

LEFT ALONE TO FIGURE IT OUT: WHAT PEOPLE LIVING WITH HIV TELL US ABOUT AOD, DIAGNOSIS AND SYSTEM GAPS.

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Background/Purpose

People living with HIV (PLHIV) continue to achieve strong clinic outcomes, yet many describe being left to navigate alcohol and other drugs (AOD) use, emotional distress, and risk alone, particularly at diagnosis. Current prevention approaches remain individualised and disconnected from lived experience. The PALS (Positive AOD Life Support) project set out to redefine the prevention problem by centring peer knowledge and community voice.

Approach

Peer-led co-design workshops (7 in total) were delivered across Queensland, including migrant and trans and gender diverse communities. Data sources included written artefacts, recorded discussions, facilitator debriefs, and pre/post surveys. A structured thematic analysis using a codebook approach was applied to identify key challenges and strategies, with cross-site triangulation to ensure consistency and depth.

Outcomes/Impact

Eight themes were identified. HIV diagnosis emerged as a critical turning point, often experienced as overwhelming, clinical, and lacking AOD-related guidance. PLHIV navigating diagnosis alone were unaware of the risks of using AOD to mediate experiences of self-stigma and social anxiety and missed opportunities to access support often led to problematic AOD use and disengagement with HIV care. Systemic barriers included limited health professional capacity, fragmented services, and regional inequities. Isolation and lack of peer-led support further reduced engagement. In response, participants identified peer support and community connection, non-stigmatising AOD information, and self-care as key strategies, emphasising relational safety and lived experience as central to AOD harm reduction.

Innovation and Significance

This work reframes AOD harm minimisation as a structural and relational issue rather than individual behaviour. By embedding peer leadership and co-design, PALS generates actionable, HIV-specific insights that directly inform integrated, person-centred prevention and harm minimisation strategies aligned with current HIV priorities.

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