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Building citizen science intelligence for outbreak preparedness and response: a mixed-method study in nine countries to assess knowledge, readiness and feasibility

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ABSTRACT

Introduction Citizen science (CS) is an emerging approach in public health to harness the collective intelligence of individuals to augment traditional scientific efforts. However, citizens' viewpoint, especially the hard-to-reach population, is lacking in current outbreak-related literature. We aim to understand the awareness, readiness and feasibility of outbreak-related CS, including digitally enabled CS, in low-income and middle-income countries.

Methods This mixed-method study was conducted in nine countries between October 2022 and June 2023. Recruitment through civil society targeted the general population, marginalised/indigenous groups, youth and community health workers. Participants (aged ≥18 years) completed a quantitative survey, and a subset participated in focus group discussions (FGDs).

Results 2912 participants completed the survey and 4 FGDs were conducted in each country. Incorporating participants' perspectives, CS is defined as the practice of active public participation, collaboration and communication in all aspects of scientific research to increase public knowledge, create awareness, build trust and facilitate information flow between citizens, governments and scientists. In Bangladesh, Indonesia, the Philippines, Cameroon and Kenya, majority were unaware of outbreak-related CS. In India and Uganda, majority were aware but unengaged, while in Nepal and Zimbabwe, majority participated in CS before. Engagement approaches should consider different social and cultural contexts, while addressing incentivisation, attitudes and practicality factors. Overall, 76.0% expressed interest in digital CS but needed training to build skills and confidence. Digital CS was perceived as convenient, safer for outbreak-related activities and producing better quality and quantity of data. However, there were concerns over non-inclusion of certain groups, data security and unclear communication.

Conclusion CS interventions need to be relatable and address context-specific factors influencing CS

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Literature on citizen science for outbreak preparedness and response mostly looked at the activities that citizens were engaged in, with less focus on the readiness and perceptions of people on citizen science.

⇒ Digital technologies has shown promise to overcome challenges faced by traditional participatory approaches; however, there is limited evidence on the readiness of communities to participate in citizen science activities, including using digital means, especially in low-income and middle-income countries (LMICs) and among hard-to-reach population.

WHAT THIS STUDY ADDS

⇒ Our findings showed that most people were unaware of citizen science and were at the lowest stage of readiness to participate in citizen science activities; however, majority were interested to participate in future citizen science activities, enabled by digital tools.

⇒ Addressing the identified barriers under cultural, social, incentivisation, attitudes and practicality factors can enable sustained citizen engagement.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Findings on context-specific factors influencing CS participation can inform policymakers and researchers when planning citizen science efforts, particularly in LMICs.

⇒ The recommendations provided can help guide civil societies in raising awareness among local communities.

⇒ Future research can investigate the proposed structured approach to advance people along the stages of readiness to participate in outbreak-related citizen science activities.

participation. Digital CS has the potential to facilitate collaboration, but capacity and access issues must be considered to ensure inclusive and sustainable engagement.

INTRODUCTION

Historically, citizen science (CS) has been widely used in environment and natural sciences.[1–3] In health, it has been increasingly used to harness the collective intelligence of individuals to augment traditional scientific efforts. Participatory approaches have proven key to effective responses in epidemics such as HIV, tuberculosis and malaria, as well as in dealing with public health issues such as chronic disease prevention, and health promotion.[4–8] We define CS as the practice of public participation and collaboration in all aspects of scientific research to increase knowledge and build trust between citizens, policymakers and researchers.[9] This involvement and empowerment of citizens beyond traditional top-down methodologies catalyses a collaborative and reciprocal relationship between stakeholders. By advocating for inclusion of all voices, CS can create more resilient and interconnected societies, better equipped to tackle global health crises such as outbreaks.[10 11]

However, current citizen engagement efforts lack continuity with citizens left out of key processes. Taking COVID-19 as an example, literature suggests that citizens were mostly engaged in data generation, with limited involvement in other aspects of research such as problem definition, data interpretation and dissemination.[9 12 13] As past outbreaks have demonstrated, this undermines mutual trust between citizens, researchers and policymakers, resulting in decreased willingness of citizens to follow public health guidelines.[14–16] It is thus important to emphasise that CS is not merely about data provision, citizens need to be seen as essential active participants across the full spectrum of research in a complex health information environment.[17–20]

To date, majority of CS research, especially for outbreak preparedness and response has been done in high-income countries with limited knowledge in low-income and middle-income countries (LMICs).[9] Furthermore, CS projects tend to reach volunteers with capacity and access needed to participate, potentially leaving out hard-to-reach populations such as marginalised/indigenous groups, and the less educated.[21] We need to shift the paradigm towards more inclusive, comprehensive and sustainable citizen engagement approaches that can facilitate bidirectional communication, and shared learning towards a collective knowledge base. One potential tool to leverage is digital-based participatory systems, which accelerated during COVID-19 and have shown promise in engaging stakeholders in new domains such as participatory modelling and data analysis.[22–26] However, challenges such as systemic digital inequity must be addressed before we can harness the full potential of digital CS.

Before implementing and scaling CS, it is crucial to first understand the perceptions and readiness of people as their voices are lacking in current outbreak-related literature. Our study focused on communities in LMICs, with an attempt to include hard-to-reach populations such as marginalised/indigenous groups. Our research questions were 'What is the level of awareness and readiness of local communities to participate in CS activities?' and "How can we facilitate CS participation in different geographies and cultural contexts?" Specific objectives include to assess: (i) awareness, relatability and knowledge of CS; (ii) level of readiness to participate in outbreak-related CS and (iii) perceived factors, including digital means, that influence CS participation.

METHODS

Study design

This mixed-method study was conducted in nine countries (India, Bangladesh, Nepal, the Philippines, Indonesia, Cameroon, Zimbabwe, Uganda, Kenya) between October 2022 and June 2023. Participants were aged ≥18 years, provided informed consent and conversant in English or any of the local languages. Recruitment for the survey was through digital platforms such as WhatsApp, or in-person visits to households, workplaces or schools by civil society representatives. Stratified sampling ensured representation in the general population, marginalised/indigenous groups, youth and community health workers (CHWs). Marginalised group included people who are marginalised either because of their medical status (eg, people living with HIV, tuberculosis) or because of socioeconomic factors. Indigenous group included people with distinct social or cultural backgrounds. To protect the anonymity of these groups, we did not collect demographics data pertaining to their status. Participants for the subsequent focus group discussions (FGDs) were randomly sampled from those who took part in the survey and consented to future research.

Study procedures

Eligible individuals completed a quantitative survey to assess awareness, knowledge, readiness and feasibility of outbreak-related CS (online supplemental file pp 2–6). Questions were based on the precaution adoption process model (PAPM) and the theory of planned behaviour (TPB). The PAPM is used to understand the decision-making process leading to action or inaction by exploring the stages of decision-making, while the TPB seeks to explain behaviours over which people have the ability to exert self-control.[27 28] More details on the frameworks can be found in online supplemental file p7. As CS was new to most participants, video/infographics were used to introduce our CS concept to participants after an initial set of questions on demographics and awareness (online supplemental file p8). All FGDs were conducted by trained team members in a setting that is comfortable for participants. The FGDs explored factors influencing

people's participation in CS activities, and their perspectives when comparing between analogue and digital methods of CS. A semi-structured FGD guide was developed using findings from the survey and literature, and pilot tested by local teams (online supplemental file p9). A sequential mixed-methods design allowed the qualitative data to provide an in-depth understanding of the quantitative findings. All study materials were translated, and procedures were conducted in either English or the local languages.

Data analysis

To detect a CS participation rate of 70% at 0.05 alpha level and 80% power, we recruited at least 280 participants from each country. We performed descriptive analysis of participant characteristics. Free-form text coding was used to analyse CS phrases described by participants. To evaluate readiness of individuals to participate in CS, we categorised them into respective PAPM stages based on their responses. We used a proportional odds ordinal logistic regression model to investigate the association of different variables with participants' readiness stage per country.[29] OR were computed, and 95% CIs were calculated using Wald tests. Overall p values per variable and country were derived using likelihood ratio tests. All statistical analysis was done using R. We also summarised the perceived factors influencing CS participation, and participants' interest and capacity to participate in digital CS.

In each country, four FGDs (six–eight participants per FGD) were conducted for the groups of general population, youth, marginalised/indigenous groups and CHWs based on substantiated number for data saturation. FGDs were audio recorded, transcribed verbatim and translated to English. Initial discussions were held with all countries to standardise a data extraction template used for coding and extraction of themes. Each country independently coded their own transcripts using thematic analysis and held regular meetings to discuss new codes and resolve disagreements. Essential themes from each country were charted into a matrix to allow comparison across countries.

Patient and public involvement

Civil society representatives were involved in identifying the research gaps, and in the conceptualisation and design of this study. Local communities were involved in the mobilisation and data collection stage. Results were shared in global and local conferences, with plans to disseminate among the communities using formats understandable by the local people.

RESULTS

Of the 2994 people who expressed interest in participating, 2912 (97.3%) completed the survey, with the rest either below eligible age or unable to provide consent. Majority of the survey were completed in-person (77.5%). Table 1 provides a summary of the survey participants' characteristics. Overall, majority of the participants were female (52.5%), median age of 30 years (IQR 22–43), with secondary school education (40·9%), married and/or living with partner (48.0%), employed (44.7%), living in rural area (44.2%) and with smartphone (69.6%) and internet access (71.1%).

CS definition

Prior to introducing our CS concept, 80.8% of participants have never heard of CS. When asked to name three CS-related phrases, 13.0% of the responses were 'never heard' or "I don't know". After introducing CS, 44.0% of the total participants said they have ever participated in outbreak-related CS, and 43.9% knew how to join and contribute to CS projects. Top three channels through which they obtain CS information were social media (62.1%), traditional media (61.1%) and word-of-mouth from family and friends (45.3%).

Figure 1 compares our initial definition of CS with the participants' understanding. Three main stakeholder groups were mentioned, with 'community' and 'government' being common while participants preferred 'scientists' over 'researchers'. When describing CS processes, both parties highlighted the importance of active participation and collaboration, citing data collection and analysis and communication as examples. Participants saw themselves playing assisting roles to scientists, highlighting their involvement in surveys, while we emphasised co-creation in all aspects of research beyond just survey. Several participants used phrases related to training and learning new skills whereas we believe that anyone can participate in CS without any scientific background. Although both parties mentioned knowledge gain as an outcome, participants viewed it as unidirectional knowledge flow from experts to communities, while we see the public as equal contributors of knowledge and experience. Participants also mentioned improved health and well-being as an important outcome through creating awareness and education. While we see trust-building as important, very few participants mentioned trust. In addition, participants saw CS as being applicable for topics such as biology, chemistry, public health, social science, pandemic, infectious diseases, environment, sanitation and natural disasters. They also mentioned settings such as schools, villages and markets where community outreach can be done. Thus, an improved definition of CS, considering the perspectives of citizens, is the practice of active public participation, collaboration and communication in all aspects of scientific research to increase public knowledge, create awareness, build trust and facilitate information flow between citizens, governments and scientists.

Stages of readiness to participate in CS

In Bangladesh, Indonesia, the Philippines, Cameroon and Kenya, majority were unaware of outbreak-related CS (figure 2A), with Bangladesh having the highest percentage (93.6%). In India and Uganda, majority were

Table 1 Participant characteristics across nine countries

	N (%)									
	Asia					Africa				
	Bangladesh (n=280)	India (n=280)	Indonesia (n=371)	Nepal (n=281)	The Philippines (n=468)	Cameroon (n=291)	Kenya (n=251)	Uganda (n=395)	Zimbabwe (n=295)	Total (n=2912)
Age (years)										
Median (IQR)	30 (25–38)	37 (23–61)	27 (21–33.5)	33 (23–47)	25 (22–44)	30 (24–40)	27 (22–39.5)	36 (23–53)	34 (24–45)	30 (22–43)
Gender										
Male	155 (55.4)	140 (50.0)	172 (46.4)	161 (57.3)	218 (46.6)	130 (44.7)	66 (26.3)	190 (48.1)	133 (45.1)	1365 (46.9)
Female	125 (44.6)	140 (50.0)	196 (52.8)	119 (42.3)	241 (51.5)	159 (54.6)	185 (73.7)	205 (51.9)	159 (53.9)	1529 (52.5)
Others	0	0	3 (0.8)	1 (0.4)	9 (1.9)	2 (0.7)	0	0	3 (1.0)	18 (0.6)
Education										
No formal education	29 (10.4)	18 (6.4)	2 (0.5)	19 (6.8)	19 (4.1)	24 (8.2)	3 (1.2)	58 (14.7)	2 (0.7)	174 (6.0)
Primary school	57 (20.4)	54 (19.3)	23 (6.2)	35 (12.5)	44 (9.4)	61 (21.0)	42 (16.7)	150 (38.0)	11 (3.7)	477 (16.4)
Secondary school	65 (23.2)	126 (45.0)	178 (48.0)	101 (35.9)	211 (45.1)	84 (28.9)	103 (41.0)	163 (41.3)	160 (54.2)	1191 (40.9)
Diploma	33 (11.8)	24 (8.6)	39 (10.5)	69 (24.6)	80 (17.1)	37 (12.7)	70 (27.9)	20 (5.1)	35 (11.9)	407 (14.0)
Degree	96 (34.3)	58 (20.7)	129 (34.8)	57 (20.3)	114 (24.4)	85 (29.2)	33 (13.2)	4 (1.0)	87 (29.5)	663 (22.7)
Marital status										
Never married	63 (22.5)	92 (32.9)	213 (57.4)	99 (35.2)	292 (62.4)	157 (54.0)	126 (50.2)	96 (24.3)	98 (33.2)	1236 (42.4)
Married and/or living with partner	213 (76.1)	176 (62.9)	129 (34.8)	167 (59.4)	137 (29.3)	122 (41.9)	85 (33.9)	240 (60.8)	129 (43.7)	1398 (48.0)
Separated/Divorced/Widowed	4 (1.4)	12 (4.2)	29 (7.8)	15 (5.4)	39 (8.3)	12 (4.1)	40 (15.9)	59 (14.9)	68 (23.1)	278 (9.6)
Occupation										
Unemployed	18 (6.4)	13 (4.6)	54 (14.6)	15 (5.3)	92 (19.7)	49 (16.8)	131 (52.2)	101 (25.6)	96 (32.5)	569 (19.5)
Employed	164 (58.6)	136 (48.6)	194 (52.3)	153 (54.4)	119 (25.4)	162 (55.7)	27 (10.7)	195 (49.4)	150 (50.8)	1300 (44.7)
Student	36 (12.9)	60 (21.4)	95 (25.6)	64 (22.8)	208 (44.4)	62 (21.3)	77 (30.7)	44 (11.1)	43 (14.6)	689 (23.7)
Retiree	1 (0.4)	16 (5.7)	4 (1.1)	21 (7.5)	14 (3.0)	1 (0.4)	2 (0.8)	4 (1.0)	2 (0.7)	65 (2.2)
Homemaker	61 (21.8)	55 (19.6)	24 (6.5)	28 (10.0)	35 (7.5)	17 (5.8)	14 (5.6)	51 (12.9)	4 (1.4)	289 (9.9)
Living area										
Urban	46 (16.4)	4 (1.4)	189 (50.9)	214 (76.2)	199 (42.5)	165 (56.7)	68 (27.1)	30 (7.6)	160 (54.2)	1075 (36.9)

Continued

Table 1 Continued

	N (%)									
	Asia					Africa				
	Bangladesh (n=280)	India (n=280)	Indonesia (n=371)	Nepal (n=281)	The Philippines (n=468)	Cameroon (n=291)	Kenya (n=251)	Uganda (n=395)	Zimbabwe (n=295)	Total (n=2912)
Peri-urban	30 (10.7)	1 (0.4)	38 (10.2)	48 (17.1)	21 (4.5)	36 (12.4)	26 (10.4)	152 (38.5)	23 (7.8)	375 (12.9)
Rural	204 (72.9)	269 (96.1)	126 (34.0)	19 (6.8)	233 (49.8)	69 (23.7)	45 (17.9)	211 (53.4)	111 (37.6)	1287 (44.2)
Slums/ Informal settler families	0	6 (2.1)	18 (4.9)	0	15 (3.2)	21 (7.2)	112 (44.6)	2 (0.5)	1 (0.3)	175 (6.0)
Mobile phone access										
No	8 (2.9)	37 (13.2)	17 (4.6)	8 (2.8)	55 (11.8)	30 (10.3)	22 (8.8)	71 (18.0)	11 (3.7)	259 (8.9)
Yes, feature phone	97 (34.6)	65 (23.2)	34 (9.2)	4 (1.4)	43 (9.2)	58 (19.9)	45 (17.9)	218 (55.2)	63 (21.4)	627 (21.5)
Yes, smartphone	175 (62.5)	178 (63.6)	320 (86.3)	269 (95.7)	370 (79.1)	203 (69.8)	184 (73.3)	106 (26.8)	221 (74.9)	2026 (69.6)
Internet access										
No	102 (36.4)	99 (35.4)	31 (8.4)	12 (4.3)	94 (20.1)	75 (25.8)	75 (29.9)	291 (73.7)	63 (21.4)	842 (28.9)
Yes	178 (63.6)	181 (64.6)	340 (91.6)	269 (95.7)	374 (79.9)	216 (74.2)	176 (70.1)	104 (26.3)	232 (78.6)	2070 (71.1)
Heard of citizen science										
No	245 (87.5)	278 (99.3)	305 (82.2)	198 (70.5)	413 (88.2)	276 (94.8)	213 (84.9)	267 (67.6)	158 (53.6)	2353 (80.8)
Yes	35 (12.5)	2 (0.7)	66 (17.8)	83 (29.5)	55 (11.8)	15 (5.2)	38 (15.1)	128 (32.4)	137 (46.4)	559 (19.2)

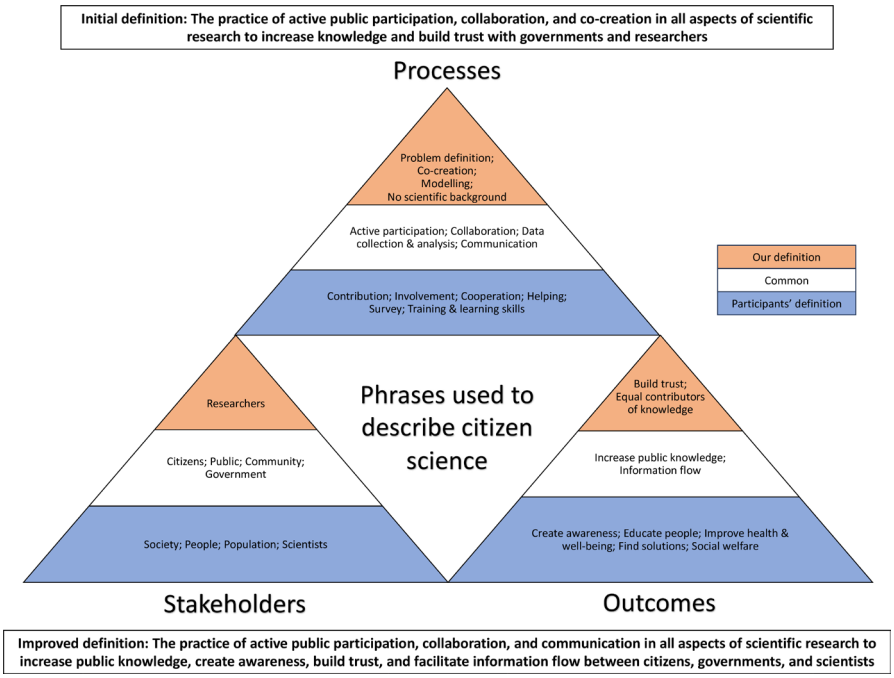

Figure 1 Refinement of the definition of citizen science with citizens' perspectives. The authors are the creator/owner of figure 1.

aware but unengaged in CS. In Nepal and Zimbabwe, majority participated in CS before, with Zimbabwe having the highest percentage (61.7%). Figure 2B visualises the comparison of variables associated with participants' readiness. In table 2, we report the association between a variable and readiness stage, quantified by p values. For categorical factors, we looked at whether there is evidence (95% CI) of a difference between the various levels and reference.

Age had an association in Bangladesh, Indonesia, Kenya and Zimbabwe. In Bangladesh, Indonesia and Kenya, older individuals were more likely to be in a higher readiness stage, as opposed to less likely in Zimbabwe. Gender had an association in India and Zimbabwe. In India, females were more ready to participate compared with males, whereas the opposite applied in Zimbabwe. Education had an association in Bangladesh, India, Nepal, Cameroon, Kenya and Uganda. The odds of being in a higher stage decreased with lower education levels. Marital status had an association in Nepal and Zimbabwe. In Zimbabwe, separated/divorced/widowed individuals, and those married and/or living with partner were more ready to participate compared with never married. Occupation had an association in India, Nepal, Uganda and Zimbabwe. Compared with those who are employed, the odds of being in a higher stage decreased for homemakers in India, and retiree, and unemployed in Nepal. Conversely, in Uganda, the odds increased for homemakers and unemployed. Living area had an association in India, Indonesia, Cameroon, Kenya, Uganda and Zimbabwe. For India and Cameroon, the association seems to be mostly driven by the finding that those living in slums/informal settler families were all in the lowest stage. Compared with those living in urban areas, individuals in peri-urban areas in Indonesia and Zimbabwe, and rural areas in Uganda were less ready to participate, while those in rural areas in Zimbabwe were more ready to participate. Mobile phone access had an association in the Philippines, Uganda and Zimbabwe. The odds of being in a higher stage increased for those with feature phone compared with smartphone. Internet access had an association in Indonesia, the Philippines and Uganda. Those with access were more likely to be in a higher stage compared with those without.

Perceived factors influencing CS participation

Participants identified the most important factors, grouped into six main categories, that will influence their decision to participate in outbreak-related CS (table 3). A comparison across countries showed some differing trends (online supplemental file p13). Under incentivisation factors, opportunity to gain new knowledge/skills was most important to 36.3% of participants, followed by the value of their participation in influencing real-world outcomes (18.2%). This was substantiated by Kenyan participants who voiced their disheartenment during the FGDs if there are no follow-ups on project outcomes. In Uganda, tangible outcomes such as monetary incentives were important. For cultural factors, 48.4% felt that language used must be easy to understand. India placed more emphasis on family upbringing, while cultural discrimination was mentioned by people in Nepal. Under social factors, being part of a community or social network was important to 53.1% of participants. During the FGDs, lack of an enabling environment including political and social unrest in some countries

Table 2 Variables associated with the stages of readiness (OR and their 95% CIs)

		OR (95% CI)								
		Asia					Africa			
Variable	Levels	Bangladesh	India	Indonesia	Nepal	The Philippines	Cameroon	Kenya	Uganda	Zimbabwe
Age (per 10 years)	P value	0.03*	0.55	0.05*	0.33	0.91	0.70	0.009**	0.12	0.04*
	Continuous	**2.30 (1.08 to 4.91)**	1.08 (0.84 to 1.38)	**1.44 (1.00 to 2.08)**	1.14 (0.88 to 1.47)	0.98 (0.72 to 1.34)	1.10 (0.69 to 1.75)	**1.58 (1.12 to 2.24)**	1.13 (0.97 to 1.31)	**0.71 (0.51 to 0.99)**
Gender	P value	0.52	0.05*	0.38	0.15	0.35	0.53	0.88	0.17	0.03*
	Male	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
	Female	1.44 (0.47 to 4.39)	**1.74 (1.00 to 3.03)**	0.79 (0.46 to 1.35)	0.69 (0.41 to 1.15)	1.34 (0.73 to 2.46)	0.79 (0.38 to 1.65)	1.05 (0.55 to 2.03)	0.74 (0.49 to 1.13)	**0.52 (0.29 to 0.93)**
Education	P value	0.003**	0.003**	0.14	<0.001***	0.90	0.002**	0.009**	0.008**	0.56
	Degree	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
	Diploma	0.63 (0.16 to 2.56)	0.53 (0.21 to 1.31)	1.10 (0.49 to 2.49)	1.38 (0.70 to 2.70)	0.99 (0.41 to 2.40)	1.14 (0.43 to 3.01)	**0.33 (0.12 to 0.91)**	2.48 (0.16 to 37.97)	1.33 (0.57 to 3.11)
	Secondary school	**0.16 (0.03 to 0.93)**	**0.31 (0.16 to 0.59)**	**0.53 (0.30 to 0.95)**	**0.51 (0.26 to 0.99)**	1.29 (0.59 to 2.85)	0.66 (0.27 to 1.60)	0.49 (0.18 to 1.39)	1.71 (0.12 to 23.56)	1.39 (0.71 to 2.74)
	Primary school	0 (N.A.)	**0.25 (0.10 to 0.63)**	1.28 (0.21 to 7.84)	**0.23 (0.09 to 0.55)**	0.80 (0.20 to 3.24)	**0.09 (0.02 to 0.53)**	**0.15 (0.04 to 0.59)**	1.73 (0.12 to 24.17)	1.45 (0.21 to 10.28)
	No formal education	0 (N.A.)	**0.15 (0.04 to 0.57)**	0 (N.A.)	**0.27 (0.08 to 0.94)**	1.21 (0.18 to 7.98)	0 (N.A.)	4.00 (0.26 to 60.77)	0.57 (0.04 to 8.49)	0 (N.A.)
Marital status	P value	0.93	0.70	0.18	0.05*	0.11	0.22	0.90	0.59	0.03*
	Never married	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
	Married and/or living with partner	0.63 (0.06 to 6.35)	1.40 (0.64 to 3.04)	0.89 (0.46 to 1.72)	0.57 (0.26 to 1.23)	2.33 (0.91 to 6.00)	1.69 (0.66 to 4.32)	1.11 (0.47 to 2.63)	1.38 (0.70 to 2.69)	**2.56 (1.14 to 5.76)**
	Separated/Divorced/Widowed	0.12 (0.12 to 0.12)	1.40 (0.29 to 6.85)	0.28 (0.06 to 1.21)	2.00 (0.51 to 7.87)	3.76 (0.97 to 14.59)	0 (N.A.)	1.27 (0.45 to 3.55)	1.57 (0.62 to 3.94)	**3.89 (1.32 to 11.48)**

Continued

Table 2 Continued

Variable	Levels	OR (95% CI)								
		Asia					Africa			
		Bangladesh	India	Indonesia	Nepal	The Philippines	Cameroon	Kenya	Uganda	Zimbabwe
Occupation	P value	0.14	0.02*	0.14	0.004**	0.73	0.84	0.44	0.02*	0.04*
	Employed	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
	Unemployed	0 (N.A.)	0.90 (0.28 to 2.87)	0.45 (0.19 to 1.11)	**0.16 (0.05 to 0.51)**	1.01 (0.36 to 2.83)	1.40 (0.53 to 3.66)	1.33 (0.51 to 3.50)	**1.73 (1.05 to 2.83)**	0.53 (0.28 to 1.01)
	Student	1.08 (0.08 to 13.92)	1.55 (0.70 to 3.45)	0.79 (0.38 to 1.66)	0.58 (0.27 to 1.21)	1.88 (0.67 to 5.31)	1.06 (0.41 to 2.76)	0.95 (0.29 to 3.08)	1.36 (0.58 to 3.20)	1.44 (0.58 to 3.62)
	Retiree	0 (N.A.)	0.66 (0.19 to 2.33)	0 (N.A.)	**0.25 (0.08 to 0.76)**	0.59 (0.09 to 3.93)	0 (N.A.)	1.71 (0.07 to 42.10)	0.12 (0.01 to 1.20)	Inf (N.A.)
	Homemaker	0 (N.A.)	**0.31 (0.15 to 0.67)**	0.30 (0.08 to 1.16)	0.47 (0.19 to 1.19)	1.17 (0.34 to 3.98)	0.80 (0.08 to 7.51)	3.93 (0.88 to 17.45)	**2.17 (1.16 to 4.07)**	0.26 (0.04 to 1.83)
Living area	P value	0.14	0.008**	0.03*	0.72	0.07	0.03*	0.02*	0.006**	<0.001***
	Urban	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
	Peri-urban	0.66 (0.10 to 4.20)	0 (N.A.)	**0.27 (0.08 to 0.83)**	1.11 (0.58 to 2.09)	0.16 (0.02 to 1.34)	1.93 (0.79 to 4.74)	1.54 (0.54 to 4.39)	0.86 (0.40 to 1.81)	**0.27 (0.10 to 0.70)**
	Rural	2.68 (0.72 to 9.97)	1.31 (0.09 to 18.35)	1.27 (0.75 to 2.16)	0.70 (0.24 to 2.02)	**0.56 (0.31 to 0.99)**	1.02 (0.37 to 2.78)	0.37 (0.13 to 1.06)	**0.40 (0.18 to 0.90)**	**3.09 (1.52 to 6.26)**
	Slums/Informal settler families	–	0 (N.A.)	1.34 (0.40 to 4.46)	–	0.69 (0.16 to 2.95)	0 (N.A.)	1.52 (0.72 to 3.23)	0.73 (0.03 to 20.13)	–
Mobile phone access	P value	0.98	0.29	0.28	0.86	0.02*	0.39	0.42	<0.001***	<0.001***
	Yes, smartphone	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
	Yes, feature phone	1.06 (0.04 to 27.14)	1.05 (0.22 to 5.08)	0.42 (0.12 to 1.54)	2.40 (0.09 to 64.44)	**3.72 (1.47 to 9.44)**	0.51 (0.09 to 2.80)	0.66 (0.26 to 1.70)	1.36 (0.47 to 3.92)	**5.32 (2.04 to 13.87)**
	No	0 (N.A.)	0.53 (0.08 to 3.35)	3.82 (0.12 to 127.03)	2.50 (0.08 to 76.16)	3.83 (0.90 to 16.25)	1.93 (0.18 to 21.12)	0.43 (0.11 to 1.67)	0.34 (0.10 to 1.14)	0.24 (0.06 to 1.03)
Internet access	P value	0.85	0.35	0.001***	0.38	0.002**	0.85	0.78	0.01**	0.29
	No	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
	Yes	1.37 (0.06 to 33.45)	2.20 (0.42 to 11.48)	Inf (N.A.)	4.07 (0.18 to 89.98)	**6.93 (1.92 to 24.97)**	0.83 (0.12 to 5.60)	0.89 (0.39 to 2.03)	**3.84 (1.32 to 11.14)**	0.66 (0.30 to 1.44)

Continued

Table 2 Continued

Variable	Levels	OR (95% CI)								
		Asia					Africa			
		Bangladesh	India	Indonesia	Nepal	The Philippines	Cameroon	Kenya	Uganda	Zimbabwe

Significant ORs are highlighted in bold. 0 (N.A.) means that all individuals with that level of the covariate were 'unaware', which made computation of the CI infeasible. Inf (N.A.) means that all individuals with that level of the covariate were 'aware, engaged, decided, took action' (for retiree in Zimbabwe) or all individuals in the reference group were 'unaware' (for internet access in Indonesia), which again made computation of the CI infeasible. More details on the distribution of variables across the stages of readiness can be found in online supplemental file pp 10–12.

The authors are the creator/owner of table 2.

*P≤0.05, **p≤0.01, ***p≤0.001.

Inf, infinity; N.A., not applicable; Ref, reference.

such as Cameroon was discussed as a deterrent. Under attitude and emotional factors, feeling empowered to resolve issues important to them was paramount to 35.3% of participants. Participants from India and Bangladesh would be more encouraged to participate if they enjoy the activities. Some participants from the youth group and marginalised/indigenous population mentioned that personal inferiority complex resulting in self-doubt and fear of speaking in public has prevented them from participating. For project-specific factors, 31.0% wanted to have a clear understanding of the expected tasks. In India and Uganda, knowing the organiser was important, which was echoed in the FGDs where mistrust in organisers was raised as a concern. Participants from Indonesia and the Philippines wanted clear project rationale, while in Nepal, people wanted a relatable project purpose. Lastly, knowledge/skills needed to perform the activities was the most important practicality factor to 25.5% of participants. In Uganda and Cameroon, time commitment was crucial, while the level of risks involved, particularly in the context of outbreak management, was important for Indian participants. This was reiterated in the FGDs where participants felt that lack of training and proper communication channels could result in inadequate knowledge/skills needed to carry out activities. Competing life priorities such as work, household responsibilities and health issues were also mentioned. Inadequate support system including lack of resources such as transport, time, money, technology and protective gear deterred participation in outbreak-related group activities due to infection risk.

Digital CS

Overall, 76.0% expressed interest to participate in CS through digital platforms assuming they have mobile phone and internet access. Zimbabwe (95.6%) and Kenya (92.4%) had the highest interest, while Uganda (37.0%) had the least. 42.6% and 41.2% of participants said they needed more training to have the skills/confidence to participate in CS using analogue and digital methods, respectively. Table 4 summarises the comparison between analogue and digital methods. Across all countries, the most mentioned outbreak-related digital CS activity was outreach and communication. Information can be passed easily and quickly through digital platforms for awareness campaigns such as preventive measures and vaccination. Outbreak management such as contact tracing and self-assessment of risk factors can also be done online. Community support in the form of daily needs and mental support came out strongly for the Indonesian participants. With advancement in technology, geo-tagging and proximity detection can be achieved through mobile applications and wearables.

Comparing analogue and digital methods, digital was preferred by participants if the research is on infectious diseases and conducted among the digital literate population in urban settings. Participants perceived digital as accessible, convenient, timesaving, enables real-time

Table 3 Perceived factors influencing participation in outbreak-related citizen science with illustrative quotes from participants

Factors	Total (n=2912)	
	N	%
Incentivisation factors		
Able to learn new knowledge/skills	1058	36.3
The value/importance of my participation in influencing real-world outcomes	530	18.2
An understanding of how the citizens science project will help me and my community	518	17.8
Monetary incentives	454	15.6
Urgency/Seriousness of the problem to be addressed by the citizen science project (eg, impact of pandemic/outbreak on my life)	352	12.1
"It is disheartening when we participate in any activity and there are no follow-ups, thereby not measuring the outcome of the activity". (Kenya, CHW)		
Cultural factors		
The language used is easy for me to understand	1408	48.4
Family upbringing	713	24.5
Religious/Spiritual belief	571	19.6
Origin/Immigration status/Acculturation	220	7.6
'Discrimination. People didn't want to participate in different culture or region's programme, even it may be good programme'. (Nepal, GP)		
Social factors		
Being part of a community/social network	1547	53.1
My friends/family are also participating	636	21.8
My loved ones are supportive	228	7.8
It is popular/trendy	204	7.0
Stigma faced if I participate	191	6.6
Having a well-known/celebrity spokesperson promoting the activities	106	3.6
'The situation of the community at that time, if there is social unrest, the activities cannot work'. (Cameroon, CHW)		
Attitude and emotional factors		
Feeling empowered to resolve an issue that is important to me	1027	35.3
I enjoy the activities	751	25.8
It gives me a sense of achievement	587	20.2
My interest level in the topic/activities	547	18.8
"I wanted to help the people(…)but I was afraid that people would not listen to me or they may take it wrong and laugh at me". (India, MI) *"Some people are inferior so they fear going to the communities". (Uganda, CHW)*		
Project-specific factors		
Having a clear understanding of what tasks are expected of me	902	31.0
Able to relate to the purpose of the citizen science project	578	19.8
Who is the organiser	447	15.4
Transparency on how the data will be handled	320	11.0
Privacy and confidentiality measures that are in place	309	10.6
Ease of finding information about the project/widespread awareness campaigns/advertisements	243	8.3
Amount of control I have over the project (active vs passive role)	113	3.9
"I don't want to participate in citizen science if the project is only for a marketing gimmick. One of the successes for citizen science is community involvement. But the community is not empowered, as if only to meet the project quota or any sort of mandatory requirements". (Indonesia, MI) *"For me, it's the organizer. If I don't know them, I might be a bit sceptical. Like if it's a company I'm not familiar with or not well-known, it's difficult to trust". (The Philippines, GP)*		
Practicality factors		
Knowledge/Skills needed to carry out the activities	742	25.5
Time commitment (hours per week)	608	20.9
Cost of participation	355	12.2
Commitment period (long-term or short-term)	334	11.5
Convenience/Location	277	9.5
The level of risks/danger involved	268	9.2
Competing priorities/stage of life I am in	184	6.3
Medium of access (eg, in-person, online, text message, call)	144	4.9

Continued

Table 3 Continued

Factors	Total (n=2912) N	%
"As we are working women, we have to come to the office from 10am to 5 pm, before that we have to do household work, look after the children, then when we reach home in the evening, we have to prepare food, teach children, etc. So, we do not get time to participate in such activities, it pushes us back". (India, MI) *"Lack of knowledge and lack of proper communication channels, If today things come from so and so, tomorrow so and so, not knowing hierarchy makes me confused of what is coming from where". (Zimbabwe, CHW)*		

The authors are the creator/owner of table 3.
CHW, community health worker; GP, general population; MI, marginalised/indigenous population.

monitoring and generates higher quality and quantity of data. It is faster to generate reports, and with time stamps and location-based information, it is also easier to supervise the work done. Many people mentioned the importance of non-contact to reduce transmission, especially in the context of outbreak-related activities. A handful mentioned that digital is more environmentally friendly. Conversely, digital was perceived to exclude people who are digitally illiterate such as the elderly, and those with no access to digital devices and internet. This was unanimously brought up by all countries as issues such as electricity supply cut, expensive data bundles and sporadic internet connection are common in LMICs. Concerns around data security such as hackers leaking confidential data, or viruses corrupting data were also raised. There was some mistrust in the true representation of online respondents as people put in less thoughts and efforts to complete online tasks, and some might be distracted by a non-conducive physical environment. Some participants highlighted that interactions through digital platforms do not allow people to ask questions for clarifications, thus communication could be unclear, and information conveyed might be easily misinterpreted. It is also harder to build relationships and rapport among stakeholders. When asked about analogue CS, the advantages stated were that this method has been used over time and is proven to be acceptable by the public. People feel more comfortable doing in-person activities, making it easier to build personal relationships and trust, resulting in better engagement and participation. Some mentioned CS is about field observations, highlighting the importance of being on the ground. Participants from the Philippines liked that in-person interactions allow group sharing and learning. Conversely, analogue was perceived as more time consuming to gather and process data. More resources such as venues, transport and manpower are needed. It is also harder to maintain physical records as paper can be lost or damaged over time.

DISCUSSION

Findings from this study suggest that CS is not a commonly known and used term in communities. Despite having participated in CS activities, most participants could not relate to the term, which is largely used and defined by the scientific community. This is not surprising as CS has evolved over the years with diverse definitions and typologies, each representing a different viewpoint and domain.[5 30] Numerous consolidation attempts have been made, but it remains challenging across disciplines.[31] In the context of outbreak preparedness and response, and the wider domain of public health, we sought to understand the perspectives of communities. By integrating viewpoints from both scientific and public lens, a more relatable definition of CS is the practice of active public participation, collaboration and communication in all aspects of scientific research to increase public knowledge, create awareness, build trust and facilitate information flow between citizens, governments and scientists. Creating resonance is an important first step to raise awareness among communities.

Examining the factors associated with participants' readiness to participate in CS, we found similarities and differences across countries. Through conversations with communities, civil societies in Zimbabwe discovered that youths are keener to participate because they view CS as a networking opportunity, and they can gain new skills which will help them in future jobs. Females in Zimbabwe face barriers such as competing life priorities which deter them from participation. In the Asian countries, employed individuals (India, Nepal) and those living in urban areas (Indonesia, the Philippines) had a higher readiness stage that can potentially be explained by an increased societal connection, avenues to obtain information and capacity to process and act on it. However, as observed by our civil society representatives in Uganda, the employed tend not to participate claiming a lack of time, preoccupied with work and seeing little to no benefit. In Zimbabwe, those living in rural areas were more likely to be at a higher stage, as these communities are usually more appreciative of opportunities to represent and be recognised. In terms of digital, those with internet access are more exposed and aware of activities happening around them and therefore more ready to participate as shown in Uganda and the Philippines. Interestingly, those with feature phones in Zimbabwe and the Philippines were more likely to participate compared with those with smartphones, as feature phone users are more likely to be from marginalised/indigenous groups who have a stronger desire to be heard, and a greater sense of society responsibility and cohesiveness.

Using PAPM as an evidence-based framework, we recommend a structured approach to effectively advance

Table 4 Comparison between analogue and digital methods of citizen science

Theme	Subtheme	Illustrative quote
Types of digital citizen science activities	Outreach, communication and awareness	"So by using digital technology we can raise awareness, knowing that awareness always aims to reach as many people as possible". (Cameroon, Y) "We can use it to pass on information to the community on how to prevent diseases by wearing masks social distancing and others". (Uganda, Y)
	Outbreak management	'Registration of COVID patients can be done staying at home through online'. (Bangladesh, MI) "We can do self-assessment for risk factors of COVID-19. We can know if we have any problem or not. We are also able to know about the location of any positive patient in our vicinity". (India, MI)
	Community support	"Self-quarantine application asking strangers, neighbours or anyone to help you to do grocery shopping. During a pandemic people can be very lonely and depressed, so a sort of social entertainment or gathering activities (online) would be helpful in difficult times to show support". (Indonesia, CHW)
	Mobile applications and wearables	"Because there are already many IT professionals and programmers, GPS can be utilized. You know how there are smartwatches worn when jogging, right? Smartwatches that also detect your heart rate. Maybe we can apply that here. It can vibrate when someone gets close, and you can step back a bit. Similar to how it works with their smartwatches". (The Philippines, GP)
Choice of analogue or digital citizen science	Dependent on research domain, population type, setting	'In pandemic, paper method is inappropriate because paper may be the medium for disease to transfer but in other period paper method is good because in this situation people try to understand more and response more'. (Nepal, GP) "Well, technology has advanced, young people now prefer digital, if you want to capture more young people you have to go digital". (Cameroon, Y)
Advantages of digital citizen science	Accessible and convenient	"One, is avoid long distance travel, and the second point is that it helps us to communicate easily with everybody, that if we have a platform that messages will be sent there, and people will get the information immediately and we will not need to move from one place to another". (Cameroon, MI)
	Real-time and timesaving	"In today's modern society, every person has a laptop, and mobile application. So, he would prefer to provide data using the mobile application. One can cover a larger area in lesser time with real-time monitoring". (India, Y) "We are in an age where time is worth more, it's fast, people prefer things that will not waste their time". (Cameroon, Y)
	Better quality and quantity of data	"Through digital platforms, there is greater data accuracy as compared to collecting data using traditional methods. For example, maybe the handwriting is not visible so you will miss out on some crucial information". (Kenya, GP) "The advantage over that is that you can have a lot of data, because you see almost everyone has at least I mean a social platform that they're registered in, so what's on you're going to have more results". (Cameroon, Y)
	Easier reporting and supervision	'In today's time most people are using mobile phones in which digital data can be managed easily and a good report can also be made quickly'. (India, GP) "It is also easy to supervise whether this means is original or not because it used to include location, state, and time everything. While nothing like this happens on paper. Means in this we can also supervise well". (India, MI)
	Safer for humans and environment	"It also has the advantage that the lesser we use paper, the safer our trees will be". (India, MI) "During the pandemic, it was better because there was nothing to touch, you had to use alcohol, and you could say whatever you wanted because it was through the phone". (The Philippines, MI)
Disadvantages of digital citizen science	Non-inclusion of all population groups	"There is no network coverage in some areas and some areas(…)even climb mountains or trees to get network(…) here in Zimbabwe we have problems, electricity, most of the time there is no electricity. You can go for three days with no power to charge phone". (Zimbabwe, GP) 'Certain cohorts will be left out of the study because most of the elderly group has not subscribed to digital platforms or modern technology, so the information won't reach them in real-time'. (Kenya, GP)
	Data security	"I think there's a possibility of somebody getting into the information system, hacking the data, obtaining the information which may be supposed to be confidential, and using the information against the group of people who provided it". (Kenya, Y)
	Mistrust in true representation	"The downside is that people may not fully express their true preferences since they tend to click through quickly due to the abundance of options. On the other hand, in cultural interactions, they are able to better articulate their thoughts and express what they truly want to say". (The Philippines, Y) "When you're online, there are many disturbances in the surroundings, especially if you have a community like ours(…)It's hard to focus, especially if your community is noisy and chaotic". (The Philippines, MI)
	Unclear communication	'People have no chance to ask questions. They only listen without asking questions'. (Uganda, GP) 'The communication, task delegation and any sort of instructions could be not clear during digital meetings'. (Indonesia, CHW)
Advantages of analogue citizen science	Proven to be acceptable	'The advantage of the paper-based method is that it is being used from earlier times. People are more comfortable with it and one can also keep a copy for records'. (India, Y)
	Builds personal relationships	"I will give more preference to field work because(…)a good relationship will be formed with the patient and they can call you anytime and when you are sitting face to face, their trust will increase". (India, GP)
	Importance of field observations	"In general, citizen science activities are when we try to observe something on the field. For example, in the market there are animals. Maybe it doesn't behave normally like a mad cow or something else, and if a neighbour is sick, you need observation from the field". (Indonesia, Y)
	Encourages group sharing	"In the traditional approach, you can still interact with different people. You will learn about their perspectives, and you can compare them to your own thoughts". (The Philippines, Y)

Continued

Table 4 Continued

Theme	Subtheme	Illustrative quote
Disadvantages of analogue citizen science	Time consuming	"With paper and pen, when you fill it out, you have to wait for 1 to 2 weeks before they encode and gather the data". (The Philippines, GP)
	Resource intensive	"In-person now, some of the disadvantages are that you need to get more resources, you need to get venue, and people will need more time to engage". (Cameroon, GP)
	Harder to maintain records	'Traditional methods are prone to loss or tear'. (Kenya, GP) 'On the downside, paper-based surveys can get wet, damaged, lost, or even burned'. (The Philippines, GP)

The authors are the creator/owner of table 4.
CHW, community health worker; GP, general population; MI, marginalised/indigenous population; Y, youth.

people along the stages of readiness to participate in CS. To improve awareness, campaigns disseminating CS concepts, in words that resonate with the communities, can be organised through social and traditional media, and word-of-mouth. To advance engagement, co-identification of problems or needs from the start and the use of tailored health communication strategies can increase relatability and relevance of CS participation to people. At the point of decision, it is pivotal to address barriers and accentuate facilitators. Our findings emphasised the need for engagement mechanisms to consider different social and cultural contexts, while addressing incentivisation, attitudes and practicality factors. Lastly, to encourage participation, capacity development, improving access and cues to action are necessary. Digital CS was perceived to be accessible, convenient and time-saving, highlighting its potential to nudge participation as most participants expressed interest if training will be provided. However, digital CS risks widening existing health inequities if not deployed responsibly. Digital divide, particularly in LMICs, was a concern voiced by our participants who mentioned lack of mobile phone and internet access. This is supported by the literature which highlighted digital inequities among women, girls

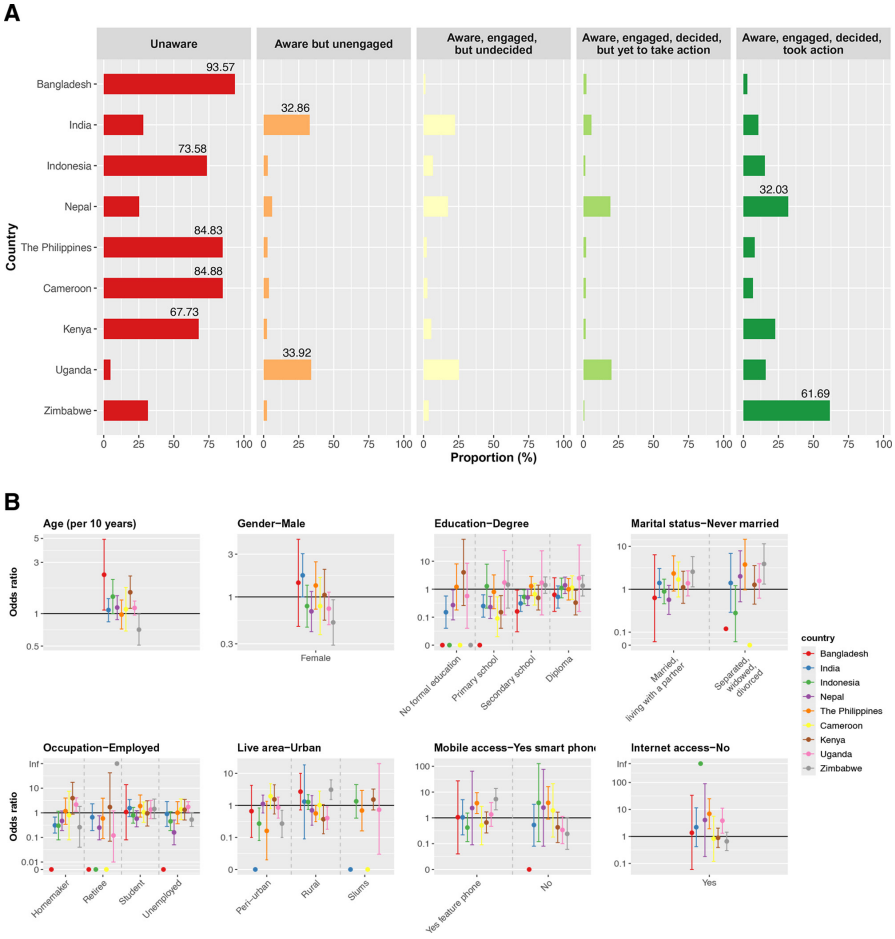

Figure 2 Stages of readiness to participate in citizen science in nine countries The authors are the creator/owner of figure 2. (A) Distribution of participants across the stages of readiness Readiness stage with the highest proportion of participants for each country has its proportion stated beside it. (B) Comparison of variables associated with participants' readiness stage (OR and their 95% CIs).

and vulnerable and marginalised populations.[32 33] To harness the full potential of digital CS, capacities of citizens need to be built as highlighted by our participants. Capacity development efforts to improve the quality of data generated from CS is also echoed in the research community.[34] By addressing the above-mentioned factors, there is potential for CS to tackle public health challenges in a more collaborative, inclusive and responsive manner. A recent review has shown that CS can increase the availability, granularity and timeliness of health and well-being-related data that could potentially contribute to the monitoring of 83% of the health and well-being-related indicators of the Sustainable Development Goals and the WHO's Triple Billion Targets.[35]

This mixed-method study allowed triangulation of our findings on citizens' perception of CS in outbreak preparedness and response. We attempted to include hard-to-reach groups in LMICs, such as marginalised/indigenous populations. However, we were not able to perform subgroup analysis on these populations due to their anonymous nature. Although we tried to ensure even age distribution, the elderly proved challenging to recruit. Inclusion of nine countries across Asia and Africa added diverse representation and allowed comparison across different social and cultural settings. It was challenging to analyse the data for stages of readiness as some countries had people almost completely concentrated in one stage for one or more levels of the covariates, making it infeasible to compute their CIs based on the Wald test. The overall p values for each variable were based on the likelihood ratio test and are therefore more reliable.

CONCLUSION

In conclusion, CS approaches need to tailor to the needs of citizens and their varying social and cultural settings. To effectively advance people along the stages of readiness to participate in outbreak-related CS, communities need to be involved in the entire process and interventions must address context-specific factors influencing CS participation. Countries can learn from each other by extracting relevant lessons that can accelerate the process. Digital CS has the potential to facilitate collaboration between stakeholders, but capacity and access issues must be considered to ensure acceptable, inclusive and sustainable engagement. Future work can further investigate the proposed structured approach to advance people along the stages of readiness.

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