



ACADEMIC RESEARCHERS' WORKSHOP

April 3, 2009

Summary Report

Submitted to:

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The Atlantic Partnership for Tomorrow's Health (PATH)
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1. INTRODUCTION AND OVERVIEW

INTRODUCTION

Dr. Louise Parker, Principal Investigator of the Atlantic PATH Research Study welcomed participants and opened the workshop by indicating that the ultimate goal of the project is to create a framework for the study of cancer etiology in Canada with a focus on life style factors, environmental exposures and gene-environment interactions. This scope of the analysis could be broadened to include other determinants of health and health outcomes (e.g., chronic disease).

Dr. Parker emphasized that this is an Atlantic Canadian study and should be viewed from the perspective of working collaboratively across the four provinces to meet the objectives of the study.

The major challenges the study faces to date are:

- Identifying a recruitment strategy that will satisfy the needs of this project and at the same time the requirements of privacy legislation; and
- Leveraging funding to support expanded data capture, data analysis, sustainability and development of a research agenda.

The purpose of this workshop was to engage the research community in the Atlantic PATH project, to ensure an integrated research agenda and the development of a strategy for targeted funding applications. More specifically, the objectives of the workshop were to:

- Build collaborations and partnerships;
- Identify research opportunities; and
- Begin building the Atlantic PATH research program.

Currently, the project is funded through the Canadian Partnership Against Cancer and will operate until March 31, 2012. The funding for conducting research associated with the collection of samples does not currently exist, but the hope is that the research community will seek funding to support various research undertakings in the future to take advantage of the data and samples collected from this large cohort nation-wide. A wealth of research collaboration opportunities will exist not just in cancer-related research but in areas such as chronic diseases. Dr. Parker encouraged participants to engage in active dialogue to

consider the collaborative research opportunities that will be available as this data bank and biorepository are established.

Fifty representatives participated – 29 from Nova Scotia, ten from New Brunswick, eight from Newfoundland and Labrador, two from Prince Edward Island, and one from Ontario.

The workshop agenda and participant list can be found in Appendices A and B, respectively.

OVERVIEW

The overview of the project was presented in the following three modules:

- Dr. Jennifer Payne, Project Manager – Progress Report;
- Dr. David Hoskin, Principal Co-Investigator – Biological Data; and
- Dr. Trevor Dummer, Academic and Research Director – Research Potential.

Progress Report

Dr. Jennifer Payne, Project Manager, presented the current status of the project. She explained that this is a cohort study that is being carried out in the four Atlantic Provinces. The volunteers (subjects/participants) will be followed for the next 30 years for cancer outcomes. However, the participants could also be followed for other diseases. The data collection includes demographic information, lifestyle information, family history, and health status; physical measures; and biological samples.

Participants must be Atlantic Canadian residents between the ages of 35 and 69 years and are being recruited using two approaches:

- On March 5th, there was a call for volunteers through the media. This approach was very effective and more than 2,000 responses were received.
- Invitation letters to individuals in the relevant age range are sent randomly on Atlantic PATH's behalf by BlueCross Medavie through an agreement with Nova Scotia Department of Health using MSI registration information targeting groups by age, sex, and geography of residence. Similar agreements with the other provinces will be sought in advance of participant recruitment in each province. However, the response to this approach has been less effective and is currently being reconsidered.

On average, participants' visits to the assessment centre take approximately two hours. Participants view an introductory video prior to giving consent. Having consented,

participants complete a series of questionnaires modules, have physical measures taken and provide biological samples (urine, saliva, blood, toenails). Initial processing of the blood is carried out at the Assessment Centre prior to shipment to the main laboratory at the MacKenzie Building at the QEII Health Sciences Centre.

The Assessment Centre is located in the West End Mall in Halifax, facilitating easy access and parking. It currently operates six days a week and each clinic is about five to six hours in duration. Each clinic can handle a maximum of 35 to 40 participants.

In Nova Scotia, participants consent to allowing their study data to be linked to health databases via their provincial health card number to allow for long term follow-up. The data and samples are all barcoded and personal identifying information is kept separate from both the data and biorepository to maintain privacy.

Biological Data

Dr. David Hoskin, Co-Principal Investigator is currently directing the biological capture for the project. He discussed the opportunities and challenges related to data capture and storage.

The biological samples include: blood (serum, plasma, buffy coat, erythrocytes), toenail clippings, saliva, and urine. All samples except toenails are processed and stored first in a conventional (-20 C) chest freezers and then moved to ultra-low temperature (-80 C) freezers for long-term storage. There are currently 5 freezer units for long-term storage of 300,000 PATH cryovials; and 1 freezer unit for storage of national samples. All freezers are on emergency power and have CO2 backup. Toenail samples are stored in a dry, dark cupboard at room temperature.

Project-related opportunities include:

- The collection of biological samples before the clinical onset of diseases such as cancer or other chronic diseases will allow for the investigation of previously unidentified exogenous and endogenous factors involved in the pathogenesis of the disease, without any confounding variables introduced by the metabolic effects of illness.
- The linkage of detailed epidemiological data with biological samples will greatly enhance their usefulness as a scientific resource.

Project related challenges include:

- Biological samples are a finite resource.

- Resources must be identified to maintain the biological sample repository beyond the five year time frame of the Atlantic PATH study and the associated national study.
- Freeze/thaw of the biological specimens must be minimized to prevent sample degradation; therefore additional infrastructure will be required once research studies are initiated.
- Inevitable sample deterioration over the 30 year lifetime of the study will introduce confounding variables that may preclude certain types of analyses at later dates.

Research Potential

Dr. Trevor Dummer, Academic and Research Director, explained that the purpose of this workshop is to begin to explore the research potential that exists as a result of this large-scale data collection project and begin to build collaborative research networks.

The questionnaires collect a significant amount of information about family history, home environment, education and occupation, health and lifestyle, personal physical characteristics, and nutrition and physical activity. Residential history will allow us to accurately georeference individuals and link Atlantic PATH data to many socio-economic and environmental datasets. (Participant invitation letter and questionnaires can be found on the Atlantic PATH website: <http://atlanticpath.ca>.)

Funding currently exists to collect data and create the biobank of samples. Additional research funding will need to be sought to carry out any research using this data. This presents considerable opportunity to collaborate on a wide range of interdisciplinary research possibilities.

Questions from Session Participants

Q: How many participants came from the volunteer group and how many came from MSI?

- A: MSI recruitment started after the initial call for volunteers and has not been very high; approximately 5% response rate to each MSI mailing.

Q: Dalhousie University – regarding ethics: is there an obligation to inform high risk participants of their results?

- A: We give participants information on their measurements (e.g. blood pressure). We would advise them of the normal range. There are critical measures thresholds where we would strongly recommend that they visit their physician. We cannot tell them about the analysis as this will occur in the future and as a result of the

anonymity associated with the data, we will not be able to link the analysis to a specific individual.

Q: How will you store the samples given that each study or specimen has different requirements for storage?

- A: We are collecting samples without knowing what sort of studies will be carried out in the future. All samples are stored at -80C to prevent hemolysis. That is one of the real challenges because we don't know what sort of tests will be available in 20 years from now.

Q: Can the participants be cancer survivors?

- A: The only criteria for selection is age and residence in the Atlantic Provinces.

KEYNOTE PRESENTATION

Professor Sir Alan Craft, Director, Northern Institute for Cancer Research (NICR) at the University of Newcastle-upon-Tyne, UK gave the keynote presentation. Professor Craft's presentation highlighted the benefits of large cohort studies for studying a specific area for disease outcomes. In the U.K. in Newcastle, in the 1940's a number of infants were dying due to infection. In 1947, one of the first cohort studies (The Newcastle 1000 Families) began including infants born in May and June 1947.

The importance of making the participants feel special is key to their continued participation in the study. Birthday cards were sent each year creating a sense of belonging. When a reunion was organized for the participants' 50th birthdays, 350 of the original participants attended. Throughout their lives, these participants have felt that they were part of an incredibly important study. (For more information, see website: http://www.ncl.ac.uk/plerg/Research/1000F/1000_home.htm)

Professor Craft pointed out that in Nova Scotia, the incidence of cancer is higher than in the rest of Canada. For every 500 men who get cancer in British Columbia, there are 675 in Nova Scotia. The Atlantic PATH study will provide excellent opportunities to determine the effect of our environment on cancer incidence and provide us with ways to potentially implement controls.

2. GROUP DISCUSSIONS

Session attendees were divided into four groups and were asked to brainstorm ideas related to funding opportunities; research strategies; and research strengths and interests.

FUNDING OPPORTUNITIES

What are the funding opportunities and how can we leverage Atlantic PATH funding to increase research capacity and income?

The following summarizes the discussion:

- Leverage funding from the Canadian Partnership Against Cancer (CPACC) to attract other research funding from a variety of groups including specific disease-related interest groups, those focused on specific populations (e.g. Acadians, African Canadians), NGOs and government.
- Build partnerships with and connections to medical schools and hospitals; and provide training opportunities for students that will attract interest and funding from more narrowly focused education-related funding organizations.
- Combine efforts with other national studies such as the National Ageing study and various wellness strategies, and seek partnerships with 'hard to reach' groups such as the National Adult Literacy Database.
- Extend access to the data to other chronic disease research.
- Share infrastructure with other, already established initiatives such as Genome Atlantic.
- Seek unrestricted grants from pharmaceutical companies and other private sector companies such as Blue Cross.
- Identify and seek opportunities to develop industry and government partnerships.

A list of various funding agencies and organizations that were mentioned by session participants is summarized in the table below:

FEDERAL FUNDING AGENCIES	PROVINCIAL AGENCIES
<ul style="list-style-type: none"> • Canadian Institutes of Health Research • Natural Science and Engineering Research Council • Northern Community Investment Corporation • Canada Foundation for Innovation • Canada Mortgage and Housing Corporation • Genome Canada • Health Canada - Tri-Council • Public Health Agency of Canada • ACOA • National Research Council 	<ul style="list-style-type: none"> • Department of Health and Community Health Services • NL Innovation Research Fund • N.B. Research Council • Newfoundland and Labrador Centre for Applied Health Research • N.B Health Research Foundation • N.S. Health Research Foundation • P.E.I. Research Institute
OTHER FUNDING GROUPS	DISEASE SPECIFIC FOUNDATIONS
<ul style="list-style-type: none"> • Atlantic Innovation Fund • Terry Fox Foundation • University Vice-Presidents Academic • Private funding agencies focused on special populations • Springboard Nova Scotia • Jane Way Foundation (NL) 	<ul style="list-style-type: none"> • Various disease-specific foundations and associations • Various cancer organizations

ROLE OF GOVERNMENT

The role of government is multi-faceted and the group felt that government should be involved in this project in a variety of ways. A strong case was made to involve government early in the Atlantic PATH project to achieve buy-in and support. Government should be asked how it would like to participate and engaged in exploring its interest in the project and the data.

The following items were mentioned as the possible roles that the government could play in this project:

In-kind support

- Similar to the type of support given to the Population Health Research Unit based at Dalhousie
- Each province could take a turn at hosting research conferences supported by government.
- Promoting and facilitating infrastructure sharing.
- Creating awareness of the project by -
 - Encouraging the public to participate;
 - Increasing networking opportunities; and
 - Recognize the value of the research publicly (which would also help to engage the general public).

Education/ Research

- Educate the public on the importance of prevention; and
- Create opportunities to study health-specific issues within provinces.

Policy Development

- Create advisory boards with scientists and health researchers, and clinicians to help government understand the issues;
- Use the knowledge provided by this study to proactively inform policy and program development;
- Link to wellness strategies, poverty reduction and other related strategies.

Provide Leverage

- Link to provincial health funding and research agencies; and
- Link with various provincial databases such as the workers' compensation boards.

RESEARCH STRATEGY

What does our research strategy look like and how do we move it forward?

The following themes emerged from the discussion around the research strategy:

CREATION OF A STRUCTURE

- The creation of a structure that promotes collaboration and includes -
 - A steering committee with provincial working groups;
 - Research clusters potentially developed around research themes that could have linkages to related NGOs;
 - Ongoing opportunities for interaction through web-based collaboration /communication tools and face-to-face meetings, workshops and conferences, to share research activities, discuss funding opportunities, facilitate knowledge-sharing, etc.; and
 - Research strategies for each province in the Atlantic region.

PUBLIC POLICY & KNOWLEDGE TRANSLATION

- Promotion of collaborative and interdisciplinary research with the goal of informing government policy-makers and influencing public policy.
- A key focus of the research strategy must be on knowledge translation and mobilizing knowledge. It should be inclusive from a geographic and social perspective.

DATA ACCESS & LINKAGES

- Establish centralized data access and develop linkages with other data sources such as -
 - E-health records to help link the data and biorepository information to other data sources; and
 - Pharmaceutical research databases as a resource to link to PATH.
- Develop protocols for access to data to ensure consistency of sampling protocols and preservation methods for later re-examination with new techniques.

LONG-TERM PARTICIPANT ENGAGEMENT

- Engage initial participants to maintain their involvement - participants need to be trusting of the study and see some feedback from it to maintain linkages over long term. Volunteers from disease advocacy groups could be approached to assist.

INCREASE AWARENESS

- Increase awareness about PATH and its opportunities through -
 - Workshops, conferences;
 - Meetings with government officials to explain advantages and opportunities;
 - Inclusion of NGO communities into specific themes;
 - Involvement of researchers, policy-makers, lawyers from the beginning; and
 - Use of media to leverage knowledge and understanding of the value of the research.
- Emphasize the general applicability of the data to different diseases, environmental situations, etc.

RESEARCH STRENGTHS AND INTERESTS

What are our research strengths and interests and how do we develop them for short, medium and long term activities?

Each province has unique assets that can be leveraged for this study. When combined, the assets of all the Atlantic Provinces with respect to cancer research and health research in general are broad and diverse. Some of the strengths that were mentioned include:

- Multidisciplinary collaboration
 - Because of the isolation of the region, Atlantic Canada is accustomed to establishing collaborations; and
 - There are large groups of well-qualified researchers at universities and tertiary care hospitals.
- Stable population base
 - Conducting research in Atlantic Canada is appealing because there is a stable population in small communities, and a wide age range allows for sub-analysis.

- Infrastructure is in place in all the provinces and there is ready access to human resources. Graduate students can be readily attracted to research projects.
- Geomatics research and education is found in a variety of schools in the region.

BUILDING ON OUR RESEARCH STRENGTHS

SHORT TERM	MEDIUM TERM	LONG TERM
<p>Open lines of communication and educate others in each province (beyond cancer)</p> <ul style="list-style-type: none"> • Break down silos by bringing people together • Organize networking activities – stop reinventing the wheel • Develop a communications strategy 	<p>Build on other research activities</p> <ul style="list-style-type: none"> • Create opportunities for studying chronic diseases • Promote multidisciplinary collaborations 	<p>Track outcomes of lifestyle and health</p>
<p>Invite non-traditional and what might be perceived to be non-related research</p>	<p>Preserve samples “very carefully” – keep up with technology to optimize research opportunities</p>	<p>Carry out comparative studies among the Atlantic Provinces</p>
<p>Engage in strategic promotion of marginal populations</p>	<p>Develop more relationships between industry and the research communities</p>	<p>Ensure knowledge translation</p>
<p>Seek funding to recruit targeted communities</p>	<p>Give back to the participants so they stay involved</p>	<p>Develop research capacity by recruiting and educating researchers for the long term</p>
<p>Clarify guidelines for access to data</p>		<p>Recruit more than 30,000 participants over the long term</p>

3. SUMMARY AND NEXT STEPS

Dr. Parker closed the session by reiterating the importance of collaboration across the Atlantic region for this study to be successful. She indicated that the roll-out of the assessment centres and the collection process will be known in the next few months and will be communicated by the next meeting. She also invited suggestions for how to provide researchers access to the repository of information that is being accumulated.

It was agreed that Atlantic PATH would create the Atlantic PATH Research Network. Individual researchers will be able to join this network, which will act as a focal point for updating the research community on Atlantic PATH and facilitate bringing together researchers to develop research studies.

It was further agreed that the group would meet twice each year at six-month intervals. The next meeting will take place in early fall, 2009; the meeting should occur in another province and any organization interested in hosting should get in touch. The focus of this workshop will be on developing specific research projects.

APPENDICES

Appendix A – Meeting Agenda

Appendix B – List of Participants

Appendix A – Agenda

MEETING AGENDA		
Item #	Item	Planned Duration
1.	Registration and coffee	10:30 – 11:00
2.	Introduction to workshop: aims and objectives	11:00 – 11:10
3.	Overview of Atlantic PATH – Progress report – Biological data – Research potential	11:10 – 11:50
4.	Keynote presentation – Professor Sir Alan Craft	11:50 – 12:10
5.	Lunch	12:10 – 12:40
6.	Introduction to breakout sessions	12:40 – 12:45
7.	Break-out sessions: – What are the funding opportunities and how can we leverage Atlantic Path funding to increase research capacity and finding income? – What is the role of the Provincial Government? – What are our research strengths and interest and how do we develop these for short, medium and long term activities? – What does our research strategy look like and how do we move this forward?	12:45 – 2:15
8.	Break- out sessions – reporting back and plenary discussion	2:15 – 2:45
9.	Summary and next steps	2:45 – 3:00

Appendix B – List of Participants

NAME, ORGANIZATION & PROVINCE	NAME, ORGANIZATION & PROVINCE
• Chris Blanchard, Dalhousie University, NS	• Colin MacDonald, GeoNova, NS
• Dan Coulombe, Department of Health, NB	• Patrick McGrath, IWK Health Centre, NS
• Georges Corriveau, NRC, NB	• Jenny MacKey, PEI Department of Health
• Bronwyn Davies, Department of Health, NB	• Dawn MacLellan, IWK Health Centre, NS
• Gail Dechman, Dalhousie University, NS	• Peter Nestman, Dalhousie University, NS
• Ron Dewar, Cancer Care Nova Scotia, NS	• Rodney Ouellette, Atl. Cancer Research Institute, NB
• Elizabeth Dicks, Memorial University, NL	• Lynn Power, ARNNL, NL
• Susan Evans, Dalhousie University, NS	• Geoff Porter, Dalhousie University, NS
• Conrad Fernandez, IWK Health Centre, NS	• Sieu Phan, National Research Council, ON
• Judith Fisher, Dalhousie University, NS	• Daniel Rainham, Dalhousie University, NS
• Ellie Flick, Atlantic Health Science Corp., NB	• Joan Sargeant, Dalhousie University, NS
• Vereesh Gadag, Dalhousie University, NS	• Natalie St. Jacques, Cancer Care Nova Scotia, NS
• Jennifer Girard, Doctors Nova Scotia, NS	• Andrea Simpson, Public Health Agency of Canada - Atlantic Region, NS
• Jane Green, Memorial University, NL	• Chris Skedgel, Dalhousie University, NS
• Roger Green, Memorial University, NL	• Sharon Smith, Eastern Health, NL
• Duane Guernsey, Dalhousie University, NS	• Dan Tulpan, National Research Council, NB
• Meghan Hamel, PEI Dept. of Health, PEI	• Peter Wang, Memorial University University, NL
• Jill Hatchette, IWK Health Centre, NS	• Hao Wang, Dalhousie University, NS
• Grace Johnston, Dalhousie University, NS	• Yunli Wang, National Research Council, NB
• Tobias Karakach, National Research Council, NS	• Cathie Watson, Cancer Care & Support Services, NS
• Anne Kearney, Memorial University, NL	• John Walter, National Research Council, NS

NAME, ORGANIZATION & PROVINCE	NAME, ORGANIZATION & PROVINCE
<ul style="list-style-type: none"> Melanie Keats, Dalhousie University, NS 	<ul style="list-style-type: none"> Fran White, Department of Health, NB
<ul style="list-style-type: none"> Elizabeth McGibbon, St. FX University, NS 	<ul style="list-style-type: none"> Michael Woods, Memorial University, NL
<ul style="list-style-type: none"> Rhoda MacCormick, Cape Breton University, NS 	<ul style="list-style-type: none"> Pollen Yeung, Dalhousie University, NS
<ul style="list-style-type: none"> Ted McDonald, University of New Brunswick, NB 	<ul style="list-style-type: none"> Bin Zhang, Department of Health, NB

ATLANTIC PATH STAFF	OTHER PARTICIPANTS
<ul style="list-style-type: none"> Louise Parker, Principal Investigator 	<ul style="list-style-type: none"> Alan Craft, Newcastle University, UK
<ul style="list-style-type: none"> David Hoskin, Co-Principal Investigator 	<ul style="list-style-type: none"> Chris Hornberger, Halifax Global (Facilitator)
<ul style="list-style-type: none"> Trevor Dummer, Academic Director 	<ul style="list-style-type: none"> Julie Turcotte, Halifax Global (Note Taker)
<ul style="list-style-type: none"> Jennifer Payne, Project Manager 	
<ul style="list-style-type: none"> Rick Hyde, Communications 	
<ul style="list-style-type: none"> Chris Spencer, IT 	
<ul style="list-style-type: none"> Brian Hennigar, IT 	