

# Community-led initiatives to enhance prevention and treatment for hepatitis C

**Hepatitis C prevention and treatment among people who inject drugs: Global progress and future requirements**

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# What are community—led initiatives?

Actions and strategies that aim to improve the health and human rights of people who use drugs, specifically informed and implemented by and for people who use drugs

Respond and determined by the needs, aspirations and priorities of people who use drugs

Include advocacy, campaigning, monitoring and evaluation of policies, and practices, direct service delivery, capacity building and funding

Committed to action, regardless of resource availability. Initiatives are based on our survival skills, forged through our fight against injustice and inequity

# Global Commitments on Community Leadership

- The important role of the community in the global HIV response has been recognised at high-level political meetings since 1994.
- The 2016 Political Declaration on HIV/AIDS included a 30% funding target for community-led initiatives. This was expanded on in the 2021 Political Declaration on HIV and AIDS, with the following:
  - 30% testing and treatment services to be delivered by community-led organisations
  - 80% of service delivery for HIV prevention for key populations to be delivered by community-led organisations
  - 60% of programmes to achieve the societal enablers, including removal of punitive laws and policies to be delivered by community-led organisations
- Funding for key population-led programmes is abysmally low at 2% of total HIV funding, with imprecise tracking of allocations for community-led responses and organisations. Rough estimate is that 7% of this goes towards community-led organisations and responses.



# Community-led Initiatives

**Peer outreach programmes (needles and syringes, education and information, referral and accompaniment, counselling)**

Peer outreach programmes provide benefits beyond the biomedical. They build trust in, and bridges to health and social services.

*“If it was provided by a peer, I would be more willing to listen” – a testimony from a woman who use drugs in Africa*



# Community-led Initiatives

## Advocacy (Influencing and Campaigning)

- People who use drugs were involved in the 2021 revision of WHO Consolidated Guidelines for Key Populations as well as WHO Guidelines on Hepatitis C. Expanded access to HCV testing and treatment became formal recommendations. Overall there is a greater focus on the role of the societal enablers (laws and policies, stigma and discrimination, community leadership) in health
- *It's Your Right Campaign – Live Free of Hep C* was co-led by AIVL. This campaign aimed to increase health literacy related to first injecting experience, and the crucial role of peers to achieve positive health outcomes.

**LIVE FREE  
OF HEP C**

GO TO [ITSYOURRIGHT.COM.AU](https://itsyourright.com.au)



# Community-led Initiatives

## Hepatitis C testing and treatment

In Indonesia community set up a buyer's club for HCV treatment in the face of government inaction. Strategies moved to direct access via a series of protests and advocacy directed the Food and Drug Administration and Ministry of Health, demanding access to Hepatitis C testing and treatment.

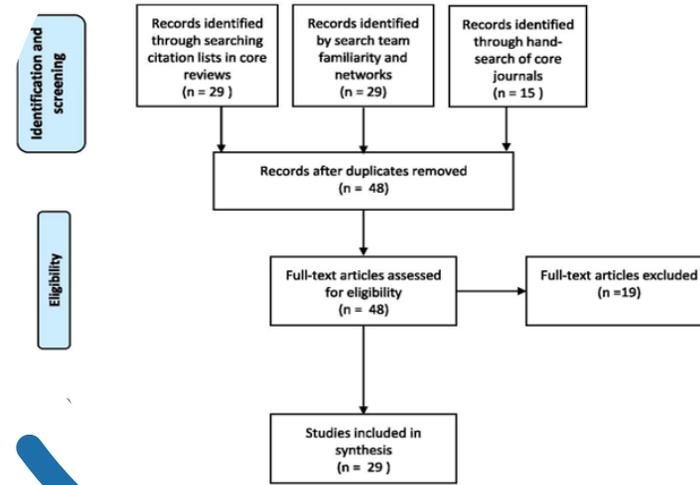
As a result, Sofosbuvir and Daclastavir were registered



# Working peers: why it works!

- A rapid review conducted by INPUD *Peer driven or driven peers? A rapid review of peer involvement of people who use drugs in HIV and harm reduction services in low- and middle-income countries* (2020) highlighted the impact of peer involvement on harm reduction service access and quality.
- INPUD published *Surviving and Thriving: Lessons in Successful Advocacy from Drug-User Led Networks* highlighting case studies from South Africa, Eastern Europe and Central Asia, United States and India on drug user-led advocacy

...driven or driven peers? A rapid review of peer involvement of people who use drugs in HIV and harm reduction services in low- and middle-income countries



# Results of Rapid Review

**Roles (I):** Harm reduction education, direct services, and peer support, counselling and referrals



**Context (C):** criminalisation, including fear of arrest and detention, clinic and service delivery environments, inequitable pay structures, stigma and discrimination



**Mechanisms (M):** Trust and empathy, community knowledge and experience, 'bridging' role and 'role model' mechanism



**Outcomes (O):** reduction in HIV incidence and prevalence, increase in safer injecting practices, increased access to, acceptability and quality of HIV and health prevention care and treatment services, lessening of stigma and discrimination

# Discussion

- Peer roles are often marginal and instrumentalised
- 'Peer driven' services often become that of 'driven peers', where roles commonly reflect how peers respond to priorities and goals set only by others
- Challenges include disparate payment structures and working conditions, and limited or lack of support, all of which act to generate tensions, undermine peer empowerment, and negatively impact on the retention of peers and the delivery of services

# Recommendations

- Despite the evidence and growing recognition on the critical role of community leadership, funding remains scarce
- For interventions to be effective, community must be involved in the design, implementation, monitoring and leadership
- Strategies to support peer involvement:
  - address criminalisation and stigma
  - enable networks of people who use drugs
  - champion relationship-building with policy makers and researchers
  - foster organisational cultures and resources that respectfully utilise peer knowledge and skills
  - Researchers, policymakers, and people who use drugs must seek new ways of engagement that shift power, make space for new forms of knowledge-making and praxis

# Conclusion

*Operationalisation of global commitments on community leadership requires first and foremost, the expansion and diversification of roles for people who use drugs within policy, programmes and research processes.*

*Peers need to be acknowledged not only as representatives of the communities they are part of, but as peers of the policymakers, researchers, clinicians and professional staff they work alongside and advise daily*