



Improving Data Collection and Abstraction to Assess Health Equity in Trauma Care

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Abstract

Current trauma registries suffer from inconsistent collection of data needed to assess health equity. To identify barriers/facilitators to collecting accurate equity-related data elements, we assessed perspectives of national stakeholders, Emergency Department (ED) registration, and Trauma Registry staff. We conducted a Delphi process with experts in trauma care systems and key informant interviews and focus groups with ED patient registration and trauma registry staff at a regional Level I trauma center. Topics included data collection process, barriers/facilitators for equity-related data collection, electronic health record (EHR) entry, trauma registry abstraction, and strategies to overcome technology limitations. Responses were qualitatively analyzed and triangulated with observations of ED and trauma registry staff workflow. Expert-identified barriers to consistent data collection included lack of staff investment in changes and lack of national standardization of data elements; facilitators were simplicity, quality improvement checks, and stakeholder investment in modifying existing technology to collect equity elements. ED staff reported experiences with patients reacting suspiciously to queries regarding race and ethnicity. Cultural resonance training, a script to explain equity data collection, and allowing patients to self-report sensitive items using technology were identified as potential facilitators. Trauma registry staff reported lack of discrete fields, and a preference for auto-populated and designated EHR fields. Identified barriers and facilitators of collection and abstraction of equity-related data elements from multiple stakeholders provides a framework for improving data collection. Successful implementation will require standardized definitions, staff training, use of existing technology for patient self-report, and discrete fields for added elements.

Keywords Health equity · Injury · Electronic health record · Trauma registry · Common data elements

Introduction

Trauma registries document patient demographics, pre-hospital care, acute care treatments, injury characteristics, outcomes, and other data [1]. In the U.S., data are abstracted from the medical record by trained staff into local trauma registries, which compile and report data to state registries, the National Trauma Data Bank (NTDB), and Trauma Quality Improvement Program of the American College of Surgeons

[1, 2]. These registries are critical to quality improvement efforts for hospitals and for researchers aiming to identify risk factors for injury, effective clinical interventions, and factors impacting patient outcomes [3]. However, critical gaps in our current trauma data collection system prohibit identification of successful, large-scale interventions to address disparities. While disparities have been documented in injury care and outcomes [4–6], research to identify the upstream mechanisms driving disparities is lacking [3]. For example, due to aggregated measures of race and ethnicity in this system, research relying on these data has often identified injury-related disparities based on a White/non-White binary, which does not provide adequate information to meaningfully address the identified disparities [3]. Additionally, research has demonstrated that community-level exposures impact health inequities [7]; however, the National Trauma

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Data Bank (NTDB) only collects injury place codes (e.g. home, work), limiting research on spatial injury patterns. This can limit researchers to use poorly representative proxies such as home address for injury location [8].

Through large-scale and systematic collection of health equity measures such as socioeconomic status, language, and detailed injury location data, we can answer crucial questions to document disparities and identify upstream targets for intervention. While there are National Trauma Data Standards that establish the required data elements, there are multiple trauma registry vendors and stakeholders which make any addition of data elements a slow process requiring broad engagement. Several organizations [9] have called for the prioritization of collection of race, ethnicity, language preference, and other socio-demographic data. These large-scale efforts begin with the collection of data from patients at Emergency Departments (ED) and hospitals and its entry into the electronic health record (EHR) by patient registration staff. Next, data abstraction by trauma registry staff into local trauma registries must be consistent and accurate. Finally, data elements must be collected consistently nationwide and implemented in every trauma system. Yet the processes by which this collection and abstraction occur are not well understood. To identify barriers and facilitators to collecting and abstracting accurate equity data elements, we assessed perspectives of national stakeholders in several U.S. regions and ED registration and Trauma Registry staff at a large, Level I trauma center.

Methods

Overview of study design

Prior work has identified 5 key equity-related data elements for priority inclusion: disaggregated race and ethnicity, language, a proxy for socioeconomic status, address where injury occurred, and longer-term health status follow-up [10]. We asked participants in this study to consider the collection, abstraction, and implementation of these variables.

Key informant interviews, focus groups, and observations

Before beginning focus groups, we conducted key informant interviews with ED (N=2) and trauma registry (N=2) supervisors to understand current processes and concerns. Trained interviewers conducted 1-h interviews and took detailed notes, which were analyzed to inform focus group interview guides.

Eleven ED patient registration staff members participated in one of 2 h-long focus groups. The interview guide included: 1) how staff currently ask race, ethnicity, language,

and pronouns; 2) positive and negative experiences with asking patients these questions; 3) trainings to ask potentially sensitive questions; 4) differences in process for collecting data depending on mode of arrival (e.g., walk-in vs. ambulance transport); and 5) recommendations for training and process improvements. Interviews were audio-recorded and transcribed verbatim. Next, two investigators observed ED patient registration staff workflow for four 4-h periods. Detailed notes were taken on process changes among different patient arrival modes, acuity, and demographics.

Thirteen trauma registry staff participated in a 1.5-h long focus group. The interview guide included details on the methods of abstracting variables, preferences for variable location and form (e.g., discrete field, open-ended), and recommendations for incorporating new elements. Next, one investigator observed trauma registry staff for two 2-h time periods. Detailed notes were taken on process changes between types of variables (e.g., discrete field, open-ended).

Analysis of focus groups with ED patient registration and trauma registry staff

Interviews were analyzed using an inductive thematic approach. We first separated interview responses into 6 domains, including overall comments and the 5 equity data elements for inclusion. Within each domain, we used an inductive approach to look for patterns in participant responses. In the next stage, we searched transcripts within each of the 6 domains for each identified theme. Throughout analysis, all themes, codes, definitions, and interpretations were discussed among the analysis team.

National Delphi process with trauma system experts

To determine a feasible process for collecting and incorporating new equity-related data elements and longer-term outcomes into state and national trauma registries, we conducted a Delphi process with national experts. Participants were selected based on expertise in the field, position or role, and diversity of location of practice. The Delphi technique is a widely used method for building consensus over iterations [11–13], as it uses anonymity to equalize influence across panel members [14, 15]. We used a web-based modified Delphi process [12] to allow for a larger and more geographically diverse group of experts to contribute.

Each expert was provided with preliminary reading, an explanation of the Delphi process, and timeline for participation in three rounds. The first round of the Delphi process consisted of open-ended questions about: 1) process of collecting, extracting, and analyzing EHR and longer-term follow-up data for trauma registries, 2) measurement of specific health equity data elements, and 3) feasibility and process of incorporation of new data elements into their

trauma registry of expertise (local, state, or national). In the second round, participants rated the feasibility of methods identified in round 1 on a 9-point scale (1-Not at all feasible to 9-Extremely feasible). We provided a definition of a feasible process as one that can be accurately and reliably completed at the participant’s site of expertise and one that required limited changes to the site’s existing protocols. Participants were given the opportunity to comment, clarify, or amend processes previously identified. In round three, we gained clarification on the methods identified in round 2. We clarified definitions, provided the comments received in round 2, and asked participants to re-rate the feasibility of methods on the same 9-point scale. Participants were again able to voice concerns.

Analysis

For round 1, responses to each question were qualitatively analyzed using an inductive thematic approach [16]. We first gathered all free-text comments into a single document, stratified by type of trauma registry (local, state, or national) and question. Two coders identified as many themes as possible that emerged across the dataset. Then, one coder classified textual meaning units based on the list of themes, refining as needed. We also sought counterexamples using the constant comparative method [17]. Finally, we combined similar recommendations into specific methods for incorporation for rating in round 2. Coders engaged in peer debriefing to increase trustworthiness [18].

For Round 2, we used the median score to measure the central tendency for panelists’ ratings. To be included in the final set, each method must have received a median feasibility rating of at least 4. To evaluate agreement among panelists, we used Gwet’s agreement coefficient estimator (AC2), which measures agreement while adjusting for agreement by chance and the degree of disagreement between panelists when agreement is high and data are ordinal [19]. Because round 3 only consisted of questions that needed clarification in terms used, we replaced these final ratings with those calculated in round 2.

Results

Using the findings from ED patient registration and trauma registry staff and trauma registry experts, we constructed a process flow diagram to conceptualize how equity data elements are collected, stored, abstracted, and shared (Fig. 1). We found conflicting process descriptions across professional groups. Specifically, we found data loss was occurring between two EHR systems used by data collection, medical, and trauma registry staff. For example, ED registration staff were inputting detailed race/ethnicity data into one system, but only aggregated race data were being transferred to the system used by trauma registry staff. A list of recommendations for collection and abstraction of data elements is in Table 1.

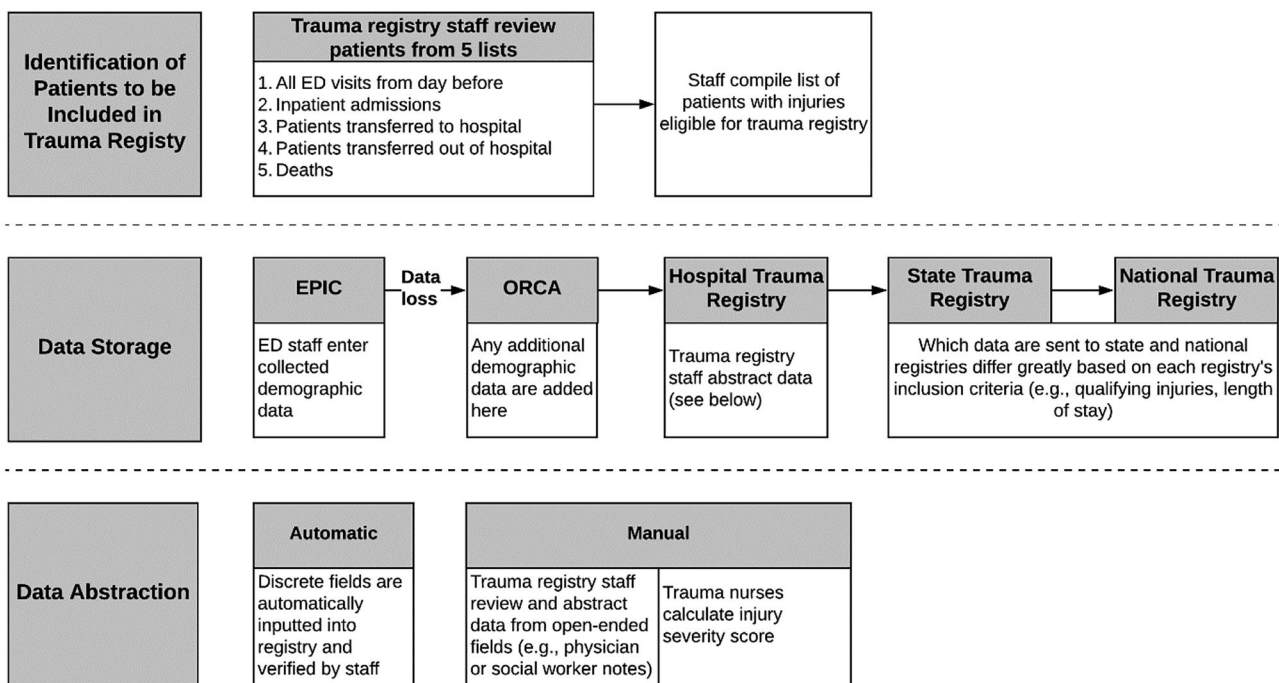


Fig. 1 Process of data collection, abstraction, and storage

Barriers, facilitators, and recommendations for equity data element collection

ED patient registration staff collect race, ethnicity, and language data verbally by questioning the patients or accompanying visitor as they arrive. Participants described patients reacting suspiciously to this process and identified specific ethnic or religious groups they perceived to act more suspiciously than others. For example, they described perceived apprehension of patients who identified as Mexican or Middle Eastern to respond to questions about race, ethnicity, or place of birth due to systemic racism and xenophobia these groups face. One staff member explained,

“If ...you come in, you’re a person of color and someone right up front is asking you, ‘What’s your nationality?’ and ‘Where are you from?’. ‘Do you speak English?’ ... You have to look at the full scope of care when you’re asking these questions up front, because the perceptions are...they come back and they feel discriminated against by the time they get through the process because they don’t feel like they got proper care having waited so long to see someone at our emergency room.”

“Certain races and ethnic groups and religious groups respond certain different ways because of political climate, so you have to be careful.”

In other cases, staff reported patients being offended when asked about their gender or pronouns as they felt these characteristics should be obvious to the staff member. In addition, several barriers sometimes led staff to assume race, ethnicity, gender, and pronouns based on appearance. Staff described barriers that caused them to use several different phrases to assess race and ethnicity. For example, staff might ask, “*What ethnicity do you identify as?*”, as well as “*What is your place of birth?*”. For

language, staff asked, “*What is your preferred language to receive medical care with?*”, as well as “*What is your first/primary language?*”. Registration staff also explained they were often unable to ask for race or ethnicity due to the urgency of the patient’s medical condition. One staff member explained,

“We’ve also already asked them like 10 deeply personal questions on the worst day of their lives... ‘I know you’re bleeding, but what’s your mom’s maiden name?’”

Staff expressed a lack of understanding as to why collecting these demographic data is important.

“I think that our registration areas are very public. Like, unfortunately, we don’t ask these questions in a very private setting. [...] I also don’t know how you could explain that as a medical necessity, right? Or an identifier, because that shouldn’t matter. It’s hard to explain.”

They recommended cultural sensitivity training and training to explain to patients why data are being collected. Additionally, staff suggested alternative technological solutions to collect these data in a more discrete and standardized form, such as allowing patients to self-identify using an electronic tablet. Finally, staff suggested process improvements to ensure data are collected from patients unable to respond due to acuity when they first arrive, such as having discharge planners or financial counselors confirm demographic fields.

Barriers, facilitators, and recommendations for equity data element abstraction into trauma registry

Trauma registry staff did not report concerns about increased workflow for any data elements collected using discrete

Table 1 Synthesis of Final Recommendations

Data Collection by Patient Registration Staff

1. Create a short script for staff to explain to patients why demographic data are collected
2. Establish a process for collecting data from patients who cannot be interviewed upon arrival due to injury acuity
3. Ensure staff investment and input in changes
4. When asking injury address, collect information on nearby landmarks, cross streets, or business names if patient is unable to identify a specific address

Data Abstraction by Local Trauma Registry Staff

1. Ensure staff investment and input in changes
2. Establish automated system (e.g., automatic text message) to collect long-term follow-up data

Considerations for Adding Data Elements to Electronic Health Record (EHR)

1. Review process of data collection, abstraction, and transport to identify system non-compatibility or data loss
2. Maximize use of discrete (rather than open-ended fields) to facilitate automatic abstraction
3. When discrete fields are not possible, designate a single location for each data element in the EHR
4. Establish a national standard for elements collected (e.g., a minimum set of languages), while allowing for flexibility for local differences

fields (instead of open-ended questions) because they could be programmed to automatically populate from the EHR. When open-ended questions are needed, staff described a dedicated location in the EHR to be a facilitator for manual abstraction. They described frustration at needing to search administrative, provider, and social work notes to locate a single element. In a conversation between two participants, they explain:

Participant 1: “Sometimes even social history, you’ll have like, you know smoking, drugs, alcohol for instance. And it looks like it’s a form that they can put an X by for yes. But in some other, like maybe the admit note is asking different things.”

Participant 2: “There’s different options. And [providers] can get very creative [...] with different variables that they can choose to answer or not. It can become quite a challenge.”

Staff indicated discrete fields would likely also reduce the frequency of conflicting information, which they often see when searching through open-ended notes.

“You know, one note will say ‘patient smokes’ or something like that. And then another one denies smoking or something, [...]”

Contrary to the ED patient registration staff’s recommendation to have multiple administrative staff confirm demographic questions to minimize data missingness, trauma registry staff believed this would increase the frequency of conflicting reports.

Staff reported address of injury as the most challenging data element to collect due to technological limitations in data compatibility among different systems. For example, the most accurate injury address data for patients arriving by ambulance is located on paperwork completed by EMTs. However, the system used by the local ambulance companies is not compatible with the EHR system. Staff confirmed feasibility of determining an address if the patient did not know an exact address but was able to provide details, such as a business name and cross streets or park trailhead.

Feasibility of implementing improved health equity data collection and entry at trauma centers

Sixteen participants contributed to at least one round of the Delphi process. Participants achieved consensus on feasibility of methods for data collection, abstraction, and incorporation into trauma registries (Table 2).

Several participants noted the importance of consistent and accurate data collection by ED patient registration staff and streamlined abstraction for trauma registry staff. Facilitators for this process included ensuring staff’s investment

in changes, simplicity of data elements added, and quality improvement checks. Participants also emphasized ensuring widespread stakeholder investment in modifying trauma registries. Nearly all participants expressed automation of the collection and abstraction process as one of the most significant facilitators. Some participants suggested having social workers asking some questions they perceived to be sensitive, such as questions about socioeconomic status (SES). They believed social workers’ training in discussing other sensitive topics would help patients feel more comfortable providing this information. However, other participants questioned this feasibility due to social workers’ already over-burdened caseloads.

Participants rated the feasibility of collecting and incorporating the 5 suggested data elements into the trauma registry. For race and ethnicity, participants felt options should be based on a national standard and that options and question phrasing should be tested with patients. For language, participants recommended a universal minimum set of languages collected for national registries, allowing flexibility for local registries to collect languages most relevant to their patient population. Participants were provided several options to collect a proxy measure for SES, including income, family size, education level, and a patient-subjective measure (e.g., “Does your income meet your household’s basic needs?”). They expressed the imprecise definitions of income, family size, or a patient-subjective measure to be a barrier to accurate, consistent collection of SES data. Like concerns raised by trauma registry staff, participants noted difficulties of collecting injury address such as patients not remembering where they were injured. Facilitators included offering several options for describing location of injury; for example, if patients are not able to provide an address, they should be given the option to describe cross-streets or landmarks. Finally, participants expressed skepticism at the feasibility of collecting longer-term outcome data from injured patients and agreement that collecting these data is important. They voiced one facilitator to collection is automating the process; for example, a low-cost automated email/text to patients would reduce financial and time costs.

Discussion

While some barriers and facilitators of collection, abstraction, and implementation of equity-related data elements differed among stakeholders, we identified recommendations for incorporating more accurate and consistent health equity data. Stakeholders indicated incorporating better equity-related data elements was crucial to identifying disparities in trauma care and outcomes. Prior research demonstrates including demographic information into the EHR may improve quality of medical care; for example, incorporating patients’

Table 2 Results of Delphi process to reach consensus of feasibility (1–9) of incorporating new equity data elements into the trauma registry

Feasibility of:	Agreement Ordinal Weighted Gwet's AC2 ^a	Central Tendency			
		Mean response	Median response	25th %ile	75th %ile
Training staff (e.g. registrar or social worker) to ask the new questions	56.70%	7.2	8	6.5	8.5
Aligning variable changes in the medical record and trauma registry at your site and the National Trauma Data System	71.20%	6.4	7	5.5	7
Aligning the trauma registry data abstraction and aggregation process with new measures	78.20%	6.8	7	6	8
Race and ethnicity being self-reported from patients. Surrogate reporting is indicated in the medical record	76.10%	6.9	7	6.5	8
Registrar asking a patient's race and ethnicity	-2.10%	5.3	6	3.5	7.5
Social worker asking a patient's race and ethnicity	59.00%	6.9	7	6	8.5
If a patient is unable to understand or answer questions in English, an interpreter, family member, or other surrogate will assist in asking demographic questions	84.50%	7.9	8.5	7	9
Registrar asking a patient the question on SES proxy	71.30%	4.2	5	3	5
Social worker asking a patient the question on SES proxy	58.20%	6.5	7	6.5	7.5
Linking additional data sources to collect geographic location of injury (e.g. traffic records, EMS records, and police records) and abstracting into the trauma registry	73.10%	6.2	7	5	7
Automated process to collect long-term follow up to reduce cost and time barriers. Note that one existing data collection service (Twilio) costs \$0.007 per text message sent to a patient	90.60%	6.2	6	6	7
Please rate the feasibility of "The existing trauma registry staff and infrastructure is responsible for maintaining patient contact information and data and overseeing the automated data collection."	57.70%	4.7	5	3.5	6
Please rate the feasibility of "Existing hospital Information Technology (IT) infrastructure supports the automated collection system and input into the existing trauma registry."	60.00%	5.2	6	4	6
Please rate the feasibility of "Patients are informed while they are hospitalized that they will receive a short follow-up survey. This information should aim to increase trust and participation in the survey."	73.70%	7.5	8	7	9
Please rate the feasibility of inserting a new data element such as "injury address" into the medical record, trauma registry and National Trauma Data System	67.80%	6.9	7	6	8
Please rate the feasibility of using existing processes for data collection and abstraction of a new data element such as "injury address" into the medical record and trauma registry	61.30%	6.5	6	5.5	7.5

^aGwet's AC2 benchmarks include: <0 is poor, 1–20% is slight, 21–40% is fair, 41–60% is moderate, 61–80% is substantial, 81–100% is almost perfect

sexual orientation can improve appropriate sexual health treatment plan development [20]. Additionally, these data offer an opportunity to identify specific sub-populations that receive inadequate care or experience inequities. Our study contributes to the literature by identifying recommendations for the incorporation of equity data into EHR and processes for collection and abstraction.

Data quality has long been a concern for researchers using trauma registry data for their studies [1]. A lack of rigorous and consistent data collection methods can lead to incomplete or erroneous data abstracted into trauma registries. As ED patient registration staff collect equity data elements, understanding their perspectives is crucial. In this study, ED patient registration staff barriers included experiences with patients reacting suspiciously

and misunderstanding data collection purposes. They indicated cultural resonance training, a script to explain equity data collection, and allowing patients to self-report sensitive items were facilitators. Previous research suggests scripts to explain to patients that demographic data are collected to review treatment patients receive to ensure equitable treatment and emphasize voluntary reporting [20, 21]. Additionally, data collection processes should prioritize self-report using a standardized tool, as the language used to ask demographic information can change the information patients provide [22]. For example, place of birth may not have any influence on an individual's ethnicity, and primary language spoken may not be the best indicator of what language a patient prefers to receive medical information [21].

For trauma registries, data quality is most easily improved by automating abstraction processes [1]. Trauma registry staff reported this automation increases efficiency as they often must search provider notes for information, which sometimes contained conflicting reports. Increased efficiency may also reduce abstraction lags before researchers may access trauma registry data. Delphi panel results indicated the importance of national standardization of elements, consistent with prior literature [1]. Reported facilitators to feasible collection, abstraction, and implementation of additional equity data elements were simplicity, quality improvement checks, and stakeholder investment in the importance of modifying existing technology.

The differing perceptions of barriers and facilitators identified by different stakeholders signal the need for an implementation guide so trauma centers can apply necessary changes to process flow, EHR fields, and trauma registry systems to incorporate equity data elements. As recommended by our stakeholders, this implementation guide should outline national standards for data collection and abstraction, while incorporating flexibility for local contexts. Additionally, each hospital should consult stakeholders at every level of data collection and abstraction to ensure a comprehensive understanding of current processes and investment in changes. In our study, we found staff are under significant time pressures and system expectations for data entry and are not given sufficient training to be able to understand the purpose and process of data collection. To ensure staff investment in patient-centered equity-related data collection, system-level training and workflow support need to be provided by institutions.

This study has some limitations. First, although we included input from national trauma system experts, we only interviewed registration staff at one level-1 trauma center. Therefore, results of focus groups with ED patient registration and trauma registry should be interpreted within this limitation; future research should consider the unique contexts of other-level trauma centers in different locations. Secondly, the focus groups with patient registration and trauma registry staff may have been subject to interpersonal dynamics that could have influenced the transparency of responses we gathered. Finally, this study does not present patients' perspectives on how their data are collected. Future research should interview these important stakeholders to understand how, when, and by whom they would like to be asked equity-related questions, as well as test the feasibility of these findings.

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Availability of data and material Given the identifiability of sources, data are not publicly available.

Declarations

Ethics approval Human Subjects approval was granted from the University of Washington Institutional Review Board under study 5571.

Conflicts of interest All authors declare they have no conflicts of interest to report.

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