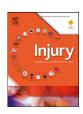


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Understanding the barriers and facilitators to trauma registry development in resource-constrained settings: A survey of trauma registry stewards and researchers



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ABSTRACT

Background: The implementation of trauma registries has proven a highly effective means of injury control. However, many low and middle-income countries lack trauma registries. Those that have trauma registries vary widely in terms of both implementation and structure. We sought to identify the most common barriers that stand in the way of sustainable trauma registry implementation, and the types of strategies that have proven successful in overcoming these barriers.

Methods: We conducted a questionnaire of trauma registry stewards and researchers in LMICs.

Results: Twenty-two individuals responded to the questionnaire representing trauma registry experiences across thirteen LMICs. The most common barriers to trauma registry implementation identified included staffing, funding, and stakeholder engagement. Many different strategies for addressing these barriers were discussed. Those mentioned by multiple respondents included the need for a trauma registry champion, fostering strong stakeholder relationships, and improving efficiency of data collection.

Conclusions: Though trauma registry implementation and structure may differ from place to place, there are many shared barriers and facilitators that can be learned from. Identifying these common experiences can help create a repository of knowledge that can better serve those looking to implement their own trauma registries in similar settings.

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Introduction

Injury is one of the world's most pervasive global health problems, killing over 5 million people a year, and leaving no country unaffected [1]. The morbidity rate is even greater; for every injury death, it is estimated that there are 20-50 additional non-fatal injuries that result in disability [2]. This impacts not only quality of life, but also productivity, leaving many individuals and their families in precarious financial situations [3].

To combat injury, well-organized trauma care systems have proven highly effective in reducing patient mortality rates [4–8]¹. However, such systems are often lacking in low-and middle-income countries (LMICs) or similarly resource-constrained settings, where the burden of injury is highest [5]. The effects of this disparity in trauma care are profound. Estimates from one study suggest that nearly 2 million lives could be saved annually if case fatality rates of seriously injured patients in LMICs paralleled those

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¹ There are multiple definitions for trauma systems; some of these definitions are based on rigorous international standards, while others are formed more loosely. We define it here as an organized, multidisciplinary response to injury at a regional level

achieved in high-income countries [4]². This number would be many times greater if one were to include the lives saved from injury prevention efforts informed by organized trauma systems as well.

A central component of organized trauma systems is the operation and maintenance of a trauma registry. Trauma registries are data surveillance systems that record information related to the injury event, care, and outcome of an injured patient. They play an integral part in reducing injury morbidity and mortality by providing the evidence necessary to inform injury control initiatives. For example, trauma registries often collect information on the location of a patients' injuries. This data can then be used to identify high-risk areas (e.g. dangerous traffic intersections) that appear in the data over and over again as sites of injury, and aid policy makers in decision making around necessary prevention initiatives (e.g. addition of a cross walk to encourage safe crossing). Alternatively, other data in the trauma registry can be used to improve the quality of trauma care a patient receives. Hospital administration can use arrival and wait time information to assess how quickly patients are being treated, and work to improve these times in situations where the delay proves detrimental to the care of the patient.

Over the past 40 years, trauma registries have become commonplace in high income countries (HIC); yet, in LMICs, trauma registries have remained scarce due to significant financial and human resource constraints that have limited their ability to be implemented and operated in a sustainable way [9,10]. Such a divide is important to address if health systems in LMICs are to be strengthened. As former director general of the World Health Organization, Margaret Chan, once said, "the real need is to close data gaps, especially in low-income and middle-income countries" [11].

Encouragingly, we are beginning to close the data gap with regard to injury. The development of innovative solutions in recent years to some of the most prominent barriers to trauma registry implementation has caused a marked increase in the number of sustainable registries in LMICs [12-14]. Globally, the experiences of implementing and operating these trauma registries serve as an important educational resource for other hospitals looking to do the same. However, it appears that there is no one right way to implement and operate a trauma registry in a LMIC. For example, in 2013, a study which sought to examine the published experience of trauma registries in LMICs concluded that approaches to trauma registry development and operation were far from uniform [12]. More recently in 2019, another study indicated similar findings with regard to data collection processes [14]. Given the highly varied contexts and challenges of these low-resource settings, such non-uniformity is seemingly essential for creating trauma registries that are adapted to local contexts. Yet, it also complicates the process for those looking to develop their own registries to know which path is best to follow. To make matters more challenging, few resources currently exist that focus specifically on summarizing the experiences of successful and sustainable trauma registry development in LMICs [10,15-17].

The objective of this paper is to address this problem. Our aim is to identify the most common barriers that stand in the way of sustainable trauma registry implementation, and the types of strategies that have proven successful time and again in overcoming these barriers. By setting aside the differences between trauma registries in LMICs and acknowledging the many shared experiences that cut across them, we can create a repository of knowledge that can better serve those looking to implement their own trauma registries in similar settings.

Methods

Study design

The design of this study was based on a cross-sectional questionnaire.

Study population

The study population consisted of a sample of trauma registry stewards from LMICs and researchers. Stewards include both trauma registry initiators and those who oversee ongoing registry operations. Researchers who helped establish the registry and publish using this data were also included in the survey population.

A structured review of the literature was conducted to identify all papers published on the experience of implementing or operating a trauma registry in a LMIC. Web of Science, CINAHL, Medline (Ovid) and Global Health databases were searched on November 15, 2018 for the terms relating to trauma registries in LMICs and key words that denote the experience of development, implementation, operation and long-term sustainability (Appendix A).

The search identified a list of 347 papers (with duplicates removed), which were screened for inclusion and exclusion based on criteria set *a priori* (Appendix B).

This left a total of 47 papers. The email address of the corresponding author or authors for each of these papers was identified (with the exception of corresponding authors on review type articles) and a request to participate in our study sent out to these individuals. If other emails for other authors were available, these were used too. Snowball sampling was also used in addition to this method. Snowball sampling is a type of non-probability sampling technique in which study subjects are asked to recruit other subjects from their networks [18]. It is particularly helpful to use when a complete sampling frame is unavailable [19], as is the case here. For the purposes of our study, if the person emailed felt that one of their co-authors could provide a more comprehensive response for the questionnaire or knew of others in the field that fit the criteria for the study, they were asked to forward our request to that individual. This provided an opportunity to talk to trauma registry stewards and researchers who might not have been identified by our literature search yet who still have relevant experience in LMIC trauma registry development. In total, 67 people were contacted.

Data collection

Questionnaire development was informed largely by the literature review described above. Barriers and facilitators described by these papers were collated and assessed for major themes and patterns, which were subsequently used to inform several questions of the survey and provide concrete examples to help respondents better interpret the question being asked. After initial development of the questionnaire, it was pre-tested for validity by three people. Two of the three had experience with developing and implementing a trauma registry; the other individual was a trauma surgeon with in-depth knowledge of trauma registries. Feedback from this pre-test was taken into consideration and modifications to the questionnaire made where necessary.

Trauma registry stewards and researchers who agreed to participate after being contacted were sent a link to access the online questionnaire hosted on the SurveyMonkey platform. The questionnaire consisted of 10 questions total and included a variety of both closed and open-ended questions. Questions ranged from the basic details of the trauma registry to more considered questions pertaining to the types of barriers that were encountered in developing, implementing or operating the trauma registry and how these

² The nearly two million statistic arrived at in this study has several limitations, namely that the data used was collected from three urban sites only and may therefore not be representative of all low, middle, or high-income countries (or the rural areas within these countries). See study for full limitations.

Table 1 Questionnaire.

No.	Question		
1	Please state your first and last name.		
2	In which country do you work or train?		
3	Is the hospital publicly or privately funded?		
4	Is the trauma registry still active (i.e. still collecting and analyzing the data?)		
	Yes		
	No		
	I don't know		
5	If yes, how long has the trauma registry been operating for?		
	Less than 2 years		
	2-5 years		
	6-10 years		
	More than 10 years		
	I don't know		
6	Which of the following barriers did you experience in implementing the trauma registry? Check all that apply.		
	Issues of funding		
	Issues of stakeholder engagement (hospital staff, hospital administration, politiciansetc.)		
	Issues of infrastructure (e.g. hardware, software, electricity, data storage, internet, equipmentetc.)		
	Issues of staffing		
	Issues of data quality or completeness		
_	Issues of data dissemination		
7	Please elaborate on the barriers you checked above. Specifically, how did these issues act as barriers to implementing the trauma registry? (e.g.		
	For issues of staffing, we didn't have enough trained staff to collect data for the trauma registry 24/7 or the trauma registry software was too		
	expensive).		
8	Which do you think was the greatest barrier you faced?		
9	How did you overcome these barriers? Please tell us about specific strategies, tools or people that helped to overcome them. If you did not		
10	overcome them, please share more about this as well.		
10	Finally, what advice would you give to someone thinking about developing a trauma registry in a resource-poor setting?		

 Table 2

 Percentage of respondents identifying with the below list of barriers.

Barriers	% of respondents (out of 22)	% from active trauma registries (out of 13)	% from inactive trauma registries (out of 9)
Issues of funding	72.7	61.5	88.9
Issues of stakeholder engagement or motivation (stakeholders might include hospital staff, hospital administration, politiciansetc.)	65.2	69.2	66.7
Issues of infrastructure (e.g. hardware, software, electricity, data storage, internet, equipmentetc.)	50.0	38.5	66.7
Issues of staffing (e.g. not enough staff to run the trauma registry, staff do not have enough timeetc.)	77.3	61.5	100.0
Issues of data quality or completeness (e.g. data is missing or inaccurate)	59.1	61.5	55.6
Issues of data dissemination (e.g. no one to disseminate the results to, results are slow to be disseminatedetc.)	22.7	30.8	11.1

were overcome (if they were overcome at all) (Table 2). The questionnaire was self-administered, and respondents were given three weeks to fill out the survey.

Data analysis

Data were analyzed qualitatively, using both content and thematic analysis. Content analysis is a partially quantitative method that involves coding data into measurable categories or themes for further interpretation [20,21]. Thematic analysis on the other hand pays greater attention to the qualitative aspects of the data and involves identifying common patterned responses or "themes" of interest within the respondents' answers [20,21]. Both types of analyses were conducted using NVivo 12. Trends were analyzed across context, including location (country), funding source (private vs. public hospital), and activity of the registry (on-going or no longer operating).

Results

Twenty-two individuals responded to the questionnaire, representing a total of 13 countries. All twenty-two individuals were physicians, fourteen of which were based in-country, and seven

of which were based out of country. One respondent answered anonymously, and their role and location in-country or out-of-country could not be identified. Most respondents answered the questionnaire based on experience from a single trauma registry, however one respondent answered based on experience from two trauma registries (Haiti and Bolivia). Thirteen respondents reported their trauma registry as active, while the remaining nine reported their trauma registry as having ceased operations. Of those that remain active, three registries have been operating for less than 2 years, one registry has been operating between 2-5 years, seven registries have been operating between 6-10 years, and two registries have been operating for more than 10 years. Four of the registries were established at private hospitals, and the remainder at public hospitals; one respondent chose not to answer this question (Fig. 1).

Barriers

Respondents were asked to check each of the barriers they faced in developing or maintaining their trauma registry from a list of six broad categories. An option of 'other' was also provided. Table 2 provides a summary of these answers. Issues of staffing was the number one most commonly selected barrier, followed by

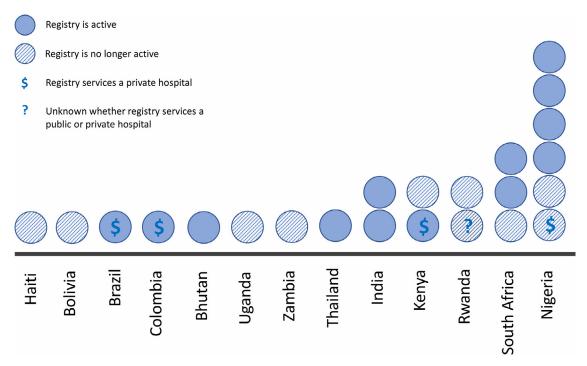


Fig. 1. Number of respondents from each trauma registry by country, funding source and active status.

issues of funding, issues of stakeholder engagement or motivation, issues of data quality or completeness, issues of infrastructure, and finally issues of data dissemination. Six respondents listed additional 'other' barriers, which included the following: external and political factors, high attrition rate and loss of data, too few people to analyze and use the datasets that were being collected by the registry, the problem of maintaining personnel and capacity building, and lastly, buy-in from surrounding facilities to conduct a system-wide analysis.

Respondents were also asked to elaborate on the above barriers that they had selected. Answers were coded according to six themes: issues of funding, issues of stakeholder engagement or motivation, issues of infrastructure, issues of staffing, issues of data quality or completeness, and issues of data dissemination. An additional category of 'external barriers' was also added to recognize the response of one participant whose answer did not fit cleanly into any of the six previously stated themes.

Issues of funding

Issues of funding was the most commonly elaborated barrier with 14 respondents choosing to comment on it. It is also the barrier that almost all subsequent barriers seem to link back to, especially issues of staffing and issues of infrastructure. Respondents frequently discussed issues with securing funding in the first place, and several discussed challenges related to having a long-term funding plan. Notably, three out of the four private hospitals reported experiencing issues of funding.

"In the absence of funding, it is difficult to acquire software and maintenance of our hardware is difficult. Buying stationery is a challenge."

"The data collection staff (nurses and doctors) expected remuneration for their time. Hospital did not have funds to compensate them after the grant funding finished."

"We purchased hardware out of pocket. No funding for anything at all."

"Lack of funding...for sustainability."

"No hospital funds to hire data-specific registry folks, really challenged staffing issues."

Issues of stakeholder engagement or motivation

Ten respondents elaborated on issues related to engagement and/or motivation across a variety of stakeholder levels, including government, hospital administration, clinicians, and data collectors. Reasons for lack of engagement varied; a lack of a research or surveillance culture was cited by some, while others identified a lack of enthusiasm around the additional workload. One respondent struggled with having to compete amongst other health care priorities for resources to reimplement their improved, more streamlined trauma registry.

"Lack of engagement of hospital administrators."

"Staff felt it simply an academic and research exercise with no impact on patient care."

"While there was interest and excitement about the registry, not much buy-in if involved regular staff completing any addition info or maintaining database."

"Research is not a common cultural norm and the use of data to "drive" initiatives within the health care setting is uncommon so that trauma registry usefulness or importance is not recognized by those who are asked to "voluntarily" collect the data."

"The biggest issue we had was staff motivation. There was buyin for the project at the highest levels, however it did not trickle down to the frontline staff. Therefore, the project was seen as an external undertaking and not a part of the system."

"Some stakeholders (hospital directors) have created barriers by prioritizing other clinical issues (Dengue, lack of resources in the Emergency Department) and blocking the reimplementation of a better, more stream-lined version of the trauma registry."

"Stakeholders are a major problem. Initially no one cared about data or research. Then when they saw how it translates into publications, they became very jealous. Despite engaging with them during development they suddenly felt they were being excluded. For example, the general surgeon now felt that their information and data was in the hands of someone else and began to feel very threatened."

Issues of infrastructure

Seven respondents elaborated on the issue of infrastructure. Several remarked on the limited availability of hardware and software required for running a trauma registry, or how their current setup was cumbersome to use. Poor internet connection was also a common issue.

"Hardware was very limited; there was no dedicated office to keep registry materials, there was no institutional internet access and we had to pay for access out of pocket. Even then, the internet access was often low bandwidth and unpredictable."

"The previous trauma registry ran for 3 years but there were many complaints about the slowness of the online system, lack of computers or internet to upload the information."

"The iPads were stolen and as a result needed to be fixed to a desk. This affected the mobility of the collection."

Issues of staffing

Issues related to staffing was a commonly elaborated upon barrier, with 13 different respondents remarking on it. Here, several key sub-themes emerged from respondents' answers. These included having limited finances to either remunerate health care workers for their efforts or otherwise hire dedicated trauma registry staff; the burden of having to conduct multiple rounds of training to account for high staff turnover; and the burden of extra work that is placed on health care workers in settings where no dedicated trauma registry staff are available.

"No dedicated registry staff. Available staff were often too busy and adding registry to their work was at time overwhelming and resulted in limited commitment and incomplete data."

"The data collection staff (nurses and doctors) expected renumeration for their time... Staff turnover was a major issue in continuing the efforts."

"The biggest barrier is not having dedicated trauma registry staff (as is the norm or common in North America) and hence the collection falling on surgery residents and interns - who it is very difficult to motivate to complete this "extra" work."

"Because of the low resources, it was difficult to ask workers to add to their regular workload especially on weekends and nights when there was less staff."

"In the absence of funding it is not possible to engage dedicated staff for the registry. Data collectors are temporary as they are doctors on rotation through the unit. This makes training tedious as each new set of data collectors have to be trained on the process."

Issues of data quality or capture

Eight respondents elaborated on the issue of data quality or capture. Missing or incomplete data was discussed by almost all respondents. To this end, several respondents also discussed the challenges of using paper-based data collection methods. Lastly, several respondents also discussed the challenges of collecting data on patients as they moved throughout the hospital during their stay.

"Paper charts used at the hospital were often missing, misplaced, out of order, incomplete."

"It is very difficult to get discharge data. we get good data at admission but following patients over the duration of their visit is a challenge."

"Percentage of missing/incomplete data was sometimes unacceptably high."

"Because the data collectors are few and temporary, data is often incomplete. Also collectors often do not have time to follow up on patients and fill in information that is missing at initial entry. Some records are lost when patients are discharged without complete data gathering. Retrieving their medical records is often difficult, and some data are simply not in the files. There is no post discharge follow up to study long term outcome."

Issues of data dissemination

With regards to data dissemination, five respondents answered in a variety of ways. Some discussed not having enough staff to mine all the data being collected, while others discussed a lack of motivation or interest from stakeholders to use data for policy. Finally, one other respondent discussed being limited by local ethics policy in that they were only allowed to use the data for approved research projects and not clinical policy development.

"The limited number of surgical trainees has meant mean that much of the data is unmined."

"There is not enough bandwidth among the clinicians (who also manage the registry) ... a bunch of non-clinician PhD/Masters have addressed the statistical needs, but not enough."

"We have published around 40 papers on various aspects of the registry data to date, mainly in the international literature as the locals do not seem interested."

External barriers

Only one respondent proposed an additional barrier that did not fit into the themes listed above. This respondent wrote of how external/political challenges have impeded their ability to reimplement the registry.

"We have run into many "external/political" barriers such as the public health department needing to prioritize focus on the fires that Bolivia experienced last August, then a medical doctor strike (in August/Sept/Oct), the general presidential election strike, then a Dengue crisis, and now the COVID-19 pandemic. Many barriers have prevented us from being able to reimplement the registry."

After asking respondents to elaborate on each of the barriers they had checked, they were finally asked to identify in their own words the greatest of these barriers that they faced. While a range of barriers emerged, several stood out as most frequently referenced (Fig 2). Eight respondents mentioned financial issues as being the most challenging barrier to overcome, and a few connected this barrier to issues of staffing-namely, having the funding required to hire and maintain a group of dedicated trauma registry staff. Three other respondents wrote of staffing issues (as independent from funding) as their most challenging barrier. Five respondents highlighted the issue of stakeholder engagement and buy-in. A common thread that connected several of these answers had to do specifically with a lack of surveillance culture; one respondent in particular lamented that hospital administration, despite being involved from the onset of the project, considered the trauma registry "less important for improving trauma care", while another respondent noted a "so what" attitude amongst stakeholders from other nearby facilities. Three respondents identified missing or incomplete data as the source of their most significant barrier. A respondent referring to their experience implementing a trauma registry in a country with multiple official languages wrote of data

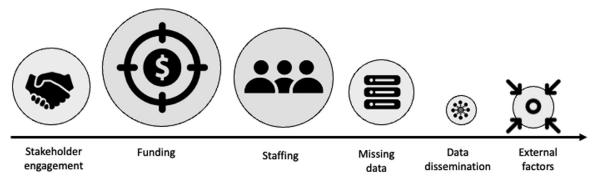


Fig. 2. Greatest barriers to trauma registry implementation and operation according to respondents. This figure illustrates respondents' answers to the question about the greatest barrier they faced in the implementation or operation of the trauma registry. Each barrier identified is proportionally sized to the number of respondents who answered with a statement that emphasized that barrier.

quality being hampered by having to translate from the languages used to fill in patient charts. Two others wrote of external factors being their most challenging barrier; one of these respondents wrote of how maintaining a trauma registry in their city was exceptionally challenging given the sheer number of patients their Trauma Centre saw in a month, while the other respondent mentioned the challenges of implementing a trauma registry amidst the political turmoil of their country. Only one respondent identified slow dissemination of data as their greatest barrier.

Facilitators

In response to how these challenges were overcome, survey respondents identified several strategies and tools that they used to facilitate successful implementation of the trauma registry—although some acknowledged that the barriers in the end were too great to overcome. Generally, the respondents answers can be categorized into five major categories based on the types of challenges they address: 1) overcoming issues of funding, 2) overcoming issues of stakeholder engagement, 3) overcoming issues of staffing, 4) overcoming issues with data quality capture, and 5) overcoming issues of infrastructure. Notably, only one respondent discussed a strategy for dissemination though they elaborated little on what it entailed.

With regard to overcoming issues of funding, several different strategies arose. One respondent suggested applying for multiple grants, and even broadening the scope of the registry to apply for additional grants. Another respondent echoed this tactic, writing that they supported funding "with different local resources available from other sources of funding not specified for the registry". Some respondents noted cutting costs where possible, using free software and volunteer resources. Some found that appealing to stakeholders higher up in the Department of Health was a successful way to secure funding. One respondent even mentioned spending their own personal money in order to keep operations afloat.

With regard to overcoming issues of stakeholder engagement, many respondents discussed the benefit of having a trauma registry champion in overcoming barriers related to initial stakeholder resistance or a general lack of support. While most people identified this champion as a physician, one respondent identified the importance of also having a dedicated nurse coordinator in ensuring the success of the registry. Other respondents commented on the use of incentivization strategies to help secure buy-in, such as aiding publication efforts or illustrating the value of the registry in relation to patient care and quality improvement metrics.

Respondents also identified several strategies that they had used to overcome issues of staffing. One strategy involved using a retrospective registry to collect data whenever the research assistant was available, while another involved ensuring that the data

collection system was as efficient as possible to minimize the time spent collecting data by already busy clinicians. To this end, a respondent even suggested using a data collection tool that could also serve as a standardized patient chart. Numerous respondents mentioned making maximal use of resources that are in abundance (e.g. doctors, nurses, clerical staff, or even students).

Only two respondents discussed tools and strategies that helped them with their infrastructure hurdles. Both respondents identified digital solutions to their respective problems. One respondent commented on how internet connection challenges had forced them to resort to paper-based collection when the internet was down; however, since REDCap— their data collection software—can now collect data offline, they are able to proceed with data collection as normal, and upload whenever the internet connection is strong again. The other respondent provided less detail on the technologies used and barriers addressed, however made note that "infrastructural deficiencies were overcome by using digital technologies".

Lastly, in terms of overcoming issues with data capture and quality, numerous strategies were put forth. Most of these concerned how to improve data capture and ensure more complete records, with several respondents recommending altering the data collection process. For example, one respondent suggested minimizing information in the data collection form that required lengthy text responses, while another suggested using an abbreviated note for minimally injured patients (instead of full resuscitation data). In a similar vein, a respondent wrote of changing up the data collection process-instead of having a final diagnosis by a physician (which was often left incomplete), the team switched to having "a provisional diagnosis done by the research and triage team" to improve data capture for this field. Others had a system in place for missing data. One respondent, referring to their retrospective trauma registry, wrote of having a pre-established method if charts were missing, since they "did not need to collect every single patient" and could still analyze the results effectively as long as their overall sample size remained large enough. Another respondent mentioned personally chasing down missing data themselves-though it was noted that this was an often timeconsuming endeavor. While only a few respondents wrote of addressing data quality, strategies put forth included frequent staff training, periodic checks of data quality, and regular meetings or workshops to discuss data quality.

Advice for others

Lastly, respondents were asked what piece of advice they would give to someone thinking about developing a trauma registry in a resource-constrained setting. Answers ranged widely, however eight common themes emerged: Have a trauma registry champion

The advice to have a trauma registry champion— that is, a person committed to seeing the process of registry development and implementation through— emerged again and again from respondents.

"Identify a person with passion and zeal to drive the effort and give them the responsibility of making it work."

"You must have a staff champion in the hospital that can mobilize buy-in. Without this frontline active project champion, the registry won't go anywhere."

"It is useful but difficult and if you can find someone who is a permanent, long term staff member and preferably in a position of leadership of some type, to be your trauma registry champion it may get pulled off, even if you don't have direct funding. Any registries in Kenya that had external funding - the one with the Bloomberg fund - became immediately non-existent once the external funding for dedicated data collectors and staff stopped."

Simplify, simplify, simplify!

Several respondents gave the advice for others to keep the design of their registries simple. Standardization of variables was also frequently mentioned.

"Think about ease of use and standardized variables."

"Keep it simple!"

"Try to keep volume of data collected per patient within achievable limits."

"Don't invent the wheel, standardize the patient encounter form to act as data collection tool."

"Different amounts of data are required depending on the severity of the injury."

"Minimally injured patients should have a fast track system that allows for fewer data points."

Use what you have

The advice to use what is available, especially as related to staffing availability, was featured amongst the answers of a few respondents.

"Make maximal use of any resources that are in abundance e.g doctors, nurses, clerical staff, students. We use doctors as we have many."

"Work within the limits of available resources."

Get designated trauma registry staff, if possible

Other respondents however contested the above advice, urging people to hire designated trauma registry staff if possible.

"Raise funding for an independent set of data collectors ... and resist the constant suggesting by the faculty to use overworked residents to collect trauma data. It simply does not work."

"Try to have people whose only job for the period (weekly or monthly) is data collection. If possible, hire dedicated trauma registry staff and train them."

Secure funding

Advice around funding was also readily given, with many respondents stressing this as one of the most fundamental components of developing a successful and sustainable trauma registry.

"There must be funding to ensure sustainability and quality."

"Find a way to get funding."

"Find funding to get it started."

Work at engaging stakeholders and creating solid partnerships

Numerous respondents gave advice around cultivating solid relationships with stakeholders at all levels. One respondent in particular counselled that ensuring there is demand and support from stakeholders for the trauma registry from the beginning is of utmost importance, as this is what will eventually sustain the registry in the future.

"Develop skills at political lobbying to induce support from administration, realizing that support based on the defined need for a trauma registry may not be forthcoming."

"Allot enough time to establish a good working relationship and convince key players of its importance."

"Institutional and staff-buy in is crucial."

"Seek potential collaborators with interest and understanding of the benefits of a trauma registry."

"Have a lot of patience. Be flexible. Engage stakeholders who are passionate about trauma and will help you advance the development and implementation."

"First make sure that there is demand for data, quality improvement and ownership of the registry right from the beginning. Intentions are always good, but sustainability becomes a major issue once funding or local champions are gone."

Prove its value

Another common theme shared amongst respondents' answers was to prove the trauma registry's 'worth'— that is, use the data to show the utility of the trauma registry for injury prevention, quality improvement, and patient care. However, value for whom is only explicitly stated by one respondent, who suggests this would allow buy-in from hospital administration. Other stakeholders for which proving the value of the registry might be important include the health care workers or staff collecting the data, though neither of these were explicitly stated. In a slightly different vein, one respondent in particular gave the advice to think carefully about the value of the trauma registry itself, and whether a full registry is necessary to accomplish similar objectives.

"Show rapid gains from the data obtained in terms of low-cost data driven improvements in trauma prevention and treatment strategies."

"Use the data to provide feedback, that shows the value of the registry and gets buy in from hospital administration."

"Use funds to maintain the database to prove its long-term utility."

"Think about what your registry will add that isn't already known / available through other registries. Cost benefit analysis – is it worth it (what will it add to the hospital in terms of patient care). These cost a lot to run. Would that money be better spent on something else? Does the registry need to be continued forever or can you do a snapshot?"

Keep at it!

Lastly, several respondents gave advice in the vein of persevering through the challenges and seeing the process through.

"Supervise the process until it becomes established."

"Never give up."

"Long term outcomes may be slow and difficult to achieve but will definitely be possible."

Discussion

Results from this questionnaire indicate a diversity of experiences in establishing a trauma registry in under-resourced areas. However, many respondents spoke of broader themes that could be commonly identified across these registries, no matter their location or hospital's funding source (i.e. public vs. private).

Barriers relating to both staffing and funding the trauma registry emerged as the first and second most common issues from respondents respectively, and is supported readily by papers that have documented or reported on their individual experience of trauma registry implementation [22–26]. A study by O'Reilly et al. (2016), which reported the lessons learned of trauma registry development in both HICs and LMICs similarly identified both funding and staffing challenges as key topics to surface in their interviews with trauma registry custodians. Here, they found that "reference to the importance of funding was almost universal" no matter the income level of the country, although, they noted that there remains a stark division in the type of funding challenges encountered in LMICs vs. HICs. Our study did not look at HIC trauma registries, however we did find a similar parallel amongst public and private hospital trauma registries. Like HIC trauma registries, it might be expected that private hospital trauma registries would be less likely to encounter difficulties with funding, however three out of four respondents answered that issues of funding were still a barrier for their private hospital registry. A perhaps more revealing question that future studies might ask is whether issues of funding threaten the existence of the trauma registry, or merely make it challenging to accomplish all of its initial objectives. Another interesting question that requires further exploration is where most trauma registries are receiving their funding from. There are multiple sources that have been written about previously, including funds from local, provincial, or national governments [27], NGOs, foreign grants [28-30], and even private companies [22]. To understand this mix and where the money is coming from to support these registries would be a critical piece of information for those looking to establish their own trauma registries in the future and should be examined in a future study.

O'Reilly et al. (2016) also found that adequate staffing, in terms of number, competency, commitment and training was mentioned by more interviewees than any other feature of the trauma registry and considered an essential component of a successful registry [16]. Such experiences closely mirror our respondents' answers that pegged staffing challenges as a significant barrier to trauma registry development. Of particular note from our study is that all nine of the respondents of inactive trauma registries reported staffing as a barrier to implementation and operation, whereas only 61% (or 8 of 13) of the respondents of active trauma registries reported the same. Though many reasons exist for funding and staffing challenges, a critical consequence of both (and mentioned frequently by respondents) is that other clinical issues often get prioritized over data surveillance activities. This is especially common in many LMICs countries, which must grapple with what some have called a triple burden of disease-high rates of infectious diseases, injuries, and now, also, non-communicable diseases - with a severely depleted health care workforce [31,32].

A study by Bommakanti et al. (2017), which researched the challenges and opportunities to trauma registry implementation through a structured review of the literature also identified a lack of funding and human resources as challenges in the studies they reviewed [10]. However, in their study, both of these challenges were greatly surpassed by the number of studies reporting data quality issues, which may be a consequence of the fact that these barriers were identified from a review of academic research publications, the focus of which center on data quality.

The other major barrier we identified in our study was engaging stakeholders and securing their buy-in to the trauma registry. Interestingly, challenges regarding stakeholder engagement or buyin was not identified as a major theme in O'Reilly et al.'s study, and only briefly mentioned in Bommakanti et al.'s literature review. Yet, from respondents' answers in our study, it emerged as a significant issue that came up time and time again. One possible reason for this divergence of results is the kinds of trauma registry experiences that O'Reilly et al. and Bommakanti et al.'s studies draw on. In both studies, information (whether by interview or literature review) was only sought from active trauma registries. However, our study included the experiences of both active and failed trauma registries, potentially illuminating barriers such as stakeholder engagement that may have proved to be insurmountable, causing these registries to fold. Alternatively, it is possible that because these stakeholder relationships can be fragile, people are less willing to speak or write as openly about their experiences for fear of damaging these relationships.

This study also identified several prominent themes related to facilitating registry development including overcoming issues of funding, overcoming issues of stakeholder engagement, overcoming issues of staffing, overcoming issues with data quality and capture, and overcoming issues of infrastructure. Despite these groupings, it is important to acknowledge that the individual efforts and strategies used to overcome the barriers discussed were often unique to each registry. For example, to tackle issues of staffing, one respondent reported having a research assistant collect trauma registry data retrospectively, to rid the need for real-time, clinicianled data collection. However, a different respondent reported the opposite, having clinicians collect trauma registry data prospectively, using an extremely efficient data collection system to minimize the time clinicians had to spend collecting data. In both cases, the issue of limited staffing is addressed but through entirely different means. Context is thus a clearly important determinant in what will work best for each registry and must be considered carefully in selecting a strategy.

Interestingly, there were a few common facilitators put forth that are seemingly important regardless of context. In particular, having a local champion to push forward the trauma registry and see it through was one of the most common answers from respondents. This sentiment has been echoed before in previous papers [16,17,33]. Such a champion seems fundamental for a variety of reasons including building strong stakeholder relationships, helping the registry secure and maintain funding, and boosting staff motivation. Another common facilitator identified across contexts was to use a minimal dataset that collected information on only what was necessary for the trauma registry. Such a dataset can reduce the amount of time collecting data, and thus requires fewer staff for both data collection and analysis. Like the strategy to have a trauma registry champion, evidence of a minimum dataset has been documented in previous publications as well, signaling that several other trauma registries have also made use of this strategy [33–36]. Identifying such facilitators that work across contexts is a critical step in encouraging trauma registry growth in other settings and should be included in frameworks or trauma registry resources going forward.

When respondents were asked to give advice to others looking to start their own trauma registry, several lines of counsel emerged. Simplification of the collection process, proving the value of the registry, and taking the time to form key stakeholder relationships were among the most common pieces of advice and indicate a strong consensus that these are important strategies for successful trauma registry implementation. Specifically, the latter two lines of counsel point to the necessity for a strong culture of engaged staff and stakeholders. At an organizational level, this ultimately means registry implementation should fit into a mission

vision of continuous quality improvement, supported by shared purpose, culture change, and empowerment.

Radical routes to solving problems across the trauma registry process were also offered. One respondent advised people to think critically about the purpose of their registry and ask of themselves, "Does the registry need to be continued forever or can you do a snapshot?". In many studies, building trauma registries and ensuring their sustainability is encouraged as a way to address the injury burden in LMICs an on-going, long-term registry is the norm. Yet, this advice to question whether sustainability is actually needed for the immediate purposes of the hospital is a critical question in contexts where registry participants simply do not have the resources to continuously maintain a full registry.

Finally, as with any study, there are limitations to our findings. First of all, questionnaires were administered in English, and thus only those in our target population who spoke English could participate. Second, the questionnaire had a response rate of 32.8%. While this is high for a population with the busy schedules of doctors and researchers and represented a variety of different countries, we are missing the experience of non-respondent LMIC trauma registries. Finally, in our call for respondents for this questionnaire, we reached out to people who are both local and foreign to the country where the trauma registry is located. In the case of the latter, respondents may have only been a part of the development phase of the registry given their residence outside of the country, and their responses of barriers and facilitators may therefore be biased towards the establishment of the registry rather than its on-going operation.

Conclusion

This study supports efforts to build successful and sustainable trauma registries in LMICs by examining barriers and facilitators to registry development reported by trauma registry stewards and researchers. The results from this study are an important first step in creating resources and guidelines that can be used to develop and bolster the number of trauma registries in LMICs going forward. Key messages from the survey results include the importance of a registry champion, fostering strong stakeholder relations, and, among other things, proving the registry's value to key stakeholders, whether that be hospital administration, or the physicians, nurses, or other staff collecting the data.

While our thematic analysis of respondents' answers has helped to neatly classify barriers and facilitators to trauma registry development in LMICs, it is important to acknowledge that the issues encountered here are in reality often interconnected in complex ways. Issues of data quality are fundamentally related to issues of staffing and issues of funding. As such, those looking to establish their own trauma registries in the future should be cognizant of the interconnectedness of these challenges and make choices based on the big picture of the trauma registry and not just a single aspect. It is also critical to recognize that the successful establishment and operation of any trauma registry must be accompanied by data-driven changes to successfully reduce injuries and improve care for the injured. Data collection on its own achieves neither.

Looking to the future, it is essential that more research be conducted on the experiences of both successful and failed LMIC

trauma registries. Others can learn from these stories and put this knowledge to use developing their own trauma registries and begin to successfully address injury through data-driven policy and informed decision-making.

Ethics approval

Written informed consent was sought prior to participation in the questionnaire. Approval for this study (2019s0009) was granted by Simon Fraser University's Research Ethics Board and the University of British Columbia's Behavioral Research Ethics Board.

Declaration of Competing Interest

The authors declare no conflict of interest.

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Appendix A

Web of science, CINAHL, medline (Ovid) and global health search

"Trauma registr*" OR "Trauma databa*" OR "Injury registr*" OR "Injury databa*"

AND

"Develop*" OR "Implement*" OR "Operat*" OR "Establish*" OR "Sustainab*" OR "Barrier*" OR "Challenge*" OR "logistic*"

"LMIC" OR "Low and middle income countr*" OR "Low income countr*" OR "middle income countr*" OR "Developing countr*" OR "Global South" OR Uruguay OR Barbados OR "Costa Rica" OR Turkey OR Mauritius OR Panama OR Serbia OR Georgia OR Mexico OR "Sri Lanka" OR "Bosnia and Herzegovina" OR Venezuela OR Brazil OR Azerbaijan OR Macedonia OR Armenia OR Thailand OR Algeria OR China OR Ecuador OR Peru OR Colombia OR "Saint Lucia" OR Mongolia OR "Dominican Republic" OR Jordan OR Tunisia OR Jamaica OR Suriname OR Belize OR Turkmenistan OR Moldova OR Philippines OR Indonesia OR Vietnam OR Palestine OR Kyrgyzstan OR Tajikistan OR Maldives OR Gabon OR Paraguay OR "South Africa" OR Egypt OR Bolivia OR Iraq OR "El Salvador" OR Nicaragua OR Guyana OR Guatemala OR Namibia OR India OR "Timor-Leste" OR Honduras OR Bhutan OR Bangladesh OR Congo OR Vanuatu OR "Lao People's Democratic Republic" OR Ghana OR Kenya OR "Sao Tome and Principe" OR Swaziland OR Zambia OR Cambodia OR Angola OR Myanmar OR Nepal OR Pakistan OR Cameroon OR Tanzania OR Nigeria OR Rwanda OR Lesotho OR Mauritania OR Madagascar OR Uganda OR Benin OR Senegal OR Comoros OR Togo OR Sudan OR Afghanistan OR Haiti OR "Cote d'Ivoire" OR Malawi OR Djibouti OR Ethiopia OR Gambia OR Guinea OR "Democratic Republic of the Congo" OR "Guinea-Bissau" OR Yemen OR Mozambique OR Liberia OR Mali OR "Burkina Faso" OR "Sierra Leone" OR Burundi OR Chad OR "South Sudan" OR "Central African Republic" OR Nigeria

Appendix B

Inclusion and exclusion criteria of literature search

Criterion:	Include:	Exclude:
Time period	No time limitation was specified for the search	NA
Language	English	Non-English language papers
Type of article	Peer-reviewed original research, peer-reviewed review type articles, and commentaries	White papers
Availability	Full-text version available	Full-text version not available
Content of paper	Papers describing the development, implementation, and/or operation of a trauma registry. Papers describing barriers or challenges associated with a trauma registry	Papers that provided an analysis of trauma registry data but provided no detailed explanation of trauma registry development, implementation or operation.
Location of trauma registry	LMICs	HICs
Type of trauma registry	General trauma registries (adult or pediatric)	Military trauma registries or narrowly focused trauma registries (i.e. injury specific registries like TBI).
Status of trauma registry	On-going or failed trauma registries (i.e. those that	Fixed-trial trauma registries (i.e. those that were
	were supposed to be on-going but failed due to	initially set out to record for only a set period of
	challenges of implementation/operation).	time).

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