Community Matters

Lessons from a Bridging the Gaps research programme

Community involvement and the quality and accessibility of harm reduction services for people who use drugs in low and middle-income countries

Photo cover: Vonecia Carswell

AFEW Kyrgyzstan, Rumah Cemara, University of Pretoria, SANPUD,
International Network of People who Use Drugs, Mainline,
AFEW International & King's College London

Community Matters

From 2018 to 2020 we implemented research to explore how community involvement impacts on the quality and accessibly of harm reduction services for people who use drugs. Three studies across Indonesia, Kyrgyzstan and South Africa were linked to a literature review. Based on our programme of research we have four core messages:

1 More ambitious support is needed for expanded community involvement in harm reduction services

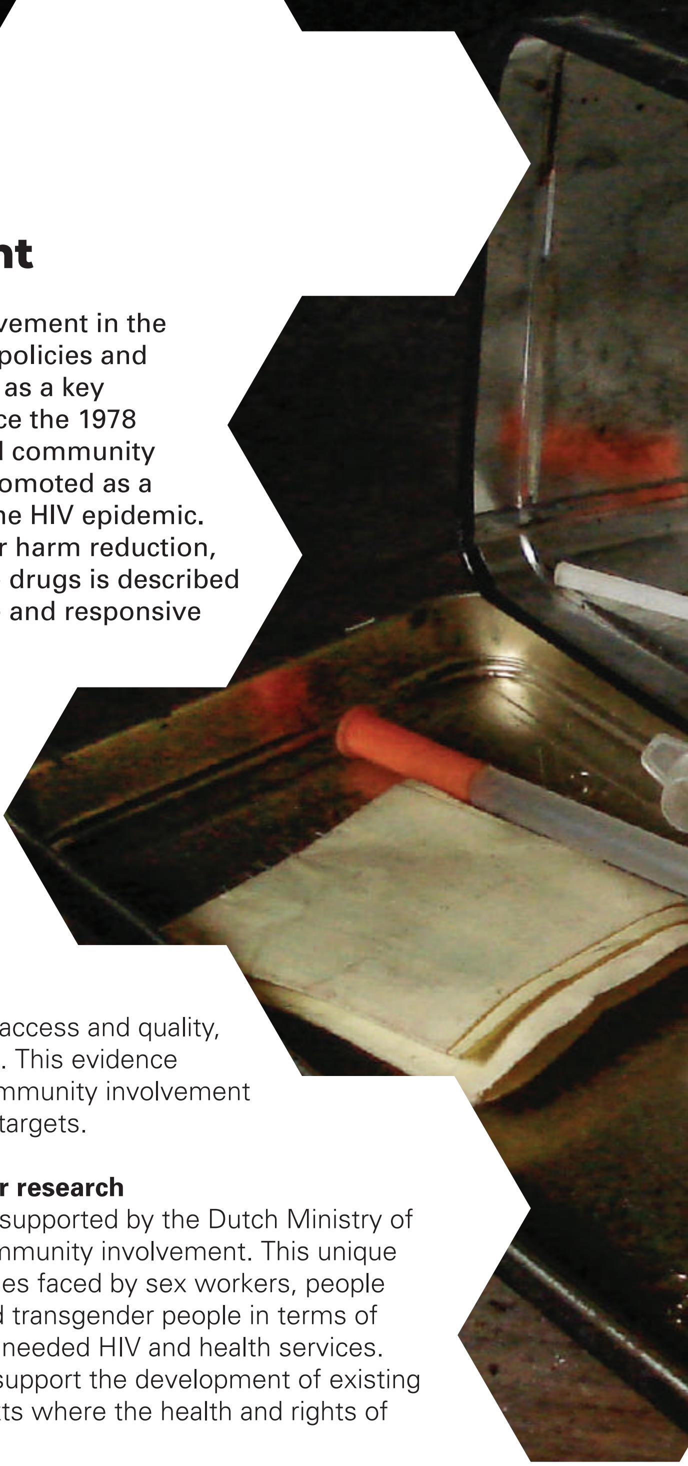
2 Community involvement can support increased access and quality of harm reduction services

3 Community leadership delivers research with impact

4 Research agendas need to expand and methodologies need to adapt

Community involvement

The importance of community involvement in the design and development of health policies and programming has been formalised as a key principle within health policy agendas since the 1978 Alma Ata Declaration. A human rights and community empowerment approach has also been promoted as a key enabler for a successful response to the HIV epidemic. Such principles are also the foundation for harm reduction, where the involvement of people who use drugs is described as central to ensuring accessible, effective and responsive harm reduction services.



Evidence for action?

Despite the often-stated benefits of community involvement for harm reduction, clear and comprehensive evidence for how different forms of community involvement have impact is limited.

There is a need for more understanding of exactly how different forms of community involvement have impact on harm reduction access and quality, especially in low and middle income settings. This evidence base is needed to guide the scaling-up of community involvement efforts globally in support of harm reduction targets.

Bridging the gaps: a global partnership for research

The Bridging the Gaps II (BTGII) programme supported by the Dutch Ministry of Foreign Affairs aims to support action on community involvement. This unique programme addresses the common challenges faced by sex workers, people who use drugs and lesbian, gay, bisexual and transgender people in terms of human rights violations and accessing much needed HIV and health services. BTGII seeks to address twin priorities: 1) to support the development of existing community involvement processes in contexts where the health and rights of people who use drugs are threatened, and 2) foster a global evidence base for community involvement in contexts of harm reduction.

Photo: Matthew T. Rader

With support from Bridging the Gaps II, we - AFEW Kyrgyzstan, Rumah Cemara and University of Pretoria with the South African Network of People who Use Drugs, along with the International Network of People who use Drugs (INPUD), Mainline, AFEW International and King's College London - implemented a programme of community led research to address this gap. We developed country level studies of particular forms of community involvement in Kyrgyzstan, Indonesia and South Africa. These studies were linked to a 'rapid review' of the literature on low and middle-income countries.


Photo: Hobi Industri

Background

Indonesia's current drug laws were enacted in 2009 and contain severe sanctions, including the death penalty, against the use and supply of controlled drugs. Nevertheless, the law does seek to promote a more effective response to HIV and public health, with significant measures introduced to steer people who use drugs away from the criminal justice system and into medical and social drugs rehabilitation. There are however continuing reports of police mistreatment and abuse of people who use drugs.

Ensuring adequate and sustainable access to Needle and Syringe Programme (NSP), Opioid Substitution Therapy (OST) and Anti-retroviral Treatment for HIV (ART) requires a reduction of the stigma and discrimination attached to drug use. The dropout rate for ART or cases lost to follow-up reaches 22%. Although national ART-related estimates specifically for PWID are not available, sub-national data suggests that access varies widely among cities. In Jakarta it is estimated that only 61% of people who inject drugs living with HIV are accessing ART services, whereas in Bandung the second largest city after Jakarta, only 27% of PWID living with HIV access ART services.

Indonesia research: peer-led case management and ART access

Community involvement: peer-led case management

Peers leading case management strategies is a priority intervention in Indonesia within harm reduction and HIV referral services, including within government-run community health centers. Rumah Cemara initiated a three-year Community-led Mobile Harm Reduction Management programme aimed at improving access to health, social and legal services for people who inject drugs and their partners/spouses in 4 priority cities.

As part of this package of services a peer case management programme to support ART retention of people who inject drugs living with HIV was initiated. Peers are integrated within harm reduction and HIV referral services, including within government-run community health centres. There has not been an in-depth qualitative study of how community engagement impacts on accessibility and quality of ART services at the site level. A core question for this research was: How does peer engagement within ART case management influence access, adherence, and quality of HIV care services offered by ART service providers?

Methods

Qualitative data was collected through semi-structured in-depth interviews with male and female people who inject drugs who are beneficiaries of the HIV care services, peer case managers, and service providers from Bandung and Jakarta.

Findings

In the two cities the research team interviewed 8 PWID as beneficiaries, 6 peer case managers, and 6 service provider representatives from health services or Harm Reduction institutions. Data analysis has identified the following key themes:

Link to HIV services: Clients, peer case managers and service providers were clear and consistent about the positive impact of peer engagement on accessibility and quality of HIV services. Peer support was a decisive link to HIV services, including ART enrolment and retention. Many clients reported that peers were also their first reliable source of information on HIV and AIDS.

Navigating complex bureaucracy: Clients described the value of peer support in helping navigate complex bureaucratic procedures associated with accessing ART. Clients often mentioned that peer case managers motivated them to seek health care support and helped them access the treatment and care they needed faster, including by simplifying administrative requirements, providing information in accessible language, and physically accompanying clients to appointments.

Confidence and trust: As a result of receiving peer support, many clients became more confident in accessing health care and expressed improved trust of health care providers.

Health and social care integration: Clients often reported that peer case management, while in theory intended to support newly-diagnosed individuals to access and stay on ART, in practice assisted clients with a much wider range of ancillary services, including referrals to psycho-social support and counselling, opioid substitution therapy, access to health and harm reduction post-release from prison, and paralegal services. Clients often mentioned that peer case managers motivated them to seek health care support and helped them access the treatment and care they needed faster, including by simplifying administrative requirements, providing information in accessible language, and physically accompanying clients to appointments.

Adherence: Respondents from all interviewee categories (i.e. peers as clients, peer case managers, and service providers) felt that the peer case management programme had a significant and positive impact on clients' ART adherence. The majority of clients reported that peer case managers played a key role in how they engaged with their ARVs by regularly reminding clients to take their medication and providing ongoing encouragement and motivation when challenges arose.

Declining quality of care with reduced funding: Due to decreasing funding for HIV prevention and care among PWID, as well as over-reliance on external donors pushing for management targets (vs. outcomes), the peer case management component has been significantly reduced in recent years. Peers, peer case managers, and service providers suggested that this change had tangible negative effects on the quality of services. Unrealistic targets that require peer case managers to assist a minimum number of clients per week or month have led to reductions in the quality of care that clients receive, including in terms of counselling and psychosocial support.

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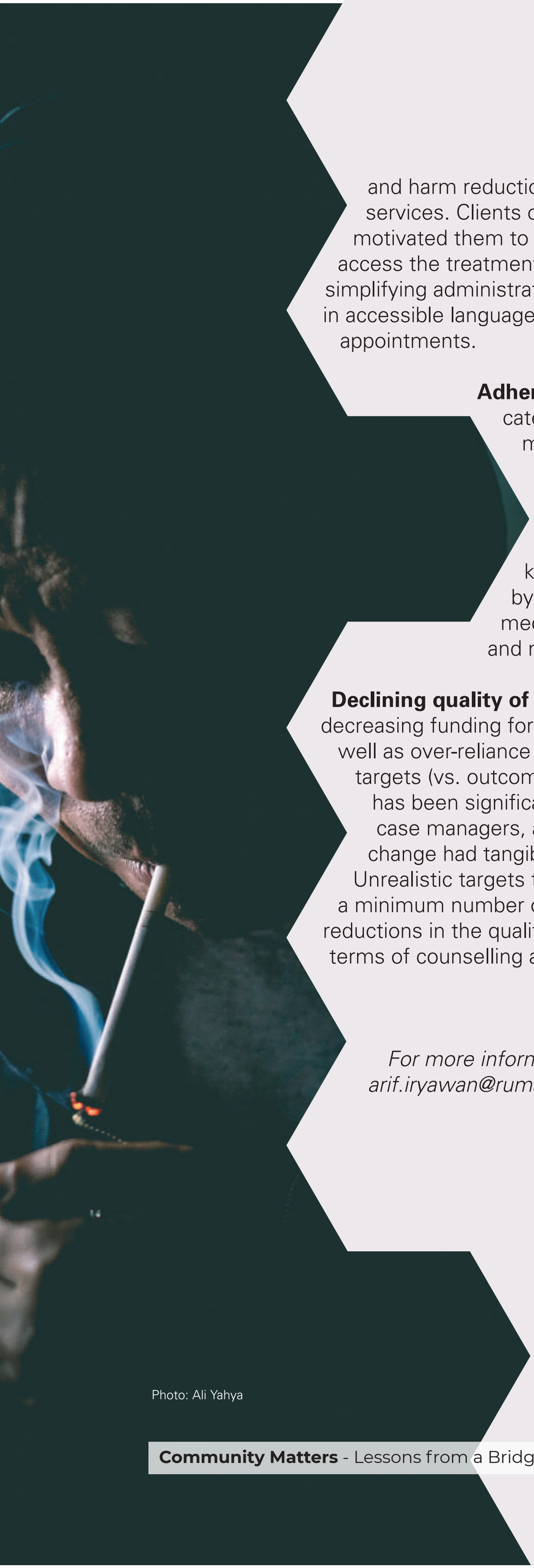

Photo: Ali Yahya

Kyrgyzstan: the experiences of women who use drugs in accessing services, and in advocating for service access and quality

Background

People who use drugs are highly vulnerable to HIV and other harms in Kyrgyzstan; whilst there is limited data, women who use drugs are particularly vulnerable. Community efforts, led by women who use drugs, have been central to advocacy and support to service access. There is limited understanding of the health and social support needs and experiences of women who use drugs in Kyrgyzstan, and of the role of community mobilization in addressing these support needs. We implemented a participatory research project to explore this gap in knowledge, building a partnership between AFEW Kyrgyzstan, Asteria and harm reduction network associations (organisations led by people who use drugs).

Community involvement: women-run drop in centres for women who use drugs

There are two centres based at the facilities of NGOs called Asteria and Podruga that are led by women and target the specific needs of women who use drugs. Within the social centers there are a wide range of services focused around a 'case management' strategy: HIV testing, needle and syringe exchange, sexual and reproductive health services, information and education, psycho social support, referral and support in legal issues and also to medical and non-medical public services. Peers provide a range of services, as well as working alongside other providers.

Alongside this service delivery role women who use drugs are actively involved in advocacy to shape the availability of harm reduction services. A particular focus for advocacy is the Global Fund Country Coordinating Mechanism (CCM). Women are also represented on Public Supervisory Boards linked to government ministries and departments.

The country team explored research-questions of how do women leaders become involved in the development and implementation of HIV policies and programs? And how does their participation affect the quality and accessibility of services in the Kyrgyz Republic? How do clients of social centers influence the improvement of the quality of services? These questions will be supported by exploring linked questions of what are women who use drugs current needs? How do current legislation and services address these?

Methods

We implemented a rapid participatory assessment in 2 cities in Kyrgyzstan, Bishkek and Osh. A quantitative survey of 100 women clients linked to existing harm reduction programs sought to understand health and social care access and needs. Qualitative interviews with 6 women leaders from the drug-user community explored the survey findings and also sought to understand the role of women who use drugs in supporting care access.

Findings

High unmet need for health and social services: The survey showed that the priority needs for women who use drugs in Bishkek and Osh are securing or renewing official documentation (46%), employment (46%), gynecological examinations and ultrasound diagnostics (30%), and accommodation (28.4%). Challenges that prevent the use of these services are the lack of a stable income (80%), the lack of identification documentation (35%), availability of childcare and schools (15%), and violence (52%). Donor-funded women's centers are currently central to providing access to services (85%). Qualitative interviews with women leaders reported that stigma and discrimination is a continuing challenge to service access, particularly from health care staff, law enforcement and family members. Limited funding for services undermines services and also the potential for partnerships and collaborations between organizations seeking to provide services.

Centres for and by women: Qualitative interviews clearly demonstrate that these community-based facilities specifically targeted at women who use drugs are the only venues where women can receive quality services free of stigma and discrimination. Reductions in funding for community-led initiatives affect the availability of services for women who use drugs.

Women's leadership: Women's leadership has been central to the gains made in service access. However, while the official position of Kyrgyz authorities is to be supportive of harm reduction, it remains challenging for women to be involved in policy and programme debates. It is necessary to maintain and develop the potential of women leaders, of whom there are very few in the country. There is strong potential among women's leaders, and a more sustainable system for the involvement of women who use drugs in national harm reduction programs should be developed.

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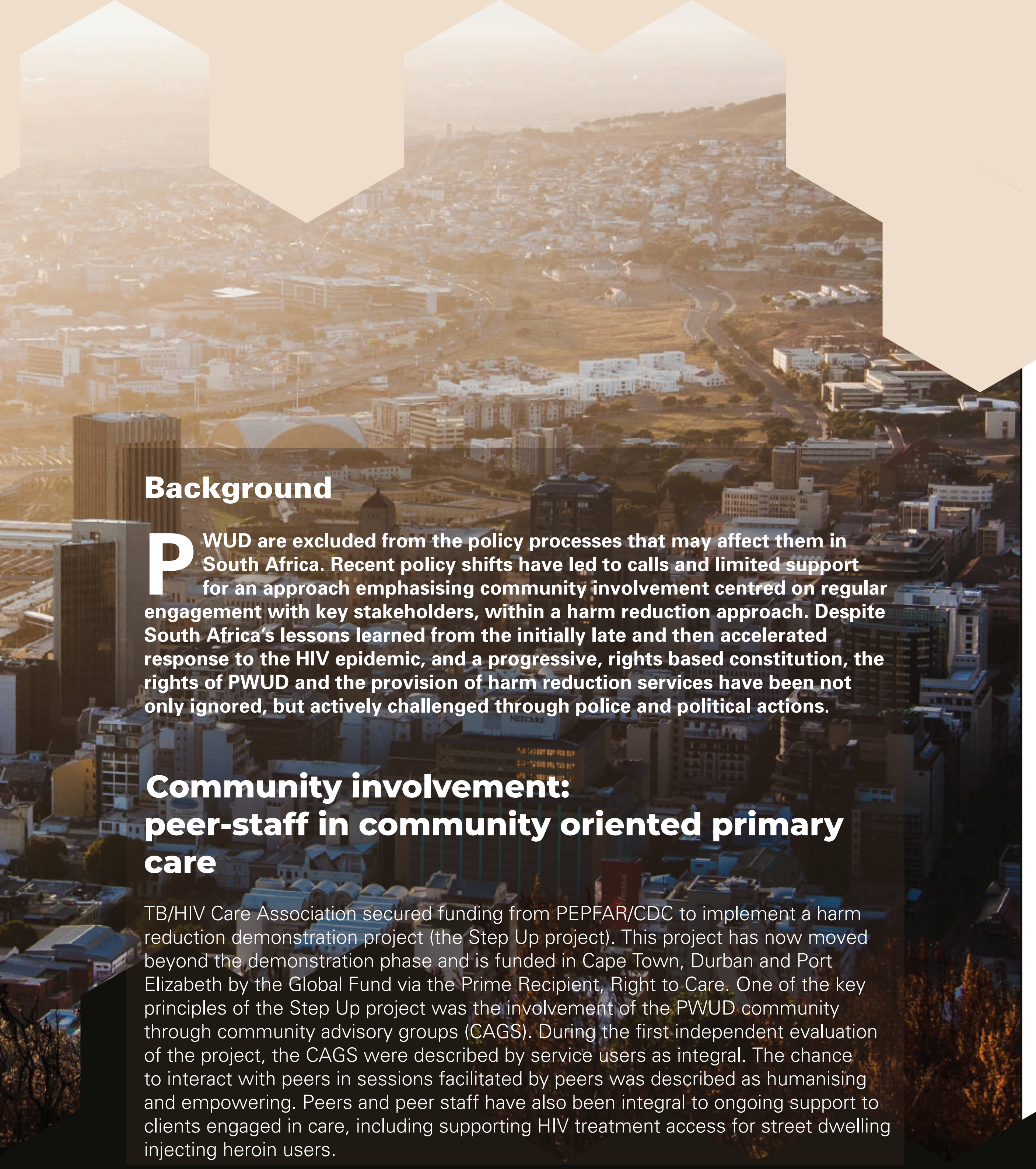
SANPUD
South African Network of People Who Use Drugs

South African research: peer-staff in community oriented primary care

Photo: Tim Johnson



Background

PWUD are excluded from the policy processes that may affect them in South Africa. Recent policy shifts have led to calls and limited support for an approach emphasising community involvement centred on regular engagement with key stakeholders, within a harm reduction approach. Despite South Africa's lessons learned from the initially late and then accelerated response to the HIV epidemic, and a progressive, rights based constitution, the rights of PWUD and the provision of harm reduction services have been not only ignored, but actively challenged through police and political actions.

Community involvement: peer-staff in community oriented primary care

TB/HIV Care Association secured funding from PEPFAR/CDC to implement a harm reduction demonstration project (the Step Up project). This project has now moved beyond the demonstration phase and is funded in Cape Town, Durban and Port Elizabeth by the Global Fund via the Prime Recipient, Right to Care. One of the key principles of the Step Up project was the involvement of the PWUD community through community advisory groups (CAGS). During the first independent evaluation of the project, the CAGS were described by service users as integral. The chance to interact with peers in sessions facilitated by peers was described as humanising and empowering. Peers and peer staff have also been integral to ongoing support to clients engaged in care, including supporting HIV treatment access for street dwelling injecting heroin users.

From this project the first two networks of people who use drugs emerged: Drug Users of Gauteng (DUG) and the Cape Town Network of People Who Use Drugs (CANPUD). Recently a national network of networks has been formed and is in the process of being formalised (SANPUD).

In 2016 the City of Tshwane turned to the University of Pretoria, Department of Family Medicine, to help develop and implement a response to the "problem" of drug use in the community. Through consultation with the Step Up Project, the community oriented substance use programme (COSUP) was developed. Based on the Community Oriented Primary Care (COPC) model of delivering health services to people in their homes, the approach embraces the principle of community participation. The developers of the COSUP programme felt that there was an opportunity to deliver a continuum of services for people who use drugs in a rights-based, non-punitive, non-pathologizing, inclusive and harm-reduction informed manner in the community. Essential to this is the inclusion of peers at various levels of service design and delivery. There are peers at each centre who play a vital role in engaging with the service users. All of these peers were once or still are service users of the OUT Step Up Project, and the majority are currently people who use drugs in one form or another. The plan is to significantly increase the number and role of peers in the project.

Core research questions to support this scale-up are: what roles do peers perform, and how are these roles perceived by non-peers? Are peers trusted and respected by others within the clinic system? How do peers influence the work of other providers in the clinic? What impact does peer involvement have on peers themselves (including health and social outcomes, including both gains and risks)? What employment, training and support systems are best for addressing the needs of peers?

Methods

The results of the preceding qualitative study informed a semi-structured questionnaire consisting of open and closed questions to be administered to peers, clinicians, management and support staff by trained peer researchers for peers and established research assistants for clinical and support staff.

Findings

Clients and peers value their work and contribution: The client survey showed clients to be extremely positive about the services they received. Most respondents 'partly agree' that they trust the peer, with nearly all saying they 'totally agree' that the peer respects them. Most agree that they can talk to the peer about their worries, that the peer is reliable, and that the peer knows the boundary between personal and working life. Peer educators provide a vital bridge via which services can be leveraged but also through which those services are given legitimacy and trust in them can be established.

Differences in perspectives on peer work across the delivery team: Peer educators consistently believe that the quality of services they deliver is higher than estimations provided by other team members. This may be the result of a lack of clarity and understanding of what peer educators specific roles and responsibilities are – both by peer educators themselves but also by wider team members. Reference guides are needed which definitively outline the roles and responsibilities of each team member – ranging from peer educators to social workers and clinical associates – so that the respective expectations and responsibilities can be accurately and openly measured.

The need for organisational clarity and development pathways: The study suggests that further empowering peer educators could be supported by developing a clear 'organisational ladder' through which peer educators could progress from an initial role with fewer responsibilities to larger roles where they are given more responsibilities and scope. This may also provide a managerial pathway by which peer educators could manage others with less experience.

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Photo: Marc st. Aun

INPUD
International Network of People who Use Drugs

Rapid review of peer involvement and harm reduction service access and quality

Background

Whilst community involvement within harm reduction services is widely promoted, this involvement is under theorized and under evidenced. Studies, particularly in high income settings, support the potential impact of different forms of community involvement on supporting access to, and the quality of, harm reduction services; although there is a limited understanding of the impacts and mechanisms for this involvement, particularly in low and middle income settings. In response to this gap, we implemented a rapid review of available peer-reviewed literature documenting the involvement of communities of people who use drugs in harm reduction programming and services in low and middle-income countries. Our aims were to support the specific programmes of work being implemented by partners in the Community Matters collaboration, and also to foster debate across the sector on how to further advance programming and policy around peer involvement in harm reduction services. The review will bring clarity and coherence to the current scientific evidence base and so foster future research agendas.

Photo: Jonathan Gonzalez

Methods

We used a rapid review approach. This approach involves an applied orientation to systematically searching and synthesizing appropriate literature, making pragmatic decisions on searching and analysis to shorten the time frame. Within this rapid and pragmatic approach, we were also guided by a realist framework. Realist approaches to evaluation and research seek to explore interventions as having particular mechanisms that lead to specific impacts, within particular contexts. Within this framework we searched core journals to find papers relating to peer involvement in harm reduction services in low and middle income settings. We found 29 scientific papers, which we analysed and explored to establish key lessons from the existing evidence base.

Findings

Trust as a core mechanism for service access and quality: Peer involvement is linked to heightened trust in services, particularly through overcoming the limiting effects of stigma and discrimination on health care access. Trust is also grounded in the specific expert knowledge that peers bring to interactions around health and harm reduction services.

Health Impact: Peer involvement in harm reduction services is linked to specific impacts on important health and social outcomes, including reduced HIV prevalence, increased HIV awareness and enhanced access to harm reduction supplies like needles and syringes.

A narrow role in the evidence base: The evidence base for peer involvement is limited and skewed to a narrow understanding of the roles that peers can take. There is an underlying instrumentalist understanding of the contributions peers can make; peers are frequently involved in order to serve needs determined by external actors (e.g. to respond to a particular knowledge gap). The contributions of peers to management and design of services is consequently little explored.

Working conditions: Issues of pay and working conditions for peers are recognised in the literature, although little studied. This conforms to the overarching narrow understanding of peers (as above).

The challenges of context: Issues of police criminalisation, stigma and hardship are little explored in-depth in the scientific literature. This comes despite the central role they play in experiences of people who use drugs, in either delivering or receiving services. A continuing limited analysis of these contextual challenges is one reason for limited policy options.

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Implications for practice, policy and research

The limited evidence base for community involvement is a signal for how principles of involvement are often not well supported in practice. This lack of examination of community involvement processes and mechanisms is one factor in why current health and social responses have failed to capitalise on the potential benefits of these approaches, and mitigate barriers to them. A limited evidence base can also be understood as part of a vicious cycle for support for community led responses: limited evidence leads to limited programmes, which undermines potential for study and evaluation, which then perpetuates limited evidence.

The findings from our collaboration are directly addressing this set of problems. We have provided detailed insight in to the operations of community involvement, and then developing arguments on the overarching evidence base and future research and policy strategies. The core lessons from our research programme are:

1 **Support for community involvement needs to be supported to be more ambitious** – the three studies show how communities of people who use drugs can effectively design, lead and manage harm reduction services that are accessible and of high quality. Currently, the broader evidence base – reflecting both underlying assumptions about people who use drugs as well as dominant research methodologies – is limited to understanding narrowly defined delivery roles, where people who use drugs are frequently forced into a subordinate role implementing externally defined interventions. Communities, governments and donors need to respond to a more ambitious and expansive definition of community involvement and the roles people who use drugs can take.

2 **Community involvement can support increased access and quality of harm reduction services** – involvement in community and clinic settings, and in the design and delivery of services can have positive impact, particularly through the knowledge communities bring and the trust they can generate. There are however conditions for these impacts. Severe stigma and discrimination, linked to criminalisation, undermines community involvement, even whilst community involvement can act to mitigate some of the ill-effects of stigma and discrimination on service access and quality. Positive working conditions, particularly pay and management, support community involvement.

3 Community involvement and leadership delivers research with impact – our studies provide further examples of how community leadership in research delivers high quality and relevant research.

4 Research agendas need to expand and methodologies adapt – the overall evidence base for community involvement is, despite the contributions of our country studies, limited. Research agendas and methodologies need to respond. Questions and research designs need to allow for i) more expansive understandings of the contributions people who use drugs can make, ii) more specific engagement and study of the macro and meso level contexts that produce vulnerability and structural violence that limit service access and quality for people who use drugs, and the role of communities in managing these structural challenges, iii) more use of the combination of quantitative and qualitative methods in order to allow for in-depth exploration of how outcomes relate to specific contexts and mechanisms.

For more information on the Community Matters research programme please contact Judy Chang, judychang@inpud.net or Machteld Busz m.busz@mainline.nl

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