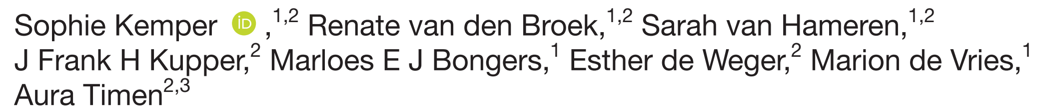
BMJ Global Health

# Voices of society: the emergence of civil-society practices aiming to engage in the management of the COVID-19 pandemic in the Netherlands



Sophie Kemper ,[1,2] Renate van den Broek,[1,2] Sarah van Hameren,[1,2] J Frank H Kupper,[2] Marloes E J Bongers,[1] Esther de Weger,[2] Marion de Vries,[1] Aura Timen[2,3]

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RvdB and SvH contributed equally.

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For numbered affiliations see end of article.

**Correspondence to**
Sophie Kemper;
sophie.kemper@rivm.nl

## ABSTRACT

During the COVID-19 pandemic, public groups mobilised themselves in civil-society engagement practices (CSEPs) aiming to improve or suggest alternative epidemic management. This study explores the motivation to establish CSEPs and their perceived contributions to epidemic management, to gain insight whether integrating views of CSEPs could add value. A systematic online search was executed to identify CSEPs focused on COVID-19 management between January 2020 and January 2022 in the Netherlands. In order to create a comprehensible overview of the identified CSEPs, relevant characteristics were gathered and mapped, for example, local or national scope, subject of action and goals. A selection of CSEPs was interviewed between April and June 2022 to study their motivators to start the CSEPs and perceived contributions to management. The search resulted in the identification of 22 CSEPs, of which members of 14 CSEPs were interviewed. These members indicated several issues that motivated the start of their CSEP, namely; shortage of equipment, sense of solidarity, and a perceived lack of governmental action, lack of democratic values and lack in diversity of perspectives in epidemic management. All respondents believed to have contributed to policy or society, by influencing opinions, and occasionally by altering policy. However, respondents encountered obstacles in their attempts to contribute such as inability to establish contact with authorities, feeling unheard or undermined, and complications due to the interplay of political interests. In conclusion, CSEPs have fulfilled various roles such as providing alternative management policies, producing equipment, representing the needs of vulnerable populations, and supporting citizens and providing citizens with other viewpoints and information. The identified motivators to establish CSEPs in this study uncover room for improvements in policy. These insights, together with the identified perceived barriers of CSEPs, can be used to improve the connection between (future) epidemic management and public priorities and interests.

### WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ During COVID-19, many bottom-up approaches, also referred to as civil society engagement practices (CSEPs), have emerged aiming to suggest alternative policies for COVID-19 management.

⇒ Cocreation with CSEPs could lead to better effectivity and legitimacy of policies.

### WHAT THIS STUDY ADDS

⇒ CSEPs have fulfilled various roles in the management of COVID-19, varying from raising attention of key stakeholders to altering policies, to giving support to citizens by disseminating a variety of perspectives regarding the COVID-19 epidemic.

### HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Creating and maintaining overviews of CSEPs within a country can uncover elements of epidemic management that are not in line with the needs of the public.

⇒ CSEPs can function as bridges between individual citizens and authorities due to their position in society.

## INTRODUCTION

Since early 2020, the COVID-19 pandemic and the corresponding policies and management have affected many aspects of citizens' lives.[1] In the epidemic management of COVID-19, continuous trade-offs were made between health, social and economic factors, with the aim of minimising negative consequences for societies.[2] Experts, healthcare institutions and policy-makers have to make these difficult decisions on trade-offs, while facing limited information, a lack of time and high levels of uncertainty.[3 4] In times of crises, input from other sources, for example, from people that are affected by or at risk during the epidemic, might be a relevant addition to epidemic management.[5 6]

In literature, there are three important rationales for including public engagement in decision-making on healthcare policy. First,

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normative rationale describes that when one is affected by a policy, one has the right to be engaged in developing it.[7] Second, substantive rationale states that the quality of policies, such as in epidemic management, could be improved by integrating the perspectives of citizens. Citizens might see problems and solutions that other parties do not.[8 9] Third, instrumental rationale describes that the process of engagement can foster transparency, trust and understanding between citizens and experts, healthcare institutions and policy-makers.[10 11] Giving the public a stronger role in epidemic management has been on the agenda for some time. In 2014, the Ebola virus disease outbreak demonstrated the importance of engaging communities in response efforts, for this to reflect communities needs and priorities.[12 13] Since the start of the COVID-19 epidemic, interest in public engagement has strengthened further.[9 14–17] Multiple research efforts have collected perspectives of citizens on epidemic management, for example, by identifying public preferences regarding lockdown or reopening policies.[11 18 19] Overall, the legitimacy and sustainability of policies depend on how well underlying public values, such as autonomy, justice and solidarity are factored in.[20] Public engagement can contribute to increase legitimacy and sustainability of epidemic management as it is thought to help policies better reflect citizens' values and priorities.

Instead of governments and researchers initiating public engagement in epidemic management it can also be initiated by citizens themselves.[21] When focusing on bottom-up approaches engaging in management, citizens rarely enter the discourse alone, but try to bundle beliefs, needs, resources and influences of individuals into one agenda in order to establish a voice and some sort of mandate.[22] Engaging bottom-up approaches in healthcare decision-making is on itself not a new topic. Mulvale *et al* engaged mental health stakeholders, people living with mental health problems and indigenous people by means of dialogues, workshops and round tables to jointly built the national Mental Health Strategy for Canada aiming to add to or amend measures.[23] Edelenbos *et al* studied the role and impact of bottom-up approaches in flood risk management and concluded that cocreation increased effectivity and legitimacy.[24] Focusing on the COVID-19 management, the engagement of bottom-up public initiatives aiming to contribute has not been extensively researched, even though various bottom-up initiatives established.

In an effort to overcome this gap, this study will focus on what we refer to as civil-society engagement practices (CSEPs). CSEPs are defined as mobilised groups of citizens that have established an interest in element(s) of epidemic management out of a certain motivation, for example, frustration with status quo or willingness to contribute, and thereby suggesting new ideas or alternative policies regarding element(s) of management. CSEPs are self-initiated by citizens, professionals or established organisations and aim to engage in and influence the process of decision-making. An international example is the global Covid Action Group, who described themselves as a citizens' task force aiming to provide guidance to policy-makers on best practices in epidemic management and to combat disinformation.[25] Zero Covid Denmark is another example that campaigned for alternative strategies in Denmark, focusing on total suppression of the virus.[26] Comparably, various CSEPs were established in the Netherlands proposing new ideas and alternative policies for epidemic management aiming to integrate their views in decision-making. The establishment of such practices reveal the tension between (potential) policies and the values, priorities and abilities of certain societal groups.[22] Moreover, representatives of CSEPs frequently appeared in the media and citizens have exclaimed support for CSEPs by becoming a member or by signing manifests and petitions. CSEPs might therewith have the potential to influence citizens' attitudes, and eventually even promoting co-operation to bridge the gap between governmental institutions and individual citizens.[27] CSEPs could thus potentially make relevant contributions to epidemic management. However, the degree to which CSEPs were actually able to make contributions and be actors is largely unknown.

To shape future public engagement in epidemic management, it would be beneficial to increase our understanding of the role of CSEPs in the decision-making process regarding epidemic management. First, information is needed on what motivated people to start CSEPs and thus possibly identify elements that were not in line with the values, priorities and abilities of people in society. Second, it remains unclear if and how the contributions of CSEPs could be utilised. Therefore, the aim of this study is to identify the motivators for establishing CSEPs aiming to influence the COVID-19 pandemic management in the Netherlands, and the contributions they experienced to have made to the process of decision-making.

## METHODS

This study used a mixed-methods approach. CSEPs were identified with a systematic online search and included based on predefined exclusion criteria. Thereafter, a mapping exercise was performed to present an overview of all CSEPs within the scope of this study. Finally, interviews with the members of a subset of CSEPs were executed between April and June 2022 to study motivators for CSEP establishment and perceived impact on epidemic management. The study protocol (code LCI-538) was reviewed by the Clinical Expertise Centre of the National Institute for Public Health and the Environment. Based on this review, they determined that the research plan does not fall under the scope of the Dutch law on medical research involving humans (WMO).

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Table 1 Sources used to identify civil-society engagement practices

| Database or source | Information about database or source and procedure |
|---|---|
| Lexis Nexis | Online database for newspapers, webpages and magazines. |
| Coosto | Online database for messages on social media platforms: Facebook, Twitter, Linkedin, Youtube, Instagram, Pinterest, Reddit. |
| Municipalities | Per province (n=12), the two municipalities with the largest population and the one municipality with the smallest population were contacted via email* |
| Regional Health Consultants and municipal health services (MHS) | MHS are decentralised public health organisations aiming to protect the health of citizens within their region. During COVID-19, their role was to execute COVID-19 management, for example, testing, contact tracing and vaccination.[41] In this study, MHS were contacted via Regional Health Consultants, who have an advisory role to MHS in their catchment areas. All Regional Health Consultants in the Netherlands (n=7) were contacted to randomly select two or three MHS in their areas and ask via email* whether these MHS knew about CSEPs in their region. |
| The Committee on Petitions and Citizen's Initiatives | The committee receives proposals from organised groups within society to be considered by the House of Representatives. These proposals aim to create, amend or withdraw a regulation of policy of the government.[42] This committee was contacted via email* |
| The Committee of the Ministry of Health, Welfare and Sports | The committee monitors the Ministry of Health, Welfare and Sports regularly debates with ministers or prepares the handling of new policy regarding Health, Welfare and Sports.[43] This committee receives letters from citizens initiatives and petitions. They were contacted via email* |
| Colleague experts at the National Institute for Public Health and the Environment | Persons who were involved in integrating societal perspectives into COVID-19 management at the National Institute of Public Health in the Netherlands. They were contacted via email* |

*A similar email was sent to these sources stating the following aspects: introduction of researchers and study, explanation of the study goal, explanation of our definition of CSEP with various examples of national and local CSEPs, request for help in identifying CSEPs that they were aware of within their region or work field, and a request for a referral to a colleague who could answer our question.
CSEPs, civil-society engagement practices.

## CSEP identification

To identify CSEPs, several sources were used, displayed in table 1. Primarily, a systematic online search was executed in the databases Lexis Nexis and Coosto, combining the keywords (and synonyms): 'COVID-19', 'Citizen and Society-led practices', and 'outbreak management' (online supplemental appendix 1 displays the full search strategy). Lexis Nexis is an online database for newspapers, webpages, magazines and messages. In this database, only content from Dutch newspapers was included (online and offline; national, regional and local). Coosto is an online database for social media platforms, of which the search included social media platforms and excluded reposts. The search in Lexis Nexis and Coosto was executed for articles and posts in the period 1 January 2020–31 January 2022. To supplement the online search, municipalities, municipal health services (MHSs) and several national committees were consulted via email about knowledge of CSEPs. Moreover, snowballing to find additional CSEPs was done via the websites of identified CSEPs.

## CSEP inclusion

The search focused on CSEPs established by citizens with various backgrounds, that aimed to contribute to epidemic management by sharing new ideas or alternative policies. The following exclusion criteria were used:

- CSEPs established by organisations that were professionally involved in decision-making and as such already influencing epidemic management, for example, governmental institutions, municipalities, NGOs, hospitals, healthcare institutions, general practices.
- CSEPs established by persons who act in the CSEP from a professional title (not from a personal title), and who are professionally involved in decision-making. As such already influencing epidemic management.
- For-profit or fundraising CSEPs.
- CSEPs solely focusing on providing aid to people struggling with the consequences of restriction measures to manage COVID-19, such as grocery delivery services. As these CSEPs are not directly focusing on contributing to controlling the spread of the virus but contributing to mitigating the side effects of measures.
- CSEPs that provided no new ideas or alternatives for COVID-19 management, and only focused on blocking management. We opted that this type of CSEPs provided too little insight into how epidemic management can be improved in the future.
- CSEPs that used epidemic management as an example to express perceived flaws in the general political situation.

The viewpoint of this study is contributing to decision-making in epidemic management. Therefore, CSEPs solely acting out of political, financial or social motivators and

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not on a decision-making level are excluded (referring to the last four criteria). The first records on Coosto (n=60) and Lexis Nexis (n=30) were independently screened by two researchers (RvdB and SvH). Screening was done based on title and abstract, or in case of ambiguity, the complete article or website. Disagreements between the researchers were discussed and resolved (RvdB, SvH and SK). After screening and discussing the first 90 records, the remaining records were independently screened by three researchers (RvdB, SvH or SK). In case of uncertainties about inclusion, the researchers deliberated until consensus (RvdB, SvH and SK). The CSEPs derived from the other sources were always discussed before inclusion (RvdB and SvH).

### CSEP mapping

A mapping exercise was conducted to gain an overview of the included CSEPs, their geographical scope, subject of action, aim, strategy or activities, and the background of founders (medical, technical, social, economic, other). The subject of action and aim uncovers possible elements in which the needs and priorities of CSEPs are not in line with epidemic management. The scope, strategy or activities and background of founders uncover possible relations between said characteristics and the extent to which CSEPs were able to contribute.[22 24 28] Information was gathered from CSEPs' websites or articles from a systematic search, or both. The exercise was independently executed by two researchers (RvdB and SvH), and discrepancies were resolved to create one final mapping table (RvdB, SvH and SK). This table was checked again after the interviews to ensure accuracy (SK).

### CSEP interviews

All CSEPs were contacted via publicly available information and invited to participate in interviews. Per CSEP, one affiliated person was invited, who had knowledge about the establishment of the CSEP, its goals and impact. The invitation was accompanied with an information letter regarding the background, aims and procedures of the study, affiliated institutes, and data use and storage. The interview started with an explanation of the study, procedures and informed consent. Written informed consent to participate and record the interview was collected. Each interview was conducted by two researchers (RvdB, SvH or SK), online or in person and lasted approximately 60 min. Debriefing of interviews among the interviewers took place afterwards to evaluate and improve the process and question guide. Within 4 weeks, a summary was sent to the participant, in order to check the accuracy of findings.

The interview guide covered the role of the participant and the aim and activities of the CSEP. Furthermore, to understand the type of practice and the people it appealed to, the organisational structure and background of members (board members and supporters) were discussed. Moreover, establishment motivators, important values, perceived impact of the CSEP and barriers to contribute were discussed. The complete interview guide can be found in online supplemental appendix 2. The interview guide drew on two frameworks. First from the framework from Edelenboss *et al*, who examined the goals, resources, strategies, relations with authorities and impact of stakeholder initiatives in flood risk management.[24] Second, the Research Excellence Framework (2018) was used to retrieve information about the perceived impact.[29] Based on this, impact was defined as: (1) conceptual; impact on knowledge, perceptions and attitudes, (2) instrumental; impact on policy and practice and (3) enduring connectivity; impact on interactions and relationships with public and authorities.[30]

### Patient and public involvement

Patients or the public were not involved in the design, conduct, reporting or dissemination of our study.

### Analysis

The interviews were transcribed verbatim and thematic analysis was performed with the software MAXQDA 2022. An exploratory analysis of the first seven interviews was independently done by two researchers (RvdB and SvH), which resulted in the development of a preliminary codebook. Codes were assigned to recurrent topics and data patterns were identified.[31] These codes were discussed, and discrepancies were resolved (RvdB, SvH and SK). Consequently, two researchers (RvdB and SvH) thematically coded the remaining interviews. Throughout the entire analysis, new inductive codes were added to the codebook through an iterative coding process. After coding, the researchers reconvened to discuss the derived categories and themes (RvdB, SvH and SK). This iterative process of individual coding, exchange, deliberation, individual learning and application ensured the capturing of important data patterns. Additionally, supportive information from websites regarding relevant findings on activities, motivators for establishment or contributions were used to cross-check and validate data patterns (SK).

## RESULTS

The search yielded 2166 hits. Twenty-two CSEPs were included in the mapping exercise and 14 CSEPs participated in interviews (see figure 1).

### Characteristics of CSEPs

Table 2 displays the mapping of CSEPs. Most CSEPs focused on national COVID-19 management (n=18), while only a few operated locally (n=4). Some CSEPs aimed to influence epidemic management as a whole (n=6), and other CSEPs aimed to influence specific elements, such as information provision (n=3), representing the needs of children and high-risk groups (n=4), face masks (n=3), digital contact tracing (n=1), COVID-19 entry pass (n=1), the nightlife and hospitality industry (n=2), personal protective equipment (PPE) (n=1) and

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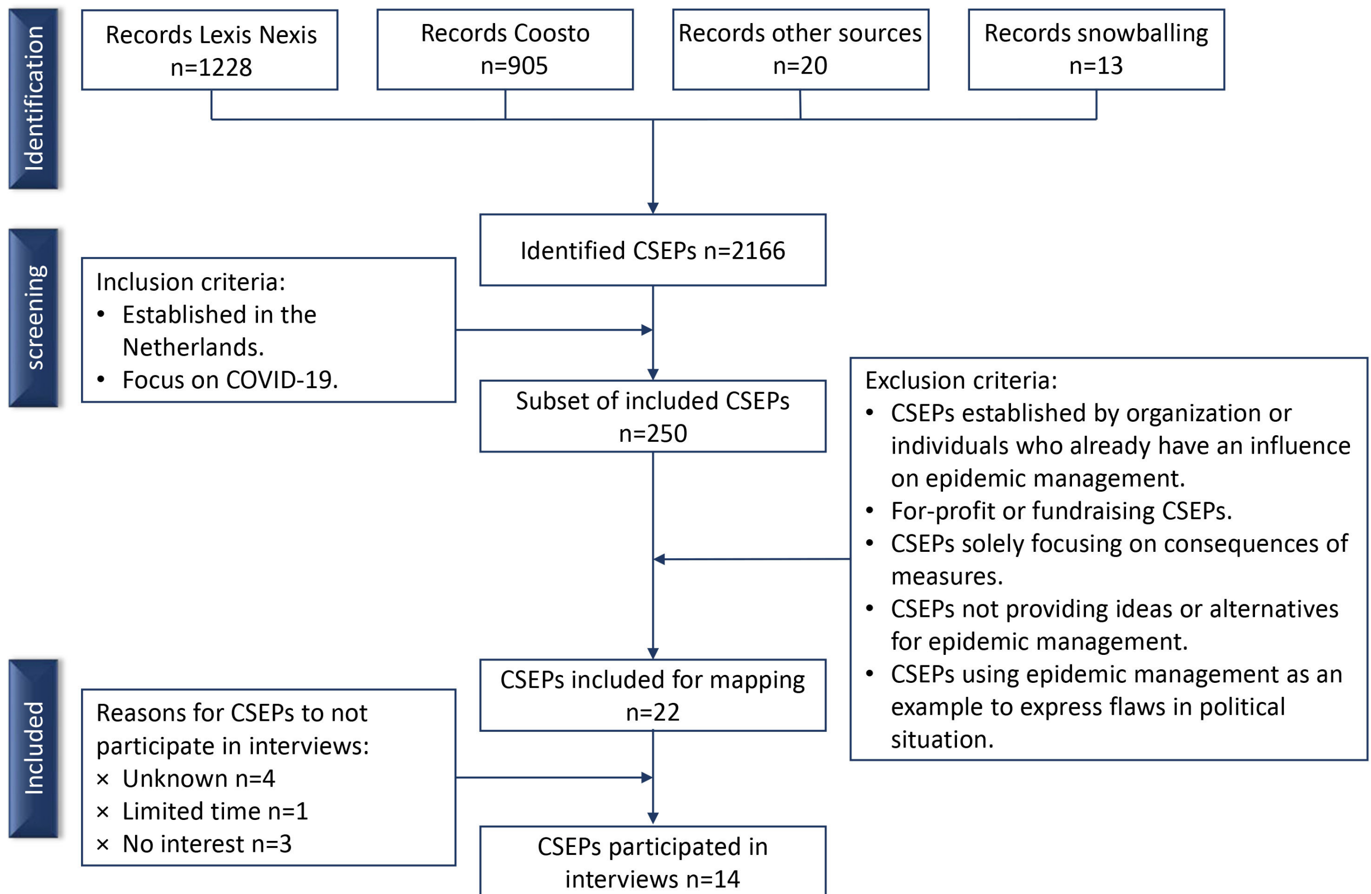


**Figure 1** Flow chart of the screening process to identify and include civil-society engagement practices (CSEPs).

testing (n=1). Many CSEPs aimed to contribute through ideas, information or alternative strategies to control COVID-19 (n=17), while other CSEPs provided practical contributions by supplying equipment and tools (n=5). Ideas, information or alternative strategies were disseminated through websites or social media to raise awareness in the public or authorities. CSEPs often executed activities such as taking legal actions (n=4), writing letters to politicians (n=2), starting petitions (n=2) and distributing equipment (n=3).

### Thematic analysis: interviews

Fourteen of the 22 CSEPs participated in interviews. Reasons to not participate were limited time (n=1), no interest (n=3) and unknown (n=4). For one CSEP, the interview involved two affiliated persons to gather the necessary information. Among the 14 CSEPs, the distribution of characteristics deviated slightly from that of all 22 CSEPs regarding geographical scope (underrepresentation of local CSEPs), and subject of action (not all subjects described in the mapping table were represented). Most interviewed CSEPs were established somewhere between January 2020 and April 2020, while a few others established at the end of 2020 and start of 2021. The number of citizens that joined these CSEPs varied greatly. Some CSEPs indicated that ten to a hundred citizens had active members contributing to plans or ideas, producing equipment or organising events. Also, thousands of citizens subscribed to newsletters, or occurring at demonstrations.

#### *Motivators to establish CSEP*

The interviews revealed five motivators for establishing CSEPs: (1) shortage of PPE, (2) perceived lack of action from government, (3) perceived lack of expert and societal diversity, (4) perceived lack of democratic values and (5) sense of solidarity. CSEPs that wanted to contribute practically by producing equipment, expressed two motivators for establishment. First, the shortage of PPE (1): Participants mentioned that they observed shortages of PPE such as face masks and disinfectant, especially at the beginning of the epidemic, and wanted to contribute by producing this. Some participants indicated that they had technical solutions already available (corresponding quotation in table 3). The second motivator expressed by some participants was a feeling at the beginning of COVID-19 pandemic that the government was not taking appropriate or too little action (2) and was downplaying the seriousness of the situation (corresponding quotation in table 3). Many participants felt that more was needed to prepare for a possible pandemic or protection of vulnerable people, reacting on information regarding the international epidemic situation and other countries' strategies. For example, most CSEPs advocated to

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**Table 2** Mapping table of the 22 civil-society engagement practices (CSEPs)

| | Geographical scope | Subject of action | Aim | Strategy and activities | Founders |
|---|---|---|---|---|---|
| CSEP 1 | National | Face masks | To change mandatory face mask use into voluntary. | Informative platform regarding scientific and non-scientific literature on the functionality of face masks; online publications about, for example, the government handling of mandatory face mask use; legal actions such as a proceeding against the state to undo the mandatory face mask use; creating societal awareness by promoting their message on, for example, postcards, posters and t-shirts. | Citizens |
| CSEP 2 | National | COVID-19 management | To be critical and create space for dialogue about COVID-19 management, to ensure limited damage of measures on society and protect freedom of choice. | Informative platform regarding the numbers of the COVID-19 epidemic such as the basic reproduction no of SARS-CoV-II, the mortality rate and the severity of COVID-19; publications online and in newspapers; letters to house of representatives. | Citizens with a medical background |
| CSEP 3 | National | COVID-19 management | To diversify the perspectives in COVID-19 management, focusing on incorporating the societal and economical perspectives. | Action plan to recover from COVID-19 and built back a resilient society considering values as inequality and democracy; platform for idea sharing about COVID-19, for example, about how to best recover from the epidemic. | Citizens with a social science or economic background |
| CSEP 4 | Local | COVID-19 information provision | To improve information provision about COVID-19 for hard-to-reach populations. | Information leaflets in multiple languages about among other the implemented restriction measures. | Citizens |
| CSEP 5 | National | COVID-19 management | To implement a nationwide COVID-19 management strategy focused on total elimination. | Informative platform regarding containment strategies, COVID-19 testing and contact tracing, herd immunity, face masks and more; a five-point action plan for COVID-19 management, focusing on containment and eradication of COVID-19 by primarily increasing testing, tracing and isolation; a petition to call for immediate containment of the COVID-19 virus, with proposed measures; contributing to legal actions such as a lawsuit against the government to demand honest and complete communication regarding COVID-19. | Citizens |
| CSEP 6 | National | Digital contact tracing | To develop an application to support contact tracing and information provision about restriction measures. | Producing an application that uses a Group-Tracing Approach in order to inform individuals of infection risks. | Citizens with a technical background |
| CSEP 7 | National | COVID-19 management | To implement epidemic management that integrates all various perspectives relevant in COVID-19 management. | Alternative COVID-19 management plan primarily focusing on risk-driven policies and protection of vulnerable populations, providing autonomy to citizens on how much risk (of infection) they are willing to take; campaigning for their plans with posters displayed all over the streets in the Netherlands, occasional media appearances and press releases. | Citizens with a medical, economic or social science background |
| CSEP 8 | National | Hospitality industry | To open the hospitality industry with appropriate restriction measures and ensure financial support for this industry. | Exit strategy to open the hospitality industry, for example, including social distancing and financial support arrangements; letters to the house of representatives. | Citizens working in hospitality industries |

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Table 2 Continued

| | Geographical scope | Subject of action | Aim | Strategy and activities | Founders |
|---|---|---|---|---|---|
| CSEP 9 | National | Children and schools | To represent the interest, needs and rights of children in education and their overall well-being in COVID-19 management. | Informative platform regarding the effects of restriction measures in schools such as face masks; online publications such as columns to provide support to parents during the epidemic; legal actions such as a proceeding against the state to undo mandatory face mask use in schools. | Citizens, parents of school-aged children |
| CSEP 10 | Local | COVID-19 information provision | To draw attention about COVID-19 and restriction measures among youth. | Rap song about COVID-19 and restrictions measures. | Citizens |
| CSEP 11 | National | Face masks | To promote the protective use and availability of face masks. | Producing face mask frames and other prevention measures; informative platform on the functionality and usage of face masks. | Citizens with a medical or technical background |
| CSEP 12 | Local | Face masks | To produce face masks and make them available for people with vital professions. | Producing free face masks. | Citizens |
| CSEP 13 | National | COVID-19 entry pass | To stop the implementation of the COVID-19 entry pass to ensure no division in society and prevent violation of fundamental rights and physical integrity. | Manifesto against the implementation of the COVID-19 entry pass with substantiation and promotion of manifesto in (social) media. | Citizens with a medical, social science, and political background |
| CSEP 14 | National | COVID-19 management | To contribute to COVID-19 management as an independent party, by functioning as an advisory organ for the government. | Analysing scientific and non-scientific information to create reports, build up information files and send letters to representatives about, for example, testing strategies; advising about national COVID-19 management based on members' backgrounds in relevant fields, and reporting this advice on social media and their website. | Citizens with a medical, technical, economic or social science background |
| CSEP 15 | National | Children and schools | To ensure the safety of children in schools by actively trying to influence restriction measures in schools. | Informative platform regarding (non-)scientific literature on the role of children and schools in the COVID-19 epidemic; sharing ideas about COVID-19 management; crowdfunding; contributing to legal actions such as legal proceedings against the government to demand fitting restriction measures for children and schools. | Citizens |
| CSEP 16 | National | The Nightlife | To open the nightlife and prevent loneliness in youth, bankruptcy and unemployment in the nightlife sector. | Action plan to open the nightlife industry by implementing measures such as ventilation, social distancing, marked walking routes, and placing hand disinfection stations. | Citizens |
| CSEP 17 | National | COVID-19 management | To create a resilient and epidemic proof democracy. | Creating awareness about important societal values such as physical autonomy and education of children; comprising ideas on making COVID-19 management more democratic and creating a resilient society; organising dialogues about pandemic preparedness with citizens (among other themes). | Citizens with a medical or social science background |
| CSEP 18 | National | COVID-19 information provision | To collect and provide information (national and international) regarding COVID-19 and its management. | Informative platform on various themes such as Long-COVID, aerosols and COVID-19 vaccination. | Citizens |

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Table 2 Continued

| | Geographical scope | Subject of action | Aim | Strategy and activities | Founders |
|---|---|---|---|---|---|
| CSEP 19 | National | Risk groups | To represent the needs of people with high risk for COVID-19 in COVID-19 management. | Plans to better represent the needs of high-risk groups in COVID-19 management policies; campaigning for containment policies to open society for all; social actions to draw attention to high-risk groups, for example, by sharing experiences through video and posters, on social media and real life, or by sending post cards to the house of representatives. | Citizens in high-risk group |
| CSEP 20 | National | Personal protective equipment | To produce face shield and other protective equipment for policy and healthcare workers. | Producing and distributing protective equipment in, for example, nursing homes. | Citizens with a technical background |
| CSEP 21 | National | Risk groups | To represent the needs of people with high risk for COVID-19 in COVID-19 management. | Plans to ensure safe participation in society for all; petitions to ensure online education for all students and vaccine accessibility for high-risk people; social actions such as organising webinars and distributing posters on social media and to the house of representatives; letters to house of representatives. | Citizens in high-risk group |
| CSEP 22 | Local | COVID-19 testing | To contain virus transmission in the mosque and surrounding area. | Set up of a local test street for visitors of the mosque and family-members of visitors. | Citizens (management of mosque) |

CSEPs, civil-society engagement practices.

employ a precautionary principle, preferring early stage containment and thereby preventing lockdown measures later on. This strategy would allow for more time to learn about the virus and produce vaccines, and would possibly be better for the long term, for example, fewer learning disruptions and mental health issues.

Participants perceived a lack of expert and societal diversity in epidemic management (3) as a motivator. They believed that epidemic management was mainly based on the perspectives of medical experts and focused solely on infection rates. Participants felt that adopting a more multidisciplinary view that integrated behavioural components, mental health and other medical perspectives would lead to better decision-making and decrease broader societal issues such as loneliness, delayed care and public dissatisfaction. CSEPs emerged to support alternative management strategies reflecting experts from various backgrounds, and some were established to

Table 3 Supporting quotes for the five identified motivators for establishing CSEPs

| Theme | Quote |
|---|---|
| 1. Shortage of PPE | 'The only protective equipment available were plastic gloves, so I started researching protective equipment, and found that face shields might be an alternative… That's how I started producing face shields for a family member, which expanded to other organizations.' (practical CSEP) |
| 2. Government not taking appropriate or too little action | 'I was very frustrated that nothing happened in the first few weeks, and that there were many difficulties in collaboration between municipalities. So at a certain point we said, let's just start our own platform.' (practical CSEP) |
| 3. Lack of expert and societal diversity in epidemic management | 'We noticed that perspectives of other groups in society received more attention than ours did. So therefore we created our own stage, our own place, which became this practice.' (CSEP, representing a societal group) |
| 4. Lack of democratic values in epidemic management | 'It was unimaginable for me that debate could not take place while very drastic measures were implemented and there was such a complicated political situation. When a situation is complicated and measures are necessary, you have to be able to disagree.'(CSEP, conceptualization of epidemic management) |
| 5. Sense of solidarity | '…You have developed a certain skill and suddenly the world is confronted with a threat and you want to do something. You want to do good. I noticed this in the people who joined our practice and worked for free.' (practical CSEP) |

CSEPs, civil-society engagement practices; PPE, personal protective equipment.

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represent specific citizen groups in society and give them a voice to ensure equal value to all lives in society (see table 3).

Another motivator was a perceived lack of democratic values in epidemic management (4). Participants already had this feeling since the start of the epidemic, stemming from the observation that only a select group of people were making decisions in management. Participants experienced no room for opinion-forming in society preceding decision-making. Contributing to this was the experience that if one would critique the course of COVID-19 management, it would be dismissed as unfavourable for society. As such, some participants emphasised the need for dialogue and critical reflection in order to exchange perspectives between stakeholders before decision-making (see table 3).

A fifth motivator according to some participants was the sense of solidarity (5) or motivation to help society. This provided them with a sense of strength and belonging, by contributing to something they strongly believed would help society (see table 3).

### *CSEPs' perceptions of contributing to epidemic management and society*

#### Contributions to management

After establishment, CSEPs tried to engage in decision-making through contact with stakeholders. The most mentioned stakeholders were hospitals, mayors, the MHS, the National Institute for Public Health and the Environment, politicians and ministries (referred to as key stakeholders). Several participants indicated that their CSEP was able to contribute by contacting key stakeholders or raising attention to issues through activities. Some participants expressed that these raised issues were brought up during debates, hearings or discussions of key stakeholders (corresponding quotation in table 4). Furthermore, 7 of the 14 CSEP indicated to have accomplished alterations to national management. According to multiple participants, one contribution was to the implementation of face mask use, social distancing and ventilation measures in schools. They said to have accomplished this by filing a lawsuit and meetings with politicians in support of these measures. Another example is the contribution to the dismissal of the so called 2G-system (see table 4). The 2G-system was proposed as a law implicating that only people who had been vaccinated or recovered from COVID-19 were allowed to access events and facilities such as bars and restaurants. According to our participants, after a few CSEPs lobbied against this law (among other groups in society) by meetings with politicians and propagating the dismissal in the media, the law was discontinued. Moreover, one participant reported contributing to the extension of mandatory face mask use in public transport, by sending letters to authorities and meetings with politicians.

#### Contributions to society

All participants expressed to have contributed to society with their CSEPs, such as influencing perceptions and opinions of citizens by media appearances and creating awareness by regional and national campaigns, about, for example, COVID-19 vaccinations, more stringent policies

**Table 4** Supporting quotes for the CSEPs' perceptions of contributions to epidemic management and society, and perceived barriers

| Theme | Quote |
|---|---|
| Contributing to epidemic management and society | |
| Raising attention of key stakeholders | 'We had a meeting with various politicians in response to our activities. We heard that part of the issues we discussed with them were brought up during parliamentary debates, so in that sense it had some effect.' (CSEP, conceptualization of epidemic management) |
| Alterations to policy | 'When we started the CSEP, there was a very concrete threat of implementing the 2G-system to manage COVID-19… When we were done, that policy was off the table.' (CSEP, conceptualization of epidemic management, referring to the 2G-system, a policy in which only people who were vaccinated or recovered from COVID-19 were allowed entry to restaurants and events) |
| Eye opener to other viewpoints for society | 'For a lot of people, we have been an eyeopener that there is also another opinion possible. We have noticed that a lot of people have felt very lonely in their position, for example at work. There seemed to be a taboo to be critical.'(CSEP, conceptualization of epidemic management, referring to epidemic management in general, and more specifically to the debate on COVID-19 vaccines) |
| Barriers to contribute | |
| Hindering full potential of CSEP | 'From a governmental point of view, this [CSEPs] is untapped potential from which, I think, the government can gain much more. There are a lot of resource-full citizens who are good at organizing themselves… I see much more of a supporting role for the government.' (practical CSEP) |
| Contact with key stakeholders | '[The National Institute involved in emergency management] is actually impenetrable. We have often called the institute, but there were no possibilities.' (CSEP, conceptualization of epidemic management) |
| Toxicity of COVID-19 debate | 'We became part of the debate and therefore also a part of the toxicity of the debate. I personally have called the police a few times.' (CSEP, conceptualization of epidemic management) |

CSEPs, civil-society engagement practices.



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and expert diversity in management. For example, one participant stated that citizens experienced the perspective of that CSEP as an eyeopener, showing citizens the possibility to other viewpoints on COVID-19 management than solely the viewpoints portrayed by authorities and media (see table 4). Furthermore, many participants stated that their CSEPs also seemingly functioned as a support system for citizens. First, because many CSEP propagated different perspectives regarding COVID-19 management, as such providing a feeling of understanding and acceptance to citizens with corresponding perspectives. Second, because some CSEPs focused on representing and supporting the needs of specific societal groups such as high-risk populations and children. For the CSEPs that contributed practically, participants expressed that many people with vital professions such as healthcare personnel in hospitals, youth care and nursing homes, felt supported.

### Barriers to contribution

All participants expressed dissatisfaction with their contributions and hoped for greater adoption by key stakeholders. When discussing how this perceived lack of contributions came about, all participants indicated to have encountered obstacles, that hindered their full potential (see table 4). These obstacles included difficulty establishing contact with key stakeholders and feeling unheard during contact (see table 4). They felt undermined, especially when sharing ideas, but not receiving any follow-up from key stakeholders. Some participants expressed the feeling that some key stakeholders would not take them seriously due to their different opinion regarding COVID-19 management. These obstacles led to demotivation and doubts about continuing as CSEPs. Participants also mentioned that certain key stakeholders expressed interest in their ideas, but deemed it unusable in decision-making, as key stakeholders were tied to certain boundaries in decision-making in power and other interests.

Society also posed barriers, as participants experienced a toxic and polarising debate, which necessitated caution in expressing views. Some CSEPs faced threats, offensive messages and consequences from employers for speaking out (see table 4). Conversely, some participants noted private support from key stakeholders, but not publicly. Participants suggested that this might be because key stakeholders feared to receive negative backlash from society. Participants felt that only two viewpoints were accepted: you either support management and the restrictions, or you do not, with no space for possible other perspectives. As a possible solution, a few CSEPs expressed they attempted to open the dialogue and create more understanding among people.

## DISCUSSION

Worldwide, CSEPs emerged to contribute to COVID-19 management with new ideas, alternative policies and self-produced tools. The present study provides an overview of 22 CSEPs that emerged in the Netherlands, operating between January 2020 and January 2022. Most CSEPs were nationally oriented, focusing on topics such as protective equipment, information provision, protecting children, continuing education, advocating for high-risk groups and urging for more diverse perspectives in epidemic management. The included CSEPs had various organisational forms, ranging from informative platforms, production and distribution facilities, to online and offline campaigns. Fourteen CSEPs were interviewed and indicated that the motivators for set up were a shortage of PPE, perceived lack of governmental action, perceived lack of diversity in perspectives in epidemic management, perceived lack of democratic values and sense of solidarity.

The motivators for establishing CSEPs in this study show overlap with similar citizen-led practices in flood risk management. In the field of flood risk management, a transition is already ongoing from a technocentric system (values centred on science and expert knowledge) to a sociotechnical one (values centred on wider social, economic and political processes), in which society, including practices set up by citizens, are engaged in planning, prioritisation and delivery of management.[32 33] Seebauer *et al* studied 70 citizen initiatives in flood risk management such as local preventive action, flood response, flood recovery and contesting current policies with governmental bodies across multiple countries such as Germany, the UK and the USA. They described that these initiatives are formed out of frustration with the status quo or as a response to a perceived lack of urgency from authorities or due to the high impact of policies on daily lives.[22] Igalla *et al* executed a systematic literature review on 89 citizen initiatives, defined as activities of citizens aimed at self-organising goods or services for their community, established in various continents such as Africa, Asia and Europe. This review focused on the outcomes of initiatives and which factors stimulated or hampered accomplishments. In this review, failure of the government or market to provide public goods was identified as a motivator to establish engagement practices.[34] Deducing from above-mentioned literature, the establishing of CSEPs may contain a message; citizens mobilise to improve practices that do not align with their abilities, needs or priorities. Understanding CSEPs can help identify important elements in epidemic management that citizens mobilise on and where their input can be valuable. This can be used to design a cocreation approach to management policies, that are more tailored to the needs and capabilities of society. Specific motivators for epidemic management, not observed in other literature, were a lack of diversity of perspectives and lack of democratic values. These could be attributed to the unique setting of the COVID-19 epidemic, that surpasses local crises in which citizen engagement is more common.[22 34] Also, time pressure in decision-making might have hindered the preservation of diversity and

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democracy, leading to the emergence of CSEPs to hold authorities accountable.[35]

Several CSEPs believed to have contributed to alterations in epidemic management. One contribution they indicated to have made was promoting awareness on inclusive and fair policies, considering high-risk groups, children and unvaccinated persons. Respondents perceived a lack of such awareness in authorities, that focused more on the majority and not on the minorities in society, both nationally and globally.[36] Furthermore, many CSEPs propagated for a more multidisciplinary approach to epidemic management, that might have contributed to the later implementation of such an approach in the Netherlands.[37] This suggests that CSEPs might have the ability to counterpart authorities and help them reflect on including relevant societal values in epidemic management. In this manner, CSEPs could potentially play a role, not only in comparable settings to the Netherlands, but also in low-resource settings. For example, Wilkinson *et al* describe that bottom-up approaches in informal urban settlements can allow for the setting's diversity and complexity when responding to COVID-19.[30] Moreover, Dintrans *et al* identified 34 initiatives that implemented quick and flexible solutions tailored to community needs during the COVID-19 pandemic in Latin America and the Caribbean. These initiatives were mostly established by community-level organisations, and played a role by supporting the COVID-19 response, at times when authorities were unable to.[38] Despite these examples, little literature is currently available regarding the role of CSEPs in epidemic management in both low-resource and high-resource settings, and further research would be valuable.

CSEPs indicated to have influenced society, by changing citizens' perception and knowledge of the COVID-19 pandemic and functioned as support systems. This makes CSEPs a potential bridge between citizens and authorities and facilitating cocreation of management that is better in line with the needs of various stakeholders. CSEPs may play a role by acquiring signals of citizens and communicating these to authorities, in order to develop policies that better align with the needs and values of citizens. However, the diversity of perspectives found in CSEPs could complicate this co-creation process. It provides both a challenge and opportunity to increase the awareness of diverse perspectives and stimulate dialogue on societal priorities.

Most CSEPs were not satisfied with their contributions and felt that they were largely dependent on the ability and willingness of authorities with decision-making power. In this study, we have portrayed the current and possible future roles for CSEPs as stakeholders in epidemic management, however, in order to draw definitive conclusions, in-depth research on the perspectives of other stakeholders is needed. However, regarding the experienced barriers of CSEPs, difficulties in establishing contact and feeling unheard are well-known issues in engagement efforts, which could already improve through better accessibility and communication with stakeholders.[39 40]

### Limitations

In this study, CSEPs could have been overlooked, specifically local CSEPs that did not position themselves online. Furthermore, we did not search academic literature databases as to our knowledge, little to no research was executed regarding this topic at that time and these CSEPs were mostly profiling themselves in the public sphere instead of the academic sphere. The interviewed subset of the 14 of the 22 CSEPs was not fully representative on all characteristics of all CSEPs. Furthermore, we only interviewed one participant per CSEP (except for one CSEP, of which we interviewed two participants), which means that the results are based on only their perspective. The participant was, in most cases, involved in the establishment of the CSEP and thus had proficient knowledge. To secure anonymity, the results are presented in an aggregated form with little detail on individual CSEPs, as we did not want to burden our participants with possible backlash. Another consideration is that our institute had an important advisory role, which could have affected responses. Being aware of this, we built connections with participants and encouraged them to speak freely, even when expressing criticism on mentioned institute. We viewed this study not only as an opportunity to better understand the landscape of CSEPs, but also as an opportunity to build bridges between the mentioned institute and CSEPs.

### Recommendations

For future outbreaks and epidemics, we recommend to create and maintain overviews of the landscape of CSEPs and corresponding goals, and identify important elements of epidemic management that CSEPs do not align with. These elements should be reflected on by authorities, in order to identify possible improvements. Furthermore, we recommend for authorities and CSEPs to create and maintain meaningful dialogue during times of crisis, and to be open for one another's viewpoints. A first step is to find a mode to conduct dialogue appropriate to the needs of stakeholders and the epidemic context.

## CONCLUSION

Overall, CSEPs fulfil various roles during pandemics, which we have seen during the COVID-19 epidemic. CSEPs can provide new ideas or alternative policies, produce and distribute equipment, monitor development of decisions on restriction measures, inform and support citizens, create space for citizens to seek connection, and campaign for a more pluralistic and democratic approach to COVID-19 management. Some of these contributions seem to have been taken to heart by authorities in the Netherlands, and thereby impacted COVID-19 management, and some attempts of CSEPs have not. In other contexts and countries, these types of

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practices have contributed to enhancing awareness and stimulating active citizenship, which is a relevant function in times of crises, when everyone has a role to fulfil. Furthermore, by gaining insight in the motivation for citizens to mobilise and establish CSEPs, one can draw lessons to improve epidemic management and allow for a closer connection to the abilities, values and priorities of the broader public.

**Author affiliations**
[1]National Coordination Centre for Communicable Disease Control, National Institute for Public Health and the Environment, Bilthoven, The Netherlands
[2]Athena Institute, Faculty of Science, VU University Amsterdam, Amsterdam, The Netherlands
[3]Primary and Community Care, Radboud University Medical Centre, Nijmegen, The Netherlands

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**ORCID iD**
Sophie Kemper http://orcid.org/0000-0003-4133-5344

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