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"If that would have lessened my symptoms, that would have been great...": a qualitative study about the acceptability of tecovirimat as treatment for mpox

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Abstract

Background Tecovirimat, an antiviral treatment for smallpox, was approved as a treatment for mpox by the European Medicines Agency in January 2022. Approval was granted under "exceptional circumstances" based on effectiveness found in pre-clinical challenge studies in animals and safety studies in humans showing minimal side effects. As clinical efficacy studies are still ongoing, there is currently limited information with regard to the acceptability of tecovirimat to treat mpox. The aim of this study is to understand prospective acceptability of use of tecovirimat as treatment for mpox.

Methods A co-produced, qualitative, focus group study design was conducted with a theoretically informed sample of people from communities at higher risk and with experience of mpox illness. Thirteen participants took part: all self-identified as cisgender male, 1 self-identified as Black British, 1 as British Asian, 5 as White, 3 as White British, 3 as White Other. Inclusion criteria were as follows: experience of mpox illness; age 18 and over; living in the United Kingdom (UK); living in the UK during 2022 mpox outbreak. Focus groups were recorded, transcribed and thematically analysed using a combination inductive and deductive coding informed by the Treatment Acceptability Framework.

Results Very few participants were aware of tecovirimat as a treatment option and none were offered it during their mpox illness. Key factors influencing acceptability found in this study were as follows: levels of trust in medicine; level of information; provider communication approach; quality of experience of mpox care. Marginalised communities at highest risk of mpox may have prior experience of structural discrimination which can greatly influence treatment acceptability.

Conclusions This exploratory study suggest that offering tecovirimat (or comparable emergency-licensed treatments) to people with mpox is acceptable, although uptake will depend on knowledge of mpox treatment options, trust in medicine and medical professionals and provision of relevant information and choice. To increase acceptability of such treatments, clinicians should ensure patients are aware of mpox symptom management options, including pain relief; acknowledge and address patient concerns upfront and within the context of non-stigmatising

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care; and communicate offers in a consistent and supportive manner in line with locally approved eligibility criteria and protocols at the time.

Keywords Mpox, Tecovirimat, Acceptability, Treatment acceptability framework, Qualitative

Background

Following the sudden appearance of mpox in numerous countries beginning in May 2022, between July 2022 and May 2023, the World Health Organization (WHO) declared a multi-country outbreak of mpox (formerly monkeypox) as a public health emergency of international concern [1]. Since the beginning of the outbreak, cases have been reported in 117 countries, the vast majority outside historically affected regions [2]. Unlike previous outbreaks, mpox transmission has been concentrated among networks of sexually active gay, bisexual and other men who have sex with men (GBMSM) and approximately 50% of persons affected worldwide are also living with HIV [3, 4]. Reported mpox symptoms have ranged from a few isolated lesions (fluid-filled blisters) to severe body lesions, encephalitis, secondary skin infections or scarring, lesions on the penis and anus and proctitis with severe pain [3, 5].

The monkeypox virus (MPXV) belongs to the same genus of orthopoxviruses as variola virus which caused smallpox. Tecovirimat (known commercially as TPOXX®), an antiviral treatment for smallpox, was approved as a treatment for mpox by the European Medicines Agency (EMA) in January 2022 (before the onset of the global mpox outbreak) [6] and is the only mpox treatment available in the European Union. The EMA approval was granted under "exceptional circumstances" based on effectiveness found in pre-clinical challenge studies in animals and safety studies in humans showing minimal side effects [7, 8]. The use of tecovirimat as treatment for mpox was also approved under exceptional circumstances by the United Kingdom (UK) Medical Health Products Regulatory Agency (MHRA) on 30 June 2022 just after the outbreak began. On 30 September 2022, the MHRA published a rapid policy statement outlining eligibility criteria for use of tecovirimat in hospitalised patients with severe disease [9]. While tecovirimat is thus fully licensed, and with data on its effectiveness in the treatment of human mpox emerging from observational clinical studies [10], as well as laboratory-based in vitro studies [11], efficacy and safety data from randomised clinical trials in different contexts [12–16] are not yet available. Exact information about the number of people prescribed tecovirimat overall is not available. However, from expert communication[1] and a published national audit [17], an estimated 34–60 individuals were offered tecovirimat between May and September 2022 in UK hospitals.

In this context, the purpose of this study is to assess the acceptability of the licensed product tecovirimat proposed for use during an outbreak for an indication for which, however, efficacy data in people with mpox are not yet available. Acceptability of a treatment has been shown to positively influence uptake, adherence, and persistence [18, 19]. As tecovirimat is not yet widely available while studies are underway, there is currently limited information with regard to the acceptability of tecovirimat to treat mpox. It is therefore important to understand acceptability from the perspective of those with experience of mpox to maximise benefits of current application of tecovirimat as well as to develop future implementation guidelines after trials.

Hence, this study aimed to:

i. Understand people's experiences of accessing mpox care and treatment to manage mpox symptoms;
ii. Explore prospective acceptability of the use of tecovirimat to treat mpox from the perspective of people with experience of mpox.

The study was commissioned by the Health Emergencies Programme of the World Health Organization to supplement expected efficacy data for tecovirimat-related guideline development with values and preferences data from most affected communities. The study was co-designed and delivered by the SHARE Research Collaborative, based at Queen Mary University of London (QMUL), and The Love Tank, a non-profit at the forefront of the mpox community response in the UK.

Methods

In February 2024, three online focus groups were conducted with people living in the UK with experience of mpox. Focus groups were chosen as a method of exploring group-level attitudes towards tecovirimat [20, 21].

[1] Provided in personal communication by email from Dr Jake Dunning MRCP PhD (Consultant, Royal Free London NHS Foundation Trust, London, UK) on 18 September 2024.

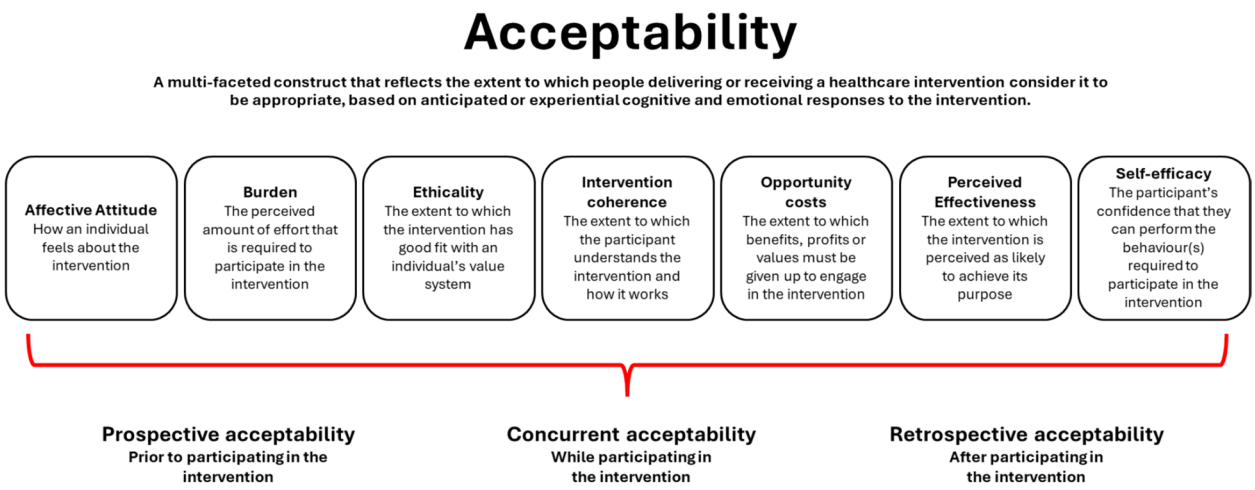

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Fig. 1 The Theoretical Framework of Acceptability (v2)

These were conducted online based on participant preference. Advertisement was carried out using Love Tank's existing networks and via social media.

Ethics approval for the study was obtained from the QMUL Ethics of Research Committee on 20 December 2023 (QMERC23.045). All participants received a participant information sheet and gave written and verbal informed consent to take part in the study.

Participant recruitment

Our theoretical basis for the sample included purposively recruiting people from communities at increased risk of mpox (e.g. GBMSM) to understand prospective acceptability in a sample of people who had experienced mpox illness and, potentially, mpox care and the offer of mpox treatment.

To understand the choice of timeframe adopted in our recruitment, between January and December 2022 there were 3732 laboratory-confirmed mpox cases reported in the UK, with > 1000 cases reported per month at the peak of the outbreak in June and July 2022 [2]. In contrast, there have been only 222 cases reported to date in 2023 and 2024 (as of May 2024) [2].

Eligible participants were therefore those who had lived in the UK during the 2022 mpox outbreak; were living in the UK at the time of the study, had experienced mpox illness while in the UK, and were aged 18 or above. No individuals who approached us for participation were excluded as all met the eligibility criteria.

Data collection

Prior to the focus groups, participants were asked to complete a brief, anonymous online questionnaire (Additional File 1) which collected information on whether they suspected they had mpox or had received a formal diagnosis (based on a PCR (polymerase chain reaction) test result); the types of symptoms they experienced, and their duration and severity of pain (rated from 0 to 10, where 0 was no pain and 10 was worst possible pain); and some basic demographic information. Survey data was summarised in descriptive statistics.

Focus groups were conducted using a semi-structured topic guide (Additional File 2) and audio-recorded with participants' consent and transcribed. Transcripts were checked against the recordings and with the team member leading the focus groups. During the focus group, participants were presented with a brief introduction to tecovirimat and informed about the lack of completed efficacy studies for tecovirimat as mpox treatment (Additional File 2), so that they could better contextualise questions about acceptability. Field notes were made immediately after the focus group discussions and shared with the research team members responsible for data analysis; it was agreed between the research team that data saturation had been reached upon completion of the final focus group.

Data analysis

Data from transcripts were initially coded inductively and grouped into preliminary nodes using a combination of Microsoft Word and Microsoft Excel (Microsoft 365 v2404; Microsoft Corporation, WA, United States). The

study was originally commissioned to gather data on values and preferences. A theoretical framework to understand acceptability was applied at the analysis stage of the study. Findings were juxtaposed to the seven constructs of the Theoretical Framework of Acceptability (TFA v2) [22] and reorganised into the framework using framework analysis [23]. Figure 1 shows the TFA and related construct definitions. Additional File 3 shows the original nodes and how they addressed the constructs.

The TFA can be used to assess prospective, concurrent and retrospective acceptability. Our study focuses on prospective acceptability of tecovirimat as the best fit with this framework. In reality, the questions were about hypothetical acceptability as viewed post hoc after having experienced the illness without the intervention. Anonymised quotes from focus group transcripts are used to illustrate the narratives in the study.

Patient and public involvement

This study was devised and conducted in partnership with The Love Tank—a non-profit serving the communities predominantly affected by mpox in the UK. All data collection materials were co-created. Recruitment and data collection was conducted by The Love Tank researchers. The data analysis and write up of findings were carried out in collaboration between QMUL and The Love Tank. The findings of this study will be disseminated to affected communities in an accessible format via The Love Tank.

Results

There were 13 participants in total (focus group 1 = 3, focus group 2 = 4, focus group 3 = 6). All participants completed the pre-study questionnaire (Additional File 1). All participants self-identified as cisgender men and self-identified as gay and/or queer. The median age was 39 (interquartile range 34, 40). All other participant demographics are provided in Table 1.

Eleven had received a confirmed mpox diagnosis from a PCR test, while two had self-diagnosed their condition as mpox (Table 2). The most common symptoms were skin or mucosal lesions (11/13), high temperature (10/13), headache (8/13), muscle aches (8/13) and shivering (8/13). "Other" symptoms included the following: "swollen thigh and penis at site of lesions", "immensely painful lips" and "severe bacterial superinfection of the throat with large white patches". Those with lesions ($n = 11$) mostly experienced them on their genitals (8/11), legs (5/11) and torso (5/11). Six reported pain from their lesions, with a mean pain score of 4.5 (SD 2.75) out of 10, and their pain lasted either 1–7 days (4/6) or 8–14 days (2/6).

Table 1 Self-reported participant demographics ($N = 13$)

Demographic	*n* (%)
Gender identity	
Cisgender male	13 (100)
Sexual orientation	
Gay / Queer	13 (100)
Ethnicity	
White	5 (38)
White British	3 (23)
White Other	3 (23)
British Asian	1 (8)
Black British – Caribbean	1 (8)
Religion	
No religion	8 (62)
Jewish	2 (15)
Muslim	1 (8)
Other	1 (8)
Prefer not to say	1 (8)
Disability	
Yes	4 (31)
No	8 (62)
Prefer not to say	1 (8)
Country of birth	
United Kingdom	8 (62)
Canada	1 (8)
Italy	1 (8)
Latvia	1 (8)
United States of America	2 (15)
Employment	
Full-time employed	7 (54)
Part-time employed	1 (8)
Self-employed	4 (31)
Retired	1 (8)
Education level	
Undergraduate degree (bachelors) or equivalent level	3 (23)
Postgraduate degree (masters, PhD) or equivalent level	10 (77)

The duration of the focus group discussions ranged between 50 and 56 min. Participants discussed perceptions and acceptability of tecovirimat based on their assessment of their care and treatment experience during their mpox illness. On balance, 7 participants broadly agreed they would accept an offer of tecovirimat, 4 were ambivalent in their responses and

Table 2 Participant-reported symptoms

	***Responses*n(%)**
Formal diagnosis of mpox (*N*=13)	
Yes	11 (85)
No, but I suspected that I had mpox	2 (15)
Mpox symptoms (*N*=13)	
Lesions (small blisters filled with fluid)	11 (85)
High temperature	10 (77)
Headache	8 (62)
Muscle aches	8 (62)
Shivering (chills)	8 (62)
Swollen glands	7 (54)
Exhaustion	5 (38)
Rash	5 (38)
Other	4 (31)
Joint pain	3 (23)
Backache	3 (23)
Respiratory symptoms (e.g. sore throat, nasal congestion or cough)	2 (15)
Location of lesions (*N*=11)	
Face	2 (18)
Torso	5 (45)
Genitals	8 (73)
Arms	1 (9)
Hands	2 (18)
Legs	5 (45)
Feet	1 (9)
Painful lesions (*N*=11)	
Yes	6 (55)
No	5 (45)
Duration of painful symptoms (*N*=6)	
1-7 days	4 (67)
8-14 days	2 (33)
Lesion pain rating (*N*=6)	
Mean (SD)	4.50 (2.75)
Min, max	0.00, 9.00

2 thought they would not take it if offered. It is important to note that no participant in this study was offered or able to access tecovirimat during their mpox illness. Three participants had been hospitalised due to severe symptoms; it is possible that tecovirimat was not available at the time of their diagnosis (most reported in focus groups being diagnosed between May and July 2022[2]) and/or they did not meet the UK eligibility criteria for emergency use (including critical illness, intractable pain, encephalitis and a range of other complications). Two additional participants perceived their symptoms as severe but were not hospitalised. Six participants described how challenges in accessing testing meant that the worst of their symptoms had dissipated by the time they were diagnosed.

The results from the participants discussions, based on the seven TFA constructs, are presented below.

Affective attitude: how an individual feels about the intervention

Acceptability was strongly influenced by trust in medicine more generally. Those with lower levels of trust had concerns about potential side-effects being minimised or not fully understood by healthcare staff, although reasons for this differed. Some described broad mistrust about whether commercial influence affected clinical decision-making in the National Health Service (NHS). For example, despite having experienced very severe mpox symptoms, one participant explained why he would have refused tecovirimat:

"I'm a bit wary…does the NHS do a good job in, you know, curing people and putting people on medication because it benefits the pharmaceutical companies? I'm a bit wary about that… because of the side effects and the associated risks and damage it could also place on the human body." Focus Group 2.

Others described how their distressing experiences of their clinical care during their mpox illness reduced their trust in medicine, with concerns relating to an excessive focus on infection control (rather than symptom management or holistic care), disregard for patient dignity and the risk of mpox-related stigma, and a display of medical uncertainty around mpox.

Some also linked these negative experiences to their identities as gay men and belonging to a minoritised community. For example, a participant described the impact of his care experience on his feelings towards tecovirimat:

"I'm left with this lingering distrust as well, if I'm being honest, of the health system based on my direct experience, but also going back to, you know, if you watch like stuff about AIDS and stuff, the concern is that because this was something that was affecting gay men more, is it being given the same degree of attention and resource? Or is it being kind of, you know, dealt with in kind of a shoddy way". Focus Group 3.

Regardless of how they felt about tecovirimat personally, most participants agreed it should continue to be made available as a choice to people with mpox, and they agree they would have liked to have been offered it as in this example:

[2] Note: Timeframe of illness was not a specific question in the questionnaire or FGD topic guide, so not all participants reported when they were diagnosed.

"I would have liked anything that could have reduced the course of the infection. I mean, obviously, then I'd have to find out what it is and if it made sense, but I would have liked the offer." Focus Group 3.

Burden: the perceived amount of effort that is required to participate in the intervention

Those who did try to access some form of treatment for their mpox illness—be it vaccine post-exposure prophylaxis, pain relief or tecovirimat—reported facing delays or what they perceived as obstruction from healthcare professionals. The burden to participate in the intervention in this case related to the effort needed to access testing, treatment or symptom management of any kind (not only tecovirimat). In the words of one participant:

"The doctor told me that I'd be able to get decent pain relief from NHS 111. I spent hours on the phone trying and they eventually gave me a prescription for codeine (…) just like a tiny bit stronger than the standard codeine you can get from Boots [local chemist] (…) it was like, oh, not really worth it." Focus Group 1.

Ethicality: the extent to which the intervention has good fit with an individual's value system

Acceptability of tecovirimat increased where participants' value systems included supporting and participating in research overall. One participant felt using a treatment that had not been fully tested in people with mpox might help generate evidence for it, and that this would be a way of volunteering for a good cause.

Another participant pointed to his cultural background as being relevant to his general attitude towards trying new medical interventions:

"I think some of my willingness to try these things probably comes from being from the US [United States] and being used to very uneven agreements about what people have access to (…) I think I'm more accustomed to that 'Oh, your doctor will let you try this random thing." Focus Group 3.

Participants felt that it would be important to communicate offers of tecovirimat in a way that would not make patients feel pressured to accept the treatment as a form of infection control (treating their own mpox to decrease onward transmission to others), as opposed to symptom management (treating mpox as a way of caring for them).

One participant described how the social pressure to avoid onward mpox transmission may have led him to accept tecovirimat (despite feeling his symptoms were insufficiently severe to use a drug not yet fully evidenced):

"Had it been presented to me at the time, maybe the pressure of worrying that I was like this contagious thing walking around would have made me take it when now with the benefit of hindsight, I would say that I probably wouldn't take because I know that my symptoms didn't go anywhere very bad." Focus Group 3.

Intervention coherence: the extent to which the participant understands the intervention and how it works

Few participants were familiar with tecovirimat at the time they had mpox; one participant had asked for tecovirimat specifically, one had heard about an antiviral treatment and had asked for it, and another had been told about tecovirimat by a health professional but was not offered it. The participants who asked for the treatment were both told that as their lesions had appeared more than 3–4 days prior, the treatment would not be of benefit (a statement that is not included in the eligibility criteria published by the UK government). The third participant was told their symptoms were not severe enough to warrant antiviral treatment. Some participants were unaware that they could access *any* form of treatment for mpox symptoms—even pain relief in some cases—and six participants discussed how challenges accessing testing meant the worst of their symptoms had dissipated by the time they were diagnosed.

Although it was explained that tecovirimat is safe to use, the lack of safety evidence on the use of tecovirimat in people *with mpox* was concerning to some participants. Examples of other drugs which were considered to have been fast-tracked too quickly and led to harm were raised.

Participants felt it was important that the following information be provided when offering tecovirimat to increase understanding of how the intervention works:

i. The existing evidence on tecovirimat (i.e. tested on animals for efficacy and tested in humans without mpox for safety);
ii. The remaining evidence gaps (i.e. efficacy and safety data in humans with mpox);
iii. Likelihood of treatment side-effects occurring in people with a disease when they have not occurred in people without a disease (e.g. based on previous drugs that have received emergency authorisation in this way);
iv. Temporary nature of the measure and clinical trials in humans with mpox currently underway to gain the evidence required for full approval.

In their own words:

"[I'd want to know] how likely is a drug that's been tested on people without mpox and proven to be safe, how likely is it to have some kind of unexpected reaction when it is with people with mpox, right?… So then I'd be fine." Focus Group 3.

Beyond feeling fully informed, participants emphasised that the delivery of the offer itself, the way in which it is communicated, would make a great difference to acceptability. For example, one participant said that while he would want to understand the limits of knowledge around tecovirimat, the language used by the provider should also be reassuring and avoidant of words implying rashness or risk:

"If I was being offered this and they framed it using language, like experimental or untested, that would probably make you anxious about what's this going to do to me. So just kind of maybe having guidelines for the doctors, like here's some phrases or here's some ways of introducing it to make sure it doesn't give people the wrong impression that this is a very new, untested drug that might have any kind of effects in somebody's body." Focus Group 1.

Opportunity costs: the extent to which benefits, profits or values must be given up to engage in the intervention

Rather than reasoning through "giving up benefits"—as this construct refers to—participants discussed "weighing up the costs" of taking part in the intervention, which they located in the perceived risk of taking a treatment not fully proven for mpox against the benefits during illness.

Factors contributing to decision-making included mpox symptom severity (were the symptoms bad enough at the time treatment was offered to warrant the risk); degree of knowledge about the consequence for their prognosis of not taking the treatment; availability of other forms of symptom management (what are the alternatives); the type and severity of known side-effects of tecovirimat (even if known only in people without mpox); and whether alternative options such as longer self-isolation were viable or not (e.g. sharing accommodation).

As explained by this participant:

"I guess it'd be a cost–benefit analysis for me (…) I would want to know, like, how sort of self-limiting is the disease? Am I likely to get through it without needing medication? And if so, I'd probably be wary of taking something that hasn't gone through a lot of tests. But then, if the disease is really severe, or, you know, I'm really desperate like, I might say, Okay, if there's enough kind of, I guess, theoretical reason to think it could work and not be very risky". Focus Group 2.

Perceived effectiveness: the extent to which the intervention is perceived as likely to achieve its purpose

Some participants contextualised the potential benefit of tecovirimat against other interventions in the mpox outbreak and in sexual health. For example, some compared tecovirimat to the mpox vaccine which they had been willing to take, noting that this too was originally intended for preventing smallpox and they could see the logic in doing the same for treatment if the two viruses are similar. Another pointed out that there was precedence for the emergency authorisation of experimental medications during the AIDS epidemic.

Some participants said they wished they had been offered tecovirimat at the time of their mpox illness, to help with their symptom management at a difficult time, indicating they perceived the treatment as likely to be effective:

"I would have liked to have been offered something instead of just kind of being told to isolate for a couple of weeks. I feel I would have liked to have had something proactive, something to try and make me feel better." Focus Group 2.

Self-efficacy: the participants' confidence that they can perform the behaviours required to participate in the intervention

There was no discussion about issues with taking the pill regimen for the treatment itself, and therefore, we did not gather any data on the construct of self-efficacy. This is further discussed in the study limitations.

Discussion

Our study provides key insights into the prospective acceptability of the use of tecovirimat as mpox treatment among people with experience of mpox during the 2022–2023 mpox outbreak in the UK, who had not been offered nor had access to the intervention at the time. Importantly, there was limited knowledge of *any* mpox treatment options among participants (including among those who were hospitalised) and many were not offered or aware of any form of mpox symptom management, including pain relief. While there are limits to the generalisability of the findings of this study to situations where people may have been experiencing or at high risk of severe disease, several important themes did emerge that address the theoretical generalisability of the constructs of the framework. The findings provide evidence about prospective acceptability that can support improvement of the offer of tecovirimat and other, comparable, emergency-licensed treatments in the context of mpox (and other outbreaks) affecting marginalised communities.

Trust in medicine and medical professionals strongly influenced acceptability of tecovirimat—with those with lower levels of trust being particularly concerned about side-effects. Mistrust of authority is more likely among those who perceive themselves to be already socially marginalised [24], making it a potentially salient issue for communities most affected by mpox and who felt stigmatised during the mpox response [5, 25, 26]. Research into

COVID-19 vaccine hesitancy among racially minoritised communities in the UK has also found vaccine safety, side-effects and the long-term effects on health to be a prominent cause of concern; acknowledging and addressing these concerns upfront may increase acceptability [27, 28]. Contextualising hesitancy within underpinning social and structural processes of marginalisation may help to avoid perpetuating mistrust [29]—indeed, the community history of AIDS treatment activism actively facilitated trust among some participants in our study. Conversely, those with high levels of trust in medicine referred to values of wanting to support scientific progress and research, and familiarity with trying new medicines.

As shown in our findings, provision of accessible, person-centred and non-stigmatising mpox care is also important for increasing tecovirimat acceptability. This finding is supported by other studies exploring patient decision-making in relation to experimental medications, where trust in the expertise of their healthcare providers is key to making patients feel safe and secure [30–32].

Importantly, findings from this study need to be understood against a broader context of health inequalities among sexual minorities and of community-wide perceptions with regard to pre-existing homophobia and marginalisation, including prior discrimination in healthcare access and treatment [33]. Recent studies have found similarly negative experiences of care during mpox outbreaks for marginalised communities in other countries, and study participants also ascribed their experiences to discrimination against LGBTQ + communities [5, 26].

We found limited knowledge of any treatment to manage mpox symptoms, potentially influencing perceptions of tecovirimat. Participants attributed this limited knowledge to service responses being primarily focused on infection control as opposed to symptom management and described considerable barriers to accessing treatment, including pain relief. Such a finding should also be interpreted against the background of inequalities in healthcare for members of LGBTQ + communities.

This lack of knowledge about the intervention aligns with findings from studies exploring the healthcare experiences of people with mpox in the UK, Australia and China [26, 33, 34]. Availability of other forms of symptom management may therefore influence acceptability of tecovirimat; this is particularly relevant in countries where tecovirimat eligibility is restricted to those with the most severe symptoms, such as the UK [9]. Since tecovirimat may be more effective when used early in the course of infection [35], it is also crucial that barriers to prompt diagnosis are removed—many participants in this study and similar studies described lengthy delays in securing a diagnosis [5, 26, 34].

Finally, our findings indicate the importance of providing people with mpox with the opportunity to make an informed choice about tecovirimat in ways that align with their broader values. Certain information on the evidence and information gaps surrounding tecovirimat, potential risk of side-effects and the ongoing efforts to gather further evidence should be provided, as well as clear instructions on how to take the medication. Further, it is important that patients do not feel pressured to accept the offer of mpox treatment, as found in studies about vaccine offers [29]. Although vaccines differ substantially from treatment, participants clearly articulated a negative perception about treatment possibly being offered to reduce onward transmission rather than improve care. Ensuring availability of other forms of symptom management would be important in supporting patient choice [30].

It is important to note that in this study, most participants were unaware of tecovirimat beforehand, and the information they received about it was shared by a trusted community health organisation, which will also have played a role in shaping their perception of the treatment. Community leaders and organisations have played a vital role in mediating knowledge between marginalised communities, healthcare providers and clinical researchers – both during the 2022–23 mpox outbreak and more broadly [25, 28, 36] – and their involvement will be essential for information sharing and promoting equitable access to tecovirimat.

Strengths and limitations

To our knowledge, this is the first study to explore the acceptability of tecovirimat as mpox treatment among people from communities at higher risk of mpox and with experience of mpox. The qualitative study design provides in-depth understandings of how acceptability is informed by individual feelings, perceptions and attitudes, by the individual experience of mpox as an illness, and by the social contexts and community-wide experience of the mpox outbreak, and how these have shaped values and preferences towards tecovirimat. This allows for a deeper understanding of equity-related issues in acceptability. These findings may have broader relevance to those seeking to optimise the implementation of emergency authorised treatment for other minoritised or marginalised groups in response to new and emerging viral threats in different contexts.

The data and findings were co-produced with a trusted community health organisation, which enabled us to reach people with experience of mpox, supported participants to share richer and more insightful accounts, and improved the accuracy of our findings.

There are nonetheless several limitations to this study. As the acceptability framework was applied at the analysis stage, we were not able to address the construct of self-efficacy, as we did not include questions about treatment-taking, and the issue did not emerge in the discussions.

Our study group were asked to consider the prospective acceptability of tecovirimat had it been offered to them with their actual lived experience, rather than in the perhaps more hypothetical situation for most of considering acceptability had they been hospitalised with medical complications or intractable pain in line with the strict eligibility criteria for access to tecovirimat in the UK [9]. While the lived experience of participants improved their understanding of mpox, this may have influenced their views on the expected outcome rather than facing an unknown. Likewise, the study did not enquire about HIV status and the perception of risk of more severe disease did not arise and was not addressed during focus group discussions.

Alternate study designs of interest would be to assess views and perceptions of prospective acceptability of tecovirimat among persons at risk but not yet ill, persons experiencing early symptoms but still unwell or among those with more severe disease in real time. In the outbreak of mpox in South Africa which began in May 2024, the first 15 of 16 cases detected were hospitalised and immunocompromised; they were offered and each accepted tecovirimat for compassionate use, despite data on the efficacy of the treatment still not being available [37, 38].

A further, equity-related limitation concerns the limited diversity in the sample: this was a highly educated sample, there were no gender diverse participants and only a minority of participants were migrants to the UK and/or from racially minoritised groups. This constrains possible comparisons and understandings of how perceptions and acceptability of tecovirimat may differ among groups experiencing additional barriers to healthcare. With the exception of one participant who asked about tecovirimat, there was also limited awareness of this medication or that it could have been an option had they been hospitalised for severe disease, which may have influenced views and perceptions collected after their illness resolved.

Conclusions

Based on the findings of this study, offering tecovirimat to people with mpox is acceptable while data on efficacy for the treatment of mpox is being collected. Subsequent uptake of the treatment would be shaped by knowledge of mpox treatment options, trust in medicine and medical professionals, and provision of relevant information and choice, as well as by the patient's own experience of the severity of symptoms due to mpox at the time of the offer. Acknowledging and addressing patient concerns upfront, and within the context of non-stigmatising care, will be important for increasing acceptability once pending studies are completed or for any offer of compassionate or monitored emergency use in the meantime. Increasing access to prompt diagnosis and treatment options is important for improved patient outcomes and effective treatment. Healthcare providers will need to be supported to communicate the offer of tecovirimat in a consistent and supportive manner and in line with locally approved eligibility criteria and protocols at the time. Community organisations trusted by marginalised groups will be key to improving knowledge of tecovirimat and promoting its equitable access once studies are completed and it becomes more widely available.

Abbreviations

EMA	European Medicines Agency
GBMSM	Gay, bisexual and other men who have sex with men
MHRA	Medical Health Products Regulatory Agency
NHS	National Health Service
PCR	Polymerase chain reaction
QMUL	Queen Mary University of London
TFA	Theoretical Framework of Acceptability
UK	United Kingdom
US	United States
WHO	World Health Organization

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12916-024-03840-y.

Supplementary Material 1.

Supplementary Material 2.

Supplementary Material 3.

Authors' contributions

The study was conceptualised by RL, IM and TW. The study was supervised by SP, IM, RL and CMO. The methodology was determined by SP and WN. The data was collected by BW, and curated and analysed by RH —with input from BW and SP. The original draft of the manuscript was written by SP and RH, and reviews and edits were conducted by all authors. All authors read and approved the final manuscript.

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The study was commissioned by the Health Emergencies Programme of the World Health Organization. IM, TW and RL are employees of the World Health Organization – their involvement in this study is outlined in the contributor statement.

Data availability

The data from this study will not be shared due to the sensitive nature of the topics discussed and the risk of re-identification despite anonymisation.

Declarations

Ethics approval and consent to participate

Ethics approval for the study was obtained from the Queen Mary Ethics of Research Committee on 20 December 2023 (QMERC23.045). All participants received a participant information sheet and gave written and verbal informed consent to take part in the study.

Consent for publication

Not applicable.

Competing interests

CMO has received honoraria for advisory boards, lectureships and travel sponsorships from Janssen, Gilead Sciences, ViiV Healthcare, MSD and Bavarian Nordic and has received research grants from Janssen, Gilead Sciences, ViiV Healthcare, MSD and AstraZeneca. SP has received research grants from Gilead Sciences and ViiV Healthcare. The remaining authors (RH, BW, WN, IM, TW and RL) declare that they have no competing interests.

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