



# ENGAGING POLICYMAKERS, POLITICIANS, AND MEDIA

January 17, 2024

Jennifer van Gennip  
Janet Butler-McPhee

ACTION HEPATITIS CANADA

**aHC**

ACTION HÉPATITES CANADA



# LAND ACKNOWLEDGMENT

Today, we are coming together on this virtual platform from all across Turtle Island, the lands and unceded territories of many different Indigenous groups and communities who have respected and cared for this land since time immemorial.

As people committed to addressing ongoing injustices and health inequities, we must recognize that many of these harms are the result of the history of colonization and its ongoing impacts, including practices and institutions that must be dismantled and reshaped to respect Indigenous People and Indigenous ways of knowing and being.

We recommit together, whenever we come together, to repairing harms and working towards a more just future for all.





Action Hepatitis Canada is a pan-Canadian coalition of 80 member organizations holding governments accountable to their commitment to eliminate viral hepatitis as a public health threat by 2030.

**[www.actionhepatitiscanada.ca](http://www.actionhepatitiscanada.ca)**



The HIV Legal Network promotes the human rights of people living with HIV or AIDS and other populations disproportionately affected by HIV, punitive laws and policies, and criminalization, in Canada and internationally. We do this through research and analysis, litigation and other advocacy, public education, and community mobilization.

**[www.hivlegalnetwork.ca](http://www.hivlegalnetwork.ca)**





# **1.OPPORTUNITIES AND CONSIDERATIONS**

## **2.THE POWER OF STORY**

## **3.ADVOCACY CASE STUDY**

# **TIMING & POLITICAL SEASONS: OPPORTUNITIES TO ENGAGE**

- Lots of ways to engage - media, social media, closed or open letters to politicians
- Consider your ask, the audience, the environment (ex. election cycle, budget cycle, public discourse)



# CRAFTING KEY MESSAGES

1. **Identify if the issue falls under municipal, provincial, or federal mandates.**
2. **Open with your issue and request.** (ie. I am writing to urge you vote against Bill X; I am calling to voice my concerns with your government's recent funding cut to...)
3. **Identify a value you share.** Frame the issue around the deepest moral value possible. Try: Our values align when it comes to setting families up to succeed...; Protecting public access to quality education is really about protecting opportunities for the next generation, which is a value I know we share...
4. **Personalize with a story/Describe the local impact.** For example, say something such as: This Bill will have an immediate impact on your constituent, five-year-old Anna, who...; Our 432 member families rely on this funding for....
5. **Repeat your one clear ask.** Use language such as: On behalf of X, I urge you to vote...; I would like to schedule a meeting to discuss further... Do not confuse your deep moral value framing such as defending family values or freedom as your ask. Your ask should be specific and easy to evaluate whether they do it or not, such as voting a certain way on a specific Bill or scheduling a meeting.

# **3 TIPS FOR ADVOCACY WRITING:**

1. The “people do things” rule
2. (Re)framing the narrative
3. Persuasive metaphors



# **“PEOPLE DO THINGS” RULE**

**“When we do not make it clear from the outset that a problem is person-made, it is cognitively inconsistent to believe that it could be person-fixed.”**

*-Anat Shenker-Osorio*



# “PEOPLE DO THINGS” RULE

“Funding was cut,”

VS

“Program closes due to Minister’s choice to defund it.”

**Don’t leave the “doers” out of your advocacy writing, it lets them off the hook and our proposed solutions make less sense.**





# (RE)FRAMING THE NARRATIVE

**“In politics, whoever frames the debate tends to win the battle.”**

*-George Lakoff*



# **(RE)FRAMING THE NARRATIVE**

“Hard to reach,”

VS

“Structurally excluded.”

**Do not accept your opponent's framing of the story as the default. Reframe it to change the terms of the debate by redefining the issue with new values or exposing faulty assumptions. Say it right, and then say it over and over.**





# PERSUASIVE METAPHORS

**“If you want to change the world,  
change the metaphor.”**

*-Joseph Campbell*



# PERSUASIVE METAPHORS

**Experiment:** two groups were given the same statistics about crime in a fictional city, but a different metaphor for crime was used for each.

Participants who read the description of crime as an **opponent** overwhelmingly favoured **tougher law enforcement** as the appropriate response.

Participants who read the version comparing crime to a **contagious virus** favoured **preventive programs** to address crime.

**Use deliberately selected metaphors – they can be a persuasive communication tool, subtly seating issues within a set of assumptions that will favour the response you seek.**



# ADVOCACY TIPS FOR RESEARCHERS:

- Frame study outcomes in relation to policy targets, if relevant.
- Consider a human rights and health equity lens.
- Maintain the humanity in the data.
- Frame your data, or someone else will.





**Questions?**



**1.OPPORTUNITIES AND CONSIDERATIONS**

**2.THE POWER OF STORY**

**3.ADVOCACY CASE STUDY**

# THE POWER OF STORY



**“Throw facts at us, we duck.  
Personify those same facts in a story, we lean in.  
Not by choice but because we are  
biologically helpless against an effective story.”**

*-Lisa Cron, Story or Die*

# THE POWER OF STORY


**“The human mind is a story processor,  
not a logic processor.”**






*-Jonathan Haidt*






# THE POWER OF STORY

RESEARCH ARTICLE | BIOLOGICAL SCIENCES | 

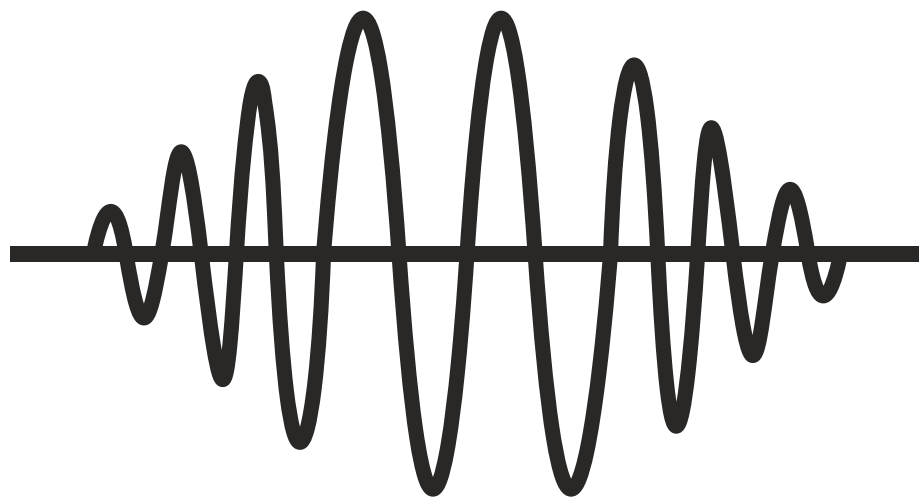
    

## Speaker–listener neural coupling underlies successful communication

[Greg J. Stephens](#), [Lauren J. Silbert](#), and [Uri Hasson](#)  [Authors Info & Affiliations](#)

Communicated by Charles G. Gross, Princeton University, Princeton, NJ, June 18, 2010 (received for review April 30, 2010)

July 26, 2010 | 107 (32) 14425-14430 | <https://doi.org/10.1073/pnas.1008662107>

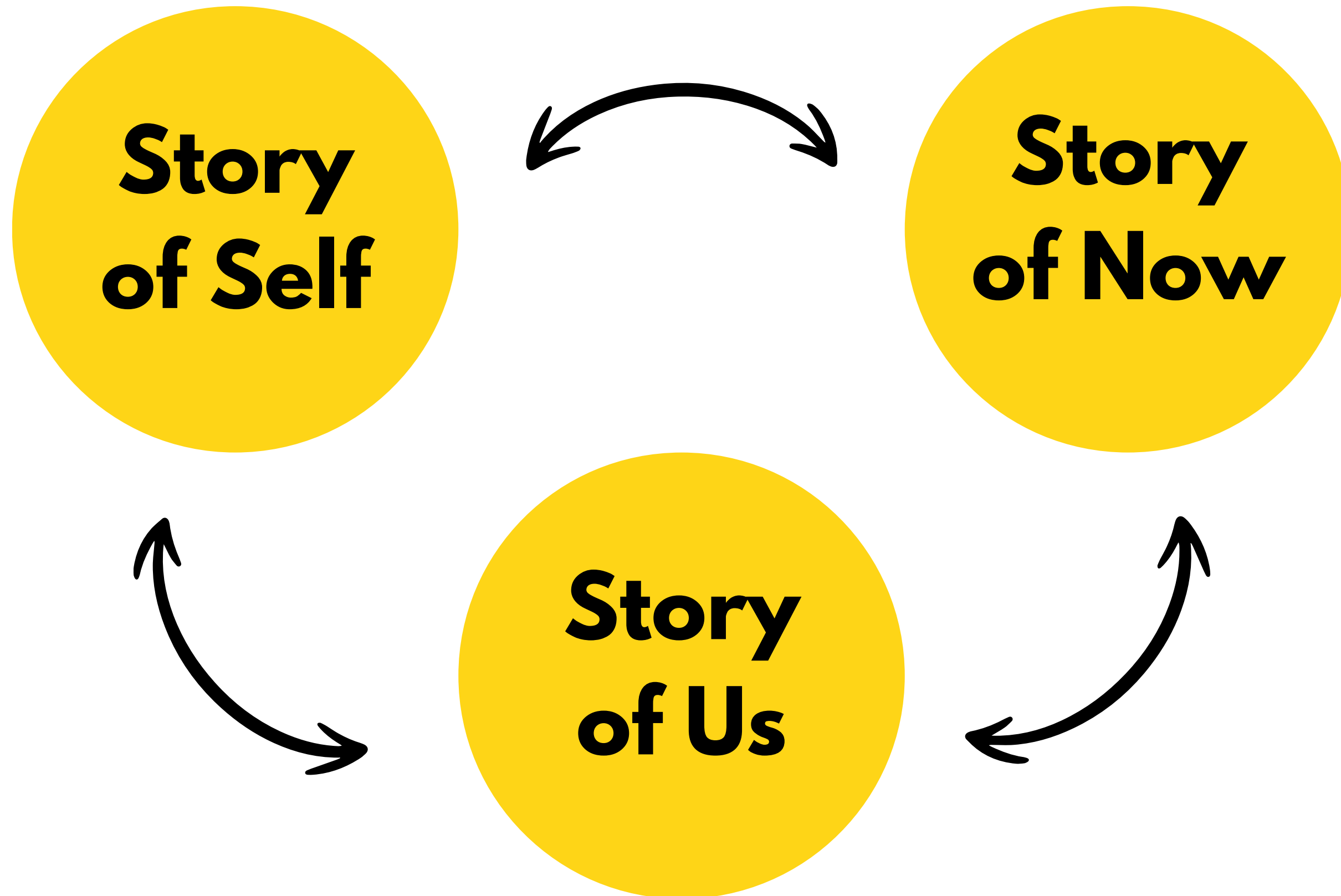


# TELLING STORIES:

1. Effectively
2. Strategically
3. Ethically

# TELLING STORIES **EFFECTIVELY**

Marshall Ganz





# **TELLING STORIES STRATEGICALLY**

- 1. Show your audience a role for themselves in your story.**
- 2. Relatable is more important than likeable.**
- 3. Summary does not equal story.**

# TELLING STORIES **ETHICALLY**

## Storytellers own their stories.

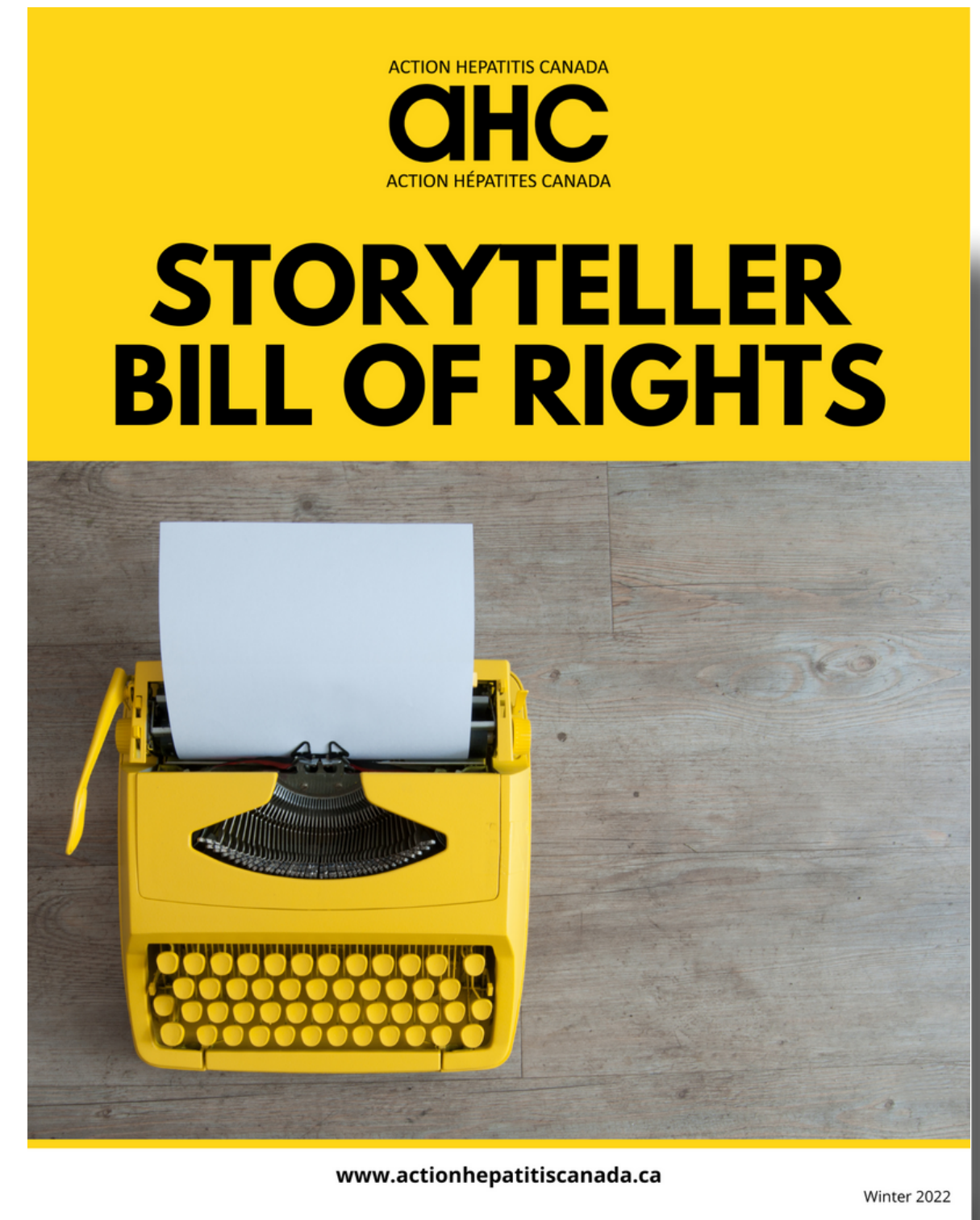
- Action Hepatitis Canada (AHC) is committed to building an ethical storytelling process that prioritizes the needs, rights, and dignity of storytellers.
- This means that the storyteller is the owner of the story and a decision-maker in our storytelling work.
- Ensuring that our project protects a storyteller's ownership of their story means embracing storytelling as more than a commodity for our organization.

## As a storyteller:

**I am the owner  
of my story.**

**I am  
supported.**

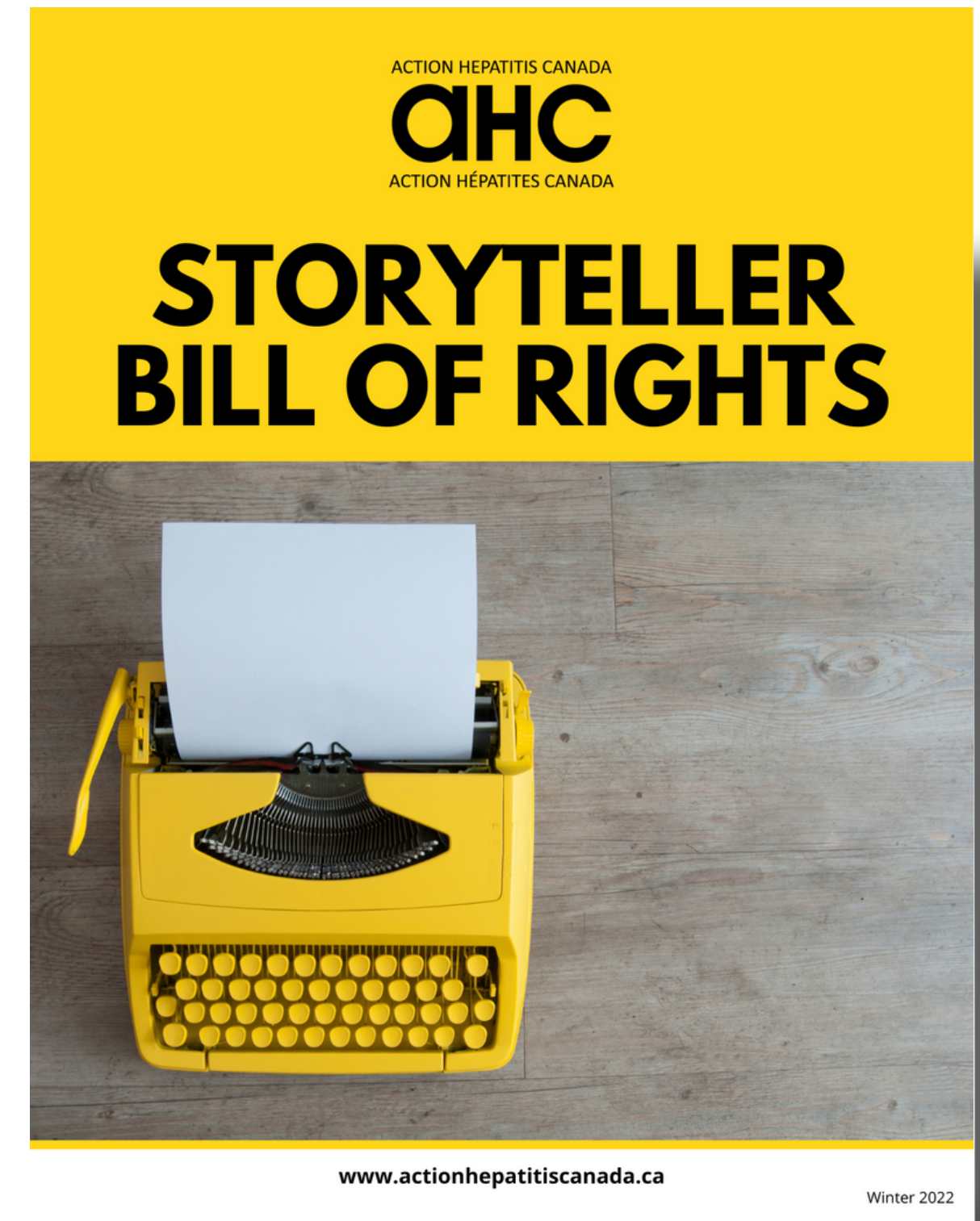
**I am a decision  
maker.**



# TELLING STORIES ETHICALLY

## I have the right to:

1. Decide which stories I share.
2. Share stories about myself and my life that are rooted in feelings like joy, discovery or learning. The expectation from AHC is not that I share difficult life experiences unless it is my choice.
3. Answer only the questions I am comfortable with during a story-sharing interview or recording.
4. Ask for support, including mental health support, throughout the process.
5. Decide how I will be represented, including my name and pronouns.
6. Choose the language(s) in which I want to tell my story.
7. Change details of my story to protect myself and others.
8. Know who the audience is, along with where and how the recording of my performance will be shared.
9. Make editing choices and creative decisions about how my story is told, written and shared.
10. Take a break or fully withdraw from the process at any time.





# TELLING STORIES ETHICALLY

**Collecting stories from people in the community is an incredible responsibility.**

## **AHC's intention is to:**

1. Ensure the **informed consent** and rights of storytellers are protected.
2. Exercise transparency in our storytelling work, including goals, processes and intentions.
3. Thoughtfully encourage a diversity of voices and experiences to participate, **without purposefully mining for storytellers' most difficult experiences.**
4. Respect the specific experience and individuality of each storyteller.
5. Be intentional in our language choice.
6. Reject and encourage the **rejection of generalizations about experiences that continue to separate people from their humanity or that elevate the lens of the audience over the safety and dignity of the storyteller.**
7. Our job as listeners is to be active, present, and to foster cultures of community storytelling as an opportunity for **sharing and healing. We cannot be transactional** with stories and extract only opportunities to perpetuate harm or exercise self-interest.



**Questions?**



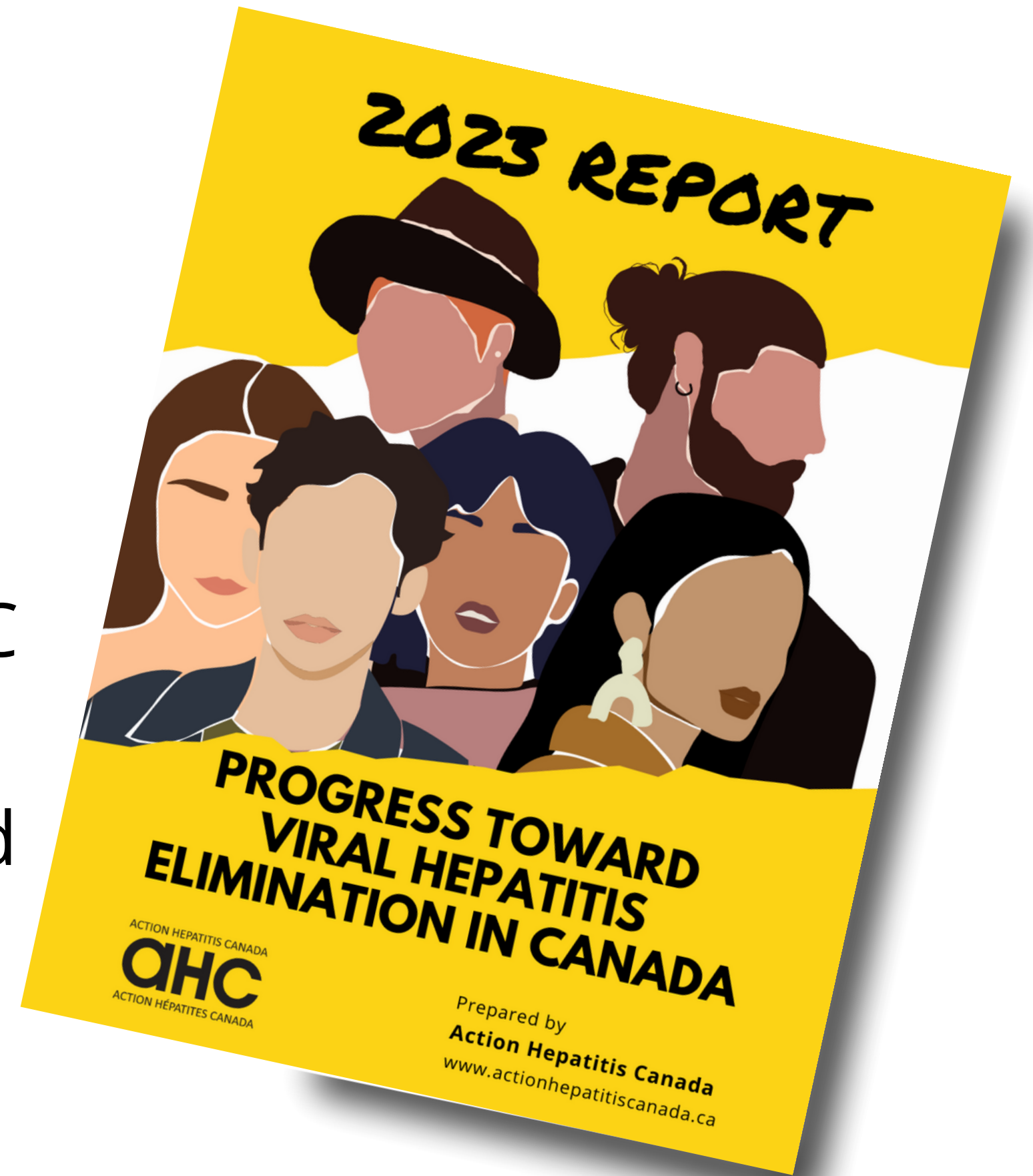
**1.OPPORTUNITIES AND CONSIDERATIONS**

**2.THE POWER OF STORY**

**3.ADVOCACY CASE STUDY**



- Biannual Progress Report (2021, 2023)
- Focus on human rights lens, health equity, and priority populations
- Six Metrics, including hepatitis C treatment access
- Ontario, Quebec, Manitoba, and Yukon not on track to reach 2030 elimination targets





# 2023: FOCUS ON MANITOBA

- Limited insight into Manitoba from a community perspective until 2022.
- Ineffective virtual meetings with government staff.
- No identified champions among physicians.
- Provincial election set for the fall.
- **Decided to go to Manitoba and tour communities to collect case studies to share with the government to hold them accountable on World Hepatitis Day.**





# MANITOBA CASE STUDIES:

## No clear path to hepatitis C care and treatment.



*"If hepatitis C doctors came to our town, came to us, like they do for Sublocade, people would be more likely to do the treatment."*

-Peer 1 living with hepatitis C in The Pas

### The Pas & Opaskwayak Cree Nation (OCN)

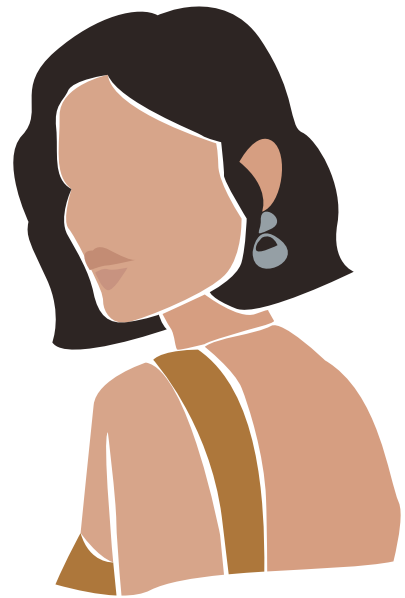
- 6 hours northwest of Winnipeg

- Peer 1 and his partner, Peer 2, both tested positive for hepatitis C in 2018.
- They believed that they could only be treated for hepatitis C once, so they wanted to wait until they were no longer using drugs as they would likely become reinfected by their many friends who are also living with hepatitis C.
- After speaking with us, both peers were highly motivated to start treatment. "It would be great to just get rid of it. It's always in the back of my mind, all the time, and [Peer 1's] mom is so worried about him," Peer 2 told us.
- However, the STBBI nurses on-site at the testing event could not do an RNA (confirmatory) test because they did not have the right signed requisition forms, and could not share a clear path to treatment, as their role ended at the referral.
- There is not a hepatitis C coordinator serving The Pas or OCN. The number of steps, the waits in between those steps, the unknowns, and the travel barriers prevent most people in the community from pursuing treatment.
- We left The Pas with very little confidence that either of these motivated individuals would be linked to hepatitis C care and treatment.



# MANITOBA CASE STUDIES:

## No clear path to hepatitis C care and treatment.



*"I've been doing this job for seven years, and I can't remember a single peer being treated for hepatitis C."*

-Swan River Network Coordinator

### Swan River

- 5 hours northwest of Winnipeg

- The Manitoba Harm Reduction Network Coordinator in Swan River has developed a trusted peer advisory council of 120 peers who work with her to distribute harm reduction supplies.
- She estimates that almost all of these peers have tested positive for hepatitis C. Living with hepatitis C has been completely normalized in this community.
- In Swan River, there are nurse practitioners who could prescribe treatment, but we are told that all hepatitis C cases are referred to a Winnipeg specialist for appointments through telehealth. It appears that the specialist requires a second confirmatory blood test six months after the initial diagnosis before prescribing treatment, criteria not listed with Manitoba Health or any other province.
- It is also the belief among the peers that people who are actively using drugs are denied treatment. This practice is not supported in an elimination approach, a human rights approach, or a public health approach to hepatitis C.

# MANITOBA CASE STUDIES:

## No clear path to hepatitis C care and treatment.



*"We have these testing events and then I thought magic happened. But there's no magic. The antibody tests are a dead end for our peers...I feel sick."  
-MHRN Selkirk Network Coordinator*

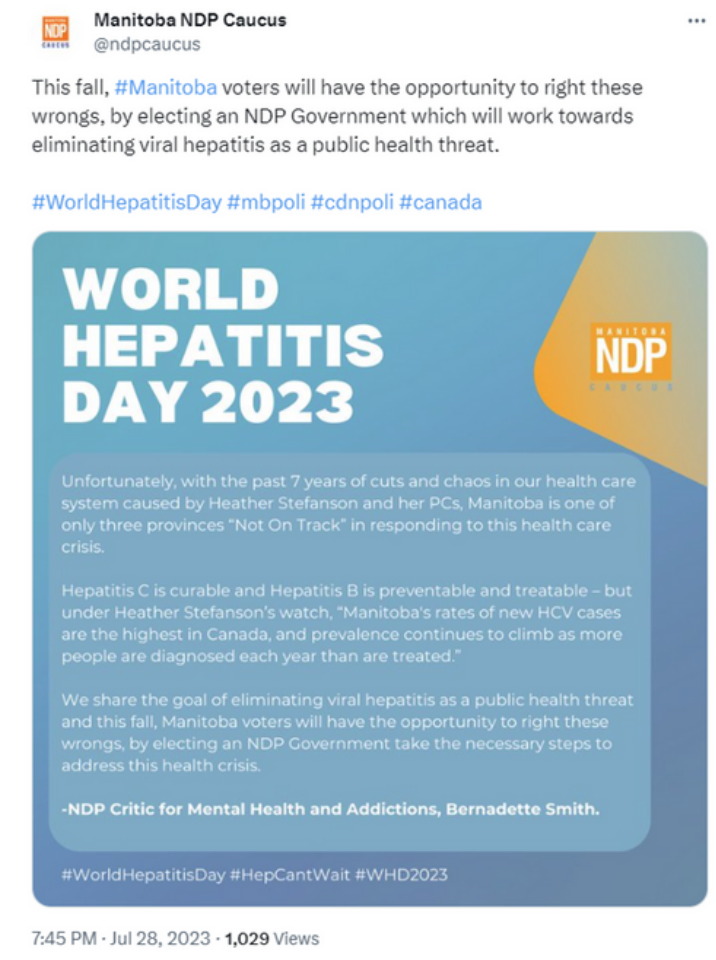
### Selkirk

- 40 minutes northeast of Winnipeg

- People diagnosed with hepatitis C are currently referred to Mount Carmel in Winnipeg for treatment. However, with no public transportation to Winnipeg, it is as difficult for residents of Selkirk to get to Winnipeg as from The Pas. "I walked once for my appointment at Mount Carmel and it took me 9 hours," shared Peer 1 in Selkirk. "That just doesn't seem like a reasonable expectation."
- Of the six peers we spoke to, there was confusion about their status. Once they learned about the difference between antibody tests and RNA tests, three were not actually sure if they were living with hepatitis C or not.
- "We need a Mount Carmel in Selkirk. And we need education. We need to know what it's about, how you get it, and how you get rid of it," summarized Peer 1. "And we need to know how we can pass it on to other people," added Peer 5.
- "We're peers. We want to save lives, but how do we save our own lives?" asked Peer 1.

# HOW WE LEVERAGED OUR PROGRESS REPORT & CASE STUDIES

- Met with Manitoba Health staff, Indigenous Services Regional Officer of Health, and Regional PHAC representative in one large meeting.
- Met with NDP Health Critic and Mental Health and Addictions Critic to share insights and ask for a commitment to get back on track if elected in October, which they provided.





# AND THEN...



- In the Manitoba meeting, staff identified that the Corrections Formulary did not benefit from the discounts negotiated by the pCPA, which was why they did not offer treatment in provincial corrections.
- So, we called the **pCPA** and requested a meeting.
- They offered to meet on August 10 - Prisoner's Justice Day. We said yes.
- We learned that while negotiated prices are technically available to all formularies in the provinces, in practice, this never happens. They suggested it's a great time to have these conversations because the pCPA is restructuring, so we'll be following up. In the meantime, when asked for advice, they suggested that the manufacturer could request conditions that discounted prices be offered to all formularies in the province, including corrections.

# NEXT...

- We asked **ISC** RMO Mike Isaac if there were more of him because he was so useful.
- He said actually, yes, and we all meet on Fridays, and we like having guest speakers. Would you and Lesley like to come speak to us?
- We said yes. That meeting happened in October.
- Also in October, we got a response from the Manitoba Health staff. "Treatment for reinfection was considered on a case-by-case basis," and this would be clarified in the updated treatment protocol, almost finalized. We countered with a recommendation, given the pervasive message that treatment was only provided once in a lifetime, to use the wording "Treatment for reinfection is encouraged."

# OUTCOMES FROM MANITOBA ADVOCACY



- ✓ Influenced provincial **hepatitis C treatment protocol**.
- ✓ Inspired a **pilot project** through MHRN to provide treatment and peer support in Swan River.
- ✓ Secured **political commitment** to get “back on track” from the incoming NDP government.
- ✓ Started a conversation at the **pCPA** to improve treatment access for people who are incarcerated.
- ✓ Raised awareness with **ISC** of their potential role in facilitating treatment access for NIHB-eligible patients when provincial barriers are preventing access.



# REFLECTION

- How did the experience work out?
- Were there questions that surprised you that need further reflection?
- Do you think your key messages were clear? Do others think your messages were clear?
- Is there anything in the story that needs to be adjusted?
- How do you feel personally about the experience, before and after?
- Are there any next steps you can take to make this a better experience?



**Questions?**



[www.actionhepatitiscanada.ca](http://www.actionhepatitiscanada.ca)

