

Sus-IT Canada Symposium

Considerations and Strategies for Encouraging Sustained IT Use in
Older Adults with Chronic Pain and Reduced Mobility

Summary Report: September 2012



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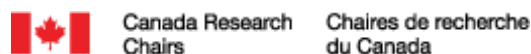
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We also acknowledge the support of Memorial University's School of Nursing.

Support for Sus-IT

We preface our report with a letter from Don Cochrane, a contributor to the Sus-IT Canada Symposium, in which he offers reflections on the symposium and encouragement for our future plans.



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Cochrane

Oct 31, 2012

Dear Wendy,

Further to our conversation this morning, I would like to take this opportunity to further offer my support and encouragement in continuing your program which I was privileged to be part of at the Sus-It Symposium. The following are perceptions, ideas and suggestions that arose in my mind on my return home.

In my studies and writings, I have always talked of life as being seasonal. *Spring* is youth and dedicated to growing and learning. *Summer* is concentrated on production, family, career, community, etc. *Autumn*, previously has meant retirement at 65. For men particularly, this has not always been a long period compared to the first two, but this season has undergone a tremendous change in the last 25 years and certainly since the turn of this century. That short season statistically would have meant a lifespan of 5 or 10 years has now doubled and the people contained in that group continued their lives. In doing so, their physical, emotional and mental capacities and capabilities continue to grow rather than declined. For many, the new *Autumn* is an extension of productivity coupled with freedom and many other choices. In the past, our culture as we know it has undergone revolutions, from an agrarian economy it turned into the industrial revolution, and in the last 25 years with particular emphasis again on the turn of the century, we are experiencing a communication revolution.

Within each season and within each revolution, there are a number of transitions. In the past, there was a transition between youth and adulthood. The end of the second world war brought about the birth of the “teenager”. The technological leaps forward created “middle age”. The newest transition has created the new senior citizen. *Autumn* and its extension of life has brought great blessings and new challenges as with all transitions. The expression “The old 80 is the new 70” sums up this bonus period of life. When all the technological improvements, (particularly in medicine, communication and mobility) are brought together, this new group has very special needs prior to entering their *Winter*. One very positive result of that is the dawning of the age of wellness.

This was very evident at your recent symposium and to see leaders in each of the areas from research to active programs was enlightening, exciting and inspiring. I came away from the Symposium asking myself, as I know the organizing group and other attendees did, the simple question: Where do we go now? The following are some suggestions that I might make to you. They are based on the goal of creating a provincial plan for Newfoundland.

1. Continue your research, particularly in the areas that study the components and groups of people that are impacted by longer and better living.
2. Measure and evaluate your assets and liabilities. These would include all other programs working in this field from pain management, mobility issues and other challenges dealt with by the new senior on a daily basis.
3. Explore widening funding opportunities from the three levels of government, the business world and community groups. This is necessary to build an appropriate networked and sustainable infrastructure.
4. Set specific target populations, geographical locations and special needs citizens.
5. Clarify your core group and build a program that spreads outwards and upwards rather than a top-down structure.
6. Create a specific overall plan with clear goals and objectives including a defined timeline.
7. Run the plan and monitor it regularly bringing the information from the wide field down to the core group and adjust accordingly.

I write this with a sense of excitement that your group in St. John and your island province is the perfect laboratory in which to test many types of programs, initiatives and specific services. Your geography, your resources, the present goodwill, the bonded nature of your population and your proximity to each other within the province are joined by the incredibly professional work you have already accomplished. If I may be of any help be assured that I will give it to the best of my physical ability.

Sincerely,
Don S. Cochrane

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SUS-IT CANADA: KEY MESSAGES

Considerations and Strategies for Encouraging Sustained IT Use in Older Adults with Chronic Pain and Reduced Mobility

Sus-IT Canada is committed to developing and implementing approaches that will help older adults with chronic pain (CP) and reduced mobility sustain their use of Information and Communication Technologies (ICT). The goal of the research team is not to promote the use of technology as such, but rather to help people *continue to use ICT comfortably and sustain their quality of life*. The following summarizes the implications of Sus-IT's findings thus far and offers a rationale for moving ahead with the next phase of its research program:

- Musculoskeletal disorders (MSD) and CP affect over 50% of adults over 65 and 70% of those over 75. Estimates suggest that 20% of the Canadian population will be affected by CP in twenty years' time. It is therefore critical to raise awareness about the tolls of CP on individuals and society, and to develop strategies to help older individuals manage their pain and reduced mobility as they continue to age.
- Why should we care about keeping older adults with CP and reduced mobility digitally engaged, in particular? If these people become disengaged, they risk becoming isolated and depressed, which makes them more likely to be admitted to long-term care facilities. Both treating depression and long-term admissions are costly to the healthcare system.
- Sus-IT Canada proposes that sustaining ICT use among older individuals, i.e., helping them remain socially connected and more in control of their lives, will not only impact their quality of life in concrete ways, but will also yield savings to the healthcare system.
- Given that Canada is a large country with dispersed rural communities that urgently needs new approaches for dealing with its aging demographic, Sus-IT Canada has the potential to become a leading player in the development and implementation of innovative programs for older people living with pain. Although it will be launched in NL, the Sus-IT program can later be exported to, and adopted by, other provinces, and has potential to be introduced in both urban and rural settings.
- To foster well-being in older adults with CP, Sus-IT Canada embraces the following: prevention, education, and access to support services; self-management and empowerment; community collaboration; and tailored healthcare support in the home. These values and goals coincide with the provincial government's existing policies regarding chronic disease, which is top among their healthcare priorities, as well as existing socio-medical and technological initiatives aimed at helping older adults.
- The symposium generated much enthusiasm and interest among the participating parties about possibilities for knowledge exchange and collaboration. Sus-IT Canada is keen to draw on the expertise of existing initiatives as a springboard to realize the next phase of its research program, which will include: an in-home assessment to understand better the barriers to sustained ICT use and how people can modify their environments to integrate ICT more comfortably into their daily lives, as well as a customized tutoring service to meet the unique needs of individuals (50+) living with CP and MSD.

EXECUTIVE SUMMARY

Considerations and Strategies for Encouraging Sustained IT Use in Older Adults with Chronic Pain and Reduced Mobility

Sustaining Information Technology Use by Older Adults to Promote Autonomy and Independence (Sus-IT) is a three-year international project funded by the New Dynamics of Aging Program. Sus-IT began in the U.K. under the leadership of Drs. Leela Damodaran and Wendy Olphert at Loughborough University. Dr. Wendy Young of Memorial University joined forces with this British research network and received Canadian Institutes of Health Research (CIHR) funding to build a Sus-IT Canada research team, which has been exploring the following hypothesis:

“Older adults living with chronic pain (CP) and reduced mobility stand to benefit from greater access to information and customized services that will help them continue to use Information and Communication Technologies (ICT) comfortably and optimally.”

Dr. Young and her team designed a symposium on this topic (summarized herein) where academics, government employees, community groups, and older individuals with CP exchanged knowledge, ideas, and approaches for devising a tailored program that meets the unique needs of individuals (50+) with CP and limited mobility. Based on the recommendations of the symposium participants, Sus-IT Canada plans to move ahead with developing an in-home assessment and tutoring program to help older people maintain their ICT use.

Why focus on older individuals with CP?

Musculoskeletal disorders (MSD) and CP affect over 50% of adults over 65 and 70% of those over 75. Estimates suggest that CP will affect as much as 20% of the Canadian population in twenty years' time. The result of arthritis and various other medical conditions, CP is extremely common, affects many people and their families, and is unfortunately poorly managed.

Why do older adults want to continue using ICT and what barriers prevent them from doing so comfortably?

ICT have become an integral part of people's everyday lives. Individuals use ICT for a variety of reasons: to communicate with family and friends; to get news and information, including medical advice; to access government services; and to play games, shop, and bank. Older adults with CP are heavy internet users but also those most likely to give up using computers. They experience the following barriers to comfortable computer use: getting in and out of chairs, or having to sit in a chair for any length of time; difficulty hitting two or more keys at once; and trouble using the mouse. As they continue to age, they may also experience additional physical, cognitive, financial, knowledge, and/or social obstacles.

Why should we care about keeping older adults with CP and reduced mobility digitally engaged in particular?

If older adults become disengaged, they risk becoming isolated and depressed, which makes them more likely to be admitted to long-term care facilities. Depression and long-term care are both significant costs in Canadian healthcare. Sus-IT Canada believes that helping to sustain ICT use among older individuals (i.e., helping them remain socially connected, more in control of their lives, and capable of living safely and comfortably in their own homes as they continue to age) will not only impact their quality of life in concrete ways, but also yield major savings to the healthcare system.

Moreover, people with CP and physical restrictions deserve premium access to resources—government, medical, adaptive technologies, pain management information, software and hardware, and support group initiatives—that can help them manage their conditions and any potential obstacles they experience in their day-to-day lives.

Which current initiatives are having success in helping people sustain their ICT use and would be assets to Sus-IT as the team builds and implements its program?

The symposium provided an opportunity for the Sus-IT Canada team to hear from people working with a variety of organizations and initiatives who are having success reaching out and making a difference in the lives of older people with CP.

The following organizations have been successful in helping individuals use technology to help them sustain their quality of life: the Independent Living Resource Centre (ILRC), the Seniors Resource Centre of Newfoundland and Labrador (SRC NL), Telecom Pioneers, and the Adaptive Technology Network, whose members include: the Disability Policy Office; Canadian National Institute for the Blind (CNIB); the Blunden Centre; the Learning Disabilities Association; the College of the North Atlantic; the NL Centre for Deafness; and the ILRC.

The following organizations may be helpful to Sus-IT when it comes to recruiting older adults with CP and MSD: The Chronic Pain Working Group; the Arthritis Society; the Newfoundland and Labrador Long Term Pain Association; and the Town of Clarenville, which, as part of the Age-Friendly Communities project, has been very successful in delivering ICT sessions to older adults.

Sus-IT Canada's goals and values coincide with government healthcare priorities in Newfoundland and Labrador (NL) regarding the management of and delivery of services to people living with CP. There was much enthusiasm among all participants at the symposium about possibilities for knowledge exchange and collaboration. Sus-IT Canada is keen to draw on the expertise of existing initiatives as a springboard to realize the next phase of its research program.

What approaches should Sus-IT Canada consider adopting as it moves forward with developing a program to help older individuals sustain their ICT use?

Based on the input of the various symposium participants, the Sus-IT Canada team arrived at a series of conclusions about how best to devise a customized program that will help older adults maintain their ICT use and quality of life. In order to help people change their environments to make computer use more comfortable, the Sus-IT team will develop an in-home assessment procedure to determine the unique needs and objectives of a given participant. This process would include providing a menu of options designed to help participants focus their goals. It would also involve supplying a resource list for participants and potentially setting up a toll-free support number they can use to access support and information.

Furthermore, Sus-IT Canada will establish a process for training and matching tutors. Tutors in the program will need a combination of skills, including technical know-how, interpersonal skills, and ethical sensibilities. These tutors will meet participants in their homes and teach them how to use ICT in keeping with participants' stated goals.

Finally, Sus-IT Canada will undertake an evaluation process, recognizing the importance of measuring program outcomes—the satisfaction of participants, their family members, and the tutors—to determine its overall impact and success.

1. INTRODUCTION

Funded in 2010 by the Canadian Institutes of Health Research (CIHR), and building on an existing research network in the United Kingdom that is supported by the New Dynamics of Aging Program, *Sustaining Information Technology Use By Older People to Promote Autonomy and Independence* (Sus-IT) is a three-year study that explores, on an international scale, the problem of digital disengagement in older adults with chronic pain and reduced mobility. Specifically, the Sus-IT team is investigating why people aged fifty years and older stop using their computers and what can be done to help them stay online.

The Sus-IT Canada Symposium was held on May 10, 2012 at Memorial University in St. John's, Newfoundland. The symposium featured twenty speakers and moderators who work in one or more of the following fields: academic research; policy and planning; knowledge development and exchange; technological initiatives; and public and community health. The Delegates' Kit for the symposium, which includes an agenda for the event, together with a list of speakers and panel topics, is appended to this report as Appendix A.

The symposium was designed to solicit feedback from different parties committed to developing methods for encouraging the sustained use of information technology—or what will herein be referred to as Information and Communication Technologies (ICT)—in older adults who experience chronic pain and reduced mobility. More specifically, all participants were motivated by the guiding principle that finding strategies to help older adults continue to use computers will enhance their quality of life in substantive ways. The symposium offered an opportunity for experts from a range of sectors to share their thoughts and recommendations on what innovative approaches the Sus-IT research team could draw on for inspiration as it works towards devising its own customized program.

The symposium provided the opportunity for the Sus-IT Canada team to:

- Hear from a variety of experts—older adults, community groups, government employees, and academics—and promote a dialogue among them in a group setting.
- Engage leaders from organizations that have had success in implementing technological tools that make concrete differences in people's lives.
- Determine what specific approaches work and what approaches do not work, based on participant feedback, in order to make informed decisions in the final phase of the Sus-IT Canada research program. The ideas and strategies discussed during the symposium and collected in this report will directly inform the development and implementation of a program that will help seniors continue to use ICT comfortably and improve their quality of life.

The panelists shared their research findings, work experience, and provided anecdotal evidence relative to the following key questions:

- Why and how do people—older people in particular—use ICT?
- Why do older adults with chronic pain and reduced mobility stop using their computers?
- What are the obstacles to ICT for individuals who have physical limitations?
- Why should we care whether these people use their computers less frequently or stop using their computers altogether?
- How can we help older adults with physical limitations continue to do the things they want to do using ICT?
- Who is currently successful in helping people maintain their ICT use and what can we learn from them?
- What approaches can be taken to help people sustain their ICT use and improve their quality of life?

At the beginning of the event, Drs. Wendy Young and Irene Hardill, and the Honourable Sandy Collins, Member of the House of Assembly for Terra Nova and Parliamentary Secretary to the Minister of Health and Community Services, welcomed the symposium speakers and attendees. Dr. Young, Lead Investigator of Sus-IT Canada, gratefully acknowledged the funding support received from CIHR; the organizational support received from Newfoundland and Labrador Centre for Applied Health Research (NLCAHR) and the Memorial University School of Nursing (SON); and the committee members responsible for coordinating the symposium: Liz Wallack, Dr. Jared Clarke, Amanda Kinsella and Rochelle Baker.

2. BACKGROUND AND CONTEXT

In their opening remarks, Dr. Wendy Young and Dr. Irene Hardill provided background information and context for the Sus-IT program. The Honourable Sandy Collins then outlined the Government of Newfoundland and Labrador's commitment to programming that will improve the health and well-being of people living in the province while ensuring their access to healthcare services. The following summarizes the inception and objectives of Sus-IT Canada and the existing government mandates in Newfoundland and Labrador that are aligned with the goals identified for Sus-IT:

A. Sus-IT Canada: Inception and Objectives

Dr. Young, Memorial University's Canada Research Chair in Healthy Aging, is part of an international team looking at why people aged fifty years and older are ceasing to use computers and what can be done to help them stay digitally engaged. *Sustaining Information Technology Use by Older Adults to Promote Autonomy and Independence* (Sus-IT) is a three-year international project led by researchers in the United Kingdom. The issue of older people going from being digitally engaged to becoming digitally disengaged was first flagged by Drs. Leela Damodaran and Wendy Olphert at Loughborough University. They established an inter-university Sus-IT team and received a grant from the New Dynamics of Ageing in the United Kingdom in 2009 (£1.102 million); Sus-IT is the largest UK research program on aging ever mounted. Subsequently, Dr. Young assembled a Canadian counterpart to link with the UK network. The Canadian team applied for and received a grant from CIHR (\$225,000), and Sus-IT Canada launched its research program "Sustaining Information Technology Use by Older People to Promote Autonomy and Independence (Sus-IT)." The goal of the project is not to recruit more users; rather, it is to encourage those who already use computers to sustain their ICT use.

In gaining access to nationally representative Statistics Canada datasets, Sus-IT Canada researchers applied their quantitative skills and discovered that digital disengagement is a significant issue in the country that requires attention and solutions. Moreover, the Sus-IT Canada team's data analysis revealed that people with chronic pain (CP) and musculoskeletal disorders (MSD) are heavy internet users; they are also, proportionately, among those most likely to abandon computer use.

The question remains: Why should we care about people going from being digitally engaged to being digitally disengaged? Dr. Young and Dr. Hardill, Co-Principal Investigators of Sus-IT Canada, summarized some compelling reasons for why this is a pressing concern, suggesting that digital disengagement has significant implications for older adults' quality of life:

- Digital technologies enable people, young and old, to access an ever-increasing range of information, goods, and services, including critical public services. Many older individuals in NL, for example, have grown children who have moved out of province to pursue economic and life opportunities elsewhere. These older adults, like many

throughout the world, are increasingly turning to ICT—email, Skype, and Facebook—to stay connected to family as well as friends. If they become disengaged, they risk becoming socially isolated.*

- Social isolation is a known risk factor in depression, and depressed individuals are much more likely to be admitted to long-term care facilities.
- Encouraging the sustained use of ICT therefore has the potential to reduce financial burdens on the country’s already overstretched healthcare system.**

* *Liz Wallack, the Symposium Coordinator and Dr. Young’s graduate student in Community Health and Humanities, is studying the use of Skype as means of connecting family caregivers of people with dementia in rural Newfoundland with the Alzheimer’s Society and the educational services it provides.*

** *Ukeme Eka, a PhD student at Memorial University, is pursuing doctoral research on precisely this question—whether people with good access to medical information on the internet are less likely to undergo preventable hospitalization than people without good internet access, all other factors being equal.*

Importantly, Sus-IT does not focus on the technologies themselves or on getting people to start using technologies. Instead, the research team has been assessing the problems and circumstances that might cause people to give up using technologies such as computers, mobile phones, and the internet. Understanding these issues is the first step in being able to determine how Sus-IT can help people overcome barriers so that they can continue to use ICT comfortably in their everyday lives.

In concluding her comments, Dr. Young outlined the three phases of the CIHR-funded Sus-IT Canada research program and the purpose of the symposium:

Phase I: Data Analysis

The Sus-IT Canada team determined that digital disengagement is a real concern. Disengagement is not abating in spite of the fact that more older adults than ever are using computers and the internet. People with CP and MSD in particular are ceasing to use ICT. This is a critical issue that requires troubleshooting and practical solutions.

Phase II: Symposium

The Sus-IT Canada Symposium was an opportunity to gain insights from experts in related fields about what methods for encouraging sustained ICT use have worked, and what challenges they have encountered. Moreover, it was a chance to hear about what approaches these experts think would work in the local Newfoundland and Labrador context.

Phase III: Piloting Approaches

This report, “Considerations and Strategies for Encouraging Sustained IT Use in Older Adults with Chronic Pain and Reduced Mobility,” summarizes the findings and recommendations shared at the Sus-IT Canada Symposium. It forms the basis upon which Sus-IT Canada will devise a program for carrying out in-home assessments and a customized tutoring program to help older individuals with CP and limited mobility continue to use ICT comfortably in their day-to-day lives.

B. Relevant Government Initiatives in Newfoundland and Labrador

The Honourable Sandy Collins, Parliamentary Secretary to the Minister of Health and Community Services and Minister Responsible for Aging and Seniors, commended Memorial University and the Newfoundland and Labrador Centre for Applied Health Research for organizing a symposium to discuss approaches for assisting older adults with CP and mobility issues sustain their use of ICT.

Over the last several years, he noted, the provincial government has invested significantly in programs aimed at increasing access to quality health care services and enhancing the overall health and well-being of Newfoundlanders and Labradoreans. The 2012 Budget included \$3 billion to improve healthcare for all residents; this figure represents approximately 40% of the entire provincial budget.

Chronic diseases are widespread and greatly impact the health of the population as well as the sustainability of the health care system. Over half of the residents (aged 12 and up) in Newfoundland and Labrador have at least one chronic disease; many people suffer from more than one. Chronic disease is also known to become more common as people age and the province has an aging population; 16% of the Newfoundland and Labrador’s residents are over 65 years of age.

In December 2011, the provincial government released a policy framework for preventing and managing chronic disease called *Improving Health Together*. The framework comprises recommendations that will guide the government over time as it continues to assist and address the needs of people living with chronic diseases—conditions that limit mobility such as CP and arthritis. Specifically, the framework aims to:

- Help individuals become more informed and play a more active role in their own health with the support of healthcare providers and the community;
- Develop an integrated approach in conjunction with healthcare providers who are working together and with the community;
- Use current information and guidelines to provide quality care to better meet the needs of individuals with chronic disease;

- Shift towards prevention—preventing disease and preventing complications and the progression of disease.

These initiatives increase awareness of the signs of chronic disease; provide information on how they can prevent and/or manage chronic diseases; and develop means for addressing chronic disease in the home, the community, and the province at large. By offering opportunities for prevention, education, and management, the government is encouraging individuals experiencing chronic disease to play a more active and empowering role in the management of their own health.

The Newfoundland and Labrador government has already implemented a number of programs, including the Provincial Chronic Disease Self-Management Program, “Improving Health: My Way.” This program consists of workshops that address a range of topics and is offered to people with chronic health conditions and their support persons to help them manage their conditions and stay healthy. Currently, the program is offered through the Regional Health Authorities in many locations across the province. More information is available on the Department of Health and Community Services website and through the NL Health Line.ⁱ

Because community action is a significant area of focus outlined in the policy framework, a Chronic Pain Working Group has been established to advance initiatives to improve CP services in the province. The Arthritis Society and NL Long Term Pain Association have representatives in this working group. Furthermore, the latter organization has received funding from the Department of health and Community Services to assist in the establishment of community-based CP support groups.

Minister Collins expressed his conviction that sustainable strategies stemming from the symposium would support CP and arthritis self-management. He was eager for the participants to explore solutions to help older adults with CP and reduced mobility continue to use ICT so that they may enjoy better social connectedness and improved access to services.

3. TARGET POPULATIONS

The following presentations provided information about people who experience chronic pain (CP) and musculoskeletal disorders (MSD); summarized research on the topic; raised important questions for further study; and made recommendations for what needs to be considered in in-home assessments.

A. Dr. Nancy Baker, University of Pittsburgh

Musculoskeletal Disorders are extremely widespread; MSD is the most common chronic condition among people of all ages. Arthritis is the most prevalent category of MSD, and is also the most elastic—it encompasses over 100 diagnoses. Approximately 70% of people over 75 have some form of MSD, while 50% of people over 65 have an arthritis-related activity limitation. According to statistics for 2011, approximately 4.8 million Canadians live with arthritis.ⁱⁱ This number is expected to increase to 7 million by 2031 (i.e., 20% of the population will be affected in some capacity). Arthritis is expected to become an increasingly significant disease in older adults over the next twenty years.

The three most common forms of MSD or arthritis are: osteoarthritis, rheumatoid arthritis, and fibromyalgia.

i) Osteoarthritis

Osteoarthritis is the wearing away of the joint; it occurs when the cartilage disintegrates and results in bone on bone movement, which causes a great deal of pain. The most common symptoms are stiffness, swelling, and pain. It manifests most often in the hands, neck, low back, hips, and knees, and occurs asymmetrically depending on which side of the body one uses most.

ii) Rheumatoid Arthritis

Rheumatoid arthritis (RA) typically starts in middle age and affects two to three times as many women as men. It impacts fewer people than osteoarthritis, and differs from the latter with respect to the underlying cause. RA is an autoimmune disease—the body essentially attacks its own tissues—and causes inflammation and deformity in the hips, knees, hands, and neck. It causes severe pain and chronic problems, and is characterized by considerable morning discomfort, stiffness, and fatigue. By contrast to osteoarthritis, RA affects both sides of the body (such as the hands, wrists, or knees), causing swelling inside as well as outside the joints. It can also attack the heart, lungs, skin, and eyes, and therefore puts people at greater risk of suffering additional problems. In the last ten years, however, some fairly effective drugs have been developed to treat inflammation. The hope is that severe deformities due to RA will become a thing of the past.

iii) Fibromyalgia

Not technically a form of arthritis, fibromyalgia typically falls under the category nonetheless. It attacks muscles and their surrounding material, not joints. Fibromyalgia usually begins in middle age; approximately 90% of the people diagnosed with it are women, even though men suffer from it as well. It is not a disease per se but rather a syndrome—a constellation of signs and symptoms that occur together. Fibromyalgia does not manifest as joint swelling, but is characterized by pain, fatigue, sleep, mood, and memory issues.

Dr. Baker's research generally centers on these three conditions and how they affect or hinder individuals' continued use of computers. In 2009, she conducted a study that explored problems experienced by people with arthritis—including osteoarthritis, RA, and fibromyalgia—when using a computer.ⁱⁱⁱ Out of the 315 people (mostly women over 45, half of whom worked) surveyed, Dr. Baker found that almost everybody had problems; some even experienced more than five problems at a time.

What problems were people experiencing when navigating the computer? Dr. Baker located a number of obstacles in the physical environment itself:

- Chairs: people had trouble sitting in them, and getting in and out of them.
- The keyboard: people had difficulty hitting two or more keys simultaneously, and also became fatigued when using the keyboard.
- The mouse: people had a hard time manipulating the mouse—positioning the cursor and clicking the buttons. Mouse buttons are especially difficult to access comfortably when people have limited mobility.

In another study conducted in 2010, Dr. Baker investigated the links among computer use, speed, age, and impairments.^{iv} Specifically, she looked at people who had had RA for a while, who were primarily female, and approximately half of whom worked; she compared them to a normative sample. It appeared that there was no significant difference in the measured speed of keyboard tasks—both groups worked at approximately the same speed; however, mouse use was impaired in the RA sample. She found that people with visible structural deformities (VSD) often used more wrist support; they tended to place the bone in their forearm and the bones in their wrists at awkward and unhealthy angles.

Based on the results of a study that she and others published in 2012, Dr. Baker outlined what people with RA or fibromyalgia are doing at work and at home to cope with the problems that they are having using a computer.^v She discovered that people experiment with a wide array of approaches, ranging from varying bodily positions to adaptive technology. Strategies for keyboard use were not consistent; however, people mainly typed for shorter periods of time and more slowly. Dr. Baker determined that people most often adopt changes related to timing—they usually reported slowing down—and they also change their physical position to be able to better interact with the keyboard. Notably, however, they do not change their

environment or start using equipment that would make them more comfortable. According to Dr. Baker, the best strategy would in fact be to change one's physical environment instead of trying to compensate with bodily adjustments and/or slowing down. If one is in the workforce, for example, it is not advantageous to slow down. Thus, it is important to troubleshoot how people can modify their environments to ensure that they continue to be able to use ICT comfortably and effectively. Moreover, people with arthritis are not always familiar with all the possibilities that exist for coping with the challenges of their disease. Dr. Baker concluded that increasing people's awareness about available ICT resources would help individuals with arthritis continue to enjoy a high quality of life.

B. Dr. Sandra LeFort, Memorial University

Dr. LeFort researches the impact of chronic pain (CP) on people's lives and the lives of their families, and is also involved in developing self-management strategies for people with CP. She developed the Chronic Pain Self-Management Program (CPSMP) in conjunction with Dr. Kate Lorig and the staff at the Stanford Patient Education Research Centre. This initiative derived from Stanford's Arthritis Self-Management Program and the Chronic Disease Self-Management Program.^{vi}

Dr. LeFort emphasized the significance of CP as a problem for the industrialized world. CP does not refer to specific diseases—there are hundreds of diseases associated with CP—and the definition varies; however, the International Association for the Study of Pain defines it as an unpleasant emotional and sensory experience that persists beyond the normal time for tissues to heal, which is usually 3-6 months. It may affect one part of the body or be widespread, and can refer to many types of disorders or be a common symptom (as in the case of arthritis, for example); however researchers still do not yet understand why pain persists in many cases.

Dr. LeFort cited four prominent surveys of CP in the adult general population with consistent results. The first was conducted in Australia in 2001; they found 18.5% of adults have CP that has lasted most days for three months.^{vii} In Denmark (2003), researchers reported that 19% of adults have had CP for longer than six months.^{viii} A large study of 45,000 people in twelve European countries (2006) revealed that 18% of people experienced pain that lasted longer than six months.^{ix} Finally, a Canadian study released in 2011 concluded that the prevalence of chronic pain (pain that lasted longer than six months) for adults older than 18 years of age was 18.9%.^x Individuals reported suffering pain several times a week; often rated their pain as greater than 5 on a scale of 0 (no pain) to 10 (worst pain possible); and disclosed that their pain was 5 or higher most days.

Although she conceded it may be a sampling error, it would appear that the highest rates of CP occur in Atlantic Canada: 21.9% people reported experiencing CP, which is three points above the national average; 50% of those people reported having had it for over ten years. Furthermore, one third rated their pain in the severe range (i.e., 8 out of 10 or higher). Although arthritis is the most common cause of CP, only 36% reported CP as a result of arthritis

while 64% had pain due to other reasons. This testifies to how pervasive and invasive CP is, and how frequently it occurs as a major symptom of other conditions. Additionally, in spite of the fact that pain tends to increase at age 65 and above, young people (over the age of 18) also have CP. From a gender perspective, 31.5% of females report CP while only 22.2% of men report it.

What is the impact of chronic pain? The following data derives from the European study conducted in 2006 (see note 9).

- Deep distress
- Functional limitations: walking, household chores, lifting, exercise, and driving.
- Depression: 21% reported having been diagnosed with depression. The true percentage may be higher since depression is under-reported.
- Sleep problems: 65% reported sleep problems.
- Low self-esteem
- Job change or job loss: 48% reported a job change of some kind and 19% reported a job loss. Financial instability is a major concern.
- Changes in social and familial relationships: between one third and one half of respondents reported impacts on relationships with family and friends. Spouses of people with CP experience higher rates of depression than their spousal counterparts.

Overall, CP entails major social, health, and workforce productivity costs. It is estimated that in Canada, CP costs an estimated \$50 billion per year. This figure reflects direct costs as well as those sustained by the individual and his or her family.

It has been acknowledged that CP is not well managed in Canada.^{xi} CP and its attendant problems lack social and medical recognition. Healthcare professionals receive very little education and training when it comes to pain. Medical students receive an average of 16 hours of training on pain; nurses receive 31 hours; veterinarians receive anywhere between 10 and 87 hours. This lack of formal education devoted to pain is not unique to Canada; it is a significant problem.

A national strategy—one that aims to improve quality of life for those with CP as well as their families—is critically needed. The Canadian Pain Society held a national pain awareness day in Ottawa; the Australians and the British have already taken similar measures. It is crucial to continue raising awareness. Dr. LeFort remarked that, on a provincial and national level, there is inadequate funding for interdisciplinary care, the gold standard recommended in evidence-based clinical practice guidelines. People have little to no access to special care services; if these services do not exist, people with CP are subject to very long wait times.

Given that services in Canada are lacking, what do people do? They go online. Generally, people go online to access health information, maintain social connectedness, and increase their sense of control. The benefits of ICT have been well documented. Stanford University, for example,

has developed an online Self-Management Program that has proven to be very effective for individuals seeking online advice regarding pain management (see above and note 6). Their program has been shown to improve participants' ability to cope with illness and enhance quality of life.

Yet, many people who turn to the internet for pain management advice do not realize that very few web sites provide good quality information. De Boer et al. (2007) found that 50% of the respondents in their survey indicated that they believed CP websites to be of good quality; one third based their treatment decisions on these online sources. Therefore, people have misperceptions about the quality of the information they are accessing online. As a result, they are either not working with optimal information or, at worst, are putting themselves at risk.

In 2011-12, Drs. Bailey, LaChapelle, LeFort, Gordon, and Hadjistavropoulos were awarded a CIHR grant to evaluate CP-related information available to consumers on the internet. Previous studies that similarly examined website quality had not employed data collection tools that were validated. As such, Dr. Bailey *et. al* chose to use a vetted rating tool called DISCERN to assess 408 CP websites; only 53 (i.e., 13%) were of high calibre.^{xii} Subsequently, the team recruited 21 people with CP from Atlantic Canada to evaluate 15 websites—the top 10 as well as 5 of lower quality—to determine if consumers could use the DISCERN tool to differentiate between higher and more mediocre sites. This method had never been employed before. They found that consumers successfully differentiate quality sites from mediocre ones, but that the DISCERN tool took too long to use. As a result, they suggest that people use key criteria for assessing website quality as a basic screening tool. There is very good information on CP available to people who are digitally connected and seeking it.

What conclusions were drawn from the research? On a practical level, recruiting people with CP as subjects was very difficult. Furthermore, CP is essentially a silent epidemic; it is often longstanding and severe, and more common in older adults and women in particular. CP is associated with a number of functional limitations that affect daily life and burden individuals, family members, healthcare systems, and society more generally. ICT has the potential to keep people experiencing chronic pain connected to good sources of information, education, and social support; however, people using ICT also need tools to help them remain well-informed and discerning about the quality of information they are accessing online.

C. Mary Reid and Valerie Penton, Disability Policy Office, Government of NL

The Provincial Government of Newfoundland and Labrador is deeply committed to improving the profile and lives of people with disabilities. There is currently a Minister Responsible for the Status of Persons with Disabilities, a Disability Policy Office, and a Provincial Advisory Council comprised of leading experts in the field. The Disability Policy Office (DPO) embraces the following mandates:

- Promoting inclusion in all aspects of society
- Engaging people with disabilities and their advocates in developing strategies and recommendations to address barriers
- Facilitating across departments, policies, and programs that promote inclusion
- Promoting positive attitudes and raising awareness

Note: the DPO does not provide individual services or interventions.

The following resources are provided across government:

- Information on accessibility standards, guidelines, and “how-to” guides
- Disability analysis of policies and programs
- Information on current trends, community priorities, and new technologies
- Links to community and other resources

In 2010, the provincial government held public consultations with persons with disabilities throughout the province in order to understand better what they perceived to be the barriers that confront them in everyday life, which resulted in a report that outlined five strategic directions.^{xiii}

1. Promote a positive understanding of disabilities to deflate negative stereotypes
2. Ensure continued engagement so that the people for whom programs are designed are a part of the conversation throughout all phases of program development
3. Alter the built environment and make it more accessible, including communication and ICT systems so that the government can disseminate information via the internet
4. Develop strong disability-related supports by changing the environment so that it better supports the individual
5. Deliver services with dignity, fairness, and respect

This strategic framework is the basis for horizontal action plans—plans that cross sectors and generations—to be executed by the Minister’s Committee in on-going consultation with the Provincial Advisory Council. People who are aging and experiencing diminished engagement via ICT are not enjoying equitable access to resources. The goal is to build a more inclusive province so that persons with disabilities have the same opportunities and choices as persons without disabilities.

Ms. Penton emphasized the important ways in which technologies present solutions for persons with disabilities. For example, people who are paralyzed are nevertheless able to activate computers with jaw movements; this enables them to do their banking and shopping online. Apps on the iPhone and iPad read the newspaper to people with impaired vision. Technologies play an important role in reducing isolation and providing people with new opportunities to overcome barriers.

Assistive technologies, which may include wheelchairs, magnifying devices, visual hearing aids, and speech software, enable people to maintain independence and participate more fully in all aspects of society. These items can be purchased off the shelf or customized to meet individual needs. Adaptive technology (AT) is a form of assistive technology that permits access to electronic information via a software or hardware component. Voice recognition, screen enlargement software, and text-to-speech programs (these convert computerized documents into speech) are all examples of AT. AT helps people with disabilities to access information and to accomplish daily tasks such as going to school or work, or communicate with friends and family. Moreover, it is a global industry estimated to be worth \$30 billion and growing.

Yet, the literature indicates high levels of AT abandonment among persons with disabilities due to a lack of:

- Coordinated service providers
- Knowledge and/or satisfaction among AT users
- Knowledge of how to use specific pieces of equipment
- Training or technical support available to help people navigate or troubleshoot problems

Critical conclusion: it is crucial to match and tailor a given technology to a specific person in order to meet that individual's unique needs. While devices such as the iPhone and iPad are useful, they do not work for everyone; for example, those who experience dexterity issues may find touch-screen technologies problematic. Finding suitable solutions means forging partnerships with governments, universities, secondary schools, businesses, community initiatives, and individuals.

Dr. Gail Wideman, a Sus-IT Symposium moderator, shared an anecdote about having met a visually impaired woman. The woman was coping extremely well, but assumed that it was probably time for her to move to a nursing home because she could no longer read her mail. Dr. Wideman noted that if this person had better access to information about AT—even knowing about something as straightforward as a magnifying glass device—she may have felt more comfortable and empowered to continue living at home. Not only can AT expand people's physical competencies, they can also help people adopt a better perspective on their ability to cope with their circumstances. In other words, the impact of technology on individuals' attitudes and self-confidence cannot be underestimated. Familiarity is also a key piece of the puzzle. If, for example, solutions are to be located in communities, it would make sense to have neighbours be enlisted to help one another. Dr. Wideman suggested that the best form of support for people to continue aging comfortably in place comes not necessarily from family or formal sources, but rather from volunteer-based supports that enable choice and control.

4. SUCCESSFUL APPROACHES

For this panel, speakers discussed their experiences working with people who have various medical conditions and talked about the successful implementation of ICT to help them manage these conditions.

A. Jon Church, Memorial University

Dr. Church came to Memorial in 1989 and was among the first cell biologists in Atlantic Canada to pursue breast cancer research. He attended the National Forum on Breast Cancer in 1993 where breast cancer survivors shared the stage for the first time with policy makers and breast cancer scientists. He suggested that two of the recommendations that came out of that forum were particularly relevant for the Sus-IT Symposium:

1. Women reported difficulty with accessing information about breast cancer;
2. Women also reported requiring greater access to survivor-directed support and networking centres.

Dr. Church was subsequently asked to participate in Health Canada's Atlantic Breast Cancer Information project whose mandate was to provide timely and effective information to women living with breast cancer. Working alongside breast cancer survivors for the first time, Dr. Church realized that a common desire for all of them was to have an opportunity to talk with one another—share stories, learn from one another's experiences, and be inspired. Motivated to help these women connect, Dr. Church initiated a Breast Cancer listserv. This was in 1995, a time when internet use was growing exponentially, but before there existed thousands and thousands of sites dedicated to breast cancer or health information. This was also prior to the advent of social media, as it exists today. Within six months, he had 1000 subscribers and received approximately 150 emails per day.

In spite of the success of the Breast Cancer listserv, Dr. Church noticed that he had very few subscribers from Newfoundland and Labrador. Since Newfoundland and Labrador is such a large province with so many dispersed rural communities, Dr. Church felt compelled to facilitate communication among women living with breast cancer who came from disparate parts of the province. To address this issue, in 1998 he launched an initiative at Memorial called the Breast Cancer Teleconferencing Network. A 1-800 number was made available and every second Saturday morning women could call in to join a conversation about any and all aspects of breast cancer.

Both the listserv and the teleconferencing program, which lasted ten years, were immensely successful. Women reported that ICT allowed them to be anonymous, independent, and "invisible"—no matter how badly they felt or how despondent they felt about how they looked, they could always get online and talk about the things they wanted to talk about. Not only

could one find support at any time (via the listserv) as well as at a designated time (the teleconference), but one could also draw on a large pool of people for support and information.

Even more interestingly, perhaps, was the fact that these two ICT initiatives actually gave rise to a series of ad hoc face-to-face meetings throughout North America and Europe. For example, a week after September 11, 2001, over 250 women from the listserv congregated in Toronto, and one of the first women to join the Teleconferencing Network, Gerry Rogers, a Canadian documentary filmmaker and NDP politician, began organizing annual breast cancer retreats throughout NL. Ultimately, ICT became a tool for facilitating and coordinating opportunities for personal contact.

Dr. Church then drew from his experience in order to make recommendations for Sus-IT. He suggested that to help older people who are homebound, it is imperative to use every tool in the toolbox and not just ICT. He expressed some reservations about the title of the program, “Sus-IT,” suggesting that it may be a misnomer: rather than promoting ICT use on behalf of large multinational companies like Apple and Microsoft, the program is dedicated to helping isolated people sustain their quality of life.

B. Don Cochrane, New Horizons Computers for Seniors Project

In 2009, the Nanaimo Disability Resource Centre (NDRC) began an outreach program directed by Mr. Cochrane that focused on teaching internet proficiency to community seniors with disabilities. Mr. Cochrane and his team trained groups of computer-savvy seniors to be tutors; the tutors, in turn, visited disabled seniors in their homes and helped them learn skills for using the computer. The goal of the program was to reach out to seniors who wanted computer assistance, but perhaps could not get out of the house too often. Not only did this program help keep seniors socially active, but it was also free of charge. The project grew far beyond original expectations. In addition to the Nanaimo-based program, the project was expanded to include Oceanside. This project was funded in part by the Government of Canada's New Horizons for Seniors Program.^{xiv}

The ins and outs of this innovative service—peer tutoring in the home—were particularly instructive for Sus-IT's purposes. The participants in Nanaimo ranged from 60 to 92 years of age, and their computer devices ranged in speed, quality, and type. The tutors going into client's homes therefore had to possess wide-ranging technical abilities. More importantly, however, they needed strong interpersonal skills in order to be able to connect and bond with the seniors they were tutoring.

Over a six-week period, volunteer tutors underwent training that entailed learning a combination of technical and interpersonal skills; each tutor was then matched with a senior. The tutors visited peoples' homes equipped with a menu from which the senior could select what he or she wanted to do or accomplish. Seniors were offered six sessions of two hours' duration. The project organizers and tutors had meetings every week to process feedback and

adjust the program accordingly; this flexibility proved to be the key to the program's success. Instead of being a top-down venture, the New Horizons-funded NDRC project was bottom-up: it was constantly revised based on frequent user feedback. The goal was to package a program that could be adopted by any organization in Canada and started up anywhere at any time.

The organizers were overwhelmed by the public demand for their services. They ran one advertisement and immediately filled their capacity. Furthermore, they intended to train twelve tutors but then received 300 applicants for tutor positions; they trained forty people and ended up requiring a second training facility so they could train eight people at once. Mr. Cochrane noted that background security checks were required for each volunteer and reminded the audience that this would need to be built into any proposed program budget.

In effect, the program was designed to provide staff, volunteer tutors, and seniors with not only information and skills, but also with a caring and positive experience. It operated on the premise that people may forget what you say (and many seniors did because they have memory problems), but they will never forget how you make them feel. The major take-home messages from the program were:

- Never make assumptions,
- Always listen to the seniors (the clients), as well as the tutors,
- Be prepared to adjust the program according to their input.

C. Kerry Byrne, Tyze Personal Networks Ltd.

Founded by Planned Lifetime Advocacy Network (Plan), which supports families who have family members with disabilities, Tyze is a for-profit and for-benefit business guided by a socially conscious mandate: no one should have to face illness, disability, aging, or caregiving alone. Tyze is focused on helping people mobilize their networks so as to maximize emotional support and access to information.

Tyze has created private, secure, online tools, offering people the opportunity to exchange messages back and forth with other users in an invitation-only, ad-free network. It offers a calendar that people can use to track medical appointments, for example, and an online place to share photos and stories.

People are using Tyze to plan activities and meet offline. People want to use and participate in networks in different ways. Through a project called *Connect for Care*, Tyze is working with CanAssist at the University of Victoria to ensure that even the most vulnerable people in society can participate in their networks. CanAssist develops customized technologies for people with disabilities.^{xv} Tyze and CanAssist are working on integrating a product developed by CanAssist called 'CanConnect' so that persons with limited familiarity with computers or cognitive or physical limitations can access their networks.

The research evidence, both qualitative and quantitative, indicates that Tyze is strengthening connections. In order to help people continue using computers, technology must meet the specific needs and wants of the individual. He or she needs to be comfortable with the technology, which means that training and support must be made available. Promoting sustainability means taking the time to determine what people want to do with technology. Setting up support circles and forging intergenerational connections are also both effective approaches for encouraging sustained computer use.

D. Nicole Beben, Saint Elizabeth Care to Know Centre

How do we (as healthcare providers) support families and clients in relation to their information needs? Ms. Beben discussed the value of customized supports and tools that allow individuals and families to have more control over the information and support they receive from their network. She had worked at TELUS on a targeted networking solution that was intended to support hospitalized children across Canada to build and maintain networks of support with emphasis on maintaining ties to their school and teachers. In her role at Saint Elizabeth, Ms. Beben was also the leader for a grants program that sought to support technology innovations that were person-centred in nature. This program fostered the creation of the first Canadian technological self-management tool (app) for teens with diabetes.

Saint Elizabeth Health Care (SEHC) is a Canadian not-for-profit charitable organization that has been providing care in the community since 1908. Its vision is to honour the human face of healthcare. SEHC partnered with Tyze to address the intersection among informal caregivers (family and friends), the person receiving the care (client), and the formal healthcare provider. Frontline healthcare providers were involved in the introduction of Tyze in the homecare setting to support the building of networks. The personal support workers (PSW) found Tyze empowering; it was a natural extension of the work they were already engaged in offering. Tyze strengthens connections between the PSW and the client. It has the potential to improve outcomes and help people attain their individual goals, and also can help healthcare providers act on information that is shared with them.

There are some implementation issues that require consideration. Knowledgeable people must be available to support the introduction of any new technology and to answer questions. Moreover, the users need to be reassured that they do not need to be overwhelmed by the available technology. Each client is unique and has distinct interests and needs that must be determined by evaluating how he or she wants to engage with ICT.

E. Carol Stanley, Chronic Pain Association of Canada

Carol Stanley has chronic pain; she shared her experience both as a chronic pain survivor and as a professional in the field of chronic pain. In 2003, she was in a car accident. Her vehicle hydroplaned and she was ejected from the vehicle when, even though she was wearing a

seatbelt, the seat itself broke. Ms. Stanley underwent many treatments but did not start finding relief until she met Dr. Sandra LeFort in 2006 who introduced her to the CP Self-Management Program. She credits the program with her survival; it taught her how to take control and become an advocate for her condition and healthcare. Most often, CP is an invisible condition and technology plays an important role in helping people avoid isolation.

The consequences of CP are severe: pain affects physical, social, emotional, and mental well-being, and contributes to feelings of worthlessness. CP entails a wide range of symptoms: sleep and appetite problems; depression; decreased energy and fatigue; spasms; confused thinking; headaches; memory loss; isolation; attention span deficits; anxiety; irritability; anger; and hygiene issues. It has an enormous impact on all aspects of one's life, and is similar to the grief one experiences after a death. It can lead to job loss, which entails financial instability and anxiety; personal relationships also come under great strain.

There exist numerous challenges for people with CP:

- Long wait-times to see pain specialists
- A lack of multidisciplinary pain clinics
- A lack of healthcare provider education about chronic pain: most medical schools devote only one day out of four years' training to issues of chronic pain
- Navigating insurance forms and applying for Canada Pension Plan support
- Difficulty finding relief
- Complexity of negotiating the medical system
- Obstacles to educating family and friends

Learning good communication skills is key to for people with CP:

- Relationships with doctors: it is important to be proactive, clear, and come prepared with questions. Taking notes is an excellent strategy.
- Relationships with family and friends: it is important to learn to ask for help and to express ones' self clearly. These relationships often require taking a leap of faith and believing that these people will love and support you no matter what.

Ms. Stanley's presentation focused on the vital role of support groups in helping people with CP regain autonomy and control over their lives, and employed the image of "taking the wheel" to articulate this message. Support groups provide a safe space where people can come to understand one another, even if they are suffering from different conditions. Often people experience similar symptoms, and the group teaches skills that help people cope with the latter and get through each day. Moreover, it is an opportunity to share knowledge of treatments such as pharmaceuticals, nerve blockers, physiotherapy, nutrition, massage, chiropractic, acupuncture, naturopathy, and homeopathy, and discuss their costs and benefits. Support groups often offer free treatments like yoga, chi gong, meditation, and breathing techniques.

Ultimately, support groups can:

- Help patients regain a sense of control;
- play a positive role in healing and recovery;
- remind people that they are not alone;
- provide a sense of belonging where patients will not be judged; and
- help patients gain access to important information and services.

Ms. Stanley emphasized that when people with CP “take the wheel,” they become empowered because they become accountable for their own health. They can set goals that are achievable, believable, conceivable, desirable, and measurable.

Joining a support group is critical step and should be supplemented with:

- positive self-talk;
- routine and structure;
- mindfulness techniques;
- good decision-making; and
- allowing others to lend their support.

Ms. Stanley’s main advice for people with CP focused on communication and positivity. With respect to communication, she suggested that people: say what they need and want out loud; recognize that people are not mind readers; be clear and concise; use examples to illustrate what they mean when talking to doctors or explaining pain symptoms to family and friends. Positive focusing entails: loving and accepting oneself exactly as one is today; finding a positive way to fill one’s time; scheduling “distractions” such as television shows, movies, visits, and outings to ensure that one has the opportunity to laugh every day; getting active to strengthen and improve; and volunteering—helping others will always have a valuable effect on oneself. It is important to strive to get perspective and realize that “it is never so bad that it couldn’t be worse.”

Support groups are a vital part of one’s recovery and healing for many pain patients. By encouraging CP patients to “take the wheel,” we can help them take back their lives.

F. Donna Power and Kathy Hawkins, Independent Living Resource Centre

The Independent Living Resource Centre (ILRC) is a consumer-controlled organization committed to providing supports, resources, and opportunities for empowerment, enabling persons with disabilities to access better information so that they can make informed life choices. The ILRC offers the following programs and services:

- Information & Networking

- Career Development
- Individual Advocacy
- Peer Support
- Volunteer
- Research & Development
- Community Access Program
- Adaptive Technology (provincial)

Specifically, ILRC also offers Adaptive Technology (AT)—technology designed to support people with disabilities so that they can use a computer more independently. They accomplish this through:

- direct support to consumers;
- a Community Access Program (CAP);
- information and education services, including training;
- a provincial youth internship project; and
- various partnerships.

Who can benefit from Adaptive Technologies (AT)? Anyone who has difficulty controlling a keyboard or mouse; seeing or understanding what is on a display or hearing auditory cues. AT benefits anyone who requires an easier or more convenient way to use a computer.

The ILRC offers the following kinds of software:

- ZoomText
- JAWS
- Kurzweil 3000
- WordQ/SpeakQ
- Key to Access
- Dragon NaturallySpeaking
- Symwriter

The ILRC offers the following kinds of hardware:

- Alternative mouse and keyboard designs. There are many different keyboard and mouse designs that make them easier to use. Hardware components usually cost money. There are however some virtual keyboards and mouse tools that are free to download.
- Touch screen monitors
- Jouse2 Sip-n-Puff
- Switches
- Web cameras
- Magnifiers
- LiveScribe Pulse Smart Pen
- Various Listening systems

The ILRC has met with success; however, the speakers suggest that the following is required for greater optimization:

- increased awareness of technological options and solutions;
- additional funding programs for AT testing;
- financial assistance to acquire technological supports; and
- free, accessible public computer venues.

In order to promote the sustainability of services such as those offered by the ILRC, there needs to be:

- Continued education and support to encourage the use of technology
- Investment in rural communities to provide broadband service
- Opportunity for peer support

5. PLANNING FOR SUSTAINABILITY

During this panel, the speakers discussed various strategies that have been successful in sustaining ICT use in senior populations.

A. Mary Ennis, Seniors Resource Centre of NL (SRC NL)

The SRC NL is a not-for-profit, charitable organization. Through various partnerships, the Centre promotes, enhances, and supports the well-being and independence of older adults throughout NL. One of the key programs they deliver is called the Peer Support Volunteer Program. Developed in 1996 and initially called the Peer Advocate Program, it is an initiative in which seniors support other seniors. The volunteers receive training from SRC NL and keep abreast of current and emerging issues that impact the lives of seniors. They are responsible for dispersing accurate and critical information to their counterparts, and advising them regarding available programs and services that meet their respective needs. Occasionally, the volunteers provide personal support as well.

One of the SRC NL's chief successes has been its ability to service rural and remote communities. It has Peer Support Volunteers in 30 communities and is currently organizing additional training for Inuit people in Labrador who want to participate in the program. In St. John's, volunteers work at a referral line; they field calls from family members who live inside and outside of the province who are concerned about their parents. In total, the SRC NL has 148 support volunteers across the province; however, Community Access Program (CAP) funding has ended, which may result in the closure of CAP sites.

The program's success lies in the fact that seniors and peer volunteers share lived experiences. Seniors avail themselves of the program because they know they can trust and speak to the volunteers, who are contemporaries and often living through similar trials—loss, poverty, isolation. Peer support is a powerful tool: it helps seniors overcome barriers to a better quality of life because it minimizes their experience of isolation.

Isolation is a major impediment to the well-being of seniors. Their family members have often moved away to pursue employment in other parts of the country, and/or they have lost a spouse; some have few or no surviving friends. Additionally, they may be forced to move because of a decline in their health, which contributes further to a sense of isolation. Impaired mobility or other disabilities incurred during the aging process can prevent seniors from participating in social activities as frequently as they once did. Sometimes isolation occurs because seniors cannot see or hear well enough to carry on a conversation and they withdraw. These circumstances often lead to depression and, in some cases, even more serious mental issues in some cases.

Of particular relevance for the Sus-IT Symposium is the fact that seniors who live in impoverished financial circumstances may not be able to avail themselves of ICT. If they do not

own computer equipment or cannot afford to purchase ICT, then this segment of the population may be excluded from an initiative such as Sus-IT. Moreover, people on fixed incomes do not go out as much and therefore are cut off from participating in many things.

Ms. Ennis shared two successful Peer Support Volunteer Program initiatives spearheaded by the SRC NL.

1. **Intergenerational Pairing:** *Twenty-four students from two different high schools were paired with twenty-four seniors; the students used their schools' computers to facilitate one-on-one teaching for seniors in skills such as how to search the internet and how to send email. This program promoted an intergenerational connectedness, and at the end of the course, each group reported that they:*
 - a. *had developed a bond of friendship with the other group;*
 - b. *had a different perspective on the other group than the one they initially held at the outset; and*
 - c. *had increased respect for one another's generation.**Affordability was not an issue because the participating schools provided the equipment.*

2. **Peer Pairing:** *Computer savvy seniors were paired with seniors who owned computers but lacked ICT know-how. These peer-to-peer tutorials were a great success. Again, because the two groups are contemporaries, they could relate to each other easily and develop a trusting and supportive dynamic.^{xvi}*

B. Linda Carter, Department of Health and Community Services, Government of NL

Linda Carter works in policy and program development and implementation at a governmental level. Her presentation, "Making IT Fit: Planning for Sustainability," was guided by the following questions:

- How might an intervention to help older adults with CP or limited mobility remain digitally engaged potentially fit within a longer term plan?
- How might an intervention be sustained, and what factors should be considered in light of a desire to facilitate sustainability?

In addition to substantive funding, which is chief among the conditions for operating a sustainable initiative, Ms. Carter identified three other parameters she deems essential to ensuring the success of a given ICT intervention:

1. **The program must be a "fit" for the individual**
The program has to be relevant, meaningful, and easy for people to make sense of and navigate.

2. The program must be integrated with other existing programs and services

The new initiative cannot be stand-alone; it must cohere with other established initiatives. If it requires the use of particular skills, the individuals must learn those skills and have an opportunity to practice them. There must be time and people available to troubleshoot should any obstacles arise. Self-management—learning how to manage one’s own condition and intricacies—is a big part of the Chronic Disease Policy framework. Learning the following skills is critical to self-management: how to problem solve; how to search for information that is personally relevant; how to make appropriate health-related decisions; and how to communicate with a health care provider.

Stanford’s Self-Management Program^{vi} (also see page 17) thrives on the “action plan” model. The key feature of this model is to set goals that are both measurable and achievable. Goals are things that a person would like to accomplish in a three-six month period, while an action plan is a goal that has been broken down into smaller, doable steps. For example, in an action plan, one might state: “This week I will do _____ (specific action) for so many minutes at a specific time of day for so many days of the week.” Interventions need to be built into an individual’s action plan, which is incorporated into his or her day-to-day activities.

In order to support self-management skills, professionals should be educated about how to promote empowerment and the development of action plans. Ms. Carter pointed out that people with a health education background, (for example, nurses such as herself) are trained to become experts in their fields and therefore to deliver information. Her suggestion is that healthcare workers and professionals in general should learn how to *listen*—to ask their patients what it is that they really need or want to accomplish, and help them realize those goals.

Raising awareness is also critical. Individuals must be made aware of existing community services and new interventions that are emerging, as well as the availability of certain technologies. Promoting an intervention and sharing its benefits publicly is very important for increasing the uptake of the program.

3. The program must also “fit” within a particular system or mandate

A program such as Sus-IT must be aligned with current trends and mandates. Ms. Carter referred to the other speakers’ presentations on existing provincial strategies: the inclusion of persons with disabilities in Newfoundland and Labrador; the policy framework for chronic disease prevention and management in Newfoundland and Labrador; the Provincial Healthy Aging Policy Framework; and in June, 2012, the government announced an initiative called Close to Home: A Strategy for Long-Term Care and Community Support Services, a ten-year strategy to guide and transform the delivery of long-term care in Newfoundland and Labrador. In April 2012, the Canadian

Pain Society (CPS), the Canadian Pain Coalition (CPC), community stakeholders, and federal officials participated in the first-ever Canadian Pain Summit. On a federal level, Sus-IT could be aligned with a National Pain strategy.

Importantly, in order for a program to be sustainable in the long term, it must entail a strong evaluation component. The people administering the program must be able to gauge its results; it also behooves them to be accountable to larger government mandates. If one is seeking government support for an intervention program, it is important to remember that governments are results oriented: What is the impact of an intervention on the individual? What difference has it made to the individual? What are the benefits of the intervention and how many individuals can benefit from it? Governments are looking to support programs that will benefit a broad range of people who span different communities, age ranges, income levels, education levels, and abilities.

6. FINAL RECOMMENDATIONS FOR PHASE III OF SUS-IT

Based on the feedback that was generated during the symposium's "break-out sessions," a series of recommendations for Phase III of the Sus-IT project were collated.

Two related cautionary reminders were put forward before people split up into groups:

- i) Sus-IT Canada should be careful not to endorse the premise that being online is better than not being online, and
- ii) its mandate should indicate clearly that Sus-IT is not an endorsement of technology as such. Rather, ICT is a means by which older adults with CP and reduced mobility might maintain their quality of life—a way of aging in place and remaining socially engaged.

Before dispersing into groups, participants agreed that Phase III of the Sus-IT program needed to contend with recruiting various participants, determining sustainable solutions, and measuring outcomes:

1. Recruiting Sus-IT Participants

Three groups were identified for recruitment:

- i) target population: older adults who want to sustain their ICT usage and are looking for help accomplishing that goal;
- ii) tutors: people who want to help these adults directly; and
- iii) existing initiatives: organizations and associations that want to develop ways of helping people sustain their ICT use.

2. Sustainable Solutions

Knowing why people want to use ICT and why they stop using the computer will dictate which solutions are tried.

3. Measurement

Once the stakeholders have developed a plan and executed it, it will be important to measure and assess it.

In order to tackle these components and execute a program, symposium participants addressed the following questions in their break-out sessions:

- What do people want to do with a computer?
- Why do individuals stop using a computer?
- Which current initiatives are having success in helping people sustain their ICT use and/or would be assets to Sus-IT as the team builds and implements its program?

The answers to these questions would in turn inform the three components outlined above.

What do people want to do with a computer?

- Communicate with family and friends
- Get information—medical and non-medical
- Get news
- Play games
- Shop
- Bank

Why do individuals stop using a computer? In other words, what are the barriers to sustained ICT use?

- Physical, Cognitive, Financial, Knowledge, Social

Which current initiatives are having success in helping people sustain their ICT use and would be assets to Sus-IT as the team builds and implements its program?

Sus-IT Canada needs to build on and partner with current initiatives. The following organizations have been successful in helping individuals use technology to improve their quality of life:

- The Independent Living Resource Centre (ILRC), the Seniors Resource Centre of NL (SRC NL), Telecom Pioneers, and the Adaptive Technology Network, whose members include: the Disability Policy Office; Canadian National Institute for the Blind (CNIB); the Blunden Centre; the Learning Disabilities Association; the College of the North Atlantic; the NL Centre for Deafness; and the ILRC.

The Symposium presentations highlighted that people living with CP and MSD are experts when it comes to their own conditions; they should be involved in developing solutions. The following organizations may be helpful to Sus-IT when it comes to recruiting older adults with CP and MSD:

- The Chronic Pain Working Group; the Arthritis Society; the Newfoundland and Labrador Long Term Pain Association; and Clarenville, which, as part of the Age-Friendly Communities project, has been very successful in delivering ICT sessions to older adults.

Symposium Recommendation: The many organizations that already exist in the community are assets to Sus-IT and should be involved in the development, implementation, and evaluation stages of its program. Sus-IT should seek the partnership of groups that are motivated to achieve similar goals—helping adults over 50 whose CP and MSD are hampering their motivation and/or ability to use computers—and are looking for assistance in actualizing those goals.

A. Recommended strategies for helping older adults with chronic pain and reduced mobility sustain their ICT use:

- In-home assessments should be pursued. The presentations made it clear that people are trying to adapt themselves to technologies as opposed to changing their environment. To help keep participants digitally engaged, Sus-IT Canada wants to help them change their environment, not themselves. Based on Mr. Cochrane's experience, the research team concluded that six in-home visits be considered.
- There must be a fit between the technology and the individual's particular needs. Each person that Sus-IT recruits needs to be asked about his or her personal goals. In turn, the support offered must be tailored to meet his or her unique goals, and also be flexible enough to accommodate the participants' varying range of ICT familiarity, from minimal to advanced.
- Program participants should be given a menu so that they have an opportunity to make choices that will disclose their needs and goals.
- Sus-IT Canada should compile and issue a list of available resources to help raise awareness of existing initiatives and sources of support.
- Sus-IT Canada should consider setting up a toll free number that links to the Adaptive Technology Network.
- The relationship between the participant and the person providing the support, the tutor, is as critical as the type of support offered. Sus-IT Canada must establish a process for training and matching tutors. The tutors must possess technical know-how as well as strong interpersonal skills.
- Cultivate opportunities for face-to-face contact—a chance for participants, tutors, developers, and stakeholders to celebrate and share stories in a group setting.
- Sus-IT should pursue discussions with telecom pioneers who have already run successful ICT projects.

B. Recommendations regarding approaches for measurement

As has been discussed throughout the report, people want to be able to use the computer without pain and discomfort for a number of compelling reasons. Sus-IT's aim is to find ways to help individuals overcome physical, cognitive, knowledge, and social barriers that are preventing them from using the computer in a comfortable way. Yet, given that Sus-IT is innovating new techniques from scratch, and because of time constraints and the lack of a comparison group, the research team concluded that it is not feasible to conduct a rigorous outcome evaluation at present. Symposium participants encouraged Sus-IT Canada to apply for additional funding to measure longer term goals and impacts. The team requires additional time to quantify the difference that their support program would make in their participants' lives. It was suggested that Sus-IT Canada measure the following in terms of individual participants in the program:

Individual Participants:

- Participants' awareness at outset regarding what options and strategies exist for facilitating computer use.
- Changes in their level of awareness regarding options and strategies after receiving support through the tutoring program
- Satisfaction with the internet along different axes: communicating with family and friends; accessing information, both medical and non-medical; getting news; playing games; and doing online banking and shopping
- Satisfaction with the nature of the help delivered
- Satisfaction with the respective tutor
- Sense of self-efficacy
- Individualized goal attainment, i.e., whether participants reach the ICT goals they set out to accomplish at the outset of the program
- Changes in social connectedness after receiving help
- Changes in self-reported skills
- Counts of hardware and software used over time
- Counts of in-home menu choices
- Use of resources guide and general resources
- Self-reported overall difference the program made

Sus-IT Canada also intends to measure the participants' family's satisfaction with the program, as well as the tutors' self-reported sense of the impact of the program. Sus-IT's measurements would also have to factor in the number of participants over time as well as the number of tutors trained over time; participants' family members may also factor into the measurement criteria depending on goals set by each individual.

C. Recommendations regarding ethics

Symposium participants raised an important ethical consideration: the Sus-IT research team would need to prepare tutors for how to handle sensitive information disclosed by participants. For example, if a participant shares with a tutor, "I fell down the stairs the other week," the tutor may feel a responsibility to report it. The Sus-IT team will need to establish clear protocols on confidentiality and appropriate disclosure. Threats to a participant's safety cannot go ignored.

Moreover, the Sus-IT team needs to consider its inclusion and exclusion criteria regarding participants. Individuals with cognitive impairments, for instance, may have difficulty retaining information. Thus, a tutor may decide that a participant would not benefit from help because he or she has a memory problem. Sus-IT needs to outline criteria for determining whether certain individuals will be excluded from the study after the tutor has conducted an in-home assessment.

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- ⁱ For further information, call the NL Health Line toll-free number at 1-888-709-2929, or visit their website: http://www.health.gov.nl.ca/health/chronicdisease/improving_health_my_way.html
- ⁱⁱ Please refer to the Statistics Canada website for more statistics regarding arthritis: <http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/health52a-eng.htm>
- ⁱⁱⁱ Baker, N.A., Rogers, J.C., Rubinstein, E.N., Allaire, S.H., Wasko, M.C. (2009). Problems experienced by people with arthritis when using a computer. *Arthritis Care & Research*, 61, 614-622. PMID: 19405002.
- ^{iv} Baker, N.A., & Rogers, J.C. (2010). Association between computer use speed and age, impairments in function, and touch typing training in people with RA. *Arthritis Care & Research*, 62, 242-250. PMID: 20191524.
- ^v Baker, N.A., Aufman, E., & Poole, J. (2012). Computer use problems and accommodation strategies at work and home for people with systemic sclerosis: A needs assessment. *American Journal of Occupational Therapy*, 66(3), 368-75
- ^{vi} Please refer to Stanford University School of Medicine's website for their Self-Management Programs: <http://patienteducation.stanford.edu/programs/cpsmp.html>
- ^{vii} Blyth, F.M., March L.M., Brnabic A.J., Jorm L.R., Williamson M., Cousins M.J. (2001). Chronic Pain in Australia: A Prevalence Study. *Pain*, 89, 127-134.
- ^{viii} Eriksen J., Jensen M.K., Sjøgren P., Ekholm O., Rasmussen N.K. (2003). Epidemiology of Chronic Non-Malignant Pain in Denmark. *Pain*, 106(3) 221-228.
- ^{ix} Breivik H., Collett B., Ventafridda V., Cohen R., Gallacher D. (2006). Survey of Chronic Pain in Europe: Prevalence, Impact on Daily Life, and Treatment. *European Journal of Pain*, 10, 287-333.
- ^x Schopflocher, D., Taenzer, P., and Jovey, R. (2011). The Prevalence of Chronic Pain in Canada. *Pain Research & Management*, 16, 445-450.
- ^{xi} See the following journal article for more details on why Canada needs a better pain management strategy: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3084407/>.
- ^{xii} For more information about DISCERN, see the following website: <http://www.discern.org.uk/about.php>
- ^{xiii} Visit the following website for a more comprehensive discussion: <http://www.aes.gov.nl.ca/disabilities/consultations.html>
- ^{xiv} Visit the following website for more information: http://www.nrdrc.org/supporting_persons_with_disabilities.html
- ^{xv} Visit the following website for more information: <http://web.uvic.ca/priorities/canassist.php>
- ^{xvi} Visit the following website for more information: <http://www.seniorsresource.ca/information.htm>

APPENDIX A



Sus-IT Canada Symposium

An Invitational symposium to explore sustainable solutions to help older adults with chronic MSK pain and/or limited mobility to continue to use technology

Funded by:
The Canadian Institutes of Health Research

**Meeting Location: Room 3454,
Memorial University School of Nursing,
Health Sciences Centre
St. John's, NL**

May 10, 2012

DELEGATE'S KIT

Event Agenda

Sus-IT Canada Symposium

Memorial University School of Nursing | Room 3454

An Invitational symposium to explore sustainable solutions to help older adults with chronic MSK pain and/or limited mobility to continue to use technology

St. John's | May 10, 2012

8:30am	REGISTRATION & CONTINENTAL BREAKFAST School of Nursing, Room 2910
9:00am	<p>Welcome Wendy Young, Memorial University Sandy Collins, Parliamentary Secretary to the Minister of Health and Community Services Irene Hardill, Northumbria University</p>
9:20am	<p>Panel I. Target populations</p> <p>Nancy Baker, University of Pittsburgh Sandra LeFort, Memorial University Mary Reid and Valerie Penton, Disability Policy Office, Government of Newfoundland and Labrador</p> <p>Moderator: Stephen Bornstein, Newfoundland and Labrador Centre for Applied Health Research</p>
10:20am	NUTRITION BREAK School of Nursing Room 2910
10:35am	<p>Panel II. Approaches that have worked</p> <p>Jon Church, Memorial University Don Cochrane, New Horizons Computers for Seniors Project Nicole Beben, Saint Elizabeth Care to Know Centre Kerry Byrne, Tyze Personal Networks Ltd.</p> <p>Moderator: Gail Wideman, Memorial University <i>*5 minute stretch break before the next panel begins</i></p>
11:50am	<p>Panel III. More approaches that have worked</p> <p>Carol Stanley, Chronic Pain Association of Canada Donna Power,* Independent Living Resource Centre</p> <p>Moderator: Valerie Penton, Government of Newfoundland and Labrador <i>* Donna Power will invite participants to test assistive technology during the symposium</i></p>
12:30pm	<p>LUNCH BREAK School of Nursing Room 2910 <i>*As space is limited in Room 2910, delegates can also use Room 3454</i></p>
1:30pm	<p>Planning for Sustainability</p> <p>Mary Ennis, Seniors Resource Centre of Newfoundland and Labrador Linda Carter and Suzanne Brake, Government of Newfoundland and Labrador</p> <p>Moderator: Jared Clarke, Memorial University</p>
2:00pm	<p>Small group discussions on key issues Facilitators: <i>Recruitment: Kerry Byrne and Don Cochrane (Notes taken by Ukeme Eka)</i> <i>Sustainable Solutions: Sandra LeFort, Memorial University (Notes taken by Wendy Young)</i> <i>Outcome Measures: Nancy Baker, University of Pittsburgh (Notes taken by Devonne Ryan)</i> <i>Ethics: Christopher Kaposy, Memorial University (Notes taken by Liz Wallack)</i></p>
2:45pm	BREAK School of Nursing Room 2910
3:00pm	<p>Final plenary Feedback from small groups</p> <p>Moderator: Jared Clarke, Memorial University</p>
4:00pm	Wrap-up

Panelists, Presenters and Moderators

Sus-IT Canada Symposium

An Invitational symposium to explore sustainable solutions to help older adults with chronic MSK pain and/or limited mobility to continue to use technology

St. John's | May 10, 2012

Nancy Baker

Dr. Baker is an associate professor in the Department of Occupational Therapy at the University of Pittsburgh. She has studied computer activity in workers with arthritis as well as workers with other musculoskeletal disorders. Her work has been funded by the Arthritis Foundation, the American College of Rheumatology and the National Institute for Occupational Safety and Health. Dr. Baker's work as a clinical therapist has focused on facilitating computer use by modifying the computer work environment.

Nicole Beben

Nicole is the Executive Director of the Saint Elizabeth Care to Know Centre (CTKC). The CTKC encourages and promotes Canadian home care by funding and supporting person-centred innovation projects. Key accomplishments include creating and launching the first social networking website for home and community care stakeholders; receiving Health Canada funding for a first of its kind investigation of evidenced-based, client-centred care; and establishing a fellowship award, in partnership with the Canadian Health Services Research Foundation, dedicated to applied research in home care. Nicole is a steering committee member on the Canadian and Ontario Caregiver coalitions and serves on the board of directors for the Canadian Home Care Association. In the coming year, Nicole will evolve the CTKC to focus on social innovation projects with partners such as George Brown College, Rotman Designworks and Tyze Personal Networks. Nicole's background includes a graduate degree in Sociology and experience with applied research, strategic planning and relationship management. Nicole's past roles include the strategic planning of community investment programs for TELUS and leading national health promotion and public awareness campaigns for The Hospital for Sick Children.

Stephen Bornstein

Dr. Bornstein completed his M.A. and Ph.D. in Political Science at Harvard University. He is currently Co-Director of SafetyNet, a Community Alliance for Health and Safety Research that studies occupational health and safety of marine and coastal work. Dr. Bornstein has also been the Director of the Newfoundland and Labrador Centre for Applied Health Research since the Centre's establishment in 1999. At the Centre, he leads the Contextualized Health Research Synthesis Program, an integrated knowledge translation program that addresses pressing health services, policy and technology questions for the provincial health system. Dr. Bornstein served as Assistant Deputy Minister of Intergovernmental Affairs in the Government of Ontario and Ontario Representative to Quebec. He is a full professor in the Department of Political Science and in the Division of Community Health and Humanities of the Faculty of Medicine at Memorial University.

Kerry Byrne

Kerry Byrne is the Director of Research at Tyze Personal Networks, a social venture that offers private personal online networks designed to support care for people facing life challenges. Kerry cares deeply about improving care for families and older adults. Through her work, she strives to give a voice to families' and patients' experiences with health care. Her areas of research expertise are in family caregiving, care transitions, home care, a network model of care, and adoption of technology in health and social care settings. When she isn't delving into her research, you'll find her happily texting, emailing, skypeing or chatting on the phone with her family and friends throughout Canada and Europe, "sometimes all at the same time," she admits.

Linda Carter

Linda is currently the acting Director of the Chronic Disease Division in the Department of Health and Community Services, Government of Newfoundland and Labrador. In this position, Linda is involved in leading the development and implementation of government policy to promote health, prevent illness and injury, and contribute to improving overall health for the people of the province; most recent of these initiatives was the policy framework released in December 2011, *"Improving Health Together: A Provincial Policy Framework for Chronic Disease Prevention and Management."* Linda works closely with the Regional Health Authorities and many community partners to advance work on chronic disease prevention and management. Linda brings to the directorship her public health nursing background and her knowledge and many years of experience as a Regional Health Educator and Health Promotion Consultant in the health and community services system.

Jon Church

Dr. Jon Church is a professor in the Terry Fox Cancer Research Laboratories, Faculty of Medicine, and Memorial University. He specializes in using telecommunications technology to link women living with breast cancer to both peer and professional support. Dr. Church owns and administers an Internet discussion list server called "Breast Cancer" which serves as an unmoderated discussion list open to researchers, physicians, patients, family, and friends of patients, for the discussion of any issue relating to breast cancer. In Newfoundland and Labrador, with the support of the Canadian Cancer Society, Dr Church also facilitates a biweekly program of support via audio teleconferencing. Dr. Church also developed a public education-dedicated webpage in conjunction with the Purple Lupin Project. With links to existing pages dedicated to basic scientific and clinical information, extensive databases concerning alternative/unconventional therapies and regional community resources, and connections to the list server, the Purple Lupin Project offers a centralized and freely accessible resource to all people affected by breast cancer.

Jared Clarke

Jared Clarke is a post-doctoral fellow with the Division of Community Health & Humanities, Faculty of Medicine at Memorial University. He completed a PhD Medicine (Neuroscience) at Memorial, and subsequently received the inaugural Healthy Aging Research Program post-doctoral fellowship from the Newfoundland and Labrador Centre for Applied Health Research. His current research interests revolve around healthy aging, with emphasis on enhanced recovery and independence following stroke. As part

of the Sus-IT Canada research team, Jared collaborates on research to better understand the value of, and obstacles to, the use of information technology in older populations.

Don Cochrane

Prior to his retirement in 2000, Don worked as the British Columbia Forest Jobs Commissioner, creating and operating the Forest Worker Transition Program for the Ministry of Forests. This program dealt with 15,000 unemployed forest workers over a 6 year period, offering them education grants in concert with unemployment insurance benefits that allowed for 2 years of retraining. Since his retirement, he has acted as a consultant on a number of projects. In 2009, he was asked by the Nanaimo Disability Resource Centre to create, administer and coordinate a special grant received by the federal government. This project became known as Internet for Seniors, a New Horizon Project. It was designed as an exploratory program planned to meet the individual needs of seniors with at least one disability. The program proved to be very successful and was based on volunteer tutors who made individual visits to seniors in their homes. It was expanded from the city of Nanaimo, to Oceanside which encompasses the communities of Parksville, Qualicum Beach and Nanoose Bay. He is also known as a humourist and speaker on aging in the 21st century. As well, he is a published author and his fourth book is due to be released this June. Don and his wife Pamela live in Parksville on Vancouver Island and are parents, grandparents and great-grandparents.

Mary Ennis

Mary Ennis has a wide range of experience working at local, provincial, national, and international levels in the non-profit, voluntary, and public sectors. She has worked with diverse organizations including women's groups, disability organizations, multi-cultural populations, youth and seniors. Mary has experience in policy analysis and development, strategic planning, Board development, financial management, capacity building and partnership development. She was involved in the negotiations to develop the United Nations Convention on the Rights of Persons with Disabilities and has presented on disability rights to a wide spectrum of organizations and agencies including World Vision International, the World Bank, the United National Population Development Fund, and a number of international conferences. She has served on a number of committees and boards including the Council of Canadians with Disabilities and Disabled Peoples International. Mary does consulting work, specializing in qualitative research methodologies, including interviews, focus groups and case studies. As well, she is the coordinator of the Peer Support Volunteer Program with the Seniors Resource Centre of Newfoundland and Labrador.

Christopher Kaposy

Chris Kaposy is an Assistant Professor of Health Care Ethics in the Division of Community Health and Humanities, Faculty of Medicine, Memorial University of Newfoundland. He is also a clinical ethicist involved with ethics consultations throughout the province of Newfoundland and Labrador. His research interests are in public health ethics, ethical issues in pregnancy, and disability studies.

Sandra LeFort

Sandra M. LeFort, RN, PhD is Professor, School of Nursing, Memorial University of Newfoundland. Her major clinical and research interests include: self-management education for chronic pain, clinical ethics, and aging. In 1996 Dr. LeFort developed the Chronic Pain Self-Management Program (CPSMP) and tested its impact for her PhD dissertation at McGill University. She has conducted further research of the program and the community-based CPSMP is now being delivered in many parts of Canada, in parts of the United States, throughout Denmark and dissemination is beginning in Australia. Dr. LeFort has received research funding from many national granting agencies including the Canadian Institutes for Health Research. She has made over 100 presentations about the broad area of chronic pain regionally, nationally and internationally and has over 60 publications to her credit. She was awarded the Nursing Excellence in Pain Management Award in 2009 and the Distinguished Career Award in 2010 from the Canadian Pain Society.

Valerie Penton

Valerie Penton is from Fogo Island, Newfoundland and is a recent graduate from Memorial University's Master of Science in Medicine Program in Applied Health Services Research. Her Master's thesis involved an assessment of services and programs related to assistive technology for people with disabilities in Newfoundland and Labrador. Valerie currently works with the Disability Policy Office, Government of NL as a Policy, Planning and Research Analyst. In this role, she undertakes research on current trends and technologies specific to accessibility of communications, information, service delivery, physical infrastructures and emerging technologies. Valerie is involved with various committees, including the Universal Design Network, the Adaptive Technology Network, and the Housing and Homelessness Network. Valerie aims to increase her knowledge in the accessibility field to help work toward inclusion of persons with disabilities. Valerie is currently working on a journal article publication with her thesis supervisor to promote awareness of the need for increased assistive technology services and programs.

Donna Power

Donna Power grew up in rural Newfoundland, playing sports, playing piano, and playing with beach rocks! She moved to St. John's to attend post-secondary school (She is a proud alumnus of Memorial University) It was in the QEII library at Memorial where she first touched a computer and found her way through the process of setting up an email account. After completing her BSc, Donna enrolled in an Information Technology Graduate Program in St. John's and started what would prove to be a career path full of twists and turns, but that eventually led her to the Independent Living Resource Centre. She has been working within the disability community since 2004 and much of that time has been dedicated to working with Adaptive Technologies. In particular, she is interested in connecting people with technology and supporting them when they use it; breaking down barriers that may get in their way; and helping ensure that everyone is included in the ever-changing world of technology.

Mary Reid

Mary Reid returned to Newfoundland and Labrador in March 2009 to accept the position of Director with the new Disability Policy Office at the Government of Newfoundland and Labrador. This office was established to support the Province's commitment to the inclusion of persons with disabilities in all aspects of society. Mary has worked with communities and governments for over 25 years to promote and achieve inclusion for persons with disabilities. She has served as Executive Director of the Independent Living Resource Centre in St. John's and worked with the City of Ottawa to establish their Office of Accessibility. Volunteer commitments have included the Council of Canadians with Disabilities, the Coalition of Persons with Disabilities – Newfoundland and Labrador and the Human Rights Association of Newfoundland and Labrador, international development projects, and several intergovernmental committees. Mary has a personal and professional commitment to full inclusion and equity for all people.

Carol Stanley

Carol is a Chronic Pain survivor who has put most all of her energy into helping people who suffer from Chronic Pain. Carol has three children, one of whom is 3 years old, which is a great motivator for her. Carol finally realized that she had to be her own advocate for pain services and in 2006 started the NL Long Term Pain Association to help others with their coping skills. Starting May 14 - 19, 2012, with the help of Chronic Disease Division in the Department of Health, they will help open five new pain patient support groups here in our province. The St. John's group has put together public presentations for the past five years during National Pain Awareness Week, which starts the first week in November each year.

Gail Wideman

Although new to her position as Assistant Professor at the School of Social Work (Fall 2009), Dr. Gail Wideman has been involved in the school as a sessional and per course instructor since 2001. Gail completed her Ph.D. in social work at Memorial in March of 2010, a M.S.W. from Wilfrid Laurier University in 1992, and a B.A. in sociology at the University of Western Ontario in 1988. Her academic interests span the fields of gerontology and community development. Throughout her career, she has been involved primarily in community-based programs and services aimed at maintaining and enhancing independence and quality of life for older persons. The broad focus of Gail's doctoral research was an exploration of the capacity for older residents to age in place in rural communities where traditional networks of support have been altered by the out-migration of younger persons. Of particular interest was learning about ways of strengthening social work practices through the development and support of what she described as "intermediate resources." Intermediate resources in Gail's research are operationalized as activities which are provided by local organizations, are user-driven and belong to the standardized categories of Instrumental or Advanced Activities of Daily Living. Using a case study design and qualitative analysis of in-depth interviews, Gail's doctoral research combined what is known about community development practices with what rural older persons and care providers say they need in order to support aging in place. Gail's current research activities include collaborative work to establish a Newfoundland and Labrador Centre on Aging as well ongoing work related to understanding the challenges and opportunities of social work practice with the volunteer sector. Gail also continues to be

involved in community-based programs for older persons as member of the board of directors of the Seniors Resource Centre, and as volunteer Chair of the Provincial Caregivers Out of Isolation Project.

Wendy Young

Wendy Young, Memorial's Canada Research Chair in Healthy Aging, is part of an international team looking at why people in this age group are quitting computers and what we can do to help them stay online. Sustaining Information Technology use by older adults to promote autonomy and independence, or Sus-IT, is a three-year international project led by researchers in the U.K. The Canadian team received \$225,000 from the Canadian Institutes of Health Research. In the U.K., there are eight universities working on Sus-IT with funding from the New Dynamics of Aging program, the largest U.K. research program on aging ever mounted.

Improving Health: *My Way*

A self-management program for people living with chronic conditions. Would you like to know how to better manage your own health? Do you have a chronic condition?

Self-management for people with chronic conditions can help you learn to be healthier.

What is a self-management program?

A six session workshop for people living with chronic conditions. The program can help you:

- Manage fatigue or tiredness
- Learn how to eat healthier
- Deal with frustration, depression, pain or isolation
- Start to become more active and/or maintain an exercise program
- Develop problem solving skills
- Communicate with family / friends / health care providers
- Get more out of life!

Session Content:

Session 1:

- Differences between acute and chronic conditions
- Using your mind to manage symptoms
- Introduction to action plans

Session 2:

- Feedback and problem solving
- Dealing with difficult emotions
- Introduction to physical activity and exercise
- Action plans

Session 3:

- Feedback and problem solving
- Better breathing
- Muscle relaxation
- Pain and fatigue management
- Endurance activities
- Action plans

Session 4:

- Feedback and problem solving
- Future plans
- Healthy eating
- Communication skills
- Problem solving
- Action plans

Session 5:

- Feedback and problem solving
- Medication usage
- Making informed treatment decisions
- Depression management
- Positive thinking
- Guided imagery
- Action plans

Session 6:

- Feedback and problem solving
- Working with your health care professional
- Planning for the future

Workshop features:

- The workshop is offered free of charge.
- The workshop is taught by two trained leaders, one or both of whom have a chronic condition.
- Registration is required as each workshop size is limited.
- The workshop builds on programs such as diabetes education or cardiac rehab.
- This workshop offers a variety of skills so people can choose the ones they want to use.

Who can take part?

Anyone with a chronic health condition is welcome, and feel free to bring a family member or friend. The program has been helpful for people with the following conditions (as well as others):

- Asthma
- Arthritis
- Cancer
- COPD
- Congestive Heart Failure
- Chronic Fatigue Syndrome
- Diabetes
- Depression
- Emphysema
- Fibromyalgia
- Heart Disease
- Lung Disease
- Multiple Sclerosis
- Obesity
- Parkinsons
- Stroke

Contact Information:

NL Health Line 1-888-709-2929

— or —

Contact your local self-management coordinator:

Eastern Health 1-709-752-3946 or 1-866-880-8998

Central Health 1-709-256-5690

Labrador Grenfell Health 1-709-897-3130

Western Health 1-709-637-5000 ext 6689

www.health.gov.nl.ca/health

ImprovingHealth@gov.nl.ca



SusIT: Sustaining ICT use by older people to promote autonomy and independence

Purpose

To help older adults continue to use ICTs

Status

Vision: developed by UK (September 2011)

Data: people with medical problems are at risk for giving up (Canadian data)

Testing: adaptive solutions (UK)

Solutions: technical, training & support (CareOnLine in the UK)

Impact on QoL and costs

People with mobility restriction or chronic pain

Staying in touch with family & friends → social inclusion → less depression

All seniors: aging in place is less costly

Preventable admissions

Diffusion and scaling up

UK: “influence the influencers” roundtables to promote a national strategy for training and support in the community

Canada: sustainable solutions symposium with academics, Arthritis Society + , volunteers, government



new dynamics of ageing
a cross-council research programme



Presentation by Irene Hardill of Northumbria University
to the Conference of British and Irish Population Geographers

27/04/2012



Population Geography:
Inter-Generational Patterns and Processes

Third Biannual British-Irish Population Conference
18-19 April 2012


Staying connected: Exploring the challenges of
sustaining digital inclusion in older age
Irene Hardill, Centre for Civil Society and
Citizenship, Northumbria University



Structure of presentation

- Anglo-Canadian research (Canadian Institutes of Health Research and United Kingdom New Dynamics of Ageing Research Initiative), Sus-IT – the everyday use of ICTs by older adults
- Critical geographies of ageing
- Sus-IT context - older adults, sustaining ICT use, the 'digital divide'
- Emerging findings from Canada and the UK (sustaining Internet and mobile phone use; online access to public services)
- Concluding comments

Who are older adults?



27/04/2012

Critical geographies of ageing

- Relational approaches - age produced in the interactions between different people, so that an individual's sense of themselves and others is partly based on generational sameness and difference.
- Geographies of ageing moves away from looking specifically at geographies of the elderly, and moves towards examining ageing through a contextual framework of life transitions.
- Critical geographies of ageing consider (old) age as a spatially constituted part of the life course and ageing as a spatialised process – applying a life course perspective to understand the spatiality of ageing, offers a lens to look at periods or moments of transitions in people's lives

Sus-IT context: older adults and ICTs

- Social scientists, including geographers, have contributed to understanding the changing choreography of everyday life through the use of ICTs.
- Older people represent a growing proportion of society, and increasing numbers make use of digital technologies in their everyday lives.
- But as people age, they face changes in health, capability and/or social circumstances which may mean they lose the capacity to use ICTs.
- Such changes may be compounded by the trend for continual enhancement and development of ICTs, often leading for example to increased complexity.
- As a result it has been predicted that significant numbers of older people will in future move from being 'digitally engaged' to 'disengage', with consequent reductions in their quality of life and independence

Digital divide?

www.usit.queensu.ca/uk




- Digital exclusion and social exclusion
- The digital divide presented as dichotomy, but is has multiple dimensions (social, spatial etc),
- Sustainability critical to understanding the divide

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Integrating ICTs into everyday life

www.ict4seniors.ca/uk



- 'Access' to and 'use' of ICTs
- Depends on scale of implication in everyday life
- ICTs need to be embedded in everyday practices

New Dynamics of Ageing programme

- What are the forces driving ageing?
- What are the influences shaping them (behavioural, biological, clinical, cultural, historical, social and technological) and how can their consequences be managed to achieve the maximum benefits for older people?
- Insistence upon the use of, 'participatory research methods to engage older people in the development of products, services or research... and the effective communication of users' views as priorities to those developing ICTs'
- Research users include older people, represents first research council programme with an Older People's Reference Group

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Sus-IT project

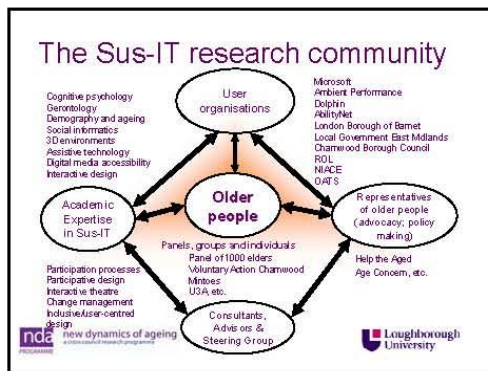
- Team based in UK and Canada: funded by The New Dynamics of Ageing Programme (NDA) and the Canadian Institutes of Health Research (CIHR)
- Examining ways of helping older people engage and stay engaged with digital technologies as they age.
- ICTs alter and influence older people's changing relationship to space and place, of their being in the world.

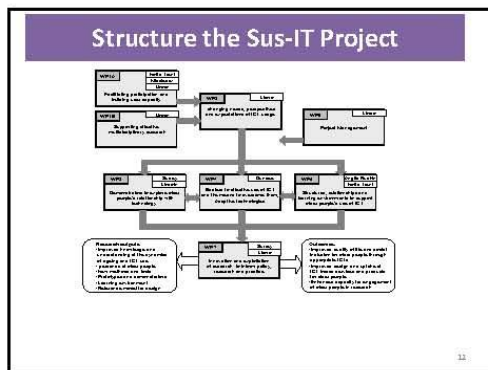
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Sus-IT objectives

- To create an engaged community of older people who will actively participate in exploring problems and solutions related to sustaining and enhancing the use of digital technologies;
- To identify and investigate age-related change through a study of a diverse sample of older people) and the implications for digital technology use and development;
- To develop and pilot a method for automatically detecting and responding to changes in user capability;
- To identify the learning and support needs associated with sustained and effective use of digital technologies and to pilot innovative mechanisms for meeting these needs;
- To generate outputs to inform policy, practice, design and research, and in turn enable older people to access, creatively shape, use and adapt digital technologies to maintain and enrich their autonomy, independence and quality of life (<http://sus-it.rooo.ac.uk/>).

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Sus-IT critical friends



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Digital Engagement Survey, UK



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Sus-IT Canada

- Focus on people with medical problems are at risk for giving up – using published statistics
- Mobility restriction or chronic pain
- Staying in touch with family & friends → social inclusion → less depression
- All seniors: ageing in place
- Sustainable solutions (academics, Arthritis Society +, volunteers, government)



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Sus-IT emerging findings

- Canadian Internet use – sustainability (Canadian data)
- Health issues and disengagement (Canadian and UK data)
- Egovernment and accessing public services online (policy issues in Canada and the UK)
- Sustaining mobile phone use (UK qualitative data)

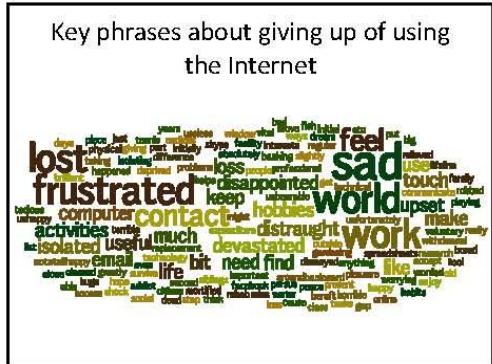
Sustaining Internet use: Canada

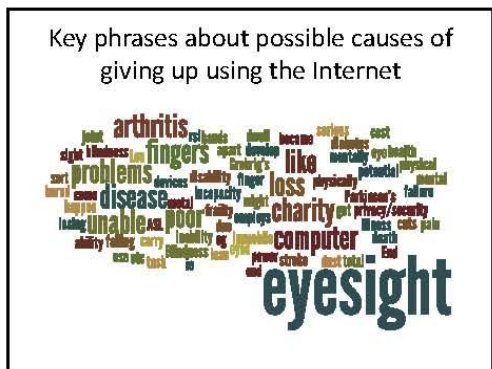
- Canadian Internet Use Survey data, 2005-9; logistic regressions
- While the non sustainer rate falling, the proportion of older non-sustainers (50+) consistently higher
- Social, spatial and temporal variations in Internet use and sustainability: cohort effect, age effect, regional differences (Atlantic Canada vs. rest of Canada)

Health issues and disengagement

- Participation and Activity Limitation Survey (PALS) data for 2006
- Understanding non-sustainers more complex than merely age-related
- Non-sustainers more likely to be single, have an activity limitation, taking prescribed medication
- Not sustaining rate is nearly three times higher among individuals with an activity limitation (9.8%) than that reported for the general Canadian population

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Type / pseudonym	Household structure / residence	Age	Employment status	Other unpaid activity	Explanation	
<i>Confident, pervasive use</i> Jenny	Owned several mobile phones. current is a touch screen, avid computer user at home	Divorced, lives alone, family live nearby	62	Works part-time in an office, uses computer as part of job	Committee member over 50 forum, strong family network, active social life	Phone, part of me, it is always in my pocket - phone integral part of everyday life
<i>Episodic use</i> Betty	She bought her 1st and only phone 8 years ago she could keep in touch with her husband 200 miles away	Widow, lives alone, family nearby, only daughter	83	Retired bank clerk	Active in local church, attends over 50 forum, tries to keep herself busy, goes out everyday	Episodic use, mobile phone meets landline, uses it to contact people by dialling numbers.
<i>Fossilised</i> Anne	Bought her 1st and only phone in her late 70s when she went on holiday to keep in touch with her son	Widow, lives alone with the support of care, she went on holiday, had to stop driving 6 months ago	90	Retired chiropodist	Attends over 50 forum, tries to get out everyday, attends keep fit etc. Only soon rarely visits	Very episodic use, mobile for 'emergencies' when out of the house - but phone battery dead

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Concluding comments

- Sustaining ICT use linked to degree of integration in everyday life
- Sustaining ICT use – social and spatial impacts on everyday life
- Importance of knowledge sharing – support systems can help people of all ages
- Disengagement not merely linked to chronological age, health & wellbeing, one-to-one support
- Coupledom, role of family, older volunteers, intergenerational support

Background materials: Nanaimo & Region Disability Resource Centre | Don Cochrane,



Nanaimo and Region Disability Resource Centre New Horizons Internet for Seniors



A program to teach Internet Skills to Seniors with Disabilities

Presented by
Don S. Cochrane
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Parksville, BC V9P 2R5
250-954-1461 donco@shaw.ca



Senior Citizens of the 21st Century

In the past 20 years, the world of the senior citizen has changed radically. Length of life has been extended and medical advances both in education and services allow for better health but the older generation is caught between the way it was and the way it is. Many seniors who have a disability, a mobility challenge or any other situation which isolates them have options provided by technology but do not know how to access them, use them or even understand them. This presentation will describe how a large city and its surrounding towns tackled that problem with surprising success. This model used technological teaching with an emphasis on bonding tutor and student to meet the seniors' personal needs and aspirations and can be copied in other communities.

This project was funded in part by Government of Canada's New Horizons for Seniors Program



The Contract and the Challenges

Two major challenges had to be dealt with within the first quarter of the program. The first was the excellent response by the public to the project and its aims. The second was to create a course of instruction for tutors which would meet their needs when they went into the field to deal with the very individualized student expectations. The tutors also had to be able to deal with the fact that each computer would have different programs on it and the skill levels of the students would range from rudimentary to intermediate.

The application for funding had been based on a concept rather than an existing operational program to meet the objectives of this project. We quickly learned that this was a project with great public interest. We also learned that the target population in Nanaimo and particularly in Oceanside did in fact have a very significant senior population. Our recruitment drive during a six week period produced more applicants than we could process during the life of the contract. At one of the two group presentations at the Society of Organized Services in Parksville, the coordinator spoke to a group of 60 seniors and we received 22 applications for either tutors or students. We then made a presentation at a large community service information event and were amazed by the interest of individuals and facilities dealing with seniors asking to participate in this project.

The grant had set a goal of 52 persons made up of 12 tutors and 40 students. The response to our initial recruitment drive alone produced applications from over 100 individuals. This group was made up of those applying to act as a volunteer tutor or to receive instruction as a student. This realization called for a considerable administrative arm to deal professionally and proficiently with this quick influx. It caused us to close applications, so that we could deal with this great display of interest.

We also realized that we could not possibly train tutors individually or in small groups, but instead needed to create a program that could be delivered in a three week, six session program. This called for the use of our own lab and equipment, but also the use of two computer labs with higher capacities than what we could offer at the Centre. We solved that problem through the cooperation of two major supporters; the Career Centre in Parksville and the Ethos Experience Works Centre in Nanaimo. They donated their facilities at a very low cost. The tutor training programs graduated 30 tutor instructors, well over our contract objective of 12.

Throughout the life of the project, the single largest challenge was that of timing. It began with the hold on the project and the need for administration, surveys of services based on the particular needs of the clients and other time factors that we had not considered. Once we had received over 100 applicants, we were limited by having to produce the tutors, who then had to be matched with the students and be given time to deliver six sessions of two hours to each of the recipients. The next timing problem was caused by seasonal and holiday considerations. In the initial stage of the program, we came face to face with summer holidays. This affected both volunteer tutors and students.

In the last month of the contract, we were in a position of having on hand a core staff, a large group of trained tutors who were willing to continue and an increasing demand by the communities to accelerate and expand the program in both locations.

Mr. Cochrane's presentation will contain the 6 W's – **Why, who, when, where, what & wow** and will explain **HOW** they accomplished it.