meet our analytic goals, such as the ability to detect subgroup differences. Because of using a convenience sample where the number of individuals invited to participate who meet our eligibility criteria cannot be accurately determined, a survey response rate was not calculated. However, because a unique survey URL was created for each participating organization, we were able to determine the percentage of completed surveys that were linked to each organization (n = 508):

- 40.4% – research organizations, such as, Kaiser Permanente Division of Research, Center for Effectiveness & Safety Research and North American Primary Care Research Group;
- 32.6% – PCORI mailing lists (random sample);
- 12.4% – institutions previously part of the Agency for Healthcare Research and Quality (AHRQ) Innovative Adaptation and Dissemination of AHRQ CER Product grants;
- 11.2% – evidence-based practice centers;
- 2.0% – institutions previously part of the AHRQ Centers for Education and Research on Therapeutics (CERTs);
- 1.4% – institutions previously part of the Developing Evidence to Inform Decisions about Effectiveness Network.

Data collection

The web-based survey was open from October 2014 to November 2014. Invitations to complete the survey were distributed via an email invitation from most organizations; two organizations: the International Society for Public Opinion Research and AcademyHealth, announced the survey in their respective newsletters. Respondents completing the survey were eligible to receive a $5 gift card. A total of 508 researchers completed the survey. The American Institutes for Research Institutional Review Board (IRB) approved this study.

Analysis

Descriptive statistical analyses (e.g., frequencies) were performed using STATA version 13 software and are interpreted based on the response scale. We examined frequency distributions for each question and collapsed or top-coded responses as needed for analyses to account for imbalanced response categories or to appropriately dichotomize scaled responses. Bivariate analyses, such as cross tabulations using Chi Square or Fisher's exact tests, were conducted to compare beliefs, values and attitudes of researchers about CER across all collected demographic characteristics (e.g., years of research experience, institution type and clinician vs nonclinician researcher) to identify differences among subgroups; statistically significant associations are reported.

Results

Survey participants

Among those who reported demographic information, the majority were white (85%) and non-Hispanic (96%). More than half (61%) were female. Nearly a third (31%) of respondents was aged 35–44 years, and 41% had worked in the research field for 16 or more years. In addition, most had been a principal investigator (78%); were not a practicing healthcare clinician (67%); were affiliated with a medical school, academic institution or teaching hospital (68%); had conducted CER – defined as an assessment of prevention, diagnosis or treatment options (69%); and recently had conducted health services research projects (60%). Respondents earned their highest degree from a variety of disciplines, including medicine (28%), psychology (12%), epidemiology (10%) and others (18%) such as anthropology, education, nutrition, public policy and social work (see Table 1).

Familiarity with & value of CER

A majority of respondents (94%) were familiar with CER, with 60% reporting they were 'very familiar' (see Figure 1). Approximately two-thirds of respondents reported experience conducting some form of this type of research: of those, 74% had conducted observational studies, 64% had conducted secondary data analysis, 54% had conducted randomized trials, 27% had conducted pragmatic trials, 41% had conducted systematic reviews and 37% had conducted dissemination and implementation. Of those who had not conducted any form of CER, nearly half (47%) identified lack of alignment with their training and expertise as the reason, one-quarter (26%) selected lack of funding opportunities and nearly one-quarter (22%) reported not obtaining funding despite trying. Most researchers perceived CER as 'very valuable' for supplying evidence relevant to clinical decision-making (83%) and helping patients make treatment choices (71%).

Conducting PC-CER

Nearly half of the respondents had conducted PC-CER (49%). Of those who had not, their reasons included lack of alignment of PC-CER with their training and expertise (36%), lack of funding opportunities (29%) and not obtaining funding despite trying (23%). Compared with groups with less experience, researchers who have been conducting research for 16-plus years were more likely to have conducted PC-CER ($p = 0.002$).

Engagement with patients &/or caregivers

Most respondents were familiar with engaging patients and/or caregivers as partners in research (43% 'very familiar' and 38% 'familiar'). Researchers with 16-plus years of experience were more likely to be very familiar with patient/caregiver involvement ($p = 0.007$). Further, 65% of the researcher sample reported experience engaging with patients and/or caregivers in research. Of those who had engaged patients/caregivers in research,

Table 1. Demographics of survey respondents (researchers).

Demographic characteristic	Frequency, n (%)
Sex:	
– Male	182 (39.2)
– Female	282 (60.8)
Race (mark all that apply):	
– White	390 (85.0)
– Black or African–American	19 (4.1)
– American–Indian or Alaska native	0 (0.0)
– Asian	54 (11.8)
– Native Hawaiian or other Pacific Islander	3 (0.7)
Age (years):	
– 18–24	2 (0.4)
– 25–34	53 (11.4)
– 35–44	143 (30.7)
– 45–54	125 (26.8)
– 55–64	112 (24.0)
– 65 or older	31 (6.6)
Hispanic, Latino/a or Spanish:	
– Yes	19 (4.1)
– No	444 (95.9)
Number of years in research field:	
– 1–6	98 (20.8)
– 7–15	179 (38.0)
– 16 or more	194 (41.2)
Respondent is practicing healthcare clinician:	
– Yes	157 (33.5)
– No	312 (66.5)
Type of research institution (mark all that apply):	
– Medical school, academic institution or teaching hospital	322 (68.4)
– Nonprofit, nonacademic research organization	116 (24.6)
– Corporate organization	39 (8.3)
– State or Federal government agency	20 (4.2)
– Other	18 (3.8)
Types of recent research projects (mark all that apply):	
– Clinical research	219 (47.0)
– Health services research	280 (60.1)
– Health economics	50 (10.7)
– Health outcomes research	227 (48.7)
– Community-based participatory research	119 (25.5)
– Comparative effectiveness research	199 (42.7)

Total respondent sample = 508. Percentages based on available demographic data.

Table 1. Demographics of survey respondents (researchers) (cont.).

Demographic characteristic	Frequency, n (%)
Areas have ever conducted research (mark all that apply):	
– Assessment of prevention, diagnosis or treatment options	321 (68.6)
– Improving healthcare systems	221 (47.2)
– Communication and dissemination of research findings	161 (34.4)
– Disparities in health and healthcare delivery	231 (49.4)
– Improving methods for comparative effectiveness research	114 (24.4)
– I have not conducted research in any of these areas	19 (4.1)
Principal investigator:	
– Yes	369 (78.3)
– No	102 (21.7)

Total respondent sample = 508. Percentages based on available demographic data.

the most common roles patients/caregivers played were identifying research topics or agendas (62%), developing research questions (59%), participant recruitment or data collection (58%), results review, interpretation or translation (53%) and dissemination of findings (47%) (see Table 2).

Further, among those researchers who had engaged with patients or caregivers, nearly 56% said it was 'very valuable' and almost a third (32%) said it was 'somewhat valuable' to their research. See Figure 2 for details on perceived value of engaging patients and/or caregivers in several specific activities. A majority of these researchers cited recruitment or data collection (62%), identifying research topics and agendas (59%), and disseminating findings (57%) as 'very valuable' roles for research engagement with patients or caregivers. Approximately a third (36%) endorsed engagement for assisting with results review and interpretation as 'very valuable'.

A majority of respondents (87%) expressed interest in engaging patients and caregivers as research partners in the future, with 63% being 'very interested'. Factors that respondents said were 'very important' for determining whether they would involve patients and/or caregivers as partners in research included being able to conduct research is relevant to patient needs (78%), the ability to recruit participants (57%), the uptake of findings in clinical practice (50%), and potential speed of dissemination of research results with patient and caregiver help (41%).

Facilitators & barriers to engaging patients/caregivers in the research process

Respondents were asked to indicate how much a variety of factors would facilitate or hinder their involvement of patients/caregivers in research. The factors most commonly cited as facilitating engagement 'a great deal' were resources to assist in the training and coordination of patient and/or caregiver partners (63%) and guidance in applying for funding of research that requires patient/caregiver partners (58%). The factors most commonly cited as hindering engagement 'a great deal' were lack of infrastructure to support involving patients as partners (48%), potential increased resources (staffing, other costs) to work with patients and/or caregivers (37%) and regulations (34%) – for example, HIPAA (Health Insurance Portability and Accountability Act of 1996) and IRB concerns (see Figure 3).

In addition, there was variation between clinician and nonclinician researchers in the reported barriers. More nonclinician researchers (24%) than clinician researchers (14%) reported limited access to patients/caregivers interested in becoming research partners as hindering their involvement of patients/caregivers 'a great deal' ($p = 0.016$). Reported barriers and facilitators did not differ significantly between researchers who reported that they had or had not ever conducted CER or PC-CER (all $p > 0.05$).

Familiarity with PCORI

Respondents were largely familiar with PCORI (52% 'very familiar' and 38% 'somewhat familiar'). Among those familiar with PCORI, 60% reported that PCORI had influenced their decision to conduct CER (26% 'a great deal' and 34% 'some') and 65% reported that PCORI had influenced their decision to involve patients as partners (32% 'a great deal' and 32% 'some'). Fewer researchers with 16-plus years of experience reported PCORI had influenced their decisions a great deal ($p = 0.023$). But, researchers with 1–6 years of experience who were familiar with PCORI were more likely to report that PCORI's efforts were very valuable ($p = 0.033$).

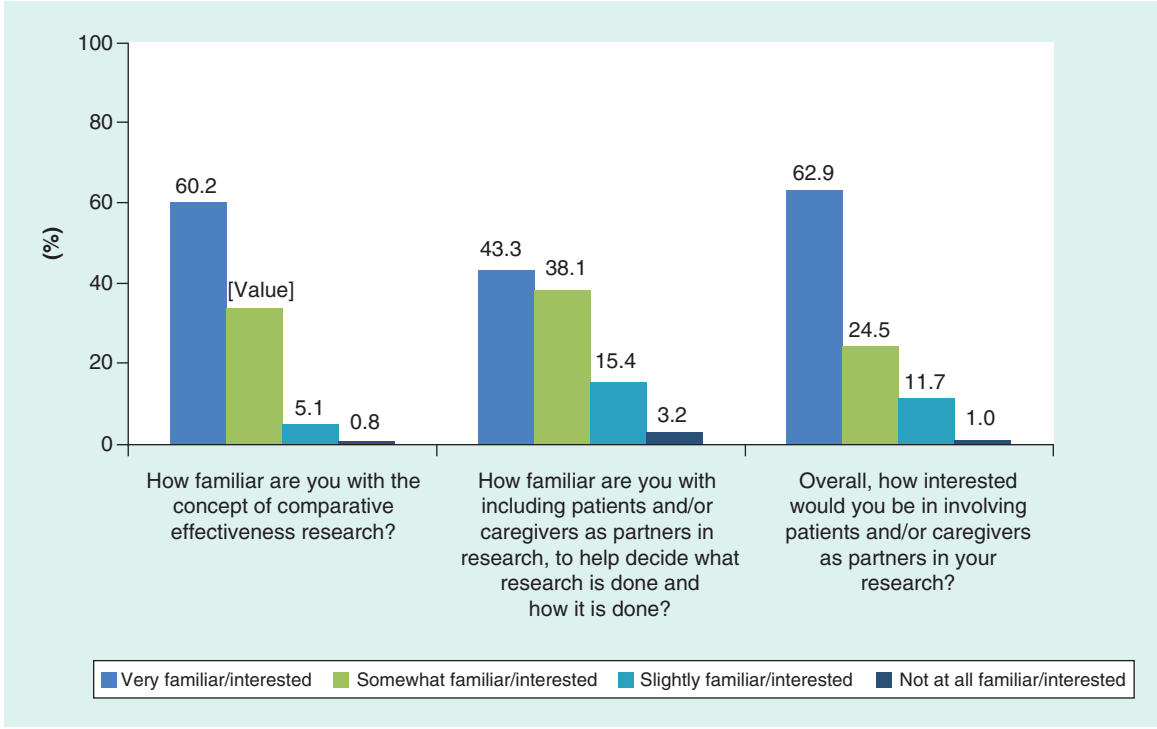

Figure 1. Familiarity with comparative effectiveness research and engaging patients and/or caregivers in research, 2014 Patient-Centered Outcomes Research Institute survey of researchers.

Discussion

An understanding of researchers' experiences, attitudes, and needs related to CER and engaging patients and caregivers as partners in the research process is a necessary foundation for facilitating future PC-CER. Across a sample of 508 healthcare researchers, there was a high level of awareness of CER, engaging patients/caregivers as research partners and PCORI, and significant agreement that CER is valuable in supplying evidence relevant to clinical decision-making and helping patients make treatment choices. However, only two-thirds of the surveyed researchers reported experience actually conducting CER studies and less than half reported conducting PC-CER. Further, even fewer had conducted randomized CER trials or pragmatic trials. These findings suggest that while there is a clear cohort of researchers interested in producing PC-CER, there is room for expansion across the larger population of researchers, particularly for approaches like pragmatic trials which are recognized as offering important benefits over traditional methods [27] and are increasingly becoming the focus of PCORI funding.

Not surprisingly, training and expertise in CER and PC-CER were consistently cited by researchers as the primary reason for not conducting this type of research. This finding suggests a need for expanded training opportunities to increase the number of researchers who feel competent in CER and PC-CER. However, a significant percentage of researchers also cited a lack of funding opportunities or inability to obtain funding despite trying as reasons for not conducting PC-CER. This suggests that additional outreach to the research community regarding funding opportunities and strategies to support application success may be helpful, as is further evaluation of the extent to which existing funding availability meets the need for research support.

Most researchers expressed familiarity with engaging patients/caregivers as partners in research. More than half reported engaging with patients or caregivers as research partners, and most of this group described the engagement experience as valuable to their research. Further, the majority of the health researchers who responded to the survey expressed interest in engaging with patients and caregivers on future studies. Taken together, these findings suggest there is a pool of researchers ready and willing to adopt patient-centered approaches to health research. However, researchers appear to have limited experience with the roles that patients/caregivers can play in the research process, with respondents most commonly reporting experience engaging with partners on identifying research topics, recruiting participants, interpreting results or disseminating findings. Consistent with other literature [18,28], these findings suggest that more work needs to be done to support researchers in engaging with

patient/caregiver partners, with particular emphasis on those where experience is the lowest (defining comparators or data analysis) and those most commonly viewed as valuable (data collection, identifying topics and dissemination). Researchers' perceived value of engagement of patients and caregivers for improving participant recruitment and data collection is not surprising given that failures in participant enrollment is a common reason for trial failure [29], but it is notable that researchers recognized the value of engagement at a variety of phases in the research process.

Although there were few demographic subgroup differences in these findings, a few trends are notable. Researchers with fewer years of research experience reported less experience with PC-CER and less familiarity with patient/caregiver engagement. Interestingly, they perceived more PCORI influence on the kinds of research they conduct, so early-career researchers may be particularly important targets for training and career development opportunities. These early-career researchers may need additional support and mentorship from more senior researchers in order to gain experience in the field. Another opportunity to expand the field is with nonclinician researchers, because they were more likely to report that limited access to patients/caregivers hindered their involvement of patients/caregivers in research. This suggests that researchers who do not regularly work with patients need new mechanisms to connect with patients.

An enhanced understanding of the barriers to and facilitators of conducting PC-CER is critical to supporting and expanding the pool of researchers able to conduct successful PC-CER. The finding that health researchers identified a number of potential barriers to conducting PC-CER is consistent with prior literature, which cites issues of institutional structure, policy and even philosophy, along with competing needs for a limited supply of time and resources, as major challenges to patient engagement in CER that must be addressed [17–19,30]. The specific infrastructure challenges noted by researchers here can be the basis for an action agenda on the part of research organization administrators and planners, particularly the lack of institutional infrastructure to engage patients as partners rather than as subjects and the limited resources for preparing researchers and stakeholders for partnership. In spite of the efforts by the National Center for Advancing Translational Sciences' Clinical and Translational Science Awards Program (CTSA) and others to train and support research teams in engaging diverse

Table 2. Experiences with engagement among researchers.

Survey topic	Frequency, n (%)
Have you ever engaged patients and/or caregivers in the planning, design, monitoring, interpretation, or dissemination or a research study?:	
– Yes	315 (65.1)
What role have patients and/or caregivers played in your research study or project? (if engaged patients/caregivers; mark all that apply):	
– Identifying research topics or agenda	192 (61.5)
– Developing the research questions	183 (58.7)
– Proposal development	130 (41.7)
– Study design: defining comparators	89 (28.5)
– Study design: defining and/or measuring outcomes	155 (49.7)
– Study design: selection or development of interventions	134 (43.0)
– Participant recruitment or data collection	181 (58.0)
– Data analysis	38 (12.2)
– Results review, interpretation or translation	166 (53.2)
– Dissemination of findings	148 (47.4)
– Other, please specify	11 (3.5)
How valuable was engaging patients and/or caregivers to your research?:	
– Very valuable	172 (55.8)
– Somewhat valuable	97 (31.5)
– Slightly valuable	34 (11.0)
– Not at all valuable	5 (1.6)

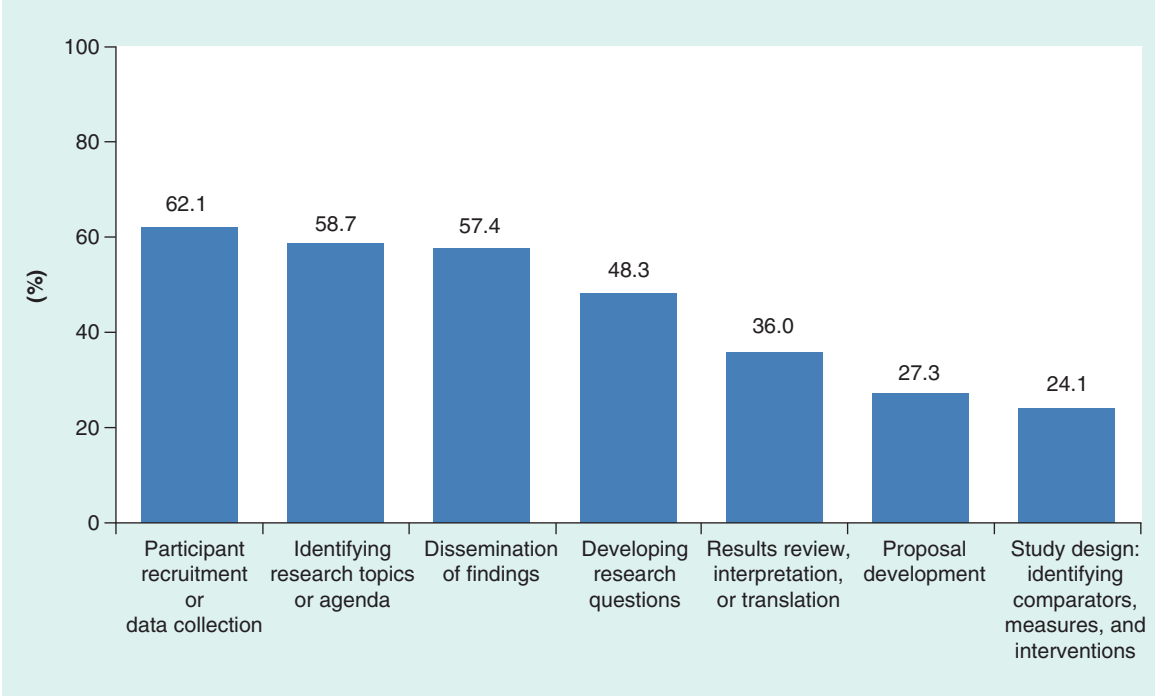

Figure 2. Perceived value among researchers of engaging with patients and/or caregivers (very valuable).

patients and communities in translational research [31], researchers also indicated need for resources to increase their training and expertise in PC-CER, particularly in the areas of recruiting and interacting successfully with patient/caregiver partners. This, too, can be part of an action agenda for research organizations and for research advocacy groups as well. As patient/caregiver engagement is often a condition of CER funding, addressing these barriers should be a high priority for research institutions and funders. The researchers participating in this survey identified clear areas where additional support is needed, including additional training, increased funding and additional resources to identify and train patients to serve in research partner roles. While PCORI has created a broad set of resources for research professionals interested in developing skills in this area through its website (e.g., the PCORI engagement rubric [32], compensation framework, and sample patient engagement plans), these may need to be tied more closely to academic centers training future health researchers or CTSA program networks to facilitate the uptake of these and other available resources.

The motivation identified by the majority of health researchers to conduct PC-CER – the study's ability to meet patient decisional needs – signals a need to ensure better communication of patient needs to researchers, and perhaps, more opportunities for interactions between patient and consumer groups and the research community. Traditionally, researchers and patients/caregivers have remained separate. Research funders and others could help to foster meaningful dialogue among researchers and patients/caregivers about gaps in the information patients need in the treatment choices. PC-CER may be further advanced through the formal integration of patients and caregivers into research conferences and journals as active contributors. Tools like the 'Patients Included' charter can help research organizations operationalize and demonstrate that their events or activities are committed to incorporating patients as coexperts, while ensuring that they are neither excluded nor exploited [33,34]. Likewise, encouraging researcher involvement in patient support or advocacy organizations could also yield better inspiration for PC-CER projects and sustainable partnerships. Last, taking steps to better accommodate patients or caregivers as research partners, such as minimizing time commitments; providing compensation; offering engagement opportunities throughout the research process; and leveraging mobile and web-based technology for interactions and information exchange, can promote participation within the context of their busy lives.

The data also show that PCORI has had an influence within the research community regarding PC-CER, even after just 2 years of initiating its research funding program, suggesting that the existence of a national institution to promote, inform, develop and fund PC-CER may be critical to ensuring the sustainability of a robust community of PC-CER researchers. Future work could address the extent to which

researcher engagement behavior follows growth in the evidence base on engagement.

Limitations

There are several limitations to this study. First, the survey was based on a convenience sample since there was no existing comprehensive national panel of health researchers. Thus, the results of this survey cannot be extrapolated beyond these respondents. This study, by design, sought to understand experiences with and attitudes toward CER and engagement among those who were conducting or were likely to conduct CER to better understand the meaningful barriers and facilitators to this type of research. Thus, respondents tended to be from health research organizations with a strong focus on CER (e.g., PCORI's mailing lists, the evidence-based practice centers and Innovative Adaptation and Dissemination of AHRQ CER Product grantees) who may have a greater working knowledge of CER and PC-CER than healthcare researchers who are not affiliated with such organizations. This commonality could also explain the limited differences in primary CER outcomes found across demographic subgroups within this pool of respondents. Future studies should attempt to include researchers from other groups who may be familiar with engagement, including investigators associated with the CTSAs, and also healthcare researchers who may not be as familiar with CER or PC-CER to more fully understand attitudes toward CER and engagement from a broader perspective. Future studies should also consider collecting specific information from respondents regarding participation in PC-CER training or working with senior mentors experienced in PC-CER. Second, as this is an evolving field, these findings from late 2014 may not accurately reflect the current state of researcher attitudes and beliefs about, or experiences with CER. Third, racial/ethnic diversity among survey respondents was limited, highlighting the need for more targeted sampling strategies to better understand the experiences and attitudes of diverse researchers, particularly in light of efforts to facilitate the conduct of patient-centeredness not only among researchers from diverse backgrounds but also with diverse patient and caregiver partners. Further research is needed to examine researcher attitudes toward and experience with conducting CER with other stakeholders beyond patients and caregivers (e.g., clinicians, administrators, payers), as well as to assess frequency and level of engagement with patients, caregivers or other stakeholders. Last, although some researchers in the study reported conducting PC-CER, this study cannot confirm the consistency or fidelity of PC-CER practices among them.

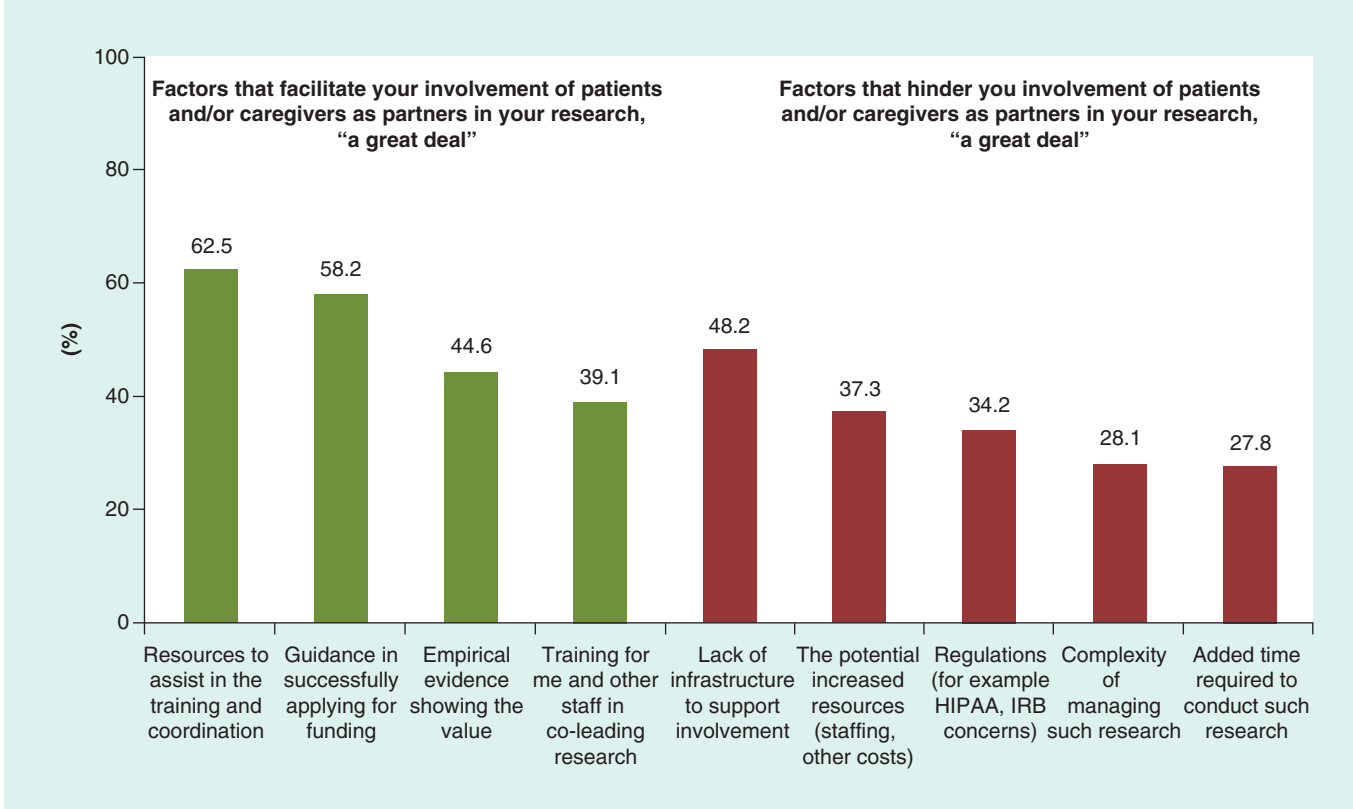

Figure 3. Facilitators and barriers of engaging patients and/or caregivers in research.

More in-depth studies are needed to examine concordance of researcher-reported PC-CER activities and intent with actual experiences. A larger mixed-methods research effort with a sample of health researchers that reflects a wider range of experience (or lack thereof) with patient-centered approaches to research would further build the evidence base in this area.

Future perspective

As patient-engaged research becomes available to the public that can be used in healthcare decision-making, we foresee an increased demand for CER that fully incorporates stakeholder needs and interests at every level of the process. In order to meet this demand, evolution of the current healthcare research arena is likely to occur in three areas. First, the structure, policies and procedures at research institutions will evolve to enable patients, caregivers and other nonresearcher stakeholders to serve as partners and coinvestigators in CER. Research institutions will need to innovate new policies and procedures that open access to stakeholder partners who are not serving as subjects. This is likely to impact a wide range of institutional procedures from the IRB to the Sponsored Programs. Second, we envision an expanded curriculum for academic and research institutions involved in training new healthcare researchers that incorporates the methods and best practices of stakeholder-engaged CER. Finally, we expect to see patient-engaged CER become fully realized and legitimized as a form of healthcare research alongside more traditional medical research. We expect to see increased development of a researcher community that is able to continue the evolution of patient-engaged CER by improving its methods, disseminating findings and expanding its application to the field of healthcare.

Supplementary data

To view the supplementary data that accompany this paper please visit the journal website at: http://www.futuremedicine.com/doi/full/10.2217/cer-2016-0063

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Disclaimer

The views expressed in this paper are those of the authors and do not necessarily reflect the official views of the PCORI, nor of the American Institutes for Research.

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Summary points

Background

- Despite increased funding for comparative effectiveness research (CER), significant knowledge gaps exist about researcher's interest in CER, barriers and facilitators to conducting CER, and attitudes and experiences engaging and partnering with patients on patient-centered CER (PC-CER).
- This study informs ongoing efforts to develop and support researcher's interest in and capacity to conduct CER and PC-CER.

Methods

- Web-based survey of 508 clinical, health services and health outcome researchers recruited through a convenience sample using professional organizations.

Results

- An overwhelming majority of respondents (94%) were familiar with CER.
- Approximately two-thirds (69%) reported ever conducting some form of CER. Nearly half of those who had not conducted any form of CER cited lack of alignment with their training and expertise as the reason.
- Most respondents were familiar with partnering with patients and/or caregivers (81%) in research, and most (87%) expressed interest in engaging patients/caregivers as research partners.
- The most commonly cited factors that would help researchers involve patients/caregivers in studies were resources to assist in the training and coordination of patient and/or caregiver partners (62%) and guidance in applying for funding of PC-CER (58%).
- Lack of infrastructure to support patients as partners in research was the most commonly cited barrier (48%).
- These findings suggest a need for expanded curriculum on patient-engaged research at training institutions or better integration with existing resources, such as Clinical and Translational Science Awards Programs, to increase the number of researchers who feel competent to conduct CER and PC-CER.

Conclusion & future perspective

- These findings indicate there is a significant opportunity for an action agenda on the part of researchers to engage patients and caregivers as partners rather than subjects and to provide resources for preparing researchers and patients/caregivers for meaningful and sustainable partnerships.

financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript apart from those disclosed.

No writing assistance was utilized in the production of this manuscript.

Ethical conduct of research

The authors state that they have obtained appropriate IRB approval or have followed the principles outlined in the Declaration of Helsinki for all human or animal experimental investigations. In addition, for investigations involving human subjects, informed consent has been obtained from the participants involved.

Open access

References

Papers of special note have been highlighted as:
• of interest; •• of considerable interest

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