

CORRESPONDENCE

Community involvement in an outbreak – One year on for mpox

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Dear Editor,

We read with interest the article by Hazra and Cherabie¹ who conclude that the classification of mpox as a sexually transmitted infection (STI) would only worsen stigma faced by those affected. The authors provide examples of US initiatives to reduce stigma and emphasise educating communities on transmission dynamics and prevention methods. There is no mention of what impacted communities think of mpox as an STI despite previous publications on this², and no details on *how* to effectively involve communities in such discussions. Mpox-affected communities should be at the heart of this discourse.

We call for a change in the global mpox response to be more community-led, through the example of involving the community in a UK clinical treatment trial as a step towards this.

The UK mpox outbreak began in May 2022 and has recorded over 3,700 cases which are disproportionately affected gay, bi, and men who have sex with men (GBMSM) who have been stigmatised as a result³. Between 38 - 50% of those have also been living with Human Immunodeficiency Virus (HIV)⁴. The PLATINUM trial is a national UK trial to evaluate the safety and efficacy of tecovirimat in non-hospitalised mpox patients. Early and rapid community leadership led to community involvement in the PLATINUM trial (**Table 1**).

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Early community involvement was enabled by trial leadership and funders prioritising community engagement. Support was provided from community organisations and a rapidly established community advisory panel including individuals previously treated for mpox and those living with HIV. Examples of their impact included changing the trial protocol to include emergency contact numbers for participants and enhancing recruitment and communication.

Despite these early initiatives, challenges remained. The extensive time for study approvals meant that the peak mpox case numbers had passed before the study started.

There has also been mounting feelings of discontent, reflecting the frustration in the GBMSM community towards the national UK mpox response. In contrast to the US, no single government representative for the mpox response was elected to tackle the outbreak, resulting in lack of coordination across intervention efforts. Instead, and consistent with the US response as noted by Hazra and Cherabie¹, already stretched and underfunded sexual health clinics have had to manage the outbreak response, such as vaccinations and referrals to trials like PLATINUM.

For years there have been calls for greater involvement of communities in our public health responses, with accessible guidance on how to do this in fields such as in HIV research⁵, and yet coordinated community-centred responses are still lacking. The activities highlighted in the PLATINUM trial are a step towards correcting this. However, significant improvements need to be made to further support community engagement in response to outbreaks like mpox, such as standardising the involvement of communities in studies and discussions such as the one outlined by Hazra and Cherabie¹, and nominating leaders of contact for outbreak responses. Greater meaningful, and continuous community engagement will ensure future trials are as effective as possible and improvements in care and control are achieved.

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Table 1: Community involvement activities in the PLATINUM trial. HIV = human immunodeficiency virus, UK-CAB = UK community advisory board

Activity name	Activity description	Impact on trial
Community advisory panel (CAP)	Includes recovered mpox patients, sexual health workers who have treated mpox patients, gay and bisexual men who have sex with men, and people living with HIV. Contributed to study protocol, participant information sheet, consent form, patient recruitment poster and flyer, participant questionnaire, press release, and website.	Increased inclusivity and appropriateness of language used in patient-facing materials.
Raising awareness	Presentation of trial at conferences by community members (e.g. HIV Glasgow). Interview with community podcast “What the Pox?”. Development of advertisement of the trial on community dating apps such as Grindr. Hosting a stall at Manchester Pride festival 2023, providing information about the trial to festival attendees.	Identification of potential avenues for raising trial awareness that are outside routine trial recruitment strategies. Increased community awareness about the trial.
Training	Training provided to CAP members on trial background, planned future training on scientific publications.	Increased community member understanding of the trial, and research in general
	Community-delivered training in stigma and HIV history to trial team as a result of steering committee recommendation.	Whole trial team invited to training and attendees gained a greater understanding of the stigma faced by groups at risk of mpox, and appropriate language and terminology used when engaging with those communities
Community representation in steering committee	A member of the CAP is a member of the trial steering committee. Training in stigma and HIV history recommended by community representative in steering committee.	Community voice present in trial governance
Communication with clinics	Advice from CAP on how to recruit potential participants in clinics across the country.	Patient-centred and language appropriate recruitment posters and flyers
Community organization engagement	Support from Terrence Higgins Trust, UK-CAB, Positively UK, NAM AIDS MAP, Prepster, and HIV i-Base. HIV i-Base, Positively UK, and the British HIV Association (BHIVA) have included the trial on their websites.	Increased community and healthcare worker awareness of the trial, including diverse high-risk community groups
Trial launch	CAP reviewed the press release, provided a statement within the release, and tweeted about the trial launch alongside supporting organisations. This, together with trial team and University tweets, potentially reached more than 1.4 million people. The trial was picked up by community media channel PinkNews.	Improving awareness for potential participants outside those normally reached by research organisation engagement.