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1 **SOCIAL MEDIA AS A PUBLIC HEALTH TOOL DURING THE UK MPOX**  
 2 **OUTBREAK: A QUALITATIVE STUDY OF STAKEHOLDERS' EXPERIENCES**  
 3

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 7

8 **ABSTRACT**

9  
 10 **Objectives:** This rapid response research explored the experiences of key stakeholder groups  
 11 during the 2022-23 mpox outbreak in the UK, and in particular the use of social media as a  
 12 tool of health promotion. The project sought to identify key lessons learned for future  
 13 epidemic and pandemic preparedness.

14  
 15 **Methods:** The qualitative study employed online focus groups and interviews with key  
 16 stakeholder communities, including activists, clinicians, policy actors, and individuals with  
 17 lived experience of mpox (LEM). N=29 stakeholders participated. Data were subject to  
 18 framework analysis, with findings discussed and conclusions reached through a face-to-face  
 19 analysis workshop.

20  
 21 **Results:** Participants emphasized the significant role of social media, particularly Twitter  
 22 (now called X), in the response to the mpox outbreak. Several benefits were highlighted,  
 23 including disseminating relevant information, tackling stigma, and generating/advancing  
 24 advocacy and collaboration. However, participants also pointed out challenges associated

1 with social media; in particular, its reliance on pre-existing networks and associated dynamics  
2 of exclusion, and the presence of misinformation.

3  
4 **Conclusion:** Social media played an important role in informal and purposive health  
5 promotion during the 2022-23 mpox outbreak, while also presenting significant challenges  
6 regarding misinformation and exclusion. We recommend that preparedness for infectious  
7 disease outbreaks must consider the role of social media as key tools for not only the  
8 dissemination of health promotion messages, but also for real-time collaboration on message  
9 development. Special attention should be paid to ensuring collaboration and dissemination  
10 strategies are explicitly orientated towards promoting the inclusion of underserved groups.

### 11 12 13 **KEY MESSAGES:**

#### 14 15 **What is already known on this topic:**

- 16 • Social media has been recognized as an important tool for health promotion with key  
17 benefits (e.g., supporting communities, fostering collaboration, or allowing  
18 advocacy). At the same time, social media can also disseminate misleading or  
19 inaccurate information, including from trusted voices.

#### 20 21 **What this study adds:**

- 22 • This study evidences that social media allowed for swift dissemination of relevant  
23 health promotion and vaccination information, for people to tackle stigma around  
24 contracting mpox, and for different stakeholders to collaborate in developing and  
25 sharing messaging.
- 26 • Our participants also explained that social media posed important problems: it relied  
27 on pre-existing networks, generated exclusion, and commonly contained inaccurate or  
28 misleading information.

#### 29 30 **How this study might affect research, practice, or policy:**

- 31 • Social media offers an opportunity for asynchronous yet rapid collaboration and co-  
32 creation of health promotion strategies and messages with community organizations.
- 33 • Despite the advantages of platforms such as Twitter, health communication strategies  
34 should leverage a range of social media, alongside more traditional modes of  
35 messaging, to help avoid forms of digital exclusions.

36  
37 **Keywords:** social media, monkeypox, public health, disease outbreaks, qualitative research

## 1 INTRODUCTION

2  
3 Mpox, formerly known as monkeypox, is a disease caused by an orthopoxvirus - the mpox  
4 virus. Endemic to Central and West Africa, since May 2022 non-endemic countries have  
5 experienced mpox outbreaks. On 23 July 2022, the World Health Organization (WHO)  
6 declared the disease a Public Health Emergency of International Concern (PHEIC) (1). As of  
7 September, 2023, over 90,000 cases have been confirmed worldwide across 111 countries,  
8 with the USA, Brazil, Spain, and France, Colombia, Mexico, Peru, and UK experiencing the  
9 majority of cases.

10  
11 The 2022-23 mpox outbreak affected primarily men who have sex with men (MSM; 84.1%),  
12 and sexual encounters were the most common type of reported transmission (82%) (2). This  
13 has led scholars to suggest that mpox, in the 2022 outbreak, is a de facto sexually transmitted  
14 infection (3) (4). In the UK, public health authorities rapidly identified gay and bisexual men  
15 who have sex with men (GBMSM) as communities with high exposure risk to mpox. Vaccine  
16 access for them was subsequently prioritized. Despite this, vaccination was not always  
17 readily accessible (5).

18  
19 On December 2022, the UK Government released a national “Public health strategy for  
20 controlling mpox”. This aimed to reduce harm, suppress UK transmission, minimize  
21 imported cases, and reduce the global burden. Among the categories of interventions  
22 considered key for meeting these goals, the UK Health Security Agency (UKHSA)  
23 recommended “community engagement and risk communication”. The strategy called for  
24 communications to target at-risk populations (especially underserved ones), focusing on  
25 vaccination, minimizing stigma, and engaging with organizations to “refine messaging” (6).  
26 This is in the context of an increased use of social media to disseminate public health  
27 messages.

28  
29 The effective use of social media for health promotion has been described as simultaneously  
30 a “unique opportunity for public health” (7) and the “defining public health challenge of this  
31 century” (8). In the UK, there is ample experience of the importance of social media in health  
32 promotion and public health gained through long-term HIV promotion (such as PrEP and  
33 U=U) and, most recently, COVID-19 (9–11). There are several benefits to the inclusion of  
34 social media in public health strategies: social media may foster collaboration and  
35 engagement between different stakeholders, support communities (especially around  
36 stigmatized conditions), serve as a platform for advocacy, and allow for the sharing of  
37 personal stories (12–16). However, scholars have also identified important challenges. Most  
38 notably, Stellefson et al. argue that social media are “a wild west for health information” (12)  
39 where users can freely interact with both accurate and inaccurate information, and Schillinger  
40 et al. consider online platforms as venues for “infodemics,” (11) or the availability of “too  
41 much information, including false or misleading information” (17). Overall, there is no clear  
42 agreement that supports the universal “effectiveness of social media to improve public health  
43 outcomes and trends” (12).

44  
45 This paper explores experiences, benefits, and challenges of the use of social media in the  
46 2022-23 mpox outbreak. It reports on qualitative data gathered through focus groups and  
47 interviews with a range of key stakeholder communities across the UK and US. It asks: what  
48 are key stakeholders’ experiences of using social media as an informal or explicit health  
49 promotion tool during the mpox epidemic in the UK, and what lessons can be learned for  
50 future epidemic/pandemic preparedness and management?

1  
2  
3  
4 **METHODS**

5  
6 **Design and setting:**

7 A qualitative study was conducted based in a series of three focus groups and ten semi-  
8 structured interviews with key stakeholder communities, which were defined as: (1) activists  
9 and people from third sector organizations involved in the mpox response, (2) clinicians and  
10 those working in medical settings related to mpox, (3) policy actors and others involved in  
11 local or national governmental responses, and (4) individuals with lived experience of mpox  
12 (LEM). While the emphasis of the project was on the UK context, participants from the USA  
13 were also invited to the clinicians', policy actors', and activists' groups to help illustrate  
14 where and how responses and experiences in the UK could have been otherwise. One  
15 individual with LEM who participated in an interview was based in Germany. Since this  
16 study involved human participants it was subject to review by the Edinburgh Medical School  
17 Research Ethics Committee (22-EMREC-054), with approval granted 22/11/2022.  
18 Participants gave informed consent to participate in the study before taking part.

19  
20 **Recruitment:** The research team included academics with a background in policy, sociology,  
21 public health, and nursing, who used their existing networks within sexual health to launch  
22 snowball sampling recruitment by disseminating invitations to eligible participants via email.  
23 Social media (Twitter<sup>1</sup>) was also used to advertise the study among people with LEM.  
24 Recruitment was performed in this way due to the rapid nature of the project, which allowed  
25 for only two weeks for recruitment. Emphasis was placed in involving participants from  
26 across all four stakeholder categories and operating in both urban and suburban or rural  
27 settings across the four nations of the UK (England, Northern Ireland, Scotland, and Wales).  
28 A total of 29 participants were involved in either focus groups or interviews, as detailed in  
29 Table 1 below.  
30

	Focus group		Interview			Total*
	UK	US	UK	US	Other	
Activists	3	3	2	1	0	9
Clinicians	6	0	1	1	0	8
Policy actors	7	1	0	1	0	9
Individuals with lived experience of mpox (LEM)	0	0	3	0	1 (Germany)	4

\* One participant took part in both a FG and a follow-up interview.

31  
32 Table 1: Breakdown of participants by stakeholder group, mode of participation, and country.  
33

34 **Data collection:**

---

<sup>1</sup> Since July 2023, Twitter has been renamed "X". However, since this research was conducted between October 2022 and March 2023, and since the name "Twitter" remains in common use, this paper employs the name "Twitter" throughout, except in the abstract.

1 The focus groups were held online via Zoom, with a professional facilitator convening these  
2 in the form of adapted “deliberative fora” (18) to prompt discussion and consideration of  
3 issues associated with the outbreak. The three focus groups were organised for one  
4 stakeholder community each (activists, clinicians, and policy actors). Participants ranged  
5 from those with moderate experience or influence (e.g., trainee doctors, local activists) to  
6 senior or high-level stakeholders with potentially regional or national roles (senior policy  
7 actors, clinical consultants, heads of large activist organizations). Emphasis was placed on  
8 facilitating the focus group as a space where every participant could contribute meaningfully.  
9 Focus groups allowed participants to exchange views and generated contrasts between  
10 participants’ experiences or contexts which triggered further discussion, although the tight  
11 time frame for discussions with busy participants placed limits on the exchanges that could  
12 take place between participants. Interviews were conducted with individuals who were unable  
13 to attend a focus group or, in one case, with a focus group participant who wished to add  
14 additional comments. No focus group was organised for participants with LEM and, instead,  
15 interviews were conducted given the privacy concerns and stigma these participants might  
16 have experienced.

17  
18 The groups were organised around a small set of broad questions about experiences of the  
19 mpox outbreak, including the use of social media (e.g., ‘How did you use social media in the  
20 response? What went well?’), and open discussion (focus group schedule available as a  
21 supplementary file). Participants’ were requested to limit their opening contributions to three  
22 minutes, but they could otherwise speak as many times as they wished. As the groups  
23 progressed, follow-up questions on emerging themes were asked. Interviews were conducted  
24 with a broad topic guide developed to attain specific detail and experience of the mpox  
25 response from participants. On average, focus groups lasted 90 minutes and interviews lasted  
26 45 minutes.

### 27 28 **Analysis:**

29 Data were subjected to framework analysis (19) combining both a deductive approach (based  
30 on expected codes and categories of interest) and open-coding conducted by two researchers  
31 in a subset of three transcripts to develop a coding framework. Broad categories were  
32 developed in relation to areas of substantive focus: Healthcare, Vaccination,  
33 Communications, Stigma, Experiences, and Other. These aligned with the study research  
34 aims, and were informed by initial encounters with the data. The data were also organised in  
35 relation to: Lessons Learned, Policy Recommendations, and Future Research. Each transcript  
36 (from focus groups or interviews) was coded by two researchers independently. A face-to-  
37 face workshop was held in London in March 2023 where researchers shared their preliminary  
38 analyses, with the analysis later extended by the first author, with key initial conclusions  
39 discussed and later concretized asynchronously.

### 40 41 **Public and patient involvement:**

42 This work was funded under an ESRC urgency response grant between October 2022 and  
43 March 2023. The short timeline precluded formalized involvement of people with LEM in  
44 project design. Staff from UKHSA were directly involved as team members in the project,  
45 and several team members also drew on lived and professional experience engaging with  
46 MSM around health and community life (including in relation to mpox).

## 47 48 49 **FINDINGS**

50

1 Across stakeholder groups, participants described how social media had played a key role in  
 2 their experiences of responding to mpox, with participants consistently mentioned Twitter as  
 3 the most relevant platform. They highlighted the benefits of social media for: disseminating  
 4 relevant information, allowing for collaboration and advocacy, and tackling stigma. However,  
 5 they also evidenced how social media had become problematic due to reliance on pre-  
 6 existing networks, patterns of exclusion, and the proliferation of inaccurate or misleading  
 7 information. These findings are summarized in Table 2 (below).

<b>Experiences of using social media in mpox responses in the UK</b>	
<b>Benefits</b>	<b>Drawbacks</b>
Dissemination of relevant information	Inaccurate or misleading information
Collaboration and advocacy	Reliance on pre-existing networks
Tackling stigma	Patterns of exclusion

10  
 11 *Table 2: Summary of findings*

12  
 13 **Benefits of social media use**

14  
 15 Dissemination of relevant information

16  
 17 In the UK, early vaccine distribution took place through mass walk-in vaccinations clinics. A  
 18 long-time HIV activist in the UK who had become a leading voice in the mpox response  
 19 explained that social media had allowed clinics to “get the word out” about vaccination  
 20 opportunities, and argued that:

21  
 22 if the massive lines for our at-risk communities to get vaccinated are not an example of how  
 23 social media got the word out and got people in line and ready, then I don’t know what is.  
 24 (FG1P17)

25  
 26 This view of social media was reinforced by a senior policy actor who commented that  
 27 “social media was really important, it was the way we shared most of our messages with  
 28 communities” (IP1). Activist stakeholders also explained how they relied on their personal  
 29 social media presence to disseminate information about mpox. For example, one participant  
 30 who, before mpox, had become a self-labelled “medical influencer” around HIV and gay  
 31 men, explained how:

32  
 33 as a healthcare worker living with HIV, I did feel that I had built the networks and that they  
 34 were prepared for something like this. This facilitated a lot the transfer of information with  
 35 other healthcare workers and with communities. (FG1P20)

36  
 37 Collaboration and advocacy

38  
 39 Twitter and other platforms also facilitated a degree of collaboration to develop messages and  
 40 generated community advocacy. One clinician working at the frontline of mpox care  
 41 commented how social media had allowed their local sexual health clinic to engage with  
 42 community partners:

43  
 44 we had informal links with quite a few kinds of community members who are very active on  
 45 social media, so we messaged them with information for them to share. (FG2P1)

1  
2 The involvement of individual social media profiles often relied on informal activities and  
3 personal networks, as opposed to involvement being carefully designed and managed by one  
4 or more institutional actors. As one activist described:

5  
6 big media and government were getting it kind of wrong [...]. The queer online community  
7 was ready for this. We mobilized everybody and went into action online. (FG1P19)  
8

9 Social media also enabled communities to advocate for better funding and improved  
10 responses. For example, a clinician explained how vaccine clinics attendees often turned to  
11 social media to complain about long waiting times outdoors and how these complaints were,  
12 in turn, picked up by local or national media and put pressure on the vaccination rollout (20).  
13

#### 14 Tackling stigma 15

16 Participants with lived experience of mpox argued that social media also allowed them to  
17 tackle feelings of stigma at the personal level. One participant who had been admitted to  
18 hospital with acute mpox-related symptoms in the UK explained how he had felt that:  
19

20 there was a lot of shame or embarrassment associated with [...] diagnosis. So I went on this  
21 militant activist attack and went very public with it, trying to remove stigma by sharing it on  
22 social media. [...] That helped reduce feelings of stigma. (LEMP11)  
23

24 One activist described how, on social media,  
25

26 You'd see people with symptoms. You'd see people actually talking about their own  
27 experiences, and I feel people appreciated seeing what's was really happening. People felt  
28 more comfortable with that information. (IP2)  
29

30 For this participant, and others, social media became a platform to share experiences and  
31 communicate with others in ways that tackled stigma and its associated isolation and shame.  
32

#### 33 **Drawbacks of social media use** 34

##### 35 Reliance on pre-existing networks 36

37 The success of using social media to disseminate information relied on the availability of pre-  
38 existing social networks and audiences. Their absence, some participants noted, precluded  
39 any effective use of social media. For example, one clinician working in a sexual health clinic  
40 in the north of England with less than 1000 followers on their official institutional Twitter  
41 account explained how:  
42

43 not having a massive audience on Twitter, like [a large flagship sexual health clinic in the  
44 UK] has made it difficult to put out our own messages. We did put some things on social  
45 media but it is quite hard to reach people so we mostly retweeted stuff other people put out.  
46 (IP4)  
47

48 That is, compared with the Twitter account for 56 Dean Street (London's flagship sexual  
49 health clinic, with almost 15000 Twitter followers) the participant's local clinic lacked the  
50 audience to use Twitter as an effective tool in their local response. Furthermore, this  
51 clinician—and others—also commented how the competing priorities in the immediate



1 response to the outbreak (including patient care and policy development) made it difficult for  
2 organizations to find capacity to work towards rapidly increasing social media audiences; as  
3 one focus group participant commented:

4  
5 we were so busy with seeing patients, writing protocols and pathways, that often  
6 communication on social media was an afterthought. (FG2P1)  
7

8 Limits on capacity in turn limited the degree to which social media might be used to expand  
9 connections and networks, and proliferate messages more widely. Instead, organizations had  
10 to rely upon pre-existing social media networks to efficiently communicate information to  
11 communities.  
12

### 13 Patterns of exclusion

14  
15 One policy actor stakeholder in the UK explained how relying on community members to  
16 disseminate messages to their networks via social media

17  
18 entrenched inequality because people who were already connected could find the information  
19 they needed but others, who wouldn't be looped in those networks, wouldn't think it was  
20 relevant to them. (FG3P22)  
21

22 That is, messages disseminated by community members or organizations via social media  
23 would oftentimes only reach people already engaged in certain conversations; for instance,  
24 people living in the same urban area, or partaking in the same hobbies or social groups (such  
25 as clubbing, or LGBT+ activism). Furthermore, as one activist reflected, relying on social  
26 media as the main communication tool

27  
28 created disparities because there are a lot of people that still don't have phones or a place to  
29 access the internet. (FG1P11)  
30

31 Through such digital exclusions, social media campaigns around mpox “privileged people  
32 that were already part of communities.” By this phrase, the stakeholder referred to already  
33 well-served communities in terms of sexual health, such as urban, white, middle-class gay  
34 men, at the expense of other groups (minoritized ethnic communities,, people living in rural  
35 settings, migrants, homeless people, and more).  
36

### 37 Inaccurate or misleading information

38  
39 At the same time, social media also facilitated the appearance of an “infodemic,” which the  
40 WHO defines as: “too much information including false or misleading information in digital  
41 and physical environments during a disease outbreak” (17). This meant that both accurate and  
42 misleading or inaccurate information was widely spread and that, often, information was  
43 foregrounded by platform algorithms that was unhelpful or irrelevant (3,12). For example,  
44 several participants commented how, in mid-July, as mpox was spreading rapidly in Spain, a  
45 tweet from a supposed doctor who pictured a man with mpox lesions riding the Madrid  
46 underground rapidly became “viral” worldwide. However, it later emerged that the man  
47 pictured was suffering from neurofibromatosis, not mpox. Online pundits and news outlets  
48 latched onto impactful but improvable, inaccurate, or outright false stories like this or, for  
49 instance, the potential for mpox to become airborne (21). This focus was often at the expense

1 of accurate, evidence-based reporting on existing knowledge about mpox transmission or  
2 community needs.

## 3 4 **DISCUSSION**

5  
6 Our study contributes to understanding the use of social media in the response to mpox in the  
7 UK. It investigates the experiences of four stakeholder communities: activists, clinicians,  
8 policy actors, and individuals with LEM. Our study highlights the benefits and drawbacks  
9 experiences by these communities when using social media in the immediate response to  
10 mpox.

11  
12 Clinician and activist stakeholders described how social media had been useful to swiftly  
13 disseminate relevant information about mpox, including information about vaccination  
14 opportunities. They also highlighted that online platforms had facilitated a degree of  
15 collaboration with community members to engage in sharing or creating information. It is  
16 worth noting that, in the experience of our participants, collaboration with community  
17 members (whether individuals or organizations) in the UK, relied on informal networks and  
18 contacts and were not systematically structured (or funded). By point of contrast, in the USA,  
19 for instance, the US Government adapted a strategy from HIV work known as ‘trusted  
20 messengers’, by which community “partner organizations” or individual popular opinion  
21 leaders would be identified and collaborations set up to develop and deliver bespoke  
22 messages to their communities (16) (such as during the Mid-Atlantic Leather Weekend (21)).  
23

24 Finally, social media also provided a space for communities to advocate for better responses  
25 from institutions and for individuals with LEM to engage in activities (such as sharing  
26 information about their diagnoses) that helped them tackle the stigma experienced from living  
27 with mpox. These findings support existing literature that argues that social media platforms  
28 may be spaces where individuals obtain and provide social support (10) or build communities  
29 (13). This role of social media is particularly relevant when individuals navigate conditions  
30 that are stigmatized, such as mpox. In these cases, social media may become a space where  
31 people who “may be reluctant to ask health care providers, family members, or peers about  
32 medical conditions can turn [...], for information and discussion about health topics that are  
33 important to them” (9).  
34

35 At the same time, however, across all stakeholder groups, participants in this research  
36 evidenced how social media also presented important drawbacks. Stakeholders, particularly  
37 clinicians, suggested that effectively mobilising social media to disseminate information  
38 swiftly relied on the availability of pre-existing networks and audiences. In turn, this often  
39 also led, as activist stakeholders articulated, to the exclusion of already-underserved  
40 communities. This is in line with existing literature that suggests that, as the ‘digital divide’  
41 narrows and digital communications becomes more prevalent, there is an increasing overlap  
42 between digital exclusion (an unequal access or capacity to use digital tools) and other forms  
43 of vulnerability and exclusion (22), generating a “digital underclass” (23). This is particularly  
44 troubling, as Seifert suggests, during periods of heavy reliance on digital tools for  
45 communication and health promotion (24), such as COVID or mpox.  
46

47 At the same time, participants across stakeholder groups also stated that, in social media,  
48 accurate and relevant information was often positioned next to inaccurate or misleading  
49 information, generating an “infodemic” (11). This pattern has already been well identified in  
50 relation to other health conditions, such as COVID or human papillomavirus (HPV) (25,26).

## Applicability beyond the UK

The findings of this research are focused on the UK context. The involvement of international stakeholders helped to provide points of contrast and illustrate alternative responses to mpox as part of the broader research, sharpening our analysis and recommendations. The UK context is characterized by significant fragmentation of provision and the existence of health services which are free at the point of use across its four nations (27). This shaped possible forms of collaboration across stakeholder communities in ways which might differ in other healthcare contexts. Nevertheless, fragmentations of healthcare systems is not unusual beyond the UK, and so the lessons learned about the challenges of this for health promotion are likely to be relevant elsewhere. Existing research has evidenced that the use of social media within public health is an existing concern in contexts where these platforms are widely used (e.g. 7,8,10,11,15). This work has already highlighted that the role of social media in disseminating information, allowing people to tackle stigma. Similarly, researchers have also evidenced the problems of misinformation and exclusion within social media platforms. Therefore, it is likely that these findings are relevant beyond the UK to other settings where social media are similarly used. Our research is less applicable in national contexts where sex between men is illegal or very highly stigmatised, reducing the likelihood of statutory healthcare actors fostering the kinds of collaborations we recommend. This underscores the enduringly damaging health implications of stigma and social and legal injustice.

## Limitations

This project conducted rapid research during a funded period of six months between October 2022 and March 2023 to capture ongoing responses to mpox and inform policy in preparation for potential future outbreaks. The limited duration of the project (which is particularly relevant for qualitative research) and the fact that it was conducted while the outbreak was still ongoing mean that this research has several limitations. First, while participants from activist, clinical, and policy communities represented wide-ranging experience and expertise, they were mostly white. This is possibly a result of the rapid snowball recruitment relying on the researchers' personal networks (the research team were all white, and largely male). Second, only a small number of participants with LEM could be recruited during the project timeframe. At least two other studies on mpox were being conducted with this group by other teams in the UK – potentially leading to community fatigue. Despite this, the sample of participants recruited among those with LEM for interviews included people of a variety of ethnic backgrounds and ages - although all identified as gay men. Third, the project employed a cross-sectional methodology (focus groups and interviews at a particular point in time), but requested participants to discuss their experiences of the mpox outbreak during the previous months. If it had been possible, a longitudinal methodology with sequential moments of data collection might have better captured differences in social media use across time. Finally, , the qualitative discussions were less dynamic than is generally desirable in focus group research, perhaps reflecting the online nature of the data collection (itself essential due to the geographic distances between participants and challenges in finding a time to collectively meet). We do not see the use of a qualitative methodology per se as a limitation, however: qualitative research is well established in the field of health research (28) and it can lead to very valuable and informative findings in the midst of public health outbreaks (29). The combination of focus groups with interviews allowed activists, clinicians, and policy actors to

1 engage with each other and contrast their experiences and contexts while interviews allowed  
2 for more privacy among people with LEM.

## 3 4 **CONCLUSIONS AND RECOMMENDATIONS**

5  
6 Our research suggests that effective mobilization of social media in the response to mpox  
7 relied on the availability of pre-existing audiences or networks in those platforms. Those  
8 participants who described either themselves or their organizations having been able to  
9 effectively disseminate messages through social media were also the ones who had a pre-  
10 existing audience in those platforms before the outbreak. On the contrary, the absence of  
11 those audiences made it difficult—when not impossible—for organizations to reach their  
12 intended publics via social media.

13  
14 Furthermore, participants’ experiences point to concerning dynamics of exclusion: our data  
15 suggests that responses to mpox on social media not only relied on pre-existing networks (as  
16 we just argued) but went further to entrench those audiences. That is, those individuals who  
17 had not partaken in given conversations or engaged in specific online platforms before mpox  
18 took place were often excluded from information sharing or collaboration during the  
19 outbreak—reinforcing exclusionary trends.

20  
21 Based on our analysis, we recommend that:

- 22  
23 1. Preparedness for outbreaks of infectious diseases such as mpox must consider the role  
24 of social media as key tools for collaborating on message development and the  
25 dissemination of information.
- 26 2. Organizations should allocate funding to developing their social media skills and  
27 audiences at a strategic level. This may include developing content, identifying  
28 partners, or building relationships that may be deployed during an outbreak.
- 29 3. Special attention should also be paid to ensuring that audiences and collaboration are  
30 built that promote inclusion of underserved groups.

31  
32 We argue that these recommendations should be acted upon before an epidemic outbreak  
33 occurs since what our participants across communities emphasized time and again for a range  
34 of examples (extending far beyond social media per se), was that, by the time an outbreak  
35 happens, it is already too late to develop the infrastructures needed.

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## 44 45 **COMPETING INTERESTS**

46 None to declare.

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### 18 **ETHICS APPROVAL**

19 This study involves human participants and was approved by the Edinburgh Medical School  
20 Research Ethics Committee (22-EMREC-054). Participants gave informed consent to  
21 participate in the study before taking part.  
22

### 23 **DATA AVAILABILITY STATEMENT**

24 No data are available since participants were not consented for data sharing.  
25

### 26 **CONTRIBUTIONS**

27 JGI and TM are joint first authors. JGI is corresponding author. All authors contributed to  
28 research design, data collection and analysis. JGI and TM led on writing these results, with  
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30 authors contributed to revising the manuscript and approved the final version.  
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11



## Supplementary file 1: Focus group and interview guide

### USING SOCIAL MEDIA AS A PUBLIC HEALTH TOOL DURING THE MPOX OUTBREAK IN THE UK: A QUALITATIVE STUDY OF STAKEHOLDERS' EXPERIENCES AND LESSONS

Garcia-Iglesias, Jaime, Tom May, Martyn Pickersgill, Jeremy Williams, Maurice Nagington, Sophie Buijsen, Ciara J. McHugh, and Jeremy Horwood.

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#### Focus group guide (activists/clinicians/policy actors)

All focus groups will start by welcoming participants and re-stating the terms of the consent form.

These will follow, roughly, this structure:

Firstly, thank you all for your time and your interest in talking to us today. We want to start by asking if you have any questions regarding the focus group information we sent prior to today's conversation?

Great, just so we're on the same page:

- We need to inform you that this focus group is being voice-recorded, but that it will be edited for anonymity. Your responses and your participation will not be made public in any way.
- We understand that we may touch upon some sensitive issues. At any point, you have the right to ask for a pause or to leave. We will also have a breakout room available if you prefer.

Do you understand these two things?

Today we want to talk about your experiences of monkeypox as activists/clinicians/policy actors.

This is part of a project we're doing to understand what the social aspects of the response to the monkeypox outbreak were, with a focus on community organising, activism, and how social media might have influenced these. However, please feel free to go on a tangent—that's frequently where the most interesting stuff comes up!

For the sake of the recording, we ask that you speak one at a time. You can use the raise-hand option at the bottom of your screens, text us on the chat, or just raise your hand. Today we have a facilitator who will support this focus group.

[The facilitator introduces themselves. Each of the researchers present also introduces themselves and provides a very brief background.]

Are there any questions before we start?

Initial questions to generate discussion:

- Can you recall when you first heard or knew about the monkeypox outbreak in 2022?
- Can you tell us how your organization/service/department started to think about it? How did they react to the news? Whom did you talk to about the outbreak? How did this change as time went by?

**Supplementary file 1: Focus group and interview guide**

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- Did you talk with other people outside from work about it? Did you find that friends or family members would ask you information about it?
- How did you (if you did) use social media during this period? What problems did you encounters? And benefits?
- How do you feel about the information available to the public? Can you share any examples of great information campaigns? And of bad ones? Did you have any role in developing information for people?
- In terms of the people you talk to during your work (patients, clients, etc.), how well informed were they? Do you have a sense of where they might have gotten the information? What kinds of people seemed to be better informed or worse informed?
- Overall, how do you feel your community responded? Do you have any insight into the way other communities responded? What was the same/different? Are there any communities that did better than others? What about people who are not MSM?

As the focus group comes to an end, it will conclude with:

We thank you for taking the time to reflect on and share your experiences. That's all our questions for now. Before we go:

- How did you feel throughout the focus group?
- How can we improve it?
- Is there anything we didn't talk about that you thought would be discussed?
- Was there anything you found surprising?

## Interview guide (participants with lived experience of mpox)

As participants are emailed the link to join the Zoom meeting, they will be reminded of the fact that they can keep their cameras off and also given easy instructions for changing their screen name as they join the session.

The introduction and welcoming will follow these lines:

Firstly, thank you for your time and your interest in talking to us today. We want to start by asking if you have any questions regarding the information we sent prior to today's conversation?

Great, just so we're on the same page:

- We need to inform you that this conversation is being voice-recorded, but that it will be edited for anonymity. Your responses and your participation will not be made public in any way.
- You may keep your camera on or off throughout. That's totally fine.
- We understand that we may touch upon some sensitive issues. At any point, feel free to just take a breather. If you would prefer to take a break or just leave the call, that's also totally fine.

Do you understand these things?

Today we want to talk about your experiences of monkeypox. This is part of a project we're doing to understand what were the social aspects of the response to the monkeypox outbreak. Do feel free to go on a tangent—that's frequently where the most interesting stuff comes up!

Are there any questions before we start?

Key questions or discussion points to ask:

- Can you tell us about how you first heard about monkeypox? When was this? Where did you hear about it? What did you think at the time? Did you talk to people about it?
- Can you tell us about how you found out you had monkeypox? How was it trying to get a diagnosis? Whom did you speak to about it?
- How was it being sick with monkeypox? What kinds of support did you get, and from whom?
- How did you use social media during that time? What social media did you use? Were you 'open' about having monkeypox? Why or why not?
- Have you been talking to others about your experiences? What kinds of people have you spoken with about it? What were their reactions?
- Using one word, how did it feel to have monkeypox?

As the interview comes to an end, it will conclude with:

We thank you for taking the time to reflect on and share your experiences. We know how difficult it may be sometimes to talk about these things, but we're incredibly grateful for your insight. That's all our questions for now.

Before we go:

- How did you feel throughout the interview?

**Supplementary file 1: Focus group and interview guide**

USING SOCIAL MEDIA AS A PUBLIC HEALTH TOOL DURING THE MPOX OUTBREAK IN THE UK: A QUALITATIVE STUDY OF STAKEHOLDERS' EXPERIENCES AND LESSONS

- How can we improve it?
- Is there anything we didn't talk about that you thought would be discussed?
- Was there anything you found surprising?

Just a final note: we will get in touch with you over email to send you a small token of gratitude in the form of a shopping voucher.