Title: Protecting Privacy and Equity: Community Advocacy for PLHIV and Marginalised Groups in NSW’s Single Digital Patient Record (SDPR)

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Background/Purpose:

The NSW Single Digital Patient Record (SDPR) aims to consolidate patient information across NSW Health facilities, yet its implementation risks exacerbating healthcare disparities for marginalised communities disproportionately affected by blood-borne viruses and stigma—including LGBTQ+ people, people living with HIV, people who inject drugs, and sex workers. Historical experiences of discrimination and breaches of confidentiality heighten concerns about digital health systems. This abstract describes a novel, community-led advocacy initiative to ensure the SDPR prioritises equity, privacy, and inclusivity.

Approach:

A coalition of peer-led, community-based organisations formed the *SDPR Advocacy Action Group* to coordinate engagement efforts. Consultations with affected communities and community service providers identified key concerns:

- HIV status visibility and risks of unauthorised disclosure,
- inadequate gender and sex markers,
- lack of safeguards for sensitive data,
- absence of community information and consultation design with marginalised communities, and
- risk of increasing stigma and discrimination.

The group’s advocacy focused on transparency around governance and oversight of the SDPR, the formal inclusion of consumer perspectives, and the integration of safeguards to ensure system-wide accountability.

Engagement strategies included direct engagement with the NSW Ministry of Health, community education, and alliance-building with health system partners.

Outcomes/Impact:

The Action Group secured formal recognition from NSW Health, including invitations to participate in SDPR design and implementation. Key achievements include:

- establishment of structured communication channels between marginalised communities and health authorities,
- recognition by NSW Health of the need to address privacy, gender inclusivity, and stigma reduction in the SDPR, and
- integration of community feedback into governance frameworks.

This initiative demonstrates the critical role of grassroots advocacy in shaping equitable digital health systems. Its success offers a model for centring marginalised voices in large-scale health innovations, ensuring they meet the needs of those most impacted by systemic inequities.