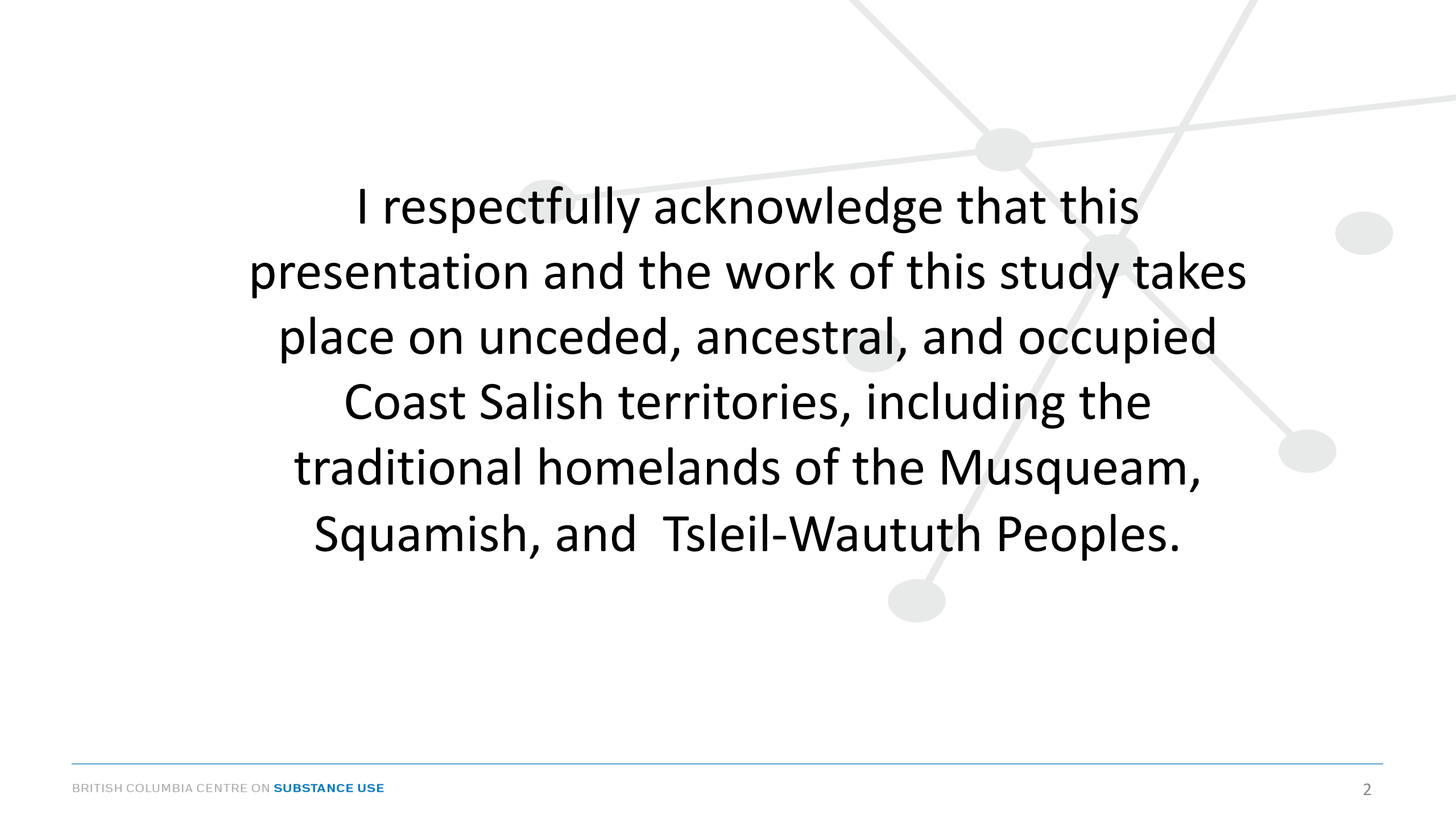


“Stigma is Where the Harm Comes From”: **Exploring Expectations and Lived Experiences** **of Hepatitis C Virus Post-Treatment** **Trajectories Among People who Inject Drugs**

October 14th, 2021, INHSU

Trevor Goodyear, Helen Brown, Annette Browne,
Peter Hoong, Lianping Ti, & Rod Knight



I respectfully acknowledge that this presentation and the work of this study takes place on unceded, ancestral, and occupied Coast Salish territories, including the traditional homelands of the Musqueam, Squamish, and Tsleil-Waututh Peoples.

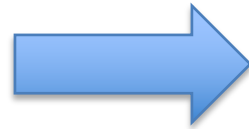
Acknowledgments & disclosures

I am thankful to the **people who shared their time and stories** for this study, **Victoria Panwala** who assisted with the initial coding, my **co-authors** who helped to prepare this presentation, and the **study funders**.

I declare no conflicts of interest.



Background



(1)



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International Journal of Drug Policy

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Research Paper

“Stigma is where the harm comes from”: Exploring expectations and lived experiences of hepatitis C virus post-treatment trajectories among people who inject drugs

Trevor Goodyear^{a,b}, Helen Brown^a, Annette J. Browne^a, Peter Hoong^b, Lianping Ti^{b,c}, Rod Knight^{b,c,*}

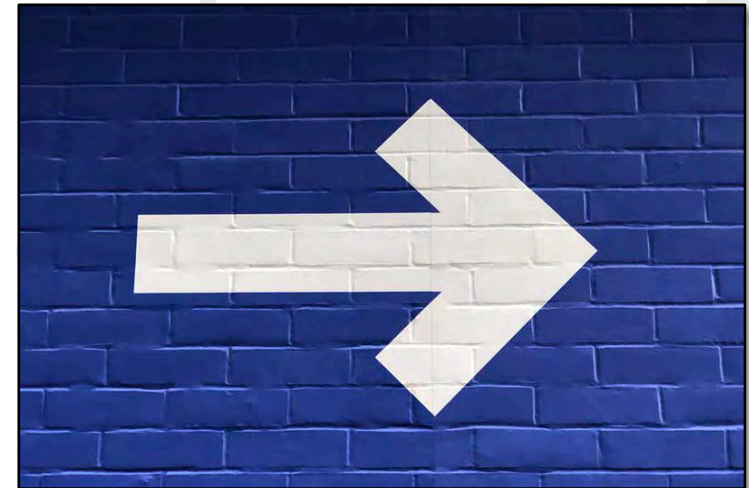
Background - People who inject drugs & hepatitis C

- ❑ **52.9%** - estimated prevalence of hepatitis C among people who inject drugs, in Canada, as of 2015 ⁽²⁾
- ❑ Advent of direct-acting antivirals (DAAs) has facilitated opportunities for hepatitis C cure
- ❑ Need for data about how to optimally **support** people who inject drugs throughout and **following hepatitis C treatment**



Study objective

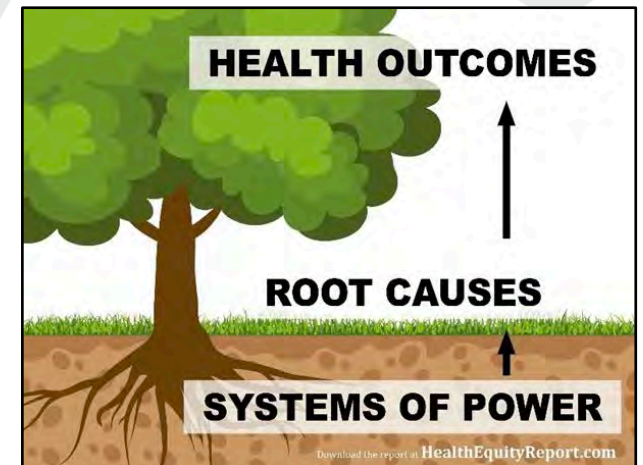
- ❑ To identify how people who inject drugs describe their **expectations** and **experiences** of health and social outcomes, contexts, and substance use practices **following completion of DAA treatment (i.e., after cure)**



Methods – Data collection



- ❑ Set in Vancouver, Canada
 - ❑ DAAs – universal, open eligibility, primary care
- ❑ Stratified purposive sampling
 - ❑ Recruitment via cohort studies with the BCCSU
- ❑ 50 semi-structured interviews – 30-60mins each
- ❑ Data analyzed thematically
 - ❑ Critical interpretive framework
 - ❑ Social constructivist grounded theory



Sample Demographics

Table 1
Characteristics of participants.

Participants	50
Age (average, range)	49 (31–66) Years
Ethnocultural identity^a	
First Nations	26 (52%)
Métis	3 (6%)
Black	1 (2%)
White	17 (34%)
Declined to answer	3 (6%)
HCV treatment status	
Pre-treatment ^b	20 (40%)
Peri-treatment	11 (22%)
Post-treatment	19 (38%)
HIV serostatus	
Positive	24 (48%)
Negative	26 (52%)
Gender identity	
Man ^c	26 (52%)
Woman ^d	23 (46%)
Two-Spirit ^e	1 (2%)

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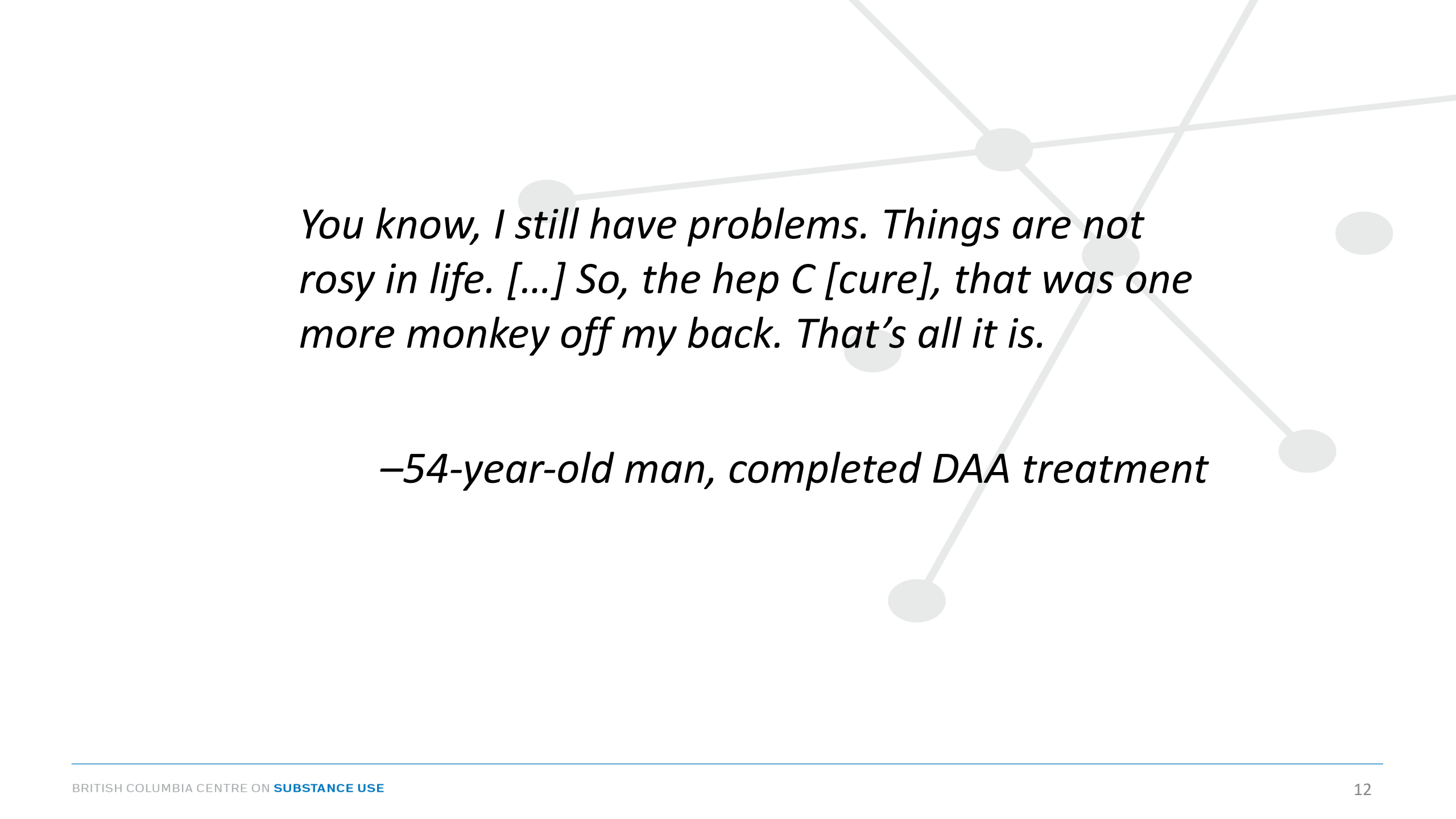
Findings – 3 key themes

1. Health and wellbeing following DAA treatment: *“It’s a big stress off your shoulders”*
2. Reducing the burden of intersecting stigmas: *“They think I’m some foreign object who’s got hep C”*
3. Navigating harm reduction and socio-structural barriers to prevent re-infection: *“I don’t want to end up in a vicious cycle”*

1. Health and wellbeing following DAA treatment

- ❑ DAAs presented renewed potential for  QoL
 - ❑ “A better life”
- ❑ Participants hoped for holistic changes in health and wellbeing (e.g., mental, emotional, social, physical) after cure
- ❑ Yet actual post-treatment changes tended to be located in physical wellbeing (e.g., sleep, appetite)
 - ❑ Or, minimal to no change following cure






You know, I still have problems. Things are not rosy in life. [...] So, the hep C [cure], that was one more monkey off my back. That's all it is.

–54-year-old man, completed DAA treatment

2. Reducing the burden of intersecting stigmas

- ❑ Shame and internalized stigma related to hepatitis C were common, as was stigmatization from others
- ❑ Stigma is harmful!
 - ❑ Mental health & sense of self
 - ❑ Healthcare access (e.g., dentist, emergency, overdose)
 - ❑ Housing, employment, relationships
- ❑ Hepatitis C cure offered the prospect of  stigma



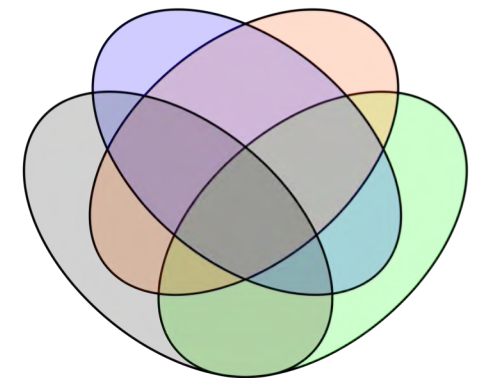
My hepatitis C and my HIV really affects me. Makes me feel really gross inside. It doesn't make me feel like a human being, usually. I don't like having them. [. . .] So, it's really hard on me.

I feel like I'll probably do a little bit more [after being cured]. Not feel so toxicated [sic] or dirty .

–42-year-old Two-Spirit person, pre-DAA treatment

2. Reducing the burden of intersecting stigmas

- ❑ Cure often resulted in feelings of pride, achievement, and hope for the future
- ❑ Unfortunately, outward displays of stigma persisted even following cure
- ❑ Especially so for folks experiencing multiple stigmas
 - ❑ E.g., substance use & HIV stigma, poverty, racism, queer/transphobia



I've been beaten around and kicked around, and society sucks today. [Interviewer: "And has that changed since you were cured?"] It's starting to. It's still, you know, that stigma – [people treat you like] you're a drug user, piece of shit, HIV [positive] person. And I think a lot of people [that I encounter] still unfortunately have that attitude.

–54-year-old man, completed DAA treatment

3. Navigating harm reduction and socio-structural barriers to prevent re-infection

- ❑ Highly knowledgeable about how to prevent hepatitis C re-infection following cure
 - ❑ Lived experiences of hepatitis C, care, & community
- ❑ Well-informed & consistent with harm reduction



3. Navigating harm reduction and socio-structural barriers to prevent re-infection

- ❑ Yet participants also expressed apprehensiveness about social and structural barriers to harm reduction
- ❑ E.g., precarious housing, poverty, stigma, violence, criminalization & policing



It's a bummer with that kind of stigma, what's going on in the world. Because that [stigma] is where the harm comes from, too, what people hide. And they may not go to a place to get [sterile] needles because they don't want people to know that they're using.



–31-year-old man, peri-DAA treatment

Implications for hepatitis C policy & programming

- ❑ Hepatitis C treatment & follow-up care must attend to health expansively – i.e., “beyond cure”⁽³⁾
 - ❑ Primary health care sector is best suited to doing so
- ❑ Limited impact of “curing” a singular stigma within a multi-stigmatized life
 - ❑ Address structural drivers of intersecting stigmas
- ❑ Re-infection prevention efforts must focus on the risk environment⁽⁴⁾, not just the individual

~~STIGMA~~

Conclusion

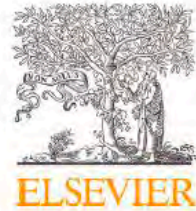
- ❑ DAAs are transforming the health and wellbeing of some people who inject drugs
- ❑ Yet hepatitis C policy must extend beyond scaling up DAAs to meaningfully advance health equity with this group
- ❑ Concerted public health investments needed
 - ❑ Anti-stigma efforts & improved social welfare system

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Thank you! Questions?

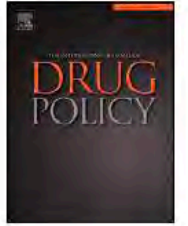
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