

## Using Administrative Health Data to Define a Cohort of Youth Affected by Chronic Health Conditions: Preparing for Cross-Sectoral Data Linkage

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### Introduction

In Alberta, 2,400 youth with chronic needs transition to adulthood every year, and many are not prepared for this change. Transferring youth from pediatric to adult-oriented care is poorly managed. To improve this process, we need to know how youth patients use health services during this period.

questions about patterns of service utilization in other sectors of care. Our next step is to link the cohort to population-level datasets (e.g., physician claims, NACRS, CIHI-DAD).

### Objectives and Approach

We used the Alberta Health Services Corporate Data Repository (CDR-9), which collects records of ambulatory visits, to define a cohort of patients with chronic disease using pediatric tertiary care; data is available from 2008 to 2016. Personal health numbers allowed for deterministic data linkage to CDR-9, registry data (e.g., death dates, moves out of province), and area deprivation indices. Eligible patients were: (a) between ages 12-15 years in 2008 (for  $\geq 2$  years observation in adulthood, after age 18), (b) involved with a Chronic Care Clinic (CCC) at Alberta Children's Hospital, and (c) had repeated CCC visits with  $\geq 3$  months between visits.

### Results

We identified 26 Chronic Care Clinics (CCC) at Alberta Children's Hospital (Calgary, Alberta), with stakeholder input. Using CDR-9, a total of 10,111 patients at the hospital were identified who were 12 to 15 years old at the start of the study window (in 2008), and who visited a CCC before age 18. Less than 1% ( $n=418$ ) were excluded due to moving out of province or having an invalid personal health number. Final sample sizes were captured across 3 algorithms (A1, A2, A3), based on frequency of CCC visits within a 2-year period: (i) A1: 2 CCC visits ( $N=4123$ ); (ii) A2:  $\geq 3$  CCC visits ( $N=2242$ ); (iii) A3:  $\geq 4$  CCC visits ( $N=1344$ ).

### Conclusion/Implications

Our identified cohort of youth affected by chronic conditions is the first of its kind in Alberta, and can answer important

