

JUDY STEED

DOING THINGS DIFFERENTLY

A
COLLABORATIVE APPROACH
TO IMPROVING CARE
FOR SENIORS

THE GREEN SHIELD CANADA FOUNDATION'S
HEALTH INNOVATION COLLABORATIVE

— MAKING CHANGE HAPPEN



JUDY STEED is an award-winning journalist and author. A former feature writer at the Globe and Mail and the Toronto Star, she is the recipient of four National Newspaper Award citations and one National Magazine Award.

She received the Atkinson Fellowship in Public Policy, which enabled her to study aging, the impact of demographics and the breakthroughs in neuroscience that are transforming our understanding of the human brain. Her 2008 Atkinson series, BOOMER TSUNAMI, published in the Toronto Star, inspired Sarah Saso, executive director of the Green Shield Canada Foundation, to launch the Health Innovation Collaborative, focusing on seniors' health issues, with Judy working to document the process.

She is the author of five non-fiction books and a pilot for a TV series. She is a moderator at Ryerson University's Life Institute, where she shares techniques to enhance memory and cognition, and reduce stress, in her course, LIGHT UP YOUR LIFE AND YOUR BRAIN. She speaks regularly to a wide range of groups on these topics.

*“If left unaddressed, our demographic challenge
could bankrupt the province.”*

— Dr. Samir Sinha
lead, Ontario’s Seniors Strategy
“Living Longer, Living Well,” 2012

“What we’ve learned from the Health Innovation Collaborative has helped us formulate a new strategy. System navigation is a critical issue. Our next step is to focus on front line care, access for health care for marginalized people and those who need help navigating the system.”

— Sarah Saso
executive director, Green Shield Canada Foundation

“HIC is a beautiful eco-system.”

— Dr. Alex Jadad
co-founder of the Centre for
Global eHealth Innovation, part of the
University Health Network

The story of the Green Shield Canada Foundation’s Health Innovation Collaborative (HIC) begins with the crisis gripping the health care system. It was identified by Dr. Samir Sinha, director of geriatrics at Mt. Sinai Hospital and the University Health Network, in “Living Longer, Living Well,” his 2012 report for Ontario’s Seniors Strategy.



“You’re not looking at an exotic species from another world. You’re looking at your future.”

-Dr. Mark Nowaczynski, Clinical Director, House Calls

THE PROBLEM

Ten per cent of older Ontarians “account for 60 per cent of our annual spending on health care for this population,” Dr. Sinha wrote. With the seniors’ population expected to double over the next 20 years, “If we neglect their needs, they are going to bounce in and out of hospitals,” Dr. Sinha says, “using very expensive forms of health care. They will need institutional care, they won’t be happy and we won’t be happy because we are not recognizing an opportunity to do better and create a sustainable health care system.”

Older adults — those 65 and older — with complex, chronic conditions drive up health care costs. They use more expensive and intensive types of services, especially in acute settings. Accounting for only 14.6 per cent of the current population, they consume nearly half of health care expenditures. Indeed, the cost of caring for older people is three times higher than for the average age and will add \$24 billion to overall costs within 20 years. (Ontario Ministry of Health statistics)

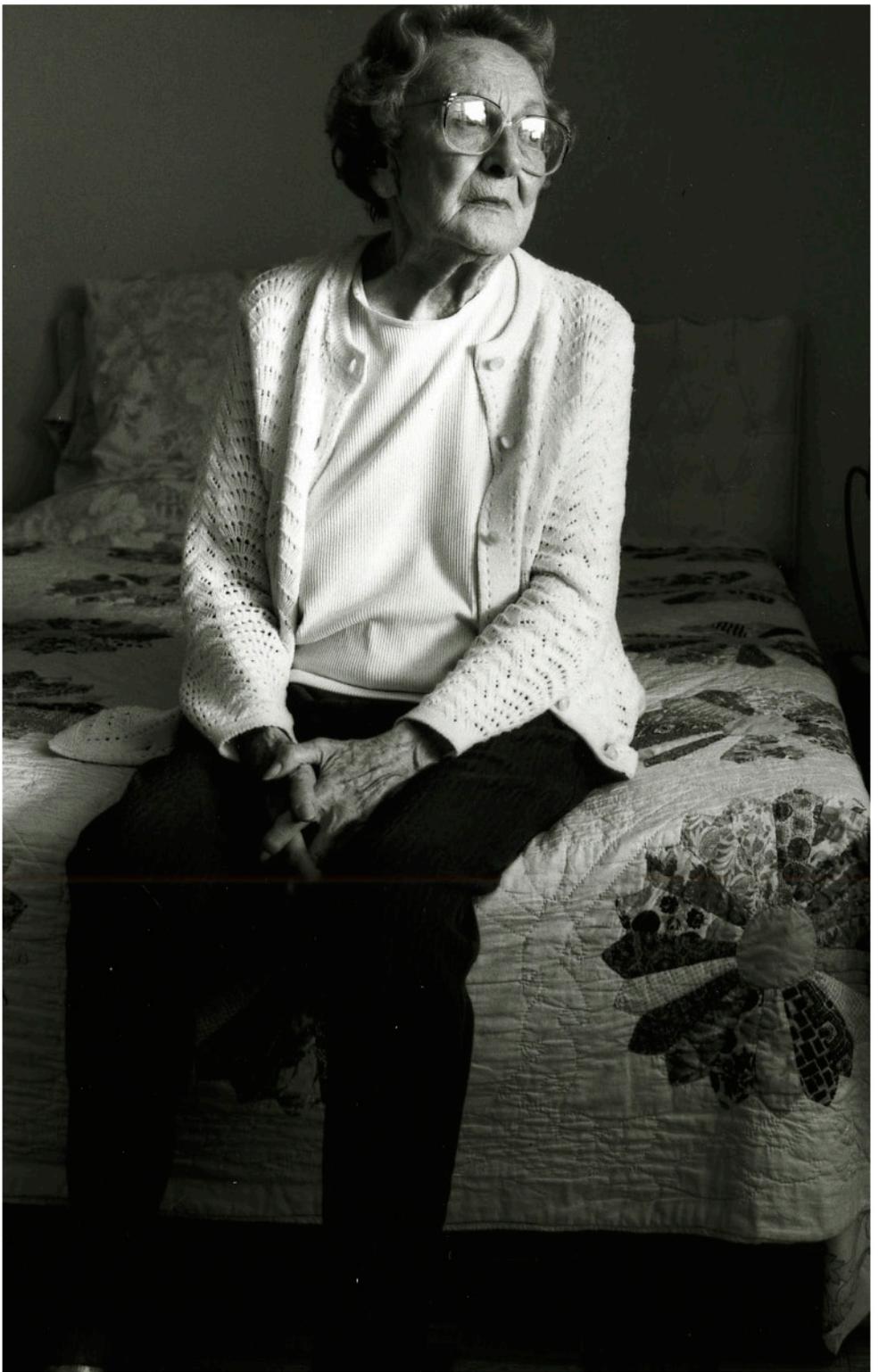
Out of Ontario's entire 2015 budget of \$131.9 billion, \$50.8 billion goes to health care, the largest single expenditure. The Drummond Report of 2012, resulting from the Commission on the Reform of Ontario's Public Services, identified the major shift in health issues toward "chronic-care questions," reinforced by an aging population and linked epidemics of obesity, diabetes and dementia. It also focused on the necessity of utilizing information technologies to engage health-care professionals and consumers.
(Ontario Ministry of Health & Long Term Care)

A hospital bed costs, on average, \$842 per day, long-term care (LTC) \$126 per day, and home care, \$42 per day. One week for 424 seniors in hospital costs \$2.5 million, in LTC, \$374,000 and at home, \$125,000.
(Ontario Ministry of Health & Long Term Care)

*Fourteen per cent of patients discharged with home care (mostly seniors) return to hospital within 30 days, and 25 per cent visit the emergency department within 30 days. As of April 30, 2015, 3,836 patients (mostly seniors) were termed ALC (alternative level of care) or “bed blockers,” ready to be discharged but held in hospital beds, awaiting appropriate care in the community. Almost 15 per cent of all hospital beds in Ontario are occupied by ALC patients whose mental and physical health deteriorates in hospital while they’re at risk of serious infection (e.g., C. difficile).
(Ontario Ministry of Health & Long Term Care)*

“You don’t have to spend much time with the elderly or those with terminal illness to see how often medicine fails the people it is supposed to help. The waning days of our lives are given over to treatments that addle our brains and sap our bodies for a sliver’s chance of benefits. They are spent in institutions...where regimented, anonymous routines cut us off from all the things that matter to us in life. Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need. Lacking a coherent view of how people might live successfully all the way to their very end, we have allowed our fates to be controlled by the imperatives of medicine, technology and strangers.”

— Dr. Atul Gawande, *Being Mortal*



THE GREEN SHIELD CANADA FOUNDATION RESPONSE

As Canada's only national not-for-profit health and dental benefits specialist, Green Shield Canada — founded in 1957 by pharmacists committed to advancing “the greater good” — set up its foundation in 1992. The Green Shield Canada Foundation (GSCF) aims to be a leading agent of social change and a catalyst for policy reform, supporting innovation that can lead to fundamental improvements in Canadian health care.

Sarah Saso, appointed GSCF's executive director in 2011, focused on the foundation's specific goals: address urgent needs, build community capacity, strengthen public policy and advance knowledge to ensure long-term change. The leadership of Sherry Peister, chair of the boards of Green Shield Canada and its Foundation, and Steve Bradie, president and CEO of GSC, had produced a strong strategic direction: to develop in-home care solutions for seniors. Saso was charged with bringing this vision to life by finding partners and projects that aligned with GSCF's goals.

WHERE TO START?

Saso studied the findings of Dr. Sinha and Don Drummond. “The purpose of reform,” Drummond wrote, “is not simply to save money, though that is a welcome consequence. The purpose is to improve the quality of the system for the benefit of all Ontarians by shifting from a

system that was built mainly for acute care – and remains largely in that mode – to a system built mainly for chronic care, which is where the aging of the population is driving Ontario’s health care needs. We cannot emphasize strongly enough that quality of care and efficiency are essential to any reform. Better care delivered smoothly and briskly across a range of needs will benefit patients and providers alike; it will also save money in the long run...”

Saso also noted an analysis undertaken by Bridgepoint Health and Boston Consulting Group in 2011 which suggested that the savings achieved through better co-ordination of care in Ontario could be in the realm of \$4 billion to \$6 billion per year. She also read Judy Steed’s 2008 Atkinson Fellowship series “Boomer Tsunami,” which highlighted the gaps in seniors’ care. Saso was struck by the fact that elders awaiting discharge from hospital – so-called “bed blockers” – were costing the system more than \$200 million a year because they didn’t have access to appropriate home care.

Saso’s research continued for close to a year. She talked to leaders in the system; she identified “silos” separating institutions and professionals, preventing the sharing of knowledge and access to resources. She saw that many people were unaware of or unable to get the care they needed. Navigating the system was a problem, as was the lack of online information that could help.

Determined to “get out in front of the tsunami before it’s too late,” her focus was clarified after meeting with Dr. Alex Jadad, a founder of the Centre for Global eHealth Innovation, within the University Health Network. “What’s the most successful program you’ve ever been involved in?” he asked. She cited a collaborative project at St. James Town (in a previous corporate role), and Jadad suggested she pursue a collaborative project in health care. It hadn’t been done, he said, and collaboration was desperately needed. Why not try?



“Eliminating unnecessary suffering is a labour of love, which requires a lot of generosity, commitment and trust. This is what we’re nurturing in the HIC.”

— Dr. Alejandro Jadad

“The HIC is truly the petri dish for the change we want to see.”

— Dr. Samir Sinha

WHY COLLABORATE?

Saso explains: “One of our strategic directions is to support the idea of care coordination to keep people living in their homes as long as possible. We chose to tackle the issue by bringing together five innovative organizations who are each dealing with the problem. Our goal was to see if by working together, over three years, we could change current outcomes and help seniors live with their conditions in the comfort of their own homes.”

As the GSCF Health Innovation Collaborative, 2012-2015, was launched, Saso worked with the five partners to clarify its goals. To:

- Improve quality and accessibility of care for seniors in the GTA region, aged 65+ with multiple complex chronic health issues.
- Expand opportunities for care at home, improving the quality of life of seniors and their caregivers.
- Reduce emergency department visits, hospital and long term care admissions/re-admissions, by improving community or at-home services and support.
- Increase the skills of personal support workers who work directly with seniors in their homes.
- Increase the availability of online and mobile resources that offer practical tools to connect seniors and their informal care givers to local healthcare providers.



THE HEALTH INNOVATION COLLABORATIVE PARTNERS

In June 2012, GSCF launched the Health Innovation Collaborative, a three-year, \$3-million commitment to work with five health care organizations whose practices and projects were trying to tackle the issue of caring for seniors with multiple chronic conditions but also those who were willing to embrace collaboration.

They are:

- SPRINT Senior Care – House Calls;
- Alzheimer Society of Toronto (AST) - Online Dementia Care Training Program;
- St. Michael’s Hospital - Virtual Ward; transition to GEMINI;
- Centre for Global eHealth Innovation - online Health eConcierge;
- Bridgepoint Active Healthcare (part of the Sinai Health System) - Health Gateway; transition to online Bridge2Health.

“There was no road map for collaboration in health care that we could find. We discovered through the HIC that, in working together, we were creating one.”

– Sarah Saso, Executive Director, GSCF

“There’s a difference between the ‘what’ and the ‘how.’ The ‘what’ – the goals of the HIC – were clearly established by GSCF. The ‘how’ – how we were going to evolve – was up to us to figure out. With Green Shield Canada Foundation’s Support support.”

– Jackie Bender, project lead, Health eConcierge

At the beginning, GSCF established a pattern of site visits, in which all the partners got to see where “each other lived.” It was very important, Saso said, for every HIC organization to “not just read about the others on paper, but to also experience their operations, to go on House Calls, to visit Virtual Ward, for example, to understand their perspective.”

1. SPRINT SENIOR CARE HOUSE CALLS

“If I didn’t go to them, they wouldn’t get any health care because they can’t come to me. These are hidden worlds: people who almost cease to exist, who have no voice. They fall through the cracks — and end up in hospital emergency departments. Each hospital admission can cost upwards of \$10,000.”

— Dr. Mark Nowaczynski

THE BEST CASE SCENARIO: MARGARET, A HOUSE CALLS CLIENT

At the age of 89, Margaret lives happily at home with her cat, her walker, her TV — she loves tennis and says “Federer’s my man.” She also has the therapeutic reclining chair “that Dr. Mark made me get.” She presses a button, raising the foot rest, then shows how the chair hoists her to standing. She has trouble getting up, on her own.

Margaret’s husband died in the 1980s, but she’s not lonely. Ask her how she’s doing and she smiles. “No complaints.” She says she’s well cared for — since SPRINT and House Calls got involved. Dr. Mark Nowaczynski first went to see her in April 2009, after the stroke that paralyzed the left side of her body. “If it wasn’t for Dr. Mark and SPRINT,” she says, “I would have been back in hospital, then a seniors home, then I would be dead because I wouldn’t have been happy.”

Her smile broadens as Dr. Mark, as he’s known, arrives for his regular visit. “How’s your breathing?” he asks. “Are you a little short of breath after exertion? How are you doing?”

Margaret grins. “I’m trying to think if there’s anything wrong with me.”

With Margaret’s permission, Dr. Mark itemizes her health issues: “Her stroke was in the right side of her brain and the left side of her body was paralyzed. She had depression as a result of the stroke — that’s how she was referred to us. She has high blood pressure, heart disease, atrial fibrillation — her heart beats out of rhythm. She has glaucoma and cataracts and retinal detachments. Osteoarthritis of hands and knees; her knees are sore, her mobility reduced. She’s on blood thinners because of a heart rhythm abnormality that can lead

to strokes. In 2013 she lost a lot of blood through her bowels; she didn't want to go to hospital and so we treated her severe anemia at home."

He notes that it's time to test her blood (because of the blood thinners) and a technician will arrive soon to take her blood.

Margaret had painful swelling in her legs, relieved when she got the therapeutic recliner/lift chair, one of the three most important items necessary to staying at home. The other two, according to Dr. Mark: a hospital bed that can be activated and, if you have stairs, a stair glider, both of which Margaret had installed. "They cost less than a month in a retirement residence," he says.

Margaret is on 11 different medications or vitamins and has a good system in place for taking her pills. She feels secure in the knowledge that her life is well-organized. Besides watching tennis on TV, she tends to her cat and spends time on the computer, "fooling around for hours," reading newspapers online and setting up bookmarks.

Only one thing bothers her: "fear of falling." She welcomes the occupational and rehab therapists who are part of the House Calls team. They make sure her house is safely set up (all loose mats removed) and that she gets appropriate exercises. She's incontinent and wears adult diapers. Every morning, a personal support worker (PSW) arrives from SPRINT to change her and her bed. She accepts the situation with equanimity. "It's quite common in old people," she says. Another PSW comes three times a week, for an hour, "to tidy up and shop." Margaret enjoys the company.

As for the danger of falling, "you're right," says Dr. Mark. "The stats are clear. Fifty percent of seniors who fall and break their hip are dead in six months."

Margaret nods. "I'm careful. If I need anything, I phone SPRINT. If I'm ill, I call Dr. Mark. I'm very lucky."

Dr. Mark Nowaczynski started doing house calls in 1991 as a family medicine resident. His frail, elderly patients – often housebound – became his main clinical interest, and in 2007 he closed his office practice and became one of the only family physicians in Ontario doing home visits full-time, not knowing he would eventually have a significant impact on public policy.

Having developed a relationship with SPRINT Senior Care, the collaboration was formalized when he moved his base of operations to SPRINT’s Merton St. headquarters the same year. Dr. Nowaczynski is clinical director of House Calls – “Interdisciplinary health care for homebound seniors” -- which has expanded under SPRINT’s direction and with the support of GSCF to care for 500 patients a year, their average age 88. The House Calls team consists of 11 people, including four doctors, one nurse practitioner, two occupational therapists, one physiotherapist, one social worker, a community paramedic and a team coordinator. Fifty medical residents and students rotate through House Calls every year. They collaborate with Mt. Sinai Hospital’s Department of Geriatrics. If House Calls’ patients end up in Mt. Sinai’s emergency department, Dr. Nowaczynski can transfer electronic files to establish patient histories and medications, improve their care and often prevent or reduce the length of admissions.

On the road, Dr. Nowaczynski sees seven or eight patients a day. “New patients take more time, ‘end of life’ takes longer,” he says, steering through traffic. Today, on his rounds, he stops in to monitor the vital signs of a 100-year-old woman who lies in bed, seemingly asleep. “The doctor is here,” her 80-year-old daughter says. The frail old woman opens her eyes and responds with a chuckle to the doctor’s gentle touch, pressing her hands together in greeting.

Instead of spending her last years confined to hospital, she’s at home, cared for by her daughters, in familiar surroundings. “She wouldn’t be at home or alive without our care,” he says. He reminds the daughter, “If there’s an emergency, don’t call 911. Call our emergency number.” The daughter nods. When her father was 96, she called 911, an ambulance came and in the flurry and stress, he

died. “That’s typical, and unnecessary,” Dr. Nowaczynski says.

“The number of Canadians over the age of 65 will double in the next 20 years, and the number over 85 will quadruple,” he observes.

Back at SPRINT’s head office, executive director Stacy Landau manages the multi-faceted offerings of her non-profit community support service agency. With a \$10-million budget — half of which comes from the Ontario Ministry of Health and Long-Term Care — and approximately 230 staff, SPRINT touches the lives of many seniors in its north Toronto catchment area. Through four supportive housing buildings, nine health-and-wellness sites, two dementia care facilities, nine community dining centres and one adult day program, SPRINT has a significant presence. It operates Toronto Ride, with a fleet of 12 vehicles to transport seniors. The agency’s 150 personal support workers — many of whom receive training from the Alzheimer Society of Toronto, an HIC partner — work in the community with SPRINT’s 4,000 clients.

A \$10 million budget may look like a lot of money, but it goes a long way, diverting thousands of people from hospitals and LTC, and keeping them in their homes, in the community, where they want to be. Home care is 20 times less expensive than hospital care. SPRINT’s services result in 53 per cent fewer hospitalizations and a 67 per cent reduction in hospital days of care. A hospital day costs \$842, on average; a day of home care, \$42.

What makes SPRINT unique? “Dr. Mark, House Calls, Ewart Angus Homes for people with dementia,” Landau says. “There’s no other funded interdisciplinary team based in the community responding to seniors’ needs and collaborating with other agencies the way we do.” The needs are vast. One SPRINT intake worker/social worker handles 20 to 30 calls from seniors every day, connecting them with everything from Meals on Wheels to a physiotherapist or a visit from a doctor. The intake worker takes their postal code, and if the client does not reside in SPRINT’s catchment area, the social worker transfers them to the appropriate source.

SPRINT participates in CNAP, the Community Navigation and Access Program, which links 33 seniors’ agencies. From 9 a.m. to 5 p.m., Monday to Friday, people can call a social worker who, using a

common intake tool, directs seniors to services ranging from adult day programs to transportation or respite care – with callbacks to ensure arrangements have been made. “System navigation is crucial,” Landau says. “It’s a daunting task to figure out how to get what you want.”

The spirit of collaboration infuses everything SPRINT does. Today, the GSCF investment is enabling the House Calls team to include a second occupational therapist, a physiotherapist and a program data administrator; and it is nurturing collaboration with other HIC members. Through the HIC, SPRINT and the Alzheimer Society of Toronto (AST) created a men’s cooking group, for men whose partners have dementia. The group enables the men to receive social support while preparing meals. SPRINT also collaborates with AST on art programs. “We work with them constantly and they refer people to our day programs,” Landau says.



2. THE ALZHEIMER SOCIETY OF TORONTO ONLINE DEMENTIA CARE TRAINING PROGRAM

“Alzheimer’s disease is the most significant social and health crisis of the 21st century. Without fundamental changes in research funding and service delivery, it has the potential to overwhelm Canadian families and our health-care system... In 2011, 747,000 Canadians were living with cognitive impairment, including dementia — that’s 14.9 per cent of Canadians 65 and older. By 2031, this figure will increase to 1.4 million... Today, the combined direct (medical) and indirect (lost earnings) costs of dementia total \$33 billion per year. If nothing changes, this number will climb to \$293 billion a year by 2040.”

— The Alzheimer Society of Canada

The online Dementia Care Training Program for personal support workers, developed by the Alzheimer Society of Toronto (AST) with GSCF funding, “transforms the way we approach our patients,” says Nabiha Batoum, a personal support worker who took the course. “We learn to see them not as the disease but as the human being they were and still are. We learn to empathize and engage with them, and it changes everything.”

“Well-trained PSWs make a huge difference in all of our lives,” says Marija Padjen, the Society’s Chief Program Officer.

PSWs — there are an estimated 90,000 of them in Ontario — are the front-line workers caring for frail elders who are very vulnerable, may not recognize their caregivers or family members, and may be withdrawn or aggressive.

Before the HIC, in order to access the AST’s certificate training, PSWs had to travel, often from the far reaches of the outer suburbs, to the Society’s headquarters in mid-town Toronto. Working long hours, sometimes at multiple jobs, and often having to make child-care arrangements, PSWs nevertheless came to the four week, 12-hour course, which costs \$150 and runs from 5 to 8 p.m. during the week (or on weekends). In 2013-2014, 500 PSWs graduated. (The online program will also cost \$150, while in-house training will continue.)

Then came GSCF funding, which enabled the AST to consult stakeholders in the creation of a “blended learning format” with live webinars, self-paced e-learning modules, discussion forums and case studies. As the Alzheimer Society of Toronto defines the Dementia Care Training Program (DCTP): “Topics include aging and the senses, dementia and Alzheimer’s disease, person-centred care, U-First!TM (Understanding behaviours and supporting the person with dementia through a team approach) and communication.”

As part of the HIC, additional online education was developed for family caregivers, including a Dementia 100 series of short courses, answering common questions and encouraging caregivers to access the Society for individualized support. “Though designed with families in mind,” the AST states, “health-care providers

also participate in these courses, to enhance their dementia-care knowledge and gain insight into caregivers' perspectives. Between April 2012 and July 2015, 64 webinars were held with 812 attendees. Webinar evaluations tell us that participants are increasing their knowledge about dementia care and that the webinars help to increase confidence in the caregiving role."

In terms of collaboration, the AST's Padjen notes that the Society has "entered into formal relationships with HIC partners." An AST social worker is based at SPRINT's Enhanced Adult Day Program on a weekly basis. Staff at SPRINT's day program and Bridgepoint participated in the DCTP and Behaviour Support Training (BSTP) certificate programs. AST continues to receive referrals from St. Michael's Hospital and to work with Health eConcierge on improving the Toronto Dementia Network website. "These projects are very exciting and have continued to add breadth and new dimensions to our collaboration," Padjen says.

The new program was developed by Andrea Nicholson, who joined the AST team as the e-learning coordinator in June 2012 — thanks to GSCF's funding. With a post-graduate diploma in gerontology and a certificate in adult education, she's the curriculum expert whose focus groups enabled her to address the needs of PSWs and caregivers. "Different people want different things," she says. "Some are more interested in live discussion and webinars, others like working on their own. Everyone wants to contact facilitators and ask questions."

Nicholson devised an approach that allows PSWs and other health-care professionals to work on case studies together, online, and do quizzes and homework in their own time. But online learning, Nicholson notes, "isn't for everyone. You have to have access to a computer and be able to comfortably participate in online chats."

By the end of February 2013, Nicholson — with the help of the development team — had expanded the number of courses offered online, including new monthly webinars for family members. "In terms of HIC itself, we researched and created the online certificate program, with a full working model, and held extensive stakeholder meetings," Padjen reports.

The online DCTP enables workers to gain insights into caring for patients while connecting with their fellow trainees. A key request from focus groups organized by the Society — as part of the HIC — was that online training be interactive, with opportunities to engage in live discussion with peers and ask questions of facilitators. In addition, trainees can attend a “pre-course” meeting to “walk through” the online format, and have their questions answered upfront,” says Padjen. “This will enable many more PSWs to earn a certificate that “teaches them to see the person, not just the disease.”

PSWs who have taken the course described, in detail, how they discovered new meaning in their work, having overcome their fear of clients in locked-down units. Learning to connect in positive ways enables PSWs to spend time doing what clients like to do, such as dance or play board games. For PSWs, it often comes as a revelation to see the dementia patient as a person with a rich history; this new approach can bring calm and joy to the client and the whole health-care team.

* * * * *

Part of the AST’s collaborative contribution to the partners was an “aging simulation,” presented during a site visit in the fall of 2012. “The simulation reminds learners that when caring for a person with dementia, they must also consider the effects of aging,” Padjen says. “After the simulation we discussed the physical and sensory losses people may experience in combination with dementia.”

Unable to see (wearing glasses that produced visual impairments), unable to hear (ear plugs in ears,) unable to walk properly, participants were made to experience various impairments. Unable to feed themselves (being fed, without being asked if they liked the food), the group was overwhelmed by the sense of vulnerability that comes with old age and dementia, by the challenges that caregivers deal with and how the AST’s training can be transformational.

Trainees who take the online course don’t miss out on the lively exchange of face-to-face interaction. Observing the Society’s class in action, it’s obvious how much the PSWs learn from each other. For instance, sharing ideas on working with depressed clients, one PSW

says she saw a family member react irritably to an old woman. “Stop crying, you live in a nice place,” the old woman was told. When the family member left, the PSW leaned down and said, “I see that you’re sad, you moved out of your home, you’re in a new environment, I can understand it must be hard.” Experiencing empathy, the old woman calmed down — which demonstrates “how important it is that we connect with our client’s fears and anxieties,” says Esther Atemo, an AST public education coordinator.

With an undergraduate degree in gerontology and a masters in leadership and management, Atemo worked as a PSW for five years while she attended university. Above all else, she teaches compassion. “If a client resists, think about the reasons why. Think about the impact of short-term memory loss. If I came to your house and knocked on your door and said, ‘I’m here to give you a bath,’ and you thought you’d never seen me before, would you allow me in? We need to understand that some people can’t tell the difference between fantasy and reality. There are reasons why clients can’t accomplish certain tasks. Two people with dementia may present with very different abilities. When I was a PSW, I was told that a certain client was lazy — because she couldn’t wash her own face, because she needed help getting into a chair.”

Atemo is passionate about the AST’s — and GSCF’s — mission to enhance the education of personal support workers. “PSWs make up 70 percent of the health-care field. There is power in numbers, but we haven’t been powerful because we’ve been afraid to speak. If we want to be advocates for our clients, we can’t be quiet.”

The Society has mobilized a massive public education campaign reaching out through seniors’ groups and churches. The AST also runs counselling programs, with specialized support groups for people with dementia, families and caregivers. Ongoing monthly support groups and a number of time-limited groups operate out of the AST’s offices at Yonge and Eglinton. PSWs and clients alike are affected by the stigma of the disease, and by the pressures of situations in which managers require workers to move faster, get patients out of bed, toileted, re-diapered, dressed, ready for breakfast, lunch, dinner. Managers “may be removed from reality and don’t understand the

needs of patients,” Atego says. That’s where compassionate PSWs play such a crucial role. “We understand the needs of our patients.”

The outcomes are positive on all sides. The estimated annual number of person-weeks of LTC averted by training 500 PSWs in dementia care is 26,700. Which amounts to an annual saving to the health care system of more than \$20 million.

3. ST. MICHAEL'S HOSPITAL VIRTUAL WARD- TRANSITION TO GEMINI

A very expensive sandwich: An elderly man lived alone and visited hospital emergency departments frequently...because he was hungry. He knew he'd be given a sandwich.

“There are a lot of things patients and staff like about being in hospital. If people need help, they know where to find it. They can press a call button. They can stop at the nursing station. The staff knows how to get the information patients need. What if we took the best elements of the hospital experience into the community?

What if we could identify patients at high risk of ending up in hospital or being readmitted and give them the care they needed before they felt compelled to come to the emergency department?”

— Dr. Irfan Dhalla, St. Michael's Hospital

Dr. Irfan Dhalla was doing a master's degree in health policy at the London School of Economics in 2007-2008 when he learned about the Virtual Ward (VW). Developed by Geraint Lewis, a British medical doctor hailed as a leader in public health, the VW concept evolved from Lewis's work in hospital emergency departments.

Lewis had observed the lack of coordinated care for high-risk patients – most of them seniors. After discharge, they often ended up in hospital instead of receiving the attention they needed in the community.

Back home in Toronto in 2008, working as a general internist, Dr. Dhalla – like Geraint Lewis before him – saw the same problems occurring with older patients at his own hospital, St. Michael's. Eager to find ways to improve care for seniors, he launched Virtual Ward at St. Michael's in 2010, with official enrollment and randomization in the VW trial starting on July 1, 2010, rolling out to Toronto General (Sept. 1, 2010), Sunnybrook (June 2011), and Toronto Western (Aug. 29, 2011). In all, 1,923 patients were enrolled in the study, which is one of the largest randomized controlled trials of a complex health intervention. Most of VW's patients were older “high intensity” users of health care, costing the system well over \$10,000 a year on average.

For GSCF's Saso, the VW was an excellent fit for the HIC. Highly collaborative, the VW team included: a Toronto Central CCAC care coordinator, a doctor, a pharmacist, a nurse, a clerical assistant and 17 MDs who rotated through the VW annually; they stayed for three weeks a year, as did Dr. Dhalla. The patients received excellent care from a team of professionals who shared knowledge, starting with home visits to see first-hand the conditions in which patients lived and whether they were able to follow the “plan” for home care and medications.

Patrick Van Rooyen, the research coordinator responsible for following up with all patients randomized into the VW program, ascertained whether they'd been readmitted to the emergency department or hospital. "It was very important to measure whether the Virtual Ward actually reduced re-admissions compared to usual care," he says. "I also captured additional information, such as LTC admissions, patient disposition and general health status."

Two years into the HIC, in April 2014, Dhalla appeared before the GSCF board and delivered the results of the Virtual Ward trial. The data demonstrated that the VW's intervention at the time of discharge did not reduce readmission to hospital for medically complex elderly patients. The research findings were published in *The Journal of the American Medical Association (JAMA)*.

Dhalla subsequently put forward a proposal, informed by the Virtual Ward results, to use the third year of GSCF funding to explore the problem at a more fundamental level, through GEMINI (a General Medicine Inpatient registry). It aims to develop a deeper understanding of frail and medically complex patients including high-intensity users of health resources -- to study them before, during and after hospital admission.

As Saso puts it, "we saw GEMINI as an opportunity to learn from the Virtual Ward, to go beyond disease-specific models. If we measure the quality of hospital care and improve it while patients are in hospital, they may not need to come back. In other words, if we treat them better when they're hospitalized, they may do better after they're released."



ST. MICHAEL'S HOSPITAL - GEMINI

“The status quo cannot continue.”

— GEMINI's Dr. Amol Verma, St. Michael's Hospital

CASE HISTORY: CILLA

Cilla, 78, is typical of many seniors who use emergency departments for their regular health care. She lives alone in a tidy apartment close to a major Toronto hospital. A retired nurse, she goes to the ER “very often,” she says, “sometimes two or three times a month.”

In February 2000, Cilla had quadruple heart bypass surgery. She suffers from ongoing, intermittent angina pain, which causes her anxiety about having a heart attack or stroke, and propels her to the ER. In the past 14 years, she has not been admitted for angina pain. “The doctors say I’m okay, I’m all right. They say, ‘Take your meds.’” She is on “about six different medications,” for her heart, low bone density and high blood pressure.

She doesn’t call her family doctor when she has an angina attack because, “to me, it’s an emergency. I can’t wait. Usually at the ER they do blood work and an ECG. When I am discharged, I call my cardiologist who says, ‘Okay, come and see me in six months.’ That’s my regular appointment.”

She acknowledges that her frequent ER visits “could be about my anxiety, being alone.” (Her family of origin is in India. The only one of five siblings to emigrate, Cilla came to Canada in 1969, in her early 30s, and worked as a neo-natal intensive care nurse for many years.) She has been encouraged to relax, and took relaxation classes for two years. When her subsidy ended, she quit the course.

After the bypass, she received home care three times a week, which included help with bathing, getting groceries, laundry and tidying the apartment. But in February, 2015, the Community Care Access Centre coordinator assessed her and said that since Cilla doesn’t require personal care, she no longer qualifies for assistance.

In February 2015, as part of the HIC outreach, Cilla was offered

a House Calls visit. Dr. Nowaczynski felt she could be helped. Encouraged to consider that regular home visits by a doctor might limit her need to go to ER, she was adamant that she preferred going to the ER. “I am a five-minute walk from the hospital to be seen by a doctor at the ER. They can do all the tests.”

Virtual Ward’s multi-disciplinary team delivered excellent care to hundreds of very sick, very frail patients, but ultimately did not reduce hospital readmissions for this population group. Yet it generated — thanks to GSCF funding — a massive collaboration across six major Toronto hospitals, and intensified the focus of professionals and policy-makers on how to achieve progress in helping seniors age at home. Replacing the Virtual Ward in the last year of funding as a GSCF HIC partner, GEMINI’s goals are specific: to measure the quality of hospital care in order to identify opportunities to improve outcomes for general internal medicine patients, to reduce the cost of health care and to improve the patient experience.

Up to 50 per cent of ER admissions are general internal medicine patients, older people with multiple chronic conditions, “and they have not been well studied,” says Verma. “These admissions have gone up 30 to 50 per cent over the last five years, because of aging and increased chronic disease, but we don’t know much about these people.”

GEMINI brings together medical practitioners and researchers dedicated to system-wide data retrieval and analysis. “Without information, we can’t improve care for seniors, and we can’t improve the system,” says Verma.

The lack of data, he adds, “is astounding. We know how to take care of people with heart attacks, but don’t know what is best for people who have a heart attack and also have lung problems, kidney problems, and diabetes. Increasingly, patients have multiple conditions and our science is behind the times. Why are rates of hospital-acquired pneumonia lower at some hospitals? Surgical studies have shown that simply by raising the head of the bed and encouraging early mobilization, we can reduce pneumonia, leading to faster discharge.” Better for patients and hospitals!

Hence the importance of the HIC. The first step: data collection by tapping into electronic health records across all hospital participants: St. Michael’s Hospital, Trillium Health Partners, the University Health Network (including Toronto General and Toronto Western), Mt. Sinai and Sunnybrook hospitals. This powerhouse

network extends further, and has been collaborating with senior researchers at the University of British Columbia, University of Calgary, University of Alberta, McMaster University, University of Ottawa and McGill University.

The GEMINI team planned the data collection and worked with its hospital partners to get ethical approvals to proceed. This was in place by September, 2015. The technical work/design went ahead, building the infrastructure at each hospital site to set up the data collection. “We’ve requested five years of data, from 2010 to 2015, that will encompass an estimated 100,000 patients,” Verma says. “It could be more. We’re on track for the first data pull this fall.”

GEMINI’s massive data pull will enable the team to “connect the dots,” creating a more detailed picture of what’s happening among the target group. “We’re hoping we’ll learn to how to better care for complex older patients,” Verma says.

Their focus: the Triple Aim of healthcare reform, an internationally recognized model designed to improve patients’ health, the experience of hospitalization and to reduce costs — possibly keeping people out of hospital to begin with.

“GSCF has enabled us to get this going,” says GEMINI’s Dr. Fahad Razak, “to demonstrate the value of our research, to engage the Ministry of Health and devise effective change within the system.” The first phase of HIC funding was for data collection and for analysts’ time.

So far, among other benefits of being part of the HIC, the GEMINI team has met with Bridgepoint’s experts; worked with Dr. Alex Jadad’s group at the Centre for Global eHealth Innovation and, through him, learned about such international researchers as Dr. Alberto Ruiz Cantero, renowned for his work on patients with complex, chronic conditions (CCCs). With the Alzheimer Society of Toronto, GEMINI colleagues have explored issues of dementia care. With Bridgepoint, they are developing projects to interview patients and caregivers in order to improve care after hospitalization.

“GSCF’s money is supporting efforts whose reach is wider than individual projects,” says Razak. “It’s also enabling GEMINI to apply for other innovation grants.”



TECHNOLOGY – NAVIGATING THE SYSTEM

4. THE CENTRE FOR GLOBAL eHEALTH INNOVATION (UNIVERSITY HEALTH NETWORK) -HEALTH eCONCIERGE

“We’re not in the business of creating content, we’re building the infrastructure, links and tools to connect and share content in service of a bigger ecosystem. We want to make it easier for providers to share information about their services, and for the public to find health services that meet their needs. We’re focusing our initial ‘proof of concept’ on HIC requirements, to increase access to information for seniors at home.”

—Jackie Bender, PhD, project lead

GSCF executive director Saso recognized, early in the development of the Health Innovation Collaborative, that technology would have to play a key role in improving access to health care. Many people don't know how to find the services and resources they need. They don't know where to start. Whom to ask. What's available. Today's elders are often not comfortable using online resources, but the advancing massive demographic — the “boomer tsunami” — is more tech savvy. And potentially better able to navigate the system, if the information is available in relevant formats.

Rossini Yue, now a PhD student, started doing research for Health eConcierge (HeC) by focusing on “interface for end users.” With a master's degree in clinical engineering and doctorate studies in health services research, she was thinking, she says, “about how lay people would use the tool.”

She started searching for health services in the community “from the perspective of patients, caregivers and professionals.” To her surprise, “it was very difficult to get information. How do I find services in my community? There's no comprehensive database. The information is often in silos. It was trial and error. Over and over in interviews with stakeholders we heard about these difficulties, which validated our idea about developing an ecosystem where many different databases could come together and be filtered to provide exactly the information people need. It made sense.”

The origins of Health eConcierge spiral back to Dr. Alex Jadad's focus on “re-inventing the models that guide our lives through global collaboration enabled by technology,” as he puts it.

Born and educated as a medical doctor in Columbia, Jadad went on to the University of Oxford, where he became one of the first physicians in the world with a doctorate in health knowledge synthesis. Moving to Canada in 1995, he worked as chief of the Health Information Research Unit at McMaster University before landing in Toronto in 2000. Four years later he helped establish the Centre for Global eHealth Innovation, a joint effort with the University Health Network, and was its Chief Innovator from 2009 to 2012. His overarching aims: to eliminate unnecessary suffering while helping people live the longest, healthiest and happiest lives

possible until their last breath.

Having proposed a new concept of health — “the ability of individuals or communities to adapt and self-manage in the face of physical, mental or social challenges” — Jadad is eager to shift delivery systems to manage “aging with chronic illnesses, which accounts for most of the expenditures of the health-care system, putting pressure on its sustainability.” In a British Medical Association editorial and other outlets, Jadad asserted the necessity that doctors and other health-care providers become more accessible through technological innovation, breaking down silos and reaching outward.

The HIC enabled Health eConcierge (HeC) to cast a wide net, engage with other partners in the Collaborative and come up with innovative approaches that were not obvious at the outset. The HeC development team included Jackie Bender as project lead, Mat Trudel as technical lead, Ashita Mohapatra, administrative coordinator, and Rossini Yue, research analyst.

Bender, a research scientist at the Centre for Global eHealth Innovation, has a PhD in Health and Behavioural Science (her thesis supervisor was Jadad). She brought to the HIC her years of study on using information technology to improve health care for people with chronic diseases. Her broader goal, shared by the HIC: to improve self-management while fostering collaboration among patients, researchers and clinicians, producing system-wide transformation. “This project requires dedicated change management,” Bender says. “We need to build awareness of the benefits of this new approach.”

Immersed in surveys about stakeholders and user experiences with online navigation, Bender led the research behind the development effort. This included individual interviews, design workshops and usability studies of design prototypes led by the Healthcare Human Factors team at the Centre for Global eHealth Innovation.

Mat Trudel worked closely with Bender, managing the technological aspects of the project — ultimately writing code. A mathematician and graduate of the University of Waterloo, Trudel has worked in health care for the last decade, mostly at UHN and the

Global Centre for eHealth Innovation.

The eConcierge team tackled that most vexatious of challenges: how to make health information so easy to access that the people who need it the most are able to find the services and practitioners they need; and feel secure knowing they have the most reliable information at their fingertips.

Ashita Mohapatra, MBA, watched closely over HeC's research and development, and saw that "the main thing people want is a one-stop shop. A comprehensive database that allows them to type in where they live and what they're looking for. It will produce the answers they need."

"At the beginning of HIC," says Trudel, "we hoped to build an ecosystem of information-sharing between service providers and the public." Their vision was truly collaborative: an iPhone app, possibly, with a database to populate it, using open-source tools, allowing everyone to participate in the ecosystem and add to it. It would have a public face, a name, and be an ever-evolving entity, existing in real time, enhanced by its users. It would level the playing field, enabling small service providers to make themselves known.

But the forces that create silos, Bender and Trudel learned, were intractable. "We underestimated the organizational inertia working against us," Trudel says. "We'd pitch our concept to groups we thought would be onside. The idea of information sharing sounds simple, common sense," but uptake wasn't assured.

Trudel says his "biggest takeaway" from the HIC is that "most people in decision-making positions don't realize that silos are a problem. We started from ground zero, explained what information silos are, but many major players didn't recognize it. As the anti-silo model, we faced an uphill battle."

Indeed, the concept of collaboration may be "trending" — everyone in health care talks about it — "but doing it, that's the tough part," Trudel says. "We needed to develop a model, to show how an ecosystem would work with other partners participating, to see what the problems would be and how they could be solved."

Though Google is the dominant player in indexing information, it's not necessarily helpful, since a Google search can yield hundreds

of hits for a single topic with no quality control. “Google offers no filtering,” says Trudel. “With HeC, we filter.”

As the HIC progressed, Bender and Trudel realized that HeC could “disappear” as a public entity; its function would be to provide the invisible “back end” forming the basis of a network, connecting other databases into a seamless whole.

“We want people to join the network, leaving the ownership to the people who curate the data,” Mohapatra says. “We’re building a platform for them to share data without giving up ownership. It’s up to other organizations to update their info and plug it in. When the info changes, our ecosystem will automatically update records of providers.” Thus making it easier and less time intensive for organizations to share timely information about their services.

One of the major innovations to come out of the HIC is that eConcierge created a standard instead of a product or service. HeC provides the back-end linkages in its mission to combine many databases in one place — to deliver a seamless experience. “Type in your need, location, and the ecosystem search engine will produce results,” Mohapatra says.

As Trudel puts it, “We want some measure of quality control but we’re not establishing a strong central authority. We want to build a system where quality control emerges from consensus, not from a centralized gatekeeper. Open is what works on the web. Open means it can grow and change.”

“Open” also means that small companies and practitioners in the health-care field will be able to establish a web presence within eConcierge. Its grassroots database will enable seniors to find occupational therapists, registered massage therapists, physios, personal support workers and others who offer services at home.

Like Wikipedia — which fosters a culture that thrives with users keeping it accurate and honest — HeC will be responsive to users’ needs and concerns. For instance: Trudel’s father contributed obscure information about electrical transformers to Wikipedia and within hours received edits, grammatical corrections and other improvements, including notations, that polished his article to a professional sheen. This is the power of an active online community,



which is the goal of eConcierge.

At the same time, Bender explained, “organizations told us that they want some control over the information contained in the Health eConcierge, to double check that it is accurate.” So the team created a flexible account system for directory administrators to validate information provided by service providers before making it public.

“We’re counting on consensus to enable us to stay flexible and deal with growth as it comes,” says Trudel. For his contribution to the HIC, he spent most of his time at the computer, writing code, working on concepts for “back-end databases,” and “front-end user navigation.” Then there was the “mushy middle,” made up of the infrastructure that links everything. “Part of the problem is lining up the right protocols and standards,” he says, alluding to the technical difficulties, “but the actual work is in building a community whose incentives are geared to encourage growth and adoption.”

Within the HIC process, Bender and Trudel were introduced by Bridgepoint experts to the Inclusive Design Research Centre at the Ontario College of Art and Design University (OCADU). They also connected with the Alzheimer Society of Toronto. Its Toronto Dementia Network (TDN) was out of date. The software, developed by the AST 10 years earlier, was “old technology,” Trudel says. Yet TDN provided valuable sources of data. With 50,000 records of dementia services in Ontario, its information was focused and deep, listing more than 300 options on a specific subject.

By bringing TDN into HeC’s new ecosystem, “we’re demonstrating how we can bridge different partners together,” Trudel says. “This is a critical model.” A benefit to the AST as a HIC partner, Trudel points out, is “a new implementation of the TDN database — a strong give for the Collaborative.”

Jackie Bender summarizes eConcierge’s achievements within the HIC: “We developed, tested and validated a web-based search and discovery platform that will make it easier for service organizations to publish their service information in a decentralized manner, and to enable seniors, their family caregivers and health professionals to find information about health and social services on the Internet easily.”

Ultimately, the Health eConcierge is a user-centred, evidence-based modular solution consisting of a powerful database infrastructure for organizations and directory administrators to publish and maintain their service information. It offers simple data entry processes for organizations and ease of access for seniors and their caregivers, including multiple search options to accommodate different users, a Google Maps feature, and Add to My List, Email and Print features for users to share information.

As a collection of related open source projects, HeC provides the necessary documentation for others to freely adopt, adapt, and implement the solution to their unique needs.

Enabled by GSCF funding, the HeC research resulted in two presentations at two scientific conferences, and an academic article that will be published in a peer reviewed journal.

CAREGIVERS SPEAK - FROM HEALTH ECONCIERGE'S STAKEHOLDER INTERVIEWS:

“It’s really difficult to try to figure out what an agency’s catchment area is... Each website is a little bit different, so some will actually have a map with their catchment on it so I’ll know, yes, this is the agency I should be referring to, but in other cases it’s not clear at all...“[It’s important]” to make sure everything’s up to date so when I’m telling a client about an agency’s transportation service, they know what they’re getting if I’m going to make a referral for them.”

“It would be great if there was a tool where we can just type in a client address and/or postal code and find exactly the agency and lines of service they need, and whether there a waiting list.”

“...A database where we could just tap on and there will be Barrie supports and services... And a list of all the different types, health and wellness, support groups, caregiver support...where it’s nicely organized and we can say, ‘Okay, hold on a second, I don’t have to call you [later]. I’m going to check my database and give you some contact information.’ That’s my wish.”



5. BRIDGEPOINT ACTIVE HEALTHCARE (SINAI HEALTH SYSTEM) — HEALTH GATEWAY TRANSITION TO BRIDGE2HEALTH

“We’re victims of our own success, keeping people alive longer. But a small proportion of these patients use a large proportion of resources — five per cent account for two-thirds of spending — and we have to change the way we care for them. The urgency of the need for innovation makes these exciting times. There’s huge will to transform the system.”

— Shawn Tracey, research scientist, Bridgepoint Active Healthcare

“For educated people who know how to find useful information on the Internet regarding self-care and disease prevention, and who also know how to deal with the health-care system, the Internet holds great promise... But for the rest of the population, including the less-educated, the elderly and those with many health problems, Internet promises will come true only if health information is designed according to their needs and capacities.”

— from a 2003 paper by Quebec healthcare experts Mike Benigeri, now a consultant in health information management, and Pierre Pluye, a family medicine professor at McGill University

Bridgepoint reaches back to the past and into the future. A hospital has existed on its site overlooking the Don Valley for 150 years. In April 2013, a new, state-of-the-art, \$622-million facility opened its doors to widespread acclaim for an institution widely regarded as a leader in managing complex, chronic conditions (CCCs) and rehabilitation.

Bridgepoint is also dedicated to improving people's lives once they leave hospital and return to the community. Hence its role in the HIC began with major enhancements to Health Gateway, its consumer database designed to support patients and caregivers in the transition from hospital to home.

Created in collaboration with the Canadian Working Group on HIV and Rehabilitation, Health Gateway added more than 130 new resources in the first year of the HIC. At the same time, thanks to GSCF funding, the team began consultations with multiple stakeholder groups and digital-marketing experts.

According to the Pew Internet & American Life Project — one of the most comprehensive ongoing surveys analyzing the use of technology and the impact of the Internet — 80 per cent of people who conduct online searches are looking for health-related information, half of them on behalf of someone else (a spouse, child or friend).

Most of the time, they're struggling. The Change Foundation's 2012 report, "Loud and Clear," detailed seniors' major concerns, such as "dead ends" in primary care and blocked transitions; the need for professionals to "connect the dots" and clarify the process; the need to improve professionals' communication with patients; including patients, families and caregivers in decisions; and caring for people who face barriers and fall behind.

The questions most commonly asked: How do I get better and live well with this condition? Manage when I get home? Find a job that accommodates my condition? Improve my quality of life? Find a more accessible place to live? Find assistive devices? Plan for end-of-life care? Find the services I need?

In 2011, Paula Gardner became research scientist at the Bridgepoint Collaboratory for Research and Innovation — fresh

from the City University of New York, where she was an assistant professor in the School of Public Health. Having completed her PhD at the University of Toronto in public health, specializing in gerontology, she was eager to bring her “trans-disciplinary” approach to CCC prevention and disease management to the Bridgepoint team, and to the HIC.

Gardner says that the GSCF’s investment enabled “the re-envisioning” of software, to improve the user experience of the site. Inclusivity, usability and accessibility were the goals. Hence the decision to work with the Inclusive Design Research Centre (IDRC) at the Ontario College of Art and Design University (OCADU).

Describing itself as “an international community of open source developers, designers, researchers, advocates and volunteers (who) work together to ensure that emerging information technology and practices are designed inclusively,” IDRC is headed by Jutta Treviranus. An internationally known expert dedicated to empowering people with various disabilities, including age-related ones, she teaches what she calls “participatory design.” It means working with the end user from the beginning of the process – which happened within the HIC. Its value is what she calls the “curb cut effect.” The curb cut on sidewalks, created for wheelchairs, is useful for baby carriages, skateboards, grocery carts and wheeled luggage. So it is with technology that’s easier to navigate; everyone benefits.

Some simple techniques include enlarging the size of print, voicing the text – and allowing users to take personalized “adjustments” with them to any online resource they use. Collaboration, as Treviranus sees it, is essential. “The primary thing that’s happening now is networks, collective production and crowd-sourcing. Many of our projects are related to something we call global public inclusive infrastructure. The idea is, because we’re networking globally, we don’t have to redundantly produce particular solutions – we can pool them together.”

Bridgepoint’s (and Health eConcierge’s) researchers, working with IDRC experts, studied human factors, analyzing how people use computer keyboards, mice and screens, how they search

and navigate sites, “to help us design better search tools,” Gardner says. From the beginning, they consulted people with CCCs, their caregivers and families.

They went into waiting rooms, showed patients the website, asked what would make it easier to find a home care coordinator, Meals on Wheels, foot care, financial planning.

“This is the future, and HIC helped us create the living lab — students and researchers studying patients.” Gardner adds: “GSCF funding allowed us to hire research assistants, all graduate students, and enabled us to leverage matching investments through Mitacs to mentor and inspire a team of students working on Health Gateway.” (Mitacs is a Canadian non-profit dedicated to stimulating research and training programs).

“We need to keep pushing research in this area to ensure the tools and resources people need to manage their health and lives are not only available — that’s the easy part — but meet them where they’re at in terms of abilities,” Gardner says.

During year two of the HIC, when the Canadian Working Group on HIV and Rehabilitation decided to shift to a national focus, with more emphasis on episodic disabilities and return to employment, the Bridgepoint team chose to “leverage the existing resource database” and repurpose the site to be called Bridge2Health in year three of the HIC.

GSCF enabled this transition, as it did the shift from Virtual Ward to GEMINI, appreciating that research projects and their personnel evolve, over time, and that progress comes from being flexible and open to new possibilities.

Search Google for “assistive devices” and you get thousands of results. Search Bridge2Health, and you get a few selected and vetted resources.

Focused on the health care needs of people with complex, chronic conditions, Bridge2Health expanded by 50 per cent, thanks to GSCF funding, adding more than 200 vetted resources to hit an all-time high of 900 items online, selected specifically for the

target demographic, as well as for caregivers. It's unique because it is not disease-specific but rather focuses on providing users with information to enable them to live better with their conditions, along the continuum of care. Information is organized into three different topics: caring for oneself, caring for others and services and equipment. The database will remain relevant thanks to ongoing cataloguing and uploading of resources – linked to Health eConcierge.

Bridgepoint scientist Shawn Tracey has worked in public health and medical research for more than a decade. Familiar with the gaps in the system, he says “it’s hard, after a month in hospital, to find yourself suddenly without assistance for medications, food and baths, and with reduced strength and mobility. It can be a shock to have to continue rehab at home.” Hence the allure of returning to the safe place, the hospital.

Especially when, in many cases, there’s little discharge planning. Patients may leave hospital with referrals, but no one knows if the referrals will materialize. “You may have a request for a PSW twice a week for bathing, and it may be denied.” People fall through the cracks.

For instance: a diabetic patient, discharged from Bridgepoint to the care of her family doctor, phoned him and got a message that he’d gone to Florida for two months, with no alternate arrangements made, no prescription renewals. “A recipe for patient readmission,” Tracey notes. “It happens all the time. Treacherous terrain. A family doctor may be totally unaware the patient is in hospital. Of course, if we had unified health records, it would be ideal.”

Tracey credits the GSCF’s innovative approach to stimulating research. “The funding environment,” he says, tends to be “very short-term, focused on evidence of positive outcomes in 12 months.” That’s often not possible, he notes.

“Green Shield Canada Foundation allowed proposals to be submitted for three years, which enables us to track changes over longer periods. The HIC model is flexible, which is fantastic, encouraging the major players to work together, which further enhances innovation.”

COLLABORATION AND EVALUATION

The GSCF ensured ongoing collaboration by hosting regular status meetings with the project leads and setting up committees to focus on communication, technology and evaluation. The partners got to know each other, shared knowledge and resources, formed new connections and referred patients from one program to another.

Regular tracking, documentation and evaluation of the HIC was crucial. Following a “request for proposal” process conducted by GSCF, Heather Smith Fowler, a research director at the Social Research and Demonstration Corporation (SDRC), came on board the HIC in September 2013. SRDC does social policy research and evaluation for a vast range of clients, including the federal and many provincial governments, non-profits, associations and foundations.

For the HIC, Smith Fowler and colleagues reviewed documents and data, interviewed projects leads and other personnel, analyzed input, facilitated joint sessions on how the process was working, and conducted a survey with the partners on the effectiveness of collaboration.

One of the strengths of the HIC was its clarity of focus, Smith Fowler says. “The partners addressed two major issues: how to better serve people with complex chronic conditions who are not well served by the system, which in turn creates inefficiencies and higher costs. And how to better integrate care, enabling major players to collaborate more effectively.”

Smith Fowler was “delighted that GSCF management not only wanted feedback on the process, but encouraged us to take a

developmental approach, to work collaboratively with the partners and help improve the initiative if possible. It was a learning process for us, too.”

SRDC representatives attended regular meetings and listened to partners share updates and express concerns about the challenges of collaborating. “I think it helped to have a third-party consultant observe and evaluate, to collect the group voice and reflect back common issues,” Smith Fowler says.

In the first year, she noted “some concern” among partners about whether they’d be able to reduce the rate of hospital emergency readmissions – one of the key measures of improvement in care for seniors with complex chronic conditions.

Saso clarified that of the major HIC goals, not all would be relevant to all partners, nor could all partners measure all goals. If an organization could measure a reduction in emergency department visits, they should, if not then they should measure another goal that fit their project.

The results of the GSCF HIC evaluation were finalized collaboratively with the project partners. “All signs point to considerable success in achieving the HIC’s short term and intermediate term goals,” Smith Fowler says, “despite design and process challenges, especially the turnover of project partners.”

SRDC’s evaluation was presented at GSCF’s October 29, 2015 Learning Event, *Doing Things Differently: A Collaborative Approach to Improving Care for Seniors*, held at Bridgepoint.

The main findings noted by SRDC were: “The HIC achieved all three collaboration goals - shared learning, networking and partnership; learning about cross-system perspectives was particularly appreciated by partners. The HIC also achieved its intermediate goal of building capacity among partner organizations to deliver better projects, meet organizational goals, and develop their work. Partners who were actively engaged throughout the initiative and had some degree of alignment with other partners tended to report more benefits from collaboration.”

SRDC’s “portrait” of the HIC, “based on interviews with project partners, as well as site visits, observations, survey responses, and a

review of HIC documents,” identified “key themes” that emerged as early as June 2014:

- GSCF was regarded as a very supportive funder
- The HIC provided an opportunity to share cross-system perspectives
- A foundation of trust was being built
- Opportunities were being developed for sharing and learning across projects
- There were signs of increases in organizational capacities
- There was potential for multiple benefits of collaboration beyond core projects

SRDC congratulated GSCF “for taking a novel approach to support innovative health care solutions for medically complex seniors. GSCF has demonstrated considerable leadership by the way in which it tackled one of the ‘wicked’ problems of the day – healthcare reform – through consultation, innovation, and collaboration.

By informing itself about the issues, connecting with organizations with new ideas – some already developed, and some still on the drawing board – and introducing them to each other under the auspices of the HIC, GSCF took the idea of collaboration and turned it on its head. While some aspects of that approach have entailed considerable challenge for the group, GSCF has been fully engaged with other HIC partners to work through these challenges, and has allocated additional resources (e.g., for training, evaluation, conference attendance) where these were seen as a potential help.”

In SRDC’s opinion, “one of GSCF’s key contributions to the HIC has been to infuse it with a spirit of experimentation, risk-taking, and learning. When a focus on impacts was starting to generate unease among HIC partners and stifle communication early on, GSCF staff reiterated the commitment to innovation and learning, and supported a move to measure process outcomes. Moreover, GSCF has fully embraced the idea of learning from failure for itself as well as the HIC. Lessons learned from the HIC have already been incorporated into GSCF’s new Frontline Care strategy. This openness and flexibility is key to learning and innovation.”

A key to achieving collaboration is enabling communication, and according to SRDC's July 2015 survey, "all partners agreed or strongly agreed that:

- The HIC facilitated communication among partners, particularly during meetings
- The HIC had well-coordinated activities and meetings
- The HIC had clear and open communication among partners
- The HIC offered an environment where differences of opinion could be voiced
- The environment fostered respect, trust, inclusiveness and openness
- Processes were in place that allowed partners to discuss how they were working together."

SRDC observed that, "with the HIC, GSCF committed itself to an experiment in social entrepreneurship, trying a new model of collaboration as a means of stimulating both organizational and systems-level change. Despite the HIC's challenges – or perhaps because of them – this experiment has yielded tremendous learning.... With its experience as the backbone organization to the HIC, GSCF has signaled the important role foundations and grant making can play in supporting the development of innovative solutions to issues of healthcare access and quality, and acting as a catalyst for change."

SRDC'S LESSONS LEARNED

Collaboration is hard, and harder in the health sector. As SRDC noted:

- The health sector has many players and settings with diverse roles, training, and organizational cultures.
- These people/organizations usually operate in siloes with very little cross-system contact. Moreover, they often have to compete for recognition and scarce resources.
- In addition, many health organizations experience high turnover - staff positions may be project-funded and therefore not permanent, and/or not well-paid.
- Understandably, clinical work or direct service usually takes precedence over committee work. For the HIC, this meant partners with clinical responsibilities were not always able to attend meetings...

SRDC made the point that, “Diversity is not the enemy of collaboration – far from it. In fact, diversity can enrich and enhance a collaborative partnership. HIC partners, for example, found that cross-system learning was one of the greatest benefits to their participation.”

It was important, within the HIC, to find “commonality of purpose.... Partners have to see the practical purpose and potential benefit of collaboration to decide it is worth the effort...Focusing on reciprocal exchanges (e.g., of information, resources, knowledge, skills, support) as HIC partners did can help reap the benefits of diversity while strengthening collaboration at the same time.”

SRDC concluded that, “Foundations have the potential to fill a gap in the current health system. Current funding streams tend to focus on research (e.g., CIHR), operations (e.g., Ministry of Health),

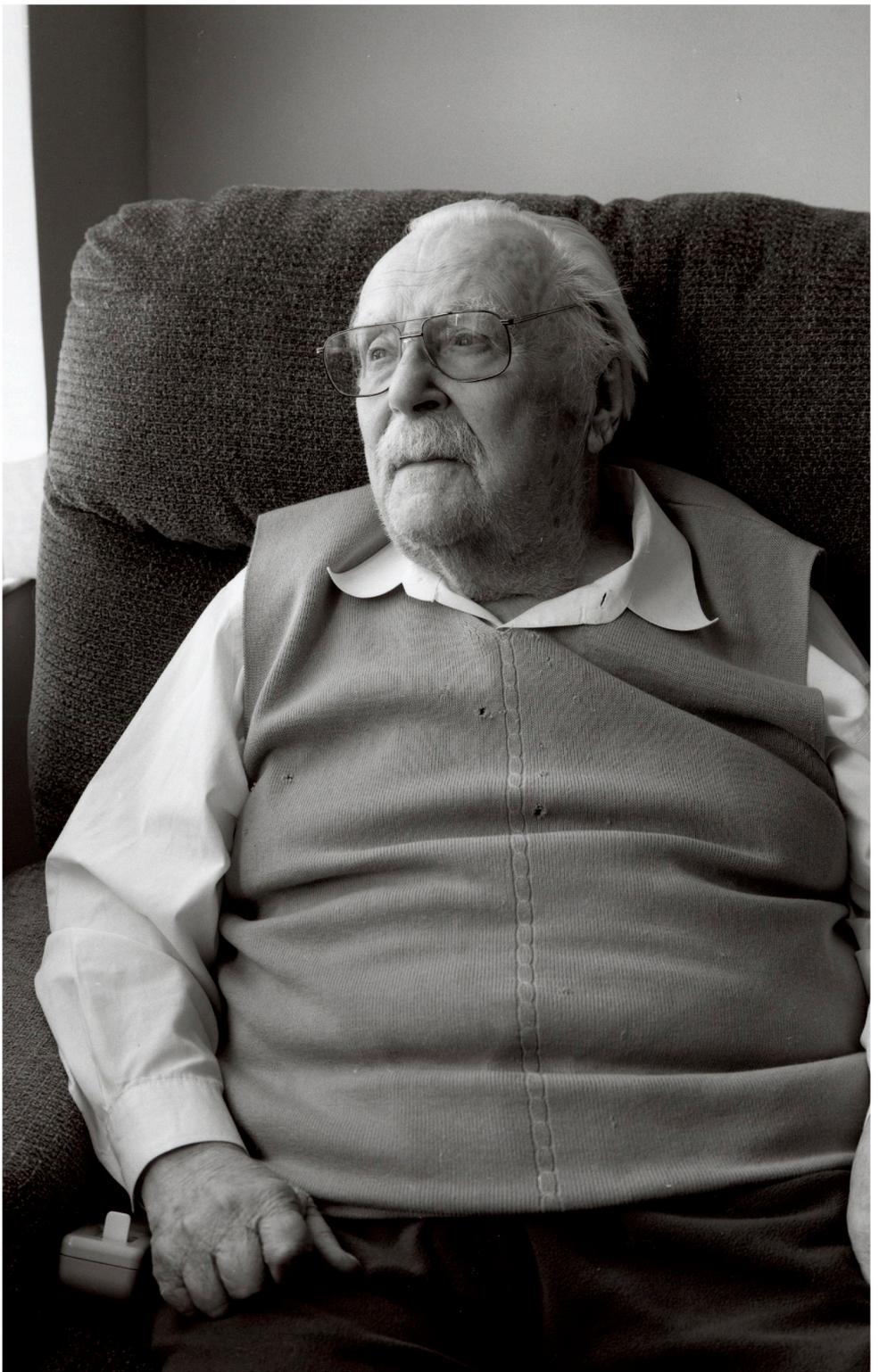
or infrastructure (e.g., Canadian Foundation for Innovation). Foundations can provide funding to projects that don't necessarily align with the eligibility requirements or priorities of other established funding streams... A particular benefit of foundations is their ability to broker connections with other individuals or organizations who can help address sustainability issues, since they tend to have a broad knowledge of their sector or sphere of activity.”

Indeed, foundations like GSCF “have the potential to have broader impact (e.g., on policy or systems-level change), to the extent they are able to use their grant-making as a tool for experimentation and learning. Evaluation of innovative, multi-pronged initiatives that address important, ‘wicked’ problems – particularly over time – can be a useful tool in this regard.”

Finally, as assessed by GSCF leaders and HIC project manager Jennifer Roynon, all the HIC partners contributed to the goal of improving the quality and accessibility of care for seniors in the GTA region, aged 65+ with complex chronic conditions. In terms of expanding opportunities for care at home, and improving the quality of life of seniors and their caregivers, AST, House Calls, and Virtual Ward had a major impact. AST increased the skills of personal support workers who work directly with seniors in their homes. A study of House Calls patients following discharge from hospital showed that patients active in the program for greater than 90 days had a 53% reduction in hospital readmissions, and a 65% reduction in length of stay if readmitted. As well, the research findings of Virtual Ward led to the creation of GEMINI, drilling down deeper to better understand patients in hospital. On the technology side, Health eConcierge and Bridge2Health identified opportunities to link to those resources and made available online and mobile services, connecting seniors and their caregivers to local healthcare providers.

“Looking to the future, GSCF is focused on continuing to be a catalyst for fundamental big picture change in Canada’s health care system, providing innovative supports and solutions.”

— Sarah Saso, executive director,
Green Shield Canada Foundation



WHAT'S NEXT?

FRONTLINE CARE: OPENING DOORS TO BETTER HEALTH

The learnings that have come as a result of GSCF's focus on care and support for seniors has strengthened the Foundation's capacity to create and deliver innovative solutions to improve access to services.

In light of their accumulated knowledge, the GSCF is keen to expand its scope of work and the populations it supports -- with a focus on frontline care, serving the health care needs of uninsured and underinsured populations.

GSCF has opened its funding doors to Canadian-based charitable organizations who share this focus of serving Canada's most vulnerable people.

As part of Frontline Care's new funding requirements (extending from one to four years), all selected grantee organizations must employ a "navigator" to connect individuals to other services that are appropriate for their situation. This could include housing, education, employment, food, clothing etc.

With respect to the GSCF's transition from in-home to frontline care, collaboration, innovation, sustainability and systemic change have always been, and will continue to be, at the core of the Green Shield Canada Foundation's funding priorities.

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