

Democratizing Data: Life Mapping as a Tool for Community-Led Insights in Malawi and South Africa

Gloriah Moses¹, Jelena Bozinovski¹, Krista Lauer¹

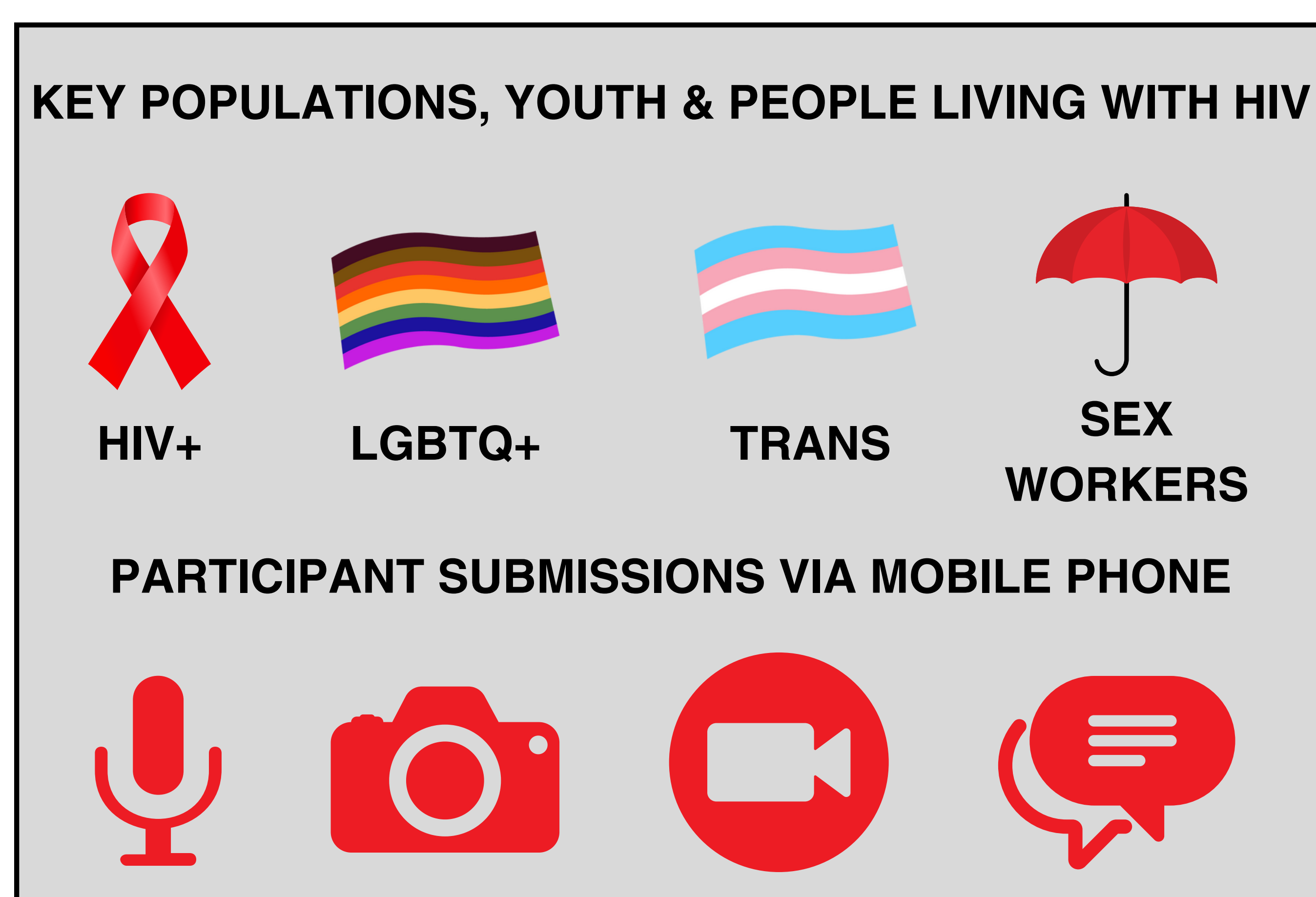
1. ITPC, Watch What Matters, Johannesburg, South Africa

Category: E9 Innovations in data collection, monitoring and evaluation

Countries of research: Malawi, South Africa,

BACKGROUND

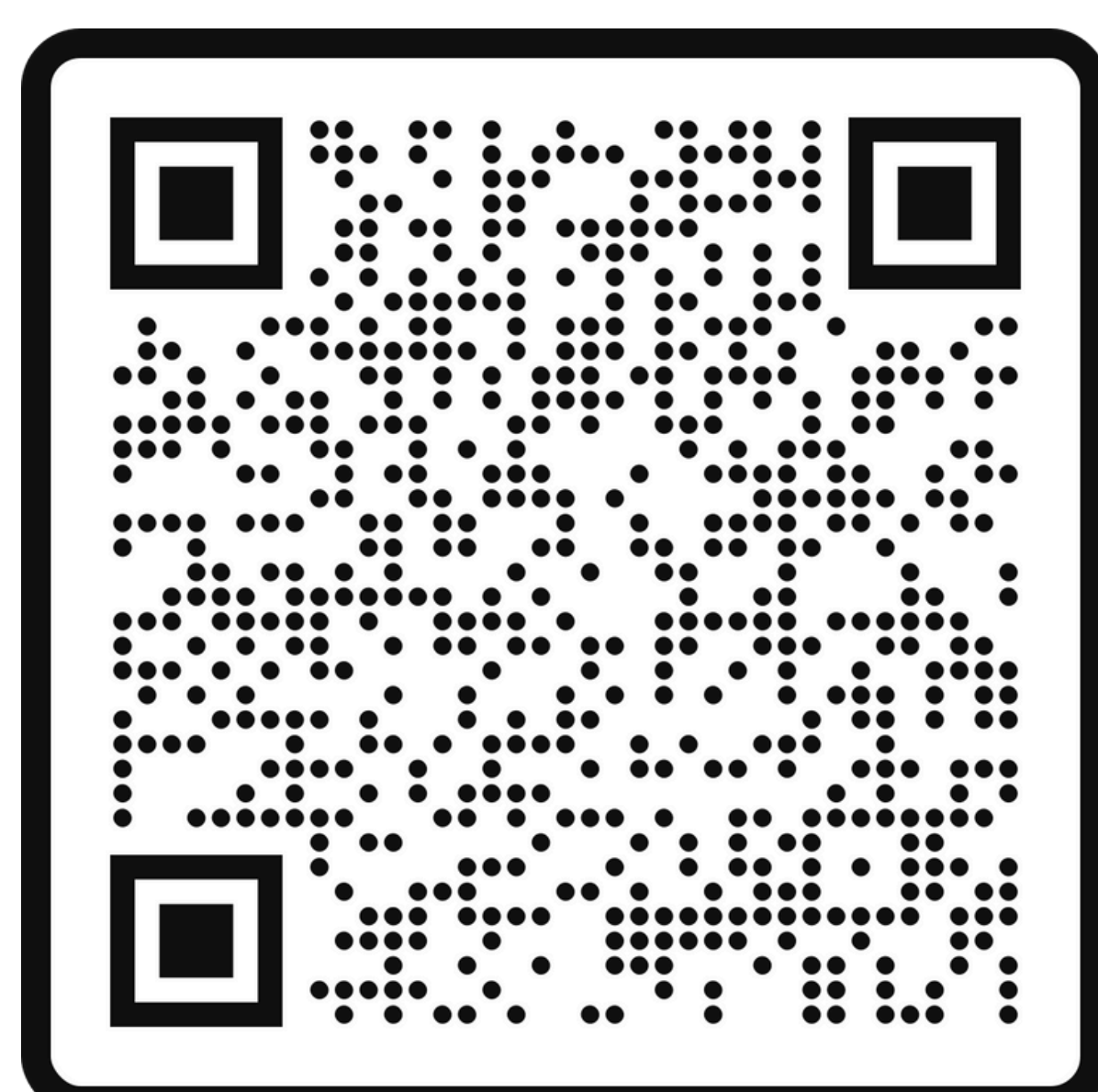
COVID-19 continues to have a profound impact on global health, particularly in low- and middle-income countries, where the need for equal access to healthcare has never been more critical. In response to this challenge, ITPC initiated the COVID-19 Citizen Science project, a community-led effort to document real-time perspectives, experiences, and advocacy priorities among people living with HIV. Citizen Science departs from traditional 'data-extraction' approaches and embraces 'data-democracy' by combining community-led monitoring, operational research, and a unique methodology known as Life Mapping.



DESCRIPTION

The Life maps (LM) initiative provided participants with mobile phones, data and training, enabling them to document their experiences and share perspectives before, during and after the COVID-19 pandemic, including access to HIV and TB testing, prevention, and treatment services. LM participants were given super-heroes name, this ensures confidentiality. The LM participants document their day to day life experiences through photos and journaling. They drawn from different typologies including Sex Workers, young people, transgender communities among others.

In addition to the day too day documentation, the participants receive themes that they give information and data on. Some of the themes include stigma and discrimination, disclosure, water and sanitation, adherence to treatment among others. To document and share the work done widely, an exhibition space was created that displays the work done:



SCAN THE QR CODE TO VIEW THE LIFE MAP GALLERY

LESSONS LEARNED

Through the monthly themes data collected and the day-to-day documentation, the LM participants shared data and information that was key in policy advocacy and creation of home-solutions including having Sex Workers peers at health facilities. Interactions with other participants allowed them to share experiences and learn from each other. During the launch of the exhibition space, one of the LM participants highlighted ***"This project gave me a safe space to share my experiences with peers who supported me by listening and sharing their own lived experiences. It helped me address mental health challenges and alcohol abuse."***

CONCLUSION

The Life Maps initiative has demonstrated the power of community-led approaches in generating actionable data, fostering resilience, and driving advocacy. Scaling up Life Mapping and similar participatory methodologies will further strengthen community ownership, data-driven decision-making, and advocacy for equitable healthcare access.



SAMPLE OF PHOTOS SUBMITTED BY LIFE MAPS PARTICIPANTS.

1. COVID-19 drives food insecurity, South Africa
2. Limited access to clean water exacerbates impact of COVID-19, Malawi
3. Access to HIV prevention services during COVID-19 pandemic, Malawi
4. Drug stockouts during COVID-19 pandemic, South Africa