



## Pan-Canadian Forum on High Users of Health Care

Summary Report

Toronto, Canada  
March 20 to 21, 2014

Health System Performance



Canadian Institute  
for Health Information

Institut canadien  
d'information sur la santé



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To lead the development and maintenance of comprehensive and integrated health information that enables sound policy and effective health system management that improve health and health care.

## Our Values

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This is a summary of the CIHI forum on high users of health care that took place in Toronto, March 20 to 21, 2014.

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# Executive Summary

Strong interest has emerged in high-cost, high-user patients—a minority of the total patient population that accounts for a large proportion of total health spending. The notion has emerged that health systems can realize significant benefits by doing a better job of managing the care of this relatively small group, especially through improving the coordination of clinical and social care.

On March 20 and 21, CIHI hosted an invitational pan-Canadian forum on high users of health care in Toronto. Forty individuals took part, including senior decision-makers from provincial and territorial health ministries and senior staff from Health Canada, Canadian Institutes of Health Research, Statistics Canada, Canadian Foundation for Healthcare Improvement and provincial health research institutes and quality councils.

The objectives of the forum were to

- Foster collective learning by providing participants with opportunities to share and discuss information regarding strategies and policy interventions related to high users in their own and other jurisdictions;
- Highlight key research priorities and identify those that are shared across Canadian jurisdictions; and
- Identify how jurisdictions can be supported with data, performance measurement, and research and analysis.

Over the course of one and a half days, participants engaged in a number of discussions. The following is a brief summary of key themes.

- Participants confirmed that the issue of high users is a priority across the country; *frequent* use and *high cost* use are both of concern.
- Capacity and priorities vary, but a wide range of activities have been undertaken across the country to measure high use. For the most part, high cost/high use has been measured using acute care data (emergency department and hospitalization), though some jurisdictions are using primary care, home and community care and pharmaceuticals data, and in some instances demographic and social services data. Participants confirmed that many high-use patients are characterized by older age, multiple chronic conditions (mainly mental health disorders, chronic obstructive pulmonary disease, diabetes and heart diseases) and social factors (e.g., lack of social support, poverty, homelessness). Participants cautioned, however, that high-cost/high-user patients are a heterogeneous group and that there are no “one size fits all” solutions to the issue.
- Two distinct approaches to high use were identified by participants. *Conceptual* approaches seek to predict high use with the goal of prevention; *operational* approaches seek to identify high users with the goal of management and reduction.

- From a program and policy perspective, participants agreed that multi-sectoral approaches and the integration of clinical and social care need to be part of a robust response to the issue of high use. The discussion revealed a range of responses across the country, including clinical and social care partnerships, “hotspotting” initiatives, coordinated chronic disease management, advanced practice paramedics, primary care clinics for homeless persons and case management. Participants, however, expressed a general concern regarding the extent to which initiatives are being evaluated. There was a sense that analytical capacity was an issue for evaluation, as was the identification of appropriate measures.
- For the future, participants felt that there could be large gains from collaborative approaches to analysis and measurement. It was suggested that jurisdictions with less developed analytical capacity in the area had much to learn from jurisdictions where a lot of work has been done. In particular, there was a request for sharing experience and expertise in evaluation methods, predictive modelling, scaling up and spreading innovative practices, and effective communication of usable information to decision-makers.

# Introduction and Background

On March 20 and 21, 2014, the Canadian Institute for Health Information (CIHI) hosted a one-and-a-half-day invitational forum in Toronto, Ontario, to focus on issues related to high users of health care.

The overarching goal of the forum was to foster and promote the exchange of approaches to conceptualization, identification and policy response around high users in Canada, as well as to identify ways in which pan-Canadian organizations can provide support to provinces and territories.

The discussion in the forum focused around four key issues:

1. What activities are being undertaken to analyze and measure high use?
2. What characteristics are associated with high use in different jurisdictions?
3. What policy responses are being/have been undertaken?
4. How can jurisdictions be better supported in their response to high use?

A copy of the agenda is available in Appendix 1.

There were approximately 50 participants, including representatives from federal, provincial and territorial governments, researchers, and senior staff from pan-Canadian and provincial non-government organizations. A full list of participants is available in Appendix 2.

This document aims to summarize the discussions that took place at the forum. It is divided into five sections:

- Summary of evidence on high users
- Conceptualizing and identifying high users across Canada
- Identifying policy responses to address high use across Canada
- A way forward
- Wrap up

# Summary of Evidence on High Users

The forum began with three presentations. The first reported on lessons learned from the English National Health Service (NHS) perspective; the second reviewed the findings from the international literature; and the third presentation reported on the current situation across Canada.

## *Martin Bardsley, Lessons From the NHS Experience With High Use*

Martin Bardsley, director of research at the Nuffield Trust in England, gave the presentation on the lessons learned from the English perspective. Policy priorities in England at the moment include the need to identify £20 billion in efficiency savings and thus a reduction of high-cost care is an area receiving considerable focus.

Dr. Bardsley noted that, in England, efforts to address high use have focused on long-term conditions (LTCs). There is a significant increase in long-term conditions, associated with the aging of the population, which results in higher costs of care. Dr. Bardsley also presented data identifying the last two weeks of life as a period of extremely high use. He also stressed the issue of ambulatory care sensitive conditions (ACSCs), which are also playing a role in high use and are potentially an area where the provision of more appropriate care could lower costs. The presentation focused on a number of conditions in this area and showed that among other ACSCs, urinary tract infections are very high and increasing in this population group. In addition, Dr. Bardsley emphasized that there is a difference between episodic high users and high users over time.

Dr. Bardsley noted some of the different initiatives being undertaken in England to address high use. One initiative is the use of predictive modelling through risk stratification to identify what can be learned from existing high users to predict future high users and to better understand the transition from non-high use to high use. Other interventions discussed included visiting community matrons, virtual wards, better integration of health and social care, and policies to improve end-of-life care outside the hospital. There is a hope that telehealth will help reduce emergency admissions in the U.K.

Dr. Bardsley stressed that execution is key and that an underlying logic model needs to be specified to facilitate implementation. He cautioned that it can take a relatively long time to demonstrate the effectiveness of interventions and he stressed the need for realistic expectations for evaluation. So far, the U.K. has been able to find savings in elective care and outpatient care.

## *Irini Papanicolas, High Users of Health Care: A Review of the Literature*

Dr. Papanicolas, from London School of Economics, presented an overview of the scoping review of the international literature on high users. The presentation covered the following topics:

- Terminology and definitions
- Characteristics of high users
- System impacts of high use
- Policies to address high use



A summary of the report on which this presentation was based can be found in Appendix 3.

*Keith Denny, Overview of Canadian Activity Related to High Users of Health Care*

The presentation summarized stakeholder interviews on descriptions, definitions, approaches to measurement and policies/initiatives to address high users in Canada. The results indicate that

- The issue is considered important across the country.
- Analysis and measurement of high use are based principally on hospital, emergency department and pharmaceuticals data.
- There are interventions under way across the country, reflecting two broad approaches: integrated care and multi-sectoral.
- Most informants believed that there are key opportunities for action in all of the following: risk modelling, system integration/continuity, primary care and social determinants of health.

A summary of the report on which this presentation was based can be found in Appendix 4.

A round of questions that followed each of the presentations raised some further important issues. For example, someone asked whether there was any information on the difference between episodic high users and high users over time. It was agreed that this was an important issue where further distinctions need to be made, in particular in understanding the transition from non-high users to high users and vice versa.

## Conceptualizing and Identifying High Users

Following these presentations, the forum was opened up for group discussion. In a cross-Canada survey, participants were asked to consider the activities their own organization/jurisdiction has engaged in to analyze and measure high use. Several participants also discussed programs being undertaken in response to high use.

### British Columbia

A distinction was noted between conceptual (prospective) and operational (reactive) approaches to identifying high users within British Columbia. The *conceptual* approach identifies the *types* of people who are high users and their characteristics in order to plan, design and implement programs that seek to prevent high use. In the past, various Ministry of Health projects have looked at the top 5% of people who used the most hospital days, but in the last three years, the ministry has developed a population segmentation approach also referred to as the “Blue Matrix.”

The Blue Matrix is a one-year retrospective analysis that segments the entire B.C. population into 13 groups based on their health status and/or need for health care across the system (physicians, hospitals, prescription drugs, and home and community care services). This approach allows the ministry to observe which groups are the high users of all publicly funded health care, as well as to better understand why these groups are high users and identify where the health care system could provide more appropriate care to meet their health care needs.

The *operational* approach is defined as identifying specific individuals who are already high users in order to provide better care and to reduce their overall use of health care. For example, after identifying that an individual had visited the emergency department 10+ times, an integrated care program was set up for her. Currently, health authorities have a range of initiatives to identify high users of acute care and to provide more appropriate care to these people. An example of the operational approach is the Breathe Well initiative. It targets individuals with chronic obstructive pulmonary disease (COPD) and identifies high users of emergency departments.

## Alberta

Work in the area of high users has become a focus in Alberta in the past year. A framework was developed that uses estimated costs to the health system for each person in the province. Of \$17 billion spent annually on health care in Alberta, \$9.6 billion has been allocated. Acute care, emergency department, other ambulatory, specialist, long-term care and primary care costs have been incorporated into the model. Other costs such as community laboratory, pharmaceutical, home care and other supportive living costs have not yet been incorporated. A cluster analysis has been performed on the top 5% of users in Alberta (based on costs). The analysis was used to group these complex and high-needs individuals into six general profiles:

- Frail elderly (largely those older than age 75)
- Complex older adults (many with significant mental health and addictions issues)
- Reproductive health (complex maternity obstetrical events)
- Complex infants/toddlers (includes neonatal intensive care unit babies)
- High-needs youth (includes mental health, addictions and injury profiles)
- High-needs children (includes those with developmental delays)

Profiles have been developed across Alberta and specific to each of 64 geographical health service areas. The profiling has revealed many key drivers specific to different communities. For example, population vulnerability, including homelessness, is key driver of high use of emergency department (ED) services in inner-city urban areas. While the existing analysis is based on cross-sectional data, longitudinal data of nine years supplemented with non-clinical (social) community data from the census is now available to perform a longitudinal study.

## Saskatchewan

Pilots are planned in Saskatchewan that will focus on high-cost users and patients with frequent use. The Ministry of Health is collaborating with health regions to launch “hotspotting” pilots for high-cost, high-user patients: one in Regina and a second in Saskatoon. To be launched in 2014–2015, these pilots will focus on patient groups that could benefit from customized care, including intensive case management that would improve patient outcomes and address avoidable costs. Types of data being used in support of these pilots include hospital, ED, physician, and drugs from the perspective of the top 1% and 5% by costs, as well as frequent and high rates of utilization. Through the ED Waits and Patient Flow initiative, the ministry and its partners will also support frequent ED users (particularly those with mental health and addictions issues) through a third pilot in 2014–2015.

Work led by the Ministry of Justice is supporting implementation of a model known as HUB and COR. The model was first developed under the auspices of Community Mobilization Prince Albert. HUB consists of policing and human service agency staff (social services, education and others) conducting a twice-weekly, multidisciplinary team meeting. These meetings review at-risk cases (including those at risk for high use) and develop immediate real-time solutions and interventions. COR consists of representatives from HUB partners who apply deeper analysis and work to make lasting changes based on the lessons they are learning together at the HUB. Provincially, intersectoral data is being integrated to support identification of high users and options to address the social determinants of high use. Future health hotspotting work will move beyond the pilots to other patient groups within the top 1%.

## Manitoba

Two examples of relevant conceptual work in Manitoba were noted. The first of these focused on frequent users of the ED.<sup>1</sup> When grouping these high users, cut-off points were determined at different levels (6 visits, 12 visits, 18 visits); the characteristics within these different cut-off groups varied considerably. Of particular note, the highest group differed from the other groups in that mental health was the predominant health issue. The second piece of work (*Who Is in Our Hospitals . . . and Why?*) focused on identifying the types of patients that are using hospitals. One of the key findings from this work showed that alternate level of care (ALC) patients ranked fifth in terms of frequency but third in terms of hospital days (17%).

There is ongoing operational work at a regional level to address high use. Examples of such initiatives looked at primary care delivered in the home, as well as the role of community paramedics. Other types of initiatives that have been used to cope with high users are home care initiatives, such as the development of special contacts with outside agencies that provide case management and help to find housing for a subset of users. While case management is expensive, it is successful.

Finally, it was noted that there is a lack of systematic engagement between acute and community care. Many stakeholders view solutions as being social- and community-based, but there is little understanding of the high-use profile. It is important to link data to better understand characteristics of high-use populations and to be open to a collaborative approach.

## Ontario

The Ministry of Health and Long-Term Care has been looking into high use for almost three years. The first approach discussed was a conceptual data-driven approach, using almost three years of data from multiple health settings (acute care, day surgery, physician claims, mental health and long-term care) and focusing on the top 1% and 5% of high-cost users. The data shows that about 40% of high users remain high users over a period of two years, and that of the initial high-use population, 20% die within the first year. The data also revealed 47 common conditions among high users, and that costs increase incrementally with the number of conditions a patient has. One of the challenges has been obtaining other data, such as pharmaceutical data. A decision will have to be made about which group to focus on in the future.

The Health Links initiative aims to create clinical and social care networks to coordinate care across Ontario. Currently, there are 54 health links in place, covering approximately 50% of the population); final coverage is expected to be 98%. The organization of each health link is very flexible. Many of the health links employ a mixture of methods to identify high users. Most frequently, users are being identified as “familiar faces” (individuals who are already high users), although workers are looking for guidance on how to target *potential* health links patients.

## Quebec

In Quebec, a number of initiatives are investigating the level of care across specific populations (such as children and seniors). High users are typically referred to as the top 5% or 10%. These initiatives will look at high users of hospital services, EDs and drugs, and analyze the data separately and together. Regional-level data has been linked across some providers, and both regional and national analyses have been conducted on the top 10% of the population.

## New Brunswick

It was noted that, in New Brunswick, a distinction is made between high *users* and high *use*, though there is limited analysis at the individual level. Key areas for high use include diabetes, mental health, COPD, ALC and congestive heart failure. Some initiatives have been implemented to address these areas, including comprehensive diabetes and mental health strategies that focus on the implementation of best practices and education; the creation of mobile crisis teams; the development of family health teams; and the development of centres that address ACSCs such as COPD. All initiatives have evaluation components; preliminary results are available for diabetes and show clinical improvements.

The observation was made that social determinants of health, especially housing, are central to the issue of high use, and initiatives need to consider how to address these if they are to work. The success of the Housing First initiative, *At Home / Chez Soi*, was cited; it first provides stable housing and then addresses health issues.<sup>2</sup>

## Prince Edward Island

The work done to date in P.E.I. has been largely conceptual and has focused on frequent users (four or more inpatient episodes in a two-year period). These users are predominantly living with chronic illness and/or mental illness. ACSCs are a big issue for the province, and COPD was noted as being the largest contributor. The approach with these groups is to educate them about their condition with a focus on self-management. Already, some small projects have been launched in the areas of COPD, diabetes and mental health; the next areas of focus will be heart failure and obesity.

## Nova Scotia

A longitudinal analysis that uses administrative data (limited to ED services from Capital Health) and focuses on the 1% of high users is under way in Nova Scotia. Results indicate that seniors, those with mental illness, and users with multiple comorbidities make up the main profile of high users.

The next step is to link data with Community Counts data, which includes geographic and demographic information, such as information on social deprivation. Work is also under way to get more coverage from electronic medical records and interRAI. The ultimate aim is to be able to target specific resources to specific populations.

## Newfoundland and Labrador

The Newfoundland and Labrador Centre for Health Information completed a report on complex care for the provincial ministry of health in November 2013. Complex care was defined as that delivered to the top 5% of users (in terms of costs); this group was identified by tracking them through hospital and physicians' visits, and drugs programs. Most of this group are characterized as being older than 65, having multiple comorbidities (frequently COPD), presenting often at the ED, lacking community support, and having mental health issues (particularly among 20- to 40-year-old males). The report did not investigate social determinants such as unemployment or homelessness. Analysts found that complex care patients can be identified with rudimentary data, but key challenges are data linkage and making the data usable for policy-makers in their decision-making.

## Yukon

Yukon has a small population (36,000), concentrated in Whitehorse (25,000 to 26,000). Some work that has been done to identify frequent users and high-cost users shows that these patients typically have mental health issues and addictions. One of the main issues the territory is facing is increased ED use, driven by a physician shortage. In response, a Referred Care Clinic was opened to reduce stress on the ED. The clinic is designed for individuals with complex needs and operates with a team of physicians, an outreach worker and a mental health nurse. In the case of one individual, ED visits were reduced from 190 to 40 in one year. The clinic also identified a number of individuals with complex needs who were previously unknown to the health care system. Overall, 5 known high users of the ED moved their care to the clinic, and 42 new users attended the clinic.

## Nunavut

With a very small (33,000), geographically dispersed population, the main issue in Nunavut is access to services. Each community has a health centre, and the focus is on improving primary health care and case management. Specialty services are provided with partners in the south. About half of the population is younger than age 25, suicide rates are high, and there is a focus on building resilience and coping capacity. Social determinants of health are viewed as one of the main issues to be addressed.

Another big challenge is the lack of electronic health records (EHRs); currently all data is collected manually. The territory is working toward an integrated EHR, but one of the key challenges is getting physicians to see the value of this. There is also a memorandum of understanding with the departments of justice and education to develop a shared information infrastructure.

# Identifying Policy Responses to Address High Use

Throughout the forum, participants discussed innovations and improvements taking place across the country to address the issue of high use, and highlighted a number of different approaches and initiatives. Several examples were presented in more detail: the Blue Matrix approach in B.C.; the cluster analysis carried out in Alberta; the Health Links program in Ontario,<sup>3</sup> and Nova Scotia's Extended Care Paramedic Program<sup>4</sup> and Collaborative Emergency Centres.<sup>5</sup> Across the groups and throughout the discussion, themes emerged that were seen by many participants as central to the innovations and improvements being undertaken across jurisdictions.

## Improved Understanding of the Profile of High Users

A theme that continued to receive a lot of attention was the conceptual work being undertaken across many jurisdictions to better understand the profiles of high users. One of the questions that remained central was whether analysts should focus on studying data on costs or data on use and, stemming from that, how they should deal with limitations in data availability in one or both of these areas.

It emerged that looking across geographical regions within jurisdictions was relatively common, as was grouping high users into different profiles. Moreover, certain profiles were found across jurisdictions, such as frail elderly individuals, patients with chronic conditions (in particular COPD and diabetes) and patients with mental illness.

There was discussion surrounding approaches to understanding and categorizing variation within profiles. It was noted that key questions regarding the profile of high users remained unanswered:

- What constitutes high use?
- What characteristics are associated with high use?
- What can be learned from patients with the same characteristics but who are not high users?
- How transitory or chronic are high-use patterns across care settings?

A presentation of the Blue Matrix initiative touched upon these questions. For example, in the B.C. sample studied, people who develop comorbidities or are newly diagnosed tend to be higher users than people with stable conditions within the same population segments. In Alberta, it has been noted that the high-user category does not consist exclusively of chronic high users but also includes people experiencing high-cost events; opportunities for improvement need to be identified across these groups. Participants noted that there will always be a top 5% of users and that success will mean changing the profile of this 5%.

The discussion also emphasized

- The potential role that predictive modelling could play in identifying future high users from existing data;
- The need to find ways to effectively communicate findings to decision-makers;
- The need to engage staff and individuals in the community; and
- The value of developing indicators of high use and incorporating them into indicator dashboards and performance measurement frameworks.

Participants generally agreed that data availability and analytical capacity constituted challenges to carrying out this type of work. In particular, it was agreed that data linkage across care services and social services would be beneficial to analyses of this sort, as would access to longitudinal data. The group stressed that great strides could be made through knowledge sharing and improved communication.

## Operational Approaches to Addressing High Use

The next major issue that was discussed focused on more operational approaches—that is, how to address individuals recognized as being high users and how to intervene in order to provide better care and reduce their overall use and cost to the system.

The idea of hotspotting was discussed as an approach to identifying high users and intervening to address their needs. Hotspotting is currently being implemented in Saskatchewan. It was initially introduced to the province by the Corrections and Policing Department of the Ministry of Justice, which engaged social workers to identify “individuals in crisis” and intervene before their situation escalated. The province is now developing a care intervention model that will build on this approach. There was considerable discussion among participants about looking across sectors to identify hotspots, making use of information from justice, education and health, and encouraging partnership across the sectors. Participants generally agreed that collaboration across these sectors was important.

Other operational approaches were shared by participants, many of which also cited the use of community or primary care resources to provide more appropriate care to high users. Nova Scotia’s extended care paramedic service, for example, treats patients at nursing homes to reduce ED visits by nursing home residents. Almost three-quarters (74%) of calls were treated in the nursing home; many of these people would have gone to the ED otherwise. Nova Scotia has also created collaborative emergency care centres, with extended hours for primary care services, to reduce nighttime ED visits. In P.E.I, initiatives specifically target COPD users. Nurse-supported patient self-management has resulted in fewer and shorter hospitalizations. Ontario’s Health Links, which is structured around patients’ needs, provides community-based care beyond health care.

## Addressing Social Determinants of Health

One of the main discussion points of the forum related to the role that social determinants play in high use. Many participants noted that homelessness and/or impoverishment were key across correctional, health care and social services.

In Nunavut, stakeholders from education, justice and health have worked together to engage individuals and communities to develop mentorship programs. There is community home care throughout Yukon, as well as Homecare for the Homeless. These initiatives have reduced admissions to acute care.

British Columbia has introduced a mental health and substance abuse program in Vancouver; it is a partnership between the police and the city. Homelessness was a key issue in British Columbia. It was found that when housing was provided to individuals, there were notable reductions in their ED use. Manitoba also noted that developing better services in shelters, employment assistance and other agencies can improve health, although this is an expensive initiative. New Brunswick participants also discussed a number of cross-sectoral initiatives targeting mental health, management of ALC patients, addiction and homelessness.

In Alberta, one hospital introduced a staged approach, which first targeted the top 5 users of the ED in 1 location, then the next 25 users, and finally the next 125 users. They found that scaling, as well as moving this approach to other locations, has been a challenge. New Brunswick participants reported a similar approach, noting that they used funds saved from generic drug prescriptions to fund these efforts.

Across and within jurisdictions, a number of different innovations, improvements and approaches were being undertaken, and the discussion moved toward the question of when to use prevention and when to use case management approaches. It was felt that there was distinction between approaches to address high *use* (prevention) and high *users* (case management).

Participants also expressed a general concern regarding the extent to which initiatives are being evaluated. There was a sense that analytical capacity was an issue, as was defining success for these initiatives.

## A Way Forward

Before concluding the forum, participants were asked what support they thought would be of assistance from federal and pan-Canadian agencies. A few key points were raised by the group:

- Some felt that CIHI and CIHR could assist in getting providers and the community on board to assist with the sharing and analysis of data—in particular, by helping to communicate the benefits of these activities to practitioners and helping them to understand change management.
- Participants noted that while the forum was a very good way to learn about ongoing initiatives across other provinces and regions, it would be beneficial to ensure that knowledge sharing continues. In particular, it was suggested that providing information on ongoing initiatives across provinces would be useful, as would linking work to broader performance aims. Similarly, it was felt that it would be useful to continue to engage in discussions with both policy-makers and analysts/researchers together, as was done in the forum.



- Participants felt that there could be large gains from collaborative approaches toward analytics. One proposal specifically suggested the development of a knowledge repository/community where provinces not currently undertaking modelling could learn and benefit from those that are. In particular, there was a request for sharing of evaluation methods, predictive modelling and projections. As a starting point, it was felt that a list of contacts with information on who is doing what work would be a good way forward.

To conclude the session, CIHI, Statistics Canada, the Canadian Foundation for Healthcare Innovation and CIHR identified current and future initiatives relevant to the issue of high users.

CIHI has a number of initiatives in the area of high users:

- Together with Health Quality Ontario and Manitoba Health, CIHI has developed a new tool—Hospital Admission Risk Prediction (HARP)—for hospitals and primary care providers to identify patients at high risk of readmission to hospital within 30 days or 15 months of discharge based on 5 or 10 patient characteristics.
- The Population Risk Adjusted Grouper (PRAG) is also in development and scheduled for release in 2015.
- A report on COPD (one of the conditions associated with high use) is scheduled for release in 2015.
- Other future initiatives include an acute care patient experience survey that will inform the development of patient-reported measures (which will proceed if enough jurisdictions show interest).
- A new indicator on multiple hospital admissions is also being developed.

With regard to data, CIHI is working with provinces and territories to

- Assist in data linkage; and
- Acquire patient-level fee-for-service physician billing data.

CIHI has also developed the National Ambulatory Care Reporting System (NACRS), which contains data for all hospital- and community-based ambulatory care:

- Day surgery;
- Outpatient clinics; and
- Emergency departments.

The Canadian Foundation for Healthcare Improvement has a number of initiatives of potential interest to forum participants, including the following:

- INSPIRED model of care for people living with COPD in the community (Implementing a Novel and Supportive Program of Individualized care for patients and families living with REspiratory Disease);
- Défi Santé—an initiative to reduce frequent use among males with mental health and addictions, adapted from the U.K.'s National Health Service approach, Community Matron. Défi Santé reduced use of hospital beds by 10%;

- Spreading Healthcare Innovations Initiative (a partnership between the Institute for Healthcare Improvement, Kaiser and the Canadian Foundation for Healthcare Improvement);
- A Canadian cohort of the Institute for Healthcare Improvement’s Triple Aim Community; and
- Patient engagement projects.

Statistics Canada has been doing analyses to identify characteristics associated with high use.<sup>i</sup> This work has identified that factors such as low socio-economic status, mental health issues, ACSCs and Aboriginal peoples living off reserves are all predictors of high use.

Key areas in which Statistics Canada can support jurisdictions include privacy and confidentiality frameworks, understanding issues of comparability across (and within) jurisdictions, bringing data sets together and better understanding data.

CIHR’s Institute of Health Services and Policy Research (IHSPR) and Institute of Population and Public Health (IPPH) have just launched a new five-year learning network called the SPOR Network in Primary and Integrated Health Care Innovations. This network focuses on new approaches to the delivery of integrated health care (including primary prevention and primary health care), both horizontally and vertically across the care continuum, to address

- Individuals with complex needs across the life course; and
- Multi-sector integration of upstream prevention strategies and care delivery models (including the assessment of upstream predictors of high system use and subsequent identification and targeting of prevention strategies and interventions).

The SPOR Network is a distributed network of networks model with provincial- and territorial-based initiatives currently in development. Given the alignment between the network’s focus and the objectives of the workshop, IHSPR and IPPH encouraged participants to connect with their respective provincial/territorial networks and offered to facilitate such connection.<sup>ii</sup>

## Wrap Up

In concluding the forum, Terry Sullivan and Jeremy Veillard noted that while there are large challenges in identifying what to do conceptually and operationally, hearing about innovations has been promising and informative. Moreover, there is a clear interest in undertaking collaborative efforts going forward in terms of capturing and analyzing data, as well as in addressing innovation and scaling. Jeremy identified some possible next steps, including

- Logistical support for self-directed communities of practice, if sufficient interest emerges from among participants, potentially with three areas of focus:
  - Analytics
  - Programs
  - Systems change
- A special issue of *Healthcare Papers* on high users
- Reconvening forum participants at CAHSPR’s 2015 conference

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i. For example: <http://www.statcan.gc.ca/pub/82-622-x/82-622-x2011006-eng.pdf>.

ii. <http://www.cihr-irsc.gc.ca/e/43626.html>; <http://www.cihr-irsc.gc.ca/e/47870.html>.

# Appendix 1: Meeting Agenda

## Pan-Canadian Forum on High Users of Health Care

### Location

Sheraton Gateway Hotel  
Alpine Room  
Terminal 3, Toronto International Airport  
Toronto, Ontario  
March 20 and 21, 2014

## Agenda

### Objectives

**Foster** collective learning, providing participants with opportunities to share and discuss information regarding strategies and policy interventions related to high users in their own and other jurisdictions.

**Highlight** key research priorities and identify those that are shared across Canadian jurisdictions.

**Identify** how jurisdictions can be supported with data, performance measurement, and research and analysis.

| Thursday, March 20, 2014 |   |
|--------------------------|---|
| Time                     | Item  |
| 9:30 a.m.                | <b>Registration and Coffee—Alpine Foyer</b>   |
| 10:00 a.m.               | <b>Welcome</b>  |
| 10:05 a.m.               | <b>Introduction and overview of agenda</b> <ul style="list-style-type: none"> <li>• Terry Sullivan, Facilitator</li> </ul>  |
| 10:15-12:00              | <b>Session 1: International and Canadian perspectives on High Use</b>   |
| 10:15 a.m.               | <ul style="list-style-type: none"> <li>• Plenary: Lessons from the NHS experience with High Use<br/>Speaker: Martin Bardsley, Nuffield Trust, UK</li> </ul>   |
| 11:00 a.m.               | <ul style="list-style-type: none"> <li>• Research on and policy for high use: a synthesizing overview of international activity<br/>Speaker: Irimi Papanicolas, London School of Economics, UK</li> </ul> |
| 11:30 a.m.               | <ul style="list-style-type: none"> <li>• What is going on in Canada? A high level overview<br/>Speaker: Keith Denny, Canadian Institute for Health Information</li> </ul>                                 |
| 12:00 noon               | <b>Lunch—Alpine Foyer</b>   |
| 1:00 p.m.                | <b>Session 2: Roundtable—How are high users identified across Canada? Sharing research and analysis</b>   |
| 2:30 p.m.                | <b>PM Break—Alpine Foyer</b>  |
| 2:45 p.m.                | <b>Session 3: Roundtable—Moving beyond description to action on high use: sharing experiences</b>   |
| 4:15 p.m.                | <b>Summing up and adjournment</b>   |
| 6:30 p.m.                | <b>Dinner—Geneva Room</b>   |

(cont'd on next page)

| Friday, March 21, 2014 |   |
|------------------------|---|
| Time                   | Item  |
| 7:45 a.m.              | <b>Breakfast—Alpine Foyer</b>   |
| 8:30 a.m.              | <b>Welcome, Recap and overview</b><br><ul style="list-style-type: none"> <li>• Terry Sullivan, Facilitator</li> </ul> |
| 8:45 a.m.              | <b>Session 4:</b> Innovation and improvement to address the issue of high use   |
| 10:15 a.m.             | <b>AM Break—Alpine Foyer</b>  |
| 10:30 a.m.             | <b>Session 5:</b> What will support innovation and improvement in the jurisdictions?                                  |
| 11:45 a.m.             | <b>Wrap-up and next steps</b>   |
| 12:15 p.m.             | <b>Lunch—Alpine Foyer</b>   |

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# Appendix 3: Scoping Review of the Literature on High Users of Health Care

## Executive Summary (Key Points)

Prepared by Dr. Irini Papanicolas for the Pan-Canadian Forum on High Users of Health Care, Toronto, March 20 and 21, 2014

This review attempts to bring together the literature in this field of research to better understand the magnitude of costs or utilization accounted for by high users, what characteristics are associated with high users and whether there are successful policies that can be used to more efficiently address their needs.

## Terminology

A significant amount of research has emerged around high use of health care services, yet the literature is marked by variation in the definitions that are used to identify high-use populations. Nevertheless, three general approaches to define high-use populations can be distinguished throughout the literature:

- Populations above a defined absolute threshold related most often to cost or utilization of health services;
- Populations above a relative threshold related to cost or utilization of health services; and
- Populations meeting some normative threshold of cost and utilization.

The terminology seems to vary according to the characteristic used to define high use; those who define high use in terms of utilization of health care services typically refer to these users as “frequent users,” while those that apply a perspective of financial cost of health care utilization typically employ the phrase “high-cost users.”

Across definitions, there is also variation in the types of services that are studied, with some studies focusing on particular service settings such as ambulatory care or inpatient, while others look across a breadth of provider settings.

A substantial proportion of the literature applies ad hoc definitions of high users that were developed for the purposes of a particular investigation. This a priori establishment of definitions—employing varied absolute or relative thresholds—can lead to large variation in findings gathered regarding high-use populations.

## Characteristics

The studies reviewed assessed a wide range of high-user characteristics. Among these, 6 general characteristics were commonly found to have some association with high use of health care services: age, sex, morbidity, generally high use of health care services, homelessness and insurance status.

Many empirical findings have shown a positive correlation to exist between high use of medical care and patient age. This finding is consistent across studies in the U.S., Canada, Sweden and Great Britain. Explanations include high spending in the last year of life.

On the other hand, some studies indicate that the average cost for elderly patients within the high-cost user cohort was actually lower than the average cost for patients in middle age, suggesting that high-cost user populations may be associated with a unique set of cost concentrations across age groups that differ from typical age-related increases in health care costs.

Most of the papers reviewed cited greater use of health care services among females throughout different health care systems, with women consistently overrepresented in frequent use and high-cost populations, regardless of health care service studied (e.g., primary care, ED use, inpatient care, pharmaceutical use), even after controlling for pregnancy.

Other studies suggest an indirect relationship between sex and health service use, suggesting that sex effects on tendency to use health care services may be influenced by separate characteristics that profile high-using populations, such as age and type of service used.

The literature has generally shown that high-use populations have greater morbidity and comorbidity burdens. High users of care are more likely to have poorer self-assessed health, high prevalence of chronic conditions, including coronary artery disease, coronary heart failure and diabetes, and a greater number of psychosocial conditions, most commonly anxiety disorders, alcoholism, schizophrenia, drug dependence and depression. Psychosocial distress, which may or may not exist alongside other mental illness, may also increase the likelihood of utilization. Patients with poorer social support structures (e.g., relatives attending to their care) tend to use more primary care services.

High users of one type of health care service have also been found to be high users of a variety of different health care services. Frequent visitors to emergency departments tend to be high users of other care facilities, including primary, outpatient and in-hospital care.

Several studies have investigated homelessness as a characteristic of high use of health care services. Recent studies have also suggested that there exists a large degree of heterogeneity in health care use within homeless populations, while some of the literature in this area has suggested that impoverishment, rather than homelessness per se, predicts high use of health care services.

High use of medical care has also been commonly evaluated with regard to insurance status, particularly in the United States. Yet, results from these different papers—even within the same setting—are conflicting and show different directions in this association. While differences in findings may be due to use of different datasets, sample conditions, methodological approaches, or may in fact reflect different approaches to defining high use, further research appears needed to clarify how insurance status impacts high use of medical care.



## Impact

In the U.S., various estimates show that 5% of the population accounts for 49% to 52% of total health expenditures and that this cost concentration has remained fairly stable over the past decades. Another study estimates the health expenditure for high users relative to control populations and finds that this population accounts for costs 4.69 times higher in episodic care, 2.72 higher in long-term community care and 1.84 higher in long-stay institutional care.

When looking at the absolute amounts of expenditure accounted for by high users in the U.S., it was estimated that only a small percentage of patients exceeded costs of \$1 million per year (0.5%) and \$250,000 per year (6.5%).

Other investigations have focused on determining the quantity of services used by high users, yet findings are varied, in particular due to different definitions of high users. Different findings suggest that high users in the U.S. make up between 17.6% and 28% of emergency department visits, while also estimating that high users account for more than 20% of all psychiatric inpatient care services.

In Canada, estimates suggest that 1% of the population accounted for 49% of combined hospital and home care costs, while 5% of the population accounted for 84% of these costs. Many studies suggest that the impact that high users have on the health care system appears to be fairly stable over time.

Reports across the provinces of Ontario, Manitoba, British Columbia and Saskatchewan have also provided estimates of quantity of use across high-use populations. Estimates and methods vary, making them difficult to compare directly. In Ontario, it is estimated that 39,000 Ontarians are responsible for 30% of hospital and home care costs. In Manitoba, heavy users of medical care were estimated to account for 45% of all hospital care days, even though this group accounts for just 2.57% of the hospitalized population and 0.33% of the provincial population.

A British Columbia study defined high users as the most costly 5% of users of fee-reimbursed services. On the basis of this definition, the authors estimated that high users were responsible for an average of \$2,902 in physician payments, 7.9 times as much as for non-high-use patients. In Saskatchewan, estimates suggest that the 20th percentile of health care utilization across each service area has a lower bound of 2 hospital visits, 32 physician visits and 29 medications per year.

Limited evidence exists from other country settings such as Finland, Sweden and Australia, and shows varied approaches and impacts. In Finland, it is estimated that 5% of the population accounted for approximately 50% of pharmaceutical expenditures in 2009. In Sweden, frequent users of the ED represented just 4% of the population but accounted for 18% of all visits to the ED in 1996. In Australia, users in the top 5% of the distribution ranking patients by total inpatient cost were associated with 38.4% of total inpatient costs and inpatient days for the population.

## Policies

Most policies that have targeted high use of health care services have been designed and implemented at the local level. Recently, policy initiatives have emerged from higher authorities, such as provincial or national authorities.

Popular media, grey literature and peer-reviewed studies all suggest that high use of health care services by homeless populations could be mitigated through targeted policy—including housing assistance and case management—and that such outcomes would positively impact health care expenditures and overuse of health care services.

Althaus and colleagues developed a grouping scheme to classify the initiatives that target high users of medical care. They identify a threefold typology to group policies targeted at high users:

- Case management programs (programs that involve a diverse set of clinical and social care stakeholders to plan and implement improved patient care schemes);
- Social worker support interventions (programs that use social care resources to improve patient outcomes); and
- Coordination care plan interventions (programs that seek to improve care by planning for improved care coordination).

Of the eight studies reviewed, five were classified as case management and three as non-case management programs.

“Virtual wards,” which seek to improve the integration of health and social care for patients at high risk of future hospitalization by recognizing and addressing their complex and interacting needs, were first introduced in the U.K. in the early 2000s and have since been applied across the country, as well as in Canada and the United States. Differences in adaptations of the virtual ward model across settings hold potential interesting findings for researchers and policy-makers. To date, few studies have been undertaken to evaluate the impact of these programs.

Similarly, the patient-centred medical home has also emerged as a potential approach to improve quality of health care, control costs and improve patient experience in the United States. The patient-centred medical home model essentially outlines mechanisms for organizing primary care to provide high-quality care across the full range of individuals’ health care needs. Despite widespread enthusiasm for the medical home concept, few peer-reviewed publications have found that applying the medical home design produces measurable improvements in the quality and efficiency of care; however, comparable reviews are limited by lack of consistent definitions and terminology.

The early medical home research appears to reflect the wide variation in both how medical homes are being designed and implemented in practice and how researchers are choosing to evaluate patient-centred medical home design and implementation. While some aspects of medical home care show promise, and many studies show favourable outcomes on one or more indicators, a few find unfavourable effects on costs, and many show inconclusive results.

Programs reviewed are varied in their approaches and target populations, as well as the extent to which outcomes are followed up and reported. Results do suggest that case management systems within and outside individual hospitals may be well equipped to monitor and respond to heavy users.

## Appendix 4: Canadian Activity in the Area of High Users of Health Care: A Summary of Stakeholder Interviews

### Executive Summary (Key Points)

Prepared by Dr. Eleni Antoniadou for the Pan-Canadian Forum on High Users of Health Care, Toronto, March 20 and 21, 2014

This study investigates stakeholder views on descriptions, definitions, approaches to measurement and policies/initiatives to address high users in Canada. The results indicate the importance of the issue, as reflected by the collection and analysis of cost and use data to measure high use principally from hospitals, emergency departments and pharmaceuticals records. The top 5% of the population accounts for 50% to 67% of the total health costs and is characterized by multiple chronic conditions and social determinants of health. Multi-sectoral policy approaches of coordinated care appeared to be the most appropriate way to address the high-user issue, while key opportunities for action included system integration, primary care and targeting social determinants.

The following presents a high-level descriptive overview of the scope and types of activity in the area of high users as captured through discussions with key informants. A list of potential key informants was provided by CIHI in order to conduct telephone interviews based on a structured questionnaire consisting of nine items. This report presents an overview of eight interviews, a mini focus group and three paper questionnaires. Eight Canadian provinces, one territory and several pan-Canadian organizations were represented, from ministries and regional health authorities, universities, research institutes and research funders.

The issue of high users was noted to be a priority in the interviews, for both participating organizations as well as governments. Only two of the respondents said that the issue is not at the top of their governments' agenda yet, but added that it is becoming a priority area for work due to the increasing evidence associated with the high costs and unmet needs of this patient group.

A wide range of activities have been undertaken by almost all participants' organizations to measure high use. In most cases, research focuses on examining clinical records for use and cost data to identify those who make excessive use of services and resources and to better understand their needs. Most respondents referred to the use of hospital, emergency and pharmaceuticals' cost and use data (in some cases, in the context of specific initiatives such as Health Links) to analyze and measure high users. Population health outcomes, morbidity patterns and expenditures were used to profile high users and differentiate them from "higher than expected

users.” Most informants reported that research in this area aims to help stakeholders better understand the complex needs of these patients to develop multi-sectoral and individualized approaches in the context of integrated care and targeting social determinants of health.

Most respondents reported using either cost or a combination of use and cost data to identify high users in their province. In most cases, they defined high users as the top 5% of the population making use of the health care system and reported that they account for 50% to 67% of total health care expenditures.

The primary approach to classifying high users was by use of acute care services (emergency department and hospitalization) across all jurisdictions; three cases considered all of the following factors to identify high use: primary care, acute care, pharmaceuticals, multiple services and high cost procedures.

The majority of informants reported that the characteristics of high-use patients are a combination of chronic conditions (mainly mental health disorders, COPD and heart diseases) and social determinants of health (e.g., poverty, homelessness). Many informants also mentioned that older age is a common characteristic of high-use patients.

One of the most important aspects of addressing the issue of high users was to identify their needs, including those relating to social determinants of health. A multi-sectoral policy approach of coordinated care among different authorities (e.g., police, social services, emergency departments) was said to be the most appropriate.

Two regional policy initiatives were known among informants and reported in the majority of the interviews: Health Links and Blue Matrix, with the former being the most widely known. Health Links was identified as a novel policy approach to address high-user needs and at the same time reduce the costs associated with their care. The policy initiative has been implemented in Ontario and involves groups of providers (hospitals, primary and community care) that are encouraged to work together to provide tailored care to high users to minimize excessive utilization and reduce expenditures.

The Blue Matrix was developed in British Columbia to understand the health care needs of the population and the type of services used in order to project future health care needs. The matrix is based on the segmentation of the population into groups on the basis of health status, from healthy and low risk to pregnancy and palliative care. The type of health care services used and the frequency of use over time were analyzed to make basic predictions for costs for particular groups.

Several case management/virtual ward projects have proved to be successful, although evaluation is still ongoing. These have included converting a former hotel to a supportive housing project for chronically homeless individuals, creating a multidisciplinary outreach support team for homeless individuals and high users, and implementing care projects for individuals with chronic conditions identified as being at risk of hospitalization or frequent emergency department use.

The majority of informants stated that it is hard to evaluate the efficacy of current interventions, as they have been recently initiated.

Most informants clearly believed that there are key opportunities for action in all of the following: risk modelling, system integration/continuity, primary care and social determinants of health.

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