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Community of trauma care partnering with stakeholders to improve injury outcomes: survey analysis and panel development

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ABSTRACT

Background In June 2021, the Injury Research Engagement Project (I-REP) was established. In 2022, we preformed focus group analysis with patients/caregiver and researchers that resulted in themes in preferences, motivations, and best practices to increase participation in trauma research. The importance of trust and well-established relationships was common across all groups. In this study, we aimed to further evaluate preferences regarding research procedures and outcomes, and develop a panel for sustained patient engagement.

Methods We performed a multiphase, mixed methods study to elicit trauma stakeholders' perspectives regarding aspects of research. Previously published phase 1 involved focus group analysis. Phase 2 vignette-based surveys and phase 3 panel formation are described here. One survey was completed by patients/caregivers, and the second by trauma researchers. We compared the responses using independent t-tests. This was followed by a webinar and development of an I-REP panel of patients/caregivers.

Results 60 patients/caregivers and 114 researchers participated in the online surveys, with completion rates of 68% and 69%, respectively. The majority of patients/caregivers were >45 years, female (66.7%), and >3 years out from their or their family member's injury (68.6%). The majority of the researchers were >35 years and male (56.2%). Participants were asked to gauge their perceptions of different research scenarios. The analysis identified themes emerging across groups. Several survey findings differed from phase 1, including motivations to participate (payment) and consent preferences (timing, approach). Racial and ethnic demographics of the participants were not collected.

Conclusions Engaging trauma stakeholders results in research more relevant to patients' needs and priorities. Qualitative engagement methods that intentionally include a more diverse population and determining the appropriate format for specific questions may lead to results that are be more generalizable. The educational webinar was well received, and several participants opted to serve as I-REP panelists to collaborate with trauma researchers moving forward.

Level of evidence IV.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ It is clear that incorporating broad patient/family/caregiver stakeholder perspectives in research design can increase research significance, but there is a lack of consensus on how best to incorporate their insights into the study design process.

WHAT THIS STUDY ADDS

⇒ This study is the first of its kind, engaging patients and caregivers to discuss how to ensure that trauma research is meaningful, respectful, and relevant to injured patients and their families.

⇒ Several online survey findings differed from earlier focus groups including motivations to participate (payment) and consent preferences (timing, researcher's approach/characteristics).

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Our findings reveal qualitative engagement methods that intentionally include a broader, larger, more diverse population and determining the appropriate format for specific questions, focus groups versus surveys, may lead to results that are more informative and generalizable.

⇒ Since this submission, the Injury Research Engagement Panel has successfully facilitated patient engagement in several trauma research study designs.

INTRODUCTION

Injury is the leading cause of death for all persons aged 1–44 in the USA.[1 2] In 2015, 2.8 million people were hospitalized after injury,[3] and more than 50 million patients receive some form of trauma-related medical care annually.[1 2] Injuries often result in varying types of disability with significant social and economic consequences.[4 5] Several studies document a reduction in quality-of-life after injury[6–11] due to survivors' significant physical and/or cognitive dysfunction. Mental health and substance abuse disorders are exceptionally common.[4 5 12–14] The National Study on the Costs and Outcomes of Trauma, for example, found that of nearly 3000 injured adults evaluated at 1 year after injury, 21% screened positive for post-traumatic stress disorder,

and nearly 7% demonstrated signs of depression.[15] Individuals who suffer physical injury are not the only ones who face life-altering consequences after injury. For patients who survive their injuries but suffer from long-term disability, their caregivers encounter significant challenges including higher levels of depression and mental health disorders[16–20] and high levels of stress and frustration.[18 21] These psychosocial effects of being a caregiver are linked with higher rates of alcohol and substance abuse,[22 23] and worse overall physical health compared with non-caregivers.[23 24]

The wide-reaching impact of traumatic injury is clear, as is the need for peer-reviewed research in the field to improve outcomes; however, no consensus exists on best research practices. Additionally, the nature of trauma research presents ethical complexities unique to the field, such as the lack of a well-established relationship between the patient, caregiver, and/or researcher, and the often incapacitated, critically ill patient requiring a legally authorized representative (LAR) and/or exception from informed consent (EFIC) for research involvement. In June 2021, with funding from a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington Engagement Award—*The Community of Trauma Care: Partnering with Patients and Caregivers to Improve Trauma Care*—the Injury Research Engagement Project (I-REP) was established. Through I-REP, we performed a multiphase, inductive exploratory qualitative study to elicit stakeholder perspectives and preferences regarding trauma research and its processes. In phase 1, we preformed focus group analysis with patients, a caregiver, and researchers that resulted in common themes in preferences, motivations, and best practices to increase participation in trauma research. The importance of trust and well-established relationships with the clinical care team were the most common across all groups.[25]

Patient and caregiver engagement has been shown to improve participant enrollment,[26] securing research funding, developing study protocols, and choosing patient-relevant outcomes.[27] A recent qualitative analysis of studies published in peer-reviewed journals found that the engagement of patients and caregivers contributes to the quality of research in multiple domains including (1) identifying research questions and outcomes important to patients and clinicians; (2) improving participant recruitment and retention; (3) improving the data collection processes; (4) improving the interpretation of results; and (5) enhancing dissemination.[28] This study further highlighted that the effects of engagement could be stratified into feasibility, acceptability, rigor, and relevance, all of which contribute to the production of high-quality research and avoid wasting resources and effort in producing studies that fail to improve the health or outcomes of patients.

Previously, the trauma research community has not systematically collaborated with patients and caregivers in conducting patient-centered outcomes research. Currently, researchers seeking to engage and partner with trauma survivors and other stakeholders must identify potential patient partners/stakeholders on their own. This poses a problem for many reasons: (1) the significant effort required could discourage researchers from this collaboration; (2) individual stakeholders may not be able to provide a generalizable perspective; and (3) selected stakeholders may not represent the wide range of patient and family race, ethnicity, age, and other demographics. We aim to ameliorate this disconnect in the trauma research community.

With the results of our phase 1 I-REP focus groups,[25] we proceeded with vignette-based surveys to obtain broader consensus on best research practices. In this study, we describe phases 2 and 3 of our I-REP initiative. In phase 2, we aimed to survey a broad range of patients, caregivers, and the trauma research community regarding research processes used with different study designs, preferred research staff characteristics, and patient-relevant research outcomes. In phase 3, we conducted an interactive educational webinar and discussion with patients, caregivers, and researchers, and formed the I-REP panel. Our ultimate goal was to create an integrated partnership with trauma survivors and caregivers to improve the understanding of participants regarding trauma research and sustain patient engagement in trauma research.

METHODS

In June 2021, with the assistance of a PCORI Eugene Washington Engagement Award, *The Community of Trauma Care: Partnering with Patients and Caregivers to Improve Trauma Care*, I-REP was established. In 2022, I-REP performed a multiphase, inductive exploratory qualitative study to elicit stakeholder perspectives and preferences.[25] The project coordinating center obtained Institutional Review Board approval to conduct the study. This protocol was reviewed and approved by WCG WIRB (IRB Protocol # 20215168). The CROSS guidelines were used to ensure proper reporting of methods, results, and discussion[29] (see online supplemental material 1).

Recruitment

A convenience sample of participants was contacted via the phase 1 focus groups, surgical/trauma professional organizations, patient advocacy organizations (Health Alliance for Violence Intervention (HAVI) and the American Trauma Society Trauma Survivors Network (ATS TSN)), and six trauma centers/clinics throughout the US. ATS TSN and HAVI coordinators referred trauma survivors and caregivers at their home sites. Researcher and clinician participants were recruited through email or direct contact by a study team member and via the Society for Trauma Nurses. All patients, caregivers, clinicians, and researchers who decided to participate were anonymous to the study team and consented at the beginning of the survey. The survey questions were randomly arranged and any questions answered were included in the analysis. The likelihood of the questions being answered was equivalent due to the random assignment.

Phase 2: vignette-based surveys

We developed and administered vignette-based online surveys to identify stakeholder preferences and values regarding research procedures and outcomes (online supplemental files 2 and 3, respectively). Participants were asked to gauge the value of different research scenarios and practices identified as relevant or problematic in phase 1. One vignette was created per research procedure of interest: survey research, study requiring blood draws, interventional drug study, study requiring follow-up, LAR consent, and EFIC. Using the vignettes as context, preferences and values were solicited regarding research approaches, researcher characteristics, and study outcomes. For the clinician/researcher survey, we asked the participants to complete it from the patient's perspective (ie, what they think is important to patients/caregivers). We used a Likert scale from 1 to 5 (1=not at all beneficial to 5=extremely beneficial; 1=not at all important to 5=extremely important; or 1=not at all comfortable to 5=extremely comfortable). The online survey was conducted on Survey Monkey between March and June 2023.

Phase 3: I-REP patient and caregiver panel

The I-REP patient and caregiver panelists were recruited in fall 2023 from prior patients and caregivers who participated in any of the I-REP phases and through partnering with organizations such as ATS TSN sites serving traditionally under-represented patient populations. As subject matter experts with valuable life experiences, patients and caregivers were compensated $100 for participating in each meeting. A formal Memorandum of Understanding (MOU) for the I-REP panel was developed based on templates from the PCORI Engagement Resources with panelists' input to outline roles and responsibilities of staff members and panelists.[30] The project team shared several patient-centric research primers (from PCORI Engagement Resources – Research Fundamentals) with panelists via email.[31] The Coalition for National Trauma Research (CNTR), the project coordinating center, will manage this panel moving forward, including participant recruitment, MOU execution, quarterly online meeting management, and coordination with trauma researchers seeking authentic patient engagement. CNTR maintains an I-REP page on its website and messages monthly about the availability of the patient panel to its Constant Contact list of more than 7000 trauma care investigators and other stakeholders.[32]

Analysis

We compared the patient/caregiver versus researcher responses using independent t-tests. Significance was set at $p<0.05$. This analysis identified the range of motivations, preferences, suggestions, concerns, influences, and experiences present in the data.

RESULTS

Phase 2: vignette-based surveys

Forty-three patients, 17 caregivers, and 114 researchers participated, with survey completion rates of 68% and 69%, respectively (see stakeholder demographics in table 1). The majority of patients/caregivers were >45 years old, female (66.7%), and >3 years out from their or their family member's injury (68.6%). The majority of the researchers were >35 years old and female (56.2%). Participants were asked to rate their value, preferences, or comfort with various research scenarios and practices identified from the phase 1 results (table 2).[25] Data analysis identified common themes emerging across groups (table 2).

Regarding the study's likelihood to benefit the patient, patients/caregivers consistently rated this less important than did researchers. For instance, when deciding whether to participate in a study, even when the study required a return visit to the hospital, patients/caregivers' mean score regarding the importance of direct benefit to the patient was lower compared with researchers (mean 2.03 vs 2.86; $p<0.001$). In other words, patients/caregivers did not consider potential benefits to the patient to be as important as researchers estimated they did. Similarly, patients/caregivers rated the importance of personal benefit lower than researchers in a medication study (mean 2.41 vs 2.99; $p=0.010$), and in a study requiring blood draws (mean 2.28 vs 3.07; $p=0.003$).

Regarding study outcomes, patients'/caregivers' preferences differed from researchers when identifying study outcomes as effective. Patients/caregivers rated the benefit of a pain medication study more highly than researchers whether the medication was found to be effective for patients with similar injuries to their own (mean 4.68 vs 4.35; $p=0.018$), the medication was found to be ineffective for the treatment of pain, but effective in treatment of anxiety (mean 4.27 vs 3.86; $p=0.013$), the medication had side effects (mean 3.92 vs 3.41; $p=0.026$), or if the medication was ineffective and would not be used (mean 3.7 vs 2.92; $p<0.001$).

Regarding the decision to participate in a research study, researcher and patient/caregiver responses differed when considering the impact of the ongoing hospital experience and the researcher's characteristics. Patients rated having previous unpleasant interactions with staff as less important than did the researchers (mean 3.39 vs 3.85; $p=0.035$) as well as having no break from talking with staff: patients/caregivers' rating on this scenario was mean 3.31 vs 4.19 for researchers ($p<0.001$). The staff appearing unhurried was less important to the patients/caregivers than to researchers (mean 3.53 vs 4.36; $p<0.001$) and less important to the patients than the researchers in a survey study (mean 3.59 vs 4.11; $p=0.012$). Having the patient's doctor introduce the study to the patient/caregiver was less important to both the patient in a survey study (mean 2.58 vs 3.09; $p=0.034$), to the LAR in an ICU study (mean 2.56 vs 3.17; $p=0.018$), and in an EFIC study (mean 2.58 vs 3.12; $p<0.001$).

Patients/caregivers consistently rated the race/ethnicity of the researcher of lower importance than did the researchers, including scenarios involving a drug study (mean 1.16 vs 2.66; $p<0.001$), LAR consent (mean 1.19 vs 2.67; $p<0.001$), an EFIC study (mean 1.14 vs 2.67; $p<0.001$), and a survey study (mean 1.15 vs 2.67; $p<0.001$). Patients also rated the researcher having personal experience with trauma as less important than did researchers (mean 2.11 vs 2.62; $p=0.016$).

For studies requiring blood draws, the patients/caregivers thought it more important than the researchers that there was almost no risk to their health for participating (mean 4.53 vs 4.2; $p=0.032$) and that the process of what would happen with blood samples be explained in detail (mean 3.97 vs 3.49; $p=0.031$). The patients/caregivers thought it less important than the researchers that they had already had all the required blood draws for the day (mean 2.38 vs 3.72; $p<0.001$) and that the sight of blood makes them queasy (mean 2.34 vs 3.65; $p=0.018$).

For studies with required follow-up, the researchers thought it more important than the patients/caregivers that follow-up was the same day as post-op visits (mean 4.42 vs 3.89; $p=0.022$), transportation and meals were arranged for the clinic visit (mean 4.15 vs 3.54; $p=0.023$), that the patient was paid (mean 3.83 vs

Table 1 Phase 2 online survey participant demographics

Variables	Patients/caregivers (n=43/17)		Researchers (n=114)	
Survey completion rate (%)	68		69	
Age in years (n)	18–24	1	18–24	1
	25–34	6	25–34	9
	35–44	5	35–44	52
	45–54	14	45–54	26
	55–64	11	55–64	11
	65+	14	65+	7
	No response	9	No response	10
Majority gender (%)	Female	66.7	Female 56.2	56.2
Time since trauma (n)	<30 days	0	Not applicable	
	1–11 months	2		
	1–3 years	2		
	>3 years	35		
	Not a trauma survivor	12		
	No response	9		

n, number of participants.

Table 2 Phase 1 focus group themes compared with phase 2 vignette-based survey themes

Vignette description ("Imagine that a patient…)	Topic	Phase 1 focus group themes	Phase 2 vignette-based survey themes
… participated in a research study while they were hospitalized after a bicycle crash. The study collected information daily about how they were feeling and if their pain medication was working well. Approximately 1 year later, a member of the research staff contacts them to share the results of the study.	*Study outcomes*: Rate how beneficial you feel this study was based on the following information you learn from the researcher.	► Sense of progress ► Improvement ► Return to pre-trauma baseline ► Regaining independence ► New knowledge/perspective	► Patients/caregivers consistently rated this less important than did researchers ► Effective when it helped others or alleviated other symptoms
… was recently in the hospital after a car crash with many injuries. They have been recovering well at home and are now at their follow-up appointment with their doctor. While checking in, the front desk staff tells them about the opportunity to participate in a voluntary survey about trauma research.	*Research approaches*: How comfortable would you be with the following study recruitment approaches?	► Use of native language	
	Researcher characteristics: As you consider your decision whether to participate in the study, how important are the following characteristics of the research staff?	► Trust ► Pre-existing/building relationship with patient/family ► Respect toward participants' time ► Transparency, honesty —clear description of research process, data collected	► The staff appearing unhurried was less important to the patients/caregivers than researchers ► Having the patient's doctor introduce the study to the patient/caregiver was less important to the patient ► Patients/caregivers consistently rated the race/ethnicity of the researcher of lower importance than did the researchers
	Survey format: Please rank the following survey formats in order of your preference (use the arrows to move the options up or down in the list, putting your most preferred on top).		► Less important to the patients than the researchers in a survey study
… is in the hospital with several rib fractures after a fall. A member of the research staff speaks with them about participating in a research study looking at the risk of developing pneumonia in patients with rib fractures.	*Blood study:* If the patient agrees to participate, the research staff will draw their blood three times during their stay.	► Trust ► Pre-existing relationships ► Transparency, honesty —clear description of research process, data collected	► Patients/caregivers thought it more important than the researchers that there was almost no risk to their health for participating ► That the process of what would happen with blood samples be explained in detail ► The patients/caregivers thought it less important than the researchers that they had already had all the required blood draws for the day ► That the sight of blood makes them queasy
… is in the hospital with a broken hip after falling at home. A staff member approaches them about participating in a research study on how people of different ages heal and recover after hip fractures.	*Follow-up required:* This study requires the patient to return to the hospital—once at 2 weeks and once at 6 months after their hospital stay.	► Additional resources—virtual options, financial incentives, transportation, meals, child care ► Accessible, welcoming environment	Researchers thought it more important than the patients/caregivers that: ► Follow-up was the same day as post-op visits ► Transportation and meals were arranged for the clinic visit ► That the patient was paid ► Parking was cost-effective and convenient ► The clinic was clean
… is in the hospital after a motorcycle crash with a broken arm and leg. A member of the research staff approaches them about participating in a clinical study about blood clot prevention in injured patients. The patient is asked to enroll in a study of a new medication. If they agree, the patient would have a 50% chance of getting the new drug and a 50% chance of getting the usually prescribed medication.	*Researcher characteristics:* As you consider your decision whether to participate in the study, how important are the following characteristics of the research staff?	► Use of native language	► Patients/caregivers consistently rated the race/ethnicity of the researcher of lower importance than did the researchers, including scenarios involving a drug study
	Personal experiences: How important would these personal experiences be to your decision whether to participate in the interventional drug study?	► Building relationship with patient/family ► Additional resources—virtual options, financial incentives, transportation, meals, child care ► Accessible, welcoming environment ► Respect toward participants time	► Patients also rated the researcher having personal experience with trauma as less important than did researchers

Continued

Table 2 Continued

Vignette description ("Imagine that a patient…)	Topic	Phase 1 focus group themes	Phase 2 vignette-based survey themes
… whose family member is in the ICU after being severely injured in a car crash, is in critical condition and on a ventilator (breathing machine). A research staff member approaches the family member to discuss a study looking at ways to lower the number of days the ventilator may be needed (ventilators help people breathe but also add to the risk of life-threatening infections). Since the patient cannot provide consent themself, the researcher asks the family member, as the LAR, to consent to their loved one's participation. (As a family member, they can act as a LAR and speak on the patient's behalf.)	*Researcher characteristics:* As you consider whether to consent to the participation of your family member in the study, how important are the following characteristics of the researcher approaching you?	► Use of native language	► Patients/caregivers consistently rated the race/ethnicity of the researcher of lower importance than did the researchers
	Personal experiences: How important would you rate the following personal experiences when weighing the decision to enroll your family member in a study?	► Building relationship with patient/family ► Additional resources—virtual options, financial incentives, transportation, meals, child care ► Accessible, welcoming environment ► Respect toward participants time	► Patients also rated the researcher having personal experience with trauma as less important than did researchers
… is in the ICU in critical condition after being severely injured in a car crash. A researcher approaches the patient's family member to discuss an experimental treatment that was used in their loved one's care. The research study has been approved with an EFIC* and thus did not require initial patient consent. As part of the process, the researcher would like to give the family member information on the study, and now get consent from them to continue the patient's participation in the study.	*Research approaches:* How helpful for family members do you think each of these ways of presenting EFIC study information would be?	► Want for explanation of study aims and potential risks ► Fear of receiving less effective study arm ► Complex topic to understand	► Having the patient's doctor introduce the study to the patient/caregiver was less important ► The staff appearing unhurried was less important to the patients/caregivers than researchers
	Personal experiences: How important would you rate the following personal experiences when weighing the decision to enroll your family member in a study?	► Use of native language ► Researcher characteristic ► Building relationship with patient/family ► Additional resources—virtual options, financial incentives, transportation, meals, child care ► Accessible, welcoming environment ► Respect toward participants time	► Researcher and patient/caregiver responses differed when considering the impact of the ongoing hospital experience and the researcher's characteristics ► Patients rated having previous unpleasant interactions with staff as less important than did the researchers

EFIC, Exception from Informed Consent; ICU, intensive care unit; LAR, legally authorized representative.

2.59; p<0.001), and parking was cost-effective and convenient (mean 4.18. vs 3.78; p=0.043). The largest difference between patients/caregivers and researchers was the importance of the clinic cleanliness (mean 4.16 vs 3.27; p<0.001).

Interestingly, several of these survey findings differed from the information observed in the phase 1 focus groups including motivations to participate (payment) and consent preferences (timing, researcher's approach/characteristics) (table 2).

Phase 3: I-REP patient and caregiver panel

The I-REP interactive, educational webinar was held in September 2023, during which we presented the findings from the focus groups and the online survey. We discussed the differences in patient/caregivers' preference and researchers' perceptions, and explained the formation and purpose of the I-REP Panel. The webinar was attended by 51 patients, caregivers, researchers, and other stakeholders. The I-REP team explained that the project's purpose was to create an integrated partnership with trauma survivors and caregivers to improve the understanding of participants' attitudes regarding trauma research participation. Given the discrepancies in patients' preferences and researchers' perceptions of patient preferences, it is clear that patient engagement in trauma research is necessary to ensure optimal patient involvement and patient-centric results. The goal moving forward is to involve patients and caregivers in all phases of research to ensure that outcome measures and research questions are meaningful, respectful, and relevant to injured patients. As of the submission of this manuscript, three quarterly web-based meetings have convened. Eighteen patient/family member panelists reviewed a total of nine new trauma studies. The panelists provided feedback and genuine enthusiasm for this work. Fifteen panelists have agreed to serve as patient-partner researchers or in other collaborative roles on five new research applications. Three panelists were invited guests at a 2-day research conference and participated in patient-focused presentations.[33]

DISCUSSION

Patient and caregiver engagement in all aspects of research, including study preparation, execution, and translation phases,[34] improves the significance and relevance of the research. Ultimately, increased research transparency promotes better evidence adoption into practice.[2] The I-REP phase 2 vignette-based surveys interestingly noted significant differences in motivations to participate in research and consent best practices compared with the common themes identified in phase 1 focus groups.[25] We can only speculate as to the origins and significance of these differences. Such disparities raise some concerns about insufficient sampling and a possible lack of respondent diversity in the surveys (compared with the focus groups). Qualitative, in-depth focus groups with the intentional inclusion of a diverse, representative population may be more accurate. It is also plausible that some questions are better suited for in-depth focus group discussion rather than a survey format; not to mention the written format may not capture input of those differently abled. For instance, one can imagine that the complex topic of EFIC is difficult to capture in a single question and may be better suited for an in-depth focus group discussion that allows for further investigation. Future research is required to determine what questions can be asked on paper and what questions must be asked in person regarding these complex topics.

Despite inconsistencies in results, importantly, we have established a process to proactively engage trauma survivors and caregivers in all phases of research development and implementation via the I-REP panel, providing an opportunity to improve trauma research methodology as a whole. Our work has led to the establishment of a panel comprised of ethnically and geographically diverse patients and caregivers, including survivors of both unintentional and violent injury, interested in partnering with trauma researchers. This panel has met with researchers quarterly since the fall of 2023. The panel activities include (1) establishing processes for the panel to collaborate with researchers in deciding what to study, designing and planning a study, finding participants, and sharing research findings; (2) providing stakeholder input on the inclusion of meaningful outcomes (patient and study outcomes); (3) assisting researchers in developing study materials and processes that are patient-centric; (4) participating in studies as patient partners (including presenting results and publications); (5) improving the quality and quantity of patient engagement in trauma research; and (6) serving as the engagement or advisory panels for ongoing projects. The panel is financially sustainable and provides enduring resources to trauma researchers and patients for new and ongoing patient engagement via annual CNTR membership dues contributed by trauma stakeholder organizations. Thus far, trauma researchers have reported that presenting new study applications to the panel provided meaningful insights in patient preferences and patient-centric outcomes.

This study has limitations; primarily, it is a small, convenience sample that may not be representative of patients, caregivers, and researchers. It may also be subject to the Hawthorne effect. The differences between the phase 1 focus group analysis and phase 2 survey analysis raise concerns about insufficient sampling and lack of respondent diversity in the latter phase. Participants' race and/or ethnicity were not collected in the demographics portion of the survey.

CONCLUSION

Engaging trauma stakeholders results in research more relevant to patients' needs and priorities. Qualitative engagement methods that intentionally include a broader, larger, more diverse population and determining the appropriate format for specific questions, focus groups versus surveys, may lead to results that are more informative and generalizable. The interactive patient-researcher educational webinar was well received, instructional on differences in patients' preferences and researchers' perceptions, and several participants decided to join the I-REP panel. Trauma researchers expressed interest in presenting to the panel and nine studies have been presented to date. Additionally, panelists are collaborating with researchers on ongoing and new trauma studies as patient partners/investigators. Long-term engagement to improve trauma research will include ongoing consultation with the I-REP panel on research projects. This will allow patients and caregivers to inform researchers about what outcomes are most important to them in a given study/focus area and express concerns they may have about a proposed project. This sustainable I-REP panel will facilitate engagement to ensure researchers pursue a responsive, relevant, and patient-centric research agenda. Addressing the identified barriers to research participation will improve research processes and communications.

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Competing interests ABN is a board member of the American Trauma Society. KJ is an employee of the American Trauma Society. MAP and PJB are employees of the Coalition for National Trauma Research. RAD is a board member for the Health Alliance for Violence Intervention. RAK has grant funding from the NIH, DOD, and Airforce. She additionally receives royalties for being associate editor of Trauma textbook. RAK has leadership roles at the WTA, CNTR and serves as the deputy editor of J Trauma Acute Care Surgery and the associate editor of Trauma Surgery Acute Care Open. ERH has grant funding from PCORI, AHRQ, and NIH/NHLBI. He has leadership roles at CNTR, NBCA, and serves as the editor in chief of Trauma Surgery Acute Care Open. DMS has grant funding from PCORI, Airforce, and CNTR/DOD. She has leadership roles at EAST, WTA, and the American Board of Surgery.

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Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information.

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