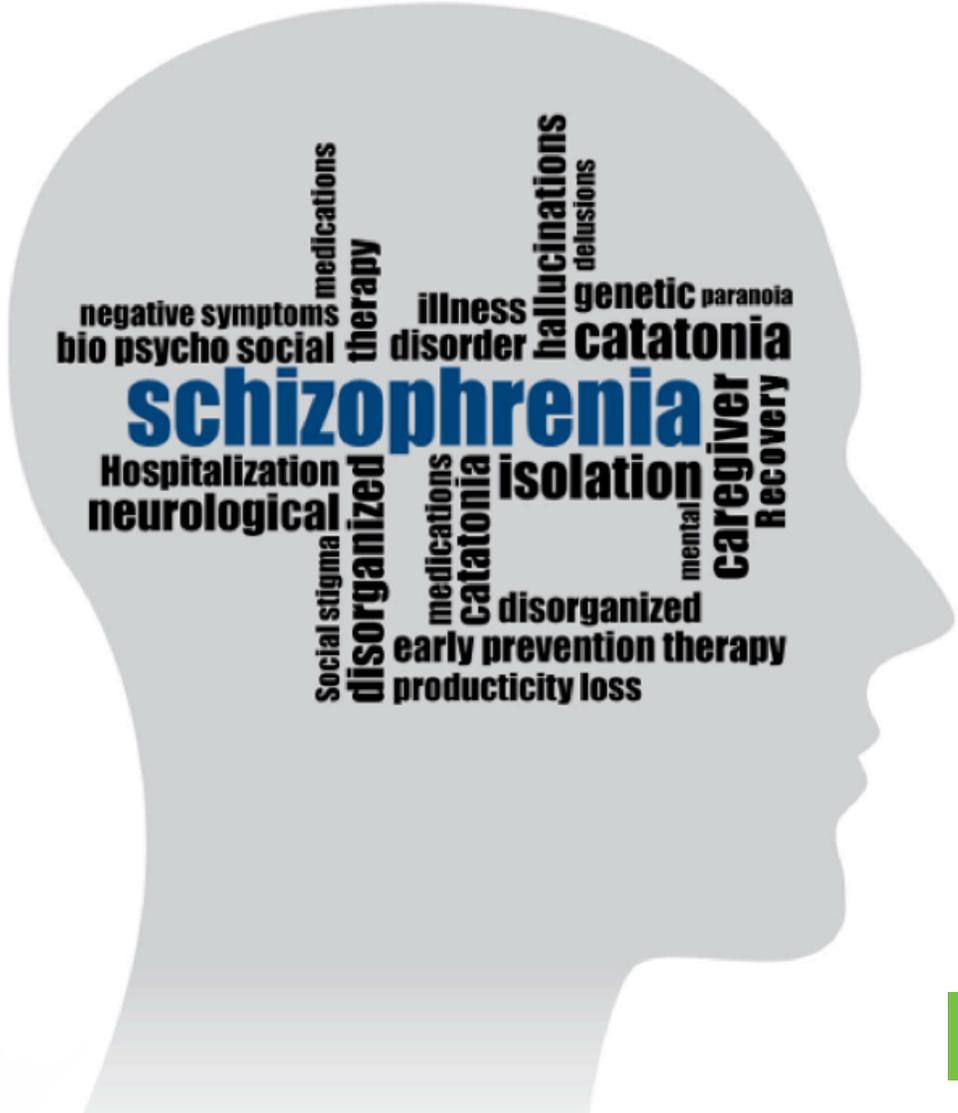


Schizophrenia in Canada

The social and economic case for a collaborative model of care



medications
negative symptoms
bio psycho social
therapy
illness
disorder
hallucinations
delusions
genetic
paranoia
catatonia
schizophrenia
Hospitalization
neurological
disorganized
social stigma
medications
catatonia
isolation
caregiver
Recovery
mental
disorganized
early prevention therapy
productivity loss

FINAL REPORT
FEBRUARY 2014

CANADA'S
PUBLIC POLICY

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“The term schizophrenia was introduced into the medical language at the beginning of [the 20th] century by the Swiss psychiatrist Bleuler. It refers to a major mental disorder, or group of disorders, whose causes are still largely unknown and which involves a complex set of disturbances of thinking, perception, affect and social behaviour.

So far, no society or culture anywhere in the world has been found free from schizophrenia and there is evidence that this puzzling illness represents a serious public health problem.”¹

-The World Health Organization, 1998

ACKNOWLEDGEMENTS

Each year, mental illness places a significant burden on patients, families, doctors and other caregivers. Schizophrenia, in particular, manifests itself in complex ways and is highly disruptive. Patients suffer not just from the illness itself, but often from social discrimination, homelessness, unemployment and addiction. The impact of schizophrenia on individuals, our society and our economy is profound.

As the Public Policy Forum explored this devastating illness, it became clear that increased awareness among all Canadians is required to generate greater support for the treatment of schizophrenia and to reduce discrimination. We concluded that a collaborative approach between key stakeholders –clinicians, affected individuals and families, patient and community support groups and policymakers – could improve the lives of the 300,000 Canadians who suffer from schizophrenia and related diseases. Our goal in developing this report is to contribute to the growing conversation about mental health in our country. Enhanced dialogue and coordination will help drive the type of change that can relieve the burdens of schizophrenia, and support those who suffer from it.

In developing this report, the Public Policy Forum relied on advice and guidance from a select group of experts representing different stakeholder groups, including clinical practice, family and social support and health economics. On behalf of the Forum, I wish to acknowledge and thank Odette Beaudoin, Ron Goeree, Francine Knoops, Ashok Malla and Chris Summerville for their assistance in helping inform this research project. David Griller also provided valuable guidance, support and edits during the development of this report.

I would also like to acknowledge and thank the generous contributions of Roche, our project sponsors who provided us with the research grant to conduct an independent analysis of the social and economic costs of schizophrenia in Canada.

Finally, a special thanks to my team at the Public Policy Forum, including James McLean for writing this report and Julia Oliveira for her project assistance.



Paul Ledwell
Executive Vice President
Canada's Public Policy Forum

CHAPTER 1: INTRODUCTION

Every year, schizophrenia disrupts the lives of hundreds of thousands of Canadians. While affecting only approximately 1% of the population, this complex, multifaceted illness places a disproportionate strain on patients, families, clinicians and other care providers. Symptoms, which vary in severity and expression, can make it incredibly difficult for patients to sustain relationships, engage in social networks or carry out routine tasks. Moreover, these social burdens extend well beyond the affected patient. Families and health professionals who provide care often find their lives interrupted and negatively impacted by the illness. Ineffective policy, poorly organized care systems and expensive medications all contribute to placing the burden directly on families. The result is higher emotional costs and lower standards of life among care providers.

The economic implications of schizophrenia are equally severe. Patients diagnosed with the illness experience a combination of debilitating symptoms that make them more prone to unemployment, discrimination, social isolation, homelessness and suicide than the rest of the Canadian population. This report shows that the billions of dollars in care that the government provides each year to people with schizophrenia is straining our country's healthcare, social services and criminal justice systems.

Schizophrenia is also responsible for significant "hidden" costs to the Canadian economy. Patients experiencing severe and untreated symptoms are often unable to work. Since onset typically occurs in individuals aged 14-35 years, schizophrenia strikes people just as they are developing vital workplace experience and career skills. In Canada and around the world, this complex illness causes more productivity losses than almost any other illness.

With approximately 300,000 Canadians suffering from schizophrenia nation-wide², the significant social and economic costs of the illness warrant the creation of a coordinated, multi-sector approach that incorporates healthcare practices, education, social support programs, pharmaceutical innovation and evidence-based public policy.

To help initiate this more holistic, multi-stakeholder approach, Canada's Public Policy Forum, in partnership with Roche, launched the *Schizophrenia in Canada* project to demonstrate the social, economic and medical effects

of schizophrenia on Canadian society. To help inform our research, we brought together a small group of people with expertise in clinical practice, health economics and social work. They provided research guidance, reviewed materials, and identified areas for further analysis.

In particular, this expert panel focused on the impact of schizophrenia's "negative" symptoms, which are characterized by diminished affect and expressivity, social isolation and withdrawal, lack of volition and an inability to derive pleasure from activities. Negative symptoms cause social and economic disruptions *and* have traditionally been difficult to treat with medication and psycho-social intervention programs.

To provide a clearer picture of schizophrenia in general, and negative symptoms in particular, this paper explores a number of key questions, including:

- What are the social and economic costs of schizophrenia, at the national, family and individual levels?
- What is the particular impact of negative symptoms?
- What innovative approaches are being developed that could alleviate negative symptoms?
- What are the potential benefits of relieving negative symptoms, and what effect could they have on patients, clinicians and care providers?

In answering these questions, this report intends to clarify the current approach to managing negative symptoms. The goal is to identify some potential strategies that could improve the lives of patients and their family members.

Through a more coordinated, multi-sector approach, it may be possible to enhance care, improve health outcomes and reduce the burdens on our society and economy.

We trust that the findings of our research will help initiate a broader discussion among patients, families, clinicians, care providers, patient groups, policy-makers and the general public that moves Canada towards better mental health practices and policies.

CHAPTER 2: THE COMPLEX NATURE OF SCHIZOPHRENIA

For centuries, societies have grossly misunderstood schizophrenia. In the past, patients were often believed to be suffering from mental retardation, demonic possession, or from exposure to poisonous materials.³ Social support programs were non-existent. Treatments, if they were administered, were often barbaric and wholly ineffective in helping the affected individual overcome his or her symptoms.

Today, we know that schizophrenia is a complex disorder, caused by a combination of neuro-biological, environmental and social factors. While the lifetime risk of developing schizophrenia and related psychotic disorders is

around 3%, in most cases (more than 70%) the onset is during adolescence and young adulthood (12-30). It is estimated that the illness affects approximately 24 million people worldwide.⁴

The impact of schizophrenia on an individuals' psychosocial functioning can be quite devastating. While the severity and combination of symptoms varies greatly among patients, even mild aspects can make engagement in social and workplace settings difficult, if not impossible.⁵ Most experts now agree that schizophrenia is a heterogeneous disease that manifests itself in at least four separate, yet interconnected "symptom domains." They include:

Positive symptoms:

Patients suffering from positive symptoms can exhibit mild to acute psychotic experiences that include hallucinations, delusions, paranoia, disorganized thinking and erratic behaviour. Positive symptoms make it difficult for patients to connect with reality. Many report that they feel overwhelmed, hear voices and see and feel things that do not exist. Irrational thought patterns are also common.

Negative symptoms:

Patients affected by negative symptoms experience significant disruptions to their psychosocial functioning (e.g. controlling their emotions and behaviours, and relating to others) which makes it difficult for them to interact with friends, family and society. These symptoms typically manifest themselves in one or more of the following ways:

- flattened mood and poor interaction with others;
- Difficulty with volition and motivation (apathy);
- Algia (difficulty speaking);
- An absence of motivation;
- Lack of pleasure in life; and
- Social withdrawal and isolation.

It is important to note that negative symptoms are divided into two subdomains based on causation: *Primary negative symptoms* are "etiologically related to the core pathophysiology of schizophrenia," indicating that their root cause is mental illness itself.⁶

Secondary negative symptoms, by contrast, are caused by external stimuli such as medication,⁷ the environment or, under some circumstances, one of the other symptom domains. Sometimes, pinpointing and removing the external cause may be enough to address their effects.

Another defining characteristic of negative symptoms is that they are longer lasting and more persistent than other symptom domains. While positive, cognitive and affective symptoms can be managed with medication,⁷ pharmacological interventions have been unsuccessful in sufficiently treating negative symptoms.⁸ Developing better medicinal treatments for negative symptoms continues to be an unmet clinical need.



Cognitive deficit:

People with cognitive symptoms often suffer impairments in day-to-day core mental abilities such as:

- Organization;
- Sustaining attention;
- Making sense of information;
- Short-term memory; and
- Planning and executing complex tasks necessary to live independently.

These deficits invariably precede the onset of the illness. Patients often report great frustration in learning and using new information. As a result, these individuals can experience difficulty with engaging in the workforce.

Affective symptoms:

Affective symptoms include dysphoria, suicidal ideation, anxiety, feelings of despair and depression.⁹

Many experts now believe that schizophrenia is actually a number of separate, interconnected illnesses rather than a single homogeneous illness. The chronic nature of schizophrenia also means that lifelong treatment may be necessary and that patients may not assume functioning comparable to their age-related, healthy peers. Figure 1 illustrates the relationship between the symptom domains as well as some of their side effects.

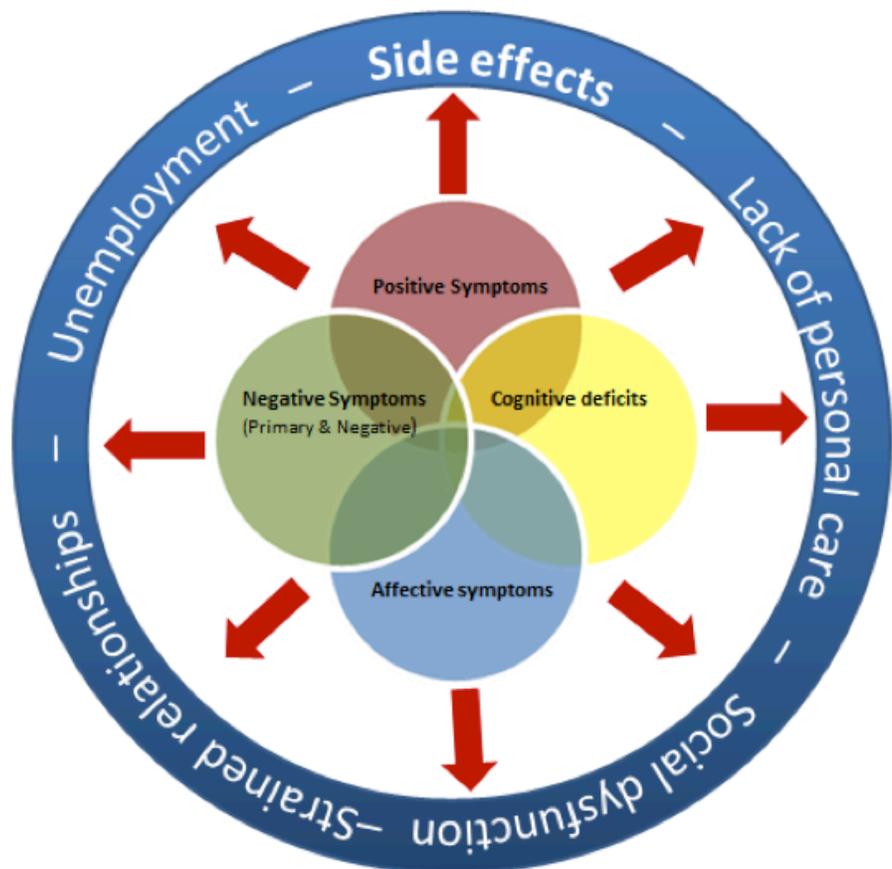


Image credit: This image was created following a meeting in April 2013 of the Public Policy Forum’s advisory group, where it was suggested that symptom domains interact and overlap with each other in different configurations (like a Venn diagram). The enveloping circle, depicting some side effects, was adapted from a presentation by the Société québécoise de la schizophrénie in September 2013.

CHAPTER 3: THE SOCIAL AND ECONOMIC COSTS OF SCHIZOPHRENIA

The case for establishing a coherent, multi-sector approach

Schizophrenia places a huge burden on our society and economy. Establishing an accurate picture of the illness' total burden on patients, families and tax payers should provide the evidence and foundation needed to focus attention and drive actionable change.

- 29% felt they were unfairly judged by employers;
- 64% responded that they anticipated to be discriminated against in applying for work, training or education; and
- 72% felt they needed to hide their illness.¹³

The social costs of schizophrenia

Schizophrenia generates an overwhelming burden on patients, families, physicians and other care providers. Those who are affected by the illness report much higher levels of stress and anxiety, suffer from more health problems and can have difficulty holding down jobs.

This section examines four areas that appear to cause the greatest hardship for those affected by schizophrenia. They include: discrimination; social isolation, withdrawal and homelessness; suicide; and the emotional and financial burdens on caregivers.

Discrimination

Stigma is one of the most prominent social challenges affecting people with schizophrenia. For decades, patients have been portrayed in film and television as unstable, dangerous and unable to participate in society. Pejorative terms, stereotypes and other discriminatory behaviour are also common despite campaigns to bring greater global awareness to mental health issues. In Canada, upwards of 96% of schizophrenia patients say they have been victims of discriminatory actions¹⁰ and it is widely believed that “stigma may be one of the single greatest barriers to employment and housing for individuals” with the illness.¹¹

In a study on the prevalence of mental health-related stereotypes in Germany, researchers found that “the perception of people with schizophrenia as being unpredictable and incompetent was most frequently endorsed by the public, followed by perceived dangerousness.”¹² A more recent analysis by Thornicroft et al. found that people suffering from schizophrenia reported experiencing discrimination in all aspects of their lives. According to the report:

- 47% of respondents claimed they had been affected by negative discrimination in making or keeping friends;
- 29% felt discriminated against by family members;

These numbers tell a very troubling story about the state of mental illness understanding and acceptance among the general population. If policymakers and other professionals are to effectively mitigate the economic costs of schizophrenia in general, and negative symptoms in particular, one useful first step would be to take steps to reduce the stigmatization that keeps many people away from social settings and the workforce.

Social isolation, withdrawal and homelessness

Dr. Michael Miller, editor in chief of the Harvard Mental Health Letter, has suggested that while “positive symptoms make treatment seem more urgent...negative symptoms are the main reason patients with schizophrenia cannot live independently, hold jobs, establish personal relationships, and manage everyday social situations. These symptoms are also the ones that trouble them most.”¹⁴

Although many people with schizophrenia interact with friends and family on a day-to-day basis, studies have found that upwards of 60% to 70% do not marry, and many have “limited social contacts.”¹ In a 2002 Australian report, researchers found that among those affected by schizophrenia, “31% live alone, 59% have an impaired ability to socialize, 35% have no frequent face-to-face contact with a close relative, 39% have no best friend with whom to share thoughts and feelings and 12% have no friends at all.”¹⁵ As discussed, negative symptoms play a key role in disrupting a patient’s ability to function socially and in the workplace.

In the absence of patient-centred, holistic treatment programs (explored in the next chapter), it is very difficult for people affected by schizophrenia to overcome the negative symptoms that cause them to withdraw from social interactions. This is especially true given that medications have not shown great success in treating negative symptoms.

Suicide

People with schizophrenia attempt and complete suicide at much higher rates than the rest of the general population.¹⁶ According to the literature, patients who experience

psychotic episodes and have limited access to care are much more likely to take their own lives.¹⁷ Sadly, many of these instances could be addressed if stakeholders were to direct additional resources and attention towards ensuring that patients are afforded the types of treatment options that they require. In their 2004 report, Taylor et al found that “the social and economic isolation suffered by mental illness patients, in particular patients with schizophrenia, may lead to the high suicide rates observed, implying the need for people with mental illness to be provided with a strong framework of social support throughout their treatment.”¹⁸

Burdens on families and caregivers

Gaps in institutional care – including inadequate access to comprehensive and early treatment, ineffective policy approaches, poorly organized systems of care, expensive and inaccessible medications and a lack of awareness among the general public – significantly contribute to placing the burden of care directly on families. To help illustrate this point, a report by the *Vancouver Sun* found that available beds for mental health patients dropped from 47,633 to 15,011 over the three decades ending in 2002.¹⁹ This is not a negative result in and of itself, except that there were few compensatory resources to support individuals who were no longer admitted to hospitals. With fewer hospital beds reserved for psychiatric patients, individuals with schizophrenia find themselves relying increasingly on their families, friends and social institutions for housing.

Numerous studies have demonstrated that those who care for patients with negative symptoms report higher levels of disruption in their own lives. For example, a 2007 report that evaluated the burden on caregivers in Germany and Britain found that the presence of negative symptoms is positively correlated to the burden on caregivers. According to the survey, “higher negative symptom scores were also significantly associated with greater family burden in ‘urging’, ‘worrying’ and ‘supervision’.”²⁰

Some studies have also found that carers often have difficulty attributing patients’ feelings of lethargy to “mental illness”, which can foster resentment and damage relations.²¹ Caregivers also experience high levels of stress due to patients’ dependence on them to function socially and perform routine tasks.²²

Understandably, dependency has a dramatic effect on caregivers’ quality of life. According to a 2012 survey conducted in Ontario, individuals caring for schizophrenia

patients report that it affects their careers (34%), relationships with friends and family (54%), personal health (50%) and that it leads to feelings of frustration (61%), sadness (49%) and inadequacy (43%).²³ The same study indicated that upwards of 30% of caregivers in Ontario report missing a total of 30 days of work due to schizophrenia-related responsibilities.²⁴

The direct economic costs of schizophrenia

Direct economic costs represent the sum total of everything spent on caring for a schizophrenia patient, including hospitalization, therapy, drugs, residential care, incarceration and other professional services. In Canada, as in other Western economically developed countries, these costs are disproportionately high relative to the number of people affected by the illness. Despite the fact that the illness affects only 1% of the global population at any one time, schizophrenia is responsible for approximately 3% of the total social and economic burden of all human disease.²⁵

After conducting a thorough literature review, we found that the complex, heterogeneous nature of schizophrenia makes it difficult to accurately assess the impact of any one symptom domain. Positive, negative, cognitive and affective symptoms are not only closely interconnected, but studies have shown that the severity of one symptom can play a direct role in exacerbating one or more of the others. In addition, patients with schizophrenia often suffer from multiple illnesses, including depression and anxiety disorders, further complicating our ability to attribute causation. It is for these reasons that few studies have been able to accurately attribute specific costs to any one symptom domain.

Notwithstanding these limitations, we were able to evaluate the social and economic costs of schizophrenia in general, and to make some informed conclusions about the socio-economic impact of negative symptoms.

Healthcare

The burden that schizophrenia imposes on healthcare systems varies among industrialized countries. Over the past decade studies have demonstrated that the direct costs of schizophrenia represented 1.7% of Canada’s national health expenditures,²⁶ while figures range as low as 1.4% and 1.6% in the Netherlands and U.K., respectively, to as high as 3% in the United States.²⁷ Among those suffering from severe

symptoms, inpatient and residential care consume much of these costs, in some cases upwards of 75%.²⁸

In Australia, researchers discovered that the direct costs of schizophrenia to their country’s healthcare system is AUS \$661 million, comprising mostly hospitalizations (60%), community mental health services (22%), medical costs (6%) and nursing homes (4%).²⁹ According to *SANE* Australia, the national mental health charity, “this represents nearly AUS \$18,000 per person with schizophrenia, over six times the spending on the average Australian’s healthcare and 1.2% of national health spending.”³⁰

Here at home, people with schizophrenia occupy one out of every 12 hospital beds in our country, more than any other single illness.³¹ In their 2005 analysis, Ron Goeree et al. found that the health and non-healthcare costs of schizophrenia in Canada amounted to over \$2 billion. Since many individuals with schizophrenia require inpatient care, hospital-related and residential care expenses make up the largest share of the direct healthcare costs in Canada.

Table 1 shows that the combined cost of acute hospital care, non-acute hospital care and residential care facilities costs the Canadian economy in excess of \$1.5 billion per year.

What percentage of these costs can be attributed to negative symptoms? In their 2008 study, Knapp et al. demonstrated that negative symptoms are perhaps the greatest contributor to high hospitalization rates and expenditures. The authors show that negative symptoms increase associated service costs in all categories except outpatient care, driving up inpatient and average monthly treatment costs.³²

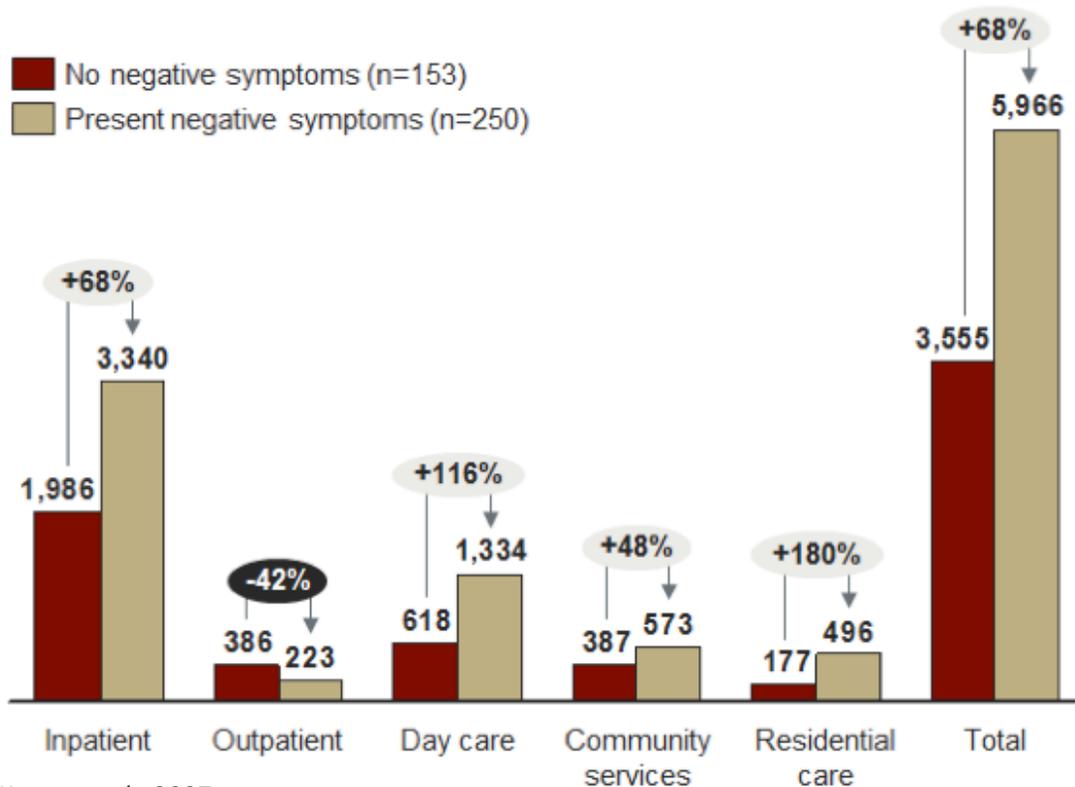
Figure 2 shows that patients with negative symptoms increase mean inpatient, day care, community services and residential care by 68% over those who exhibit no negative symptoms. These findings clearly demonstrate how a greater focus on treating negative symptoms – through new treatment options, greater collaboration among healthcare providers, and improvements in healthcare policy and education – has the potential to lower Canada’s overall healthcare service costs.

TABLE 1: Direct costs related to schizophrenia in Canada

Social Service	Cost in Canadian dollars
Acute hospital care –	\$474 million
Non-acute hospital care –	\$761 million
Residential care facilities –	\$340 million
Prescription medications –	\$150 million
Psychiatric and community mental health clinics –	\$142 million
Incarceration –	\$82 million
Professional billings -	\$61 million
Administration costs of income assistance plans –	\$4.98 million
Attempted suicide (not including hospitalization) –	\$4.49 million
Suicide (not including hospitalization) –	\$1.6 million
Sub-total of health and non-healthcare costs –	\$2.022 billion

Source: Ron Goeree, et al. 2004

Figure 2: The impact of negative symptoms on the mean costs of social services use in five European countries
(unadjusted for background and clinical characteristics, in £)



Source: Knapp et al., 2007.

Social programs

In terms of non-medical expenditures, administering income assistance plans and helping patients cope after suicide attempts incur the highest non-medical expenses relating to schizophrenia in Canada.³³

Due to the direct effects of schizophrenia, as well as the social stigma that surrounds mental illness, a large proportion of those suffering from this illness rely on social assistance. Among economically developed countries, individuals with schizophrenia find it difficult to find employment, with only 12.9% employed in the UK, 15% in Canada, 10% in the U.S.³⁴, and 30% in Germany.³⁵ To a large extent, the social challenges highlighted above contribute to these low employment numbers and patients' systemic reliance on social assistance programs. It also helps to explain why a large proportion of Canada's chronically homeless population (35%-50%) suffer from schizophrenia.³⁶

Policymakers, in collaboration with patients, families, clinicians, community support groups and other stakeholders, should re-evaluate social policies that aim to help people with schizophrenia. Through a more targeted approach, it may be possible to deliver enhanced care in ways that empower patients, return more people to the workforce, and reduce the financial burden placed on social programs.

In 2011, the Canadian Mental Health Association (CMHA), Ontario, and the Schizophrenia Society of Ontario issued a report that offered practical recommendations on where and how policymakers could improve service delivery while lowering costs. The recommendations include:

- 
1. Reconsider the concept of mandatory treatment as a provision of social assistance benefits;
 2. Provide adequate income levels;
 3. Foster social inclusion through employment and other community involvement;
 4. Improve access to income supports and benefits; and
 5. Enhance system integration.³⁷

Criminal justice system

Incarceration expenditures and costs borne by the criminal justice system also generate significant direct economic costs. A 2002 study by Fazel and Danesh found that “typically about one in seven prisoners in western countries have psychotic illnesses or major depression.”³⁸ Unfortunately, many penal institutions are not equipped with the expertise, medications or resources necessary to properly assess and care for individuals with schizophrenia. As a result, inmates often do not receive adequate care, leading to increased costs and, tragically, a failure to help those affected by the illness.

With upwards of 10% of Canada’s prison population affected by “some form of schizophrenia,”¹ it is not surprising that the illness placed a \$61-million burden on our criminal justice system in 2004.³⁹

Policymakers seeking to reduce the burden that the illness places on our penal system should consider working with clinicians, care givers and other professionals to develop better approaches to identifying, processing and treating people affected by schizophrenia. The objective would be to provide better care to patients and to head off incidents that might bring them into the criminal justice system.

In their 2005 study, Ron Goeree and his colleagues support this assertion, suggesting that policies and programs that make it easier to return patients to the workforce – such as supporting early interventions, reducing the need for hospitalization, and better assessment and treatment options for patients who have committed criminal acts – have “the potential to make a significant contribution in reducing the cost of this severe mental illness in Canada.”⁴⁰

It is important to note that having schizophrenia is not in itself enough to prompt criminal behavior. Numerous studies show that mental disorders and criminal behavior are correlated when the illness is left untreated and when substance abuse is a factor.

The indirect economic costs of schizophrenia

The indirect costs of schizophrenia reflect lost productivity and participation in the workforce due to the positive, negative, cognitive, and affective symptoms and impairments associated with the illness. As discussed, patients struggle with living independently, functioning socially, and working effectively. Productivity loss is further exacerbated by the fact that disease onset occurs in individuals aged 14-35 years. This means that patients are removed from the workforce during crucial years of educational and career development and advancement.

Due to uncertainties over earning potential and other variables, the indirect costs of schizophrenia have traditionally been difficult to quantify in monetary terms. However, numerous studies have attempted to put a dollar value on the economic costs of removing someone from the workforce. In Goeree et al’s 2005 study, approximately 70% of the total schizophrenia costs in Canada were related to productivity losses.⁴¹ These figures appear to correlate to figures in other economically developed countries. For example, in Australia the indirect costs of the illness were estimated to be 60% of total schizophrenia costs in that country.

In 2004, Knapp, Mangalore and Simon provided an analysis of the available studies that quantify the global costs of lost productivity. Although some of these studies are out of date, illustrating them here should nevertheless provide policymakers and other stakeholders with a better appreciation for the sheer size of schizophrenia’s “hidden” or indirect costs.

Table 2: The global costs of lost productivity

Country	Source	Total cost of productivity losses (in CAD)
Australia	Carr et al., 2003	\$847 million
Canada	Goeree et al. 1999 Goeree et al. 2005	\$1.23 billion \$1.41 billion
U.K.	Guest and Cookson, 1999	\$138 million
U.S.A.	Rice and Miller, 1996	\$12 billion

Source: Knapp, Mangalore and Simon, 2004

Another practical way of measuring the indirect economic burdens of schizophrenia is through Disability Adjusted Life Years (DALYs). DALYs represent the number of healthy, productive years lost due to illness or premature death. A team of health economists discovered that schizophrenia accounts for approximately 1% of all DALYs worldwide, comprising approximately 8,960 lost productive years for men and 8,728 for women, respectively.⁴² They found that this lost productivity is “almost completely due to the disability burden (98.7% for males and 98.2% for females) rather than to premature death (1.3% for males and 1.8% for females).”⁴³

Since negative symptoms cause patients to withdraw from social and occupational settings, there is reason to believe that they are responsible for many of these costs. In fact, empirical evidence to support this claim is growing. The following points summarize some of the more recent findings:

- Researchers at the Johns Hopkins Bloomberg School of Public Health in Baltimore found that patients suffering from negative symptoms are far less likely to participate in the workforce. According to their study, “a 20% reduction in negative symptoms from the median would increase the mean rate of unsupported employment by 2 percentage points, to 11.6%, compared to a 0.26% increase for symptoms of depression [and] a 0.4% increase for positive symptoms...”⁴⁴
- An article that appeared in the Harvard Medical School Family Health Guide⁴⁵ and a 2013 report by *The Work Foundation*⁴⁶ show that the social disruptions caused by negative symptoms are a key contributor to lost economic opportunities.

- A study based on Canadian data (Cassidy et al. 2010) found that the presence of negative symptoms is a good predictor for a patient’s future functionality levels, considering the positive correlation between “poor functionality and negative symptoms such as avolition and asociality.”⁴⁷

In sum, schizophrenia places an enormous burden on the economy by robbing people of their ability and desire to work. While the complexity of the illness has made it difficult to quantify how much each symptom domain costs the economy, many experts, including those cited above, agree that the anti-social characteristics of negative symptoms are a significant contributor to the billions of dollars in productivity losses the illness causes each year.

Additional research is required

Researchers should consider if and how it might be possible to accurately measure the monetary costs of negative symptoms. During our analysis, it became clear that there was an absence of quantitative studies that ascribe an exact dollar value to any one symptom domain. This suggests that the complex nature of schizophrenia, and the interplay between symptoms, makes it too difficult to assign causation. However, this requires further examination.

Much of the available economic data on schizophrenia was compiled in the 1990s and early 2000s. This information should be updated to reflect inflation and population changes as well as advances in approaches to treatment. A fresh examination of the economic burden would be worthwhile given the impact of the disease on the Canadian economy. New data would inform public policy options and investment strategies.

CHAPTER 4: TREATING NEGATIVE SYMPTOMS

The social and economic costs of schizophrenia provide a strong incentive for mental health experts, practitioners and policymakers to work together to reduce suffering and the impact on our social services. This chapter considers some of the approaches and interventions currently being practiced. Our research indicates that more work needs to be done by all stakeholders to help support innovative treatment options.

1. Strategy: the shift towards a recovery-oriented model

Over the last two decades, there has been greater acceptance that care providers need to adopt a more patient-centered approach that empowers schizophrenia patients and focuses on “recovery” rather than “cures.” In the past, some researchers have discovered that the

traditional psychosocial rehabilitation (PSR) approach encourages patients to rely on government assistance, fosters dependency on care providers, and expects patients to be passive participants in their recovery.⁴⁸

The recovery model, in contrast, gives patients the knowledge, tools and support they need to become more independent and overcome many of the symptoms they struggle with each day. If supported and encouraged by governments and other stakeholders, the recovery model could help bring down the social and economic costs of the illness by encouraging self-sufficiency and lessening dependence on families and social assistance programs. Table 3, taken from Neely Laurenzo Myers’ 2010 study, illustrates the differences between the traditional PSR model and the newer recovery approach.

Table 3: Treatment principles of the “traditional” PSR model vs. the “recovery-oriented” model in the U.S. mental health care system

Principle	PSR model	Recovery model
Goals	<i>Rehabilitation:</i> stabilize illness, reduce negative impacts of illness; avoid rehospitalization.	<i>Recovery:</i> community reintegration; a meaningful life for clients; minimize negative impacts of “traditional” mental health care.
Assumptions	A person with psychiatric disability experiences “impairments, dysfunctions, disabilities, and disadvantages” that mental health services should reduce.	Anyone can achieve recovery with hope, empowerment, and peer support.
Treatment locales	Psychiatric hospitals, nursing homes, community-based centres.	The additional option for peer-run programs and drop-in centres.
Treatment relationship	Case manager: educated, licensed professional directs client; physical, narrative and emotional boundaries limit reciprocity.	Recovery support specialist or peer support specialist: experienced former mental health consumer as advisor; collaborative decision-making that gives consumer final choice; reciprocity encouraged.
Key treatment terminology	Compliant, stable, adherent, not rehospitalized.	Freedom, empowerment, hope, autonomy, self-determination, social reintegration, anti-coercion, self-advocacy.
Medications	Prescribe and comply; involuntary or forced treatment when necessary; coercion is for client’s own good.	Educate and support; avoid involuntary treatment and coercion; use “advance directives”.

Money management	Guardian/payee relationship.	Help client learn financial independence.
Personal choice	Paternalistic caretaking: consumers may need help to make the right choices when they are “sick”.	Self-determination: consumers will best learn personal responsibility by making their own choices even if they try and fail.
Employment	Some people cannot work due to their psychiatric disability and need to receive government disability benefits to survive.	Everyone can work with the proper support; no one should be expected to live on meager disability benefits.
Housing	Some people need to live in nursing homes and other protected environments.	Everyone should be able to find affordable, safe housing in the least restrictive setting.

Source: Neely Laurenzo Myers. (2010). *Culture, Stress and Recovery from Schizophrenia: Lessons from the Field for Global Mental Health*. *Culture, Medicine and Psychiatry journal*. 34(3).

2. Tactics

Holistic (multimodal) early treatment

A number of innovative treatment options are providing patients with education and support to live independent lives. For example, multifaceted, community-based early intervention programs have built on the recovery model approach and have been widely endorsed by mental health professionals. The approach aims to identify illness early, prompting access to comprehensive treatment with a strong recovery orientation and involving many different, concurrent interventions. They include:

- Optimal (and usually low) doses of medication;
- Psychosocial therapy, including family engagement, education and integration in the treatment;
- Social skills improvement; and educational reintegration into general society;
- Employment skills training and vocational rehabilitation; and
- Cognitive behavioural therapy.⁴⁹

Intervening during the initial stages when a patient exhibits psychotic symptoms can help reduce the severity and longevity of residual negative symptoms. Compared to individuals who do not receive immediate care, patients who undergo early, patient-centred interventions see their

prognosis and functionality improve over the long term. The objective of this multimodal approach is to intervene early in the lifecycle of the illness – before, during, or shortly after a patient experiences first-episode psychosis (FEP).

The strength and success of this treatment option comes from its personalized, holistic approach. According to Australian researchers Mihalopoulos et al., “evidence from randomized controlled trials in Denmark and the United Kingdom has demonstrated the superiority of specialized early intervention programs over standard care on a broad range of outcomes including symptomatic and vocational, social functioning, and reduced inpatient care and treatment dropout...”⁵⁰ Importantly, the savings that this approach could provide in terms of reduced need for hospital beds could be quite substantial.

Further, Phillips et al. demonstrate through their research that targeting young people who are considered “ultra high risk” of developing a psychotic disorder with personalized, patient-centered interventions requires fewer clinical resources, as well as less money and time than more general treatment approaches.

In the United States and elsewhere, the *Prevention and Recovery in Early Psychosis* (PREP) program has been a successful example of an early, personalized intervention model that provides enhanced care while reducing costs of traditional healthcare services. PREP is an evidence-based approach that provides a customized two-year treatment plan and a central support team wherever a client needs it. By using a combination of the intensive psychosocial

treatments listed below, PREP is able to treat clients with lower doses of medications than usual, and with fewer hospitalizations.⁵¹ Based on a patient's individual need, this program combines a number of different approaches, including:

- Extensive outreach and community education;
- Medication management;
- Multifamily groups;
- Early intervention;
- Strength-based care management;
- Educational and vocational support;
- Neuroplasticity-based cognitive remediation; and
- Cognitive behavioral therapy.

In Ontario, the provincial government embraced early intervention programs in 1999 when it partnered with the *Ontario Working Group on Early Intervention in Psychosis*. Patients and families received enhanced assistance through coordination of counseling, information-sharing and support networks.⁵²

Medication

A key, but by no means exclusive, component of the holistic early treatment model is the medication that helps to control the thought, perception and mood symptoms associated with schizophrenia. Antipsychotic drugs have been successful in treating positive symptoms for many years. Until recently, however, professionals have found it difficult to consistently treat negative with medication.⁵³

Today, over 100 drugs aimed at reducing negative symptoms and related side effects are being studied in clinical trials.⁵⁴ Some of these medications show promise and are being investigated to see if they help correct negative symptoms and cognitive deficits.⁵⁵ New options for schizophrenia patients, including atypical antipsychotics and long-acting injectables, have recently received regulatory approval. As these new medications enter the marketplace and become more widely used, we will learn more about their long-term efficacy and side effects.

As research progresses and advanced or different classes of medications become available, many or all negative symptoms might be brought under control. This would allow other psychosocial rehabilitative and re-integrative efforts from professionals to work better, and would allow patients to function better in their families, communities, and workplaces, reducing social and economic strain.

Additional treatment programs

In addition to the interventions mentioned above, healthcare and social care professionals are testing other innovative approaches. For example, investigators discovered that schizophrenia patients who received 80 hours of computerized training over the course of 16 weeks became better at “monitoring reality.”⁵⁶ This improvement coincided with increased activation in the medial prefrontal cortex, which supports successful reality-monitoring processes.⁵⁷ Compared to their pre-training assessments, people who had received computerized cognitive training were better able to distinguish between the words they had made up themselves and those that had been presented to them.

Mindfulness therapy and aerobic exercise are also being increasingly used to help treat persistent symptoms of anxiety often exhibited by schizophrenia patients. Together, these two approaches can alleviate:

- Feelings of depression;
- Social isolation;
- Low self-esteem;
- The perception of auditory hallucinations;
- Promote healthier sleep patterns;
- Improve behavior; and
- Help maintain healthy weight.⁵⁸

These and other treatment options provide some optimism that many of the social and economic challenges outlined in Chapters 2 and 3 could be reduced. Many healthcare professionals agree that patient-centered, holistic approaches may be the best way to address the biological, social and environmental causes of schizophrenia. Further work is required to develop medications that can provide the same level of relief from negative symptoms that is currently possible for positive and cognitive symptoms.

Greater collaboration in treatment delivery

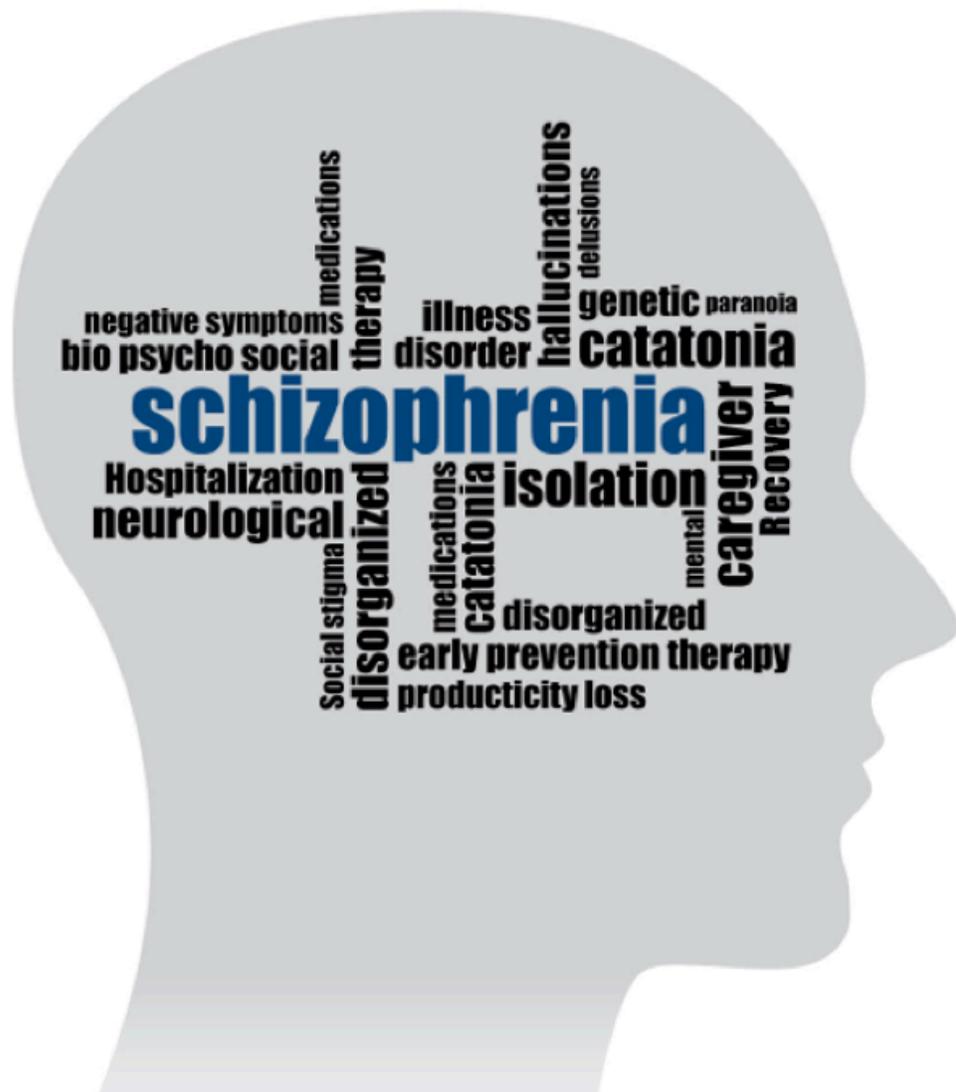
From a public policy standpoint, the case for developing a sound multi-stakeholder framework to address the social and economic effects of schizophrenia is overwhelming. This approach would need to devote greater resources and enhance collaboration to reduce the impact of this illness on healthcare and social services.

Understanding the interventions outlined above, and committing resources to them, can dramatically improve the lives of patients, caregivers and other stakeholders. These positive developments can lead to important personal, social and economic benefits, including:

- Improved prognosis and faster recovery;
- Lower treatment costs and decreased need for hospitalization;
- Lower medium to long-term healthcare costs;
- Lower doses of medication;

- Enhanced attendance at school or work;
- Reduced family disruption and distress;
- Reduced risk of suicide (many patients attempt suicide before they receive treatment underscoring the need for early intervention).⁵⁹

Policymakers, clinicians, family support groups and other stakeholders should consider working together to determine where resources can be shared, how they can improve and provide greater access to treatment programs and develop an *effective* pharmacological response that can treat negative symptoms. This would represent an important first step towards improving the lives of patients and caregivers.



CHAPTER 5: CONCLUSION

Schizophrenia affects only 1% of the Canadian population but it has a tremendous impact on our country. Those affected by the illness are often unable to work or function socially, placing a significant burden on our country's health and social services.

Of the four symptom domains discussed in this report, negative symptoms appear to have the greatest impact on individual functioning and recovery, and hence our society and economy. The negative symptom domain is complex. Treating it is difficult. And coordinating multifaceted approaches involving services and stakeholders is challenging.

In Chapter 4, we show that multimodal or “holistic” early interventions are viewed as the best approach for improving outcomes and possibly for relieving negative symptoms. Implementing this approach efficiently and effectively will require greater coordination and collaboration among clinicians, families, governments, and researchers to ensure that patients receive the treatments that best address their needs. This may require the creation of a framework or strategy, supported by public policy that clearly outlines stakeholders' roles and responsibilities in providing better service delivery and care.

In addition, the medications developed to mitigate negative symptoms have fallen short. However, a number of innovative new drugs currently in clinical trials have shown promise in providing relief to individuals. Further work in this area, including support from governments, may yield progress that could return thousands of patients to the workforce while reducing burdens on our health and social institutions.

Successfully addressing the effects of schizophrenia in general, and negative symptoms in particular, would have a profound impact on patients and families. It would help to reduce the pain, suffering, and isolation that lead many to withdraw from the workforce and society, and sometimes take their own lives. As we have seen, there is also a strong economic case for treating schizophrenia in a much more organized way. The productivity losses and fiscal strains on our health and social institutions due to the illness are significant.

From a government perspective, these social and economic considerations should provide enough incentive to develop a common framework for greater treatment coordination. As policymakers and other stakeholders seek new ways to improve care and lower costs, a useful first step might be to explore options for greater coordination and collaboration among clinicians, care providers, and policymakers. More than just an altruistic pursuit, such an undertaking could produce significant social and economic benefits to patients, families, and our country.



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APPENDIX 1: EXPERT PANEL MEMBERS

Odette Beaudoin

President of the Board of Directors, Société québécoise de la schizophrénie

Since 2004, Odette Beaudoin has been president of the Société québécoise de la schizophrénie (SQS). She is also a member of the board of directors of the Schizophrenia Society of Canada (SSC). She belongs to the Quebec Bar, and the Ordre des psychologues du Québec. She is the president and legal representative for the Comité d'éthique de la recherche du Centre de recherche Fernand-Séguin. She is a member of the Liaison Committee on Research Ethics at l'Université de Montréal.

M^{me} Beaudoin has given presentations to audiences on mental health awareness. She also spent three years teaching a series of workshops for families coping with mental illness.

Ron Goeree

Professor, Department of Clinical Epidemiology and Biostatistics, McMaster University

Mr. Goeree is a Professor in the Department of Clinical Epidemiology and Biostatistics at McMaster University and Director of the Programs for Assessment of Technology in Health (PATH) Research Institute at St. Joseph's Healthcare Hamilton (SJHH). He is a member of the Centre for Evaluation of Medicines, also affiliated with SJHH. His main research interests are centered on health technology assessment (HTA), decision analytic modeling and economic evaluations. Mr. Goeree teaches in the Health Research Methodology Program at McMaster University, where he developed a course in advanced decision analytic modeling and founded the Field of Specialization for health technology assessment. He is the 2012 recipient of the CADTH HTA Excellence Award for lifetime and sustained achievement. He is co-editor of Value in Health and sits on the editorial boards of Medical Decision Making and the Journal of Medical Economics. Mr. Goeree received his undergraduate and graduate degrees from McMaster University.

Francine Knoops

Senior Policy Advisor, External Affairs, Mental Health Commission of Canada

Francine Knoops is a Senior Policy Advisor with the Mental Health Commission of Canada (MHCC), which she joined in 2009. She contributed to the development of *Changing Directions, Changing Lives: the Mental Health Strategy for Canada* (2012) and led the development of the MHCC document "*Case for Investing in Mental Health in Canada*" (2013).

She served the Canadian Psychiatric Association for 14 years, first as the Director of Professional and Public Affairs and then as Associate Executive Director. She also worked as a program consultant and analyst in health and social policy areas in the federal government. Ms. Knoops' early career gave her considerable experience of social and medical challenges at the grass roots level. She worked as a health and social planner for the Social Planning Council of Ottawa-Carleton, as a community organizer and front line community services coordinator in an inner city neighbourhood social services program, and as national coordinator of a federation of regional and provincial human rights organizations.

Ashok Malla

Director, Prevention and Early Intervention Program for Psychoses, PEPP-Montréal, Douglas Institute, Professor, Department of Psychiatry, McGill University

Dr. Malla is a Professor of Psychiatry at McGill University where he holds a Tier 1 Canada Research Chair in Early Psychosis and Director of the Clinical Research Division and the Prevention and Early intervention Program for Psychoses (PEPP-Montréal) at the Douglas Mental Health University Institute. His clinical and research interests have been primarily related to multidisciplinary research in schizophrenia with special emphasis on psychopathology, role of stress, neurobiological and social predictors of outcome, clinical trials, early diagnosis and case identification, community interventions to reduce delays in treatment and quality of life. He has published over 140 peer reviewed articles, held many peer reviewed research grants and been an advisor on program development and research in early intervention in psychotic disorders in several countries including Canada and the U.S.

Chris Summerville

Chief Executive Officer, Schizophrenia Society of Canada

Born in Alabama, Mr. Summerville moved to the land of the Canada in 1985. He has served as a pastor, chaplain, teacher, administrator and mental health service provider through 40 years of professional work in Canada and the U.S. he has dedicated his life “to enabling the walking wounded to become wounded healers.” Although Mr. Summerville regards schizophrenia as one of the most confounding and wounding illnesses a person can experience, he believes that recovery is more probable today than ever before. He has doctorate from Dallas Theological Seminary and is a Certified Psychosocial Rehabilitation Practitioner (CPRC) with the International Association of Psychosocial Rehabilitation Services. He is one of the 11 non-governmental board members of the Mental Health Commission of Canada as well as the CEO of the Schizophrenia Society of Canada.

RESEARCH TEAM

Paul Ledwell

Executive Vice President, Public Policy Forum

Paul Ledwell is Executive Vice-President at the Public Policy Forum (PPF), where he leads the Forum’s work on innovation and public governance and contributes to thought leadership in areas such as economic development, health, and the environment. He joined the Forum in April 2009, bringing 20 years of leadership experience in policy, research, and public advocacy, and extensive work with partners in government, academe, private and voluntary sectors, and the media. Previously, Paul served as President of the Institute on Governance, as the first Director of Government Relations at the University of Ottawa, as Executive Director of the Canadian Federation for the Humanities and Social Sciences and as the Chair of the Canadian Consortium for Research. He has provided senior leadership on national initiatives, including the National Dialogue on Higher Education and the Congress of the Humanities and Social Sciences. He has been a commentator in the media, an invited speaker to conferences in Canada and around the world, and has appeared before parliamentary and other national committees on social and economic policy.

James McLean

Project Lead, Public Policy Forum

James joined the Public Policy Forum in 2010 after completing a master’s degree in international public policy from the Balsillie School of International Affairs at Wilfrid Laurier University. Previously, James was employed as a Balsillie Fellow at the Centre for International Governance Innovation (CIGI), as a researcher with the Washington, D.C.-based Hudson Institute, as Research Lead with the Canadian Constitution Foundation and as the Historical Research Manager with the Town of Shelburne. Since becoming part of the Forum research team, James has contributed to projects with a focus on governance and international issues.

David Griller

Consultant, Genspark Consulting

David was a partner with SECOR Consulting for more than 20 years and recently founded Genspark Consulting. David works extensively with the brand name pharmaceutical industry and with leading research organizations including, for example, Roche, Pfizer, Sanofi-Aventis, Sanofi-Pasteur, BMS, AstraZeneca, Merck, Purdue Pharma, Pharmascience, Rx&D, the Ontario Institute for Cancer Research, Health Canada, Industry Canada, Genome Canada, Genome Quebec, the CHUM hospital consortium, Rx&D, and a number of universities and small biotech firms. He has written two books and several articles on the pharmaceutical industry and has been an invited speaker at many conferences. David spent the early part of his career as a research chemist and published approximately 200 papers and patents. He also co-founded and managed an Oncozyme Pharma from the lab bench to clinical trials. and continues to serve as a director.

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NOTES

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