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Assessing barriers, opportunities and future directions in health information sharing in humanitarian contexts: a mixed-method study

Shuait Nair,[1] Aurelia Attal-Juncqua,[2] Aashna Reddy,[3] Erin M Sorrell,[2,4] Claire J Standley [ID] [2]

For numbered affiliations see end of article.

Correspondence to
Dr Claire J Standley;
claire.standley@georgetown.edu and
Dr Erin M Sorrell;
erin.sorrell@georgetown.edu

ABSTRACT

Objectives Health information sharing continues to play a crucial yet underappreciated role in humanitarian settings, to guide evidence-based disease prevention, detection and response. We conducted a mixed-methods study to investigate and analyse existing approaches and practices to health information sharing across humanitarian settings over the past 20 years.

Setting We sought to identify studies from any self-described humanitarian setting worldwide, and also targeted experts familiar with refugee settings, specifically long-term camps in Kenya, Jordan and Bangladesh, for key informant interviews.

Participants The systematic review did not directly involve participants. The identified reports were largely retrospective and observational, and focused on populations affected by humanitarian crises worldwide. Participants in the key informant interviews were experts with either broad geographical expertise or direct experience in refugee camp settings.

Primary and secondary outcome measures Our study was qualitative, and both the systematic review and analysis of key informant interview responses focused on identifying themes related to barriers, tools and recommendations used between stakeholders to share health information, with a particular emphasis on infectious disease and surveillance data.

Results We identified logistical challenges, difficulties with data collection and a lack of health information sharing frameworks as the most significant barriers to health information sharing. The most important tools to health information sharing included the use of third-party technologies for data collection and standardisation, formalised health information sharing frameworks, establishment of multilevel coordination mechanisms and leadership initiatives which prioritised the sharing of health information.

Conclusions We conclude that health information sharing can be strengthened in humanitarian settings with improvements to existing frameworks, coordination and leadership tools, in addition to promotion of health information communication. Furthermore, specific recommendations for improving health information sharing should be pursued according to the nature of the humanitarian setting and the efficacy of the health system present.

Strengths and limitations of this study

► Health information sharing is integral to the delivery of healthcare interventions in humanitarian settings, yet its effective execution in humanitarian contexts has proven to be challenging and inconsistent over the past 20 years, suggesting the need for investigation of the barriers and opportunities affecting information sharing in these contexts.

► Our mixed-methods approach allowed for exploration of both published data and expert perspectives on these themes, on a global scale, and with an emphasis on refugee populations.

► One limitation to the systematic review was that we only included articles in English, and performed non-exhaustive snowball sampling, particularly in the grey literature.

► Our key informant interviews were focused on experts with familiarity in refugee contexts, and thus their insights may not automatically be applicable across all other sorts of humanitarian crisis.

► Finally, we recognise our own positions of privilege, as researchers based at a US-based institution, which may create limitations in our ability to analyse the findings and provide recommendations, though sought to mitigate this through our key informant interviews with individuals working directly with populations affected by humanitarian crises.

INTRODUCTION

Our world is experiencing an ever evolving and increasing series of events, both man-made and natural, that contribute to creating and/or sustaining humanitarian crises. These events, occurring individually or in complex series, severely threaten the health, safety and well-being of populations.[1] Humanitarian crises disrupt the basic services required to sustain life, including access to food, clean water, secure shelter and psychosocial support.[2] Health services may also be directly affected through destruction of critical medical and public services infrastructure,

emigration of or even direct attacks on health personnel, and various barriers to medical supply chains. Disruptions to preventive health services can lead to re-emergence of previously controlled or vaccine-preventable diseases, or emergence of novel diseases, for example, if the disaster event creates new habitats for vector species or encourages new forms of contact between humans and animals, increasing the risk of zoonotic spillover.[3] The stress and trauma of a humanitarian crisis can also increase susceptibility to a variety of acute and chronic health conditions. Many humanitarian crises are further characterised by population displacement, which, in addition to the above factors, adds further health risks, including exposure to new diseases, violence along the displacement pathway and barriers to healthcare access at the destination as well as along intermediate points. With limited resources, and constrained by physical access in some cases, as well as other potential logistical, financial and political barriers, humanitarian response actors must make difficult decisions regarding provision of services. The novel coronavirus pandemic, COVID-19, has further exacerbated these challenges, where effective public health response and containment measures—such as physical distancing, the use of personal protective equipment and regular, proper sanitation and hygiene—can be challenging and difficult to implement in humanitarian settings, and particularly in facilities or settlements for internally displaced persons, asylees or refugees.[4]

Within humanitarian settings, host governments, non-governmental organisations (NGOs) and international organisations (IOs) have traditionally combatted the presence and spread of disease with the delivery of minimum packages of essential health services.[5] However, the delivery of health services in any healthcare system cannot be effective without data on the needs and types of services required by the target population. Thus, just as ministries of health do in their respective nations, humanitarian actors establish health information systems in humanitarian settings to collect and interpret the health needs of the affected populations. Effective health information sharing between the various actors and stakeholders present within humanitarian response settings has been a consistent challenge since the establishment of the modern humanitarian operational response, as codified by the Sphere Handbook two decades ago.[2] Indeed, some of the negative outcomes of recent disaster responses across the globe have been linked to the use of fragmented health information sharing structures.[6] Additionally, humanitarian settings have been reported to be more prone to disturbances in their disease surveillance reporting systems, weakening the collection of health information and in turn compromising the efficacy of health information sharing.[7] With the COVID-19 pandemic throwing these issues into sharp relief, the importance of health information sharing and collaboration between humanitarian stakeholders for rapid detection and response to epidemics cannot be overemphasised. The objective of this study was to investigate and review existing approaches to health information sharing in humanitarian settings.

METHODS

We employed a mixed-methods approach to collect data on health information sharing in humanitarian contexts, consisting of a systematic literature review of health information sharing in humanitarian settings combined with key informant interviews with subject matter experts, focused on refugee camps. The review was not registered due to its non-clinical nature.

Systematic literature review
Search queries

We performed a systematic search in PubMed and Web of Science databases to identify literature pertaining to health information systems in humanitarian settings. Synonyms for 'health information sharing' and 'humanitarian setting' were used to select abstracts for consideration. The full search syntax can be found in online supplemental file S1.

The inclusion criteria were defined to include English language papers published from the year 2000 onward in the selected databases. The cut-off of 2000 was selected because the Sphere Handbook was published this year, establishing an early precedent for coordinated humanitarian disaster operations.[2] Furthermore, the year 2000 marked the recognition of the broader societal impacts of health emergencies (specifically infectious disease outbreaks) internationally, as outlined by the United Nations Security Council Resolution 1308.[8] We applied two content-based inclusion criteria to the articles screened for this review, which were (1) humanitarian setting context and (2) reported health information coordination and/or sharing. These inclusion criteria were used to optimise the inclusion of articles for full-text review that emphasised health information sharing in humanitarian emergencies, including investigations of health data collection, efficacy studies of health information sharing tools, and 'retrospective' studies examining challenges with health information sharing. The last search was performed in May 2020.

In addition to the use of a systematic search, the reviewers identified additional articles for full-text review through non-exhaustive snowball searching of grey literature, including academic theses and published reports from the WHO and think tanks.

Data extraction

The full-text articles were reviewed independently by one research team member using a prepared review protocol, with the contents of each article analysed for descriptions of health information sharing in humanitarian settings. For each article, we recorded the humanitarian context (including country or countries of focus), any barriers to health information sharing mentioned, the parties involved in health information sharing, any

identified tools used to promote health information sharing (including leadership, coordination, framework and promotional tools), and future recommendations. The findings from each article were then reviewed again by at least one additional reviewer. Any disagreements were resolved through discussion and/or input from a third reviewer. Four of the 25 papers scanned for full-text review were excluded (see online supplemental file S1). Note that the full review protocol can be accessed in online supplemental file S1. No amendments were made to the review protocol.

Since all the studies used in the literature review were observational, qualitative and retrospective rather than experimental, we did not find the risk of bias due to challenges with randomisation, blinding and statistical analysis to be relevant in our analysis. For this reason, we did not develop a risk of bias assessment for our study. However, we appreciate that there still exist biases in our findings, namely from only looking at peer-reviewed publications in English. All biases in our findings, including publication bias, are addressed in detail in the limitations section of our discussion.

Key informant interviews

Acknowledging that insights related to health information sharing in humanitarian settings may not always be captured in peer-reviewed publications, we complemented our literature review with key informant interviews with non-governmental, governmental and IO experts familiar with health aspects of humanitarian responses. These interviews were performed in parallel with a related investigation of health services in protracted refugee camps, and so focused on informants with experience working in refugee camp settings. To maximise the application of our findings across a wide variety of humanitarian settings, we sought key informants with either broad geographical expertise or with direct experience in camp settings that differed in terms of size, security, involvement of host government actors and time since establishment. The semistructured interviews were designed to collect data on health information systems and sharing between entities working in refugee humanitarian settings, and particularly their alignment with national health information systems of the host governments. A full list of interview questions can be found in online supplemental file S2.

Interviews were conducted between July 2019 and March 2020. Responses were captured via written or typed notes or, with the interviewee's consent, via audiorecording, and transcribed electronically. Qualitative data from the responses were extracted using a standardised template, and coded according to the study themes, including examples of coordination/ information sharing; barriers preventing information sharing; and tools used to promote information sharing.

Patient and public involvement in research

Due to the nature of this systematic review, neither patients nor the public were involved in our research. However, we sought to ensure that topics of relevance to target affected populations were addressed in the key informant interviews, through using open-ended questions and a semi-structured interview approach. We will ensure that the research is shared with all key informants, many of whom directly work with populations affected by humanitarian crises.

RESULTS

A total of 21 articles were analysed in the literature review. The results of the literature review are summarised in table 1. The full list of articles identified throughout the search, as well as our analytical framework for extracting themes, can be accessed via the Open Science Foundation repository (DOI: 10.17605/OSF.IO/KU2NF).[9]

Context of health information sharing

Most of the studies identified in the literature described humanitarian crises in general terms. However, there were a number of studies that focused on a specific geographical or contextual setting, including areas affected by conflict, refugee camps, natural disasters, and non-camp-based refugee settings (figure 1). Since we had anticipated an overlap between health information sharing and disease surveillance in humanitarian settings, we then determined how many of the studies included specific consideration of disease surveillance or outbreaks with relation to the setting. Five of the 21 studies included a focus on disease surveillance or outbreaks; Pedi *et al* and Wazny *et al* with respect to general humanitarian settings, Bradt and Drummond and Bozorgmehr *et al* in refugee settings, and Spiegel *et al* within Yemen.[10–14]

Participating entities in health information sharing

The most common set of entities engaged in health information sharing referenced by the reviewed articles and key informant interviews involved three types of humanitarian actors: NGOs, IOs and the host government, usually the health ministry or equivalent public sector health authority. Among the types of NGOs mentioned in the literature were international NGOs, national NGOs, and local organisations active within a particular humanitarian setting. Differing accounts were provided on the degree of communication between international and national NGOs, suggesting context-specific variation in information sharing. Diggle *et al*, for instance, reported that in humanitarian settings in conflict-ridden and contested areas such as in Syria, international NGOs worked remotely through local or national NGO actors and coordinated activities frequently.[15] Similarly, Olu *et al* observed that international NGOs and national NGOs were closely engaged in the Disaster Risk Reduction platform developed for sharing health information and coordinating health delivery within humanitarian settings in

Table 1	Overview of results from literature review	
(A) Classification of studies into different humanitarian contexts		
Context of Health Information Sharing	Humanitarian settings (General)	7 (10, 11, 18, 20, 22, 23, 26)
	Conflicted-afflicted areas	7 (14, 15, 16, 19, 27, 28, 30)
	Refugee camps	3 (12, 17, 25)
	Non-camp-based refugee settings	2 (13, 21)
	Natural disasters	2 (24, 29)
(B) Classification of Studies According to Health Information Sharing Parties Involved		
Parties Involved in Health Information Sharing	NGO—NGO	15 (10, 11, 12, 13, 14, 15, 16, 17, 20, 21, 25, 26, 27, 28, 30)
	NGO—government	9 (13, 14, 16, 19, 23, 24, 25, 28, 30)
	All stakeholders of a humanitarian emergency (general)	2 (22, 29)
	Other	3 (11, 13, 18)
(C) Classification of Studies According to Health Information Sharing Barriers Mentioned.		
Barrier to Health Information Sharing	Challenges accessing humanitarian settings	6 (14, 16, 17, 18, 19, 28)
	Delays and difficulties in data collection data collection/analysis	10 (10, 11, 13, 15, 16, 17, 20, 21, 25, 28)
	Lack of standardisation and integration of health information	4 (13, 21, 22, 26)
	Untrustworthy or unreliable governments	3 (15, 19, 23)
	Other	5 (14, 16, 17, 23, 24)
(D) Classification of Studies According to Health Information Tools Used.		
Health Information Sharing Tools Used	Third-party technologies to assist with data collection, standardisation, or sharing	4 (15, 22, 23, 26)
	Rudimentary/informal methods of data collection in places with weak health information systems	3 (11, 12, 20)
	Coordination mechanisms	7 (14, 16, 17, 18, 19, 24, 25)
	Formalised information sharing frameworks	6 (10, 13, 14, 16, 29, 30)
	Leadership/prioritisation initiatives	2 (21, 27)

NGO, non-governmental organisation.

northern Uganda.[16] Conversely, Buzard, for example, noted that in refugee camps in Tanzania, there was an observed lack of communication between international and national NGO workers in performing health-related activities.[17]

A few studies noted variations to this health information network, mentioning networks which included either only NGOs, NGOs and IOs, or NGOs and health ministries. Interestingly, several studies highlighted health information sharing beyond the NGOs, IOs, and health ministries. In an article examining the scope of military coordination of health-related humanitarian projects, Drifmeyer and Llewellyn reported health information coordination between the US Department of
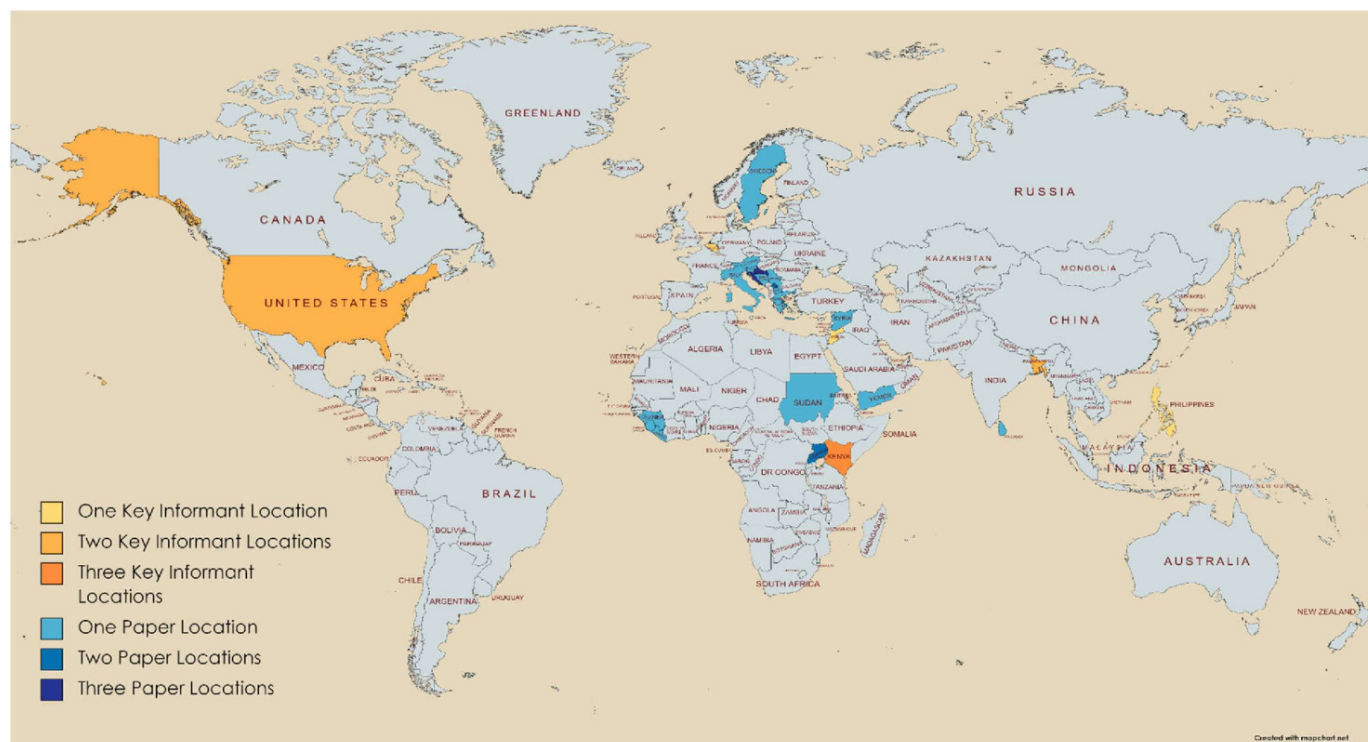
Figure 1 Geographical map of humanitarian settings identified in literature review and locations of key informants. The articles included in the systematic literature review examined humanitarian settings across three continents, including countries such as: guinea, Sierra Leone, Liberia, Uganda, Sudan, Yemen, Syria, Italy, Sri Lanka, Sweden, Italy, Austria, Slovenia, Croatia, Bosnia and Herzegovina, Kosovo, Macedonia and Greece. The key informants Interviewed were based in four continents and included countries such as: Kenya, Bangladesh, Philippines, Jordan, Belgium and the USA.

Defence's military humanitarian assistance programmes and local humanitarian organisations.[18] A study of health information sharing among refugees and asylum seekers across Europe by Bozorgmehr *et al* highlighted how information coordination also occurs between governments in the sharing of health data.[13] Finally, a recently published article by Wazny *et al* examining the potential uses of crowdsourcing in health information collection brought forth the novel concept of health information sharing between NGOs and the public, in which both parties use crowdsourcing platforms such as Frontline SMS, Geochat and Ushahidi to share health information regarding disease outbreaks and epidemics in humanitarian settings.[11]

Barriers to health information sharing

The most significant barrier to health information sharing identified through the literature review was logistical challenges associated with health data collection. As the first step to health information management, data collection plays a pivotal role in health information sharing—without accessible/available data, there can be no effective health information sharing. One pertinent challenge to data availability mentioned across several studies was the fundamental difficulty of accessing humanitarian settings and affected populations. While Yagub noted the challenge many NGOs experienced in accessing humanitarian settings afflicted by violence, Buzard expressed the challenge in directly accessing refugee camps posed by

environmental challenges, specifically during the rainy season.[17 19] Similar challenges were observed by respondents in our key informant interviews (figure 2A). One respondent, with experience as a healthcare worker in Cox's Bazaar also noted the geographical challenges to accessing Rohingya refugee camps, stating that the terrain and monsoons made it difficult for refugees and healthcare workers to access healthcare facilities: 'We would sometimes have to walk about 40 min from the main road to get to some of the healthcare services inside of the camps…it's also very hilly terrain…for the elderly or disabled, this was an incredibly difficult challenge to overcome.'

A second challenge to health data collection was the burden of work placed on healthcare workers, who often felt as though they had no time to organise and compile the health data of a patient following a visit with the overwhelming number of patients requesting treatment. As one respondent observed in Cox's Bazaar, 'The workload was so high—they (healthcare providers) were seeing so many patients in a day that the reporting was an afterthought…It was just a really big challenge to have people spend time to try to fill out these forms correctly when they were seeing 150 patients a day.' To some degree, this challenges the assumption that improved information sharing will always lead to better population health outcomes, especially if it comes at the expense of availability or quality of clinical care. A further complication
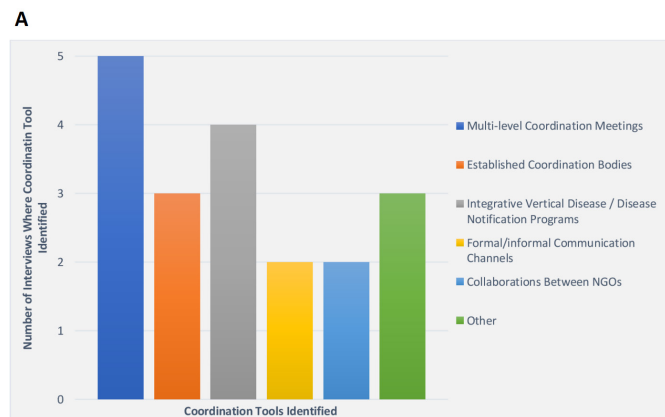
A

B

Figure 2 Key informant interview data on (A) barriers to health information exchange and (B) coordination tools used in health information exchange. A total of 12 key informants were interviewed. Their responses to select questions regarding the barriers to and tools for health information exchange were recorded and categorised. Note that each informant could cite multiple barriers and tools. HIS, Health Information System; IO, international organisation; NGO, nongovernmental organisation.

relates to having accurate basic demographic data to account for the target population. This is a major barrier in any humanitarian setting; a health data collection study by Thomas *et al* even pointed out that basic information about victims of humanitarian emergencies such as Civilian Registration Vital Statistics is often lacking.[20] An additional layer of complexity is added to non-enclosed humanitarian settings. As observed by Purdin *et al* and Diggle *et al* in studies of humanitarian settings beyond refugee camps, the existence of shifting front-lines and hidden populations exacerbate the difficulty of collecting accurate health data.[15 21] Finally, timeliness of data collection can impact its actionability, and thus value in being shared. A recently published paper on the use of crowdsourcing in health information sharing in humanitarian settings by Wazny *et al* reinforced the time-sensitive connection between health data collection and health information sharing, observing that lags in data collection for epidemiological surveillance push back the time in which health information can be appropriately shared, in order to be useful.[11]

With respect to health information sharing, once data have been collected, our review identified the lack of standardisation of health information and (lack of) integration of health information systems between humanitarian actors as a barrier. Bozorgmehr *et al* reported that little effort was made to standardised health data within or between European Union (EU) countries collaborating to provide infectious disease health services to refugees and asylum seekers.[13] As a result, health facilities receiving incoming asylum seekers or refugees transferred from other medical facilities in the EU were provided with mostly non-standardised paper-based medical records or informal communications regarding the health of the asylum-seekers and refugees, making personalised treatment more of a challenge. Fernandez-Luque and Imran observed that a lack of integration of online and traditional information sources among NGOs and IOs led to lowered data interoperability and hindered health information sharing in humanitarian settings.[22] Standardisation challenges were also notable between NGOs/IOs and governments. This was highlighted by a key informant familiar with Zaatari camp, who stated that the health information system used within the camp was not integrated with the Jordanian Ministry of Health's health information system, resulting in less robust health information exchange.

Additional concerns towards health information sharing mentioned in the literature included having an unreliable or untrustworthy government with whom to share health information. Among the primary concerns cited with the sharing health information with governments was a fear that patient data regarding places of origin, ethnicity, and HIV status could put certain individuals at risk of persecution or further stigmatisation by their governments, especially if health data are not adequately protected.[23] One respondent highlighted the importance of sharing the medical records of resettled refugees with health providers in the destination country, to facilitate continuity of care, but also noted how this can result in data confidentiality and security issues, especially when there are different laws or regulations governing health data protection across jurisdictions. A related concern against exchanging health information with governments mentioned by Thieren was a worry that governments would mismanage metrics such as mortality from infectious diseases in order to undermine the severity of a humanitarian crisis within their country or to encourage the continued flow of tourism within the country.[23] Building off Thieren, Yagub emphasised how distrust in data sharing between NGOs and governments often emerged when NGOs believed that governments lacked the knowledge, skill, or capacity to translate any health information shared into an actionable response (such as health service delivery), contributing to the reluctance to share health data with governments.[19] Even in the instances that NGOs and IOs trusted governments, decisions against sharing health information to governments still occasionally occurred due to the risk

of government-held information falling into hostile hands, especially within conflict-ridden regions. Within opposition-contested regions of Syria, for instance, Diggle *et al* noted that NGOs would refrain from sharing health information with governments due to the inability of government and opposition forces to coordinate health safety activities for humanitarian populations and out of fear that the health information would ultimately be abused by opposition forces.[15]

Other barriers to health information sharing identified within the literature included a fear of losing competitive funding among NGOs with the sharing of organisational-derived health information; confidentiality issues regarding patient health information; and the sheer number of humanitarian actors that would require coordination for a health information sharing structure to be in place.[16 23 24] Among the key informant interviews, additional barriers to health information sharing mentioned included the politicisation of vulnerable populations in humanitarian settings, lack of funding and manpower, and a lack of awareness by NGOs of the importance of coordinating disease surveillance in humanitarian settings with the national health system.

Tools used in health information sharing

Our literature search and key informant interviews identified tools to support both improved data collection and health information sharing. Among the tools for data collection, we identified two patterns—the use of third-party technologies to assist with data collection and the use of low-tech and/or innovative methods of data collection in places with less robust or well-established health information systems. Specific third-party technologies mentioned in the literature were m-Health and e-Health applications for remote health data collection by Diggle *et al* and artificial intelligence technology in epidemiological surveillance and outbreak detection by Fernandez-Luque and Imran.[15 22] During a key informant interview, a UNICEF worker in Cox's Bazaar noted the use of the District Health Information System two software (DHIS2) for health information collection and analysis in Rohingya refugee camps. In humanitarian settings with weakened health information systems and a lack of Civilian Registration and Vital Statistics, alternative methods of data collection included rapid epidemiological assessments, verbal and social autopsies, and crowdsourcing for the sharing of non-patient related health information remotely.[11 12 20]

In addition to health data collection, the literature revealed a number of tools that have been employed to optimise the efficacy and efficiency of health information sharing. These tools can be broken down into coordination, leadership, and framework tools. One of the primary coordination tools utilised in the studies were partnership models, namely between NGOs and the government as detailed by Riccardo *et al* or between different NGOs as described by Buzard.[17 24] Collaborations between NGOs, IOs and governments were frequently noted among the key informant interviews in refugee camps

such as Dadaab and Cox's Bazaar that employed vertical disease notification systems, characterised by a top-down approach to initiation and implementation, and typically a single disease focus. Four of the eleven key informant interview respondents reported the use of vertical disease notification programme models between NGOs and the host government, while two reported the use of collaborative partnerships between NGOs as tools used to promote health information exchange in refugee camps (figure 2B). Other coordination tools referenced in the identified literature included the holding of meetings among local, state and national humanitarian actors to promote health information exchange among all relevant humanitarian stakeholders[16 25]; the use of coordinating bodies such as humanitarian information centres, the Inter-Agency Standing Committee, and the Large International NGO Coordination; and adherence to normative initiatives such as the Sphere Project and Standardised Monitoring and Assessment of Relief and Transition Protocols.[23 26] A health programme director at Cox's Bazaar interviewed for this study also reported the use of coordination bodies such as the Inter-Sector Coordination Group in coordinating health activities. The leadership tools put forth by the studies focused on making health information sharing a clear and defined job for organisations. The tools included task-shifting, as recorded by Purdin *et al* and the assigning of a lead agency to spearhead health information exchange, as described by Szilard *et al* and Fowler *et al*.[21 27 28] Finally, the framework tools utilised by the studies encompassed both WHO-based health information sharing operational and coordination tools like the cluster model and the Health-EDRM (Emergency and Disaster Risk Management) framework, in addition to non-WHO related formalised health information sharing channels.[14 29] For instance, in preparation for the Ebola outbreak, Pedi *et al* explained how NGOs in West Africa used their own standard operating procedures (SOPs) to initiate health information sharing within their disease surveillance mechanisms.[10]

Cited recommendations

Our research highlighted four main potential avenues for improving health information, namely the use of frameworks as well as leadership, coordination and advocacy tools in support of implementing or maintaining a health information sharing platform. Specific recommendations for each avenue are detailed in figure 3.

One point within this flowchart figure is worth expanding on, regarding the use of meetings as an effective leadership and coordination mechanism. As outlined by Buzard, every meeting centred on health information sharing should have: (1) A defined purpose of the meeting; (2) A system of rotating the chairing of meetings to allow for better capacity building and diversity; (3) A way to ensure NGOs maintain continued attendance at meetings and coordinate within themselves to share health information between different rungs of the organisation hierarchy and (4) A detailed distribution of
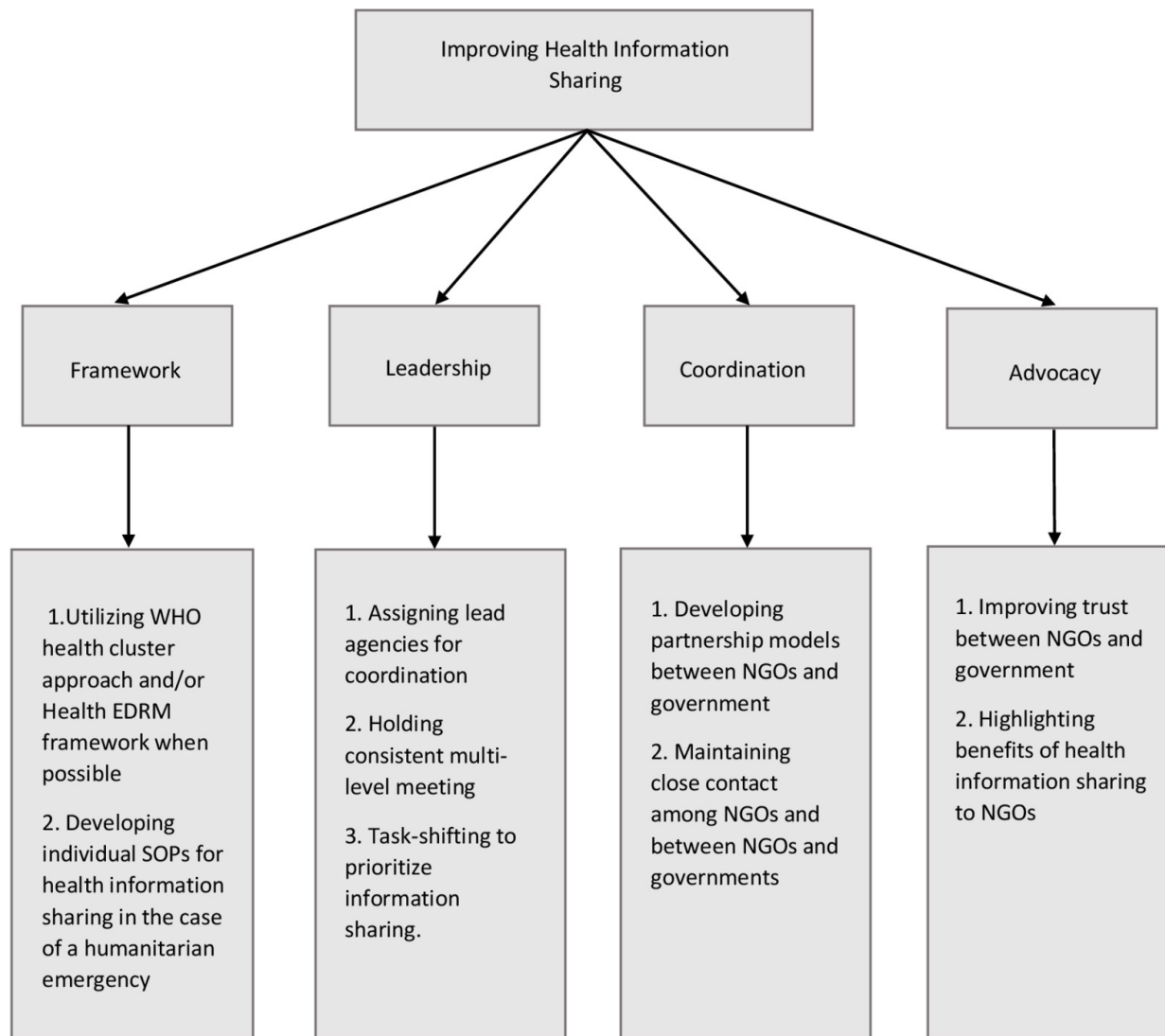
Figure 3 Cited recommendations to promoting health information sharing in humanitarian settings. Recommendations provided by literature review articles and key informant interviews were compiled and categorised into four categories: framework, leadership, coordination and encouragement. EDRM, Emergency and Disaster Risk Management; NGOs, non-governmental organisations; SOP, Standard Operating Procedure.

the accurate minutes of a meeting so that information at meetings always remains accessible.[17] We note that points 3 and 4 can act in concert; for example, a country director of an NGO programme who attends a national-level inter-agency meeting can use the distributed minutes to coordinate internally with staff at the camp-level, and vice versa. This way, information-exchange can occur across different levels with minimal additional effort from staff in terms of note-taking or writing reports. These guidelines provide a simple structure to optimise the efficacy of meetings.

DISCUSSION

Our study focused on examining health information sharing as an integrative field connected to the collection, standardisation, and exchange of data, particularly from a disease surveillance perspective. To our knowledge, this

is the first study to do so in the context of humanitarian settings. We have identified varying degrees of effort towards health data collection, health data standardisation and health information sharing between organisations in humanitarian settings. Efforts towards improved data collection appeared to be the most advanced, likely because they occur within the context of the organisation performing routine humanitarian functions, and for internal organisational monitoring and evaluation processes. Among the studies, there was little evidence of effective health data standardisation and mixed evidence of effective information exchange mechanisms. In situations that warranted information exchange, raw (unstandardized) health data was often conveyed from one organisation to another using informal information channels.[13 30] In some humanitarian settings, the lack of trust and coordination between stakeholders, especially

NGOs and the government, exacerbated the challenge of systematically standardising health data and sharing health information.[14 18 19] However, insights from our key informant interviews indicated that in other settings such as Dadaab camp, strong relationships between camp organisations and local governmental health authorities facilitated productive health information exchange and positive public sector intervention in promoting the health of vulnerable populations. Finally, in spite of the emphasis on establishing collaboration models and regular meetings for health information exchange between different types of humanitarian actors, we did not find studies that substantiated the efficacy of such systems in sharing health information with data-driven research.

Limitations

There were a number of limitations of this study, which may impact the depth and generalisability of the findings. First, in terms of study design, our searches consisted of articles published in English, primarily from the peer-reviewed literature. The level of snowballing we conducted was limited and we did not conduct formal searches within the databases of IOs like the WHO, International Organisation for Migration, or Médecins Sans Frontières for reports that might not have been published in peer-reviewed journals. Additionally, the identification of only 21 articles on health information sharing in humanitarian settings could itself be considered a limitation of this analysis. The lack of literature on the subject might suggest a lack of recognition of health information sharing as a key driver to effective healthcare delivery. Further, we recognise that humanitarian organisations, working at the front lines of disease surveillance and health service provision, may have limited time and professional motivation to publish in peer-reviewed journals, reducing the availability of evidence on health information sharing, as well as other interventions, in the academic literature.

Our key informant interviews were limited to experts with experience in refugee camp settings, and while we made every effort to interview individuals from different sectors and countries, it is possible we missed important perspectives, particularly with respect to non-camp settings. We noticed a corresponding evidence gap in the peer-reviewed literature with respect to non-displacement-related humanitarian settings. Of the 21 full-text articles reviewed in this study, only two articles focused on natural disasters, with another two articles only focusing on non-camp-based humanitarian settings. Therefore, the following analysis on health information sharing applies most strongly to displacement-related settings such as refugee camps, where health information sharing systems and structures are already in place. We suspect that the barriers related to data collection and health information sharing may be even more acute in non-displacement or camp settings, where coordination, leadership and operational infrastructure for information sharing may be less

readily available. Related to this, as a proxy for gathering data from geographically distinct regions, we actively sought to interview experts with either global experience or who had directly worked in camps in Kenya, Jordan and Bangladesh. Clearly, there are far more regions and countries that have previously or are currently facing humanitarian crises, and which may have distinct barriers or opportunities related to health information sharing not described here.

Finally, our own position as researchers based in the USA may result in biases related to the analysis and subsequent recommendations. Although we sought to incorporate field perspectives through the key informant interviews, including locally employed staff of national and international NGOs, our methods were not able to capture the perspectives of the populations and individuals most directly impacted by humanitarian crises. We feel strongly that these voices are critical for developing and sustaining health data collection and information-sharing approaches that best serve affected communities and meet their health needs, and encourage future research efforts in this space to develop methodologies with an explicit community-centred design.

Future Recommendations

Based on the differing circumstances of humanitarian settings described in the selected articles and key informant interviews, we have constructed a flowchart depicting the way in which a humanitarian organisation or actor can optimise health data collection (figure 4). The recommendations vary according to a number of factors, including whether the humanitarian setting has a well-established routine health data collection system, whether data is timely collected, whether Civilian, Vital and Registration Statistics are recorded, and whether technology is accessible. It should be noted that the flow chart does not offer a novel nor all-encompassing set of guidelines on how a humanitarian setting can strive to improve its health data collection. Rather, the purpose of the flow chart is to (1) account for the fact that humanitarian settings vastly range in the degree to which they have formalised structures and technology, and (2) remind humanitarian actors of what data collection structures and practices currently exist.

Ultimately, our recommendations for improving health information sharing are as follows:

1. Ensure an optimal method of data collection is adopted within a humanitarian setting that matches health system capacities, with the longer-term goal of strengthening a nation's health systems for improved health data collection for all contexts.
2. Develop methods for standardising health information collected by NGOs, IOs, governments (including the military), and the public within a country and across borders (if applicable). This may include encouraging all humanitarian settings to use minimum essential data sets as a means for health data standardisation, as well as protection of those data as needed. Additional
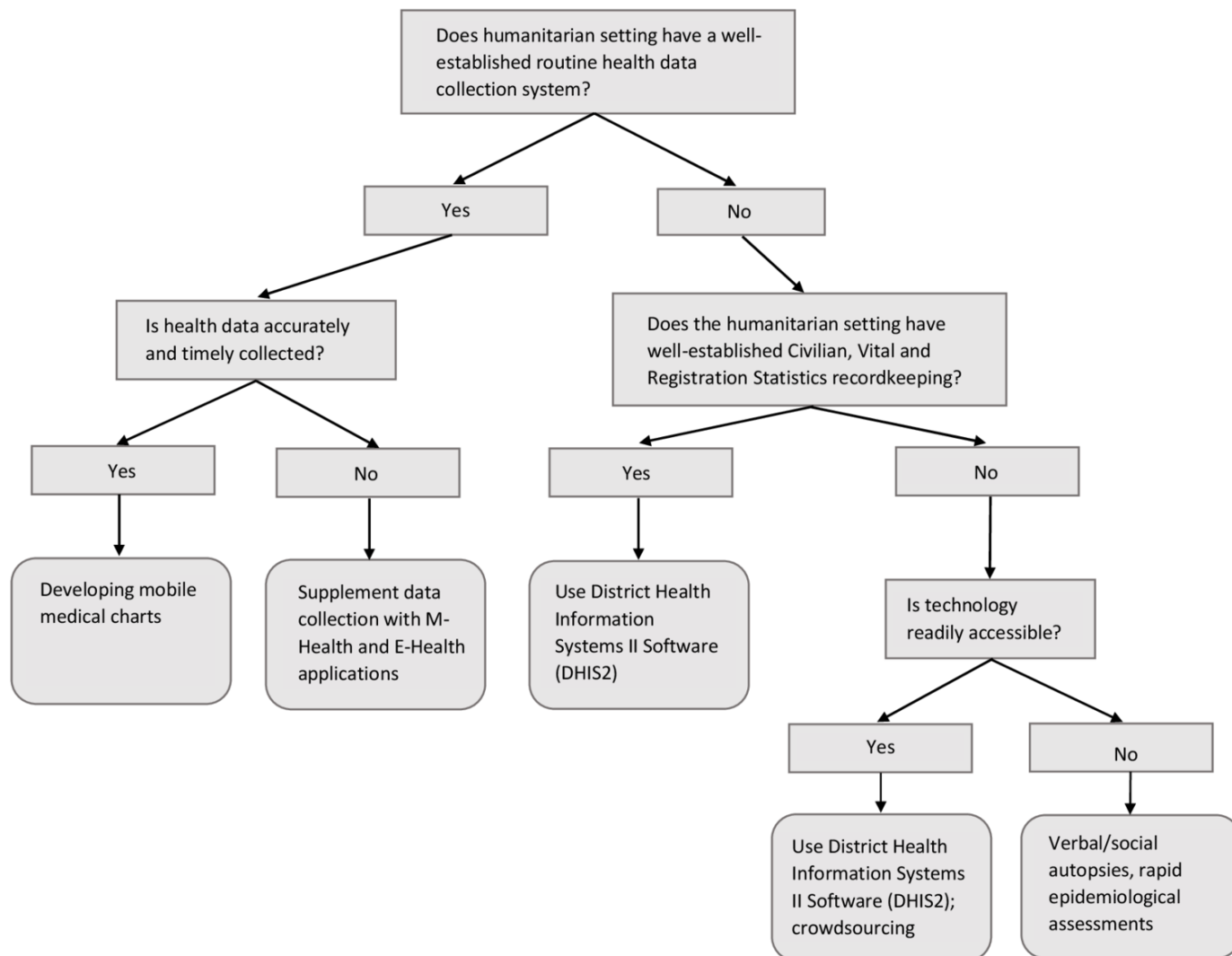
Figure 4 Recommendations for improving health data collection in humanitarian settings. Data collection methods used in literature review articles and key informant interviewers were compiled and organised according to the type and strength of the humanitarian setting which they were identified to be most suitable for. These results were then integrated into the following flow chart to provide a suggested framework for which a humanitarian setting can determine the data collection tools most optimal for their environment.

standardisation measures should also be implemented, including the use of coordinating models such as the cluster system and adherence to the Sphere Handbook; the extent and specific nature of the measures used should be adapted to the existing health system, to maximise capacity strengthening and sustainability.

3. Promote health information sharing mechanisms by utilising existing formalised frameworks and tools for health information sharing, relying on strong leadership and well-researched collaboration models between parties engaging in health information sharing, and highlighting the benefits of health information exchange.

4. Support implementation research to assess the impacts and outcomes of efforts to improve health information sharing in humanitarian settings, with particular emphasis on ensuring no loss of access to or quality of clinical care.

This study provides a comprehensive overview of the tools currently being used by different humanitarian actors to promote health information sharing, in addition to data sharing and standardisation. We hope that this systematic review can serve as a repository for progress that has been made throughout the world in humanitarian settings on information sharing in humanitarian settings.

Our systematic review provides a tangible structure to the processes of improving data collection, data standardisation and health information systems, considering the pre-existing conditions within a humanitarian setting. Researchers and humanitarians should continue to monitor and document the use and efficacy of current WHO health information sharing frameworks such as the cluster approach and Health-EDRM framework, in addition to well-researched collaboration models, to maximise the effectiveness of health information sharing.[16 29]

Some ministries of health may also already aggregate data from different sources internally; further effort should be made to use these sources further, provided appropriate data protection and consent processes are in place. Most importantly, researchers should emphasise the importance of health information sharing and the benefits that it may confer to participating organisations.

This systematic review could provide the basis for a health information sharing toolkit, where humanitarian actors can plan how to improve their internal and external coordination processes depending on their structures, the humanitarian setting and available resources. Such a toolkit could complement existing standards, such as those included in the Sphere Handbook, with particular applicability in contexts with weakened or fragile national health systems and be designed with alignment to existing modular health information systems, like DHIS2.[2]

CONCLUSION

Health information sharing between NGOs, IOs and host governments represents an important area of future innovation for enhancing how health and disease data from emergency-affected populations is collected and used for improved health outcomes. Given the importance of contextual factors, a standardised platform for global application may not be a feasible option; instead, stakeholders could focus on increasing the interoperability of existing data collection, sharing and analysis approaches. The development of a toolkit to promote greater information sharing, that is adaptable across different contexts and aligned with international standards and existing platforms, could further facilitate coordinated methods for health data collection and sharing between humanitarian actors and related stakeholders.

Author affiliations
[1]Walsh School of Foreign Service, Georgetown University, Washington, District of Columbia, USA
[2]Center for Global Health Science and Security, Georgetown University, Washington, District of Columbia, USA
[3]School of Nursing and Health Studies, Georgetown University, Washington, District of Columbia, USA
[4]Department of Microbiology & Immunology, Georgetown University Medical Center, Washington, District of Columbia, USA

Twitter Claire J Standley @ClaireJStandley

oversaw the overall project, and serve as guarantors of the final publication and its contents. All authors reviewed and edited the final manuscript draft.

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ORCID iD
Claire J Standley http://orcid.org/0000-0002-4291-9723

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