

Civil society priorities for global health: concepts and measurement

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Abstract

The global health agenda—a high stakes process in which problems are defined and compete for the kind of serious attention that promises to help alleviate inequities in the burden of disease—is comprised of priorities set within and among a host of interacting stakeholder arenas. This study informs crucial and unanswered conceptual and measurement questions with respect to civil society priorities in global health. The exploratory two-stage inquiry probes insights from experts based in four world regions and pilots a new measurement approach, analysing nearly 20 000 Tweets straddling the COVID-19 pandemic onset from a set of civil society organizations (CSOs) engaged in global health. Expert informants discerned civil society priorities principally on the basis of observed trends in CSO and social movement action, including advocacy, programme, and monitoring and accountability activities—all of which are widely documented by CSOs active on Twitter. Systematic analysis of a subset of CSO Tweets shows how their attention to COVID-19 soared amidst mostly small shifts in attention to a wide range of other issues between 2019 and 2020, reflecting the impacts of a focusing event and other dynamics. The approach holds promise for advancing measurement of emergent, sustained and evolving civil society priorities in global health.

Keywords: Global health, civil society, agenda setting, priorities, social media, Twitter

Key messages

- This study advances concepts and approaches to systematically analysing civil society priorities in global health.
- CSO, NGO and social movement advocacy, programmes, and monitoring and accountability activities are markers of prioritization in the civil society arena.
- Systematic analysis of CSO Tweets shows a punctuation in attention to coronaviruses amidst mostly incremental shifts for a wide range of other issues between 2019 and 2020.

Introduction

Global health agenda setting is a high stakes process in which problems that are transnational in scope or causal dynamics are defined and compete for the kind of serious attention that promises to help alleviate the burden of disease and its inequitable distribution (Kingdon, 1995; Collin *et al.*, 2002; Shiffman and Smith, 2007; Koplan *et al.*, 2009; Parkhurst and Vulimiri, 2013; Walt and Gilson, 2014; Shiffman *et al.*, 2016; Smith and Shiffman, 2018). It occurs in a highly decentralized global health governance context (Walt *et al.*, 2009; Youde, 2012). A new approach to conceptualizing and measuring the global health agenda suggests it is comprised of priorities set within and among a host of interacting stakeholder arenas,

including governmental, international aid, United Nations, scientific knowledge communities, industries, civil society and others (Figure 1) (Hilgartner and Bosk, 1988; Shiffman *et al.*, 2010; Smith and Gorantla, 2021a, b). This study informs crucial and unanswered conceptual and measurement questions with respect to civil society priorities in global health.

The two-stage inquiry first explores the concept of civil society priorities in global health and ways of identifying them via insights from 21 interviews with key informants based in South and Southeast Asia, Sub-Saharan Africa, Central and South America and North America. The second stage pilots a novel approach to systematically measuring priorities by analysing the content of nearly 20 000 Tweets from a purposefully selected subset of 150 civil society organizations (CSOs). The analysis straddles the COVID-19 pandemic onset, facilitating measurement of a significant shift in attention that corresponds to a major focusing event alongside relatively small shifts for most other issues. The study refines the concept of civil society priorities and introduces a novel approach to their measurement among subsets of CSOs, which may be defined by participation, geography, political context and other criteria.

‘Civil society’ can be defined very broadly, but health policy analysis scholars tend to focus on: (1) ‘voluntary associations that are entirely or largely independent of government and that are not primarily motivated by commercial concerns’ (Najam, 2000, p. 378); and (2) groups ‘that either deliver health interventions or lobby for change in policy

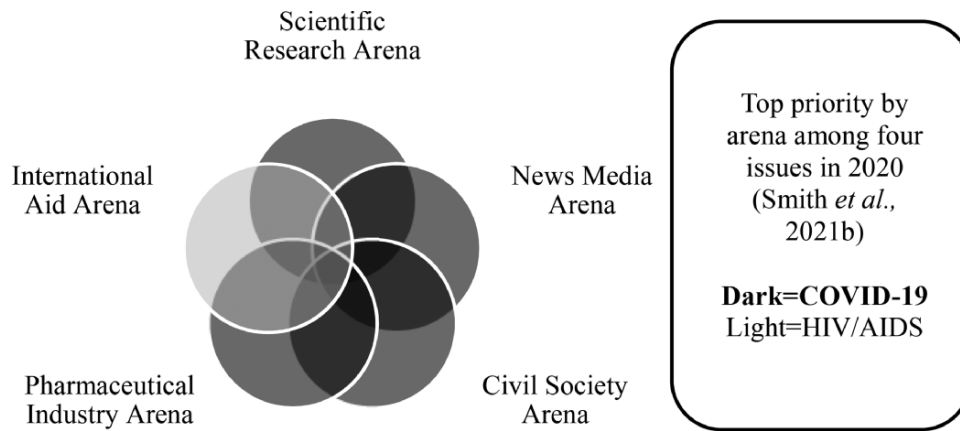


Figure 1. An arenas model for global health

to tackle global health problems' (Doyle and Patel, 2008, p. 1928; Smith *et al.*, 2016; Storeng and de Bengy Puyvallée, 2018; Smith, 2019; Smith *et al.*, 2021b). In this context, civil society typically refers to a wide range of organizational forms, including domestic and international CSOs, NGOs, social movements, professional and labour associations, transnational advocacy networks and faith-based organizations, among others. Featuring actors with diverse beliefs, interests (e.g. principled, financial) and positions on issues, civil society is not monolithic. Transparency in criteria for study inclusion and limits of representation are therefore essential, with segments of civil society typically the focus of study (Salamon, 1994; Doyle and Patel, 2008; Smith *et al.*, 2016; Storeng and de Bengy Puyvallée, 2018; Mitchell *et al.*, 2020).

Measurement of priorities in global health focuses on the kinds of resources allocated and commitments—stated, institutional and financial—demanded of and made by myriad actors to address problems (Shiffman and Smith, 2007; Shiffman *et al.*, 2010; Fox *et al.*, 2011; 2015; 2021; Bump *et al.*, 2013; Smith and Gorantla, 2021a, b). The concept of 'civil society priorities' was recently introduced as part of an arenas model for global health agenda setting, conceiving them as being comprised of the subjects to which such resources are being allocated at any given time and pointing to a need for more robust measurement (Smith *et al.*, 2021b). That study surveyed CSO programme and fundraising activities documented on organizational websites, comparing attention to four issues over two time-periods. Additionally, civil society representatives are often asked for their perceptions of the overall status of certain global health issues, and surveys are conducted to gauge priorities within issue-specific networks (Bump *et al.*, 2013; Copeland *et al.*, 2014; Smith and Shiffman, 2016). None of these approaches offers comparative insight across the full range of possible priorities or claims representation of civil society writ large, and such measures are difficult to track systematically and at scale. Recent scholarship on transnational digital advocacy suggests that publicly available social media data might be used to overcome some limitations of other measurement approaches (Hall *et al.*, 2020; Karpf, 2020).

This study draws on this scholarship, seeks expert insights to civil society priorities and the specific types of commitments that signal prioritization in the arena, and systematically analyses empirical evidence from CSO Tweets.

Methodology

Carried out in two stages, this study explores the concept and ways of identifying civil society priorities in global health and then pilots a novel approach to measuring them systematically, comparatively and over time. The first stage was informed by semi-structured interviews with a purposefully selected set of civil society actors with expert knowledge of global health agenda-setting dynamics (Table 1). Email invitations were extended to 40 individuals identified through the author's networks, snowball sampling and online searches undertaken to add insights from experts working on a diverse set of health issues and based in a range of world regions. Study recruitment ended when interviews no longer yielded new insights. A total of 23 informants participated in interviews; data from 2 were later excluded because they did not speak directly to the research questions. Informants ($n=21$) were based in South and South-east Asia ($n=6$), Sub-Saharan Africa ($n=5$), Central and South America ($n=3$) and North America ($n=7$). Nearly two-thirds held director-level positions ($n=13$), with others in programme management ($n=6$) and consulting positions ($n=2$).

Interviews lasting 58 min on average were conducted between April and August of 2021 via Zoom. Interview transcripts were coded thematically using MAXQDA2020 and analysed along the two lines of inquiry. Interview questions probed: (1) whether and how informants distinguish between civil society priorities and the broader global health agenda, checking for conceptual resonance of and specifications needed when measuring civil society priorities in global health; and (2) indicators informants used to assess an issue's priority level/agenda status (terms used interchangeably) in the civil society arena and more broadly, verifying sufficient distinction for independent analysis. Informants were asked to juxtapose their perceptions across the pre-pandemic era 2018–19 and the COVID-19 era 2020–21 for expanded insights and to increase the relevance of responses.

Based on insights from interviews and burgeoning research attention to transnational digital advocacy, the second stage of the study explored a way of analysing social media content for evidence of prioritization among a subset of CSOs (with 'CSO' encompassing various organizational forms) active in global health. Twitter is a forum in which CSOs invest resources to disseminate global health advocacy messages, share health promotion activities (e.g. reports, conferences, programmes,

Table 1. Expert informants

Interview #	Informant location	Position	CSO office and programme locations
1	USA	Program Director	Six continents; programmes in >50 countries
2	USA	Associate Director	Africa and Asia; offices in >5 countries
3	Kenya	Regional Director	Africa, Asia, Australia
4	USA	Associate Director	Five continents; >50 countries
5	Kenya	Project Director	Africa; >10 countries
6	USA	Associate Director	Six continents
7	Guatemala	Executive Director	Guatemala
8	USA	Senior Fellow	Africa, Asia, Latin America; >25 countries
9	USA	Senior Program Manager/Consultant	Africa, Asia, Latin America; >50 countries
10	South Africa	Program Coordinator	>15 Countries
11	Vietnam	Country Director	Four continents; focus South and Southeast Asia
12	Uganda	Executive Director	Uganda
13	Bolivia	Executive Director	Bolivia
14	India	Executive Director	India
15	Bangladesh	Regional Director	Four continents; focus South and Southeast Asia
16	Zambia	National Coordinator	>5 Countries
17	India	Director	India
18	USA	Senior Associate	Four continents; >50 countries
19	Nepal	Senior Research Advisor	Four continents; >20 countries
20	India	Consultant	India
21	Guatemala	Country Representative	Four continents; >50 countries

Summary of organizations' focal health issues (*n*)

Health systems (5); sexual and reproductive health (4); NCDs (3); communicable diseases, including HIV (3); nutrition (2); child and adolescent/youth health (2); gender (2); water (1); sanitation (1); cancer (1); mental health (1); family health (1); Universal Health Coverage (1); access to medicines (1)

webinars, campaigns) and call for commitments from others. The distribution of attention to health issues and resources indicative of prioritization was analysed in original Tweets posted by a subset of CSOs to (1) gain insights into their priorities for global health and (2) gauge the potential of such an approach to offer broader insights if applied to more representative data. Retweets and likes, indicators of Tweet impact, were excluded from the analysis.

A census was taken of three sets of purposefully selected (not representative) CSOs engaged in global health agenda setting, including: those holding official consultative status with the World Health Organization in 2020 (*n* = 137) ([World Health Organization, 2020](#)); provision of written inputs to the 2012 Health Global Consultation (*n* = 50) ([Task Team for the Global Thematic Consultation on Health in the Post-2015 Development Agenda, 2013](#)); and a set identified through analysis of global health research articles published in 2019 and 2020 (*n* = 20, from a review of 50 articles obtained using a Web of Science search for 'civil society' OR 'nongovernmental organization' OR 'nonprofit' OR 'non-profit' OR 'third sector' OR 'voluntary' OR 'NGO' OR 'transnational advocacy network' OR 'independent sector' AND 'global health' OR 'international health'). In all, 27 duplicates were removed, leaving *n* = 180. After removing 18 CSOs without active Twitter accounts, 4 CSOs with non-English language Twitter accounts and 8 CSOs that did not generate original Tweets during the study period, 150 CSOs met the inclusion criteria (a list with Twitter handles and original Tweet volume can be found in supplementary Appendix A, see online supplementary material). Approximately 83% of CSOs in the complete sample of 180 produced original Tweets during the study period.

Using a Twitter Academic account, usernames were entered into Social Feed Manager (a program that collects Twitter data) to begin harvesting each CSO's last

Table 2. Summary descriptive statistics for original Tweets of 150 CSOs

	3rd Quarter 2019	3rd Quarter 2020	Difference between periods
Original Tweets	7772	11 999	4227
Mean	51.81	79.99	28.18
Median	25.5	51	2.5
Mode	0	1	1
Range	0–311	0–508	0–508

~3200 Tweets (the maximum allowed by the program) in December of 2020 ([George Washington University Libraries, 2016](#)). Original Tweets were harvested from the third quarter (1 July to 30 September) of 2019 (*n* = 7772) and 2020 (*n* = 11 999)—substantial time periods straddling the pandemic onset. Summary descriptive statistics appear in [Table 2](#). Nearly all of the Tweets in both time periods (96%) reflect posting inclusive of the vast majority of CSOs selected for inclusion, with 86% posting in 2019 and 96% posting in 2020. The largest contributor posted ~4% of Tweets in each period while the mean contribution was ~0.66%—no single or small set of CSOs dominated.

The original Tweets were exported to Excel and then to MAXQDA2020 for thematic analysis of issues and resource commitments using Lexical Search and Word Frequency analysis tools. [Table 3](#) lists the issues and terms included in the Lexical Search, including those identified as civil society priorities in interviews alongside an expanded set of Sustainable Development Goals for Health and Well-being (SDG3) targets. Advanced Search in Excel was used to identify 'COVID' in segments of original Tweets gathered in the Lexical Search. Attention to global health issues (e.g. HIV/AIDS, gender-based violence, road traffic injuries) and not sentiment—whether

Table 3. Issues included in lexical search

SDG	Health issues	Lexical Search terms
2	Nutrition, food security, hunger	nutrition* OR food security* OR hunger* OR malnourish*
3.1	Maternal health	maternal* OR pregnan*
3.2	Child health	child* OR newborn* OR neonat* OR infant* OR adolescen*
3.4	Cancers	cancer*
3.3	Hepatitis	hepatitis*
3.3	HIV/AIDS	HIV*, AIDS* OR HIV/AIDS*
3.3	Malaria	malaria*
3.3	Neglected Tropical Diseases	NTD* OR tropical disease* OR tropicaldisease*
3.3	Tuberculosis	tuberculosis* OR tb*
3.4	Noncommunicable diseases and risks	NCD* OR noncommunicable*
3.4	Cardiovascular disease	cardiovascular* OR CVD* OR stroke*
3.4	Diabetes	Diabetes*
3.4	Mental health	Mental*
3.5	Alcohol use (harmful)	alcohol*
3.5	Narcotic drug abuse	narcotic* OR drugabuse* OR drug abuse*
3.6	Road traffic accident injuries and deaths	roadsafety* (no results for road traffic; traffic results for humans; injuries not road)
3.7	Sexual and reproductive health	sexual* OR reproduc* OR SRH* or SRHR* OR abortion* OR family plan* OR familyplan*
3.8	Universal Health Coverage	UHC* OR Universal Health Coverage
3.9	Pollution or contamination (air, water, soil)	pollut* OR contaminat* OR water
3.A	Tobacco control	tobacco*
3.B	Vaccines	vaccine*
3.B	Medicines	medicine*
3.D	Global health security	healthsecurity* OR health security* OR pandemicprep* OR pandemic prep*
5	Social equity (gender)	gender*
5.2	Gender-based and other violence	gender-based violence* OR GBV* OR violence*
13	Climate change	climate*
Not applicable	Social determinants of health	socialdeterminant* OR social determinant* OR SDH*
Not applicable	COVID-19/Coronavirus	COVID* OR Coronavirus*

Notes: In the health issues column, bold text is used for issues identified in interviews and plain text for an expanded set of SDG3 targets. Issues represented in between 1.5% and 35% of Tweets (Lexical Search results) in the 2019 and 2020 Tweet samples are highlighted in grey. Health systems issues were identified in interviews, but not included in the Lexical Search due to measurement difficulties related to the issue's complexity.

supportive or detracting—was analysed (Kingdon, 1995; Dowding *et al.*, 2016).

The analysis of Tweets shows which issues and types of resource commitments a subset of CSOs highly engaged in global health posted about on Twitter during the third quarters of 2019 and 2020. The findings are not generalizable to

civil society writ large, but represent trending issues among a specific group of CSOs. Regional representation, variation in social media use, and the influence or impacts of Tweets were not analysed. Nonetheless, the analysis helps to overcome limitations of individual knowledge and recall bias inherent to interviews and surveys, covers a substantial time period and helps to build a platform for the systematic study of civil society priorities in global health.

Findings

Findings are organized by research stage, beginning with expert informant reflections on conceptual issues and perceptions of civil society priorities and status indicators in relationship to the global health agenda more broadly, showing that they distinguish between the respective (if overlapping) agendas. Findings from the thematic analysis of CSO Tweets follow, highlighting issues identified in interviews and a broader set of health issues and types of resources most frequently Tweeted about by a subset of CSOs during the third quarters of 2019 and 2020.

Stage 1: expert insights into concepts, priorities and status indicators

Asked to identify civil society's top priorities for global health and the main indicators they used to rank issues highly, participants reported on several of each. Many also addressed conceptual issues regarding scope (local to global) and interest (e.g. principled, financial) dynamics surrounding civil society. Informants used an average of 3.8 different constructs (range 1–6) to frame civil society. They portrayed civil society as being comprised of national, regional and broader international movements ($n = 14$ interviews), CSOs ($n = 19$) and NGO networks ($n = 20$), with most using the terms interchangeably. Some also portrayed civil society as being comprised of grassroots ($n = 9$) and community-based ($n = 5$) organizations and families ($n = 1$).

Sixteen participants observed relationships between the priorities of civil society groups and interests that often overlap with those of other actors and arenas. Eleven linked civil society priorities with principled interests (Interviews 1, 3, 5, 7, 8, 9, 10, 12, 15, 17, 19).

They observed

'genuine commitment to an issue' (Interview 15, Bangladesh),
'the true problems' (Interview 12, Uganda), and
'more of a human rights, equity, inclusiveness perspective' (Interview 8, USA).

Another offered that

'...when we talk to CSOs or CBOs in those regions [with poor health indicators], for them, healthcare becomes more important than the global health priorities' (Interview 17, India).

Ten participants observed strong orientation to organizations' financial interests, noting dependence on international donors (Interviews 3, 6, 9, 10, 11, 12, 15, 17, 19, 21). Some informants based in South Asia and Sub-Saharan Africa observed pressure to align with national government priorities (Interviews 11, 12, 16, 19). One said, for instance,

'...no matter what, the COVID-19 is the priority for the government. So if you don't talk about that or if you not make it your own organization activities, the government not listen to you.... So even [if] we are working for noncommunicable diseases, we still have mentioned about COVID-19 somehow in some way' (Interview 11, Vietnam).

Three participants (Interviews 3, 19, 20) observed the power of global agendas, noting, for example,

'...every CSO they have their own priority, but I think somehow it is related to SDGs because this is where there is a declaration from UN as well. So I think everybody would like to be in that perspective to achieve those components' (Interview 20, India).

Variation in scope and interests among CSOs was noted as participants observed a wide range of civil society priorities for global health. During the pre-pandemic period, they most frequently reported social equity and determinants of health ($n=8$) as being top civil society priorities, followed by health systems ($n=6$), gender-based and other violence ($n=5$) and, with four reports each, child health, noncommunicable diseases (NCDs)/chronic care, and, collectively, HIV/AIDS, tuberculosis or malaria. During the pandemic

era, reporting on coronavirus/COVID-19 ($n=16$, up from $n=0$) and mental health ($n=6$, up from $n=1$) surged, while reporting on nine other issues declined.

Showing that participants meaningfully distinguished narrower civil society priorities from the broader global health agenda, perceptions of the latter clustered around a smaller and differing set of issues pre-pandemic (Figure 2). Pre-pandemic, NCDs and chronic care ($n=10$) were most frequently identified, followed by HIV/AIDS, tuberculosis and malaria ($n=9$), child health ($n=8$), health systems ($n=8$) and sexual, reproductive and maternal health ($n=7$). During the pandemic period, COVID-19 was nearly universally identified ($n=18$). Reporting on mental health ($n=10$) and social equity and determinants of health ($n=6$) as top issues increased significantly, while reporting on several others declined sharply between the time periods. Responses showed less alignment between civil society priorities and the broader global health agenda before the pandemic compared to the later period.

Also showing that the concept of civil society priorities in global health resonated, informants identified several indicators thereof. They most frequently pointed to the focus of the work of CSOs, NGOs and social movements ($n=8$), and more specific advocacy campaigns ($n=5$), monitoring and accountability activities ($n=4$), and social media themes ($n=3$). A country representative of a large transnational CSO offered an example and then explained,

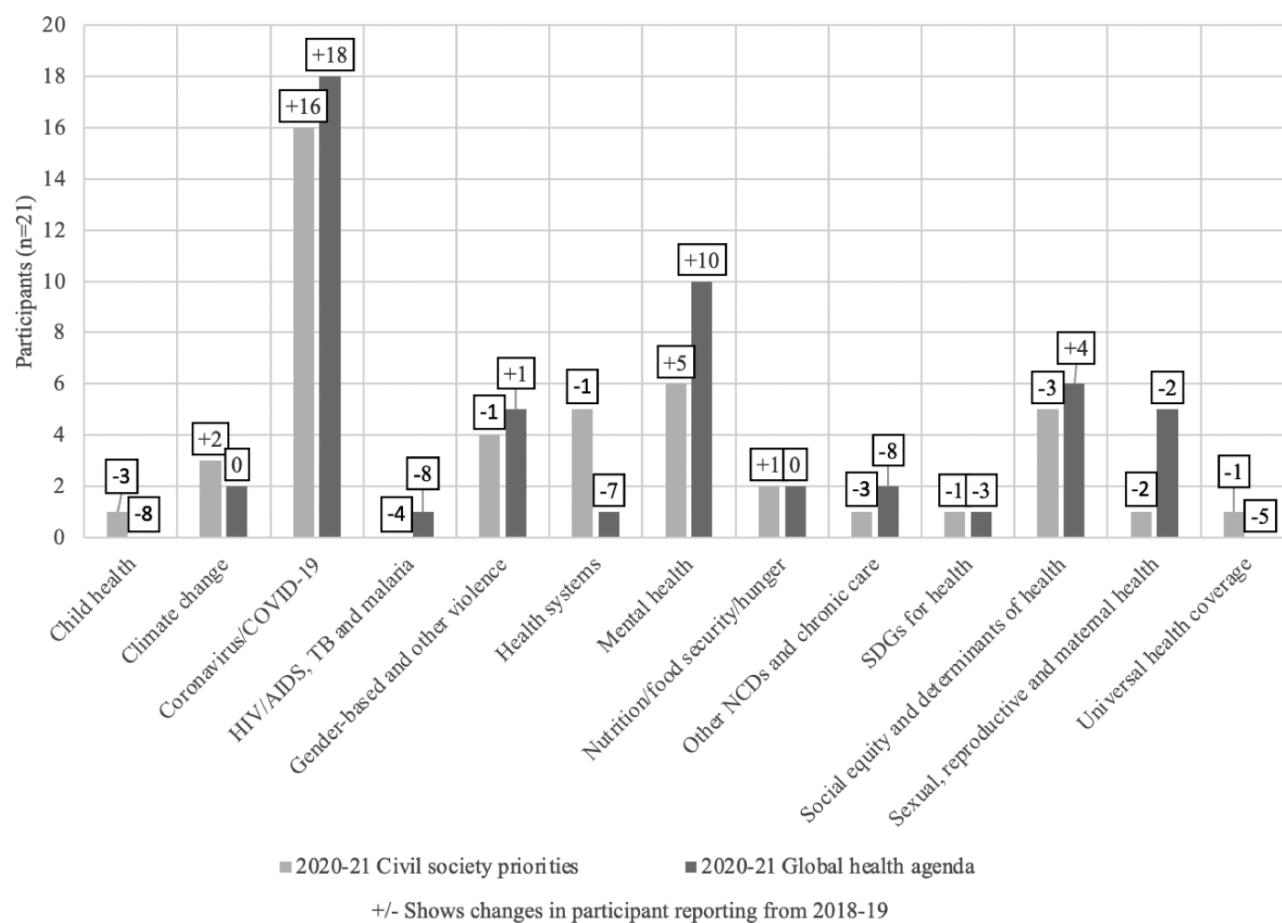


Figure 2. Informant perceptions of top civil society and broader global health priorities

‘...it’s up to civil society to then go and do the shadow reports and have their own spaces and advocate and say this is what’s really happening’ (Interview 21, Guatemala).

Others pointed to social media as a source of data on accountability and advocacy activities, stating:

‘...now, you have, of course, different types of media, including social media, just to highlight those issues and also to highlight those issues with evidence.... And so we also now directly—civil society is now able to advocate for actions to curb some of those issues’ (Interview 16, Zambia).

A Senior Program Manager observed

‘...dialogue on social media platforms that include what people are doing, what people are calling for’ (Interview 9, USA).

Participants also noted webinar topics, demonstrations, calls to action and conference themes ($n=1$ each). None reported specifically on financial resource commitments, although budgets support CSO activities.

By contrast, when participants were asked to identify the main indicators they used to rank issues high on the broader global health agenda, more than three quarters ($n=16$) identified commitments of financial resources. A quarter noted institutional commitments like monitoring, evaluation and reporting activities ($n=3$) and the focus of work for counterparts in other organizations ($n=2$, both pre-pandemic). They also identified topics of global conventions, declarations and goals ($n=5$) and larger-scale international meetings, primarily conferences, workshops and consultations ($n=6$, all pre-pandemic).

Topics of conversations occurring in myriad venues and with various stakeholders were also widely reported ($n=10$). For instance, an Executive Director (Interview 14, India) observed

‘national and global level conversations’.

A Senior Associate at another CSO summarized,

‘...Knowing what’s on the global health agenda is really about...everything from the people I follow on Twitter to the meetings I attend that are talking about global challenges’ (Interview 18, USA).

Others spoke about direct and indirect conversations (including those held via social and traditional media, newsletters, webinars, etc.) with and among donors, governments, foundations, colleagues, CSOs and other key stakeholders (Interviews 6, 8, 10, 11, 15).

Stage 2: health priorities and status indicator representation in CSOTweets

Lexical Searches of the original Tweets of 150 CSOs engaged in global health agenda setting covered 28 issues identified in interviews, including an expanded set of SDG3 targets (Table 3; Figure 3). Only four issues approached or

exceeded 5% share of all original Tweets in either time period. Tweets on three of these issues, including child health, sexual and reproductive health and HIV/AIDS, declined in 2020 as each came to share the spotlight with ascendent COVID-19 in 25–30% of Tweets. COVID-19 was explicitly represented in one-third of all Tweets in the 2020 sample, up from no mention of coronaviruses in the 2019 sample. Among the 16 issues identified in a threshold of 1.5% or more Tweets in either period (grey highlights in Table 3), only three issues other than coronavirus/COVID-19 specifically increased in representation, including nutrition/food security, hepatitis and vaccines. In all, 12 of the 28 issues identified as civil society priorities in interviews and SDG targets failed to gain >1.5% share in either time period (without highlights in Table 3).

The Word Frequency analysis revealed attention to a much broader range of issues. Figure 4 shows the 30 health issue terms with the largest proportional representation in the 2019 and 2020 samples. A total of 12 new issue terms reached the top 30 in 2020, bringing the total to 42 top tier health issue terms. Of those new to the 2020 list, 7 were related to the pandemic (#covid19, covid-19, coronavirus, #coronavirus, mask, pandemic, vaccine), 2 to Alzheimer’s disease, and 1 each to violence, vision and disability. Only 5 issue terms exceeded 5% share of all Tweets in either sample, including #covid19 (largest at 24%), health, pandemic, child and covid-19; of these, only health and child appeared in the 2019 sample—when they were the two most highly represented terms at 14 and 7%, respectively. Representation declined for more than half (62%) of the 42 top tier issue terms between the two periods. Overall, issue representation changed incrementally (by an absolute difference of 0.1 to 3.2%) between the two periods for most issues—only covid-19, pandemic and #covid19 changed substantially (by an absolute difference of >5%). Lexical Searches on the terms identified through Word Frequency analysis show: (1) the seven pandemic-related terms appeared in 36% of all Tweets in the 2020 sample; and (2) the top 30 issues appeared in 54 and 66% of all Tweets in the 2019 and 2020 samples, respectively.

Hashtags (#), flagged keywords that help people follow and show support for topics on Twitter (n.d.), were well represented among the top 30 issues in both time periods. Six of the 12 hashtags that made the top 30 issues list in 2019 showed evidence of commitment via advocacy campaign messages, including three promoted by the Global Fund Advocates Network (n.d.) to call for action on HIV/AIDS, tuberculosis and malaria (#stepupthefight, #endtheepidemics and #getbackontrack). At least three others were promoted via advocacy campaigns, including #worldhepatitisday, #healthforall and #visionfirst (International Diabetes Federation, 2019; UHC 2030, n.d.; World Hepatitis Alliance, n.d.). Of the other 6 hashtags, some featured framing consistent with topic indexing (e.g. #hiv and #diabetes) and some advocacy that was more difficult to link with a specific campaign (e.g. #srhr [sexual and reproductive health rights]). In 2020, only 7 hashtags made the list—the top 2 hashtags were newly created #covid19 (featured in 24% of Tweets) and #coronavirus (2%), followed by diminishing shares to each of #hiv, #worldhepatitisday, #globalhealth, #endalz (end Alzheimer’s Disease) and #srhr.

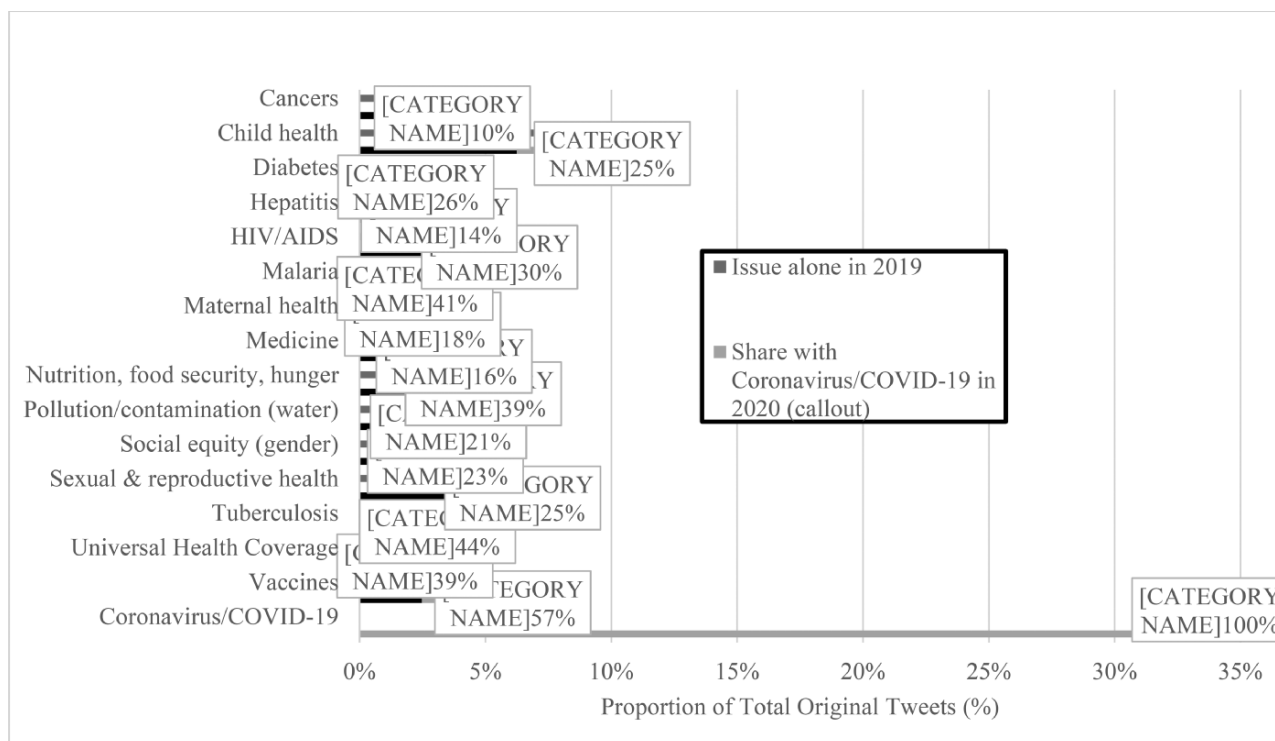


Figure 3. Lexical Search results for health issues identified in interviews and SDGs

Tweets were also analysed for use of terms reflecting the kinds of rhetorical, institutional and financial resource commitments that scholarship and study informants suggest are indicative of prioritization (Fox *et al.*, 2011; 2015; 2021). Word Frequency analysis shows that such resources were major topics of the 150 CSOs' original Tweets in both time periods (Figure 5). Use of such terms is understood to include self-reported attention and resource allocations, commitments made by others, and calls for others to act. In the 2019 sample, the top five terms included 'work, help, support, report and research'. In 2020, 'webinar and service' entered the top five alongside 'help, work and support'—all increased in proportional representation over the same quarter in 2019. Among the 30 most frequently used resource commitment terms, 24 appear on both lists. Six on the list in 2019 fell out of the top 30 in 2020, with 'investment' declining most steeply (by >80% to 0.62%). Two terms that increased 5-fold in representation ('webinar' and 'respond'), along with 'worker' (up from 1.4% to 2.5%), 'session' (up from 1.5% to 2%), 'launch' (stable at 1.5%) and 'supply' (tripled to 1.5%) ascended to the top 30 in 2020.

The top 35 resource terms (excluding 'call', which requires contextual analysis) were run through Lexical Searches of Tweets and interviews to better assess their overall representation in the datasets. The terms were used in all 21 interviews, and were used collectively 2814 times—an average of 134 times per interview, including by the interviewer and informants. The resource terms featured comparable representation in the 2019 and 2020 Tweet samples at 63 and 64%, respectively. Collectively, they appeared 8417 times in 2019 and 13 324 times in 2020. In sum, the types of resource terms considered indicative of priority were major topics of interviews and Tweets.

Discussion

This study explores and refines concepts and approaches to analysing civil society priorities in global health. The first stage of the study provides support for the concept of civil society priorities, suggesting that while they may overlap those in other stakeholder arenas, they are not one and the same and may be observed and measured. The second stage of the study builds on insights from expert informants and recent research on transnational digital advocacy, showing that analysis of publicly accessible social media content offers a pathway to systematic measurement of priorities among civil society actors in global health. The analysis shows how Tweets by a specific group of CSOs about global health issues and resource commitments differed between the third quarters of 2019 and 2020, reflecting impacts of the COVID-19 pandemic focusing event and other dynamics.

The first stage of the study asked experts based in diverse world regions which global health issues they perceived to be on the agenda in the civil society arena and more broadly just prior to and during the first ~18 months of the pandemic. Did they distinguish between them? And how did they know? Conceptualizing civil society primarily in organizational terms and recognizing priorities as being shaped by principled, financial and existential interests, they reported that COVID-19 rose precipitously in both contexts during 2020–21. There was more variation in the immediate pre-pandemic period when perceptions of civil society priority for social and health systems issues contrasted with reports of broader priority for NCDs and Global Fund diseases (Figure 2). In sum, organized civil society priorities in global health often overlap but may also be meaningfully distinguished from those set in other arenas.

2019			Top Health Issues	2020		
Percent Tweets	Rank	Terms		Terms	Rank	Percent Tweets
14.2%	1	health	#covid19	1	24.4%	
7.0%	2	child	health	2	13.5%	
3.9%	3	disease	pandemic	3	7.4%	
3.6%	4	[at]globalfund	child	4	6.8%	
3.0%	5	#stepupthefight	covid-19	5	5.8%	
2.7%	6	#endtheepidemics	disease	6	3.7%	
2.5%	7	#getbackontrack	risk	7	3.5%	
2.4%	8	#hiv	vaccine	8	3.1%	
2.2%	9	treatment	food	9	2.9%	
2.1%	10	#globalhealth	treatment	10	2.2%	
2.1%	11	risk	alzheimer	11	1.9%	
2.1%	12	medicine	#coronavirus	12	1.9%	
2.0%	13	#uhc	eye	13	1.7%	
1.9%	14	#worldhepatitisday	#hiv	14	1.7%	
1.9%	15	gender	water	15	1.6%	
1.8%	16	abortion	#worldhepatitisday	16	1.6%	
1.8%	17	cancer	#globalhealth	17	1.5%	
1.8%	18	water	violence	18	1.4%	
1.7%	19	hiv	nutrition	19	1.3%	
1.7%	20	#srhr	vision	20	1.3%	
1.7%	21	#healthforall	reproductive	21	1.3%	
1.5%	22	nutrition	mask	22	1.2%	
1.5%	23	#diabetes	hiv	23	1.2%	
1.4%	24	food	abortion	24	1.2%	
1.4%	25	sexual	#endalz	25	1.2%	
1.4%	26	reproductive	disability	26	1.1%	
1.3%	27	eye	#srhr	27	1.0%	
1.3%	28	#genderequality	cancer	28	1.0%	
1.3%	29	pregnancy	sexual	29	1.0%	
1.1%	30	#visionfirst	coronavirus	30	0.9%	

Note: Gray highlights show which issues moved up in rank in 2020. Bold shows which terms were not in the top 30 in the other sample.

Figure 4. Word Frequency analysis results: top health issues appearing in CSO Tweets

An arenas model for global health agenda setting posits that status is conveyed by specific types of resource allocations, and informants differentiated civil society on this point, as well. They emphasized the work national, regional and transnational civil society organizations do—civil society priorities are distinguished by action, including advocacy, programme, and monitoring and accountability activities. In contrast, perceptions of status on the broader global health agenda were most widely informed by financial resource allocations and conversations observed in myriad venues, including meetings and social media.

The second stage of the study explores social media as a potential avenue to advance large-scale and systematic measurement of civil society priorities for global health as expressed in original Tweets, extending beyond perceptions that are subject to positional and recall bias. Three issues stood out for representation in ~5 to 9% share of original Tweets by the 150 CSOs in either time period in lexical searches on interview topics and an expanded set of SDG targets, including child health, sexual and reproductive health, and HIV/AIDS. Coronaviruses rose from no mention in 2019 to explicit representation in one-third of all Tweets in 2020,

2019			Top Resource Commitments	2020		
Percent Tweets	Rank	Terms		Terms	Rank	Percent Tweets
9.4%	1	work	help	1	9.5%	
8.4%	2	help	work	2	9.1%	
6.4%	3	support	support	3	8.6%	
4.3%	4	report	webinar	4	4.9%	
3.8%	5	research	service	5	4.4%	
3.5%	6	policy	provide	6	4.3%	
3.4%	7	service	research	7	4.2%	
3.3%	8	investment	report	8	4.1%	
3.3%	9	program	action	9	2.8%	
2.9%	10	event	policy	10	2.7%	
2.8%	11	provide	resource	11	2.6%	
2.5%	12	fund	worker	12	2.5%	
2.4%	13	article	event	13	2.2%	
2.4%	14	study	program	14	2.2%	
2.4%	15	call (to action)*	system	15	2.2%	
2.3%	16	news	study	16	2.2%	
2.3%	17	project	session	17	2.0%	
2.0%	18	review	project	18	2.0%	
2.0%	19	plan	call (to action)*	19	2.0%	
2.0%	20	evidence	programme	20	1.9%	
2.0%	21	action	fund	21	1.9%	
2.0%	22	programme	build	22	1.9%	
1.9%	23	resource	train	23	1.8%	
1.9%	24	leader	plan	24	1.6%	
1.8%	25	system	leader	25	1.5%	
1.8%	26	conference	launch	26	1.5%	
1.8%	27	build	supply	27	1.5%	
1.7%	28	talk	respond	28	1.5%	
1.7%	29	information	news	29	1.5%	
1.7%	30	train	information	30	1.5%	

Notes: Gray highlights show which issues moved up in rank in 2020. Bold shows which terms were not in the top 30 in the other sample. *A statistically significant (.95 CI) sample of results for 'call' was analyzed to determine proportional representation of 'call to action' versus other uses of the word 'call'.

Figure 5. Word Frequency analysis results: top resource commitments appearing in CSO Tweets

a punctuation reflecting effects of the COVID-19 pandemic focusing event (Baumgartner and Jones, 1993; Birkland, 1997; Smith et al., 2021b).

A more expansive Word Frequency analysis largely echoed interview and Lexical Search findings, but revealed increasing levels of attention from the CSOs to three previously unidentified issues: Alzheimer’s disease, disability and violence.

The broader set of issues is likely due to the larger and particular composition of the group of CSOs in the Twitter analysis compared to interviews (which are also limited by issues of incomplete knowledge and recall bias). The increase in attention to Alzheimer’s disease is likely due to a nearly 20-fold increase in messaging by Alzheimer’s Disease International, which contributed nearly 2.6% of all Tweets in the 2020

sample. The increase on the topic of violence may reflect efforts of the network UN Women leveraged to combat violence against women during the pandemic (Mintrom and True, 2022). Reasons for increasing attention to other issues in the set of Tweets at a time when COVID-19 appeared to crowd out several others—18 of the top 30 issues in 2019 declined in relative status during 2020, with at least 7 displaced by pandemic terms—are ripe for further investigation (Figure 4).

The Word Frequency analysis showed that child health remained among the top topics of original Tweets (~7% in both periods) among the subset of CSOs, with #covid19 surging in 2020—the singular hashtag appeared in 24% of all Tweets in the quarter. Overall, the top 30 global health issue terms appeared in >50% of all Tweets in each respective time period. This clustering likely reflects limited carrying capacity and fierce competition in the arena for finite reservoirs of attention and resources (Hilgartner and Bosk, 1988). Results of the Word Frequency analysis mirror the kind of stability and dramatic shifts that Baumgartner and Jones (1993) theorized for government agendas, but they are observed in a new (sub)arena.

Widespread social media messaging on the top 35 resource commitment terms (appearing in >60% of Tweets during both time periods) shows that this subset of CSOs used Twitter to report on and call for action on global health issues, suggesting the platform is a potentially rich source of readily accessible data on civil society priorities in global health. The representation of resource commitment terms in Tweets remained largely stable, with 25 of the top 30 terms consistent between time periods. The two lists of top terms reflect some changes during the COVID-19 era, however. The rise of ‘webinar’ is not surprising given recent technological advances and pandemic-era restrictions on gathering, but the precipitous declines of ‘investment’ and ‘evidence’ are surprising—reasons for stability and change are important topics for future investigation.

Conclusion

Global health agenda setting scholarship has long sought to explain the rise, fall and staying power of issues, but use of a model to specify in which arenas these dynamics occur and who commits which kinds of attention and resources has only recently emerged. Based upon expert insights and thematic analysis of nearly 20 000 CSO Tweets posted before and during one of the most consequential crises of the past century, this study offers new insights into civil society priorities in global health and ways in which they might be identified and systematically measured among relevant (and specified) subsets of actors.

The study advances the systematic measurement of a wide range of civil society priorities in global health over time as expressed in original Tweets that report on and call for various kinds of resource commitments. It shows that among a subset of CSOs attention to the novel coronavirus soared while it held relatively steady for most other health issues between 2019 and 2020. The study’s findings are consistent with punctuated equilibrium theory (Baumgartner and Jones, 1993), but applied within a new arena. Though the study does not engage in causal analysis, COVID-19’s presence in a large proportion of Tweets in 2020 alongside widespread if incremental

declines in attention to other issues hints at possible crowding out effects. Increasing attention to violence may reflect crowding in effects fuelled by the pandemic and a widely supported advocacy campaign aimed at reducing violence against women (Mintrom and True, 2022).

It is vital that the potential of this approach to analysing civil society priorities in global health be further investigated (e.g. How closely do priorities expressed via Twitter and other social media platforms track with institutional and budgetary commitments?) and refined (e.g. improving representation of civil society and using machine learning tools to analyse meaning and sentiment). This analysis offers preliminary proof of concept among a relatively limited set of high-capacity transnational CSOs. Future research should analyse agenda setting dynamics and outcomes among meaningful segments of civil society that may be defined by geography, political context, network membership and other criteria. Doing so promises to advance measurement of emerging, sustained and evolving civil society priorities in global health.

Supplementary data

Supplementary data is available at *Health Policy and Planning* online.

Data availability

The Twitter IDs and organization names associated with Tweets studied are available in Appendix A in the online supplementary material. Requests for additional information may be subject to review by Twitter.

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Author contributions

S.L.S. conceived and designed the study, collected and analyzed data, drafted and revised the article, and approved the final submitted version.

Reflexivity statement

I acknowledge my position as a US-based academic who conducts health policy analysis research at international, national and sub-national levels, with a focus on neglected problems and low- and middle-income countries. Throughout this study, I drew on my expertise and strove to set aside assumptions and to invite and elevate under-represented perspectives from civil society.

Ethical approval. The Institutional Review Board at Virginia Tech granted this study exempt status (#20-588).

Conflict of interest. None declared.

Authorship statement

This article is single-authored by a researcher at an institution based in a high-income country. The research is conducted in the macro-level global health agenda setting context.

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