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SHARING to create knowledge in a crisis

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COMMENTARY

May 2022 saw a new health crisis—the most extensive and geographically widespread mpox (formerly monkeypox) outbreak and the first in which sustained human transmission is reported outside western and central Africa.¹ The availability and acceptability of vaccines at the beginning of the outbreak was unclear. The outbreak was declared a Public Health Emergency of International Concern within 3 months.¹ There have been more than 86 000 infections reported to the WHO.²

The outbreak impacted health systems that were already overstretched by the COVID-19 pandemic. In the UK, sexual health services were at the forefront of the mpox response alongside the most-affected communities. Clinical leaders raised the alarm about the risks posed to core sexual and reproductive health services by unplanned and unfunded mpox activity. The concerns were significant reductions in service availability for HIV testing and prevention, management of sexually transmitted infections and access to reproductive health interventions, including long-acting reversible contraception. Organisations across the sexual health and HIV sector came together to call for urgent government action.³

Unlike in the pandemics of HIV and COVID-19, mpox is a known pathogen with existing treatments and vaccines.⁴ Why then did it spread so rapidly and what was the effect on sexual health services?

Healthcare workers in newly affected countries had to overcome a vast knowledge gap and implement novel diagnostics and therapeutics at pace. Mpox has been affecting humans since 1970, but, like many other diseases that predominantly affect the global South, scant attention was paid until it arrived in the Global North.⁵ At the same time, it was clear that this outbreak differed significantly from previously described epidemiological and clinical patterns. Similar to the beginning of the HIV pandemic, mpox was transmitted within the sexual networks of men who have sex with men (MSM). It was also clear that people living with HIV were disproportionately affected. This presented the challenge of potentially increasing stigmatisation of this already marginalised group and the opportunity to leverage the well-established collaborations between MSM communities, activists and their clinicians. Case definitions were, however, clearly in need of revision.⁶ Adopting a practice-based approach to knowledge production in rapidly evolving situations from within the situation at hand enables workable solutions to emerge in complex and rapidly evolving settings.⁷

This is what we saw at the start of the COVID-19 pandemic where amid the hazmat suits, and funerals of colleagues, family members and patients, doctors at Wuhan hospitals nonetheless wrote up huge case series at heroic speed.⁸ Their detailed front-line descriptions of epidemiology, the natural history, and clinical and laboratory findings quickly became the accepted case definitions, forming the basis of international public health policy on shielding and vaccination. This enduring contribution to science is full of lessons for future pandemics.

But is academic heroism a sustainable response? It is challenging for research groups to respond without funding and amid academic pressure to publish competitively, leading to single centres writing up their own, small volume case series under pressure to have the science attributed to their academic institution. This academic pressure lends itself to individualism and/or nationalism rather than intellectual collectivism and constrains the opportunity for meaningful community involvement in research.

So, with small numbers of cases scattered worldwide, there was a need for collaborative academic leadership to bring clinical teams together. Leadership came from within The Sexual Health and HIV All East Research (SHARE) Collaborative. Based at Queen Mary University of London (<https://shareresearch.org.uk/>), SHARE is a multidisciplinary and collaborative research group established in 2021 with funding from Barts Charity. SHARE has an embedded community advisory board and is grounded in social justice principles and aims to deliver culturally competent research on health equity in infections. In response to the mpox outbreak, SHARE expanded to create SHARE-NET—an international collaboration of researchers from 16 countries to develop a large globally relevant case series. The collaborative codesigned an iterative case report form, capturing detailed information on key population characteristics, including sex, gender identity, sexual orientation, and ethnic and racial heritage, and complete clinical details. Within the first 9 months, SHARE-NET members contributed data to create a convenience-sample case series consisting of 528 cases of confirmed human mpox infection from 5 continents, 16 countries and 43 collaborating clinics.⁹ The SHARE-NET group went on to characterise the manifestations of mpox among 136 women, both cisgender and transgender, and non-binary individuals from 15 countries and three WHO regions who were at risk of being overlooked in this crisis as it predominantly, but not exclusively,



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affected MSM.¹⁰ Striking and concerning findings on the clinically very serious intersections between advanced HIV and mpox have come from the third case series on 382 people with mpox and advanced HIV infection in 19 countries. This led the authors to call for a change of international guidelines to include mpox as an opportunistic pathogen and for this severe form of mpox to be considered an AIDS-defining condition.¹¹

What about the population at risk? Community organisations, particularly those working with MSM with significant HIV experience, were central to the UK mpox response. The SHARE team co-produced, with community organisations—the Love Tank¹² and Sophia Forum,¹³ a locally relevant UK-based community survey answered by 1932 people (1750 men, mainly MSM) to understand their views about the existing media public health and media messaging as well as vaccination.¹⁴

To understand the potential effects on the international sexual health workforce and the risks to service delivery, the SHARE team joined forces with leaders of the professional bodies for sexual health and HIV internationally to codesign and disseminate a survey instrument. A manuscript is in preparation.

How could this newly established and unfunded global collaboration work so effectively? Collaborative leadership that champions the power of the collective underpinned the coalition. Despite academic and clinical pressures, this evidences willingness to collaborate and share experiences and data for better public health based on larger datasets. Co-creating research for and with those most affected, be it people with mpox, community organisations, or front-line staff, ensures the research questions are pertinent. The outputs of the work can be impactful in creating and changing policy. The key pillars of social justice—access, knowledge, diversity, participation and human rights—are visibly embedded in every piece of work. The knowledge gained applies to the most vulnerable across the world.

Peter Sands, chief executive of the Global Fund for HIV, TB and malaria, reflects that the world has had three pandemic wake-up calls in a row, yet most people are still asleep: ‘We must foster an even greater ethos of collaboration. In our increasingly interconnected world (...) meeting these challenges requires working outside of national and global siloes.’¹⁵

What more will it take? Learning from crises such as mpox is crucial for the next dangerous emerging/re-emerging pathogen. SHARE-NET has created new ways to take us forward.

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