Item 4.3

Family & Community Medicine
UNIVERSITY OF TORONTO

RESEARCH PROGRAM

Creating a Practice Based Research Network (PBRN) in the Department of Family and Community Medicine, University of Toronto

BUSINESS PLAN

PRESENTED TO DFCM EXECUTIVE FROM THE PBRN STEERING COMMITTEE

DECEMBER 20, 2011

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EXECUTIVE SUMMARY

The University of Toronto (UofT) Department of Family and Community Medicine (DFCM) proposes to embark on an exciting new journey with the creation of a Practice-Based Research Network (PBRN). A PBRN is a network of family physicians and other primary care clinicians and their practices, working together to answer community-based health care questions and translate research findings into practice.

In creating a PBRN, the DFCM will build on its existing research strengths and expertise, as well as on the enthusiasm and positive momentum of the PBRN planning retreat held in March 2011, which was attended by the DFCM Chiefs, researchers and other leaders from within the Faculty and research community. The North York General Hospital (NYGH) will play a pivotal role in the DFCM PBRN with the endowed Gordon Cheesbrough Chair in Family Medicine serving as the DFCM's PBRN Director.

This document outlines the business plan to initiate a DFCM-wide PBRN and ramp-up implementation over a 5 year period. An Interim PBRN Director and a Founding Board will initiate the PBRN research projects over the next 12-24 months, support pilot studies and provide seed funding for junior researchers, and begin to develop PBRN scientific, ethical, and financial policies and procedures. The PBRN will transition to a permanent Governing Board in 2014.

The DFCM Chairs office (@ $100,000/yr) and 14 DFCM Family Medicine Teaching Units (each @ $10,000/yr) are asked to share the vision and support the DFCM-wide PBRN initiative. These annual contributions will support core PBRN staff, operating costs through the 5-year start-up phase, provide seed funding, and grow the PBRN to the point where it can successfully secure large research grants and be self-sustaining by 2016. The PBRN's ability to become self-sustaining is predicated on the fact that there is growing recognition of the importance of primary care as the cornerstone of the Canadian healthcare system, and there is new interest in, and funding sources for, primary healthcare research.

The DFCM-wide PBRN will be able to capitalize on the "power of the collective" through engaging partners with similar interests and goals, collaborating with experienced researchers who have important clinical questions in the community, engaging funders and creating strategic partnerships. Creating the PBRN in collaboration with NYGH's endowed Gordon Cheesbrough Chair will position the PBRN for success. With the PBRN, community-based research will become a core part of the DFCM enterprise. It will also help integrate and further the objectives of DFCM's other key programs, including research, postgraduate and undergraduate education, and quality improvement.

INTRODUCTION

The University of Toronto Department of Family and Community Medicine (DFCM) is the largest Family Medicine training program in North America – possibly the world – with almost 1,200 faculty and 360 Family Medicine residents who serve a diverse patient population estimated at over 1 million patients. The department is recognized internationally for its clinical, educational and research excellence. Its 14 teaching units, 4 rural sites and 38 teaching practices are at the forefront of primary care renewal.

DFCM's research performance in 2010 included:

- Research grants - 72 peer-reviewed grants ($9,066,848 from 46 funding sources) and 13 non peer-reviewed grants ($4,724,867 from 11 funding sources);
- Publications – 220 peer-reviewed and 90 non-peer reviewed publications; and
- 8 Career Awards, including Career Scientists, Canada Research Chairs and Endowed Research Chairs.

With its research achievements, expertise in medical education, commitment to improved health outcomes, and the integration that already exists between community and academic practices, the DFCM is well situated to lead and facilitate a practice-based research network (PBRN). PBRNs are groups of family physicians and other primary care clinicians and practices working together to answer community-based healthcare questions and translate research findings into practice. PBRNs engage clinicians in clinical research, quality improvement activities, and an evidence-based culture in primary care practice to improve the health of all[1].

In March 2011 the DFCM held a PBRN planning retreat to:

1. Engage key stakeholders in developing a DFCM-wide PBRN;
2. Share knowledge and experience about other PBRNs in North America and abroad;
3. Articulate a vision, mission and guiding principles for a DFCM PBRN;
4. Explore and build consensus on a governance structure, business model and scientific oversight for a PBRN; and
5. Establish an action plan for creating a DFCM PBRN.

[1] Agency for Health Care Research and Quality

Participants in the retreat included DFCM leaders, DFCM researchers and individuals with PBRN expertise. There was a high level of buy-in and support for the DFCM to move forward with a PBRN. See *Appendix 1* for the PBRN Retreat Report Executive Summary.

Building from the retreat, this business plan proposes the creation of a DFCM-wide PBRN. Research conducted by the DFCM PBRN will be relevant to various audiences, including family physicians and other primary care clinicians and researchers, the university and hospitals, the Ontario Ministry of Health and Long-term Care, funders and patients. The objective of this document is to describe a business model for the PBRN, to be presented to the DFCM Executive Committee for discussion. This document outlines possible governance and operational structures, a start-up budget, and describes how the PBRN will transition to be a permanent DFCM entity.

We propose that DFCM move quickly to initiate the PBRN and promote name recognition. Although it may start with smaller projects, as the PBRN builds its reputation and capacity, it is anticipated that it will scale up to bigger projects over time.

The PBRN will play an important role in mentorship and building the DFCM's research capacity. The vision is that research conducted by the PBRN investigators will lead to new knowledge about important clinical questions that will be generalizable to community based primary healthcare. The ultimate goal of the PBRN is to allow researchers to conduct internationally relevant research, which will translate into improved quality and health outcomes for patients.

VISION (*to be determined*)

Options to consider:

- *Knowing more. Practicing for better health*
- *Improving health through research*
- *Community based research to improve primary healthcare*
- *Practice based research to improve primary healthcare*
- *Practice and community based research to improve primary healthcare*
- *Practice and community based research to improve health*

New Suggestions (that people have not considered):

- *Community research, community health, healthier citizens*
- *Community based research to improve health*
- *More knowledge. Better care. Improved health.*
- *Promoting better information, decisions and health* (part of BMJ article title)

MISSION

To improve the health of our patients and communities by collaboratively addressing primary healthcare questions and translating research findings into practice.

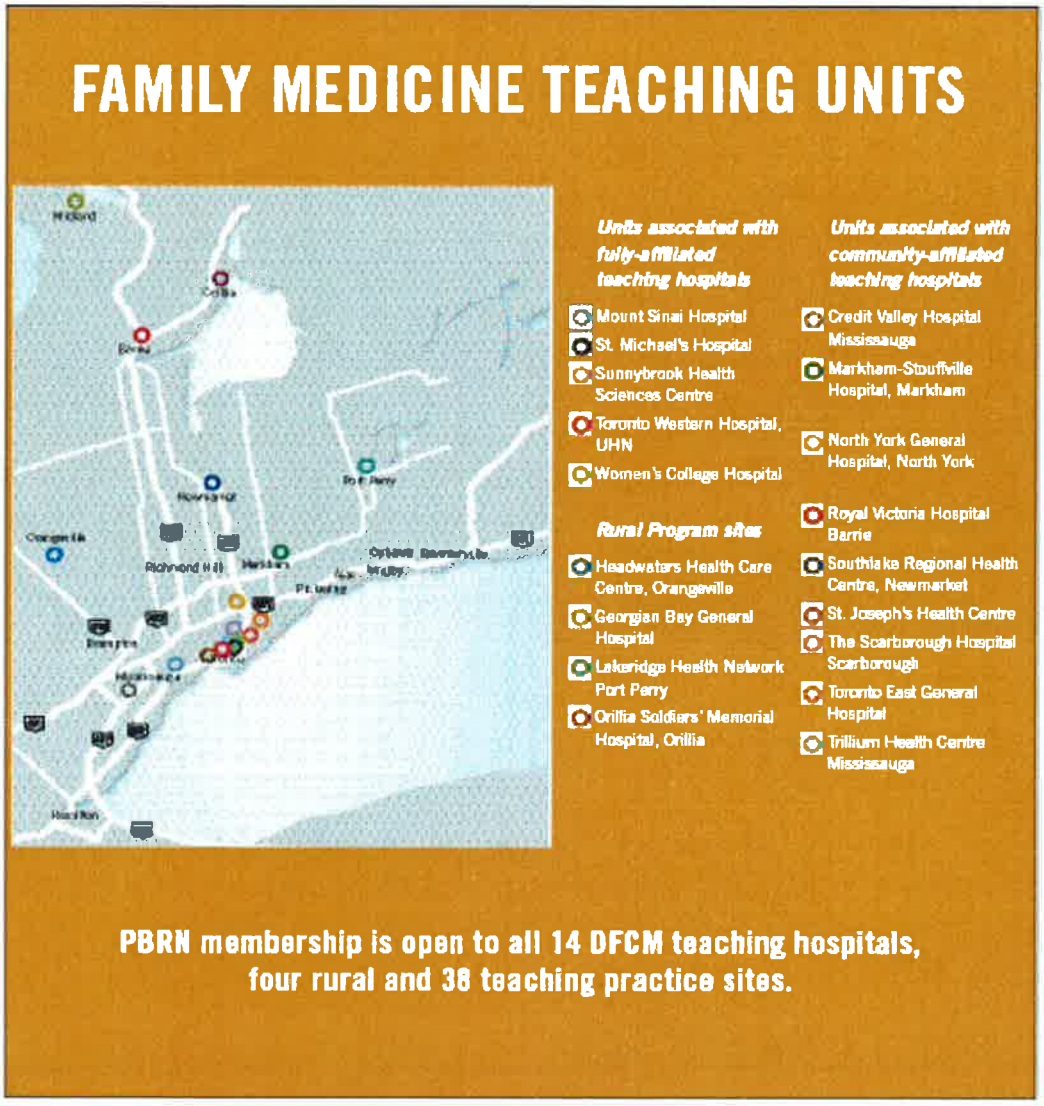
To fulfill our vision and mission, we will:

- Align with the mission, vision and values of the Department of Family and Community Medicine, the Family Medicine Teaching Units and teaching sites.
- Conduct a broad range of research including observational studies, intervention studies, clinical trials, and quality of care and knowledge translation research.

- Establish an evidence based culture in primary care practice that will be embraced by the inter-professional healthcare teams that work in the DFCM teaching practices and units.
- Conduct ethical and methodologically sound research.
- Engage current DFCM researchers and encourage new researchers through training and mentorship.
- Engage DFCM clinicians and trainees in enhancing their research skills and quality of care.
- Advance the timely translation of knowledge into practice and influence new directions for inquiry and research.

MEMBERSHIP

PBRN membership is open to all 14 DFCM teaching hospitals, 4 rural and 38 teaching practice sites.



GOVERNANCE STRUCTURE

FOUNDING BOARD

A PBRN Founding Board will be established with the following composition:

- DFCM Chair or designate;
- PBRN Interim Director (will Chair the Founding Board);
- FMTU Chief;
- DFCM Vice-Chair Education;
- DFCM Research Director;
- DFCM QI Director;
- AHRC Director;
- U of T researcher;
- 4 DFCM researchers (2 from community and 2 from academic sites); and
- Community representative with a business background.

The term of the PBRN Founding Board will be up to two years commencing March 2012.

In conjunction with an Interim PBRN Director, the mandate of the Founding Board will be to:

- Confirm PBRN membership, create an identity and begin to promote the PBRN;
- Work with North York General Hospital (NYGH) to recruit a permanent PBRN Director, who will also be the endowed NYGH Gordon Cheesbrough Chair;
- Establish the permanent PBRN governance structure, board and committees;
- Develop PBRN scientific, ethical, and financial policies and procedures;
- Develop a mechanism to address conflict or competition over resources;
- Develop data collection and management mechanisms;
- Initiate a PBRN Research Forum;
- Approve initial PBRN projects, provide letters of support to include in grant submissions and allocate project seed funding;
- Build strategic relationships and seek funding to support PBRN infrastructure costs; and
- Establish communications and KT strategies.

PERMANENT GOVERNING BOARD

The Founding Board will transition to a permanent PBRN Governing Board in 2014. The Founding Board will recommend how the permanent Board should be constituted and develop terms of reference for the permanent Board and its subcommittees. An example of a permanent governance structure is described in *Appendix 2* and includes an Executive Committee, Scientific Advisory Committee, Ethics Advisory Committee and Community Advisory Committee.

OPERATIONAL MODEL

LOCATION

We propose that the DFCM PBRN secretariat be located at North York General Hospital (NYGH). When appointed, the NYGH's new Gordon Cheesbrough Chair in Family Medicine will hold the position of DFCM PBRN Director. The advantages of this collaboration and of locating the PBRN at NYGH include:

- The focus of the new NYGH Gordon Cheesbrough Chair will be practice-based research.
- NYGH is a long-standing, community-based site within the DFCM with strong ties to community physicians and collaborative relationships with other hospitals.
- NYGH has years of experience in practice-based research with NorTReN (i.e. its own PBRN), which is also a member of the Canadian Primary Care Sentinel Surveillance Network (CPCSSN).
- The PBRN and the Gordon Cheesbrough Chair are new initiatives which are integrally linked together. A combined effort will allow both NYGH and the DFCM to maximize and streamline their efforts.

STAFFING AND BUDGET

Start-up

An Interim PBRN Director (0.5 FTE) will be hired for a one-year term starting January 2012. This interim position will be funded by the DFCM Chair's Office. It is anticipated that the permanent Gordon Cheesbrough Chair/PBRN Director will be in place January 2013, at which time NYGH's endowment fund will cover the costs of the Endowed Chair/PBRN Director. The DFCM Chair's Office will continue to make an annual contribution after Year 1 to support other PBRN operating costs.

A Research Associate/Administrator (1.0 FTE) will be hired to start January 2012 for a one-year term (renewable). This individual will work with the Interim PBRN Director to prepare policies/procedures, plan and manage meetings and events, prepare research grant proposals, support researchers and research projects, engage the PBRN members and researchers, and provide other administrative support. The DFCM Research Program and NYGH (*to be confirmed) will each cover half of this start-up cost in 2012. NYGH is committed to providing space for the PBRN Director and staff, as needed.

The DFCM Research Program office staff will support the start-up PBRN, as needed. These staff include: Research Director; Associate Research Director; Senior Biostatistician; Biostatistician; Research Program Coordinator; and Research Administrator. All other relevant DFCM programs (e.g. Library, Communications, Strategic Planning, etc.) will participate and support the PBRN during the start-up period, as needed.

The DFCM's 14 Family Medicine Teaching Units (FMTUs) will each be asked to make an annual $10,000 contribution to help support the PBRN operating costs, which include a Project Seed Fund that will help fund pilot studies and help junior and inexperienced researchers initiate research projects. The FMTUs are encouraged to seek support from their hospital foundations towards their PBRN contributions and their PBRN research.

Permanent

To be successful, the PBRN must have a predictable and steady financial base. As noted above, the DFCM and teaching units are asked to work together to help support base PBRN operating costs until such a time as the PBRN is self-sustaining.

As the PBRN grows, additional PBRN staff will be required to support research projects and central PBRN activity. The types of positions required include: PBRN Coordinator; Research Assistant(s); Research Associate(s); Data Manager; Statistician; Methodologist; and IT Support. Initially (and possibly longer-

term), the PBRN may wish to access the services of an organization like the Applied Health Research Centre (AHRC), which already has such staff in place. ARHC is located at St. Michael's Hospital and is a full service, academic, clinical research coordination centre for Phase II through Phase IV multi-centre clinical trials of varying size and across a range of therapeutic areas. AHRC provides scientific support, project management, data management, site management, trial monitoring and other services. AHRC builds its operating costs into grant proposals.

The base start-up cost of the DFCM PBRN is estimated to be $289,250 in Year 1, growing to $405,853 by Year 5 (see *Appendix 3*). The start-up budget represents a small number of core PBRN leadership and research administrative staff. The DFCM Research Program and/or AHRC would provide project development and research infrastructure support to the PBRN. Project implementation would be contingent on research projects being funded. The DFCM Executive is being asked to approve and support this start-up budget and core PBRN staff model.

As PBRN revenues increase, the PBRN can begin to contemplate expanded operating budget models. It is expected that the PBRN will be phased in over a 3-5 year period and by 2016 should be self-sustaining with demonstrated capability to secure and support itself through large grants (see the PBRN Implementation Timeline in *Appendix 4*). Where permitted, funding to support central PBRN infrastructure and administrative costs will be built into grant proposals. The PBRN should also seek a strategic partnership with a donor or a national/provincial organization that is able to support annual operating costs. Two scenarios of how the expanded PBRN operating budget might grow are presented in *Appendix 5*:

- Scenario 1 represents costs for a full capacity PBRN where the PBRN grows in 5 years to provide full services, including all project development, all research infrastructure, all EMR data collection and management, and all project-specific prospective data collection.

- Scenario 2 represents a hybrid model where the PBRN controls EMR data collection and management, but outsources where data are housed. The DFCM would continue to partner with AHRC for research infrastructure and managing project-specific prospective data collection.

These two scenarios build from the start-up budget as the PBRN develops and evolves. Again, the recommended approach is that the DFCM create the core start-up PBRN infrastructure and only begin to expand staff and infrastructure over time as PBRN revenues increase and are able to support expanded operating costs.

Once the PBRN is fully operational, it is anticipated that NYGH would be accredited to hold CIHR grants. To the extent possible, PBRN research funding will be consolidated and flow through NYGH (note: PIs will continue to choose whether to flow funds through their hospital site, the university, or they could flow them through the PBRN). NYGH will be responsible for administering PBRN funds and submitting annual audited financial statements to the DFCM. NYGH will need to build HR and financial infrastructure to manage the financial and accounting aspects of the PBRN.

RESEARCH PROJECTS, SCIENTIFIC PROCESS, RESEARCH METHODOLOGY, ETHICS

Start-up

The Interim PBRN Director will work with the DFCM's Research Program to establish the PBRN Founding Board by March 2012. The Interim Director will work with the Founding Board to develop interim research, ethics and financial policies and procedures.

A DFCM-wide PBRN Research Forum will be planned to be held in September 2012. The purpose of the Forum will be to bring the DFCM leaders and researchers together to review, amend and approve the interim policies and procedures and to make recommendations to the Founding Board about the PBRN's

initial research activity. The following information will also be presented at the Forum in order to initiate the PBRN's research activity:

- Research resources that already exist within the DFCM;
- Studies already underway or soon to be initiated;
- Brainstorming of research project ideas;
- A draft process re: how to determine which projects are important, have scientific merit, are doable and should go forward under the PBRN;
- A draft process re: how to support projects with seed funding; and
- Strategies re: where to apply for funding as a PBRN, or with other PBRNs.

The initial research projects are intended to promote the DFCM PBRN name recognition, to begin to build the PBRN's reputation and to promote buy-in. The focus will be small, easy, implementable projects. The PBRN will provide letters of support to PIs, as needed, indicating that the PBRN provides a venue for conducting research. The Project Seed Fund will provide $75,000 each year to fund pilot studies and help junior and inexperienced researchers initiate projects.

Once PBRN research projects are underway, and during this founding phase of the PBRN, there will be a flexible approach to research proposal development and implementation, i.e. current practice with respect to funding flow and project administration will prevail to meet the needs of researchers, institutions and hospitals.

Permanent

It will be important for the PBRN to have continuous activity and keep studies going at all times. While the PBRN is transitioning to its permanent structure, its focus should continue to be quick, successful, relevant projects, building the PBRN track record, yet also looking for opportunities to do larger studies.

The permanent PBRN will use a blended model of generating and implementing research ideas. Research projects will percolate up (bottom-up) from the Community Advisory Committee, teaching sites, individual clinicians and researchers, etc. Research ideas will also be identified by the Scientific Advisory Committee, Community Advisory Committee and/or Governing Board (top-down) based on strategic goals and partnerships. Projects will only be implemented at sites interested in participating in a given project.

Advantages of the blended model include:

- Promotes autonomy and engages people in studies that will make a difference in their own setting.
- Provides rules of engagement for all and a central coordinating structure to support research projects.
- Allows research questions to merge together methodologically in a way that will capture funding.
- Allows the PBRN to maximize strategic partnerships and tap into funding for strategic initiatives.

The Scientific Advisory Committee will be responsible for providing advice on, and overseeing the scientific, methodological and ethical parameters of, all future PBRN research projects. An Ethics Advisory Committee will work with the Scientific Advisory Committee to address ethical issues arising from PBRN research, such as:

- Obtaining physician and patient consent for all new data collection.
- Streamlining the process of obtaining multi-site ethics approval.
- Establishing policies around transmission of data.
- Establishing policies on pharmaceutical and medical device clinical trials.

DATA

Start-up

Flexibility will be exercised in the way the PBRN initially collects and stores data. There are three primary types of data that PBRN researchers will collect/use:

Type of Data	Housed
Project-specific, prospectively collected data to answer specific research questions, e.g. data collected in RCTs, surveys, etc.	Location TBD, e.g. NYGH; remains with the lead researcher; Applied Health Research Centre (ARHC)
Electronic Medical Record (EMR) data	FMTUs; some housed by eHealth or CPCSSN; other location TBD
ICES administrative data	ICES (including project-specific linkage of EMR data with ICES data)

Depending on the question(s) being asked, researchers may use one of the above data sources or they could use a combination of multiple data sources. The complexity of studies undertaken will be according to what is feasible for the stage of development of the PBRN. As the PBRN grows, data collection needs, privacy considerations and data storage will be determined on a project by project basis. In the case of large scale studies requiring complex prospective data or randomization, the DFCM may wish to partner with ARHC. In the case of projects that involve ICES data, the project will be conducted in conjunction with ICES researchers.

Permanent

The DFCM's teaching units and sites hold large amounts of patient data. As mentioned above, primary healthcare research data can be EMR based, it can be administrative data held by ICES, or prospectively collected data. Further investigation is required by the Founding Board to determine the best and most feasible approach to future PBRN data collection and management. Some options to consider are:

1) Data continues to exist in a number of locations (EMRs, ICES, etc.).
2) Consolidate EMR data in one location. This would require the DFCM to:
    a. Build its own central PBRN data warehouse (note: will need to seek one-time infrastructure funding to support this), or
    b. Hire this function out to an organization with expertise in data collection and management (e.g., eHealth, etc.).

Appendix 6 summarizes the status of EMR implementation in the DFCM's 14 FMTUs. *Appendix 7* explores various options re: data collection/management. These issues and options will be considered under the interim PBRN leadership to be finalized under the permanent leadership of the Gordon Cheesbrough Chair/PBRN Director, with a data collection/management plan to be tabled by the end of 2013. The approach taken for data collection/management will need to be reflected in the PBRN ongoing operating budget.

COMMUNICATIONS

Communications about the PBRN's activities and achievements are critical. Initially, the Interim PBRN Director will work with the DFCM Communications Coordinator to ensure regular PBRN updates are included in DFCM's existing communiqués. A PBRN listserve will be established for those in attendance at the PBRN Research Forum and all other interested parties will be welcomed to join.

Over the longer-term, the PBRN will engage a communications/KT officer and communication mechanisms will include but not be limited to the following:

- DFCM website;
- Listserve;
- Newsletter and News Digest;
- Annual meeting/event; and
- Site visits.

BUILDING RELATIONSHIPS

Key to the PBRN's success will be its ability to build relationships. The DFCM will need to raise awareness about the PBRN across the research community, the broad community of family physicians and other target audiences and stakeholders. Relationships must be established with key organizations that have funding and provide direction for future research priorities, such as:

- Agency for Health Promotion and Protection;
- Canadian Institute of Health Research;
- College of Family Physicians of Canada;
- Community Care Access Centres;
- Local Health Integration Networks;
- Ministry of Health and Long-term Care;
- Ontario College of Family Physicians;
- Physicians' Services Incorporated Foundation;
- Canadian Institute for Health Information; and
- Public Health Agency of Canada.

The PBRN should also build additional relationships, such as:

- Hospital Research Ethics Boards;
- Institute for Clinical Evaluative Sciences;
- Local research units, data management and IT teams within the hospitals;
- Other PBRNs;
- UofT departments that focus on interprofessional research (e.g., occupational therapy, physiotherapy, nursing);
- UofT graduate programs, e.g. Master of Public Health, Health Promotion; and
- UofT Vice-Dean of Research and the Research Ethics Board.

SUMMARY

This business plan outlines the key components of a DFCM-wide PBRN, including proposed governance, financing and how to initiate PBRN research projects. Creating the PBRN in collaboration with NYGH's endowed Gordon Cheesbrough Chair will position the PBRN for success. Investment by the DFCM and teaching units will provide the core infrastructure needed to grow the PBRN to the point where it can successfully secure large research grants and be self-sustaining.

The DFCM PBRN will be able to capitalize on the "power of the collective" through engaging partners with similar interests and goals, collaborating with experienced researchers who have important clinical questions in the community, engaging funders and creating strategic partnerships. Our ability to succeed is predicated on the following facts:

- There is growing recognition of the importance of primary care as the cornerstone of the Canadian healthcare system.
- There is new interest in, and funding sources for, primary healthcare research.
- The DFCM brings strength in numbers, diversity and wisdom of researchers, as well as diversity in patient populations. Building a PBRN within an academic network is powerful.
- The DFCM has a strong brand and is the largest department of family medicine in the country. With almost 1,200 faculty, opportunities are strong for developing partnerships with the community and for outreach to donors.
- With different family physician payment models (capitation), opportunities and time for participation in the PBRN are greater.
- Up-to-date data are already available and captured in a timely way. Current EMR implementation enables movement away from paper-based data collection.
- The DFCM is connected to world class knowledge translation (KT) expertise in Toronto and ample resources within UofT.
- Integration with NYGH, the DFCM's new QI Program and other DFCM programs will make the department and the PBRN stronger.

APPENDIX 1 – DFCM PBRN PLANNING RETREAT REPORT OF OUTCOMES, MARCH 11, 2011

EXECUTIVE SUMMARY

The Department of Family and Community Medicine (DFCM) held a PBRN planning retreat to:

1. Engage key stakeholders in developing a DFCM-wide PBRN.
2. Share knowledge and experiences about PBRNs.
3. Articulate a vision, mission and guiding principles.
4. Explore governance structures, business models and scientific oversight.
5. Build consensus on governance structures, business models and scientific oversight.
6. Establish an action plan for creating the DFCM PBRN.

Over the course of the day, the retreat achieved these objectives. Stakeholder engagement was manifest in the broad range of attendees: representatives from every DFCM teaching site, most DFCM Investigators, senior leaders from the Faculty of Medicine and invited PBRN leaders from Canada, the U.S. and U.K. Presentations and a variety of interactive formats generated lively discussion and built consensus that a DFCM-wide PBRN is both necessary and achievable.

Department Chair Lynn Wilson and Dean Catharine Whiteside opened the retreat by commending the foresight and readiness of the DFCM for developing a PBRN. An expert panel identified characteristics of successful PBRN's drawn from the literature and practical experience. Roundtable discussion groups identified key strengths, weaknesses, opportunities and challenges (SWOC Analysis). Further group work led to proposals for vision, mission, principles and organizational models. The day concluded with presentations on priorities for advancing the DFCM's PBRN.

The full report highlights the major points from presentations and group discussions. Appendices include the list of participants, biographies of all presenters and presentation slides. Records of small group discussions and evaluations of the retreat have been retained as archival documents.

The SWOC Analysis identified the following major issues:

Strengths: DFCM size and diversity, availability of data, local infrastructure in Teaching Units, a newly launched Quality Improvement (QI) Program, and strong links with world class knowledge translation (KT) expertise.

Weaknesses: multiple electronic medical record (EMR) systems, limited infrastructure support for some researchers, a perceived lack of awareness of research in family medicine, and difficulty engaging physicians.

Opportunities: for enhancing research, education and scholarship across the DFCM and for profiling family medicine within the health care system. PBRNs help to demystify research, enabling it to become an integral aspect of academic practice.

Challenges: tension between research ideas from community and funder-driven priorities, securing sustainable funding for an infrastructure, availability of reliable data, and engaging patients.

An idea-generating and consensus-building discussion method ("Round the World Café") led to a suggested mission statement: "*To collaboratively address primary care research questions and translate findings into practice to improve community health*". Two possible vision statements were put forward: *"Better Answers for Better Health" and "Knowing More. Practicing for Better Health"*. An extensive list of pragmatic principles was created, aligning with the DFCM mission and reflecting the Faculty's research role.

The recommended business model combined elements of both bottom-up and top-down approaches, balancing structure with autonomy - a collaborative group that engages people in a variety of roles and sites. Leadership at both the central DFCM and local levels will be essential, along with clinical, administrative and research expertise.

Identified priority actions were: establishing a governance structure with a Board and Executive for quick decisions as well as Community and Scientific Advisory Committees; leveraging EMRs; gaining small wins that reflect Ministry of Health and Long Term Care (MoHLTC) priorities; and developing appropriate metrics of progress and success.

Strategies to promote and *sustain* a research culture within participating sites include:

- Linking with QI initiatives
- Providing support for achieving performance incentives in exchange for participation
- Offering to train researchers
- Providing supervision of resident research projects

There was extensive discussion of the merits and risks of engaging in industry-sponsored research. As stated by a participant, "research transforms everything we do." Thus there is a responsibility to undertake trials that will inform clinical practice and address gaps in knowledge.

Priority actions for enabling effective use of EMR's for the PBRN include:

- Beginning with small but important projects
- Clean data including improved coding and data validation
- Aligning with DFCM's EMR Task Force and User's Group

To create buy-in at local sites it will be critical to have the support of the Chief and to identify a local primary care research champion. Forging relationships between community and DFCM researchers, among data management and IT teams, and with hospital research units will all position the DFCM PBRN for success.

In closing remarks, PBRN Steering Committee Chair David White provided a summation of the day's work: "We have begun to formulate our vision, mission, and business plan and laid a foundation from which to move forward. We need to be very clear of who we are serving, who we are doing the research for, and the importance in improving the lives of our patients. Today's deliberations have enabled the launch of a PBRN. If we start this up, we will not stop!" This report's recommendations will be presented to the Executive as the basis for launching a DFCM-wide PBRN.

APPENDIX 2 – EXAMPLE OF A PERMANENT PBRN GOVERNANCE MODEL

PBRN Board

The PBRN will be governed by a Board of 15-20 members. PBRN staff (PBRN Director and Coordinator) and the DFCM Research Director will sit as ex-officio members on the Board. Board membership could include:

- 2 representatives from the Scientific Advisory Committee
- 2 representatives from the Community Advisory Committee
- 1 representative from the Ethics Committee
- 2 Family Medicine Chiefs (1 from community site and 1 from academic site)
- 1 Resident
- 1 Inter-professional representative
- 3 or more representatives of DFCM core programs and teaching sites
- 2 or more representatives of Funding Organizations/Strategic Partners
- Others TBD

Executive Committee

Executive Committee membership could include:

- Chair of the Board
- Gordon Cheesbrough Chair/PBRN Director (will Chair the Executive Committee)
- Chair of the Scientific Advisory Committee
- Chair of the Ethics Advisory Committee
- Chair of the Community Advisory Committee
- Family Medicine Chief

- DFCM Research Director
- Quality Improvement Director or Chair
- DFCM Postgraduate and Undergraduate Program Directors
- Other PBRN staff as required (e.g. Coordinator, Financial officer, Communications officer)
- Others TBD

The Executive Committee will have authority to make PBRN business decisions on behalf of the Board.

Scientific Advisory Committee

Scientific Advisory Committee membership could include:

- Gordon Cheesbrough Chair/PBRN Director
- QI endowed Chair
- DFCM Research Director
- 4 researchers (2 from community sites and 2 from academic sites)
- 2 clinicians from PBRN sites
- Statistician and/or methodologist
- Others TBD

Ethics Advisory Committee

Ethics Committee membership could include:

- U of T Ethics representative
- 4 DFCM Ethics representatives (2 from community sites and 2 from academic sites)
- Others TBD

Community Advisory Committee

A Community Advisory Committee of 9-10 individuals could include key stakeholders such as:

- Community Care Access Centres
- Local Health Integration Networks
- Family Health Teams
- Public Health
- The United Way
- Patient representatives
- Business representative
- Others TBD

APPENDIX 3 – PROPOSED PBRN START-UP BUDGET

Start-up with core PBRN staff only; DFCM provides project development support and partners with AHRC for research infrastructure.
Project implementation is contingent on projects being funded.

	Year 1 (2012)	Year 2 (2013)	Year 3 (2014)	Year 4 (2015)	Year 5 (2016)	
EXPENSES						
Personnel Costs						**Notes:**
PBRN Director (0.5 FTE)	$100,000	NYGH in-kind	NYGH in-kind	NYGH in-kind	NYGH in-kind	After Year 1, this position will be covered by the Gordon Cheesbrough Chair endowment fund.
Research Associate (1.0 FTE)	$81,250	$83,688	$86,198	$88,784	$91,448	$55,000-75,000/yr plus 25% benefits; assume $65,000; 3% annual increase.
PBRN Coordinator (1.0 FTE)			$75,000	$77,250	$79,568	$55,000-70,000/yr plus 25% benefits; assume $60,000; 3% annual increase.
Research Assistant (0.5 FTE)			$28,125	$28,969	$29,838	$45,000-60,000/yr plus 25% benefits; assume $45,000; 3% annual increase.
Subtotal	**$181,250**	**$83,688**	**$189,323**	**$195,003**	**$200,853**	
Other Costs						
Meetings	$10,000	$10,000	$15,000	$15,000	$20,000	
Annual Membership Event			$35,000	$35,000	$35,000	
Travel (staff)	$5,000	$5,000	$5,000	$5,000	$5,000	
Supplies, Services	$3,000	$5,000	$10,000	$10,000	$15,000	
Communications/KT		$15,000	$20,000	$25,000	$25,000	
Professional Development (staff)	$5,000	$10,000	$10,000	$10,000	$10,000	
Marketing	$10,000	$20,000	$20,000	$20,000	$20,000	
Subtotal	**$33,000**	**$65,000**	**$115,000**	**$120,000**	**$130,000**	
Project Seed Funding	**$75,000**	**$75,000**	**$75,000**	**$75,000**	**$75,000**	Review seed funding after Year 3.
Total Expenses	**$289,250**	**$223,688**	**$379,323**	**$390,003**	**$405,853**	
REVENUES*						
DFCM Chair's Office	$100,000	$100,000	$100,000	$100,000	$100,000	Covers Interim PBRN Director in Year 1.
DFCM Research Program	$40,625					Covers half of the Research Associate cost in Year 1.
FMTUs Contribution	$140,000	$140,000	$140,000	$140,000	$140,000	$10,000 per FMTU.
NYGH (NOT CONFIRMED)	$40,625	NYGH in-kind	NYGH in-kind	NYGH in-kind	NYGH in-kind	Covers half of the Research Associate cost in Yr 1. Chair/PBRN Director costs are in-kind Yr2 on.
Donor or Strategic Partnership						
Total Funding	**$321,250**	**$240,000**	**$240,000**	**$240,000**	**$240,000**	
Grant Revenues Required	**($32,000)**	**($16,313)**	**$139,323**	**$150,003**	**$165,853**	

* In-kind contributions from DFCM include: Research Director; Associate Research Director; Senior Biostatistician; Biostatistician; Research Program Coordinator; Research Administrator; Library, Communications Coordinator, and Strategic Planning Coordinator.

* In-kind endowed Chair contribution from NYGH will cover the salary of the Chair/PBRN Director starting Year 2 onwards.

APPENDIX 4 – PROPOSED PBRN IMPLEMENTATION TIMELINE

Start Continue Stop

	2011	Start-up Year 1 (January - December 2012)												Start-up Year 2 (January - December 2013)												Year 3 (2014)	Year 4 (2015)	Year 5 (2016)
	Dec	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D	Jan-Dec	Jan-Dec	Jan-Dec
DFCM Executive Approval																												
PBRN Naming Contest																												
Interim PBRN Director																												
Interim Research Associate/Asst																												
Founding Board																										Mar-14		
Develop Interim Research, Ethics and Financial Policies and Procedures																												
Forum																												
Allocate Seed Funds and Initiate Small Projects																											Review	
Endowed Chair/Permanent PBRN Director																												
Other Staff (TBD)																												
Develop Plan re: Ongoing Data Collection/Management																												
Develop Permanent Governance Model, TofR, etc.																												
Establish Permanent Governance Structure																												
Implement Data Plan																												
Multiple Studies Per Year																												
Large Grants																												
Financially Self-Sustaining																												

APPENDIX 5 – BUDGET SCENARIOS: PBRN GROWTH

SCENARIO 1: Build to full capacity with in-house PBRN research infrastructure and data collection/management.

	Year 1 (2012)	Year 2 (2013)	Year 3 (2014)	Year 4 (2015)	Year 5 (2016)	
EXPENSES						
Personnel Costs						Notes:
PBRN Director (0.5 FTE)	$100,000	NYGH in-kind	NYGH in-kind	NYGH in-kind	NYGH in-kind	After Year 1, this position will be covered by the Gordon Cheesbrough Chair endowment fund.
Research Associate (1.0 FTE)	$81,250	$83,688	$86,198	$88,784	$91,448	$55,000-75,000/yr plus 25% benefits; assume $65,000; 3% annual increase.
PBRN Coordinator (1.0 FTE)			$75,000	$77,250	$79,568	$55,000-70,000/yr plus 25% benefits; assume $60,000; 3% annual increase.
Research Assistant (1.0 FTE)			$28,125	$57,938	$59,676	$45,000-60,000/yr plus 25% benefits; assume $45,000; 3% annual increase. Yr 3 = 0.5 FTE
Statistician (1.0 FTE)			$40,625	$83,688	$86,198	$55,000-75,000/yr plus 25% benefits; assume $65,000; 3% annual increase; Yr 3 = 0.5 FTE
Methodologist (1.0 FTE)			$68,750	$141,625	$145,874	$110,000 plus 25% benefits; 3% annual increase, Yr 3 = 0.5 FTE
IT Support (1.0 FTE)			$28,125	$56,250	$57,938	$45,000-60,000/yr plus 25% benefits; assume $45,000; 3% annual increase. Yr 3 = 0.5 FTE
Finance						TBD by NYGH
Human Resources						TBD by NYGH
Subtotal	**$181,250**	**$83,688**	**$326,823**	**$505,534**	**$520,700**	
Other Costs						
Meetings	$10,000	$10,000	$15,000	$15,000	$20,000	
Annual Membership Event			$35,000	$35,000	$35,000	
Travel (staff)	$5,000	$5,000	$10,000	$10,000	$15,000	
Supplies, Services	$3,000	$5,000	$10,000	$10,000	$15,000	
Professional Development (staff)	$5,000	$10,000	$15,000	$20,000	$20,000	
Communications/KT		$15,000	$20,000	$25,000	$25,000	
Marketing	$10,000	$20,000	$20,000	$20,000	$20,000	
Subtotal	**$33,000**	**$65,000**	**$125,000**	**$135,000**	**$150,000**	
Project Seed Funding	**$75,000**	**$75,000**	**$75,000**	**$75,000**	**$75,000**	Review seed funding after Year 3.
Data Warehouse						
Data Manager (1.0 FTE)			$40,625	$83,688	$86,198	$55,000-75,000/yr plus 25% benefits; assume $65,000; 3% annual increase; Yr 3 = 0.5 FTE
Server				$6,000	$6,000	
Software/Licensing				$10,000	$10,000	
Local Data Requirements				$60,000	$60,000	$6000 x 10 sites.
Database (Oracle or MS SQL)				$10,000	$10,000	
Set-up/consulting/privacy/security				$25,000	$25,000	
Subtotal	**$0**	**$0**	**$40,625**	**$194,688**	**$197,198**	
Total Expenses	**$289,250**	**$223,688**	**$567,448**	**$910,222**	**$942,898**	
REVENUES*						
DFCM Chair's Office	$100,000	$100,000	$100,000	$100,000	$100,000	Covers Interim PBRN Director in Year 1.
DFCM Research Program/NYGH	$81,250					Share cost of Research Associate in Year 1. (NOT CONFIRMED)
FMTUs Contribution	$140,000	$140,000	$140,000	$140,000	$140,000	$10,000 per FMTU.
Donor or Strategic Partnership						
Total Funding	**$321,250**	**$240,000**	**$240,000**	**$240,000**	**$240,000**	
Grant Revenues Required	**($32,000)**	**($16,313)**	**$327,448**	**$670,222**	**$702,898**	

* In-kind endowed Chair contribution from NYGH will cover the salary of the Chair/PBRN Director starting Year 2 onwards.

SCENARIO 2: Hybrid where DFCM outsources the housing of EMR data and partners with AHRC for research infrastructure and project specific prosective data collection.

	Year 1 (2012)	Year 2 (2013)	Year 3 (2014)	Year 4 (2015)	Year 5 (2016)	
EXPENSES						
Personnel Costs						Notes:
PBRN Director (0.5 FTE)	$100,000	NYGH in-kind	NYGH in-kind	NYGH in-kind	NYGH in-kind	After Year 1, this position will be covered by the Gordon Cheesbrough Chair endowment fund.
Research Associate (1.0 FTE)	$81,250	$83,688	$86,198	$88,784	$91,448	$55,000-75,000/yr plus 25% benefits; assume $65,000; 3% annual increase.
PBRN Coordinator (1.0 FTE)			$75,000	$77,250	$79,568	$55,000-70,000/yr plus 25% benefits; assume $60,000; 3% annual increase.
Research Assistant (1.0 FTE)			$28,125	$57,938	$59,676	$45,000-60,000/yr plus 25% benefits; assume $45,000; 3% annual increase. Yr 3 =0.5 FTE
Subtotal	**$181,250**	**$83,688**	**$189,323**	**$223,972**	**$230,691**	
Other Costs						
Meetings	$10,000	$10,000	$15,000	$15,000	$20,000	
Annual Membership Event			$35,000	$35,000	$35,000	
Travel (staff)	$5,000	$5,000	$5,000	$5,000	$5,000	
Supplies, Services	$3,000	$5,000	$10,000	$10,000	$15,000	
Data Collection/Management			$100,000	$100,000	$100,000	Estimate only.
Communications/KT		$15,000	$20,000	$25,000	$25,000	
Professional Development (staff)	$5,000	$10,000	$10,000	$15,000	$20,000	
Marketing	$10,000	$20,000	$20,000	$20,000	$20,000	
Subtotal	**$33,000**	**$65,000**	**$215,000**	**$225,000**	**$240,000**	
Project Seed Funding	**$75,000**	**$75,000**	**$75,000**	**$75,000**	**$75,000**	Review seed funding after Year 3.
Total Expenses	**$289,250**	**$223,688**	**$479,323**	**$523,972**	**$545,691**	
REVENUES*						
DFCM Chair's Office	$100,000	$100,000	$100,000	$100,000	$100,000	Covers Interim PBRN Director in Year 1.
DFCM Research Program/NYGH	$81,250					Share cost of Research Associate in Year 1. (NOT CONFIRMED)
FMTUs Contribution	$140,000	$140,000	$140,000	$140,000	$140,000	$10,000 per FMTU.
Donor or Strategic Partnership						
Total Funding	**$321,250**	**$240,000**	**$240,000**	**$240,000**	**$240,000**	
Grant Revenues Required	**($32,000)**	**($16,313)**	**$239,323**	**$283,972**	**$305,691**	

* In-kind contributions from DFCM include: Research Director; Associate Research Director; Senior Biostatistician; Biostatistician; Research Program Coordinator; Research Administrator; Library, Communications Coordinator, and Strategic Planning Coordinator.

* In-kind endowed Chair contribution from NYGH will cover the salary of the Chair/PBRN Director starting Year 2 onwards.

APPENDIX 6: STATUS OF EMR IMPLEMENTATION IN DFCM FMTUs (JUNE 2011)

FULL IMPLEMENTATION	EMR	IMPLEMENTATION WITHIN 12 MONTHS	EMR
Sunnybrook Health Sciences Centre	Practice Solutions	UHN -Toronto Western FHT	Legacy to Practice Solutions by Spring 2011
Toronto East General Hospital	Practice Solutions	St. Michael's Hospital	Implementing Practice Solutions
St. Joseph's Health Centre	Practice Solutions	Women's College Hospital	Implementing Practice Solutions
Southlake Family Health Team	Practice Solutions		
Markham Stouffville Hospital	Practice Solutions		
Mount Sinai Hospital	Nightingale		
Credit Valley Hospital	ACCURO by Optimed		
Royal Victoria Hospital	Clinicare		
Trillium Health Care Centre	X-Wave		
North York General Hospital [Note: all NYGH community sites have implemented EMRs, however, the FMTU at NYGH will implement an EMR (Practice Solutions) within 12 months.]	Nightingale and Practice Solutions used in community practices		

APPENDIX 7: OPTIONS RE: PBRN DATA COLLECTION / MANAGEMENT

Where to house DFCM PBRN data?

Option	Background Information	Pros/Cons	Questions	Cost to DFCM
AHRC	The Applied Health Research Centre is located at SMH and is a full service, academic, clinical research coordination centre for Phase II through Phase IV multi-centre clinical trials of varying size and across a range of therapeutic areas. AHRC provides scientific support, project management, data management, site management, trial monitoring, and other services.	- Lots of experience - Would be a valuable resource to DFCM researchers - Have process for accessing and analyzing large data sets; very secure - They manage/collect data and run projects. Have staff to do both. - DFCM would own the data - AHRC prefers to enter LT arrangement rather than transitional	- Does AHRC have any experience in extracting and managing longitudinal EMR data?	None (costs built into grant proposals)
eHealth	eHealth's mission is to deliver a comprehensive, patient-focused, secure and private electronic system that will improve the way patients receive care.	- Have facilities and infrastructure to securely house large data sets - Currently house 16-18% of EMR data - DFCM would manage the data - Slow responses, bureaucratic	- Still need to decide where to build infrastructure to extract data and upload (VPN) to central host - Long-term sustainability?	?
CPCSSN	The Canadian Primary Care Sentinel Surveillance Network is a sub-entity of the CFPC, whose core business is to collect data and to organize and maintain a sentinel surveillance system contributing to knowledge development about the health of Canadians and to conduct research that strengthens the study of Canadian primary healthcare. Nine PBRNs across Canada are part of CPCSSN. It is funded until 2015 by the Public Health Agency of Canada and funding includes a FT data manager in each PBRN.	- Build on what has already started in EMR data collection - Opportunity to collaborate provincially/nationally on exchange of data - CPCSSN is still working on making data extraction more meaningful	- How easy/difficult would it be for CPCSSN to collect data from additional EMRs (impact on their budget)? - Would DFCM be limited in terms of type of data collected and how easily it could be extracted?	?
ICES	The Institute for Clinical Evaluative Sciences is a legal entity with authority under the Ontario privacy legislation to use Ontario patient data for research purposes. ICES is linked to Ministry data holdings related to hospitals, physician billings and drugs. ICES collects Practice Solutions data from physicians at some FMTUs (e.g. NYGH, TEGH).	- Provide excellent health system research - Data belongs to ICES and is only used within ICES - ICES data projects must involve an ICES scientist as PI or co-investigator	- If not suited for housing the PBRN data, is there a way to exchange data/information that would be of benefit to both ICES and DFCM?	?
DFCM in-house	Data collection/management is not a core function of the DFCM.	- No experience - Costly	- Better to rent function elsewhere, where expertise and infrastructure already exist	Min $60-80K/yr plus Data Manager @ $55-75K/yr (plus benefits)