



International AIDS Society

[iasociety.org](https://iasociety.org)

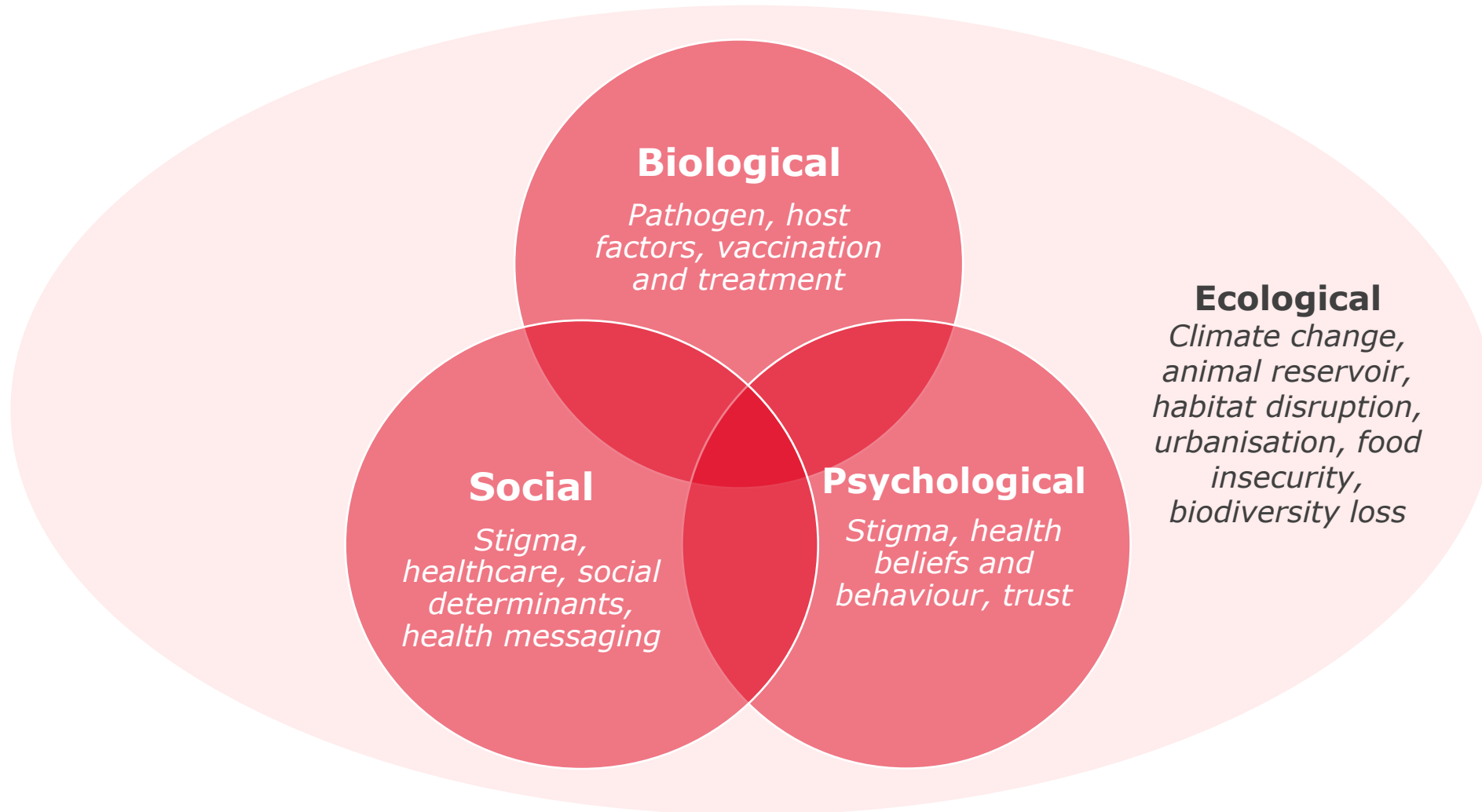
# Ensuring a community-led and equitable response to mpox

## Dr Shema Tariq

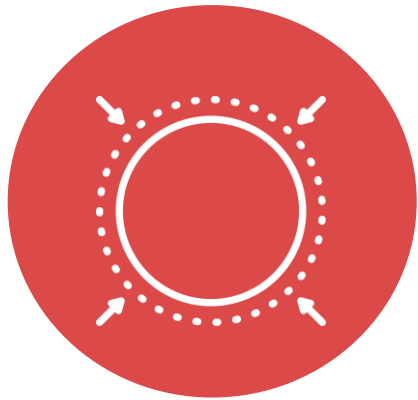
1 October 2024



# Mpox is an eco-biopsychosocial problem



# Key sociocultural challenges



**Marginalised  
groups**



Stigma and  
discrimination



Information and  
misinformation



Mistrust of  
institutions



Global health  
inequity



## **Why does community involvement matter?**

- Knowledge and expertise
- Trust and transparency
- Cultural and local relevance
- Reach marginalised groups
- Reduce stigma
- Context-sensitive solutions
- Sustainable change
- Mutual learning and upskilling
- Maximise impact

# Community involvement in the mpox response



Community-led interventions



Health promotion



Advocacy and policy change








Peer support



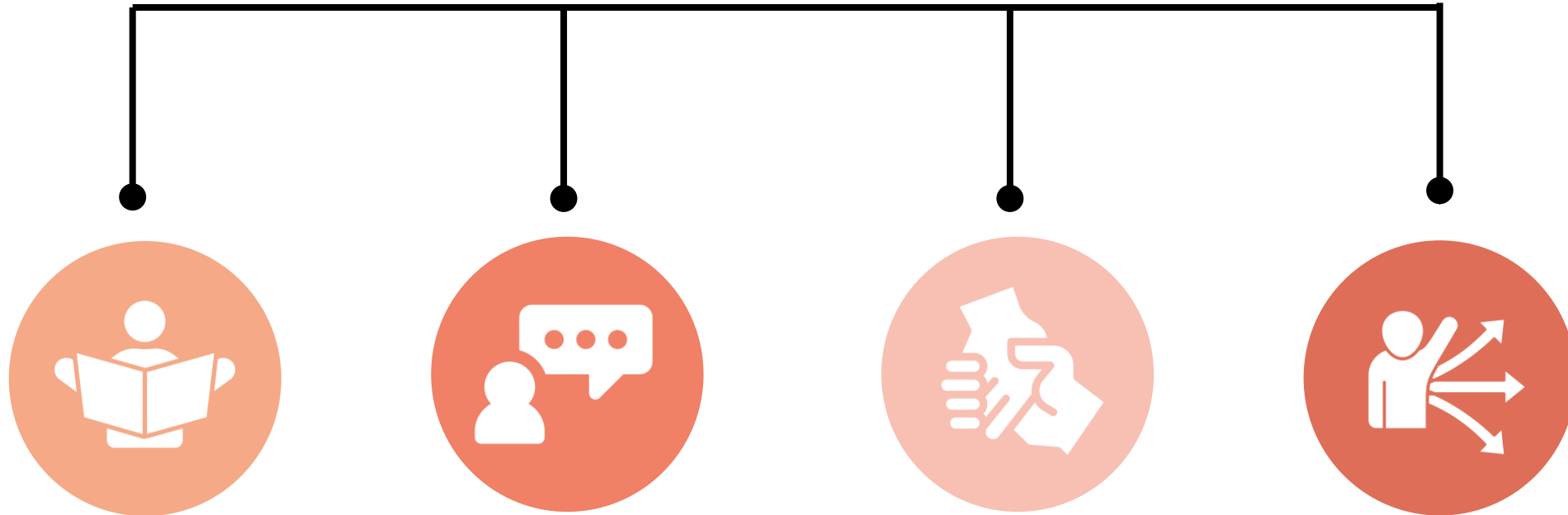
Involvement in research

Aim: To develop contextual understandings of the lived experiences of mpox

	 <b>News media</b>	 <b>Social media</b>	 <b>Focus Groups</b>	 <b>Interviews</b>	 <b>Photography</b>
<b>Italy</b>	✓				
<b>Nigeria</b>	✓	✓	✓	✓	
<b>Thailand</b>	✓	✓	✓	✓	✓
<b>United Kingdom</b>	✓	✓	✓		



### International Community Advisory Group



Review

Feedback

Support

Guide

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I believe that active community participation is essential for impactful research. It's crucial that research addresses the real needs of those most affected by health issues. Given the inherent power dynamics in society, it is vital for me, as a CAB member, to feel that my input is being genuinely considered, not just heard as a research subject. This approach is key to effectively understanding and addressing health inequities.

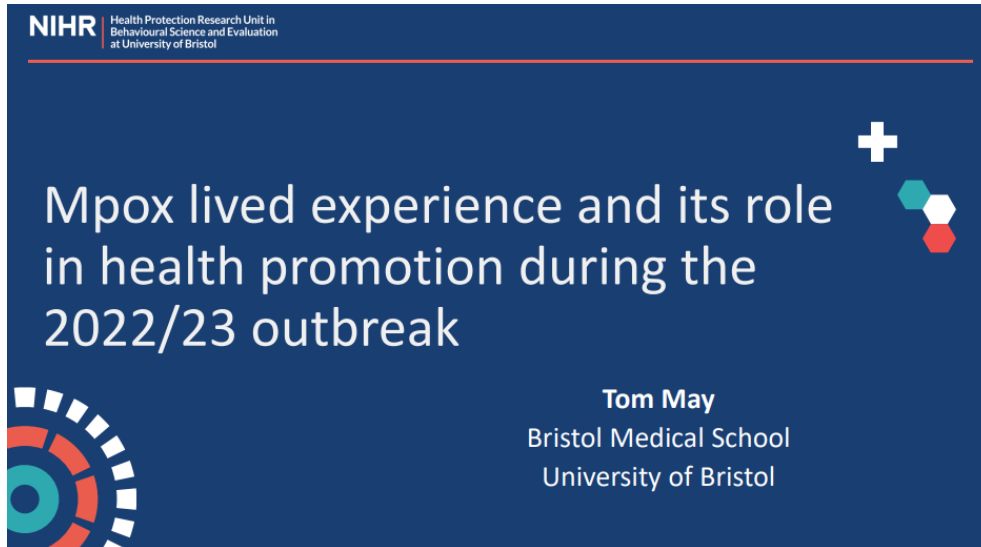
*Leonardo Pavam (Previous Chair, VERDI CAB)*



NIHR Health Protection Research Unit in Behavioural Science and Evaluation at University of Bristol

# Mpox lived experience and its role in health promotion during the 2022/23 outbreak

Tom May  
Bristol Medical School  
University of Bristol



SHARE RESEARCH FOR HEALTH EQUITY

## Harm reduction of mpox: evidence reviews and values & preferences study with affected populations

Dr Sara Paparini (QMUL)  
[S.Paparini@qmul.ac.uk](mailto:S.Paparini@qmul.ac.uk)

Queen Mary University of London World Health Organization the Love Tank FUELLING COMMUNITIES Since 2016




SHARE RESEARCH FOR HEALTH EQUITY

the love tank Sophia

### MPXV UK community survey: a co-produced survey on perceptions of public health and media messaging

Sara Paparini, Ryan Whitacre, Melanie Smuk, John Thornhill, Chikondi Mwendera, Sophie Strachan, Will Nutland, Chloe Orkin.  
26<sup>th</sup> October 2022

Queen Mary University of London NHS Barts Health NHS Trust BARTS CHARITY




INSTITUTE FOR GLOBAL HEALTH

UCL

## Experiences of mpox illness and case management among cis and trans gay, bisexual and other men who have sex with men in England

T Charles Witzel, Andrew Ghobrial, Romain Palich, Hannah Charles, Alison J Rodger, Caroline Sabin, Alex Sparrowhawk, Erica RM Pool, Mateo Prochazka, Roberto Vivancos, Katy Sinka, Kate Folkard, John Saunders, Fiona M Burns

UK Health Security Agency

NIHR National Institute for Health Research

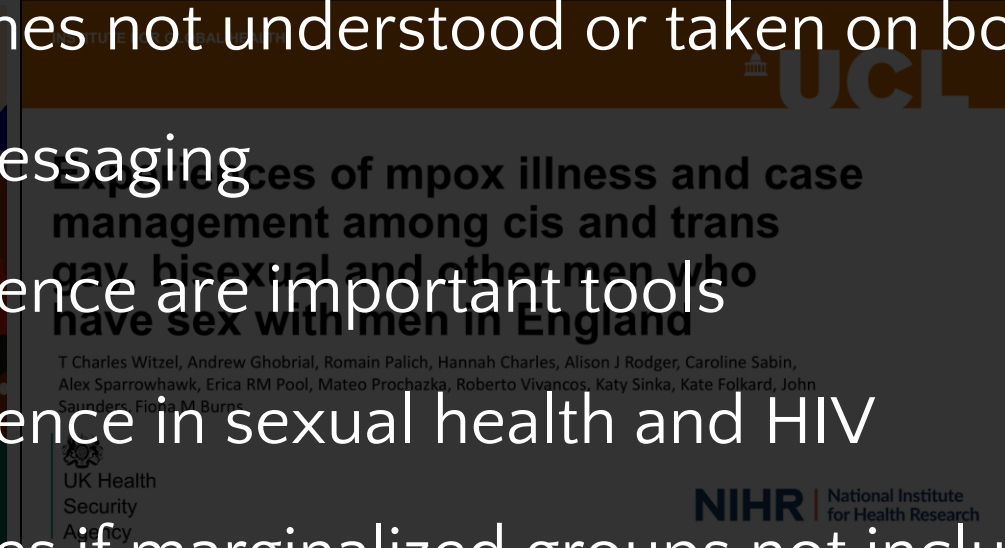
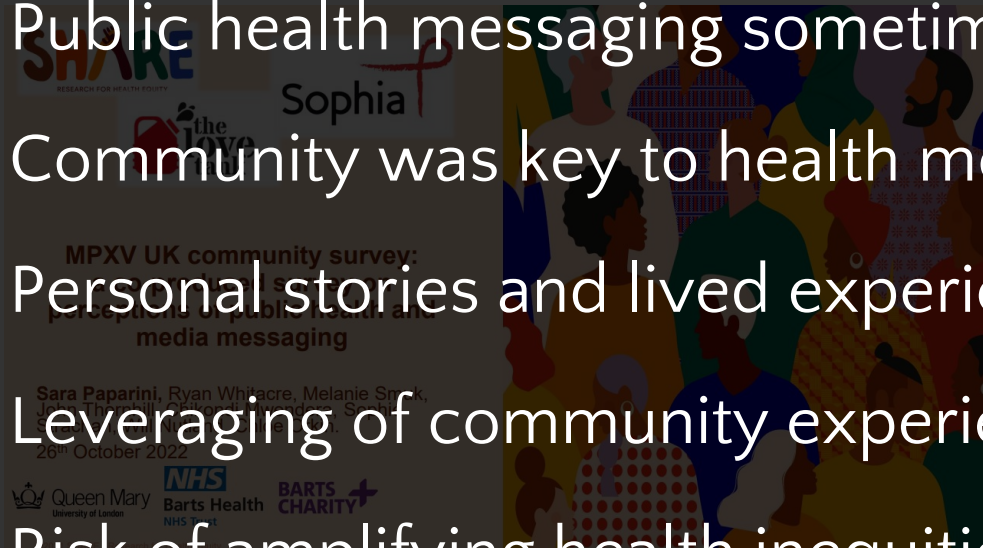
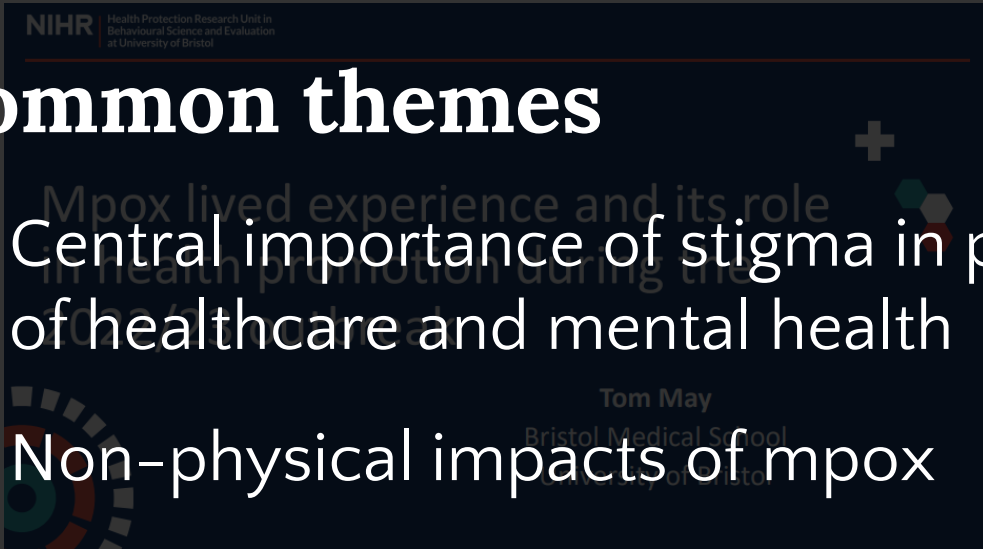


References:

- May T, Towler L, Smith LE, et al. *BMC Public Health*. 2023;23(1):2265.  
Witzel TC, Ghobrial A, Palich R, et al. *EClinicalMedicine*. 2024;70:102522.  
Paparini S, Whelan I, Mwendera C, et al. *Infect Dis (Lond)*. 2024;56(8):589-605.

# Common themes

- Central importance of stigma in prevention, accessing care, experience of healthcare and mental health
- Non-physical impacts of mpox
- Public health messaging sometimes not understood or taken on board
- Community was key to health messaging
- Personal stories and lived experience are important tools
- Leveraging of community experience in sexual health and HIV
- Risk of amplifying health inequities if marginalized groups not included



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Given the population approach to mpox in the EU is eradication, routine access to effective vaccines would be the main community need. This now has to be planned against the background of a single global manufacturer and the urgency of prioritising vaccines to central Africa. As cases will continue in high-income countries, healthcare needs to be person-centred and non-judgemental - with several surveys during 2022 reporting that healthcare didn't always have these qualities.

*Simon Collins (HIV i-Base, EATG and UK-CAB, VERDI CAB member)*

# Acknowledgements

- VERDI Qualitative Study Team: Nadia Sam Agudu, Davide Bilardi, Sarah Denford, Thomas Guadamuz, Tom May, Beth Mallory, Marthe Le Prevost, Anya Maclaren, Emily Nicholls, Chinye Osa-Afiana, Charlie Witzel
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- Chiara Longhi (EATG), Parminder Sekhon (NAZ) and Afrihealth Optonet
- Sara Paparini

