

INPUD
International Network of People who Use Drugs



taking back what's ours!

A documented history of the
movement of people who use drugs

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Introduction

INPUD is a global constituency-based network of people who use illicit drugs, including people who are on pharmacotherapy programmes. We are committed to harm reduction, human rights and the meaningful participation of the drug using community in the development, implementation and monitoring of all policies, programmes, services, and initiatives that impact upon drug users lives. We aim to raise the voices and perspectives of the drug using community and its organisations in global advocacy spaces and processes. The network is committed to the principles sketched out in the Vancouver Declaration - 'Nothing about us without us - a manifesto by people who use illegal drugs' - and adheres to the following core principles in all of its advocacy, lobbying and capacity building work: 1) Pro drug user rights 2) Pro self-determination 3) Pro harm reduction and safer drug use 4) Respecting the rights of people to use drugs or not 5) Anti-prohibitionist 6) Pro equality.

INPUD's work sits within and helps to connect the larger drug user rights movement, a social movement fighting for the human rights, self-determination and equality of people who use drugs. Although there is still much to do to achieve this goal, activists within this movement have been at the forefront of challenging criminalising, prohibitive laws and policies in the face of oppression, marginalisation and widespread stigma. Successes have been tangible, for example in the form of harm reduction programmes, and also more abstract, for example encouraging a larger range of bodies to speak out in favour of drug policy reform and rethink taken-for-granted, discriminatory attitudes towards drug use. The ways that hard-won successes have been achieved, and the manifold challenges navigated and overcome, differs across the world, by region, by country, and by community.

INPUD and Rights Reporter Foundation have produced an original ten-part film series involving drug user advocates from around the world, providing their reflections on the drug user

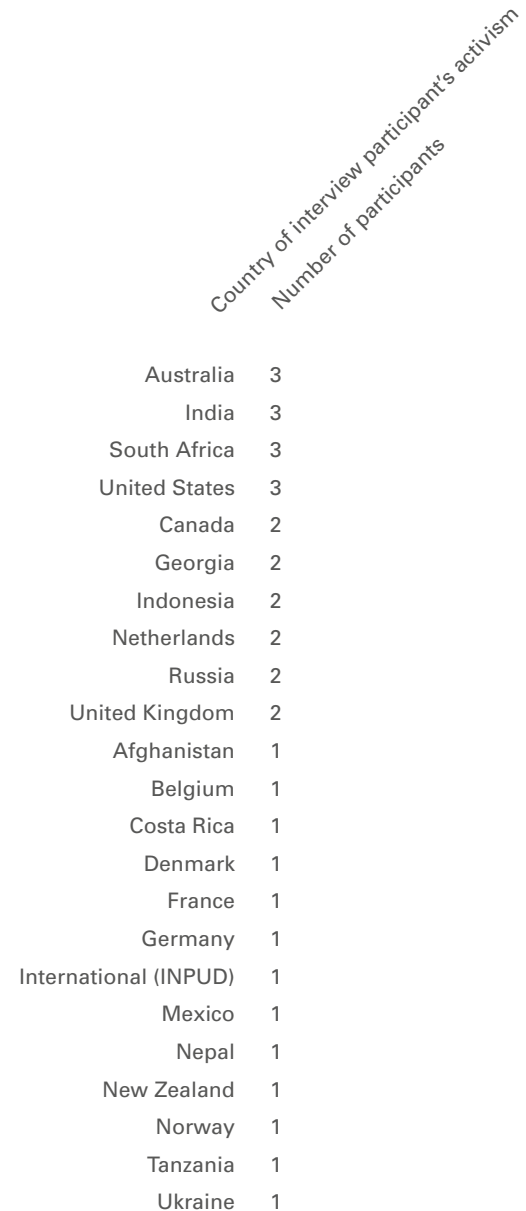
rights movement. This film, *Taking Back What's Ours! An oral history of the movement of people who use drugs* is being released as part of the [HIV 2020](#) online conference. This accompanying qualitative research project, drawing on accounts from 34 activists across the globe, seeks to document the meanings that people who use drugs attribute to the movement, the challenges and tensions they perceive working within and outside the movement, and strategies for effecting positive change. The report seeks to amplify the voices of leading advocates and identify common features of the movement, while also paying attention to the influence of contextual factors that may facilitate or impede progress towards the movement's goals. In doing so, this report aims to celebrate the movement's strength and resilience despite the overwhelming challenges, and consider the lessons learned from a generation of pioneering activists that may inspire a newer generation to build upon and extend their successes.

Methodology

This report is based on semi-structured interviews conducted with 34 persons who use drugs, all leading activists/advocates for drug user rights, over the course of 8 months between September 2019 and May 2020. Fig. 1 shows the countries where participants have undertaken their activism activities, mindful that some participants now live in different countries, for example if they are working for a regional organisation or network. Interviews were conducted in English by interviewers based in the country of the participant with understanding of drug user activism; in certain cases, questions were asked in the participant's preferred language, and the participant responded in English.

Questions covered: the participant's involvement with the drug user rights movement, and impacts on the participant's

Fig. 1



personal life; lessons learnt from the participant's career, in terms of successes achieved and overcoming challenges; and the participant's views on criminalisation, the link between people who use drugs and the HIV/AIDS movement, and messages they might wish to share with previous or future generations of drug user rights advocates.

Interviews were audio and video recorded, and transcribed. We conducted a thematic-style analysis of the transcripts. Firstly, we familiarised ourselves with participants' accounts through reading of the transcript together with the audio recording. Then, interviews were coded, with a focus on the macro-level content of the account (i.e. the broader experiences and insights of participants, as opposed to nuances of language or discourse). After coding, comparison across interviews allowed for the generation of themes, under which findings are organised in the following sections. We also considered and noted insights and experiences which differed from the overall direction of a theme, and some of these are discussed in the section on 'The importance of context as an enabler or barrier to successful activism'.

How do activists define the drug user rights movement?

A fight for basic human rights

All participants without exception regard the fight for the respect, protection and fulfilment of the inalienable human rights of people who use drugs as a defining, fundamental feature of the drug user rights movement (hereafter referred to as 'the movement'). The movement has promoted self-determination, the notion that "people who use drugs are people" (Angela), and the "upholding [of] human dignity" (Anand). Fundamentally, it is a "peace generating kind of movement" (Brun), born out of necessity, "passion" (Charles) and fighting for social justice for people who use drugs, at times when the

scale of human rights violations in many countries has been staggering. Indeed, many participants became involved in movement after they or those close to them had experienced "life-threatening events" (Andria). The movement is about the rights to self-determination over one's own body, decision-making and consciousness. Furthermore, although participants phrased this more implicitly, the movement has also been concerned with achieving broader economic, social and cultural rights for people who use drugs, such as the right to access appropriate, non-judgemental and non-coercive health services, and safe housing.

The movement is not only about people who use drugs having access to the resources that society can offer, but also society having access to the resources that people who use drugs can offer; indeed, many participants highlighted the positive contribution they have made to their communities and societies, and want people who use drugs to be welcomed as "resources" (Arild) for society rather than "scapegoated" (Jude) for societal problems. The movement is about being at the heart of decision-making, and "meaningful involvement" (Simon) when policies are being made and implemented, in the spirit of 'Nothing about us, without us.'¹

A movement fighting criminalisation and prohibition

Participants were unanimous that empowerment of people who use drugs and full respect for their rights can only be achieved by "dismantling prohibition" of drug use and drug possession (Jude). Criminalisation, and the repressive, oppressive laws and policies through which it is enacted, have been and continue to be at the root of all other harms and violations people who use drugs experience. Criminalisation of people who use drugs

1. Canadian HIV/AIDS Legal Network (2005). "Nothing About Us Without Us": A manifesto by people who use illegal drugs. Available at: <http://www.aidslaw.ca/site/wp-content/uploads/2013/04/Greater+Involvement+-+Bklt+-+Drug+Policy+-+ENG.pdf>

has been an impediment to engaging with public and community-services and has also created obstacles to finding employment and other opportunities which may help to “resolve” (Shaun) potentially more problematic aspects of drug use. Several participants discussed criminalisation as a “tool of racism” (Andria) and an “imperialist, colonialist” policy (Zoe), the direct consequences of which - police brutality, violence, extortion and arbitrary arrests – have disproportionately affected Black, Brown, indigenous and poorer people who use drugs due to “apartheid-style policing” (Shaun). Fundamentally, criminalisation is not “science-based” (Hollis), “makes no sense” (Jude), and the associated so-called War on Drugs was seen as “the single most catastrophic global public policy fiasco disaster” (Geoff), “a political construct” which has cost countless lives. Participants spoke of ulterior motives driving the War on Drugs, for example as a “proxy” (Shaun) for repressive governments to achieve their political goals and retain a strong grip on power, or as economic fuel for a “1.5 trillion dollar... mass incarceration” industry in the US (Robert).

On a psychological level, drug prohibition and the criminalisation of people who use drugs has meant that the marginalisation, oppression and violence that many experience simply for using drugs “retraumatise” (Andria) people who may have initially arrived at drug use because of trauma and who continue to experience trauma. For example, a study in Indonesia found that nine in ten women who inject drugs had “faced violence by their intimate partner in the last year” (Putri). Criminalisation in turn has caused people who use drugs to internalise stigma, deepening a sense of self-blame and shame. As well as mental distress, the harms and risks associated with criminalisation have meant that many people who use drugs “hide in the shadows” (Andria) and have not felt able to be open as someone who uses drugs, let alone as a more public-facing activist.

A source of empowerment, meaning and belonging

In the face of the “overwhelming oppression” (Annie) and “othering” (Jude) of people who use drugs, the movement is about empowerment, liberation, and fighting stigma, discrimination, and self-stigma at a time when being open about drug use can still come at a huge personal cost.

Discussing the impact of the movement on their personal life, many participants recounted painful rejection they had experienced from their families and communities, especially when they were first open about their drug use. One participant’s family saw his activism as “amoral... and self-centred” (Simon). However, several participants’ families and communities had become much more “respectful” (Raheem) and “supportive” (Joergen) once the participants became more involved in activism. Other participants described how the movement itself has provided a family for its members, a “home... where I belong” (Annie), a union of “amongst the most talented, gifted and blessed individuals on the planet” (Robert). At the same time, some activists described a sense of ‘role conflict’ between supporting their immediate family and their community of people who use drugs, sometimes because of being “physically absent” (David) and “too busy” (Happy) due to their activism.

The sense of belonging and pride imparted by activism and membership of the movement has given many participants a profound sense of existential mission and meaning: it “creates and keeps my connection to life and gives me purpose” (Louise). Many participants discussed how being an advocate for the rights of people who use drugs has helped them to overcome “internal stigma and shame” (Jude) and to feel “at peace” (Miguel). This was especially the case for activists who discovered alternatives to abstinence and 12-step approaches through their involvement in the movement, since an abstinent philosophy has often reinforced the idea that social inclusion and acceptance is contingent on being “clean” (Shaun), thus perpetuating self-stigma. For many activists, discovering the principles of harm reduction,

and an empowering movement which stresses that problems are caused by the drug war and not by drug use itself, has provided a “very loving and very non-judgemental” (Louise) alternative.

Links and tensions with the HIV movement

Participants also felt that the HIV/AIDS epidemic had been important in galvanising the drug user movement, which “dove-tailed” (Jude) into funding for HIV and Hepatitis-C prevention for people who use drugs, through provision of harm reduction services such as sterile needles and syringes, and methadone provision. Indeed, from many participants’ perspective, funding for these services helped to encourage the emergence and coalescence of the drug user rights movement.² HIV activist organisations of the 1980s, such as ACT-UP, inspired drug user rights activists, with many people who use drugs involved in the HIV response “suddenly realising they were agents of change” (Andria). The crisis of HIV created the urgency to spur on a drug-user led movement, providing legitimacy as well as resources to a movement that in many parts of the world was “going against the local beliefs and belief system” (Jude).

Many activists explained the introduction and scale-up of harm reduction as a pragmatic decision by governments, to prevent transmission from people who use drugs to ‘the general population’ and reduce costs to the health system, rather than driven by a genuine shift in values. While the spread of harm reduction services, especially in Western Europe, had been welcomed, many activists advocated for a broad view or “full spectrum” (Brun) of harm reduction, as a philosophy originally inspired by “anarchist ethics, which said that we have to challenge everything and that nothing should be assumed” (Shaun). Indeed, some participants were concerned that aspects of harm

2. The “dovetailing” of the drug user rights movement on HIV funding can be considered an example of ‘resource mobilisation theory’ as discussed in the study of social movements. See McCarthy & Zald, 1977. Resource Mobilization and Social Movements: A Partial Theory. Available at: <https://www.journals.uchicago.edu/doi/abs/10.1086/226464>

reduction have become overly sanitised, reduced to a schema of biomedical interventions to prevent HIV and blood borne virus transmission. One particular concern regarding HIV prevention funding underpinning the drug user rights movement has been the artificial separation of services for people who may inject drugs (the overwhelming focus of HIV prevention programmes) from those who do not inject drugs. More broadly, participants expressed concerns that harm reduction has become co-opted by a medicalised, pathologising approach that positions drug use as a “mental health disorder” (Edo), “brain disease” (Ernesto) or “soul sickness” (Brun) that in turn constructs people who use drugs as “sick, apologetic patients” (Mat).

Aware that HIV-related funding may impose a more narrow, technocratic agenda, many activists stressed the need to remain focused on community empowerment and “liberation” (Ann), and ending criminalisation and oppression of people who use drugs.

What have been the challenges in sustaining a resilient drug user rights movement?

How criminalisation has constrained the movement

Some of the manifold challenges experienced by the drug user rights movement have been similar to those that may affect any social movement. For example, a classic model of social movements traces four stages that social movement typically pass through, of emergence, coalescence, bureaucratisation, and decline (which may be due to failures, co-optation, or such success that the previously marginalised movement becomes mainstream).³ However, the challenges the drug user rights movement has faced have been uniquely intensified by criminalisation and prohibition.

3. Christiansen, J. (2009). Four stages of social movements. Ebscohost Research Starters: Academic Topic Overviews. Available at: <https://www.ebscohost.com/updates/imported/thisTopic-dbTopic-1248.pdf>

Firstly, the movement has been fighting to safely and legally use drugs that are referred to by the Single Convention on Narcotic Drugs as “a serious evil”; this has posed a fundamental challenge for activists, repeatedly told that what they fight for poses a grave danger for individuals and societies. Criminalisation of people who use drugs has often complicated ‘coming out’ as an activist, and their ability to organise, assemble, and “collectivise” (Simon), to travel and meet other activists. As one activist stated, “The very thing that unites us puts us at risk” (Mat). Indeed, criminalisation and marginalisation has meant that many people who use drugs have ended up “in constant contact with the law” (Miguel), and have had limited access to housing and good health that could in turn enable greater involvement in more formal activism. The constant threat of arrest, and also preventable disease, overdose and death due to the “polluted” (Joergen) or “toxic” (Zoe) unregulated drug supply, thus continually risks immobilising activists and the movement losing momentum. Criminalisation creates huge time and money pressure; life for people who use drugs is expensive and many live “really hectic” lives (Jude).

Thus the overwhelming impact of prohibition has meant that while the movement can celebrate significant successes, these represent a “bandaid on a severed artery” (Geoff) if the War on Drugs is continuing to wreak havoc further upstream. For example, referring to Portugal where drug use (in small amounts) has been partially decriminalised,⁴ one activist merely described this as a tweak to the overall continuing “system of oppression” (Geoff). Criminalisation has “fuelled the user movement, because we have to fight for our human rights” (Joergen), but has introduced a huge host of challenges, above all because of the detention and deaths of so many leading activists.

4. INPUD (2018). Is Decriminalisation Enough? Drug User Community Voices from Portugal https://www.inpud.net/sites/default/files/Portugal_decriminalisation_final_online%20version%20-%20RevisedDec2018.pdf

Representing the most marginalised people who use drugs

A key challenge that participants raised is ensuring that the drug user rights movement remains representative of the individuals most affected by criminalisation and marginalisation, as parts of the movement have evolved and become increasingly professionalised and bureaucratised. Participants generally stated that while most people ‘use drugs’ in some sense of the word (with alcohol, tobacco, coffee and even sugar used as examples of commonly used drugs), the movement needs to represent those who have experienced “suffering” (Bikas) because of their drug use or have “looked into the bowels of prohibition” (Jude). Many participants recommended an inclusive, flexible “broad church” movement “embracing our fluidity, our sense of community diversity, being welcoming of people who seek to be part of our community for their own reasons and on their own terms” (Charles). Indeed, there was a sense among certain participants that the movement needs to embrace and listen to anyone who wishes to make a contribution, because of the high turnover: “We are losing people at a pretty insane rate. And we don’t have time or the ability to not listen to folks” (Louise).

A tension several participants raised is that often people who actively use drugs cannot openly represent their community, for example because of risks to their safety from being open about their drug use, so people who “used to use drugs... have the voice” (Simon). Thus it is vital for leading activists to remember that they are “representatives first” (Charles), and that the “voices of people who are using regularly - [that] become so marginal - need to be elevated” (Zoe) within the movement.

The complexities of working with funders

Participating activists underscored the challenge for a movement which has been continually beset by funding challenges. These challenges have not only included a lack of funding, but also a lack of control over existing funding that could allow groups of

people who use drugs to self-determine their activities and strategic direction.

There is a need for broader funding beyond harm reduction in the context of HIV prevention, which has provided much of the financial support, for example through the Global Fund (to Fight AIDS, Tuberculosis and Malaria). With absent, or uneven and unpredictable, support from domestic governments, many organisations led by people who use drugs have been reliant on funding for specific, defined services (such as needle and syringe programmes) rather than for broader advocacy activities aiming for systemic change. As one participant stated, “governments just... do the bits that they’re worried about, which is viral transmission or overdose” (Jude). Participants stressed the need for more core funding, for example from philanthropic funds, in order to stand up against prohibition and criminalisation, policies which themselves have made the rights of people who use drugs a “hard sell” (Geoff) compared to other social justice issues. The limited funding means there has been little time or resource for anything other than ‘firefighting’ the widespread, immediate harms caused by prohibition, rather than organising more strategically to fight prohibition itself. Without the government tackling the root causes and effects of the criminalisation and marginalisation of people who use drugs, activists have ended up in “a reactive position... fighting for people’s lives” (Zoe). There is also the more practical implication that a lack of core funding has made it challenging to run and administer organisations, for example “keeping an office going” (Simon), and hiring and training paid staff who could sustain the movement; as one participant stated, “You need to invest in us if you expect big things from us” (David).

Several participants highlighted the unpredictability, inconsistency and incoherence of funding as a common experience, for instance with drug user rights organisations rapidly going from being funders’ “flavour of the year” (Hollis) to having to shut down. Where there is funding, it must filter down to

the level of the community and sustain a pipeline of activists: “That’s how to be a resilient movement, by not making it about us. Making it about the next guy and the next guy and the next guy” (Nelson). The scarcity of funding has also often created friction or competition among networks of people who use drugs “when different donors have the same agenda, but they don’t communicate with each other” (Edo), emphasising the importance of funders streamlining their programmes. Many participants discussed the need for donors and funders to trust organisations led by people who use drugs more, feeling that their organisations have been subjected to disproportionate scrutiny. They felt that the input of people who use drugs has sometimes been “tokenised” (Ann) by funders, who have set the agenda rather than allowing the organisations to “define what we see as success” (Mat). Some participants also critiqued the one-size-fits-all approach of funders, imposing expectations and goals for programmes that may be inappropriate or ill-suited to the context.

Resisting co-optation and bureaucratisation

Difficulties in securing and retaining funding overlaps with another dilemma discussed by participating activists, namely how to balance ‘having a seat at a table’ - a voice in high-level decision-making and policy implementation - with ensuring a focus remains on grassroots activism and responding to the needs of communities most directly affected by prohibition.

Some participants discussed the activist movement having become overly professionalised, taking on a technocratic or bureaucratic character that may have facilitated attempts to work with actors “in the system” (Edo), but has sometimes problematically “shifted priorities” (Bikas) and presented a barrier to genuine representation of the majority of people who use drugs. Problems of co-optation were most often discussed in the context of global, UN-style activities; as one participant stated, “the biggest limitation to building strong drug user led

movements is people not willing to share the power that they get that comes along with getting on that UN gravy train, and then you don't want to get off" (Hollis). Indeed, there was awareness that organisations too concerned with influencing at higher levels of policymaking may have become less resilient and prepared to tackle emergencies at the community-level, such as the overdose crises in Canada and the US.

As the movement has become more professionalised, increasingly represented at high-level conferences and forums, participants recommended keeping a focus on informal activities to keep movement "lively" and "developing" (Anton). In the view of many participants, organisations and projects require support to develop "organically" (Anya), rather than being moulded into overly corporate structures which can create "organisational toxicity" (Anya) and create "complex institutional set-ups" (David). Indeed, while some level of bureaucratisation and structure has been beneficial, it is important to avoid imposition of values on organisations led by people who use drugs, and to allow members' creativity and momentum to underpin organisations' direction, even if that means the group "morphs into" or "cleaves off" (Ann) into something different and unforeseen.

Training and supporting activists to remain resilient

An additional challenge associated with professionalisation is that while the insights, expertise and lived experience of people who use drugs must underpin drug policy and science, people who use drugs may also want or need to learn new formal skills to further their activist work within the movement.

Especially at the regional or global level, activists for drug user rights have needed to become "fluent" (David) working with a complex assemblage of UN agencies, scientific organisations and NGOs. Discrimination and marginalisation has meant that many people who use drugs have not "gained access to education... And so this is a population that you can't just dump a lot of money on. You need to help them and assist them in

becoming capacitated. That doesn't mean you need to be patronising or directive." (Shaun). Such capacity building could range from improving technical skills to manage an organisation, such as managing budgets, to "learning the language of diplomacy" (Jude). While funding is necessary for such activities, participants also stressed the importance of mentorship in order to sustain and upskill a pipeline of activists and advocates, knowing that "our generation will come and our generation will go" (Charanjit).

Specific training and support is also needed to alleviate the psychological and emotional distress that many drug user rights advocates have experienced. There are particularly high levels of "burnout" (Judy) in the movement of people who use drugs, with many activists dealing with health problems, complex employment, living or family situations, and grief and loss after witnessing the preventable deaths of friends and colleagues in their movement and community. Other activists' deaths can lead to a sense of "inertia", of "hitting your head on a brick wall" (Jude) in the campaign against prohibition and can cause the momentum to evaporate. As one participant stated, "When we lost our leaders, part of the community lost their enthusiasm to fight for the rights of drug users and to continue the struggle" (Putri). The scale of bereavement and grief can make the slow pace of change even more frustrating, and activists require support to cope with the "heaviness" (Angela) of being an activist, and with the alienation and stigmatisation which has affected and continues to affect so many people who use drugs. Indeed, one participant recommended formal psychological support for activists, "supervision in terms of psychological counselling... that should be paid for by the grant givers and by the organisations" (Shaun). Participants also spoke of the importance of imbuing the movement's activities with fun and a sense of humour wherever possible, despite the seriousness of the mission: as one stated, "We need to laugh more" (Theo) and another that "it has to be enjoyable, the work" (Anya).

Overcoming inter-personal and inter-organisational differences

A final area of challenges for a resilient movement discussed by the participants relates to how activists for the rights of people who use drugs resolve conflicts and differences.

One very practical issue concerns the language of the movement. With most global discussions and advocacy activities conducted in English, non-English speaking activists “resent not being able to participate” and to access the relevant information (Brun). Dedicated funding is required for “translation, for people to hear it in their own language in the same moment” (Ernesto). At country level, one language still tends to dominate which complicates communication between different groups of activists, and often the most marginalised people who use drugs may speak a language other than that spoken by the principal activist groups. At a more conceptual level, different societies and cultures may have varying discourses for talking about drug use, which makes interpersonal and inter-organisational dialogue and understanding so important. As one participant stated, “context is everything” (Ann); for example, a faith-based organisation with “sober” in the name may seem to signal an abstinence-based approach although it may in fact be largely composed of people who actively use drugs. Indeed, building the movement internationally “really requires people to see and connect with each other across culture, across international boundaries, across languages, and to see our common humanity as drug users” (Mat).

This relates to a broader challenge, about maintaining trust between people who use drugs and networks who are in such different situations, often facing hugely varying circumstances but brought together in response to the same urgent crisis of prohibition. The scarcity of funding has created huge tensions between organisations, and especially when drug user rights groups are institutionalising more formally, “what I’ve seen historically is people just eat each other up” (Zoe).

Some activists commented on “a feeling that we’re fighting between each other, instead of sitting together and saying, ‘Okay, how can we use this as a complex, overall strategy for everyone’” (Anya).

In terms of more individual-level conflict, participants referred to the “infighting” and “lateral violence” (Jude) which has existed in parts of the movement, a phenomenon whereby marginalised and oppressed groups direct anger inward and onto their peers.⁵ Nonetheless, the emphasis of participants was often on the need to “meet people where they are... and just keep working on it” (Ann), calling out unacceptable behaviour or prejudice but ultimately “trying to build people up, because we need strong people to work together” (Jude). As one participant stated, if there is conflict within or between organisations, a restorative approach has often proved more effective than replicating “practices of the criminal justice system where we exile people or we go after people” (Zoe).

Overall, activists were aware of the real risks of being “divided and conquered” (Ernesto), and emphasised the importance of maintaining unity and building trust when circumstances may militate against this. As one example, developing organisations’ policies and rules collaboratively, working out the details of funding, budgets and governance arrangements, has built trust among members, so that they “complete each other” rather than “compete with each other” (Edo). Furthermore, keeping everyone’s focus on the long-term goal of decriminalisation can help to “amalgamate” the movement and prevent “splintering” (Simon). Above all participants highlighted the need for organisations and the broader movement to remain a safe, welcoming space, where “you can be open and be yourself and live your life in a full and expressive way” (Annie).

5. Clarke, Y., Augoustinos, M., & Maline, M. Lateral violence within the Aboriginal community in Adelaide: “It affects our identity and wellbeing”. Available at: <http://manage.journalindigenouwellbeing.com/index.php/joiw/article/view/35>

How do activists effect the process of change?

In the face of such challenges, it is important to celebrate the participation of drug user rights activists in the processes of creating change at the local, national, regional and international levels, especially given that criminalisation and stigma can lead to an “invisibilisation” (Ernesto) or “anonymisation” (Tonny) of people who use drugs that often erases and excludes them from public policy. Many participants stated that even the fact that organisations and movements led by people who use drugs exist and have survived is itself a success; the movement’s “existence until 2019 is itself an achievement” (Bikas). The fact that some people who use drugs are moving “from the streets to the tables” (Happy) and having a voice in policymaking and agenda-setting, is a considerable achievement to celebrate.

The spread of needle exchanges, access to harm reduction, availability of opioid substitution therapy and naloxone in certain countries, and drug consumption rooms in certain Western European countries and Canada, were all cited by activists as concrete, hard-won successes. Often with little support, organisations led by people who use drugs had mobilised from the bottom-up to build an evidence base for enhanced policies and interventions, such as in New Zealand where activists worked to “build up a body of evidence around, getting the government to understand that, they needed to change that law” (Charles). There was a sense of pride from certain participants that their countries had played a pioneering role within their region, for example in Tanzania as “the first Eastern African country to implement very good harm reduction programs like needle and syringe programmes, a methadone programme, and also the engagement and involvement of people who use drugs” (Happy).

Although less tangible, a significant and fundamental success of the movement for many activists was the feeling of purpose, belonging and meaning it has given them and their

peers, replacing previous feelings of disconnection, shame and self-stigma. Some participants also mentioned the increasing humanisation of people who use drugs as a success, as the start of the long journey towards winning over the hearts and minds of the general population, since “politicians don’t move unless the general population moves. They’re reliant on votes and they will do whatever the vote is saying” (Shaun). Indeed, there have been some subtle but meaningful changes in how policymakers, legislators and scientists talk about drug use, thanks to the involvement of people who use drugs in policymaking, for example changing wording of South Africa’s National Drug Master Plan from “a drug free South Africa, to a South Africa free of drug abuse” (Shaun). This notion of people who use drugs telling their stories, to show “there are real faces behind some problems that may seem abstract to decision makers” (Anya) was a common thread throughout participants’ accounts, recognising that personal stories have the power to “disrupt the narrative” (Shaun) and taken-for-granted views on drug use.

An adaptive mix of strategies

While participants naturally held different views about how change could best be achieved, there was a general consensus regarding the need for a “mix of strategies” (Anya) underpinned by a flexible, adaptive approach and always meaningfully involving people who use drugs. For example, sometimes protest, civil disobedience or radical action may be appropriate, while at other times or simultaneously, strategic litigation or negotiation may be a route to change. The relative balance of these strategies has necessarily varied according to context; as one participant concluded, “The strategies the movement has used over the decades to try and achieve their aims have been suited to the times” (Jude). A good example was the action undertaken to influence the Commission for Narcotic Drugs (CND); INPUD members and other NGOs organised protests featuring activists in cages outside the CND entrance, to draw attention to the unjust incarceration

of people who use drugs and the “literally and figuratively imprisoning” (Judy) nature of drug policies. At the same time, activists worked progressively to build capacity of members to engage with and better understand the complex processes of the CND, and INPUD now has credibility even within this conservative body.

Indeed, most participants underlined the importance of building diverse coalitions incorporating a variety of skills in order to push for change on different fronts, including campaigning, advocacy, scientific and research skills, and knowledge of political, legal and financial systems. Some members may feel better equipped to organise protests, others to lobby, others to work with government, and others to speak to the media. As one participant stated, “Success happens when different coalitions come together” (Zoe). Fundamentally, people who use drugs must be the ones to lead, define the strategy, and leverage their talents, bearing in mind that “drug users are innovators. We constantly have to adapt and change to the changing drugs, changing risk, changing environments, changing policing attacks on our community, and we show such creativity in that world” (Mat). While innovating, it is also important for different networks in the movement to share knowledge, to promote strategies that are effective and thus avoid “reinventing the wheel” (Nelson). Participants agreed that the movement needs pluralism, a diversity of ideas, strategies and passions, and ultimately to combine these “under one umbrella” (Simon) in order to speak with “a unified voice” (Charles) to bureaucrats, scientists and politicians external to the movement.

Building partnership around common causes

Participants spoke of working with actors external to the movement as a crucial but challenging element of effecting the change process. Partnership and collaboration between groups and networks led by people who use drugs with more established organisations – for example those working in HIV - can provide more credibility, and greater “levels of governance and reputation”

(Shaun), provided they do not impose their values and encroach on the drug user rights organisation’s freedom to operate and set the agenda. While allies and partnerships were often desirable, many larger organisations – even if working towards similar goals to the movement of people who use drugs – may be “very reluctant to step into this area... It is difficult to get people to partner with us, to try and end prohibition” (Geoff).

At times however, strategic alliances may involve more stealth and ingenuity, working to benefit from opportunities afforded by partnership with organisations who may have very different end goals. As one participant stated, about the experience of working with a more recovery-oriented organisation to gain access to a meeting space, “If I said we’re starting a user’s union, we’re really militant and we’re trying to get drugs legalised, they’d just go ‘Fuck off’” (Ann). In some contexts though, where partners have sought to enforce their values and agenda in a directive manner, the best response has sometimes been to ‘go it alone’; for instance, “when local policy makers were so busy talking about recovery that they wouldn’t engage with harm reduction, we just withdrew from the policy forums and focused on helping our peers” (Mat).

Joining with other “like-minded” (Simon) activist groups, and “being rooted in other people’s movements” (Zoe), such as movements fighting poverty, decriminalisation of sex work, and for racial justice, gender and LGBTQ equality, were also seen as integral to the liberation of people who use drugs from criminalising, oppressive systems. In one participant’s words, “Intersectionality is what makes every movement strong”, and it is important to recognise that “there’s huge risks and huge challenges for some people more than others”, for example women who use drugs being at particular risk of sexual violence.⁶ Participants thus saw allying with complementary social movements as crucial for an urgent “fight [that] will take all of us” (Louise).

6. INPUD (2014). Drug User Peace Initiative: A war on women who use drugs. Available at: https://www.unodc.org/documents/ungass2016/Contributions/Civil/INPUD/DUPI-A_War_on_Women_who_Use_Drugs-Web.pdf

While allies are vital, participants were clear that people who use drugs must have the ultimate say in decision making, since allies “will do the work but won’t wear the hair-shirt” (Jude). An illustrative example of this insight, discussed by several participants, was progress made in decriminalisation or legalisation of cannabis; while considered a positive development, many felt that the systemic impact of this change had been limited, in part because the market has been co-opted by large businesses, and that fewer people being arrested for cannabis possession simply meant more arrests for people using other drugs. As one participant stated, “The people that they want in jail, they’re still incarcerated. They just found another way to do it” (Jude), thus showing how incremental progress towards decriminalisation/legalisation of some drugs, whilst not others, may have created new inequalities and fault lines within the movement of people who use drugs.

Working within and outside the system

While participants on the whole suggested that a plurality and diversity of strategies was required to effect change, there were subtle differences of opinion in terms of how closely to work with established policymaking, legal, social and scientific systems that may constrain and co-opt as much as they enable change. Some activists suggested that being in the room and having a presence where decisions are made is a crucially important first step; you “don’t have to say anything. You just have to be there” (Jude), and this may be a first step to sensitising those in power to issues people who use drugs face. Presence ‘in the room’ or ‘at the table’ may encourage use of more humanising and less stigmatising terminology, for example shifting a high-level committee away from stating that Hepatitis C is transmitted through injecting drug use to “transmitted through sharing contaminated equipment” (Jude). At the same time, it is vital that the presence of people who use drugs ‘at the table’ is meaningfully valued, as there is the possibility that “people... say they want you at the table, but

when you’re at the table, there’s all sorts of ways and tactics and strategies that are used that stigmatise you and diminish your voice” (Annie). There is always the risk that representation from people who use drugs in these more high-level policymaking fora becomes “clientised and tokenised” (Ann), to ‘tick a box’ rather than to invite authentic engagement.

As such, there was a clear message from participants that dialogue, diplomacy and negotiation with governments and policymakers must be balanced and coordinated with more radical strategies in order to drive progress. As one participant expressed, activists have to be “open for dialogue, while being radical on the ground... [and] have a dialogue in debate” (Tonny). While working with powerful actors in the mainstream establishment can be a force for change, it can come with risks even beyond being co-opted and neutralised. Indeed, one participant discussed working with the pharmaceutical industry as a “tricky thing”, providing the organisation with funding but with the additional motive that “they want to go through the back door to our network and to set off some arguments or other things or for their medication over a way of treatment... we have to be clear on the way we handle this”. In many contexts, especially where authorities are highly prohibitive and repressive, it may be impossible to fully resolve the discontinuities between more grassroots-level action and working with more established bodies, since “you start sitting at the table, and suddenly you can’t be as radical about the things you want to say. You start trying to push things incrementally, and sometimes that works and a lot of times it doesn’t work” (Zoe). Indeed, there was a sense from some participants that the involvement of drug user advocates at high-level meetings of drug policy, bureaucracy and research, and the everyday worlds of people who use drugs themselves, are somewhat irreconcilable, and the different modes of engagement across drug user networks should be considered as “two different kinds of drug user groups” (Ann). Therefore, although a challenge to

achieve given the inevitable trade-offs between being more radical and dissident versus working ‘within the system’, it is vital that activists working within the system continue to elevate the most marginalised voices and networks, who may have no access to government funding or official recognition.

Being willing to change strategy and adapt to any opportunities the system offers was seen as a means to precipitate meaningful change in the eyes of certain participants. One activist in Indonesia described how their organisation previously had no links to the government whatsoever, and would critique the government but without eliciting any reaction: “We were just hitting ourselves against a brick wall... then we started to change our strategy, and so we started to get acknowledgment from the government, to get them to know us..., hear us and put us as an equal partner” (Edo). At the same time, this participant suggested the need to have “one foot half in the system, and one half outside the system” in order to “play the game” of changing policies and perceptions, and ensuring developments at the policy level are communicated effectively back to the grassroots level of the people who use drugs whom activists represent.

Much of the challenge stems from the slowness with which more systemic and abstracted change happens, in sharp contrast to the urgency of the crises many people who use drugs and their communities are facing on the front line around the world. It can feel like working with bodies deeply embedded within a prohibitive system like the CND represents “tinkering with a system, you know, and you’re looking at small changes” (Judy). However, with the appropriate follow-up outside the system and on the ground, high-level actions can lead to tangible progress at the local level. The development of the IDUIT (Implementing Comprehensive HIV and HCV Programs with People who Inject Drugs: Practical Guidance for Collaborative Interventions) guidelines⁷ is one good

example, where people who use drugs were involved and consulted to develop what has now been adopted as normative guidance by the Global Fund. By conducting training sessions with community-based advocates, “we’ve seen [IDUIT] lead to... real substantial changes, I think, at the national level... having community advocates using it to advocate on harm reduction policy in their country, and seeing some wins like the inclusion of buprenorphine” (Judy). Often the progress made can only be recognised with hindsight: “When you’re in it, you don’t necessarily believe you’re getting anywhere... But when you look back, in retrospect, a lot has changed in just a few years” (Angela). Indeed, the message from many activists was that meaningful change, especially if enacted through official channels, has taken huge amounts of time to achieve. One activist recounted how searching for funding and an institution to implement a naloxone programme in Denmark “altogether took nine years” (Joergen) since an initial discussion between activists and doctors.

Therefore, mobilisation by activists working at the higher-level can help to secure gains for people who use drugs working on the front line. It may particularly be the case for countries where the government is extremely oppressive and prohibitive that working strategically at the regional or global level is the only way to maintain pressure for change. For example, a case has been ongoing for several years in the European Court of Human Rights, brought by Russian activists against the Russian government after being denied access to methadone and buprenorphine.⁸ While the court ruled in the Russian government’s favour, “participation in this process has... empowered people and inspire more people to actively fight for their human rights” (Anya). Some activists, even in oppressive contexts where positive changes have been limited or even reversed, discussed being encouraged by some tentative worldwide trends towards decriminalisation, instilling them with an optimistic

7. INPUD (2017). Implementing Comprehensive HIV and HCV Programmes with People Who Inject Drugs. Available at: <https://www.inpud.net/en/iduit-brief-guide-people-who-use-drugs>

8. V. Junod & O. Simon. (2020). *Abdyusheva and Others v. Russia: a Sadly Missed Opportunity*. <https://archive-ouverte.unige.ch/unige:131253/ATTACHMENT01>

sense that progress towards ending prohibition is “just a matter of time” (David).

Yet for many, the political stasis on drug policy reform in most countries and globally has meant that many activists have had to bypass the official avenues in order to undertake the changes that are desperately needed at the local or neighbourhood level. As one activist stated, “We can’t wait for the slow tick-tock of politics anymore” (Robert). Indeed, participating activists related how they had, for example, set up illegal drug consumption sites in the face of government inaction in Canada, or “brought in Naloxone illegally and distributed it amongst people who use drugs so that they wouldn’t die” (Zoe). While these activists spoke elsewhere of the importance of advocacy within official high-level spheres, their direct actions to bring about change demonstrate the importance of “local solutions to local problems” (Simon). Indeed, in countries like Canada, what began as an illegal project of a drug injection site changed laws and policies around opening sites and around overdose response “overnight” (Zoe). This is a good example of “taking power back” (Robert): “It’s time we no longer allow ourselves to be invited to others’ table. It’s time we started inviting them to *our* table, right?”

The importance of context as an enabler or barrier to successful activism

As the preceding sections on progress and challenges faced by the drug user rights movement show, there are significant tensions, dilemmas, complexities and differences of opinion in terms of what the movement stands for and the ways that meaningful change can be achieved. Inevitably, such a brief report seeks to find commonalities and unifying threads in participants’ narratives in order to tell a coherent story of the movement. However, this section seeks to focus specifically on differences across the contexts and populations of people who use drugs, and to demonstrate how

the ability to put lessons learnt into practice depends on a range of political, legal, socio-economic, cultural and structural factors.

The resilience of activists in the face of extreme oppression

Although sharing many perspectives and examples of successes, activists’ geopolitical context clearly emerged as the most significant determinant of possibilities for empowerment, advocacy and change.

Activists working in South and South-East Asia for example spoke of the conservative laws and policies that have silenced and repressed drug-user led activism, which “make it very difficult to be very vocal and get ourselves recognised as a legal entity” (Anand). They drew attention not only to the widespread compulsory drug detention centres in many South-East Asian countries, but also private rehabilitation centres, where many coercive practices and human rights violations have taken place. Activists based in this region saw clear evidence of ‘copycat politics’, with extrajudicial killings of people who use drugs in the Philippines catalysing authoritarian, repressive policies in other Asian countries, such as Sri Lanka’s reintroduction of the death penalty for drug offenses.⁹ This climate has made it extremely challenging to engage with those in power, who oppose any notion that “drug users can be part of the change” (Raheem) and whose policies often contravene both scientific evidence and human rights principles. In countries like Afghanistan, the criminalisation and ostracisation of people who use drugs has prevented any harm reduction initiatives from getting off the ground. In one participant’s words, “criminalisation does not allow us to help our community. Our organisation does not have a sufficient budget to deal with harm reduction in Afghanistan” (Raheem). In the absence of government support, international

9. Human Rights Watch (2019). Sri Lanka: Resuming Death Penalty a Major Setback. Available at: <https://www.hrw.org/news/2019/06/30/sri-lanka-resuming-death-penalty-major-setback>

NGOs such as Médecins du Monde have stepped in to provide methadone treatment.

This is similarly the case in certain African countries, where new activist leaders and organisations have emerged relatively recently. In the absence of government support in countries like Tanzania, Médecins du Monde has established a centre providing harm reduction services, such as sterile needles and syringes, alongside antiretrovirals. People who use drugs continue to face huge challenges, being both criminalised and pathologised, and yet by engaging with the government and working through bodies like the Tanzania Country Coordinating Mechanism for the Global Fund, “we are at least being heard... and listened to” (Happy). There have also been particular challenges in South Africa, where funding for people who use drugs has been very closely tied to the HIV/AIDS movement, in the country with the highest number of people in the world who are living with HIV. One participant referred to a schism opening up between people who use drugs and the HIV movement, seeing “the move of HIV activists to deny the rights of people who use drugs. I’m seeing an attempt to distance the HIV movement from the people who use drugs movement... As HIV funding decreases, so funding for drug user movements decreases, but the two are inextricably linked” (Shaun). Indeed, activists here highlighted how many of the tangible successes for people who use drugs in South Africa have been achieved through leveraging HIV prevention funding. Although there has been progress in engaging with the government, “very little funding or support for this movement comes from South African soil. Most of it comes from international funding” (Angela). While the relatively new status of the movement in South Africa has presented challenges, one participant felt that the speed of progress owed much to learning from activists in other parts of the world: “I think we are lucky. We got to learn from a lot of other countries... I think the best thing is that we didn’t have to invent anything, it’s all been

done before. And, we were lucky we could just run with it... A lot has happened and, we have a long way to go still. But we’re moving” (Nelson). This demonstrates the importance of international sharing of lessons within the movement for people who use drugs, while remaining mindful of how context inevitably shapes what is achievable.

In Eastern Europe and Central Asia, activists discussed how the political climate has not only repressed people who use drugs themselves but also civil society activism more broadly. As an activist in Russia commented, “the obvious problem is that the country is run by a dictatorship, so it’s not much that the civil society movement do, but they are doing their best” (Anya). In this context, not only are people who use drugs and practices like harm reduction criminalised, but also activism by people who use drugs; in Russia, “people are being arrested just for protesting for the rights of people who use drugs” (David).

Despite such overwhelming top-down pressures, activists in these contexts were clearly not deterred and saw such oppression as a spur for political resistance. Additionally, some held out hope of getting through to governments: “We need to remain engaged with key stakeholders, UN agencies, and the extent possible with the government. I know it’s very challenging. It’s easier said than done, but then we still need to ensure that we are there to show the human face of who we are, you know, and how we contribute to the community and our society” (Anand). Activists based in relatively more liberal countries frequently expressed their solidarity with and admiration for activists based in countries experiencing particularly acute oppression, such as the Philippines, Russia, and the US; as one participant stated, “those people who are just being traumatised and brutalised beyond belief, and they’re still standing up fighting... I think that’s mighty and I’m really proud of them all” (Jude). Indeed, several participants mentioned the importance of celebrating and amplifying the work being undertaken in much more oppressive and lower-resource settings, where “drug user

movements work, and they are alive, and they doing a wonderful job under very bad conditions” (Dirk).

Effects of the War on Drugs on activism in Latin America

The situation in these countries may be compared and contrasted with the Latin American region, where the extreme violence of the global ‘War on Drugs’ has dominated domestic and regional policies and discourses around drug use. Activists advocating for drug user rights are often stereotyped as being “drug traffickers” (Ernesto), and people who use drugs have become “guilty by association” because of the “big cloud” (Brun) of the War on Drugs. As much of the drug use across the region is non-injecting drug use, and rates of HIV among people who use drugs communities have been low, activists related that the region has historically “been left out of most of the harm reduction initiatives and grants, and ... the Global Fund processes” (Ernesto). This has made it more challenging to formalise activist networks led by people who use drugs, with the Latin American Network of People who Use Drugs starting up relatively recently, in 2011. With limited resources, it has been challenging to organise not only at the regional level but even nationally. The two participating activists from Latin America drew attention to the use of drugs among the continent’s indigenous groups. For example, in Mexico, drug use as an element of “traditional plant medicine” (Brun) is well-documented and established. However, drug use has since taken on a “very decadent and obscure aspect” and, amid the violence of the drug war, become symbolically associated with the “sin” and “deviance” (Brun) of modern, Western culture and dissociated from traditional drug use. As such, it is challenging to build diverse coalitions of people who use drugs, for example bridging between users of traditional psychedelics like peyote and “street drugs” such as cocaine and heroin. This means that while left-wing governments, such as Uruguay, have made moves towards legalisation of cannabis and harm reduction, the politics of drug use are complex and left-wing governments

are not automatically supportive of drug user rights, as they may see “drug use as part of the capitalist movement” (Ernesto). In addition to differing mindsets around drug use, there are practical challenges for activists based in large cities seeking to represent rural indigenous communities, since the lack of funding and organisational infrastructure for activism led by people who use drugs has made it very difficult to “synchronise and align” (Brun).

Persistent discrimination and inequalities in more permissive contexts

In contrast, activists from more inclusive welfare states such as Norway, Denmark, Germany and the Netherlands, more removed from the crises of the global drug war, naturally felt more included in decision-making on drug policy. In countries like the Netherlands, partial decriminalisation has contributed to a more “relaxing situation” for people who use drugs, meaning “we don’t need to hide ourselves that much” (Theo). At the same time, “we are not looking out for other people anymore, and that’s a negative part of it” (Theo), implying that as people who use drugs have become more integrated into the mainstream, the drug user rights activist community may have become less strong and defined. Even in a country like Norway, described as “pragmatic, diplomatic and cooperative” (Arild), changes can feel slow, political opposition remains to initiatives such as drug consumption sites, and many people who use drugs are marginalised, in poor health, and subjected to police harassment and criminalisation.

Indeed, many of the activists in relatively more permissive societies spoke of some of the paradoxes and discontinuities in terms of how people who use drugs are considered and treated as citizens. For example, in Vancouver, Canada, there has been significant progress in changing hearts and minds, and establishing safe drug consumption sites. For example, harm reduction policies are now considered ‘vote-winners’: “you cannot win a civic election ... if you’re going to come in and shut down all the, harm

reduction and the injection sites in Vancouver” (Ann). However, access is lacking in terms of “access to toilets and... housing. It’s just bizarre that... those are so hard to get. They’re much harder to get than an injection site” (Ann); in these contexts, seemingly more controversial initiatives have been easier to advocate for and achieve than comprehensive access to basic services for people who use drugs. Furthermore, reduced and more select criminalisation in more liberal contexts such as Canada and Australia may further intensify disparities in the disproportionate incarceration of certain groups, such as indigenous and Black people who use drugs.

Political turmoil and its implications for drug user rights activism

Despite these huge discrepancies in the experiences of drug user rights activists across and within geographies and contexts, there was an awareness that change can come very suddenly, and neither increasingly progressive nor regressive policies are a given when drug policies can shift so rapidly in response to a political transition. One example provided by participants of policies moving in the wrong direction was the ban on opioid substitution therapy in parts of Ukraine after annexation by Russia. At a more local level, activists can find they are working effectively in collaboration with policymakers, only to suddenly find themselves “thrown under the bus” (Nelson) in order for politicians to make a statement, since “unfortunately in politics they play with what’s popular, not with what’s correct” (Nelson). Participants had also experienced instances where policymakers and authorities had promised to deliver on activists’ demands for change, and the activists had consequently de-escalated their protests and organising, only to find that no policy changes materialised. One activist associated with Georgia’s White Noise movement had experienced this, with the result that “many people who had trusted White

Noise, they lost it” (David) and momentum for drug policy reform came to a halt. Given the upheaval that political changes and reversals can wreak for movements led by people who use drugs, participants suggested it is important to work strategically where possible to ensure continuity. For example, one activist suggested “We need standard operating procedures that will stay there to lead the law so that any leader who comes after... can also follow what the other one has implemented” (Happy).

Learning from past generations, inspiring future generations

A final theme which featured strongly across all participants’ accounts, and which cuts across the previous themes, was the importance of activists telling their stories, sharing their insights, and inspiring and training other people who use drugs to become involved in and lead their movements.

Upskilling and training activists is important not only for understanding how the relevant governmental, legal, health-care and research systems work but also for instilling newer advocates with a sense of confidence and self-belief. As one participant stated, “By getting the training, people improve their confidence, and then they feel... yeah, I can be an agent of change” (Andria). As another participant commented, “You have to be willing to bring other people up in this movement... You’ve got to be transparent and share that information and teach” (Hollis); this could be, for example, by bringing younger or newer advocates along to high-level meetings with donors in order to share and pass on knowledge and experience. Many experienced advocates wanted to provide a newer generation with the kind of support and advice from which they themselves had benefitted earlier in their career: “A lot of younger advocates come with great new ideas and from different backgrounds, and we owe it to them, just like how my mentors took

Key successes of the movement

- In the Netherlands, activists convinced government ministers to fund a harm reduction service led by people who use drugs starting from the late **1970s**, and then solidifying in the **1980s** in response to HIV/AIDS. “We were firstly only focusing on harm reduction on HIV prevention... and then we found out it’s better to have a broader view on the project, and to fight for the interest of users” (Theo).
- Activists representing people who use drugs, including Marsha Burnett and Omayra Morales, came together to address the **1998** UN General Assembly Special Session on ‘the World Drug Problem’: “they gave these really fantastic dynamic speeches, saying, ‘This is how your policies are actually affecting our lives’” (Andria).
- In Vancouver, Canada, activists led the founding of Insite, the first government-sanctioned supervised injection site, in **2003**. This built on more informal supervised injection sites activists had established in the 1990s. “We had illegal sites before that, but having the government pay for it was a big deal. There’s other downsides to it - they wouldn’t open another one for over 10 years...” (Ann), meaning that organisations such as VANDU have continued to run informal, non-government-sanctioned supervised injection sites in Vancouver. Later, in 2017, in Moss Park, Toronto, activists set up an unsanctioned supervised drug consumption site based out of a tent and trailer in response to soaring overdose deaths. In the face of inaction from authorities, “we went ahead and opened one ourselves” (Zoe).
- In the UK, activists who use drugs worked with primary care doctors to establish concrete guidelines for working in primary care with people who use cocaine and crack, published in **2004**. “The GPs [primary care doctors] were able to lose their stigma and

discrimination against us as crack users, because they started to work with us and understand us” (Mat).

- After fifteen years of negotiations between activists and government in Denmark, the Prime Minister announced in **2007** that heroin treatment would be introduced, and since **2010** people have access to heroin on prescription. The government said that the programme would be “permanent, and not a trial – because you can’t give users heroin and take it away again” (Joergen).
- Working with the government’s National AIDS Control Organisation, activists helped develop the first standard operating procedures for implementing buprenorphine among people who use injecting drugs in India in **2008**. “The activist community has been very active and very, very strong when it comes to coming together and advocating with the government. They have been able to... recently gain access to take-home doses” of buprenorphine in Northeast Indian states such as Manipur and Nagaland (Charanjit).
- Thanks to activists in Tanzania, in **2011** a methadone programme was launched, with an amendment to the drug bill meaning that people would receive treatment if found in possession of drugs, a “great achievement” (Happy).
- Activist organisations such as VOCAL NY played a significant role in pressuring New York state to expand its Hepatitis C testing law, in **2014**, and continue to push for treatment access for everyone living with Hepatitis C; and “there are other examples of that throughout the country” (Robert).
- Since 2016, there have been moves from the Norwegian government to decriminalise drug use and shift “from punishment to help”, thanks to tireless activism from people who use drugs. “The Health Minister [Bent Høie] answered us in the media and said,

okay, when all of you oppose criminalisation, then I must be for decriminalisation of use and possession” (Arild).

- In a previous iteration of South Africa’s National Strategic Plan, there was just one sentence about evidence-based programmes for people who use drugs. However, now thanks to activists’ efforts to raise awareness regarding the health of people who use drugs, “in the latest plan that will be implemented [from 2017] until 2022, for people use drugs, interventions are mentioned; needle and syringe programs are mentioned; and human rights abuses are mentioned” (Nelson).
- Activists were involved in shaping and producing the Implementing Comprehensive HIV and HCV Programmes with People Who Inject Drugs (IDUIT), published in 2017 and adopted as normative guidance by the Global Fund. “I think it was unusual in that the very process of it, and of developing it, was consultative and did involve people who use drugs” (Judy).
- The work of Dan Bigg, who passed away in 2018, to distribute naloxone and thus prevent overdose deaths was mentioned by many participants as an example of direct action that saved thousands of lives.

me in and showed me the ropes” (Zoe). This is crucial to ensure the sustainability of the movement, helping contribute to an “organic transitioning of leaders” (Bikas) rather than an exclusive club. For some participants, training new leaders was the top priority from the point of view of sustaining the movement: “The first job of every leader is to find more leaders” (Mat). Indeed, leaders have generally amassed significant tacit knowledge, expertise and networks, and so when leadership changes, there can be big “gaps in communications” and a loss of “institutional memory” (Simon).

Several participants also discussed how much younger advocates have to teach the older generation, suggesting that older activists should have “an open arms policy for new ways of thinking” (Brun) and listen and be receptive to younger advocates’ “drive, passion... and experience” (Angela). Indeed, there was a sense from many participants that learning can be a horizontal, multi-directional process, rather than a vertical process; activists need to learn not only from the movement’s leaders, but also from those they represent, and all the voices of people who use drugs. As one participant said, “Every place is a school, and every person is a teacher... listen to the voice of the grassroots, what happens on the grassroots level. You cannot avoid their voice” (Edo). Participants frequently voiced their admiration for activists working within contexts where activism by people who use drugs is more burgeoning and less well-established, and hoped that these newer and older generations could mutually learn from and be inspired by each other. One activist was encouraged by evidence of knowledge and lessons being shared between different areas of the global movement: “When I see now what’s going on in Africa, if you see the many user groups organising themselves, trained and getting advice from us, that makes me very happy and optimistic... We can learn from them now and they don’t have to make the same mistakes as we did, and of course they will make mistakes, otherwise you don’t learn... We still have a long way to go, but we’re getting somewhere” (Tonny).

Finally, with the movement having lost many leaders to “failed policies” (Robert), participants emphatically spoke of “standing on the shoulders of giants”, and discussed how leaders in the movement have provided invaluable examples and lessons of how to push for change and empowerment in the face of prohibition and oppression. The fact that they “were brave enough to risk their life” (Edo) and “came up with terrific, creative ideas” (Ann) has inspired activists to “continue their fighting” (Edo) in hugely challenging and dangerous situations. Stories of success and progress allow people who use drugs to “sit up a little taller” (Ann), hence the importance of memorialising and sharing the life stories and pioneering work of activists who have gone before. Indeed, remembering specific activists’ unique and distinctive approach can be a guide to how to act in the here-and-now, a reminder to keep those in power “on their toes and doing the right thing” (Andria). Memorialisation not only reminds activists of the importance of this fight, but is also vital in the context of helping address the trauma and bereavement the community of people who use drugs has experienced after the deaths of so many loved and respected fellow activists. Often, activists have achieved a huge amount on behalf of a small, specific, highly localised community of people who use drugs; they are “the unsung heroes of our movement” (Mat) who deserve broader recognition. Keeping the stories of these activists alive, and using them to inspire and engage people within and outside the movement to end the drug war “is the best way we can honour people who’ve gone on, to continuously talk about them, to not let their stories die” (Zoe)

Conclusion

The 34 participants’ accounts richly demonstrated the overlapping and contrasting lived experiences of activists fighting for the rights of people who use drugs around the world. Perhaps the most common thread unifying these experiences was a sense of collective pride, hope and resilience, even in contexts where participants were more pessimistic about the prospect of positive, meaningful change. The participating activists’ accounts illustrated many tensions and fault lines in the movement that become intensified due to criminalisation and marginalisation, for example between the activist and their family, between advocates working within official, more professionalised systems versus those outside, and between and within communities of people who use drugs. That said, participants expressed a clear determination to remain united, and to rally around a common goal of ending prohibition and the failed policy of the ‘War on Drugs’. To this end, memorialising and paying tribute to previous generations of leading activists can inspire newer activists to become involved in the movement, and to continue what is often an exhausting, emotionally draining fight, given the slow pace of change and even in some countries, regressing towards more punitive laws and policies. However, many activists recognised that change may seem limited in the present, but looking back can provide a sense of how far the movement has actually come in overcoming challenges and achieving success. Participants suggested that it is vitally important to keep the stories of the previous generation of activists alive, not only to honour these pioneers and empower newer advocates but also to win over hearts and minds to the notion of more humane and progressive drug policies. Reflecting on the strength of previous activists and the movement overall generated a profound sense of hope for participants, a belief perhaps that with continued activism, progress towards ending prohibition and the war on drugs is only a matter of time.



The International Network of People who Use Drugs (INPUD) is a global peer-based organisation that seeks to promote the health and defend the rights of people who use drugs. INPUD will expose and challenge stigma, discrimination, and the criminalisation of people who use drugs, and its impact on the drug-using community's health and rights. INPUD will achieve this through processes of empowerment and advocacy at the international level, while supporting empowerment and advocacy at community, national and regional levels.

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