



The Terry Fox Research Institute's Atlantic Dialogue on patient-centred care in a personalized treatment world

K. Curwin MBA BJourn, M. Johnston MD,*† and S. Sutcliffe MD*†*

ABSTRACT

The words “personalized medicine” are used daily now in cancer care and research conversations. But what do those words really mean to us as patients, caregivers, physicians, managers of the health system, or researchers? Do we know how personalized medicine will affect us over the next decade? Are we prepared?

Those and other questions are part of a continuing conversation that the Terry Fox Research Institute is having with the Canadian public in 2010 as part of its public research and outreach project, The Pan-Canadian Dialogue Series on *Cancer: Let's Get Personal*. The first dialogue was held in St. John's, Newfoundland and Labrador, April 12, to coincide with the 30th anniversary of the Terry Fox Marathon of Hope. It featured speakers and panellists from Newfoundland and Labrador, Nova Scotia, New Brunswick, and Prince Edward Island. Three core issues framed the Atlantic discussion: cancer and population health, cancer and the health system, and the science behind cancer care.

KEY WORDS

Patient-centred care, personalized medicine, cancer, genetics, genomics, health system, prevention

1. INTRODUCTION

The words “personalized medicine” are used daily now in cancer care and research conversations, often describing a common goal of providing the right

treatment for the right person at the right time. But most observers will agree that this rather simplistic definition doesn't fully describe today's reality—specifically, that cancer control and care are about much more than treatment. Nor does it explain the challenges of moving evidence-based findings into real-world settings in ways that are practical, implementable, affordable, and sustainable—even if they are the right things to do.

What, then, do those words really mean to us as patients, caregivers, physicians, managers of the health system, or researchers? Do we know how personalized medicine will affect us over the next decade? Are we prepared?

Those and other questions are part of a continuing conversation that the Terry Fox Research Institute (TFRI) is having with the Canadian public in 2010 as part of its public research and outreach project, The Pan-Canadian Dialogue Series on *Cancer: Let's Get Personal*.

The first dialogue was held in St. John's, Newfoundland and Labrador, April 12, to coincide with the 30th anniversary of the Terry Fox Marathon of Hope. It featured speakers and panellists from Newfoundland and Labrador, Nova Scotia, New Brunswick, and Prince Edward Island and was webcast to selected audiences in Atlantic Canada. Three core issues framed the Atlantic discussion: cancer and population health, cancer and the health system, and the science behind cancer care.

2. THE CORE ISSUES

2.1 Cancer and Population Health

Social behaviours, lifestyle, and other risk factors such as obesity, environment, and genetic susceptibility figured prominently in the discussion of cancer and population health. The session lead, epidemiologist Dr. Louise Parker (Dalhousie University, Halifax, NS), provided cancer statistics for the Atlantic provinces and data that gave historical context and background to a compelling case for increasing the role of prevention in cancer control.



The Terry Fox Research Institute
L'Institut de recherche Terry Fox

Atlantic Canada has the highest rates of cancer in Canada, with Nova Scotia having the highest mortality for women, and Newfoundland and Labrador having the highest mortality for men. For every 500 men who die of cancer in British Columbia, 613 will die in New Brunswick, 660 will die in Nova Scotia, 607 will die in Prince Edward Island, and 643 will die in Newfoundland and Labrador. The excess burden from cancer in Atlantic Canada is enormous.

“We know about tobacco; we know about diet, body weight, alcohol, and occupational and environmental exposures. These together account for about half of all the cancer that we experience as a society—and that will be half of all the cancers that are going to affect one in two of our children,” Parker said.

Advertising campaigns for tobacco and fast food (French fries, for instance) have promoted “happiness on a stick,” she emphasized, pointing to their influence on behaviour and lifestyle. Although society doesn’t yet have an “appetite” for it, Parker suggested that perhaps we need to consider restricting sales and marketing of, or taxing, inappropriate food products to create some of the social change that is needed and not currently being pursued. “We need to develop partnerships in cancer prevention, and we need to do cancer prevention better, and we need to do it faster than we have done so far with tobacco,” Parker remarked.

Health care ethicist Dr. Chris Kaposy [Memorial University of Newfoundland (MUN), St. John’s, NL] spoke of the timeliness of a recent conversation with medical students completing rural placements in Newfoundland and Labrador. The students were struck by the rates of hypertension and diabetes in the communities they had visited. “Some said that up to one hundred per cent of the patients they saw in these communities had one of these chronic health problems. They all thought that diet was a major cause, and that poor diet was associated with high rates of poverty in these communities. In rural areas of the province, nutritious food can be very expensive and hard to find, [and] so many people do not eat well.”

Political solutions are part of the answer in reducing the incidence of cancer in rural Canada, Kaposy said. “If we really want to combat diseases such as cancer in rural communities, we should contemplate political solutions. Social programs and taxation policies that put more money in the hands of the rural poor could help improve their diets, which might also improve the incidence of cancer.”

Looking at prevention from a very broad perspective, considering multiple strategies rather than targeting a specific population or action group, changing society without pointing the finger of blame at individuals, and supporting personalized decision-making so that people can choose a healthy lifestyle that is right for them were among the actions

suggested. “To really prevent cancer and chronic disease, we have to get to the very root and prevent them through interventions at the community, policy, and political levels,” remarked Dr. David Allison, medical officer of health, Eastern Health.

~

Personalized medicine is about identifying factors—both genes and environment—that compromise health by contributing to chronic disease and cancer, and about reducing their impact at the societal and individual levels alike to improve personal outcomes.

~

Dr. Donna Murnaghan (University of Prince Edward Island, Charlottetown, PE) asked participants to focus on the future for the sake of our children and grandchildren. “What is the legacy that we are providing in terms of cancer prevention, cancer diagnosis, and survivorship? How are we working to help advance cancer [control] for Canada? Not just for Atlantic Canada, but for all of us? Preventing cancer is really upstream thinking. It’s not one child at a time. It takes a whole community to raise a child.”

Providing children with positive reinforcement—so that they feel good about themselves, have a sense of autonomy, and feel connected to their peers and family—prevents youth from engaging in unhealthy behaviours. “Linking action and science for prevention that is driven and created by youth and accessible to them rather than adult thinking and models is what will help to make a difference,” Murnaghan said.

Dialogue attendee and geneticist Dr. Jane Green (MUN) spoke about the need to identify as “high risk” those families in which more cancer occurs than is expected because of certain genes and environmental factors, and to institute screening so that diagnoses and interventions can be offered earlier. “Certainly the family doctors and specialists ... seeing clusters of people in the same family or from the same community with the same type of cancer, should use the knowledge of a genetic predisposition to permit earlier diagnoses and better outcomes.”

Two-time cancer survivor Dr. Krista Wilkins (University of New Brunswick, Fredericton, NB) provided a word of caution as patient-centred care and personalized treatment moves forward. “Cancer patients and their families often get caught in the ‘blame game,’ finding themselves in the position [in which] they feel that they have caused the cancer.... This sense of self-blame may be perpetuated by societal images that equate cancer with personal responsibility.... The concern with focusing solely on personal responsibility for cancer is that we may dissociate cancer from the complex interaction of societal factors that have contributed to its development.” Individual and social responsibility for cancer control both need to be explored, she remarked.

~

Personalized medicine: Illness is personal. The burden of illness is shared by patients, families, and society. Experiencing cancer is not a question of individual guilt or personal blame. The “roots” of illness (cancer) lie in a complex interplay of genes, exposure, environment, and circumstance.

~

2.2 Cancer and the Health System

Medical oncologist Dr. Kara Laing (Dr. H. Bliss Murphy Cancer Centre, St. John’s, NL; Figure 1) said that striving for excellence in cancer care requires a change in how we think about cancer care in the broader sense and a focus on what is important to patients. Patient-centred care involves providing patients with the necessary information about their health, their cancer diagnosis, and their treatment choices, she said. The health care system, she continued, has a responsibility to empower patients to make choices and to give them the support they need to do so.

Patients need information, access to care, the ability to make choices, and support for their choices. Integrated, coordinated care is important, as is extending help to the patient navigating a complex system as they move through the continuum of care. Provision of care spans an elaborate spectrum in a world in which cancer treatment is rapidly changing.

In considering personalized care, a transition is under way. Generic cancer treatment (same approach for all) has yielded to the current stratified approach (treatment allocation according to prognostic groupings) and is moving toward a future personalized approach (based on the unique characteristics of the individual) in which each patient seems almost to have a unique bar code that incorporates many pieces of information to be taken in to account in a highly personalized treatment decision.



FIGURE 1 Oncologist Dr. Kara Laing (podium), with panellists (from left to right) Mr. Chris Skedgel, Dr. Pierre Whitlock, Ms. Pam Bowman, and Mr. Geoff Eaton.

Health care professionals think about the disease characteristics, Laing remarked, but they also need to think about the patient and what makes that individual’s treatment choice unique. “Where do they live? Where are they going to get their cancer surgery or treatments? What mindset or what experiences are they bringing forth at the time of their diagnosis? Who relies on them at home? Are they a primary caregiver? Are they looking after grandchildren?”

Where multidisciplinary teams—within and outside the health system—are providing care, integration and coordination become important to patients. Access to health information that is current and accessible is important, but so is protection of that information. Patient access to new therapies through clinical trials is also important. “I’ve always been involved in clinical trials as a way to let patients have earlier access to new therapies. But when we think about doing trials now, the resources are limited. We don’t have a lot of core funding, and particularly in Atlantic Canada, we need to make sure that the trials are available to our patients to participate in, but also that they’re applicable to the population,” remarked Laing.

Setting priorities is important as new therapies are evaluated and existing therapies are reviewed, all competing for resources within the system. Patients and their families must be an integral part of this priority setting, said Laing.

Survivors spoke of experiences with the health care system that were as individual as they are. A 14-year breast cancer survivor, panellist Ms. Pam Bowman of New Brunswick, articulated the very different journeys that she and her husband, who succumbed to bladder cancer, experienced. Her husband’s chemotherapy treatments were administered in hospital, and he found the visits long and painful. With a spinal fracture caused by a tumour, he endured regular ambulance rides to the centre, followed by long hours on a gurney waiting to see the oncologist, and then more time waiting for a room to become available for treatment. Often, he had to stay overnight to receive treatment the following day. Neither the patient nor the hospital found this experience beneficial. “From a humanitarian point of view and an economic point of view, I’m sure there were ways that [his care] could have been improved.”

Patient care is about doctors and nurses not just talking to each other, but “looking after all of me,” remarked Mr. Geoff Eaton, who was first diagnosed with cancer at age 22. His personal integration into his care was his priority as a patient. Complementary and alternative medicine were also important, he said. “It’s my life, and I really want you, as a health system, to help me save it. But I don’t want you to do that at the cost of all the quality that I may have left in my life. Quality of life is such an essential; personalized care has to include quality of life.”

~

Personalized medicine is about seeing each person as an individual and as a functioning member of society with aspirations, responsibilities, circumstances, and commitments—as a “whole” rather than a “sum of the parts.”

~

Hematologist and clinical oncologist Dr. Pierre Whitlock of Moncton, New Brunswick, said that the cancer care system today is under pressure for good reason. Much progress has been made with regard to good new medications and treatments, and the technology for screening tests (positron-emission tomography, magnetic resonance imaging, and computed tomography imaging) and surgical procedures is improving, but not every province or every patient can access them, he emphasized. Further, as more patients survive longer, they are also staying in the system longer, and their progress must be followed. “This [situation] puts a lot of pressure on the health system. As an oncologist, I am seeing more patients, but we need to involve more nurses, dieticians, and [allied] professionals in care.”

To manage and to avoid having the system “crash,” more doctors, nurses, and allied professionals are needed now for treating cancer patients and long-term survivors, Whitlock said. “We have to realize that, eventually, a lot of people here will have cancer, and we have to be prepared for those patients.”

Patient characteristics, societal values, and the distribution of goods according to price were briefly addressed by Mr. Chris Skedgel, lecturer in the Department of Medicine at Dalhousie University and research health economist for Capital District Health Authority in Halifax, Nova Scotia. “Patients have characteristics that society values differently ... but everyone understands that resources are limited and [that] demand will always be greater than [the] supply. Somehow, we need to prioritize how we allocate our limited health care resources.”

The question that health care economics is trying to grapple with now, said Skedgel, is “‘How do we resolve these inconsistencies in how we are allocating resources?’ The thinking these days is ‘Well, there are a lot of different facets in what we value in health care.’” Sometimes value is placed on what will help the sickest patient, sometimes on what will extend life furthest, and other times on reaching a particular age. Skedgel pointed out that a move is under way to evaluate characteristics based on the patient rather than the whole population.

2.3 The Science Behind Cancer Care

Moving discoveries into clinical cancer care is a process in which progress is incremental and deliberative, said session lead and surgical oncologist

Dr. Geoff Porter, head of the Capital Health Cancer Care Program in Halifax, Nova Scotia.

How to define “discovery”? It may be a novel finding in the laboratory, a new technology, new radiation equipment, or a new drug. All of those interventions enter the clinic through patients enrolled in studies that look at drug toxicity or tolerability (phase I), rates of response to new therapies (phase II), or new treatments (post phases I and II) in comparison with the current standard of care (phase III). The approval process for new treatment modalities is complex, requiring regional, provincial, and national approvals. Also, multiple feedback loops must be completed before a treatment becomes an accepted standard of care.

Knowledge plays the biggest role. “Existing knowledge with regard to the disease and treatment and new knowledge come together to establish the potential impact of the discovery,” said Porter. Other drivers include the degree of burden of the given cancer, its stage, its incidence, and its effects. Porter used a baseball metaphor to describe how progress in cancer treatment or care is made: it is largely a series of singles that combine to score runs. “Feasibility of research and feasibility of the potential treatment in the clinical arena are also important drivers. As we have already heard, economics plays a major role.”

The process is challenging and lengthy, with many criticisms regarding the current state of affairs: timing, public expectations (“hype versus hope”), small incremental advances, a bar of efficacy that is set too low, nonalignment of statistical and clinical significance, a bar for safety standards that is set high, regulatory and ethical issues, large “all-comer” studies with a bias toward unselected patients and a heterogeneous patient population. “It can take more than a decade to get a legitimate novel discovery into clinical care where it can make a difference for cancer patients,” said Porter.

The issue of efficacy (success in a controlled environment) versus effectiveness (real-world success) is increasingly being recognized. And Porter suggested that good translational research will have a significant impact on effectiveness. He pointed to the introduction, with the health care reform bill in the United States, of comparative effectiveness research, which evaluates various interventions and strategies to prevent, diagnose, treat, or monitor cancer. Canada does this kind of research well, he remarked, but it needs to do it more. “Our purposeful system has served cancer patients well, but it clearly needs to evolve as we [move into] the molecular and genomic era in which cancer patients and potential cancer patients will live. In my view, the Atlantic node of the [TFRI] is going to be very critical to this evolution.”

For cancer patients who wonder why researchers have not yet arrived at the finish line and have not solved the riddle despite the tens of billions of dollars that pour into the global cancer research initiative, oncologist Dr. Stewart Rorke from St. John’s, Newfoundland and

Labrador, had this response: “Cancer is hundreds of diseases that are all very different and complex. But there is hope. We have conquered and solved some of these riddles.”

One of the rare cancers with which Rorke has dealt is gastrointestinal stromal tumour. He sees 12 to 20 cases of this rare type of sarcoma annually in his province. Several years ago, the disease was viewed as untreatable and chemoresistant. With a novel oral chemotherapy on the market, “this death sentence [was turned] into a chronic disease almost overnight for many people,” Rorke said. “As Dr. Porter said, we are looking for base hits and putting the pieces together, solving the cancer pieces one at a time.... Not every cancer will have a specific key that will unlock the riddles so precisely, and that’s why the basic science, the ongoing research to understand cancer in its many forms, needs to continue. We have to continue hoping.”

~

Personalized medicine is about the ability of the individual to access novel interventions derived from unique (molecular) understandings of their cancer and the host biology (for example, gastrointestinal stromal tumour and its therapy, imatinib), and how the transfer of new knowledge can be accelerated into “real world” clinical settings.

~

Dr. Eshwar Kumar, for 26 years a practicing oncologist, co-leads New Brunswick’s provincial cancer organization, where he helps to plan and implement provincial cancer control strategies. Stating that the present health care system is unsustainable, he also said that it is not practical for the system to embrace every new treatment or therapy. “There are many new technological developments and many new drugs being introduced into clinical care, and not enough thought is given as to how their use is going to impact the system, especially if not accompanied by new dollars.... The pressures to try something new are enormous, and while one wants to offer the latest treatment, [that new treatment is not always] necessarily the best option.”

Intensive application of human resources is required in many instances to implement new technology and therapies. Offering new treatments using current delivery models isn’t feasible because of resource insufficiency. Culture also interferes with uptake. “We protect our area of practice very strictly; unless we become more broad-minded and allow an expansion of the scope of practice of our colleagues, we will never be able to meet the demands of the system,” Kumar remarked.

And what is needed for the system to work better? The answers include a focus on which services need to be delivered rather than on who should deliver them,

the choice to foster collaboration, and openness to alternative service delivery models. These approaches may help to reduce the burden for patients and for the system, “helping us to achieve our goals of more effective clinical treatments, [and improvements in] the quality of the lives of the patients we treat.”

~

“Personalized medicine” is about the ability of the health system to respond to the demands of personalization, given that such medicine may be more costly, labour-intensive, and pursuable only if choices are made between the priorities competing for health resources.

~

2.4 System Preparedness for Change

Dialogue co-chair and medical and radiation oncologist Dr. Simon Sutcliffe (TFRI) articulated the urgency for public conversations concerning critical issues so that the public is prepared for the coming personalized medicine world in which “genomics is really underwriting risk, health, treatment, and prognosis.” He pointed to a published talk by *Globe and Mail* public health reporter André Picard that described the need for media to present debates about health accurately and at a level the public can understand, and to promote scientific literacy within the public.

Central to any conversation regarding personalized medicine is access to tissue and biosamples. Having patient consent is vital, so that relevant personal information from the patients is available for health care professionals having to make decisions. “We are nowhere near that at the present moment ... and we haven’t really come to terms with what is necessary [about] information and its usage to actually fuel and facilitate personalized medicine.”

Sutcliffe predicted that personalized molecular medicine will be driving health care decisions within 5 years and that, within 10 years, it “will be a violation of human rights if we don’t make it available to patients who expect it from us.” The time is not very far away when genomics will affect the lives of individuals in various ways, influencing their choices and decisions, he said.

Sutcliffe also pointed to computerization and the advent of the Information Age as an example of a change that is having the kind of societal impact that personalized medicine is expected to have. Comparing progress in genomics and molecular medicine with the progress of the computer era, he explained that the “hardware” is now available: the science and technology for the \$1000 genome workup exists. Personalized medicine is now at the stage that the computer industry reached in the ’70s, ’80s, and ’90s, discussing applications of the technology and related issues such as speed, size, portability, and user friendliness. “It was 70 years from the [first

computer hardware] to a social network that owned the Internet and owned the language of information technology,” Sutcliffe remarked.

Will it take 70 years for molecular medicine to fully take hold? Whether it will or not, it is imperative to begin thinking now about how to manage when it does. “We will have to get pretty focused now and say, ‘Across society, across patients, public, providers, we’ve got to start thinking. What are the decisions we have to start putting into place that will cause molecular medicine to actually be a key piece, an integral piece, not only of how we practise, but a part of our social fabric?’”

~

Personalized medicine is about applying health and illness interventions according to unique, personal attributes, including genes and environment. The science and technology is here now. Where we lag is in our readiness for application, implementation, and personalization of resource allocation for the practice of personalized medicine.

~

5. SUMMARY

In summarizing the sessions, dialogue moderator Dr. Verna Skanes (MUN) noted how forums such as these—and maybe forums in other parts of the health care system—are needed so that collaboration among health professionals in Atlantic Canada will become more frequent and promote provision of the best health care for citizens. More thinking is also required about further collaboration between provinces. Additionally, more “outside the box” thinking is needed—specifically, “How can things be done more efficiently than in the past?”

Participant feedback supported such actions. The dialogue “underlines the need for mutual cooperation for all,” remarked one attendee. Said others, “We have lots of work ahead of us.... [We need] more talk on the importance of access to specialized cancer care.” “It made me realize how much more change needs to take place.” “We may be missing opportunities [for prevention] and [for mobilization of] community resources because of a focus on individualized specialized care.”

Will these discussions result in change? The dialogue has begun. This conversation implores us to listen to diverse viewpoints; to make important and hard decisions sooner rather than later; to respect and consider the needs of the individual patient always, but within the context not only of what is best, but what is right, fair, and sustainable for current and future generations; and to achieve the goal of delivering the best care—with the best possible outcome—to every patient.

Thirty years ago, young Terry Fox showed us just what is possible if we try. It is up to each of us, as Mahatma Gandhi is reported to have said, to be the change we wish to see in the world.

~

To view the complete remarks of the session leads and panellists, please visit www.tfri.ca/dialogues.

Correspondence to: Kelly Curwin, The Terry Fox Research Institute, 675 West 10th Avenue, Vancouver, British Columbia V5Z 1L3.

E-mail: kcurwin@tfri.ca

* The Terry Fox Research Institute, Vancouver, BC.

† Atlantic Dialogue co-chairs.