PROTECTING PRIVACY AND EQUITY: COMMUNITY ADVOCACY FOR PLHIV AND MARGINALISED GROUPS IN NSW'S SINGLE DIGITAL PATIENT RECORD (SDPR)

A Coalition-Led Response from PLHIV, LGBTQ+, Sex Worker, PWID and Health Consumer Groups

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WHO ARE WE?

Community-based organisations have long led advocacy within the NSW Health system for people living with HIV (PLHIV), LGBTQ+ communities, people who inject drugs (PWID), sex workers, and others affected by HIV, hepatitis C and other BBVs.

We are a coalition of peer-led, community-based organisations advocating to ensure the implementation of the NSW Single Digital Patient Record (SDPR) protects and promotes the rights of our communities.

Our coalition includes:

acon	Positive Life NSW The voice of all people living with HIV
swop SEX WORKERS OUTREACH PROJECT	Hepatitis NSW
NUAA NSW USERS AND AIDS ASSOCIATION	Bobby Goldsmith Foundation
Being Mental Health Consumers	HEALTH CONSUMERS NSW

WHY THIS MATTERS

The rollout of the SDPR across NSW public hospitals and community health services raises significant concerns about privacy, data security, and the potential for increased stigma and discrimination toward marginalised communities.

These concerns are not hypothetical. Stigma in healthcare has long undermined access and equity:

- PLHIV experience breaches of confidentiality and judgement
- LGBTQ+ people are subject to misgendering and inappropriate care
- People who use drugs face criminalisation, deterring engagement in care
- Sex workers encounter moralistic attitudes and substandard treatment

Such experiences erode trust in the health system and deepen health disparities.

National and state strategies in HIV, hepatitis C, and LGBTQ+ health recognise the impact of stigma and discrimination, and the importance of addressing it. We believe the SDPR should be part of the solution, not another barrier.

CONTACT

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WHAT IS THE SDPR?

The Single Digital Patient Record is a transformational NSW Health program aiming to provide an integrated, statewide view of patient care by replacing multiple legacy systems. It will:

- Introduce a unified Electronic Medical Record (eMR), Patient Administration System (PAS), and Laboratory Information Management System (LIMS)
- Be rolled out across 228 public hospitals, 600+ community health centres, and 200+ pathology sites
- Be led by the SDPR Implementation Authority in collaboration with LHDs, specialty health networks, eHealth NSW and NSW Health Pathology

OUR ADVOCACY APPROACH

The coalition took early and proactive steps to ensure community voices are heard:

- Convened forums (online and in-person) to raise awareness and gather feedback
- Engaged directly with the SDPR Implementation Authority to raise concerns
- Created and distributed accessible information (factsheets, social content) for our communities
- Called for system changes that centre community safety, privacy, and choice

Our advocacy priorities include:

- Meaningful community engagement in SDPR design and governance
- Strong privacy protections and data transparency
- Consumer control over visibility and sharing of sensitive information
- Respect for chosen names, gender identities, and anonymity where needed
- Limiting irrelevant or potentially harmful data collection
- Clear limits on sharing information with external agencies, including law enforcement and researchers

OUTCOMES & NEXT STEPS

Our advocacy has led to key moments of influence:

- Formal recognition by NSW Health and inclusion in SDPR design and governance
- Established communication pathways between community organisations and the SDPR Implementation Authority
- NSW Health commitment to addressing privacy, gender diversity, and stigma concerns
- Community perspectives integrated into early SDPR frameworks

This initiative highlights the power of community-led advocacy to influence digital health equity. It offers a model for centring lived experience in major health system transformations.