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REVIEW ARTICLE

Co-creating a Mpox Elimination Campaign in the WHO European Region: The Central Role of Affected Communities

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Between May 2022 and September 2023, the World Health Organization (WHO) Regional Office for Europe engaged in a collaborative effort with affected communities to address the outbreak of mpox in the region. This concerted endeavor led to the development of a risk communication campaign specifically tailored to address the perceptions and needs of the target audience, thereby contributing to the control and the long-term goal of mpox elimination.

Various community engagement interventions were implemented, including the establishment of an informal civil society organizations' working group to provide feedback on the WHO mpox campaign, webinars targeting event organizers, and roundtable discussions with country-level responders. The invaluable feedback garnered from the community was utilized to customize materials and extend outreach to groups that may have been overlooked in the initial response.

This successful initiative underscored the immense potential of placing communities at the forefront of emergency response efforts, equipping them with the necessary resources, engagement, and empowerment. This offers 1 model of co-creation that can be applied to health emergencies. It is asserted that the pivotal role played by communities in this response should be recognized as a valuable lesson and incorporated into all emergency responses, ensuring sustained community involvement and empowerment throughout the entire emergency cycle.

Keywords. civil society organizations; community engagement; emergency preparedness; infectious disease outbreaks; mpox.

Mpox, the disease caused by infection with *Orthopoxvirus monkeypox*, is a zoonotic disease that has historically affected countries in Central and Western Africa and constitutes a significant public health threat as a reemerging pathogen [1]. (The case definitions for mpox can be found at: https://www.who.int/emergencies/outbreak-toolkit/disease-outbreak-toolboxes/mpox-outbreak-toolbox). Following the first case on 7 May 2022, the simultaneous emergence of more cases of mpox in several European countries and beyond Europe led the World Health Organization (WHO) to declare a public health emergency of international concern in July 2022 [2] (https://www.who.int/news/item/14-08-2024-who-director-general-declares-mpox-outbreak-a-public-health-emergency-of-international-concern). The earliest known mpox case, identified through the European Surveillance System, had a specimen date of 7 March 2022, discovered via retrospective testing. The first reported symptom onset was 17 April 2022. Initial cases were part of a family cluster and among attendees of sexual health services in the United Kingdom (UK) [3]. Sexually active gay men, bisexual men, and other men who have sex with men (GBMSM) were disproportionately affected and cases occurred among sex workers and transgender and gender-diverse people. During the 2022 outbreak, racist and stigmatizing language online, in other settings, and in some communities was observed and reported to the WHO; in accordance with the *International Classification of Diseases* update process, the WHO held consultations to gather views from a range of experts, as well as countries and the general public. Following this process, "mpox" became the preferred term, replacing monkeypox (see https://www.who.int/news/item/28-11-2022-who-recommends-new-name-for-monkeypox-disease).

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Risk communication, community engagement, and infodemic management (RCCE-IM) interventions have been integral to these efforts. In particular, community engagement (CE) has been at the forefront of the pandemic response and has proven to be instrumental in controlling the mpox outbreak [4]. Embracing CE as an integral ethical component in outbreak responses is crucial, especially when vulnerable populations are affected [5].

In response to different health emergencies, the WHO Regional Office for Europe has recognized the importance of co-development and co-delivery of interventions with affected communities [6]. Co-development, or co-creation, brings forth 3 main vital benefits: (1) appropriateness of the response by ensuring cultural sensitivity and, therefore, increased acceptance from communities; (2) maximization of resources by reducing duplication of efforts; and (3) leveraging already established community structures, systems, and skills [7].

This article explores the role of co-development and co-delivery of interventions toward mpox control and elimination as a resource for health authorities, partners, and other stakeholders working in health emergencies.

METHODS: SETTING AN INCLUSIVE RESPONSE

By late 2022 and early 2023, the tide had turned with the number of mpox cases decreasing markedly, and new cases stopped being reported systematically in most Member States of the WHO European Region (comprised of 53 Member States covering Western, Central, and Eastern Europe, the Western Balkans, the Caucasus, and Central Asia). Concurrently, the WHO Regional Office for Europe made substantial strides in the systematic planning and execution of strategies toward mpox elimination, by offering an integrated approach that leverages a whole-of-society collaboration for effective disease control [8].

The importance of RCCE-IM was demonstrated by active engagement with affected community representatives and civil society organizations (CSOs) in the mpox outbreak from June 2022 to September 2023 in a European region-wide campaign. Response interventions included co-creating a toolkit for event organizers during the summer of 2022, identifying trusted community influencers to co-deliver important information and advice, and developing RCCE-IM strategies and content supporting the mpox elimination strategy launched in 2023 [9, 10].

The WHO Regional Office for Europe established an informal working group (WG) for CSOs in June 2022, which regularly met during the peak period of the mpox outbreak that occurred between June and November 2022 and subsequently reconvened meetings throughout 2023. The WG set up a 2-way channel for CSOs to co-develop and co-design interventions, such as hosting webinars on relevant topics to the mpox response and identifying community influencers to co-deliver public health advice.

Table 1. Overview of Civil Society Organizations Included in the Mpox Working Group

Type of Organization	No. of Organizations
National or local HIV groups	10
Regional LGBTQI+ groups	2
Sexual health service providers	2
Academic research institutions	2
Regional network of sex workers	1
Regional HIV organizations	1

Abbreviations: HIV, human immunodeficiency virus; LGBTQI+, lesbian, gay, bisexual, transgender, queer or questioning, intersex, and others.

During an initial informal briefing on the mpox outbreak in June 2022, CSOs were invited to express their interest in participating in the WG, resulting in 8 CSOs joining. This process was repeated during an informal consultation in March 2023, leading to an additional 10 CSOs joining the WG. Members included CSOs working on human immunodeficiency virus (HIV) prevention, LGBTQI+ (lesbian, gay, bisexual, transgender, queer or questioning, intersex, and others), and sex workers' rights. The WG is composed of representatives from HIV/AIDS organizations, advocates, and health professional representatives who attended the informal briefings, and there were no formal inclusion criteria. The representatives were from Cyprus, Ireland, Italy, France, Germany, Portugal, Spain, and the UK, both from national organizations and regional European networks (Table 1).

From 2 June 2022 to 28 August 2023, the CSO WG convened 15 meetings in summer and autumn 2022 and were held every other week and monthly in spring and summer 2023 with varying participation from the 18 CSOs depending on their availability and interest. The objective was to offer feedback on the toolkit developed in 2022; the toolkit underwent an update in May 2023, alongside the drafting of campaign messages and materials. The 2022 toolkit, whose target audience was event organizers, comprised comprehensive RCCE-IM guidance during pre-event, event, and post-event phases. Relevant components included social media tiles, laminated posters, video clips from a press conference held with LGBTQI+ Pride event organizers, talking points for event hosts, an animated video for big screens, and an informative leaflet on mpox. The 2023 toolkit had a broader audience of health authorities, CSOs, event organizers, and sex-on-premise venues. Table 2 presents the key recommendations based on feedback from CSOs, gathered through general deliberations and circulating drafts for comment during the mpox response in 2022 and 2023.

Table 2. Summary of Key Recommendations From Civil Society Organizations and Associated World Health Organization Action, 2022–2023

Key Recommendations From CSOs	Year	WHO Action
It is essential to directly target sexually active GBMSM (both cisgender and transgender) using explicit imagery of mpox signs and symptoms that aligns with their experiences and identities. Such imagery resonates with them, fostering a sense of identification.	2022	Photos of rashes and lesions (around the face) and the body were included in social media materials, and a photo library was made available of genital lesions and rashes on request.
Addressing stigma toward the LGBTQI+ community, which experiences marginalization in numerous countries, is paramount. However, it is crucial not to let this overshadow the need for targeted interventions within the affected communities.	2022	Materials within the 2022 toolkit were developed to target members of affected populations attending mass gatherings.
LGBTQI+ representatives expressed concern that canceling large events like Pride would stigmatize their community and be counterproductive. Sexual networks would continue to be active but become less visible and harder to reach.	2022	This feedback was taken on board by the Regional Office in its statements on mpox, which included specific recommendations not to postpone or cancel Pride events.
Approaches need to consider the specific situation and context in different countries.	2022	The WHO Regional Office for Europe reached out to community groups doing outreach for 24 large and mass gathering events in 12 countries across the region.
Health authorities should consider leveraging mass events for outreach and engagement rather than opting for cancellation.	2022	The toolkit for event organizers focused on how to organize mass gatherings safely and reach participants with public health advice.
Reaching groups left out of the response is important to engage the LGBTQI+ community and its more marginalized members who are disproportionately affected.	2023	Marginalized and underreached groups within the LGBTQI+ community that may have been left out of the mpox response, such as sex workers and transgender and gender-diverse people, were explicitly included in the updated toolkit published in May 2023. Additional settings, such as sex-on-premise venues, were also included.
Promoting preventive measures, including vaccination, should be a key focus for spring and summer 2023 mass gatherings.	2023	News stories and photo and video series published online focused on CSOs within WHO Regional Office for Europe channels promoting mpox vaccination and encouraging preventive measures. Once the vaccination was made available and intradermal use approved, the 2023 RCCE-IM toolkit for mpox elimination included materials on vaccination with recognition that availability of vaccines varies across the region.[a]
Community organizations reported informally that a considerable amount of their outreach and social media initiatives were funded independently, frequently by diverting resources from other projects.	2022–2023	Presentations to Member States and policy briefs included recommendations to fund civil society.

Abbreviations: CSO, civil society organization; GBMSM, gay men, bisexual men, and other men who have sex with men; LGBTQI+, lesbian, gay, bisexual, transgender, queer or questioning, intersex, and others; RCCE-IM, risk communication, community engagement, and infodemic management; WHO, World Health Organization.

[a]More information on recommendations regarding vaccination can be found in the WHO Europe policy brief on vaccination: https://iris.who.int/bitstream/handle/10665/361985/WHO-EURO-2022-5988-45753-65829-eng.pdf?sequence=1.

RESULTS: A CHRONOLOGY OF CSO ENGAGEMENT

Two-Way Communication Was Established With CSOs at the Beginning of the Response

The mpox outbreak coincided with the start of the season during which LGBTQI+ Pride events were held in cities across Europe. Several roundtables, both online and in person, followed, initiated by the WHO Regional Office for Europe and country offices to foster dialogue between health authorities and communities affected by mpox. CSOs also organized their own webinars; for instance, a regional network working in Eastern Europe and Central Asia hosted a webinar with CSOs from the UK and a WHO expert to learn from ongoing experience. An overview is provided in Table 3.

The Second Year of Mpox Response Was Conducted With Communities at the Core

In early 2023, efforts began to develop a regional strategy for mpox elimination. Therefore, the WHO Regional Office for Europe held an informal consultation with the CSO WG to gather insights on community priorities toward this goal. This included feedback to update the toolkit for event organizers based on lessons learned and emerging needs, including engaging groups that might have been left out of the initial response. An advanced draft of a WHO Regional Office for Europe policy brief containing the strategy for mpox control was shared with members of the informal CSO WG for review, and their feedback was consolidated into the final document [8].

As a result, the 2023 mpox elimination campaign launch in May consisted of a range of products and activities benefiting even more from communities' insights and outreach. The campaign launch included a social media live event with community representatives; a web story leveraging the 1-year mark to applaud country and community achievements and call for renewed efforts to eliminate mpox in the region; the publication of a compendium of case studies featuring the role of communities at the core of the mpox response [11]; the publication of an updated mpox toolkit (co-developed and tested with CSOs with updated public health advice and considerations for additional affected communities); social media tiles (tested with CSOs); and videos of community members reflecting on successes and challenges of the mpox response [11].

Table 3. Overview of World Health Organization–Organized Webinars

Date	Location	Group	Purpose/Outcome
27 July 2022	Online—regional	LGBTQI+ Pride event organizers	The primary focus of the webinar was unveiling the 2022 mpox toolkit, jointly created by the WHO Regional Office for Europe and the ECDC, for their feedback and use. In addition to the RCCE-IM section, this toolkit equipped health authorities and event planners for public health preparedness, risk assessment, EWAR, event-based surveillance, and contact tracing. The utility of these tools was shown through presentations by Portugal's health authorities working on Lisbon Pride, the WHO Country Office in Lithuania preparing for Baltic Pride, and a regional network of Pride event organizers. The webinar also provided a platform for questions from emergency responders.
4 August 2022	Online in Montenegro	Doctors, HIV groups, and civil society	Clinicians and health authorities attended these roundtables, ensuring that emergency responders could receive community insights.
12 August 2022	Online in Armenia	HIV and LGBTQI+ groups, WHO Country Office in Armenia, and UNAIDS	The WHO Expert Talk on mpox, co-organized by the WHO Country Office in Armenia and UNAIDS, brought together >100 representatives and focused on response strategies, testing, and stigma reduction.
23 August 2022	Online in Kazakhstan	HIV and LGBTQI+ groups, WHO Country Office	The ECDC/WHO Europe toolkit was presented and international best practice on engaging communities was presented.
7 September 2022	Online in Kyrgyzstan	HIV groups, WHO Country Office	The ECDC/WHO Europe toolkit was presented and international best practice on engaging communities was presented.
29 September 2022	Czech Republic	Doctors, HIV groups, and CSOs	A special session was held for the LGBTQI+ community in the Czech Republic to prepare organizations working on mpox response with affected communities.
29 November 2022	Online—regional	An informal advisory group of RCCE-IM practitioners, academics, CSO representatives, and international organization representatives	Practitioners from health authorities and academic experts recognized the substantial contribution of community-based organizations' engagement in RCCE-IM in controlling the outbreak. However, they noted the need for more inclusive CSO engagement, particularly considering marginalized groups such as the trans community, migrants, and sex workers based on their expert opinions and feedback received from affected communities. The discussion at the review suggested that more tailored approaches were needed across the region. It highlighted that stigmatization risks could be mitigated through inclusive message creation and the establishment of community feedback networks [30].

Abbreviations: CSO, civil society organization; ECDC, European Centre for Disease Prevention and Control; EWAR, early warning, alert, and response; HIV, human immunodeficiency virus; LGBTQI+, lesbian, gay, bisexual, transgender, queer or questioning, intersex, and others; RCCE-IM, risk communication, community engagement, and infodemic management; UNAIDS, Joint United Nations Programme on HIV/AIDS; WHO, World Health Organization.

Importantly, trusted influencers working with the WHO Regional Office provided a platform to amplify outreach to affected communities and further engage event organizers and target populations. A transgender community leader called for vaccination and protective measures against mpox at a ballroom event in Berlin, Germany, targeting the often-excluded transgender and gender-diverse community. Members of this community at the ballroom were interviewed about their experiences with mpox, and the videos were used to create a social media campaign with the purpose of amplifying the impact of interventions [12]. Similarly, a sexual health advocate from Barcelona shared his personal experience with mpox via media and social channels in 2022. In an interview, he reflected on how he felt when experiencing painful and frightening symptoms of mpox at a time when health information and advice were hard to come by. A UK journalist who had experienced mpox created a podcast series called "What the pox?" discussing the multifaceted aspects of mpox; 1 episode featured the incident manager of the mpox response for the WHO Regional Office for Europe, an academic within the CSO WG, and community representatives [13].

One of the takeaway messages provided by the CSOs in 2023 was the need for a greater emphasis on reaching underserved populations with RCCE-IM interventions, which led the WHO Regional Office for Europe to address these points in campaign content co-designed and co-delivered in the outbreak. This included mpox impacts on sex workers and people living with HIV.

Two men who are part of the affected communities and actively engaged in community work in Barcelona, Spain, were interviewed. They share a passion for advocating for LGBTQI+ rights and combating stigma, with 1 man publicly identifying as a sex worker and the other openly discussing his HIV status. An Argentinian man living in Barcelona, Spain, who is also a volunteer at a sexual health center, used his platform on Instagram to inform his followers about mpox and its risks, especially for people living with HIV [14, 15].

DISCUSSION

During emergencies, CE empowers social groups and networks, leveraging their strengths and capacities to enhance local participation, ownership, adaptability, and communication [16]. Part of this is the increased acceptance and uptake of guidance from health authorities and public health institutions, through the delivery of health information, advice, and interventions by and for affected communities and that these communities trust [17]. Selecting effective communication channels and trusted key influencers is 1 of 4 fundamental RCCE-IM principles leading to increased trust [18]. This article explored approaches of co-development and co-delivery of interventions toward mpox control and elimination for health authorities, partners, and other stakeholders working in health emergencies to implement in future emergencies.

The limited success of public health interventions observed in some emergencies can be attributed to many factors, but one is the use of a one-size-fits-all approach or a top-down methodology for designing the intervention [19]. Engagement tailors interventions and develops localized solutions to tackle the interplay between individuals, communities, and settings [19]. Essential to this approach are partnerships between health authorities and local community actors enabling the co-development and co-delivery of interventions that are tailored to the needs and contexts of affected populations [20].

Co-designing and co-delivering RCCE-IM interventions has been attributed to increased acceptance and uptake of protective measures toward eliminating mpox among affected communities [2]. WHO's future health emergency preparedness, response, and resilience architecture has community protection at its core [21]. Using a community-centered approach and systematic engagement to co-create and co-deliver with community stakeholders across the emergency cycle can be a win-win situation as it simultaneously benefits health authorities, CSOs' affected communities, and national and international organizations. It may also achieve greater community support for emergency preparedness, response, and resilience in future health emergencies.

The primary objective of co-creation is to enhance the inclusion of individuals affected by the policies, programs, measures, or research being carried out for their benefit. This is achieved by actively empowering them to contribute to the entire process and monitoring its outcomes. It enables them to become strong advocates for transformative initiatives and changes in public policies and interventions that effectively address their specific health needs [22].

For example, the experience of CE interventions conducted by the WHO's Regional Office for Europe underscores the imperative of eliminating stigma and discrimination against affected groups across all communication channels, including in legacy media, social media, and healthcare settings. Such prejudice inflicts emotional distress upon communities already grappling with outbreak-related anxieties and hampers the establishment of trust between health authorities, health workers, and these communities. Stigma and discrimination, in turn, negatively impact health-seeking behaviors, accessibility to health services, and the adoption of preventive measures, extending beyond mpox to broader health concerns [10]. Given the current and historical marginalization of many LGBTQI+ communities, it is vital to recognize the influential role of trusted figures within these communities. Co-designing and co-delivering interventions involving representatives from these affected communities can aid health authorities in mitigating stigma and discrimination, building trust, and empowering them to be part of the mpox response. Experience from the WHO Europe mpox campaign demonstrates the possibility of involving communities in tackling stigma. For example, the experiences from men in Barcelona highlight the importance of respectful healthcare interactions and the need for inclusivity and public discussions regarding the outbreak without stigmatization.

In the mpox response in the European region, the co-design and co-delivery of public health campaigns allowed for a tailored approach that considered the unique characteristics and needs of heterogeneous affected communities. Beyond varying cultural practices, language barriers, socioeconomic conditions, and access to healthcare, members of the affected communities broadly include GBMSM, sex workers, transgender and gender-diverse people, migrants, people experiencing homelessness, and racial and ethnic minorities.Similar strategies were adopted across the region by Member States. For example, in the UK, the SHARE multidisciplinary and collaborative research group co-developed and co-produced mpox materials with community organizations. SHARE has an embedded community advisory board grounded in social justice principles, aiming to deliver culturally competent research on health equity in infections [23]. In France, the community association AIDES has developed a response based on 4 levers: links with public authorities, development of actions in the field, communication with the concerned communities, and involvement in research. This community mobilization has been important, sought after, and recognized by public authorities [24]. Evidence outside the European region also highlights that local responses and empowering communities can be effective. For example, as mpox cases surged across Australia, Victoria's Department of Health enlisted local public health units. The South East Public Health Unit at Monash Health implemented targeted initiatives, including capacity building for health professionals, early diagnosis, contact tracing, vaccine delivery, and CE. These efforts led to the effective local elimination of mpox within 6 months [25]. During the coronavirus disease 2019 (COVID-19) pandemic in Bhutan, local government leaders, associations, religious figures, and social media influencers were engaged to disseminate critical information and induce positive behavioral change. The Ministry of Health leveraged existing CE systems, exemplified by the "Our Gyenkhu" campaign, to

engage popular actors, comedians, singers, and creative artists from the Bhutanese entertainment industry in the fight against COVID-19 disinformation [26].

The co-creation and co-delivery approach delineated in this article is merely 1 example. Alternative models exist, such as health authorities directly financing and providing technical guidance to community organizations tackling mpox to develop RCCE-IM initiatives and campaigns. Informal feedback from various community organizations conveyed that a significant portion of community outreach and social media campaigns were self-financed, often utilizing funds reallocated from their other activities. An inclusive governance framework where a community organization directs its campaign and adapts public health advice can facilitate the delivery of RCCE-IM interventions from a trusted organization in harmony with the community's lived experiences. Inclusive governance includes the allocation of financial resources and technical assistance to community organizations to foster a stronger rapport with affected communities.

Within health and community settings, co-development and co-delivery take on various interpretations. In essence, co-creation encompasses any collaborative effort involving diverse methods and processes to foster collective creativity. However, until now, only a few methodologies have guided the effective integration of stakeholders' and citizens' values with scientific evidence, particularly during health emergency responses. These include participatory action research, community-based participatory research, deliberative engagement, and co-production of knowledge. It is essential to conduct additional research to understand better the structure of diverse collaborations between health authorities and community bodies. There is a significant need to delve deeper into the efficacy of varying strategies to comprehensively understand the most effective methods.

The mpox response in the WHO European Region can be considered an initial springboard to continued and sustained CE during emergency responses. The activities undertaken to co-develop and co-deliver public health interventions are a step toward tailoring interventions to community needs, thus facilitating the targeting of crucial public health advice, meaningful engagement, and support to those in need. For the approach outlined in this article, the co-production of knowledge was the primary methodology adopted. While it facilitated the development of tailored interventions, it also faced limitations such as the need for substantial time and resources.

Where data are collected, there is evidence that communities of color were disproportionately affected by mpox; however, they may not have been reached in most national efforts [27, 28].

Further research is essential to identify and document the key factors contributing to successful co-creation processes to address the challenges faced by those seeking to innovate in RCCE-IM [29]. With WHO's new concept of Community Protection in health emergencies, it is imperative to provide best practices on effective methodologies during emergency responses. The generation and reporting of this knowledge will prove invaluable in developing innovative public health interventions for health emergencies.

This article must be interpreted while keeping in mind several limitations. The findings and approaches discussed are based on specific case studies from the WHO European Region, which may not be directly applicable to other regions with different sociocultural, economic, and political contexts. The success of CE initiatives often depends on the availability of resources, including funding, trained personnel, and infrastructure, which can hinder implementation and sustainability. Additionally, the effectiveness of CE can vary significantly depending on the level of community trust, existing community structures, and the presence of influential local leaders. There is also a lack of comprehensive data on the long-term impact of CE initiatives on public health outcomes, necessitating further research to evaluate their sustained effectiveness. While localized approaches have shown success, scaling these initiatives to a national or global level presents challenges, including maintaining the quality and consistency of interventions. This manuscript relies on informal feedback from community organizations, which may not provide a comprehensive or unbiased view of the effectiveness of CE initiatives, highlighting the need for formal evaluation mechanisms. Furthermore, this initiative was documented post-completion and more rigorous methods are required to advance understanding of community engagement strategies and their effectiveness to better capture the dynamics and outcomes of CE efforts.

CONCLUSIONS

As the world increasingly embraces inclusive approaches in emergency responses, co-designing and co-delivering interventions with community actors emerge as key success factors for effective health emergency response. There is a clear call for further documentation and evidence gathering about the essential strategies, methodologies, and success factors that can sustain CE in emergencies, backed by research and RCCE-IM practice. Concrete examples, like the one presented in this perspective, serve as valuable sources of knowledge in understanding the centrality of CE and underscore the importance of extending and sustaining it for effective emergency management. By empowering communities and fostering active participation, we can better equip ourselves to tackle future emergencies and safeguard the health and resilience of our societies.

Notes

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