

ConCaRe™ Contenance Care Registry: Using Longitudinal Data to Better Understand the Intermittent Self-Catheterization User Experience

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Introduction

While intermittent catheterization is the “gold-standard” to manage neurogenic lower urinary tract dysfunction (NLUTD), limited data exist on the daily experiences of individuals using intermittent self-catheterization (ISC).^{1,2} A longitudinal study collecting self-reported data from individuals who perform ISC to manage bladder emptying would provide insight into their daily use, habits, and experiences.^{3,4}

This study aims to build an electronic patient-reported outcomes registry of adults who use ISC long-term.

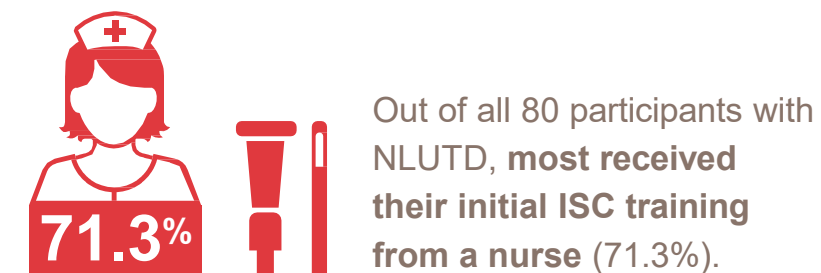
Method

ConCaRe™ continence care registry is a multinational registry designed as a prospective, observational longitudinal study among individuals who perform ISC. Recruitment efforts focus on community-dwelling individuals aged 18 and older using ISC who can self-enroll in the registry on a rolling basis.

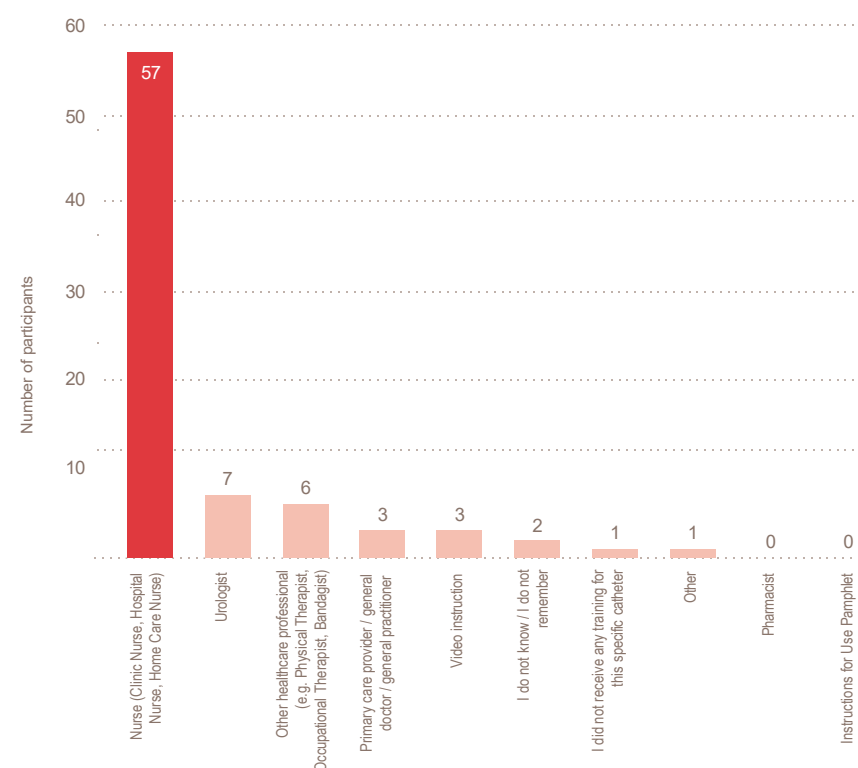
Questionnaires are electronically distributed monthly for one year, then quarterly for up to five years and include the Intermittent Self-Catheterization Questionnaire, EuroQoL-5D, and RAND modified Medical Outcomes Study Social Support Survey, which explore **quality of life and satisfaction, health care utilization, and factors influencing catheter choice.**^{5,6,7}

Results

As of December 19, 2022, baseline data from **93** (71% US; 29% CA) participants aged 20-86 years (average=51.4; median=53) (**73.1% male**) are presented.

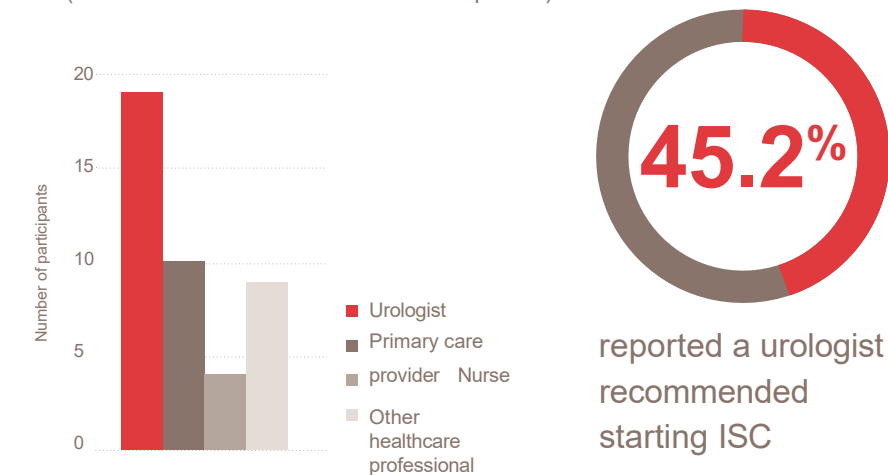


When you first started using intermittent catheters, from whom or what source did you receive your FIRST training in intermittent self-catheterization?



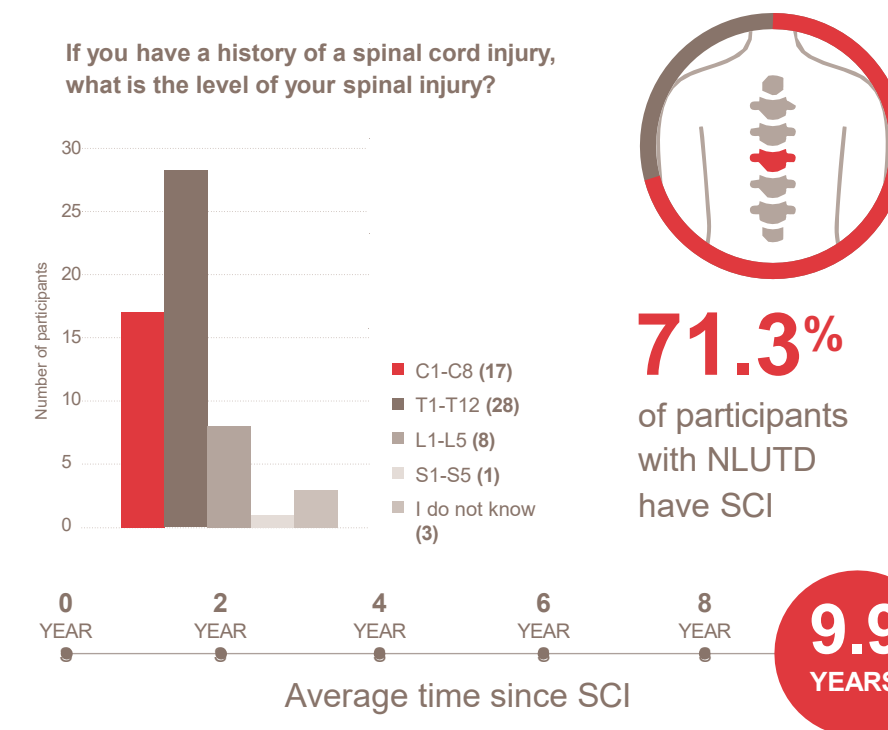
Eighty (80) of the 93 participants (86.0%) self-reported having conditions associated with NLUTD. Of the **42 participants** with NLUTD who started using ISC after using another method to empty their bladder, **45.2%** reported a urologist recommended starting ISC.

Who recommended you to start performing intermittent self-catheterization? (“Pharmacist” was not chosen as a response.)



Fifty-seven (57) of the 80 participants with neurogenic bladder (**71.3%**) self-reported having a spinal cord injury (SCI). Average time since SCI was **9.9 years** (range= [1.7, 39.2]; median=5.8).

If you have a history of a spinal cord injury, what is the level of your spinal injury?



Conclusions

As recruitment approaches the target **[600 participants]**, outcomes will continue to be monitored over time.

Data yielded from the ConCaRe™ continence care registry will help to characterize ISC utilization in different populations by gender, age, location, and comorbidities.



Implications for Practice

A better understanding of the ISC user’s experience will help to inform clinical practice to identify areas of unmet patient needs and opportunities for clinician support.

[WIRB;IRB Study #: 1304189; ClinicalTrial.gov Identifier NCT04924569]

Use the QR codes to share the recruitment flyer with your ISC patients who may be interested in enrolling in ConCaRe™ continence care registry.



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Disclosures

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