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Identifying Service Utilization Patterns in Primary Care by Young People with First-Episode Psychosis

Nicole Schoer
The University of Western Ontario

Supervisor
Anderson, Kelly K.
The University of Western Ontario

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Abstract

Minimizing the duration of untreated psychosis in the first few years after illness onset is essential for improving prognosis for people with psychotic disorders. Leading up to the first onset of psychosis, many people experience early signs and symptoms, suggesting that there may be help-seeking or service utilization prior to first diagnosis. The family physician has been found to play a pivotal role in the pathways to care for people with first-episode psychosis. In this study, we used health administrative data from Ontario to construct a population-based retrospective cohort. These data were used to explore whether people with psychotic disorders had distinctive patterns of primary care service utilization in the six years preceding the first diagnosis of psychosis, relative to the general population comparison group matched on age, sex, and postal code. Our findings suggest that people with psychosis contact primary care over twice as frequently during the six years leading up to first diagnosis, relative to the general population. They have higher contact frequency across nearly all conditions, including mental health, physical conditions, and preventative health-related contacts. We also used Latent Class Growth Modelling to identify three distinct service utilization profiles: low, medium, and high-increasing usage, and we used negative binomial models to identify characteristics associated with each trajectory. Findings from this study can help inform initiatives to support Canadian family physicians and improve detection of early psychosis in primary care, which has implications for improved social, educational, and professional development in young people with first-episode psychosis.

Keywords

First-episode psychosis, service utilization, help-seeking, primary care, health administrative data

Summary for Lay Audience

It is important for people who are experiencing psychosis to receive appropriate treatment as soon as possible. Before the start of psychosis, people may experience changes in their normal behaviour that may lead to a visit with a family physician. The family physician will record the patient's symptoms for each visit, which may contribute to a final diagnosis later. If a family physician can recognize specific symptoms and diagnose a patient with psychosis sooner, that patient will receive appropriate treatment faster. However, not much is currently known about how people with psychosis seek help from family physicians. We will use Ontario Health Insurance Plan (OHIP) data to look at how family physician use differs between people who are diagnosed with psychosis and the general population during the time before the start of psychosis. We found that people with psychosis visit a family physician over twice as much as the general population before the start of psychosis. We also found that they visit family physicians for all health conditions, including mental health, physical health and preventative health visits. We also used a statistical technique that identifies distinct subgroups of people with psychosis following a similar pattern in the number of visits to a family physician over time. We found three subgroups: low, medium, and high-increasing number of visits to a family physician. It is important to study these patterns of family physician use in order to improve family physicians' recognition and diagnosis of psychosis so that people with psychosis can get appropriate treatment sooner. Receiving appropriate treatment sooner is important for reducing the burden on people with psychosis. The start of psychosis usually happens during adolescence and young adulthood, which overlaps with major life and developmental changes. Receiving appropriate treatment sooner means that people with psychosis will have improved social, educational, and professional development.

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Abbreviations

ADG	Aggregated Diagnosis Groups
BIC	Bayesian Information Criterion
CAPE	Client Agency Program Enrolment
CI	Confidence Interval
CME	Continuing Medical Education
COPD	Chronic Obstructive Pulmonary Disease
DAD	Discharge Abstract Database
DUP	Duration of Untreated Psychosis
ED	Emergency Department
EDC	Expanded Diagnosis Clusters
EPI	Early Psychosis Intervention
FEP	First-Episode Psychosis
FP	Family Physician
HIV	Human Immunodeficiency Viruses
ICD	International Classification of Disease
IQR	Interquartile Range
LCGM	Latent Class Growth Modelling
MHA	Mental Health & Addictions
NACRS	National Ambulatory Care
NOS	Not Otherwise Specified
OCC	Odds of Correct Classification
OHIP	Ontario Health Insurance Plan
OMHRS	Ontario Mental Health Reporting System
ONMARG	Ontario Marginalization Index
OR	Odds Ratio
PCPOP	Primary Care Population
PHIPA	Personal Health Information Protection Act
RPDB	Registered Persons Database
RR	Risk Ratio
RUB	Resource Utilization Band

Chapter 1

1 Introduction

An episode of psychosis is characterized by the presence of delusions, hallucinations without insight, disorganized thought and behaviour patterns, and negative symptoms.[1] Delusions are fixed false beliefs that are maintained even when evidence is presented that contradicts them. Hallucinations without insight are perceptions occurring in the absence of corresponding stimuli where the person is unable to recognize them as hallucinatory.[2] Delusions and hallucinations are known as *positive* psychotic symptoms.[3] Positive symptoms are often accompanied by *negative* symptoms which can include social withdrawal, decline in functioning, depression and anxiety problems, sleeping problems, diminished emotional expression, and avolition.[1,4–7] Although these are typical symptoms, a first onset of psychosis may have a more heterogeneous presentation, and people may also present with mood syndromes, personality disorders, substance use disorders, and post-traumatic stress disorder.[3]

Psychosis is the defining feature of non-affective psychotic disorders (i.e., schizophrenia, schizoaffective disorder, delusional disorder, schizophreniform disorder, and brief psychotic disorder), which affects 1-2% of the population worldwide, but it can also occur in bipolar disorder and major depressive disorder (known as affective psychoses).[2,8] Overall, there is an approximate 3% lifetime prevalence of psychotic disorders.[9] It was estimated that in 2012, there were approximately 143,000 patients with chronic non-affective psychotic disorder in Ontario, costing the Ministry of Health and Long-Term Care approximately 2 billion CAD, mainly due to costs related to psychiatric hospitalizations and long-term care.[10,11]

The onset of psychosis usually occurs during adolescence and young adulthood, which coincides with major life and developmental changes such as forming a stable identity and peer network, vocational training, and intimate relationships.[3] For example, participants who developed psychosis reported difficulty or uncertainty in making contact with others and social withdrawal during adolescence.[12] Further, patients with schizophrenia have an increase of other chronic diseases, and two to three times the mortality rates of those in the general population, possibly

related to lifestyle factors (i.e., unhealthy diets, excessive smoking and alcohol use, lack of exercise), adverse effects of anti-psychotic drugs, delayed diagnosis of physical illness and insufficient treatment, and a heightened risk of suicide and accidents.[13–19] People with schizophrenia are among the most disadvantaged in the healthcare system, leading to premature death of these patients by up to 20 years.[15] One study found that this excess mortality due to schizophrenia could be lessened by reducing patients' smoking and improving the management of medical disease and mood disturbances.[20] Self-harm is also common during the pre-treatment phase of first-episode psychosis (FEP),[21] and a subset of people experiencing FEP may commit an act of violence before they present for treatment.[22] Psychosis not only has a large impact on the sufferer, but also their family and caregivers. Family members often experience distress and difficulties, especially if the sufferer is young or is having ongoing functional impairment.[23] Identifying people at high risk for developing psychosis before or soon after they experience full-blown psychotic symptoms is crucial for reducing the burden on these young people and their families.[24–26]

A pre-psychotic stage, also known as the prodrome or clinical high risk stage, is the period that begins with pre-psychotic disturbance representing a deviation from a person's previous behaviour, and extends to the onset of psychosis.[25,27–29] One study found that people with schizophrenia may experience a prodromal phase of up to five years in length, characterized by depressive, negative, and cognitive symptoms accompanied by a decline in functioning, followed by a year with increasing psychotic symptoms before a first diagnosis is made.[30] This suggests that there may be help seeking for mental health problems up to 6 years prior to first diagnosis. It has been found that patients who develop psychosis after being engaged with mental health care services in the prodromal phase have better short-term clinical outcomes and are less likely to require psychiatric hospital admission than patients who do not present until the first-episode,[31] although this may be a result of confounding by factors that influence overall prognosis, such as socioeconomic status.[32] This prodromal period is important for early diagnosis and management of symptoms and long-term prognosis and outcomes.[25,33–35]

Following the onset of psychosis, efforts to diagnose and minimize the duration of untreated psychosis (DUP) within the first two years are essential for improving long-term outcomes,

which include reductions in positive and negative symptoms, increased likelihood of remission, and improvements in social functioning.[26,33–36] It is well established that an extended DUP is associated with poorer outcomes, and research also suggest that gains from reducing DUP are likely to be greater if the reduction in DUP occurs early in the course of illness.[33] Further, patients with a delay of one or more years between the onset of symptoms and initiation of treatment demonstrated poorer negative and positive symptomology upon admission to hospital, and longer DUP was associated with greater functional impairment and more severe psychopathology at presentation to treatment, although these findings do not account for potential confounders such as socioeconomic status.[37] Early psychosis intervention (EPI) services were designed to minimize this interval between onset of symptoms and initiation of treatment.[26,31,38]

EPI services focus on symptom detection and comprehensive care, which includes ameliorating presenting psychological, social or physical symptoms, as well as vocational dysfunction, early in the course of illness.[3,26,31,36,39] EPI services have been shown to be effective and cost-effective in improving outcomes in FEP. For example, those who used EPI programs had lower rates of all-cause mortality, emergency department (ED) presentation, and suicide.[40,41] One systematic review found that early intervention services including family intervention have clinically important benefits over standard care, including reductions in the risk of relapse and hospital admission.[42] Another study found that eight years after initial treatment, early intervention patients had lower levels of positive psychotic symptoms, were more likely to be in remission, and had a more favourable course of illness than the controls.[43] Early psychosis programs can treat at one-third the cost of standard public mental health services and there is support for cost effectiveness.[15,43,44]

One method of entry to EPI services is a referral from a family physician (FP), however, there are other pathways to care. Pathways to care describe the modes by which patients with mental health problems access help, which includes the help-seeking behaviour of the patient and family, the accessibility of mental health services, and the identification of and response to symptoms by each contact on the pathway to care.[45] Contacts on the pathways to care can include formal or professional contacts such as FPs, EDs, outpatient mental health providers,

mental health inpatient care, and police, as well as informal contacts such as friends or family. However, the FP has been found to play a pivotal role in the pathways to care for people with FEP.[46] Involvement of a FP on the pathways to care reduces the likelihood of negative and aversive pathways to care (i.e., police, ambulance or ED) and reduces the likelihood of subsequent in-patient admission.[46–48] Increasing FP involvement in the pathways to care of young people with early psychosis is beneficial for improving service-related outcomes.[49] Thus, the current study aims to investigate help-seeking patterns in primary care by young people with FEP in the six years leading up to diagnosis and compare them to the general population in order to improve detection, referral, and treatment of early psychosis.

1.1 Structure of the Thesis and Role of the Student

This thesis follows The University of Western Ontario's School of Graduate and Postdoctoral Studies monograph format. Chapter two provides a review of the literature and chapter three details the methodological aspects of this thesis. Chapter four presents the study's findings and chapter five discusses the findings in the context of existing literature and outlines the strengths and limitations of this study.

The candidate was responsible for submitting a dataset creation plan to ICES that selected all variables of interest for this thesis. The candidate was then provided the dataset, created by an ICES Analyst, and all analyses were conducted by the candidate through a secure online portal.

Chapter 2

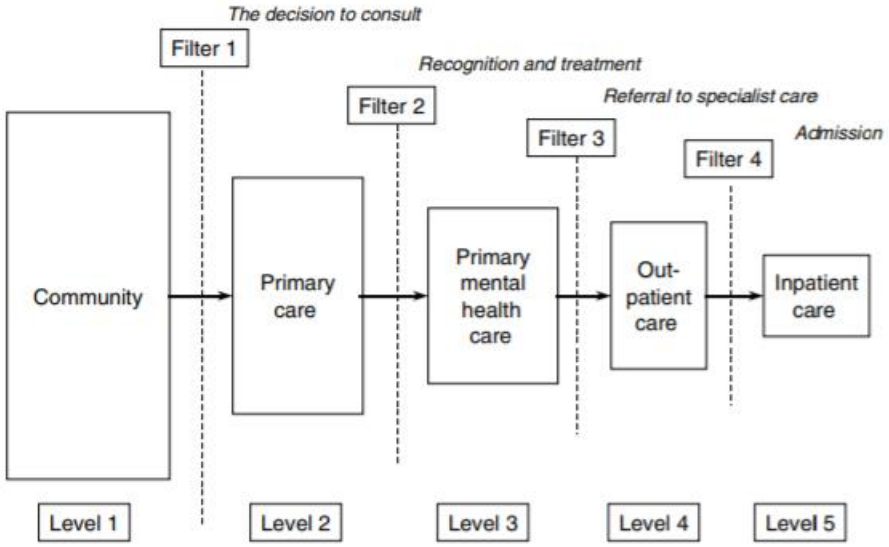
2 Literature Review

This chapter provides an overview of pathways to care for people with FEP, particularly highlighting the role of the FP.

2.1 Pathways to Care

Pathways to care, or the modes by which patients with mental health problems access help,[45] are highly dependent on the social, cultural, and health service context.[50] These aspects influence the help-seeking or service utilization behaviour of both the patient and their family, the accessibility of mental health services, and how each service provider on the pathway identifies and responds to symptoms.[45] The Goldberg & Huxley model of pathways to mental health care[51] provides a framework for understanding how people move into and through the health-care system, specifically with four filters between five levels of care (Figure 2.1). The model identifies five sectors of care: community, primary care, primary care for mental health problems, outpatient mental health care, and inpatient care. The first level is the community, which includes some psychiatrically symptomatic or distressed people, and the second level is the subset of symptomatic people who seek help from a FP. The FP may only identify psychiatric illness in a subset of those who sought help, comprising the third level. The fourth level includes people who were then referred to outpatient mental health specialist services and present to these services to receive care. The fifth level includes people who are admitted to inpatient care. Each sector is a more specialized level of care within the health-care system. People may pass through each of the four filters depending on consultation, diagnostic, referral, and admission decisions.[51]

Figure 2.1 The Goldberg & Huxley model of pathways to mental health care[51,52]



As such, it has been found that the pathways to care for young people in the early stages of psychotic illness are complex, with multiple diverse contacts and associated treatment delays.[45,53] For example, a study by Flora et al mapped the complex pathways to care for people with FEP in an EPI program in Toronto, Canada.[54] This study reports that the total number of contacts on the pathways to care ranged from one to 28, and that people have repeated contacts back and forth between different services, as well as repeated contacts within the same service.[54] Other studies also report that young people with early psychosis often make multiple help-seeking attempts across different health services, and may experience negative and aversive pathways to care.[47,55,56] Negative pathways to care may involve the police, ED, or inpatient unit, and are associated with poor patient experience, disengagement from services, and high costs.[47] People with psychotic disorders report more difficulty in accessing care and greater barriers to care than the general population,[57] demonstrating the importance of in-depth investigation in this topic in order to improve the help-seeking or service utilization process for this population.

2.1.1 Types of Contacts

People with early psychosis or FEP have diverse contacts with health care services on their pathways to care. Primary care providers are the most widely consulted service for general mental health reasons in Canada.[58] Studies of the pathways to care of people with FEP have identified schools, EDs, outpatient mental health providers, mental health inpatient care, social workers, family members or relatives, close friends, and police as potential contacts on the pathway.[59–62] The role of adults in the lives of young people with FEP is very important. Family members were seen as a crucial support[63,64] and having a family member involved in help-seeking[53] was found to shorten the delay in seeking help, perhaps because they assist in initiating the help-seeking process.[55,65] Lack of family involvement on the pathway to care increased the likelihood of a negative care pathway.[66] People experiencing full symptoms of psychosis were more likely to contact mental health professionals or inpatient services, whereas in the prodrome or early phases of illness were more likely to contact FPs and other professionals.[67] A different study reports that psychologists, social workers and counsellors were more likely to be contacted by those who initiate help seeking before the onset of FEP.[7] Among all people with FEP, the most common types of service contacts at some point in the pathway to care were EDs, FPs, and psychiatrists.[7] One study reported that half of people with FEP had contacted a FP at some point during their pathways to care.[61] Additionally, prior evidence suggests that people with FEP saw between four and six different health care providers or services before receiving appropriate care,[68] with a tendency for more general help-seeking contacts early on the pathways to care and more specialized services later on,[61,62] which supports the notion that FPs can play a pivotal role on the pathways to care.

2.1.1.1 First Contact

The first contact on the pathways to care influences a person's subsequent contacts. A systematic review reported that, in order of frequency, people with FEP's first contacts were FPs, psychiatrists or specialized services, faith or traditional healers, EDs or inpatient units, family or friends, and social workers.[53] FPs were in the top three most frequent first contacts in 24 out of the 29 studies (83%) in this same review.[53] Other evidence suggests that the most frequent first contact was a mental health professional for people experiencing full psychosis, but FPs were

more likely to be the first contact among people in the prodrome or early stages of illness, or when patients sought help on their own account.[67] As such, FPs are frequently the first contact on the pathways to care, which enables them to greatly influence subsequent contacts on the pathways to care.

2.1.1.2 Referral Source

The referral source refers to the contact on the pathways to care that resulted in a person with FEP receiving appropriate treatment, usually defined as EPI or other specialized psychiatric services. A systematic review reported that the most frequent referral sources that result in an individual obtaining the necessary service were ED or inpatient units, self-referrals, FPs, hospitals, helplines, and outpatient units.[53] Another systematic review reported that the referral source for the largest proportion of patients was emergency services in 9 of 22 studies (41%) and a FP in 8 studies (36%).[69] Further, two studies found that the majority of FEP patients were referred to mental health services by a FP.[70,71] Other studies note that psychiatrists in private practice,[7] family, and friends[62] also provide referrals to appropriate treatment programs. A Canadian study found that FPs frequently assisted in referral to EPI programs.[37] Thus, FPs can play a significant role in referring people with FEP to appropriate treatment on their pathways to care.

2.1.1.3 Diagnosis Source

The diagnosis source refers to the contact on the pathways to care that assigns the first or index diagnosis of psychosis. One study found that half of cases received their index diagnosis of psychosis in the ED[46] and another study reported that approximately 30% of youth with FEP receive their first diagnosis from a FP.[72] FPs can therefore influence pathways to care and timely access to appropriate treatment through symptom detection and diagnosis.

2.1.2 Reason for Contact

Those who seek help on their pathways to care may do so for psychiatric symptoms as well as somatic complaints. Previous research suggests that the majority of people diagnosed with

psychotic disorders had been help-seeking for other mental disorders prior to the onset of psychosis[4] and had some indication of mental health care need or at least one mental health diagnosis during the previous year before first psychotic disorder diagnosis.[60] To illustrate further, one study reports that 29% of patients were found to have made a FP visit for a mental health concern during the year before a first psychotic disorder diagnosis,[60] and another study found that in the four years preceding the index diagnosis of psychosis, 60% of people were in contact with their FP for a mental health concern.[46]

More specifically, in patients who sought professional help before the onset of psychosis, the most common reasons for seeking help were for feelings of sadness or depression, anxiety or stress, and cognitive disruptions such as memory or concentration problems, feelings of confusion or "weird" or distracting thoughts,[7] as well as anxiety and mood disorders, substance use disorders and adjustment disorders.[4] More women sought help for anxiety, mood, and adjustment disorders and more men sought help for substance use and personality disorders.[4] Similarly, another study found that twelve symptoms were associated with a subsequent psychotic diagnosis: attention-deficit or hyperactivity disorder–like symptoms, bizarre behaviour, blunted affect, problems associated with cannabis, depressive symptoms, role functioning problems, social isolation, symptoms of mania, obsessive-compulsive disorder–like symptoms, sleep disturbance, problems associated with cigarette smoking, and suicidal behaviour (including self-harm).[73] In contrast to help seeking before the onset of psychosis, explicit mention of hallucinations or delusional thinking were the most common reason for seeking help after the onset of psychosis.[7] In regard to somatic complaints, one study investigated visits to a hospital (inpatient and ED) for somatic diseases before the first diagnosis of schizophrenia. Moderate associations between a varied range of physical diseases and conditions and risk of subsequent schizophrenia diagnosis were found and included circulatory system diseases, digestive system diseases, genitourinary system diseases, respiratory system diseases, skin diseases and nutritional or metabolic disorders.[74] Accordingly, the symptoms people with early psychosis or FEP seek help for on their pathways to care are heterogenous, and require further in-depth research to better inform FP recognition and detection.

2.1.3 Number of Contacts

The number of contacts on the pathway to care may give an indication of the complexity of help-seeking and service utilization. In one study it was reported that one third of patients had four or more contacts in their pathways to care before receiving antipsychotic medication or entering an EPI program.[37] One study found the median number of contacts before entry into an EPI program was five,[59] while two other studies reported three,[46,61] and one study reported one.[62] A systematic review reported that in twenty-eight studies, the number of contacts before receiving specific services had a mean of 2.9 and ranged from 0 to 15.[53] The variability in number of visits before receiving appropriate treatment may reflect the challenge in early detection of psychosis symptoms in the prodromal period by different healthcare services and the uncertainty on how to proceed, refer, or confirm diagnosis after symptoms are recognized,[75,76] as well as differences across health systems in regard to referrals for specialized care. This suggests additional research may be needed to target future interventions to improve detection and diagnosis of FEP and expedite referral pathways.

2.1.4 Socio-demographic Factors

Socio-demographic factors including race or ethnicity, immigration status, age, sex and location of residence influence help-seeking, service utilization, and the pathways to care for people with FEP in many ways.

Race or ethnicity has consistently been shown to influence treatment delay and service use outcomes. Stigma may operate differently in European-origin, African-origin and Caribbean-origin groups, affecting help-seeking.[68] For example, Caribbean groups in Canada have been found to have lower odds of having FP involvement on their pathway to care, compared to White groups, which may reflect a delay in contact with services until emergency services are needed.[48] Another study similarly found that Black groups have a decreased likelihood of FP involvement and also an increased likelihood of police involvement, relative to White groups.[50] A study in a systematic review found that a quarter of African-American people in the study had at least one contact with police[77] and in another study, over half of Black participants had police involvement on their pathway to care.[53,78] Black Caribbean groups and Black African groups also experienced

worse service use outcomes than White British groups.[79,80] In Asian groups, EDs were four times more likely to be the first contact along the help-seeking pathway, than for White groups.[81] Asian groups were less likely to have more than two contacts on their pathways to care[47] and also experience fewer involuntary hospitalizations than Black or White groups.[81]

In regard to immigration status, first generation immigrants have been found to have a significantly longer delay in help-seeking.[70] Immigrants have a higher rate of first mental health contact in the ED, and more so for more recent immigrants than longer-term immigrants.[82]

There is also evidence that age influences the pathways to care. One study reported a modest correlation between age and delays in treatment, as it was found that the time from help-seeking contact to adequate antipsychotic treatment was significantly longer for young people, suggesting young people have greater delay in the initiation of treatment.[7] Another study found that increasing age was associated with a longer time to contact with psychiatrist,[46] and people diagnosed with schizophrenia at age 22 years and older had more primary care visits than people diagnosed below age 22.[8]

Sex also has an association with the pathways to care. It has been said that gender stereotypes contribute to pathways to care in different ways for men and women. For example, women reported trying to seek care, but family members and service providers questioned their attempts, whereas men reported having difficulty talking about their symptoms as they did not want to appear weak.[83] It was found that males were almost five times more likely to make first contact with the ED,[81] males were less likely to be admitted by a FP,[66] and males were more likely to be admitted involuntarily.[69,84] Males also have fewer contacts on the pathway to care than females[46,62] and males are less likely to have prior contact with the ED or hospitalizations.[46] Females initiated more help-seeking contacts than men, which suggests they may be more likely to seek help for their symptoms of psychosis.[62]

In regards to location of residence and pathways to care, delay to appropriate services was significantly longer for patients from highly urbanized areas.[70] Thus, socio-demographic factors

including race or ethnicity, immigration status, age, sex, and location of residence need to be considered when investigating pathways to care for people with FEP.

2.1.5 Clinical Factors

There is some evidence that specific diagnostic groups may have different experiences on their pathways to care. For example, it has been found that people with schizophrenia are more likely to experience involuntary admission, compared to those with psychotic mood disorder;[85] in contrast, another study reported that people with bipolar disorder are more likely to experience involuntary admission, and those with depressive psychosis are less likely to experience involuntary admission, compared to people diagnosed with schizophrenia.[66] A recent Canadian study found that 70% of those with affective psychosis and only 26% of those with schizophrenia spectrum disorders were admitted to a hospital on their pathways to care.[37]

Further, severity of illness can impact pathways to care. One study found that case severity was not associated with time to contact with a psychiatrist in the two years after first contact, but in the third year, case severity becomes strongly associated with a shorter time to contact among those who have not yet had contact with a psychiatrist.[46] A recent Canadian study reports that pathways to care involving inpatient admissions are associated with more severe psychopathology and poorer functioning in people with schizophrenia.[37] Thus, clinical factors need to be taken into account when examining the pathways to care for people with FEP.

2.1.6 Barriers to Help-Seeking

Other than sociodemographic and clinical factors, there are other influences on the pathways to care for people with FEP. For example, delay in treatment is often due to sufferers not wanting treatment[86] due to type of symptoms, coping styles, locus of control, and help-seeking behaviour.[45] Stigma is a very common barrier to help-seeking.[55,59,63,87] A meta-analysis found a small- to medium-sized negative median effect size of stigma on help-seeking.[88] A meta-synthesis identified six themes in relation to stigma on pathways to care among the target population: ‘sense of difference’, ‘characterizing difference negatively’, ‘negative reactions

(anticipated and experienced)', 'strategies', 'lack of knowledge and understanding', and 'service-related factors'.[89] Another common barrier to help-seeking is the lack of knowledge regarding the symptoms of psychosis.[55,59,67,87] Other barriers to help-seeking include: availability of services,[55,67] self-reliance,[59] uncertainty,[59] fear of the psychiatric system,[63] difficulty expressing experiences,[87] lack of awareness or understanding on help-seeking behaviour,[87] poor psychosis detection skills among professionals,[87] poor quality of care due to health providers' negative attitudes and behaviour towards mental illness,[68] avoidance,[64] and influence of significant others in their social network.[64] These barriers to help-seeking, in addition to healthcare system, sociodemographic, and clinical factors, influence the pathways to care for people with FEP.

2.2 The Role of the Family Physician

As discussed, the FP plays a prominent role on the pathway to mental health care in people with FEP. Patients with serious mental illness view primary care as the cornerstone of their health care and prefer to consult their own FP rather than be referred to a different FP with specific mental health knowledge.[75] More specifically, for people with FEP, contact with primary care tends to occur early in the help-seeking pathway,[61] and it has been shown that people with schizophrenia have increased visit rates in primary care compared to controls at least six years prior to first diagnosis.[8] People who contacted primary care had a reduced likelihood of contact with the ED and inpatient services,[46] and patients referred by FPs were less likely to be hospitalized or require emergency services.[71] Involvement of a FP on the pathway to care reduces the likelihood of negative and aversive pathways to care, such as police, ambulance and the ED, and reduces the likelihood of inpatient admission.[49] Further, a Canadian study reports that involving inpatient units on the pathway to mental health care were 18.5 times more costly than pathways without,[44] such as pathways involving outpatient care through a FP. Taken together, this evidence suggests that FPs have a positive influence on the pathways to care for people with FEP.

However, there are still areas for improvement. For example, it has been found that those with FEP who are in contact with a FP on their pathways to care had nearly three times more health service contacts before receiving appropriate care than those who had no contact with a FP,[46] and

where there was higher FP involvement, people with FEP saw a greater number of health care services before receiving appropriate care.[54] Further, people with FEP whose first contact is with primary care tend to have longer delays to psychiatric treatment,[46] and those with FEP who were referred to mental health services by a FP had a significantly longer referral delay than patients who were referred by emergency services or other medical professionals.[70] These findings emphasize the pivotal role that primary care plays in pathways to care of people developing or presenting with psychosis symptoms, but also suggest that more in-depth research is necessary to inform strategies to improve pathways to care involving FPs.

2.2.1 Family Physician Knowledge, Attitudes, and Training

Most of the prior research on the role of the FP in pathways to care for people with psychosis have involved surveys. The use of primary care leading up to FEP presents an opportunity for earlier detection and initiation of treatment if primary care physicians are able to recognize the symptoms and respond accordingly.[49] However, one study reports that only half of FPs were able to correctly identify all the signs and symptoms of early psychosis, and only half felt comfortable initiating treatment for psychotic symptoms.[90] Many FPs report lacking confidence in their diagnostic skills for first episode psychosis,[91] and early detection is a diagnostic challenge for FPs when psychosis can take many months to emerge following the prodromal period.[75] Another study reports that FPs under-identify the insidious features of early psychosis,[92] which is further exacerbated by the fact that FPs are most often contacted by people with insidious features, rather than people with positive psychotic symptoms, who are more likely to seek help from a mental health professional.[61] There can be uncertainty on how to proceed when FPs identify signs of early psychosis and some FPs also feel they lack the knowledge to treat these patients[75] thus FPs seldom initiate treatment and prefer to refer to or consult with psychiatric services for diagnosis.[75,76] Stigma, resources, and confidence are cited as impediments to the management of schizophrenia in primary care.[93] These findings suggest that FPs need more support in the role that they play in the pathways to care for people with FEP.

As such, there is some research on implementing education and training programs for FPs in relation to symptom recognition, diagnosis, and referral for FEP. For example, one study found

that there was a significant increase in the number of referrals after FP training, and the referrals were more direct than in the months preceding the training. FPs also had high satisfaction with the training and found it clinically useful.[94] Another study also reports that FPs with training in early detection referred a greater proportion of their FEP cases and less of their patients experienced delays in initial assessment and treatment by the early detection team.[71] However, one study reports that FP training is insufficient to alter referral rates to early-intervention services or reduce the DUP, but found that it does facilitate faster access to new early-intervention services.[95] A systematic review conducted in 2011 stated that FP education campaigns do not by themselves reduce DUP or increase the number of referrals.[96] Thus, it is unclear whether these interventions at the primary care level are effective in improving detection and referral rates.

Additional research has also investigated the relationship between FPs and secondary mental heath care services in order to pinpoint areas for intervention. Overall, most FPs find early intervention services useful.[97] However, studies have found that the relationship between primary care and the mental health team lacked communication.[98] For example, less than one third of FPs had regular contact with a mental health team, and a majority reported that they rarely had information about the diagnoses and treatment of FEP patients referred.[98] Another study reported delay in referral because of inaccessibility of mental health services.[76] Having regular contacts with mental health services had a major impact on FPs reducing delay to psychiatric consultation, and in the level of information received after referral, which suggests that there is benefit in improving this network of services.[98] Another study found that having a liaison between primary and secondary care improved the clinical effectiveness and cost-effectiveness of detection of people with or at high risk of developing a FEP.[99] It has been reported that FPs want more information about identifying early psychosis, a closer liaison with psychiatric services, and a rapid assessment or intervention service,[100] and research is needed to better inform these areas.

2.3 Knowledge Gap

To date, much of the research related to help-seeking and service utilization in FEP has focused on overall pathways to care and general help-seeking behaviours among people with early psychosis or FEP.[45,53,69] There is a lack of literature on patterns of primary care service utilization for people with FEP, and even less for the period prior to first diagnosis for people with early psychosis. Prior research has used surveys of FPs which do not capture cases of FEP who do not engage frequently with FPs. One previous study has used a psychiatric case register[4] and two previous studies have used health administrative data to investigate this topic, but one was conducted in Europe[8] and one was conducted in Montreal, Canada.[46] In order to design and implement initiatives to support Canadian FPs in the role that they play in pathways to care to people with FEP, we need a better understanding of the trends in primary care service utilization by people with FEP in Canada. The objective of this study is to use population-based health administrative data from Ontario to conduct an in-depth investigation of primary care service utilization patterns preceding a first diagnosis of psychotic disorder.

2.4 Summary and Rationale

Exploring primary care service utilization by young people with FEP is extremely valuable for understanding the care provided by FPs and how we can better support FPs in the important role that they play as a key contact for mental health services. In turn, this could help improve detection and treatment efforts for early psychosis in primary care and enable specialty services to better support FPs in this capacity. This will not only benefit patients by providing more timely access to psychiatric care but could reduce the demand on the health care system and its resources by decreasing use of emergency services, for example. Because the onset of FEP typically occurs in young adulthood, early detection and treatment has important implications for improved social, educational, and professional development in young people experiencing FEP and the well-being of their families.[101]

2.5 Objectives

The purpose of this study was to investigate whether people aged 14 to 35 years with FEP between 2005 and 2015 in Ontario have distinctive patterns of primary care service utilization in the six years preceding the first diagnosis of psychosis, relative to a general population comparison group matched on age, sex, and postal code. Specifically, the objectives were to:

1. Describe the frequency of primary care use among people with FEP in the six years preceding diagnosis, relative to the general population;
2. Describe the timing of primary care use among people with FEP in the six years preceding diagnosis, relative to the general population;
3. Describe the diagnostic codes associated with primary care visits among people with FEP in the six years preceding diagnosis, relative to the general population; and
4. Identify distinct primary care service utilization profiles among people with FEP in the six years preceding diagnosis.

Chapter 3

3 Methods

This section provides an overview of the methods used in the current study. The RECORD reporting guidelines for studies using health administrative data were used, and the checklist is presented in APPENDIX A.[102]

3.1 Study Design

Population-based health administrative data were used to construct a retrospective cohort of people aged 14 to 35 years with newly diagnosed psychotic disorder between 2005 and 2015, and a comparison group from the general population matched on age, sex, and forward sortation area (first three digits of postal code). Information on all contacts with primary care for the six-year period preceding the index diagnosis of psychotic disorder were extracted.

3.2 Data Sources

Data were obtained from ICES, which is an independent, not-for-profit research institute that holds a vast repository of health-related data, including population-based health surveys, patient records, and clinical and health administrative data for the entire population of Ontario. ICES is a prescribed entity under section 45 of Ontario's Personal Health Information Protection Act (PHIPA), enabling analysis and compilation of statistical information related to the management, evaluation and monitoring of, allocation of resources to, and planning for the health system. Projects conducted under section 45 do not require review by a Research Ethics Board. The following databases were used in the current study.

Registered Persons Database (RPDB; 1990-2015): This database contains limited socio-demographic information about people registered for the Ontario Health Insurance Plan (OHIP),[103] such as date of birth, sex, date of death (if applicable), and postal code. This database

was used to determine age for cohort creation, age, sex, and location of residence for matching, and for cohort description.

Ontario Mental Health Reporting System (OMHRS; 2005-2015): This database contains information on all people receiving care in a designated adult psychiatric inpatient bed.[104] This database was used to identify cases of FEP, for cohort description, and for covariates.

Discharge Abstract Database (DAD; 1988-2015): This database contains administrative, clinical, and demographic information on hospital discharges (including deaths, sign-outs, and transfers) from all non-psychiatric inpatient beds (after 2005), and all inpatient admissions prior to 2005.[105] This database was used to identify cases of FEP, for cohort description, and for covariates.

National Ambulatory Care Reporting System (NACRS; 2000-2015): This database contains data for hospital-based and community-based ambulatory care including day surgery, some outpatient and community-based clinics, and EDs.[106] This database was used to identify cases of FEP, for cohort description, and for covariates.

Ontario Health Insurance Plan Claims Database (OHIP; 1991-2015): This database contains most of the physician billing claims paid for by the Ontario Health Insurance Plan, which provides the population of Ontario with universal insurance of medically necessary services. It includes data from approximately 94% of physicians in Ontario, as it does not include physicians working in Community Health Centres or Health Service Organizations, and some physicians paid through methods other than fee-for-service .[107,108] Non-fee-for-service physicians are compensated via an Alternate Fee Plan which can include salary, capitation or a combination, and they are incentivized to submit "shadow billings" as if they were being paid through fee-for-service so that a record of their services is available. Approximately three-quarters of non-fee-for-service physicians submit shadow billings to OHIP and are included in the OHIP database.[107] This database was used to identify cases of FEP and to create outcome variables.

Client Agency Program Enrolment (CAPE; 1999-2015): This database contains a list of patients rostered to a primary care organization, including information on patients' association to a specific physician.[109] This database was used for covariates.

Primary Care Population (PCPOP; 2004-2008, 2010, 2012, 2014): This database, which was derived by ICES, provides information on demographic variables, primary care rostering, chronic diseases flags, ED visits, and hospital readmissions. This dataset includes all people in Ontario who are deemed alive and eligible for OHIP at the index date and had contact with the healthcare system within seven years of the index date.[110] The lookback window varies from one year to ten years depending on the health indicator description. To create this dataset, each person was assigned to a FP using the CAPE tables at ICES. For FPs not practicing in these models, a "virtual roster" method was used, which assigns non-rostered patients to the FP who had the highest value of billings for eighteen core primary care OHIP fee codes in the previous two years. In its validation study, this algorithm assigned each participants' regular primary care providers accurately (compared to participants' self-report data) in approximately 83% of cases.[111] The dataset for the closest fiscal year where the index date of the PCPOP dataset occurs before the index date of the subject was used (e.g., subject's index date is March 1, 2005 so the 2004 PCPOP dataset was used). This database was used for covariates.

3.3 Cohort Definition

The cohort included young people aged 14 to 35, residing in Ontario between April 2005 and March 2015, with a first diagnosis of psychotic disorder (described below) and a matched population-based comparison group. People were excluded if they were missing data for age and sex variables (<1%). Missing information on postal codes is very uncommon and postal code information was complete for everyone included in the cohort.

3.3.1 Case Definition

New cases of psychotic disorder (i.e., the index event) were identified by either a primary discharge diagnosis of non-affective psychosis (i.e., schizophrenia, schizoaffective disorder,

schizophreniform disorder, or psychosis not otherwise specified [NOS]) from an inpatient admission, or at least two OHIP billing claims or ED visits with a diagnostic code for non-affective psychosis in any 12-month period. A modified version of this algorithm has been validated at ICES using medical charts[112] and diagnostic codes are listed in APPENDIX B. The original algorithm identified cases of chronic psychotic disorder by either a psychiatric hospitalization or 2 medical doctor visits in any 24-month period with a diagnosis of schizophrenia, schizoaffective disorder or psychotic disorder NOS. The index date was defined as the discharge date for index cases identified from hospitalizations, or the first service date for index cases identified from two physician or ED visits. Using this algorithm, 39,449 cases of psychotic disorder were identified.

3.3.2 Comparison Group

All members of the general population who are eligible for OHIP and have no record of a diagnosis for psychotic disorders (schizophrenia, schizoaffective disorder, or psychosis not otherwise) were randomly assigned an index date from the distribution of index dates in the group of people with FEP. Four comparisons per identified FEP case were randomly sampled from the general population, matched on age, sex, location of residence using postal code, and index date (+/- 6 months), using the greedy method without replacement. These matching variables were chosen due to their documented association with pathways to care and primary care use.[8,46,113,47,53,54,57,61,65,69,72] Although it may impact the frequency of primary care service use, cases and comparisons were not matched on clinical variables because this may match away any effect, which will impede our ability to meaningfully assess primary care service use in this population. Population-based comparisons were chosen, as opposed to a cohort of people with other diagnoses, in order to be representative of the general population and act as a baseline level of primary care service utilization. In total, 157,796 matched comparisons were selected.

3.4 Variable Definitions

The following variables were selected from ICES databases or were created using existing variables in ICES databases. A detailed description of variables and their definitions are provided in APPENDIX C.

3.4.1 Outcome Variables

The outcome variables used in this study are primary care service use indicators related to the number of contacts and the OHIP diagnosis code associated with the primary care contact. The following variables were derived from the OHIP data for all primary care contacts in the six-year period preceding the index date for both cases and the comparison group:

Number of primary care contacts: Total number of contacts with primary care in the six years prior to the diagnosis date, defined by counting the number of OHIP fee codes billed per person in the six years preceding the index date. Counts were generated for the total number of visits, the number of visits per year, and the number of visits bimonthly over the six-year observation period.

Number of primary care contacts per diagnostic category: Total number of primary care contacts per diagnostic category in the 6 years prior to the index date, defined by counting the total number of contacts to primary care per OHIP diagnostic code category (Table 3.1) per person. A binary flag variable was also created for each diagnostic category, defined by the total number of primary care contacts per OHIP diagnostic code category (Table 3.1) being greater than zero, in order to identify those who contacted primary care at least once with a given diagnostic category in the six-year observation period.

Table 3.1 OHIP diagnostic code categories and examples of included diagnoses

OHIP Diagnosis Code Category	Examples of Included Diagnoses
Infections and Parasitic Diseases	Intestinal infectious diseases, tuberculosis, bacterial diseases, HIV Infection, viral diseases, venereal diseases, mycoses, helminthiases
Neoplasms	Malignant neoplasms, benign neoplasms, carcinoma in situ, neoplasms of uncertain behaviour
Endocrine, Nutritional and Metabolic Diseases and Immunity Disorders	Endocrine glands, nutritional and metabolic disorders, immunity disorders
Diseases of Blood and Blood-Forming Organs	Anaemia, coagulation defects, hemorrhagic conditions
Diseases of the Nervous System and Sense Organs	Central nervous system, peripheral nervous system, eye, ear and mastoid,
Diseases of the Circulatory System	Rheumatic fever and heart disease, hypertensive disease, ischaemic and other forms of heart disease, cerebrovascular disease, diseases of arteries, diseases of veins and lymphatics
Diseases of the Respiratory System	Common cold, sinusitis, tonsillitis, laryngitis, bronchitis, pneumonia, influenza, emphysema, pulmonary fibrosis
Diseases of the Digestive System	Diseases of oral cavity, salivary glands and jaws, diseases of esophagus, stomach and duodenum, other diseases of intestine and peritoneum, hernia
Diseases of the Genito-Urinary System	Diseases of the urinary system, male genital organs, breast and female pelvic organs, disorders of female genital tract
Complications of Pregnancy, Childbirth and the Puerperium	Pre-eclampsia, vomiting, prolonged pregnancy, normal delivery, multiple pregnancy, foetal distress, prolonged labour, post-partum complications
Diseases of the Skin and Subcutaneous Tissue	Infections, inflammatory conditions, corns, calluses, ingrown nail, acne
Diseases of Musculoskeletal System and Connective Tissue	Arthritis, joint derangement, intervertebral disc disorders, lumbar strain, osteoporosis, scoliosis, flat foot
Congenital Anomalies	Spina bifida, hydrocephalus, cleft palate, chromosomal anomalies

Table 3.1 con't. OHIP diagnostic code categories and examples of included diagnoses

Perinatal Morbidity and Mortality	Prematurity, post maturity, birth trauma, respiratory distress syndrome, other conditions of fetus or newborn
Symptoms, Signs and Ill-Defined Conditions	Non-specific abnormal findings
Accidents, Poisonings and Violence	Fractures and fracture-dislocations, dislocations, sprains, strains and other trauma,
Family Planning	Advice on contraceptive use, sterilization or abortion
Immunizations	All types
Illegitimacy	-
Baby Care	-
Annual Health Examination	-
Without Diagnosis	-
Senile Dementia or Presenile Dementia	-
Affective Psychotic Disorders	Schizophrenia, manic-depressive psychoses, other paranoid states, other psychoses
Non-Psychotic Disorders	Anxiety neuroses, personality disorders, sexual deviations, psychosomatic illness, adjustment reaction, depressive disorder
Substance Use Disorder	Drug dependence, drug addiction, alcoholism
Social Problems	Economic problem, marital difficulties, parent-child problems, educational problems, occupational problems, legal problems, social maladjustment
Alcoholic Psychosis	Including delirium tremens, Korsakov's psychosis
Drug Psychosis	-
Childhood Psychoses	-
Tobacco Abuse	-
Habit Spasms	Tics, stuttering, tension headaches, anorexia nervosa, sleep disorders, enuresis
Behaviour Disorder	-
Hyperkinetic Syndrome	-
Delays in Development	Dyslexia, dyslalia, motor delays
Intellectual Delay	-

Number of primary care contacts for a mental health & addictions (MHA) reason: Total number of primary care contacts for a mental health and addictions reason in the 6 years prior to the index date, defined by counting the total number of contacts to primary care per person with diagnosis or fee codes related to mental health and addictions services in the 6 years prior to the index date. OHIP diagnosis and fee codes related to mental health and addictions services are

listed in APPENDIX D, and are based on a validation study using health administrative data conducted by Steele et al.[114] A binary flag variable was also created, defined by the total number of primary care contacts for a mental health reason being greater than zero, to identify people who contacted primary care for a mental health reason at least once in the six-year observation period.

Number of primary care contacts for a non-mental health reason: Total number of primary care contacts for a non-mental health reason in the 6 years prior to the index date, defined by counting the total number of contacts to primary care per person with diagnosis or fee codes not related to mental health services in the 6 years prior to the index date (i.e., OHIP diagnosis and fee codes not listed in APPENDIX D). A binary flag variable was also created, defined by the total number of primary care contacts for a non-mental health reason being greater than zero, identifying people who contacted primary care for a non-mental health reason at least once in the six-year observation period.

3.4.2 Covariates

Sociodemographic factors: These variables included age, sex, neighbourhood-level income quintile, and residence location (rural vs. non-rural). Age at index date was categorized into groups (14 to 17, 18 to 20, 21 to 23, 24 to 26, 27 to 29, 30 to 32, or 33 to 35), rather than used as a continuous variable, due to privacy and re-identification risk. We also had information available on neighbourhood-level dependency, material deprivation, ethnic concentration, and residential instability assigned using the O*ntario Marginalization Index (ONMARG; 2006, 2011),* which is a census- and geographically-based tool that measures multiple dimensions of marginalization including economic, ethno-racial, age-based, and social marginalization, at the neighbourhood level in Ontario.[115] The ONMARG index was developed using a theoretical framework and factor analysis and has been demonstrated to be stable across time and different geographic areas. The ONMARG dimensions are described in Table 3.2.[116]

Table 3.2 ONMARG dimension descriptions

Dimension	Description
Residential Instability	Refers to people who experience high rates of family or housing instability including types and density of residential accommodations and family structure characteristics.
Material Deprivation	Refers to inability for individuals and communities to access and attain basic material needs including incoming, quality of housing, educational attainment and family structure characteristics.
Dependency	Refers to people who don't have income from employment including seniors, children, and adults who work with no compensation.
Ethnic Concentration	Refers to concentrations of recent immigrants and people belonging to visible minorities.

Clinical factors: These variables include type of psychotic disorder diagnosis (cases only), number of aggregated diagnosis groups (ADGs), presence of a chronic medical or psychosocial condition, resource utilization band (RUB) and number of expanded diagnosis clusters (EDCs). The Johns Hopkins Adjusted Clinical Groups system categorizes illnesses into 32 diagnostic clusters, known as ADGs, with similar clinical criteria and expected need for healthcare resource based on International Classification of Disease (ICD) codes (ICD version 9, 9-CM or 10). Diseases or conditions are placed into a similar ADG based on five clinical dimensions: duration of the condition, severity of the condition, diagnostic certainty, etiology of the condition, and specialty care involvement. The ICD diagnosis codes are obtained from both physician billing claims and electronic hospital discharge abstracts.[117] Using the identified ADGs, variables were also created to identify people who had chronic medical and chronic psychosocial conditions. The Johns Hopkins Adjusted Clinical Groups system also ranks overall morbidity level into six categories so that individuals who are expected to use the same level of resource are grouped

together, even if they have different illnesses, known as the RUB.[118] The Johns Hopkins Adjusted Clinical Groups system also categorizes diagnosis codes into 190 disease-specific clinical categories, known as EDCs.[119]

Service-use history: Variables were created to indicate whether each person had access to a regular family physician, a psychiatric hospitalization in the previous 2 years preceding the index date, any hospital admissions in the previous 2 years preceding the index date, a psychiatric ED visit in the 2 years preceding the index date, or any ED visits in the 2 years preceding the index date.

All covariates were measured at the index date.

3.5 Statistical Analyses

Analyses were conducted using SAS (Version 9.4) and R (Version 3.3.0). We used frequencies and proportions for sociodemographic, clinical factors and service-use history variables to describe the sample, and standardized differences were computed to determine if significant differences between case and comparison groups were present. Standardized difference scores measure the effect size between two groups and are independent of sample size. Given that the sample size of the current study is large, a small effect size with minimal clinical significance may nonetheless be statistically significant, and thus it is important to use a method that is independent of sample size in order to prevent spurious findings.[120] Standardized differences can be interpreted as an estimate of the strength of the relationship or average difference between means or proportions, expressed in standard deviation units, between two groups.[121] Standardized differences greater than 0.10 were considered significant.

For objectives one though three, we opted to not include any adjustment variables in our statistical models for two reasons. Firstly, covariates such as clinical factors or service-use history variables will impact the frequency of primary care service use and including these variables in analyses may adjust away any effect, which will impede our ability to meaningfully

assess primary care service use in this population. Secondly, cases and their comparisons are matched on age, sex, and location of residence.

The first objective was to describe the frequency of primary care service use among people with FEP in the six years preceding diagnosis, and to compare this to the general population, as represented by the comparison group. We calculated the median number of contacts with primary care and the associated interquartile range (IQR) for people with FEP and their comparisons. An unadjusted negative binomial regression model was also used to compare the number of primary care contacts in the six years prior to the index date, and robust variance estimators were used to account for the matched design. Results are presented as rate ratios (RR) with the associated 95% confidence interval (CI).

The second objective was to describe the timing of primary care use among people with FEP in the six years preceding diagnosis, relative to the general population. The median number of contacts with primary care and the associated IQR per year for the six years prior to index date for cases and their comparisons are presented, and standardized differences were used to determine the statistical significance of any differences between groups. A graph displaying the proportion of people who contacted primary care, measured on a bimonthly basis for the 6 years prior to index date for people with FEP and their comparisons, is presented. Graphs displaying the same information stratified by whether people had an ED contact or hospitalization for a MHA reason prior to the index diagnosis and stratified by age at index group (14 to 20, 21 to 29, 30 to 35) are also presented. Change-point analysis was used to detect changes in the average number of contacts with primary care per person bimonthly for the 6 years prior to index date for persons with FEP. Change-point analysis is used to model the process of a sequence of observations undergoing sudden change at unknown times and to determine the point at which a change occurred.[122] The R changepoint package was used for analysis. Specifically, the cpt.meanvar function with the binary segmentation (i.e., "BinSeg") method was used to detect at least one change in the mean and/or variance of the data. Binary segmentation searches for a single changepoint in the entire data, and where one is identified, the data are split into two at this location. Then the single change point procedure is repeated on each part of the dataset and they are split further if changepoints are identified in either part.[123] However, this method does

not take into account multiple testing and thus, may contain false positive change points.[124] Change point location, mean before change point, mean after change point, and percentage of mean difference are presented. Each change point location is identified by an integer between 1 and 36, 1 representing two months before diagnosis and 36 representing 72 months or 6 years before diagnosis. Mean before and after change point are presented as the average number of contacts with primary care bimonthly per person with FEP.

The third objective was to describe the OHIP diagnosis codes associated with the primary care contacts among young people with FEP in the six years preceding first diagnosis, relative to the general population. We calculated the proportion of people in the case and the comparison groups who contacted primary care at least once for each diagnostic category (Table 3.1). Unadjusted log-linked binomial models with robust variance estimators to account for the matched design were used to compare the relative risk of contacting primary care with a specific OHIP diagnosis category in the six years prior to the index date between people with FEP and the matched comparison group. Results are presented as risk ratios (RR) and 95% CIs.

The fourth objective was to identify distinct service utilization profiles among people with FEP in the six years preceding diagnosis and compare these to service utilization trajectories in the general population for the same time period. Latent class growth modelling (LCGM) was used to identify sub-groups of cases and comparisons who had distinct patterns of primary care service utilization in the six years prior to the index date. LCGM is a technique used to identify distinct subgroups of people following a similar pattern of change over time on a given variable.[125] First, a linear trajectory was modelled for one group, then additional groups were added until the model fit worsened. With the number of groups determined, the optimal polynomial equation (i.e., trajectory shape; linear, quadratic, cubic) for each trajectory was tested until the model fit worsened and non-significant polynomial terms were removed, resulting in the final model.[126] Parameter estimates, including trajectory size, test statistics, standard errors, significance for each parameter, posterior probabilities, and odds of correct classification (OCC) are presented. P-values less than 0.05 determine the statistical significance of parameters or trajectory shape. Average posterior probabilities of group membership are presented, which approximates internal reliability for each trajectory and values greater than 0.70 to 0.80 indicate the trajectories group

individuals with similar patterns of change and discriminate between individuals with dissimilar patterns of change.[125] OCC, which measures the trajectories' predictive power, are also presented. A value of 1 means the trajectory has no predictive power and as the model becomes more predictive, the OCC increases. OCC should be at least 5.0 for all groups for good model fit.[127] Bayesian Information Criterion (BIC), an index used to compare competing models with different numbers or shapes of trajectories,[125] was used to calculate the Log Bayes Factor, where a positive value indicates that the more complex model in the calculation is a better fit for the data, compared to the null (less complex) model in the calculation. Values from 2 to 6 provide moderate evidence, values from 6 to 10 provide strong evidence, and values above 10 provide very strong evidence for the more complex model.[125] Variables entered in the LCGM include the number of primary care contacts per year and the number of years prior to diagnosis (i.e., 1 through 6). The number of primary care contacts were categorized into deciles (0, 1, 2 to 4, 5 to 7, 8 to 10, 11 to 14, 15 to 18, 19 to 25, 26 to 37, 38+ visits) for the model to run without error. Adjusted log-linked binomial models were used to compare the relative risk of belonging to the different trajectories in the LCGM model based on sociodemographic factors, clinical factors, and service-use indicators, which included age at index (14 to 23 or 24 to 35 years old), sex, location of residence (i.e., rural or urban), index diagnosis, presence of any ADG chronic medical condition, presence of any ADG chronic psychosocial condition, any contact with the ED or a psychiatric hospitalization for a MHA reason in the last two years and having a regular FP. These variables were chosen based on prior knowledge of their relationship with primary care service utilization, rather than through statistical methods. Multicollinearity was tested and there was no indication of multicollinearity for these variables. Results are presented as risk ratios (RR) and associated 95% CIs. Proportions and standardized differences were used to compare factors associated with primary care service utilization between the different case trajectories in the LCGM model to identify factors associated with different levels of service use in people with FEP.

Chapter 4

4 Results

This chapter presents the study findings including the frequency and timing of primary care service utilization, the OHIP diagnosis codes associated with primary care use, and service utilization profiles for people with FEP relative to the matched comparison group.

4.1 Cohort Characteristics

In total, 39,449 incident cases of non-affective psychosis (schizophrenia, schizoaffective disorder, schizophreniform disorder, or psychosis NOS) were identified over the ten-year period between April 2005 and March 2015, and 157,796 matched comparisons were selected. Sociodemographic characteristics by group are presented in Table 4.1. The largest age bracket (20%) was 18 to 20 years and the smallest age bracket (11%) was 33 to 35 years, with a larger proportion of the sample (64%) being male. The largest proportion of people (29% of cases and 25% of the matched comparison group) were in the lowest neighbourhood-level income quintile, and the smallest proportion of people (14% of cases and 17% of the comparison group) were in the highest income quintile. Most of the sample (91%) lived in an urban location. No significant differences between people with early psychosis and their comparisons were found for socio-demographic variables including age, sex, neighbourhood income quintile, location of residence, and the ONMARG variables (dependency, deprivation, ethnic concentration, and instability), as a result of matching by age, sex, and location of residence. Half of people with psychosis were diagnosed with a schizophrenia spectrum disorder, and half were diagnosed with psychosis NOS.

Table 4.1 Sociodemographic Characteristics for Cases and Comparison Group

		Cases	Comparison Group
		n (%)	n (%)
Age at Index Date	14 to 17 years	5317 (13.5%)	21268 (13.5%)
	18 to 20 years	8085 (20.5%)	32340 (20.5%)
	21 to 23 years	6963 (17.7%)	27852 (17.7%)
	24 to 26 years	5533 (14.0%)	22132 (14.0%)
	27 to 19 years	4893 (12.4%)	19572 (12.4%)
	30 to 32 years	4380 (11.1%)	17520 (11.1%)
	33 to 35 years	4278 (10.8%)	17112 (10.8%)
Sex	Male	25049 (63.5%)	100196 (63.5%)
	Female	14400 (36.5%)	57600 (36.5%)
Income Quintile	1 (lowest)	11298 (28.6%)	39949 (25.3%)
	2	8419 (21.3%)	33043 (20.9%)
	3	7215 (18.3%)	29771 (18.9%)
	4	6553 (16.6%)	27915 (17.7%)
	5 (highest)	5692 (14.4%)	26298 (16.7%)
Rural	Urban	35920 (91.1%)	143818 (91.1%)
	Rural	3515 (8.9%)	13935 (8.8%)
Dependency	5 (high)	683 (1.7%)	2592 (1.6%)
	4	2044 (5.2%)	8034 (5.1%)
	3	3609 (9.2%)	14677 (9.3%)
	2	11472 (29.1%)	46229 (29.3%)
	1 (low)	21257 (53.9%)	85119 (53.9%)
Deprivation	5 (high)	9380 (23.8%)	37070 (23.5%)
	4	14432 (36.6%)	57602 (36.5%)
	3	5489 (13.9%)	22111 (14.0%)
	2	5870 (14.9%)	23879 (15.1%)
	1 (low)	3894 (9.9%)	15989 (10.1%)
Ethnic Concentration	5 (high)	32560 (82.5%)	129932 (82.3%)
	4	3466 (8.8%)	14186 (9.0%)
	3	1825 (4.6%)	7670 (4.9%)
	2	875 (2.2%)	3451 (2.2%)
	1 (low)	339 (0.9%)	1412 (0.9%)
Residential Instability	5 (high)	19294 (48.9%)	76787 (48.7%)
	4	7350 (18.6%)	29435 (18.7%)
	3	3004 (7.6%)	12076 (7.7%)
	2	4006 (10.2%)	16358 (10.4%)
	1 (low)	5411 (13.7%)	21995 (13.9%)
Index Diagnosis	Schizophrenia Spectrum	19408 (49%)	N/A
	Psychosis NOS	20041 (51%)	N/A

Service-use history indicators by group are presented in Table 4.2. Significant differences between people with early psychosis and the comparison group were found for all service-use history indicators. A larger proportion of people with early psychosis were in the higher RUB categories, relative to the comparison group. The largest proportion of people with early psychosis (53%) were in the RUB quintile three whereas the largest proportion of people in the comparison group (32%) were considered non-users. The RUB ranks overall morbidity level into six categories so that individuals who are expected to use the same level of resource are grouped together, even if they have different illnesses. This finding suggests that people with early psychosis utilize health care resources at a much greater frequency than the population comparison group in the six years prior to first diagnosis.

Most people in the comparison group (80%) had less than five ADGs whereas just less than half of people with early psychosis (47%) had the same. A larger proportion of people with early psychosis were in the 6 to 9 ADGs or 10+ ADGs groups, relative to the comparison group. People with early psychosis have a median number of EDCs of 7 (IQR = 4 to 11), whereas the comparison group had only 2 (IQR = 1 to 5). ADGs and EDCs reflect physical comorbidities and thus people with psychosis have a higher number of physical comorbidities than people in the comparison group. Twice as many people with early psychosis had a chronic medical condition, relative to the comparison group (33% vs. 15%). Similarly, most people with early psychosis (79%) had a chronic psychosocial condition, whereas only a small proportion of the comparison group did (16%). This also suggests that people with early psychosis have more comorbidities, both physical and psychosocial, than those in the comparison group. 12% of people with early psychosis have had a hospitalization for a MHA reason in the 2 years prior to first diagnosis whereas only 0.37% of the comparison group have had the same. 33% and 57% of people with early psychosis have visited the ED for a MHA reason or any other reason (not MHA reason), respectively, in the two years prior to first diagnosis, whereas the corresponding proportions in the comparison group were 2% and 27%. These findings suggest that people with early psychosis utilize EDs or hospitalizations for MHA reasons at a higher rate than those in the comparison group. Most people with early psychosis (72%) have a regular FP whereas only approximately half of the comparison group (56%) do.

Table 4.2 Service-Use Indicators for Cases and Comparisons

		Cases	Comparison Group	Standardized Difference
		n (%)	n (%)	
Resource Utilization Band (RUB)	0 (Non-user)	1873 (4.8%)	50753 (32.2%)	***0.76***
	1 (Healthy users)	883 (2.2%)	12500 (7.9%)	***0.26***
	2	4658 (11.8%)	32955 (20.9%)	***0.25***
	3	20977 (53.2%)	48174 (30.5%)	***0.47***
	4	8942 (22.7%)	12607 (8.0%)	***0.42***
	5 (Very high users)	2116 (5.4%)	807 (0.5%)	***0.29***
Number of ADGs	1 (Low, less than 5)	18688 (47.4%)	126788 (80.4%)	***0.73***
	2 (Medium, 6-9)	13190 (33.4%)	25025 (15.9%)	***0.42***
	3 (High, greater than 10)	7571 (19.2%)	5983 (3.8%)	***0.50***
Has Chronic Medical Condition	No	27919 (70.8%)	134150 (85.0%)	***0.35***
	Yes	11530 (29.2%)	23646 (15.0%)	***0.35***
Has Chronic Psychosocial Condition	No	8378 (21.2%)	132700 (84.1%)	***1.62***
	Yes	31071 (78.8%)	25096 (15.9%)	***1.62***
Had Psychiatric Hospitalization in 2 Years Prior to Index Date	No	34700 (88.0%)	157207 (99.6%)	***0.50***
	Yes	4749 (12.0%)	589 (0.4%)	***0.50***
Had Hospitalization in 2 Years Prior to Index Date	No	35502 (90.0%)	149777 (94.9%)	***0.19***
	Yes	3947 (10.0%)	8019 (5.1%)	***0.19***
Visited Emergency Department for a MHA Reason in 2 Years Prior to Index Date	No	26412 (67.0%)	155124 (98.3%)	***0.91***
	Yes	13037 (33.1%)	2672 (1.7%)	***0.91***
Visited Emergency Department in 2 Years Prior to Index Date	No	16780 (42.5%)	114530 (72.6%)	***0.64***
	Yes	22669 (57.5%)	43266 (27.4%)	***0.64***
Has Regular Family Physician	No	11187 (28.4%)	69188 (43.9%)	***0.33***
	Yes	28262 (71.6%)	88608 (56.2%)	***0.33***
		Median (IQR)	Median (IQR)	
Number of EDCs		7 (4 to 11)	2 (1 to 5)	***0.98***

4.2 Frequency of Primary Care Use

The first objective was to describe the frequency of primary care service utilization among people with early psychosis in the six years preceding diagnosis and compare this to the general population. The median number of contacts with primary care in the six years leading up to diagnosis was 19 (IQR = 10 to 36) for people with early psychosis and 8 (IQR = 1 to 18) for the comparison group (standardized difference = 0.82). The findings from the negative binomial regression model suggest that people with early psychosis contact primary care over twice as frequently in the six years leading up to first diagnosis, relative to the comparison group (RR = 2.22, 95% CI = 2.19, 2.25).

4.3 Timing of Primary Care Use

The second objective was to describe the timing of primary care service utilization among people with early psychosis in the six years preceding diagnosis, relative to the general population. The median number of primary care contacts per year begins to increase approximately two years before diagnosis for people with early psychosis, with no change for the comparison group over the six-year observation period (Table 4.3). The median number of primary care contacts for people with early psychosis at six years before diagnosis is two (IQR = 0 to 5) and at one year before diagnosis is four (IQR = 2 to 9). The median number of primary care contacts for the comparison group remains steady at one (IQR = 0 to 3) for all six years leading up to first diagnosis.

Table 4.3 Median and IQR of number of contacts with primary care per year for cases and comparisons, for the 6 years leading up to first diagnosis

	Cases	**Comparisons**	**Standardized difference**
	Median (IQR)	**Median (IQR)**	
1 Year Before Diagnosis	4 (2 to 9)	1 (0 to 3)	***0.98***
2 Years Before Diagnosis	3 (1 to 6)	1 (0 to 3)	***0.58***
3 Years Before Diagnosis	2 (0 to 6)	1 (0 to 3)	***0.50***
4 Years Before Diagnosis	2 (0 to 5)	1 (0 to 3)	***0.46***
5 Years Before Diagnosis	2 (0 to 5)	1 (0 to 3)	***0.44***
6 Years Before Diagnosis	2 (0 to 5)	1 (0 to 3)	***0.42***

The proportion of people who contacted primary care at least once, counted bimonthly, for the six years leading up to diagnosis is presented in Figure 4.1. The proportion of people with early psychosis that contacted primary care at least once is higher than the comparison group at approximately 32% at six years before first diagnosis, which increases to 64% at 2 months before first diagnosis. The proportion of the comparison group that contacted primary care at least once remains steady at approximately 22% over the entire period. The data, with the cases stratified by whether the case had contact with the ED or a hospitalization for a MHA reason, is presented in Figure 4.2. People with psychosis who had contact with the ED or a hospitalization for a MHA reason contacted primary care at a higher frequency than people with psychosis who did not have contact with the ED or a hospitalization for a MHA reason.

Figure 4.1 The proportion of cases and comparisons that contacted primary care at least once, counted bimonthly, for the six years leading up to diagnosis

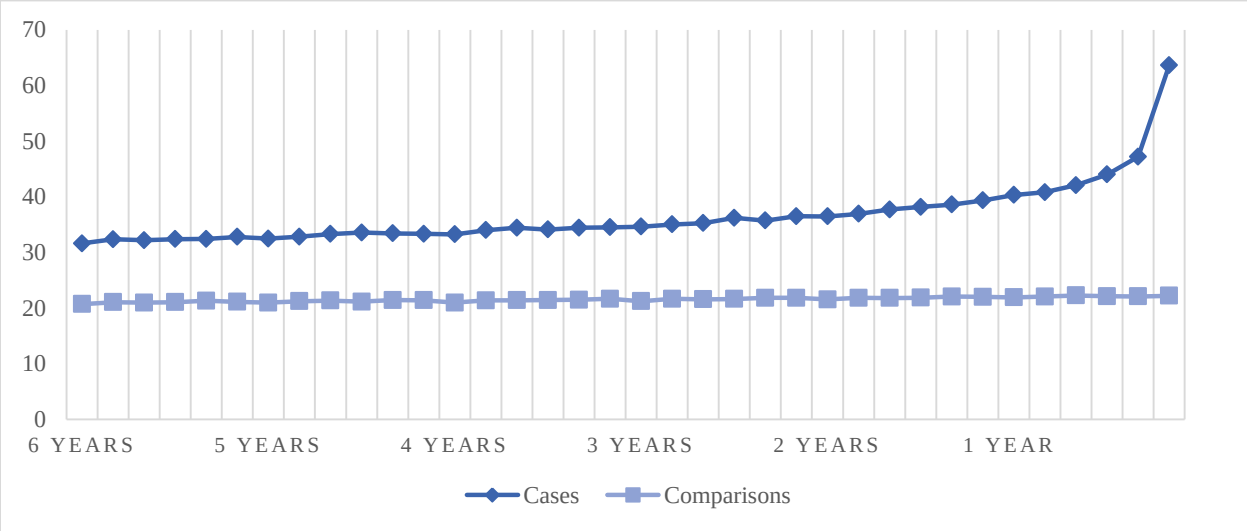
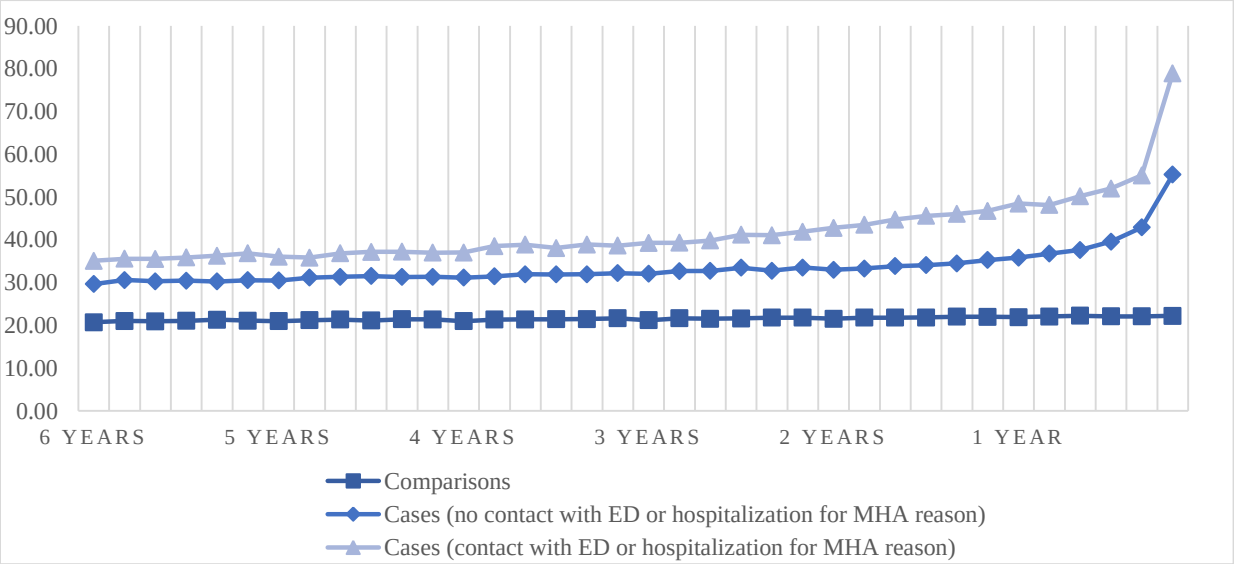


Figure 4.2 The proportion of cases and comparisons that contacted primary care at least once, counted bimonthly, for the six years leading up to diagnosis, stratified by whether the case had contact with the ED or a hospitalization for a MHA reason



As presented in Table 4.4, the rate of primary care service use varies over the six years leading to first diagnosis and between age groups. In the 14 to 20 age group, the RR for number of contacts with primary care increases from 1.63 (95%CI = 1.59, 1.67) at six years before diagnosis to 3.00 (95%CI = 2.93, 3.08) at one year before diagnosis. In the 21 to 29 age group, the RR for number of contacts with primary care increase from 1.84 (95%CI = 1.79, 1.89) at six years before diagnosis to 3.19 (95%CI = 3.11, 3.27) at one year before diagnosis. In the 30 to 35 age group, the RR for number of contacts with primary care increases from 2.01 (95%CI = 1.93, 2.09) at six years before diagnosis to 3.25 (95%CI = 3.14, 3.36) at one year before diagnosis. The rate of primary care use increases with increasing age as well as with each year leading up to diagnosis.

Table 4.4 Association between time before diagnosis and number of primary care contacts over the six years leading up to first diagnosis, stratified by age group

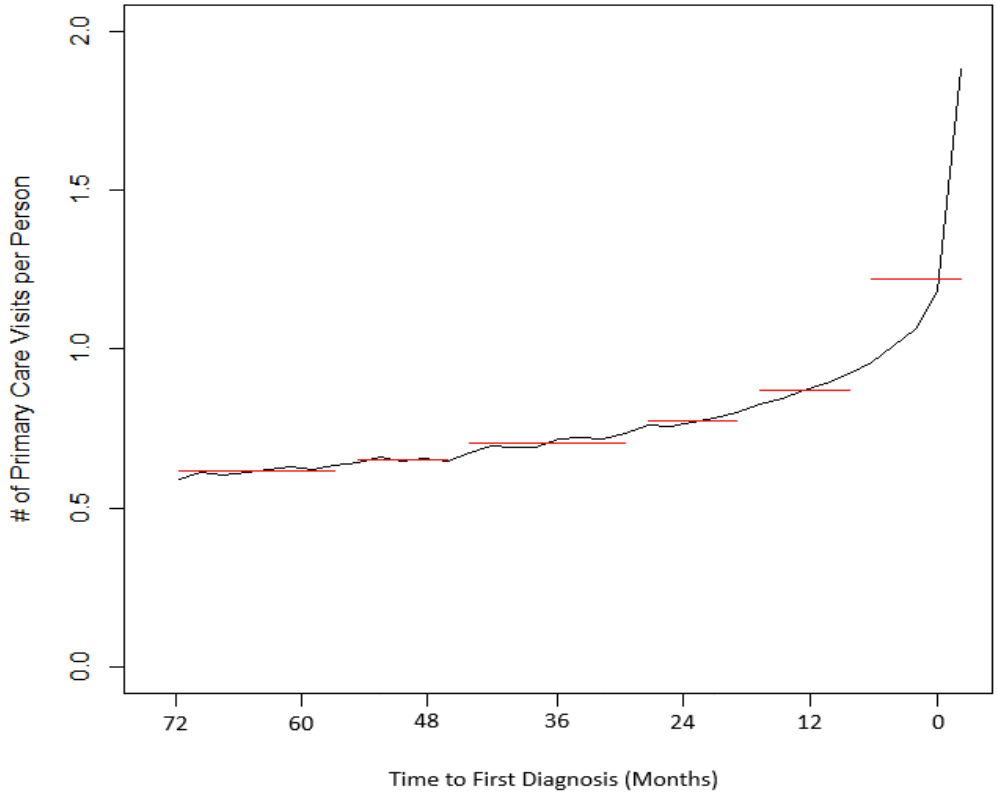
Time	Group	RR (95% CI)		
		Ages 14 to 20	**Ages 21 to 29**	**Ages 30 to 35**
1 Year Before Diagnosis	Comparisons	Reference		
	Cases	3.00 (2.93, 3.08)	3.19 (3.11, 3.27)	3.25 (3.14, 3.36)
2 Years Before Diagnosis	Comparisons	Reference		
	Cases	2.14 (2.08, 2.20)	2.35 (2.29, 2.42)	2.47 (2.37, 2.56)
3 Years Before Diagnosis	Comparisons	Reference		
	Cases	1.90 (1.85, 1.95)	2.16 (2.10, 2.22)	2.24 (2.16, 2.33)
4 Years Before Diagnosis	Comparisons	Reference		
	Cases	1.79 (1.73, 1.85)	2.02 (1.96, 2.07)	2.14 (2.05, 2.22)
5 Years Before Diagnosis	Comparisons	Reference		
	Cases	1.71 (1.67, 1.76)	1.91 (1.86, 1.96)	2.06 (1.98, 2.14)
6 Years Before Diagnosis	Comparisons	Reference		
	Cases	1.63 (1.59, 1.67)	1.84 (1.79, 1.89)	2.01 (1.93, 2.09)

As presented in Table 4.5 and Figure 4.3, five change points were detected in the average number of primary care contacts per person with early psychosis, measured bimonthly, over the six years leading up to diagnosis. Change points were detected at 56, 46, 30, 20 and 10 months prior to first diagnosis. The percentage mean difference between change points increases slightly at each time point from 105% at the first to second change point to 113% at the third to fourth time point. There is a larger increase in the percentage mean difference (140%) from the fourth to fifth change point, which occurs at 10 months before first diagnosis.

Table 4.5 Change point locations, means before and after change points, and percentage mean difference between change points for average number of primary care visits per case, measured bimonthly, over the six years leading up to diagnosis

Change Point Location	Mean Before Change Point	Mean After Change Point	% Mean Difference
56 months to diagnosis	0.617	0.652	105.78
46 months to diagnosis	0.652	0.705	108.07
30 months to diagnosis	0.705	0.774	109.77
20 months to diagnosis	0.774	0.872	112.62
10 months to diagnosis	0.872	1.219	139.82

Figure 4.3 Average number of primary care contacts per case, counted bimonthly, over the six years leading up to first diagnosis (black line) and change point locations detected (red lines)



4.4 OHIP Diagnosis Codes Associated with Primary Care Use

The third objective was to describe the OHIP diagnosis codes associated with primary care contacts among people with early psychosis in the six years preceding diagnosis, relative to the general population. The OHIP diagnosis categories associated with primary care contacts for people with early psychosis and the comparison group leading up to the index date, stratified by sex, are compared in Table 4.6 and Table 4.7, respectively. OHIP diagnosis categories with low proportions (<1%) are provided in APPENDIX E. Both male and female people with early psychosis have higher visit prevalence across nearly all conditions, including mental health, physical comorbidities, and preventive health related diagnoses, compared to their matched comparisons. Overall, 76% of male cases visited primary care with an OHIP diagnosis code related to MHA at least once in the six-year observation period, and 95% visited at least once with an OHIP diagnosis code related to a physical condition (Non-MHA). In comparison, 84% of female cases visited primary care with an OHIP diagnosis code related to MHA at least once in the six-year observation period, and 97% visited at least once with an OHIP diagnosis code related to a physical condition (Non-MHA). In male cases, the highest prevalence OHIP diagnosis codes were for non-psychotic disorders (70.2%), diseases of the respiratory system (66.1%), accidents, poisonings and violence (63.5%), diseases of the skin and subcutaneous tissue (50.2%) and diseases of the nervous system and sense organs (45.0%). In female cases, the highest prevalence OHIP diagnosis codes were for non-psychotic disorders (81.1%), diseases of the genito-urinary system (65.9%), diseases of the skin and subcutaneous tissue (59.3%), diseases of the nervous system and sense organs (59.0%), and accidents, poisonings and violence (60.9%). Male cases were over 27 times more likely to contact primary care with an OHIP diagnosis code related to affective psychotic disorders (RR=27.53; 95%CI=24.25, 31.25) than the comparison group, over six times more likely to contact with an OHIP diagnosis code related to substance-use disorder (RR= 6.11; 95%CI=5.84, 6.40) and over six times more likely to contact with an OHIP diagnosis code related to childhood psychoses or autism (RR=6.41; 95%CI=5.52, 7.44), relative to the comparison group. Female cases were over 23 times more likely to contact primary care with an OHIP diagnosis code related to affective psychotic disorders (RR=23.70; 95%CI=20.84, 26.95), over six times more likely to contact with an OHIP diagnosis code related to substance use disorder (RR=6.25, 95%CI=5.82, 6.72), six times more likely to contact with an OHIP diagnosis code related to behaviour disorder (RR=6.00;

95%CI=5.50, 6.55), and over four times more likely to contact with an OHIP diagnosis code related to hyperkinetic syndrome (RR=4.82; 95%CI=4.18, 5.55), relative to the comparison group.

Table 4.6 Proportions of male cases and comparisons that contacted primary care at least once in the six years leading up to first diagnosis, risk ratios and the associated standardized difference and 95% confidence intervals for each OHIP diagnosis category

OHIP Diagnosis Code Associated with Contact	Cases	Comparisons	RR	95% CI
	%	%		
Mental Health Related				
Mental Health & Addictions Services (Overall)	75.6	21.6	3.49	3.44, 3.54
Non-Psychotic Disorders	70.2	18.4	3.81	3.75, 3.87
Substance Use Disorder	17.0	2.8	6.11	5.84, 6.40
Behaviour Disorder	11.6	2.8	4.23	4.02, 4.45
Habit Spasms (i.e., tics, stuttering)	9.4	3.4	2.74	2.61, 2.89
Social Problems	8.9	2.6	3.43	3.25, 3.63
Affective Psychotic Disorders	7.4	0.3	27.53	24.25, 31.25
Hyperkinetic Syndrome	6.2	1.7	3.60	3.37, 3.85
Tobacco Abuse	2.0	0.8	2.53	2.26, 2.83
Childhood Psychoses or Autism	1.8	0.3	6.41	5.52, 7.44
Delays in Development	1.7	0.5	3.72	3.27, 4.24
Physical Condition Related				
Non-Mental Health & Addictions Services (Overall)	95.4	75.5	1.26	1.26, 1.27
Diseases of the Respiratory System	66.1	51.0	1.30	1.28, 1.31
Accidents, Poisonings and Violence	63.5	44.7	1.42	1.40, 1.44
Diseases of the Skin and Subcutaneous Tissue	50.2	37.0	1.36	1.34, 1.38
Diseases of the Nervous System and Sense Organs	45.0	30.4	1.48	1.45, 1.50
Diseases of Musculoskeletal System and Connective Tissue	42.3	30.3	1.40	1.37, 1.42
Symptoms, Signs and Ill-Defined Conditions	42.0	23.9	1.76	1.73, 1.79
Infections and Parasitic Diseases	41.4	29.9	1.39	1.36, 1.41
Diseases of the Digestive System	40.7	24.2	1.68	1.65, 1.71
Without Diagnosis	30.0	20.4	1.47	1.44, 1.50
Diseases of the Circulatory System	24.4	14.8	1.65	1.61, 1.70
Diseases of the Genito-Urinary System	17.3	10.2	1.69	1.64, 1.75
Endocrine, Nutritional and Metabolic Diseases and Immunity Disorders	12.2	7.9	1.54	1.48, 1.60
Neoplasms	4.4	3.6	1.25	1.17, 1.34
Diseases of Blood and Blood-Forming Organs	3.9	2.2	1.75	1.63, 1.89
Preventative Health Related				
Annual Health Examination (Adolescents)	22.1	16.3	1.36	1.32, 1.40
Immunization	10.8	9.4	1.15	1.10, 1.20
Family Planning	1.2	1.3	0.98	0.87, 1.11

Table 4.7 Proportions of female cases and comparisons that contacted primary care at least once in the six years leading up to first diagnosis, risk ratios and the associated standardized difference and 95% confidence intervals for each OHIP diagnosis category

OHIP Diagnosis Code Associated with Contact	Cases	Comparisons	RR	95% CI
	%	%		
Mental Health Related				
Mental Health & Addictions Services (Overall)	84.1	31.9	2.64	2.60, 2.67
Non-Psychotic Disorders	81.1	29.1	2.79	2.75, 2.83
Habit Spasms (i.e., tics, stuttering)	12.7	5.2	2.44	2.31, 2.58
Substance Use Disorder	12.3	2.0	6.25	5.82, 6.72
Social Problems	11.7	3.7	3.15	2.96, 3.35
Affective Psychotic Disorders	10.9	0.5	23.70	20.84, 26.95
Behaviour Disorder	8.4	1.4	6.00	5.50, 6.55
Hyperkinetic Syndrome	2.9	0.6	4.82	4.18, 5.55
Tobacco Abuse	2.2	0.8	2.57	2.23, 2.96
Physical Condition Related				
Non-Mental Health & Addictions Services (Overall)	97.2	77.6	1.25	1.25, 1.26
Diseases of the Genito-Urinary System	65.9	47.5	1.39	1.37, 1.41
Diseases of the Skin and Subcutaneous Tissue	59.3	43.7	1.36	1.33, 1.38
Diseases of the Nervous System and Sense Organs	59.0	39.6	1.49	1.46, 1.51
Accidents, Poisonings and Violence	60.9	38.8	1.57	1.54, 1.60
Infections and Parasitic Diseases	54.0	37.6	1.45	1.41, 1.46
Diseases of the Digestive System	58.9	36.8	1.60	1.57, 1.63
Symptoms, Signs and Ill-Defined Conditions	54.3	33.0	1.64	1.61, 1.68
Diseases of Musculoskeletal System and Connective Tissue	47.0	32.8	1.43	1.40, 1.46
Without Diagnosis	39.8	28.4	1.40	1.37, 1.43
Diseases of the Circulatory System	31.5	18.7	1.69	1.64, 1.74
Complications of Pregnancy, Childbirth and the Puerperium	23.3	18.6	1.25	1.21, 1.30
Endocrine, Nutritional and Metabolic Diseases and Immunity Disorders	21.0	12.9	1.63	1.57, 1.69
Diseases of Blood and Blood-Forming Organs	13.3	8.3	1.61	1.53, 1.69
Neoplasms	10.8	7.8	1.39	1.31, 1.46
Congenital Anomalies	1.7	1.0	1.71	1.47, 1.99
Preventative Health Related				
Family Planning	45.9	38.0	1.21	1.18, 1.23
Annual Health Examination	34.5	28.6	1.21	1.17, 1.24
Immunization	15.3	13.1	1.17	1.12, 1.23
Baby Care	1.0	0.7	1.49	1.23, 1.80

4.5 Service Utilization Profiles

The fourth objective was to identify distinct primary care service utilization profiles among people with early psychosis in the six years preceding diagnosis and compare with the general population. In people with early psychosis, the number of primary care contacts per year was best fit by a three-group model with linear, quadratic, and cubic terms. BIC was used to determine each possible model's fit and is provided in APPENDIX F. Figure 4.4 shows the trajectory of each group, Table 4.8 presents the estimates of trajectory parameters, and Table 4.9 presents the estimated number of primary care visits per year for each trajectory.

The first trajectory (n = 23,380; 59% of cases) identified people with early psychosis with low and steady primary care usage (second decile or 1 visit) with an increase to almost the third decile (2 to 4 visits) approximately one year before first diagnosis. The second trajectory (n = 13,468; 34% of cases) identified people with early psychosis with medium and steady primary care usage (third decile or 2 to 4 visits) with an increase to the fourth decile (5 to 7 visits) approximately one year before first diagnosis. The third trajectory (n = 2,601; 7% of cases) identified people with early psychosis with high and increasing primary care usage, beginning at the fifth decile (8 to 10 visits) at approximately six years before first diagnosis and steadily increasing each year to the seventh decile (15 to 18 visits) at approximately one year before first diagnosis. The posterior probabilities of each of the three trajectories are 0.93, 0.89 and 0.94, respectively. Values greater than 0.70 are considered acceptable and indicative of high assignment accuracy,[127] which provides support that the model fit is appropriate. Further, the OCC for each of the three trajectories are 39.86, 24.27 and 47.00, respectively. Values greater than 5.0 suggest that the model has high assignment accuracy,[127] which also provides support that the model fit is appropriate. The linear, quadratic and cubic parameters are significant which suggests that the shape fitted to each trajectory in the model is appropriate.

Figure 4.4 Estimated trajectories of number of primary care contacts per year for the six years leading up to first diagnosis in cases

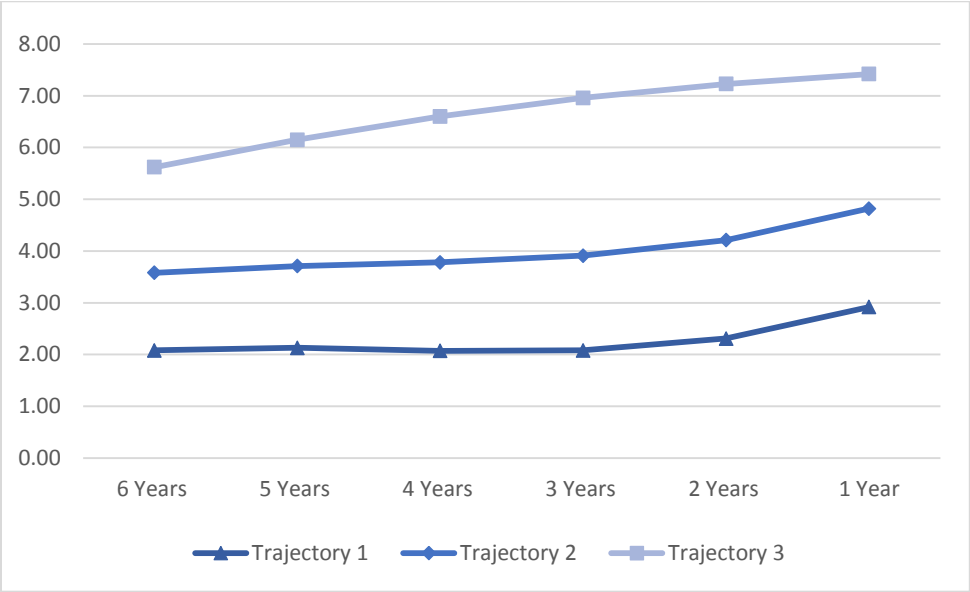


Table 4.8 Estimates of trajectory parameters in cases

Trajectory	Sample Size	% Sample	Posterior Probability	OCC	Parameter	β (SE)	p-value
Low	23,380	59.27	0.93	39.86	Intercept	2.05 (0.01)	< 0.0000
					Linear	0.14 (0.02)	< 0.0000
					Quadratic	-0.13 (0.01)	< 0.0000
					Cubic	0.03 (0.00)	< 0.0000
Medium	13,468	34.14	0.89	24.27	Intercept	3.58 (0.02)	< 0.0000
					Linear	0.21 (0.02)	< 0.0000
					Quadratic	-0.09 (0.01)	< 0.0000
					Cubic	0.02 (0.00)	< 0.0000
High-Increasing	2,601	6.59	0.94	47.00	Intercept	5.62 (0.03)	< 0.0000
					Linear	0.58 (0.03)	< 0.0000
					Quadratic	-0.04 (0.01)	< 0.0000

Table 4.9 Estimated number of primary care contacts in deciles per year leading up to diagnosis and the associated 95% confidence interval for each trajectory in cases

Trajectory		6 Years	5 Years	4 Years	3 Years	2 Years	1 Year
Low	# Visits	2.08	2.13	2.07	2.08	2.31	2.92
	CI	2.06, 2.12	2.10, 2.15	2.05, 2.10	2.06, 2.11	2.29, 2.33	2.90, 2.95
Medium	# Visits	3.58	3.71	3.78	3.91	4.21	4.82
	CI	3.55, 3.61	3.68, 3.74	3.75, 3.81	3.88, 3.94	4.18, 4.24	4.78, 4.86
High-Increasing	# Visits	5.62	6.15	6.60	6.96	7.23	7.42
	CI	5.55, 5.68	6.10, 6.20	6.54, 6.65	6.90, 7.01	7.17, 7.29	7.34, 7.50

In the comparison group, the number of primary care contacts per year was best fit by a three-group model with linear and quadratic terms. BIC was used to determine each possible model's fit and is provided in APPENDIX F. Figure 4.5 shows each groups' trajectory, Table 4.10 presents the trajectory parameter estimates and Table 4.11 presents the estimated number of primary care visits per year for each trajectory. The first trajectory (n = 80,548; 51% of comparisons) identified people in the comparison group with low and steady primary care usage (first decile or 0 visits). The second trajectory (n = 66,156; 42% of comparisons) identified people in the comparison group with medium and steady primary care usage (second decile or 1 visit). The third trajectory (n = 11,092; 7% of comparisons) identified people in the comparison group with high and steady usage (fourth decile or 5 to 7 visits). The posterior probabilities of each of the three trajectories are 0.97, 0.91 and 0.92, respectively. Values greater than 0.70 are considered acceptable and indicative of high assignment accuracy,[127] which provides support in that the model fit is suitable. Further, the OCC for each of the three trajectories are 97.00, 30.33 and 34.50, respectively. Values greater than 5.0 suggest that the model has high assignment accuracy,[127] which also provides support in that the model fit is suitable.

Figure 4.5 Estimated trajectories of number of primary care contacts per year for the six years leading up to first diagnosis in comparisons

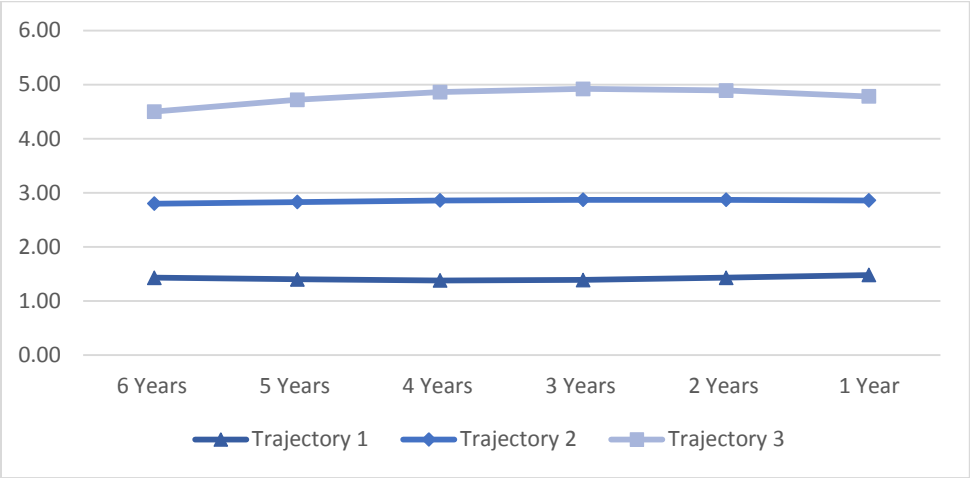


Table 4.10 Estimates of trajectory parameters in comparisons

Trajectory	Sample Size	% Sample	Posterior Probability	OCC	Parameter	β (SE)	p-value
1	80,548	51.05	0.97	97.00	Intercept	1.39 (0.00)	< 0.0000
					Linear	-0.05 (0.00)	< 0.0000
					Quadratic	0.01 (0.00)	< 0.0000
2	66,156	41.93	0.91	30.33	Intercept	2.80 (0.00)	< 0.0000
					Linear	0.04 (0.00)	< 0.0000
					Quadratic	-0.01 (0.00)	< 0.0000
3	11,092	7.03	0.92	34.50	Intercept	4.50 (0.01)	< 0.0000
					Linear	0.27 (0.01)	< 0.0000
					Quadratic	-0.04 (0.00)	< 0.0000

Table 4.11 Estimated number of primary care contacts in deciles per year leading up to diagnosis and the associated 95% confidence interval for each trajectory in comparisons

Trajectory		6 Years	5 Years	4 Years	3 Years	2 Years	1 Year
1	# Visits	1.43	1.40	1.38	1.39	1.43	1.48
	CI	1.42, 1.44	1.39, 1.40	1.38, 1.39	1.39, 1.40	1.42, 1.43	1.47, 1.49
2	# Visits	2.80	2.83	2.86	2.87	2.87	2.86
	CI	2.79, 2.81	2.83, 2.84	2.85, 2.87	2.86, 2.88	2.87, 2.88	2.85, 2.87
3	# Visits	4.50	4.72	4.86	4.92	4.89	4.78
	CI	4.48, 4.52	4.71, 4.74	4.85, 4.88	4.90, 4.94	4.87, 4.91	4.76, 4.80

4.5.1 Differences Between Case and Comparison Trajectories

The service utilization models for people with early psychosis and people in the comparison group both use three trajectory groups, however the people with early psychosis use primary care at higher deciles than the comparison group, specifically for case trajectories one and three. Further, the trajectories for the comparison group remain stable, whereas the trajectories for people with early psychosis all increase. Specifically, trajectory three increases steadily over the six years whereas trajectories one and two remain stable until an increase is seen at one year before first diagnosis in people with early psychosis.

4.5.2 Group Differences Between Case Trajectories

Sociodemographic factors, service-use indicators, and clinical factors were compared between the three trajectory groups for people with early psychosis, and the results are presented in Table 4.12. The RRs presented in this paragraph refer to adjusted RR values. People with early psychosis were more likely to be in low-usage trajectory versus the medium-usage or high-increasing usage trajectories if they were male (RR = 1.39, 95%CI = 1.36, 1.42) and were less likely to be in the low-usage trajectory if they have a regular FP (RR = 0.91, 95%CI = 0.90, 0.92), have a chronic medical condition (RR = 0.63, 95%CI = 0.61, 0.64), have a chronic psychosocial condition (RR = 0.78, 95%CI = 0.77, 0.79), or had contact with the ED or a hospitalization for a MHA reason in the two years prior to diagnosis (RR = 0.87, 95%CI = 0.86, 0.89). There were no significant differences between the low-usage trajectory and the medium-usage or high-increasing usage trajectories regarding index diagnosis, age and location of residence. People with early psychosis were more likely to be in the medium-usage trajectory versus the low-usage or high-increasing usage trajectories if they have a regular FP (RR = 1.42, 95%CI = 1.37, 1.47), have a chronic medical condition (RR = 1.36, 95%CI = 1.32, 1,40), have a chronic psychosocial condition (RR = 2.32, 95%CI = 2.19, 2.45), or had contact with the ED or a hospitalization for a MHA reason in the two years prior to diagnosis (RR = 1.09, 95%CI = 1.06, 1.12) and were less likely to be in the medium-usage trajectory if they were subsequently diagnosed with psychosis NOS (versus schizophrenia spectrum disorder; RR = 0.94, 95%CI = 0.92, 0.97) or are male (RR = 0.70, 95%CI = 0.68, 0.72). There were no significant differences between the medium-usage trajectory and the low-usage or high-increasing usage trajectories

regarding age or location of residence. People with early psychosis were more likely to be in the high-increasing-usage trajectory versus the low-usage or medium-usage trajectories if they are older (24+, RR = 2.55, 95%CI = 2.33, 2.80), have a regular FP (RR = 1.12, 95%CI =1.01,1.24), have a chronic medical condition (RR = 4.10, 95%CI = 3.76, 4.48), have a chronic psychosocial condition (RR = 6.70, 95%CI = 5.18, 8.67) or had contact with the ED or a hospitalization for a MHA reason in the two years prior to diagnosis (RR = 1.70, 95%CI = 1.56, 1.85) and were less likely to be in the high-increasing-usage trajectory if they were subsequently diagnosed with psychosis NOS (versus schizophrenia spectrum disorder; RR = 0.86, 95%CI = 0.79, 0.93) or are male (RR = 0.38, 95%CI = 0.34, 0.41). There were no significant differences between the high-increasing-usage trajectory and the low-usage or medium-usage trajectories regarding location of residence.

The OHIP diagnosis categories associated with primary care use were also compared between the three trajectory groups for people with early psychosis, and the results are presented in Table 4.13, Table 4.14, and Table 4.15 for mental health, physical conditions and preventative health-related contacts, respectively. The three OHIP diagnosis code categories with the highest prevalence in the three trajectories were the same and included non-psychotic disorders (62.5%, 90.2%, 96.6%), diseases of the respiratory system (57.2%, 89.2%, 93.5%) and accidences, poisonings, and violence (50.3%, 78.6%, 89.5%), respectively. The prevalence for each of these OHIP diagnosis code categories increased with each of the three trajectories and this was also the case for almost all other OHIP diagnosis code categories.

Table 4.12 Differences in sociodemographic factors, service-use indicators, and clinical factors between case trajectory groups

	Group (vs. other 2 groups)	Unadjusted RR	95% CI	Adjusted RR	95% CI
Index Diagnosis (ref = schizophrenia spectrum)	1 (vs. 2+3)	1.09	1.07, 1.11	1.01	1.00, 1.02
	2 (vs. 1+3)	0.90	0.88, 0.93	0.94	0.92, 0.97
	3 (vs. 1+2)	0.80	0.74, 0.86	0.86	0.79, 0.93
Age at Index Date (ref = younger age group, 14-23)	1 (vs. 2+3)	0.87	0.86, 0.89	0.98	0.98, 1.00
	2 (vs. 1+3)	1.05	1.02, 1.08	0.97	0.95, 1.00
	3 (vs. 1+2)	2.85	2.62, 3.10	2.55	2.33, 2.80
Sex (ref = female)	1 (vs. 2+3)	1.62	1.59, 1.66	1.39	1.36, 1.42
	2 (vs. 1+3)	0.60	0.58, 0.62	0.70	0.68, 0.72
	3 (vs. 1+2)	0.31	0.29, 0.33	0.38	0.34, 0.41
Family physician access (ref = no regular FP)	1 (vs. 2+3)	0.74	0.73, 0.76	0.91	0.90, 0.92
	2 (vs. 1+3)	1.71	1.65, 1.78	1.42	1.37, 1.47
	3 (vs. 1+2)	1.49	1.36, 1.63	1.12	1.01, 1.24
Location of residence (ref = urban or non-rural)	1 (vs. 2+3)	1.01	0.98, 1.04	1.01	1.00, 1.02
	2 (vs. 1+3)	1.00	0.95, 1.05	1.00	0.96, 1.05
	3 (vs. 1+2)	0.93	0.81, 1.06	0.94	0.81, 1.10
Chronic medical condition (ref = no chronic medical condition)	1 (vs. 2+3)	0.54	0.53, 0.56	0.63	0.61, 0.64
	2 (vs. 1+3)	1.68	1.63, 1.72	1.36	1.32, 1.40
	3 (vs. 1+2)	4.94	4.56, 5.34	4.10	3.76, 4.48
Chronic psychosocial condition (ref = no chronic psychosocial condition)	1 (vs. 2+3)	0.61	0.60, 0.62	0.78	0.77, 0.79
	2 (vs. 1+3)	2.85	2.70, 3.01	2.32	2.19, 2.45
	3 (vs. 1+2)	10.86	8.47, 13.93	6.70	5.18, 8.67
Contact with ED or hospitalization for a MHA reason in 2 years prior to diagnosis (ref = no contact)	1 (vs. 2+3)	0.73	0.72, 0.75	0.87	0.86, 0.89
	2 (vs. 1+3)	1.40	1.36, 1.44	1.09	1.06, 1.12
	3 (vs. 1+2)	2.18	2.03, 2.35	1.70	1.56, 1.85

* Group 1 = Low, Group 2 = Medium, Group 3 = High-Increasing

Table 4.13 Proportion of cases in case trajectory groups that contacted primary care at least once for each of the mental health related diagnosis codes

OHIP Diagnosis Code Category	Group 1	Group 2	Group 3	St. Diff. (1 vs. 2+3)	St. Diff. (2 vs. 1+3)	St. Diff. (3 vs. 1+2)
Alcoholic Psychosis	0.2	0.3	0.7	0.04	0.02	0.07
Behaviour Disorder	6.8	15.9	14.3	***0.28***	***0.26***	***0.13***
Delays in Development	1.0	2.4	2.0	***0.10***	***0.10***	0.04
Senile Dementia or Presenile Dementia	0.2	0.6	0.9	0.06	0.04	0.07
Drug Psychosis	0.5	0.6	1.5	0.03	0.01	0.09
Habit Spasms (i.e., tics, stuttering)	5.5	15.8	29.2	***0.39***	***0.25***	***0.52***
Hyperkinetic Syndrome	2.9	8.2	7.0	***0.22***	***0.21***	0.09
Intellectual Delay	0.6	1.5	1.5	0.09	0.08	0.05
Mental Health & Addictions Services	68.2	93.2	98.1	***0.70***	***0.60***	***0.67***
Childhood Psychoses	1.0	2.2	1.3	0.09	***0.10***	0.01
Non-Psychotic Disorders	62.5	90.2	96.6	***0.72***	***0.61***	***0.70***
Affective Psychotic Disorders	5.4	12.1	20.5	***0.28***	***0.18***	***0.37***
Social Problems	5.8	14.5	22.3	***0.33***	***0.23***	***0.37***
Substance Use Disorder	9.7	19.7	43.1	***0.38***	***0.18***	***0.70***
Tobacco Abuse	1.3	2.7	5.3	***0.12***	0.06	***0.19***

* Group 1 = Low, Group 2 = Medium, Group 3 = High-Increasing

Table 4.14 Proportion of cases in case trajectory groups that contacted primary care at least once for each of the physical condition related diagnosis codes

OHIP Diagnosis Code Category	Group 1	Group 2	Group 3	St. Diff. (1 vs. 2+3)	St. Diff. (2 vs. 1+3)	St. Diff. (3 vs. 1+2)
Accidents, Poisonings and Violence	50.3	78.6	89.5	***0.66***	***0.53***	***0.71***
Diseases of Blood and Blood-Forming Organs	4.0	10.9	18.7	***0.30***	***0.20***	***0.37***
Diseases of the Circulatory System	16.6	38.4	61.1	***0.58***	***0.39***	***0.79***
Congenital Anomalies	0.8	2.3	3.5	***0.13***	***0.10***	***0.14***
Diseases of the Digestive System	31.2	67.6	87.7	***0.87***	***0.65***	***1.02***
Endocrine, Nutritional and Metabolic Diseases and Immunity Disorders	8.8	22.4	37.9	***0.44***	***0.29***	***0.57***
Diseases of the Genito-Urinary System	20.3	53.2	73.7	***0.80***	***0.59***	***0.91***
Infections and Parasitic Diseases	31.9	64.5	77.2	***0.74***	***0.58***	***0.73***
Diseases of Musculoskeletal System and Connective Tissue	30.1	61.1	80.7	***0.73***	***0.54***	***0.88***
Neoplasms	3.9	9.5	18.0	***0.27***	***0.16***	***0.38***
Diseases of the Nervous System and Sense Organs	36.2	68.0	82.1	***0.73***	***0.57***	***0.77***
Non-Mental Health & Addictions Services	N/A	N/A	N/A	***0.37***	***0.35***	***0.29***
Symptoms, Signs and Ill-Defined Conditions	33.9	62.0	78.6	***0.65***	***0.49***	***0.76***
Perinatal Morbidity and Mortality	0.2	0.5	1.7	0.07	0.03	***0.14***
Complications of Pregnancy, Childbirth and the Puerperium	3.3	14.4	27.6	***0.45***	***0.29***	***0.55***
Diseases of the Respiratory System	57.2	89.2	93.5	***0.80***	***0.69***	***0.66***
Diseases of the Skin and Subcutaneous Tissue	40.8	70.5	80.2	***0.66***	***0.54***	***0.63***
Without Diagnosis	25.1	44.0	55.8	***0.45***	***0.34***	***0.49***

* Group 1 = Low, Group 2 = Medium, Group 3 = High-Increasing

Table 4.15 Proportion of cases in case trajectory groups that visited primary care at least once for each of the preventative health related diagnosis codes

OHIP Diagnosis Code Category	Group 1	Group 2	Group 3	St. Diff. (1 vs. 2+3)	St. Diff. (2 vs. 1+3)	St. Diff. (3 vs. 1+2)
Annual Health Examination	20.1	35.4	39.9	***0.36***	***0.30***	***0.31***
Family Planning	7.8	29.5	43.3	***0.63***	***0.46***	***0.63***
Immunization	10.3	15.8	14.5	***0.16***	***0.15***	0.06
Baby Care	0.7	1.3	1.0	0.05	0.06	0.00
Illegitimacy	N/A	N/A	N/A	0.02	0.01	0.04

* Group 1 = Low, Group 2 = Medium, Group 3 = High-Increasing

Chapter 5

5 Discussion

This chapter discusses the findings of the thesis in the context of prior knowledge, the implications of the study findings, as well as the strengths and limitations of the study.

5.1 Overview

Identifying people at high risk for developing psychosis before or soon after they experience full-blown psychotic symptoms is crucial for improving outcomes.[24,25] Prior research suggests that the majority of people are in contact with primary care for a mental health concern in the years leading up to a diagnosis of psychotic disorder, and approximately 30% of youth with FEP receive their first diagnosis from a FP.[7,46,72] One study suggests that contact with primary care tends to occur early in the help-seeking pathway, and is often the first-contacted professional.[61] Thus, the overall objective of the current study was to conduct an in-depth investigation of service utilization patterns in primary care preceding a first diagnosis of psychotic disorder. More specifically, the study objectives were to describe the frequency of primary care use, the timing of primary care contacts and the OHIP diagnosis code categories associated with primary care contacts among people with early psychosis, relative to the general population. Further, this study aimed to identify distinct service utilization help-seeking profiles among people with early psychosis in the six years preceding diagnosis.

5.2 Interpretation of Study Results

5.2.1 Frequency of Primary Care Use

Our findings suggest that people with early psychosis visit primary care at a higher frequency than the general population during the six years preceding first diagnosis, with over twice as many primary care contacts relative to the population comparison group. There was also higher visit frequency with increasing age.

Other studies using health administrative data to investigate prodromal help-seeking or service utilization report that a large proportion of young adult patients make help-seeking attempts prior to the first diagnosis of psychosis,[4,46] as seen in the current study. Two previous studies from the UK found that people with psychotic disorders have higher visit rates in general practice compared with people without psychotic disorders,[8,73] with differences evident up to six years prior to first diagnosis, although the cohorts included people of all ages.[8] This pattern was similarly found in the current study, where young people with early psychosis have a higher number of contacts with primary care compared to the comparison group, in all six years leading up to first diagnosis. However, the study by Norgaard and colleagues reported that cases of schizophrenia used daytime primary care 43% more than controls during the six years before diagnosis (RR = 1.43, 95%CI = 1.39, 1.48),[8] which is a smaller effect size than the RR of 2.22 (95%CI = 2.19, 2.25) found in the current study. We investigated all contacts to primary care, without distinguishing between daytime or afterhours care, and this may explain the larger effect found or it could be a result of the cohorts having different age ranges. Further, the study by Norgaard et al. also found that cases diagnosed with schizophrenia after age 22 had more primary care contacts than cases diagnosed before age 22,[8] which is similar to the pattern found in the current study – higher primary care visit frequency with increasing age.

People with other medical conditions also show higher use of healthcare services in the time leading up to first diagnosis. For example, one study found that people who were subsequently diagnosed with chronic obstructive pulmonary disease (COPD) had 54% more GP visits in the year leading up to diagnosis, compared to controls without COPD (IRR = 1.54, 95%CI = 1.51, 1.58).[128] Another study reports that females who were subsequently diagnosed with a benign tumour had higher odds of visiting their GP between 5 and 9 times (OR = 1.25, 95%CI = 1.14, 1.38) and greater than 10 times (OR = 1.35, 95%CI = 1.20, 1.53) in the two years leading up to diagnosis, compared to the control subjects.[129] Further, a study reports that cases who were subsequently diagnosed with a sarcoma contacted primary care at a higher rate than controls, beginning at twelve months to diagnosis and peaking in the final month (IRR = 12.41, 95%CI = 12.41, 15.54).[130] These findings suggest that the patterns of primary care use observed in the current study may not be unique to people with psychotic disorders.

5.2.2 Timing of Primary Care Use

The current study found that people with early psychosis contacted primary care at an increasing rate, whereas the general population contacted primary care at a steady rate during the six years preceding diagnosis. The number of primary care contacts per year begins to increase approximately two years before first diagnosis for people with early psychosis, with no change for the comparison group over the six-year observation period. People with early psychosis who had contact with the ED or a hospitalization for a MHA reason had higher primary care usage in all six years of the observation period prior to diagnosis, compared to cases without contact. The largest increase in number of primary care contacts in people with early psychosis occurs at ten months before diagnosis.

A prior study in the UK by Norgaard and colleagues reported that consultations with primary care measured bimonthly from six years before index diagnosis showed an increased use of consultations among cases compared with controls, and a distinct increase observed specifically during the last two months before first diagnosis.[8] Another study in the UK by Sullivan and colleagues reported increasing primary care consultation rates during the five years before the index diagnosis, compared with controls.[73] Although both of these studies involved patients of all ages, this same pattern of increasing contacts with primary care among people with early psychosis is observed in the current study. For contacts occurring close to the index date, these repeated contacts may reflect a FP's difficulty in recognizing early signs and symptoms of psychosis. Alternatively, psychotic disorders evolve over time and more than one consultation may be needed to gather enough information to confirm a diagnosis. It may also suggest uncertainty regarding diagnosis, or that the FP may be conservative in providing a psychosis diagnosis due to the seriousness of the term and consequences for the patient. Finally, it may also reflect an absence of partnership with EPI programs and other specialized mental health services, as the FP may be having difficulty connecting with psychiatric care.[61,75,90–92,131] Contacts occurring many years before the index diagnosis could potentially be explained by poor premorbid adjustment – people who are later diagnosed with schizophrenia often experience emotional problems, interpersonal difficulties, and neuromotor, language and cognitive

impairments in childhood before psychotic symptoms emerge during adolescence or young adulthood.[132] Overall, this pattern of increasing consultation rates should signal to the FP that there is something wrong and offers an opportunity for intervention.

Further, the UK study by Norgaard and colleagues found that people of all ages with at least one contact to the ED or a hospitalization for a MHA reason before their index diagnosis showed higher use of primary care during all six years before their diagnoses, compared to people without contact.[8] This same pattern of higher use of primary care in people with early psychosis with a contact with the ED or a hospitalization for a MHA reason is also observed in the current study. In contrast to our findings, Norgaard and colleagues found that cases with no ED or a hospitalization contacts for a MHA reason before diagnosis had normal FP attendance rates (i.e., similar to controls) until three to four years before diagnosis.[8] In the current study, however, people with early psychosis with no ED or a hospitalization contacts for a MHA reason before the first diagnosis still contacted primary care at a higher rate compared to the comparison group at least six years prior to diagnosis, although lower than cases who had contact with the ED or a hospitalization for a MHA reason.

The pattern of increased health care utilization leading up to diagnosis of a health condition has also been found in other patient groups, with variations in the timing of increase depending on the particular health condition. For example, one study reports that most patients had few clinical encounters until approximately six months before a diagnosis of pancreatic cancer, where a rise in healthcare utilization was seen.[133] Another study reports increased healthcare utilization as the patient approached an inpatient surgical procedure.[134] Further, a study reports that contacts with FPs, out-patient clinics and EDs all increased over the fourteen years before lower extremity amputation, particularly with larger rise in the last two years.[135] Another study reports that the rates of contacts with general practice increased significantly from nine months prior to sarcoma diagnosis.[130]

5.2.3 OHIP Diagnosis Codes Associated with Primary Care Use

Males and females with early psychosis have higher contact frequency across nearly all conditions, including mental health, physical conditions, and preventative health related contacts, compared to the matched comparison group. Over three quarters of people with early psychosis contacted primary care at least once for a MHA related reason over the six-year observation period, compared to less than a third of the comparison group.

A prior study by Simon and colleagues from the USA found that 29% of young adult patients had a primary care visit with a mental health diagnosis during the year before a first psychotic disorder diagnosis,[60] and another study in Canada by Anderson and colleagues found that in the 4 years preceding the index diagnosis of psychosis, 60% of young adult patients were in contact with primary care for a mental health concern.[46] The discrepancy in these numbers compared to this study's findings may be a result of the different observation period,[46] the different study context (USA vs. Canada),[60] or that this study's findings are stratified by sex. Another study reported that, based on primary care consultation patterns in the five years before diagnosis, twelve symptoms are associated with a subsequent psychotic diagnosis: attention-deficit/ hyperactivity disorder-like symptoms, bizarre behaviour, blunted affect, problems associated with cannabis, depressive symptoms, role functioning problems, social isolation, symptoms of mania, obsessive-compulsive disorder–like symptoms, sleep disturbance, problems associated with cigarette smoking, and suicidal behaviour, although this cohort included people of all ages in the UK.[73] Similarly, the current study found the following related primary care diagnoses in the six years before diagnosis to be significantly associated with a subsequent psychosis diagnosis: behaviour disorder, substance use disorder, non-psychotic disorders, social problems, and tobacco abuse. One study in the UK by Rietdijk and colleagues found that most young adult patients sought treatment for anxiety and mood disorders, substance use disorders, and adjustment disorders before the onset of the first psychotic episode.[4] More women sought help for anxiety, mood, and adjustment disorders and more men sought help for substance use and personality disorders.[4] In the current study, most people with early psychosis did seek help for other mental disorders leading up to first diagnosis (i.e., non-psychotic disorders including anxiety, depression, personality disorders, adjustment disorders); however, given that these disorders were grouped together for analyses, it cannot be determined whether there were sex

differences in the proportion of people with early psychosis who contacted primary care for help with specific mental disorders separately. However, a higher proportion of men than women with early psychosis contacted primary care with an OHIP diagnosis code related to substance use disorder in the current study, which is in line with previous findings. A study in the UK by Sorensen et al. documented that people of all ages with schizophrenia had a higher number of somatic hospital contacts before a first diagnosis compared with mentally healthy individuals,[74] a pattern also seen in the current study with primary care contacts. The heterogeneity in diagnostic codes used for visits preceding diagnosis are expected given the heterogenous symptoms seen in prodromal psychosis and are consistent with other studies using health administrative data to investigate prodromal help-seeking and service utilization.[4,46] Additionally, people with schizophrenia often have other physical comorbidities,[13–19] which may account for the increased number of primary care contacts related to physical health conditions. Finally, the increased number of contacts related to preventative health may be a result of a family physician practicing opportunistic prevention, where each contact provides an opportunity for the prevention of illness and encouragement of healthy lifestyles, and may include the provision of additional services unrelated to the reason for presentation.[136]

5.2.4 Service Utilization Profiles

Three trajectories of service use over the six-year observation period were identified for people with early psychosis: low usage, medium usage, and high increasing usage. Both the low and medium usage trajectories remain steady until an increase at one year before diagnosis, whereas the high increasing trajectory increases steadily over the six-year observation period. Three trajectories of service use were identified for the comparison group: low usage, medium usage, and high usage. All three trajectories remain steady over the six-year observation period with no increases as observed in the trajectories of people with FEP. All three trajectories for people with FEP confirm higher frequency of primary care use than the comparison group.

Previous research found two service utilization patterns for prodromal schizophrenia: (1) multiple psychiatric contacts and general practitioner visits during at least 6 years before the index schizophrenia diagnosis; and (2) no psychiatric contacts before the diagnosis and normal

general practitioner attendance rates until three to four years before diagnosis, followed by an increase.[8] As mentioned previously, the second pattern is not consistent with the current study results and additionally, these patterns were identified using stratified graphs with multiple variables, rather than Latent Class Growth Modelling as in the current study.

Further, the trajectories identified in the current study may not be unique to psychotic disorders and instead may be expected prior to the first diagnosis of other serious medical conditions. For example, using group-based trajectory modelling, a study on health-care utilization prior to the diagnosis of pancreatic cancer found four distinct trajectories: late acceleration, early acceleration, high outpatient utilization, and high overall utilization. The most common trajectory was few clinical encounters until six months prior to diagnosis, where there was a large increase in service utilization,[133] which is a similar trend seen in the low and medium use trajectories in the current study. Further, the current study also identified a trajectory where increases in health care usage were seen earlier than other trajectories (high-increasing usage trajectory), which is similar to the early acceleration trajectory reported in the aforementioned study.[133]

5.3 Strengths

There are numerous strengths of this study. These findings provide in-depth information on the patterns of primary care use among young people with early psychosis using population-based health administrative data. This study also investigates the OHIP diagnosis codes associated with service utilization from the FP, which was a limitation of previous research on this topic,[8] in addition to the number and timing of contacts with primary care. Further, this study uses a large sample that includes a cohort of all cases of non-affective psychotic disorder in Ontario and a matched cohort from the general population.

5.4 Limitations

There are limitations of this study that must be taken into consideration when interpreting the results. This study is limited by the variables available in the ICES databases, and is therefore missing some important confounding factors, such as the severity of symptoms and the acuity of first presentation. Additionally, this study was unable to adjust for race and ethnicity due to restrictions on access to specific variables related to race and ethnicity, which has a documented association with access to care.[50,68,137–139] The databases also do not have information on the timing of onset of psychotic symptoms and thus this study cannot decipher between service utilization for prodromal psychosis or active psychosis, which may confound the patterns observed. Further, it is possible that other comorbidities concurrently developed with psychosis and may also contribute to service utilization in this population, but since the clinical factors were only measured at the index date, we cannot decipher whether this is the case.

The ICES databases were also not developed for research purposes, and the validity of codes entered in the database may not be accurate due to under- or over-coding of diagnoses and inaccurate recording of information due to interpretation, illegibility, terminology, unreliability and incompleteness, since there is a lack of diagnostic standardization across professionals.[140,141] For example, it has been found that primary care physicians provide mental health services in the context of shorter general medical visits that may not be coded with specific mental health service codes,[114,142] as physicians are limited to one diagnostic code per encounter. There is a disconnect between physician documentation for clinical care and for billing and coding.[141] Further, a qualitative study investigating barriers to data quality in administrative data reported that the majority of barriers to high quality data coding exist in the data generation process where physicians complete documentation for each healthcare interaction, which has been consistently shown in other studies as well.[140]

In assigning an OHIP diagnosis code for the primary care contact, when multiple contacts on same day occurred only the first diagnosis code entered into the OHIP database was retained, and thus, the diagnosis code retained may not provide an accurate description of the real diagnosis associated with the primary care contact. For example, a physician may submit several MHA-related claims for a patient on the same day and to avoid duplicate counting of visits, only the

first MHA claim for any given unique patient-provider combination is retained. If a patient visited two independent physicians on any given day, then that would be recorded as two separate contacts to primary care.

The current study used a modified algorithm to detect people with FEP. The original algorithm[112] was validated using the health records of psychiatric inpatients with chronic schizophrenia for feasibility and sample size. The validation study found that using physician service claims and hospitalization data improved sensitivity, whereas using hospitalization data only had the highest specificity and positive predictive value. The authors noted that if one is interested in capturing close to the entire population of people with chronic psychotic illness, then including physician visits for case detection would be advantageous but the false positive rate would be higher.[112] The current study used a combination of hospitalization data and physician service claims. Cases were identified by either a primary discharge diagnosis of non-affective psychosis (i.e., schizophrenia, schizoaffective disorder, schizophreniform disorder or psychosis NOS) from a hospital bed, or at least two OHIP billing claims or ED visits with a diagnostic code for non-affective psychosis in any 12-month period. Thus, the current study identified an inclusive and representative cohort of people with FEP, especially of people with less severe forms of early psychosis, but may include false-positive cases. Further, the cases identified in this study were not psychiatric inpatients like in the sample used to validate the original algorithm and the algorithm was developed for chronic psychotic disorders, not first onset psychotic disorders as seen in the current study; thus, the algorithm performance may not be as stated in the original validation article.[112]

This study also defined the cohort using non-affective psychosis (i.e., schizophrenia, schizoaffective disorder, delusional disorder, schizophreniform disorder, and brief psychotic disorder), as we are unable to identify people with affective psychosis (i.e., bipolar disorder and major depressive disorder) using health administrative data, and therefore results do not generalize to those experiencing affective psychosis. Further, EPI programs often have an age restriction of 14 to 35 years. Due to the lookback window of six years, someone who was diagnosed with FEP when they were young teenagers would have service utilization data from childhood.

Finally, the administrative data used in the current study did not capture all contacts with primary care. Nurse practitioners or salaried physicians working in Community Health Centres or Health Service Organizations, for example, are not captured in the OHIP database. These nurses or physicians often provide primary care services in clinics for underprivileged populations or populations that do not have access to services covered by OHIP, and these services would not be recorded in the OHIP database. In 2012, approximately 60,000 Ontarians used Community Health Centres and were more likely to be low-income, immigrants and had higher levels of morbidity and co-morbidity.[143] Further, physicians compensated through Alternate Fee Plans (non-fee-for-service physicians) are also not included in the OHIP database, although ICES states that these plans only account for 5% of total physician expenditure and these physicians are incentivized to submit "shadow billings" as if they were being paid through fee-for-service so that a record of their services is available.[107,108]

5.5 Future Research

Future research is needed to better understand the patients' perspective on patterns of primary care use leading up to diagnosis. More information could be collected to complement the health administrative data. For example, patients could advise on symptoms they were experiencing before diagnosis that they sought help for, and their overall experience interacting with FPs for these symptoms. Further, future research could prospectively follow the identified service use trajectories to evaluate long-term outcomes related to psychotic illness or compare the primary care service utilization in the current study to that of other mental health diagnoses.

5.6 Conclusion

Exploring primary care service utilization by young people with FEP is extremely valuable for understanding the care provided by FPs, and how we can better support FPs in the important role that they play as a key contact for mental health services. The study findings suggest that people with early psychosis use primary care at much higher frequency leading up to diagnosis than the

general population, which offers opportunities for early intervention. The patterns of service use presented in this study strongly support the notion that family physicians play an active and key role on the pathways to care for young people with FEP. The information gathered in the current study can inform interventions aimed at better supporting FPs in their role in pathways to care for people with FEP, such as additional training and resource allocation to improve necessary collaborations between primary care and EPI programs. In turn, this will improve the detection of early psychosis in primary care, which has large implications for improved social, educational and professional development in young people with FEP.

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Appendices

APPENDIX A The RECORD statement – checklist of items, extended from the STROBE statement, that should be reported in observational studies using routinely collected health data

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Title and abstract					
	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found		RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included. RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract. RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in	Abstract

				the title or abstract.	
Introduction					
Background rationale	2	Explain the scientific background and rationale for the investigation being reported			Introduction
Objectives	3	State specific objectives, including any prespecified hypotheses			Literature Review- Objectives
Methods					
Study Design	4	Present key elements of study design early in the paper			Methods- Study Design
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection			Methods- Study Design
Participants	6	*(a) Cohort study* - Give the eligibility criteria, and the sources and methods of selection of participants. Describe		RECORD 6.1: The methods of study population selection (such as codes or algorithms used to identify subjects) should be listed in	Methods- Cohort Definition

		methods of follow-up *Case-control study* - Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study* - Give the eligibility criteria, and the sources and methods of selection of participants *(b) Cohort study* - For matched studies, give matching criteria and number of exposed and unexposed *Case-control study* - For matched studies, give matching criteria and the number of		detail. If this is not possible, an explanation should be provided. RECORD 6.2: Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided. RECORD 6.3: If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at	

		controls per case		each stage.	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.		RECORD 7.1: A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.	Methods-Variable Definitions and Appendices
Data sources/ measurement	8	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group			Methods- Data Sources
Bias	9	Describe any efforts to address potential sources of bias			Discussion-Limitations
Study size	10	Explain how the study size			Methods- Cohort Definition

		was arrived at			
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why			Methods-Statistical Analyses
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) *Cohort study* - If applicable, explain how loss to follow-up was addressed *Case-control study* - If applicable, explain how matching of cases and controls was			Methods-Statistical Analyses

		addressed *Cross-sectional study* - If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses			
Data access and cleaning methods		..		RECORD 12.1: Authors should describe the extent to which the investigators had access to the database population used to create the study population. RECORD 12.2: Authors should provide information on the data cleaning methods used in the study.	Methods- Study Design and Data Sources
Linkage		..		RECORD 12.3: State whether the study included person-level, institutional-level, or other	Methods- Study Design and Data Sources

				data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided.	
Results					
Participants	13	(a) Report the numbers of individuals at each stage of the study (*e.g.*, numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed) (b) Give reasons for non-participation at each stage. (c) Consider use of a flow diagram		RECORD 13.1: Describe in detail the selection of the persons included in the study (*i.e.*, study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram.	Results- Cohort Characteristics
Descriptive data	14	(a) Give characteristics of study participants (*e.g.*,			Results- Cohort Characteristics

		demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) *Cohort study* - summarise follow-up time (*e.g.*, average and total amount)			
Outcome data	15	*Cohort study* - Report numbers of outcome events or summary measures over time *Case-control study* - Report numbers in each exposure category, or summary measures of exposure *Cross-sectional study* - Report numbers of outcome events or summary			Results

		measures			
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period			Results
Other analyses	17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity			Results

		analyses			
Discussion					
Key results	18	Summarise key results with reference to study objectives			Discussion-Interpretation of Study Results
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias		RECORD 19.1: Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported.	Discussion-Limitations
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant			Discussion-Conclusion

		evidence			
Generalisability	21	Discuss the generalisability (external validity) of the study results			Discussion-Strengths
Other Information					
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based			Acknowledgements
Accessibility of protocol, raw data, and programming code		..		RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	Appendices

*Reference: Benchimol EI, Smeeth L, Guttmann A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD Working Committee. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine* 2015; 12(10).

APPENDIX B List of Diagnostic Codes for Cohort Definition

OMHRS:

Schizophrenia & schizoaffective disorder:

295 (295, 295.X, or 295.XX)

Psychosis NOS:

298 (298, 298.X, or 298.XX)

DAD (ICD-10):

F20 = SCHIZOPHRENIA

F200 = PARANOID SCHIZOPHRENIA

F201 = HEBEPHRENIC SCHIZOPHRENIA

F202 = CATATONIC SCHIZOPHRENIA

F203 = UNDIFFERENTIATED SCHIZOPHRENIA

F204 = POST-SCHIZOPHRENIC DEPRESSION

F205 = RESIDUAL SCHIZOPHRENIA

F206 = SIMPLE SCHIZOPHRENIA

F208 = OTHER SCHIZOPHRENIA

F209 = SCHIZOPHRENIA, UNSPECIFIED

F25 = SCHIZOAFFECTIVE DISORDERS

F250 = SCHIZOAFFECTIVE DISORDER, MANIC TYPE

F251 = SCHIZOAFFECTIVE DISORDER, DEPRESSIVE TYPE

F252 = SCHIZOAFFECTIVE DISORDER, MIXED TYPE

F258 = OTHER SCHIZOAFFECTIVE DISORDERS

F259 = SCHIZOAFFECTIVE DISORDER, UNSPECIFIED

F29 = UNSPECIFIED NONORGANIC PSYCHOSIS

DAD (ICD-9):

295 = SCHIZOPHRENIAS

29500 = SIMPL SCHIZOPHREN-UNSPEC

29501 = SIMPL SCHIZOPHREN-SUBCHR

29502 = SIMPLE SCHIZOPHREN-CHR

29503 = SIMP SCHIZ-SUBCHR/EXACER

29504 = SIMPL SCHIZO-CHR/EXACERB

29505 = SIMPL SCHIZOPHREN-REMISS

2951 = HEBEPHRENIA-UNSPEC

2952 = CATATONIA-UNSPEC

2953 = PARANOID SCHIZO-UNSPEC

2954 = AC SCHIZOPHRENIA-UNSPEC

2955 = LATENT SCHIZOPHREN-UNSP

2956 = RESID SCHIZOPHREN-UNSP

2957 = SCHIZOAFFECTIVE-UNSPEC

2958 = SCHIZOPHRENIA NEC-UNSPEC

2959 = SCHIZOPHRENIA NOS-UNSPEC

298 = OTHER PSYCHOSES

2980 = REACT DEPRESS PSYCHOSIS

2981 = EXCITATIV TYPE PSYCHOSIS

2982 = REACTIVE CONFUSION

2983 = ACUTE PARANOID REACTION

2984 = PSYCHOGEN PARANOID PSYCH

2988 = REACT PSYCHOSIS NEC/NOS

2989 = PSYCHOSIS NOS

<u>OHIP DXCODE</u>

295 = SCHIZOPHRENIA

298 = OTHER PSYCHOSES

APPENDIX C Complete list of variables and their definitions

Variables Already Created in Dataset	
Main Comparison Group	
fep_case	Cases versus controls defined as: 1 = incident case of first-episode psychosis (FEP; i.e., index event) 0 = controls sampled from the general population, matched on age, sex, and location of residence (postal code from RPDB)
Baseline Characteristics	
sex	Sex from RPDB at index date (M or F)
agegrp	Age on the index date, calculated based on date of birth from RPDB, categorized into 14-17, 18-20, 21-23, 24-26, 27-29, 30-32, or 33-35.
incquint	INCQUINT from %GETDEMO (1 = lowest income quintile, 5 = highest income quintile) at index date
rural	RURAL from %GETDEMO (1 = rural, 0 = non-rural) at index date
dependency	DEPENDENCY_Q_CSD from ONMARG (1 = least marginalized, 5 = most marginalized)
deprivation	DEPRIVATION_Q_CSD from ONMARG (1 = least marginalized, 5 = most marginalized)
ethniccon	ETHNICCON_Q_CSD from ONMARG (1 = least marginalized, 5 = most marginalized)
instability	INSTABILITY_Q_CSD from ONMARG (1 = least marginalized, 5 = most marginalized)
index_dx	Index diagnosis of psychotic disorder, classified as follows: 1 = schizophrenia spectrum (ICD-9 = 295.x, ICD-10 = F20, F25) 2 = psychosis NOS (ICD-9 = 298.x, ICD-10 = F29)
Main Exposures or Risk Factors	
rub	RUB from %GETACG (0 = no or invalid diagnoses [non-user], 1 = healthy users, 5 = very high users)
adg_total	Number of ADGs for each patient (0 to 32)
adg_cat	Categorize the total number of ADGs calculated as follows: 1 = low (adg_total < 5) 2 = medium (adg_total = 6-9)

	3 = high (adg_total ≥ 10)
adg_chronic_medical	Flag any chronic medical condition from %GETACG, classified as follows: 0 = no chronic medical conditions 1 = at least one chronic medical condition (CADG = 5 [chronic medical: unstable], 6 [chronic medical: stable], 9 [chronic specialty: unstable])
adg_chronic_psych	Flag any chronic psychosocial condition (i.e., recurrent or persistent), classified as follows: 0 = no chronic psychosocial conditions 1 = at least one chronic psychosocial condition (ADG = 24 [psychosocial: recurrent or persistent, stable] or 25 [psychosocial: recurrent or persistent, unstable])
edc_total	Number of EDCs for each patient (0 to 264)
hosp_mh_2y	Count the number of psychiatric hospitalization in the 2 years prior to the index date. • From DAD var DX10CODE1 with any of the following ICD-10-CA codes: F04 to F99, or DX10CODE2 to DX10CODE10 = X60-X84, Y10-Y19, Y28 AND DX10CODE1 ne F04 to F99 • From OMHRS: o If var AXIS1_DSM4CODE_DISCH1 complete (i.e,. listed diagnosis from below present) use AXIS1_DSM4CODE_DISCH1 o No, use PROVDX1 o DSM-IV: Any (including missing diagnoses; excluding 290.x or 294.x) o Exclude OMHRS admissions if AXIS1_DSM4CODE_DISCH1 in: (290.x OR 294.x) • Include visits/admissions with suspect diagnoses (suspect = T). Hospitalizations must be constructed as episodes of care as follows: 1. Pull all DAD and OMHRS records between the specified calendar years (CY) being examined for this indicator with an ICD-10-CA primary discharge diagnosis of F04 to F99 or DSM-IV codes, excluding 290.x and 294.x 2. Identify the IKNs found for these records 3. For only the IKNs identified in the previous step, pull all DAD records from 1988 onwards and all OMHRS records for all diagnoses, i.e. not only mental health diagnoses, and create episodes by adjoining OMHRS/DAD records that overlap within (+/-) 1 day. These will be considered part of a single episode. 4. Use discharge diagnoses and other variables from the final discharge of the episode 5. Note, if 2 or more records have the same discharge date as the

	discharge date of the episode, use an OMHRS discharge diagnoses, if applicable (i.e. if one record is DAD and one is OMHRS, take the OMHRS diagnoses) SAS code location for episode creation can be located here: /users/qli/projects/MHA/p2014.0900.300.004_MHASEF_Phase1_Age0To24/02_cre8epi_final.sas NOTE 1: Definition derived from ICES MH Indicators document. Refer to Acute Care section, indicator #1 (p. 10) and p 13 for diagnostic groupings.
hosp_mh_2y_flag	Flag if patient had at least one psychiatric hospitalization in hosp_mh_2y 0 = no psychiatric hospitalizations in past 2 years 1 = at least 1 psychiatric hospitalization in past 2 years
hosp_any_2y	Count number of any other hospitalizations (DAD or OMHRS) in the 2 years prior to the index date, not captured in hosp_mh_2y.
hosp_any_2y_flag	Flag if patient had at least one admission captured in hosp_any_2y variable. 0 = no hospitalization in 2 years prior to index date 1 = at least one hospitalization in 2 years prior to index date
ed_mh_2y	Count the number of ED visit in the 2 years prior to the index date for a mental health/addictions reason. Use %GETNACRS, DX10CODE1 with any of the following ICD-10 codes: • ICD-10-CA: F04 to F99 (excludes dementia) OR • (X60-X84, Y10-Y19, Y28) in Dx10Code2 to Dx10Code10 AND no specified Mental Health code in Dx10Code1 (F04 to F99) Exclude: • Scheduled ED visits (INCLSCHEDULED=F) • Transfers from another ED (FROM_TYPE=’E’; DEDUP=’T’ in %GETNACRS) NOTE 1: Definition derived from ICES MH Indicators document. Refer to Acute Care section, indicator #1 (p. 10) and p 13 for diagnostic groupings.
ed_mh_2y_flag	Flag if patient had at least 1 ED visit captured in the ed_mh_2y variable: 0 = no ED visits

	1 = at least 1 ED visit for a mental health reason
ed_any_2y	Count ED visits in the 2 years prior to the index date for any reason not captured in the ed_mh_2y variable
ed_any_2y_flag	Flag if patient had an ED visits for any reason captured in the ed_any_variable: 0 = no ED visits 1 = at least 1 ED visit for any reason not included in ed_mh_2y
fp_access	Person is assigned to a FP in the regular_fp variable on the index date, classified as follows: 0 = no regular FP (R_TYPE=N in PCPOP, and patient not rostered to a FP in CAPE) 1 = regular FP (R_TYPE = R or V in PCPOP, or patient is rostered to a FP in CAPE)
Other Variables	
indexfdate	Year of index diagnosis

Variables To Be Created By Student Using OHIP Records

Outcomes	
PCV_total	Total number of primary care visits, defined by counting the number of FEECODEs billed from OHIP for each patient
PCV_Y1 – PCV_Y6	Number of primary care visits per year for each of the 6 years prior to index date, defined by counting the number of FEECODEs billed per person from OHIP in each of the 6 years prior to the index date
decPCV_Y1-decPCV_Y06	PCV_Y1 – PCV_Y6 variables categorized into deciles for LCGM analyses
PCV_Y1A, to PCV_Y1F - PCV-Y6A to PCV_Y6F	Number of primary care visits bimonthly for each of the 6 years prior to index date, defined by counting the number of FEECODEs billed per person from OHIP every 2 months for 6 years prior to the index date
PCV_Y1A_Flag, to PCV_Y1F_Flag - PCV-Y6A_Flag to PCV_Y6F_Flag	Flag if patient had at least 1 primary care visit captured in each of the PCV_Y1A, to PCV_Y1F - PCV-Y6A to PCV_Y6F in the 6 years prior to the index date per patient

InfectionParasite	Count the total number of visits to primary care with DXCODE = 002-136 (Category: Infections and Parasitic Diseases) from OHIP in the 6 years prior to the index date per patient
InfectionParasite_Flag	Flag if patient had at least 1 primary care visit captured in the InfectionParasite variable: 0 = no visits, 1 = at least 1 visit
Neoplasms	Count the total number of visits to primary care with DXCODE = 140-239 (Category: Neoplasms) from OHIP in the 6 years prior to the index date per patient
Neoplasms_Flag	Flag if patient had at least 1 primary care visit captured in the Neoplasms variable: 0 = no visits, 1 = at least 1 visit
Endometabolic	Count the total number of visits to primary care with DXCODE = 240-279 (Category: Endocrine, Nutritional and Metabolic Diseases and Immunity Disorders) from OHIP in the 6 years prior to the index date per patient
Endometabolic_Flag	Flag if patient had at least 1 primary care visit captured in the Endometabolic variable: 0 = no visits, 1 = at least 1 visit
Blood	Count the total number of visits to primary care with DXCODE = 280-289 (Category: Diseases of Blood and Blood-Forming Organs) from OHIP in the 6 years prior to the index date per patient
Blood_Flag	Flag if patient had at least 1 primary care visit captured in the Blood variable: 0 = no visits, 1 = at least 1 visit
Nervous	Count the total number of visits to primary care with DXCODE = 320-389 or 780 (Category: Diseases of the Nervous System and Sense Organs) from OHIP in the 6 years prior to the index date per patient
Nervous_Flag	Flag if patient had at least 1 primary care visit captured in the Nervous variable: 0 = no visits, 1 = at least 1 visit
Circulatory	Count the total number of visits to primary care with DXCODE = 390-459 or 785 (Category: Diseases of the Circulatory System) from OHIP in the 6 years prior to the index date per patient

Circulatory_Flag	Flag if patient had at least 1 primary care visit captured in the Circulatory variable: 0 = no visits, 1 = at least 1 visit
Respiratory	Count the total number of visits to primary care with DXCODE = 460-519 or 786 (Category: Diseases of the Respiratory System) from OHIP in the 6 years prior to the index date per patient
Respiratory_Flag	Flag if patient had at least 1 primary care visit captured in the Respiratory variable: 0 = no visits, 1 = at least 1 visit
Digestive	Count the total number of visits to primary care with DXCODE = 521-579 or 787 (Category: Diseases of the Digestive System) from OHIP in the 6 years prior to the index date per patient
Digestive_Flag	Flag if patient had at least 1 primary care visit captured in the Digestive variable: 0 = no visits, 1 = at least 1 visit
GenitoUrinary	Count the total number of visits to primary care with DXCODE = 580-629 or 636 or 788 (Category: Diseases of the Genito-Urinary System) from OHIP in the 6 years prior to the index date per patient
GenitoUrinary_Flag	Flag if patient had at least 1 primary care visit captured in the GenitoUrinary variable: 0 = no visits, 1 = at least 1 visit
Pregchildbirth	Count the total number of visits to primary care with DXCODE = 632-635 or 640-677 (Category: Complications of Pregnancy, Childbirth and the Puerperium) from OHIP in the 6 years prior to the index date per patient
Pregchildbirth_Flag	Flag if patient had at least 1 primary care visit captured in the Pregchildbirth variable: 0 = no visits, 1 = at least 1 visit
Skin	Count the total number of visits to primary care with DXCODE = 680-709 (Category: Diseases of the Skin and Subcutaneous Tissue) from OHIP in the 6 years prior to the index date per patient
Skin_Flag	Flag if patient had at least 1 primary care visit captured in the Skin variable: 0 = no visits, 1 = at least 1 visit
Muscoloskeletal	Count the total number of visits to primary care with DXCODE = 710-739

	or 781 (Category: Diseases of Muscoloskeletal System and Connective Tissue) from OHIP in the 6 years prior to the index date per patient
Muscoloskeletal_Flag	Flag if patient had at least 1 primary care visit captured in the Muscoloskeletal variable: 0 = no visits, 1 = at least 1 visit
CongenitalAnom	Count the total number of visits to primary care with DXCODE = 741-759 (Category: Congenital Anomalies) from OHIP in the 6 years prior to the index date per patient
CongenitalAnom_Flag	Flag if patient had at least 1 primary care visit captured in the CongenitalAnom variable: 0 = no visits, 1 = at least 1 visit
PerinatalMorbidMort	Count the total number of visits to primary care with DXCODE = 762-779 (Category: Perinatal Morbidity and Mortality) from OHIP in the 6 years prior to the index date per patient
PerinatalMorbidMort_Flag	Flag if patient had at least 1 primary care visit captured in the PerinatalMorbidMort variable: 0 = no visits, 1 = at least 1 visit
NonSpecificAbnormal	Count the total number of visits to primary care with DXCODE = 790-799 (Category: Symptoms, Signs and Ill-Defined Conditions) from OHIP in the 6 years prior to the index date per patient
NonSpecificAbnormal_Flag	Flag if patient had at least 1 primary care visit captured in the NonSpecificAbnormal variable: 0 = no visits, 1 = at least 1 visit
AccidentPoisonVio	Count the total number of visits to primary care with DXCODE = 802-894 or 918-959 or 977-998 (Category: Accidents, Poisonings and Violence) from OHIP in the 6 years prior to the index date per patient
AccidentPoisonVio_Flag	Flag if patient had at least 1 primary care visit captured in the AccidentPoisonVio variable: 0 = no visits, 1 = at least 1 visit
FamilyPlan	Count the total number of visits to primary care with DXCODE = 895 (Description: Family planning, contraceptive advice, advice on sterilization or abortion) from OHIP in the 6 years prior to the index date per patient

FamilyPlan_Flag	Flag if patient had at least 1 primary care visit captured in the FamilyPlan variable: 0 = no visits, 1 = at least 1 visit
Immunization	Count the total number of visits to primary care with DXCODE = 896, 960-969 (Description: Immunization – all types) from OHIP in the 6 years prior to the index date per patient
Immunization_Flag	Flag if patient had at least 1 primary care visit captured in the Immunization variable: 0 = no visits, 1 = at least 1 visit
Illegitimacy	Count the total number of visits to primary care with DXCODE = 903 (Description: Illegitimacy) from OHIP in the 6 years prior to the index date per patient
Illegitimacy_Flag	Flag if patient had at least 1 primary care visit captured in the Illegitimacy variable: 0 = no visits, 1 = at least 1 visit
BabyCare	Count the total number of visits to primary care with DXCODE = 916 (Description: Well baby care) from OHIP in the 6 years prior to the index date per patient
BabyCare_Flag	Flag if patient had at least 1 primary care visit captured in the BabyCare variable: 0 = no visits, 1 = at least 1 visit
AnnualHealthExamAdol	Count the total number of visits to primary care with DXCODE = 917 (Description: Annual health examination adolescent/adult well vision care) from OHIP in the 6 years prior to the index date per patient
AnnualHealthExamAdol_Flag	Flag if patient had at least 1 primary care visit captured in the AnnualHealthExamAdol variable: 0 = no visits, 1 = at least 1 visit
WithoutDiagnosis	Count the total number of visits to primary care with DXCODE = 999 (Category: Without Diagnosis) from OHIP in the 6 years prior to the index date per patient
WithoutDiagnosis_Flag	Flag if patient had at least 1 primary care visit captured in the WithoutDiagnosis variable: 0 = no visits, 1 = at least 1 visit

Dementia	Count the total number of visits to primary care with DXCODE = 290 (Description: Senile dementia, presenile Dementia) from OHIP in the 6 years prior to the index date per patient
Dementia_Flag	Flag if patient had at least 1 primary care visit captured in the Dementia variable: 0 = no visits, 1 = at least 1 visit
PsychoticDis	Count the total number of visits to primary care with DXCODE = 295, 296, 297, 298 (Description: Schizohrenia, manic-depressive psychoses, other paranoid states, other psychoses) from OHIP in the 6 years prior to the index date per patient
PsychoticDis_Flag	Flag if patient had at least 1 primary care visit captured in the PsychoticDis variable: 0 = no visits, 1 = at least 1 visit
NonPsychDis	Count the total number of visits to primary care with DXCODE = 300, 301, 302, 306, 309, 311 (Description: Anxiety neuroses, personality disorders, sexual deviations, psychosomatic illness, adjustment reaction, depressive disorder) from OHIP in the 6 years prior to the index date per patient
NonPsychDis_Flag	Flag if patient had at least 1 primary care visit captured in the Non-PsychoticDis variable: 0 = no visits, 1 = at least 1 visit
SubstanceUseDis	Count the total number of visits to primary care with DXCODE = 303, 304 (Description: Alcoholism, Drug dependence) from OHIP in the 6 years prior to the index date per patient
SubstanceUseDis_Flag	Flag if patient had at least 1 primary care visit captured in the SubstanceUseDis variable: 0 = no visits, 1 = at least 1 visit
SocialProb	Count the total number of visits to primary care with DXCODE = 897, 898, 899, 900, 901, 902, 904, 905, 906, 909 (Description: economic problems, marital difficulties, parent-child problems, problems with aged parents or in-laws, family disruption/divorce, education problems, social maladjustment, occupational problems, legal problems, other problems of social adjustment) from OHIP in the 6 years prior to the index date per patient
SocialProb_Flag	Flag if patient had at least 1 primary care visit captured in the SocialProb

	variable: 0 = no visits, 1 = at least 1 visit
AlcPsychosis	Count the total number of visits to primary care with DXCODE = 291 (Description: Alcholic psychosis, delirium tremens, Korsakov's psychosis) from OHIP in the 6 years prior to the index date per patient
AlcPsychosis_Flag	Flag if patient had at least 1 primary care visit captured in the AlcPsychosis variable: 0 = no visits, 1 = at least 1 visit
DrugPsychosis	Count the total number of visits to primary care with DXCODE = 292 (Description: Drug psyhosis) from OHIP in the 6 years prior to the index date per patient
DrugPsychosis_Flag	Flag if patient had at least 1 primary care visit captured in the DrugPsychosis variable: 0 = no visits, 1 = at least 1 visit
ChildhoodPsychoses	Count the total number of visits to primary care with DXCODE = 299 (Description: Childhood psychoses [e.g., autism]) from OHIP in the 6 years prior to the index date per patient
ChildhoodPsychoses_Flag	Flag if patient had at least 1 primary care visit captured in the ChildhoodPsychoses variable: 0 = no visits, 1 = at least 1 visit
TobaccoAbuse	Count the total number of visits to primary care with DXCODE = 305 (Description: Tobacco abuse) from OHIP in the 6 years prior to the index date per patient
TobaccoAbuse_Flag	Flag if patient had at least 1 primary care visit captured in the TobaccoAbuse variable: 0 = no visits, 1 = at least 1 visit
HabitSpasm	Count the total number of visits to primary care with DXCODE = 307 (Description: Habit spasms, tics, stuttering, tension headaches, anorexia nervosa, sleep disorders, enuresis) from OHIP in the 6 years prior to the index date per patient
HabitSpasm_Flag	Flag if patient had at least 1 primary care visit captured in the HabitSpasm Diagnosis variable: 0 = no visits, 1 = at least 1 visit

BehaviourDisorder	Count the total number of visits to primary care with DXCODE = 313 (Description: Behaviour disorders of childhood and adolescence) from OHIP in the 6 years prior to the index date per patient
BehaviourDisorder_Flag	Flag if patient had at least 1 primary care visit captured in the BehaviourDisorder variable: 0 = no visits, 1 = at least 1 visit
HyperkineticSyndrome	Count the total number of visits to primary care with DXCODE = 314 (Description: Hyperkinetic syndrome of childhood) from OHIP in the 6 years prior to the index date per patient
HyperkineticSyndrome_Flag	Flag if patient had at least 1 primary care visit captured in the HyperkineticSyndrome variable: 0 = no visits, 1 = at least 1 visit
DelaysinDevelop	Count the total number of visits to primary care with DXCODE = 315 (Description: Specified delays in development [e.g., dyslexia, dyslalia, motor retardation) from OHIP in the 6 years prior to the index date per patient
DelaysinDevelop_Flag	Flag if patient had at least 1 primary care visit captured in the DelaysinDevelop variable: 0 = no visits, 1 = at least 1 visit
IntellDevelopDelay	Count the total number of visits to primary care with DXCODE = 319 (Description: Mental retardation) from OHIP in the 6 years prior to the index date per patient
IntellDevelopDelay_Flag	Flag if patient had at least 1 primary care visit captured in the IntellDevelopDelay variable: 0 = no visits, 1 = at least 1 visit
Yr1-Yr6	Calendar year which corresponds to variables PCV_Y1 – PCV_Y6, which are the 6 years prior to index date per patient
Yr01-Yr06	Number of years prior to diagnosis per year for the 6 years prior to index date year (1-6)
MHAServices	Count the number of prior primary care visits to a family physician or pediatrician for a mental health reason in the 6 years prior to the index date. See Appendix D for OHIP diagnosis and fee codes.
MHAServices_Flag	Flag if patient had at least 1 primary care visit captured in the MHAServices variable:

	0 = no visits, 1 = at least 1 visit
NonMHAServices	Count the total number of primary care visits NOT for a mental health reason in the 6 years prior to the index date per patient using the OHIP fee codes not included in the MHAServices variable.
NonMHAServices_Flag	Flag if patient had at least 1 primary care visit captured in the PhysicalServices variable: 0 = no visits, 1 = at least 1 visit
Index_dx_cat	Changing index_dx variable from string format to numerical format. 1=schizophrenia, 2=psychosis NOS
Sexnum	Converting the sex variable from string format to numerical format. 0=Female and 1=Male
Agenum	Converting the agegrp categorical variable from string format to numerical format. 0=”14-17” through 6=”33-35”
Agebin	Binary age variable. 0=14-23 1=24-35
Psychhospcon	Variable identifying 0=controls, 1=cases with no psychiatric hospital visits, 2=cases with psychiatric hospital visits (identified using variables hosp_mh_2y_flag and ed_mh_2y_flag)
Group	Latent class growth modelling trajectory the individual belongs to (1, 2 or 3)

APPENDIX D Diagnostic and fee codes used to define a primary care visit for a mental health reason

Based on Steele, L. S., Glazier, R. H., Lin, E., & Evans, M. (2004). Using administrative data to measure ambulatory mental health service provision in primary care. Medical Care, 42(10), 960–965. https://doi.org/10.1097/00005650-200410000-00004

OHIP Fee Codes

- Comprehensive Primary Care Codes
    - A001 – Minor Assessment
    - A003 – General Assessment
    - A007 – Intermediate Assessment
    - A903 – Pre-operative Assessment
    - E075 – Geriatric General Assessment Premium
    - G212 – Allergy injection alone
    - G271 – Anticoagulant supervision
    - G372 – Injection with visit
    - G373 – Injection sole reason
    - G365 – Pap Test
    - G538 – Immunization with visit
    - G539 – Immunization - sole reason
    - G590 – Influenza immunization - with visit
    - G591 – Influenza immunization - sole reason
    - K005 – Primary Mental Health Care
    - K013 – Counseling – Individual Care
    - K017 – Annual Health Exam – Child after second birthday
    - P004 – Minor prenatal assessment
- Pediatric Service Codes
    - A260 Paediatrics – 75 minute consultation
    - A265 Consultation – Paediatric

- A662 Paediatrics – 90 minute consultation
- K122 Paediatric psychotherapy individual, per unit
- K123 Paediatric psychotherapy family, per unit

- Mental Health Service Codes
  - K005 Primary mental health care
  - K007 Psychotherapy
  - K623 Assessment for involuntary admission

OHIP Diagnosis Codes

- Mental Health Diagnostic Codes
  - 295 Schizophrenia
  - 296 Manic-depressive psychoses
  - 297 Other paranoid states
  - 298 Other psychoses
  - 300 Anxiety neurosis, hysteria, neurasthenia, obsessive-compulsive neurosis, reactive
  - 301 Personality disorders
  - 302 Sexual deviations
  - 306 Psychosomatic illness
  - 309 Adjustment reaction
  - 311 Depressive disorder
  - 303 Alcoholism
  - 304 Drug dependence
  - 897 Economic problems
  - 898 Marital difficulties
  - 899 Parent-child problems
  - 900 Problems with aged parents or in-laws
  - 901 Family disruption/divorce

- 902 Education problems
- 904 Social maladjustment
- 905 Occupational problems
- 906 Legal problems
- 909 Other problems of social adjustment

APPENDIX E OHIP diagnosis categories with low proportions (<1%)

Males

OHIP Diagnosis Category	Cases	Comparisons	Standardized Difference	RR	95% CI
	%	%			
Drug Psychosis	0.72	0.03	***0.11***	24.97	16.87, 36.94
Alcoholic Psychosis	0.28	0.02	0.07	11.67	7.34, 18.54
Senile Dementia or Presenile Dementia	0.38	0.04	0.07	8.44	5.92, 12.04
Intellectual Delay	0.96	0.12	***0.11***	7.90	6.36, 9.82
Illegitimacy	0.05	0.02	0.02	2.82	1.35, 5.91
Perinatal Morbidity and Mortality	0.17	0.08	0.03	2.23	1.54, 3.24
Complications of Pregnancy, Childbirth and the Puerperium	0.28	0.16	0.03	1.79	1.35, 2.36
Congenital Anomalies	1.37	0.77	0.06	1.77	1.56, 2.01
Baby Care	0.90	0.55	0.04	1.63	1.39, 1.90

Females

OHIP Diagnosis Category	Cases	Comparisons	Standardized Difference	RR	95% CI
	%	%			
Alcoholic Psychosis	0.22	0.01	0.06	17.71	7.80, 40.22
Drug Psychosis	0.41	0.03	0.08	14.75	8.49, 25.62
Senile Dementia or Presenile Dementia	0.42	0.04	0.08	11.62	7.08, 19.07
Childhood Psychoses or Autism	0.80	0.08	***0.11***	9.79	6.97, 13.73
Intellectual Delay	0.87	0.10	***0.11***	8.77	6.41, 11.99
Illegitimacy	0.05	0.03	0.01	1.75	0.72, 4.25
Perinatal Morbidity and Mortality	0.81	0.57	0.03	1.42	1.15, 1.76

APPENDIX F BIC information used to determine LCGM model fit for cases and comparisons

Cases

Number of groups	BIC	Log Bayes Factor	Error (if applicable)
1	-485191	-	
2	-451905	66572.00	
3	-441541	20728.00	
4	-437853	N/A	At least 1 group has <5% of sample
5	-433303	N/A	At least 1 group has <5% of sample
6	-431089	N/A	At least 1 group has <5% of sample
7	-429724	N/A	At least 1 group has <5% of sample
3 (Traj #1 cubic)	-441250	582	
3 (Traj #2 cubic)	-441434	214	
3 (Traj #3 cubic)	-441545	-8	
3 (Traj #1 and 2 cubic)	-441176	148	

Comparisons

Number of groups	BIC	Log Bayes Factor	Error (if applicable)
1	-1668119	-	
2	-1514207	N/A	False Convergence
3	-1458688	418862	
4	-1440715	N/A	False Convergence
5	-1428130	N/A	False Convergence
3 (Traj #1 cubic)	-1458693	N/A	False Convergence
3 (Traj #2 cubic)	-1458694	12	Cubic parameter not significant
3 (Traj #3 cubic)	-1458694	N/A	False Convergence

Curriculum Vitae

Name: Nicole Schoer

Post-Secondary Education and Degrees:

M.Sc. Epidemiology and Biostatistics
Western University
London, Ontario, Canada
2017-2019

H.B.Sc. Mental Health Studies and Applied Statistics
University of Toronto
Toronto, Ontario, Canada
2012-2016

Honours and Awards:

Western Graduate Research Scholarship 2017-2019

Publications:

Schoer, N., Huang, C.W., & Anderson, K.A. (2019). Differences in Duration of Untreated Psychosis for Racial and Ethnic Minority Groups with First-Episode Psychosis: An Updated Systematic Review & Meta-Analysis. *Social Psychiatry and Psychiatric Epidemiology.* Advanced online publication. doi:10.1007/s00127-019-01737-3

Presentations:

Schoer, N., Rodrigues, R., Reid, J., Ryan, B.L., Lizotte, D.J., Booth, R., MacDougall, A.G., & Anderson, K.K. (2019, June). Identifying Help-Seeking Patterns in Primary Care by Young People with First-Episode Psychosis. Poster presentation at Trillium Primary Care Research Day, Toronto, ON.

Schoer, N., Rodrigues, R., Reid, J., Ryan, B.L., Lizotte, D.J., Booth, R., MacDougall, A.G., & Anderson, K.K. (2019, May). Identifying Help-Seeking Patterns in Primary Care by Young People with First-Episode Psychosis. Oral presentation at Canadian Society for Epidemiology & Biostatistics, Ottawa, ON.

Schoer, N., Rodrigues, R., Reid, J., Ryan, B.L., Lizotte, D.J., Booth, R., MacDougall, A.G., & Anderson, K.K. (2019, April). Identifying Help-Seeking Patterns in Primary Care by Young People with First-Episode Psychosis. Poster presentation at London Health Research Day, London, ON.

Schoer, N., Huang, C.W., & Anderson, K.A. (2018, November). Differences in Duration of Untreated Psychosis for Racial and Ethnic Minority Groups with First-Episode Psychosis: An Updated Systematic Review & Meta-Analysis. Oral presentation at The Department of Epidemiology & Biostatistics' Student Rounds, University of Western Ontario, London, ON.

Schoer, N., Huang, C.W., & Anderson, K.A. (2018, September). Differences in Duration of Untreated Psychosis for Racial and Ethnic Minority Groups with First-Episode Psychosis: An Updated Systematic Review & Meta-Analysis. Poster presentation at the Canadian Academy of Psychiatric Epidemiology Scientific Symposium, Toronto, ON.