

SSC Key Messages Survey

1. Purpose of the survey

The Education and Advocacy Committee of the SSC wants your help in defining key messages for the Society. Please share this broadly within your community of volunteers, staff, board and supporters. Your responses will remain private. It is preferable to do it on-line. However, a PDF version will be provided. Please feel free to print this and share it with your community. Return hard copy surveys to Neasa Martin, 15 Wayland Ave, Toronto, ON M4E 3C6.

PLEASE COMPLETE THE SURVEY BY JULY 9TH 2010. We know this is short notice. In appreciation 3 participants will be selected to receive prizes for contributing. If you would like your name included in the draw provide your email which will be used ONLY for this purpose.

Dr. Judith Newman explains key messages are... what you want your audience to remember and react to. They are a means to an end and assert your viewpoint. Key messages are opinions that you can back up with proof and case examples. They get audiences involved in your issue and curious about what you have to say. Curiosity is the first step to participation.

Key Messages are:

- * Concise: avoid jargon and acronyms
- * Active: make every sentence active
- * Positive: talk about what one can do, not what you can't
- * Short: one memorable sentence, 10-15 seconds to say.
- * Specific: address a particular challenge and audience

Each Schizophrenia Society is an independent organization but together share a common mission, purpose and 'brand identity'. Politicians will not get behind a divided community and common key messages will help the Societies speak with a unified voice with government, stakeholders and our membership. Yet Canada is a vast and diverse land with important regional differences. Differing perspectives are to be expected. By using a consensus-based approach we can focus on those messages which unite us all and give us a dynamic vision of who we are and where we want to go.

We would like to thank the Executive Director's group for their input into the survey design. Survey results will be presented for discussion at a round-table meeting at the Annual Conference being held in St. John's Newfoundland July 26th to 28th 2010 (more information to follow). Thank you for completing this survey. Your contribution matters! Contact us with questions or concerns:

Judith McKenzie: judith@uoguelph.ca
Florence Budden: fbbudden@nf.sympatico.ca
Neasa Martin: neasamartin@primus.ca

2. Who is participating in this survey

1. Which best describes your role within the Schizophrenia Society?

- Board member
- Family/caregiver
- Person living with a mental illness
- Program volunteer
- Staff
- Other (please specify:

SSC Key Messages Survey

2. What is your age?

3. How long have you been involved with the Schizophrenia Society?

4. In which province/territory do you live?

Alberta

British Columbia

Manitoba

New Brunswick

Newfoundland

Northwest Territories

Nova Scotia

Nunavut

Ontario

Prince Edward Island

Quebec

Saskatchewan

Yukon

5. Yes - please put my email into a prize draw!

3. Overarching key messages

SSC Key Messages Survey

1. How strongly do you agree with the following statements?

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Unsure
Common key messages will help the Society communicate with government, funders, stakeholder and the public.	jn	jn	jn	jn	jn	jn
Emphasizing disability, suffering, burden and the risk of suicide associated with schizophrenia increases the likelihood that governments will support funding for treatment and research.	jn	jn	jn	jn	jn	jn
Emphasizing disability, suffering, burden and the risk of suicide is discouraging to people living with schizophrenia, their families and the public.	jn	jn	jn	jn	jn	jn
Our Society is doing a good job in engaging people living with schizophrenia in planning decisions.	jn	jn	jn	jn	jn	jn
People living with schizophrenia need to play a key role in program, planning and decision-making within the Society.	jn	jn	jn	jn	jn	jn
Personal contact and story telling is an effective way to educate the public about schizophrenia.	jn	jn	jn	jn	jn	jn
Program, education and policy decisions need to draw from research evidence, promising and best practices.	jn	jn	jn	jn	jn	jn
There is a high level of agreement across the Schizophrenia Societies regarding key messaging.	jn	jn	jn	jn	jn	jn
Other (please specify)						

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4. Treatment and support services

People living with schizophrenia report experiencing poorer quality of health, and have less access to treatment and social services relative to other health conditions. The following key messages are drawn in large part from the Quality of Life Survey undertaken by the SSC. Over 1,086 people participated giving us a detailed understanding of what people want and clear direction to the SSC regarding messages they would like to see communicated. The full report is available at: <http://www.schizophrenia.ca/FINALSSCQOLReport.pdf>.

SSC Key Messages Survey

1. How strongly do you support the following key messages?

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Unsure
All Canadians living with schizophrenia are entitled to equitable access to appropriate health and mental health treatments.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Considering the body, mind and spirit is an important focus for treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Early diagnosis, comprehensive treatment and supporting social inclusion improves recovery.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health care providers need to promote hope, optimism and the capacity for recovery.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health services need to provide practical assistance with housing, income support, employment, community connections	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medications are important but quality of life is more than symptom management.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Optimal treatment includes access to medications, counseling, psychotherapy, peer support, rehabilitation and recovery services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People living with schizophrenia want to feel respected, listened to and included in planning decisions. Health and social services need to include people as partners in treatment planning and shared decision-making.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recovery-focused services include teaching skills in medication self-management, independent living, ways to avoid crisis and prevent illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Schizophrenia is treatable and recovery is possible.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Services need to support people in achieving their own self-defined QOL goals.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Side effects from medications can compromise quality of life and concerns are often ignored, dismissed or minimized.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The majority of people feel medication improves their quality of life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The Societies need to promote hope, optimism and the capacity for recovery.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Timely access to effective medications and supportive treatment results in fewer episodes of illness, hospitalizations and reduces the risk of suicide.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treatment success needs to be measured beyond symptom management and include enhancing social inclusion and quality of life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
While 'cure' may not yet be possible for everyone living with schizophrenia recovering a good quality of life is.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other / comment (please specify)

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5. Role of Families and Friends

Families, care givers and friends are critical to recovery. They play a vital role in supporting people in emotional, social and psychological ways. Families report feeling unsupported, devalued and left out of treatment.

SSC Key Messages Survey

1. How strongly do you support/agree with the following messages.

	Strong support	Support	Neutral	Don't agree	Strongly disagree	Unsure
Families need to be included, respected and consulted by professionals. When this does not happen it is a major source of stress and diminishes quality of life.	jn	jn	jn	jn	jn	jn
Families/caregivers have their own unique need for information and support. This must be included as part of a recovery focused service system.	jn	jn	jn	jn	jn	jn
Families/caregivers need educational tools to understand how to support recovery.	jn	jn	jn	jn	jn	jn
Families/caregivers play a critical role in recovery and need to be included in treatment planning.	jn	jn	jn	jn	jn	jn
People living with schizophrenia say being seen as capable, feeling accepted by family and having others believe in their capacity for recovery is critical to their quality of life.	jn	jn	jn	jn	jn	jn
The support of friends is critical to recovery. The Society can play a critical role in supporting friends to stay involved and encouraging broader social engagement.	jn	jn	jn	jn	jn	jn
Other (please specify)						

6. Social inclusion and reducing discrimination

People living with schizophrenia experience profound levels of discrimination and social exclusion which affects every area of their lives including:

- high levels of unemployment leading to poverty and isolation.
- decreased access to education and training
- loss of human rights in health care facilities
- loss of friendships and family supports
- rejection by neighbours and denial of housing
- denial of mortgages and life insurance
- poorer quality of health care
- higher levels of incarceration
- negative portrayal by media
- families also experience painful stigma and discrimination.

The stigma and discrimination has a negative impact on self esteem, self-efficacy and quality of life. Self-stigma causes people to not pursue their life goals, refuse treatment and at its most extreme end their lives. This was identified as a priority issue in the recent quality of life survey. Both people living with psychotic disorders and their families want this to be a priority issue for the Schizophrenia Societies to address.

SSC Key Messages Survey

1. How important are the following messages?

	Very important	Important	Neutral	Not important	Very unimportant	Unsure
Addressing stigma and discrimination is a shared concern. We all have a role to play in removing the barriers to social inclusion.	jn	jn	jn	jn	jn	jn
Being engaged in peer support, advocacy, and education activities is empowering and reduces self-stigma.	jn	jn	jn	jn	jn	jn
Employment & education are important to social inclusion. Systemic barriers to employment are more of a problem than the individual's ability to work.	jn	jn	jn	jn	jn	jn
People living with schizophrenia do not receive equal access to medications, health & social services. This is discriminatory.	jn	jn	jn	jn	jn	jn
People living with schizophrenia have a right to access the same supports & services as all members of their community.	jn	jn	jn	jn	jn	jn
Reducing stigma & discrimination requires changing policies and practices which limit opportunity.	jn	jn	jn	jn	jn	jn
Social exclusion is widespread for people living with schizophrenia.	jn	jn	jn	jn	jn	jn
Stigma & discrimination towards people living with schizophrenia, their families & those who provide care is widespread. This seriously compromises quality of life.	jn	jn	jn	jn	jn	jn
Stigma and discrimination is a barrier to social inclusion including participating and contributing socially and economically to ones community, and enjoying the same rights as all citizens.	jn	jn	jn	jn	jn	jn
The rights of people living with schizophrenia need to be respected within the health and social service systems. People feel their rights are routinely denied.	jn	jn	jn	jn	jn	jn
Other (please specify)						

7. How you frame schizophrenia matters:

The research reveals that framing schizophrenia as a serious brain disease that is biologically based, chemically mediated and genetically influenced is contributing to an increase in stigma and discrimination. Anti-stigma initiatives have focused on bringing public attitudes into alignment with medical opinion, teaching the signs and symptoms of illness and emphasizing morbidity, disability and mortality. This approach is based on the belief it will reduce the sense of blame and shame attached to mental illness and the perception that illness is caused by character weakness, family dysfunction or personal failings. This approach has been widely adopted by mental health professionals and family organizations with the hope that it will lead to greater understanding, compassion and support for research and treatment.

The research instead reveals that this approach is contributing to greater stigma, deepening fears of violence towards people with schizophrenia, a desire for social distance and a greater tolerance for risk containment through coercive treatment. The very things people complain compromise their quality of life. Promoting schizophrenia as a genetic disease of the brain has been found reinforces a sense of the immutability of illness, incompetence and incapacity. The result is a greater pessimism for recovery. It is also felt this framing may contribute to a less optimistic view towards schizophrenia and reduced financial support by governments for treatment.

Much has been written on the stigmatizing impact of whether mental illness is framed as a disease, disorder, or condition. Professional bodies are beginning to use less stigmatizing language in discussing schizophrenia and promoting a more optimistic outlook. For example see the UK's National Health Service Schizophrenia Annual Evidence Update 2010. <http://www.library.nhs.uk/mentalHealth/ViewResource.aspx?resID=345136&pgID=1>

This research creates a conundrum for the Schizophrenia Society in considering how to promote a greater understanding of schizophrenia, emphasizing its serious nature and the importance of seeking treatment without increasing stigma.

SSC Key Messages Survey

1. What do you think?

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
The Schizophrenia Societies should focus MORE on the disabling nature of the illness along with the efficacy of treatment.	jn	jn	jn	jn	jn
The Schizophrenia Societies should focus LESS on the disabling nature of the illness along with the efficacy of treatment.	jn	jn	jn	jn	jn
Other (please specify)	<input type="text"/>				

2. Please rank your approval for the following messages.

	High	Medium	Low
Schizophrenia is a serious brain disease which interferes with a person's ability to think clearly, manage emotions, make decisions, and relate to others.	jn	jn	jn
Schizophrenia is a major psychiatric disorder, or cluster of disorders, characterized by psychotic symptoms that alter a person's perception, thoughts, affect, and behaviour.	jn	jn	jn
Schizophrenia is a serious medical condition. The symptoms typically include problems with attention, thinking, social relationships, motivation and emotion.	jn	jn	jn
Other (please specify)	<input type="text"/>		

3. Please rate your level of approval for the following statements.

	High	Low
The exact cause of schizophrenia is not known. Genetics, environmental factors such as stress and trauma, viruses and substance use are believed to be linked with development of schizophrenia.	jn	jn
What causes schizophrenia is not yet known. There are wide variations in the presentation, course and outcome in schizophrenia. It is thought to result from a complex interaction between biological, social, psychological, cultural and economic factors.	jn	jn
Other (please specify)	<input type="text"/>	

8. Criminalization of mental illness

"Every day in Canada, there are countless individuals suffering from mental illness who fall through the cracks of the health system only to find themselves involved in the criminal justice system" (Hylton 1995, 46) According to the World Psychiatric Association, 15 to 20 per cent of inmates in Ontario's prison system have a psychiatric illness with five to seven per cent of those who suffer from a serious mental illness. With the reduction in the number of psychiatric beds all across the country, the laying of charges and demanding forensic hospitalization under the Criminal Code are the only alternatives to abandonment or jailing. Police are spending significantly more time responding to calls related to mental illness. Wait times for psychiatric assessment for patients brought to hospital by police is long and growing. Seventy-one percent of men are assessed as having a mental illness upon admission to prison. Fourteen percent of inmates were receiving psychiatric treatment before they were incarcerated. There is NO training available for front line corrections staff in managing mental illness and addictions.*

*Facts from Quick Facts: Mental Illness & Addictions in Canada. www.mooddorderscanada.ca/page/quick-facts

SSC Key Messages Survey

1. How strongly do you agree/disagree with the following statements.

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Diversion programs and mental health courts are cost effective options for managing individuals, while meeting societal objectives of protection and justice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Improved access to recovery-oriented mental health and community support services will reduce the incarceration of people living with schizophrenia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Properly trained police and Crown prosecutors understand when diversion can be appropriately used to ensure the safe and fair treatment of people living with schizophrenia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The criminalization of mental illness is a form of discrimination which re-enforces negative stereotypes.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The increasing trend towards criminalization of mental illness is the result of inadequate supports and services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The Schizophrenia Societies must tackle the criminalization of mental illness as a top priority.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. Other:

9. Evaluation of survey

Please provide feedback on the quality and value of this survey.

1. How strongly do you agree with the following statements?

	Strong agree	Agree	Neutral	Disagree	Strongly disagree
The survey was easy to understand.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It was important to undertake this survey.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This survey was too long.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The right questions were asked.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How could the survey be improved?

THANK YOU for taking the time to complete this survey. The results will be summarized and presented for discussion at the July Annual Meeting in Newfoundland.