

# **INTERMITTENT CATHETERS: TOWARD AN INCLUSIVE ACCESS POLICY IN ONTARIO**

Provincial Intermittent Catheter Working Group  
Policy Recommendations  
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## 1. EXECUTIVE SUMMARY

### **The Provincial Intermittent Catheter Working Group**

The following policy report, intended for submission to the Assistive Devices Program (ADP) at the Ministry of Health and Long Term Care, is the end result of a collaborative research and consultative effort involving intermittent catheter users, clinicians, policy-makers, and patient association representatives based in Ontario who have collectively formed the Provincial Intermittent Catheter (IC) Working Group (See details in **Appendix A**). Having identified a pressing need to re-evaluate the policies surrounding urinary catheters, the time-limited IC Working Group seeks to provide a forum for interested clinicians, organizations, individuals with physical disabilities and policymakers to advocate for appropriate, evidence-based access to intermittent catheters for Ontarians. As such, it has worked to:

- Bring together a coalition of clinicians, organizations, individuals with physical disabilities and policymakers to examine and address issues related to intermittent catheter use in Ontario
- Compare international best practice with existing practice in Ontario (and Canada) while assessing the current evidence base in order to inform provincial health policy
- Release a position paper based on the IC Working Group's overall findings that will guide policy development
- Advocate to provincial policymakers to ensure that Ontario provides adequate access as per the best available evidence for individuals needing access to intermittent catheters

### **Key Elements**

Seeking to bridge science and policy, the structure of the current report reflects its three, central aims, which are as follows:

1. To provide an up-to-date picture of the evidence base on intermittent self-catheterization (ISC), particularly as it relates to individual health and well-being, safety, and overall quality of life;
2. To present ISC not only as a biomedical issue, but also a social and adaptive one intimately tied with the daily activities of its users;
3. To outline a list of evidence-based, health-policy recommendations in support of the population concerned, such that Ontarians with chronic urinary retention have the capacity to choose the intermittent catheter type and routine that best fits their medical and lifestyle needs irrespective of their condition, disability, and/or socioeconomic status.

## Key Findings

- Intermittent catheterization (IC) continues to be among the main methods of choice for individuals with bladder-emptying problems due to neurogenic or non-neurogenic causes.
- Compared to uncoated catheters, single-use, hydrophilic catheters can serve as safeguards against risks of short and long-term complications such as urinary tract infections (UTIs) and the build-up of urethral scar tissue (known as urethral strictures).
- When presented with a choice, most ISC users prefer single-use, hydrophilic catheters over standard or uncoated catheters. A recent U.K. study with generalizable results found hydrophilic catheters to be cost-effective in comparison to uncoated catheters.
- Unlike the guidelines issued by the Canadian Urological Association (CUA), best practices adopted by various international and regional associations do not support the reuse of intermittent catheters, and the optimal technique for cleaning catheters between uses is as of yet unclear in the existing evidence base. Moreover, no catheters produced for reuse are currently sold in Canada; ISC users in Ontario who reuse are thus exposed to risks that manufacturers have not investigated.
- Among the OECD, as well as other industrialized countries, Ontario (and Canada for the most part) remains an outlier when it comes to public access to and provision for intermittent catheters. In Canada, both the Saskatchewan Aids to Independent Living and the Société de l'assurance automobile du Québec provide 100% coverage, with other provinces (i.e. Alberta) exploring broadening access.
- According to a telephone-based survey conducted by the IC Working Group with a conveniently-sampled group of Ontarians who use or have experience with intermittent catheters, the reuse of intermittent catheters mostly arises from a mix of financial constraints and inadequate or wholly absent public support. This finding was corroborated by the observation that almost all interviewees who could afford a single-use ISC routine actually *chose* to follow such a routine, even in cases where they had initially been on a clean/multiple-use ISC routine.

## Recommendations & Actionable Items

- The Provincial Intermittent Catheter Working Group recommends that the Government of Ontario take the data, analysis, and case study presented in this report into account and reconsider the public access channels currently in place for Ontarians in need of intermittent catheters as a result of medical conditions and/or disabilities associated with chronic voiding disorders.
- A funding mechanism similar to that of the [ADP](#), the IC Working Group proposes, would be appropriate to emulate when establishing a public program for intermittent catheters and supplies in Ontario. Local Health Integration Networks (LHIN's) in Ontario can be the vehicle for organizing and implementing such a program.

- [The Government of Ontario](#) should take into consideration recent developments in the evidence base on ISC; the policies and guidelines of most [OECD](#) countries and relevant international and regional associations, respectively; as well as the reported concerns of Ontarians using ISC, acknowledging that long-term ISC users are advised to follow a single-use catheterization routine to lower risks of UTI and other related complications as well as enhance satisfaction and quality of life outcomes.
- The Government of Ontario should consider rationalizing the programs in Ontario that currently fund intermittent catheters and ancillary supplies to ensure every individual that needs a catheter has access to one.
- Given that the [ADP](#) funding mechanism is already in place and is well-established, it would make for an appropriate model based on which a specific program for intermittent catheters and relevant supplies can be created.
- Public health authorities, clinicians, nurses, and trend-setting bodies like the [Canadian Urological Association](#) (CUA) should ensure that all affected Canadians are fully informed that intermittent catheters are safest as single-use devices.
- The Canadian Continence Foundation recommends that healthy intermittent catheter use requires ICs to be used only once (single use) and a catheterization frequency of 5 to 6 times per day to avoid urinary tract infections.
- By and large, the IC Working Group believes that improving access to intermittent catheters will go a long way toward ensuring that Ontario's healthcare system is equitable, sustainable, and accessible to all Ontarians irrespective of medical condition, disability, and/or socioeconomic status. The impacts of enabling individuals to afford sterile, single-use intermittent catheters will help decrease the burden of preventable UTI's and physical damage, thereby reducing the number of unnecessary ER visits and hospitalizations. Moreover, it will have a significant impact on users' quality of life, promoting individuals' sense of independence, adaptability, and ability to attend to work, family, and other responsibilities.

## 2. GLOSSARY OF TERMS

- **Bacteriuria:** The presence of bacteria in the urine with or without associated symptoms of infection.
- **Catheter-associated urinary tract infection (CA-UTI):** The occurrence of local or distant clinical symptoms or signs attributable to bacteria present either within the urinary tract or in the bloodstream.
- **Catheterization routine:** concerns whether an individual uses a new, sterile catheter for every procedure, or cleans and reuses a catheter multiple times.
- **Hydrophilic catheter:** an intermittent catheter that, with or without the addition of water, allows virtually friction-free insertion and removal of the catheter without the use of a lubricating gel.

- **Idiopathic bladder:** bladder dysfunction of which the cause of pathology is not clear
- **Indwelling catheter:** A catheter that is inserted into the bladder via the urethra and remains in place for a period of time.
- **Intermittent catheter:** a catheter that is inserted into the bladder only when urine needs to be drained.
- **Intermittent self-catheterization (ISC):** insertion and subsequent removal of an intermittent catheter for bladder drainage undertaken independent of a nurse or caretaker.
- **Neurogenic bladder:** refers to a number of urinary conditions in people who lack bladder control due to a brain, spinal cord or other neurological problem.
- **Overflow incontinence:** loss of urine with over-distention of the bladder caused by bladder neck obstruction or an underactive bladder muscle.
- **Urethral stricture:** narrowing of a section of the urethra that causes a blocked or reduced flow of urine.
- **Urinary catheter:** a hollow tube usually made of plastic inserted into the bladder via the urethra or through a continent stoma to drain it of urine.
- **Urinary incontinence:** defined by the International Continence Society as the complaint of any involuntary leakage of urine.

### 3. INTRODUCTION

Prepared for submission to the Ministry of Health and Long Term Care in Ontario's [Assistive Devices Program \(ADP\)](#), this health policy report represents part of a wider effort by the Provincial Intermittent Catheter Working Group (hereafter referred to as "the IC Working Group") to advocate for improved access to intermittent catheters (ICs) in Ontario. The report is divided into four main sections:

- An **overview** of the existing evidence base on intermittent (self-) catheterization; single- and multiple-use catheterization routines; intermittent catheter types; and common complications of long-term catheterization and its impacts on health and quality of life.
- A **health system analysis** of the burdens borne by the health system due to a lack of appropriate access to intermittent catheters and evidence-based best practices.
- A **qualitative descriptive study** based on telephone-based interviews conducted with a conveniently sampled group of eight individuals (two men and 6 women) using a semi-structured questionnaire.
- A set of evidence-based **policy recommendations** in line with current policies and recommendations in OECD countries on urethral catheterization for improving the health and well-being of long-term users of intermittent catheters, and for moving towards a more equitable and patient-focused assistive devices policy in Ontario.

### 3.1 OVERVIEW

The data, analyses, and recommendations presented in this report are the outcome of a desk study and telephone-based survey conducted by the IC Working Group throughout the summer of 2016. Moreover, research activities were coupled with multiple consultation rounds the Group held at Spinal Cord Injury Ontario's regional office in Toronto.

### 3.2 INTERMITTENT CATHETER POLICY IN ONTARIO

In Ontario, as in many Canadian provinces, a non-trivial gap in the public support programs available for users of intermittent catheters continues to exist. It was this that provided the original impetus for the aforementioned organizations to come together and present this issue before the Government of Ontario. A more detailed breakdown of the sources of funding for intermittent catheters is provided in **Chapter 5**.

- Unlike the United Kingdom (U.K.) and the United States (U.S.), as well as most jurisdictions in other OECD countries, the reimbursement structure for intermittent catheters in Ontario excludes many users in need of such assistive medical devices.
- Those ineligible often have no choice but to pay for their monthly supplies out-of-pocket.
- Further, having to bear the costs of catheters and catheterization supplies (e.g., lubricant, gauze, betadine, etc.) places a constraint on people's budgets and leads many to reuse intermittent catheters intended only for single-use.
- Given that the ADP no longer includes urinary catheters under the [list of devices types](#) it funds, except in cases involving an ostomy, the primary source of funding that most people seek is the [Ontario Disability Support Program \(ODSP\)](#).

### 3.3 RELEVANT MEDICAL CONDITIONS

This section lists the medical conditions most commonly seen in users undertaking intermittent catheterization.

- Spinal cord injury (SCI)
- Spina bifida
- Cerebral stroke
- Bladder cancer
- Prostate cancer & benign prostate hyperplasia (BPH)
- Multiple sclerosis (MS)
- Parkinson's disease

As **Table 2** indicates, a significant proportion of individuals with urinary retention become fully dependent on intermittent catheterization for complete bladder emptying.



*Table 2: Urinary Retention and IC Users in Canada*

<b>Condition</b>	<b>Urinary Retention Population</b>	<b>Estimated IC Population</b>	<b>IC Incidence Rate</b>
Spinal cord injury	69,000	34,000	0.0048%
Spina bifida	3,500	2,800	0.0003%
Benign prostate hyperplasia (BPH)	30,000	15,000	0.0017%
Multiple sclerosis	30,000	15,000	0.0014%

(See **Appendix B** for a summary of epidemiological data for relevant medical conditions)

#### 4. INTERMITTENT SELF-CATHETERIZATION (ISC)

This section of the policy report provides a literature review focusing on the procedure of intermittent self-catheterization (ISC), as compared to indwelling catheterization; clean and sterile or aseptic routines of ISC; catheters available for ISC; as well as health complications and impacts on quality of life.

##### 4.1 OVERVIEW

The practice of intermittent, or “in/out,” catheterization in community and home settings away from the hospital gained widespread popularity in the 1970’s, following the American urologist Jack Lapides’s landmark paper on what became known as clean intermittent catheterization (CIC). Generally, the success of intermittent catheterization is presented in comparison with indwelling catheterization, an alternative method involving a permanently attached Foley catheter.

According to Lapides’s idea of CIC, the key to preventing UTI’s is avoiding high intravesical pressure and over-distention of the bladder (De Ridder et al., 2005), thus stressing the importance of scheduled catheterization on a daily basis to prevent the buildup of urine in the bladder and the complications associated with that. Over the past two decades, however, intermittent catheter technology has advanced as single-use, hydrophilic catheters entered the market and led to improvements in health and quality of life outcomes for many users. This has spurred an ongoing debate among users, researchers, clinicians, nurses, and policymakers on what the optimal routine of intermittent catheterization looks like.

##### 4.2 WHAT IS INTERMITTENT SELF-CATHETERIZATION (ISC)?

Considered the gold standard of bladder management today, intermittent catheterization involves the insertion of an intermittent catheter into the bladder via the urethra (or a continent channel such as a Mitroffanoff) to drain the bladder of urine, and the subsequent removal of that catheter from the bladder. When individuals undertake it independent of a nurse or caregiver, it is known as ISC.

The success of this method for individuals with neurogenic lower urinary tract dysfunction (NLUTD) derives from its convenience and minimally invasive nature.

Compared to indwelling catheterization—a technique in which a so-called Foley catheter is connected to the bladder on one end and to a drainage leg bag on the other—IC has been shown to promote independence, giving individuals more control over bladder emptying and improving quality of life outcomes. Moreover, it allows individuals to maintain continence, is supportive of sexual expression, and is associated with a lower frequency of UTI's (Hunter & Cowie, 2014). **Table 3** outlines the central advantages of intermittent catheterization in comparison to indwelling catheterization.

*Table 3: Advantages of Intermittent Catheterization over Indwelling Urinary Catheters*

● Improved self-care and independence
● Reduced risk of common indwelling catheter-related complications
● Reduced need for equipment (e.g., drainage bags)
● Less barriers to intimacy and sexual activities
● Reduced risk of UTIs
● Potential for reduced lower urinary tract symptoms (frequency, urgency, incontinence) between catheterizations

Source: Adapted from Newman & Willson, 2011

### 4.3 SINGLE USE V. REUSE IN INTERMITTENT SELF-CATHETERIZATION

There are two, main types of ISC routines: multiple use and single use. In a sterile environment, as in a hospital, single-use is always practiced. As for home and community settings (i.e., CIC, or CISC when undertaken independently), both single and multiple-use are followed, despite scientific evidence recommending single use.

#### 4.3.1 CLEAN INTERMITTENT SELF-CATHETERIZATION (CISC)

CISC refers to self-catheterization in home or community (i.e., non-sterile) settings. In practice, CISC users can be multiple-users or single-users. In their guidelines on neurogenic lower urinary tract dysfunction (NLUTD), the European Association of Urology (EAU) states that clean technique entails “disposable or cleansed reusable catheters, genitals washed.” (Hudson & Murahata, 2005). In Canada, however, **all manufacturers of intermittent catheters indicate that they should not be reused**, as safety considerations for the latter have not yet been properly investigated. In other words, **there are no approved re-usable intermittent catheters by Health Canada** and as such, **all intermittent catheters sold in Canada are not designed for reuse**. This routine, however, remains common practice. Many individuals reuse catheters originally intended for single-use, often due to cost-related constraints. For example, a large Canadian survey of people with SCI conducted by Woodbury et al. (2008) found that 55% reused catheters. Similar figures were reported by Cameron et al. (2010) in an American survey and in contacting various manufacturers; they have estimated similar re-use data with individuals using a new catheter every 1-4 days. Reusing catheters identified and approved for single-use, however, presents multiple risks:

- **Insufficient safety and efficacy**, as most plastic catheters (including hydrophilic catheters) are made for single-use only.
- **Contamination with bacteria due to sub-optimal cleaning techniques** (e.g., through the formation of a biofilm-like layer of bacterial organisms on the catheter).

Whether by choice or not, individuals who reuse intermittent catheters clean or disinfect them using a variety of techniques (**Appendix B**), some more effective than others. Due to the lack of reliable, evidence-based research and guidelines on intermittent catheter cleaning best practices, perceptions of this routine have changed over the past decade and both ISC users and healthcare professionals today prefer single use intermittent catheters.

## 4.4 TYPES OF INTERMITTENT CATHETERS

### 4.4.1 OVERVIEW

This section will provide an overview of the main categories into which intermittent catheters can be divided. As catheter technology has advanced, so has the complexity of the procedure for nurses/caretakers and users alike. The introduction of hydrophilic coated (HC) catheters has not only expanded the range of choices available to short- and long-term users, but also led to novel insights on how factors such as ease of insertion and friction cannot be neglected when evaluating the suitability of a catheter. Portability also figures among the aspects that manufacturers have focused on innovating in recent years, particularly with so-called closed system catheters, for example. This kind of intermittent catheter integrates all the equipment (i.e., the catheter, water-based lubricant, and drainage bag) into a self-contained system.

### 4.4.3 HYDROPHILIC COATED (HC) CATHETERS

First developed in the early 1980's, hydrophilic coated (HC) catheters have a layer of polymer coating bound to the catheter surface. This “water-loving” layer absorbs and binds water to the catheter, creating a smooth and slippery surface that eases the insertion of the catheter into the urethra. The friction-reducing layer remains intact and ensures that the urethra is lubricated during catheterization. As with all coated, intermittent catheters, HC catheters are indicated and approved for single-use only. While some HC catheters require manual water addition for activation, other “ready-to-use” HC catheters already have water on the surface.

There is a growing body of evidence surrounding the use of HC catheters. For example, HC catheters have been **proven to reduce UTIs** (DeRidder 2005, Cardenas 2011), as well as minimize surface friction with lower mean withdrawal friction and lower hematuria compared to single-use uncoated IC with lubricant added (Stensballe, 2005). Evidence suggests that single-use HC catheters reduce the risk of UTIs by 64% and the risk of hematuria by 43% as compared to non-hydrophilic catheters<sup>1</sup>. Also, long-term use of HC catheters is reported to **prevent urethral trauma and complications** that occur after long-term use because of damage to the urethral wall from repeated catheterizations<sup>2</sup>.

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<sup>1</sup> Li L, Ye W, Ruan H, Yang B, Zhang S, Li L. Impact of hydrophilic catheters on urinary tract infections in people with spinal cord injury: Systematic review and meta-analysis of randomized controlled trials. Arch Phys Med Rehabil 2013;94:782-7

<sup>2</sup> Perrouin-Verbe B, Labat JJ, Richard I, Mauduyt de la Greve I, Buzelin JM, Mathe JF. Clean intermittent catheterisation from the acute period in spinal cord injury patients. Long term evaluation of urethral and genital tolerance. Paraplegia 1995;33:619-624

Moreover, a number of studies, including randomized controlled and blinded studies, have shown that **HC catheters are preferred by patients and improve quality of life** – because HC IC require less time for catheterization, are more convenient and cause less pain of insertion (Stensballe 2005; Sutherland et al 1996; Bjerklund Johansen et al 2007; Cardenas et al 2011)<sup>3</sup>.

#### 4.4.4 COMPACT HC CATHETERS

Compact HC catheters are hydrophilic coated intermittent catheters that differ based on their discreet, compact design which facilitates ease of use. Normally improvements in quality of life is assumed to follow as a result of treatment; however, in some cases treatment itself might have a significant impact on quality of life<sup>4</sup>. The ISC-Q (Intermittent Self-Catheterization Questionnaire) was developed to evaluate patient quality of life aspects specific for those who perform ISC.

Evidence strongly supports the benefits of HC compact catheters in terms of safety, preference, and improving quality of life<sup>5</sup>. An international randomized, multicenter, crossover study shows that the discreet design of the compact catheter significantly improves patient quality of life related to intermittent catheterization. In the study quality of life was measured using the ISC-Q score and a 28% higher score was observed when the compact catheter was used compared to standard coated intermittent catheters. The results were consistent in patients able to walk and wheelchair users, and each group showed a significant increase in ISC-Q score. The improvement in quality of life was supported by the secondary objective of preference, since 63% of the patients in the study preferred the compact catheter<sup>6</sup>.

#### 4.4.5 UNCOATED CATHETERS

Also called standard catheters, uncoated intermittent catheters are usually made of polyvinyl chloride (PVC), silicone, latex, or teflon. Unlike coated intermittent catheters, uncoated catheters can arguably be reused for up to one week. (**Manufacturers of these catheters, however, do not indicate that they are in any way reusable.**) Despite their popularity among ISC users, there is as of yet no sufficient evidence on how best to clean these for reuse. Further, long term exposure to catheterization with uncoated catheters has been reported to cause an increase in urethral irritation and bacteriuria, and as such has a negative impact on patient satisfaction.

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<sup>3</sup> Diokno AC, Mitchell BA, Nash AJ, Kimbrough JA. Patient satisfaction and the LoFric catheter for clean intermittent

<sup>4</sup> Chartier-Kastler E, Lauge I, Ruffion A et al: Safety of a new compact catheter for men with neurogenic bladder dysfunction: a randomised, crossover and open-labeled study. *Spinal Cord* 2011; 49: 844.

<sup>5</sup> Li L, Ye W, Ruan H, Yang B, Zhang S, Li L (2013) Impact of hydrophilic catheters on urinary tract infections in people with spinal cord injury: systematic review and meta-analysis of randomized controlled trials. *Arch Phys Med Rehabil* 94:782–787

<sup>6</sup> Chartier-Kastler E, Amarenco G, Lindbo L, et al. A prospective, randomized, crossover, multicenter study comparing quality of life using compact versus standard catheters for intermittent self-catheterization. *J Urol* 2013;190:942–7.

## 4.5 MAJOR COMPLICATIONS OF ISC

Urinary tract infection (UTI) is the most common catheter-associated complication. However, long-term catheterization can also result in urethral trauma, bladder cancer, and urethral strictures and damage, conditions that may at times warrant surgical intervention. Other potential effects include urolithiasis, epididymo-orchitis, epididymitis, and pyelonephritis (Chartier-Kastler & Denys, 2011). Causality is usually difficult to establish when assessing these complications. However, factors such as frequency and routine (single-use or multiple-use) of catheterization, catheter type, manual dexterity, ease of insertion and withdrawal, lubrication, and general patient comfort significantly influence risks and impact health and quality of life outcomes.

### 4.5.1 URINARY TRACT INFECTIONS (UTI'S)

That various definitions have been used to describe UTI's has created difficulties for researchers seeking to review its epidemiology in the literature. Bacterial infections of the urinary tract may involve upper or lower parts of the urinary system, which include the urethra, bladder, ureters, and kidney. Among hospital-acquired (or "nosocomial") UTI's, around 75% are associated with a urinary catheter. The most important risk factor for developing a catheter-associated UTI (CA-UTI) is prolonged use of the urinary catheter, as in indwelling catheterization, for example. Thus urinary catheters should only be used when indicated and should be withdrawn from the bladder once they are no longer needed.

Given that the detection of bacterial organisms in the urinary tract is not in itself an indicator of a UTI, it is important to distinguish between asymptomatic bacteriuria and symptomatic UTI. Asymptomatic bacteriuria involves the presence of a positive urine culture in the absence of clinical symptoms. While it increases the risk of symptomatic UTI, it does not require treatment with antibiotics. According to Cowie & Hunter (2014), the unnecessary treatment of asymptomatic bacteriuria is associated with increased antimicrobial adverse effects as well as reinfection with resistant strains of bacterial organisms. Nevertheless, asymptomatic bacteriuria is often mistaken for UTI, and the two are difficult to differentiate particularly in institutionalized individuals.

Associated impacts on patient quality of life, resulting from UTIs, include:

- Pain
- Inability to work
- Frequent doctor consultations
- Frequent urine analysis
- Risk of antibiotic resistance
- Frequent antibiotic use
- Risk of antibiotic resistance
- Risk of complications like kidneys failure
- Risk of reduced life expectancy
- Risk of hospitalization

### 4.5.2 URETHRAL STRICTURES

A urethral stricture is a narrowing of the urethra that leads to the obstruction of urine flow, which in turn creates or exacerbates existing bladder-emptying problems. It involves the buildup of scar tissue caused by traumatic injury, instrumentation (e.g.,

catheter use), congenital malformations, malignancy, or infection (by way of inflammation). The accumulating scar tissue constricts the internal walls of the urethra. This condition is considered to be one of the long-term complications of intermittent catheterization, especially when factors such as sufficient lubrication, comfort, and ease of catheter insertion and withdrawal are neglected.

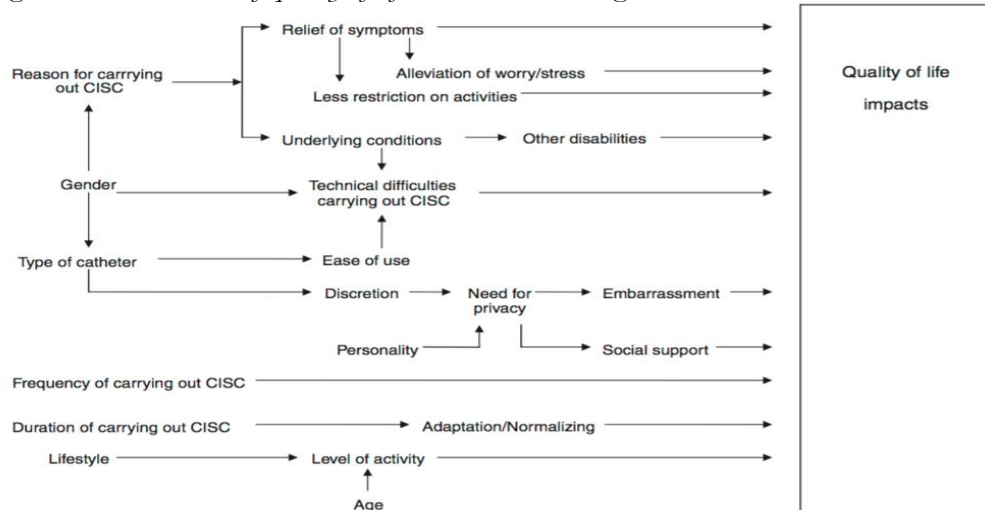
#### 4.6 ISC AND QUALITY OF LIFE

Biomedical and social aspects of ISC are not mutually exclusive. On the one hand, having the choice to use the catheter most suitable to an individual's medical needs and the means to follow a sustainable catheterization routine can help improve patient satisfaction and long-term health outcomes. On the other hand, being satisfied and comfortable with one's chosen catheter, the procedure itself, and the extent to which it can be performed in various contexts away from home (e.g., at work, at school, during travel, etc.) has a significant impact on compliance and perceived quality of life.

The impact of ISC on users' quality of life has not been widely investigated in the literature (Shaw et al., 2007), despite the fact that it touches almost every domain of their daily lives—home, work, school/university, travel, and so forth. The biomedical and social-adaptive determinants of the quality of life for ISC users are wide-ranging and largely interconnected (**Figure 5**). The authors of the qualitative descriptive study report that positive impacts were related to things like the relief of prior symptoms, while negative ones were centered around the practical issues encountered on a daily basis as well as psychological and cultural aspects related to worry and stigma. The analysis that emerged from their sample of ISC users in addition to their review of the quality of life literature are noteworthy:

- The need to carry out ISC several times a day has the potential to create practical and psychosocial difficulties.
- Response to ISC is variable and depends on factors such as duration of use, reason for use, sex age, lifestyle, gender, and type of catheter used.
- Difficulties in carrying out ISC, such as lack of appropriate public facilities, physical and technical difficulties, embarrassment and the time involved, may deter people from carrying out the procedure as recommended and thus negatively impacts compliance.

Figure 5: Determinants of quality of life in individuals using ISC



Source: Shaw et al. (2007)

## 5. ACCESS TO INTERMITTENT CATHETERS & SUPPLIES IN ONTARIO

### 5.1 OVERVIEW

This section of the report will provide an overview of the main avenues of support in place for individuals seeking access to intermittent catheters in Ontario, which range from governmental and non-governmental programs to employment-based insurance. In addition, international comparisons of other OECD countries' current approach to intermittent catheter provision will be contrasted with Canada's.

### 5.2 SOURCES OF FUNDING FOR INTERMITTENT CATHETERS IN ONTARIO

In Ontario, there are provincial and federal programs in place to support some individuals who require urinary catheters on a daily basis as a result of a medical condition and/or disability. In addition, for those fortunate enough to be employed, private insurance can also help cover the high costs of urinary catheters and ancillary supplies. According to the survey we conducted; the mean cost of monthly catheters and supplies was CAD \$335.81; however, there was a large variance from approximately CAD \$0 (i.e. metal catheter) to CAD \$2,500 per month for a specialized single-use catheter due to numerous injuries. Nevertheless, equitable access to intermittent catheters in Ontario has suffered, partly due to the complex and constantly changing nature of the segment of the population with chronic, bladder-emptying problems. The following table lists the main federal, provincial, and non-governmental programs potentially available for ISC users:

Table 4: Governmental and Non-Governmental Sources of Funding in Ontario

Program	Who is Eligible?	Coverage
Veteran Affairs (Disability Benefits)	Individuals with service-related medical conditions and/or disabilities	Full coverage

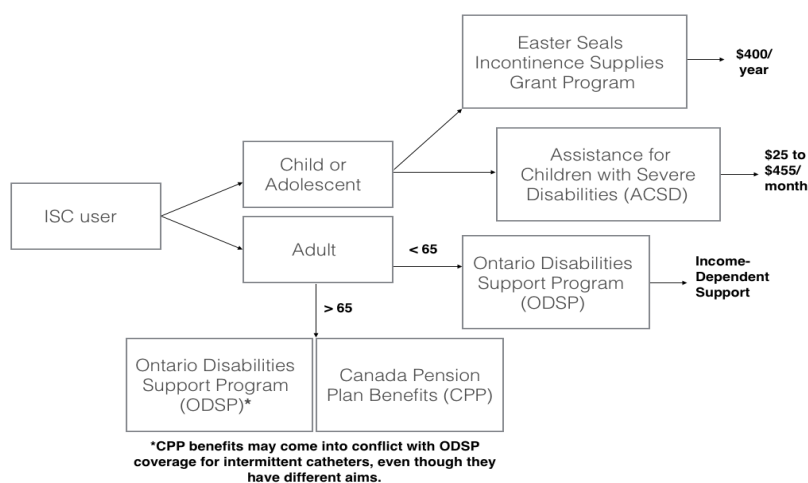
Non-insured Health Benefits (NIHB) for First Nations and Inuit	Registered First Nations and recognized Inuit	36 catheters/3 months
Ontario Disabilities Support Program (ODSP)	Ontario residents aged 18 or above determined to be in financial need while meeting the program's definition of a person with a disability, or be a member of a Prescribed Class*	1 catheter / day; however some patients may request additional catheters for full coverage with a letter and rationale from a physician
Assistive Devices Program (ADP)	Individuals with an ostomy	75% of approved price(s)
Workplace Safety and Insurance Board (WSIB)	Individuals with a workplace-related injury	85% of worker's take-home pay (if they cannot work because of work-related injury or illness)
Assistance for Children with Severe Disabilities (ACSD)	Ontario residents aged 18 or under who have a severe disability which results in a functional loss, live at home with their families, and have high costs as a result of their disability (e.g., medical supplies)	Between \$25 & \$455/month
Automobile Insurance	Ontario residents with an automobile-related disability who have purchased for medical, rehabilitation and attendant care benefits	Depends on the purchased accident benefits; can range from \$65,000 to \$3,000,000
Easter Seals Ontario (Incontinence Supplies Grant Program)	Ontario residents between 3 to 18 years of age with a valid Ontario health card, who have a chronic disability resulting in irreversible incontinence or retention problems lasting longer than 6 months requiring the use of incontinence supplies	Up to \$400/year for intermittent and/or Foley catheters); up to \$900 for external male catheters
Multiple Sclerosis Society of Canada (Quality of Life Grant, Ontario & Nunavut Division)	A written confirmation of diagnosis of multiple sclerosis from a medical doctor; residence within the regional/chapter catchment area; healthcare professional assessment of need; Funding availability	Dependent on total amount of funding received from all other access channels as well as available grant funds; cannot be considered a guaranteed source of financial support
Private Health Insurance	Individuals who are covered under private or workplace health insurance	Partially to 100% depending on the health insurance plan

\*Note: A person is considered to be in financial need if the costs of their household's basic living expenses are more than their household's income and assets.



Ever since the ADP program ceased to fund intermittent catheters in cases not involving ostomy-related surgeries (i.e., for urethral use), most self-catheterizing individuals in Ontario have sought access through the ODSP program, as it is often reported to cover most or all catheter-related costs when physicians successfully advocate on behalf of their patients using additional forms, enabling eligible individuals to freely choose the intermittent catheter that most suits their needs and improves their satisfaction. However, many Ontarians who seek income support through ODSP find that they are ineligible simply because they happen to be employed, leading them to dedicate a significant portion of their monthly budgets toward intermittent catheters and ancillary supplies (**Figure 7**).

Figure 7: Public Sources of Funding for (Urethral) Intermittent Catheters in Ontario



### 5.3 INTERNATIONAL DEVELOPMENTS IN INTERMITTENT CATHETER POLICY

Canada remains an outlier among OECD and other industrialized countries in its catheter policies and recommendations (**Table 5**). While most if not all OECD countries have recognized the health and health-economic benefits of single-use ISC routines, Canadian Urological Association (CUA)-approved brochures on male and female ISC allow for the use of an intermittent catheter for a week or until physical damage is noticed. As such, the CUA’s guidelines explicitly support the reuse of intermittent catheters despite developments in the scientific literature as well the current stance of North American and European clinical organizations.

Recent developments in the United States provide an example of health policy responding to changes in the evidence base. Responding to a set of guidelines released in 2007 by the Department of Veterans Administration, the Centres for Medicare and Medicaid (CMS) in the U.S. increased monthly coverage of coated or uncoated intermittent catheters to 200 catheters in 2008. The guidelines warned that urinary catheters, including intermittent catheters, are single-use devices (as per the FDA and manufacturers’ indications), and as such a reuse policy cannot be justified. Today, there are Medicare reimbursements for various HC and uncoated catheters: IC straight tip, coude tip, and closed sterile kit/“touchless” catheters. In Ontario, the reimbursement

structure currently in place has not taken such developments into account yet.

*Table 5: International Comparisons of Catheter Policies & Use Guidelines*

Country	Provision for IC's/month	Recommended Routine	Hydrophilic IC reimbursement
Canada	Depends on individual situation	Re-use	No
Korea <sup>i</sup>	Up to 180/month	Single use	Yes
United States	200/month	Single use	Yes
United Kingdom	No limitations	Single use	Yes
France	No limitations	Single use	Yes
Switzerland	No limitations (10% co-payment)	Single use	Yes
Spain	No limitations	Single use	Yes
Netherlands	No limitations	Single use	Yes
Austria	Lump sum	Single use	Yes
Norway	No limitations	Single use	Yes
Belgium	Lump sum (4/day)	Single use	Yes
Germany	No limitations	Single use	Yes
Italy	120/month/ limits for sets	Single use	Yes
Denmark	No limitations	Single use	Yes
Sweden	No limitations	Single use	Yes
Czech Republic	No limitations	Single use	Yes
Slovakia	120 a month	Single use	Yes
Poland	Lump sum (30% co-payment)	Single use	Yes
Greece	No limitations	Single use	Yes
Hungary	150/month	Single use	Yes
Japan, Algeria, Portugal, Australia, New Zealand		Single use	Yes <sup>ii</sup>

i. Note: Currently, this mainly applies to spina bifida patients; a single-use policy for spinal cord injury patients is underway. Korea has introduced full reimbursement also for SCI.

ii. In some of the countries Hydrophilic IC is covered for specific indications or dependent on region/health insurance provider

*Table 6: International Comparisons of Catheter Policies & Regulations*

Country	Intermittent Catheter Policy & Regulations
Canada	<p>There are no federal regulations restricting single-use catheter reprocessing and reuse; there are variations across provincial policies (<b>Appendix F</b>) where some provinces restrict the reuse of all single-use devices and others allow it as long as it is carried out by licensed third-party re-processors.</p> <p><u>Woodbury et al.</u> reported registered reuse in approximately half of the patients they studied for both uncoated (47%) and hydrophilic (46%) catheters, and it has been reported that cleaning catheters is the norm.</p>
United States	The Centers for Medicare and Medicaid Services of the Department of Health and Human Services eliminated mandatory reuse in intermittent catheterization

	in 2008. All urinary catheters <sup>7</sup> , regardless of the planned usage, require a prescription that ensures the associated costs are covered by most insurance plans (e.g. Medicare). The US Food and Drug Administration ( <a href="#">FDA</a> ) require the same quality, performance and safety on reused devices as for original single-use devices.
United Kingdom & the European Union	The National Health Service in the UK does not allow the reuse of devices marked as single use by manufacturers and most European countries have also banned the reuse of single-use catheters <sup>8</sup> . France has a total ban on reuse single-use catheters or other medical devices <sup>9</sup> . Similarly, Sweden has a set of essential requirements to be met and patient consent to be received for reuse of devices. Spain and Portugal have formally banned the reuse of single use devices such as catheters <sup>10</sup> .
Italy	Provision of disposable medical devices for daily repeated use, such as catheters for IC, is currently regulated by the Ministry of Health, which defines a list of medical devices supplied directly to patients and reimbursed by the Italian NHS. The Italian Ministry of Health does not recommend reuse of single-use devices but there is no explicit ban for reprocessing/reusing activity in the national legal framework <sup>11</sup> .
Australia	In Australia, catheter reuse is prevalent ( <a href="#">47-50%</a> ), despite scientific evidence highlighting issues with reusing. Catheters used for all urinary catheterization are listed as medical devices on the Australian Register of Therapeutic Goods (ARTG). Catheters are also labeled at a manufacturing level as single-use items, to be used on an individual patient during a single procedure and then discarded <sup>12</sup> .

## 6. HEALTH SYSTEM CONSIDERATIONS

### 6.1 OVERVIEW OF HEALTH SYSTEM CONSIDERATIONS

This section of the report will seek to point out the alignment of an inclusive intermittent catheter policy with the Ministry of Health and Long Term Care’s commitment to an equitable, sustainable, and patient-centred healthcare system in Ontario, as presented in [Patients-First: Action Plan for Healthcare](#). In addition, examples of the health economic burdens associated with a selective and limited intermittent catheter policy will be provided, mainly in relation to the costs of preventable cases of UTI, the most common complication of long-term catheterization.

<sup>7</sup> Håkansson, M. Å., Neovius, K., & Lundqvist, T. (2016). Healthcare Costs Associated With Hydrophilic-Coated and Non-Coated Urinary Catheters For Intermittent Use in the United States. *Urologic Nursing*, 36(5).

<sup>8</sup> Favero MS. Requiem for reuse of single-use devices in US hospitals. *Infect Control Hosp Epidemiol* 2001;22:539–41.

<sup>9</sup> Håkansson, M. Å. (2014). Reuse versus single-use catheters for intermittent catheterization: what is safe and preferred? Review of current status. *Spinal cord*, 52(7), 511-516.

<sup>10</sup> Kuo, E. T. (2000). An Indecipherable Debate? An Overview of Opposing Perspectives and the Search for a Coherent Regulatory Scheme for the Reprocessing and Reuse of Single-Use Medical Devices.

<sup>11</sup> Tessarolo, F. (2012). Critical issues in reprocessing single-use medical devices. In *Causa International Symposium* (Vol. 1, pp. 1-35).

<sup>12</sup> Collier, R. (2011). Reprocessing single-use devices: an international perspective.

## 6.2 ACCESS: BRIDGING HEALTH POLICY WITH INDIVIDUAL OUTCOMES

Generally, the structure of a health system comprises all the institutions, organizations, individuals, laws and policies that work in tandem to promote, maintain, and restore health in a given population. The “input” elements of any health system are centred around its governance, financing, workforce, and technologies. On the other hand, the “outputs” are indicated by measures of individual health and quality of life, health equity, system responsiveness, and financial risk protection, among others.

One of the central factors separating inputs and outputs is access (**Figure 7**). Indeed, the first key objective outlined in Ontario’s *Patients-First* vision is improved access, which is best achieved by ensuring that all Ontarians enjoy equitable access to health services and essential medical products and technologies that are of high quality, safety, efficacy and cost-effectiveness—to be used in accordance with scientifically informed guidelines and cost-effective measures (**Table 7**).

Table 7: Key Objectives of “Patients-First: Action Plan for Health Care”

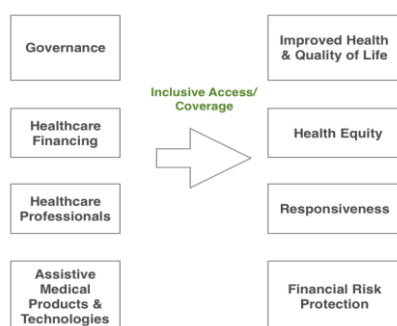
Key Objectives
1. Improved Access
2. System Integration
3. Patient-Centred Support
4. Sustainability

Source: Adapted from the *Patients First* [website](#)

According to the [World Health Organization’s \(WHO\) Health Systems Framework](#), a well-functioning health system is one that delivers:

- **Good governance** through evidence-based, health policy frameworks supported by mechanisms of oversight, strategic coalitions, appropriate regulations and incentives, and transparency and accountability.
- **Good health services** through effective, timely, sustainable, and safe care interventions to individuals who need them, supplied by a coordinated and specialized workforce of health professionals in primary, secondary, and other care sectors.
- **Good financing** through the procurement of adequate funds for health such that individuals can utilize health services as needed, while also being protected from financial impoverishment associated with having to pay for health services and/or essential medical devices out-of-pocket.

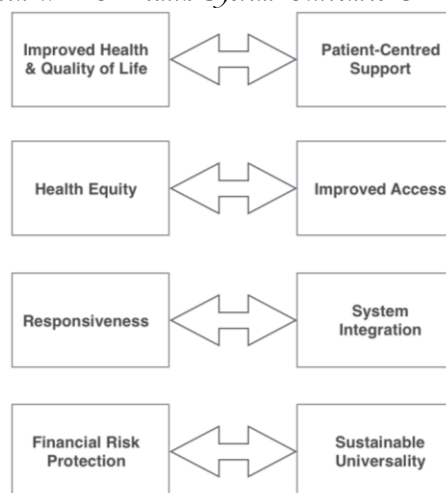
Figure 7: The Structure of the Health System: Inputs & Outputs



Source: Adapted from the World Health Organization (WHO)’s Health Systems Framework

By improving access to intermittent catheters through an inclusive health policy, the IC Working Group believes that the Ministry’s key objectives, as laid out in Patients-First, can align better with the internationally standardized health system goals and outcomes within the WHO’s framework (**Figure 8**). Access to modern intermittent catheters would also align with the obligations in the UN Convention on the Rights of Persons with Disabilities (UNCRPD). For example, Article 25 in the UNCRPD obliges Canada to ensure that persons with disabilities can enjoy the highest attainable standard of health without discrimination on the basis of disability. In particular article 25 obliges Canada to provide persons with disabilities the same range, quality and standard of free or affordable health care as provided to other persons, which is not the case today when it comes to intermittent catheters. Article 5 in the UNCRPD further ensures that persons with disabilities receive reasonable accommodation which eliminates individualized discrimination. This should also be the case when it comes to intermittent catheters in Ontario. Providing individuals with long-term voiding problems with the capacity to choose their intermittent catheters and means to adopt a single-use ISC routine will be conducive to better health and quality of life, health equity standards, responsiveness, and financial risk protection.

*Figure 8: Alignment Between WHO Health System Outcomes & Patients-First Key Objectives*



## 6.2 THE HEALTH ECONOMICS OF CATHETER-RELATED COMPLICATIONS

While it is difficult to estimate the number of individuals with CA-UTIs in Ontario, the fact that **UTIs are expensive to treat** and are the **most common complication associated with long-term ISC** warrants attention by clinicians and policymakers alike. As **Table 8** shows, the estimated average cost to treat a lower UTI is CAD \$5,272, whereas upper UTIs cost CAD \$3,903 (age-adjusted). Hospitalization for either upper or lower UTIs involves a significant average length of stay, ranging from 3 to 6 days. Similarly, a study by Bermingham et al. (2013) concluded that costs borne by the system for treating a symptomatic UTI range between USD \$62 and \$3,450, depending on the severity of the infection. Others have found CA-UTI-related costs to be between USD \$600 and \$4800. This is compounded by the fact that in Canada, **there exists a 27% resistance from patients to the antibiotics used to treat UTIs.**

The differential outcomes associated with the use of different intermittent catheters has

led the scientific community to compare the cost-effectiveness of different types of intermittent catheters, with a view to finding the optimal balance between cost and quality-adjusted life years (QALY). In a recent study from the United Kingdom, Clark et al. (2015), using probabilistic decision analysis, found that **hydrophilic coated (HC) catheters were a cost-effective solution** in comparison with uncoated (UC) catheters, with an incremental cost-effectiveness ratio (ICER) of £6100 per quality-adjusted life year (QALY) gained, which falls within the U.K.'s [National Institute for Health and Care Excellence](#) (NICE) threshold of £20,000–£30,000 per QALY. This result, the authors note, should be generalizable to the Canadian context, as the data used was drawn from international sources. In Japan, a parallel study displayed similar results, concluding that single-use HC catheters are indeed cost-effective devices<sup>13</sup>.

In short, the high, but mostly preventable, costs of CA-UTI's in addition to the cost-effectiveness of HC catheters support an inclusive intermittent catheter policy premised on scientific evidence and individual choice. We can see that both the individual and systemic impacts of reusing intermittent catheters in ISC due to inadequate access matter. With ISC mostly taking place in unmonitored settings in the community, the absence of reliable ISC guidelines and public support exposes both the individuals and the healthcare system to preventable health risks and health-economic burdens, respectively.

*Table 8: Health Economic Data for Lower & Upper UTI Cases in Canada*

Type	Age Group	Estimated Avg. Cost	Estimated Avg. Cost (all age groups)	Avg. acute length of stay days	Volume
Lower UTI	29-364 Days (pediatric)	\$4,229	\$5,494	3.3	1511
	1-7 years (pediatric)	\$3,770	\$5,494	2.9	792
	8-17 years (pediatric)	\$4,320	\$5,494	3	342
	18-59 years (adult)	\$5,255	\$5,494	4.3	4,209
	60-79 years (adult)	\$5,625	\$5,494	5.4	9,321
	80+ years (adult)	\$5,775	\$5,494	6.2	12,282
Upper UTI	29-364 Days (pediatric)	\$4,421	\$4,206	3	767
	1-7 years (pediatric)	\$3,711	\$4,206	3.2	673
	8-17 years (pediatric)	\$3,814	\$4,206	2.8	559
	18-59 years (adult)	\$3,617	\$4,206	3.3	4,635
	60-79 years (adult)	\$4,744	\$4,206	4.8	2,349
	80+ years (adult)	\$5,625	\$4,206	6	1,310

Source: CIHI

<sup>13</sup> Watanabe, T., Yamamoto, S., Gotoh, M., Saitoh, T., Yokoyama, O., Murata, T. And Takeda, M. (2015), Cost-Effectiveness Analysis of Long-Term Intermittent Self-Catheterization with Hydrophilic-Coated and Uncoated Catheters in Patients with Spinal Cord Injury in Japan. Lower Urinary Tract Symptoms. doi:10.1111/luts.12122

## 7. CASE STUDY

### 7.1 CASE STUDY OVERVIEW

This section will outline and discuss the results of a qualitative, telephone-based survey conducted by the IC Working Group with a conveniently sampled group of eight individuals who regularly currently use or have worked with intermittent catheters. The overall aim of this case study is to present the personal narratives of Ontarians who use intermittent catheters or have had experience working with such users on a day to day basis. Notable among our findings were the following shared concerns:

- In spite of the variation seen in the use of intermittent catheters in Ontario, there was a unanimously expressed need for an inclusive intermittent catheter policy via the ADP program.
- All survey participants emphasized having been worried about the public support programs available for ISC users, and the eligibility criteria for these programs particularly during life-stage transitions (e.g., from pediatric to adult).
- Many survey participants switched to a single-use routine from a clean/multiple-use one, but *only* when they had the means to do so (e.g., recipients of employment benefits and/or individuals in high income brackets).
- Most survey participants faced numerous co-morbidities both related and unrelated to their bladder-emptying problems.

### 7.2 CASE STUDY METHODOLOGY

- Eight, semi-structured telephone-based interviews were conducted throughout July and August, 2016.
- A group of eight (n=8; 6 females, 2 males) individuals was conveniently sampled with the help of various members of the IC Working Group, most of whom work and/or interact with users of intermittent catheters.
- The average age of the sample was 44 years.
- The medical conditions reported by the interviewees were:
  - Spina bifida
  - Spinal cord injury
  - Breast cancer with spinal tumor
- The income ranges reported by the interviewees were as follows:
  - <\$20,000 (1)
  - \$20,000 - \$40,000 (2)
  - \$40,000 – \$60,000 (1)
  - \$80,000 - \$100,000 (1)
  - >\$100,000 (2)
- The questionnaire focused on issues of ISC use, access, complications, and quality of life outcomes. (See **Appendix D** for a detailed breakdown of responses and overall themes.)
- After obtaining the informed consent of all participants, interviews were recorded and subsequently transcribed and anonymized.

### 7.3 MAIN THEMES

The analysis of interviewees' responses to each of the 20 questions revealed key concerns and difficulties that almost all participants shared in their daily experience with self-catheterization. To begin with, the majority of respondents had been using ISC for at least a decade. Moreover, nearly all reported self-catheterizing at home and wherever they could access an appropriate restroom in public (e.g., at work, the gym, etc.). While only half were on a single-use routine, an experienced healthcare worker noted that the majority of users today are opting for single-use routines to eliminate, or at least lower, the risk of UTI's and other ISC-related complications.

To prefer a single-use routine, however, is not the same as to have the means to follow it: one respondent who currently pays for her intermittent catheters out-of-pocket, for example, follows a multiple-use catheterization routine because she wasn't grandfathered into the ADP Incontinence Grant, which she used to receive when she was young alongside her parents' insurance. Another, an 18-year-old girl with spina bifida, has just transitioned into adult care and is worried that she may lose her ODSP benefits once she starts earning a salary—the nature of her condition renders her ineligible for ADP funding. (Indeed, the only respondent who reported being eligible for ADP funding had a stoma.)

***“It’s the reason I’m able to stay alive!” – Ontarian with spina bifida referring to intermittent catheterization***

But funding concerns were not limited to young adults: it was noted that disabled seniors aged 65 or older risk losing their ODSP benefits as soon as they start receiving Canada Pension Plan (CPP) benefits. For instance, a respondent told the story of a senior in Ontario who could not save his benefits from ODSP. Unable to afford intermittent catheters, he had to switch to an indwelling (or Foley) catheter, which has been shown to be associated with a higher frequency of UTI's than its intermittent counterpart.

***“As Ontario citizens, we are not treated the same if we have a disability.” – regional health worker, referring to perceived inequities in Ontario’s healthcare system***

Overall, more than half of respondents agreed that their current ISC routines (single-use v. multiple use/reuse) were significantly influenced by the funding and/or income they received. For those who were on CISC, public washroom availability and accessibility, as well as catheter user-friendliness were among the top challenges mentioned. No less important, however, was preventing infections: one respondent who reused intermittent catheters reported struggling with 3 to 4 UTI's a year, while another noted that these infections were becoming more frequent with age.

***“The government needs to know that there are people who have medical issues and that there should be some form of access and/or assistance when people end up in these kinds of situations. Individuals end up in these kinds of situations out of nowhere...It takes on your budget and your salary.” – cancer patient and ISC user***



In terms of quality of life, the interviewees saw that **intermittent catheterization was a significant improvement** compared to indwelling catheterization, as it allowed for greater independence and flexibility with daily life activities (e.g., work, travel, family and other responsibilities). For example, one respondent shared the sense of gratefulness she had when she stopped using indwelling catheters. Improvements notwithstanding, the ISC users believed that complications such as UTI's and urethral strictures could have been prevented by using one catheter at a time and adopting safer self-catheterization strategies in the long-term.

## 8. POLICY

### 8.1 ISSUE

- The **health** and **quality of life** of thousands of individuals with chronic, voiding problems have been impacted by inadequate access to intermittent catheters in Ontario. Due to the substantial costs of these assistive medical devices and their ancillary supplies, many users resort to reusing their intermittent catheters, in spite of the **infection risks, absence of evidence-based cleaning best practices, and safety issues** associated with multiple-use routines.
- This problem also extends to users of indwelling or permanent catheters who find the switch to intermittent catheterization simply **unaffordable**.
- As the [Assistive Devices Program \(ADP\)](#) currently subsidizes urinary incontinence supplies for ostomy patients, it can serve as a model to emulate when seeking to establish an **inclusive** and **equitable** program to support **all long-term users of urinary catheters**. Such a move would be in line with the key objectives laid out in the Ministry of Health and Long Term Care's *Patients-First* action plan.
- With respect to public access and official guidelines on this issue, the health systems in Ontario and across many provinces in Canada are **outliers** in comparison with those in other OECD countries (see **Chapter 5** for international comparisons and **Appendix F** for interprovincial comparisons).

### 8.2 BACKGROUND

- Over 3.3 million Canadians at all ages experience incontinence; one in four women middle-aged or older, many individuals with neurological disorders and spinal cord injuries, in addition to the over 90% of those in long-term care.
- Intermittent catheterization, undertaken either independently (ISC) or with the help of a nurse/caretaker, is among the main methods of choice for individuals with bladder-emptying problems due to neurogenic (e.g., spinal cord injury) or non-neurogenic (e.g., benign prostate hyperplasia/prostate enlargement) causes.
- The advantages of intermittent catheterization over indwelling catheterization have been clearly documented in the literature. They include: lower frequency of urinary tract infections (UTI's); improved sense of independence; reduced need for ancillary equipment; less barriers to intimacy and sexual activities; and the potential for

reduced lower urinary tract symptoms in between catheterizations.

- Urinary retention, a consequence of bladder dysfunction that may render urinary catheterization a **medical necessity**, affects a significant portion of the population in Ontario. For example, an estimate of the number of intermittent catheter users with spinal cord injury, spina bifida, and multiple sclerosis in Ontario stands at around **38,014**. The total number, however, is almost certainly higher, as voiding problems are observed in a broader set of medical conditions and/or disabilities (see **Chapter 3** for relevant medical conditions).
- When presented with a choice, **most ISC users prefer single-use, hydrophilic catheters** over standard or uncoated catheters (which tend to be cleaned and reused, despite the lack of reliable and evidence-based catheter-cleaning guidelines). A recent U.K. study with generalizable results found hydrophilic catheters to be cost-effective in comparison to uncoated catheters.
- In Ontario, the reuse of intermittent catheters largely arises from a mix of financial constraints and inadequate or wholly absent public support. This finding was corroborated by the IC Working Group's observation that almost all survey participants who could afford a single-use ISC routine actually **chose** to follow such a routine, even in cases where they had initially been on a clean/multiple-use ISC routine.
- Unlike the guidelines issued by the Canadian Urological Association (CUA), **best practices adopted by various international and regional associations do not support the reuse of intermittent catheters**, and the optimal technique for cleaning catheters between uses is as of yet unclear in the existing evidence base.
- Cost comparisons for reuse and single use should consider the material costs for the catheters used along with costs associated with add-on lubricants, sterilization methods, washing, complications and time spent. For instance, a recent [cost comparison](#) between two catheterization techniques in the hospital setting found that the more expensive (single-use, hydrophilic) catheter was associated with a lower total cost for the hospital based on savings on additional lubricants used and nurse time spent.
- Overall, the existing structure of public support programs for users of intermittent catheters in Ontario is **selective**, with the individual's medical condition and/or disability determining his/her access opportunities to the assistive medical device.

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## 11. APPENDIX A: THE IC WORKING GROUP

Formed in May 2016, the IC Working Group is an Ontario-based patient advocacy collective composed mainly of healthcare professionals, health administrators, public policy experts, students, and clinicians who work with or represent individuals in Ontario with medical conditions and/or disabilities commonly associated with chronic, bladder-emptying problems. Reflecting the epidemiological diversity of the latter population, the following group members represent the interests of individuals with a wide range of conditions and disabilities, many of whom use intermittent catheters for daily bladder management:

*Table 1a: Member Organizations of the Provincial Intermittent Catheter Working Group*

Organization	Description
	Spinal Cord Injury Ontario is a not-for-profit organization that works to assist people with spinal cord injuries and other physical disabilities to achieve independence, self reliance and full community participation.
	Spina Bifida & Hydrocephalus Association of Ontario is a not-for-profit organization that seeks to build awareness and drive education, support, care, research, and advocacy to improve the quality of life of individuals with spina bifida and/or hydrocephalus.
	Muscular Dystrophy Canada supports people affected by muscular dystrophy and related muscle diseases. Together, these rare conditions are referred to as “neuromuscular disorders.”
	The Ontario Neurotrauma Foundation (ONF) supports research and practice in the field of neurotrauma, to the benefit of everyone with a personal or professional interest in neurotrauma. The non-for-profit funds research on traumatic brain injury (TBI), spinal cord injury (SCI), and injury prevention.
	The Anne Johnston Health Station (AJHS) is a not-for-profit community health centre providing a wide range of programs and services that promote the health and well-being of youth, seniors and people with physical disabilities. Its programs include primary health care, disease prevention, health promotion and community development.

At its inaugural meeting, the IC Working Group’s mandate and roles and responsibilities were set and unanimously agreed upon by its working and advisory members (**Table 1b**): The time-limited group is to provide a forum for interested clinicians, organizations, individuals with physical disabilities and policymakers to advocate for appropriate, evidence-based access to intermittent catheters for Ontarians. It hopes to accomplish this by:

- Bringing together a coalition of clinicians, organizations, individuals with physical disabilities and policymakers to examine and address issues related to intermittent catheter use in Ontario

- Comparing international best practice with existing practice in Ontario (and Canada) while assessing the current evidence base in order to inform provincial health policy
- Releasing the current position paper based on the IC Working Group’s overall findings that will guide policy development
- Advocating to provincial policymakers to ensure that Ontario provides adequate access as per the best available evidence for individuals needing access to intermittent catheters

*Table 1b: Working & Advisory Group Members of the IC Working Group*

<b>Core Working Group Members</b>	<b>Organization</b>
Jennifer Hou, Advanced Practice Nurse Educator	University Health Network
Peter Athanasopoulos, Senior Manager, Public Policy and Government Relations	Spinal Cord Injury Ontario
Dr. Anthony Burns, Psychiatrist	Lyndhurst Centre
Margaret Cheung, Director of Primary Care	Anne Johnston Health Station
Penney Deratnay, Advanced Practice Nurse Educator	Lyndhurst Centre
Dr. Dean Elterman, Urologist	Toronto Western Hospital
Tara Jeji, Program Director, Spinal Cord Injury	Ontario Neurotrauma Foundation
John Shepherd, Graduate Student	Rehabilitation Sciences Institute, University of Toronto
Elaine Wilson, Executive Director	Spina Bifida & Hydrocephalus Association of Ontario

<b>Advisory Group Members</b>	<b>Organization</b>
Dr. Keith Sequeira, Psychiatrist	Parkwood Rehab Institute
Dr. Blayne Welk, Urologist	St. Joseph’s Healthcare
Stacey Lintern, Executive Director	Muscular Dystrophy Canada
Chantelle Maubert-Stewart, Regional Services Coordinator	Spinal Cord Injury Ontario
Dr. James Milligan	The Centre for Family Medicine

## 12. APPENDIX B: EPIDEMIOLOGICAL DATA FOR RELEVANT MEDICAL CONDITIONS

Bladder-emptying or voiding problems generally arise from neurogenic or non-neurogenic (e.g., idiopathic) causes of bladder dysfunction. In either case, the consequences usually include urinary retention, which poses significant risks of urinary tract infection (UTI) and renal failure due to incomplete emptying. Many individuals with urinary retention also develop urinary incontinence—or involuntary leakage of urine—a separate condition that affects at least 3.3 million Canadians.

- Urinary retention—incomplete bladder emptying that results in the build-up of residual urine in the bladder—is observed in a wide range of medical conditions affecting bladder function, most notably spinal cord injury, spina bifida, multiple sclerosis, and benign prostate hyperplasia (BPH).
- Chronic cases of urinary retention may also present with urinary incontinence, a distinct condition involving the loss of normal control over the bladder. According to a study commissioned by the [Canadian Continence Foundation](#), the number of

individuals living with incontinence is likely to increase as the population ages, as the prevalence of the condition tends to increase with age.

- Being the most common form of incontinence, urinary incontinence affects individuals' ability to carry out daily life activities, and has been shown to have an impact on various indicators of quality of life.
- Canadians with urinary incontinence have more frequent visits to their physicians and spend more time in hospitals and nursing homes than Canadians without it.
- In summary, the serious health risks of chronic urinary retention and the anxiety and stigma associated with different types of urinary incontinence create the need for urinary catheterization.

### TABLE 1: SUMMARY OF EPIDEMIOLOGICAL DATA FOR RELEVANT MEDICAL CONDITIONS

The following table lists recent estimates of the number of cases and incidence in Ontario of the relevant medical conditions outlined in **Section 3.2**. Note, however, that the number of observed cases for each condition is not equivalent to the number of individuals using intermittent catheters. The risk of developing voiding problems, neurogenic or otherwise, varies from one condition to the other. Further, not all individuals who do develop short or long-term urinary retention undergo or perform intermittent catheterization. For example, not all individuals with spinal cord injury develop urinary retention, and among those who do, only a proportion—albeit a significant one—turn to intermittent catheterization for long-term bladder management. The same applies to all other relevant conditions listed below and discussed throughout the report. (It is noteworthy that the following list is not comprehensive, but tries to capture the conditions most associated with neurogenic or other bladder dysfunction. Other conditions include diabetic neuropathy, neuromuscular disorders, pelvic surgery, and cauda equina syndrome due to lumbar spine pathology.)

*Table 1: Number of Observed Cases and Incidence in Ontario of Relevant Medical Conditions*

Condition	Number of Observed Cases (Ontario)	Incidence (New Cases/Year) (Ontario)
Spinal cord injury	33,140 (2010)	600 (2010)
Spina bifida	3,469 (2010)	27 (2004/05; 2010/11)
Stroke	170,000 (2013)	25,500
Bladder cancer	87.1/100,000 (2012)	4,696 (2012)
Prostate cancer	1,147/100,000 (2012)	8,500 (2012)
Multiple sclerosis	38,000*	1,830 (2010/11)
Parkinson's disease	28,191 (2010)	6,570 (2010)

\***Note:** Estimate based on estimates provided by the Toronto chapter of the MS Society of Canada

For example, in the cases of spinal cord injury, spina bifida, and multiple sclerosis, we see that 49%, 80%, and 50% of patients with (neurogenic) urinary retention across Canada undergo or perform intermittent catheterization, respectively (**Table 2**). Based on these figures, we can estimate the following for Ontario:

- Out of 33,140 spinal cord injury patients in Ontario, 16,239 are likely to be ISC users.
- Out of 3,469 spina bifida patients in Ontario, 2,775 are likely to be ISC users.
- Out of 38,000 multiple sclerosis patients in Ontario, 19,000 are likely to be ISC users.

## SPINAL CORD INJURY

Spinal cord injury (SCI) is a lifelong disability that has a profound impact on the health and well-being of individuals. In Canada, the economic cost of this chronic condition is shared among provincial governments, individuals, and private insurers. While Athanasopoulos (2013) reported that there are 17,000 Ontarians living with a permanent SCI in Ontario, [figures](#) cited by Spinal Cord Injury Ontario put this estimate at 33,140. According to a study by Jin Jeong et al. (2010), approximately 70% of all SCI patients qualify for intermittent catheterization. Generally, it is the region of the spinal cord affected that determines whether or not normal brain-bladder communication is damaged.

- Following a spinal cord injury, messages between the bladder and the brain cannot travel properly through the spinal cord, causing a disruption in normal voiding. Consequently, the bladder may become either flaccid or spastic.
- The flaccid bladder loses detrusor muscle tone and does not contract for emptying; it is also referred to as an underactive bladder (UAB). As a result of incomplete emptying, urine build up overstretches the bladder, which can damage the bladder wall and increase the risk of urinary tract infection (UTI).
- The spastic or “hyperactive” bladder presents with detrusor over-activity; it is sometimes referred to as an overactive bladder (OAB). The reflexive contractions seen when the bladder fills with urine can cause incontinence.
- In some cases, a coordination problem develops between the bladder sphincters and the detrusor muscles, a condition known as bladder sphincter dyssynergia.

## SPINA BIFIDA

Spina bifida is a neural tube birth defect that occurs within the first four weeks of pregnancy. During this period, the spinal column fails to develop properly, resulting in varying degrees of permanent damage to the spinal cord and nervous system more generally.

- The causes of this condition remain unclear.
- Almost all individuals born with spina bifida will experience some form of bladder or bowel dysfunction that they must learn to manage. According to Veerpoten (2008), 90% of spina bifida patients qualify for intermittent catheterization.
- In the case of bladder dysfunction, intermittent catheterization has become a popular bladder management technique for many health- and lifestyle-related reasons discussed in the next chapter.
- The [Ontario Brain Institute](#), in a 2015 report titled *Brain Disorders in Ontario*, reported that there are around 3469 individuals living with spina bifida in Ontario.
- The prevalence of this condition is estimated at 1/1000 live births.

## CEREBRAL STROKE

According to the [Ontario Stroke Network](#), a stroke is caused by a disruption in blood flow to a part of the brain. It occurs due to blood vessel rupture or blockage. Cell death results when neurons and other brain cells in the affected region are deprived of glucose and oxygen. The longer the deprivation, the higher the likelihood of permanent brain



damage.

- Every year, there are around 25,500 new stroke events and 15,500 hospital inpatient admissions in Ontario.
- It is reported that 15% of stroke patients develop neurogenic bladder dysfunction.

## BLADDER CANCER

Bladder cancer is the 5th most common cancer in Canada, 4th most common among men and 12th most common among women. An estimated 4,696 Ontarians are diagnosed with bladder cancer each year.

- Because of an 80% recurrence rate, bladder cancer is the most expensive cancer to treat on a per-patient basis.
- Many cases of bladder cancer involve symptoms of bladder spasms and increased frequency and urgency of urination.

## PROSTATE CANCER & BENIGN PROSTATE HYPERPLASIA (BPH)

The [Canadian Cancer Society](#) reports that prostate cancer is the most common cancer to affect Canadian men, making up 24% of all cancer cases reported in men in 2015. One in eight men will be diagnosed with the disease in their lifetime. As for incidence, 2012 estimates counted 8,500 new cases of prostate cancer. As in other cancers, this type involves prostate cells losing normal control over growth and division; in other words, they no longer function as healthy cells.

Nevertheless, not all irregularly shaped prostates are cancerous. Enlarged prostates can be benign, as seen in benign prostate hyperplasia (BPH). This condition is common in men over 50 years of age. BPH may exert pressure on the urethra, thus squeezing it and reducing urine flow. Complications of this condition include urinary stoppage, bladder infections, bladder stones, and back-pressure on the kidneys.

## MULTIPLE SCLEROSIS

Multiple sclerosis (MS) is an autoimmune, neurological disorder that affects the brain and spinal cord. In diagnosed individuals, the immune system attacks myelin, the protective covering surrounding nerves, causing inflammation and disrupting the transmission of neural impulses across nerve fibers. According to the [MS Society of Canada](#), Canada has the highest rate of MS worldwide.

- [Statistics Canada](#) reports that in 2010/2011, there were 93,535 individuals living with MS in Canada.
- In Ontario, the Ontario chapter of the MS Society of Canada estimates the number of individuals in Ontario living with MS to be 38,000.
- One of the prominent symptoms of MS is bladder dysfunction, which in some cases lead to urinary storage and/or emptying problems that require bladder management techniques like intermittent catheterization.
- 40 to 90% of those affected develop neurogenic bladder dysfunction. In cases that have progressed to a severe stage, this estimate can reach 100%.

## PARKINSON'S DISEASE

Parkinson's disease is a neurodegenerative illness caused by the loss of dopamine-producing cells in the brain, which results a cluster of mobility-related symptoms such as tremor, rigidity, loss or slowness of voluntary movement, and postural instability. It is not yet fully clear what causes the depletion of these cells.

- Many individuals with Parkinson's disease develop bladder problems. According to the [Bladder and Bowel Foundation](#), two common issues are urge incontinence (loss of urine associated with a strong desire to void) and nocturia (the need to empty one's bladder at night/ bed wetting).
- [Statistics Canada](#) reports that in 2010/2011, there were 54,897 individuals living with Parkinson's disease in Canada.
- According to the Ontario Brain Institute (OBI) [report](#), *Brain Disorders in Ontario*, just above half of this population (28,191) resides in Ontario.
- 37-72% of individuals with Parkinson's disease develop neurogenic bladder dysfunction.

## 13. APPENDIX C: REUSE OF INTERMITTENT SELF-CATHETERIZATION

Cleaning/disinfecting intermittent catheters involve techniques that include soap and water; antiseptic solutions; microwaving; and boiling in water (Hunter & Cowie, 2014). According to Sherbondy, significant variation exists in the cleaning and sterilizing techniques used by patients, even when given uniform instructions. In his study, 63% of patients also reported that their catheters melted when microwaved. Also 44% of catheters washed with antibacterial soap yielded E.Coli vs. 26% with combined antibacterial soap and microwave treatment (2002). Clean technique also involves hand washing with soap and water, cleaning the perineum on a daily basis, and removing any fecal matter that may be present. Another well-known technique, the so-called [Milton Method](#), takes at least 15 minutes (6 times per day or 1.5 hours daily) to complete and uses a sterilizing solution and cold water. How effective these cleaning techniques are, however, remains unclear. Indeed, in a recent review of CIC, Lamin & Newman (2016) found that "catheter cleaning between catheterizations has no basis in evidence-based research and is performed using a variety of methods as instructed by the clinician instituting IC."

### STERILE OR ASEPTIC INTERMITTENT SELF-CATHETERIZATION

The sterile or aseptic technique of intermittent catheterization is mostly performed in hospital settings, where the risk of catheter-associated UTT's (CA-UTT's) can be very high. This technique requires the use of ancillary equipment such as gloves, wipes, trays, and/or collection bags. In home and community settings, the clean technique is more common, in which an intermittent catheter is either reused or disposed after a single-use. Understood this way, single-use, intermittent catheters work well with sterile, aseptic, or clean techniques, as long as they are not reused or misused in ways contrary to manufacturer indications.

In the long run, single-use ISC may decrease overall healthcare costs because the routine is associated with a lower risk of catheter-related complications (such as UTT's, lesions,

and urethral trauma) as well as a higher convenience factor for the user. Moreover, discarding a catheter after a single-use precludes misuse by long-term users concerned about the affordability of these devices. The [European Association of Urology](#) (EAU) recommends aseptic technique as the method of choice for managing NLUTD.

## PROCESS AND ISSUES FOR SINGLE-USE VS. RE-USE

Below, as shown in the Figure, there is a large difference in the number of steps an IC user must go through in a re-use vs. single-use scenario. With most users catheterizing up to 6 times per day (2,190) per year, the context for ‘ease of use’ also needs to be highlighted, particularly given that many users are not only catheterizing in their homes, but also in the community, at work, or school. We see this in patient surveys, for example that have shown that 93% feel that cleaning and re-using their catheter has a *significant* or *some* impact on their lives, and 97% feeling *very uncomfortable* or *uncomfortable* cleaning and re-using their catheter in a communal space.

Figure 1. Re-use vs. Single Use (Pre-Lubricated) Process



## 14. APPENDIX D: QUESTIONNAIRE & THEMATIC ANALYSIS

### A) General

Q1: How long have you been using intermittent catheters?

R1: In the case of spina bifida: since birth

As for spinal cord injury: it ranges from a day to as long as they've been injured

R2: Since birth

R3: He has been using intermittent catheter since he was a patient at Lyndhurst [Centre], during his rehabilitation back in August, 2000. But intermittent catheters were used on him following his initial injury in the hospital (acute care) in July, 2000.

R4: 18 years (since birth)

R5: 10 years

R6: May 20th: started using indwelling (Foley) catheters. After seeing her urologist in mid-June, she switched to using intermittent catheters

R7: Over 40 years

R8: About 44 years

The majority of respondents were long-term IC users; that is, most have been performing or undergoing intermittent catheterization for over 6 months. 75% of respondents have been catheterizing for at least a decade.

Q2: What medical condition and/or disability has created your need for catheterization?

R1: N/A

R2: Spina Bifida

R3: C7 incomplete traumatic spinal cord injury.

R4: Spina Bifida

R5: She is a C5/C6 quadriplegic. She received a stoma about 10 years ago, and now performs intermittent catheterization from her belly button. Her initial accident was 23 years ago; prior to getting a stoma, she used indwelling catheters

R6: breast cancer patient who had a tumour in the canal of her spine

R7: Spina Bifida

R8: Spina Bifida

Spina bifida and spinal cord injury were the two most common conditions among respondents in this sample. However, one respondent with breast cancer reported a tumour in the canal of her spinal cord, while another received a stoma following her spinal cord injury.

Q3: On average, how many times do you catheterize in a day?

R1: 6 times a day

R2: Every 4 to 5 hours; not during the night

R3: 4 times a day; every 6 hours

R4: 6 to 8 times a day

R5: 5 to 6 times a day

R6: 5 to 6 times a day

R7: 6 to 8 times a day

R8: 4 to 5 times a day

The average number of times respondents catheterized per day was around 5.56 times/day → 6 times/day.

Q4: Do you self-catheterize, or does a caretaker usually perform the procedure for you? (Probes: Where do you mostly catheterize? Is this the setting in which you're most comfortable?)

R1: Half and half; can't give exact percentage

R2: self-catheterizes, wherever she can find an accessible washroom

R3: self-catheterizes, mostly at home; 1 to 2 times at work; comfortable catheterizing in public washrooms

R4: She received assistance until 3rd grade, at which point she was taught how to self-catheterize; most comfortable catheterizing at home, but this varies depending on the time of year

R5: self-catheterizes at work; at the gym; at home; in bed

R6: self-catheterizes; prefers to be at home, but, since she is employed full time, she finds that she has to self-catheterize at work, and is able to do so.

R7: self-catheterizes, at work, at home, and/or outdoors

R8: self-catheterizes; work, home and in the community

Almost all respondents reported self-catheterization at home and elsewhere (e.g., at work

or the gym). The main concern for respondents was the availability of accessible, public restrooms.

Q5: What type(s) of catheter do you currently use?

R1:

If they [users/patients] are paying out of pocket, they might be seeking the cheaper one, not necessarily the one they need

Some need the ones with the Coude (or “elbow”) tip, which are more expensive

A lot are using MED-RX catheters

Those who have funding can use Coloplast coated ones. Moreover, the self-contained “lipstick” ones or “all in one” are portable and allow people to freely participate in daily life activities

R2: Metal catheter (preferred over plastic catheters)

R3:

BARD Red Rubber catheter: Coude and Olive tips ([Source](#))

Not hydrophilic; non-coated

Not lubricated; uses a separate tube of lubricant to lubricate it

R4:

14 FR, latex-free catheter

Could not find whether or not the catheter was hydrophilic

Non-lubricated

R5: MEDLINE, male 16 inch, latex-free 14 FR: non-hydrophilic; non-coated; non-lubricated

R6:

Coloplast Speedicath Compact Eve ([hydrophilic coating](#))

Recently, she was sent straight tip, pre-lubricated ones recently for intermittent catheterization

Has also tried non-lubricated catheters, which require manual lubrication

R7: AMICI; non-hydrophilic; non-coated; non-lubricated

R8: MED-RX disposables; non-hydrophilic; non-coated; non-lubricated

While most respondents reported using plastic, non-hydrophilic catheters, their choice of catheter brand and specification varied. Brands mentioned included AMICI, MED-RX, MEDLINE, Coloplast, and BARD. One respondent used a metal catheter, which she expressed a preference for over its plastic counterpart.

Q6: Do you discard a catheter after a single-use, or do you reuse the same catheter multiple times? (If single-use: Have you changed from a reuse regime to a single-use one, and, if so, what motivated you to do so?)

R1:

Some people have to use them and try and disinfect them through boiling or microwaving

Lots of diligent people cannot reuse because they continually get infections

The majority of people are single-using to eliminate the risk of infection

There was an individual without funding for catheters, who would reuse for around a week without cleaning appropriately; now, he is very sick and his bladder is in such bad shape that he is continually ill

R2: Reuses after disinfecting and sterilizing a catheter on a daily basis; she has always

been on this regime

R3: Single-use; has never reused

R4:

Discards after single use

Switched from reuse to single-use in an attempt to reduce infections

R5: Discards after single use

R6:

Single-use; never reused. People have said that you can reuse the straight tip [catheters], but she doesn't want to take the chance [expose herself to risks of infection, for example], despite higher costs

Has always been on a single-use regime

R7:

Reuses (one a week at work; one a week at home)

When she was young, she would use one at a time. She had funding at the time from her parents' insurance plus the ADP Incontinence Grant, which she no longer has (wasn't grandfathered into the program)

Currently, she has to pay for catheters out of her own pocket

R8: Reuses due to cost, for the most part

3/8 respondents reported reusing, while 4/8 were on single-use regimens. One experienced healthcare worker reported that the majority of users today are opting for a single-use regimen to eliminate, or at least lower, the risk of infection.

Q7: What would you estimate is the monthly total cost of catheters used?

R1:

Catheter, gauze, and lubricant costs have to be considered

Those who use Coude tips (because they need to) face higher costs

"How often do you pee in a day? Have you ever thought that it costs you \$2.50 every time you take a leak?"

IC is only one part of maintaining one's overall health status; you also have the gloves, the gauze, the dual drainage using a condom and extension tube (for those who are incontinent in-between catheterizations)

One individual, for example, faces a cost of \$1300 a month to look after his health status

R2: Just purchased one for \$125; submitted to ODSP to see if they would cover it, which they did.

R3:

Around \$2,500/year just for catheters

Secondary supplies (especially when not using a hydrophilic catheter) include lubricant (\$7/month); sterile gauze (\$9.36/month); and wet naps (8.79/month)

This adds up to an estimated annual cost of \$2525.15, or \$210.42/month

R4:

\$45 for a box of 100 catheters (i.e., \$0.45/catheter); uses around 180 catheters a month

If she pays \$0.45/catheter and uses 180 catheters every month, her monthly total cost for catheters stands around  $0.45 \times 180 = \$81$ . But the given the number of catheters sold in the box purchased, 2 boxes/month would cost \$90

Under ODSP, she is allowed 2 boxes of 100 every 25 days; so far her usage hasn't exceeded that

R5: Uses 6 a day; about \$1 each (30/carton);  $6 \times 30 =$  around \$180/month

R6: For the Compact Eve, she pays \$125 for 30 catheters (i.e., around \$4.16/catheter);

given that she catheterizes around 5 times a day:  $5 \times 4.16 = 20.8/\text{day} \rightarrow 20.8 \times 30 = \$624/\text{month}$

R7: \$65 to \$70 (avg. \$67.5) for a box of a 100 (i.e., \$0.68/catheter); Uses 3 a week on average, so for every month, she uses around 12 catheters for a total of  $12 \times 0.68 = \$8.16$

R8: \$133 for 200 catheters; \$0.67 per catheter; so  $0.67 \times 4.5$  catheterizations/day =  $\$3.015/\text{day} \rightarrow 3.015 \times 30 = \$90.45/\text{month}$  or \$1,085/year

The mean monthly cost for used catheters was around \$335.81, while the median stood at \$152.50. The highest monthly cost reported was \$1300, and the lowest \$68.

## B) Access

Q8: What is your monthly out-of-pocket expenditure on catheters?

R1:

If you're on ODSP, you get coverage. Otherwise, say if your CPP disability amounts to \$1 above the ODSP threshold of eligibility, people "pay from their food money to pee." Someone on CPP disability who exceeds the threshold for ODSP is paying to go to the bathroom, "and has no money because he's paying to stay alive. And I'm seeing that more."

R2: \$0 (no monthly out of pocket expenditures)

R3:

\$0 for catheters

Despite being part-time, Leandre gets full benefit entitlements (unlimited coverage of medical supplies)

$\$2,500 \times 12 = 30,000/\text{year}$  – all covered

R4: \$0 for catheters (no monthly out of pocket expenditures on catheters)

R5: Her insurance from work pays 90% of total costs. In addition, ADP funding amounts to \$393.75 every 6 months. So in total, she doesn't pay out-of-pocket for her catheters

R6: \$0 for catheters. Her work insurance pays for this, but she has to pay for sterilizing materials (e.g., betadine)

R7: \$65 to \$70 (avg. \$67.5)

R8: \$0 (was grandfathered into a bi-annual incontinence grant from Westpark Hospital)

Most respondents reported no monthly out-of-pocket expenditures related to catheters. However, those with urinary catheter coverage have either been grandfathered into a grant; are eligible for ADP funding *only* because of a stoma; are eligible for ODSP; or receive private work insurance. One respondent noted that disabled seniors often risk losing their ODSP benefits as soon as they start receiving CPP benefits—in principle, however, ODSP and CPP should not be clashing, if for no other reason than because their purposes differ.

Q9: Are you receiving any funding and/or reimbursement for intermittent or other catheters in Ontario?

R1:

ODSP is the one that most people try to fit in; Toronto might have something for lower income people, but nothing in most regions across the province

Once you're on ODSP and fill a mandatory special necessity (MSN) form, have it signed

by a doctor, and submit a quote that matches the medical supplies put down on MSN, you can receive full coverage/funding for intermittent catheters

*“As Ontario citizens, we are not treated the same if we have a disability.”*

People could be on ODSP for years, and once they hit 65, federal funding (e.g., CPP) is going to exceed ODSP funding, at which point the latter will stop. Individuals have to actively show that the cost of their medical needs (e.g., catheters and supplies) *exceeds* what they receive in federal funding at or after age 65 to maintain their ODSP benefits. E.g., there is this individual who couldn't save his benefits from ODSP and couldn't afford IC's and had to switch to an indwelling catheter [which is associated with a higher frequency of UTI's]

Some people who end up with extra supplies donate them to others who might need them

R2: ODSP; previously used to get funding through parents' private insurance

R3:

Primary source of income is a structured settlement from gymnastics accident. Secondary source of income comes from employment income

Apart from this, he does not have any specific insurance (e.g., ODSP or WSIB) that covers medical supplies

If financially challenged and did not have coverage through work, then he could very well be forced to reuse as a result

R4:

ODSP (and parents' work-related health insurance/benefits, as needed). She also used to receive an Easter Seals grant when she was younger, which covered 5 months' worth of catheters every year

So far costs have been met, and much better so than in paediatric care. For example, ODSP approved funding for the pre-lubricated catheters that she was prescribed

Either way, the risk that reuse-based routines would impose on her health is not worth it

R5:

ADP and work insurance; ADP funding is deposited automatically into her bank account (\$393.75 every 6 months)

Once a year or once every two years, she has to fill out a form and have a doctor sign it to ensure that she still needs this service. She added that if she did not have a stoma (and was instead performing urethral catheterization), she would not qualify for ADP funding)

If she had no funding at all, she probably would reuse the catheters and would have to find time to sterilize and reuse them

R6:

Primarily, Manulife insurance (via employer); secondary funding is out-of-pocket

\$600 to \$700/month *just* for the catheters

She feels that she is very fortunate for the insurance she has, the absence of which would put a dint in her daily living [expenses]

She notes that there is “zero [public] support” for this issue

She believes she is lucky enough to be earning a decent living that allows her to maintain a single-use regime [one which would otherwise be unsustainable]

R7:

Not for bladder incontinence; only for bowel incontinence, because she has a colostomy (for which she receives an ADP Grant)

If there was better access to urinary catheters in Ontario, she would definitely change her catheterization routines.

She is happy with catheters currently in use. She started off with metal ones, and then moved to red rubber ones. MENTOR was the only one on the market at the time, which



kept getting more expensive. Finally found AMICI, which she is happy with.

R8:

Incontinence grant (from West Park Hospital)

While he likes the current brand of disposables he is using, he would switch to a single-use routine if it were to become a feasible option

Respondents were either receiving funding through ODSP, private work insurance, or an ADP grant in cases involving surgery (e.g., ostomy). More than half of the respondents agreed that their catheterization routine is significantly related to the funding and/or income they receive. One respondent expressed that *“as Ontario citizens, we are not treated the same if we have a disability.”*

### C. Cleaning Technique (For Reuse Only)

Q10: What kind of technique(s) do you follow when cleaning a catheter for reuse?

R1: Washing, boiling, and microwaving. Some used to use vinegar and water solution

R2: Boiling in water

R3: Doesn't currently reuse, but noted that when he left Lyndhurst, the cleaning technique he was given was a microwaving cleaning technique. Later on at Sunnybrook Hospital's urology department, other techniques were recommended like dishwashing soap

R4: N/A

R5: N/A

R6: N/A

R7: Warm water and soap

R8: Depends on setting/facility. It ranges from toilet paper wiping to a full rinse

The cleaning techniques reported were washing, boiling, microwaving, vinegar and water, dishwashing soap, wiping with toilet paper, and warm water and soap.

Q11: How often do you perform this technique?

R1: Majority of people would throw them out; years ago, more people used to clean and try to reuse; nowadays, it's not as common that people are disinfecting their catheters. Mostly, they're getting a new one after every use

R2: Twice a day, and in between uses

R3: N/A

R4: N/A

R5: N/A

R6: N/A

R7: After every catheterization

R8: After every use

Among those who reuse, cleaning frequency ranged from after every use to twice a day.

Q12: How long does it take you to fully clean a catheter?

R1: N/A

- R2: Boils it for 5 to 7 minutes
- R3: N/A
- R4: N/A
- R5: N/A
- R6: N/A
- R7: Five minutes or less
- R8: Less than 2 minutes

Given the responses of the three participants who answered this question, the average duration was ~4 minutes.

Q13: What would you say has made this process easier on a daily basis?

- R1: N/A
- R2: Privacy and availability of accessible washrooms
- R3: N/A
- R4: N/A
- R5: N/A
- R6: N/A
- R7: Easier to use soap and warm water than sterilize
- R8: Being at home where the sink is beside toilet makes the overall process more simple and easy

Given the responses of the three participants who answered this question, the factors conducive to IC were privacy, availability of accessible washrooms, and ease of cleaning technique

Q14: What would you say has made this process more difficult on a daily basis?

- R1: N/A
- R2: N/A
- R3: N/A
- R4: N/A
- R5: N/A
- R6: N/A
- R7:
  - The difficulty is to prevent UTT's.
  - The height of the toilet can be an issue
  - Finding a washroom can be an issue
  - If in a public place, she doesn't clean the catheter directly after catheterization (but wipes its exterior for the time being)
- R8: Public facilities may not be accommodating (e.g., when the catheter had to be taken out of the stall and washed over a public sink)

Given the responses of the two participants who answered this question, the challenges perceived included preventing infections; and public washroom availability, accessibility and IC user-friendliness

Q15: Has this technique been effective in preventing infections and/or physical damage?

R1: For some people, cleaning technique is insufficient and they use a brand new one every day (this works out if they are on ODSP, through which they can get funding for each catheter)

R2: N/A

R3: N/A

R4: N/A

R5: N/A

R6: N/A

R7: Yes and no; she still has frequent UTI's – 3 or 4 a year

R8: Somewhat; with age, he is noticing that he is getting more infections

Participants responded hesitantly here, mainly given the lived consequences of reusing intermittent catheters. One respondent noted that she has 3 or 4 UTI's a year; another mentioned that his infections are becoming more frequent with age.

Q16: Have you ever considered switching the catheterization regime you are currently on? (Probe: Are you on your current regime by choice or because of certain constraints? If the latter, tell me more about these constraints and how they have limited your choice.)

R1: N/A

R2: By choice

R3: N/A

R4: N/A

R5: N/A

R6: N/A

R7: Little bit of both

R8: Cost and habit are the two main factors underlying his current routine

While one of the three respondents claimed that they are following their regimen by choice, the other two provided a more balanced perspective taking both cost and habit into account.

### C) Outcomes & Quality of Life

Q17: How would you describe the impact of intermittent catheterization on your overall quality of life?

R1:

Elimination of infection

Once you get a number of infections, it's really hard to find an antibiotic to treat them/get rid of them. The problem is the compounding of infections, which often leads to antibiotic resistance

The other thing is keeping the bladder in a healthy state, rather than having an indwelling catheter for the long-term, which weakens the bladder over time and exposes an individual to a risk of bladder cancer

Overall, "it's more normal"

If it's under control, IC can improve physical and emotional health in users

R2:

Doesn't impact at all; doesn't need to share this [aspect of her life] with anybody  
However, it has increased her sense of independence; ability to carry out her role(s) and responsibilities at work; and ability to participate in her community and attend to family responsibilities

R3:

Because he hasn't had any major difficulties obtaining products and self-catheterizing, he doesn't feel that it's had a significant impact on his quality of life. Also relevant here is that the incidence of bladder infections for him is very low

He agrees that he has a sense of independence, is able to carry out his work, and participate in the community

The only case where his intermittent catheterization routine may become a hindrance is during travel, particularly if access to washrooms is limited

R4:

The challenges she faces often have to do with finding accessible washrooms wherever she happens to be. In sports, as a Ringette player, she struggled when she felt the need to find a washroom during a game

She finds that the new, pre-lubricated (HC) catheters she has been prescribed are easier to carry around and can be packed and used easily

She notes that IC has increased her ability to participate in her community and attend to family responsibilities

R5:

Intermittent catheterization has improved her quality of life greatly in comparison with indwelling catheterization. She was always worried that her catheter would "plug" and she would go dysreflexic and be stuck with no help

Now she is able to catheterize independently; can do it on the plane; is not in as much pain anymore; can wear whatever she wants; and doesn't have to worry about tubes and leg bags

She feels IC has increased her sense of independence; ability to carry out her role(s) and responsibilities at work; and ability to participate in her community and attend to family responsibilities

R6:

She is grateful that she doesn't have to wear a Foley catheter anymore. But she is always self-conscious of whether or not she is leaking [incontinent] every a 3 to 4 hours

She feels that compared to indwelling catheterization, IC has increased her sense of independence. As for her ability to carry out her role(s) and responsibilities at work, she thinks IC has neither increased nor decreased it. Nor has it decreased her ability to participate in her community and attend to family responsibilities

R7:

She is limited to a time schedule. In her case, she used to be able to go 4 hours without catheterizing; but now she can only go 2.5 to 3 hours.

[Wherever she might be,] she has to know that there will be a washroom nearby

She had surgery as a child involving an artificial sphincter, which worked for 10 years but then broke down. The urologist decided to remove it and proceed with a bladder augmentation procedure

Most of the time she is leak free. But if she's not feeling well, has an infection, drinks a lot of liquids (especially caffeinated beverages), then she will get into issues

The main issue for her is the proximity of an accessible washroom in public (e.g., on a parade route)

R8:

*“It’s the reason I’m able to stay alive!”*

He feels that it has increased his sense of independence; improved his ability to carry out his role and responsibilities at work because of facilitating continence, though he still struggles with infections and their impact on his work schedule; likewise for his ability to participate in his community and attend to family responsibilities

A predominant theme centered around the fact that IC was a significant improvement compared to indwelling catheterization, as it allows for greater independence and flexibility with daily life activities (e.g., work and, in the case of portable HC, travel). Once again here, washroom proximity and accessibility in public were mentioned. Moreover, one respondent expressed her concern with antibiotic resistance mainly due to how common UTT’s can be in this context, both in hospitals and the community.

Q18: What complications have you faced as a result of intermittent catheterization?

R1:

UTT’s; fissure/tear; scrotum filling with urine

Complications result in ER visits and/or hospitalizations, and when they do, the chance of septicaemia is present as well. In the case of epididymitis, some have had to have their testicles removed

R2:

Sometimes has UTT’s but always keeps medication on hand for when she runs into problems (has prescription)

Hasn’t had to go to the ER and/or be hospitalized, but keeps medications on hand just in case the need arises

R3:

He developed a urethral stricture twice (scar tissue), which is caused by catheterization and makes catheter-insertion more difficult

Underwent two urethrotomies in which the urethra is cut longitudinally where the scar tissue has built up and an indwelling (Foley) catheter is inserted and left for two weeks while the urethra heals around it. Subsequently, the patient can return to intermittent catheterization. This procedure has a very limited long-term success (5 to 10%), but is still performed nonetheless

Following his 2<sup>nd</sup> surgery, he was scheduled for urethroplasty in order for his urethral stricture(s) to be removed. After using indwelling catheters during the healing period, he had enough “urethral rest”, but was only able to catheterize with 2 types of catheters (those currently in use)

A third surgery he underwent involved making a passage to the bladder through the lower abdomen through which a Foley is inserted

These complications, he thinks, are the result of long term catheterization

Different products could have led to different outcomes. One problem is that there is very little research on the incidence of urethral strictures associated with different types of catheters. It’s also possible that the amount of lubricant played a role as well. There was a time when he had a spastic sphincter, and was using an anaesthetic lubricant (\$12 to \$13 per tube; 10 tubes a month) paid for by ODSP. Because of the cost, he was trying to limit his use of lubricant, and had to obtain a doctor’s note in order for ODSP to pay for that lubricant. He believes that as a result of using less (anaesthetic) lubricant, his frequent exposure to friction during catheterization may be one of the causal factors underlying the development of urethral strictures

R4:

When she was younger, she used to get infections from reusing catheters  
Switched to a single-use routine; UTI's reduced significantly

R5:

She never had an issue with UTI's/bladder infections  
Since her bowel treatment, she has had bypass issues over the past 6 months

R6: No, but she is very careful and nervous

R7:

Severe UTI's (for which she had to be given IV)  
Because she has frequent UTI's, her urologist has given her a prescription for antibiotics that are generally good for bladder infections. In her teenage years, she was on a small dose of antibiotics all the time, and when that protocol was stopped, she started having UTI's more frequently  
When she senses a UTI coming on, she takes antibiotics  
She has had to go for an ER visit, albeit rarely. It's usually a combined issue that leads to this, not simply a bladder infection  
She believes such complications could have been prevented by using one catheter at a time

R8:

UTI's mostly; bladder and kidney stones  
He has been having infections back to back since May; generally, he has 2 to 3 a year  
When he feels like he might have an infection, he phones the family doctor; provides a urine sample; and an antibiotic is prescribed if needed  
He has had medical intervention due to bladder stones  
He believes that such complications could have been prevented by not reusing catheters and making sure things are clean

The most common complications of IC that emerge out of this sample are UTI's and urethral strictures, which respondents believe could have been prevented by using one catheter at a time and adopting safer IC strategies. Some respondents reported an ER visit due to a UTI, while others saw that their long-term, suboptimal IC regimen in the past has led to the development of urethral strictures, which may require multiple surgeries to be performed.

#### D. Wrap-Up

Q19: Is there anything else I haven't asked you about that you would like to add or share?

R1:

Some cut back on the number of uses; instead of 5 times/day, they would catheterize twice only. This results in overflow incontinence and potentially reflux back into the kidneys  
Years ago, ADP did fund urinary supplies, starting with a certain age group. And those who were on it were grandfathered in. A 56 year-old lady with spina bifida, for example, gets her funding from this old ADP program, as she was grandfathered in.  
For ADP, the rule of thumb is that they will give you money if surgery is involved – ileal conduit or supra-pubic catheterization. "If you get the knife, you get funding."  
People don't realize that ODSP took on the role from ADP to fund this kind of medical

supplies; no longer can we go to Ontario Works because everything [in this regard] is now linked to ODSP

R2: N/A

R3: N/A

R4:

What used to be called the ADP Grant (now called the Easter Seals grant) was not sufficient to cover all the costs associated with intermittent catheterization

Now with adult care: having proper documentation from a healthcare professional allows her to get everything she needs. She hasn't had a problem getting catheters and doing things like travelling

She finds the wide range of catheter prices problematic, not to mention that even the most basic ones can be expensive

In regards to the factors that might impact her ODSP coverage, her monthly income is important. What she works in a month, however, doesn't really affect her medical needs (and thus shouldn't undermine her coverage)

The frustrating part with ODSP is some of the stuff wasn't explained up front. For instance, she is not sure if there's a way to properly document her transition from paediatric to adult care

Biggest issue is the price variance; there should be a more standard baseline

(Interviewer: Lots of people have no coverage under ODSP in Ontario; a lot of people who work full time but don't have work insurance are getting very little, if any, funding. We're talking mostly to the ADP program for them to start giving grants, while making recommendations to ODSP)

R5:

She always has a purse containing catheterization essentials that she always carries with her

She has pre-lubricated catheter samples (in green packaging) that she is yet to try. Surgery (bladder augmentation) has had a big impact on her life, particularly given the discomfiting nature of indwelling catheters

R6:

*"The government needs to know that there are people who have medical issues and that there should be some form of access and/or assistance when people end up in these kinds of situations. Individuals end up in these kinds of situations out of nowhere...It takes on your budget and your salary."*

*"Easier access [to urinary catheters and similar medical devices] would be nice."*

R7: N/A

R8:

When he was full time, the benefits of his private insurance program did not cover incontinence supplies. He believes this has to change

If the public system isn't going to fill the [funding] gap, it should be available through private insurance that you pay for

An already existing program that is not income-tested, ADP is the one place that's accessed by people who are on social assistance, but also by those who aren't (like himself). If you are not on social assistance, you often find that government branches that provide it are overworked, so having people who are working but not on social assistance going to them would be extra work that they don't need

ADP or a department in the Ministry of Health would be a reasonable avenue [for allocating grants for IC users]

*"Adding us [intermittent catheter users] to the mix of social services would be a bad idea"*

The general sentiment among respondents points to the fact that there is a non-trivial

funding gap in Ontario that cannot be ignored anymore, ever since ODSP took over ADP's responsibility for covering urinary catheters. The government ought to acknowledge that the current avenues for access to intermittent catheters has left many individuals with disabilities with little to no coverage. Even further compounding the limits of access are the high IC and supplies expenses—almost always unplanned for in individual budgets. One cancer patient lamented that *“the government needs to know that there are people who have medical issues and that there should be some form of access and/or assistance when people end up in these kinds of situations. Individuals end up in these kinds of situations out of nowhere...It takes on your budget and your salary.”*

Q20: The responses you have provided may stimulate additional questions or need for further clarification. If so, may we contact you in the future?

- R1: Yes
- R2: Yes
- R3: Yes
- R4: Yes
- R5: Yes
- R6: Yes
- R7: Yes
- R8: Yes



## 15. APPENDIX E: DIAGNOSING URINARY TRACT INFECTIONS

*Table: Surveillance Definitions for Urinary Tract Infections (UTI's)*

Criteria	Comments
<p><b>1. At least 1 of the following sign or symptom subcriteria:</b></p> <ul style="list-style-type: none"> <li>a. Acute dysuria or acute pain, swelling or tenderness of the testes, epididymitis, or prostate</li> <li>b. Fever or leukocytosis and at least 1 of the following localizing urinary tract subcriteria:               <ul style="list-style-type: none"> <li>i. Acute costovertebral angle pain or tenderness</li> <li>ii. Suprapubic pain</li> <li>iii. Gross hematuria</li> <li>iv. New or marked increase in incontinence</li> <li>v. New or marked increase in urgency</li> <li>vi. New or marked increase in frequency</li> </ul> </li> <li>c. In the absence of the fever or leukocytosis, then 2 or more of the following localizing urinary tract subcriteria:               <ul style="list-style-type: none"> <li>i. Acute costovertebral angle pain or tenderness</li> <li>ii. Suprapubic pain</li> <li>iii. Gross hematuria</li> <li>iv. New or marked increase in incontinence</li> <li>v. New or marked increase in urgency</li> <li>vi. New or marked increase in frequency</li> </ul> </li> </ul> <p><b>2. One of the following microbiologic subcriteria:</b></p> <ul style="list-style-type: none"> <li>a. At least <math>10^5</math> cfu/ml of no more than 2 species of microorganisms in a voided urine sample</li> <li>b. At least <math>10^2</math> cfu/ml of any number of organisms in a specimen collected by in-and-out/intermittent catheter</li> </ul>	<p>UTI should be diagnosed when there are localizing genitourinary signs and symptoms and a positive urine culture result. A diagnosis of UTI can be made without localizing symptoms if a blood culture isolate is the same as the organism isolated from the urine and there is no alternate site of infection. In the absence of a clear alternate source of infection, fever or rigors with a positive urine culture result in the non-catheterized resident or acute confusion in the catheterized resident will often be treated as UTI. However, evidence suggests that more of these episodes are likely not due to infection of a urinary source.</p> <p>Urine specimens for culture should be processed as soon as possible, preferably within 1-2 hours. If urine specimens cannot be processed within 30 minutes of collection, they should be refrigerated. Refrigerated specimens should be cultured within 24 hours.</p>

Source: Canadian Nurse Continence Advisor Association

## 16. APPENDIX F: INTER-PROVINCIAL COMPARISONS OF PUBLIC FUNDING SOURCES FOR INTERMITTENT CATHETERS

Table: *Public Sources of Support for Catheter Supplies, by Province*

<b>Province</b>	<b>Program/Source</b>
Alberta	<ul style="list-style-type: none"> <li>● Alberta Aids to Daily Living (AADL)</li> </ul>
British Columbia	<ul style="list-style-type: none"> <li>● Home Care</li> <li>● Equipment and Assistive Tech. Initiative (EATI)</li> </ul>
Newfoundland and Labrador	<ul style="list-style-type: none"> <li>● Special Assistance Program (SAP)</li> <li>● Special Child Welfare Allowance (SCWA)</li> </ul>
Manitoba	<ul style="list-style-type: none"> <li>● Employment and Income Assistance for Persons with Disabilities (EIA)</li> </ul>
New Brunswick	<ul style="list-style-type: none"> <li>● Health Services Incontinence Program</li> </ul>
Nova Scotia	<ul style="list-style-type: none"> <li>● Services for People with Disability (SPD)</li> <li>● Employment Support and Income Assistance (ESIA)</li> </ul>
Ontario	<ul style="list-style-type: none"> <li>● Ontario Disability Support Program (ODSP)</li> <li>● Assistance for Children with Severe Disabilities (ACDS)</li> <li>● Easter Seals Society</li> <li>● Workers Compensation</li> <li>● Auto Insurance</li> </ul>
PEI	<ul style="list-style-type: none"> <li>● Disabilities Support Program (DSP)</li> </ul>
Quebec	<ul style="list-style-type: none"> <li>● Programme d'aide sociale et le Programme de solidarité sociale</li> </ul>
Saskatchewan	<ul style="list-style-type: none"> <li>● Saskatchewan Aids to Independent Living (SAIL) Paraplegia Program</li> </ul>