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Author(s) Morrow, Marina; Malcoe, Lorraine Halinka

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13 Ethics, Research, and Advocacy: The Experiences of the NAOMI Patients Association in Vancouver's Downtown Eastside

SUSAN BOYD, DAVE MURRAY,
AND NAOMI PATIENTS ASSOCIATION

Introduction

CAUTION
This may have the ability to attain?
The path to freedom is there, if one chooses.
The tools were not given readily and the road isn't clear.
Please give us a compass, a clear day,
and a home.
NAOMI, she was a gift of freedom, a taste,
but she didn't give me her number!!!

(S., cis male NPA member)

The above poem was written by a former participant in the North American Opiate Medication Initiative (NAOMI), the first clinical trial of heroin-assisted treatment in the Downtown Eastside of Vancouver, British Columbia, Canada. The participant later became a member of the NAOMI Patients Association (NPA). The poem expresses the freedom that the participant experienced while part of the clinical trial. It also points to his dismay when the clinical trial ended and a permanent heroin-assisted treatment program had not been established.

The NPA, located in Vancouver's Downtown Eastside neighbourhood, is an independent group that formed almost three years after the NAOMI heroin-assisted treatment trial had ended. When patients exited the NAOMI trial, they were denied the medicine that had proved effective for them. The NPA began organizing former trial participants to support one another and to advocate for continued treatment. However,

the association's purpose quickly expanded to include original research and more. In this chapter we highlight the ways in which the NPA in the Downtown Eastside is part of a larger social movement that is pushing the boundaries of academic and mainstream understandings of drug use, treatment, and policy directions. We draw on the brainstorming sessions and writing workshops conducted by the NPA in the fall of 2011. In the first section of the chapter is a brief discussion about the social justice movement to change drug policy. The next section discusses the Downtown Eastside and ethical considerations. We then turn to the four areas of work by the NPA, including details of the group's formation and their research results, advocacy, and recommendations for better drug-trial ethics, using the example of the group's efforts to improve conditions within a new trial, SALOME. The chapter concludes with a discussion of ongoing advocacy efforts by the NPA, which changed its name to SALOME/NAOMI Association of Patients (SNAP) in 2013, as it strives towards social justice for its members and others who may be negatively affected by drug research, treatment, and policy.

Drug Prohibition and Its Failure

The emergence of a group like the NPA springs from a long history of the unjust treatment of those in Canada who use criminalized drugs. More than a century ago, in 1908, Canada passed the Opium Act with little parliamentary debate. A number of scholars argue that Canada's first narcotic legislation was shaped by race, class, and gender fears rather than pharmacological evidence of harm, in order to support the regulation of opium (N. Boyd, 1984; S. Boyd, 2015; Comack, 1986; Giffen, Endicott, & Lambert, 1991). Within a few years, law-abiding individuals who had used these substances legally became criminals. Meanwhile, doctors were stripped of their right to prescribe narcotics for drug maintenance purposes to anyone who was addicted. Over time, the Royal Canadian Mounted Police (RCMP) became both enforcers of Canada's new drug laws and primary knowledge producers about criminalized drugs and the people who used them. Thus, law enforcement played a significant role in shaping drug policy in Canada (Carstairs, 2005; Giffen et al., 1991; Nolan & Kenny, 2003). Harsh prison sanctions, rather than treatment, became the norm, and those labelled criminal addicts in Canada faced cold turkey in a prison cell. From 1928 to the early 1970s the RCMP's division of narcotic control maintained case files for known "Addicts." These files contained detailed information, including police and court records and correspondence with doctors (Carstairs, 2005;

Giffen et al., 1991). Later, psychiatric knowledge also became instrumental in supporting the status quo of a punitive system. Rather than challenge the Division of Narcotic Control and the RCMP, psychiatry represented criminal addicts as doubly deviant – criminal *and* pathological – and as best treated in secure prison units (Stevenson, Lingley, Trasov, & Stansfield, 1956).

However, as the medical knowledge of drug addiction grew, methadone maintenance programs were eventually established in some urban areas of Canada in the late 1950s and the 1960s. Still, since their inception, these maintenance programs have been compromised by rigid rules, shifts in policy, and ideologies that continue to represent patients as deviant. Although methadone is beneficial for some long-time opioid users, it clearly does not work for everyone, and retention is poor (Carter & MacPherson, 2013; Luce & Strike, 2011; Reist, 2011). Thus, heroin-assisted treatment continues to be advocated for some chronic opioid users (Strang, Groshkova, & Metrebian, 2012) as a more ethical and just option.

For this reason, heroin-assisted treatment (HAT) became an area of greater interest among researchers seeking better ways to treat some chronic opioid users (Strang et al., 2012). The benefits of HAT are backed by a plethora of international studies demonstrating that it is safe and effective for these users (Strang et al., 2012). In Vancouver advocates felt that conventional treatments, such as methadone maintenance, and abstinence from drug use should not be the only treatments available to improve health. The NAOMI HAT clinical trial (2005–8) sought to test whether HAT was an effective treatment for some patients in Canada. In January 2011, participants who had taken part in the trial decided to form the NPA to support one another directly and also to advocate for a permanent HAT program. At the very least, they demanded that HAT trials should transition into permanent programs, as they have done in every other country, rather than abandon patients at the end of the trial without support. Their efforts marked a new point in Canada's drug policy history: the NPA transformed former HAT patients and research subjects into knowledge producers and social justice advocates.

Social Justice Movement for More Ethical Drug Policies

In order to understand the many strands of the NPA's work for ethical policy, it is vital to understand the global social justice movement to change prohibitionist drug policy and its reliance on criminal law. In Canada the first contemporary challenges to prohibitionist drug policy emerged in the 1950s in Vancouver, BC, in relation to heroin addiction, and in the 1960s

and 1970s nationally in relation to cannabis use (Martel, 2006). However, it was not until 1981, with the establishment of the first drug users union, Junkiebond, in Rotterdam, the Netherlands, that heroin users formally came together to advocate for more ethical drug policy. Junkiebond sought change at both the local and the national levels by demonstrating against coercive treatment and establishing the first needle exchange in the Netherlands in 1984 (Friedman et al., 2007). Later, similar peer-based, drug-user organizations that demanded ethical services, treatments, and an end to drug prohibition were established in the United Kingdom, Australia, Europe, Canada, and other nations.

In Canada one neighbourhood in particular became the site of many forms of contestation of the drug prohibition's punitive framework: Downtown Eastside in Vancouver, a diverse community and Canada's poorest urban neighbourhood. It has a visible street scene, and homes there, for many people, consist of single-room-occupancy establishments. The street scene is directly related to gentrification and cutbacks at the federal, provincial, and local levels, which have led to poverty and a lack of social housing and private space (Culhane, 2011; Pedersen & Swanson, 2010). For women, the neighbourhood is the site of much violence, often linked to everyday life but also to the sex trade; poor and Indigenous women are most affected (Bennett, Eby, Govender, & Pacey, 2012; Bungay, Johnson, Varcoe, & Boyd, 2010). Negative outcomes of drug prohibition – police profiling and the criminalization of heroin, cocaine, and other drugs – are played out on the streets daily, rather than behind closed doors. Thus, owing to their visibility, the poor and marginalized people in the Downtown Eastside are more vulnerable to arrest, imprisonment, and occasionally drug-related violence (S. Boyd, 2015; Carter & MacPherson, 2013; Oscapella & Canadian Drug Policy Coalition Policy Working Group, 2012) – an unethical and harmful outcome.

However, it would be a mistake to only describe the neighbourhood in negative terms. It has also long been the home to many families, friends, and cultural institutions and the site of a number of resistance movements highlighting issues such as gentrification and the lack of affordable housing, violence against women, drug policy, and police brutality (Bennett et al., 2012; Boyd, MacPherson, & Osborn, 2009; Howard et al., 2002; Pedersen & Swanson, 2010; VANDU, 2013). Activists in the Downtown Eastside continue to strive for improvement of the conditions of people living in the area and to advocate for structural change. The neighbourhood also has a thriving artistic community that hosts plays, poetry readings, storytelling, art shows, films, music events, and annual cultural events.

In the mid-1990s activists came together in the Downtown Eastside to form a social justice movement for change in drug policy (Boyd et al., 2009). They demanded an end to punitive drug prohibition and campaigned for the provision of social and health supports, including more harm-reduction services, such as a safer injection site and heroin-assisted treatment. They sought recognition and action to stem the public health emergency in the neighbourhood, which included alarming rates of drug overdose, as well as transmission of the human immunodeficiency virus (HIV) and the hepatitis C virus. Canada's first drug users union, the Vancouver Area Network of Drug Users (VANDU), emerged in 1997 from this activism (Boyd et al., 2009).

In response to a public health emergency in the Downtown Eastside in 1997, harm-reduction services in the neighbourhood did increase. Harm reduction seeks to reduce the harms associated with the use of drugs (both legal and criminalized) and to offer practical, non-judgmental services in which abstinence is not primary, but one option among many. Owing to the advocacy of VANDU and other key organizations and individuals, such as Bud Osborn, in 2001 the City of Vancouver recommended the establishment of safer injection sites and other harm-reduction services, such as HAT (Boyd et al., 2009). In 2005 the first HAT clinical trial, NAOMI, opened its doors in the Downtown Eastside.

The Emergence of NAOMI Patients Association

All NPA members were once research subjects in the NAOMI HAT trial. As mentioned previously, NAOMI was a ground-breaking clinical trial that tested whether HAT could lead to benefit for the people suffering from chronic opiate addictions who had not benefited from other treatments. Similar to earlier clinical trials outside of Canada, the NAOMI findings demonstrated that HAT was a safe and effective treatment that improved physical and psychological health among participants (NAOMI Study Team, 2008). Other improvements were also observed, including the decreased use of illicit "street" heroin, reduced criminal activity, and the spending of less money on illegal drugs. At that time, the Canadian NAOMI trial was the only heroin-assisted study that failed to continue offering HAT to its participants after the study had ended (SALOME, 2012b). This occurred despite evidence suggesting that continued HAT treatment is beneficial and that ongoing involvement by "experiential" drug users is essential in order to develop ethical drug policy. For example, the 2005 publication *Nothing about Us without Us: Greater,*

Meaningful Involvement of People Who Use Illegal Drugs; A Public Health, Ethical, and Human Rights Imperative, by the Canadian HIV/AIDS Legal Network (2005), is a manifesto demanding that experiential users be invited to collaborate at all stages of research and program development. In 2011, VANDU also developed ethical guidelines for researchers who sought to work with the organization. The World Health Organization (WHO) and UNAIDS's 2011 report *Ethical Engagement of People Who Inject Drugs in HIV Prevention Trials* make similar recommendations, including that the research subjects of clinical trials be provided with continued treatment at the end of the trial if the medicine or treatment is found to be effective. In fact, as early as 2006, Dan Small and Ernest Drucker wrote about these issues in relation to NAOMI. They noted that there was a large body of evidence demonstrating the effectiveness of HAT. They also noted that NAOMI failed to provide access to a permanent HAT program after patients exited the trial (even when the results of the trial were positive). They also questioned participants' consent under duress (Small & Drucker, 2006).

Responding to this failure and the needs of some participants who had been research subjects in NAOMI, Dave Murray established the NAOMI Patients Association in 2011, almost three years after the HAT trial had ended. Murray saw many NAOMI participants struggling after they exited the trial; thus, he sought to provide a place to offer them support. He and other NPA members established a group with a set of goals that are outlined in the following mission statement (Boyd & NPA, 2013):

> We are a unique group of former NAOMI research participants dedicated to:
> - Support for each other
> - Advocacy
> - Educating peers and the public
> - Personal and political empowerment
> - Advising future studies (heroin and other drugs) and permanent programs
> - Improvements in consent and ethics
> - The right to a stable life and to improvement in quality of life

NPA's goal is to have alternative and permanent public treatments and programs, including HAT programs.

These goals demonstrate the group's commitment to ethical change in drug policy. Below, we discuss in detail the four ways in which these goals have been put into action by the association: member support, social research, advocacy, and the formulation of policy recommendations.

Member Support

From the beginning, the NPA was intended to help members. The group of (men and women) meets on Saturdays in the common meeting room at the VANDU rental space in the Downtown Eastside. Ten to forty members attend each meeting, and men outnumber women, reflecting the NAOMI study's population. All of the members are on social assistance or disability benefits. Many have poor health, the majority live in single-room-occupancy units or social housing in the area, and some are homeless. Because NPA has no formal outside funding, VANDU's support has been essential. VANDU provides a safe place for NPA members to meet, small stipends for member participation, and representation on the VANDU board. NPA and VANDU are also members of provincial, national, and international organizations that advocate for the rights of people who use criminalized drugs, such as the BC-Yukon Association of Drug War Survivors, the Canadian Association of People Who Use Drugs (CAPUD), and the International Network of People Who Use Drugs (INPUD).

Research for Social Change

In May 2011 the NPA decided to undertake its own research about members' experiences as NAOMI research participants. NPA members met with co-author Susan Boyd in March 2011 and invited her to work with them. After much discussion about community-based research for social change (see Carroll, 2004) they decided to conduct qualitative research consisting of focus groups, individual interviews, brainstorming sessions, and writing workshops with NPA members. The NPA members also planned to co-author a report based on the research and their experiences (see NPA & Boyd, 2012).

Below, we draw from the brainstorming sessions and writing workshops. In addition, we include other writing pieces that were submitted at NPA meetings from April to November 2011. At the NPA writing workshops, which were held during the group's weekly meetings, members wrote poems and short essays about their lives. Sandy Cameron's poem "Telling Stories" was adopted by the NPA to guide its research process (Cameron, 2013). The NPA writing workshops were modelled after other ongoing workshops in the neighbourhood. Many organizations in the Downtown Eastside, including VANDU, have conducted writing workshops so that the experiences of residents are heard and shared in and outside of the

area. These workshops are also political practices that bring to light people's activism and personal struggles, including their fight for social justice.

NPA WRITING WORKSHOPS

In the writing workshops members were given a pen and paper. Workshop leaders explained to participants that any form of writing was acceptable (poetry, story, one line, etc.) and that participation was voluntary. The NPA group members surprised even themselves, and a proliferation of stories emerged.

WAITING, CREATIVITY, FRIENDSHIP, EVERYDAY LIFE

A number of NPA members wrote about their childhood and the human condition, often with a focus on the need for connection and self-expression.

Untitled essay

When I close my eyes I see a young boy with a fishing pole walking the booms on the lake. He's surrounded by mountains, all around is clear clean water and most of all there's LIFE all around.

The water and air is busy with beings with a single purpose. That's the point, they have a purpose. All my life I've wondered what my purpose was/is. All my life I've tried everything I could to find out what my purpose is. I start out with my emotions on high then when I realize that what I'm doing isn't it. I crash hard.

Self-realization means that we have been consciously connected with our source of being. Once we have made this connection, then nothing can go wrong. No one can ask another to be healed but he can let himself be healed, and thus offer the other what he has received. Who can bestow upon another what he does not have?

And who can share what he denies himself?
That which is injurious, loses its capacity to harm.
When it is brought into the light. (L., cis male NPA member)

Peaceful Sunshine

Peaceful Sunshine
Darkened Skies.
Cloudless Sundays
in July's Days.
The Sun so hot
While the water so cold. Just to cool down is a wondrous way to pass
the time away.

One day at a time or until we have peace and happiness as well all should have with Every Sound with every Speech with everyone Listening to me all in tune all in time to only Bring out the Best in All of Us. (R., cis male NPA member)

Other members combined personal insights with accounts of the confines of conventional drug treatment, such as methadone maintenance.

A Day in the Life
The sun is shining. I'm going to the beach. There's families here and the waves are awesome. It smells like my Nova Scotia home. Seaside odours, fish & chips, sail boats in the harbour and tankers going to trade all over the world.

Oh no! I'm not feeling well, all of a sudden my nose is running, my bones are aching. It's the liquid hand-cuffs. Methadone. I forgot because the sun was shining, and I felt free. But I'm not. It was only a dream. (D., cis female NPA member)

In Canada, and especially in the Downtown Eastside, drug use is gendered. For example, marginalized women in the neighbourhood who consume crack cocaine have less access to health care and harm-reduction services (Bungay et al., 2010). Another NPA member wrote about the conditions of her life as an adult woman living in the Downtown Eastside (DTES) for fifteen years. She writes about the impact of using criminalized drugs in this space and the effects of the prohibitionist policy:

From my heart
I have been a "resident" in the DTES for 15 years now and still every day I am in some way or other shocked, surprised, stunned or confused by something I either see, hear, or experience personally. Not all bad! Please don't misunderstand – a lot of interesting, beautiful and yes sometimes flat out great things have gone on over these 15 years or so.

One thing however stands out far above everything and that is how so many of us still have our "humanity" intact.

Most of us have been lied to, robbed, beaten up, ripped off, blamed wrongfully, accused of, given credit for or not given credit for all sorts of stuff. Yet, here we are – still saying "Hi, how are you?' – sharing whatever we can, trusting the next "guy" and yes – trying to get that 1 hoot of hoots.

For myself, dope has somehow become less and less important – probably because it has been less and less good dope. My down habit seems to be less (amount-wise) as time goes by.

Maybe it has something to do with losing "friends" to dope or dope-related circumstances – who really knows? By the end of today (God forbid) there could be 1 less of us here. The survival instinct and skills we have acquired are amazing. We seem to be a bunch of "energizer bunnies."

I know most of us are physical survivors of massive amounts of sugar – even though the majority of us are seriously underweight. We live on the stuff. It really should be illegal too. Just joking. Joining another important survival skill we need.

At the beginning, middle and end of each day, I find myself just shaking my head – usually thinking to myself what the fuck are we doing. I am reminded of a dog chasing its tail. Wow it hurts when you catch it! But usually you never do.

The best I can do is to keep carrying on as best I can, trying to keep my "human" self intact. (C., cis female NPA member)

The writings that follow continue along the theme of friendships that have developed over time, loss, and living in the Downtown Eastside. They also highlight the lives of marginalized women in the neighbourhood, and the violence experienced by many; poor, racialized, and Indigenous women are vulnerable to legal and social discrimination, "structural and "every day" violence," health problems, drug arrests, prison time, child apprehension, and stigma (S. Boyd, 2015; Bungay et al., 2010; Robertson & Culhane, 2005).

Dear Sophie,
Of lives and times

How often do friends leave? The immediate intensity of sadness for myself and we find ourselves to face and or to cope with the horrific news of the loss of dear others that were close to an individual whose broken few and the toughness of the street wears even on our expression day to day.

We'll miss you Sophie.

With love,

(M., cis male NPA member)

Bathroom Floor

Once again I find myself
alone, contemplating
life while sitting on brick
red tiles that make the
bathroom floor. Since the

only thing that I am wearing
is a t-shirt and g-string,
the cold tiles feel so great
Pressed against my flushed
and hot skin.
Thinking, I realize that all
through my life that one
constant and comforting
thing is the hundreds of
hours that I have spent
in this tiny room shutting
Out every thing. The place
where plans are developed,
decisions made and sins
confessed. Also, where I
cry, laugh and apply the
makeup that hides the
purple/blue marks that
cover most of my body,
the red lines caused from
tears running down my
cheeks non-stop. Or the
true feelings that I spend so
much time trying to hide, the one
place that I can be my true
self and not feel the sharp
hot sting of his slap.
I, like so many women, have
learned that hiding is the
way to live. Following every
word of the man that we think loves us and for that
love we live like prisoners locked away. (M., cis female NPA member)[1]

The NPA members also wrote about their experiences as subjects of clinical research. It is important to understand that for a short while unadulterated legal heroin was available to NAOMI research subjects in a clinical setting. During that time, outside of the clinical study, heroin was not legally available elsewhere in Canada. Although heroin can be bought illegally, it is expensive, adulterated, and only available from the illegal market. Thus, users are vulnerable to arrest and to possible drug overdose

because the quality is never certain. For many NPA members, the NAOMI clinical trial provided a respite, and they saw their lives improve (Boyd & NPA, 2013).

NAOMI participants had to visit the clinic three times a day at designated time slots – morning, afternoon, and evening – to receive their medication. They were observed prior to, during, and following their dose. Thus, the participants spent a lot of their day with each other at the clinic. Whereas the focus groups highlighted some of the positive experiences of NPA members in the NAOMI trial (see Boyd & NPA, 2013), some NPA members chose to write about the negative outcome of being a NAOMI research subject.

Memories at the Corners of My Mind

The way we were.
NAOMI
Emotion = ANGER
Angry at myself, sometimes reminded me of being in school, being disruptive questioning authority. (D., cis male NPA member)

Untitled Poem

Still down here
can't remember how many years
had lots of laughs
and lots of tears
not sure how or when it will end
know all kinds of people can't call 1 a real friend
maybe tomorrow maybe next year
but when it is over don't shed a tear
'cause the misery is over. I hope . . . (K., cis male NPA member)

NAOMI (Trials?)

How can I (we) be the lucky one? Chosen as 1st grade "A," fresh, unquestioning meat? To be lucky enough, chosen 1st to receive, FREE grade "A" dope from places and parts unknown?
Did I care?
Should I care?
If I didn't care, who could care?
Then: No one (seemed) to care.
Now: EVERYONE (seems) to care!
Raising new issues, NEVER thought of then, only thought of now?

How can this be?
Were we: so far gone, all that mattered was . . .
No! Cost . . .
No!! work . . .
No!!! MORE DRUGS (given FREE)
Back to the Grind, just like I've never left!
So . . .
Why, did I even bother to be a "trial" RAT 4 NAOMI?
To be left hanging, with No rope!
Thanks NAOMI. (J., cis female NPA member)

Others wrote about NPA meetings. NPA members expressed concern in their writing about the lack of an adequate exit strategy for NAOMI participants – that a permanent HAT program was not established following the clinical trial – and about the realities they faced after exiting the study: having to buy criminalized drugs once again, being vulnerable on the street, and having to participate in drug treatment programs that had already failed them (which had been one of the criteria for being a research subject in the NAOMI clinical trial in the first place).

Untitled Essay

I'm not sure what I'm suppose to write here, since I just occurred on the scene here late and everyone is already writing their letters I suppose you'd call this for lack of a better word. So here I sit writing.

Also just got news that a girl we all knew just passed away, she was a junkie. I suppose nobody knows why she died exactly only that she did.

I suppose life's like that, you're here one minute, gone the next. What's it all for, what's it all about, who knows? All I know for sure is one day we'll all find out. (M., cis male NPA member)

Untitled Essay

This is my very first meeting that I decided to attend.

I had completely forgotten that VANDU held a committee meeting every Saturday. The meeting time is usually held at the hours of 12:00 – 1:00 and $5.00 is awarded to people who decide to attend. (J., cis female NPA member)

NICE
PEOPLE
USE
DRUGS (D., cis male NPA member)

Advocacy

The NPA recognizes the importance of reaching out to drug-user and harm-reduction groups, researchers, and policymakers. Its goal is to effect change so that HAT becomes a permanent program that fits the needs of people who use it; thus, they recommend advocacy on many fronts. At the end of 2011 the NPA research project, including the writing components noted earlier, neared completion; the NPA then co-authored a report to communicate its findings: *NAOMI Research Survivors: Experiences and Recommendations* (NPA & Boyd, 2012). They also communicated the results of their research at a number of public events in the Downtown Eastside during the winter of 2011–12, including at VANDU, and at national and international conferences. In the following years the association continued to present locally, nationally, and internationally; thus, the experiences of NPA members – being the first people in contemporary North America to receive HAT – and NPA's recommendations for future studies and programs were heard by a wide range of audiences.

Recommendations for the Drug Trial SALOME

The very existence of the NPA (and VANDU) shows that the people who use criminalized drugs in Vancouver's Downtown Eastside do not accept their fate without fighting for more ethical drug policy. The decision by former NAOMI trial participants to hold weekly meetings at VANDU after the study had ended was a first step in allowing individuals to support each other and to express themselves and their experience. Their research and advocacy continued to connect members to a social justice movement for greater ethics in drug policy and for an end to drug prohibition. Their most recent advocacy again confirms this connection. At the end of 2012 another major clinical trial began in Vancouver's Downtown Eastside: the Study to Assess Longer-term Opiate Medication Effectiveness (SALOME) examined whether hydromorphone (Dilaudid) was as beneficial as diacetylmorphine (heroin) for "people suffering from chronic opioid addiction who are not benefiting sufficiently from other treatments" (SALOME, 2012a). SALOME also assessed whether "those effectively treated with these two injectable medications can be successfully switched and retained to the oral formulations of the medications" (SALOME, 2012a). The SALOME website stated that Canada was the only country that terminated HAT following the NAOMI clinical trial even though the treatment showed success. Thus, SALOME researchers stated that they had applied

"for research funding to continue investigating effectiveness of licensed injectable opioids (the SALOME trial)" (SALOME, 2012b). However, countries around the world have been testing the effectiveness of HAT, not hydromorphone.

To test the researchers' hypothesis, the SALOME trial compared the effectiveness of six months of injectable diacetylmorphine with that of six months of injectable hydromorphone; for select research subjects they also examined the effects of switching from injectable to oral medication after six months of treatment. Using a lottery system, people who registered for the trial and were deemed eligible were contacted. The clinical trial expected that research subjects would participate in the study for one year, followed by a one-month transition period in which they would be encouraged to participate, once again, in conventional treatments, such as methadone maintenance, drug-free treatments, and detox programs (treatments that had proven to be ineffective for these participants) (SALOME, 2012a). As noted earlier, the repeated failure of treatment efforts for participants is in fact part of the criteria for selection of participants in SALOME, as was the case in NAOMI. Similar to the NAOMI trial, SALOME did not include a strategy for creating a permanent HAT program following the study.

Prior to SALOME opening its doors, NPA members met with SALOME researchers and provided valuable input from their experiences as NAOMI research subjects. They also shared their recommendations for future HAT trials and maintenance programs (NPA & Boyd, 2012, p. 10). NPA recommended:

- that, when experimental drug maintenance programs are over, clients (research subjects), for compassionate reasons, should receive the drug they were on as long as they need it;
- an umbrella of support and services, such as housing, and access to medical treatment, all under one roof;
- access to welfare workers and Ministry representatives familiar with the area;
- access to nutritious food for self and family;
- support to move life forward through enrolment in school and trades, as well as family unification;
- access to family and criminal lawyers, education/advocacy skills, and advocates;
- diverse routes of drug administration for its clients: oral, smoking form, and injection; and finally
- that time on site be used to support, educate, and advocate.

Further, the NPA recommended that all future studies and programs include NPA and other heroin users in the development of the projects and that they should be part of the team from the beginning to the end (Boyd & NPA, 2013). In the future, the NPA would like to see the establishment of HAT programs that are less rigid, less medicalized, and less regulated. The NPA favours HAT models that are social and cultural spaces of inclusion rather than highly medicalized and hierarchal spaces.

Although the SALOME researchers put into place some NPA recommendations, the larger issues concerning lack of an exit plan and the setting up of a permanent HAT program were not addressed at that time. This raised many concerns for NPA members.

The NPA and other advocates continued to push for change in SALOME's policy. In 2012 the NPA consulted with a drug-policy lawyer for Pivot Legal Society. The society is a non-profit organization in the Downtown Eastside that strives to "use the law to address the root causes of poverty and social exclusion" (Pivot Legal Society, 2012). By working with Pivot Legal Society and by developing other forms of advocacy, the NPA hoped to change the course of events for SALOME participants and others who would benefit from HAT programs (rather than clinical trials).

In 2013 the NPA changed its name to SALOME/NAOMI Association of Patients (SNAP) to reflect its membership better. At that time many members were patients in the new HAT trial, SALOME. In early 2013, SNAP sent a community support letter to Providence Health Care, British Columbia's health provider, and copied it to a number of prominent players in the SALOME trial and health care in the province. It was endorsed by local residents, as well as by Libby Davies, a Member of Parliament for Vancouver East at that time, and organizations in and outside of the Downtown Eastside. The community letter supported the provision of a permanent HAT program in Vancouver. It asked that SALOME and Providence Health Care immediately provide a more feasible exit strategy for its research participants and a permanent HAT program for them (Boyd & NPA, 2013).

Owing to the extensive advocacy efforts on many fronts since late 2012 and early 2013, Providence Health Care has been striving for a more feasible exit strategy for clinical trial patients. For example, in 2013 some physicians who were in attendance at Providence Crosstown Clinic in the Downtown Eastside where SALOME was conducted submitted requests to Health Canada for special access to injectable heroin for individual patients. In addition, Providence Health Care began looking into other treatment options for SALOME patients exiting the clinical trial. In early 2013, patients who

were to exit the trial were kept in an interim program at Crosstown Clinic, and Providence Health Care began to discuss the possibility of providing oral hydromorphone to some SALOME participants as a treatment option after the trial. By September that year some former SALOME patients were also receiving injections of hydromorphone at Crosstown Clinic. Also in September 2013, the Special Access Program, Health Canada, approved twenty-one HAT applications for former SALOME patients to continue to receive treatment for three months after they exited the trial. However, quickly following this landmark approval the federal government changed the rules of the Special Access Program, and the then health minister, Rona Ambrose, condemned the initial decision. In October 2013 the new rules of the Special Access Program stated that heroin, and other criminalized drugs, could no longer be requested by physicians for their patients, even when drugs had been shown to benefit the patients' health.

Advocates stressed that there was a wealth of studies demonstrating the effectiveness of HAT for chronic opioid users and, at that time, none for Dilaudid (Strang et al., 2012); thus, they argued that it was unethical to withhold HAT from SALOME patients when they exited the clinical trial. On 13 November 2013, five SALOME patients (four being long-time SNAP members), with co-plaintiff Providence Health Care of British Columbia, filed a constitutional challenge in the BC Supreme Court to overturn the federal government's decision to prevent further Special Access requests for heroin-assisted treatment. They argued that the Special Access Program's new regulations were unconstitutional and infringed on the Charter Rights of former SALOME patients. In May 2014 Chief Justice Hinkson of the BC Supreme Court granted an injunction for SALOME trial participants, providing an exemption from the new federal Special Access policy that prohibited doctors from prescribing heroin to patients for whom other conventional treatment options had been ineffective. Thus, it was ruled that the SALOME participants, if eligible, should receive HAT from Providence Health Care physicians until the trial was heard. However, it was not until the end of November 2014 that some former SALOME participants began to receive HAT at Crosstown Clinic.

SNAP continues to meet weekly, and January 2015 marked their four-year anniversary. A celebration honouring their tenacity and activism was held in February that year, attended by SNAP members and their supporters. In September 2016, Health Canada, under the leadership of a Liberal-led federal government, announced that the former Special Access Program policy would be reinstated; thus, as this chapter goes to press, Special Access Program requests for HAT can be submitted by physicians on behalf of their

patients. And in response to this policy shift, the Supreme Court challenge will no longer be heard.

Conclusion

The SALOME/NAOMI Association of Patients just celebrated its sixth-year anniversary. The association continues to advocate for ethical, socially just drug policy. Along with international, national, and local groups they challenge drug prohibition and its reliance on criminal law and punitive policy. They support efforts to legally regulate all currently criminalized drugs, the establishment of drug policy and services based on human rights, ethical research, and the inclusion and expertise of people who use currently criminalized drugs. SNAP's immediate goal is to see HAT programs – a proven, safe, and effective treatment – established in Canada; this goal has not yet been accomplished.

SNAP also challenges conventional understandings of people who use criminalized drugs, especially those who use heroin. With almost no resources except human effort, the NPA members set out to tell their stories, to conduct social research for social change, to communicate their findings and recommendations, and to be at the table advocating for drug policy reform. SNAP's motivation is simple: it does not want to see other people suffer from failed prohibitionist drug policy and unethical drug treatment and research practices.

SNAP members are part of the fabric of Canadian life; their health, social, economic, and human rights must be considered. SNAP is also part of a global social justice movement to end prohibition and the criminalization and pathologization of people who use criminalized drugs such as heroin. SNAP encourages other groups to advocate for change and to engage in creating their own community-based research to tell their own stories.

NOTE

1 This poem was printed in Megaphone's *Voices of the Street* (2010), p. 20. *Megaphone* is a magazine sold on the streets of Vancouver by homeless and low-income vendors. It is published by the non-profit Street Corner Media Foundation. In 2010 Megaphone launched the *Voices of the Street* literary issue that focused on the stories of people who live in the Downtown Eastside of Vancouver.

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