

Using population-level integrated health data to monitor and assess patients' progression across care and treatment continuums

Care cascades

Care cascades are visual tools used to track patients' journeys across illness and care stages such as screened or diagnosed, referred to care, treatment assessment, treatment, and status of treatment goal (e.g., viral suppression or cure). They can be constructed at various levels, from groups of patients at one or more clinics to entire geographic areas such as a health authority or province. Care cascades¹ are usually presented as bar graphs, showing stages of care for a particular disease, and the number or portion of people progressing through each stage, thereby helping to rapidly identify stages where patients fall out of care and where barriers to care progression may be occurring; determine program effectiveness; and monitor progress toward achieving desired health outcomes.

Using integrated health data

Tracking patients across disease and care stages at the population level requires integrating data from multiple sources, such as surveillance and diagnostic laboratory data, health care utilization and prescription medication dispensing data, disease registries, and vital statistics records. Data linked at the patient level are used to produce population-level estimates of care and treatment progress, which are visualized as a care cascade. Because health and administrative data already exist, integrating them to estimate these measures is an efficient method to assess care cascades, and

This article is the opinion of the BC Centre for Disease Control and has not been peer reviewed by the BCMJ Editorial Board.

eliminates many biases associated with other types of data sources (e.g., clinical or cohort studies).

Care cascades for hepatitis C

While hepatitis C virus infection is associated with various liver and nonliver complications and high morbidity and mortality, the advent of highly effective direct-acting anti-

In BC, the stage of care with the largest improvement in recent years has been driven by the availability of direct-acting antiviral medications, shown to improve all-cause mortality and reduce the risk of cirrhosis and liver cancer.

viral medications has revolutionized its management, prompting the World Health Organization to issue global hepatitis elimination goals.² To monitor progress toward achieving these goals, systems tracking patient progress across hepatitis C virus illness and care stages are needed. To this end, in British Columbia, laboratory testing, prescription dispensation, mortality, and other health care administrative data have been integrated to create the BC Hepatitis Testers Cohort (BC-HTC), which contains health information on over 2 million BC residents.

BC-HTC has helped identify gaps along the hepatitis C virus care con-

tinuum,³ such as many patients not receiving confirmatory hepatitis C virus RNA testing after a positive hepatitis C virus antibody test. These findings supported improved care-provider training, resources for care providers and patients, and a reflexive hepatitis C virus RNA testing pilot study at the BCCDC Public Health Laboratory. Having multiple data sources in the BC-HTC permits hepatitis C virus care cascades to be stratified by age, gender, geographic location, disease stage, comorbidities, and co-infections. Stratification of hepatitis C virus care cascades based on these characteristics identified gaps in urban, rural, and remote services delivery, and highlighted how well population-specific needs are being met.

In BC, the stage of care with the largest improvement in recent years has been driven by the availability of direct-acting antiviral medications, shown to improve all-cause mortality and reduce the risk of cirrhosis and liver cancer. However, the cascade of care in BC demonstrates continued gaps in treatment uptake among people with a history of injection drug use.⁴ Curing hepatitis C virus among people who inject drugs can prevent transmission to others, but to improve real-world health outcomes and meet hepatitis C virus elimination goals, more comprehensive harm reduction, addiction, and mental health supports are required.

Care cascades for other health conditions

Care cascades have been used to track care and treatment progress for HIV

Continued on page 80

Continued from page 79

advisories. The FNHA's drinking water safety program manager and environmental health officers work with ISC to resolve drinking water issues and provide sustainable access to safe drinking water in First Nations communities.

- ISC provides training for First Nations water systems operators, and supports the Circuit Rider Program, which provides training and mentorship by highly experienced and certified operators and works with operators in First Nation communities to support operation of drinking water systems.
- First Nations leaders have expressed interest in determining and developing priorities and strategies for safe drinking water legislation and a framework that would effectively support safe and sustainable drinking water for communities.
- First Nations water operators in BC and Yukon have launched their own network (First Nations' Operators

Water Net) to support and advocate for their profession.

This great work needs to be sustained and expanded. Community or public water systems may not address all water needs in First Nations communities; the federal fiduciary responsibility to these communities needs to be extended to fund and support smaller systems, which also serve residents in First Nations communities. We also need to recognize that First Nations view water holistically, extending beyond what comes from the tap to source water and issues that arise in watersheds. Joint collaboration across First Nations communities, local governments, provincial ministries and regional health authorities, and land owners is needed to achieve effective source water protection.

While supporting the continued drive to improve services, we also need to highlight what is going *well* in First Nations communities. The development of highly skilled women

and men as water treatment plant operators and caretakers of their water, installation of modern-day treatment facilities, and a supportive network of community, government, and FNHA staff have all contributed to a reduction in the number and duration of advisories. The excellent work carried out by First Nations water treatment plant operators, community-based drinking water monitors, community health staff, and many others in communities who support provision of safe drinking water is but one example of First Nations individuals and communities leading wellness.

References

1. Maheswaran C. Water, water everywhere but not a drop to drink! BCMJ 2018;60:195. www.bcmj.org/cohp/water-water-everywhere-not-drop-drink.
2. First Nations Health Authority. Drinking water safety program. Accessed 31 January 2019. www.fnha.ca/what-we-do/environmental-health/drinking-water-safety-program.

bccdc

Continued from page 78

infection, tuberculosis, substance use treatment, and syphilis partner notification. This concept can easily adapt to other diseases to improve health outcomes. However, various data sources need to be integrated and updated at the provincial level in order to track gaps in services, which in turn can inform how services are best delivered to improve health outcomes.

—**Sofia R. Bartlett, PhD**
Postdoctoral Fellow, BCCDC,
and Department of Pathology and
Laboratory Medicine, UBC
Adjunct Associate Lecturer, Kirby
Institute, University of New South
Wales, Australia
—**Terri Buller-Taylor, PhD**
Research Manager, Hepatitis
Education Canada, BCCDC, and

Department of Pathology and
Laboratory Medicine, UBC
—**Mel Krajden, MD, FRCPC**
Medical Director, BCCDC
Professor, Department of
Pathology and Laboratory
Medicine, UBC
—**Naveed Z. Janjua, MBBS, DrPH**
Senior Scientist, BCCDC
Clinical Associate Professor,
School of Population and Public
Health, UBC

Disclaimer

All inferences, opinions, and conclusions drawn in this article are those of the authors and do not reflect the opinions or policies of the BC Ministry of Health and data stewards.

References

1. BC hepatitis testers cohort, UBC Centre for Disease Control. Hepatitis C cascade of care in BC, 2012. Accessed 24 January 2019. <https://bchtc.med.ubc.ca/hepatitis-c-cascade-of-care-in-bc>.
2. World Health Organization. Global health sector strategy on viral hepatitis 2016-2021. Accessed 24 January 2019. www.who.int/hepatitis/strategy2016-2021/ghss-hep/en.
3. Janjua NZ, Kuo M, Yu A, et al. The population level cascade of care for hepatitis C in British Columbia, Canada: The BC hepatitis testers cohort (BC-HTC). *EBioMedicine* 2016;12:189-195.
4. Janjua NZ, Islam N, Wong J, et al. Shift in disparities in hepatitis C treatment from interferon to DAA era: A population-based cohort study. *J Viral Hepat* 2017;24:624-630.