

# Eliminating mpox in the WHO European Region – a response with communities at its heart: a case studies compendium



#### **ABSTRACT**

This compendium provides case studies on community engagement in the response to the mpox outbreak in the WHO European Region. It shares experience on emergency preparedness, surveillance, risk communication and the adaptation of community-based services that cover sexually transmitted diseases to meet the demands of the mpox outbreak.

#### **KEYWORDS**

COMMUNITY ENGAGEMENT EMERGENCY PREPAREDNESS MPOX (MONKEYPOX) RISK COMMUNICATION SURVEILLANCE

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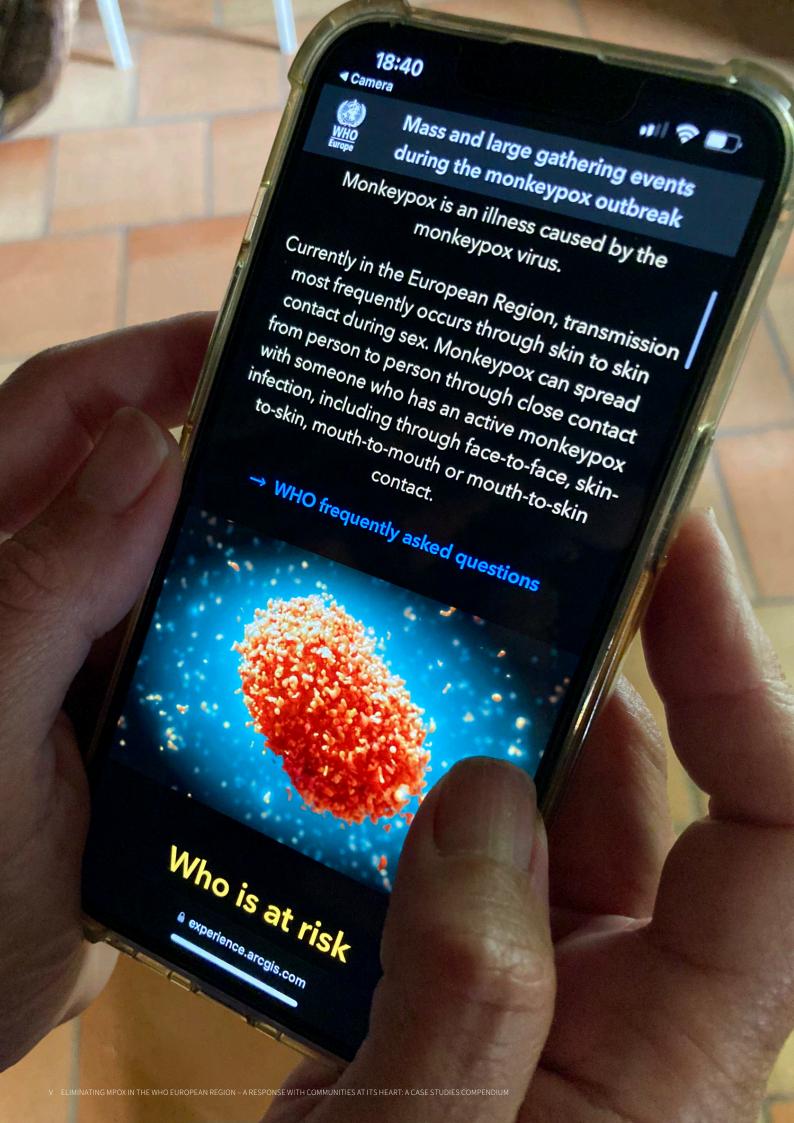
## Eliminating mpox in the WHO European Region – a response with communities at its heart:

a case studies compendium



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#### **Foreward**

Soon after the first cases of mpox were identified in the WHO European Region in May 2022, WHO Member States began to report rapidly rising and worrying spikes in transmission, with patients often experiencing painful and unfamiliar symptoms. It quickly became clear that the outbreak was impacting mostly gay, bisexual and other men who have sex with men (GBMSM) and communities of trans and gender diverse people linked to the same sexual networks. Alongside programmes of epidemiological surveillance and testing, urgent community outreach and insights were needed to ensure that these key populations could protect themselves and prevent onwards transmission.

The engagement and collaboration of organizations serving the GBMSM population with health authorities in the response to mpox in the European Region has been truly exceptional. Many health authorities have drawn on the critical experience and relationships built by civil society organizations (CSOs) with the groups most affected, particularly in relation to communitybased programmes on HIV and sexually transmitted infection prevention. Others have facilitated CSOs to take on important roles in the emergency response. Community members have also been essential partners in understanding the risk perception of the communities themselves and their needs, the evolution and impact of the outbreak and the barriers to preventive and protective measures. Throughout the outbreak, WHO has bridged top down and grass roots up approaches to working with both health authorities and community groups, providing technical support, guidance and capacity building through the Regional Office and our country offices.

A year into the mpox response, the decreasing case numbers seen in the Region are likely due to a combination of increased risk perception and uptake of protective measures among affected groups thanks to community-based interventions, alongside increased immunity, whether through vaccination or infection. However, the epidemiological data shows a long tail of low numbers of cases, making the end of the outbreak difficult to predict. Continued vigilance is required. Spring and summertime could bring a resurgence of cases both in the Region and globally. This could be triggered by the resumption of events and other mass gatherings, a lack of access to vaccines and testing capacities in countries,

importation from countries with sustained transmission or recurring zoonotic importation from established reservoirs.

Preventing stigma and discrimination of already marginalized groups continues to be a hugely important part of the response to mpox. Reaching and building trust particularly with groups left behind, such as trans people, sex workers, migrants and homeless people, who might not be connected to the formal health system, is an ongoing challenge.

This compendium of case studies captures just a few examples of the many impressive initiatives to confront mpox taking place across the diversity of the European Region. They highlight the multidisciplinary work needed to approach mpox from all sides, including joint work between health authorities, clinicians, sexual health service providers, event organizers and CSOs. This kind of collaboration will be fundamental to the eventual elimination of mpox. It is hoped that this resource will offer inspiration to those seeking to strengthen their preparedness and response strategies and provide a record of lessons identified which can be applied to future disease outbreaks.

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#### **Case studies:**

The case study on the establishment of the mpox Incident Management Support Team was based on video interviews with Antonio Gerbase and Pietro Vinti, consultants on HIV and sexually transmitted diseases for the WHO Regional Office for Europe, Richard Pebody, Programme Area Manager for Infectious Hazard Management, WHO Regional Office for Europe and Leonardo Palumbo, Community Engagement Officer at the WHO Regional Office for Europe. Interviews were conducted between 7–10 March 2023.

The case study on mpox surveillance was based on a video and written interview carried out with Hamish Mohammed, Consultant Epidemiologist leading on surveillance of sexually transmitted infections, United Kingdom Health Security Agency on 23 February 2023, as well as a conversation with Alex Sparrowhawk, HIV and Ageing Manager, Terrence Higgins Trust, which took place on 14 March 2023.

The case study on mpox testing in Serbia was based on a written interview with Milos Peric, Programme Coordinator at Association RAINBOW, Serbia, on 7 February 2023.

The case study on behavioural and cultural insight surveys undertaken in Albania was based on a video interview conducted on 30 January 2023 with Fatjona Kamberi, Head of the Research Centre for Public Health, the Ismail Qemali University of Vlorë.

The case study on discretionary social assistance for sex workers in France was based on a video interview conducted with Jules James, European Sex Workers Alliance; and Eva Vocz, the responsible officer for advocacy for sex workers, Act Up, Paris, conducted on 7 January 2023. Written interviews were also conducted with Pierick Bergeran, a senior civil servant in the French Ministry of Health; and Berthe de Laon, Federation Parapluie Rouge, between 9–15 March 2023.

The case study on outreach during Dublin's 2022 Pride events in Ireland was based on a video interview conducted with Adam Shanley, MPOWER programme manager, HIV Ireland on 20 January 2022.

The case study on working with sex-on-premises venues in Portugal was based on a video interview conducted on 16 March 2023 with Miguel Rocha, public health nurse, *Grupo de Ativistas em Tratamentos* (GAT) [Treatment Activist Group] Portugal.

The case study on mpox vaccination in Latvia was based on interviews conducted in Latvia between 7–10 December 2022 with Alexander Ivanayev, board member of Mozaika; Inga Liepina, Senior Expert in the Environmental Health Division at the Latvian Ministry of Health; Dr Uldis Mitenbergs, Head of the WHO Country Office in Latvia; and Kaspars Zalitis, board member of Mozaika and Alexander Ivanayev, board member of Mozaika. Follow up information was provided by Dr Inga Azina, Head of the Outpatient Department of the Latvian Centre of Infectious Diseases, on 7 March 2023.

The case study on reducing stigma in Romania was based on an interview conducted on 24 March 2023 with Florin Buhuceanu, Association ACCEPT, Romania.

The case study on journalists who are reducing stigma around mpox was based on interviews conducted between 22–25 November 2022, and written follow up conducted in March 2023, with journalist Martin Joseph and producer Jamie Wareham.

The case study on preparedness through outreach to vulnerable groups in the United Kingdom was based on a video interview conducted on 28 February 2023 with Qaisar Siddiqui, Under the Radar coordinator, the Love Tank.

The case study on preparedness and readiness in Kazakhstan was based on a video interview conducted on 10 March 2023 with Bibigul Aubakirova, National Professional Officer, and Assel Gabbassova, Risk Communication and Community Engagement consultant, WHO Country Office, Kazakhstan

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#### **Abbreviations**

**BASHH** British Association of Sexual Health and HIV

COVID-19 coronavirus disease 2019

**CSOs** civil society organizations

**ECDC** European Centre for Disease Prevention and Control

GAT Grupo de Ativistas em Tratamentos [Treatment Activist Group]

**GBMSM** gay, bisexual, men who have sex with men.

**HEP A** Hepatitis A

IHR International Health Regulations (2005)

IMST incident management support team

LGBTQI+ lesbian, gay, bisexual, transsexual, queer and intersex

MSM men who have sex with men

NHS National Health Service

PHEIC public health emergency of international concern

**PrEP** pre-exposure prophylaxis

RCCE risk communication and community engagement

**STI** sexually transmitted infection

**TESSy** the European Surveillance System

THT Terrence Higgins Trust

**UKHSA** United Kingdom Health Services Agency

**UTR** Under the Radar

#### Introduction

This compendium of case studies has been developed for health authorities, community organizations representing and serving populations affected by mpox, event organizers and health workers, including sexual health service providers. It is intended to offer inspiration to such readers to renew or maintain their efforts to achieve and sustain mpox elimination.

The compendium follows the policy brief entitled "Considerations for the control and elimination of monkeypox in the WHO European Region: the need for integrated national operational plans" produced by the WHO Regional Office for Europe (WHO Regional Office for Europe, 2023a). The policy brief outlines the need for Member States to develop country plans that integrate mpox into wider programming on disease prevention and control, with particular linkages to sexual health initiatives and a strong focus on engaging relevant community groups. While continued reintroductions into Europe will almost certainly occur, and could develop into new localized or dispersed outbreaks, the policy brief recommends a range of actions Member States should take to achieve and maintain the interruption of sustained person-to-person transmission of mpox.

From the co-creation of high-quality national surveillance systems with attendant laboratory diagnostics, to the development and implementation of national action plans which are integrated into established HIV and sexual health services, the policy brief recommends close work at every step of the way with affected communities and their often marginalized members. It highlights the need for strong risk communication and community engagement (RCCE) to ensure the acceptance and sustained uptake of preventive measures amongst groups affected by mpox. It outlines how public health interventions and clinical management are critical to ensuring cases are rapidly identified and managed. It encourages Member States to identify large and mass gatherings where targeted interventions with civil society organizations (CSOs) and event organizers could occur, and to provide equitable access to vaccines and ensure a high uptake among the most affected people and communities. It asks that all public health interventions, including clinical care, are carried out without stigma and discrimination. The diverse experience presented in this compendium touch on many of these topics,

underscoring the central role of communities across the response: placing communities at the heart of the mpox response has been essential in controlling mpox in our Region, and will be key to eliminating it too.

#### **Document outline**

Although numerous examples of innovative work exist across the Region, practical constraints allow the inclusion in this compendium of just one or two example case studies under each of the following headings:

- · Emergency response
- Surveillance
- Testing
- Behavioural and Cultural Insights
- Social assistance
- · Mass gatherings
- Prevention and control measures
- Vaccination
- Risk Communication
- Preparedness.

Each case study primarily focuses on the heading that they are presented under, but all illustrate work across a range of areas – these areas are listed at the beginning of the study under "Main themes". The interview tool used to guide and structure the case study interviews can be found in the Annex.



## Lessons identified from the mpox outbreak response

A summary of the lessons identified from the case studies is presented below. These ten lessons identified are aimed at health authorities, relevant CSOs, event organizers and health workers, to help with inspiration as they plan for the 2023 mass gathering season, reflect on areas for improvement and to aid them in their ongoing efforts to control and eventually eliminate mpox.

- 1. A multidisciplinary response to the mpox outbreak is critical, with a broad range of specialists contributing diverse and complimentary perspectives during the different phases of the response. Any response strategy to such a disease should have the flexibility to adapt as more is understood.
- 2. Many of the successful responses to the mpox outbreak based their ability to rapidly respond on strong, pre-existing relationships between health authorities and stakeholders from a range of disciplines and backgrounds, including clinicians, sexual health experts and CSOs. Efforts should be made to develop and nurture relationships before an outbreak occurs.
- 3. To reach affected communities, health authorities need to listen to the communities themselves and understand their risk perception and needs, as well as the barriers to both accessing health and social services and adopting preventive and protective behaviours. Two-way listening with representatives of affected communities has increased trust and the legitimacy of the response. It has allowed health authorities to make sure health advice is communicated through language using channels most likely to resonate and to reach communities directly.
- 4. All efforts should be made to avoid stigma and discrimination towards affected groups in any form of communication, including in the media and in health-care settings. Stigma and discrimination not only cause hurt to communities who may already be facing the stress associated with an outbreak but can also affect trust between health authorities and communities, affecting health-seeking behaviours, access to health services and uptake of preventive measures, not just related to mpox but more generally.

- 5. Social listening insights have been consistently gathered and analysed to inform the response, but these should be complemented with more behavioural and cultural insight studies by countries. Gathering behavioural and cultural insights into perceptions and knowledge of affected communities and health workers can be an important step in tailoring interventions to address the mpox outbreak. Sharing systems, methodologies and approaches could help fill in gaps, allow for comparable studies across the Region and prepare for future mpox outbreaks.
- 6. Health authorities should leverage trusted relationships between communities and CSOs and the work already in place to co-design or delegate outreach or service delivery. CSOs are also an important partner to reaching under-served and marginalized groups with services and social protection. Community-driven responses have been instrumental in risk communication, outreach and behaviour change to bring down mpox numbers. When CSOs work together with health authorities and receive recognition, financial and technical support, they can offer both surge capacity and an important avenue for engaging populations affected by mpox and the most underserved members of the community. Community-based health services (vaccination, testing and counselling) provided by CSOs may result in higher uptake due to greater trust. CSOs can also link underserved groups to the formal health system.
- 7. The activities of HIV and sexually transmitted infection (STI) prevention significantly overlap with the prevention of mpox. Many lessons can be drawn from the HIV and STI response around sensitive approaches to epidemiological surveillance, testing, case management and outreach.
- 8. Health authorities should prepare for outbreaks of mpox even in countries where mpox risk perception is low. Proactive measures that prepare health systems for potential outbreaks means countries are well positioned to tackle events as they occur and are in line with International Health Regulation (2005) (IHR) requirements (WHO, 2005).
- 9. As the outbreak has evolved, many of the most health literate members of the affected communities have taken measures to inform and protect themselves against mpox. Efforts must be made to reach underserved groups and marginalized members of these communities, such as migrants, younger people, homeless people, rural dwellers, sex-workers and trans people. Innovative and targeted approaches that bring public health advice and services to underserved groups tend to work best. Data-led approaches, combined with a flexible outreach strategy are helpful in identifying underserved groups.
- 10. Mpox practices and measures need to be embedded into local or national policies or guidelines. Embedding programming on mpox into sexual health and HIV programmes at the national or subnational level can ensure their sustainability.



#### **CASE STUDY: EMERGENCY RESPONSE**

## Creating a multidisciplinary team responding to the needs of affected communities – the WHO Regional Office for Europe's mpox Incident Management Support Team (IMST).

#### What this case study is about

This case study looks at the multidisciplinary composition of the WHO Regional Office for Europe's response to mpox, through interviews with four participants.

#### Why it is important

The emergency response to mpox has depended on rapid access to technical expertise and experience from a range of disciplines. In particular, sexual health expertise and connections to affected communities have proved invaluable in tackling an evolving outbreak. The early establishment of a coordination mechanism is crucial in a response as it allows for flexibility in bringing in new experts as needed and the monitoring of response progress. This helps to ensure that the response is adaptive and can evolve as the situation demands, allowing for a more effective and efficient response overall.

#### **Main themes**

- Emergency response
- Multisectoral coordination

## The establishment of the WHO Regional Office for Europe IMST

The WHO Health Emergencies Response Programme has an Emergency Response Framework (WHO, 2017) which outlines how it operates. When an outbreak or other such event occurs, the framework details the steps to follow to assess the outbreak, its risk and how it should best be managed. If it is found to represent a cause of concern, this triggers a grading process based on criteria set out in the IHR (WHO, 2005).

In April 2022 a small number of unusual cases of mpox were reported in the United Kingdom that had no evidence of the infection having been acquired in an endemic country. WHO worked together with health authorities in the United Kingdom to try to determine the origin, which led to the discovery of many more cases, and the realization that mpox had been circulating in the United Kingdom, and in other countries in the European Region, for some time:

Through IHR mechanisms, other countries were alerted and started to look and find cases as well and then quite quickly it became a multicountry outbreak; the number of cases increased exponentially and it quickly became apparent that the outbreak was extending well beyond Europe to the Americas and then also globally.

#### **Richard Pebody**

Programme Area Manager for Infectious Hazard Management WHO Regional Office for Europe

On 14 June 2022 the outbreak of mpox in the WHO European Region and the Pan American Health Organization area was graded as the highest level of emergency, Level 3, making it an event requiring a global WHO response and the mobilization of Organization-wide assets to provide support to regions and country offices. The grading of mpox triggered the activation of WHO's Incident Management System, which provides a standardized yet flexible approach to managing emergency response. This approach is recognized internationally as best practice for emergency management and has as the core functions of leadership; health operations and technical expertise; risk communication and community engagement; partner coordination; health information and epidemiology; planning and monitoring; operations support and logistics; and finance and administration.

Within 24 hours of the grading, WHO had established an IMST at regional and headquarter level to mobilize and coordinate Organization-wide and partner support for the response.

We had the learning from COVID-19 [coronavirus disease 2019] and rapidly created the pillars needed to manage the response. Health information and surveillance, laboratory diagnostics and key interventions including contact tracing and public health interventions, vaccination, clinical management and infection control. When the importance of sexual transmission became apparent, then getting those with expertise in sexual health involved was really central to the response. Risk communication and Community Engagement has been mainstreamed into the work of so many different functions.

Richard Pebody WHO Regional Office for Europe

HIV and STI consultant Pietro Vinti was brought into the IMST to share his extensive experience of working with key populations, and Antonio Gerbase, a medical doctor with a long-standing experience of working on HIV and STIs with WHO, also started as a consultant for the IMST.

#### The work of the IMST

The IMST gathered at regular weekly meetings, which allowed for the disemmination of epidemiological updates and other information relavent to the various response pillars, response co-ordination and strategic decision-making. Given the huge amount of information circulating at the beginning of an outbreak, these meetings offered an opportunity to keep up with the evolution of the emergency, understand the full scope and implications of the outbreak and track and evaluate the response activities taking place. This avoided duplication, ensured a good fit between activities and approaches and offered an opportunity to maintain strong working relations across all colleagues involved in the response.

The situational awareness that was generated by the team meetings informed every pillar of the response. Responses included supporting countries with mpox diagnostics to be able to identify suspected cases and then sequence them; working with the European Centre for Disease Control and Prevention (ECDC) to create a weekly regional surveillance bulletin to which countries could report cases and the unfolding epidemic could be monitored across the Region; developing vaccine policy; and determining optimal clinical management for this new manifestation of the infection. Promoting protective behaviours, such as practising safer sex, and later accepting the mpox vaccine, has been a major focus of the RCCE pillar within the IMST structure. Engagement meetings with community actors representing affected groups, as well roundtables with community members in different countries across the Region, have been key in guiding the work of the IMST.

## A standardized yet flexible system serving and engaging communities

One of the merits of the IMST is that it is flexible, adaptable and scalable and can therefore address expanding (or shrinking) needs for services and support.

As the challenges have become clearer, we've had to adapt and shape the response accordingly; it's really important to not be too rigid. It became more and more apparent that the sexual health component was a really central part of the outbreak, so interacting with colleagues from different aspects of the sexual health world became really clear. And then of course, the fact that it was particularly affecting the GBMSM community. Ensuring that we were engaging appropriately with these groups including through community leaders, became really important.

Richard Pebody WHO Regional Office for Europe

Mapping CSOs already active in the mpox response, usually national or local organizations working on HIV prevention or advocacy for LGBTQI+ [Lesbian, gay, bisexual, transgender, queer and intersex] rights, was a necessary step, in order to build on and maximize existing efforts, highlight good practices and avoid duplication. Through this collaboration, the RCCE team provided meaningful contribution to strategies to combat the spread of mpox at mass gatherings. These mass events offered an opportunity to outreach to affected communities groups; at the same time evidence showed that sex parties and sex-on-premise venues increased likelihood of mpox exposure more than large gatherings themselves. Engaging with affected communities through organized events allowed for the dissemination of practical and targeted health advice and services. The Joint WHO Regional Office for Europe/ECDC Monkeypox Resource toolkit to support national authorities and event organisers in their planning and coordination of mass and large gathering events [(WHO Regional Office for Europe and ECDC, 2022a)] co-created and tested with ECDC and CSOs was largely used by countries and community organizations. Partnership between health authorities and community groups was powerful in supporting pride events to provide mpox information through their channels.

Leonardo Palumbo

Community Engagement Officer WHO Regional Office for Europe

In the early stages of the outbreak, based on his clinical expertise, Antonio Gerbase was able to draw parallels with other STIs that can be transmitted through skin-to-skin contact, but are predominantly sexually transmitted, which helped to characterize the novel outbreak.

Cognizant of the stigmatizing and discriminatory language historically used around HIV, and the negative impact this had on communities and their uptake of health services, the IMST thought carefully about trying to minimize and avoid stigma and discrimination – bringing in people with the correct expertise enabled a greater level of sensitivity. Pietro Vinti was able to draw on his contacts and understanding of the GBMSM community to provide first-hand insight:

Being part of the community and working with the community, in terms of communication, I have a good sense of what kind of language might be acceptable to people because it was my day job. It's useful to have a member of the community in the IMST. It's one thing for another knowledgeable person to talk about men who have sex with men, probably appropriately, but when it's talking about you, then you have a different perspective.

Pietro Vinti

HIV and STI consultant
WHO Regional Office for Europe

#### The integration of sexual health expertise

As well as sharing lessons learned from public health programmes on HIV and STIs with the wider team, the sexual health expertise that the consultants brought into the multidisciplinary IMST informed numerous documents, for example, on sex-work during the outbreak, and guidance on the language needed to avoid stigma and discrimination. Additionally, prior mapping, outreach efforts and relationships developed by HIV and STI programmes with community organizations were leveraged to bring in crucial voices and experience.

Every emergency needs a multidisciplinary team because there are different factors to consider and it cannot be expected that just one person or one team will have all that. If we consider that a minority community is affected, it is especially important to fully address their specific needs and characteristics. In the case of mpox it is minority groups that in many places still face stigma and discrimination so you need specific knowledge to reach that group, you cannot just use the tools that you use to reach the general population. But you don't need to reinvent the wheel. Since the same communities have been affected by HIV and other STIs, you already have some tools that you can use to reach them. You just need to absorb the knowledge that is already there and use people that have worked in that field to make this bridge.

Pietro Vinti

WHO Regional Office for Europe

Within the IMST, interaction is a pleasure.
There are no power games and our input was appreciated because although WHO Regional
Office for Europe have huge experience of how to deal with emergencies, they didn't have a person with experience in STIs. People were flexible and willing to learn. This dialogue [on the mpox response] was one of the best experiences in my professional life in public health.

Antonio Gerbase HIV and STI expert WHO Regional Office for Europe

#### **RCCE and Infodemic Management**

One key intervention in the mpox response has been the creation of an informal working group building on the mapping done by the IMST's HIV/STI specialists to maintain continued dialogue and engagement between the IMST and community representatives.

Participants [in the working group] from civil society organizations said that our online meetings with them were important to keep up to date with the evolving understanding etc. From our side, we learned so much from the innovative and community-focused approached happening all over the Region. Through the CSO meetings, we provided a forum for sharing this good practice and building an effective response.

Leonardo Palumbo WHO Regional Office for Europe

Good practice from CSOs has been captured in the stories that the emergency communications team published on the community response (WHO Regional Office for Europe, 2023b). In addition to information gathered from community organizations, to inform the IMST about concerns, identify information voids and monitor rumours and misinformation about mpox, the Regional Office set up a social listening system – both online and offline – to track conversations. Listening to people's narratives and detecting dangerous signals is critical to make messaging relevant and discard false information before it spread.

Some key findings from this social listening have been that there was:

- fatigue and disbelief due to the many emergencies hitting the European Region (the mpox outbreak happening during the coronavirus disease 2019 (COVID-19) pandemic and the war in Ukraine);
- discussion around transmission, with the rumour that monkeypox is airborne, can infect an entire population, be fatal and cause blindness and scarring;
- conversation around stigma for instance that mpox is a "gay disease"; and
- widely expressed fear of monkeypox symptoms especially scarring from lesions.



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## **Challenges**

Changes to the emergency status of mpox will means changes in WHO's response structure, the IMST and funding. The transition from the acute phase of the emergency into a longer-term strategy will mean moving responsibility for mpox coordination into new spaces and supporting the integration of mpox measures into existing sexual health services.

With cases declining, momentum and enthusiasm to eliminate mpox may also wane. The WHO Regional office for Europe is working on a strategy for mpox elimination to provide a clear pathway towards this achievable goal.

Pietro Vinti, WHO Euope, stated that "Working with communities, I hear a lot of frustration around access to vaccination, and in some places, stigma and discrimination still exists in the health-care sector."

Underserved groups still require additional, better targeted outreach:

CSOs have clearly indicated that trans people, sex workers, undocumented migrants, refugees and rural communities need to be better targeted if we want to eliminate mpox. This means working directly with those communities to link them to health systems and expand the mass gathering approach to fetish festivals, circuit parties, cruises, alternative prides and transpride.

Leonardo Palumbo WHO Regional Office for Europe

If mpox transmission in Europe is halted, sexual health expertise and capacity to manage potential future outbreaks must be maintained within Member States.



### Lessons identified



Clear leadership and strategy, a rapid response and the ability to adapt to new data is crucial when confronting novel disease outbreaks. This includes the ability to bring in disease specific and community specific expertise when needed.

Multidisciplinary listening and learning is important: "Choose your people well. Choose people with big ears and small mouths."

**Antonio Gerbase** WHO Regional Office for Europe.

Having a whole-of-society approach to IMST is essential to reflect community voices and needs and make the response efficient and effective.

Multisectoral expertise is crucial to the emergency response, including representatives from affected communities.



#### **CASE STUDY: SURVEILLANCE**

#### Handling sensitive messages with joint, proactive communication to retain trust in surveillance and sexual health services in the United Kingdom.

#### What this case study is about

This study describes how the surveillance team of a government agency worked with a CSO to communicate changes to the notification status of mpox in the United Kingdom.

#### Why it is important

This case study shows how transparent and proactive communication is important during outbreaks, and that working with stakeholders to share sensitive messaging can help to maintain trust in services, particularly in times of change and uncertainty.

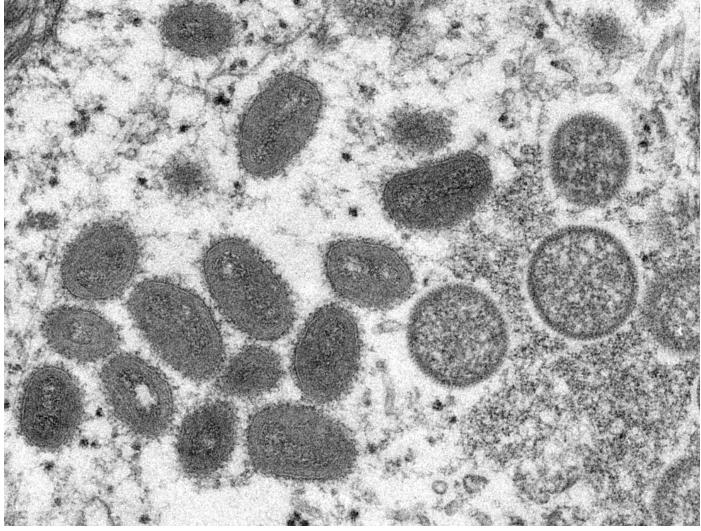
#### **Country context**

The United Kingdom is a high-income country with over 67 million inhabitants (World Population Review, 2023).

#### **Main themes**

- Surveillance
- Reducing stigma
- Preparedness
- **RCCE**

A close-up image of the mpox virus.



## Background on the surveillance of HIV and STIs in the United Kingdom

Unlike many other high-income countries, HIV and STIs are not nationally notifiable diseases in the United Kingdom. For notifiable diseases (such as shigella, hepatitis A, B and C), there is an obligation on behalf of a health-care practitioner to notify the relevant public health officer upon detecting a case. Nonetheless, while HIV and STIs are not nationally notifiable, several systemic factors contribute to comprehensive, robust and high-quality surveillance within the country.

One of these factors is the legacy of sexual health care in the UK: not only is genito-urinary medicine a dedicated medical speciality in the country, but in 1917, an open access network of sexual health services was created. Since then, given the stigma associated with STIs, sexual health services have been provided with a higher level of confidentiality and anonymity than in other health-care settings. In practice, this means that people can seek care anonymously or using an alias. With the advent of a more centralized National Health Service (NHS) decades later and increasing use of electronic patient records more recently, the government's policy position is that health-care records at sexual health services remain distinct from individuals' general health record. This promotes public trust in sexual health services, and in the public health surveillance conducted in this setting by the United Kingdom Health Security Agency (UKSHA), an executive agency, sponsored by the governmental Department of Health and Social Care.

Secondly, while the public health response to notifiable diseases includes local public health teams called Health Protection teams who carry out contact tracing and following up cases, in the case of HIV and STIs, a dedicated workforce within sexual health services, entitled Sexual Health Advisors, performs partner notification and management (e.g., contact tracing of the sexual partners of someone diagnosed with an STI) in a specialized and sensitive way.

## The mpox outbreak in the United Kingdom

Prior to the detection of mpox in the United Kingdom in May 2022, only a handful of cases had been identified, all of which were associated with travel to endemic areas, with no evidence of community transmission (WHO, 2022a). Therefore, in May 2022, mpox was not a notifiable disease in the UK. However, given the recognition of clinical severity, in particular for Clade I (previously the Congo-Basin clade) of mpox, where the case fatality rate might be as high as 10%, there was a strong public health rationale to make mpox notifiable to ensure the best possible ascertainment of cases and rapid public health action. Therefore, mpox was named as a notifiable disease in the United Kingdom on June 8.

#### Changes in notification

As a notifiable disease, the public health actions regarding mpox would be managed by Health Protection teams, whereas care, diagnosis, testing and vaccination would be provided by sexual health services within which there is a culture and established practice of additional confidentiality and privacy safeguards. At a time when media attention on mpox contained some extremely stigmatizing language, people who had been assured of privacy at sexual health services were suddenly being asked to share their name and their contact information when they were tested for mpox. Sexual health services, being the point of contact for most cases, were now having to have difficult conversations with patients who presented with an illness compatible with mpox, but bearing in mind that there are a number of other STIs with similar presentation of genital ulcers and rash, such as primary syphilis or genital herpes.

Yes, we have a clear legal basis to do surveillance on notifiable diseases but it's not a one-size-fits-all approach in every setting, and there's a culture of practice around confidentiality and STIs and HIV services that needs to be respected.

#### **Hamish Mohammed**

Consultant Epidemiologist leading on surveillance of STIs United Kingdom Health Security Agency (UKHSA)

Local health protection teams were reporting a clear spike in mpox cases within GBMSM, with certain sexual behaviour, such as visits to sex-on-premises venues, creating an additional layer of sensitivity to be navigated. Based on conversations with key community stakeholders such as the Terrence Higgins Trust (THT), the United Kingdom's leading HIV and sexual health charity and Naz, an organization that works with people of Black and Asian ethnicities, the reaction was one of concern:

Some people were making parallels to the early days of HIV and AIDS and how there was hysteria and, a lot of stigmatization of gay men and backlash. And it was a big fear that that sort of thing could rise up again. Also connected to that was the fear that people would not come forward if they felt that information about themselves was not going to held in the same ways as it had been previously.

Alex Sparrowhawk
Terrence Higgins Trust (THT)

#### Response

The thing we didn't want to change or compromise was public trust in the personal data collected by the Sexual Health Service, for mpox or for the purposes of HIV and STI surveillance.

Hamish Mohammed

Rather than waiting for a reaction, UKHSA pursued a proactive approach, recognizing several risks associated with the change in reporting requirements as mpox became notifiable: a) that people may not come forward for testing; b) when vaccines are offered, people may not come forward for vaccination because of the perception that their privacy would be compromised; and c) that people may exercise their right to opt out of surveillance systems for HIV and STIs in reaction to mpox reporting changes. These concerns were also raised by the British



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Association for Sexual Health and HIV (BASHH), the society of health-care practitioners working in sexual health services. After discussions with BASHH, THT and Naz, there was agreement that communication and transparency with key populations was essential to achieve control of mpox. As a result, UKHSA jointly drafted text with these partners to explain, in plain language, what sort of personal information would be collected when someone was tested for mpox at a sexual health service and the justification for doing so. This was included in a "Frequently Asked Questions" mpox feature on the THT website. (Terence Higgins Trust, 2022)

We were heavily reliant on UKHSA fact checking the information, taking what they were producing. And our relationship with UKHSA also enabled us to ensure not only that the webpage had the correct information, but so did our colleagues, especially the THT Direct helpline, and those who perform outreach in community venues. And we sit in the community as an organization that's over 40 years old now. We've built long-standing trust with that group of people, and people like myself who are involved in the response are gay or LGBT themselves. We could say things more bluntly, whereas if UKHSA said it, it would have come across as homophobic, or 'you're judging gay men'. It was a really important relationship.

Alex Sparrowhawk
Terrence Higgins Trust (THT)

UKHSA also requested that community stakeholders monitor concerns from their clients about privacy being a barrier to coming forward, for testing, contact tracing or vaccination.

What enabled us to do this was the existing relationships between ourselves and our community stakeholders. There was a collective will to get the messaging right and to be transparent and open and find the best potential way to communicate it.

Hamish Mohammed UKHSA

What was important was that trust was already there, so that when UKHSA approached us to talk about that work in particular we felt we were able to discuss concerns but also trust that they would listen to us and that they were doing things in the best interest of people affected.

Alex Sparrowhawk
Terrence Higgins Trust (THT)

UKHSA also undertook parallel work with BASHH taking joint ownership of drafting updates that were cascaded to BASHH members via their newsletter or on their website (British Association for Sexual Health and HIV, 2022).

The take home was that as long as you were open, honest and transparent about why things are being done differently most people didn't object.

Hamish Mohammed



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#### **Looking forward**

Cases of mpox have fallen dramatically in the European Region, including in the United Kingdom. Sexual health services continue be responsible for care, counselling, testing, treatment and vaccination while public health practitioners continue to monitor case numbers.

There is a collective sigh of relief. The system has given tens of thousands of vaccine doses, 65 000 plus doses at the last count. I hope we don't have a resurgence in cases, but if we do, we have a series of mitigation measures in place to head off any privacy concerns.

Hamish Mohammed

#### **Impact**

Between May and August 2022 THT had a webpage dedicated only to mpox. During this period, it received 71 000 page views (61 000 unique views), with an average time of 5 minutes 20 seconds spent per view (compared to an average of 2 minutes 14 seconds on the THT website).

This intervention helped to maintain public trust, both in sexual health services themselves and in the level of privacy that they provide, and collaboration deepened the relationship between THT and the UKHSA surveillance team.

### Lessons identified



Strong relationships and alignment with key stakeholders allowed UKHSA to hear and amplify the voices of both the affected community and service providers that are contributing to the surveillance system. In this case it was sexual health services, but in other countries it might be in general practice, dermatology departments or infectious disease departments.

It goes to show that these relationships need to exist. There needs to be communication ongoing around our activities all the time rather than just when there's an emergency. The fact UKHSA knew who to contact at the very beginning helped. The fact that we were involved from the start meant that we weren't responding to this as we went along. To be able to do that together was much easier than coming in days or weeks later and trying to decipher what actions had already happened.

Alex Sparrowhawk Terrence Higgins Trust (THT)

Actions to reduce stigma and protect confidentiality protect trust in wider health systems and can encourage or help to sustain the uptake of services.

Proactive and transparent messaging, delivered through appropriate channels in language that reflects the target audience is most effective and maintains trust.

#### WHO's role and available resources

In the response to the multi-country outbreak in the European Region, The WHO Regional Office for Europe and the ECDC established a country reporting system for newly-identified cases via the European Surveillance System (TESSy), which allowed for rapid understanding of the epidemiological situation and development of the outbreak. A detailed summary and analysis of case-based data reported through TESSy since 2 June 2022 by all the countries and areas of the WHO European Region can be found in the Joint ECDC-WHO Regional Office for Europe surveillance report (ECDC and WHO Regional Office for Europe, 2023a).

Following the meeting of the IHR Emergency Committee on the Multi-Country Outbreak of monkeypox (mpox) and declaration of mpox as a Public Health Emergency of International Concern (PHEIC), WHO issued a number of Temporary Recommendations for Member States (WHO, 2023a).

In December 2022 WHO updated the interim guidance related to surveillance, case investigation and contact tracing for mpox (WHO, 2022b). This built on and further developed initial advice relevant to contact tracing contained in the joint interim advice from WHO and ECDC on risk communication and community engagement for mpox (WHO Regional Office for Europe and ECDC, 2022b). In August 2022, the WHO Regional Office for Europe also developed a considerations document on mpox control and elimination aimed at decision-makers and policy-planners, to support planning for the prevention and preparedness of mpox (WHO Regional Office for Europe, 2022a). An operational planning document entitled, Considerations for achieving and sustaining mpox control and elimination in the WHO European Region: the need for integrated national operational plans, has also been published (WHO Regional Office for Europe, 2023a).

The Regional Office for Europe reached out to ministries of health and national CSOs to ensure that public health advice was being shared across Member States before upcoming mass gatherings. Maintaining confidentiality is one of the ways that CSOs and health authorities can build trust with communities and address concerns around stigma.



#### **CASE STUDY: TESTING**

## How community outreach by a trusted organization in Serbia led to increased referrals for mpox testing.

#### What this case study is about

This case study details the work of a Serbian CSO who expanded their HIV outreach activities to refer participants of EuroPride for mpox testing.

#### Why it is important

This case study shows that trusted community-based organizations, with the support of health services, can refer individuals for mpox testing as part of their outreach activities on STIs and HIV.

#### **Main Themes**

- Testing
- Community engagement
- Mass gatherings
- Reducing stigma

#### **Country context**

Serbia is an upper-middle income country in south Europe with just over 7 million inhabitants. Its capital city Belgrade has a population of nearly 1.3 million people (World Population review, 2023).





#### **Description of organization**

Association RAINBOW was established in 2004 with the aim of improving the lives of lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI+) people and their families, primarily in small and rural communities in Serbia, with a special focus on multiply marginalized persons such as: LGBTQI+ persons who live with HIV/AIDS, LGBTQI+ Roma people and LGBTQI+ people with disabilities, among others. The association aims to do this by developing and providing health and social services which are not always available to these groups of people and through the education of professionals from various fields about non-stigmatizing ways of working with LGBTQI+ people and reducing discrimination towards them.

#### **Background**

Since 2006, Association RAINBOW has been active in the field of HIV/AIDS, mostly with GBMSM and primarily though outreach work, which includes rapid testing and confidential counselling conducted in a mobile medical van. The Association regularly conducts testing at bars and clubs attended by their target groups, but clients can also make an appointment at alternative locations that suits them. All activities related to HIV/AIDS prevention and testing have been implemented in cooperation with the Serbian Ministry of Health, the Institute for Public Health and City Institutes for Public Health with whom Association RAINBOW has signed a memorandum of cooperation. Representatives of Association RAINBOW are also members of the Country Coordinating Mechanism (the national committee that oversees Global Fund grants) and the Working group of the Ministry of Health for pre-exposure prophylaxis (PrEP).

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#### EuroPride (12-18 September, 2022)

An increase in stigma towards the LGBTQI+ communities in the weeks before EuroPride 2022 negatively affected Association RAINBOW's preventive activities and outreach work on mpox. During the Pride event, discriminatory messages were publicly posted about the LGBTQI+ population in relation to mpox, which contributed to increased incidences of verbal and physical violence during the event. People were therefore reluctant to go to a specific venue and ask for assistance. Nonetheless, during EuroPride Association RAINBOW managed to implement significant preventive activities.

Association RAINBOW also aimed to map all hotspots relevant to the work of sexual health outreach teams; determine the most appropriate communication channels and referral pathways for mpox testing; and increase access to health services for those who were suspected having mpox or COVID-19 infection. An action plan was made with Pride organizers in that if a Pride attendee reported a suspicion of having mpox to a volunteer, the case was reported to one of the volunteer team leads, who then reported to Association RAINBOW. The Association would then contact the respective health-care contact person to gather information regarding where the participant can access testing and medical care.

A leaflet on mpox, its transmission and prevention strategies was produced and tested to be distributed among EuroPride participants, together with information on who to contact in order to get assistance.

#### **EuroPride activities**

Association RAINBOW drew on its established activities in HIV prevention among key populations to reach people affected by mpox during EuroPride: outreach using the mobile van took place at pre-existing defined locations and newly opened hotspots in Belgrade, where a team of seven outreach workers provided counselling services on HIV, mpox and other STIs. They also offered rapid tests for HIV and syphilis although it was not possible to provide mpox testing, as there is no approved rapid antigen test.

During EuroPride, Association RAINBOW intensified mpox related public health advice on social networks and dating apps such as Grindr, which was enabled by funding from the WHO Country Office. This led to higher visibility of their activities and as a result they received some ad hoc requests from people in other cities than Belgrade. Engagement with local medical units, infectious disease centres in state hospitals and health-care services for STIs and HIV/AIDS ensured that individuals with symptoms were referred to local departments of infectious diseases in state hospitals for testing.

#### На које симптоме мајмунских богиња треба да обратим пажњу?

- осип са или без пликова, на било ком делу тела (почев од уста, ануса или гениталија ако се преноси током секса)
- запаљење и бол у ректуму
- оток лимфних чворова
- повишена температура

Ови симптоми могу бити праћени главобољом, боловима у мишићима и мањком енергије.





#### Како се преносе мајмунске богиње?

Да бисте добили мајмунске богиње, морате бити у **блиском** контакту са неким ко има мајмунске богиње, или са контаминираним предметима и материјалима.

Мајмунске богиње се најлакше преносе током директног контакта кожа на кожу - као и током секса.

#### Како да се заштитим?



Информишите се о симптомима и начину преноса мајмунских богиња на www. batut.org.rs



Практикујте безбеднији секс, укључујући ограничавање

броја сексуалних партнера и избегавање секса са непознатим особама



Одржавајте хигијену руку, користећи сапун и воду или средство за дезинфекцију на бази алкохола.

Ако мислите да сте у већем ризику да добијете мајмунске богиње, обратите се свом лекару да бисте сазнали како да смањите ризик од инфекције.





A leaflet in Serbo-Croatian which describes the symptoms of mpox and protective measures against it. Leaflet not available in English.

#### Challenges

Of those who were referred for testing for mpox, eight people informed outreach workers that they had been tested and three of them received a mpox diagnosis. The other individuals with potential symptoms either refused to get tested, reporting a fear of stigma, or did not inform outreach workers about their next steps. As previously mentioned, stigma and discrimination impacted on the work of outreach units, limiting the number of people who came forward during EuroPride.

Furthermore, in addition to the longer waiting times to receive results as described above, free mpox testing is not available for non-nationals, requiring most individuals to travel home to seek testing.

#### Current and future plans

In 2022 Association RAINBOW founded the CheckPoint centre in Belgrade for men who have sex with men (MSM), people living with HIV, and the LGBTQI+ population, in order to ensure that critical services (voluntary, confidential counselling and testing, psychological support, PrEP/ post-exposure prophylaxis and STI counselling and referrals) for these populations can be provided outside national health-care facilities, in one place, within a community-based safe space. The association also advocates for continued efforts to sensitize the staff of public health institutions and facilities towards the needs of LGBTQI+ individuals who still report high levels of stigma.

Association RAINBOW is in the process of standardizing outreach as a service. It has been accredited by the Republican Institute for Social Protection, and in the future will provide training and assistance to organizations and professionals who want to engage in outreach.

## Lessons identified



The involvement of CSOs with experience in HIV outreach, including counselling and testing among key populations, was crucial in reaching people most affected by mpox, to provide them with information about risks, prevention, treatment and referral for testing and care.

The availability of both counselling and testing in a safe and accessible environment is crucial for the prevention of STIs, including mpox, among heavily stigmatized populations.

The activities in HIV prevention significantly overlap with those needed for mpox prevention.



#### **Impact**

During the EuroPride week, outreach workers reached 4620 participants with preventive advice on mpox and distributed leaflets to them (only leaflets handed out together with verbal advice were counted during the outreach service). In total, 221 counselling conversations and rapid-tests for HIV and syphilis were provided, with 11 HIV and 17 syphilis reactive results (incidence of 5.0% and 7.7%, respectively) from individuals from Serbia as well as Albania, Bosnia and Herzegovina, the Russian Federation and Türkiye. All were appropriately referred to the necessary confirmatory tests. Out of the 221 people tested for HIV and syphilis, 26 reported potential concurrent mpox symptoms. Serbian individuals were referred for testing. Advice was given to all to self-isolate as much as possible and to avoid close contact with others. Since those with mild symptoms faced a waiting time of 10 days before any test results could be accessed, foreign individuals were requested to seek testing in their country of residence as most were only staying in Serbia for a few days.

Nationally, the number of people from key populations requesting voluntary testing for HIV in public clinics appears to be lower than the number of those seeking referral for testing in Association RAINBOW's mobile units, implying that individuals prefer to use communitybased services.

#### WHO's role and available resources

WHO Country Office in Serbia supported Association RAINBOW with funding to offer training for their outreach workers on mpox. Representatives of WHO conducted training for the Association's team, who in turn cascaded training for the volunteers and organizers of EuroPride. The objective of the training was to increase levels of knowledge about mpox, including transmission, symptoms and protective measures, with a view to providing information that increases the protection of the target population against infection and to minimize the risk of further transmission in case of infection.

WHO has a questions and answers webpage on mpox testing for both individuals and communities available (WHO, 2023b) and interim guidance for the laboratory testing of the mpox virus has been developed (WHO, 2022c).



#### **CASE STUDY: BEHAVIOURAL AND CULTURAL INSIGHTS**

## Identifying gaps in knowledge and practice on mpox among Albanian health-care students to inform training needs.

#### What this case study is about

This case study shows how Albanian academic researchers are using Behavioural and Cultural Insights to inform continuous professional development and university education for health-care workers on mpox.

#### Why it is important

This case study shows the importance of understanding the attitudes and perceptions of health workers towards disease outbreaks. A greater appreciation of these views can illuminate areas for capacity building and reveal vulnerabilities among populations, particularly among whom risk-perception is low.

#### **Main topics**

- Behavioural and Cultural Insights
- RCCE
- Infection Prevention and Control

#### **Country context**

Albania is an upper-middle-income country with a population of around 3 million people in the Western Balkan area of south eastern Europe (World Population Review, 2023).



© Fatjona Kamberi

#### Background to the study

In October-November 2022, academics from Vlorë University's research Centre for Public Health in south western Albania conducted a study among healthcare students, including those from nursing, medical and physiotherapy programmes in relation to their knowledge, awareness and attitudes about mpox. The goal was to assess and understand the students' knowledge and practices as well as their information needs on the mpox emergency, with a view to informing risk and behaviour change communications and enhancing the training curriculum for health-care workers.

The academics had already published research articles in relation to COVID-19, particularly focusing on the impact of the pandemic on different target groups of the population including nursing students and health-care professionals. These investigations had revealed gaps in knowledge on protective measures, high levels of vaccine hesitancy and the strong impact of the pandemic on the mental health of health-care workers, so, when the mpox outbreak was announced in May 2022, it was deemed valuable to reinvestigate with the focus on mpox and health-care students.

#### **Approach**

Led by Fatjona Kamberi, nine researchers (with a background in nursing and general medicine), did an initial literature review during they were unable to find any scientific articles or other information on mpox that had been released by national public health authorities. They also surveyed the grey literature in blogs or articles published in various magazines or journals, but information was limited. According to information from the Albanian Ministry of Health (May 2022) and the department of infectious diseases at the National Institute of Public Health, although preparations had begun to enable diagnosis of mpox in laboratories within the country, no cases of mpox were reported in Albania (Albanian Ministry of Health, 2022). This fact, plus a perception that the group most impacted by mpox during this outbreak, MSM, were not active in Albania in large numbers, caused researchers to believe that risk perception was low.

The study was formulated to create evidence-based information that would help the country prepare for health emergencies, even in the context of low risk-perception, as in the case of the mpox outbreak. Questions for the survey were devised based on mpox information published by WHO (WHO, 2022d and WHO, 2023c). The questionnaire was first created in English and then translated into Albanian, with the language adapted to be clearly understandable by the target population. It was then distributed online via the free Google Forms platform to faculties of health at various universities in Albania, including the University of Vlorë, the Medical University of Tirana, and the University of Elbasan (all public universities), as well as a small number of mostly private universities in Tirana, the capital. Participation in the study was voluntary.

#### **Results**

Of 1000 questionnaires distributed, responses from 739 students were received, with just over half from the University of Vlorë (52.9%). Most respondents were female (89.7%), aged between 18-21 years old (88.8%) and the majority were bachelor's students in the field general nursing, midwifery and physiotherapy.

The first question asked students what they knew about mpox. Around 80% of students reported that they knew it was a virus, but 14% reported not knowing anything about it whatsoever. Around 30% of participants reported not having any information about mpox, while 40% did not have any information about its symptoms. About 30% of respondents did not know how to prevent an mpox infection, with 25% mentioning the use of hand disinfectant, 22% mentioning avoiding sex, 17% responding that people should limit their number of sexual partners, and around 45% mentioned vaccination. In all, 23% of students said they would feel stigmatized if they got mpox, while 41% of students in the study said that if they got ill, their family members would also be at risk of exposure to mpox.

Twenty-two percent of participants believed the mpox vaccine had numerous side effects and 13% of the students in the study believed they would become seriously ill if they received the mpox vaccine. Approximately 15% of students believed vaccines in general to be unsafe, while 43% had no opinion. About 32% of students had not been vaccinated against COVID-19 and 44% of students had never been vaccinated for seasonal influenza.

#### **Challenges**

The researchers were unable to locate a validated questionnaire on mpox for free use online, so they had to create their own, based on publicly available information from WHO Regional Office for Europe, which was time consuming.

All researchers worked on the survey and study on a voluntary basis, within the framework of their university jobs, but without extra funding.

In this way we can provide new information and create knowledge and transfer this but to do this research on a voluntary basis is very difficult to do because there is no culture for it. As a researcher, you are seen as a strange person, asking difficult questions.

#### Fatjona Kamberi

Head of the Research Centre for Public Health the Ismail Qemali University of Vlorë

According to the lead researcher, it is difficult to be published in peer-reviewed, indexed international journals that aim to maximise impact without collaborating with international partners. On the other hand, if articles are published in international journals, they will not be read by a national audience because readers are not comfortable with English.

#### **Future plans**

The researchers aim to publish their findings in a peer-reviewed Albanian journal so that the results will be available to a national audience. However, they have identified gaps in how the findings of academic research are applied to practical training and practice in hospitals:

After the publication of an article, I feel a little bit disappointed because you have to implement the results and that is the most challenging thing for a researcher because we are very good at operational research, but without funding and support you can't carry out implementation research. And if you don't implement the results of your research, you get demotivated.

Fatjona Kamberi University of Vlorë

To rectify this, the researchers plan to organize continuous professional development training workshops for health-care workers, credited by the national Health and Social Care Insurance Agency in relation to infectious diseases such as mpox, COVID-19 and hepatitis B. This training will be available for free on the University website. The knowledge gaps identified in the survey will be addressed to improve the knowledge of health-care professionals, provide coping strategies and suggest other areas of practice where findings may be applicable. The researchers also plan to conduct the survey among current health-care professionals to understand the real gaps in relation to knowledge and practice. A further follow up study is also planned to understand whether the situation reported in their research is replicated among students in other universities.

Based on the findings of studies on student knowledge, attitudes and practices relating to various diseases including mpox, revisions to the curricula of the study programmes in nursing and midwifery at the University of Vlorë's Faculty of Health are planned. The survey results will also be used to provide evidence-based coping strategies for health-care students at the beginning of their clinical training.

I wanted to complete a puzzle in relation to infectious diseases in context. This also helps to create a better curriculum for ourselves and other training materials that can be used afterwards. The results can be applied to different research projects in our institution, as well as providing health-care professionals with more solid clinical practice and greater quality of care in relation to the patient.

#### Fatjona Kamberi

University of Vlorë

# Lessons identified



Behavioural insights research can help to understand barriers to and drivers of healthy behaviours among health-care workers as well as other target populations.

Taking a structured and rigorous approach to collecting behavioural insights is important for defining a health problem and allows for the development of an effective, tailored response.

Health workers are a key source of insight and can be an important target population for tailoring interventions, policies and communication as they are often the direct source of health advice.

Academic institutions can play an important role in collecting behavioural insights data and sharing results with health authorities and other decision-makers.

Behavioural insights research needs to be complemented with rapid community feedback, particularly during emergencies, for timely access to insights to inform the response.

#### WHO's role and available resources

In early September 2022 the WHO Regional Office for Europe proactively circulated information on the Regional response strategy on mpox and epidemiological reports on the outbreak to an informal network of academics and expert practitioners established during the COVID-19 pandemic. The Regional Office asked them about any planned studies on mpox risk perception, risk behaviours, access to services, stigma and all related issues – or other behavioural research relevant to the mpox response. Fatjona Kamberi was one of the researchers in this network and shared details of her planned survey with the Regional Office.

Fatjona Kamberi presented the results of her team's survey during an informal RCCE expert group consisting of RCCE practitioners, academics, CSO representatives and international organization representatives, organized in November 2022 to review the mpox response. The aim of the presentation was to explore the role of misinformation and risk perception amongst the target group: numerous information voids were identified as well as a low willingness to get vaccinated. In the same month, The Regional Office also produced a policy brief on Behavioural and Cultural Insights for mpox control and elimination (WHO Regional Office for Europe, 2022b). In February 2023 the Regional Office's informal network was formalized when the Regional Director for Europe, Dr Hans Kluge, appointed a Technical Advisory Group on RCCE in the WHO European Region. Fatjona Kamberi is one of the members of this new Advisory Group.







#### **CASE STUDY: SOCIAL ASSISTANCE**

## Discretionary social assistance for sex workers as a means to limiting mpox transmission in France.

#### What this case study is about

This case study describes how a coalition of organizations representing sex workers in France collaborated with the French Ministry of Health to develop a scheme that provides discretionary social assistance for those who need to isolate due to mpox infection.

#### Why it is important

This case study shows how social assistance is one tool to encourage adherence to isolation. It also shows how a forum for communication between community representatives and health authorities resulted in recognition of an under-served group's needs during the mpox outbreak.

#### Main topic featured

- Social assistance
- Reaching vulnerable populations
- Reducing stigma
- RCCE

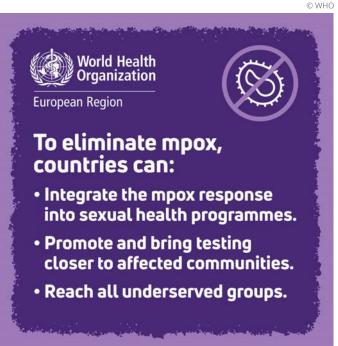
#### **Country context**

France is a high-income country with a population of almost 68 million people. It's capital city, Paris, has a population of just over 12 million inhabitants (World Population Review, 2023).

### The situation of sex workers during the mpox outbreak

Sex-work is legal in France however, it is illegal to pay for sex. When the outbreak occurred, sex workers, in particular GBMSM, reported through regular meetings and networks that they felt very exposed to the mpox outbreak. Whereas most people could choose to take a break from sex while transmission was high, sex workers were dependent on the income brought in by their sexual activity. During the COVID-19 pandemic, similar concerns had been reported, however, at that time, female workers were equally affected.





It's not like sex workers can just stop or have a break in their sexual activity. It is a matter of survival, especially for workers in precarious economic situations.

#### Eva Vocz

Officer responsible for advocacy for sex workers Act Up-Paris, France

Act Up-Paris is an HIV/AIDS campaigning organization that brings together members of the LGBTQI+ community. It is partnered with several other organizations, including a Chinese organization for sex workers called *Roses d'Acier* [Roses of Steel], the *Syndicat du travail sexuel* [union for sexual work], and the *Fédération Parapluie Rouge* [Red Umbrella Federation], which represents most community health and sex worker associations in France. They began to receive questions from the media on mpox, many of which were sensationalist and stigmatized GBMSM, blaming them for transmission. Since the media had not considered the difficult position of sex workers during the outbreak, Act Up raised concerns on behalf of these organizations which generated some media coverage.

#### Collaboration

Act Up was one of a number of organizations approached by the General Directorate for Health to take part in regular meetings on the mpox outbreak.

From the start of the epidemic, the General Directorate for Health worked in close collaboration with sexual health actors and dedicated associations. Weekly meetings were organized up to September 15 (they subsequently reduced in frequency) with associations likely to contribute to preventative actions within the MSM community and sex workers. Particular attention was paid to the risk of stigmatization in this prevention strategy.

#### Pierick Bergeran

Senior official, Ministry of Health and Prevention General Directorate of Health, France

At these meetings, Act Up and organizations representing sex workers coalesced around a request for financial compensation, to cover living expenses if sex workers' income was affected by mpox.

It's kind of a luxury for some people to be able to isolate [...] We underlined the point that without financial compensation people would keep working and mpox transmission would increase.

**Eva Vocz** 

Act Up-Paris, France

#### Social assistance vouchers

As a result of these discussions, the General Directorate of Social Cohesion concluded an agreement with the Red Umbrella Federation. The agreed scheme is:

Aimed at providing exceptional and complementary assistance to TDS/PSP [travailleurs du sexe [sex workers]/personne en situation de prostitution [person in prostitution]] who must isolate themselves for 21 days following an infection by the mpox virus so that they can have access to essential goods. The subsidy granted in this context was for an amount of €125 000 for the year 2022 (possibly renewable in 2023).

Pierick Bergeran

Ministry of Health and Prevention General Directorate of Health, France

The subsidies are distributed in the form of a voucher which can be used in any shop to cover essential goods and food. Red Umbrella distributes these vouchers via intermediary organizations that work with transgender sex workers and GBMSM to support people with mpox. When an organization identifies or is contacted by a person who needs to isolate, they are immediately provided with a voucher — allocation is based on declaration and no proof is asked. Red Umbrella also conduct outreach on the streets to inform sex workers about the importance of preventive and protective measures, including isolation, and the availability of the vouchers.

The vouchers are available all over France, and outreach is also conducted to sex workers via the internet.

#### Challenges and enabling factors

All sex worker organizations that took part in meetings with the General Directorate for Health agreed on a need for social protection of sex workers which strengthened their request and prompted this priority need to be met.

The daily financial assistance provided was nominal but contributing to basic expenses meant that extremely vulnerable sex-workers were better able to isolate.

Low staffing levels within Red Umbrella Federation extended the time taken to draft the agreement and there were also some misunderstandings about the administration's operating methods.

There were some geographical limitations to the sex workers reached since not all areas, especially rural areas, have structures to provide outreach, but equally, the impact of mpox is less in these areas than in large cities.

#### **Impact**

Vouchers were provided to 309 people. However, it is understood that some vouchers were shared by sex workers with other sex workers, meaning that the total number of people to benefit from the vouchers has been around 400 so far.

#### **Future steps**

Even though the transmission of mpox has dramatically reduced, the voucher system continues to be available to those who apply and there is potential for the scheme to be renewed.

#### WHO's role and available resources

An informal working group was convened to co-develop a risk communication toolkit for event organizers, inform RCCE messages with community insights, and share community engagement interventions for the mpox outbreak (WHO Regional Office for Europe, 2022c). The informal RCCE CSO working group met between June and November 2022 to review different approaches to reaching communities as the outbreak continued. In March 2023, the working group reconvened with a focus on engaging CSOs towards mpox elimination: this entails reaching groups left out of the response, such as sex workers. WHO has also produced public health advice for sex workers (WHO, 2022e).

# Lessons identified



Community health organizations can relay important issues and articulate the needs of affected groups and discussion and collaboration with these organizations allows for a better understanding of barriers to preventive and protective measures during outbreaks.

A positive point is that this outcome really managed to show that community health organizations are important and essential to end the outbreak. What was helpful was to have community led organizations regarding health speak for themselves.

**Eva Vocz** Act Up-Paris, France

It is important that health authorities map the diversity of organizations representing all affected communities, including sex workers, in order to identify the most effective channels to the affected community.

A space for dialogue between health authorities and CSOs should begin early in an outbreak. The organization of these exchanges benefits from a clear and shared framework, include the sharing of constraints imposed within the context of public decision-making.

Delegating the distribution of social assistance tools (such as vouchers) to a trusted community organization is a way to reach those who need them most.

The prevention of mpox should be integrated into the overall sexual health and prevention of STI policy among sex workers, in order to improve the effectiveness of actions.

Representatives of sex workers should be integrated into discussions on sexual health at the national and regional levels.



#### **CASE STUDY: MASS GATHERING**

## The value of engaging an affected community as key agents in a health emergency response in Ireland.

#### What this case study is about

This case study shows how an Irish community-based organization expanded its existing HIV and sexual health outreach work to meet the extra demands of large and mass gatherings during the mpox outbreak.

#### Why it is important

This case study shows how ongoing collaborative partnerships with community-based organizations can be leveraged and boosted during health emergencies. Co-designing interventions with an affected community to be the agents of that response is mutually beneficial — communities are better engaged and able to protect themselves, and health authorities benefit from the organizations' skilled manpower, community knowledge, and trusting relationships. Although mass gatherings can amplify transmission, this case study shows how they are also a valuable opportunity to share public health messaging, particularly if this is conveyed through language and channels used by event goers.

#### Main topic featured

- Mass gatherings
- RCCE
- Working with sex-on-premises venues
- · Reducing stigma
- · Multisectoral coordination

#### **Country context**

Ireland is a high-income country with a population of just over 5 million people. It is rapidly urbanizing; the capital city, Dublin, has a population of around 1 256 000 inhabitants (World Population Review, 2023).

#### Description of organization or programme

The MPOWER programme at HIV Ireland is a suite of peer-driven responses to the sexual health and well-being needs of gay and bisexual men and has been running since 2020. MPOWER operates a number of communitylevel interventions which work with GBMSM, most of which focus on developing low threshold access points to HIV and STI testing, for example by making rapid HIV testing available from trained peers in clubs or sex-onpremises venues. MPOWER also developed Ireland's first HIV self-test service, available to order for free online. Their paid outreach team consists of five people who support key populations with information, referrals and connection to care across Ireland. They do this online as well as in person at clinics and other venues, such as bars and clubs, with which they have developed good working relationships.

### MPOWER's work during the mpox outbreak

When the first cases of mpox were identified in the United Kingdom and Portugal, a National Crisis Management Team was convened in Ireland that included MPOWER as a community-based organization. Due to their innovative work on peer-led rapid testing for HIV, the organization had already developed a strong constructive relationship with the health service, specifically its sexual health aspect and had been a member of a previous national outbreak control team. The mpox National Crisis Management Team included multiple stakeholders from the Health Service Executive including: national and regional public health leads; the Health Protection Surveillance Centre (epidemiology); clinical lead for sexual health; infectious disease consultants; representatives from Community Operations, Acute Operations, Communications, the National Immunisation Office and the Research and Guideline Development Unit, as well as representatives from the Department of Health, the National Virus Reference Laboratory and MPOWER.

From the beginning, both our government and our health service turned to MPOWER for meaningful engagement and to get a steer from a community perspective. We were humbled but also, I think it was very important that we were there at the table from the beginning.

#### **Adam Shanley**

MPOWER Programme Manager **HIV Ireland** 

MPOWER approached the Health Service Executive and the Department of Health with a proposal that outlined the additional community-based work they felt was necessary to tackle the mpox outbreak. Further to the service agreement already in place, MPOWER requested and was granted extra funding to cover the necessary increase in its activities, including outreach to venues, connecting people to services and the production of new risk communication materials.

MPOWER called on the existing pool of 50 volunteers involved in rapid HIV testing and conducted a full day's training on what was currently known about mpox, and the preventive and protective measures volunteers would be asking community members to consider. MPOWER then worked with the community organization Man2Man.ie and the Health Service Executive to produce communication materials using language that was appropriate for the community. In this 'alert' phase of their response, volunteers visited bars and clubs throughout June to have conversations and share flyers about mpox.

#### **Pride**

In June MPOWER ramped up their activities to meet the challenge of outreach during Dublin Pride, a huge annual event with an estimated 50 000 attendees. Thanks to the small but well-connected LGBTQI+ community in the city, many gay bars and clubs offered their spaces or events as a vehicle for messaging and outreach: MPOWER was given access to all of the Pride events including the threeday long Block party. Big screens during this event and throughout the Pride march carried their messaging.

#### Sex on premises venues

MPOWER also sent volunteers and materials with health advice to sex-on-premises venues. These venues are somewhat under the radar and also visited by MSM who do not identify as gay or bisexual and a large rural community travels to the capital to visit them. Prior to the mpox outbreak, work had been carried out over a longer period to convince both the management of the premises and public health colleagues that collaborative work was important and MPOWER acted as a go-between to bring together the stakeholders and encourage dialogue. During the mpox outbreak therefore, trust had already been built, and the benefits of collaboration established: sex-on-premises venues have helped encourage health-seeking behaviours that make them key players in public health and are therefore less likely to be shut down during outbreaks. Venues happily accepted posters about mpox; leaflets were taken and interactions with clientele were positive.

All pride events and the Block party were ticketed, so MPOWER was able to contact every attendee (27 000 over 3 days) via email with information about mpox and then send a follow up email a week to 10 days after the block party telling people about symptoms to be aware of. They also utilized dating apps like Grindr to disseminate messages.



An mpox poster displayed in the bathroom of a gay bar in Dublin.



Staff and volunteers from MPOWER, Ireland.

© Adam Shanley

#### **Impact**

In total 66 outreach sessions were conducted: every day in June – Pride month – and at least once a week up to Christmas. The outreach took place in all of the main gay bars in Dublin. Each session was 90-120 mins long - giving a total of up to 130 hours spent providing face-to-face contact time within the community.

In addition, MPOWER's poster campaign was displayed in all of these gay bars and Dublin's one sex on premises venue as well as in MPOWER's LGBTQI+ community centre and for gay club nights.

Over the course of the outbreak response MPOWER developed five different flyer designs (What is mpox?, Symptoms/Services, Safer Sex, Informed Choices and Vaccine Available) all available in three languages (English, Spanish and Portuguese). MPOWER provided the community with around 25 000 flyers over the course of the outreach.

#### Next steps

Falling case numbers have led to a drop off in vaccination rates after intense demand at the beginning of the outbreak; MPOWER is working with epidemiologists to analyse how perceptions of reduced risk may lead to changes in behaviours.

We have bombarded our community with a lot of messaging and people have had enough. In this next phase we need to be more innovative and that's where maybe looking at more data-led approaches to vaccination or engagement will be really important.

**Adam Shanley HIV Ireland** 

Following the initial "alert" phase of the outbreak, MPOWER has developed communications that focus on people continuing their sex lives yet with the recognition that mpox has not yet been eliminated.

We've learned from decades of messaging to our community that telling people not to do something isn't the approach. Now we are offering an informed choices piece- this is what this is, this is how to look out for symptoms and where to get tested.

**Adam Shanley HIV** Ireland

MPOWER continues to sit on the National Crisis Management team and other breakout working groups. By analysing demographic details of those who have signed up for vaccination they have identified two key groups that may not have been served by existing outreach and health service infrastructure, namely Dublin's large Latin American community, and MSM under the age of 18. They are working on strategies to reach these potentially vulnerable groups with better information and services and looking at ways to integrate mpox vaccination into other sexual health services, for example outreach on syphilis.

From a community perspective it's really important that we don't leave anybody behind, and dismantle structural barriers to support. We have to recognise that a resurgence of mpox isn't beyond the realms of possibility.

**Adam Shanley HIV Ireland** 

# Lessons identified



Including community-based organizations in national crisis response mechanisms is critical to engage communities and receive their support in response efforts.

Flexible funding arrangements enabled resources to be repurposed for an emergency.

Finding surge capacity to rapidly expand sexual health outreach during the mpox outbreak was essential. Financial support for CSOs can facilitate the ability to conduct outreach activities, including by increasing the number and capacity of volunteers to work with eventgoers during a mass gathering.

Using multiple channels to reach eventgoers helped to increase impact. Personal conversations, leaflets, posters, social media, dating apps, on-stage videos and announcements all conveyed public health advice around mpox.

Trusted relationships between community organizations and commercial venues, built before emergencies, can enable access to underserved groups.

Data-led approaches, combined with a flexible outreach strategy are helpful to identify underserved and marginalized groups, with a view to eventually eliminating mpox.

The WHO Regional office for Europe recommends strong coordination among policy-makers, service providers and community-based organizations serving those at highest risk of exposure to mpox, as essential for bridging service delivery and access.

#### WHO's role and available resources

To help countries develop strategies to control mpox, in June 2022 the WHO Regional Office for Europe and the ECDC published joint interim advice for public health authorities on summer events during the mpox outbreak (ECDC and WHO Regional Office for Europe, 2023b). Accompanying the interim advice, a mpox resource toolkit (WHO Regional Office for Europe and ECDC, 2022a) was developed to support national authorities and event organizers in their risk assessment, planning and coordination of large and mass gathering events, and to provide public health advice through risk communication and community engagement interventions. The toolkit acts as a one-stop-shop and includes technical guidance, trainings, readyto-use and customizable tools for: public health preparedness and risk assessment; early warning, alert and response; event-based surveillance; contact tracing; and RCCE including health information and advice on monkeypox for mass gatherings.

The WHO Regional Office for Europe has also developed a mobile friendly web tool with interactive dashboard (WHO Regional Office for Europe, 2022d). The tool provides an up-to-date assessment of the in-country situation, links to the websites of local health authorities, advice on available preventive measures, as well as links to WHO guidance.



#### **CASE STUDY: PREVENTION AND CONTROL MEASURES**

## How a community-led organization worked with sex-on-premises venues in Portugal to reduce transmission of mpox.

#### What this case study is about

This case study describes how rapid and open dialogue between a trusted community provider of sexual health services and sex-on-premises venues allowed for dissemination of public health advice, leading to greater risk perception of mpox transmission routes and increased access to vaccination, facilitated by the flexibility of health authorities.

#### Why it is important

Infection prevention and control measures in venues where sex occurs can help to mitigate the transmission of mpox by engaging both users and management of these sex-on-premises venues with public health advice on prevention and protective measures. Through their network of stakeholders, CSOs can reach under-served group. The reduction of stigma around mpox leads to a greater acceptance of preventive and protective measures, and more information-seeking and health-seeking behaviours.



#### **Main themes**

- Infection Prevention and Control
- · Working with sex-on-premises venues
- Vaccination
- RCCE
- Reducing stigma
- Multisectoral coordination

#### **Country context**

Portugal is a high-income country in southern Europe with a population of just over 10 million people. It's capital city, Lisbon, has just over 500 000 inhabitants (World Population Review, 2023).

#### **GAT Portugal**

GAT (Grupo de Ativistas em Tratamentos, Treatment Activist Group), was founded in 2001 as a CSO that advocates for legal and policy changes that positively affect the health, rights and quality of life of people living with HIV or at increased likelihood of exposure. It is based in the capital, Lisbon and they provide sexual health services through a network of checkpoints.

GAT has multiple funding sources: public funding comes from the Regional Health Authority, with whom they have a cooperation agreement and private funding comes from the pharmaceutical industry, the medical devices industry and individual donations. They are partnered with the AIDS Healthcare Foundation and Coalition Plus. GAT's mpox response relied on current staff from GAT sexual health centres mostly visited by sex workers, migrants, cisgender men and trans people who have sex with men. Together the centres have 13 part-time physicians, eight nurses and 12 community health workers. All GAT centres include the populations mentioned above in service design and delivery.

When cases of mpox were detected in Portugal, within the scope of their cooperation agreement with the Regional Health Authority, GAT began to offer mpox testing at the above-mentioned GAT centres in partnership with the national reference laboratory for STIs. GAT has more than 10 years of experience in offering integrated HIV and STI testing services and has built long-standing trust with health authorities and MSM through its outreach and community participation. It made sense for them to take a big role in the mpox response.

HIV was the starting point, and since we have had this relationship for some time and the structure is built, we can use our experience and services because it's all about the same thing – a transmissible infection needs to be detected, treated promptly and linked to care. Is there a prevention tool? A vaccine? Even better. They knew that we had the trust of the community, which was an enabler for us to reach people faster.

#### Miguel Rocha

Public Health Nurse Grupo de Ativistas em Tratamentos (GAT) [Treatment Activist Group], Portugal

GAT was able to convene a range of community stakeholders for training on mpox, including venues such as saunas, bars and sex-on-premises venues where testing outreach had taken place. Information shared was aligned with that provided by the National Health Authority in Portugal, WHO and the ECDC and signposted with where to refer anyone with suspected mpox symptoms. GAT also started a mpox helpline, to offer information on the disease and to triage and refer people who were sexual contacts or exposed to mpox for postexposure prophylaxis. The helpline proved important because contact tracing was not always possible; many sexual contacts were anonymous (for example, through the dating app Grindr) so individuals were self-reporting based on likely exposure. This helpline also provided access to vaccine prescription and immediate booking at GAT Checkpoint LX and GAT Intendente.

### Infection Prevention and Control – WHO's mpox guidance

Venues where sex occurs usually have standardized protocols for frequent cleaning of these spaces, but GAT shared the latest advice on mpox to help them strengthen existing measures. As a distributor of condoms as part of its STI and HIV outreach programmes, GAT continued to supply condoms to venues, but, as per the recommendations, informed people that they would not protect them against mpox.

#### Reducing transmission and avoiding stigma

The managers of sex-on-premises venues discussed what they could do to limit transmission of the virus. The suggestion of screening on entry was rejected on the basis that it would cause stigma and discrimination.

That idea was really frowned upon by some other stakeholders and for our part, it's not evidence-based and not recommended because it will lead to discrimination only. What is important is self- assessment. That you refer people who report symptoms and that you refer people who have contact with mpox to us and to our mpox helpline.

#### Miguel Rocha

Grupo de Ativistas em Tratamentos (GAT) [Treatment Activist Group], Portugal

Sex-on-premises venues are commercial venues and there is a financial imperative for them to stay open. Rather than putting venues off sharing public health advice about mpox however, this contributed to a willingness to take actions to limit transmission and prevent any potential spread of the disease. Venues had had previous experience of outreach from GAT and a few had hosted pop-up testing for HIV and other STIs. They shared materials and put up posters.

We knew that, of course, if this was ongoing, more measures and probably more repressive measures would be in place — that's normal in public health with transmissible diseases.

#### Miguel Rocha

Grupo de Ativistas em Tratamentos (GAT) [Treatment Activist Group], Portugal

As part of work to increase literacy about the signs and symptoms of mpox, GAT worked jointly with the General Health Authority during Pride to create and distribute highly memorable cards with a QR code that linked more public health advice.

Some people were uncomfortable and defensive about receiving them because they felt that they were being targeted because they were MSM. The cards worked, because the mpox helpline was flooded with calls and more people were detected and linked to care. But it did not please everyone.

#### Miguel Rocha

Grupo de Ativistas em Tratamentos (GAT) [Treatment Activist Group], Portugal

#### Increasing access to vaccination for sex-on-premises staff

From September onwards, preventive use of the vaccine was available.

Community stakeholders [sex-on-premises venues such as bars, hostels and saunas] directly approached GAT to vaccinate their workers. At the time though, even for preventive use, occupational vaccination was not considered, so they were not eligible. However, we knew that they faced exposure, even though they were not necessarily part of a sexual network.

#### Miguel Rocha

Grupo de Ativistas em Tratamentos (GAT) [Treatment Activist Group], Portugal

GAT approached the National Health Authority with their request and an informal agreement was reached to vaccinate staff of sex-on-premises venues who requested it. They visited venues, did triage for vaccination and then provided vaccination at vaccination points.

Staff from three venues were vaccinated – a sauna, hostel accommodation that offered massage and had sex on premises, and one bar that has a dark room (a room where people can have anonymous sex).



© WHO

#### Challenges and enabling factors

At the beginning of the outbreak there was uncertainty about the disease, its modes of transmission and presentation.

There were times when vaccine availability did not match demand:

My main stress working on the hotline was when people working in sex-on-premises clubs were asking to be vaccinated but I could not help them.

#### **Miguel Rocha**

Grupo de Ativistas em Tratamentos (GAT) [Treatment Activist Group], Portugal

Screening visitors to commercial sex-on-premises venues would cause discrimination.

GAT's extensive experience and strong network of stakeholders enabled it to reach out quickly to a wide range of relevant bodies.

#### **Impact**

As of March 2023, GAT has taken 1313 mpox helpline triage calls, 387 people have received mpox post-exposure prophylaxis, 2010 people have received at least one dose of mpox vaccine through GAT centre and 20 000 people have been reached with GAT's information campaign on mpox.

GAT was very present from the beginning of the outbreak sharing all available information. We already had a very strict hygiene policy so my focus was to make sure everyone was aware of the problem. I put posters everywhere and online also. All my staff was offered the mpox vaccine by GAT and I was very grateful for that.

#### Manager

Trombeta bath and sauna Lisbon

### Lessons identified



Trusted CSOs have the means to communicate on protective and preventive measures to communities. When supported and facilitated by health authorities they can respond at speed and with greater impact.

CSOs that work with under-served communities are well-placed to identify their needs.

A large body of knowledge exists in the field of HIV prevention and outreach, and this is highly relevant to the mpox outbreak.

With HIV prevention comes integrated testing and with that a combination of prevention and linkage to care. And so we have to talk with everybody with the community, with the health authorities, with the hospital units, with the primary health care units.

#### Miguel Rocha

Grupo de Ativistas em Tratamentos (GAT) [Treatment Activist Group], Portugal

To work effectively with sex-on-premises venues takes a multilevel-approach including respect for human rights.

When human rights are not respected, people hide or are isolated. Then when we think about sex work, besides human rights, we need to think about worker rights and that's another level of conversation. So the first thing is to do "Nothing about us, without us." That is a phrase from HIV activism. If authorities do not start with this approach, they may expect that commercial businesses will not want to work with them right away.

#### Miguel Rocha

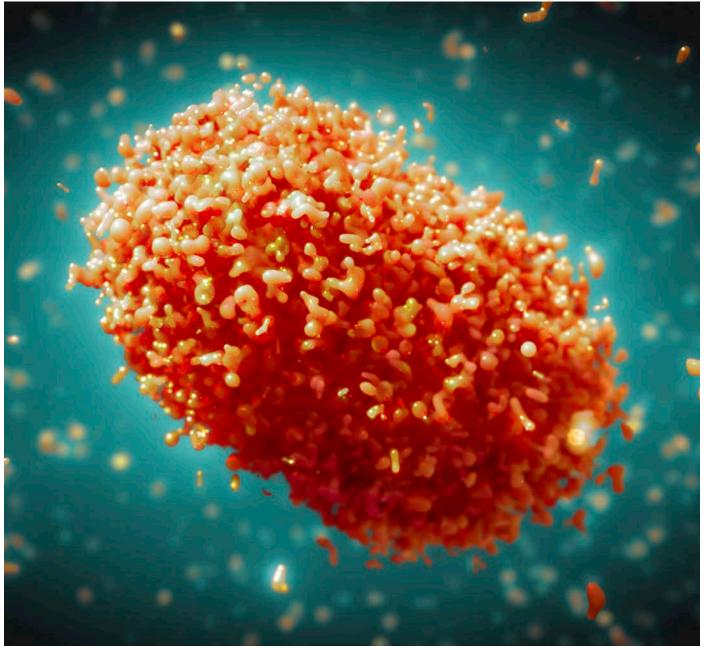
Grupo de Ativistas em Tratamentos (GAT) [Treatment Activist Group], Portugal

Flexible arrangements can also allow health authorities to partner with community groups and commercial venues to reach underserved communities.

Local health authorities have a key role to play in the response as they can better coordinate and work with local community groups and commercial venues.

Hotlines are key to connecting responders and affected groups, understanding perception and providing health advice.



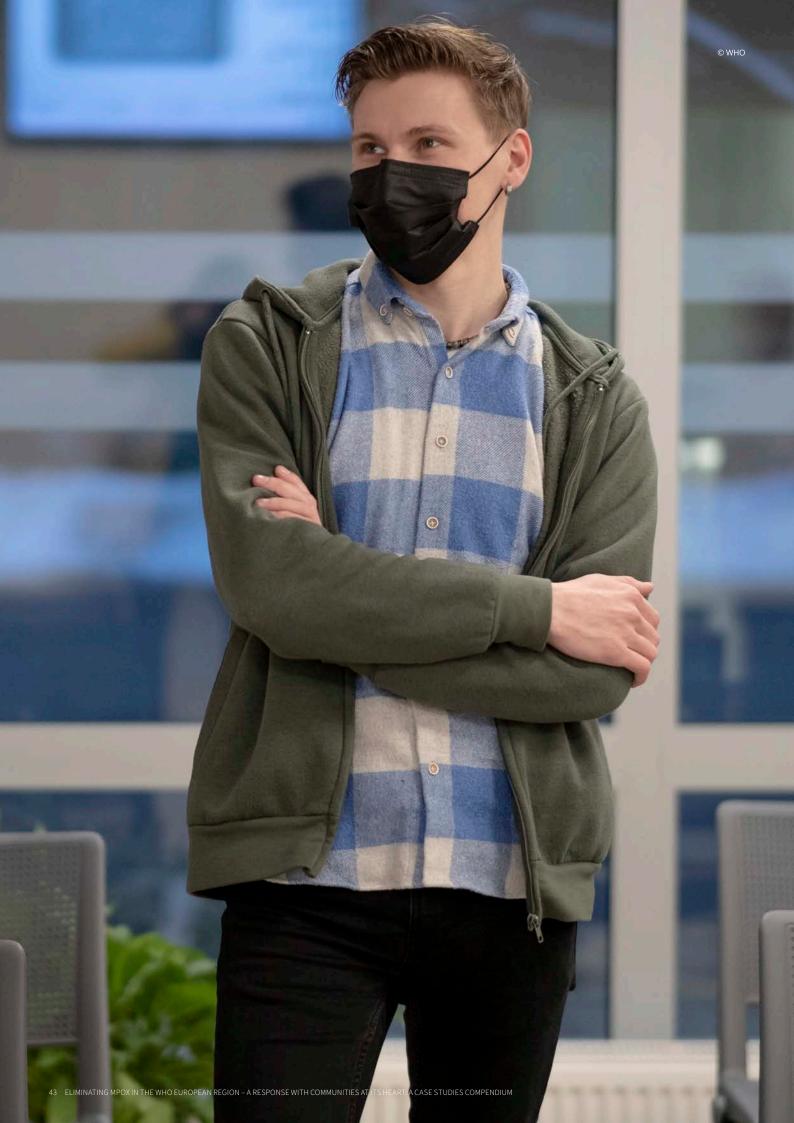


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#### WHO's role and available resources

In June 2022 WHO published interim rapid response guidance on Clinical Management and Infection Prevention and Control with regards to mpox (WHO, 2022f), which provided advice on hand hygiene, environmental cleaning, the recommended personal protective equipment needed by cleaning staff, and the management of linen and towels. The toolkit for event organizers (WHO Regional Office for Europe and ECDC, 2022a) also included advice on cleaning sex toys to prevent transmission of mpox. The Portuguese Ministry of Health also issued national guideline on infection and prevention control for mpox which echoed WHO recommendations (Ministry of Health of Portugal, Portuguese National Health Service and Portuguese General Directorate of Health 2022).

At a WHO webinar in August 2022 the Ministry of Health of Portugal presented the experience of Portugal of initiating a dialogue with community-based organizations, MSM and coordination with HIV/STI testing and care centres, as well as venues, such as bars and sex-on-premises businesses. This dialogue was essential in preparing for Pride events; the Pride March on 18 June and Lisbon Gay Pride on 25 June 2022. WHO has also produced public health advice for sex-on-premise venues.



#### **CASE STUDY: VACCINATION**

## How cooperation and collaboration between health authorities and affected communities are increasing access to mpox vaccination in Latvia.

#### What this case study is about

This study looks at collaboration between a community-based organization and the national Ministry of Health to increase access of key populations to mpox vaccination in Latvia.

#### Why it is important

This case study shows how strong coordination among policy-makers, service providers and community-based organizations serving communities affected by mpox is essential for tailoring policies, interventions and communication. It shows the effectiveness of engaging organizations that represent affected communities to conduct communication, outreach and linkage to health services.

#### **Main topics**

- Increasing access to vaccination
- Reducing stigma
- RCCE



A young man registers for mpox vaccination at the Latvian Centre for Infectious Diseases, Riga.

#### Country profile

Latvia is an upper middle-income country in eastern Europe with a population of 1 900 000 people. Around 68% of its population live in urban areas, and its capital, Riga, has a population of approximately 625 000 inhabitants (World Population Review, 2023).

#### **Description of the CSO Mozaika**

Mozaika was established in 2006, with the mission of increasing awareness of and advocating for the rights of LGBTQI+ individuals in Latvia. As well as political advocacy, the organization supports LGBTQI+ people with information and services on HIV and other STIs, through a test point and HIV PrEP point. Furthermore, their offices operate as a meeting and training space that is used by other LGBTQI+ groups in the country. Mozaika has been engaged in long-term collaboration with the Ministry of Health as part of its outreach on sexual reproductive health and plays an active role in several consultative mechanisms with them.

One good thing about Latvia being a small country is that you can reach out, there is no six degrees of separation.

Kaspars Zalitis Board member of Mozaika

### Multistakeholder cooperation during the mpox response

When the first cases of mpox were reported in Europe in May 2022, Mozaika began speaking with community members about how to avoid infection; they in turn expressed concerns that they would face stigma if they reported mpox symptoms to their family doctor or asked for a pre-exposure vaccine. Identifying these concerns as a barrier to health care and vaccine uptake, Kaspars Zalitis of Mosaika reached out to the Ministry of Health:

We had our first meeting quite quickly, not just with the Ministry of Health but with literally all possible stakeholders – the Latvian Centre for Disease Prevention and Control, the National Health Service, the Centre of Infectious Diseases, the reference laboratory. We'd just had one outbreak – COVID-19. We didn't need another. So, it was better to work together. Why not use the opportunity?

Kaspars Zalitis Mozaika

#### Vaccine referral policy

The Ministry of Health and Mozaika together formulated a new vaccine pathway to respond to concerns that fears of stigma were affecting vaccination uptake. Under this new pathway, if someone feels they may have increased likelihood of exposure, whether or not they are part of an affected community, a close contact of someone diagnosed with mpox or a medical worker, they can choose how to be referred for vaccination. They can visit their doctor, or the Centre for Disease Prevention and Control, but if they prefer, they can self-refer through Mozaika. They are then given an appointment time and helped to fill out a short health questionnaire before receiving their vaccination from a friendly, non-stigmatizing health professional at the Latvian Centre for Infectious Diseases, where staff are particularly experienced in working with marginalized populations. The written regulations of the Latvian Ministry of Health have been updated to prescribe the engagement of Mozaika in the vaccination referral process, legitimizing its involvement in the pathway and providing a clear blueprint for others to follow.

Our work with the LGBT community to raise awareness about accessing vaccination applied the snowball method – we started to speak about [the new vaccine pathway]. We didn't use too much social media because we [GBMSM] didn't want to be negatively labelled as had happened with other pandemics which affected men in the last century.

Kaspars Zalitis Mozaika

WHO's interim guidance on vaccination for mpox (WHO, 2022g) recommends the priority groups who should receive primary preventive vaccination, namely, those at increased likelihood of exposure, including GBMSM.

Our community is not homogenous. We are all very different, but we all need good health and the ability to prevent diseases. We have these mpox vaccines and we need to use them. That's the main task of vaccines – to be used, not to stay in the fridge!

#### **Inga Liepina**

Senior Expert in the Environmental Health Division Latvian Ministry of Health

#### **Challenges**

According to Mozaika, some MSM initially regarded mpox as a disease they were only likely to catch in other countries. Since official mpox numbers were low nationally, risk perception was also low, despite many anecdotal unreported cases. Outreach by Mozaika, including personal testimonies by board members who had experienced the painful symptoms of mpox helped to convince people to get vaccinated.

To eliminate all transmission, I think the most important part is to educate and build the community where people can trust each other and they can talk, because many people don't talk, and they don't go to doctors, and they think, 'Hmm, do I have mpox or do I not have it?' and they just don't treat it and they pass it along.

Alexander Ivanayev Board member of Mozaika

The community-based vaccination pathway was only offered in the capital Riga, so people living in rural areas would need to travel to access it.

Mozaika has a dedicated but small number of volunteers, which limits its capacity to provide services. Furthermore, it received no additional institutional funding for activities, but did receive some private donations.

#### **Impact**

High levels of satisfaction were reported about the service, with health workers relating to the professionalism of Mozaika staff, and community members to the welcoming and non-stigmatizing reception provided.

With 48 people having been referred for vaccination through the Mozaika pathway, this was more than double the number of those referred via other specialists (doctors of infectious diseases, dermatologists and family doctors for example).

As a result of this collaboration between the Ministry of Health and a community organization, there is improved access to vaccination for those most at affected. Avoiding discrimination, fighting stigma, serving the most vulnerable and engaging communities are essential to tackle this outbreak. It is a great example of how, by working together, we can arrive at an outcome which benefits everyone.

**Dr Uldis Mitenbergs** Head of the WHO Country Office in Latvia

This cooperation between all of the stakeholders directly affected the trust of the community towards Mozaika and it increased the trust towards medical institutions. I think this trust will go further and further.

Kaspars Zalitis

#### **Next steps**

Mozaika and the Latvian Ministry of Health continue to work together on the issues of sexual reproductive health and prevention of HIV. Mozaika has also strengthened relationships with the Latvian Centre for Infectious Diseases for future cooperation.

### Lessons identified



Community-based organizations are well positioned to collect and share the detailed insights necessary to understand barriers to and drivers of uptake of preventive measures.

Verbal communication can be an effective way to raise risk perception in certain close-knit, small-scale contexts.

Reducing stigma in relation to mpox vaccination increases uptake and may build trust in other health services and authorities.

Trusted community organizations can potentially provide surge capacity during outbreaks.

With technical and/or financial support, community-based organizations with experience of HIV outreach can potentially adapt their services to respond to new outbreaks connected to sexual health.

Carefully tailored policies, interventions and communication, based on an understanding of the behaviours, perceptions and contexts of people affected by mpox are key to controlling and eventually eliminating mpox in the European Region.

#### WHO's role and available resources

Since the beginning of the mpox outbreak, the WHO Country Office in Latvia has been sharing technical guidance and best practices for tackling mpox with stakeholders. This has included a mpox policy brief series from the WHO Regional Office for Europe (WHO Regional Office for Europe, 2022e) that summarizes policy recommendations, knowledge and interim technical guidance on mpox. Thanks to close contacts with both the Ministry of Health and Mozaika, WHO were able to facilitate dialogue between stakeholders and encourage their collaboration to develop a community-based vaccine referral pathway.

We have received some good practices from the WHO and when we modified some of them, we brought it up with the Ministry of Health. The Head of the WHO Country Office assured the Ministry of Health that these practices are good and the work went on and now it has been implemented.

**Kaspars Zalitis** 

Mozaika





#### **CASE STUDY: RISK COMMUNICATION**

#### Communicating without stigma about mpox.

#### What this case study is about

This study examines the work of a journalist and podcaster who has been prominent in speaking about mpox and looks at the communication choices necessary to avoid stigmatizing affected groups.

#### Why this case study is important

Communicating about mpox in a non-stigmatizing way is important to protect affected groups from hurtful and discriminatory language and actions. Equally, addressing the health and information needs of MSM (the group most affected by the mpox outbreak) in ways that reduce stigma can lead to increased health-seeking behaviours, better engagement with health services and greater trust. Working with journalists from affected communities can help disseminate health messages sensitively and effectively.

© WHO



#### Main topics featured

- Reducing stigma
- RCCE

#### **Country context**

The United Kingdom is a high-income country with over 67 million inhabitants (World Population Review, 2023).

#### "What the Pox?"

"What the Pox?" podcast is a 10-part exploration of some of the issues raised by the mpox outbreak through interviews with patients and experts, including Dr Richard Pebody, who leads the High-threat Pathogen team at the WHO Regional Office for Europe. It is also interlaced with Martin's own mpox experience and is aimed primarily at GBMSM who want to learn more about the disease, including the social and cultural context in which the outbreak occurred.

When I was home alone with mpox in all kinds of pain, feeling scared and alone, I had very little information, so I went online to find help. What the Pox? is the information and support I wish I'd had at my disposal when I was going through mpox.

Martin Joseph "What the Pox"

#### Changing the language around mpox

In What the Pox, Martin Joseph is communicating predominantly to a community that he is part of, MSM, particularly those who have multiple sexual partners. Communicating clearly about how some sexual behaviours make this group most vulnerable to the virus has been crucial, but it has been equally important not to cause stigma or feed into misinformed stereotypes.

Martin Joseph initially planned to produce an anonymous podcast, but soon realized that candid conversations about sex and mpox symptoms were an important element in helping people get through a new and little-understood disease outbreak. He recognizes the difficulties in talking about sex, but thinks it is crucial to provide people with accurate information.

Part of the reason I didn't want to do it was because of shame and stigmatization. But I just thought I have to do it because actually the one thing that got me through my journey was reading other people's accounts online.

Martin Joseph "What the Pox

He attributes the success of the podcast to the fact that it did not place stigma on the lifestyle of any of its listeners but addressed their health and information needs, offering solidarity and personal stories alongside expert voices:

What we did shouldn't have been any different – but it was. We allowed people to come and listen about mpox without homophobia, transphobia or prejudice. No shame or stigma; that was our tagline – you can listen and not be judged for the person you are. The media should and can do that – if they make a distinct editorial choice. It's vital they do because stigma stops people from getting the information they need, which leads to this and other viruses spreading further. That's why getting it right is so important.

Martin Joseph "What the Pox'

He also advocates for more global vaccine and resource sharing and improved health-care services for the LGBTQI+ community. Furthermore, he calls for more to be done to tackle homophobia, which he too sees as a barrier to reducing human-to-human transmission and achieving the goal of eliminating mpox from the Region.

#### Challenges and enabling factors

Much of the mainstream media is unwilling to address societally taboo subjects and there have been many episodes of misrepresentation and sensationalism that have led to discriminatory backlash.

If all the newspapers had put information about mpox out in the same way as they did with COVID-19, like, this is just a health emergency and everyone had just stepped up, it would have been dealt with so much faster. People would have been less in the dark, and there wouldn't have been the secrecy and the shame. But what happened was the information that came out was that this is gay man's disease or this is dirty.

Martin Joseph "What the Pox"

However, when health authorities and experts work with journalists who have high levels of recognition and respect, it can amplify the trust in information. Equally, working with journalists with specific links to affected communities, and reaching them in the channels they use is key to disseminating messages successfully. When journalists have close links with the community most affected by mpox, it can bring a greater understanding of the issues at play.

#### **Impact**

Collaboration between the WHO Regional Office for Europe and community-based journalists was mutually beneficial – not only did WHO spokespeople offer them up-to date, evidence-based data on mpox, but podcasts such as What the Pox enabled the Regional Office to gain access to a key audience for risk communication messages.

Working with the WHO helped connect the dots between our on-the-ground coverage and the wider global picture on mpox. It became clear that no matter how co-ordinated any local action was, without global action mpox could become endemic in many more countries. Their tracking of data and the science behind the virus was an invaluable resource for the documentary. as were the interviews we did with WHO professionals.

Jamie Wareham

**Executive producer** "What the Pox"

Talking to journalists who have a personal understanding of the issues around the mpox outbreak has been really important for WHO. Not only can they reach affected communities, but as public health experts, we can learn from them about how to communicate without stigma or discrimination.

#### **Richard Pebody**

Programme Area Manager for Infectious Hazard Management, WHO Regional Office for Europe

### Lessons identified

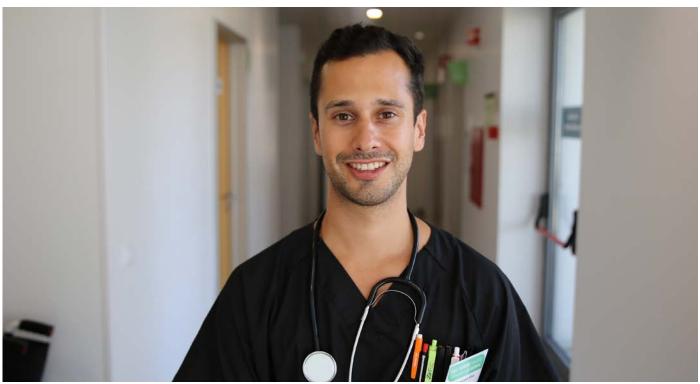


Stigmatizing language around mpox can put unfair blame on communities at increased risk, leading to further discrimination. Stigmatizing mpox can lead to people hiding their symptoms or not seeking help when needed.

Candid conversations about sexual behaviour through the right channels can reduce stigma, share important information and increase people's understanding of how to protect themselves.

When health authorities work with trusted voices from affected communities, they can share information through effective channels and language.

Listening to and learning from those who speak for and to affected communities enables health authorities to better reach those communities with language that resonates with them.



#### WHO's role and available resources

The WHO Regional Office for Europe's collaboration with GBMSM and the CSOs that represent them has helped to disseminate crucial, non-stigmatizing information via multiple channels and platforms throughout the summer of 2022 and beyond. WHO has published public health advice on understanding, preventing and addressing stigma and discrimination related to mpox (WHO, 2022h) which states that:

- media outlets must be provided with accurate information and guidance about mpox and encouraged to integrate non-judgmental language into their reporting.
- journalistic reporting which overly focuses on individual behaviour or assigns blame may increase stigma towards people who may have the disease or who may be part of a community that is incorrectly blamed or perceived as being responsible for its spread.

In addition, WHO organized a webinar on managing stigma in health-care settings in public health emergencies such as mpox which is available online (WHO, 2022i).



A social media image produced by AIDshilfe advocating for language on mpox that does not cause stigma or discrimination.

### Promoting non-stigmatizing language in Germany

Deutsche Aidshilfe, a German organization engaged in HIV prevention and support for those living with HIV promoted new language to replace stigmatising terms. Deutsche Aidshilfe's prevention programme for gay, bisexual, trans and other men, who have sex with men called IWWIT (Ich Weiss Was Ich Tu – I know what I'm doing) put out messages on social media challenging the term 'risk group' and suggesting alternative, non-stigmatising language.

Ferenc Bagyinszky, Executive coordinator, AIDS Action Europe, reports that the general experience of Deutsche Aidshilfe around mpox was quite positive: "We had many journalists asking how they could report correctly without reproducing stigma. The Robert Koch-Institute (the German government's central scientific institution in the field of biomedicine) is always very interested in our comments on their texts and always tries to avoid stigmatization. "It is a good example of communication at eye level between a government agency and an NGO."

- Risk group currently the most affected group
- · Gay scene gay community
- Monkeypox mpox

They also published a blog article featuring an interview with a man who had mpox to remove stigma about discussing the condition. The blog gave a straightforward account of the symptoms he had experienced and talked about the social and medical support he had received. Ferenc Bagyinszky, the Executive coordinator of AIDS Action Europe, reports that the general experience of Deutsche Aidshilfe around mpox was quite positive:

We had many journalists asking how they could report correctly without reproducing stigma. The Robert Koch-Institute (the German government's central scientific institution in the field of biomedicine) is always very interested in our comments on their texts and always tries to avoid stigmatization. It's a good example for equalranking collaboration between governmental authorities and community and nongovernmental organizations.

WHO recognized that the name "monkeypox", initially used for the disease, has a stigmatizing effect on those affected. Following consultations with global experts, in November 2022, WHO began using the new preferred term mpox as a synonym for monkeypox (WHO, 2022j).



#### **CASE STUDY: RISK COMMUNICATION**

#### How one CSO in Romania is influencing the language used around mpox.

#### What this case study is about

This study describes the actions of a CSO in Romania to bring changes to language around mpox that was stigmatizing MSM and causing a discriminatory backlash that anecdotally prevented some people with mpox from seeking treatment.

#### Why it is important

Stigmatizing language around mpox can lead to negative stereotyping of affected groups. This may impact on their well-being, as well as their health-seeking behaviours and their perceptions of health care services. Small changes in language and communications, especially when informed by the communities most affected, can help prevent stigma and increase trust in health services.

© Romanian Ministry of Health



An information leaflet produced by the Romanian Ministry of Health describing the virus, its symptoms and mode of transmission. This Romanian leaflet is not available in English.

#### **Main themes**

- RCCE
- · Mass gatherings

#### **Country context**

Romania is an upper-middle-income country in Central Europe with a population of nearly 20 million people. The capital, Bucharest, has almost 2 million inhabitants (World Population Review, 2023).

#### **Association ACCEPT**

Association ACCEPT was the first nongovernmental human rights organization in Romania to promote LGBTQI+ rights at national level. It was established in 1996 and a year later, the association launched a national and international campaign to decriminalized same-sex relationships, and subsequently, in 2002, this law was repealed. The organization has previously run anti-discrimination workshops in Romanian schools.

We use human rights language primarily, which is about the rights of affected people. It's not exactly a medical language. In terms of our health work, we have a history of supporting HIV prevention and treatment. What we have done is to identify gatekeepers in local communities to put people in contact with specialists who can offer referrals to specialized medical units. And we put pressure on those medical units to serve these beneficiaries and respect their sense of dignity.

#### Florin Buhuceanu

Activist

Asociația ACCEPT [Association ACCEPT] and the Euroregional Center for Public Initiatives.

When the mpox outbreak was declared by WHO, Association ACCEPT began to circulate information about mpox among colleagues within the various LGBTQI+ organizations in their network.

It's a network we have of local LGBTI organizations we have created for tackling HIV stigma, so of course we started to pay attention to the social, political, and public dimensions of this infection outbreak.

#### Florin Buhuceanu

Asociația ACCEPT [Association ACCEPT] and the Euroregional Center for Public Initiatives

Some language used to describe the mpox outbreak stigmatized MSM.

In the media, the message was that homosexuals are guilty of spreading mpox. That was the narrative and they were speaking again and again about sexual orientation.

#### Florin Buhuceanu

Asociația ACCEPT [Association ACCEPT] and the Euroregional Center for Public Initiatives

The organization contacted the Romania Ministry of Health to request that all language used about mpox in the public space spoke about sexual behaviours rather than sexual orientation being a risk-factor for the transmission of mpox, and to focus on preventive and protective measures in communications.

That [a focus on sexual behaviours over sexual orientation] became the mantra of the Ministry of Health. It was important to start this conversation, to try to avoid the stigmatization of LGBTQI+ people, because as a community, we were facing this backlash.

#### Florin Buhuceanu

Asociația ACCEPT [Association ACCEPT] and the Euroregional Center for Public Initiatives

#### **Risk Communication on mpox at Pride**

During Bucharest Pride the Ministry of Health sought the support of Association ACCEPT's communication team to review the language of a leaflet on mpox that would be disseminated at the marches.

We cooperated with several physicians that the Ministry of Health allocated to us, in order to adapt information on mpox into a leaflet that focused on MSM. Our job was to look exclusively at the language they used to be sure that it would not reinforce any stereotypes against the LGBTQI+ community. We tried to keep the language as neutral as possible.

#### Florin Buhuceanu

Asociația ACCEPT [Association ACCEPT] and the Euroregional Center for Public Initiatives

Association ACCEPT advocated for the presence of a booth at Bucharest Pride featuring information and medical counselling if needed. The Ministry of Health responded by organizing medical experts to offer information and leaflets. This was unprecedented at a Pride event in Romania.

#### **Challenges**

Association ACCEPT's main role is to campaign for human rights, so any work done specifically on sexual health means that a consultant with specific expertise needs to be contracted.

The outbreak presented an opportunity for collaboration, but ongoing forums for communication between health authorities and CSOs that focus on HIV and STIs are currently limited. Currently the lack of funding for the National HIV/AIDS Strategy and a national strategy in the field of sexual and reproductive health makes it difficult to operationalize activities on a national scale in the field of prevention, especially among key populations. Civil society experts point to this being a long-term challenge. Creating an interministerial and intersectoral mechanism comprising relevant ministries and with CSOs representing the key affected groups may reinvigorate dialogue with civil society and create the possibility of periodically evaluating progress. Throughout the outbreak, WHO has suggested extending technical, financial and human resources to the community to enable community-based action.

#### **Impact**

Stigmatizing language can lead to negative stereotyping of affected groups, which may impact on their well-being, health-seeking behaviours, and perceptions of health care services. Association ACCEPT's efforts to change the language and communications around mpox helped prevent stigma and increase trust in health services. The focus on sexual behaviour rather than sexual orientation as a risk factor for transmission of the disease reduced stigma towards MSM.

#### Next steps

Association ACCEPT and the Euroregional Center for Public Initiatives have begun the process of reaching out to local groups, local community leaders and the owners of bars and saunas serving key populations on the need to communicate on sexual health issues. They hope to design a social media campaign on sexual health, targeting primarily MSM, especially those who are engaged in sex with multiple partners and sex workers.

At the moment we are trying to reconnect with community leaders to find out what they see as feasible to be done in their own communities.

Florin Buhuceanu

Asociația ACCEPT [Association ACCEPT]

#### WHO's role and available resources

WHO has issued specific guidance on preventing and addressing stigma and discrimination related to mpox (WHO, 2022h), which advises to talk about the behaviours that can lead to acquiring or contracting mpox if the virus has entered social networks without talking about people spreading mpox or infecting others, as this implies that someone is doing this intentionally. The guidance also recognizes that health facilities are often the first point of care for people with symptoms that could be mpox. Stigmatizing language and behaviour within health institutions can also impact heavily on patient well-being and their willingness to seek treatment or testing, and discrimination may affect access to health care, and therefore impact on physical and mental well-being.

It is important to ensure that health workers understand and use appropriate terminology and language to ensure that people feel comfortable and respected while accessing care. This includes making health-care facilities welcoming and nonjudgmental places, where people can trust that their privacy and confidentiality will be respected. People seeking care at health facilities for any reason should be treated with kindness, confidentiality and respect by health workers (WHO, 2022h).

The WHO Regional Office for Europe mpox elimination strategy, Considerations for achieving and sustaining mpox control and elimination in the WHO European Region: the need for integrated national operational plans, (WHO Regional Office for Europe, 2023a) recommends that Member States should activate their existing (or establish new) health and multisectoral coordination mechanisms, usually through the ministry of health and/or national public health centre, to strengthen all aspects of readiness for responding to mpox.

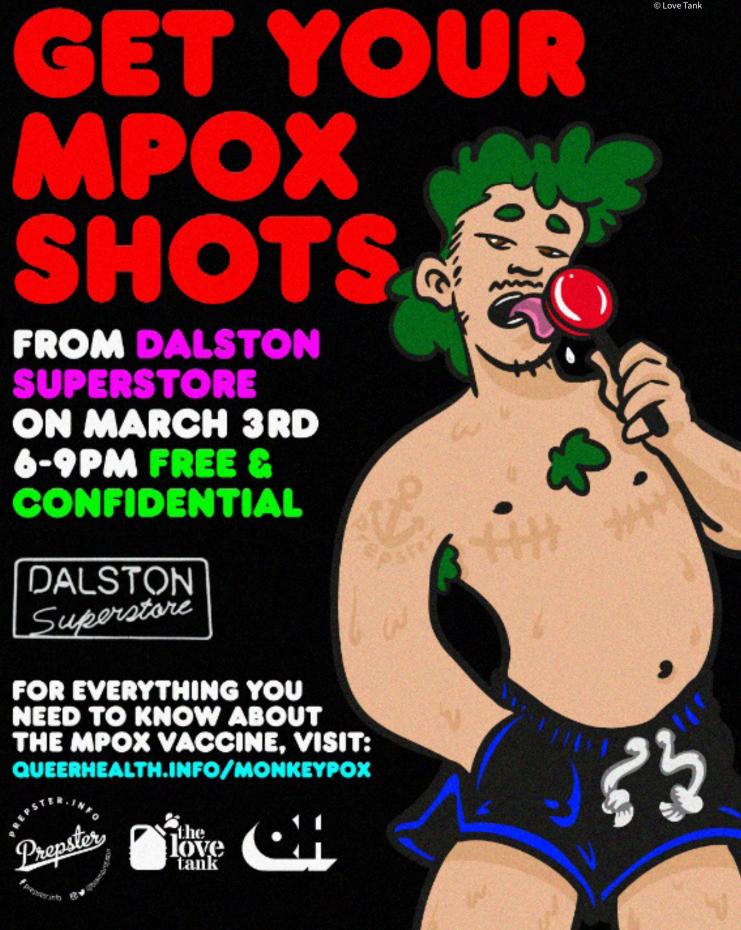
### Lessons identified

Multidisciplinary approaches to health outbreaks that include a variety of voices, including those of the communities most affected, are better able to respond to health needs. These collaborations should ideally be continued over the long-term in order to be better prepared for future outbreaks.

Stigmatizing language and behaviour and discriminatory actions can impact negatively on well-being and health-seeking behaviours.







Mpox vaccination poster featuring a transmasculine participant. Materials are designed by community members for community members.

#### **CASE STUDY: COMMUNITY PREPAREDNESS**

## How community engagement in the United Kingdom is helping to prepare for and prevent a possible resurgence of mpox

#### What this case study is about

This case study shows how an organization that employs staff from a community affected by mpox is helping to prepare for a possible resurgence of mpox through outreach to underserved groups.

#### Why this case study is important

Community engagement can facilitate access to marginalized and underserved groups. Organizations that understand the concerns and attitudes of affected communities are well-placed to reach them with messaging on preparedness and continued vigilance against mpox.

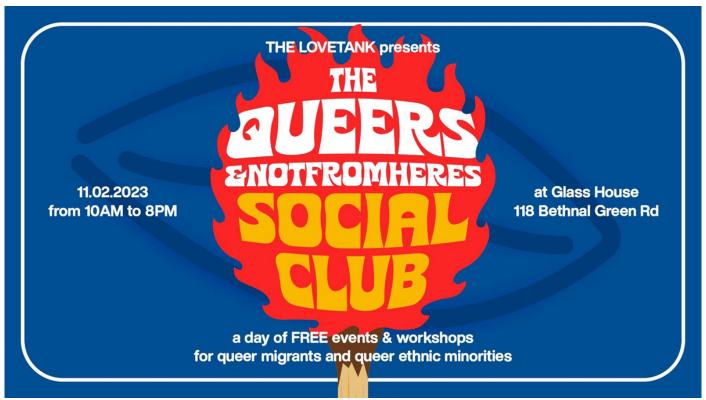
#### **Main themes**

- Preparedness
- RCCE
- Vaccination
- Reducing stigma

#### **Country context**

The United Kingdom is a high-income country with over 67 million people. The capital London, has a population of nearly 9 million (World Population Review, 2023).

A social media post from the UK's Love Tank.



© Love Tank

#### Background to the initiative

The Love Tank was established in 2018. It is a London-based not-for-profit community interest community that developed from the work of PrEPster – a grass-roots community initiative that educates and advocates for access to HIV PrEP. It has a staff of ten people, many of whom are part time, who come from the communities they represent. Therefore, many have also experienced forms of discrimination and disadvantage based on belonging to LGBTQI+ communities and other groups, such as migrant grorups, people who are housing insecure and Black and Asian ethnicities.

Based on The Love Tank's prior experience and connections with clinical services and the GBMSM community, from the beginning of the mpox outbreak, its staff and volunteers conducted numerous sexual health outreach activities in coordination with local NHS Trusts. These activities included pop-up mpox vaccination events in clubs and sex-on-premises venues where attendees could receive information on preventive and protective measures and get vaccinated by a team of NHS medics or referred on for testing.

Most of the time when we're doing outreach at, say, a very busy place like a club, if we don't have an in-house vaccine event happening on that day, we'll have little wallet size cards which on the back have a QR code. The QR code will take you to our website and our website will have information about mpox. Where can I get a first and second shot? What are the possible side effects?

Qaisar Siddiqui The Love Tank

#### **Under the Radar (UTR)**

Mpox case numbers have now fallen, but there are still some groups who are less likely to have been vaccinated. Following conversations with the relevant communities, the Love Tank created the UTR mpox vaccination programme, which conducts sexual health outreach for under-served groups within the 32 boroughs of London, focusing on GBMSM migrants, Black and Asian ethnicities and people who are housing insecure. It also conducts outreach to trans communities and MSM who don't identify as gay or bisexual.

Some of the people we connect with don't feel comfortable being open about their sexual orientation. They might still be engaging in regular sexual activity, but might not be as up to date with their sexual health.

#### Qaisar Siddiqui

Under the Radar Vaccine Coordinator, The Love Tank

The Love tank and PrEPster are well known, enabling the UTR programme to make use of a well-known brand, established contacts and a wealth of communications materials. However, a key factor that enables the UTR programme and other Love Tank initiatives to connect with their target audiences is that the staff intentionally represent the communities they are working with:

When we show up to these events and we encourage people to get their vaccines, we're not coming out from the outside, we're people who have been part of these communities for decades. By this I mean the team itself largely consists of people of colour, migrants, trans people, people who have experienced housing insecurity, or some combination of the above.

Qaisar Siddiqui The Love Tank

Funding for UTR staff time at events and clinical staff time for the vaccination team as part of the UTR programme is provided by the UKHSA and NHS England, London Region. Vaccination costs are covered by the NHS. Venues are receptive and do not charge for space.

#### **UTR** activities

The UTR programme has moved away from trying to reach the least vaccinated demographic at general events that feature pop-up vaccination outreach. Instead, they identify events aimed at specific communities, for example, a club night aimed at migrants, and base themselves where the target demographic is.

We find this is by far and away the most effective way to get shots into arms because people are less likely to show up just for a vaccine but are much more likely to go to a club and think 'OK, well, there's a vaccine. Now I'm gonna go get myself vaccinated.' If people see their two friends going to get the vaccine right now, they are far more likely to go and get it.

Qaisar Siddiqui The Love Tank

The organization does not only target evening entertainment, however. They have found that daytime events are sometimes more appropriate to reach migrants and people who might be housing insecure. For example, they held a vaccination event at a popular, free, day-time board games event at the London LGBTQI+ centre. They also work closely with The Outside Project, whose focus is on LGBTQI+ people experiencing housing insecurity and homelessness and offer information and vaccination in their meeting place.

#### **Challenges**

While The Love Tank works predominantly in London, the capital's population is not static and the target population for vaccination is therefore constantly shifting. Funding and staff limitations do not allow for a greater geographical range of activities.

Low footfall at events can lead to low vaccination numbers, which is not cost-effective and can be demotivating. According to Qaisar Siddiqui, demand has fallen because: "Some MSM no longer see mpox as an emergency. Many are not anti-vaccination but are fatigued by COVID-19 vaccination and have a low personal risk perception of mpox."

Working with migrants and those who are housing insecure can inhibit record taking as they don't have a permanent address. Contacting people to remind them to take a second vaccine can be challenging. MSM who do not identify as gay or bisexual can be averse to taking precautions which they feel only apply to those groups.

#### **Preparedness**

Every March, a large fetish event called Darklands takes place in Antwerp, Belgium. It was after this and other similar events in 2022 that a spike was seen in mpox cases. In preparation for Darklands, which is attended by MSM from all over Europe, The Love Tank have devised a new programme of work called Ready for It.

© Love Tank



A social media image promoting the Love Tank's Ready For It campaign.

A part of their messaging on proactive sexual health, the programme asks people to get ready for spring and summer mass gatherings by ticking off a range of transmissible infections such as hepatitis A, human papilloma virus (HPV)<sup>1</sup> and mpox.

We're asking 'How are you looking after yourself? By getting all the necessary vaccines that you need before you go to this big sexual networking event. We find that softening that information a little bit is motivating people to think proactively about their vaccines and about their sexual health and that way they don't just think about this one mpox issue.

Qaisar Siddiqui The Love Tank

The WHO-recommended primary target population for HPV vaccination is girls aged 9–14 years (for the prevention of cervical cancer). Vaccination of secondary target populations, e.g. females aged ≥15 years, boys, older males or MSM, is recommended only if this is feasible and affordable, and does not divert resources from vaccination of the primary target population or effective cervical cancer screening programmes. Few countries have met this condition and HPV vaccination for MSM is not yet widely offered (WHO, 2022k).

#### **Impact**

#### **UTR**

Seven events were held in the latest round (2023), reaching 80 individuals with vaccination. Events held in 2022 reached over 300 individuals, including at Black Pride, in the United Kingdom.

At smaller events, additional vaccinations (COVID-19, influenza, and in spring, hepatitis A and B and HPV) have sometimes been offered, with about a third of those receiving mpox vaccination also receiving other vaccines. The events are demonstrating good engagement with the key target audiences.

Feedback from NHS partners is good: some report being able to administer more mpox vaccines at UTR events than in clinics.

#### Ready for it

The social media campaign for Ready for It has received a high number of organic impressions via Twitter (i.e., no promotion budget with them)

The target group have given good feedback on the campaign, citing an appreciation of the humour, diversity of imagery, and the use of images that the target group identify with. Further positive feedback appreciates that the Ready for It campaign has been positioned as a morerounded programme of work, that does not only focus on mpox and that the content has been produced by people with reach into, and who know about the "scene" that is being targeted (and why).

#### WHO's role and available resources

Representatives from the Love Tank participated in the WHO Regional Office for Europe's informal working group on RCCE to bring community perspectives into the response and share tips for reaching the MSM community while developing the toolkit for monkeypox. In addition, both the WHO Regional Office and the ECDC documented several community outreach activities at the beginning of the outbreak in a publication entitled Risk Communication and Community Engagement Approaches during the Monkeypox outbreak in Europe (WHO Regional Office for Europe and ECDC, 2022b)

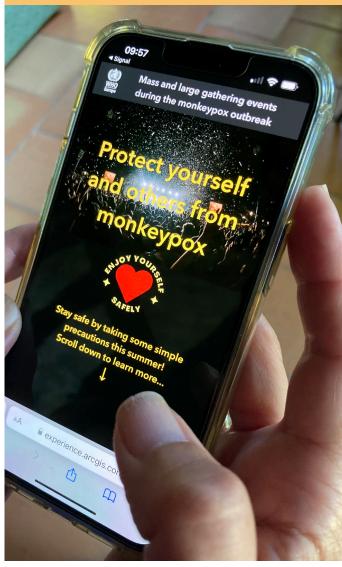
### Lessons identified



Community engagement, including selecting staff with a lived experience of the affected demographic builds a community-oriented approach that connects with communities, including marginalized groups.

Going to where the target group is, rather than expecting them to seek out sexual health services, gives the best chance of successful outreach.

A flexible approach to vaccination outreach is needed to persuade under-served or vaccine-hesitant groups.



#### **CASE STUDY: HEALTH WORKER PREPAREDNESS**

## Ensuring a more effective response to mpox by building preparedness in Kazakhstan

#### What this case study is about

This case study shows how a country that had not yet experienced a case of mpox prepared its health workforce to detect, treat and advise on mpox. The preparedness campaign consisted of a series of webinars for health workers on how to treat, detect and engage with patients and the wider community about mpox; and the dissemination of information materials to the general population, especially communities potentially at increased risk, so they could be on the look-out for symptoms, should any cases occur.

#### Why it is important

When mpox case numbers are low or not yet reported, low risk perception may lead to lack of preparedness and readiness (Silva, Anteneodo and Ferreira, 2023). Even in the absence of officially reported cases, it is important that countries build the capacity of the health workforce to respond at speed if necessary and alert the communities they serve of the signs and symptoms of mpox, how to protect themselves from it and what to do in case of infection.

#### **Country context**

Kazakhstan is an upper middle-income country in central Asia. It has a population of around 19.5 million people, in an area of 2.725 million square kilometres (World Population Review, 2023).

#### **Main themes**

- · Preparedness and readiness
- Infection Prevention and Control
- RCCE

A poster produced by the WHO Country office in Kazakhstan describing the symptoms of mpox, how it is transmitted and explaining protective measures. The poster is in Kazakh language and not available in English.

#### Mpox epidemiology in Kazakhstan

To date, there have been no recorded cases of mpox in Kazakhstan. Nonetheless, when the mpox outbreak was declared a Public Health Emergency of International Concern in June 2022, staff at the WHO Country Office in Kazakhstan, based in the capital city of Astana responded by providing science-based information regarding mpox to prepare health workers and community groups. For Kazakhstan, mpox is new disease and health-care workers had limited knowledge about it. They also worked to inform the population, particularly affected communities, about the symptoms of the disease, and to alert them to seek medical support without delay if they suspected infection.



The Country Office has strong connections with the National AIDS centre and, through it, to the network of 20 AIDS centres at oblast (regional) level. With the support of the WHO Regional Office for Europe, the Country Office reached out to these AIDs centres to invite health workers and CSOs to educational webinars on mpox.

The Office presented three internal webinars on:

- laboratory aspects, clinical diagnosis and the epidemiological situation, on 2 June 2022 and 29 July 2027 with 498 total attendees;
- RCCE, on 23 August with over 300 participants;
- clinical Management of mpox, presented by Dina Pfeifer (Medical officer, WHO Regional Office for Europe), who shared images of mpox symptoms occurring in the novel outbreak on 22 August. More than 200 participants attended.

Feedback was positive, with particular praise from academic participants.

There was a big interest at that time, because of the PHEIC declaration and because it was a very unknown disease. There was so many questions and a lot of interest in this disease.

**Bibigul Aubakirova** WHO Country Office, Kazakhstan

Additionally, the team have adapted materials provided by the WHO Regional Office for Europe, designing posters in both Kazakh and Russian languages to display in AIDS centres and other medical facilities, and leaflets to disseminate among CSOs and others.

#### Challenges and enabling factors

Stigma faced by the GBMSM community means they are not able to communicate publicly about issues that concern them. According to Bibigul Aubakirova:

It's a stigmatized population. You don't see any kind of festivals or big events. However, there is a network of AIDS centres and local NGOs supporting these groups, so we hope that these leaflets can be disseminated with the support of these and local NGOs.

It would be great to have a risk communication specialist at the country level who would be fully dedicated to support the WHO Health Emergencies programme, especially in emergency situations.

**Bibigul Aubakirova** 

WHO Country Office, Kazakhstan.

Limited human resources to tackle the mpox outbreak existed in the Country Office team, especially around RCCE. Competing priorities have led to delays in the production of risk communication products.

Preparedness means that when emergencies do happen, relationships and systems are already in place so that the emergency response can take place more speedily and smoothly. In advance of emergencies, connections should be made with relevant organizations. The series of webinars built these connections and provided a two-way communication channel for health authorities to hear concerns from the community.

Previously established good relations with the network of AIDS centres in the country allowed for strong participation of relevant health workers in webinars, and an important feedback loop on risk perception and understanding.

#### **Impact**

Several hundred health workers and CSO workers that serve affected communities were reached with important information on preventive and protective measures against mpox.

Over 500 000 posters and leaflets have been printed and disseminated to AIDs centres and nongovernmental organizations in the country.

### Lessons identified



Building the capacity of health workers to identify mpox and sharing public health advice with groups at increased risk is an important part of emergency preparedness that reduces the likelihood of undetected transmission.

It is crucial to act quickly at the beginning of an outbreak. This is when attention to the issue is highest. Waiting too long may mean that it's harder to generate interest from frontline responders and affected communities.

Clinics and community organizations working in HIV and STI prevention can be valuable partners in mpox response. This is because there may be overlap between the groups most affected by these infections and mpox, and both may face similar issues around social stigma. Therefore, these organizations already have established trust with the groups most affected from mpox, making them key channels for reaching these communities.

#### Box 2. Preparedness and readiness for other countries and areas

The WHO Europe identified 18 priority Member States and areas (Albania, Armenia, Azerbaijan, Belarus, Bosnia and Herzegovina, Georgia, Kazakhstan, Kosovo<sup>2</sup>, Kyrgyzstan, Montenegro, North Macedonia, Republic of Moldova, Serbia, Tajikistan, Turkmenistan, Türkiye, Ukraine and Uzbekistan) that either lacked diagnostic capacity, or the supplies needed to respond to the outbreak. The WHO Regional Office for Europe was then able to procure and deliver US\$ 1.2 million worth of supplies, helping strengthen the health systems of these countries and territories for dealing with mpox. Thanks to a collaboration with German biotech company TIB Molbiol, 57 000 PCR tests were distributed, which will allow for up to 5000 samples to be tested for mpox in each of the priority countries/areas. The correct use of these was supported through a training programme delivered both on-site and remotely.

Support to Member States is available upon request through dedicated trainings and workshops in the areas of surveillance, RCCE, public health interventions, clinical management, and vaccination. One such training was organized by the WHO Balkan Hub together with the Regional Office for Europe in November 2022 and included 34 participants from eight Member States and areas.



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#### **ANNEX 1.**

### Interview tool

#### Staff/official of ministry of health or other organization that ran the intervention

#### Introduction

Hello, my name is ....... [name] ......... I am working on project for the World Health Organization (WHO) to document how your...[discipline/area of work] responded to the 2022 mpox outbreak in the European region.

WHO want to write up a short case study about the intervention to ...... [describe in a few words] ..... which took place in [your country / your region / your community] .... [approx. date] ..... [date]

Do you remember this intervention?

Yes. / No

Are you willing to talk to me about it?

Yes / No

[If the person you are talking to answers "no" to either of these questions then STOP THE DISCUSSION]

Are you happy for me to record our discussion and use some of your words as quotes? I will send you the quotes for review before we use them

Yes / No

[If answer is Yes]

Thank you. I will start recording. If at any point you wish to say something "off the record" please let me know and I will stop recording.

[If answer is No]

That is fine. I will not record our discussion and I will not attribute any quotes to you.

### Table A1. Interview guide – staff

Theme & timing	Type of Question	Question	Information sought
Background / context (Approx. 10 minutes)	Narrow focus	Please could What was your role in the intervention? you tell me your name and the name of the organization you work for?	Name and organization
	Medium focus	What was your role in the intervention?	Details of role in intervention and scope of knowledge
	Medium focus	Do you have any videos or photographs showing the intervention (or people/places involved with it)? Do you have any posters or artwork? Do you have reports, evaluations or data about the activity? If yes to any, seek permission to use it in the case study Can you tell me a bit about what was going on with mpox in your [country/region/ community] when the intervention was launched? Why was this intervention needed?	Access to photos or data and permission to use them What does photo/artwork/data show? Why is it important? Country/community context Deeper understanding of health issues/ challenges intervention was designed to address
Theme & timing	Type of Question	Question	Information sought
Details of the intervention	Narrow focus	When did the intervention start? Is it still going? If not, when did it stop?	When did the intervention start? Is it still going? If not, when did it stop?
	Narrow focus	What were your experiences of the [project / initiative] after that?	Was there a clear objective or target set at the beginning of the intervention? If so, were staff aware of it?
	Narrow focus	What groups or types of people was the intervention trying to reach?	Was the target audience clearly defined? If so, were staff aware of it
	Narrow focus	Which organizations were involved in running the intervention? Who did what?	Which organizations were involved and brief description of their roles
	Narrow focus	Can you recall how many people in your organization (and its partners) worked on this intervention? What other resources were needed? (e.g. premises, equipment, supplies services)	Approximate overview of resources needed to run intervention
	Wide focus	Tell me a bit about what the intervention did (or still does)? What would you do on a day-to-day basis when you were working on this intervention?	Description of work done or service offered What were, or are, the key outputs/services delivered number of people reached or served by intervention Individual perspective on how intervention worked (add human interest to case study)
Impact (approx. 5–10 minutes)	Medium/wide focus	What impact did the intervention have? Further prompts if needed: What achievement(s) are you most proud of? How did it help to prevent/manage the mpox outbreak? Do you have some examples?	How did the intervention make a positive difference? In general terms, what are the key successes/outputs? Are there specific examples or success stories that show the intervention's value?
Key factors for success/ key limitations (approx. 5–10 minutes)	Medium focus	What do you think were the factors that helped this intervention happen and be successful? Were there challenges or gaps that limited the success of the intervention?	What were keys to success (e.g. availability of funding/expertise, cooperation with partner(s), leadership/political will, public trust,)? For example, shortages of staff or funding, lack of cooperation, policy or legal barriers, social stigma of affected groups
Lessons learned (approx. 4–7 minutes)	Medium focus	What do you think health officials in other countries can learn from this intervention?	Probe for key "lessons learned" and most important things people trying to run this type of intervention need to know

The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

#### **Member States**

Albania

Andorra

Armenia

Austria

Azerbaijan

Belarus

Belgium

Bosnia and Herzegovina

Bulgaria

Croatia

Cyprus

Czechia

Denmark

Estonia

**Finland** 

France

Georgia

Germany

Greece

Hungary

Iceland

Ireland

Israel

Italy

Kazakhstan

Kyrgyzstan

Latvia

Lithuania

Luxembourg

Malta

Monaco

Montenegro

Netherlands (Kingdom of the)

North Macedonia

Norway

Poland

Portugal

Republic of Moldova

Romania

**Russian Federation** 

San Marino

Serbia

Slovakia

Slovenia

Spain

Sweden

Switzerland

Tajikistan

Türkiye

Turkmenistan

Ukraine

**United Kingdom** 

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