

# **Sustaining meaningful community involvement and influence in research: Lessons on system level barriers and enablers from a 10-year community/research partnership**

## **Authors:**

GRAHAM BROWN<sup>1</sup>, JANE COSTELLO<sup>2</sup>, PETRINA HILTON<sup>1</sup>, RICHARD KEEN<sup>3</sup>, JOHN RULE<sup>4</sup>, MELISSA WARNER<sup>5</sup>

<sup>1</sup>Australian Research Centre in Sex, Health and Society, Melbourne, Australia,

<sup>2</sup>Positive Life New South Wales, Sydney, Australia, <sup>3</sup>Living Positive Victoria, Melbourne, Australia, <sup>4</sup>National Association of People With HIV Australia, Sydney, Australia, <sup>5</sup>Queensland Positive People Brisbane, Australia

## **Background/Purpose:**

The meaningful involvement of communities is a central principle of the Australian HIV and Hepatitis C responses, and this includes within research. However, community involvement in research is often conceptualised as participation rather than an influential collaboration in the priority setting, design, and conduct of research, and maintaining relationships over the long term.

Beginning in 2014, the W3 Project collaborated with peer and community-led organisations to explore the system-level role these organisations play in the HIV and hepatitis C response. The study required peer staff and researchers to undertake the simultaneous role of drivers, participants, and analysts in the research.

## **Approach:**

To identify the successes, challenges and learnings in relation to sustaining long-term and meaningful participation of PLHIV peer organisations in research, we drew together the insights and experiences from across the 10 years of the study.

## **Outcomes/Impact:**

The W3 Project experienced both successes and significant challenges in maintaining the research collaboration as we navigated the introduction of systems thinking, the competing pressures on peer organisations and their communities, research funding challenges, and the ongoing impact of epidemics (HIV, hepatitis C and COVID-19).

The W3 Project provided insights into the nuances of community-engaged research practice and the ongoing benefits, barriers, and enablers to the meaningful participation of communities and their peer organizations. This required looking beyond research methods to system level factors such as flexibility in research resources and management; sustained two-way trust, benefits and commitment; and the visible valuing of peer participation and leadership by research to counter system-level stigma.

## **Innovation and Significance:**

Recognizing peer organizations as active participants and drivers within community and policy systems can help clarify their role in research. Achieving meaningful collaboration with peer organisations requires looking beyond good practice methods

to the system-level factors with attention to the system-level benefits, barriers, and enablers.

**Disclosure of Interest Statement**

*The W3 Project was funded by Australian Government Department of Health. No pharmaceutical grants were received in the development of this study.*