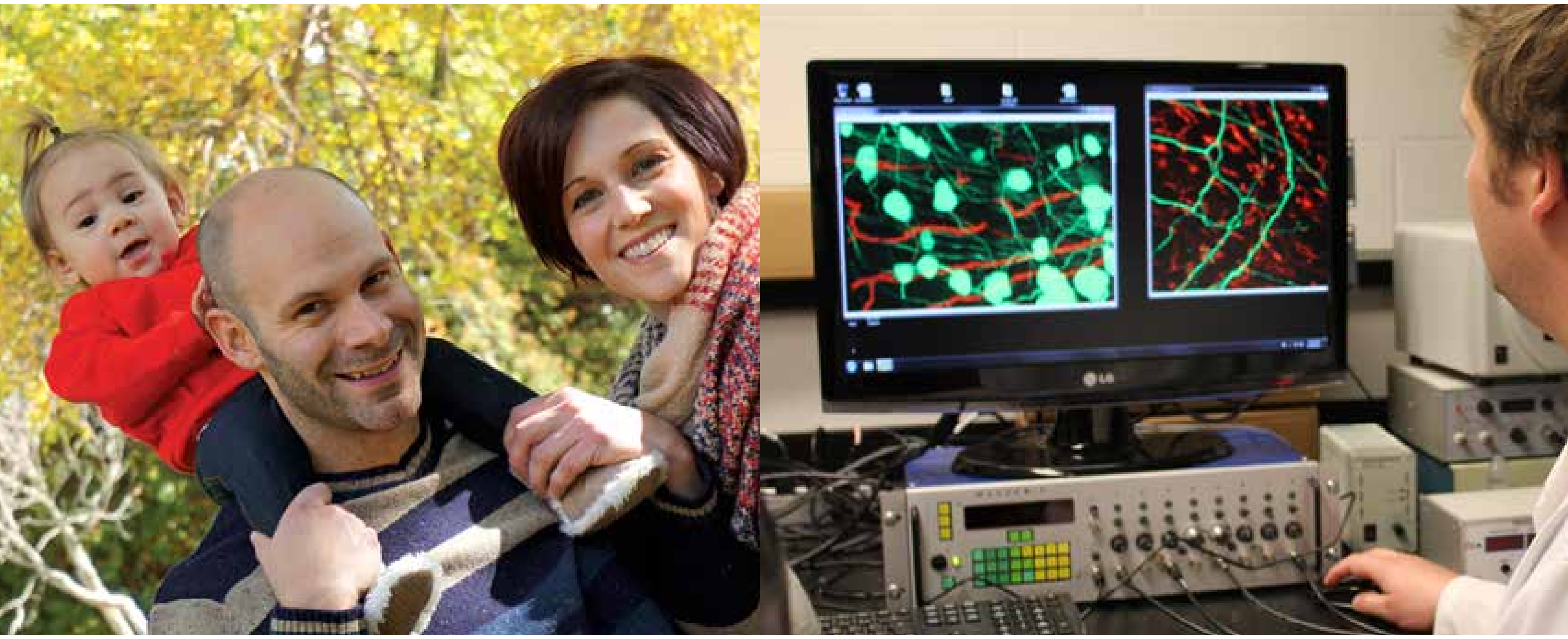
Multiple Sclerosis Advisory Panel Recommendations



To improve care, support research and education, and increase access to clinical trials

February 2016

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of
Saskatchewan

Acknowledgements

The Panel would like to thank all people living with MS, families, caregivers, members of the public, health care providers, educators and researchers who contributed valuable information to our efforts by participating in a survey and other consultations. The Panel would also like to thank the staff and volunteers from the Multiple Sclerosis Society of Canada for their support and contributions to this document, and in particular Erin Kuan, president of Manitoba and Saskatchewan Divisions, and Dr. Karen Lee, vice president of research. Thank you, as well, to John Jacques for serving as facilitator for our group.

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About The Multiple Sclerosis Advisory Panel

The Province of Saskatchewan convened the Multiple Sclerosis Advisory Panel of Saskatchewan in July 2014 and asked its members to develop recommendations that outline options for improving MS care, education, and research in Saskatchewan. The diverse 11-member group is comprised of people living with MS and advocates for people experiencing MS, researchers, and medical specialists. The following recommendations in this document were reached by consensus among the members of the advisory panel.

The panel members are:

Dr. Robert Hickie, Professor Emeritus, Department of Pharmacology, College of Medicine, University of Saskatchewan; Board Member of College of Medicine Alumni

Dr. Andrew Kirk, Neurologist, Neurology Division Head, Department of Medicine, College of Medicine, University of Saskatchewan

Dr. Katherine Knox, Physiatrist, Associate Professor, Department of Physical Medicine and Rehabilitation, College of Medicine, University of Saskatchewan; Director, MS Clinic Saskatoon City Hospital

Dr. Gordon McKay, Professor Emeritus, College of Pharmacy and Nutrition, University of Saskatchewan; Board Chair, Saskatchewan Health Research Foundation

Corey Miller, Vice President Integrated Health Services, Saskatoon Health Region

Eugene Paquin, Board Member, MS Society of Canada; Government Relations Chair, MS Society of Canada – Saskatchewan Division

Dennis Patterson, Peer and Education Counselor, MS Health Centre; Board Member, MS Society of Canada - Saskatchewan Division

Daryl Stubel, Executive Director, Office of Disability Issues

Dr. Anthony Traboulsee, Neurologist, Associate Professor and Director of the MS Clinic at UBC Hospital, Vancouver Coastal Health and University of British Columbia

Dr. Valerie Verge, Professor, Department of Anatomy and Cell Biology, University of Saskatchewan; Director, Cameco MS Neuroscience Research Center

Michelle Walsh, Board Member for Canadian Neurovascular Health Society; MS Patient & Advocate

Letter to the Minister

February 2016

To The Honourable Dustin Duncan

Minister of Health

The Multiple Sclerosis Advisory Panel of Saskatchewan was convened by the Government of Saskatchewan in July 2014 and asked to provide recommendations to the Ministry of Health regarding options in MS education, research, and support in our province. Specifically, the government asked the panelists to produce recommendations that would provide:

- support and/or education services to improve the **care experience** of Saskatchewan people living with MS, their families, and their caregivers;
- support for MS **research and education** in Saskatchewan; and
- opportunities for Saskatchewan people living with MS to participate in **credible clinical trials** that focus on improving a person's condition and/or symptom relief.

The recommendations contained in this report aim to provide the government with guidance on an approach to address the challenges that MS poses and improve the lives of people impacted by MS. The recommendations address all three of the above themes the panel was tasked to address, and are relevant to other neurodegenerative diseases that require complex clinical care and continuing research. Furthermore, the recommendations made in this report are consistent with the Saskatchewan Disability Strategy's recently released report "People Before Systems: Transforming the Experience of Disability in Saskatchewan".

We appreciated the opportunity to participate in this important work.

The Multiple Sclerosis Advisory Panel of Saskatchewan

Bonnie Gleim joined the MS Society of Canada after her MS diagnosis. Shown enjoying the outdoors with husband Stacey and daughter Madison, the Eastend business owner organizes a successful MS walk in her community every year, serves on the MS Society national board and is incoming chair for the Saskatchewan Division board. *Photo by Dwane Morvik Photography*

Multiple Sclerosis - What is it?

Multiple sclerosis (MS) is a neurological disease of unknown origin involving the brain and spinal cord. Myelin (the fatty substance that surrounds and insulates nerve fibres) and the nerve cells themselves are involved. The nerve cells in the brain and spinal cord lose function, resulting in physical and cognitive impairments. Typically diagnosed by age 40, it is a progressive disease that can affect balance, memory, vision, bladder function, and mobility, while also taking an emotional and financial toll. There is no known cure.

Canada has one of the highest MS prevalence rates in the world at 240 per 100,000 people. It is even higher in Saskatoon, estimated at 340 per 100,000 based on one study. Provincial prevalence rates are not known but are estimated to be high given the high prevalence rate in Saskatoon.

There are three main types of MS. About 85 per cent of people living with MS have relapsing-remitting MS (RRMS) at the time that they are diagnosed. RRMS is characterized by an onset of symptoms followed by short or long periods of recovery. The MS Society of Canada estimates 50- to 70-per-cent of people diagnosed with RRMS eventually “convert’’ to secondary progressive MS, a form in which relapses and remissions become less apparent, the impact of the disability accumulates, and maintaining steady employment can become difficult. Primary progressive MS features a slow accumulation of disability without relapse. In the latter stages of the disease, vision and motor function often are poor and help is needed with day-to-day living.

Every day three more Canadians are diagnosed with MS.

Based on a study published in 2007, Saskatoon has one of the highest rates of MS prevalence in the world.

MS is similar to other neurodegenerative diseases in that it is accompanied by chronic conditions which can impact the quality of life of the person living with the disease, as well as their family and caregivers. The unpredictability of the disease progression presents unique challenges in both the diagnosis and treatment of the disease. Given that the episodic symptoms of the disease vary greatly for each individual, it is difficult to predict which supports may be required and when they are necessary. The unpredictability and episodic nature of MS can affect income, employability, mobility, mental health, and a wide variety of day-to-day activities, affecting the overall quality of life of a person affected by the disease.

Best Practices

One of the largest North American organizations of MS health professionals, the Consortium of Multiple Sclerosis Centers, has identified the following best practices:

Those affected by MS should have:

Full and timely access to healthcare

Timely and accurate diagnosis of MS, MS-related symptoms, and non-MS-related conditions

Accurate information and skilled advice provided by experts in MS care

Treatment that is timely, appropriate, and cost-effective

Continuity of care

Collaborative and interdisciplinary approach to care

Care that is sensitive to culture

Support for health-related quality of life issues

SOURCE: http://c.ymcdn.com/sites/www.mscare.org/resource/resmgr/docs/cmsccareofthoseaffectedbyms.pdf

Current State of Care

In Saskatchewan, a person is typically referred by his or her family physician to a neurologist when a neurological problem is suspected. The neurologist may establish a diagnosis and recommend a path of care. There is some variability in the length of time to access neurological care, diagnostic testing, and future follow-up care in Saskatchewan. Persons with MS may continue to follow up with their family physician after diagnosis. Some persons with MS do not have a family physician or do not access primary care regularly. Some do not continue to follow up with a neurologist after diagnosis.

When a person with MS has concerns that may be related to their MS, some of the options for care and support in Saskatchewan include:

a) discuss with their family physician;

b) review by a neurologist they have seen previously;

c) a request for referral to another neurologist, physiatrist or physician with varying levels of experience in MS care;

d) a trip to the emergency department or a walk-in clinic;

e) seeking advice from a part-time Saskatchewan MS Drugs Program nurse educator located at Saskatoon City Hospital; or

f) seeking advice from a nurse with specialized training (if enrolled in a nursing support program related to disease-modifying therapies).

In addition to some of the options listed above, some persons with MS have also sought out medical tourism options.

Importantly, Saskatchewan does not have in place a provincial, standardized care pathway for people with MS, one that would ensure they have timely access to individualized care and support services. Additionally, Saskatchewan people currently do not have access to any MS specialist neurologists in the province.

By building on existing services and through innovations in education and research, Saskatchewan can better address the needs of people living with MS. Improvements in MS care could also have a significant positive influence on the care of other people living with neurodegenerative diseases.

Current services include:

- MS care and support delivered by primary care providers throughout the province;
- Neurologists in private practices located in Regina and Saskatoon;
- Neurologists in academic practices located in Saskatoon;
- Non-specialized part-time therapy services provided at Saskatoon City Hospital and Regina's Wascana Rehabiliation Centre;
- Non-specialized community-based therapy and home care services;
- MS clinics operating out of health region facilities in Saskatoon (Saskatoon City Hospital) and Regina (Wascana Rehabilitation Centre). At the time of this report, a physiatrist (a rehabilitation

physician) and a neurologist offer MS clinics at Saskatoon City Hospital on certain days. At Wascana Rehab, a neurologist provides MS clinics on certain days. An MS clinic in this context refers to clinic services provided in a setting where all the people being served have MS, a related disease, or suspected MS. Some clinics are not scheduled every week, or are offered alongside other services in the same location. Some people with MS also receive system navigation and consultation services provided by family physicians and primary care providers with an interest in MS.

- Some income support and disability services may be provided by Social Services for people living with disabilities, including those living with MS.
- Funding for some specialized equipment is available through Saskatchewan Aids to Independent Living, Ministry of Health.
- Pharmaceutical MS disease-modifying treatments established based on current evidence-based and consensus-driven practices are funded through the Ministry of Health's Saskatchewan MS Drugs Program.
- A longitudinal clinical research database involving persons funded for MS disease-modifying treatments through the Saskatchewan MS Drugs Program.
- Recruitment of an MS Clinical Research Chair at the University of Saskatchewan is currently underway.
- Services provided to people living with MS, their families, and their caregivers by community-based organizations such as the MS Society of Canada.
- MS research conducted through facilities, such as the Cameco MS Neuroscience Research Center located in Saskatoon, are advancing the science of MS.
- A longitudinal clinical research database including persons with MS seen at the MS Clinic at Saskatoon City Hospital, dating back to approximately 1972.
- Since 2013, persons seen at the Saskatoon City Hospital MS clinic are participate in the Canadian Multiple Sclerosis Monitoring System (CMSMS) national registry. The CMSMS aims to improve and inform quality of care for people living with MS and is administered by the Canadian Institute for Health Information.

Currently, Saskatchewan does not have an MS specialist (neurologist with fellowship in MS).

This significantly hampers both patient care and the ability for Saskatchewan people living with MS to participate in multi-site clinical trials.

Current State of Support for Research in Saskatchewan

Currently, the majority of MS neurological research in Saskatchewan is conducted through the Cameco MS Neuroscience Research Center (CMSNRC). The CMSNRC was created in 1996 through a partnership of the University of Saskatchewan, the Saskatoon Health Region, the MS Society of Canada (Saskatchewan Division), and Saskatoon City Hospital Foundation. Its main facilities are located in Saskatoon City Hospital. CMSNRC's goal is to find new treatments for MS and other related neurological and neurodegenerative disorders.

The research centre combines fundamental biological and clinical research to improve the quality of life of those living with MS. The research conducted through this multidisciplinary approach also aims to reduce the impact of disability progression, improve health care outcomes, and reduce long-term costs for people living with MS, their families, and their caregivers. Funding for the establishment of the CMSNRC and the continued operational costs are provided primarily through the Saskatoon City Hospital Foundation's "Quest for a Cure" campaign with individual research grants being won in intense competitions by the principal investigators.

> "In both MS research and health care delivery in Saskatchewan, brilliant ideas are generated. The goal is to improve the lives of people with MS. The challenge is to obtain the resources to make these ideas become realities."
>
> Dr. Valerie Verge, Director, Cameco MS Neuroscience Research Center

Dr. Valerie Verge at Saskatoon's Cameco MS Neuroscience Research Center, where she is director and leads a team exploring nerve cell damage from injury or disease, and strategies for prevention or treatment.

Leadership and Support for Community-Driven Research Priorities

Media reports of a possible cure for the disease were a focus of the Canadian MS community in 2009. Italian researcher Paolo Zamboni asserted that the narrowing of veins, called chronic cerebrospinal venous insufficiency (CCSVI), is present in all people with MS. Zamboni claimed the symptoms of MS could be relieved through what came to be known as "liberation therapy," a surgical procedure involving venous angioplasty to clear and expand veins in the neck of a person with MS.

In September 2011, the government of Saskatchewan committed to support 86 Saskatchewan people living with MS to participate in a U.S./Canada double-blind clinical trial to test the effectiveness of the CCSVI intervention. Of the half dozen who were able to travel to New York and participate in the study, three underwent the CCSVI treatment and three received a control procedure without the CCSVI intervention.

In September 2013, however, researchers at the Albany Medical Center in New York cancelled the trial, stating there were too few U.S. participants to produce statistically valid results. Given that the trial was closed and so few people participated, it is difficult to say whether patients who received the CCSVI intervention fared better than those who did not receive the full intervention.

Other research resulted in some case series reports that indicated some participants experienced improvement after the procedure and other case reports that described harm. One randomized controlled trial out of Buffalo reported that there was no improvement from the procedure, with a trend towards worsening in the group that received treatment.

Shortly after news of the Albany trial's termination, a study published in the United Kingdom medical journal *The Lancet* concluded that Zamboni's MS vein theory was deemed an unlikely cause of MS. The study was led by Saskatchewan and British Columbia researchers and included people from both provinces. No significant difference in the frequency of blocked veins was found among those people with MS when compared to people without MS.

"Our results confirm that venous narrowing is a frequent finding in the general population, and is not a unique anatomical feature associated with [MS]," study lead Dr. Anthony Traboulsee said. "We realize that for many people with MS, this will be a disappointment." Traboulsee, a neurologist from the University of British Columbia and a member of the Saskatchewan MS Advisory Panel, says he continues to study the effects of the vein clearing technique because of the marked improvements of many who have undergone the procedure. Traboulsee estimates that 3,000 Canadians have travelled out of the country to receive the treatment, which is not an insured service provided in Canada.

When the end of the Albany study was announced, the Saskatchewan Ministry of Health committed to working with its health and research partners to explore other options to improve the care and treatment of people living with MS, their caregivers, and their families. Months of discussions culminated in the July 2014 announcement of the formation of this advisory panel.

Consultation with the MS Community

The world can be a very difficult place for people living with MS and those who love and care for them. It can also be extremely frustrating, especially for those living in rural areas with limited access to support services.

As part of public consultations done through an online survey, the majority of people living with MS and their caregivers, spouses, and partners identified that they do not feel the health care and support services they need are available. Those who felt this way pointed to difficulty seeing a neurologist, costly supports, and complex navigation of the system as some of the main barriers to accessing services they need.

A summary of some of the challenges and barriers in the current system, as experienced by people living with MS, families, caregivers, researchers, and care providers

Lacey Warnock was diagnosed with MS at age 19. Now expecting her second child with husband Jason, she is involved with the MS Society. Soon after receiving her diagnosis, she got this tattoo on her forearm: "I can be changed by what happens, but refuse to be reduced by it."

Timely access to neurologists/specialists, required investigations, treatment, and follow-up care

"Being accurately diagnosed quickly would improve the odds of dealing with and living with the disease. People should be seeing MS neurologist specialists often and as quickly after diagnosis as possible."

"People should have access to a MS specialist (not just a neurologist but one who focuses on MS and stays current with up-to-date research and treatment options)."

"We have to travel for my wife to Edmonton to see a neurologist that just specializes in MS."

"Recruitment and retention of specialists is vital. Because there are so few neurologists, they are under pressure to see too many people and have a difficult time developing individualized treatment plans for each person. By increasing the number of specialists there will be an increase in the level of care each person living with MS will be able to benefit from."

"The waitlist for an MRI is too long. The contrast only works on lesions that are active in the past 2 months so when you have to wait 8 to 10 months, you don't get a clear picture. Also, people with MS should have more regular MRIs because it is a good way to (assess) disease progression."

"Improvements to drug coverage must happen. It is unfair for an MS patient to not be able to have access to medication if they have not used it within a year. Having to have two episodes before qualifying again is unfair. The criteria needs to change for easier access when the patient feels they need it."

"Speed up follow-up care once test results have been received so that treatment can be started. I am 41 years old and employed full-time. I have been off work since mid-October and have yet to start any treatment. I now won't see the neurologist until the first week in January. I want my life back!"

Researchers at the Cameco MS Neuroscience Research Center in Saskatoon investigate MS and other neurological conditions.

Lack of local supports for people living with MS in rural areas

“There should be better access to MS specialized care and support for rural residents, including programs, visiting specialists, and specialized nursing care along with well-educated, specialized family physicians who can manage care.”

“Some MS patients like my wife cannot take long trips to go to see neurologists. Telehealth facilities in rural centres could allow them to have face-to-face meetings with practitioners.”

“It would be nice to have a community nurse in rural towns for blood work. It is hard getting to the city and affording the costs associated with ongoing care on disability.”

“To get proper care means five hours in the car.”

“No walk-in clinics in our area, family doctor is over an hour drive away and hard to get timely appointments.”

Rural and remote residents often need to travel long distances to access services.

Support, educational, and care services for people living with MS and their families tailored to different stages of the disease provided by up-to-date health care providers.

"I would value having one source of information that has all the programs and services available that I could become a "member" of and receive regular updates of changes and additions."

"More publication of available services is needed so that everyone is aware and informed about everything that is out there for them. Knowledge is key."

"It would be so beneficial to have some financial support for exercise classes, physiotherapy sessions, massage therapy etc. as all of these are so important to people with progressive MS where no MS drug therapies are available or effective."

"There are few support services that are easily accessible or tailored for an individual patient. There is no one place to get information on the wide variety of issues one with MS faces."

"People need to come to our homes and help us to build our strength and help us to gain some independence back. There is only so much a spouse can do without burning out."

"One improvement to personal needs is to make alternative or complimentary naturopathic medicine more viable."

"Care workers need to know more about the disease and alternative treatments and therapies such as exercise. We need the neurologists to listen to the people with MS and see where they can get relief from different symptoms. We know some of these therapies won't cure MS but many will relieve some symptoms and make life easier."

"We need a fully functioning MS Clinic in Regina where patients can be referred for a number of issues such as counselling directly related to MS, physiotherapy, massage therapy, drug therapy counselling that is not directly related to one particular drug manufacturer, and assistance in finding devices or programs that are suited and helpful to people with MS."

"A clinic where there are coordinated assessment and medical services which views me as a whole person with various challenges, all related to MS, but which are very different for each individual. Right now it is piecemeal depending on what I identify as a problem. Service providers try their best to help, but none have been "experts" in dealing with MS."

"As a younger person with MS, it would be nice to have long-term care housing that is designed with younger people in mind. Currently, my only options are care facilities tailored to an ageing population."

Access to/participation in latest research/trials/studies

"I am not aware of any clinical trials that involve benefits to patients with progressive MS at this time. But it is very important that people who could benefit are given the opportunity to participate."

"There seems to nothing out there for a person with progressive MS. It's all for people with relapsing remitting MS. I feel very left out."

"I think that medical research of any types draws researchers to the province which, in turn, increases the overall attractiveness of the province to doctors, specialists and folks who produce research. This is good for the social net and for the economy – a rare win/win policy option. I'd be pleased to see my tax revenue go towards kick starting a program like this."

Dr. Ruiling Zhai conducts neurological research at Saskatoon City Hospital's Cameco MS Neuroscience Research Center.

Maintaining employability

"Although I personally have a flexible work arrangement, I know the majority of people with MS are unemployed, in part because employers do not offer flexible hours, or flexible hours are only available in low paying jobs."

"Medically things seem to be good, good doctors, medication, etc. However, support for people having issues with maintaining a job is not there. There needs to be more financial support for people with MS."

"I would have loved to talk to someone about how my former employer treated me once it became common knowledge that I had MS. It hurt me to realize that I was now a potential liability to my employer. It hurt me more to realize that I could not obtain a loan, mortgage, or insurance. I refer to myself as being 'one of the uninsurable'."

Consultation conclusion

The above themes from the consultation summary represent what people living with MS, their families, caregivers, researchers, and care providers say are the majority of the barriers in the current system. It is clear that there is a pressing need to improve the quality of care for people living with MS as well as the research and education capacity in Saskatchewan. Moreover, there is a necessity to effectively share the best information available and advance our understanding of the disease. As a jurisdiction with one of the highest MS prevalence rates in the world, Saskatchewan can afford no less.

Vision

That every person in Saskatchewan diagnosed with MS has access to appropriate care and support as close to home as possible through an inclusive blend of services, education, and research that empowers people living with MS, their families, and their caregivers with the tools they require to meet their distinct and diverse needs.

The Panel's recommendations were developed around the following guiding principles: **Collaboration**, **Empowerment**, **Independence**, **Education**, and **Best Practices**.

Our recommendations strive to meet and build on the best practices as outlined by the Consortium of Multiple Sclerosis Centres and other MS experts. The aim is for every person affected by MS in Saskatchewan to have access to timely and appropriate care, the most accurate information available to support disease and symptom management and the services necessary to attain the highest quality of life possible, all while being treated with respect and dignity. By empowering people, health care providers, and researchers with the necessary tools and education, Saskatchewan can become a centre for excellence in MS care and research.

- **System-wide collaboration** between the health system, community organizations, research organizations, and individuals to provide the best services and supports to those living with MS.
- **Empowerment** through designated supports, timely access to services that enable those affected by MS to better navigate and use the existing information and services currently provided.
- **Independence** for people affected by MS to maintain their dignity, to manage their care, to participate in decision making, and to sustain a high quality of life. Supports will be available regardless of geography or financial status.
- **Education** that informs both health care providers and people with MS to understand the complexity and unpredictability of the disease thereby enabling those living with MS to better utilize the system and supports available.
- **Best practices** ensure that recommendations are supported by established evidence or sound rational for improving the lives of people with MS in a manner that has shown in other centres of excellence to be feasible.

Recommendations

Introduction

The MS Advisory Panel was convened to provide specific recommendations to the Ministry of Health to ensure that:

1

Saskatchewan people, their families, and their caregivers have access to support and education to ensure the best possible care and supports while living with MS.

2

Saskatchewan supports MS research and opportunities to enhance MS research capacity in the province.

3

Saskatchewan people with MS are eligible to participate in credible MS clinical trials that focus on improving their condition and/or symptom relief.

Summary List of Recommendations

THEME 1: Care

Specific recommendations to improve the care and support experience for people living with MS, their families, and their caregivers.

Recommendation 1.1 – **Develop a provincial strategy to educate, recruit and retain MS specialist neurologists and an MS multidisciplinary health care team.**

Recommendation 1.2 – **Develop roadmaps of access to care for all persons with MS (including persons in remote and rural communities and at different stages of the disease).**

Recommendation 1.3 – **Create a Saskatchewan-specific MS provincial registry compatible with the existing Canadian Multiple Sclerosis Monitoring System (CMSMS).**

Recommendation 1.4 – **Create an ongoing degenerative neurological diseases advisory council.**

THEME 2: Research and Education

Specific recommendations for MS research capacity and education.

Recommendation 2.1 – **Support the work of an MS Clinical Research Chair at the University of Saskatchewan.**

Recommendation 2.2 – **Support research funding through the Saskatchewan Health Research Foundation (SHRF) for MS-related projects.**

Recommendation 2.3 – **Enhance MS educational opportunities for students, researchers, and health care professionals.**

THEME 3: Clinical trials

Specific recommendations for opportunities for Saskatchewan people living with MS to participate in credible clinical trials.

Recommendation 3.1 – **Provide enhanced administrative and clerical support for the Saskatchewan MS registry for the purpose of facilitating research and clinical trials.**

Recommendation 3.2 – **Develop sustainable infrastructure support for a unit dedicated to clinical trials, including training and resource allocation.**

Recommendation specifics

THEME 1: Care

Specific recommendations to improve the care and support experience for people living with MS, their families, and their caregivers.

Improved supports and care is the goal of the Theme 1 recommendations. Best practices in other jurisdictions suggest people with MS should not have to wait more than six weeks to see a neurologist. Care should be timely and cost-effective and take a multidisciplinary approach involving providers who are best suited to help meet the individual needs of people affected by MS.

Recommendation 1.1 – Develop a provincial strategy to educate, recruit, and retain MS specialist neurologists and an MS multidisciplinary health care team.

MS is an increasingly complex disease. There are now eight medications provided by the Saskatchewan MS Drugs Program for disease-modifying treatment of relapsing-remitting MS. The newer drugs require extensive monitoring and are not without risk. There remains no disease-modifying treatment for progressive forms of MS. Interest in rehabilitation and alternative treatment approaches continue to grow. Previously trained neurologists from the University of Saskatchewan have left the province and hold prestigious positions in MS centers of excellence (including the Mayo Clinic).

Saskatchewan requires a provincial strategy to recruit and retain MS specialists in the province. MS specialists recognize that a complex disease is best approached, not in solo practice, but instead by a team of health care professionals who can help people living with MS address the many aspects of living with their disease.

MS is a complex disease and is best approached by a multidisciplinary team.

This team would include additional neurologists, physiatrists and nursing support with specialty training in MS. Additionally, the team would include services available from neuro-psychology, physiotherapy, occupational therapy, and social work specialists who have additional training or education in MS care.

Recommendation 1.2 – Develop roadmaps of access to care for all persons with MS (including persons in remote and rural communities and at different stages of the disease).

Roadmaps for people living with MS, their families, caregivers and other health care providers would guide effective and consistent care. In MS, timely treatment with disease-modifying therapies or early intervention when a person is in difficulty could result in reduced risk of disability or reduce the impact of the disability. Roadmaps with target timelines for care and care options could be developed and made widely available. Examples include:

- Timelines by which persons with suspected MS, active MS symptoms, or disease progression should be assessed by an MS specialist.
- How to access MS specialists from remote communities by phone or other innovative approaches such as Telehealth and video calling applications.
- Timelines in which an MRI should be completed for a person with MS when triaged as semi-urgent.
- When to suspect a relapse, what to do, and who to contact or notify.
- Timelines in which access to disease-modifying therapies and escalation therapy should be available to those who may benefit from these therapies.
- A roadmap for pharmaceutical disease-modifying therapies based on existing evidence-based, consensus guidelines.
- Consistent with the recently released Saskatchewan Disability Strategy, develop a roadmap to assist in:
    - Identifying the latest in technical aids, devices and equipment, how to access them and which equipment items requires the prescription of a physician;
    - A listing of resources and suggested steps for accommodating MS in a vocational setting;
    - Community-based organizations offering supports and services that would be beneficial to those living with MS; such as the parking program for persons with disabilities; peer support etc.

Currently, in some areas of the province, a person with MS experiencing a relapse can wait weeks or months to see a neurologist. Early treatment may minimize further inflammation and damage to the nerves. Early treatment reduces the risk of early disability progression. Early access to specialized equipment may also prevent falls and other serious complications related to MS.

Early treatment reduces the risk of nerve damage and early disability.

Specialized MS nurses with outreach capacity to every health region could serve as a conduit to the roadmaps as well as educational and support services while ensuring resources are used effectively and efficiently.

The opportunity exists to draw on the work from the recently released Saskatchewan Disability Strategy to improve the lives of people experiencing disability and also

address the unique needs of people impacted by MS and their caregivers.
The strategy outlines the following “Priority Outcome Areas”:

- People Before Systems;
- Safeguarding Rights and Safety;
- Increasing Economic and Social Inclusion;
- Building Personal and Community Capacity;
- Creating Accessible Communities; and
- Becoming an Inclusive Province.

For more on the Saskatchewan Disability Strategy, titled People Before Systems: Transforming the Experience of Disability in Saskatchewan, see here: www.saskatchewan.ca/disabilitystrategy.

The Saskatchewan Disability Strategy has put forward a series of recommendations to the Government of Saskatchewan to address the needs of people experiencing disability in the province. People impacted by MS and experiencing disability will benefit from the recommendations in the strategy. In particular, the strategy’s recommendations pertaining to accessibility and inclusion (economic, social, and personal supports), coordinating and navigating the system (i.e. roadmaps), and building the capacity of service providers complement the MS Panel’s recommendations and can be realized through system-wide collaboration to better support people living with MS, their families, and their caregivers.

Roadmaps can also draw on evidence-based research into quality improvement and standards of care such as the American Academy of Neurology’s multiple sclerosis quality measures, the Consortium of Multiple Sclerosis Centers’ “Recommendations for Care of Those Affected by Multiple Sclerosis”, and the National Institute for Health and Care Excellence’s “Multiple sclerosis: management of multiple sclerosis in primary and secondary care.”

Roadmaps can help standardize care and also be used to help optimize the provision of services so that a long trip to the city to see a neurologist, for instance, can also include a visit to the physiotherapist and nutritionist. Roadmaps may also help to alleviate the need for long distance travel entirely or help to avoid hospital admissions. Through widely available MS roadmaps specific to the Saskatchewan health care system, people with MS, their families and caregivers, and health care providers would be empowered with the information and tools to better understand and anticipate the optimal path for care.

Recommendation 1.3 – Create a Saskatchewan-specific provincial MS registry compatible with the existing Canadian Multiple Sclerosis Monitoring System (CMSMS).

In order to enhance care, plan resources, and evaluate the impact of future MS care, Saskatchewan must know where the people with MS are located and how their disease is changing. There is also a need to understand which resources people with MS are accessing. The CMSMS was created with a similar mission – to monitor and enhance the care of persons with MS. Currently, only people seen at the Saskatoon MS clinic, a minority of people with MS in Saskatchewan, are enrolled in the CMSMS. A comprehensive Saskatchewan provincial registry is needed for the primary purpose of monitoring and improving care. A provincial registry would also facilitate research as outlined under Theme 3 below.

Of those who responded to the panel's public survey, more than 90 per cent of people living with MS would participate in a confidential registry and would be interested in opportunities to participate in clinical trials.

For more on the CMSMS registry, see here: www.cihi.ca/en/types-of-care/specialized-services/multiple-sclerosis/canadian-multiple-sclerosis-monitoring-system

Recommendation 1.4 – Create an ongoing degenerative neurological diseases advisory council.

The creation of an ongoing advisory council would be a means to support the assessment of care interventions and seek feedback from people living with MS and other degenerative neurological diseases. The advisory council would provide a network for MS agencies and stakeholders to interact, address gaps, and monitor implementation so that efficiency and opportunities for enhancing care and supports are maximized. The advisory council would also be a platform for the generation of research priorities and funding opportunities. The council membership would include members of MS agencies and stakeholder groups as well as members from other degenerative neurological disease organizations and stakeholder groups.

THEME 2: Research and Education

Specific recommendations for MS research capacity and education.

Recommendation 2.1 – Support the work of an MS Clinical Research Chair at the University of Saskatchewan.

> “Saskatchewan should have an MS neurologist who leads clinical care, and research. Furthermore, the province should have better access and training for medical support staff and funding to allow access to these services for people living with MS.”
>
> Survey comment

At time of writing, the University of Saskatchewan’s search for an MS Clinical Research Chair is in progress. The primary role of the MS Chair will be to strategically prioritize research efforts in Saskatchewan. However, the incumbent will require clinical resources and infrastructure to conduct clinical research in MS. It is important to note that although an MS Clinical Research Chair would be a boon to the province, he or she would be most effective while working in conjunction with other neurologists and team members to advance clinical care and support. He or she will also be a clinical resource to other health care providers and the people of Saskatchewan living with MS. The incumbent could utilize a comprehensive Saskatchewan MS registry for insight into areas requiring further research or for the recruitment of persons with MS into clinical trials. The incumbent may have other innovative ideas for the conduct of research and care in Saskatchewan. The recommendations of the panel presented in this document are likely to facilitate the recruitment and retention of our future chair.

Recommendation 2.2 – Support research funding for MS-related projects through the Saskatchewan Health Research Foundation (SHRF).

Saskatchewan can build and strengthen the MS research capacity in the province through support of biomedical, clinical, and population health research, the latter to include a call for strategic initiatives impacting rural and remote communities.It is the intent that such a research program initiative would develop seed ideas and generate preliminary data that would then be used in federal research funding applications (i.e., MS Society of Canada and the Canadian Institutes of Health Research). The smaller level of provincial investment at the initial stages would be used to win more substantial research funds required for longer term and larger capacity investigations.

Furthermore, there are many worthwhile investment opportunities through linkages with broader industry and research partners. These opportunities can be leveraged while maintaining the integrity and objectivity of the research.

Recommendation 2.3 – Enhance MS education for students, researchers, and health care professionals

It is possible to enhance MS education in the province by:

- Empowering students, researchers, and all health care providers with the knowledge of MS treatment approaches and when to refer for MS specialist support.
- Providing students from many disciplines with a clinical learning opportunity.
- Providing sustainable continuing medical education (CME) funding for a Saskatchewan multidisciplinary MS clinical team to stay up-to-date on best practices.
- Enhancing training and engagement in MS Research by hosting the MS Society of Canada's endMS Summer School.

The lack of knowledge about MS among many front-line health care providers can lead to delayed treatment and unnecessary referrals that do not make appropriate use of scarce system resources. It can be frustrating to those impacted by MS.

One way to address the deficit is to create learning opportunities for students from multiple disciplines to learn about MS before they venture out into clinical practice. A multidisciplinary Saskatchewan MS team could provide such a learning opportunity for students. The team could also provide outreach consultation services to health professionals already in the community. The MS multidisciplinary team would require ongoing support for educational opportunities (i.e. conference attendance and other CME activities) in order to stay up to date in their practices.

Potential Online Educational Tools for Providers

1. Roadmaps for MS care
2. Brief videos by MS expert on:
    - keys to diagnosing MS
    - state of treating and managing relapsing-remitting MS with disease-modifying therapies
    - state of managing progressive MS
    - state of pain, spasticity and fatigue management
3. Provide CME credit for accessing this material

The MS Society of Canada's annual endMS Summer School is an appropriate forum for increasing knowledge about MS among a range of researchers at the trainee level. The program enables trainees from a variety of disciplines to come together in a small-group setting to learn about MS-relevant research topics. These small-group sessions are designed to facilitate networking, collaboration, and information exchange among participants. The program alternates its focus each year between basic research and clinical and population health research. Partnering with the MS Society of Canada to host a summer session of the endMS Summer School would enable the province to enhance knowledge and skills relevant to MS research, foster opportunities to conduct MS research in Canada, and increase the intent among trainees to pursue MS research for the long term.

THEME 3: Clinical trials

Specific recommendations for opportunities for Saskatchewan people living with MS to participate in credible clinical trials.

Recommendation 3.1 – Provide enhanced administrative and clerical support for the Saskatchewan MS registry for the purpose of facilitating research and clinical trials.

A comprehensive Saskatchewan MS registry would be central to advancing MS research in the province. In addition to serving care and monitoring needs, support should be provided for the registry to be used for the purpose of recruiting persons interested in participating in clinical trials or for survey studies. Through the Saskatchewan registry, people with MS would have the opportunity to volunteer for participation in research. Many people impacted by MS are empowered by actively participating in research opportunities which may be aimed at addressing questions of relevance to their situation or experiences. The registry would be ideally suited to investigate the use of alternative treatments and therapies trialed by others impacted by MS and could lead to novel approaches to care for future study.

Administrators, physicians, and multidisciplinary staff working in MS care should be allocated protected time within their job descriptions to participate in facilitating or conducting MS research. Sufficient staffing is required to cover the clinical loads when clinical research is being conducted. Research initiatives may include multi-centre-based clinical trials, innovative investigator-initiated research, models of care research, and research aimed at enhancing people's quality of life.

> "Improve potential partnerships with existing researchers to provide opportunities for Saskatchewan people living with MS to be included in trials without having to travel beyond the provincial borders."
>
> Survey comment

Current interests in person-centered research include:

- Data collection on actual population of Saskatchewan residents diagnosed with MS.
- Progression of disease and progressive needs (met/not met) such as housing, transportation, medical care.
- Therapies available and currently utilized by MS clients (disease-modifying therapies (DMT) and other ancillary therapies).
- Other therapies such as exercise and diet with positive effects on morbidity.
- Roles, education, and support for caregivers.
- Gaps in diagnosis and care as well as the availability of professional support.

Recommendation 3.2 – Develop sustainable infrastructure support for a unit dedicated to clinical trials, including training and resource allocation.

To capitalize on the expertise of the MS Clinical Research Chair as well as the data provided by the proposed Saskatchewan MS registry, the Ministry of Health could support the enhancement of the Clinical Trial Support Unit at the University of Saskatchewan.

Clinical trial units are typically housed in a university and led by a principal investigator (in this case, the MS Clinical Research Chair). The unit would provide necessary supports such as:

- space to see clients,
- space to store regulatory documents and drugs being studied,
- space to process blood samples,
- support staff (trained research nurses, coordinators, research assistants), and
- infrastructure (contract support, budget management, ethics boards).

The benefits to clients and stakeholders, as well as the health system as a whole, would be considerable.

In addition to providing benefits to clients and the health system, ongoing support for the clinical trial unit would create a sustainable system for MS research in the province. A clinical trial in a participant's home jurisdiction enables them access to new therapies several years before they are on the market and also provides enhanced care through a better provider-to-patient ratio. On a provincial level, a clinical trial unit can decrease drug costs to the health system, as the individual participants in a clinical trial are not likely to be on provincially funded disease-modifying therapies. Moreover, the unit would increase employment for researchers and support staff with an interest in MS.

Building more MS research capacity in Saskatchewan was important to 85 per cent of respondents to a survey by the advisory panel, with the most common suggested focal points for this research being (not in order):

- to find a cure,
- to determine why there is such a high prevalence of MS in Saskatchewan, and
- better disease management.

The opportunity exists to build on the existing Clinical Trial Support Unit in Saskatoon (CTSU), formally the Saskatoon Centre for Patient Oriented Research. According to the University of Saskatchewan, the CTSU is "a joint initiative of the University of Saskatchewan's College of Medicine, the Saskatoon Health Region and the Saskatchewan Cancer Agency, provid[ing] investigators at the three member institutions with the resources, know-how and facilities needed to conduct clinical research. It does so in a manner that withstands legal scrutiny and follows good clinical practice guidelines."

Conclusion

Imagine a future in Saskatchewan where families and caregivers were better supported by informed and compassionate health care providers, where health care professionals had the resources to produce better outcomes by working in effective teams, and where researchers had the infrastructure and resources to advance the understanding of the science underlying a disease marked by unpredictability and complexity. A better future for Saskatchewan's MS community is within our grasp and we can already recognize what some of its primary features should be.

> People impacted by MS should not have to wait more than six weeks to see a neurologist.

So long as the cause and cure of MS remain unknown, much of the effort to improve supports and care must focus on treating symptoms and their progression. Best practices in other jurisdictions suggest people impacted by MS should not have to wait more than six weeks to see a neurologist. Care should be timely and cost-effective, using a multidisciplinary approach that involves a team of specialist MS health care providers who are best suited to help meet the individual needs of people affected by MS. There should be better accommodation for people unable to work and more help for spouses or loved ones providing support to them. People living with MS should have a single point of access to MS-related resources.

Education is key for all health care providers. Roadmaps which provide initial recommendations for how to manage common scenarios in persons with MS, and how and when to refer patients for specialist care would enhance awareness and education about MS. Continuing medical education (CME) courses and conferences would ensure MS care providers are up to date in their practices. These initiatives would no doubt enhance the care experience of persons living with MS in Saskatchewan.

The leadership of a future MS Clinical Research Chair along with the implementation of a provincial Saskatchewan MS registry and enhancement of the clinical trial unit could serve to focus Saskatchewan research and give people living with MS opportunities to participate in clinical trials appropriate to their circumstances. Research into the cause and potential cure of MS should occur in parallel to the work undertaken to reduce the impact of symptoms and enhance quality of life.

> We have the opportunity to shape Saskatchewan into a centre which strives towards excellence in neurological research and clinical care.

We have the opportunity to shape Saskatchewan into a centre which strives towards excellence in neurological research and clinical care. While it is important to maintain the integrity and objectivity in research, the MS Advisory Panel acknowledges that there are worthwhile investment opportunities through linkages with industry and research partners. By building on the current research and clinical care capacity, Saskatchewan can advance the science of MS research and improve the lives of those living with MS, their families, and their caregivers.

The recommendations provided in this report serve as a guide for government:

- to improve the care experience and support for people living with MS, their families, and their caregivers;
- to support MS research and education; and
- to continue to seek opportunities for Saskatchewan citizens to participate in credible clinical trials.

With the prospect of continued focus and collaboration, the future is promising for the many people of Saskatchewan who are directly and indirectly affected by MS.

Appendices

Appendix 1: MS Advisory Panel Members

The following chart provides a biographical snapshot of members of the Saskatchewan MS Advisory Panel, which was convened in July 2014.

MS Advisory Panel			
Role	Panel Member	Position	Community
Patient / Family Representatives	Dr. Robert Hickie	Professor Emeritus, Department of Pharmacology, College of Medicine, University of Saskatchewan; Board Member of College of Medicine Alumni	Saskatoon
	Dennis Patterson	Peer and Education Counselor, MS Health Centre; Board Member, MS Society of Canada - Saskatchewan Division	Regina
	Michelle Walsh	Board Member for Canadian Neurovascular Health Society; MS Patient & Advocate	Beechy
Medical Experts	Dr. Katherine Knox	Physiatrist, Associate Professor, Department of Physical Medicine and Rehabilitation, College of Medicine, University of Saskatchewan; Director, MS Clinic Saskatoon City Hospital	Saskatoon
	Dr. Andrew Kirk	Neurologist, Neurology Division Head, Department of Medicine, College of Medicine, University of Saskatchewan	Saskatoon
	Dr. Anthony Traboulsee	Neurologist, Associate Professor and Director of the MS Clinic at UBC Hospital, Vancouver Coastal Health and University of British Columbia	Vancouver, BC

MS Advisory Panel			
Role	Panel Member	Position	Community
Health Organizations	Dr. Gordon McKay	Professor Emeritus, Department of Pharmacology, College of Medicine, University of Saskatchewan; Board Member of College of Medicine Alumni	Saskatoon
	Corey Miller	Professor Emeritus, College of Pharmacy and Nutrition, University of Saskatchewan; Board Chair, Saskatchewan Health Research Foundation	Saskatoon
Stakeholder Organizations	Corey Miller	Vice President, Integrated Health Services, Saskatoon Health Region	Saskatoon
	Eugene Paquin	Board Member, MS Society of Canada; Government Relations Chair, MS Society of Canada - Saskatchewan Division	Saskatoon
	Daryl Stubel	Executive Director, Office of Disability Issues	Regina

Appendix 2: Recommended Sequencing of MS Advisory Panel's Priority Recommendations

The following groupings of recommendations into phases reflect the need for some actions to lay the foundations for future work. The items within a phase are not necessarily listed in sequential order, as some recommendations may be implemented concurrently. Please see the chart below for details about the Panel's suggested sequencing of the implementation of its recommendations.

Phase I

***Recommendation 1.1* – Develop a provincial strategy to educate, recruit, and retain MS specialist neurologists and an MS multidisciplinary health care team.**

- Recruit specialist MS neurologist(s) and the Saskatchewan MS Clinical Research Chair while providing the multidisciplinary clinical infrastructure for these positions including nursing support (with specialty training in MS), clinic management, clerical support, and other specialty-trained clinical support as may be needed by people living with MS. This would address existing gaps in patient care, increase research and clinical care capacity in Saskatchewan, and allow for Saskatchewan people living with MS to participate in clinical research. Current recruitment for MS Clinical Research Chair and MS neurologist with specialty training in MS are ongoing. However the Panel is aware that successful recruitment of MS specialists may be contingent upon clinical infrastructure not currently in place.

***Recommendation 1.4* – Create an ongoing degenerative neurological diseases advisory council.**

- Create an outcomes-based network of stakeholders with an interest in degenerative neurological diseases so that efficiencies and opportunities for enhancing care and supports are maximized. This would be a platform for stakeholders and people living with MS (as well as other degenerative neurological diseases) to interact, address gaps, monitor implementation of the recommendations, generate research priorities, and identify funding opportunities.

***Recommendation 2.2* – Support research funding through the Saskatchewan Health Research Foundation (SHRF) for MS-related projects.**

- Provide additional funding to SHRF to develop a call for proposals to cultivate 'seed ideas' and generate preliminary data to be used in federal research funding applications (i.e., MS Society of Canada and the Canadian Institutes of Health Research). The smaller level of provincial investment at the initial stages would be used to win more substantial research funds required for longer term and larger capacity investigations.

Phase II

Recommendation 2.3 – **Enhance MS educational opportunities for students, researchers, and health care professionals.**

- Firstly, support investment in the MS Society of Canada's annual endMS Summer School as an appropriate forum for increasing knowledge about MS among a range of researchers at the trainee level. This would enable the province to enhance knowledge and skills relevant to MS research, foster opportunities to conduct MS research in Canada, and increase the intent among trainees to pursue MS research for the long term. Visiting trainees and the existing multidisciplinary team of Saskatchewan health care providers and researchers would benefit from this opportunity. Secondly, support investment in the multidisciplinary researcher and clinician human resource plan to take on more educational and teaching responsibilities.

Recommendation 1.3 – **Create a Saskatchewan-specific MS provincial registry compatible with the existing Canadian Multiple Sclerosis Monitoring System (CMSMS).**

- Provide funding for the enhancement and expansion of the CMSMS to include a Saskatchewan MS registry. The registry would allow the province to better plan MS services and ongoing patient care, inform researchers of current trends, and allow for research tailored to Saskatchewan people living with MS.

Recommendation 1.2 – **Develop roadmaps of access to care for all persons with MS (including persons in remote and rural communities and at different stages of the disease).**

- Work with the MS multidisciplinary health care team and the ongoing degenerative neurological diseases advisory council to develop roadmaps with target timelines for care and care options. This will greatly improve access to care and supports for health care professionals, people living with MS, their families and caregivers.

Phase III

Recommendation 3.1 – **Provide enhanced administrative and clerical support for the Saskatchewan MS registry for the purpose of facilitating research and clinical trials.**

- Build on the successful development of the Saskatchewan MS registry to conduct survey-level research important to people with MS and help identify people living with MS who have previously expressed interest in participating in clinical trials. Provide additional human resource support for administrators, physicians, and multidisciplinary staff working in MS care to participate further in facilitating or conducting MS research. Sufficient staffing is required to cover the clinical loads when clinical research is being conducted. Clinical loads and research engagement would be anticipated to increase over time with the earlier introduction of Phase 1 and 2 activities.

Recommendation 2.1 **– Support the work of an MS Clinical Research Chair at the University of Saskatchewan.**

- For the MS Clinical Research Chair to strategically prioritize research efforts in Saskatchewan, recommendation 1.1 must first be successfully implemented. The chair would be most effective while working in conjunction with other neurologists and team members to advance clinical care, support, and research. The incumbent could utilize a comprehensive Saskatchewan MS registry for insight into areas requiring further research or for the recruitment of persons with MS into clinical trials. As well, the incumbent may utilize or expand existing multidisciplinary care and research services to execute their research vision.

Recommendation 3.2 **– Develop sustainable infrastructure support for a unit dedicated to clinical trials, including training and resource allocation.**

- Capitalize on the expertise of the MS Clinical Research Chair as well as the data provided by the Saskatchewan MS registry to enhance the clinical trials unit at the University of Saskatchewan. Ongoing support for a clinical trials unit would create a sustainable system for MS research in the province. The opportunity exists to build on the existing Clinical Trial Support Unit in Saskatoon (CTSU).

MS Advisory Panel – Sequencing of Priority Recommendations

Phase 1

Recommendation	1.1	1.4	2.2
Description	Develop a provincial strategy to educate, recruit and retain MS specialist neurologists and an MS multidisciplinary health care team	Create an ongoing degenerative neurological diseases advisory council.	Support research funding through the Saskatchewan Health Research Foundation (SHRF) for MS-related projects.
Start	1-Apr-16	1-Apr-16	1-Apr-16
End	1-Sep-16	Ongoing	Ongoing commitment in each fiscal year
Apr-Jun 2016	Begin recruit-ment process	▨	▨
Jul-Sep 2016	▨	▨	
Oct-Dec 2016	MS specialist and team in place	▨	
Jan-Mar 2017		▨	
Apr-Jun 2017		▨	▨
Jul-Sep 2017		▨	
Oct-Dec 2017		▨	
Jan-Mar 2018		▨	
Apr-Jun 2018		▨	▨
Jul-Sep 2018		▨	
Oct-Dec 2018		▨	
Jan-Mar 2019		▨	

MS Advisory Panel – Sequencing of Priority Recommendations	Phase 2	Recommendation	2.3	1.3	1.2
		Description	Enhance MS educational opportunities for students, researchers, and health care professionals. (specifically: endMS Summer school)	Create a Saskatchewan-specific MS provincial registry compatible with the existing Canadian Multiple Sclerosis Monitoring System (CMSMS).	Develop roadmaps of access to care for all persons with MS (including persons in remote and rural communities and at different stages of the disease).
		Start	1-Aug-16	1-Oct-16	1-Jan-17
		End	1-May-17	1-Sep-17	1-Jan-18
		Apr-Jun 2016			
		Jul-Sep 2016	Begin process with MS Society		
		Oct-Dec 2016	▨	Begin construction of registry	
		Jan-Mar 2017	▨	▨	▨
		Apr-Jun 2017	Hold Conference (May 2017)	▨	▨
		Jul-Sep 2017		Registry complete	▨
		Oct-Dec 2017			▨
		Jan-Mar 2018			▨
		Apr-Jun 2018			
		Jul-Sep 2018			
		Oct-Dec 2018			
		Jan-Mar 2019			

MS Advisory Panel – Sequencing of Priority Recommendations

Phase 3

Recomm-endation	3.1	2.1	3.2
Descrip-tion	Provide enhanced administrative and clerical support for the Saskatchewan MS registry for the purpose of facilitating research and clinical trials.	Support the work of an MS Clinical Research Chair at the University of Saskatchewan (recruitment currently underway).	Develop sustainable infrastructure support for a unit dedicated to clinical trials, including training and resource allocation.
Start	1-Jun-17	1-Apr-16	1-Apr-18
End	1-Sep-17	Ongoing	1-Apr-19
Apr-Jun 2016		Support to begin upon successful recruitment	
Jul-Sep 2016		▨	
Oct-Dec 2016		▨	
Jan-Mar 2017		▨	
Apr-Jun 2017	Begin recruitment	▨	
Jul-Sep 2017	Admin and clerical staff in place	▨	
Oct-Dec 2017		▨	
Jan-Mar 2018		▨	
Apr-Jun 2018		▨	▨
Jul-Sep 2018		▨	▨
Oct-Dec 2018		▨	▨
Jan-Mar 2019		▨	▨

Please note: Each of the dated columns at the top of the chart represent a fiscal quarter (ie. "1-Apr-16" = April 1, 2016 to June 30, 2016)

Appendix 3: Specific Initial Recommendations to Improve the Care Experience for People Living with MS through a Team Approach

Prepared by the Saskatchewan MS Advisory Panel, 2014-15.

- Create new, and enhance existing, effective specialized MS multidisciplinary care with outreach capacity to urban and rural areas of Saskatchewan.
- Enhancements to the specialist multidisciplinary care team. The team should have the capacity to travel and organize clinics at other health care centres, depending upon patient need.
- Virtual clinics (video conference) and/or other outreach services should be made available to the people living with MS, their families, and their caregivers through enhanced communication strategies between the specialized MS multidisciplinary team, other health service providers and MS Society client services.
- Recommendations for human resource planning for the MS specialist multidisciplinary care team include:
    - Future projected human resource support should be based on up-to-date provincial prevalence rates of MS and demand for services.
    - At a minimum, the province of Saskatchewan should have two MS neurologists with fellowship training in MS, or equivalent (to ensure adequate specialized MS neurological consultation services at all times).
- Complemented by the MS Clinical Research Chair
    - Several community neurologists with additional continuing medical educational training could serve people out of the physical space of the multidisciplinary clinic in order to facilitate person-centred multidisciplinary care (each neurologist providing a minimum of one day per week of MS care).
    - Saskatchewan should have a minimum of 1.5 full-time-equivalent nursing support with specialty training in MS to assist with care, monitoring, clinical research, and MS education.
    - Several physiatrists with continuing medical educational training in multidisciplinary MS care should serve clients out of the physical spaces of the MS clinic (each providing a minimum of one day per week of MS care).
    - Services should be available from neuro-psychology, physiotherapy, occupational therapy, and social work specialists who have additional training or education in MS care.
- A program administrator and clerical support should be responsible for person-centred scheduling and service evaluation (including the coordination of imaging, urology, and ophthalmology services).

- Training of care providers:
    - MS physicians and nurses should have the opportunity to take a “mini-sabbatical” at an existing MS centre of care out of the province, or undertake an equivalent experience, prior to assuming an MS care role in the clinic.
    - Continuing educational conference leave and funding should be provided to all physicians and multidisciplinary staff on a regular basis to ensure the highest standard of care is being provided across all disciplines.
- Referral process:
    - Any physician may refer people with suspected MS or with an established MS diagnosis to the MS Clinic.
    - A request for referral should include the duration of the presenting complaint or problem, a recent neurological screening examination, and any relevant investigations ordered or completed.
    - After a person has been referred once to MS clinic services and a diagnosis of MS is confirmed, a new referral from a physician is not required to access review services.
    - Any health care professionals or individual with MS, or impacted by MS, may contact the MS Clinic nurses for educational resources or for advice about health system navigation (irrespective of whether or not they have a previous connection with MS Clinic services).
- Continuity, communication and frequency of care:
    - People living with MS should continue to be seen at least annually by their family physicians for their primary care and for ongoing review and management of their MS-related symptoms.
    - People living with MS should be given the opportunity for a face-to-face review at least annually with a physician providing services at the MS Clinic. Depending on needs, some people living with MS will be better served by annual review with a neurologist (and others by a physiatrist) providing MS care.
    - Physicians providing services to people living with MS should provide the individual and the primary care provider a treatment or management plan summary in writing.
    - Newly diagnosed people and/or people with active or progressive disease (or those at higher risk for complications related to their MS) may require more frequent or urgent follow up with their MS physician specialist.
    - A person with a prior diagnosis of MS or suspected MS may contact the MS Clinic nurse to request a review or to request more information concerning their individualized treatment plan.
- Develop enhanced medical imaging capacity in all Saskatchewan health regions and especially in major centres where research and clinical care capacity is located.

Appendix 4: Review of Best Practices/Current Evidence in MS Care

Prepared by: Katherine Knox, Director MS Clinic and Darren Nickel, clinical research support Department of Physical Medicine and Rehab/ College of Medicine

Submitted to: MS Advisory Panel for Environmental Scan

Topics covered:

1. Diagnosis, symptomatic disease management and rehabilitation care
2. Disease modifying therapy treatment

Process: Reflection on clinical practice experiences and *brief* scoping review of published guidelines, consensus opinions and/or systematic reviews. A comprehensive review is not possible with current resources/timelines. **Note:** In some cases, recommendations for practice cannot be based on the evidence, as the evidence as reported by systematic reviews is inconclusive (more research needed). Here we present practice recommendations based on evidence supporting particular recommendations.

1. Diagnosis, symptomatic disease management and rehabilitation care

*National Institute for Health and Care Guidelines http://www.nice.org.uk/guidance/cg186 Multiple Sclerosis **Clinical Guideline** 184 – last updated October 2014 – based on evidence published up to April 2014.*

Some key priorities for implementation (condensed from the institute's guideline):

- Consultant neurologist should diagnose MS based upon current criteria.
- Consultant neurologist should offer oral and written information at that time.
- Should offer person with MS a face-to-face appointment with an MS healthcare professional within 6 weeks of diagnosis.
- Coordinated care should take a broad multidisciplinary approach, involving those who can best meet the needs of the person.
- Encourage them to engage in aerobic and resistance exercise and advise that exercise may have beneficial effects on their MS; it will not have harmful effects on their MS.
  - Consider referral to guidelines or a supervised program.
  - Supervised exercise programs may be particularly helpful for those with mobility problems or fatigue.
- Oral methylprednisolone 0.5g daily for 5 days for relapse – non-specialists should consult with specialists here to help determine appropriateness.
- Do not use fampridine to treat mobility issues in MS; it is not cost effective.

- Offer the person with MS a single point of care to help with coordination and access.
- Ensure access to resources to facilitate establishment of personal goals and means to achieve them – possibly through rehabilitation specialists and therapists with MS expertise.
- Ensure a comprehensive review of all aspects of care at least once a year with healthcare professionals with expertise in MS.

Khan F, Turner-Stokes L, Ng L, Kilpatrick T, Amatya B. ***Multidisciplinary rehabilitation*** *for adults with multiple sclerosis. Cochrane Database of Systematic Reviews 2007, Issue 2. Art. No.: CD006036. DOI: 10.1002/14651858.CD006036.pub2.*

- ‘strong evidence’ for inpatient multidisciplinary rehab producing short-term gains in levels of activity and participation.
- ‘moderate evidence’ for in- and outpatient rehab programs improving disability, bladder-related activity, and participation outcomes up to 12 months later.
- *‘strong evidence’ for low intensity programs over longer periods for longer term gains in quality of life.*
- “MD rehabilitation programs do not change the level of impairment, but can improve the experience of people with MS in terms of activity and participation” (p.2).
- “The evidence presented in this review supports the recommendation that patients with all types of MS should undergo regular specialist evaluation and follow up to assess their need for appropriate rehabilitation intervention as well as maintenance therapy in order to maximize their capacity for independent living and societal participation. The type and setting of the rehabilitation treatment (inpatient, community) should be individualized based on patients’ specific needs” (p.14).

Rietberg MB, Brooks D, Uitdehaag BMJ, Kwakkel G. ***Exercise therapy*** *for multiple sclerosis. Cochrane Database of Systematic Reviews 2004, Issue 3. Art. No.: CD003980. DOI: 10.1002/14651858.CD003980.pub2.*

- “In summary, the present research synthesis suggests that exercise therapy can be beneficial for patients with MS on isometric strength, physical fitness and mobility-related ADLs such as time needed for transfer, walking cadence and balance time. In addition, positive findings were found for outcomes related to mood, such as anxiety and depression. Finally, no evidence was found that specific exercise therapy programs were more successful in improving activities and participation than other exercise treatments. (p.9)”
- Note: Since this review, further individual papers published supporting benefit of various exercise therapy programs for MS; including toolkits and outreach support for adherence to home exercise therapy programs.

Daniel Hind, Jack Cotter, Anna Thake, et al. Cognitive behavioural therapy for the ***treatment of depression*** *in people with multiple sclerosis: a systematic review and meta-analysis. BMC Psychiatry 2014, 14:5*

- "…Seven eligible studies (n = 433) were identified, which evaluated the effect on depression of CBT delivered individually (3 studies *of which 2 were delivered by telephone*), in a group (3 studies) and by computer (1 study)" (abstract).
- …When treating depression in people with multiple sclerosis, CBT appears to confer a medium treatment effect (0.5 SD) compared with standard care and some alternative psychotherapeutic interventions. In the small number of studies where data was provided, CBT also improved disease-specific quality of life in comparison to standard care" (p.9).
- "Further research should explore optimal durations and modalities of treatment for patients with different characteristics... and the cost-effectiveness of this intervention within this population" (p.11).

Rosti-Otajärvi EM,Hämäläinen PI. ***Neuropsychological rehabilitation for multiple sclerosis****. Cochrane Database of Systematic Reviews 2014, Issue 2. Art. No.: CD009131. DOI: 10.1002/14651858.CD009131.pub3.*

- "Twenty relevant studies comprising a total of 986 participants (966 MS participants and 20 healthy controls) were identified and included in this review. Low-level evidence was found that neuropsychological rehabilitation reduces cognitive symptoms in MS. However, when analysed individually, 18 out of the 20 studies showed positive effects. Cognitive training was found to improve memory span and working memory. Cognitive training combined with other neuropsychological rehabilitation methods was found to improve attention, immediate verbal memory and delayed memory.

  "It is worth noting that the small numbers of patients in the studies and some methodological weaknesses reduce the level of the evidence. To further strengthen the evidence well-designed, high-quality studies are needed"
  (Lay Summary).

2. Disease modifying therapies

Multiple Sclerosis Coalition. ***The use of disease-modifying therapies in multiple sclerosis****: Principles and current evidence. 2014. Principles and Current Evidence. Date accessed: September 18, 2014. http://c.ymcdn.com/sites/www.mscare.org/resource/resmgr/PDF/DMT_ConsensusMSC_color.pdf*

- "Due to significant variability in the MS population, people with MS and their treating clinicians require full access to a range of treatment options. … Individuals' access to treatment should not be limited by their frequency of relapses, level of disability or personal characteristics such as age, gender or ethnicity" (p.21).

Mark S. Freedman, Daniel Selchen, Douglas L. Arnold, Alexandre Prat, Brenda Banwell, Michael Yeung, David Morgenthau, Yves Lapierre, on behalf of the Canadian Multiple Sclerosis Working Group. ***Treatment Optimization in MS****: Canadian MS Working Group Updated Recommendations. Can J Neurol Sci. 2013; 40: 307-323*

- "…a change in treatment may be considered in any RRMS patient if there is a high level of concern in any one domain (relapses, progression or MRI), a medium level of concern in any two domains, or a low level of concern in all three domains. These recommendations for assessing treatment response should assist clinicians in making more rational choices in their management of relapsing MS patients" (abstract).
- "While therapy may be considered for any CIS patient and generally recommended for CIS patients with a moderate to high burden of disease, the long-term benefits are uncertain. Early versus delayed treatment has been shown to reduce the rate of conversion to MS and to lower the annualized relapse rate, however, long-term disability outcomes were unaffected in the five-year follow-up of BENEFIT and in the ten-year follow-up of CHAMPS.7,8 The decision to treat should be made on an individualized basis in consultation with the patient" (p.315).
- "A permanent escalation to a second-line agent would be indicated in patients with a suboptimal response to a first-line therapy, or an aggressive course from disease onset. A change in therapy may also be necessary according to patient preference for a less frequent dosing schedule or for an oral therapy" (p.316).

CADH Therapeutic review. ***Recommendations for drug therapies for relapsing remitting MS****. October 2013. Volume 1. Issue 2C. http://www.cadth.ca/en/products/therapeutic-reviews/relapsing-remit-multiple-sclerosis/reports*

- At the time of the report, alemtuzumab and teriflunomide were not approved by Health Canada for the treatment of RRMS, therefore they were not included in the recommendations.
- CADH Recommendations consider the cost-effectiveness analysis.
- Summary of recommendations (p.3):

1. The Canadian Drug Expert Committee (CDEC) recommends glatiramer acetate or interferon beta-1b as the initial pharmacotherapies of choice for patients with RRMS.
2. CDEC recommends that patients with RRMS who have failed to respond to, or have contraindications to, glatiramer acetate as the initial treatment be treated with interferon beta-1b. Similarly, CDEC recommends that patients with RRMS who have failed to respond to, or have contraindications to, interferon-beta-1b as the initial treatment be treated with glatiramer acetate.
3. CDEC recommends that subsequent pharmacotherapies for patients with RRMS who have failed to respond to, or have contraindications to, glatiramer acetate and interferon beta-1b be selected from dimethyl fumarate, fingolimod, and natalizumab. The selection should be based on cost and individual safety concerns.
4. CDEC recommends that combination therapy for treatment of RRMS not be used.

Appendix 5: Summary of Saskatoon MS Clinic

Prepared by: Katherine Knox, Director Saskatoon MS Clinic, Department of Physical Medicine and Rehab, College of Medicine, University of Saskatchewan

Submitted to: Saskatchewan MS Advisory Panel for Environmental Scan

History

The Saskatoon Multiple Sclerosis Clinic was first established by Dr. Walter Hader in 1979 as a joint partnership between the Saskatoon Health Region and University of Saskatchewan. Support in kind from the MS Society of Canada for clinic operations began in 1979. Around the time the Saskatoon MS Clinic was established there was a movement in Canada to create centrally located "specialized MS clinics" to address the unique needs of persons with MS.

The Saskatoon MS Clinic is an active member of the Canadian Network of MS Clinics. This network is a "national network of academic and community based clinics established (2001) for the advancement of patient services, education and research in Multiple Sclerosis". http://www.cnmsc.org/

Resources and funding support

Space is provided in kind by the Saskatoon Health Region at Saskatoon City Hospital. Up until June 30th 2015, the MS Society of Canada funded a 0.8 FTE administrative coordinator. The Ministry of Health and the College of Medicine have provided one year in-term funding for the MS clinic administrative position (~0.7 FTE from Ministry and 0.3 FTE from College of Medicine – sustainability uncertain). This funding also covers some postage and copying expenses and some clinical infrastructure support for clinical research. The Saskatoon Health Region (SHR), through the Rehabilitation portfolio, provides in-kind limited occupational therapy and physiotherapy services. Therapists rotate onto outpatient services from the inpatient tertiary general rehabilitation service. Most therapists have extensive neuro-rehabilitation experience, although MS-specific expertise and interest is variable. The MS Clinic is provided with between 30 and 140 therapy one-hour appointment slots (occupational therapy and physical therapy combined) per year, with volumes largely determined by competing demand for therapy services required for the general rehabilitation inpatient service. This inpatient service is recently under more system pressures.

The MS Clinic also refers patients with MS to the Physical Medicine and Rehabilitation Day Program. This program is able to provide a limited numbers of sessions, usually with a wait list time of between several weeks and several months for the first appointment. The number of new referrals to this program ranges from between 14 and 35 per month. The number of patients with a diagnosis of MS referred to the day program is not readily available at the time of this environmental scan. Physicians can refer patients directly to the Rehab Day Program Services without the need to refer to the MS Clinic first. The day program allows patients to access state of the art rehabilitation equipment including, functional electrical stimulation cycling, suspended body weight treadmill walking, a pressure mapping system and trials using different mobility aids and adaptive equipment. Much of this equipment is donated by the Saskatoon City Hospital Foundation. The foundation has also committed to a fundraising campaign for an MS Clinical Research Chair.

There are no formal social work, psychology or speech language services covering the MS Clinic and these services have limited coverage within the Rehabilitation Day Program Services. Patients seen at the MS Clinic are referred to Community Mental Health services for publically funded neuropsychological assessments or counselling services, providing they live within a reasonable distance of Saskatoon. Wait times are weeks to several months for these latter services.

The SK MS Drugs Program (SK Ministry of Health) operates out of the physical space of the MS clinic. This program provides funding for a 0.8 FTE MS nurse specialist whose scope of practice includes education about MS drugs and also nursing support for all aspects of MS care. Therefore there is significant involvement of the SK MS Drugs Program nurse also in tending to patient care issues for patients seen at the MS Clinic or who may contact the clinic for educational services. This increase in nursing capacity for other aspects of MS nursing care has only recently (2013) been made possible since the SK MS Drugs Program employed an administrative coordinator to look after the administrative aspects of the SK MS Drugs Program. This change allowed the nurse increased capacity to provide more direct care and educational services.

Over the years, some of the patient education and nursing services support has been provided through research funding. Infrastructure for clinical data base support has been limited, however ongoing clinical databases have been maintained in some form with preservation of historical records. In 2010, the College of Medicine provided funding for a half-time research coordinator for the Saskatoon MS Clinic which has led to renewed capacity for clinical research activities.

Physicians who see patients out of the physical space of the MS clinic are either on salary at the University of Saskatchewan (Katherine Knox) or bill privately.

Currently two physiatrists (Dr. Knox and Dr. Hader) and one neurologist recently (Dr. Voll – cross appointment with Dept. of PM&R) see patients out of the physical space of the clinic. Dr. Boyle (neurology) previously saw patients out of the physical space of the MS clinic. Dr. Hader will be retiring from seeing patients in December 2014.

Volumes

Dr. Knox and Dr. Hader each have approximately 20% of their time allocated to direct face to face MS clinical care. Annual MS clinic volumes for face to face visits average approximately

400 visits per year. Approximately 70 to 100 of these are new referrals each year. The director also has approximately 10% protected time for MS clinic administrative activities. The majority of the clinic administration time is spent providing in-house staff education, outreach education and care and collaborating with the nurse with the MS Drugs Program, especially with respect to triaging. The frequency and duration of these contacts are currently not well tracked, although tracking phone follow-ups are now beginning as part of the Canadian MS Monitoring System activities. Currently Dr. Voll aims to have one half-day clinic quarterly out of the space of the MS Clinic, but also triages high-priority patients referred to the MS Clinic who require neurology services through his private clinic.

Appendix 6: Increasing MS Research Capacity and Opportunities in Saskatchewan – Developing a Call for MS Research Proposals via Saskatchewan Health Research Foundation (SHRF)

Prepared by: Dr. Valerie Verge, Director, Cameco MS Neuroscience Research Center

Monies invested by the Government of Saskatchewan as part of a request for investment into MS health research would be administered through the Saskatchewan Health Research Foundation, who would be charged with adjudicating the process and developing a call for proposals. SHRF would likely strike an advisory panel to help articulate the scope of a Call for Proposals for MS research. Insight could be drawn from the Call for Proposals that was developed to fulfill the objectives of a million dollar investment into spinal cord injury research (SCI) made by the Government of Saskatchewan in conjunction with a request by the Rick Hansen Foundation and Saskatchewan researchers. Relative to the number of SCI researchers in Saskatchewan, we have considerably more capacity in the area of MS research at both the clinical and especially biomedical levels. As such, significant uptake of this opportunity would be predicted. Importantly, these types of investments would be instrumental in developing seed ideas and generating preliminary data that could then be used to win larger grants in federal research funding programs (i.e., MS Society of Canada and the Canadian Institutes of Health Research).

In the case of the previous proposal for SCI research, areas of need were identified and targeted for funding in the call for proposals that went forward in June 2011. Similarly, areas of need should be targeted for MS research. **In MS, there is a particular need for more patient-oriented and translational MS research, including proof of principle work to advance discoveries towards new interventions or testing alternative or re-purposed approaches that will improve MS health outcomes. Given the breadth of the MS research community here in Saskatchewan and in order to maximize the potential for outcomes, this call for proposals would be for clinical and health services research and biomedical research related to MS in Saskatchewan.**

In the clinical and health services research stream, SHRF might envisage requesting proposals addressing a wide range of MS outcomes, including quality of life and disability progression. Priority should be given to translational (bedside to practice) and patient-oriented research. Research proposals should be encouraged from a variety of disciplines, including the social and behavioral sciences.

In the biomedical research stream, SHRF might envisage requesting proposals related to developing, refining and testing devices, drugs, or therapies to improve MS outcomes. Priority should be given to translational (bench to bedside) and proof of principle research. Researchers using animal models will need to justify the model's relevance to achieving human clinical trials.

Supported research in both streams should focus on improving health outcomes for MS patients and moving research findings into policy or practice. All funded research should align with objectives that have been set out by the advisory panel, and might include the following:

- reduce the impact of disability progression;
- improve health care outcomes;
- reduce long-term cost; and
- improve quality of life for those living with MS.

Funding Envelope for the MS call for Research Proposals

We envision this funding envelope to be $2 million over five years. SHRF would hold competitions over a period of several years to align with the flow of government funds ($400,000/year) for this initiative. The first competition would be several months after allocation of these funds and subsequent competitions would be set according to available funds and be announced well in advance of deadlines.

SHRF might aim to support one to two clinical grants and three to four proof of principle grants in each competition. Grant amounts and terms might be as follows:

- Clinical or health services research grants: Up to $100,000/year for two years.
- Biomedical grants: Up to $50,000/year for two years

Appendix 7: Select References

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Appendix 8: Consultations

Neil Pierce, President Alberta and NWT Division, and National Vice President Of Government Relations, Multiple Sclerosis Society of Canada – re: Alberta Health Services, “The Way Forward: Alberta’s Multiple Sclerosis Partnership”

Deans of Health Sciences, University of Saskatchewan (Medicine, Pharmacy, Physical Therapy, and Nursing)

Saskatchewan Public MS Survey

Saskatchewan Primary Care Provider MS Survey

Saskatchewan neurologists with interest in MS

Saskatchewan family physicians with interest in MS

The Saskatchewan Medical Association (SMA), Primary Health Care Committee

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