



# TRAUMATIC BRAIN INJURY RESEARCH PARTNERSHIP

## Business Plan

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## I. ACKNOWLEDGEMENTS

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Members of the Steering Committee:

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## II. GLOSSARY OF TERMS AND ACRONYMS

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### **Traumatic Brain Injury**

The Brain Repair Centre defines traumatic brain injury (TBI) as being caused by an external force such as a collision, fall or assault that produces a change in the central nervous system's structure and/or functions, including the spinal cord. TBI is a subset of acquired brain injury (ABI) which refers to temporary or permanent brain damage or dysfunction occurring after birth.

### **Traumatic Brain Injury Research Partnership (TBIRP)**

The Traumatic Brain Injury Research Partnership is an interdisciplinary collaboration of researchers, clinicians, TBI survivors and their families, and other collaborators who come together for the purposes of engaging in specific research related to traumatic brain injury. Other terms that have been used to describe the TBIRP are TBI program, initiative and cluster.

### **Five-Pillar Continuum**

The five-pillar continuum includes prevention and public health, pre-hospital, acute care, inpatient and outpatient rehabilitation, and concludes with the TBI survivor's integration into their community.

### **Types of Research**

There are four types of research to be carried out by the TBIRP:

- Bench / basic – also called fundamental research relates to scientific research aimed to improve scientific theories for improved understanding or prediction of natural or other phenomena.<sup>1</sup>
- Pre-clinical - is a stage of research that begins before clinical trials (testing in humans) can begin, and during which important feasibility, iterative testing and safety data are collected. Products may include new medical devices, drugs, gene therapy solutions and diagnostic tools.<sup>2</sup>

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<sup>1</sup> Wikipedia / [https://en.wikipedia.org/wiki/Basic\\_research](https://en.wikipedia.org/wiki/Basic_research)

<sup>2</sup> IBID / [https://en.wikipedia.org/wiki/Pre-clinical\\_development](https://en.wikipedia.org/wiki/Pre-clinical_development)

- Clinical - determines the safety and effectiveness (efficacy) of medications, devices, diagnostic products and treatment regimens intended for human use.<sup>3</sup>
- Health, Social Sciences, Epidemiology and Policy – covers a wide range of disciplines that typically use qualitative and quantitative research methods and could include psychology, sociology, public administration, economics, and funding, organization, and delivery of healthcare. Research project involve population-based studies that describe various elements and characteristics of the illness, evaluate or compare the efficacy of program delivery models and seek to understand the patient’s experience and satisfaction at different phases of the care continuum.

**Knowledge Translation**

Knowledge translation (KT) is defined as a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system.<sup>4</sup>

**Formal Care Providers**

Include numerous health professions who comprise a formal healthcare system and are paid to deliver various types of care, services and programs including prevention, diagnosis, specialized and ongoing treatment and rehabilitation at different points along a continuum of care.

**Informal Caregivers**

Family, friends, or volunteers who provide unpaid assistance and support with various activities of daily living tasks such as transportation and personal care to persons who need ongoing support, such as TBI survivors, to remain in their own homes and community-based residential settings (Adapted from Turner & Findlay, 2015).<sup>5</sup>

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<sup>3</sup> IBID / [https://en.wikipedia.org/wiki/Clinical\\_research](https://en.wikipedia.org/wiki/Clinical_research)

<sup>4</sup> Canadian Institutes for Health Research (CIHR) / <http://www.cihr-irsc.gc.ca/e/29418.html#2>

<sup>5</sup> Adapted from Turner & Findlay, 2015

## Societies / NGOs

Societies/NGOs are non-governmental organizations that are independent from government. They are often funded by donations but some avoid formal funding altogether and are run primarily by volunteers. NGOs are highly diverse organizations engaged in a wide range of activities, and take different forms in different parts of the world. Some may have charitable status, while others may be registered for tax exemption based on recognition of social purposes. Many are founded on the basis of political, religious, or other special interests such as diseases and disabilities<sup>6</sup>

## Interdisciplinary

Describes [research] studies that use methods and insights of several established disciplines or traditional fields of study to pursue knowledge; applied to complex topics that can only be understood by combining the perspectives of two or more fields; requires insights from diverse disciplines to solve complex problems [such as TBI].<sup>7</sup>

## Glossary of Terms

ABI – Acquired brain injury  
BRC – Brain Repair Centre  
BIANS - Brain Injury Association of Nova Scotia  
CIHR – Canadian Institutes of Health Research  
CIHI – Canadian Institute of Health Information  
CHEB – Collaborative Health Education Building, Dalhousie University  
DHW – Nova Scotia Department of Health and Wellness  
FoM – Dalhousie Faculty of Medicine  
INMHA - Institute of Neurosciences, Mental Health and Addiction, CIHR  
InTBIR - International Initiative for Traumatic Brain Injury Research  
IWK – IWK Health Centre  
LAE – Nova Scotia Department of Labour and Advanced Education  
NCE – Networks of Centres of Excellence  
NSCC – Nova Scotia Community College  
NSHA – Nova Scotia Health Authority

<sup>6</sup> Adapted from Wikipedia [https://en.wikipedia.org/wiki/Non-governmental\\_organization](https://en.wikipedia.org/wiki/Non-governmental_organization)

<sup>7</sup> Adapted from Wikipedia <https://en.wikipedia.org/wiki/Interdisciplinarity>



NSHRF – Nova Scotia Health Research Foundation  
NSERC- Natural Sciences and Engineering Research Council  
PI – Principal Investigator  
SSHRC - Social Sciences and Humanities Research Council  
TBI – Traumatic Brain Injury  
TBIRP – Traumatic Brain Injury Research Partnership

### III. EXECUTIVE SUMMARY

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#### Background

Traumatic brain injury (TBI) survivor Peter Covert, along with his friend and supporter, Ken Nason, approached the Brain Repair Centre (BRC) in January 2014 with a vision for improving the lives of TBI survivors. TBI is the major cause of temporary and long term disability in industrialized and developing countries.<sup>8</sup> Based on extrapolated Canadian data, more than 5,000 Nova Scotians sustain a TBI annually, accounting for estimated costs of nearly \$75 million for healthcare services, \$115 million in lost productivity, and several millions of dollars for informal caregiver costs and out-of-pocket expenses. The social and long term implications of TBI are enormous and with an aging population, increased survival rates and longer life spans, the economic burden of TBI over the coming years will only be exacerbated.

With TBI survivor participation and in partnership with experts (researchers, clinicians and service providers) across several disciplines, non-governmental organizations (NGOs), and government, the BRC developed a patient-centric, inter-disciplinary and collaborative research model that aims at influencing prevention policies for all Nova Scotians and improving outcomes for TBI survivors.

#### Key Considerations

The context within which this plan has been developed includes some of the following key considerations:

- TBI research is an emerging priority globally, nationally and in NS.
- In line with the recent Federal Science Review panel findings, this model is poised to address the need to strengthen the foundations of Canadian research.
- TBI research is complex, and multi-faceted as our approach details in this document. As well, there are challenges to fit its scope within the requirements of a typical project specific call for research proposals funded by Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council (NSERC), and Social Sciences and Humanities Research Council (SSHRC).
- Funding larger scale and inter-disciplinary projects is challenging. Funding models such as CIHR are predominately investigator driven. Large scale projects such as Networks of Centres of Excellence (NCEs) and consortia driven initiatives are often funded through specific, one time calls, or on a four-year cyclical basis.

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<sup>8</sup> Humphreys, J, Wood, R.L., Phillips, C. J., & Macey, S. (2013). The costs of traumatic brain injury: a literature review, *ClinicoEconomics and Outcomes Research*, 2013:5 281–287



- The proposed model concept is unique both in terms of public policy and operationally. The model promotes patient driven research projects, and exploits and capitalizes on existing talent and facilities to bring the concept of a living laboratory to the fore.

Mounting concern for TBI is evident in NS given demographic and other trends identified previously, and the presence of high risk industries and the military. In addition, contact and other sports, motor vehicle accidents and falls are significant contributors to TBI. These factors, combined with the small size of the population and existing research expertise within the 11 universities that includes acute care treatment and rehabilitation capability, positions NS as an “ideal living laboratory”. What’s at stake is prevention of TBI and improvement of the lives of TBI patients in NS and elsewhere. In addition, a rationalized model encompassing all aspects of our healthcare system is a desirable outcome.

### **Traumatic Brain Injury Research Partnership Model**

**Mission:** Enabling research from TBI prevention through community integration for three levels of injury (mild, moderate and severe) in an inter-disciplinary, collaborative and patient-centered environment. Research will be conducted across a five-pillar continuum that includes:

- prevention and public health;
- pre-hospital treatment;
- in-hospital acute care;
- inpatient and outpatient rehabilitation; and
- community integration.

**Vision:** Transforming TBI outcomes for Nova Scotians by enabling excellence in prevention and post-injury research.

**Four strategic priorities** that will guide the TBIRP:

1. **Research** - Leverage the BRC’s research expertise to enhance the lives of Nova Scotians with traumatic brain injuries.
2. **Education** - Facilitate education, training and knowledge exchange opportunities.
3. **Partnerships** – Cultivate and maintain partnerships to enhance the TBIRP, including: clinicians and other health and social service providers, government, academia, industry, societies/ NGOs, patient networks, funders, and other brain research centres.
4. **Capacity and Sustainability** - Build capacity, infrastructure and financial support to successfully launch and sustain the TBIRP.



The TBIRP will be led by a Program Director who will work with four research teams engaging in a range of research including: basic/bench; pre-clinical; clinical; and health, social services, epidemiology and policy. Ideally the TBIRP could be housed in the Collaborative Health Education Building (CHEB) located on the Dalhousie campus and in close proximity to the hospitals and the rehab centre. The funding requirement for this business plan is \$25,000,000 over five years with an assumption that there will be four Endowed Research Chairs each with \$3,000,000.

The next steps include the BRC spearheading efforts with stakeholders to achieve the vision of transforming outcomes for Nova Scotians and TBI survivors by enabling excellence in prevention and post-injury research in our 'living laboratory' environment.

# 1. INTRODUCTION

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## BACKGROUND

Traumatic brain injury (TBI) survivor Peter Covert, along with his friend and supporter, Ken Nason, approached the Brain Repair Centre (BRC) in January 2014. Based on his experiences over the last almost 50 years, coupled with his untiring advocacy for this “community”, Peter had a vision for improving the lives of TBI survivors.

Worldwide, TBI is the leading cause of death and disability and as a result many years of productive life are lost. By the mid 2000s, the World Health Organization recognized the importance of TBI as a global public health challenge. Survivors often endure years of disability in varying degrees depending on the severity of their injury. This is largely attributed to improvements to pre-hospital and acute care. As Peter so often reminded us, TBI survivors require a comprehensive and holistic approach which supports their return to their communities as fully participating citizens.

TBI is a complex disability and survivors need individualized care plans and services built upon evidence-informed practices. Consequently, inter-disciplinary research is necessary comprised of team members from multiple disciplines who bring specialized expertise where the aim is to improve patient outcomes through excellence in research. Epidemiological and health services research is also necessary to assist in tailoring and targeting effective preventive programming where the overall goal is to reduce the occurrence of TBI.

The BRC spear-headed the development of a partnership and, together with experts (researchers and clinicians) across several disciplines, NGO’s, and government, and always with Peter Covert and Ken Nason prodding and clarifying, created a model for achieving better outcomes for TBI survivors and Nova Scotians in general. What transpired became known as the Traumatic Brain Injury Research Partnership (TBIRP). It will facilitate inter-disciplinary collaborations among basic researchers, clinicians, social scientists, government, industry and community. Its raison d’etre includes a continuum from prevention through to post-injury research to return brain injury survivors to a full and meaningful life. Support to develop this business model came from the Nova Scotia Department of Health and Wellness (DHW), and ultimately the necessary funding was provided by the Nova Scotia Department of Labour and Advanced Education (LAE).

The BRC is largely a neuroscience research institute. However, through initiatives such as the TBIRP, the BRC has been providing leadership through developing a strategy including policies and plans to establish this business model. It has and will continue to act as a hub that unites and connects the TBI “community” –including researchers, clinicians, patients, government, service providers, the private sector, societies, etc.— to build understanding and support for the TBIRP business model. With the TBIRP, the BRC is initiating a patient-centric, collaborative, inter-disciplinary model that includes research across a five-pillar continuum: prevention and public health, pre-hospital, in hospital acute care, inpatient and outpatient rehabilitation, and community integration.

## **ALIGNMENT WITH DALHOUSIE, NOVA SCOTIA AND FEDERAL GOVERNMENT PRIORITIES**

### **Dalhousie University**

Dr. Richard Florizone, the President of Dalhousie University, has identified that his success will depend on the extent to which new initiatives will advance the university’s core mission of teaching, research and community service. This business plan builds on the President’s criteria for his vision by creating a traumatic brain injury (TBI) research cluster consisting of Endowed Research Chairs through attracting new investments to the BRC. Funding will also be sought to further the teaching and community integration components through programs including knowledge translation and dissemination of research to promote best practices, to educate patients and the public, and to train emerging researchers. Further, this inter-disciplinary, patient-centric collaborative TBIRP research enterprise is also in alignment with Health and Wellness, one of Dalhousie’s four priority research areas.

Recently, Dalhousie’s Faculty of Medicine completed a strategic plan – *DalMedForward*. The BRC was identified as one of two innovative initiatives that “lead their fields in Canada and around the world”.<sup>9</sup> Building on this recognition, the collaborative research model for the TBIRP falls in line with the priority initiatives outlined in the Faculty’s plan where the success of the TBIRP will enhance the Faculty’s profile in traumatic brain injury.

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<sup>9</sup> Dalhousie University Faculty of Medicine; *DalMedForward* 2016 -2020, page 2.

## Nova Scotia Government

*Now or Never*<sup>10</sup>, a report on the Nova Scotia economy released in 2014, positioned post-secondary institutions as anchors for regional economic and social development through fostering partnerships and creating environments built on collaboration and innovative research solutions. As the TBIRP unfolds we have aspirations that by attracting research dollars from industry, foundations, donors, and others, Dalhousie TBI researchers will be leaders in finding solutions, products and approaches to improve outcomes and curb the upward trend in incidents of TBI's in Nova Scotia and elsewhere.

The Nova Scotia Department of Labour and Advanced Education, through its stated objectives in the 2016-2017 Business Plan, will foster innovation through research and development. Further, it has identified that it will facilitate the creation of a provincial R&D strategy to effectively bridge the gap between the current state of Nova Scotia's R&D capacity and the commercialization of R&D. The TBIRP could be specifically referenced as a model to accomplish these objectives.

Additionally, the Nova Scotia Department of Health and Wellness formed an Acquired Brain Injury Advisory Group in 2015 to fulfil its commitment to help brain injury survivors.<sup>11</sup> The Honourable Leo Glavine, Minister of Health and Wellness stated that "the government will develop a strategy aimed at improving long-term support services for those with acquired brain injuries."<sup>12</sup> Leona Burkey, the Executive Director of the Brain Injury Association of Nova Scotia, who is the Co-Chair of this group stated, "While we have high-quality medical services in the province, we must do more to help survivors' recovery and their return to a productive life."<sup>13</sup>

## Concussion – A Federal Government Initiative

The Federal government has recognized "concussions are a serious public health issue" and that public education is one strategy to counteract the rising incidence through school teams, community sports, and recreation settings.<sup>14</sup> Nova Scotia has been a leader in

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<sup>10</sup> Nova Scotia Commission on Building Our New Economy. (2014). *Now or Never: An Urgent Call to Action for Nova Scotians*.

<sup>11</sup> Acquired Brain Injury Group Announced; Health and Wellness; November 6, 2015 11:41 AM

<sup>12</sup> Nova Scotia to address gaps in care for brain injuries, health minister says; THE CANADIAN PRESS; Published October 16, 2014 - 2:51pm

<sup>13</sup> Acquired Brain Injury Advisory Group Announced. Nova Scotia Department of Health and Wellness News Release, November 6, 2015.

<sup>14</sup> Government of Canada (2016). Statement by Ministers Qualtrough and Philpott on "We Can Do Better: The Governor General's Conference on Concussions in Sport", News Release, December 6, 2016

advocating for helmet use by cyclists and skiers through creating solid research evidence to support this public policy decision. We expect the TBIRP will build on this success to improve prevention efforts alongside improvements in clinical care.

Taken together, the aligned priorities across academia and governments, coupled with the increasing emphasis on concussion management by governments and others, and adding in the rising incidence of TBI alongside the challenges of being a TBI survivor, point to the need for a TBI research cluster under the BRC.

## OUR APPROACH TO FORMING A TBI RESEARCH CLUSTER

The BRC determined it needed to develop a business model in response to Peter Covert's concept of getting individuals back on track with their lives. Together with Peter, Ken Nason and the BRC, a notional working model was designed. As the BRC was already receiving its operational funding from LAE, it first approached this department for funding to support the project. LAE agreed with the caveat that the BRC obtain support in principle from the Department of Health and Wellness (DHW). Coincidentally, the BRC was an active participant on DHW's ABI Strategy. Hence, the request was sent to DHW and support received for the TBIRP. The project was launched after developing a RFP. Halifax Global Inc. was the successful bidder and subsequently hired to assist in the TBIRP business model development.

In order to design a TBI research cluster within the BRC, we used various methods to collect and analyse information about programs nationally and internationally. We gathered practices and lessons from selected TBI peer literature and reports. We tapped into existing research expertise within the BRC. We sought input through roundtable discussions and interviews. The analytical phase of this project involved consolidating these findings from the following data collection efforts to provide the foundation for this plan.

- Two roundtable discussions with 34 stakeholders including BRC researchers, NSHA clinicians, service providers and government officials;
- Creation of an inventory of researchers and clinicians involved in TBI research activities at Dalhousie, Nova Scotia Health Authority and IWK Health Centre;
- Environmental scan and review of 14 Canadian, US and international brain research and clinical treatment centres;
- Compilation of TBI statistics worldwide, for Canada and for Nova Scotia from various sources including: QE II Emergency Department Information System (EDIS) database and the NS Trauma Program's poster entitled *Characteristics and patterns of major trauma brain injury in Nova Scotia: a 13-year retrospective analysis*;

- Review and interpretation of selected literature on TBI including economic impact of health expenditures and costs from lost productivity due to temporary and permanent disability;
- Telephone interviews with four Canadian university-affiliated TBI research centres; and
- Consultation with the Medical Neuroscience Department, Faculty of Medicine, Dalhousie University to obtain technical input regarding start-up and ongoing Traumatic Brain Injury in Context

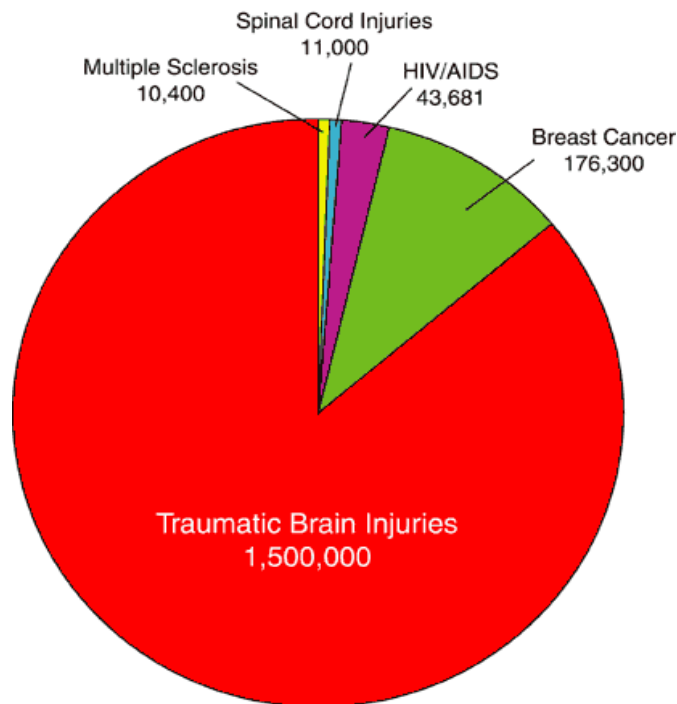
## 2. TRAUMATIC BRAIN INJURY IN CONTEXT

### SOCIODEMOGRAPHIC CHARACTERISTICS OF TBI

#### The Worldwide View of TBI

TBI is the major cause of temporary and long term disability in industrialized and developing countries (See Appendix A for global, Canadian and NS statistics). TBI has long lasting effects and is defying conventional treatment because of its heterogeneity and complexity as a central nervous system disorder.<sup>15</sup> As the following chart shows, the annual incidence of TBI (based on US data) is many times greater than that of Multiple Sclerosis, Spinal Cord Injury, HIV/AIDS and Breast Cancer combined.<sup>16</sup>

Comparison of Annual TBI Incidence in the United States



<sup>15</sup> Humphreys, J, Wood, R.L., Phillips, C. J., & Macey, S. (2013). The costs of traumatic brain injury: a literature review, *ClinicoEconomics and Outcomes Research*, 2013:5 281–287

<sup>16</sup> Compiled and arranged by the Brain Injury Association of America based on data from the Centers for Disease Control and Prevention, American Cancer Society and National Multiple Sclerosis Society



A conservative estimate by the WHO in 2006<sup>17</sup> reported the annual incidence (occurrence) of TBI at 600 cases per 100,000 persons for Europe and North America. However, the degree of injury severity varies widely, with an estimated 11 severe cases and 600 mild cases per 100,000. Two thirds of those affected are young males and, as well, rising injury rates for children and older women are of concern.

The three main causes of TBI are motor vehicle accidents (MVAs), falls and violence, however, their relative importance varies among countries. While the prevalence (i.e., number of persons living with TBI) is not well documented, estimates from the United States research suggests one to two percent of the population lives with a TBI disability. Lifetime costs of a severe TBI survivor are approximately \$6.7 million (US dollars).

The US research has focused on documenting health care usage patterns among those with a TBI or concussion related injury. In 2009, population-based studies in the US estimated that 248,418 children (age 19 or younger) were treated in Emergency Departments (EDs) for sports and recreation-related injuries that included a diagnosis of concussion or TBI. Between 2001 to 2009, the rate of ED visits for these sports and recreation-related injuries rose 57 percent for those 19 years and younger. Hospitalization rates only increased by 11 percent and death rates decreased by 7 percent. Among non-fatal TBI-related injuries men had higher rates of TBI hospitalizations and ED visits than women. There were higher rates of use of healthcare services by persons aged 65 years and older.<sup>18</sup> Of consequence, are the implications of these findings for direct healthcare expenditures which given the rising rates of use for younger and older persons could result in a significant burden to society.

## TBI in Canada

The research documenting the incidence of TBI in Canada is emerging and, a study by Caro<sup>19</sup> estimated that 192,000 people were affected by TBI in 2010, as illustrated in Appendix A. According to Dr. Michael Cusimano,<sup>20</sup> TBI accounts for the third-highest number of

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<sup>17</sup> World Health Organization. (2006). Chapter 3.10 Traumatic brain injuries in *Neurological disorders: public health challenges*.

<sup>18</sup> [https://www.cdc.gov/traumaticbraininjury/get\\_the\\_facts.html](https://www.cdc.gov/traumaticbraininjury/get_the_facts.html)

<sup>19</sup> Caro, Denis HJ (2011) Traumatic Brain Injury Care Systems: 2020 Transformational Challenges, *Global Journal of Health Science*, 3 (1); 19-29.

<sup>20</sup> CIHR Institute of Neurosciences, Mental Health and Addiction (2012). *New Opportunities in Traumatic Brain Injury Research: Advancing the National Agenda Workshop Report Toronto ON April 12-13, 2012*

hospital days in Canada. There is increasing evidence that multiple mild TBIs may predispose patients to early onset dementia, later substance-use disorders and mental illness.

One trend that will have a major influence on Canada is the rising proportion of TBI's in elderly people. WHO (2006) data has shown that falls are a leading cause of death and hospitalizations for this population. While reliable, specific data on the financial costs of TBI are lacking, falls cost the Canadian economy about \$7 billion each year, with direct costs from TBI estimated at about \$151 million.<sup>21</sup> More recently, the federal government has expressed concern about the acute and long-term risk factors associated with youth and sports-related concussions.<sup>22</sup>

### The Nova Scotia Picture

Data about incidence in NS was gathered from various sources highlighted in Appendix A. Currently, the best available evidence to compile an epidemiological profile for TBI in NS is a 2014 *Annual Report of the NS Trauma Program*<sup>23</sup> and a study by Green et al (2016).<sup>24</sup> Key findings from these sources are:

- TBI is a significant cause of mortality and morbidity in NS.
- Incidence of TBI over a period of time (2002-2015) increased with age and was highest in the  $\geq 60$  age group, as was TBI-related mortality.
- The highest percentage of all hospitalized trauma cases (n=5816) and major trauma cases (n=1051) were aged 65 years and older.
- In patients under 40 years of age, many TBIs were due to MVAs.
- Falls were the most common mechanism of injury in patients aged  $\geq 40$  years.

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<sup>21</sup> Finès, P. (2015). Estimating costs of health care for neurological conditions in Canada in 2031, Presentation to the Health Analysis Division, Statistics Canada, slide 33

<sup>22</sup> Government of Canada (2016). Statement by Ministers Qualtrough and Philpott on "We Can Do Better: The Governor General's Conference on Concussions in Sport", News Release, December 6, 2016

<sup>23</sup> Provincial Data Summary from Nova Scotia Trauma Program (2014). Trauma Registry Report on Injury in Nova Scotia Provincial Report for Data Year 2012-13

<sup>24</sup> Green, R., Kureshi, N., Fenerty, L., Thibault-Halman, G., Erdogan, M., Walling, R., & Clarke, D. (2016). *Characteristics and patterns of major traumatic brain injury in Nova Scotia – a 13 year retrospective analysis.*

- Rates of TBI varied across provincial geographic locations, ranging from 65.4 injuries (Victoria County in Cape Breton) to 24.5 injuries (Shelburne County) per 100,000 NS population (see map in Appendix A).

As these trends illustrate, TBI is an important policy issue for NS. We decided to pictorially represent the socioeconomic implications for NS. Using Caro's (2011)<sup>25</sup> estimate of 192,000 people in Canada being affected by TBI various incidence rates were calculated for Nova Scotia as shown in the snapshot found in Appendix B. These data were subsequently used to forecast the economic cost of TBI in NS described in the next section.

The snapshot illustrates the profile of TBI injuries in NS for 2010 and in particular these cases have the potential to consume different types of healthcare and other community-based services contingent on the severity of TBI injury:

- There were 5,378 new cases with varying degrees of TBI severity:
  - 4,840 mild cases, some of which involved EHS transport or walk-in visits to EDs or family physicians;
  - 376 moderate cases, many of which involved EHS transport or walk-in visits to EDs; and
  - 161-269 severe cases, all of which involved EHS transport to EDs and some admissions to in-patient hospitalization or follow-up healthcare such as rehabilitation, etc.
- There were 18,760 Nova Scotians living with TBI (which BIANs considers to be a conservative estimate).
- Of the estimated 5,378 new cases in NS with varying degrees of TBI severity:
  - 4,424 ED visits are projected;
  - 896 hospitalizations are projected; and
  - Of the hospitalized TBI survivors, 238 cases will be either temporarily or permanently disabled (and subsequently add to the prevalence of Nova Scotians living with TBI).

## ECONOMIC IMPACT FOR NOVA SCOTIA

It is clear the sociodemographic trends for TBI and the concomitant use of healthcare services and other types of supportive care including ongoing rehabilitation have economic consequences for the government of NS. The consequences of a TBI event can have

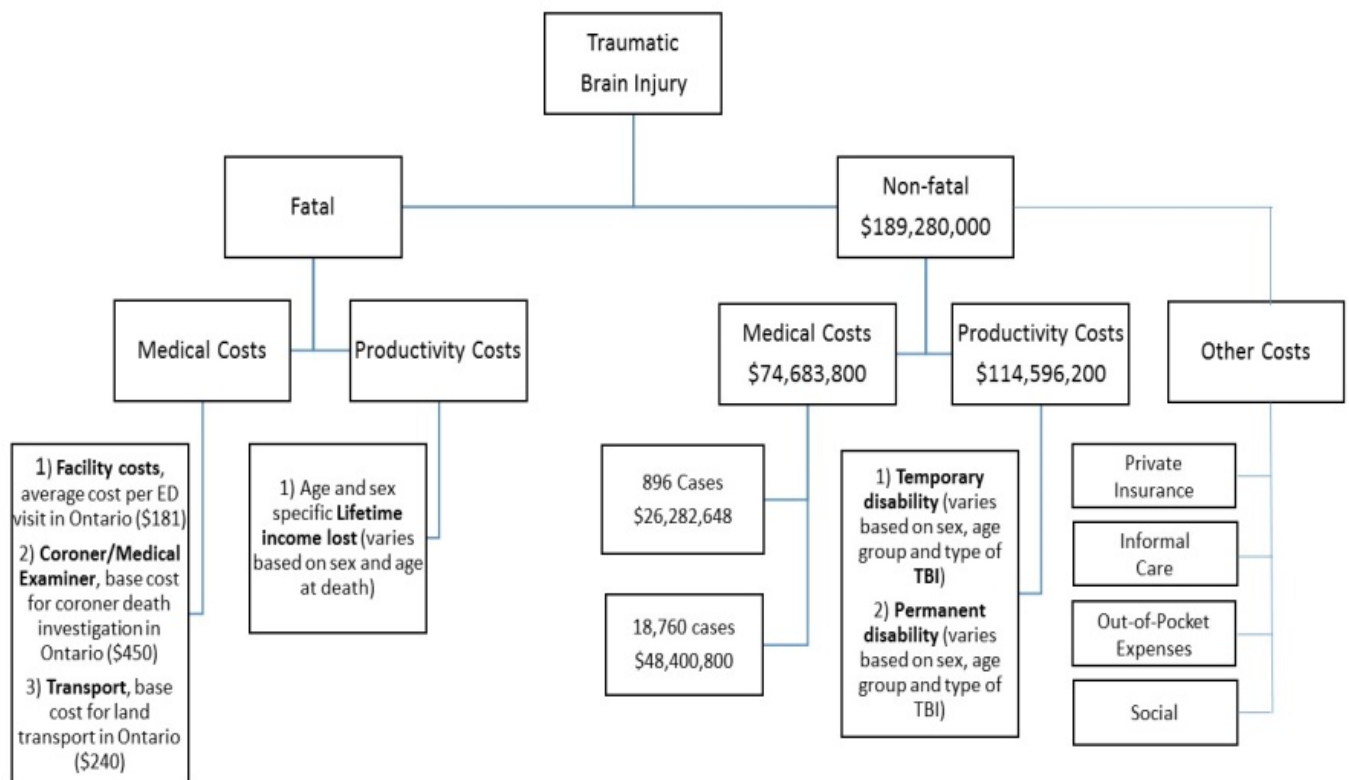
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<sup>25</sup> Caro, Denis HJ (2011) Traumatic Brain Injury Care Systems: 2020 Transformational Challenges *Global Journal of Health Science*, 3 (1); 19-29.

significant impact on the lives of survivors and their families as more and more individuals survive brain injuries with the advent of new emergency medicine and acute care treatments.

The following diagram illustrates projected annual costs for both new and ongoing TBI cases in Nova Scotia based on the 2010 incidence. These expenditures include estimates of spending by the provincial government for in-hospital acute care and follow-up treatment for a TBI as well as productivity costs due to lost income from temporary and permanent disability resulting from a TBI.

### Nova Scotia Cost Estimates for TBI Cases\*



\*Diagram is adapted from Fu et al (2016).

There are substantial costs incurred during the first and subsequent years following a TBI. For example, healthcare services used by TBI survivors include expenditures for acute care, physician and emergency department visits, inpatient and outpatient rehabilitation and home care.<sup>26</sup> Detailed cost estimates based on the Care (2011) data are shown in Appendix C.

These projected expenditures for NS include only those paid through public sector or government spending. These do not include costs paid by private insurance or out-of-pocket by patients. In addition there are costs related to informal caregiving involving the in-kind time contributed by families, friends and volunteers who provide ongoing support to TBI survivors. While the spending on formal healthcare delivered to TBI survivors is substantial coupled with the unknown cost of informal caregiving, the WHO is equally concerned about the rising societal costs resulting from lost income due to permanent or temporary disability.<sup>27</sup>

The economic burden for NS appears to be substantial as the following 2010 government spending projections demonstrate:

- In 2010, non-fatal TBIs cost the province of NS \$189,280,000.
- Annual spending of \$74,683,800 for healthcare services to TBI patients and survivors. To put this in perspective, the total 2016 – 2017 budget for the Nova Scotia Department of Health and Wellness is \$4.1 billion<sup>28</sup>, representing 46% of the total government budget.<sup>29</sup>
- The estimate for lost productivity is calculated at \$114,596,200.

## RESPONDING TO THE NEED – THE TBIRP OPPORTUNITY

### Dalhousie TBI Research Capacity

Our inventory identified that approximately 30 scientists are either currently engaged in brain-related research or interested in pursuing TBI-research. We documented numerous pockets of TBI expertise within the following research categories: basic/bench; pre-clinical;

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<sup>26</sup> Chen, A., Bushmeneva, K., Zagorski, B., Colantonio, A., Parsons, D., & Wodchis W. P. (2012). Direct cost associated with acquired brain injury in Ontario. *BMC Neurology*, 12:76 -87

<sup>27</sup> World Health Organization. (2006). 3.10 Traumatic brain injuries in *Neurological disorders: public health challenges*.

<sup>28</sup> Business Plan 2016 – 2017, Nova Scotia Department of Health and Wellness; p. 6

<sup>29</sup> Canadian Institute for Health Information (2016). *National Health Expenditure Trends, 1975 to 2016*; p. 20

clinical; and health, social sciences, epidemiology and policy. Furthermore, some capacity is already present across the five pillar continuum:

- **Prevention and Public Health:** Nova Scotia researchers at the IWK Child Safety Program and QE II Neurosurgery Department have been at the forefront of prevention and advocacy studies resulting in the use of helmets for children, adolescents, and adults in biking, skating and skiing. Wearing a helmet while biking became mandatory in NS through the advocacy effort from research conducted by Dr. David Clarke and others.
- **Pre-hospital:** The QE II Emergency Department through the EDIS and the NS Trauma Program are in early stages of profiling the occurrence of TBI (refer to Green et al, 2016). Neuroscientists including Rafuse and Friedman are located in the Faculty of Medicine.
- **Acute care:** QE II Neurosurgery involves BRC member, Dr. David Clarke and others; Dr. Clarke is also a co-investigator with the Canadian Traumatic Brain Injury Research Consortium; Trauma physicians at the IWK and QE II, NS Trauma Program in conjunction with Diagnostics at the IWK and QE II have conducted brain-related research.
- **Inpatient and outpatient rehabilitation:** Faculty of Medicine as well as at the Faculty of Health Professions and healthcare providers such as the Rehabilitation and Supportive Care, and Continuing Care Divisions, and Vocational Program under the Nova Scotia Health Authority are sponsoring TBI research aimed at improving quality and patient safety.
- **Community integration:** Faculty researchers in the Community Health and Epidemiology Department and the Maritime Strategy for Patient-Oriented Research (SPOR) unit have epidemiological and health services research expertise.

### Capitalizing on “Location, Location, Location” – Our Living Laboratory

Our round tables were the first opportunity that such a span of expertise was convened locally around the theme of traumatic brain injury. With some 34 participants in attendance, it was a demonstration of the rich and diverse perspectives that can be brought to bear on a particular subject matter (TBI) using an inter-disciplinary, collaborative approach.

This was possible because of the existence and proximity of research on trauma care, acute care, and rehabilitation services at Dalhousie. In addition, these representatives from the following agencies, groups and interested parties involved in our round tables recognised the uniqueness of the opportunity and would likely continue their involvement in some capacity in our TBI research enterprise:

- **Provincial government:** Disabled Persons Commission, Chief Public Health Officer and various departments such as Health and Wellness, and Labour and Advanced Education
- **Service providers:** NSHA rehabilitation centre; home and continuing care, employment support agencies
- **Federal government:** Public Health Agency of Canada, Health Canada, Department of National Defense, Veterans Affairs
- **Industries:** including those associated with rising TBI injuries such as construction
- **Non-government organizations:** BIANs, Sports NS and others.

### **TBI Research in Canada and Internationally**

A review of 14 TBI research programs in Canada, the US and internationally shows there is variation in structure and focus including: free standing; government and independently governed; university / subset of a faculty; and military led, for example. The research focus in these programs includes either a TBI concentration or TBI research embedded within an overarching neuroscience perspective.

There were two program models: university based research centres (dedicated knowledge creator) and research integrated with TBI care delivery (hybrid model). The promising practices gleaned from these were used as a guide in developing the operational model for the TBIRP and related programs. Our research also revealed several national initiatives and organizations focused on advancing knowledge about TBI.

Further, it appears that while there is important TBI research being conducted across Canada, we learned there is no overarching strategy to connect and develop comprehensive capacity with identified expertise across the continuum of care that TBI patients navigate. It became clear that opportunities for research partnerships across the country would be desirable. Our strategy, from a policy perspective, could also provide a framework to better coordinate and target research activities.

Phone interviews were conducted with selected TBI researchers from McGill University, Hotchkiss Brain Institute, University of British Columbia (UBC), and the Toronto Rehabilitation Institute. We learned that collaboration among Canadian TBI university researchers and clinical scientists is evolving; however, to date it appears there is limited participation by researchers from Dalhousie and other Atlantic Canada universities. A TBIRP will consolidate the research expertise at Dalhousie and offer visibility, as well as provide a platform from which to strengthen national and international collaborations.



According to its website, the Institute of Neurosciences, Mental Health and Addiction (INMHA) is one of 13 Canadian Institutes for Health Research (CIHR) and is the foremost advocate for research funding for TBI at the Federal level. Through the CIHR and the INMHA, Canada has formed an alliance with several stakeholders, including the Ontario Neurotrauma Foundation, the Hotchkiss Brain Institute, and the Fond de recherche du Quebec – Santé who have jointly established a Canadian TBI initiative that is connected with InTBIRP, an internationally funded program of research.

The Canadian Traumatic Brain Injury Research Consortium formed in January 2016, is comprised of a large contingent of Canadian scientists led by Drs. Jamie Hutchison and Alexis Turgeon. They were awarded \$1,824,513 by CIHR over four years to advance Canadian TBI research capacity. As far as we have been able to ascertain, Dr. David Clarke and perhaps one or two others are the only representatives from Atlantic Canada.

A key learning from our interviews pertained to the Canadian TBI Research Consortium and its focus on developing cross jurisdictional and inter-disciplinary research throughout Canada. In fact, it seems members are developing a proposal to seek long range federal research funding to create a national TBI Network Centre of Excellence (NCE) funded by the federal government NCE Program.

The BRC is well positioned to launch the TBIRP given its track record by neuroscientists who have obtained national research funding from CIHR, NSERC, SSHRC, in addition to funding from the Ontario Neurotrauma Foundation and local funders such as the Nova Scotia Health Research Foundation and Dalhousie Medical Research Foundation.

### **Summarizing Our Findings: Knowledge Needs and Research Gaps in Nova Scotia**

Various gaps were identified through facilitated round table consultations. Discussions with key informants, opinion leaders and committee members throughout the project highlighted challenges of knowledge users. A summary of these includes:

- There are multiple organizations that currently track different data about TBI. This includes the NS Trauma Program and the IWK, in addition to the QE II Emergency Department Information System and administrative data about hospital and physician utilization housed at Health Data Nova Scotia. No single entity has ownership of TBI data and as a result an overall epidemiological picture of TBI for NS is currently not available. These data are not linked, nor are the data standardized. There is no formal agreement to share data among trauma treatment and rehabilitation services and others such as physicians who treat dispersed patient populations throughout Nova Scotia.



- There is limited knowledge about “mild” TBIs and concussions since most patients do not seek treatment at Emergency Departments. Data for those who seek treatment from a family physician are not recorded or analysed through a centralized and standardized TBU patient registry.
- There is no epidemiological or health service use information about special populations affected by TBI such as under-served communities of African Nova Scotians, Indigenous Peoples, or those who are incarcerated or homeless.
- Nova Scotians participating in sports or recreational activities where concussions are predominant are echoing concerns and looking for answers as this issue has been gaining a lot of attention both nationally and internationally.
- One of the round tables included service providers and other NGOs who discussed gaps in knowledge about TBI within their respective practice and policy areas. Opportunities were identified where TBIRP could close these gaps through community-engaged research with the Workers’ Compensation Board of Nova Scotia, sports organizations, and high risk industries that are vulnerable to TBI occurrences such as construction and forestry operations.
- Given the significant military presence in Nova Scotia, much could be learned to help improve outcomes for this population consisting of deployed and retired soldiers and reservists.
- Through our conversations with other Canadian brain research centres we learned about the lack of significant Nova Scotia and Atlantic Canadian involvement with CIHR funded TBI research initiatives.

## CAPITALIZING ON THE BRC’S STRENGTHS TO ADDRESS THE TBI NEED IN NS

### An Established Track Record

The opportunity to contribute “supporting evidence” is the value proposition underpinning a TBI research partnership. TBI research is in a nascent state of evolution at all levels. Consolidating local expertise, connected to national and international initiatives at a time when there is growing demand provides a compelling opportunity for the BRC to contribute to the Faculty of Medicine’s goal of international leadership in health research.

A significant asset associated with establishing a TBIRP at Dalhousie is the 10-year track record of the BRC and its reputation as an established brain research centre. Affiliated scientists have attracted more than \$9 million in external research funding. During the last

three years, numerous researchers have leveraged the BRC knowledge translation grants of \$270 thousand to obtain more than \$3 million in additional research funding.

### **Linking Existing Research and Treatment Expertise**

The BRC is located on the Dalhousie campus across the street from the only adult rehabilitation centre in Nova Scotia, and around the corner from the two largest tertiary care hospitals and trauma centres in the province. Its closest neighbour is Dalhousie's new Collaborative Health Education Building (CHEB), an ideal and optimal location for the TBIRP. The CHEB's primary focus is bringing together clinician scientists and educators from different disciplines and faculties to influence team-based multidisciplinary healthcare. Further, given its location, it is ideally suited to housing a collaborative, inter-professional 'living laboratory' initiative.

### **Leveraging Our Current Capacity**

Already we have several elements of a TBIRP: there is research and clinical TBI expertise across all five pillars in the continuum. These individuals have a track record of securing research funding from both national and provincial granting agencies. While the existing data sources (NS Trauma Program Registry, QEII Emergency Department Information System, Health Data Nova Scotia and the IWK) are independent of one another, one of the first efforts will be to explore how to link them in order to advance the epidemiology of TBI in NS. This will lead to better understanding of the health services offered and related costs, patient navigation needs and experiences, and the role of informal caregivers. These efforts are supported by our single payer health system combined with one provincial health authority which offer a springboard for data consolidation and transfer of knowledge.

A solid core of interest exists among Dalhousie researchers, IWK and QE II clinicians, government officials, patient organizations, and community-based service providers in pursuing a collaborative TBI research program. Furthermore, most physicians associated with TBI diagnosis and treatment are remunerated through Academic Funding Plans which require them to participate in research, teaching and community service. Some of these physicians are already collaborating with BRC researchers in conducting TBI research which provides a platform to continue building collaborative, inter-disciplinary projects.

Forming a TBIRP under the BRC would provide visibility for Dalhousie and by consolidating our TBI research expertise, this would offer opportunities for researchers to connect with and participate in formalized research collaborations, such as the jointly funded Canada, US and European Union InTBIR and the Canadian Traumatic Brain Injury Research Consortium. Furthermore, this platform would provide the impetus to build stronger linkages among researchers along the five-pillar continuum, as well as among knowledge users including TBI survivors, patient care advocates, service providers, clinicians, and government policy makers.

The ABI Advisory Group, commissioned by the NS Health and Wellness Minister, has recently completed its work in developing a provincial strategy that is currently under review by the Nova Scotia government. Clearly, the NS government, (specifically the Departments of Labour and Advanced Education, and Health and Wellness) has recognized the need through the funding provided to the BRC to develop a TBI research partnership in tandem with the work completed by the ABI Advisory Group. We are optimistic this extensive research will provide government with the evidence it needs to continue to support the TBIRP.

### **Payback and Economic Benefits Derived through Research**

There can be economic benefits arising from a TBIRP. As a province Nova Scotia consists of complexities and characteristics in which research could contribute ways to counteract the economic burden associated with TBI over the coming years:

- With an aging population, Nova Scotia will experience a higher number of TBIs in accordance with the current trends where data shows that falls are the most common cause of TBIs among the elderly.<sup>30</sup> Over a three year period from 2014 to 2016, the QEII Emergency Department showed an increase of 7.8% of TBI occurrences in those aged 66 and older.<sup>31</sup> This was corroborated by Green et al who found the “incidence of TBI increased with age and was highest in the >60 age group as was the TBI-related mortality and concluded that TBI is an important issue in Nova Scotia, especially in our elderly population.”<sup>32</sup>
- Increased survival rates and longer life spans are due to more sophisticated diagnostics, treatments and technologies. “Advances in TBI research so far have created new opportunities for improved surveillance and for effective, acute and long-term medical care and rehabilitation. These increased survival rates will exacerbate not only the formal and informal health care costs, but also have implications for escalating out-of-pocket costs to families and caregivers, and program and other costs to the educational, social services and justice systems.”<sup>33</sup>

We have described how we have arrived at some uniquely Nova Scotia “drivers” influencing the development of the TBIRP. We have delineated the benefits of this research

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<sup>30</sup> McIntyre, A., Teasell, R., Aubut, J. Traumatic Brain Injury and Older Age, ERABI Research Group, 2013.

<sup>31</sup> Emergency Department Information System; QE II Health Sciences Centre.

<sup>32</sup> Green, R., Kureshi, N., Fenerty, L., Thibault-Halman, G., Erdogan, M., Walling, R., & Clarke, D. (2016). Characteristics and patterns of major traumatic brain injury in Nova Scotia – a 13 year retrospective analysis. Poster presented at the Canadian Association of Emergency Physicians

<sup>33</sup> Tabish, S.A. & Syed, N. (2015). Recent advances and future trends in traumatic brain injury. *Emerg Med* 5: 229.



enterprise for the Faculty of Medicine, Dalhousie, the provincial government and Nova Scotians. These are but a fraction of the opportunities that could be identified through ongoing engagement with and involvement of knowledge users including TBI survivors, their families and communities, service providers, societies/NGOs, and industry and government. The small population base in Nova Scotia, along with the proximity of researchers, clinicians, rehabilitation specialists and other health and social service providers constitute a 'living laboratory' in which the TBIRP could make a real difference in people's lives, contribute to managing the escalating social and economic costs associated with a traumatic brain injury, and at the same time, become a world leader in the TBI research field.

### 3. RESEARCH GOALS, TBIRP CONCEPT AND PRINCIPLES

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#### Research Goals

The research goals of the TBIRP are aimed at influencing prevention policies for all Nova Scotians and improving outcomes for TBI survivors. The research will be carried out in an inter-disciplinary, collaborative environment that brings together researchers, clinicians and other health professionals, and a variety of collaborators including TBI survivors, caregivers, government, industry, NGOs/societies, and sports bodies.

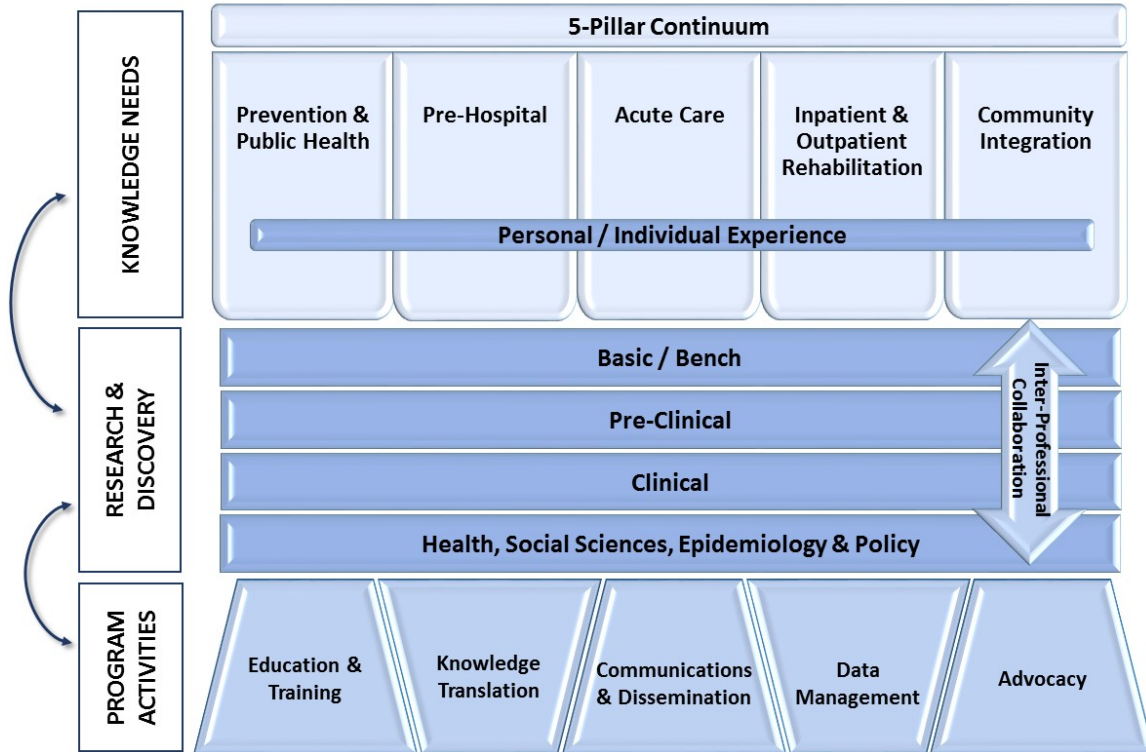
#### TBIRP Concept

The TBIRP concept is illustrated using both linear and circular diagrams. It revolves around an inter-professional, collaborative research model as described in the research goals. The model has been designed along a five-phase continuum shown in the graphic below, defined by individual experiences, including prevention of injury and TBI survivor experiences following injury. The five-phase continuum includes prevention and public health, pre-hospital treatment and acute care, inpatient and outpatient rehabilitation, concluding with the patient's re-integration into their community.

The research and discovery section of the model represents activities in response to knowledge needs, which could come from a range of research including: basic/bench; pre-clinical; clinical; and health, social sciences, epidemiological, and policy research. The arrow shows the inter-professional and collaborative nature of the research enterprise.

The program activities relate to the operations of the TBIRP in support of the research program and include education and training, knowledge translation, communications and dissemination, data management, and advocacy.

## TBIRP Concept Model – Linear



A circular view of the TBIRP concept is shown below as four concentric circles with the knowledge needs revolving around the personal/individual experience including that of injury prevention and post-injury survival and care. Similar to the linear model, the research and discovery response and the program activities are defined by the knowledge needs.

## TBIRP Concept Model - Circular



### Principles underlying the TBIRP

The following principles are aligned with one of Dalhousie's priority research areas, health and wellness, that includes a cluster related to "clinical patient-oriented research and translation to health outcomes, services and policy"<sup>34</sup>

- All research will be focussed on prevention and improving the TBI survivor's individual, personal experience and outcomes.
- Research will be conducted into mild, moderate and severe TBIs across a five-pillar continuum that includes: prevention and public health, pre-hospital

<sup>34</sup> Dalhousie University Strategic Research Plan; 2013; page 18

treatment and acute care, inpatient and outpatient rehabilitation, and community integration.

- Research and discovery will include a range of research disciplines: basic/bench; pre-clinical; clinical; health, social sciences, epidemiology and policy.
- Researchers will build on the neuroscience related research knowledge inherent at the BRC to further their TBI research.
- Research will be conducted using a collaborative, inter-disciplinary model that includes engagement with patients, families, caregivers and community to the extent possible.
- All research will be conducted using a rigorous research design to accelerate scientific progress and adherence to ethical scientific standards.
- Knowledge transfer will be a central component of the research enterprise.
- Treatment and investigational interventions will be included in the research context depending on the research being conducted.
- The TBIRP will report annually to its stakeholders and funders.



## 4. MISSION, VISION AND STRATEGIC PRIORITIES

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### MISSION AND VISION

#### Mission

Enabling research from TBI prevention through a continuum of impacts (mild, moderate and severe TBIs), in an inter-professional, collaborative and patient-centered environment.

Research will be conducted across a five-pillar continuum that includes prevention and public health, pre-hospital treatment and acute care, inpatient and outpatient rehabilitation, and community integration.

#### Vision

Transforming TBI outcomes for Nova Scotians by enabling excellence in prevention and post-injury research.

### STRATEGIC PRIORITIES

#### Overview

There are four strategic priorities that will guide the TBIRP:

1. **Research** - Leverage the BRC's research expertise to enhance the lives of Nova Scotians with traumatic brain injuries
2. **Education** - Facilitate education, training and knowledge exchange opportunities
3. **Partnerships** – Cultivate and maintain partnerships to enhance the TBIRP, including: clinicians and other health and social service providers, government, academia, industry, societies/ NGOs, patient networks, funders, and other brain research centres.
4. **Capacity and Sustainability** - Build capacity, infrastructure and financial support to successfully launch and sustain the TBIRP.

#### Strategic Priorities, Objectives, Tactics and Measures

Objectives

Tactics

Measures

	Objectives	Tactics	Measures
1.	<b>Research</b> - Leverage the BRC's research expertise to enhance the lives of Nova Scotians with traumatic brain injuries		
1.1	Be recognized as a leader in traumatic brain injury research	<ul style="list-style-type: none"> <li>• Create and cultivate an inter-professional, collaborative research enterprise across the five-pillar continuum that includes mild, moderate and severe TBIs</li> <li>• Attract/retain researchers who will advance TBI research across the five-pillar continuum</li> <li>• Capitalize on the proximity of researchers, hospitals and the rehabilitation centre in Halifax to develop the TBIRP in a 'living laboratory' environment by exploring the creation of a TBI research hub in the Collaborative Health Education Building (CHEB)</li> </ul>	<ul style="list-style-type: none"> <li>• Number of research collaborations underway in each pillar with an increasing number of peer reviewed publications and increased research funding over the first five years</li> <li>• Number of invited presentations at grand rounds, conferences and workshops, and feedback</li> <li>• Full roster of four internationally renowned researchers in place</li> <li>• Established TBIRP facility</li> </ul>
1.2	Measurably improve prevention and care outcomes and costs for Nova Scotians with a traumatic brain injury	<ul style="list-style-type: none"> <li>• Engage and involve patients, family and community in research</li> <li>• Support and enable translational and outcomes-based research and related infrastructure through researcher/clinician/service provider collaborations</li> <li>• Create communications pathways to support data, information and knowledge exchange across disciplines and across the province</li> </ul>	<ul style="list-style-type: none"> <li>• Number of research collaborations that include patients, family and community</li> <li>• Research impact on clinical, service and program applications and policy</li> <li>• Established communication methods, readership penetration and feedback</li> </ul>

	<b>Objectives</b>	<b>Tactics</b>	<b>Measures</b>
1.3	Embed a culture of inter-disciplinary collaboration between researchers, clinicians, other health and social service professionals, patients and families, and other collaborators	<ul style="list-style-type: none"> <li>• Develop a collaboration policy and operating guidelines based on best practices</li> <li>• Add a Collaboration Grant to the BRC Knowledge Translation (KT) grant portfolio to support development of collaborative research</li> <li>• Host forums to share knowledge and lessons learned</li> </ul>	<ul style="list-style-type: none"> <li>• Adherence to collaboration policy and operational guidelines</li> <li>• KT grants are leveraged to attract other research monies</li> <li>• Number of forums hosted, attendance and fee</li> </ul>
1.4	Analyze the health care system and associated costs in TBI.	<ul style="list-style-type: none"> <li>• Facilitate harmonized data collection</li> <li>• Develop protocols, approaches and associated costing models in the healthcare system related to TBI</li> </ul>	<ul style="list-style-type: none"> <li>• Develop harmonised terminology</li> <li>• Conduct data collection and reporting</li> <li>• Develop models for TBI with associated costing</li> </ul>
<b>2.</b>	<b>Education - Facilitate education, training and knowledge exchange opportunities</b>		
2.1	Enhance educational opportunities for TBI researchers, collaborators, trainees and medical students and other health professionals	<ul style="list-style-type: none"> <li>• Create ongoing educational opportunities for TBI researchers</li> <li>• Establish a mentoring program through a research exchange network to build research capacity among, for example, early career researchers</li> <li>• Provide educational, training and networking opportunities to support inter-disciplinary collaborations among researchers and clinicians</li> </ul>	<ul style="list-style-type: none"> <li>• Number of educational, training and networking opportunities, attendance and feedback</li> <li>• Number of mentorships and feedback from early career researchers</li> </ul>
2.1	Enable knowledge exchange opportunities between researchers and Nova Scotians	<ul style="list-style-type: none"> <li>• Engage families, patients and societies in research and program activities</li> <li>• Provide fellowships and support to trainees (post-doctoral fellows,</li> </ul>	<ul style="list-style-type: none"> <li>• Number of families, patients and societies involved in research and program activities over a five year period</li> </ul>

	Objectives	Tactics	Measures
		graduate and ungraduated students) <ul style="list-style-type: none"> <li>Support researchers in creating and engaging in education and knowledge exchange opportunities with the societies/NGOs, service providers, patients and families</li> <li>Facilitate education opportunities including online tools, fact sheets, webinars and seminars</li> </ul>	<ul style="list-style-type: none"> <li>Number of fellowships and supports provided to trainees</li> <li>Number of education and knowledge exchange opportunities, participation and feedback</li> <li>Use of online tools, attendance at webinars and seminars, and feedback</li> </ul>
3.	<b>Partnerships</b> – Cultivate and maintain partnerships to support the TBIRP, including: clinicians and other health and social service providers, government, academia, industry, societies/ NGOs, patient networks, funders, and other brain research centres.		
3.1	Ensure the TBIRP’s strategic objectives are in alignment with those of the Office of the Vice-President of Research and the Faculty of Medicine	<ul style="list-style-type: none"> <li>Participate in the Faculty of Medicine’s (FoM) anticipated workshop to identify teams/clusters best prepared to advance the research goal of “achieving national/ international recognition for accomplishments in important areas of health research”<sup>35</sup></li> <li>Identify other opportunities to align with the strategic objectives as an outcome from the FoM workshop</li> </ul>	<ul style="list-style-type: none"> <li>TBIRP team / cluster identified in ‘Wave 2’ as helping to advance the FoM’s goal toward national / international recognition for accomplishments in important areas of health research</li> </ul>
3.2	Design a research program tailored to meet the needs of TBI survivors, families, partners and knowledge	<ul style="list-style-type: none"> <li>Conduct a needs assessment to identify a body of potential research opportunities and prioritize over a five year period</li> <li>Develop a collaborative research program that defines the research parameters of the TBIRP</li> </ul>	<ul style="list-style-type: none"> <li>Results of needs assessment and prioritization communicated and integrated into research program</li> <li>Annual research reports</li> </ul>

<sup>35</sup> Dalhousie University, Faculty of Medicine, Strategy in Motion; October 31, 2016; pages 5 and 6

	Objectives	Tactics	Measures
	users	<ul style="list-style-type: none"> <li>• Create opportunities to engage with partners on a regular basis such as an annual planning workshop, a semi-annual seminar series, and quarterly update meetings</li> </ul>	<p>communicated to partners and stakeholders</p> <ul style="list-style-type: none"> <li>• Number of engagement opportunities, attendance and feedback</li> </ul>
3.3	Create opportunities to develop local partner relationships with industry, government, societies/NGOs, and foundations	<ul style="list-style-type: none"> <li>• Showcase TBI research at various events throughout the year</li> <li>• Identify opportunities to participate in and contribute to programs and events hosted by partners</li> <li>• Collaborate with societies/NGOs in joint fundraising and other activities</li> </ul>	<ul style="list-style-type: none"> <li>• Feedback on showcased TBI research</li> <li>• Number of partner events in which TBI researchers have participated, attendance and feedback</li> <li>• Impact on funds raised because of TBIRP involvement</li> </ul>
3.4	Enhance engagement with research partners across the country and internationally	<ul style="list-style-type: none"> <li>• Participate in formalized research collaborations, such as the jointly funded Canada, US and European Union TBI research collaboration, and the Canadian Traumatic Brain Injury Research Consortium</li> <li>• Pursue participation in the anticipated call for a National Centre of Excellence (NEC) in the spring of 2017</li> <li>• Position the TBIRP as a facilitator to bring together research groups across the country and internationally</li> </ul>	<ul style="list-style-type: none"> <li>• Established participation in formalized research collaborations with participation in committees or activities</li> <li>• Participation in the NEC call (if it materializes)</li> <li>• Over a five year period, TBIRP is recognized as a leader in facilitating TBI research groups nationally and internationally</li> </ul>
4.	<b>Capacity and Sustainability</b> – Build capacity, infrastructure and financial support through the BRC to successfully launch and sustain the TBIRP.		
4.1	Build human resources capacity and infrastructure	<ul style="list-style-type: none"> <li>• Recruit a Program Director, Technical Manager, Administrative Coordinator and Knowledge Translator to manage program development, administrative and fundraising activities related to the TBIRP</li> </ul>	<ul style="list-style-type: none"> <li>• Recruitment and hiring process is completed and appropriate</li> <li>• Infrastructure is in place within specified timelines</li> </ul>

	<b>Objectives</b>	<b>Tactics</b>	<b>Measures</b>
		<ul style="list-style-type: none"> <li>• Add additional human resources to the BRC to support development and growth of the TBI research cluster as one of the four BRC clusters</li> <li>• Put in place appropriate infrastructure including systems, technologies and processes to support expansion of program activities (education and training, knowledge translation and dissemination, data management and advocacy)</li> <li>• Pursue the possibility of locating the TBIRP in the CHEB</li> </ul>	
4.2	Develop a funding and sustainability strategy	<ul style="list-style-type: none"> <li>• Develop and implement a funding and sustainability strategy including, among other things, revenue generation through contracted research and clinical trials</li> <li>• Engage with foundations to establish the BRC as the co-ordinating body through which to funnel activities related to neuroscience research</li> <li>• Identify and engage champions who can open doors to potential funders</li> </ul>	<ul style="list-style-type: none"> <li>• Funding and sustainability strategy is in place within specified timelines and results are achieved as planned</li> <li>• Established relationships with foundations, and neuroscience related activities are funnelled through the BRC</li> <li>• Champions are engaged and have successfully opened doors</li> </ul>

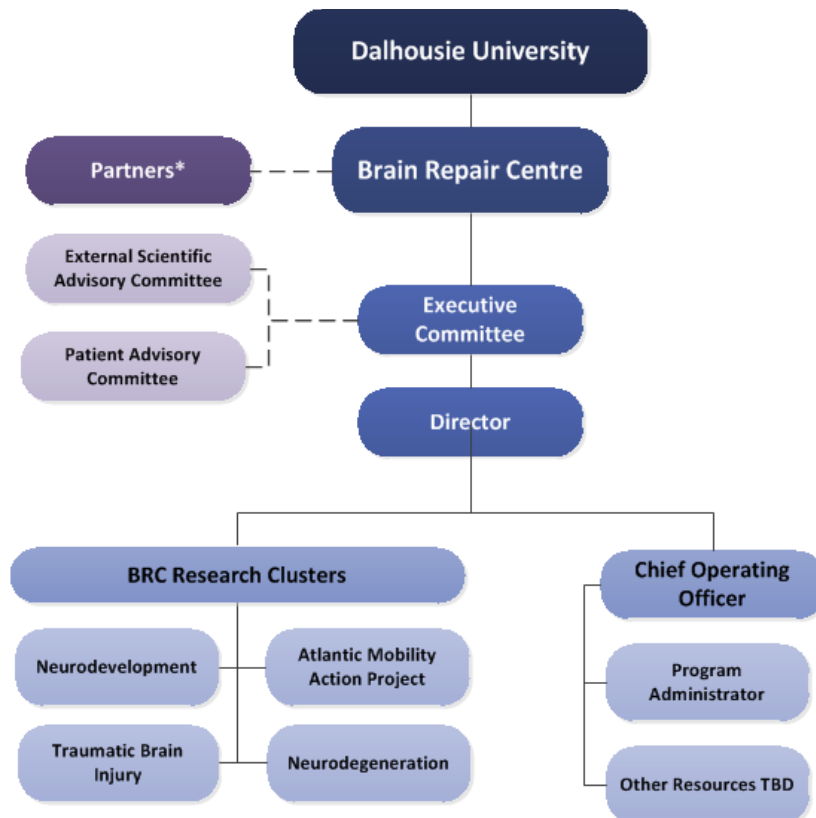
## 5. ORGANIZATIONAL STRUCTURE

### OVERSIGHT

Ultimate oversight for the TBIRP resides with the BRC which is accountable to Dalhousie University and specifically to the Senate and the Vice-President of Research. On a day-to-day basis, the TBIRP Program Director is accountable to the BRC Director and the Chief Operating Officer. The Program Director will work closely with the Principle Investigators (PIs) to provide support for the research and facilitate collaboration (s). The PIs are individually accountable for their research to their funders and collaborators.

### BRC STRUCTURE

The organizational structure is shown in the diagram immediately below.



\*Partners include: Health, Government, Academia, Industry, Societies & Patient Networks, Funders, other Brain Research Centres

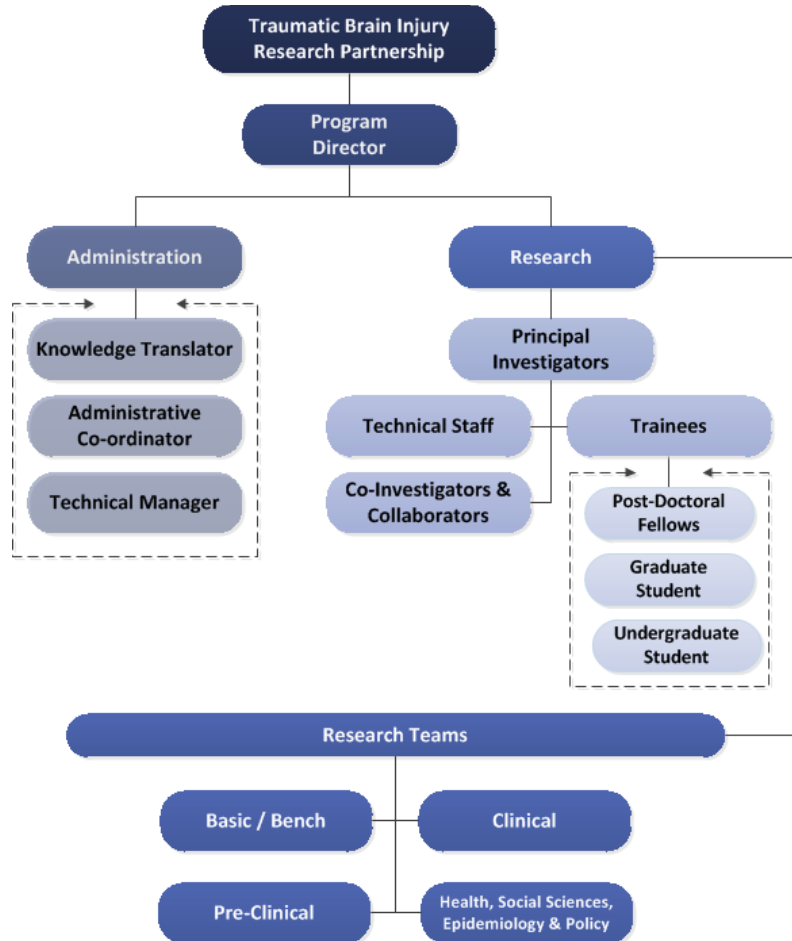
## Accountabilities and Responsibilities

<b>Role Title</b>	<b>Description</b>
<b>Executive Committee</b>	Provides strategic oversight
<b>Partners</b>	Role of partners could be as collaborators, funders, advisors and experts. Partners include organizations in various sectors including: health, government, academia, industry, societies and patient networks, foundations and other financial organizations, and other brain research centres
<b>BRC Director</b>	Has overall accountability for the BRC
<b>External Scientific Advisory Committee and Patient Advisory Committee</b>	Provide input and expert advice to the research programs at the BRC
<b>Four Research Clusters</b>	Carry out the research program at the BRC. They include: neurodevelopment, neurodegeneration, Atlantic Mobility Action Project, and traumatic brain injury
<b>Chief Operating Officer</b>	Provides day-to-day management of the BRC and its programs
<b>Program Administrator</b>	Responsible for supporting the program activities and the research teams
<b>Other Resources</b>	May be hired and/or contracted as needed to provide communications, marketing, fundraising, strategic advice and other support as identified.



## TBIRP STRUCTURE

The TBIRP will consist of an administration team and four research teams as shown in the graphic below.



### Accountabilities and Responsibilities

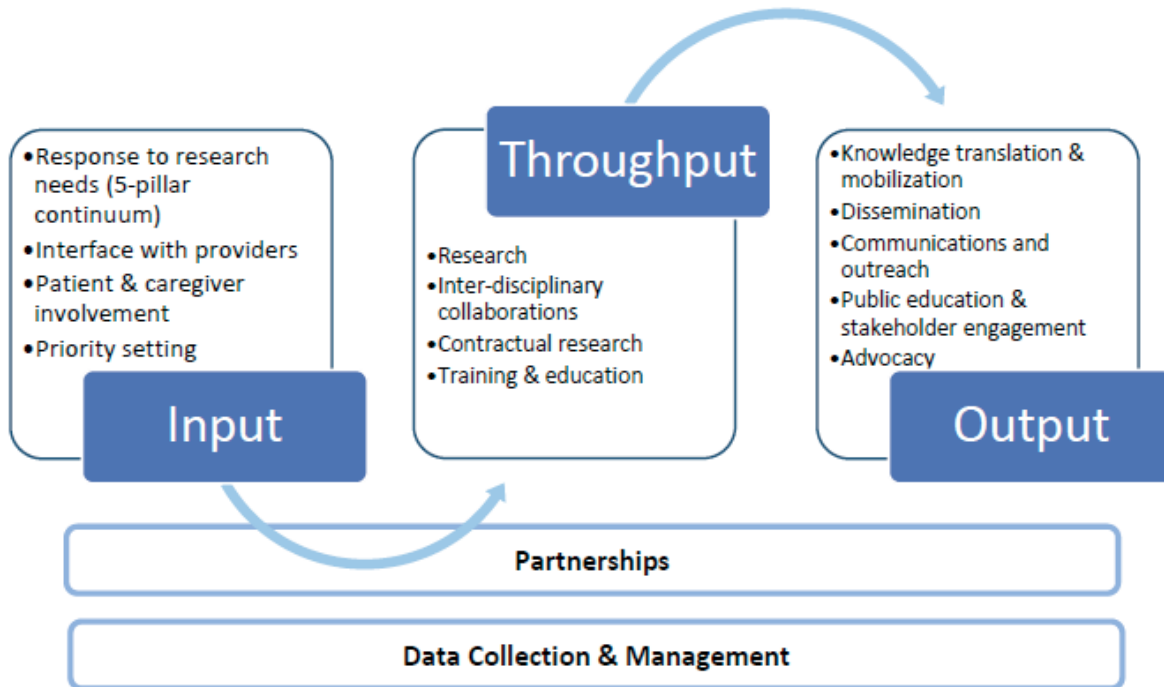
Role Title	Description
Program Director	Responsible for administration, management, fundraising and oversight of the TBIRP research program including collaboration among the PIs. The Program Director will also maintain their own research lab with their time split 60% / 40% respectively

<b>Role Title</b>	<b>Description</b>
<b>Knowledge Translator</b>	Develops knowledge mobilization strategies, methodologies and tools; researches trends and policy developments; builds and manages relationships with researchers and collaborators; manages stakeholder communications
<b>Administrative Coordinator</b>	Provides support to the Program Director and the Research Teams, and works closely with the BRC Program Administrator
<b>Technical Manager</b>	Coordinates equipment across all the TBIRP labs; oversees the management of data; responsible for software acquisition and purchasing of supplies.
<b>Principal Investigators</b>	Responsible for the preparation, conduct, and administration of a research grant, directing the research and managing the research team and collaborators, and reporting to the funding body. Also responsible for engaging with stakeholders and community
<b>Technical Staff</b>	Support the research through data collection and data management, managing lab equipment, coordinating clinical trials, and liaising with the Technical Manager
<b>Co-Investigators and Collaborators</b>	Role is defined by the nature of the research study. Co-investigators and collaborators could include other researchers from Dalhousie or other brain research centres, TBI patients/survivors and their families, societies/NGOs, industry and others.
<b>Trainees</b>	Participate in research studies by performing experiments, and leading or supporting other laboratory activities. Trainees include Post-Doctoral Fellows, and Graduate and Undergraduate students.

## OPERATIONAL REQUIREMENTS

### TBIRP Operating Model

The TBIRP operating model which consists of numerous program activities is shown as an input, throughput, output process in the diagram below.



Input to the model will be predicated on the research responding to the needs of the public for prevention purposes, and those of TBI survivors, caregivers, and providers in the post injury phases, as described previously in the five-pillar continuum. The input model also assumes that there will be a priority-setting process as defined by the BRC to create the program of TBI research that the TBIRP will undertake.

Throughput in the model involves the activities associated with carrying out the research in an inter-disciplinary, collaborative and distributed environment, as collaborators may be at some distance from Halifax, either in other parts of Nova Scotia, or elsewhere nationally or internationally. It also includes contractual research that may be generated through industry partners or other collaborators on a fee-for-service basis, and training and education of trainees, clinicians, other health professionals, and patients and caregivers, as a key element of the model.

Output from the model will include:

- Knowledge translation, which could involve clinical practices/services, products, and/or policy application(s);
- Dissemination of the research through journals, conferences and seminars; communication through the website, social and traditional media, and other communication vehicles;
- Outreach to family physicians, other health and service providers across the province;
- Public education and stakeholder engagement, which may involve public seminars, roundtable discussions, etc.; and
- Advocacy, particularly to influence public policy, essential to bringing about change to programs and services, and public understanding and behaviour.

The two underpinnings of the model are partnerships and data. Partners, described previously, will help determine the research program by identifying needs, and providing input and knowledge; they will participate in the research through collaborations, and they will be recipients of the research knowledge through the various output mechanisms described above. Data collection and management, including the standardization and dissemination of data are an essential research and education resource.

## **Skills**

Perhaps the two most important skills required to ensure success are leadership and the ability to collaborate. The collaborative, inter-disciplinary will be promoted between academic and clinical “cultures”. While this occurs now between individual researchers and clinicians, the TBIRP is breaking new ground by embracing this as a central way in which it intends to operate.

The Program Director and Principle Investigators will need to provide leadership and demonstrate willingness to embrace an inter-disciplinary and collaborative approach. In addition, various technical, communication, engagement, administrative and data management skills, etc. will be required.

## Infrastructure

The key infrastructure needs are defined by space, furniture, equipment, and policies and guidelines.

- **Space** will need to be appropriate for a collaborative, inter-disciplinary research environment envisioned in this business plan. The CHEB provides an ideal opportunity to create such an environment.
- **Laboratory furniture and equipment** will be required for four research teams. The bench, pre-clinical and clinical teams will require a more elaborate fit out than the health and social sciences teams.
- **Office and meeting space, and furniture** for the four research teams and the Program Director and their team will need to include space to support collaborative activities (e.g. comfortable meeting chairs, walls that are white or black boards, furniture that can easily be reconfigured to meet the needs of a given group).
- **A database** that could be linked and that builds on existing data sources, and that provides reliable data.
- **Computer hardware and software**, patient and clinician surveillance software, photocopier and other office equipment to support research and administrative activities.
- A primary tool to facilitate the collaboration approach will be the development of **policies and guidelines**, which might include, among other things, the following:
  - Aligning research needs and interests at the outset through mechanisms such as a needs survey;
  - Establishing key operating principles including active and equal participation, setting clear targets, articulating shared expectations i.e. by formulating a research plan, and sharing rewards and benefits;
  - Developing communication channels such as posting minutes of meetings, e-blasts, and research project updates;
  - Ensuring transparent decision-making by involving team members on committees and in information meetings; and
  - Promoting engagement through events, committee work, and seminars.

## 6. COMMUNICATIONS ACTION PLAN

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This Communications Action Plan is for the period March 31, 2017 to the launch of the TBIRP. It is a transition plan intended to judiciously focus resources where they are critically needed to help move the project from concept to reality.

### **Background**

The BRC has identified a significant need and an opportunity for the establishment of a unique TBIRP. This concept has now been fleshed out in this business plan which will guide the efforts to move forward.

### **Purpose**

The Communications Action Plan is intended to provide direction and structure to communications activities over the next 12-18 months when the TBIRP will officially be launched with at least one researcher in place.

### **Approach**

The activities outlined in this action plan will support the work being undertaken during the business planning process through to launch and keep key stakeholders engaged and informed. It would be premature to have an official launch or announcement of the TBIRP; therefore, communications activities must reflect the developmental phase of this initiative. This gestational reality dictates the need for an action plan that is targeted and strategic. Broad-brush approaches will not be necessary or effective at this stage in the project and widespread visibility is not necessary at present.

### **Goals**

- To inform key stakeholders about the TBIRP, spark their interest and garner greater support
- To identify and confirm financial, community, government and industry support for the TBIRP
- To establish a solid communications foundation on which activities and planning can be built following the official roll-out of the initiative

## Audiences

Key audiences are those who can champion, advocate, fund, and otherwise directly support advancement of the TBIRP. They are:

<b>Dalhousie University</b>	<ul style="list-style-type: none"> <li>• President</li> <li>• Vice President Research</li> <li>• Deans of Health Professions and Medicine</li> <li>• Faculty of Medicine Medical Research Advisory Committee</li> </ul>
<b>Brain Repair Centre</b>	<ul style="list-style-type: none"> <li>• Researchers</li> <li>• Staff</li> </ul>
<b>Health-related Organizations and Individuals</b>	<ul style="list-style-type: none"> <li>• Nova Scotia Health Authority, CEOs and Vice Presidents, senior staff key roles</li> <li>• IWK Health Centre, including the Vice President of Research (position is shared with the NS Health Authority)</li> </ul>
<b>Health and Hospital Foundations</b>	<ul style="list-style-type: none"> <li>• Dalhousie Medical Research Foundation</li> <li>• IWK Foundation</li> <li>• QEII Health Sciences Foundation</li> <li>• Nova Scotia Health Research Foundation</li> </ul>
<b>Community Organizations and Associations</b>	<ul style="list-style-type: none"> <li>• Brain Injury Association of Nova Scotia (BIANS)</li> <li>• BioNova</li> <li>• Atlantic University Sport</li> <li>• Sport Nova Scotia</li> <li>• Other sports organizations</li> </ul>
<b>Provincial Government</b>	<ul style="list-style-type: none"> <li>• Ministers – Health and Wellness, Labour and Advanced Education, Community Services</li> <li>• Deputy Ministers -- Health and Wellness, Labour and Advanced Education, Community Services</li> <li>• Department of Justice</li> <li>• Department of Health and Wellness</li> <li>• Disabled Persons Commission</li> </ul>
<b>Federal government</b>	<ul style="list-style-type: none"> <li>• Health Canada – Minister, Deputy Minister</li> <li>• Public Health Agency of Canada – President</li> <li>• Minister of Sport and Persons with Disabilities</li> <li>• Nova Scotia Members of Parliament</li> </ul>

	<ul style="list-style-type: none"> <li>• Corrections Canada</li> <li>• Veterans Affairs</li> <li>• Department of National Defence</li> </ul>
<b>Industry</b>	<ul style="list-style-type: none"> <li>• Pharmaceutical companies</li> <li>• Equipment manufacturers</li> </ul>

*Note: This list will need to be refined and a database of key contacts developed.*

## Tactics

*Note:* (1) These tactics must complement and be integrated with the TBIRP fundraising plan. (2) There are two significant and anticipated opportunities that may arise this year and that would help to increase awareness of and support for the TBIRP: a provincial election and release of the provincial ABI strategy. If either or both should happen, the BRC and the TBIRP Working Group should be prepared to move quickly to reach out to key stakeholders and generate support.

### KEEP STAKEHOLDERS EASILY INFORMED.

1. **Website central** - The BRC website remains a cornerstone of communications efforts. A section should be dedicated to information and updates about the TBIRP.
2. **Monthly e-newsletter** - This is an easy, inexpensive way to share information, celebrate progress, and update audiences.

### KEEP STAKEHOLDERS PERSONALLY INFORMED.

1. **Face-to-face updates** - A list of key stakeholders should be identified who have the ability and authority to drive the project forward. Face-to-face meetings should be scheduled with these people. A specific ask should be made during the meeting (e.g., for financial support, organizational support, initiative support). At the conclusion of these meetings, an information kit can be provided or distributed electronically following the meeting. A PowerPoint presentation should be prepared about the Partnership, its purpose and its benefits.
2. For audiences who cannot be connected with face-to-face or who are not critical to the initial stages of the project, a personal letter should be sent outlining the importance and benefits of the Partnership and how the recipient can help move the initiative forward.



3. Ongoing follow-up will be required with each of these key stakeholders. A database detailing contacts, communication efforts and outcomes should be created.
4. **Information kit** - Fact sheets on traumatic brain injury, the proposed TBIRP, and the economic, health and social benefits of the research centre should be prepared. The info kits can be delivered directly to key stakeholders and the fact sheets posted online. Other material, such as news items and recent research in the field can also be included in the kit.
5. **Community meeting(s)** - There are not the resources nor the time – or the need – to meet with a wide range of stakeholders at this point, and certainly not one-on-one, face-to-face meetings. However, it is important to have a broad base of support, awareness and understanding especially within the community. Hosting a breakfast get-together, luncheon or afternoon coffee break for local organizations and key individuals over the course of establishing the TBIRP. One get-together could be held early in the process and the other as the partnership nears launch, to update stakeholders on progress and next steps. The intent is to be accessible and transparent while not taxing resources.

#### KEEP STAKEHOLDERS STRATEGICALLY INFORMED.

1. **Briefing note** - A briefing note should be prepared for use with government stakeholders and senior executive members at Dalhousie University. The briefing note will highlight the purpose of the TBIRP, the benefits, and the potential ask.
2. **Annual research meeting** - This event is an opportune time to reach out directly to the research community to build greater awareness and support. A presentation on the TBIRP could be offered and the information kits distributed.

#### KEEP STAKEHOLDERS VISUALLY INFORMED.

1. To help make the TBIRP real in the minds of key stakeholders, it may be appropriate to create a landmark to give the Partnership a visual identity. This can be used on letterhead, in PPTs, on fact sheets and other collateral.

## 7. FINANCIAL MODEL

### OVERVIEW

The funding requirement for this business plan is \$25,000,000, with the majority of the costs being incurred in the first two years of the Plan. The financial details can be found in Appendix D.

The ongoing funding to operate the TBIRP under the BRC will be pursued through various sources. It is expected the Principal Investigators will be funded as Endowed Research Chairs. One option is to apply for this funding from federally supported research organizations such as CIHR, SSHRC, and NSERC. Private funding for these chairs could also be sought from philanthropic foundations and individuals with an interest in TBI. The operating costs for the TBIRP will be sought from numerous sources including: in-kind contributions, targeted donations from key stakeholders such as industry and provincial and federal government grants. One novel way to approach the Nova Scotia government is by illustrating how funds for the TBIRP could be raised through adding a surcharge to motor vehicle driving infractions or as an add-on to motor vehicle registrations and driver licences. The BRC has explored these options through a research study that explained how other jurisdictions raise funds to support scientific research from programs such as surcharges and dedicated revenues. During our roundtable consultations, it was also suggested the TBIRP pursue contractual arrangements to create high quality scientific evidence that could inform policy and practice decisions by industries, sports organizations, military or government entities such as the Public Health Agency of Canada, NS Disabled Persons Commission or Chief Public Health Officer for NS. Initially, however the BRC recognizes that core funding must be obtained to launch the TBIRP.

### RESEARCH AND ACADEMIC COSTS

	Year 1 2018-19	Year 2 2019-20	Year 3 2020-21	Year 4 2021-22	Year 5 2022-23	5 Year Totals
Compensation	6,094,000	6,188,000	188,000	188,000	188,000	12,846,000
Set up costs	2,125,000	1,375,000				3,500,000
Annual costs	47,000	71,000	112,000	112,000	112,000	454,000
	<b>8,266,000</b>	<b>7,634,000</b>	<b>300,000</b>	<b>300,000</b>	<b>300,000</b>	<b>16,800,000</b>

## Compensation

The Plan provides for four Principal Investigators/Endowed Research Chairs at a funding requirement of \$3,000,000 each for a total cost of \$12,000,000. Two of these positions will be added in each of the first two years for a total of \$6,000,000. There is no ongoing compensation expense for these positions since the amounts paid will be covered by the endowments received. It is assumed that the annual salary and benefits to be paid to each of the Principal Investigators will be \$200,000.

Each of the Principal Investigators will have a technical support person at a cost of \$47,000 each for a total of \$188,000.

## Set up costs

The most significant elements in this area are renovations, site preparation, labs and equipment configurations required for research activity. For the Basic Bench, Pre-Clinical and Clinical Principal Investigators this cost will total \$1,000,000 each, and \$400,000 for the Health Services, Social sciences, Epidemiological and Policy Principal Investigator.

In addition, there are relatively small workspace furniture and miscellaneous costs to be incurred.

## Annual costs

Each of the Principal Investigators will have expenses associated with travel, conference expenses and miscellaneous activity, not directly associated with research projects.

## OPERATIONAL ACTIVITY

	Year 1 2018-19	Year 2 2019-20	Year 3 2020-21	Year 4 2021-22	Year 5 2022-23	5 Year Totals
Operational Activity						
PI Research Activity	300,000	600,000	600,000	600,000	600,000	2,700,000
TBIRP Inter-disciplinary, Multi-Team Research		300,000		300,000		600,000
Program Activity	180,000	190,000	200,000	210,000	220,000	1,000,000
	<u>480,000</u>	<u>1,090,000</u>	<u>800,000</u>	<u>1,110,000</u>	<u>820,000</u>	<u>4,300,000</u>

## **Research Activity**

In order to attract high quality Principal Investigators there must be research funding available. Accordingly, there will be a provision for \$150,000 per year per Principal Investigator for their research within their area of expertise. This will cover a research team comprised of a post-doctoral fellow, student research trainees and direct project related expenses. The total cost associated with this research is \$2,700,000.

A key differentiator for the TBIRP will be the ability for researchers from various disciplines to work on collaborative research projects. This will also assist in attracting top researchers to the TBIRP. These projects will be larger and more complex and the assumption made is that there will be two of these projects each for \$300,000, one in Year 2 and one in Year 4, for a total of \$600,000.

In total, the research budget is \$3,300,000.

In addition, it is expected that the research activity in and reputation of the TBIRP will attract Federal Government funding. It is hoped that by year 4 or 5 this will at least double the research budgets. This incremental research funds inflow/outflow is not reflected in these projections, since there is zero net impact.

## **Program Activity**

A critical activity of the TBIRP will be the dissemination of knowledge.

TBIRP will develop and hold two workshops per year. In addition, the Knowledge Translator will be travelling and communicating with stakeholders throughout Nova Scotia.

The Communications/Awareness/Advocacy element will include the development of a Traumatic Brain Injury Annual Conference to be held on an annual basis here in the Province. It is anticipated that this will become a mainstay on the annual calendars of brain researchers and interested parties from across Canada and beyond.

These activities are essentially the roll out of research learnings into the medical and related community workplaces. This is a significant outcome of the activities undertaken in the Traumatic Brain Injury Research Partnership!

## ADMINISTRATION

	Year 1 2018-19	Year 2 2019-20	Year 3 2020-21	Year 4 2021-22	Year 5 2022-23	5 Year Totals
Compensation	432,000	432,000	432,000	432,000	432,000	2,160,000
Expense	456,000	332,000	314,000	324,000	314,000	1,740,000
	888,000	764,000	746,000	756,000	746,000	3,900,000

## Compensation

The administration team is made up of four positions all of which are filled at the outset.

Position	Responsibilities	Annual Salary Including Benefits
Program Director	Has the overall responsibility for activities undertaken within the TBIRP	\$140,000
Administration Support	Supports the Program Director in stakeholder engagement as well as supporting operational program activities.	\$82,000
Technical Manager	Supports the Program Director as well as coordinates activities amongst the research teams	\$105,000
Knowledge Translator	Leads the Program activity for the TBIRP including all communication and outreach events	\$105,000
<b>Total cost</b>		<b>\$432,000</b>

## Expenses

TBIRP will require space for 12 employees, 12 research assistants and 6 visitors/collaborators. In addition, there is lab space and meeting rooms, a reception and waiting area and common space for a total of 8,000 sq. ft. At a per square foot cost of \$30.00 the annual rent expense will total \$240,000 per year for a total of \$1,200,000 over the 5 years. It is assumed that this will be provided in-kind by Dalhousie University.



Other costs include some set up expense, such as computers, renovations and furniture, as well as ongoing general administration costs including travel, communication and IT maintenance.

## **SUMMARY**

	<b>Year 1</b>	<b>Year 2</b>	<b>Year 3</b>	<b>Year 4</b>	<b>Year 5</b>	<b>5 Year</b>
	<b>2018-19</b>	<b>2019-20</b>	<b>2020-21</b>	<b>2021-22</b>	<b>2022-23</b>	<b>Totals</b>
<b>Totals</b>	<b>9,634,000</b>	<b>9,488,000</b>	<b>1,846,000</b>	<b>2,166,000</b>	<b>1,866,000</b>	<b>25,000,000</b>

The need to hire the Principal Investigators as Endowed Research Chairs and the high set up costs results in a front end loaded financial plan but the greatly reduced ongoing operations starting in year 3 provides for the offset that would continue indefinitely. This coupled with the high probability of attracting external research funds will ensure a heightened level of invaluable traumatic brain injury research activity in Nova Scotia for the betterment of the population of Nova Scotia and beyond.

## 8. IMPLEMENTATION FRAMEWORK

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This implementation framework provides a preliminary overview of the key activities required to launch the TBIRP and assigns notional timelines to give the reader a sense of the order of magnitude of this undertaking. The approach will be to first secure administrative operational funding and endowment funding for the four PIs. However, for the purposes of this plan, we have assumed that the administrative and endowment funding is in place so that the TBIRP Program Director (PD) and the PIs can be recruited.

Once the PD is hired, the Administrative Coordinator will be brought on board within the first two to four months to support the implementation activities which include:

- Locating and acquiring space (preferably in the CHEB), and furnishing and outfitting the administrative space and putting other infrastructure in place within the first six months.
- Developing the funding and sustainability plan;
- Recruiting the PIs (the financial plan assumes they will come on board over a two year period);
- Outfitting the labs and putting the research teams in place, dependent on each PI coming on board;
- Recruiting the Knowledge Translator and Technical Manager once the first PI is fully functional and recruitment of the second PI is underway;
- Developing the research plan, and the communications, dissemination and engagement/ outreach plans as the four PIs come on board and their specific research areas of expertise and interests are known; and
- Formalizing national and international collaborations over a period of time.

<b>Implementation Activity</b>	<b>Year 1</b>	<b>Year 2</b>	<b>Year 3</b>	<b>Year 4</b>	<b>Year 5</b>
Recruit Program Director	*				
Recruit Administrative Coordinator	→				
Locate and outfit space	→				
Develop Funding and Sustainability Plan	→				
Recruit Principal Investigators	→				
Outfit Labs and Recruit Research Teams		→			
Recruit Knowledge Translator and Technical Manager	→				
Develop and Implement Research Plan		→			
Develop and Implement Program / Communications / Outreach Plan		→			
Formalize National and International Collaborations		→			



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## **APPENDICES**

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**APPENDIX A – EPIDEMIOLOGY OF TBI**

**APPENDIX B – ESTIMATES OF CASES FOR NS**

**APPENDIX C – NS COST ESTIMATES FOR TBI CASES**

**APPENDIX D – DETAILED FINANCIAL PLAN**

## APPENDIX A – EPIDEMIOLOGY OF TBI

### Global Statistics

Source:

World Health Organization. (2006). 3.10 Traumatic brain injuries in *Neurological disorders: public health challenges*.

### INCIDENCE AND PREVALENCE

- The annual incidence (occurrence) of TBI is conservatively estimated at up to 600/100,000 in North America and Europe.
- The degree of injury varies widely, with an estimated 11 severe and 600 mild cases per 100,000 people.
- Two thirds of those affected are males, with the young and elderly (women in particular) among the most vulnerable.
- Data from many parts of the world consistently show a peak incidence rate in children, young adults and elderly people. Males are injured two to three times as often as women.
- Prevalence of TBI measures the total number of injuries at a point in time or in a period interval; the calculation should include all those with TBI sequelae such as impairments, disabilities, handicaps or complaints, plus all the newly diagnosed cases at the defined time or time interval.
- While the prevalence of TBI is not well known, estimates from the United States research indicates that one to two percent of the population lives with a TBI disability.

### CAUSES

- The three main causes of TBI are motor vehicle accidents (MVAs), falls and violence but their relative importance varies from county to county.
- The most common mechanism among older people is falls.
- Motor vehicle accidents are a major cause among young men.
- Injuries from MVAs are forecast to become the third most-common cause of death, because economic improvements are causing motorization rates to increase around the world.

## RISK FACTORS

- Although people in all spheres are affected by TBI, risks related to injury, treatment, and outcome are affected by such factors as sex, age and social status.
- Studies have shown high rates of TBI in vulnerable populations such as homeless, disabled, incarcerated and Aboriginal people, as well as those in mental health institutions.
- 59 percent of the US military had evidence of TBI, and of these, 56 percent were moderate to severe
- People 70 years or older have a relatively high incidence of head injuries, and in these patients falls are the most common cause. Many factors contribute to the increased risk for falls in elderly people: gait impairment, dizziness, previous stroke, cognitive impairment, postural hypotension, poor visual acuity and multiple medications.

## IMPLICATIONS

- Lifetime costs of a severe TBI survivor are approximately \$6.7 million (US dollars).
- A number of significant neurological and psychosocial problems result from TBI.
- Moderate or severe TBI increases the risk of dementia by two to four-fold.
- Although disability after mild TBI is not accurately measured and therefore usually underestimated, most patients can make a good recovery with provision of appropriate information and without requiring additional specific interventions.
- Any information that is available about the economic consequences of TBI is mostly related to costs of hospitalization, which probably constitute only a relatively small part of the total costs. TBI-associated costs can be subdivided as follows: direct costs: hospitalization, outpatient care, rehabilitation; indirect costs: lost productivity, in particular after moderate or severe injuries; intangible costs to patients, families and friends: related to death or reduced quality of life.
- The importance of rehabilitation is consistently underestimated, not least because of its cost. It is a regrettable truth that this part of the treatment lacks the drama of the primary treatment and is consequently more difficult to fund. It is nonetheless of great importance since TBI damages young lives for whom rehabilitation is as important for the regaining of function as primary treatment is for the saving of life.
- Patients with moderate to severe TBI should be routinely followed up to assess their need for rehabilitation. There is strong evidence of benefit from formal interventions, particularly more intensive programs beginning when the patients are still in the acute ward. The balance between intensity and cost-effectiveness has yet to be determined.

## U.S. Statistics

Source: [https://www.cdc.gov/traumaticbraininjury/get\\_the\\_facts.html](https://www.cdc.gov/traumaticbraininjury/get_the_facts.html)

### INCIDENCE

- In 2009, an estimated 248,418 children (age 19 or younger) were treated in Emergency Departments (EDs) for sports and recreation-related injuries that included a diagnosis of concussion or TBI.
- From 2001 to 2009, the rate of ED visits for sports and recreation-related injuries with a diagnosis of concussion or TBI, alone or in combination with other injuries, rose 57 percent among children (age 19 or younger).
- There are approximately 52,000 deaths and 275,000 hospitalizations per year, however many of those affected by TBI do not seek medical attention.

### CAUSES

- The leading causes of TBI are:
  - Falls (40.5 percent);
  - Unknown/other (19 percent);
  - Motor vehicle-accidents (14.3 percent);
  - Struck by/against events (15.5 percent); and
  - Assaults (10.7 percent)
- From 2006–2010, falls were the leading cause of TBI, accounting for 40 percent of all TBIs in the United States that resulted in an ED visit, hospitalization, or death. Falls disproportionately affect the youngest and oldest age groups:
  - More than half (55 percent) of TBIs among children 0 to 14 years were caused by falls.
  - More than two-thirds (81 percent) of TBIs in adults aged 65 and older are caused by falls.
- Unintentional blunt trauma (e.g., being hit by an object) was the second leading cause of TBI, accounting for about 15 percent of TBIs in the United States for 2006–2010.
  - Close to a quarter (24 percent) of all TBIs in children less than 15 years of age were related to blunt trauma
- About 75 percent of all assaults associated with TBI occur in persons 15 to 44 years of age.

## RISK FACTORS

- Among TBI-related deaths in 2006–2010:
  - Men were nearly three times as likely to die as women.
  - Rates were highest for persons 65 years and older.
- The leading cause of TBI-related death varies by age.
  - Falls were the leading cause of death for persons 65 years or older
  - MVAs were the leading cause for children and young adults ages 5-24 years
  - Assaults were the leading cause for children ages 0-4.

## HEALTHCARE UTILIZATION

- Over the past decade (2001–2010), while rates of TBI-related Emergency Departments (ED) visits increased by 70 percent, hospitalization rates only increased by 11 percent and death rates decreased by 7 percent.
- Among non-fatal TBI-related injuries for 2006–2010:
  - Men had higher rates of TBI hospitalizations and ED visits than women.
  - Hospitalization rates were highest among persons aged 65 years and older.
  - Rates of ED visits were highest for children aged 0-4 years.
  - Falls were the leading cause of TBI-related ED visits for all but one age group.
  - Assaults were the leading cause of TBI-related ED visits for persons 15 to 24 years of age.
- The leading cause of TBI-related hospitalizations varied by age:
  - Falls were the leading cause among children ages 0-14 and adults 45 years and older.

## Canadian Statistics

Sources:

CIHR Institute of Neurosciences, Mental Health and Addictions website. <http://www.cihr-irsc.gc.ca/e/45665.html>

Cusimano, Dr. Michael, St. Michael's Hospital, University of Toronto in CIHR Institute of Neurosciences, Mental Health and Addiction (2012). *New Opportunities in Traumatic Brain Injury Research: Advancing the National Agenda Workshop Report Toronto ON April 12-13, 2012.*

## CHARACTERISTICS OF TBI

- The epidemiology of civilian mild traumatic brain injuries reveals that two-thirds occur in males and TBIs are common among the young and the elderly.
- Acute and long-term risk factors associated with youth and sports-related concussions are a major concern.
- TBI accounts for the third-highest number of hospital days in Canada.
- TBI accounts for half of all deaths from trauma

## IMPLICATIONS

- There is increasing evidence that multiple mild TBIs may pre-dispose patients to early onset dementia, later substance-use disorders and mental illness.
- One trend that will have a major influence on TBI in Canada is that the proportion of elderly people that is expected to be about 26 percent of the population by 2025.
- While reliable, specific data on the financial costs of TBI are lacking, falls cost the Canadian economy about \$7 billion each year, with direct costs from TBI estimated at about \$151 million.
- U.S. cost estimates of TBI are estimated at \$76 billion annually which include direct (i.e., healthcare) costs and indirect (i.e., productivity) costs; Canada's costs can be extrapolated to about \$10 billion.

## Nova Scotia Statistics

Sources:

Brain Injury of Nova Scotia. (2007). *Needs Assessment Report.*

Emergency Department Information System. QE II Health Sciences Centre . Data provided in January 2017.



Green, R., Kureshi, N., Fenerty, L., Thibault-Halman, G., Erdogan, M., Walling, R., & Clarke, D. (2016). *Characteristics and patterns of major traumatic brain injury in Nova Scotia – a 13 year retrospective analysis*. Poster presented at the Canadian Association of Emergency Physicians

Provincial Data Summary from Nova Scotia Trauma Program (2014). *Trauma Registry Report on Injury in Nova Scotia Provincial Report for Data Year 2012-13*.

## INCIDENCE

- There were 5816 trauma cases admitted to Nova Scotia hospitals in 2012-13.
- For 2012-13, there were 1051 major trauma cases; approximately 50 percent or 525 of these cases experienced some level of TBI (defined by the Trauma Program as injury to the head and neck body region)

## CAUSES

- In patients under 40 years of age, most TBIs were due to MVAs.
- Falls were the most common mechanism of injury in patients aged  $\geq 40$  years.
- The most common places of injury for major trauma cases were streets and highways and home.

## RISK FACTORS

- Incidence of TBI increased with age and was highest in the  $\geq 60$  age group, as was TBI-related mortality.
- The ratio of males to females with major trauma cases was 2.5:1.
- Rates of TBI varied with geographic locations, ranging from 24.5 to 65.4 injuries per 100,000 population (see map at end of this appendix)

## HEALTHCARE UTILIZATION

- The highest percentage of all hospitalized trauma cases (n=5816) and major trauma cases (n=1051) were aged 65 years and older.
- As shown in following table, between 2001 and 2006,
  - 2,380 people were admitted to NS hospitals with a diagnosis of TBI; over the five-year period the increase was 13.7 percent.
  - These statistics do not include cases to the ED who were not admitted to hospital or mild injuries that were not reported to the health care system.

**NS Hospital Admissions For Inpatient Cases Based On Diagnoses Of TBI**

Year	Inpatient Cases Based On Diagnoses Of TBI
2001-02	460
2002-03	466
2003-04	420
2004-05	511
2005-06	523
<b>Average</b>	<b>476</b>
<b>Total</b>	<b>2380</b>

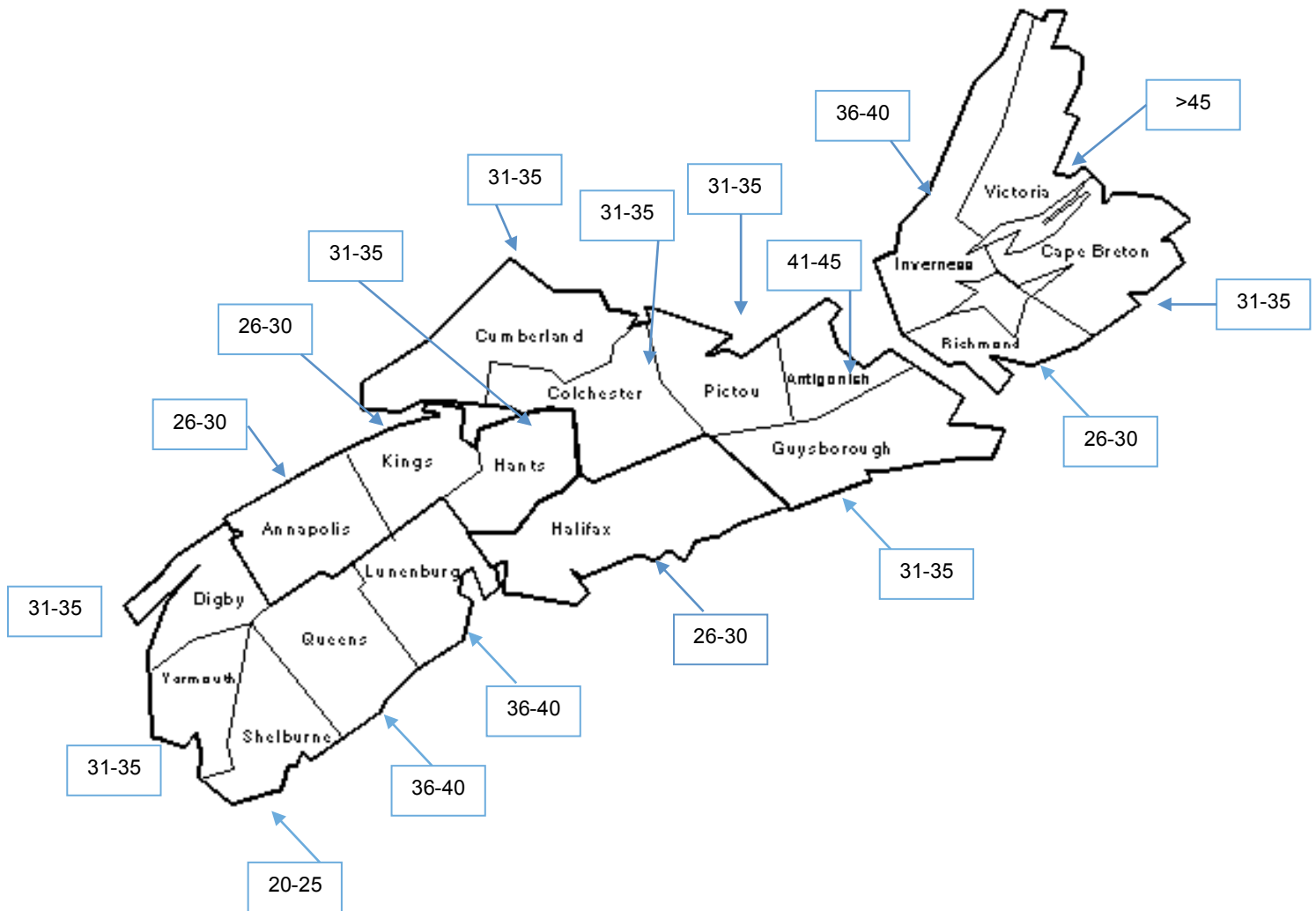
Source: Brain Injury of Nova Scotia. (2007). *Needs Assessment Report*.

- According to the QEII Emergency Department Information System, for the years 2014 to 2016, the Central Zone of the NSHA
  - Experienced a rise in number of ED visits for TBI cases (n=689; n=755; n=791) which represented a 14.8 percent increase.
  - The number of ED visits for TBI cases in persons over the age of 65 grew from 179 in 2014 to 226 in 2016 which represents an increase of 26.2 percent.
  - While the vast majority of cases with TBI were not hospitalized, the percentage of cases presenting to the EDs in Central Zone were that were discharged to their communities decreased from to 6.8 percent (645/689) in 2014 to 3.1 percent (767/791) in 2016.

**IMPLICATIONS**

- In Nova Scotia, TBI is a significant cause of morbidity and mortality; approximately 50% of major traumas seen annually in the province involve TBI.
- Rates of TBI varied with geographic location, ranging from a low of 24.5 to high of 65.4 injuries per 100,000 population; the low rates occurred in the southwestern area of the province while the highest rates were in the Cape Breton County of Victoria and Antigonish County.
- Incidence of TBI increased with age and was highest in the ≥ 60 age group, as was TBI-related mortality.
- TBI is an important issue in Nova Scotia, especially given the high proportion of elderly persons.

**Rates of TBI Per Capita in NS Counties  
2002-2015 (Green et al, 2016)**



## APPENDIX B – ESTIMATE OF TBI CASES FOR NS

The statistics for TBI in Nova Scotia are based on 2010 Canadian data for TBI found in Caro (2011). This research estimated that 192,000 people in Canada were affected by TBI in 2010 and using this baseline data, various indicators for NS were calculated as shown in the table below. The data for TBI cases in NS were extrapolated using the Nova Scotia proportion of the Canadian population which is 2.8 percent. The incidence for NS is estimated at 5,376 cases. There were 4,400 visits to emergency departments. TBI hospital admissions were projected at 896 per year. Earlier research by the Brain Injury Association of Nova Scotia from 2007 reported an average of 476 hospitalizations between 2001 and 2005<sup>36</sup>.

### ESTIMATES OF TBI CASES FOR NOVA SCOTIA IN 2010 IMPUTED FROM CANADIAN DATA

Category	Jurisdiction	
	Canada	Nova Scotia See note 2 for methodology used to calculate number of TBI cases
Estimated Numbers for 2010 See note 1 for data source		
Population	34,125,000	938,183
Total Number of TBI Cases (incidence)	192,000	5376
Pre-Hospital Deaths	4,400	123
Hospital Deaths	1,560	44
Emergency Department Visits	158,000	4424
TBI Hospital Admissions	32,000	896
Discharged Cases with TBI Disabilities	9,000	252
TBI Mortality Cases	6,000	168
Population Living with TBI Disabilities (prevalence)	670,000	18,760
Direct and Indirect Costs (US\$)	\$6,760,000,000	189,280,000

Note 1 - Caro, Denis HJ (2011) Traumatic Brain Injury Care Systems: 2020 Transformational Challenges *Global Journal of Health Science*, 3 (1); 19-29.

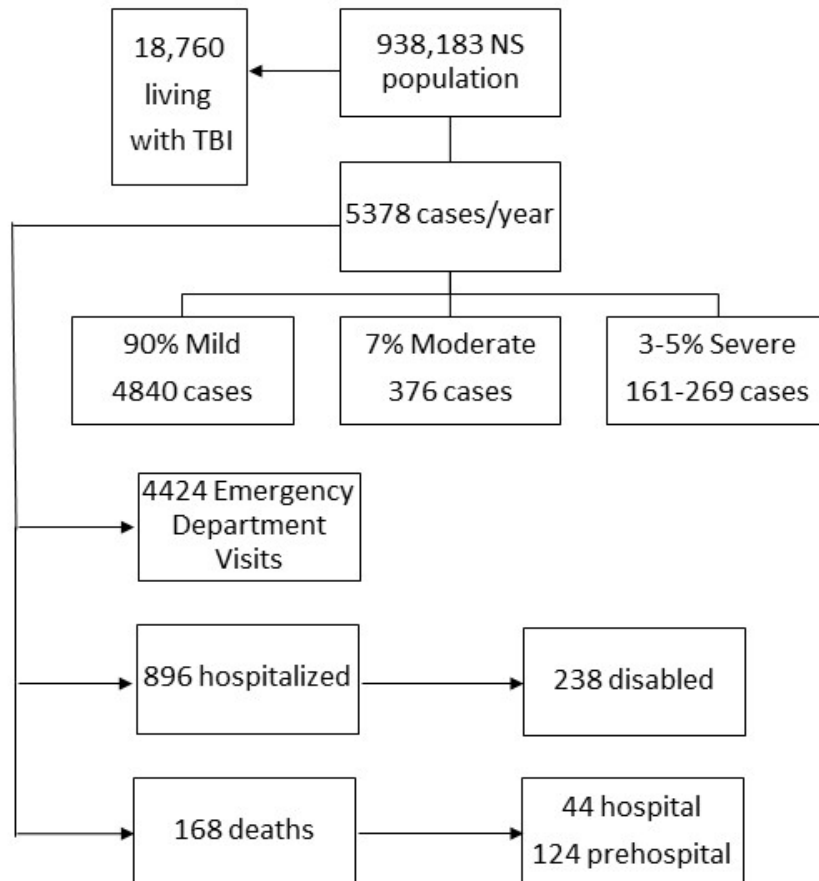
Note 2 - The NS TBI cases were calculated based on imputing 2.8% of Canadian TBI cases, since the proportion of NS population is 2.8% of the Canadian population

<sup>36</sup> Brain Injury Association of Nova Scotia. (2007). *Needs Assessment*. Unpublished Report.

Using Caro's (2011) estimate of 192,000 people in Canada being affected by TBI in 2010 various incidence rates were calculated for Nova Scotia as shown in the snapshot below.

## Snapshot of TBI in NS

*Data inputted from Caro (2011).*



## APPENDIX C – NS COST ESTIMATES FOR TBI CASES

The following table illustrates annual costs for both new and ongoing TBI cases in NS. Caro (2011) provided timely access to data we needed to calculate estimates of spending by government on healthcare costs and approximations of productivity costs from lost income due to temporary and permanent disability. However, we recognize the limitations of using these data, but it is the best evidence available.

### NS GOVERNMENT COST ESTIMATES FOR TBI CASES

Type of Service	Total Number of Cases for NS See Note 1	Unit Cost per TBI Case See Note 2	Estimated Annual Cost for Nova Scotia
Emergency Department Visits	4424	\$187	\$827,288
Hospital Admissions	896	\$19,083	\$17,098,368
Inpatient Rehabilitation	896	\$5363	\$4,805,248
Physicians	896	\$3242	\$2,904,832
Home Care	896	\$722	\$ 646,912
Total Healthcare Spending For Incidence of 896 TBI Cases		\$28,410	\$25,455, 648
<b>Annual Cost of Healthcare Including 896 Hospitalized TBI Cases + ED visits</b>			\$26,282,648
<b>Annual Cost Of Healthcare for Prevalence of 18,760 Cases</b>	18,760	\$2580	\$48,400,800
<b>TOTAL HEALTHCARE COSTS</b>			\$74,683,800
<b>TOTAL PRODUCTIVITY COSTS ESTIMATED</b>			\$114,596,200
<b>TOTAL ANNUAL COSTS OF NONFATAL TBI FOR NS</b>			\$189,280,000

Note 1 – TBI statistics are estimated using Canadian TBI cases extrapolated from Caro, Denis HJ (2011) Traumatic Brain Injury Care Systems: 2020 Transformational Challenges *Global Journal of Health Science*, 3 (1); 19-29.

Note 2 – Unit costs for healthcare services are based on Ontario fees as published in Chen, A., Bushmeneva, K., Zagorski, B., Colantonio, A., Parsons, D., & Wodchis W.P. (2012) Direct cost associated with acquired brain injury in Ontario. *BMC Neurology*, 12:76 -87