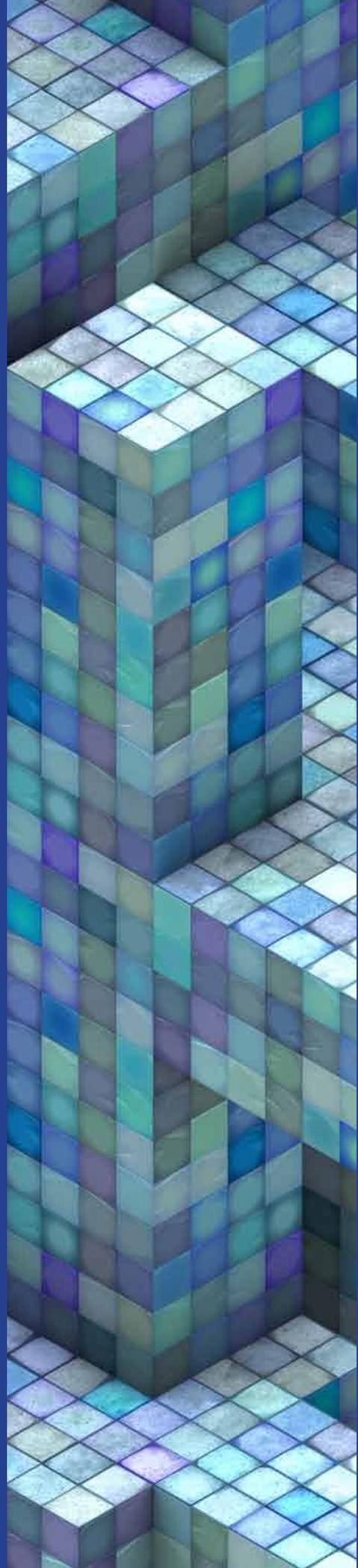


**Research
Methods
Unit Report
to the
Community
2010-2015**





Research Methods Unit Team
(back, left to right) Daniela Meier, Olga Kits, Adrian Levy,
Chris Theriault, Joe Fraser, Pat Berrigan, Steve Doucette
(front, left to right) Lisa Underwood, Kara Thompson,
Sandra Pauls

Message from the RMU Scientific and Administrative Leads

It hardly seems possible that the RMU is five years old! Just a few years ago our investigators told us they needed support in specific areas to enable them to better conduct high quality clinical and health services research. To respond to their needs, we set out to gather together a group of knowledgeable individuals with the skills the investigators required. We called this group the Research Methods Unit (RMU). This report chronicles the RMU's journey from idea to reality and profiles our work, our people and our hopes for the future. As the RMU has increased the services it offers, it has attracted more research projects and investigators to utilize its consulting services.

Between 2011 and 2014, the RMU supported 291 research projects; providing consulting, mentorship and training; and contributing to strategic initiatives at Capital Health, the IWK Health Centre and Dalhousie University. The collaborative networks among these institutions have contributed to the RMU's overall success in achieving its objectives.

Over the past years, the RMU team has worked to:

- contribute to increasing the quantity and quality of research in the community
- expand consulting capacity
- increase our profile and facilitate opportunities to increase the amount, scope and quality of methods support we provide
- enhance our infrastructure relationships across a collaborative network
- enhance pedagogical activities for clinical and health services research methods
- establish financial operations priorities consistent with their mandate

The RMU now has seven consultants who provide support in research design and methodology, biostatistics, database development and management, and health economics. Please read on to learn about these team members, their clients and the work they have accomplished together.

We extend a sincere thank you to our collaborating partners, Capital Health, the IWK Health Centre and Dalhousie University for their support of the RMU. We also thank our RMU consultants whose talents and expertise have contributed to advancing research excellence in Nova Scotia. As for the future, we look forward to extending our services to support researchers across the province in the new Nova Scotia Health Authority. We also will continue to broaden our support of collaborative research to inform improved patient care and quality of life.

Adrian Levy
Dalhousie Professor/Head
NSHA District Chief, Community Health & Epidemiology

Lisa Underwood
Director, NSHA Research Service

RMU Past to Present

In early 2008, the idea of a clinical research support and training centre was put forward to the research community. From January to March of that year, meetings were held with fifteen Capital Health departments and divisions to determine the infrastructure researchers required to strengthen and expand their research programs. Without exception, those who participated stressed the need not only to build upon existing strengths, but also to develop new capacity in the areas of research methodology, database design and management and data analysis.

Researchers identified what they needed most to move the research agenda ahead:

- statistical supports at the collaborative and service levels
- qualitative research methods support
- linkages among the many existing databases that would result in high quality, reliable data and encourage research partnerships within and external to Capital Health

The original concept of a Research Methods Unit (RMU) came about as a way to meet these research capacity requirements. The development of the RMU was spearheaded in 2009 and 2010 by Adrian Levy, the Dalhousie Professor/Head and Capital Health District Chief, Community Health & Epidemiology, and Lisa Underwood, the Capital Health Director of Research Services. In 2010 Capital Health, the IWK Health Centre, and the Dalhousie Faculties of Medicine, Health Professions, and Dentistry agreed to support the establishment of the RMU.

When the first full-time RMU employee was hired in April 2010, the RMU in its entirety was comprised of an Implementation Plan concept document and a budget. In the following year, the RMU secured and renovated space, built its consulting infrastructure, and added staff in qualitative methods, statistical analysis, and systematic reviews. In June 2011 an RMU Open House attracted a large crowd as the RMU was officially launched by senior representatives of Capital Health, the IWK Health Centre and Dalhousie University.

Since 2011, the RMU team has grown to include seven consultants, a manager, and a finance/administrative officer. Leadership is provided by a director and an administrative lead. Consultants offer expertise in study design, research methods, biostatistics, database design and management, and health economics.

Current partners include the Nova Scotia Health Authority, IWK Health Centre, and Dalhousie University Faculties of Medicine, Health Professions, and Dentistry. Existing partnerships are developing and evolving, and new ideas, partners, stakeholders, and opportunities for linkages are welcomed.

RMU services are excellent value for money. In fact, the RMU provides many services free of charge, including the initial one-hour consultation, preparatory work required for the initial meeting, ongoing project management, support for research design (both quantitative and qualitative) as outlined in the table on the opposite page, support in the context of preparing a statement of work and quote for grant applications, and mentorship in the context of a project.

The fees charged by the RMU to its clients cover only a small portion of its operating expenses. RMU services will strengthen and broaden research capacity throughout the province and are integral to attracting new researchers to the area and growing and supporting the local research community.



RMU biostatisticians Steve Doucette and Kara Thompson provide expertise in many statistical software packages, systematic reviews and meta-analysis.

RMU Services for Researchers

Study Design/ Epidemiology	Research Methods	Biostatistics	Database Development/ Management	Health Economics
<ul style="list-style-type: none"> • review of and feedback on proposed study design (quantitative, qualitative and mixed methods study designs) 	<ul style="list-style-type: none"> • randomization 	<ul style="list-style-type: none"> • statistical analysis for systematic review and meta-analysis 	<ul style="list-style-type: none"> • design and development of research databases prior to data collection 	<ul style="list-style-type: none"> • health economic literature review • economic costing • advice on primary cost data collection
<ul style="list-style-type: none"> • review and feedback on research question 	<ul style="list-style-type: none"> • sample size and power calculations 	<ul style="list-style-type: none"> • data analysis 	<ul style="list-style-type: none"> • advice on cleaning and maintaining datasets and preparing data for analysis 	<ul style="list-style-type: none"> • advice on measuring health-related quality of life • economic modelling • health technology assessments • cost effectiveness and cost utility components
<ul style="list-style-type: none"> • review and feedback on sample size and power calculations 	<ul style="list-style-type: none"> • development of statistical analysis plan 	<ul style="list-style-type: none"> • result interpretation 	<ul style="list-style-type: none"> • data management 	<ul style="list-style-type: none"> • cost effectiveness analysis • cost utility analysis • literature-based costing • Monte Carlo Sensitivity Analysis
		<ul style="list-style-type: none"> • write-up of methods section • results 	<ul style="list-style-type: none"> • support for geographic information system (development of maps) 	<ul style="list-style-type: none"> • write-up of methods section (health economic component) • interpretation of results (health accounting)

RMU Research Innovation

Creating New Possibilities with Web-based Database Applications

In 2013, demand increased in the research community for secure, reliable, consistent, and cost-effective database infrastructure. There was no systematic process for the creation and deployment of databases created for specific research projects. This gap existed equally for clinical trials, chart reviews, surveys, and other observational studies. These studies almost exclusively relied on the utilization of Microsoft Office products, such as Excel and Access for data entry and storage. RMU recognized that there was an opportunity to support the research community by finding a solution to ensure more secure and consistent data storage processes and facilities. What was needed was a robust database infrastructure comparable to other professional research institutes in Canada.

RMU set out to develop infrastructure to allow researchers to collect and enter de-identified research data into a professionally designed system. This infrastructure can be used not only for data entry but also facilitates data linkage to enable more complex research. As a result of this development, the potential for collaborative and interdisciplinary research within and across NSHA, IWK Health Centre, Dalhousie University, and among

other collaborative academic and health institutions could be expanded.

In partnership with NSHA IT Project Management Office (PMO) and Infrastructure Departments, RMU secured access to NSHA's server space, initiated the set-up of an application development environment for its database specialists and developed a process to deploy web applications.

Utilizing this infrastructure, the RMU can provide robust web-based database applications in areas such as:

- single and multi-site clinical trials
- single and multi-site randomized control trials
- chart reviews
- facilitate data linkage between multiple study and administrative databases
- technology as an intervention
- direct study participant data entry

Through this project, the RMU was able to create a collaborative relationship with the NSHA IT PMO, providing the RMU access to additional IT staff in order to take on complex database projects in the future.

Collaboration/Partnership with DoM

The Department of Medicine (DoM) and the RMU have partnered for four years with a Memorandum of Understanding (MOU). The MOU provides for the secondment of two DoM staff to the RMU, which results in a more robust team of RMU professionals. In return, DoM researchers receive credit hours and access to all RMU staff to support their research.

DoM that includes access to a wider range of expertise and services as well as increased efficiency and accountability for consultant activity. The MOU has been renewed for two years.

Since 2012, the RMU has supported a total of 108 DoM projects through this arrangement.

This arrangement brought with it the opportunity to implement research methods consulting support for the

RMU -- A look back

No retrospective is complete without remembering RMU team members who have moved on.

Camille Angus was the manager of the RMU for several years. She was instrumental in setting up the RMU structure and establishing day-to-day operation of the unit.

Raewyn Bassett, the first qualitative methodologist who worked at the RMU, introduced a qualitative research workshop series in January 2009.

Robin Parker, formerly the RMU clinical research librarian is now the Information Services Librarian at the W.K. Kellogg Health Sciences Library.



Camille Angus



Raewyn Bassett



Robin Parker

Training and Mentorship provided by the RMU

RMU Qualitative Health Research Seminar Series

Every winter the RMU offers a six-session seminar series on qualitative health research and its methods. Within the clinical setting, qualitative health research is taking on a more prominent role because its methods offer powerful tools where context is important, where measurement is difficult and where issues are sensitive and multifaceted, particularly in areas such as improving patient safety, clinical decision-making, patient satisfaction, patient self-management, collaborative care, access to healthcare, and data-driven and IT-based interventions. Methods and tools such as observation, interviews, focus groups, systematic reviews, textual analysis, and the use of media (photographs, video) can generate valuable data for research studies.

Biostatistics Seminar Series

RMU consultants developed and facilitated a three-part biostatistics workshop series in the Department of Anesthesiology. The workshops were aimed at increasing researchers' confidence when dealing with statistical methods related to clinical research. Individuals were given the opportunity to learn common statistical approaches in the research setting. Typical outcome data were discussed using a variety of examples specific to health research and participants were encouraged to discuss related techniques specific to their own research needs. Topics also included the processes and principles of the analysis of continuous, dichotomous and time-to-event data and the importance of setting up relevant outcomes to specific hypothesis.

Health Economics Seminar Series

Starting in the fall of 2015, the RMU will offer a three-part workshop series on health economics. The objective of the workshop series will be to provide participants with an understanding of commonly used techniques in health economics. Topics to be covered include: types of economic analysis; techniques for measuring costs; techniques for measuring health related quality of life; and techniques used in health economic modeling. Participants will be able to apply workshop materials to their own projects, which will broaden the scope of local research.

Qualitative Methodologist Olga Kitts explains interview techniques to a client.

RMU Committee Contributions

RMU consultants serve as members on a number of Committees, including:

- Nova Scotia Health Authority Research Fund Review Committee
- Executive Committee for Halifax local SAS Users Group (SHRUG)
- Executive Committee for Halifax Generic Statistical Software Users Group
- Health Data Nova Scotia Data Access Committee
- Maritime SPOR Support Unit Research Planning Group
- Maritime SPOR Support Unit Training Advisory Committee
- Research in Medicine Research Committee, Dalhousie Faculty of Medicine
- Resident Research Committee
- Statistical Society of Canada Accreditation Committee



Scientific Lead

Research Me

Methods Support
Scientific Director
Epidemiologist
Qualitative Methodologist

Statistical Support
Two biostatisticians

Database Support
Two database sp



Patrick Berrigan - Health Economist

Pat Berrigan holds a BSc from Dalhousie University with a double major in Mathematics and Economics, an MA from Memorial University majoring in Economics, as well as additional graduate training in Economics from the University of Alberta. As the RMU's health economist, Pat works with researchers and decision makers from across the province to help improve the efficiency and sustainability of Nova Scotia's healthcare system. Pat's professional experience includes: research-policy design and analysis, economic analysis in support of research investment and decision making; and project management in research settings. His interests include: development of metrics to measure research quality; impacts of research expenditure on health and economic indicators; and impacts of income distribution on health and economic indicators.

Pat works with researchers and decision makers from across the province to help improve the efficiency and sustainability of Nova Scotia's healthcare system. Pat's professional experience includes: research-policy design and analysis, economic analysis in support of research investment and decision making; and project management in research settings. His interests include: development of metrics to measure research quality; impacts of research expenditure on health and economic indicators; and impacts of income distribution on health and economic indicators.



Steve Doucette - Biostatistician

Steve Doucette is the Senior Biostatistician for the RMU and an adjunct research associate in the Department of Community Health and Epidemiology, Dalhousie. He holds a Master's degree in Mathematics and Statistics (specialization in Biostatistics) from the University of Ottawa. Prior to joining the RMU, Steve worked as a methodologist for a health research group in Ottawa (OHRI). His areas of interest include design and analysis of clinical trial data, diagnostic testing, propensity matching for case control studies, and meta-analytic techniques for pooling multiple trial data. He has experience with statistical software, including SAS language and SPSS for both data manipulation and analysis; NCSS/PASS for sample size calculations; Comprehensive Meta-Analysis for performing systematic reviews. His research interests are to further continue performing essential work in the area of health research, clinical trials, biostatistics, systematic reviews and meta-analysis and to diversify his knowledge of these and other disciplines.

Steve Doucette is the Senior Biostatistician for the RMU and an adjunct research associate in the Department of Community Health and Epidemiology, Dalhousie. He holds a Master's degree in Mathematics and Statistics (specialization in Biostatistics) from the University of Ottawa. Prior to joining the RMU, Steve worked as a methodologist for a health research group in Ottawa (OHRI). His areas of interest include design and analysis of clinical trial data, diagnostic testing, propensity matching for case control studies, and meta-analytic techniques for pooling multiple trial data. He has experience with statistical software, including SAS language and SPSS for both data manipulation and analysis; NCSS/PASS for sample size calculations; Comprehensive Meta-Analysis for performing systematic reviews. His research interests are to further continue performing essential work in the area of health research, clinical trials, biostatistics, systematic reviews and meta-analysis and to diversify his knowledge of these and other disciplines.



Joe Fraser - Research Database Specialist

Joe Fraser is the Research Database Specialist for the RMU and an affiliate with the Department of Community Health and Epidemiology, Dalhousie University. Working with the RMU Senior Research Database Specialist, Joe's role includes building and programming databases and preparing data for statistical analysis. Joe holds Bachelor's degrees in English and Education, and most recently graduated from the Centre of Geographic Sciences in Lawrencetown, NS, where he was recognized for his work in Cartography by National Geographic and the Canadian Cartographic Association. Before joining the RMU, Joe was employed as a GIS specialist and programmer. He designed custom web-mapping tools to share infrastructure data between departments of the Halifax Port Authority, and oversaw the creation of mapping data produced for the Nova Scotia Geomatics Centre. Joe's main interests include database and GIS technology and computer programming.

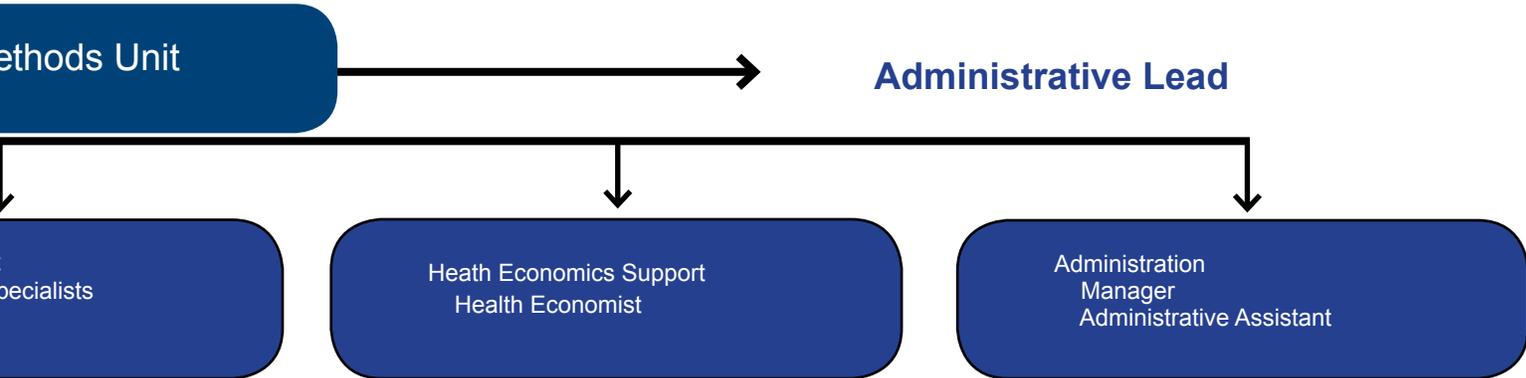
Joe Fraser is the Research Database Specialist for the RMU and an affiliate with the Department of Community Health and Epidemiology, Dalhousie University. Working with the RMU Senior Research Database Specialist, Joe's role includes building and programming databases and preparing data for statistical analysis. Joe holds Bachelor's degrees in English and Education, and most recently graduated from the Centre of Geographic Sciences in Lawrencetown, NS, where he was recognized for his work in Cartography by National Geographic and the Canadian Cartographic Association. Before joining the RMU, Joe was employed as a GIS specialist and programmer. He designed custom web-mapping tools to share infrastructure data between departments of the Halifax Port Authority, and oversaw the creation of mapping data produced for the Nova Scotia Geomatics Centre. Joe's main interests include database and GIS technology and computer programming.



Olga Kits - Qualitative Methodologist

Olga Kits is the Qualitative Methodologist for the RMU and an adjunct lecturer in the Dalhousie Department of Community Health & Epidemiology. Olga received an MA from Queen's University, Kingston, Ontario and a BA(H) from Hood College, US. Before coming to NSHA and Dalhousie, she worked in research and policy at the College of Physicians and Surgeons of Ontario, the Ontario Ministry of Health & Long Term Care (health information & sciences branch), and for the ten-year review of the Ontario Regulated Health Profession Act. She has been involved in qualitative health research for over 20 years and has participated in a large variety of single and multi-site research studies, using a variety of methods, at the local, national, and international levels in university, regulatory, and government settings. Olga teaches and tutors in the Research in Medicine (RIM) program at the Dalhousie Medical School and runs a six-week Qualitative Health Research & Methods seminar series at NSHA. Olga's main

Olga Kits is the Qualitative Methodologist for the RMU and an adjunct lecturer in the Dalhousie Department of Community Health & Epidemiology. Olga received an MA from Queen's University, Kingston, Ontario and a BA(H) from Hood College, US. Before coming to NSHA and Dalhousie, she worked in research and policy at the College of Physicians and Surgeons of Ontario, the Ontario Ministry of Health & Long Term Care (health information & sciences branch), and for the ten-year review of the Ontario Regulated Health Profession Act. She has been involved in qualitative health research for over 20 years and has participated in a large variety of single and multi-site research studies, using a variety of methods, at the local, national, and international levels in university, regulatory, and government settings. Olga teaches and tutors in the Research in Medicine (RIM) program at the Dalhousie Medical School and runs a six-week Qualitative Health Research & Methods seminar series at NSHA. Olga's main



interest is the improvement of Canada’s public health care system through qualitative and mixed methods research. Olga is also a member of the NSHA Research Fund Review Committee and a member of the Maritime SPOR Support Unit (MSSU) Training Advisory Committee.



Adrian Levy - Scientific Director

Adrian R. Levy, PhD, is Scientific Director of the RMU as well as Professor and Head, and NSHA Chief of the Department of Epidemiology and Community Health at Dalhousie University. His doctoral dissertation was done at McGill University in epidemiology, and he completed post-graduate training at

McMaster University in economic evaluation. Before coming to Halifax, Dr. Levy was a faculty member in the School of Population and Public Health at the University of British Columbia where he was supported by Scholar and Senior Scholar Awards from the BC Michael Smith Foundation for Health Research and a New Investigator Award from the Canadian Institutes of Health Research. His academic interests lie in health services research and include health technology assessment, pharmacoepidemiology, quality of life, economic evaluation, and access to care.



Daniela Meier - Manager

Manager for the RMU, Daniela Meier holds degrees in Psychology (BA Hon.) and Public Health (MPH) from the University of British Columbia. Before coming to the RMU, Daniela worked in research with the Centre for Health Evaluation and Outcome Sciences in British Columbia. Daniela also

has extensive policy experience through her previous work with both the Nova Scotia and Yukon Governments. Daniela works with senior academic and health centre administrators in ongoing development of the RMU, oversees consulting operations, and leads the consulting team. Her main interests include: evidence-informed health policy decision-making, rural and remote health, homelessness, mental health and addictions, prevention, health promotion, and social determinants of health.



Chris Theriault - Senior Research Database Specialist

Chris Theriault, is the Senior Research Database Specialist at the RMU and adjunct research associate in the Department of Community Health and Epidemiology, Dalhousie. Chris completed his Engineering degree at Dalhousie, specializing in Industrial Engineering. He is available for consultation on data management needs including database creation, data preparation and cleaning, and data analysis. Prior to joining the RMU, Chris’ experience in health research databases was built through more than five years of supporting a variety of research projects led by members of the Department of Medicine. Chris’ engineering background has exposed him to large-scale industrial applications of data management that are directly applicable to the larger projects supported by the RMU. Drawing upon this experience, Chris is able to fit the appropriate data management system for research projects. He has writing expertise in syntax or code for algorithms of varying complexity, producing summary scores and other calculated results. Areas of recent activity include Hematology, Rheumatology, Respiriology, Endocrinology, Physical Medicine, Rehabilitation and Psychiatry.

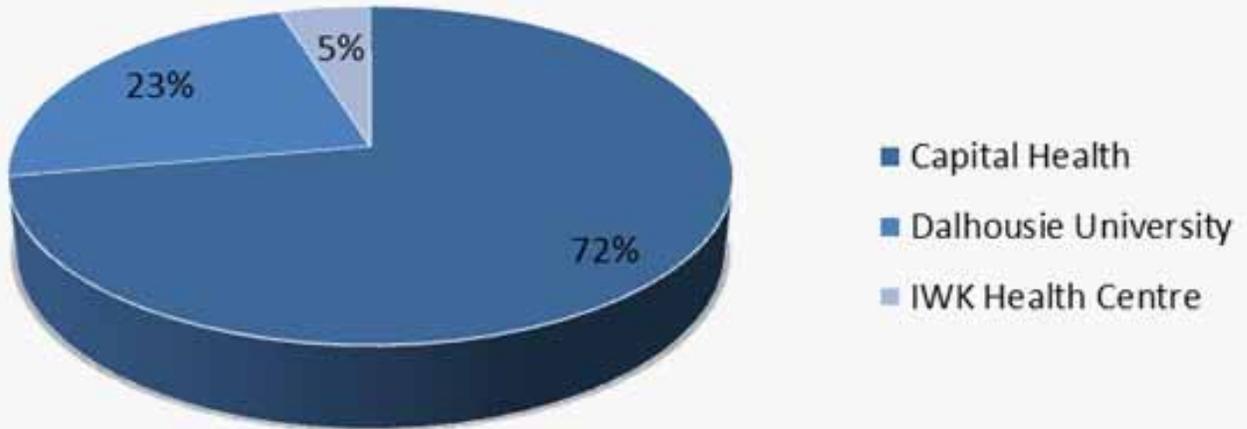


Kara Thompson - Biostatistician

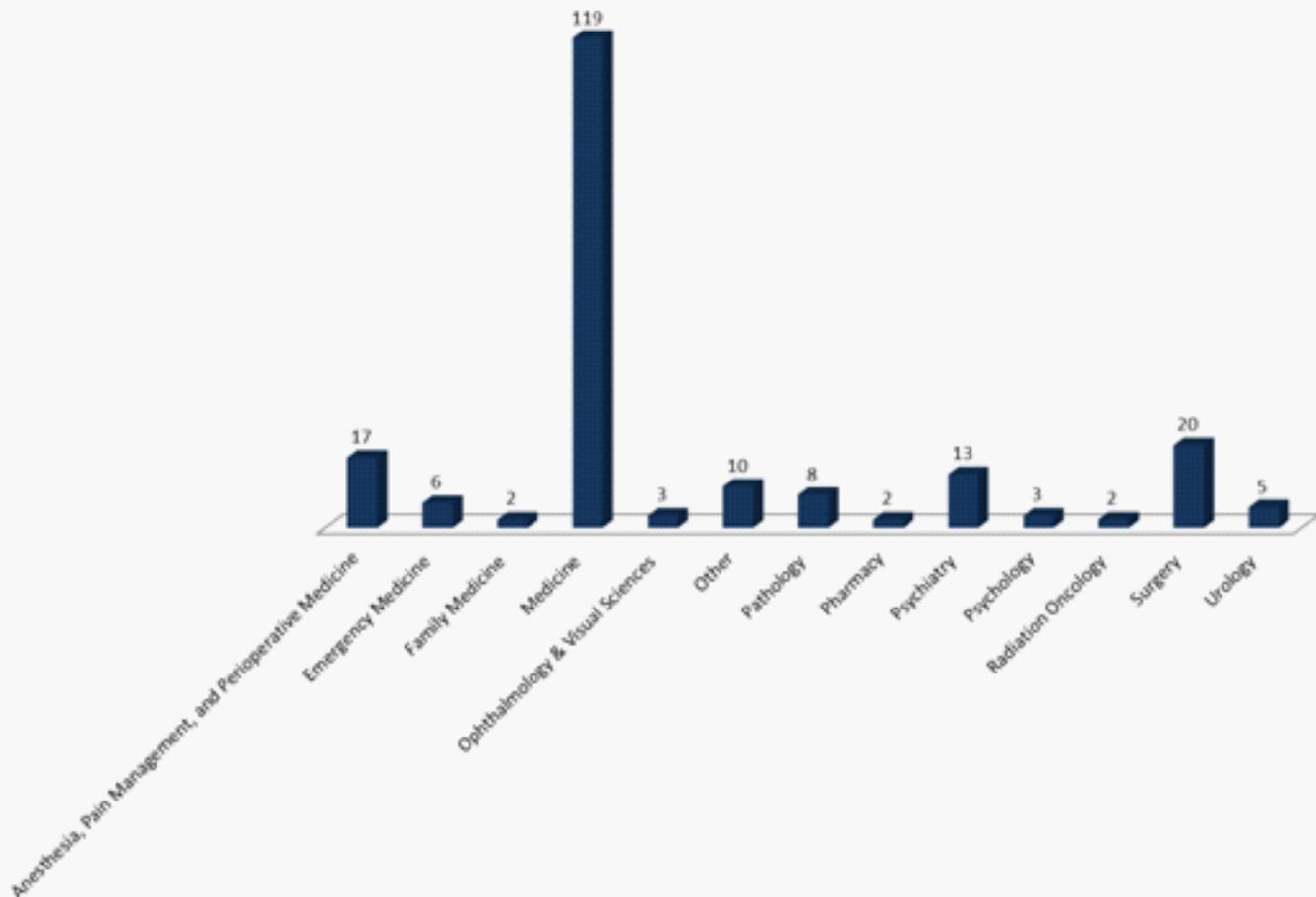
Kara Thompson, the second biostatistician in the RMU, holds a faculty position as Lecturer, in the Department of Medicine, Dalhousie. Kara graduated from the University of Guelph with a BSc in Toxicology and an MSc in Applied Biostatistics. Prior to joining the RMU, she worked as

a biostatistician in the Department of Medicine Research Office for ten years. Her interests include systematic reviews and meta-analysis, Cox proportional hazards modeling, competing risk analyses and the application of these and other statistical methods to practical research initiatives. She is experienced in the following statistical packages for data analysis: SAS, R Studio, SPSS, Comprehensive Meta-Analysis, RevMan, and NCSS/PASS.

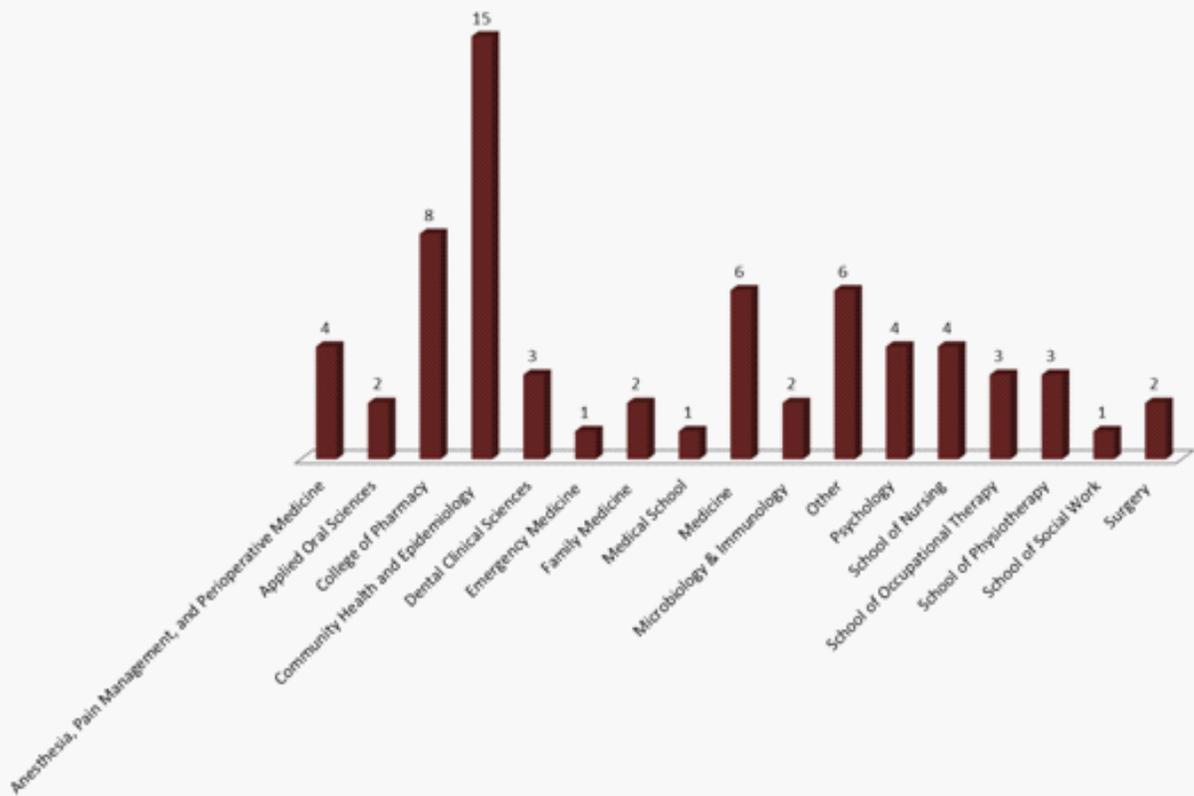
Number of Projects by Institution (Dec. 2011-Dec. 2014)



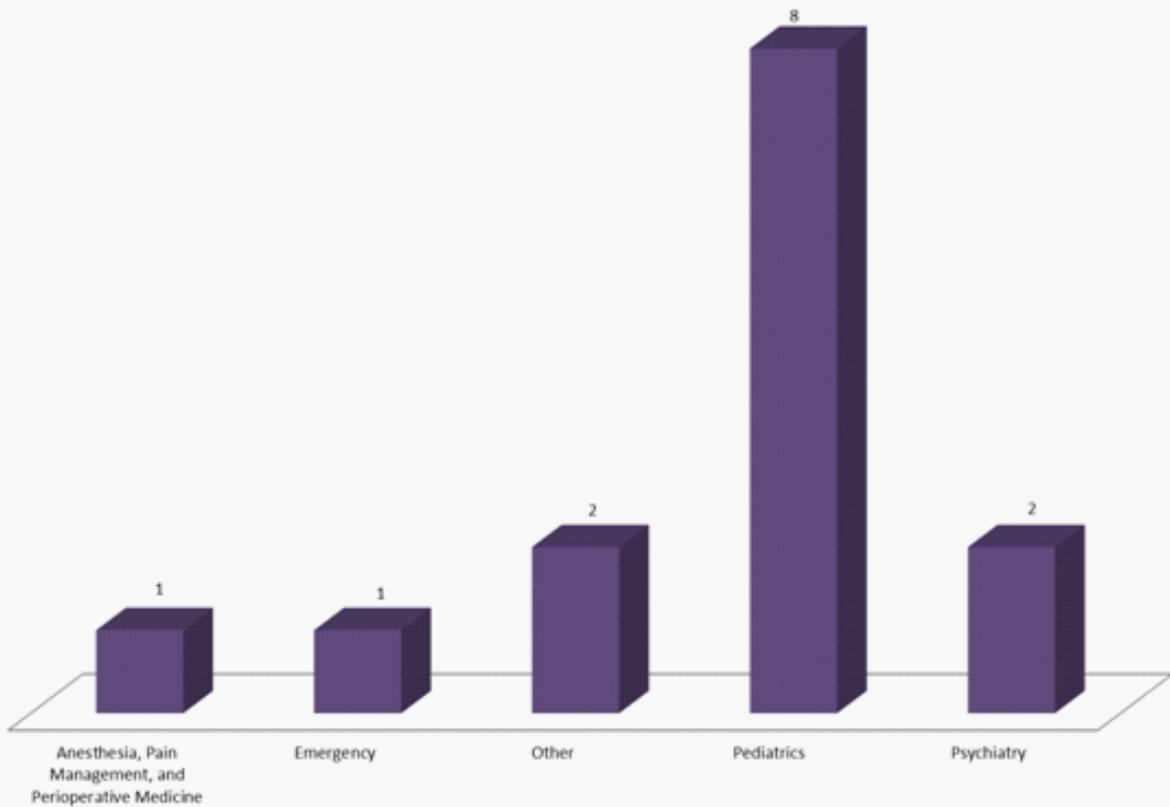
Capital Health - Projects by Department



Dalhousie University - Projects by Department



IWK Health Centre - Projects by Department



Researcher Profiles

FORBOW: Helping Youth Forgo Mental Illness

In 2009, when Dr. Rudolf Uher was considering a move to Nova Scotia, one of his early contacts was Dr. Adrian Levy, who told him about the launching of a new organization called the Research Methods Unit and the services it would offer. Neither of them could know at the time that a few years later, Dr. Uher would be an RMU client.

When Dr. Uher moved to Halifax in 2012 as the Canada Research Chair in Early Intervention in Psychiatry, he found that Nova Scotia's population provided him with a stable patient base eager to participate in research—an ideal setting for a longitudinal study. Dr. Uher and his research team are in the middle of such a study: FORBOW (Families Overcoming Risks and Improving Opportunities for Well-being). This investigator-initiated, three-year study is designed as a youth cohort, multisite, randomized control trial. It poses the research question: Can intervention in children and adolescents reduce the risk of developing severe mental illness?

FORBOW participants include youth from the general population and youth whose parents have severe mental illness. Dr. Uher is interested in learning about any unusual experiences; for example, if they ever hear voices that no one else can hear. Participants apparently enjoy their contact with the FORBOW team because they are eager to return for follow-up interviews. Their parents are supportive, too, and pleased to have their children participate in the study.

By the nature of the study, FORBOW requires a tremendous amount of data collection. Common practice would see the researchers interviewing participants and later entering the data into a computer program. With RMU support, they can do these two tasks simultaneously. RMU consultants Chris Theriault and Joe Fraser developed a real-time entry database that allows the researcher to enter the information as the participant reveals it to them. Dr. Uher says he truly appreciates the accessibility he has to the database designers at the RMU, and the fact that he did not have to hire and supervise a programmer or work with an external service provider. He notes, "FORBOW is a complex tool which simplifies the data collection process for my team."

Intensely interested in finding the answer to the FORBOW research question, Dr. Uher says there have been both successes and challenges along the way. Successes include study recruitment (187 enrolled, well on the way to meet the March 2015 target of 200) and the formation of an enthusiastic and dedicated FORBOW

team. Challenges include convincing colleagues to refer patients to the FORBOW study and the ongoing search for funding to extend FORBOW beyond its initial three years.

Dr. Uher observes that so far FORBOW has provided some surprising results both in the percentage of youth who report unusual experiences and in the relationship between stimulant medication and unusual experiences. As FORBOW continues to enroll more participants and gather more data, Dr. Uher says, "I believe this kind of research enables the medical community to make more of a difference for positive outcomes in young people with early indications of mental health issues. Mental health is something we can learn."



Dr. Rudolf Uher is looking for an answer to the question: Can intervention in children and adolescents reduce the risk of developing severe mental illness?

Research Profiles

EPCAT II Study

The EPCAT II study is a CIHR-funded, double-blind, randomized, controlled trial to determine if aspirin is at least as effective as rivaroxaban for the prevention of venous thromboembolism after total knee and hip arthroplasty. This large study (N-3426) is being conducted at fifteen institutions across Canada. Dr. David Anderson is the investigator-sponsor for this study and Susan Pleasance is the Project Manager.

In February 2012 the EPCAT II team reached out to the RMU when they were applying for funding. They included quotes for statistical oversight, data base construction and summary reports as part of their application to CIHR. The RMU was able to provide them with the documentation they required to lead them to a successful application with the CIHR.

The RMU has:

- *provided statistical support for our project, including assistance with sample size calculations and randomization blocks for study drug assignment*
- *been instrumental in the development of a database and subsequent linked reports. Linked reports include tabular and graphical representation of recruitment, comparative analysis of actual vs. expected completion dates and Data and Safety Monitoring Board reports. The efficiency and precision noted in providing database-generated reports further instills confidence in the quality of the data.*

To date, The EPCAT II team reached 65 percent of their recruitment target and have been pleased with the RMU-designed data infrastructure. They expect that the study will continue for another year until 2016. At that time they hope to be able to assess the economic impact of administering aspirin in comparison to rivaroxaban. Until then, they will continue to collaborate with the RMU to assist with data cleaning, summary reports and final study analysis queries.



RMU database specialists Joe Fraser and Chris Theriault (left to right) discuss the database requirements of a research project with a client.

Researcher Profiles

LINC Study

The LINC Study (The Everyday Experience of Living and Managing a Neurological Condition) was one of a suite of studies funded by the Public Health Agency of Canada. Collectively, the studies were entitled National Population Health Study of Neurological Conditions (NPHSNC).

The NPHSNC was announced in June 2009 with a commitment of \$15 million. The purpose was to fill gaps in knowledge about individuals with neurological conditions, their families and caregivers. Under the lead of co-PIs Tanya Packer and Joan Versnel, the LINC study was a collaboration involving Dalhousie's School of Occupational Therapy (Faculty of Health Professions), Queen's University, University of Manitoba, the University of Prince Edward Island and Memorial University.

The LINC study sought to understand the everyday lives of people with neurological conditions, who strive to work, go to school, raise families and participate in the community. Data was collected in four key areas: participation, self-management, health status and health utilization. Recognizing the complexity of people's lives, a tiered approach used mixed research methodology. This approach allowed both breadth and depth of understanding. The combined methods allowed for a diverse use of strategies to capture data from multiple sources, in multiple ways and from multiple perspectives.

The LINC team approached the RMU about working with them after they launched the on-line population survey using the Opinio platform at Dalhousie University. The RMU helped them clean and manage the data. With both a population survey and a cohort study to manage, there was extensive work required to clean the data. The use of "skip logic" in the survey tools also meant that extensive work was needed to code the data, impute missing values and score the standardized tools and derived variables. LINC members had consultations with several members of the RMU and worked closely with research database specialists and biostatisticians during the data management and analysis processes.



Members of the LINC Study Team pose for a photo

The LINC team has completed the requirements of their contribution agreement with the Public Health Agency of Canada and submitted their final report. In March 2014, The Public Health Agency of Canada, working with the Neurological Health Charities Canada (NHCC), Health Canada, the Canadian Institutes of Health Research and Expert Advisory Groups, submitted a final synthesis report to the federal Minister for Health.

The findings of the LINC study have been incorporated into the report "Mapping Connections: An understanding of neurological conditions in Canada", which was released in September 2014. It is expected to help both governments and stakeholders plan programs and health services for Canadians living with these conditions and to identify the scope for prevention. Members of the LINC investigative team and several students continue to work on publications to disseminate the findings of the LINC study to a wider audience.

Daniela Meier, Program Manager
Research Methods Unit
Centre for Clinical Research
5790 University Avenue, Room 112
Halifax, Nova Scotia B3H 1V7
Canada
Tel: 902-473-2949
daniela.meier@nshealth.ca

Produced by Research Services
Nova Scotia Health Authority
May 2015

Original photography–Gerard Walsh, Emily Walker
Edit and design–Emily Walker

