

OUR STORIES IN SAFE HANDS? ETHICS AND ACCESS IN HIV MEMORY WORK

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Background/Purpose:

Remembrance and memory have long been central to Australia's response to HIV. Over four decades, a substantial body of historical material has documented the efforts of communities, health-care workers, organisations, researchers, and governments to end HIV-related deaths. These materials are now held across a diverse and fragmented network of memory institutions—including government, university, private, and community-run collections. This review examines their accessibility, custodianship, and ethical stewardship, guided by a critical question: how accessible are the material histories of people with HIV in Australia to those living with HIV today?

Through a desk-based assessment, the project examined collections with a focus on discoverability, access conditions, and custodial transparency. Findings reveal a complex and often opaque landscape, shaped by overlapping institutional, legal, and practical barriers that frequently limit community access.

The review identifies two intersecting sets of barriers: those characteristic of memory institutions more broadly, and those shaped by the specificities of the HIV sector. General challenges include reliance on academic affiliation for access, opaque or inconsistent request processes, and the restriction of materials to on-site-only access. Sector-specific issues include the dissolution of community organisations that once mediated access, enduring concerns around privacy and reidentification, and the evolving medical, social, and cultural landscape of HIV in Australia. These intersecting dynamics complicate decisions around stewardship and access, often resulting in risk-averse approaches that prioritise institutional protection over meaningful community engagement.

These barriers often reproduce historical exclusions—positioning people with HIV as subjects of research rather than as rightful custodians of their own narratives. While the challenge of removing or lessening these barriers has no simple solution, this review aims to prompt renewed dialogue about equity, responsibility, and access in HIV histories. Without intervention, there is a growing risk that the histories of people with HIV—carefully preserved over decades—will remain out of reach to the very communities they were created to serve.

Approach:

Outcomes/Impact:

Innovation and Significance:

Disclosure of Interest Statement:

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