



MARCH 2023

Responding to Mpox:

Communities,
Communication,
and Infrastructures






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Responding to Mpox: Communities, Communication, and Infrastructures

Jaime Garcia Iglesias
University of Edinburgh*

Jeremy Williams
IPPO, University College London*

Maurice Nagington
University of Manchester

Tom May
University of Bristol

Sophie Buijsen
University of Edinburgh

Ciara J. McHugh
Queen's University Belfast

Jeremy Horwood
University of Bristol

Martyn Pickersgill
University of Edinburgh

Joanna Chataway
University College London

Richard Amlôt
UKHSA

(*Authors contributed equally to the work)



Preface by Richard Angell

The 2022 Mpox outbreak saw clinicians, activists, and community organisations, like the Terence Higgins Trust, step up to the challenge of responding at speed to the virus. Based on the experiences of those involved from the UK and internationally, this timely report offers an opportunity to reflect on the outbreak - as well as to ensure that the lessons from it are learned beyond the context of Mpox.

We welcome the report's findings and recommendations including those around the vital role played by community organisations, sexual health services, and gay and bisexual men who have sex with men (GBMSM) in responding to the outbreak. We further welcome the account of how communities and individuals rallied to respond, as well as the recommendations for how successes in this area can be harnessed for the future.

This report shows that responding well to future scenarios will require greater collaboration and emphasises the need for better resourcing those organisations on the frontline of sexual health. These are long-term challenges in which so far governments, including the UK, have fallen short. Without better collaboration and adequate funding, we cannot successfully address the health inequalities that this report identifies as underlying experiences of Mpox.

While the 2022 outbreak was difficult, this report allows us to acknowledge both the successes and challenges of the response and, most importantly, provides the opportunity for its lessons to be applied into the future.

Richard Angell,
Chief Executive of the Terence Higgins Trust

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Executive Summary

The 2022 Mpox outbreak saw **community organisations and sexual health services rise to the challenge** of rapidly responding to a public health emergency. Nevertheless, the experience showed that successfully **responding to an outbreak** is often dependent on **preparedness, planning, and existing infrastructure**, and success in future outbreaks and scenarios may depend on this work being undertaken now.

This report sets out key findings about the successes and challenges in the response to Mpox in the UK and internationally and makes research-based policy recommendations for future similar contexts. These include suggesting that:

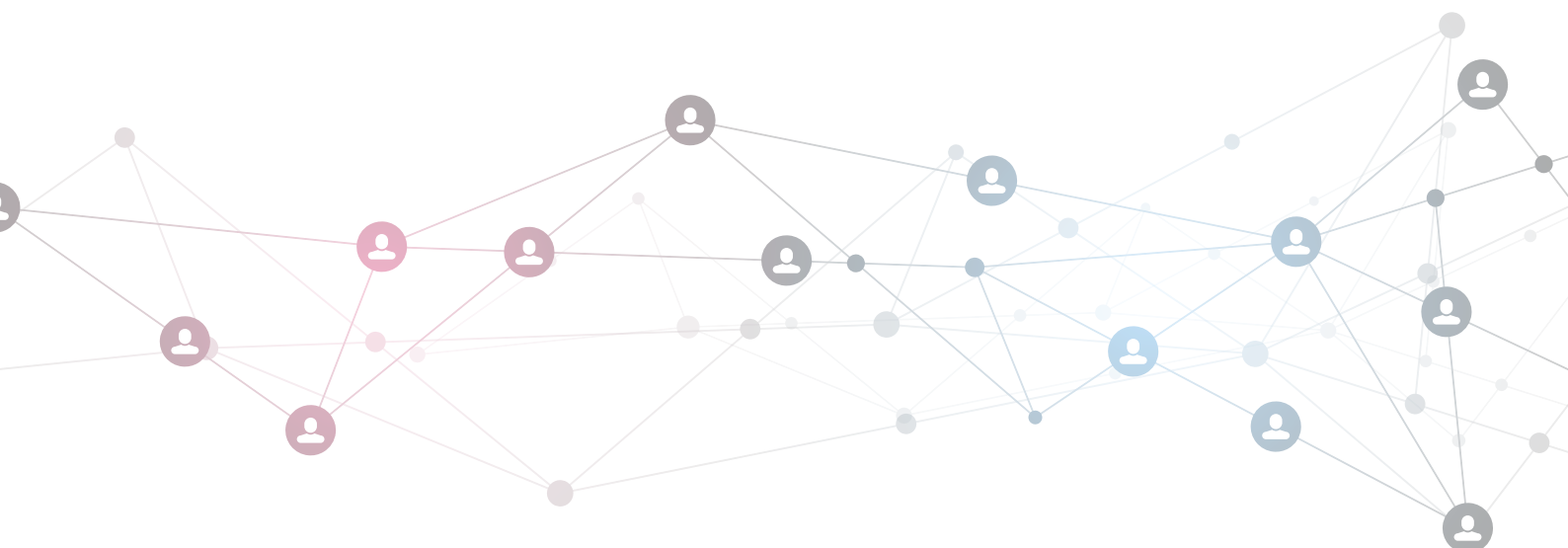
- Collaborative relationships with community organisations should be proactively fostered before an outbreak occurs, to build preparedness and resilience; and that

- Governments should appreciate and appropriately resource social and medical infrastructure, including sexual health services, as these are key actors in responding to an outbreak such as Mpox.

For other future scenarios including a potential rebounding of cases, the report further recommends actions including:

- Deploying successful interventions such as co-producing messaging with and for affected communities; and
- Targeting support to those facing additional barriers to accessing healthcare.

The full list of key findings and policy recommendations is collated on the next page. The report also sets out further avenues for research illuminated by the project and its findings.



Summary of Key Findings and Policy Recommendations

AREA	KEY FINDINGS	POLICY RECOMMENDATIONS
<p>The Importance of Collaboration</p>	<ul style="list-style-type: none"> Established collaborative networks were key to responding quickly and effectively to the Mpox outbreak Community organisations played an important role in developing and distributing information that was suitable and impactful for affected communities Successful collaborative networks were commonly based on prior relationships as well as investments made in these Rapid responses to pandemics often need to proceed despite imperfect data 	<ul style="list-style-type: none"> Collaborative networks should be developed, supported and integrated into service provision and planning for future outbreak scenarios Support data infrastructures to enable effective collaborative use during outbreaks to facilitate direct access to treatment
<p>Knowledge and Experiences from HIV and COVID-19 to MPox and Beyond</p>	<ul style="list-style-type: none"> Clinicians, policymakers, and activists mobilized their experiences, knowledges, and skills acquired in relation to HIV and COVID-19 when responding to Mpox There were negative legacies from COVID-19 which impacted Mpox responses, such as clinician and activist burnout Some clinicians, policymakers and activists emphasized how it was disheartening to see that some of the lessons learned when dealing with the COVID-19 pandemic had not been applied to the Mpox outbreak 	<ul style="list-style-type: none"> Ensure identified processes are established so lessons can be learned from past outbreaks, and knowledge collected and retained for future use

Summary of key findings and policy recommendations

AREA	KEY FINDINGS	POLICY RECOMMENDATIONS
Infrastructure	<ul style="list-style-type: none"> • The Mpox response involved the rapid repurposing of existing infrastructure • Existing infrastructure influences responses, and high-quality, consistent links between clinicians and communities facilitate responses to public health emergencies • Regular planning meetings between clinicians is an effective way to maintain healthcare infrastructure that is responsive to novel emergencies 	<ul style="list-style-type: none"> • Make long-term investments in both public health infrastructure and in the social infrastructure which supports responses to scenarios such as Mpox • Focus investment on developing high quality, long term, and collaborative relationships that links front line clinicians, public health professionals, community representatives, and community spaces • Review the legislative changes implemented during COVID-19 for what long-term changes could be beneficial for responding rapidly yet equitably and proportionately in emergency situations
The Importance of Leadership	<ul style="list-style-type: none"> • Examples of effective leadership in the response highlighted the need to both provide information and guide action • People’s experience of providing or receiving care varied widely due to pre-existing differences between regions and health organisations • ‘Meta leadership’ - i.e. leading both within and between organisations, in a fragmented system - may be an important approach to develop within complex healthcare scenarios • It was often professional organisations that proactively acted as leaders in some contexts 	<ul style="list-style-type: none"> • Engage prominent leaders to guide strategy, including regarding communications • Encourage, develop and promote skills of cross-organisational ‘meta-leadership’ to facilitate effective collaboration during a multi-agency outbreak response • Government organisations should support and empower healthcare providers, third sector and community organisation partners to develop their ability to respond to future outbreak scenarios

Summary of key findings and policy recommendations

AREA	KEY FINDINGS	POLICY RECOMMENDATIONS
<p>The Importance of Messaging</p>	<ul style="list-style-type: none"> • Potential information gaps may have meant that some individuals were not aware of their risk of infection and whether they should be vaccinated against Mpox • Community and grassroots organisations were seen as credible sources to disseminate messaging and refute and limit misinformation 	<ul style="list-style-type: none"> • Rapidly and continually communicate relevant and accurate information on risk behaviours, symptoms and vaccine eligibility to at-risk populations • Ensure frontline organisations are equipped with resources and timely information updates to ensure credible, relevant, and relatable information is disseminated widely
<p>Stigma, and Difficulties with Getting Messaging Right</p>	<ul style="list-style-type: none"> • The avoidance of potential stigmatisation was a challenge during the response, with differing perspectives on how this could best be achieved • Effective messaging often relies on a targeted, rather than one-size-fits-all, approach 	<ul style="list-style-type: none"> • Develop tailored messages and communication strategies to target those at more risk in outbreak scenarios
<p>The Role of Social Media</p>	<ul style="list-style-type: none"> • Social media (including dating apps) became a powerful mechanism for communicating about Mpox • Health promotion messages on social media relied on individuals' personal networks or on influencers, which led to disparities in relation to who the messages reached • Some institutions lacked social media preparedness, with communication not prioritized 	<ul style="list-style-type: none"> • Develop communication strategies that build relationships with key social media partners that can be prioritised and mobilised during future outbreaks

Summary of key findings and policy recommendations

AREA	KEY FINDINGS	POLICY RECOMMENDATIONS
Developing Messaging	<ul style="list-style-type: none"> Personal stories can be powerful, but only if they come from sources that audiences trust (regardless of veracity) Personal stories have the potential to contribute to the development and circulation of fear and stigma 	<ul style="list-style-type: none"> Co-produce messaging with community actors who know the organisations, groups and individuals affected by an outbreak scenario, rather than imposing 'one size fits all' messaging from national communicators. Prepare for future scenarios in advance by proactively working with communities to identify networks of trust and trusted messengers which can be mobilised for public health message dissemination Develop a communications strategy that builds in mechanisms to solicit, incorporate, and evolve from stakeholder and audience feedback
Vaccination	<ul style="list-style-type: none"> Vaccine delivery relies on both actual vaccine availability and effective communication about availability Mass vaccination events may have reinforced pre-existing inequalities in relation to access to healthcare 	<ul style="list-style-type: none"> Undertake equality, diversity, and inclusion audits of vaccine delivery programmes to ensure they address rather than reinforce pre-existing health access inequalities
Healthcare Justice	<ul style="list-style-type: none"> Additional barriers existed for some individuals and groups in accessing care during the Mpox outbreak There was a demand for broader support for people with Mpox, especially in terms of isolation such as that available to individuals during COVID-19 Some communities were potentially "left behind" in funding, vaccine, and communication, including those not accessing healthcare 	<ul style="list-style-type: none"> Rapidly and continually communicate relevant and accurate information on risk behaviours, symptoms and vaccine eligibility to at-risk populations Ensure frontline organisations are equipped with resources and timely information updates to ensure credible, relevant, and relatable information is disseminated widely

Summary of key findings and policy recommendations

AREA	KEY FINDINGS	POLICY RECOMMENDATIONS
Resourcing	<ul style="list-style-type: none">• Although experience across different contexts varied, sexual health services were often under-resourced, despite seeing the majority of Mpox cases• This had knock-on effects on the provision of their core healthcare activity• Some sexual health services also felt left alone to deal with Mpox away from the rest of the healthcare system	<ul style="list-style-type: none">• Recognize the role of sexual health clinics in providing frontline care and appropriately fund and support them so that they are adequately prepared and resourced for future outbreak scenarios



Introduction

Mpox—formerly known as Monkeypox— is a zoonotic infection endemic to Central and West Africa. Between 2022 and 2023, non-endemic countries experienced an unprecedented outbreak of the disease. In August 2022, the World Health Organisation deemed the outbreak a “public health emergency of international concern.” By March 15th 2023, 86,516 cases had been confirmed across 110 countries, with 111 deaths. The 2022-2023 outbreak disproportionately affected gay, bisexual, and men who have sex with men (GBMSM), which accounted for 82.1% of cases, and people living with HIV.[1] A combination of campaigns to change social and sexual practices and vaccination has significantly reduced new diagnosis in the Global North. However, significant numbers of cases continue to appear in a range of countries, including Brazil, Colombia, Mexico, and Peru.

Amid the early outbreak, the International Public Policy Observatory (IPPO) at University College London convened a group of researchers and policy makers to discuss the social dimensions and implications of Mpox. A project was subsequently funded by the Economic and Social Research Council (ESRC) to conduct rapid research on the social aspects of the Mpox outbreak and distil relevant, evidence-based

policy recommendations for the future. Between October 2022 and March 2023, the project focused on exploring community organising and information sharing in relation to Mpox, including the influence of social media and the experiences of underserved communities. This report summarises the main findings and recommendations arising from that research.

This report aims to collect and critically analyse the knowledge and experience of clinicians, policy makers, activists, and people with lived experience of Mpox, to produce relevant recommendations for future outbreaks of Mpox or other infections, contributing to key preparedness at all levels.

About this report

This report includes five sections. Each section or sub-division begins with a summary of key findings from the evidence gathered from participants. This is accompanied by a supporting narrative and, where appropriate, quotes from individuals who participated in the project. The sections or sub-sections then close with policy recommendations based on the findings. The final substantive section of the report then sets out the implications of our findings for future social science research related to the Mpox outbreak.

Background

In May 2022 a case of Mpox was reported in the UK, just months after COVID-19 legal restrictions had been lifted. As had been the case with previous isolated cases, the patient had recently travelled to Nigeria, one of the countries in which Mpox is endemic.[2] However, cases started to appear in the UK among people who had not been in contact with an infected person, nor visited an endemic country. In endemic countries, Mpox commonly spreads zoonotically (animal-to-human transmission), although in recent years there is evidence of human-to-human transmission [3]. UK officials identified GBMSM as a community with high exposure risk of Mpox with the virus spreading predominantly through sexual contact.

Vaccine Access and Distribution

In the summer of 2022, the MHRA approved two existing smallpox vaccines for the prevention of Mpox. The sudden increase in demand for these vaccines caused a shortage of available doses. A JCVI consultation led to the approval of administering the vaccines intradermally, as this method reduced the required dosage from 0.5ml to 0.1ml.

The UK quickly prioritized vaccine access to high exposure risk populations. From June to August 2022 the NHS administered 50,000 Smallpox (MVA-BN) vaccines; by October UKHSA obtained 150,000 doses.[4] Distribution is currently circulated through vaccination sites and sexual health clinics, with eligibility focused toward GBMSM. Shortages of the vaccine limit availability to a single dose, until further vaccines become available.

Community Engagement

When speaking of community engagement, there are two ideas of what 'community' means. 'Community' can refer to individuals connected through their identity (e.g. GBMSM and LGBTQIA+). This type of community is often visible through individuals vocal in public, such as through social media or engagement in activism. On a larger scale, 'community' also references civil society. In this case, it refers to third-sector organisations focused on articulating and catering to the needs of LGBTQIA+ groups or individuals. Within this report we use 'community' to refer to the latter.

As news of Mpox broke, media outlets expressed fear of another pandemic.[5, 6] When it became clear that the virus was spreading mostly among GBMSM populations, responsibility for handling this outbreak was delegated to sexual health services and community organisations. In response to previous outbreaks within marginalised communities, government bodies were aware that community organisations play an important part in the dissemination of relevant health information (eg. the work that was done to identify methods for providing and de-stigmatising PrEP use within harder to reach communities).[7]

UKHSA lists "Community Engagement" as the first targeted intervention for Mpox, stating "Engagement with LGBT and sexual health organisations will also continue to help refine messaging and activity".[8] This can be seen on the NHS Mpox website linking to Terrence Higgins Trust, a sexual health charity, for further information. [9] Here, we see policy directives enhancing communication through third-sector networks.

Overall, these directives demonstrate a focus in the UK on sexual health networks with priority directed towards access and communication at GBMSM populations.

Process

Evidence Collection

This project sought to foreground the experience of both those affected by, as well as those responding to, the outbreak. To do so, evidence was collected through a series of online roundtable discussions. These took place with:

- Activists and people from third sector organisations involved in the response
- Clinicians and those working in medical settings responding to the outbreak
- Policymakers and others involved in governmental response to the outbreak, including senior NHS staff shaping local or regional healthcare policy
- Individuals directly affected by or with other lived experience of Mpox

The roundtables took the form of facilitated “deliberative fora”.[10, 11] Qualitative interviews were also conducted with participants who could

not attend the relevant roundtable, as well as those who wanted to expand on their comments. Participants were drawn from the UK as well as other countries including the US, Canada, and Germany.

Ethical approval for the project was granted by the Edinburgh Medical School Research Ethics Committee (22-EMREC-054). Roundtables and interviews were audio-recorded, transcribed, and anonymised, and individuals were informed that they were free to speak on this basis.

Formulating the Findings and Recommendations

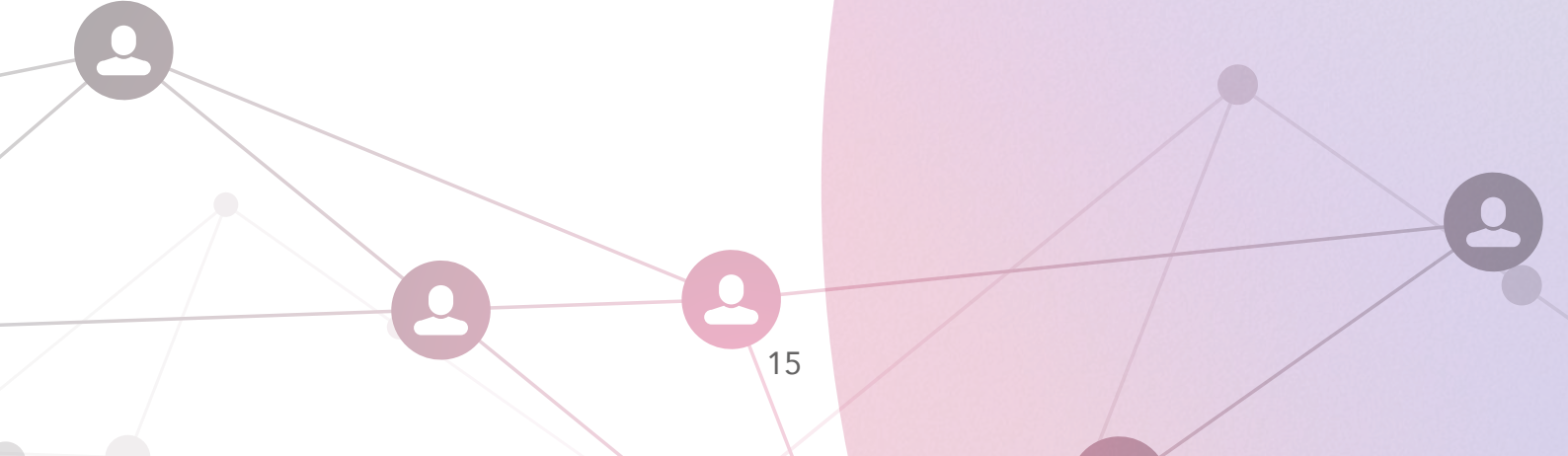
The project team then analysed transcripts of each of the roundtables and interviews, looking for insights across different thematic areas of the Mpox outbreak and response. In February 2023, the project team then met in-person to agree on findings and recommendations, together with identifying areas for future research.





The project team worked together to translate the insights, findings, and recommendations, into the final report. During this process, they held a stakeholder workshop in Manchester in March 2023 where they presented their initial findings to an audience of invited stakeholders.

The project also consulted with the United Kingdom Health Security Agency (UKHSA) on its findings and recommendations to ensure they were future-oriented and feasible. While an initial focus of the project was the response to Mpx in the United Kingdom, this report has been formulated to be potentially applicable across a range of national, regional, and local contexts.



Findings and Recommendations

This section sets out the project's findings under the following key thematic areas:

1. **Responding to the Outbreak**
2. **Messaging**
3. **Vaccination**
4. **Healthcare justice**
5. **Resources**

Some of the thematic areas feature sub-divisions, with each beginning with the key findings, and closing with policy recommendations to prepare for or apply in future scenarios.

Responding to the Outbreak

This section focuses on the ways in which healthcare systems and community organisations responded to the outbreak.

The Importance of Collaboration

Key Findings

- Established collaborative networks were key to responding quickly and effectively to the Mpox outbreak
- Community organisations played an important role in developing and distributing information that was suitable and impactful for affected communities
- Successful collaborative networks were commonly based on prior relationships as well as investments made in these
- Rapid responses to pandemics often need to proceed despite imperfect data

Collaborative approaches to gay men's health have a long history and find their roots in feminist approaches to healthcare which informed how gay men self-organised and demanded more equitable and participatory systems of care during the AIDS crisis.[12] Participants suggested that this philosophy of care quickly found its way into the approach taken to respond to Mpox.

However, a lack of consistent engagement resulted in some clinicians and activists feeling left out of decision-making processes and information channels. This, they argued, created additional challenges:

One of the biggest frustration[s] would be that information would go out from gov.uk [the UK Government's website] nationally without discussing it with us or giving us insight first. So something would suddenly go on gov.uk or Twitter and we had no idea that it was coming: all these recommendations we had never heard of and, five minutes later, we had patients ringing us about them.

- A sexual health clinician in the UK

In the cases in which a closer and collaborative approach occurred, it was possible to agree upon messaging that effectively resonated with the experiences of the communities it targeted. As one activist put it, "it's the old motto, nothing about us without us." In some contexts, effective collaboration also benefitted from the mobilisation of pre-existing networks, such as the existence of community advisory groups, or civil society reference groups.

Across contexts, participants highlighted that collaborative approaches had been key to producing high-quality, non-stigmatising information which filtered across to communities. It would then frequently be up to individual community members to further share these messages with their networks:

Being very honest, but actually there was a very significant community. People that were scared themselves and were coming to me.

- An individual with lived experience of Mpox in the UK

Collaborations also relied on effective sharing and use of data. Some participants suggested that, in fact, data sharing became a barrier to collaboration during the response:

We actually had to negotiate, fight almost tooth and nail to know the number of vaccines [...] agreed. And that was closer to our estimate. But you know, you get asked for evidence... Why are you asking us repeatedly for data? Unless it's a stonewalling tactic?

- A public health clinician in the UK

This limited data-sharing meant that some clinical services were constrained in their ability to communicate timely information to service users:

Even the health boards [health authorities in some parts of the UK] that we work closely with, you know, sometimes something will have information and we just don't even know about it until months later because it's not something that's communicated to us.

- An activist in the UK

On the contrary, in some other settings, data was used in a way that facilitated collaboration and helped direct services to offer more targeted approaches:

The Medical Office in [the city]... could tell us... where people got the infections... We knew the hotspots where we had to focus on and [we got the data] within a few days.

- A German sexual health charity worker

In summary, the types of collaboration forged in the HIV/AIDS pandemic were quickly recognised as being necessary to manage the Mpox outbreak. In some cases, the types of collaborative relationships already existed; in others they did not, and establishing productive relationships during a time of crisis was difficult or even impossible. Our participants also evidenced that data sharing is a key element of effective collaboration.

Policy Recommendations

- Collaborative networks should be developed, supported and integrated into service provision and planning for future outbreak scenarios
- Support data infrastructures to enable effective collaborative use during outbreaks to facilitate direct access to treatment

Knowledge and experiences from HIV and COVID-19 to Mpox and beyond

Key Findings

- Clinicians, policy makers, and activists mobilised their experiences, knowledges, and skills acquired in relation to HIV and COVID-19 when responding to Mpox
- There were negative legacies from COVID-19 which impacted Mpox responses, such as clinician and activist burnout
- Some clinicians, policymakers, and activists emphasized how it was disheartening to see that some of the lessons learned when dealing with the COVID-19 pandemic had not been applied to the Mpox outbreak

All the stakeholder groups in this project underscored how both HIV/AIDS and COVID-19 were clear antecedents to responses to the Mpox outbreak in 2022. These groups explained how they had relied on their experiences of HIV and COVID-19 when responding to Mpox. This took several forms. In some cases, institutions and clinicians repurposed ways of working and skills that had been developed for COVID-19, such as cleaning routines or phone appointments. In other cases, policymakers' experience of working with HIV helped them acknowledge the need for a holistic approach to Mpox that focused not only on its biology but also on its social context:

It was rapidly clear that professionals who had experience of HIV and of working with gay, bisexual and other men who had sex with men had to be included. We had to acknowledge that there was something going on from the science perspective and also something from the community perspective.

- A senior policymaker in the US

Clinicians and activists also noted that the proximity and even overlap between the COVID-19 pandemic and the Mpox outbreak added to already-severe burnout and stress. They also argued that responses to Mpox had been hampered by changing relations of trust in government advice and interventions:

After the AIDS crisis and gay men being left to fend for ourselves, the CDC [Centre for Diseases Control] eventually regained some sense of stature and trustworthiness until it all collapsed again during COVID-19 with Trump. When Mpox came along, the public didn't know exactly whom to trust. We were in a position reminiscent of the early AIDS in that gay men and queer organizations had to figure it out for ourselves and the messengers became largely other queer people or other queer organizations, not the government.

- A long-term HIV activist in the US

Finally, many participants also showed anger as they reflected that many of the lessons which should have been learned from COVID-19 were not deployed in response to Mpox. They cited a lack of effective leadership, an absence of financial support for those having to isolate, and what they regarded as poor policy planning as evidence of COVID-19 lessons having already been forgotten. For example, a policymaker remarked that the importance of equitable access learned during COVID-19 had not been adequately applied to Mpox:

I would say that we haven't yet learned from COVID-19 about how to ensure that there's equitable access right from the beginning.

- A local policymaker in the UK

Policy Recommendation

- Ensure identified processes are established so lessons can be learned from past outbreaks, and knowledge collected and retained for future use

Infrastructure

Key Findings

- The Mpox response involved the rapid repurposing of existing infrastructure
- Existing infrastructure influences responses, and high-quality, consistent links between clinicians and communities facilitate responses to public health emergencies
- Regular planning meetings between clinicians is an effective way to maintain healthcare infrastructure that is responsive to novel emergencies

Responses to the Mpox outbreak relied heavily on existing healthcare infrastructures. However, the features of this infrastructure varied. For example, in some areas there were well established clinical networks. These meetings helped facilitate a reflective approach to sexual health planning:

In our area, we already had a sexual network that met quarterly where we normally discuss emerging infections and that kind of things, and we involve the third sector or voluntary sector and other organisations like primary care, so that was a really useful channel to disseminate.

- A clinician working in sexual health in the UK

In other areas, the existing infrastructure went beyond clinicians to include regular and extensive contact with bars and sex on premises venues, where outreach events were conducted pertaining to sexual health. In such cases it was feasible to rapidly bring together a broader range of people to discuss a common approach to Mpox early in the outbreak. These wider reaching but also pre-existing networks between health services and communities were valuable in developing and rapidly disseminating behavioural change messages and vaccination information. Additionally, some areas had well established vaccination teams that were co-opted to conduct vaccination:

We were very fortunate because being on an acute trust, we had a large COVID-19 and flu vaccination team that we could capitalize onto Mpox.

- A clinician working in sexual health in the UK

In such cases, this made distributing the vaccination easier. However, some participants also highlighted that the speed at which policies had been developed or modified during COVID-19 to facilitate rapid changes to services did not exist during Mpox:

There were some derogations from planning, policy and legislation [for COVID-19 powers] to allow us to change the use of say, a shop to a health premises for vaccination without going through planning permission...

- A Public Health Director in the UK

Policy Recommendations

- Make long-term investments in both public health infrastructure and in the social infrastructure which supports responses to scenarios such as Mpox
- Focus investment on developing high quality, long term, and collaborative relationships that links front line clinicians, public health professionals, community representatives, and community spaces
- Review the legislative changes implemented during COVID-19 for what long-term changes could be beneficial for responding rapidly yet equitably and proportionately in emergency situations

The Importance of Leadership

Key Findings

- Examples of effective leadership in the response highlighted the need to both provide information and guide action
- People's experience of providing or receiving care varied widely due to pre-existing differences between regions and health organisations
- Meta leadership' - i.e. leading both within and between organisations, in a fragmented system - may be an important approach to develop within complex healthcare scenarios
- It was often professional organisations that proactively acted as leaders in some contexts

The response to the outbreak provided valuable lessons in terms of organisational leadership, both within and outside governments and the third sector. In terms of government leadership, there was a feeling in some contexts that lessons around the importance of clear communication of scientific advice from the COVID-19 pandemic had not been translated into similar communication from a clear, trusted figurehead. Similarly, clinicians in the United Kingdom felt that guidance from government and some strategic levels of management in clinical settings could have been clearer, with decisions in the initial outbreak often left up to clinicians working at the local level. A "significant weakness was [that] there was no national plan", said one individual involved in policymaking in the UK, while another had been "really disconcerted about strategic-level communication, campaigning and health promotion". In the UK, this led to the UK Government Department of Health and Social Care being criticised as absent from the policymaking on Mpox, with a perception of a lack of willingness from civil servants and politicians to make decisions.

I don't feel there was a lot of support or guidance from the people with the vaccines or how to make risk-stratification decisions. There was a lot of 'this should be decided at local level' which was not helpful for many clinics with large patient numbers.

- A sexual health clinician in the UK

However, as with many of other areas of the response, this was not a uniform picture: there was considerable variation across countries and contexts. This was even the case internally within the UK, with one clinician noting that "the response was very different in different centres", continuing, "we set up a chat in the first week to try and share what everyone was doing in the area. [...] Some of the sectors were covered by non-NHS [private] providers who struggled with the fact that they were not affiliated to an NHS acute trust [public healthcare systems with acute care capabilities], so they couldn't manage anything out-of-hours". Nevertheless, some other clinicians felt that an overly centralised initial response denied them the flexibility they felt they needed to adapt.

In the United States, successful aspects of the outbreak response highlighted the importance of 'meta-leadership', such as there being a national Mpox response team co-ordinating across different pieces of government, not all of which were traditionally public health. Meta-leadership is defined as "providing guidance, direction, and momentum across organizational lines that develop into a shared course of action and commonality of purpose among people and agencies that are doing what may appear to be very different work".[13]

Relatedly, the experience of the professional organisations and the third sector in the UK demonstrated the importance of alternative sources of leadership, particularly in a fragmented system. In addition to the role played by the Association of Directors of Public Health, the leadership and co-ordinating role shown by the British Association of Sexual Health and HIV (BASHH) was praised. This included BASHH

co-ordinating a public joint statement with a coalition of third sector organisations in July 2022 demanding greater funding to respond to the outbreak.[14]

Policy Recommendations

- Engage prominent leaders to guide strategy, including regarding communications
- Encourage, develop and promote skills of cross-organisational 'meta-leadership' to facilitate effective collaboration during a multi-agency outbreak response
- Government organisations should support and empower healthcare providers, third sector and community organisation partners to develop their ability to respond to future outbreak scenarios

Messaging and Communication

The Importance of Messaging

Key Findings

- Potential information gaps may have meant that some individuals were not aware of their risk of infection and whether they should be vaccinated against Mpox
- Community and grassroots organisations were seen as credible sources to disseminate messaging and refute and limit misinformation

Among activists and people with lived experience, there was a perceived lack of clear and consistent official guidance pertaining to symptoms, risk practices, and vaccine availability. In some cases, this appeared to influence people's perceptions of Mpox risk and

susceptibility. For example, in the earlier stages of the outbreak an absence of information meant some considered their risk of contracting Mpox to be low. One participant commented how they would have adapted their social and sexual practices to mitigate risk if made more aware of Mpox, including its severity, earlier:

So there's a weird situation where, prior to being affected, my perception was that it was very low risk...actually, what if I knew what I know now? I probably would have a different perspective on the risks and how I should have managed my behavior.

- An individual with lived experience of Mpox in the UK

This information gap meant that some people reported receiving mixed messages regarding symptoms and risk, often through a range of sources including social media:

But people still really weren't clear about the actual medical side of it of like, you know, do I need a vaccine? Should I stop having sex? You know, all these different things, like, it was that sense of, like, people not really being clear on what was going on.

- An activist in the UK

In contexts where there was a perceived absence of official guidance, community and grassroots organizations became important channels for communicating and disseminating Mpox information. For people with lived experience, such information was perceived as credible and relatable, and had the capacity to reach communities or groups marginalized from official communications. There was recognition that rapid and up-to-date information would be particularly valuable in mitigating harms, including confusion regarding Mpox risk, susceptibility, and eligibility for vaccination. The timely sharing of information was also important in limiting the potential for misleading or inaccurate information to circulate via social media. In these situations, some activists and

clinicians argued that it would be important to receive honest and timely information from official sources that could be disseminated to service users:

At the end of the day, people just wanted to know what was going on. And I think that was largely the same with COVID. And it's hard when the people in charge also don't know what's going on. But I think just people being as honest as possible about it and just kind of setting expectations even if those expectations are, we don't really know right now. But we are working on it like, I think just making sure people are aware that stuff is being done, I think is useful.

- An activist from the UK

Policy Recommendations

- Rapidly and continually communicate relevant and accurate information on risk behaviours, symptoms and vaccine eligibility to at-risk populations
- Ensure frontline organisations are equipped with resources and timely information updates to ensure credible, relevant, and relatable information is disseminated widely

Stigma and Difficulties with Getting Messaging Right

Key Finding

- The avoidance of potential stigmatisation was a challenge during the response, with differing perspectives on how this could best be achieved
- Effective messaging often relies on a targeted, rather than one-size-fits-all, approach

All stakeholder groups highlighted the difficulties and tensions in developing effective messaging that was both informative and targeted to those most in need, while also being non-stigmatising. Some clinicians and policy makers reported concerns that targeted and tailored information that emphasized the role of sex in transmission would lead to the further stigmatisation of GBMSM [gay, bisexual, and men who have sex with men] populations and behaviours, which previous research had already identified as a concern.[15] To mitigate this, generic messaging focusing on how 'anyone can get Mpox' was preferred in many contexts. One US-based participant reported how they utilized knowledge and experiences from HIV/AIDS to adopt a non-targeted communication strategy that did not stigmatize specific communities:

We had to really look at the HIV playbook to figure out ways to express what we were learning real-time about risk and exposures without over narrowing the story to focus on a single community from the beginning. We wanted to avoid a 'Gay-related Mpox'.

- A leading policymaker in the US

Some participants with lived experience reported preferring messages that avoided linking gay sexual behaviours with Mpox transmission and acquisition. These perceptions were most pronounced among those who appeared concerned about being stigmatised as reckless or

promiscuous or being 'outed' to others. However, others welcomed targeted messaging that would ensure those most 'at risk' were not overlooked in official communications. As a person with lived experience from the UK said, "the message was anyone can get monkeypox, which wasn't necessarily helpful for targeting those who were actually at higher risk of exposure." Some participants reported being comfortable with a targeted approach:

The gay community is a bit more open to having conversations about risky behaviours, about drugs, about sex, about infectious diseases. So I think I welcome it [targeted messaging].

- An individual with lived experience of Mpox in Germany

Some felt that broad messaging communicated to GBMSM communities through specific channels (such as community organisations, or venues) would be the optimal method to reach populations most at risk of contracting the virus, whilst limiting possibilities for stigma. One person with lived experience cited how a city in Germany had successfully implemented targeted messaging inside GBMSM spaces during Pride festivities. They felt this was an effective and non-stigmatising method for communicating Mpox information, including symptoms and vaccination sites, to an at-risk population:

It was posters in every bar there was posters and adverts of not only to be aware of the symptoms, but also there were QR codes to tell you where to get vaccinated.

- An individual with lived experience of Mpox in the UK

However, whilst community organisations recognised that such an approach was an effective public health communication strategy, there was concern that other GBMSM populations, including those marginalised or disengaged from GBMSM spaces, venues and support, would have limited exposure to material and information disseminated through these

channels. One policy maker was concerned that an approach reliant on the organic dissemination of information could therefore increase health inequalities:

For me, it was the targeted communication, particularly through social media, to people at risk of Mpox, so that they understood their risk and could understand where to access vaccination... we felt quite frustrated about the process, in part because UKHSA [UK Health Security Agency], for one reason or another, didn't feel empowered to release funding to do some targeted communication. So they were in a position where they were relying on organic communication that was much more kind of broadcast-led and that, from our perspective, risked entrenching inequality because people who were already connected could find out the information they wanted but, many others who were not in those networks wouldn't necessarily look at the information that was being put out and think, this is relevant for me.

- A health policymaker in the UK

That is, there was a concern that generic messages would not meet the needs of specific communities even if shared through targeted channels. Nevertheless, in order to refine messaging in futures scenarios, further work is required to develop innovative approaches to rapidly evaluate messages, their reception, and impact.

Policy Recommendations

- Develop tailored messages and communication strategies to target those at more risk in outbreak scenarios

The Role of Social Media

Key Findings

- Social media (including dating apps) became a powerful mechanism for communicating about Mpox
- Health promotion messages on social media relied on individuals' personal networks or on influencers, which led to disparities in relation to who the messages reached
- Some institutions lacked social media preparedness, with communication not prioritised

The key role of social media during the Mpox outbreak was highlighted by all stakeholder groups. A participant commented that the Mpox outbreak had shown the power of social media as a health promotion tool:

I don't think there's ever been a better example of how social media has had a positive effect on public health ever in history. [...] If the massive lines for our at-risk communities to get vaccinated is not an example of how social media got the word out and got people in line and ready, I don't know what is.

- A long-term activist in the UK

Social media was used for a variety of purposes, including disseminating information about Mpox and vaccination, demanding more funding or policy changes, or sharing personal accounts. Many with lived experience of Mpox highlighted how social media enabled them to get in touch with other people who had Mpox and share their own experiences. Two UK participants who had been admitted to hospital with Mpox and had shared frequent updates about their condition on social media explained that doing so "helped reduced feelings of stigma."

Participants also suggested that reliance on social media for information about Mpox happened

because mainstream communication channels (such as newspapers or TV) and governmental institutions did not provide the information communities demanded. An activist commented how social media allowed queer communities to fill this information gap:

Big media were getting it kind of wrong, and I think we were prepared. The queer online community was ready for this. We mobilized and everybody went into action.

- An HIV activist in the US

Participants argued that the most effective communication about Mpox on social media often originated not from government accounts, which had limited reach, but from the personal accounts of individuals with large pre-existing audiences. These included influencers, who were also understood to be trustworthy by their audiences. Several participants from the US explained how this was successfully harnessed by the government response, which collaborated with influencers to develop accurate and effective messaging. This successful use was possible thanks to pre-existing expertise within the government of collaborating with community influencers to disseminate messages. In the UK, some participants commented that organizations lacked both the experience of collaborating with influencers and the skills to develop effective messaging from their organizational accounts:

We have a health promotion partner within our services who put out some tweets for us. But we also have informal links with quite a few kinds of community members who are very active on social media, so we messaged them personally with stuff.

- A clinician in the UK

This led to almost an entire reliance on individuals sharing information from their personal accounts. In either case, whilst this kind of personal communication benefitted from the pre-existing trust built between individuals and their audiences, reliance on personal networks generated significant disparities: people who

did not belong or engage with these online communities were effectively left out of information streams.

Policy Recommendation

- Develop communication strategies that build relationships with key social media partners that can be prioritised and mobilised during future outbreaks

Developing Messaging

Key Findings

- Personal stories can be powerful, but only if they come from sources that audiences trust (regardless of veracity)
- Personal stories have the potential to contribute to the development and circulation of fear and stigma

The importance of collaboration and co-production between those making policy responding to the outbreak, and those responding on the ground, was often highlighted by participants. This saw successful responses, such as one from a large German city, co-producing messaging across different layers of responses to the outbreak, from the strategic to the local. This co-production enabled the creation of messaging that was contoured to fit the context by those most aware of it. Co-production was not limited to questions of tone or content, but also supported the identification of the

ideal conduits for messages to reach intended audiences. In turn, these conduits could then feed back how messaging was received to ensure it could be refined and adapted for maximum efficacy. The lack of such a feedback loop in the UK was noted as unfortunate by some activists.

Community organisations do outreach and were talking to people directly on dating sites or in bars and could have used that information to know what members of the public experience was and what they needed which could have been fed back to authorities.

- An activist in the UK

As during the COVID-19 pandemic, the efficacy of trusted messengers in successfully communicating, particularly with hard-to-reach groups, was also noted. Trusted messengers refer to community partners with whom government or healthcare agents have relationships, and who are capable of effectively and responsibly collaborating in the production and delivery of messaging for their audiences. These trusted messengers can be celebrities, brands, or venues.

We started with the core of work we have historically done with our trusted messengers in the HIV/STI space. So we had to translate the response from a chronic infectious disease to an acute one. [...] We had to also look at new partners. [...] The key barriers are really trust and stigma. And so we had to demonstrate that we had a commitment to accountability to get some of those messengers on board.

- A policymaker in the US

In terms of communicating with communities and individuals who historically may have had good reason to be sceptical of government messages due to their identity or sexual health status, trusted messengers and their networks provided a conduit where potential barriers to dissemination could be overcome.

Policy Recommendations

- Co-produce messaging with community actors who know the organisations, groups and individuals affected by an outbreak scenario, rather than imposing 'one-size-fits-all' messaging from national communicators.
- Prepare for future scenarios in advance by proactively working with communities to identify networks of trust and trusted messengers which can be mobilised for public health message dissemination
- Develop a communications strategy that builds in mechanisms to solicit, incorporate, and evolve from stakeholder and audience feedback

Vaccination

Key Findings

- Vaccine delivery relies on both actual vaccine availability and effective communication about availability
- Mass vaccination events may have reinforced pre-existing inequalities in relation to access to healthcare

Vaccination was a key element in participants' comments about Mpox. Clinicians, policymakers, and activists made clear that demanding vaccine availability and encouraging people to seek vaccination were key pillars in the Mpox response. However, participants often underscored the challenges generated by the scarcity of vaccine doses. Participants with lived experience explained that both finding information about when and where vaccines were available and then getting vaccinated were incredibly challenging. One participant from the UK commented that finding the vaccine became a "Twitter treasure hunt" as opportunities to get vaccinated would oftentimes be announced on individuals' Twitter accounts. Participants also highlighted the stark geographical inequalities, with many more vaccines seemingly available in London than in other areas.

I kept thinking, if I'm struggling to [get the vaccine] in London, what hope does someone living in the deepest part of Gloucester have, for example?

- A person with lived experience in the UK

Clinicians and activists acknowledged that mass vaccine events, operating on first-come first-served basis, were effective in delivering high numbers of vaccines but reinforced pre-existing health access inequalities:

The problem that we had with our mass vaccine walks were that they were first-come, first-serve. There were up to four- or five-hour queues for it, and it was

predominantly white, cis gay men that would be willing to stand in long queues at the margin of a busy road here.

- A clinician in the UK

Participants have suggested that ensuring vaccines reached specific communities required collaborating with community partners and developing bespoke strategies.

In terms of vaccine distribution, clinicians and policy makers both in the UK and US highlighted that effective delivery of vaccines relied on mobilized COVID-19 vaccinations teams, which had experience of organizing mass vaccine programmes:

We did have really great support from the actually from the COVID-19 vaccination team, who we engaged with at the beginning of the outbreak. They were reasonably quiet because they hadn't started on their autumn push of COVID-19 vaccination. So we actually got nurses coming over from the vaccine centre to be our Mpox nurses.

- A clinician in the United Kingdom

Policy Recommendation

- Undertake equality, diversity, and inclusion audits of vaccine delivery programmes to ensure they address rather than reinforce pre-existing health access inequalities

Healthcare Justice

Key Findings

- Additional barriers existed for some individuals and groups in accessing care during the Mpox outbreak
- There was a demand for broader support for people with Mpox, especially in terms of isolation such as that available to individuals during COVID-19
- Some communities were potentially "left behind" in funding, vaccine, and communication, including those not accessing healthcare

Like COVID-19 and other infectious disease outbreaks, all stakeholder groups felt that those most acutely affected by Mpox were communities facing additional barriers to engaging with health care services and support, including lower-income populations and racially minoritized communities. Social and geographic marginalisation from existing systems of support, including sexual health services and LGBTQIA+ networks and spaces, limited exposure to important health promotion materials disseminated through these channels. As one activist described, "it privileged people that were part of communities, who were the ones that got the information they needed". This created a situation whereby those accessing services and support were those already engaged with and proactive in maintaining sexual health:

I think the groups that fared better within the community were ones that were already pretty connected to sexual health services. So people who were going to get tested regularly, people who like already knew where to look. I think, the people who fared worse were the ones who don't have as much access to that information. And so, like people outside of pretty much the city [...] people from kind of more rural areas weren't really getting the same access to information or to appointments or vaccines or anything.

- An activist in the UK



Many of these communities also faced additional barriers – including work and other social responsibilities (e.g., caring) - that undermined their ability to engage and adhere with Mpox public health mitigation measures. For these populations, it was important to provide additional support to ensure equitable access to measures and interventions, including vaccines and isolation. This included financial support for those otherwise unable to isolate for prolonged periods. [16] As one Public Health Director in the UK noted: “the other thing that would have been useful [for Mpox] was what we did during COVID-19, when we had the ability to provide practical, financial and emotional support to help people who had to self-isolate”. Furthermore, the provision of additional forms of communication that reached those disengaged or marginalised by approaches that were being used during the outbreak was also regarded as potentially helpful:

Social media worked well but also created disparities because there are people that still don't have phones or people who don't have access to the internet.

- An activist in the US

Policy Recommendation

- Target support for those facing additional barriers to engaging with services or mitigation measures (e.g. financial, practical and emotional support for self-isolation, pop-up vaccination clinics at accessible locations)

Resourcing

Key Findings

- Although experience across different contexts varied, sexual health services were often under-resourced, despite seeing the majority of Mpox cases
- This had knock-on effects on the provision of their core healthcare activity
- Some sexual health services also felt left alone to deal with Mpox away from the rest of the healthcare system

Sexual health services were often at the frontline of caregiving during the outbreak. While the resourcing of such services varies across contexts, evidence from the UK suggests that these services – although widely praised for the commitment of their staff – were often under-equipped in terms of the resources to manage a rapidly unfolding and complex situation. This in turn led to knock-on effects for those seeking sexual health testing, prevention services or contraception. Some individuals reported problems in accessing HIV testing early in the outbreak, as services struggled to cope with increased demands.

The sudden additional demands related to Mpox forced some services to prioritise Mpox-related care over other sexual health work, the demand for which was still as present as ever. Furthermore, a perceived lack of available information early in the outbreak led to these services having to provide reassurance to patients worried about their perceived unclear prospects:

I had to tell my patients that I understood all the issues they were worried about, but that we had to work on other things. I [only] had 20 or 30 minutes [with each patient].

- A sexual health clinician in the UK

The difficult position in which some sexual health services were placed was sometimes exacerbated by a feeling shared by some clinicians that the rest of the healthcare infrastructure had left them to deal with Mpox alone. These feelings existed among those working in smaller settings as well as those operating in larger services. One clinician in the US noted that Mpox “sucked a huge amount of capacity out of the [sexual health] teams”, while another revealed that the outbreak “hit hard” because “we are the place where all of the dermatological, sexually transmitted infections ends up if nobody else can take care of them”. Another, in the UK, complained that: “It was a high impact infectious disease, but because it was sexual health, the rest of our hospital basically washed their hands of it.”

The outbreak highlighted the key role played by sexual health services and their overall value beyond their day-to-day work. Nevertheless, issues remained over their levels of resourcing:

What I am completely and utterly shocked by is the lack of funding [...] and also having just come from the pandemic where there was money whenever we needed that money, it's not equitable to me.

- A policymaker in the UK

As with other aspects of societal organisation, the recent experience of the COVID-19 pandemic demonstrated the possibility of funding being made available where required with the requisite political will. Some participants felt that this did not occur in the Mpox response, with attendant equity issues given the disease's concentration in the GBMSM community.

Policy Recommendation

- Recognise the role of sexual health clinics in providing frontline care and appropriately fund and support them so that they are adequately prepared and resourced for future outbreak scenarios

Future Research

In conducting this research, we have also established important gaps in the knowledge that require further exploration. We identify these here as priority areas for future research.

Regarding the **production of knowledges** about and during an outbreak, future research should explore the experiences of stakeholders engaged by government institutions. Social science research should focus on considering how different forms of knowledge and expertise were produced and mobilised during the Mpox outbreak, by whom and about whom, and how the very notion of an outbreak, its beginning and its end, were generated and deployed.

Our report identified that pre-existing **infrastructures** were key to articulating the response to Mpox. Research should urgently focus on identifying what infrastructures ‘work’ during an outbreak (and how a well-functioning infrastructure is characterised as such), how they are built and sustained, and redeployed. Similarly, for both messaging and infrastructures, future-oriented work should consider the long-term feasibility and survival of the partnerships, relationships, and collaborations built in response to Mpox. In addition, work should consider the lessons learned from the Mpox response about effective leadership.

In terms of **collaboration** between governmental institutions and community partners and individuals, it is necessary that we better understand the role of community-based messengers, most notably social media influencers, during an outbreak. It is also important that we consider the role of

commercial partners, such as sex-on-premises venues or apparel stores, in disseminating health messaging.

Social media has been a key element of the response to the Mpox outbreak. Research should further consider the potential limitations or drawbacks of relying on social media, especially personal social media, for communicating health messaging during an outbreak. This research might explore the ethics of using social media, the dynamics between audiences and content producers, and accountability.

Research is needed that evaluates the benefits and limitations of rapid co-production and development of **messages**, as well as the impact of these ways of working on effective dissemination. Researchers should also look at the financial, social, and emotional burden of developing and sharing messages during an outbreak, and how these are spread among partners.

Vaccination remains a key concern for Mpox. Future inquiry should consider the multiple ways in which people engage with vaccines and critically assess how vaccine engagements intersect with structural healthcare inequalities and broader perspectives around and experiences of vaccination.

Finally, given the **limited resources** of all healthcare systems, it is essential that research assesses and evaluates which interventions, structures, and ways of working are most effective during a pandemic outbreak such as Mpox.

Future Research Questions

Knowledges:

- What were the experiences of partners and stakeholders during the outbreak response, and how did these shape collaborations?
- How was knowledge produced during and about the Mpox outbreak, by whom, and about whom?
- How were the social and behavioural sciences leveraged to support (including through challenging assumptions) policy and practice responses to Mpox?

Infrastructure:

- What infrastructures work during an outbreak? how are they built and sustained, and redeployed?
- In what ways might institutional and organisational infrastructures be repurposed for other health emergencies?
- How can institutional memory of successful infrastructures be secured?

Collaboration:

- How did prior collaborations inform the scope and nature of health service and community responses to Mpox? What is the role of commercial partners, such as sex-on-premises venues, in disseminating health messages?
- To what extent did international networks shape national and local responses?

Social Media:

- What is the role of community-based messengers such as social media influencers during an outbreak?
- What are the limitations or drawbacks of relying on social media, especially on personal social media, for communicating health messaging during an outbreak?
- What assumptions about social media use are embedded within policy and practice responses to infectious disease, and what are the ramifications for at-risk populations?

Messaging:

- What are the benefits and limitations of rapid co-production of messages?
- How does rapid-coproduction work and what is its effectiveness?
- What are the financial, social, and emotional costs of messaging and who bears the burden of these costs during an outbreak?

Vaccination:

- How do people engage with and access vaccines?
- How do vaccine engagements intersect with structural healthcare inequalities and broader vaccine hesitancy?
- Did poor accessibility of vaccines demotivate at-risk individuals from seeking vaccination?

Resources:

- In a context of finite resources, what interventions, structures, and ways of working are most effective during an outbreak?
- How were resources effectively channelled?
- In what ways did the stigma associated with sex, sexual health, and in particular GBMSM, impact on the resources that flowed from policymakers following the Mpox outbreak in non-endemic countries?

List of Acronyms and Terms

AIDS	Acquired Immunodeficiency syndrome
CDC	Centers for Disease Control and Prevention
GBMSM	Gay, bisexual, and other men who have sex with men
Health board	Organisational unit of NHS Scotland, responsible for providing services in a particular region
HIV	Human Immunodeficiency Virus
IPPO	International Public Policy Observatory
JCVI	Joint Committee on Vaccination and Immunisation (UK)
LGBTQIA+	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual, and other gender and sexual minorities
MHRA	Medicines and Healthcare products Regulatory Agency (UK)
NHS	National Health Service (UK)
NHS Trust	An organisational unit within the NHS in the UK providing services to a specific area
PrEP	Pre-exposure prophylaxis for HIV
THT	Terrence Higgins Trust
UKHSA	United Kingdom Health Security Agency
WHO	World Health Organization

About the Authors

Jaime Garcia-Iglesias is Mildred Baxter Postdoctoral Fellow at the Centre for Biomedicine, Self and Society. He has a background in sociology and humanities and specialises in the intersection of health, internet and sexuality, with a focus on gay men. ORCID: [0000-0002-8841-5635](https://orcid.org/0000-0002-8841-5635)

Jeremy Williams is a Senior Research Fellow and Policy Evidence Lead at the International Public Policy Observatory (IPPO) at University College London. He has taught and lectured extensively on urban politics, culture, and everyday life, and leads IPPO workstreams including on Place and Spatial Inequalities, and Net Zero. ORCID: [0000-0001-8000-9926](https://orcid.org/0000-0001-8000-9926)

Maurice Nagington is a Lecturer in Health Sciences at the University of Manchester. His research interests focus on the intersections between the culture and lived experiences of health amongst gay men. His recent work has covered topics on viral pandemics, and chemsex. ORCID: [0000-0003-4914-0322](https://orcid.org/0000-0003-4914-0322)

Tom May is a Research Fellow in the NIHR Health Protection Research Unit (HPRU) in Behavioural Science and Evaluation (NIHR HPRU), Bristol Medical School, University of Bristol. His research focuses on developing and optimising effective healthcare interventions and services, especially in relation to substance use, HIV, hepatitis C and sexual health. ORCID: [0000-0003-3077-523X](https://orcid.org/0000-0003-3077-523X)

Sophie Buijsen is a PhD student at the Science, Technology and Innovation subject area of the University of Edinburgh. Her research is on the knowledge practices of teenage girls on the subject of sex and sexuality. ORCID: [0000-0002-0527-3441](https://orcid.org/0000-0002-0527-3441)

Ciara J. McHugh is a Leverhulme Doctoral Scholar at the Mitchell Institute for Global Peace, Security and Justice at Queen's University Belfast.

Her research in International Political Sociology spans across areas of gender-responsive policy analysis, critical surveillance and social movement studies. ORCID: [0000-0001-8737-0175](https://orcid.org/0000-0001-8737-0175)

Jeremy Horwood is Professor of Social Sciences and Applied Health Research at The Centre for Academic Primary Care (CAPC), Bristol Medical School, University of Bristol. He is Intervention Optimisation and Implementation Theme Lead for NIHR Health Protection Research Unit (NIHR HPRU) in Behavioural Science and Evaluation and co-director of the Sexual Health Improvement Programme (SHIP) Health Intergration Team. ORCID: [0000-0001-7092-4960](https://orcid.org/0000-0001-7092-4960)

Martyn Pickersgill is Professor of the Sociology of Science and Medicine, Edinburgh Medical School, the University of Edinburgh. He is Director of Research in the Usher Institute, and Associate Director of the Centre for Biomedicine, Self and Society. Martyn is a member of the ESRC Strategic Advisory Network, and a member of the Scottish Science Advisory Council. ORCID: [0000-0001-9807-9148](https://orcid.org/0000-0001-9807-9148)

Joanna Chataway is Professor and Head of the Department of Science, Technology, Engineering and Public Policy (STeAPP) in the Faculty of Engineering Sciences at University College London. With a background in policy research and evidence for policy, science and technology policy, she leads the International Public Policy Observatory. ORCID: [0000-0002-5370-4007](https://orcid.org/0000-0002-5370-4007)

Richard Amlôt is Deputy Director, Behavioural Science and Insights at the UK Health Security Agency, and visiting Professor of Practice in the Psychology of Health Protection in the Department of Psychological Medicine at King's College London. He is also the UKHSA co-Director of the NIHR Health Protection Research Unit (NIHR HPRU) in Behavioural Science and Evaluation. ORCID: [0000-0003-3481-6588](https://orcid.org/0000-0003-3481-6588)

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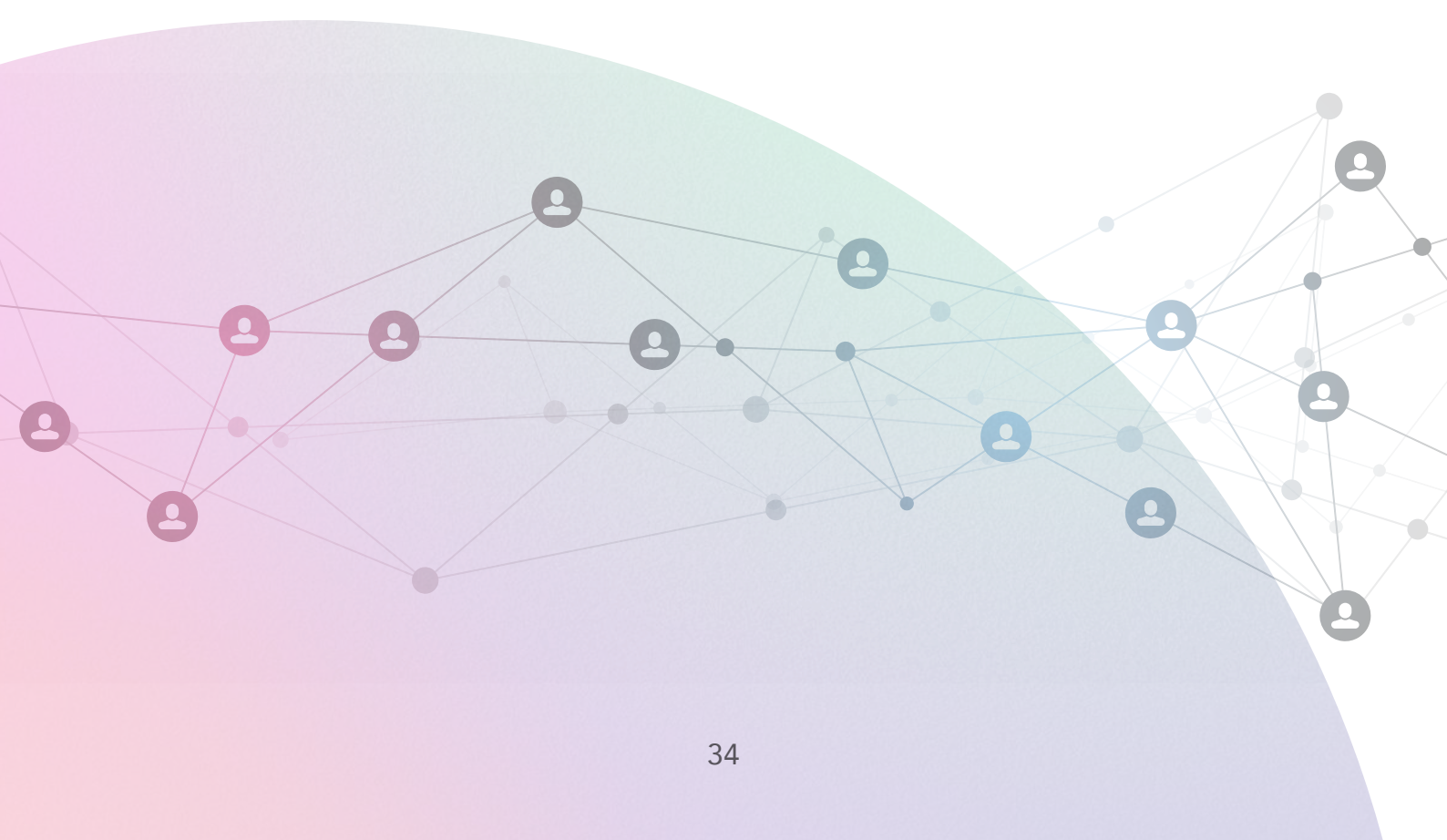
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