



## RESEARCH ARTICLE

# Re-Accessing Mental Health Care After Age 18: A Longitudinal Cohort Study of Youth Involved with Community-based Child and Youth Mental Health Agencies in Ontario

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## Abstract

**Objective:** About 20-26% of children and youth with a mental health disorder (depending on age and respondent) report receiving services from a community-based Child and Youth Mental Health (CYMH) agency. However, because agencies have an upper age limit of 18-years old, youth requiring ongoing mental health services must “transition” to adult-oriented care. General healthcare providers (e.g., family physicians) likely provide this care. The objective of this study was to compare the likelihood of receiving physician-based mental health services after age 18 between youth who had received community-based mental health services and a matched population sample. **Method:** A longitudinal matched cohort study was conducted in Ontario, Canada. A CYMH cohort that received mental health care at one of five CYMH agencies, aged 7-14 years at their first visit (N=2,822), was compared to age, sex, region-matched controls (N=8,466). **Results:** CYMH youth were twice as likely as the comparison sample to have a physician-based mental health visit (i.e., by a family physician, pediatrician, psychiatrists) after age 18; median time to first visit was 3.3 years. Having a physician mental health visit before age 18 was associated with a greater likelihood of experiencing the outcome than community-based CYMH services alone. **Conclusion:** Most youth involved in community-based CYMH agencies will re-access services from

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physicians as adults. Youth receiving mental health services only within community agencies, and not from physicians, may be less likely to receive physician-based mental health services as adults. Collaboration between CYMH agencies and family physicians may be important for youth who require ongoing care into adulthood.

**Key Words:** *child, adolescent, young adult, mental health services, transition to adult care, adolescent health services, health services*

## Résumé

**Objectif:** Environ 20 à 26 % des enfants et des adolescents souffrant d'un trouble de santé mentale (dépendant de l'âge et du répondant) déclarent recevoir des services d'un organisme communautaire de santé mentale pour enfants et adolescents (SMEA). Toutefois, puisque les organismes ont une limite d'âge supérieur de 18 ans, les jeunes nécessitant des services de santé mentale doivent faire la « transition » aux soins pour adultes. Les prestataires de soins de santé généraux (p. ex., les médecins de famille) dispensent probablement ces services. La présente étude visait à comparer la probabilité de recevoir des services de santé mentale par un médecin après l'âge de 18 ans entre un jeune qui avait reçu des services de santé mentale et un échantillon apparié dans la population. **Méthode:** Une étude de cohorte longitudinale appariée a été menée en Ontario, Canada. Une cohorte SMEA qui recevait des soins de santé mentale à l'un des cinq organismes SMEA, âgés entre 7 et 14 ans à leur première visite (N = 2,822), a été comparée pour l'âge, le sexe, les contrôles appariés par région (N = 8,466). **Résultats:** Les jeunes des SMEA étaient deux fois plus susceptibles que l'échantillon de comparaison d'avoir une visite de santé mentale par un médecin (c.-à-d. par un pédiatre, médecin de famille, des psychiatres) après l'âge de 18 ans le temps moyen avant une première visite était 3,3 ans. Avoir une visite de santé mentale avec un médecin avant l'âge de 18 ans était associé à une plus grande probabilité de connaître le résultat que par les services SMEA communautaires à eux seuls. **Conclusion:** La plupart des jeunes impliqués dans les organismes communautaires SMEA accéderont de nouveau aux services de médecins en tant qu'adulte. Les jeunes recevant des services de santé mentale uniquement d'organismes communautaires et non de médecins peuvent être moins susceptibles de recevoir des services de santé mentale par un médecin en tant qu'adultes. La collaboration entre les organismes SMEA et les médecins de famille peut être importante pour les jeunes qui nécessitent des soins constants à l'âge adulte.

**Mots clés:** *enfant, adolescent, jeune adulte, services de santé mentale, transition aux soins pour adultes, services de santé pour adolescent, services de santé*

## Abbreviations

CYMH = Child and Youth Mental Health  
 OHIP = Ontario Health Insurance Plan  
 MCYS = Ministry of Child and Youth Services  
 MD = Material Deprivation (Ontario Marginalization Index)  
 RPDB = Registered Persons Database  
 MHLTC = Ministry of Health and Long Term Care  
 ICES = Institute for Clinical Evaluative Sciences  
 ICD = International Classification of Diseases

## Introduction

In Canada, about 18% of youth (aged 12-17 years old) have an identified mental health disorder, and between 43-61% of these youth have some type of contact with mental health services in adolescence (based on youth or parent-report, respectively) (Comeau et al., 2019; Georgiades et al., 2019). Youth and families access mental health services from different providers and across multiple settings or sectors of care (e.g., community agencies, schools, hospitals) (Ford et al., 2007; Leaf et al., 1996; Reid et al., 2011; Tobon et al., 2013). According to a recent population-based survey in Ontario, about 20-26% of children and youth with

a mental health disorder (depending on age and respondent) report receiving services from a community-based Child and Youth Mental Health (CYMH) agency (Comeau et al., 2019; Georgiades et al., 2019). CYMH agencies offer a range of specialized mental health services, including assessment and treatment services (e.g., individual or family counselling, day treatment, residential care), for youth and families with varying levels of distress and impairment (Canadian Institute for Health Information, 2015). Unfortunately, demand for services in CYMH agencies is increasing, particularly for long-term counselling and therapy (Canadian Institute for Health Information, 2015). Yet, because CYMH agencies have an upper age limit (typically 18 years old in most jurisdictions), youth requiring ongoing mental health services must eventually “transition” from child to adult-oriented services. Little is known about which youth are likely to re-access mental health services in young adulthood. This information is important for system planning and understanding transitions to adult care among youth involved with CYMH agencies.

Very few studies have examined mental health service utilization during adolescence through to young adulthood, or

during the transition period (ages 12-25) (Cappelli et al., 2014; Singh et al., 2010). Some research has examined this among youth treated for severe mental illness [e.g., psychosis, schizophrenia; (Addington & Addington, 2009; Boydell et al., 2013)] and those treated close to the age of transfer [16 to 18 years old, (Cappelli et al., 2014)]. A large proportion (40-60%) of older adolescents with severe mental illness, given their age and disorder severity, are referred to specialized adult mental health services in the community [e.g., mental health centers, substance abuse treatment programs, adult psychiatrists (Addington & Addington, 2009; Cappelli et al., 2014)]. In contrast, for the vast majority of youth involved with community-based agencies in childhood or adolescence, specialized adult mental health services are unlikely to be suitable (or immediately accessible) in young adulthood (Schraeder & Reid, 2017). This may especially be the case for youth with less severe or remitting mental health problems (e.g., anxiety, mild depression), who do not meet eligibility for specialized adult services (Islam et al., 2016; Singh et al., 2010). As a result, general healthcare providers (such as family physician) are likely most accessible for ongoing mental health care for young adults (Schraeder et al., 2020). However, empirical evidence to support the role of family physicians during the transition to adult care, particularly for those leaving community-based CYMH services, is lacking.

This study, to the best of our knowledge, is the first in Canada to link community-based mental health agency data with provincial health data to examine utilization of physician-based mental health services during the transition period. Our main objective was to describe the use of physician-based mental health services (i.e., mental health-related visit to a family physician or pediatrician, or to a psychiatrist) before and after age 18 years old among a youth cohort who had received community-based CYMH services in Ontario ("CYMH youth"). We also sought to compare the probability of receiving physician-based mental health services in young adulthood between CYMH youth and a matched population comparison sample, and to explore possible predictors of receiving this care. We hypothesized that the CYMH community sample would be more likely than the comparison samples (youth from the general population) to experience the outcome (i.e., a mental health-related physician visit after age 18).

## Methods

### **Study Design and Setting**

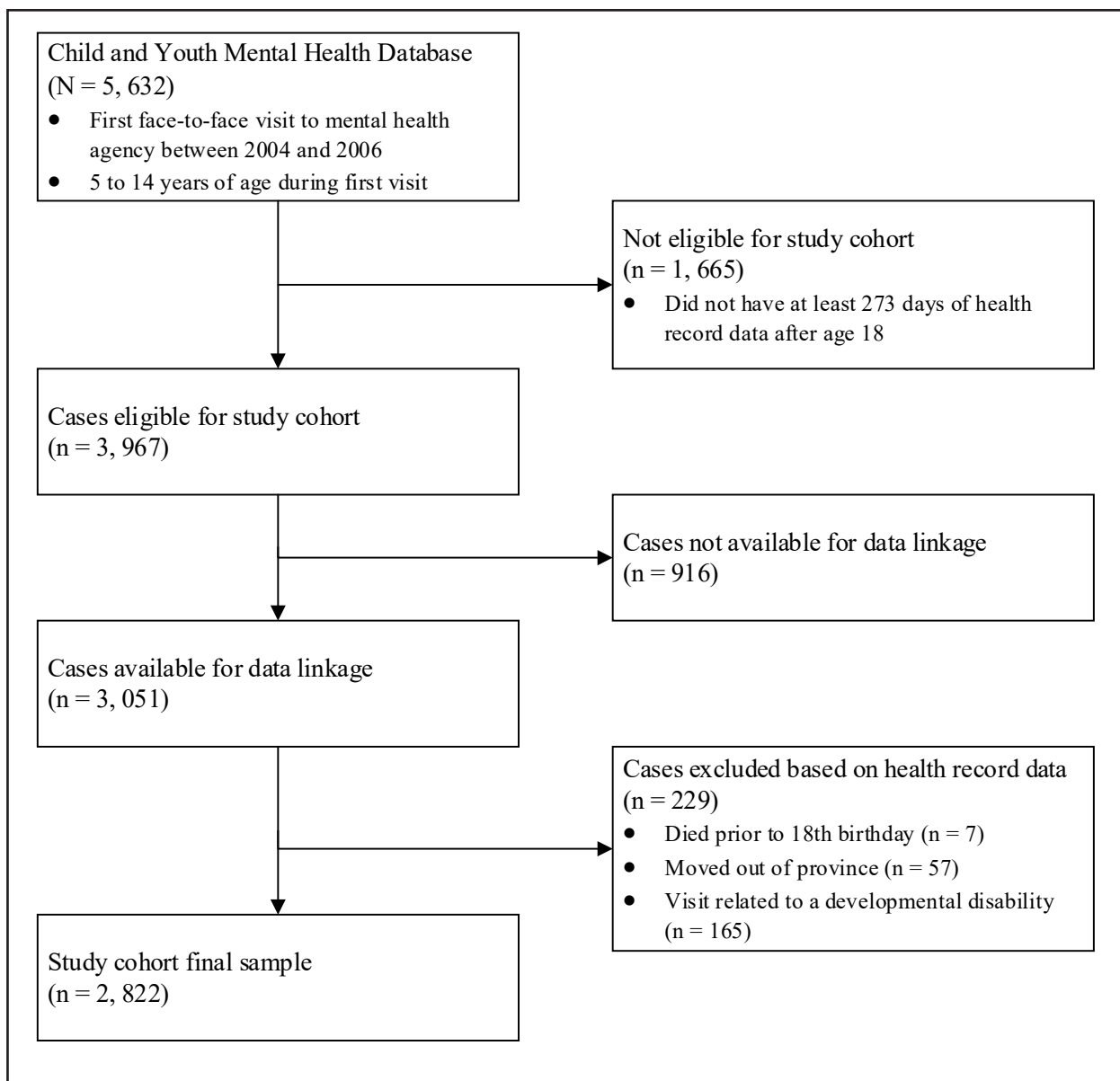
This was a longitudinal matched cohort study in the province of Ontario, Canada. Ontario is the most populated province (13.6 million), representing 40% of the country's

population. Our two main data sources were: (1) *community CYMH agency data* from a Child and Youth Mental Health Dataset (CYMH-D; N = 5,632) obtained in a previous study and held at the University of Western Ontario (Reid et al., 2019); and (2) *population health data* from datasets held at the Institute for Clinical Evaluative Sciences (ICES). The CYMH-D was brought into ICES in order to link youth's data to population health data records. At the time this study took place, mental health services offered within Ontario CYMH agencies were funded by the Ministry of Child and Youth Services (MCYS; renamed the Ministry of Child, Community and Social Services after provincial election in 2018). Then in April 2019, oversight for all CYMH agencies were transferred to the Ministry of Health and Long-term Care). Healthcare by physicians is funded through the single payer Ontario Health Insurance Plan (OHIP). Eligibility criteria for the CYMH-D and process for data linkage to health data are described below. This study was approved by the institutional review board at Sunnybrook Health Sciences Centre, Toronto, Canada, and the research ethics board at Western University (REB#-106553).

### **Data Sources and Linkage**

**Community CYMH agency data.** The CYMH-D contained administrative data for youth who had received care within any of five Ontario CYMH agencies, serving 5-18 year olds. Participating agencies were accredited by (Children's Mental Health Ontario, n.d.) and those serving rural and urban populations in Eastern, Central, and Southwestern Ontario were purposively sampled. In a previous study, eligible youth were 5-14 years old at their first in-person CYMH visit (between 2004-2006). Raw data in electronic format were sent to our research team from each agency and included: youth's date of birth, sex, and visit data [e.g., date, type of contact (e.g., telephone, in-person)]. Only face-to-face visits were included; telephone visits were excluded because it was unclear whether these were for administrative purposes (e.g., rescheduling appointments), or if treatment was provided. Children identified with a developmental disorder (e.g., Autism) at intake, or who were receiving care within an agency program for developmental disorders were excluded; the long-term needs of these youth were not the focus of study.

**Population health data.** In Ontario, the majority (94%) of physicians' direct patient care is captured in the OHIP dataset (Rhodes et al., 2006; Steele et al., 2004). ICES holds population-based datasets for the province through a research agreement with Ontario's Ministry of Health and Long-Term Care (MHLTC). In accordance with the Personal Health Information Protection Act, datasets (e.g., OHIP)

**Figure 1. Participant eligibility flowchart**

were linked using unique encoded identifiers and analyzed at ICES.

The Registered Person Database (RPD) is a central database at ICES housing demographic information (e.g., sex, date of birth, postal code) for Ontario residents registered for provincial health insurance coverage. Using probabilistic linkage (Howe, 1998; Jaro, 1995), this database was used to link health datasets to the CYMH-D based on youth's date of birth, sex, postal code, and initials. Once linked, each individual was given an encoded identifier prior to the creation of this study's dataset to comply with privacy protocols.

### Samples

**Child and Youth Mental Health cohort.** In the CYMH-D (N = 5,632), youth were as young as 4-years old at their first CYMH visit. For the current study, we first selected a subsample of youth who were age 18.75 years old or older (n = 3,967); thus, they had at least 8 months of healthcare data after age 18. Of this subsample, 77% (n = 3,051) were able to be probabilistically linked to the RPD and health datasets at ICES (i.e., had a valid health identifier number). A small percentage (2%) were subsequently excluded (i.e., moved out of province), as were youth (n = 165) who received physician-based services for a developmental disability visit to

align with our community sample eligibility criteria. Figure 1 presents a flowchart of eligibility of the final sample ( $N = 2,822$ ). Seven youth died after age 18 but contributed to analyses ( $M$  age at death = 20.2 years,  $SD = 1.1$ ).

**Non-CYMH sample (matched comparison).** A randomly selected comparison sample was obtained from the RPD, as described above, and matched on sex, year of birth, and Census division (a region of residence; (Statistics Canada, n.d.)) Three controls were selected for every case (Hennessey et al., 1999; Wacholder et al., 1992). Notably, the control sample was not a ‘non-mental health’ sample; although controls did not receive services from a community-based CYMH agency, they may have received physician-based mental health services before age 18. It is very unlikely that youth in our comparison sample would have accessed mental health services from another community-based CYMH agency, since our comparisons were matched by age and residence, and agencies usually provide services for entire counties.

## Variables

**Demographics.** Variables included youth’s sex, urban/rural residence, neighborhood income, and area-level deprivation index (a proxy for socioeconomic status). *Residence* was determined by linking individuals’ postal codes from the RPD to the 2006 Canadian Census; the 2006 Census was used to align with the year closest to when participants entered the study. *Neighborhood income* quintiles, based on the province as a whole, were computed using individuals’ Dissemination Areas or rural area (i.e., communities <10,000 people), which are geographical areas with small, relatively stable populations (between 400-700 persons) with similar economic and social conditions. *Neighborhood socioeconomic status* was based on the Ontario Material Deprivation index (Durbin et al., 2015; To et al., 2013), a census- and geographically-based index derived to show differences in marginalization and understand inequalities in health and social well-being. For each individual, their index score reflected the quintile for the dissemination area in which they resided.

**Mental health service use.** In-person visits to a CYMH agency were obtained from the CYMH-D; physician-based mental health visits to a physician were obtained from OHIP claims data. Physician-based visits included visits: (i) with a general or mental-health specific service fee code, *with* a mental health diagnostic code by a family physician or pediatrician, *or* (ii) to a psychiatrist. Non-physician-based visits (e.g., emergency department, psychiatric hospitalizations) were excluded, as this would not normally be considered part of routine physician-based services in adulthood.

In claims data, diagnostic codes represent the main “reason for the visit” and are coded using the 10<sup>th</sup> revision of the International Classification of Diseases. These codes are submitted by physicians with “billing codes” (insurance procedures) at each visit. For adult populations, select codes have excellent specificity (97%) and adequate sensitivity (81%) for mental health service use (Steele et al., 2004). Adult-specific codes, however, do not capture all mental health care for youth; childhood diagnoses such as ADHD were not included in previous studies. For this study, two family physicians and a pediatrician independently reviewed all diagnostic and billing codes for their relevance to youth mental health problems; consensus of codes was achieved through group discussion (code list available as Supplementary Materials).

**Groups and outcome variable.** The main grouping variable was receiving care within a community CYMH agency before age 18 (cases) or not (comparisons). The outcome was first adult physician-based mental health visit (after age 18). Diagnosis and service provided (from claims data) and physician specialty (i.e., family medicine, pediatrics, psychiatry; ICES Physician Database) described this visit.

## Analyses

All analyses were performed using SAS Enterprise Guide 6.1 (SAS Institute Inc., Cary, North Carolina, USA, n.d.) and completed at ICES by ICES analysts. Time to outcome (i.e., having an adult physician-based mental health visit), was determined using survival analyses (Hosmer et al., 2008). Time to outcome was computed in days from the origin (18<sup>th</sup> birthday), coded as Day 0. Comparisons were given an index date (Day 0) that aligned with cases’ first CYMH visit. Survival analysis is designed for time-to-event data where not all participants experience the outcome and participants have variable follow-up durations. Follow-up times varied in the CYMH sample due to variable entry times into the study (i.e., first CYMH visit). Data were used up to the outcome, or to the point of censoring (lost to follow-up), whichever occurred first. (Cleves et al., 2010; Hosmer et al., 2008)

The Kaplan-Meier method was used to generate survival curves based on life-table estimates (e.g., probability of experiencing the outcome per day), and to test the proportional hazards assumption. The main grouping variable was entered into three Cox regression models. First, a crude model derived a hazard ratio (HR), comparing the likelihood of the outcome between cases and comparisons. Second, in an adjusted model, the effect of community-based CYMH services on the outcome was assessed after adjusting for the potential added effect of a covariate (i.e., receiving



**Table 1. Comparison of characteristics between four cohort groups based on Cox stratified model**

| Characteristics  | Community CYMH +<br>physician-based mental<br>health <sup>a</sup><br>(n = 2088)<br>n (%) | Community CYMH only<br>(n = 734)<br>n (%) | Physician-based mental<br>health only<br>(n = 2895)<br>n (%) | No mental health<br>(n = 5571)<br>n (%) |
|--|--|---|--|---|
| Age at start of study window                               | M = 11.11 (SD = 1.76)  | M = 11.50 (SD = 1.65)                     | M = 11.0 (SD = 1.80)   | M = 11.4 (SD = 1.75)                    |
| Sex (% female)   | 826 (39.6%)  | 1,164 (40.2%)                             | 313 (42.6%)  | 2,253 (40.4%)                           |
| Residence  |  |   |  |   |
| Rural  | 327 (15.7%)  | 471 (16.3%)                               | 137 (18.7%)  | 4,600 (16.6%)                           |
| Urban  | 1,757 (84.1%)  | 2,471 (83.5%)                             | 595 (81.1%)  | 925 (82.6%)                             |
| Neighborhood income quintile                               |  |   |  |   |
| Missing  | *  | *   | 9 (0.3%)   | 60 (1.1%)                               |
| Q1 (lowest)  | 446 (21.4%)  | 155 (21.1%)                               | 544 (18.8%)  | 977 (17.5%)                             |
| Q2   | 488 (23.4%)  | 162 (22.1%)                               | 614 (21.2%)  | 1,109 (19.9%)                           |
| Q3   | 467 (22.4%)  | 145 (19.8%)                               | 657 (22.7%)  | 1,292 (23.2%)                           |
| Q4   | 396 (19.0%)  | 160 (21.8%)                               | 609 (21.0%)  | 1,236 (22.2%)                           |
| Q5 (highest)**   | 285-287** (13.6-13.7%)   | 108-110** (14.7-14.9%)                    | 462 (16.0%)  | 897 (16.1%)                             |
| Ontario Marginalization index <sup>b</sup>                 |  |   |  |   |
| Missing  | 20 (1.0%)  | 8 (1.1%)                                  | 36 (1.2%)  | 117 (2.1%)                              |
| Q1 (least deprived)  | 383 (18.3%)  | 153 (20.8%)                               | 588 (20.3%)  | 1,235 (22.2%)                           |
| Q2   | 454 (21.7%)  | 187 (25.5%)                               | 665 (23.0%)  | 1,383 (24.8%)                           |
| Q3   | 462 (22.1%)  | 152 (20.7%)                               | 621 (21.5%)  | 1,225 (22.0%)                           |
| Q4   | 357 (17.1%)  | 110 (15.0%)                               | 473 (16.3%)  | 775 (13.9%)                             |
| Q5 (most deprived)   | 412 (19.7%)  | 124 (16.9%)                               | 512 (17.7%)  | 836 (15.0%)                             |
| Total CYMH Visits (IQR)                                    |  |   |  |   |
| Median (Q1-Q3)   | 8 (2-21)   | 4 (1-9)                                   | NA   | NA                                      |
| Duration of CYMH involvement in months (IQR)               | 6.97 (0.87-24.13)  | 2.12 (0.03-9.53)                          | NA   | NA                                      |
| Duration between last CYMH visit and age 18 in years (IQR) | 5.75 (4.34, 7.47)  | 5.8 (4.52-7.53)                           | 6 (4.54-7.73)  | 5.64 (4.24-7.22)                        |

Note. NA = Not applicable. CYMH = Child and Youth Mental Health. IQR = Interquartile range; Median (Q1,Q3).

<sup>a</sup> Physician-based mental health refers to mental health visit to a physician (e.g., family physician, pediatrician, psychiatrist) based on Ontario Health Insurance Plan physician claims data.

<sup>b</sup> The Material Deprivation was used, which is an aggregate measure of six indicators based on the percentage of cases in the DA:

- (1) individuals aged 20 years and over without a high school graduation;
- (2) lone parent families;
- (3) individuals receiving government transfer payments;
- (4) individuals 15 years old and over who are unemployed;
- (5) individuals living below the low-income cut-off (defined by Statistics Canada and adjusted for family and community size); and
- (6) households living in dwellings in need of major repair. Q = quintile.

\* Cell sizes suppressed due to n < 5.

\*\* Ranges provided to ensure suppressed cells cannot be re-calculated, in accordance with ICES reporting guidelines.

**Table 2. Comparing visit characteristics for youth who had one or more physician mental health visits after age 18**

| Characteristics   | Community CYMH +<br>physician-based mental<br>health<br>(n= 2,088) | Community CYMH only<br>(n= 734) | Physician-based mental<br>health only<br>(n= 2,895) | No mental health<br>(n= 5,571) |
|---|--|---------------------------------|---|--------------------------------|
| At least one physician-based mental health visit after age 18 (% of total individuals in sub-group) | n = 1197 (57.3%)   | n = 239 (32.6%)                 | n = 1323 (45.7%)                                    | n = 1226 (22.0%)               |
| Median survival time (when 50% experienced outcome) after age 18                                    | 29 months  | 84 months                       | 49 months   | †                              |
| Type of provider first physician-based mental health visit after age 18                             |  |                                 |   |                                |
| Family physician  | 76.70%   | 91.60%                          | 82.80%  | 94.70%                         |
| Psychiatrist  | 8.80%  | 6.3-7.9%**                      | 13.10%  | 4.9-5.2%**                     |
| Pediatrician  | 4.70%  | *                               | 3.70%   | *                              |
| Diagnostic code at first physician-based mental health visit after age 18 a                         |  |                                 |   |                                |
| Anxiety disorders   | 52.50%   | 64.80%                          | 55.30%  | 64.60%                         |
| Depression  | 11.70%   | 8.80%                           | 12.10%  | 9.30%                          |
| Hyperkinetic syndrome of childhood (commonly ADHD)  | 7.00%  | *                               | 6.20%   | 1.80%                          |
| Behavior disorders  | 5.40%  | *                               | 4.70%   | *                              |
| Drug dependence   | 3.60%  | 5.00%                           | 2.40%   | *                              |
| Other childhood mental health disorders (e.g., habit spasms, tics)                                  | 3.10%  | 7.50%                           | 4.70%   | 6.50%                          |

Note. CYMH = Child and Youth Mental Health. ADHD = Attention Deficit-Hyperactivity Disorder. Physician-based mental health visit based on Ontario Health Insurance Plan physician claims data.

† Survival is greater than 50% at median survival time.

<sup>a</sup> Not all diagnostic codes provided; thus percentages do not equate to 100%.

\* Cell sizes suppressed due to n < 5.

\*\* Ranges provided to ensure suppressed cells cannot be re-calculated, in accordance with ICES reporting guidelines.

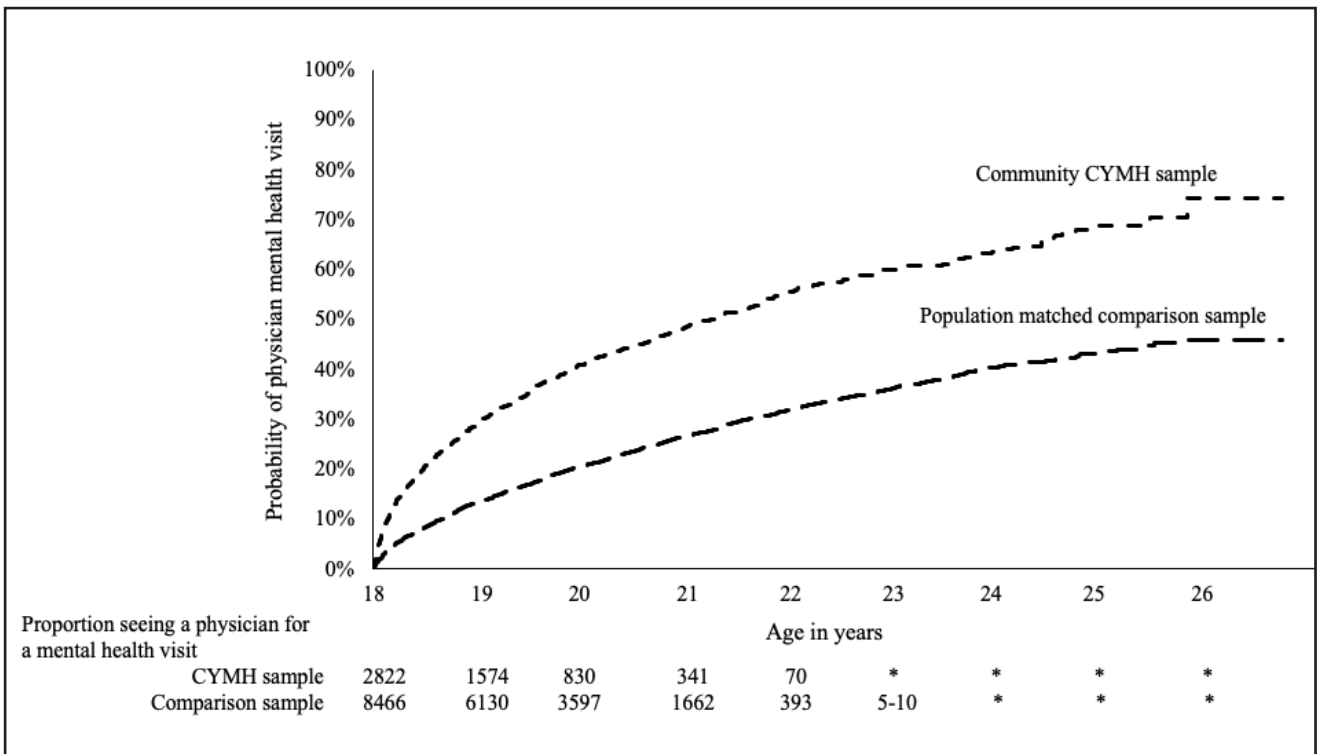
physician-based mental health services between start of agency involvement and before age 18). Finally, a stratified Cox model visually described the effect of the covariate on the outcome over time, between cases and comparisons. Descriptive statistics for four groups, from this stratification, are provided. Because the stratified model assumes no interaction between the grouping variable and covariate, an interaction model was tested. An alpha level of  $p < .05$  was used to test for statistical significance.

## Results

### Descriptive Findings

The CYMH sample consisted of 2,822 youth and a matched non-CYMH comparison sample consisted of 8,466 youth. The majority (60%) of the CYMH sample were male and on average 11.2 years old at their first CYMH visit (SD= 1.70; Range= 7-14 years). Most youth (84%) resided in urban communities and lived in neighborhoods that were evenly distributed across deprivation quintiles. The average length

**Figure 2.** The Kaplan-Meier curves show the probability of having an physician-based mental health visit (i.e., mental health visit by a family physician, pediatrician or psychiatrist) as a function of time since a youth’s 18th birthday (presented as age in years) for CYMH cohort vs. comparisons. The number of youth followed up for each time interval (number at risk) is shown underneath the x-axis. CYMH refers to Child and Youth Mental Health Services. \*Cell sizes suppressed due to n < 5.



of follow-up, from age 18, was 3.9 years; with a maximum of up to 8 years (or age 26). From the CYMH sample, 70% (n = 2,088) had prior physician involvement, defined as at least one physician-based mental health visit between the start of their CYMH agency involvement to <18 years old (55%, 17%, 27% visited a family physician, pediatrician, or psychiatrist, respectively); thus, 30% did not. In the comparison sample, 34% (n = 2,895) had at least one physician-based mental health visit (70%, 17%, 14% visited a family physician, pediatrician, or psychiatrist, respectively). Table 1 summarizes descriptive characteristics for the four groups that resulted from our stratified Cox model, as described in the methods. Notably, in the CYMH sample, youth who also visited a physician for mental health care before age 18 had a higher total number of CYMH visits (Median = 8) compared to those without physician involvement (Median = 4).

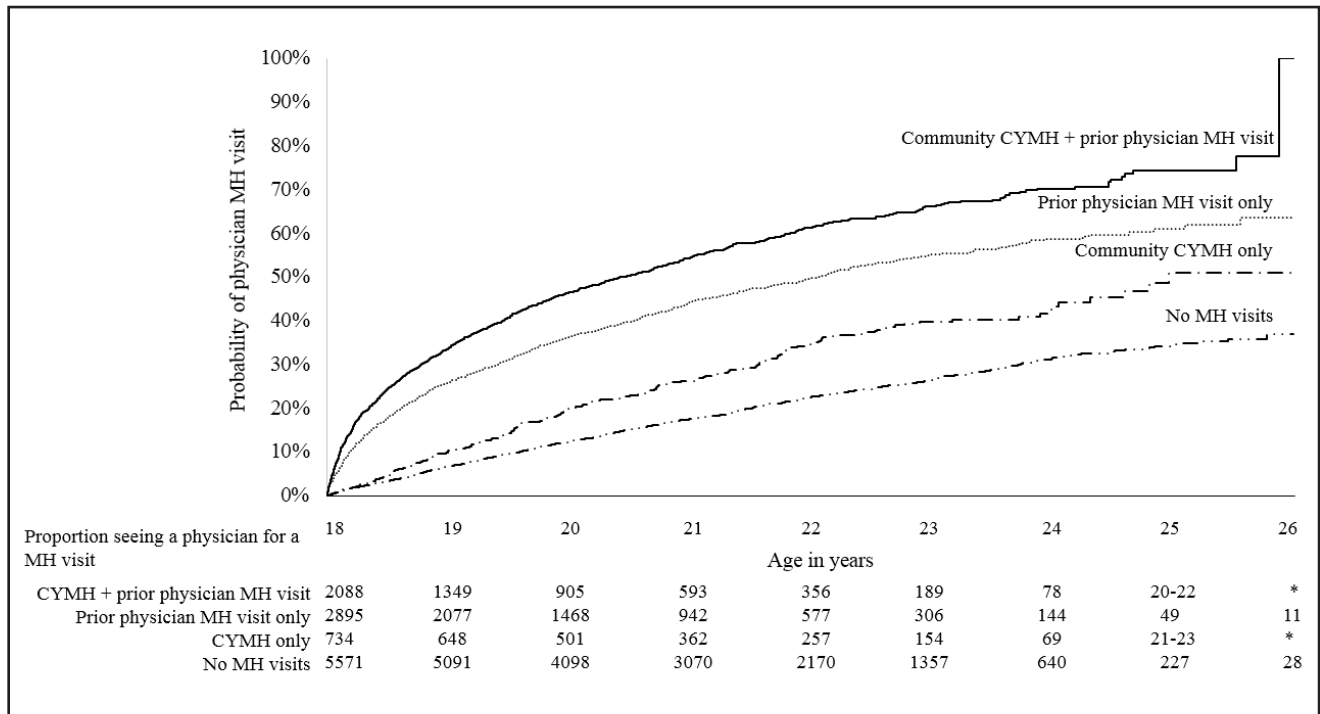
**Time to Outcome (First Physician-based Mental Health Visit After Age 18)**

As depicted in Figure 2, Kaplan-Meier survival curves show the probability of having a physician-based mental health visit after age 18 for the CYMH and comparison samples. The crude Cox model revealed the CYMH sample was twice as likely as comparisons to have a physician-based mental health visit (HR= 2.09; 95% CI= 1.95-2.22; p <.0001). Based on life-table analyses, 25% of the CYMH sample had a physician-based mental health visit within 10 months after their 18<sup>th</sup> birthdate, and 50% did so by 40.5 months.

A stratified Cox model (presented in Figure 3) showed the effect of community-based CYMH services stratified by youth’s prior physician involvement (i.e., between start of CYMH agency involvement and <18 years old). The effect of group (i.e., community-based CYMH services as a youth, or not) remained significant after adjusting for also having physician-based mental health visit before age 18,



**Figure 3.** The Kaplan-Meier curves show the probability of having an physician-based mental health visit (i.e., mental health visit by a family physician, pediatrician or psychiatrist) as a function of time since a youth's 18th birthday (presented as age in years) for the four groups from the stratified Cox model. The number of youth followed up for each time interval (number at risk) is shown underneath the x-axis. CYMH refers to Child and Youth Mental Health Services. \*Cell sizes suppressed due to  $n < 5$ .



but the adjusted HR was lower than in the crude model ( $HR_{\text{adjusted}} = 1.43$ ; 95% CI= 1.34-1.54;  $p < .0001$ ). In the adjusted model, after accounting for group, the probability of having a physician-based mental health visit after age 18 was 2.77 times higher among youth with prior physician involvement than those without ( $HR_{\text{adjusted}} = 2.77$ , 95% CI=2.58-2.97;  $p < .0001$ ). The effect of prior physician involvement was the same for cases and comparisons (i.e., no interaction), indicated by the similar distance between survival curves. In other words, prior physician involvement made it more likely to have a physician-based mental health visit after age 18 for both groups. Figure 3 shows that youth who received community-based CYMH services *and* prior physician involvement were most likely to have a physician-based mental health visit as adults. Comparisons (non-CYMH youth) without prior physician involvement were least likely to have a physician-based mental health visit as adults.

Table 2 summarizes descriptive information related to the *first* physician-based mental health visit in young adulthood.

Of those with a visit ( $n = 3,985$ ; total youth across all four groups), 85% were seen by a family physician; the rest were seen by a psychiatrist (11.8%) or pediatrician (2.8%). Across groups, youth were most likely to be seen by a family physician; youth with prior physician-based mental health services were more likely to be seen by a psychiatrist after age 18 than those who had not. The most common diagnostic code across all physician visits was anxiety (>50% across groups).

## Discussion

This study compared the probability of receiving physician-based mental health services in young adulthood between an Ontario-based sample of youth involved with CYMH community agencies, and a demographically matched population-based sample. Youth involved with community-based CYMH agencies were mostly male (60%), which likely reflects an over-representation of boys with externalizing disorders in treatment (Reid et al., 2019). CYMH youth were twice as likely as comparisons to receive

physician-based mental health services as young adults (ages 18-26). Our findings also revealed the majority of CYMH youth (70%) received some mental health care by physicians *before* young adulthood, most commonly by family physicians. These youth had a higher total number of CYMH visits and longer duration of involvement at CYMH agencies than youth who had CYMH involvement but had not visited a physician for mental health care prior to age 18. In the comparison sample, 34% received physician-based mental health services before age 18, comparable to other population-based studies in Ontario (MHASEF Research Team, 2015). Interestingly, in both samples, receiving physician-based mental health services before age 18 was significantly associated with the outcome re-accessing mental health services in young adulthood. Youth involved with CYMH agencies alone, without physician involvement, were less likely to re-access mental health services in young adulthood than those with both physician and community CYMH agency involvement.

These findings are important for two key reasons. First, they provide evidence that childhood-onset mental health problems can be long-lasting, *even* with “early” intervention (i.e., during childhood or adolescence). We found that receiving care in a CYMH agency, or by a physician, was strongly related to receiving mental health care in young adulthood. Previous treatment follow-up studies, which follow youth 1-5 years post-treatment, have reported high rates of recurrence and persistence for children’s mental health problems [e.g., depression, anxiety, ADHD, etc. (Curry et al., 2011; Greene et al., 1997; Manassis et al., 2004; Nevo & Manassis, 2009; Sim et al., 2004; Vitiello et al., 2011)]. A major strength of our study was our long follow-up period - 6.5 to 12 years post-CYMH services - spanning adolescence and young adulthood. The possibility of needing ongoing care into adulthood is recognized by many youth and families who receive CYMH care (Schraeder et al., 2018), but typically not recognized by the systems that care for them. We therefore must pay closer attention to post-treatment periods, particularly as youth approach the arbitrary “age of transfer” (i.e., 18 years old), since many may require ongoing care beyond the children’s mental health system.

Second, our study provides further evidence of fragmentation within Canada’s mental health “system” (McGihon et al., 2018; Stewart & Hirdes, 2015; Yung, 2016). By linking community CYMH agency data and health record data (i.e., physician claims), we found that 26% (n= 734) of the CYMH sample were *only* seen within a CYMH agency, and never by a physician for mental health problems, before reaching adulthood. This group was significantly less likely to receive physician-based mental health care as adults

(33% of this group received this care) compared to youth who received physician-based mental health care before age 18 (57% of this group received physician care). Some CYMH youth may not have needed, or declined, mental health services offered to them in adulthood; this cannot be determined from our data. Receiving mental health care by a CYMH agency *and* a physician (most likely a family physician) likely provides an opportunity for treated youth to also become connected to the healthcare system, in case problems recur during young adulthood. There are recent initiatives in Canada (ACCESS-Open Minds), similar to Australia’s headspace programs (Rickwood et al., 2014) that aim to help communities enhance the systems that care for older children, youth, and young adults with mental health problems, including co-location of family physicians and specialized mental health clinicians (Abba-Aji et al., 2019; Malla et al., 2019). Further research is needed to understand whether these models can be effectively scaled up to address all youth who may require ongoing care into adulthood, given that the population prevalence of mental health contact with CYMH agencies is 5.9% (Reid et al., manuscript under review).

### ***The Role of Family Physicians for Youth “Transitioning” to Adult Care***

Family physicians are the first professional that most parents turn to with concerns related to their child’s mental health (Brugman et al., 2001; Rushton et al., 2002; Sayal, 2006) and many refer youth and families to community services for help. However, the role of family physicians post-treatment, or after families have engaged with community-based mental health services, is poorly understood (Bhawra et al., 2016; Schraeder et al., 2017). This was first noted by the authors of the “TRACK” study in the United Kingdom (Singh et al., 2010) which followed a youth cohort (N=154) treated by publicly-funded mental health services in childhood and adolescence. In this cohort, 85% of youth were considered to need ongoing mental health care in adulthood by their youth mental health provider; yet, only 49% “transferred” to adult mental health services [e.g., to inpatient psychiatric services, adult psychiatrists, etc. (Paul et al., 2013; Singh et al., 2010)]. A secondary analysis of these data revealed 53% of those who failed to transfer (e.g., not eligible) were discharged to their family physician as young adults (Islam et al., 2016). Similarly, in our study, most young adults were first seen first by a family physician (mainly for issues related to anxiety or depression); a very small percentage were first seen by a psychiatrist after the age of transfer. If family physicians will become responsible for caring for most CYMH treated youth in adulthood, then we must carefully consider and support the role they

will take on in managing transitions and mental health care over the lifespan, including during and after CYMH treatment (McGorry, 2007; Patel et al., 2007; Schraeder et al., 2020).

### **Considerations for Future Research**

This study is the first longitudinal matched cohort study to examine mental health service utilization across community CYMH agencies and Canada's healthcare system. Our cross-sectoral approach to understanding mental health service utilization was a major strength of this study. Our methods, and findings, highlight a need for better system integration across community and healthcare sectors which provide youth mental health services (Boyle et al., 2019).

This study is not without limitations. First, we were not able to compare our cohort to those who were excluded ( $n = 961$ ; invalid health identifier) on any health-related variables as these youth could not be linked to health records. Secondly, of the 49% ( $n = 5,571$ ) of youth in our cohort who did not receive mental health care by a physician or community agency (before age 18), it is possible they may have accessed mental health services from other sectors (e.g., school, urgent care clinics). Youth could have accessed mental health services privately (e.g., private psychologist); however, a small percentage of the population with mental health problems access care privately (Duncan et al., 2019). Some youth might also have received care from another healthcare provider (e.g., social worker, nurse); in Canada, services provided by non-physician healthcare professionals are not available in population health datasets. Billed mental health services in Ontario, delivered by physicians, is therefore an underestimate of all mental health services available to the population. Further, with respect to physician billing, we noted a low incidence of behavior disorder diagnoses in adulthood, which may be an artifact of a lack of codes to capture these problems (e.g., no codes exist for adult ADHD). Only about 17% of our cohort were old enough to have follow-up data beyond age 24, which may have limited our ability to accurately capture service utilization during this period.

The proportion of youth *in need of* adult mental health care could not be determined in our study. It was not possible with our data to know if *not* having a mental health visit reflected poor access to adult care (e.g., youth not able to access their family physician), symptom improvement, or remission. Similarly, for youth in our cohort who received physician-based mental health services in young adulthood, it was not possible to know if this care was appropriate and/or matched their level of need. After age 18, rates of successful "transition" could therefore not be reported as there

was not a clear denominator of who required adult mental health care. Criteria to identify individuals with long-term mental health needs is in its infancy (Purcell et al., 2015; Schraeder & Reid, 2017). As recommended by others (Barwick et al., 2004; Boyle et al., 2019), implementation of standardized measures to routinely collect outcome data at CYMH agencies, which could be linked to population-level healthcare records, would be a worthwhile investment in order to understand whether youths' involvement with other healthcare services (e.g., by physicians) is needed based on their measured need for mental health care post-treatment.

Finally, our survival analyses focused on prior mental health involvement during childhood and adolescence as the only predictor of future service utilization in young adulthood. Examining additional predictors (e.g., geographical accessibility to primary care or other mental health services; socio-economic characteristics of young adults) is a goal of our future work and needed to inform practice and policy recommendations. For example, identifying factors associated with increased use of mental health care by young adults could inform the development of preferred and effective transition services.

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## Conflicts of Interest

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## Presentation information

K. Schraeder completed this study as part of her doctoral dissertation (Clinical Psychology) at Western University in London, Ontario, Canada. Her dissertation has been published in the university’s electronic thesis repository. This study was presented as a poster at the International Population Data Linkage Network Conference, Banff, Alberta, Canada: September 12-14, 2018.

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