



2019

2nd Annual Alberta Renal Research Retreat Executive Summary



INTRODUCTION

The second annual Alberta Renal Research Retreat was held on May 10 and 11, 2019 at the Rimrock Resort Hotel in Banff, Alberta, Canada. The retreat was jointly hosted by the University of Alberta and University of Calgary Nephrology Research Groups as well as the Kidney Health Strategic Clinical Network (KH-SCN) and the Interdisciplinary Chronic Disease Collaboration (ICDC). Thirty-six participants attended the retreat (See Appendix One) and addressed the following:

OBJECTIVES:

1. To learn and leverage opportunities to conduct research within the incoming Connect Care electronic medical record platform
2. To have the opportunity to share and develop ideas for future research projects with a chance to get feedback from colleagues across the province
3. To provide an opportunity to network and build collaborations with fellow renal researchers across the province.

These objectives were developed with broad input from the Nephrology community and from feedback from the inaugural retreat in June, 2018, which indicated that a longer retreat

was necessary to discuss the future directions of Nephrology research in Alberta. Connect Care was identified as a key opportunity as the system goes live in November, 2019 and provides a plethora of new tools and opportunities for researchers. Connect Care has powerful properties for patient recruitment for trials which currently can consume a significant amount of time and resources. Additionally, data analysis tools will allow researchers to access and analyse data much more quickly and easily and will provide opportunities for significantly improved learning.

This summary focuses on the outcomes of two Breakout Sessions and the overall direction of discussion at the retreat. Several speakers provided lessons learned using an electronic health record platform and Connect Care within the AHS environment. Local experts described examples of what worked well, how to avoid pitfalls of a new system and where they saw the best future opportunities. Additionally, local experts leading health research studies provided their global view on how researchers could maximize these new tools. This provided participants with the necessary information to be able to actively participate in the Breakout Sessions. See Appendix Two for the full agenda and Appendix Three for the presenter bios.



BREAKOUT SESSION 1: PREPARING FOR USE OF CONNECT CARE IN NEPHROLOGY RESEARCH

The purpose of Breakout Session #1 was to discuss opportunities for Connect Care in three research areas: Clinical & Pragmatic Trials, Decision Support and Secondary Uses of Data. Groups spent 30 minutes discussing each research area and rotated. Moderators coordinated these discussions and probed for greater understanding and meaning so that each discussion group built upon previous input.

GROUP ONE: CLINICAL & PRAGMATIC TRIALS

Potential Opportunities:

- Ability to identify eligible research participants
- Potential to register trials within Connect Care
- To educate on potential research opportunities
- To inform on results of completed research
- Provide a larger repository of potential participants
- Develop registries for clinical research
- Capture PROMs/PREMs
- Launch surveys/questionnaires
- Provide real-time reporting
- Enable accurate, timely, broad evaluation/identification of clinical outcomes/adverse events
- Ability to study rare diseases and follow longitudinally
- Facilitate monitoring of clinical research
- Conduct feasibility assessments to evaluate patient population for specific research criteria
- Implement program wide intervention/operationalize processes - potential for cluster randomization/evaluation
- Alerts to inform patient enrollment status in research
- Provide flexibility to randomize by site, physician, or other criteria

Identified requirements:

- Validated algorithms to measure outcomes
- Upfront work to ensure data variables captured for clinical care will enable quality measurement, quality improvement and research
- Technology to enhance accuracy of outcome assessment/develop validated outcomes
- Employ two-way communication with patients/clinicians/health care entities through MyCharts
- Ability to link/interface with other data systems – i.e., Primary Care
- Embedded culture of pragmatic randomization into clinical care

GROUP TWO: DECISION SUPPORT TOOLS

The ability to customize decision support tools would greatly enhance the experience and improve usability. This customization could be based on factors such as:

- Patient condition and stability: could dictate whether alerts were frequent or less frequent. If the patient had a recent ED visit or had certain demographic characteristics, different alerts could be useful
- Physician experience or preference: Physicians with a heavy case load may need less alerts than a physician who has less experience
- Guideline strength or novelty: Guidelines related to safety may need a hard stop while guidelines with less evidence could be opted out
- Site: Each facility has certain infrastructure and processes that may need customization for alerts
- Patient discharge may need extra support to ensure medications are reduced, stopped or restarted
- Strategic importance of the KH-SCN. Decisions surrounding home dialysis, transplant or primary care may warrant extra decision support tools to assist in creating more high-value care
- Variation of care: Where the greatest variation of care exists, there may be a need for additional decision support

The ability for decision support tools to provide incentives and physician feedback will enhance use:

- If the system can reduce some of the paperwork, physician use would likely increase
- Link the system into the physician audit and feedback system so that real-time information is provided
- Provide a system that can be updated with current information

GROUP THREE: SECONDARY USES OF DATA

How will Connect Care enhance Secondary Data Use?

- Ability to create alerts (and turn them on and off) in-system is a very valuable feature
- Predictive analytic capabilities (e.g., AKI risk)
- Audit and feedback
- Post-marketing / post-implementation project surveillance abilities
- Patient portal, ability to self-report/input data may exclude some and may not have uptake of all patients
- Benefits to all research areas coming together and functioning under one roof: e.g., transplant, basic science, clinical trials, health services research, etc.
- Ability for devices and dialysis machines to directly download data (on dialysis runs, etc.) into Connect Care and make it available in real-time (allows for remote monitoring e.g. BP etc., timely intervention of patients' symptoms and facilitates research)
- Potential of registries would be helpful for CKD, transplant (living donors in Alberta)
- Ability to shared and have data move with patients from other provinces (help with national trials)
- Identify trends - ability to capture data on patients outside AHS (e.g. labs/tests done) / systems need to talk to each other.

Current data repositories (AKDN / ICDC) cannot be replaced:

- Data quality is superior
- Creatinine calibrations not reproducible in Connect Care (labor intensive/complex process/ requiring clinical interpretation and expertise that AHS is not able to provide)
- Retrospective data is available in current data repositories
- Explore opportunities to archive data from other sources within AKDN but need to look at the benefit of keeping based on research needs)
- Benefits to having all historical data in one place: PARIS, NIS, Pathology, Transplant programs OTTR and ALTRABase, home dialysis database

We do not know what has been included in Connect Care:

- Establish KPIs
- Data definitions / develop validated algorithms to identify conditions
- Preemptive transplant algorithms

Concerns about the validity / accuracy of the data in Connect Care as well as ability to access historical data, only as good as data being entered:

- Likely will not meet all of our needs and will not be fully functional (especially for research) for years
- Data duplication between systems e.g., in hospital/ outpatient are concerns

What variables are important to collect for current and future research?

- Need to consider data elements and how they may affect/ impact health outcomes
- Process measures/time stamps
- Social determinants of health – will we be able to link to them (e.g. income, social supports available at home etc.)
- Health behaviors-- e.g. smoking, substance abuse/ addictions (monitoring changes in these behaviors from baseline are important to capture as well)
- Levels of education
- Frailty – how does it influence outcomes?
- Disease severity
- Organ donation preferences/choice
- Personal directives
- Inpatient medications dispensed
- AHS ambulatory clinics – medications
- Processes of care
- BMI
- Blood pressure targets
- Family history
- Pediatric patients – having the ability to link to their family history/health records
- Transplant – linkages between donors and recipient information
- Self-reported race, ethnicity, gender
- Phenotyping kidney disease patients over the progression of their of disease (AKI to end-of-life care)
- Information on everyone starting dialysis – ask questions about eligibility for transplant
- Reasons for PD failure (loss)
- Shared care models are difficult (number of people accessing chart and entering information. Need to be able to identify physicians responsible for care of each patient)
- Physician Score Cards and ability to track provider behaviors

Challenges with secondary use of data:

- Proper privacy legislation not in place under HIA
- How do we anonymize free text fields (difficult to archive – maybe consider machine learning to automate this / develop algorithms for free text fields)
- How do we get patients to properly consent to share info while understanding risks of disclosures (registries, open text fields etc.)? Privacy concerns e.g. patients with mental conditions, cognition problems etc. How do we get them to consent to be contacted? Opt-in and Opt-out. What if patient changes their mind in the future, how do we change this option in the system later on?
- How do we integrate PROMs and PREMs data?
- Ability to share data inside versus outside firewalls

BREAKOUT SESSION 2: DEVELOPING PROJECTS/INITIATIVES TO LEVERAGE CONNECT CARE

The purpose of Breakout Session #2 was to develop high-level project proposals across three different research priority areas, seek input from the broader kidney research community, and to identify potential partners across the province. Each group discussed the rationale/importance of the project, the objectives, and how it may or may not be able to leverage Connect Care. Project leaders presented discussion key point to the full group and received additional comments and advice. Below is a description of each project:

Multi-prong approach to Precision Health for Dialysis Patients

Dialysis patients are high-users of acute care and therefore incur high costs and are more likely to be admitted to hospital. The objective is to identify and address high ED users; who they are and modifiable factors, including social determinants of health. The intervention would be to implement and evaluate various care initiatives to see if patient care could be improved. An example would be the Peter Lougheed Centre Urgent Care Unit.

Living Kidney Follow-Up Registry

Provincial follow-up care is currently sub-optimal and provincial risk assessments are unclear. Donors and their families feel as if post-donation follow-up could be improved. There are guideline recommendations such as annual follow care (BP, CR, UA). The objective would be to devise a strategy to improve follow-up care. There are short and long term outcomes for better risk assessment provincially that could be implemented and improve education for future donors and evaluation of post-donors.



F. Perry Wilson, MD, MSCE (left) speaking to the team about AKI

AKI Prevention-Medication Safety

An opportunity exists to reduce AKI by better educating patients to better manage medication as their health changes. For example, how to deal with a flu episode through MyChart. The objectives are to reduce AKI and associated avoidable harms and to improve the patient experience.

CONCLUSION

At the conclusion of the retreat, Dr. Matthew James provided a summary of the key discussion points from the various presentations and breakout sessions:

- Alberta's universities are working on processes to facilitate research in Connect Care via provincial initiatives and investing in people and development of processes to make this work
- AHS sees the value of research using this system – development mechanisms and BPAs
- Innovative work can be done using Connect Care
- We are well-positioned in Nephrology due to expertise, strong research community in terms of people and teams and commitment to Quality Improvement.

We thank all the presenters and participants for their active contributions to the discussion of Connect Care in Alberta and we look forward to leveraging these opportunities in Nephrology research.



APPENDIX ONE: RETREAT PARTICIPANTS

Anke Banks	Loreen Gilmour	Ngan Lam	Kerry McBrien	Neesh Pannu	Terry Smith
Aminu Bello	Brenda Hemmelgarn	Eddy Lang	Louise Morrin	Robert Pauly	Cello Tonelli
Jeff Bakal	Matthew James	Colin Latter	Dan Muruve	Rob Quinn	Andrew Wade
Justin Chun	Kailash Jindal	Jeff Ma	Stefan Mustata	Leora Rabatach	Kevin Wen
Mo Donald	Scott Klarenbach	Janice MacKay	Erin Navid	Doreen Rabi	Perry Wilson
Meghan Elliott	Anita Kozinski	Braden Manns	Leigh Niwa	Paul Ronksley	Becky Wong

APPENDIX TWO – DETAILED AGENDA

Friday, May 10	Topic	Presenter(s)
8:30am - 9:15am	INFORMAL NETWORKING BREAKFAST (Hawthorn C)	
9:15 am – 9:30 am	Welcome Address <ul style="list-style-type: none"> Agenda and Objectives for the Day 	Brenda Hemmlegarn Matt James Scott Klarenbach Neesh Pannu
9:30am – 10:30am	Presentation #1 <ul style="list-style-type: none"> Health Research in the Connect Care Environment 	Doreen Rabi Léora Rabatach
10:30am – 11:30am	Presentation #2 & #3 <ul style="list-style-type: none"> Incorporating Connect Care into Health Services Research Studies Health System Access for Research Purposes: Overview & Direct System Access 	Jeff Bakal Becky Wong
11:30am – 11:45am	HEALTH BREAK (Wildrose Prefunction)	All
11:45am – 12:45pm	Presentation #4 <ul style="list-style-type: none"> Exploring the potential for clinical and health services research conducted on an EHR platform. 	Eddy Lang
12:45pm – 1:30pm	LUNCH & NETWORKING (Hawthorn C)	All
1:30pm - 1:45pm	KH-SCN PRIHS 5 Funding Opportunity Discuss PRIHS 5 Roadmap (attached)	Scott Klarenbach Neesh Pannu
1:45pm – 3:30pm	Breakout Session #1 Preparing For Use of Connect Care in Nephrology Research Discuss Opportunities from Connect Care in three Research themes (Groups Rotate): <ul style="list-style-type: none"> Secondary Uses of Data Decision Support Clinical & Pragmatic Trials 	Moderators: Anita Kozinski Loreen Gilmour Janice MacKay
3:30pm – 4:00pm	HEALTH BREAK (Wildrose Prefunction)	All
4:00pm – 5:00 pm	Presentation #5 <ul style="list-style-type: none"> Living the Dream (?) of Electronic Health Record Research 	Perry Wilson
5:00pm – 6:00pm	FREE TIME	All
6:00pm – 7:00pm	NETWORKING COCKTAIL (Wildrose Prefunction)	CASH BAR
7:00pm - 9:00pm	NETWORKING DINNER (Hawthorn C)	CASH BAR

Saturday, May 11	Topic	Presenter(s)
8:30am - 9:00am	INFORMAL NETWORKING BREAKFAST (Hawthorn C)	
9:00am – 10:00am	Presentation #6 <ul style="list-style-type: none"> <li data-bbox="402 428 899 459">• The Future of In-System Inquiry & Research 	Colin Latter Leigh Niwa
10:00am –10:30am	<ul style="list-style-type: none"> <li data-bbox="402 493 987 525">• Strategic Planning for Future Funding Opportunities 	All
10:30am – 11:45am	Breakout Session #2 <ul style="list-style-type: none"> <li data-bbox="402 604 1117 667">• Development of Initiatives and Projects that can Leverage these Opportunities to Address KH-SCN Priority Areas (attached) 	Moderators: Anita Kozinski Loreen Gilmour Janice MacKay
11:45am – 12:00pm	Summary, conclusions, and next steps for the future	Brenda Hemmlegarn Matt James Scott Klarenbach Neesh Pannu
12:00pm	DEPART BANFF	

APPENDIX THREE – PRESENTER BIOS



Dr. Doreen Rabi University of Calgary

Dr. Rabi is an academic endocrinologist and cardiovascular health outcomes researcher at the Cumming School of Medicine, the O'Brien Institute for Public Health, and the Libin Cardiovascular Institute at the University of Calgary. Dr. Rabi is a Canadian leader in national guidelines for cardiovascular risk reduction. She is the co-chair of the 2018 Diabetes Canada Clinical Practice Guidelines Methods Committee and has been the chair of the Hypertension Canada/CHEP recommendations since 2016. Dr. Rabi also participates on the Canadian Cardiovascular Guidelines Harmonization Endeavor (C-CHANGE) committee.

Léora Rabatach, MSc, University of Calgary

Léora is a manager of Communications for the W21C Program in the O'Brien Institute for Public Health. She has worked in communications and fund development in both public and private sectors for over 18 years, and specializes in: strategic communications planning, media relations, knowledge management/knowledge translation, ROI/measurement, event planning, web development, issues management, copywriting, and editing. Léora completed her undergraduate degree in biology and physical anthropology at the University of Calgary (1999), and followed this with a Master in Medical Science from the University of Calgary's Department of Community Health Sciences in the Cumming School of Medicine. Her research focused on measuring stakeholder engagement for quality improvement projects in Strategic Clinical Networks (SCNs) in Alberta. Other research has focused on exploring clinical care pathways (areas of care and evaluation methods for outcome measures), and understanding how electronic health record data - specifically Epic Systems - have been used for research in other areas of the world.



Dr. Jeff Bakal, Alberta Health Services

Dr. Bakal is the Program Director for Provincial Research Data Services at Alberta Health Services which incorporates the Alberta Strategy for Patient Oriented Research (SPOR) data platform and Research Facilitation teams. He has over 15 years of experience working with Health Services data and Randomized Clinical Trials, in a variety of medical areas. He completed his PhD jointly with the Department of Mathematics and Statistics and the School of Physical Health and Education at Queen's University. He has worked on the methodology and analysis of several international studies in business strategy, ophthalmology, cardiology, geriatric medicine and the analysis of kinematic data resulting in several peer reviewed articles and conference presentations. His current interests are in developing statistical methodology for time-to-event data and the development of methodology to develop the use of secondary data sources.

Becky Wong MSc, MBA Alberta Health Services

Becky joined AHS in 2012 is currently Director of Health System Access within the Innovation & Research Management portfolio. The Health System Access (or “HSA” – previously known as Provincial Research Administration (“PRA”) is comprised of a team of Advisors and Coordinators to assist and facilitate researchers’ access to AHS provincial resources such as data, AHS network, electronic medical record systems, facilities, staff and patients. HSA also has accountability for contracts and financial matters related to research outside of Edmonton Zone, and works closely with NACTRC within the Edmonton Zone. Prior to joining AHS, Becky held business development and administrative positions in the pharmaceutical and biotech industries, and in the innovation and commercialization sectors. She completed her BSc and MSc at the Cumming School of Medicine, University of Calgary and her MBA at McMaster University.



Dr. Eddy Lang University of Calgary

Dr. Lang is a Professor and Department Head for Emergency Medicine at Cumming School of Medicine- University of Calgary and Alberta Health Services, Calgary Zone. His areas of interest are knowledge translation, evidence-based medicine and operations research. He is a member of the GRADE working group and has led the development of GRADE-based clinical practice guidelines in pre-hospital care in the US as well as with the International Liaison Committee for Resuscitation. Dr. Lang is also an award-winning educator having received recognition at both the university, national and international levels. He also serves as Senior Editor for the Canadian Journal of Emergency Medicine, Associate Editor for both ACP Journal Club and the International Journal of Emergency Medicine. In addition, he is a member of the Canadian Task Force on Preventive Health Care (CTFPHC). Dr. Lang chaired the Canadian Association of Emergency Physicians Conference (CAEP) 2018 and he was appointed as the Scientific Director of the Emergency Strategic Clinical Network ESCN in Alberta.

F. Perry Wilson, MD, MSCE Yale School of Medicine

Dr. Wilson received his BA in biochemistry from Harvard University before attending medical school at Columbia College of Physicians and Surgeons. After completing internship, residency and nephrology fellowship at the University of Pennsylvania, he obtained a Masters in Clinical Epidemiology at that institution as well. He was brought on to the faculty of the Yale School of Medicine in 2014, where he currently directs the Yale Program of Applied Translational Research, a multi-principal investigator group with a mission to bring novel diagnostic and therapeutic modalities to the patient bedside. Dr. Wilson’s research interests are broad and focus on “interventional data science”. Using machine-learning, real-time data analytics, and robust clinical phenotyping, Dr. Wilson and his team attempt to target diagnostic and therapeutic interventions to patients at the point of care. He is the Principal Investigator on multiple NIH and DOD funded studies, including the largest-ever randomized trial of an automated Acute Kidney Injury alerting system. In addition to his academic writing, Dr. Wilson has been a featured contributor to the Milwaukee Journal Sentinel, Intellectures, the Huffington Post, Medscape, and MedPage Today.





Colin Latter Alberta Health Services

As Program Director, Colin leads a team of clinical Informaticians, with various clinical backgrounds, who facilitate the development and adjudication of clinical content (i.e., Order Items). These order items (lab tests, medications, and procedures) are developed by clinicians from across Alberta and incorporate the evidence and best practices and leverage existing work from within Alberta and beyond. The Foundational Knowledge team also has a role in supporting the Connect Care Clinical Decision Support Committee and helping to facilitate the requests that come to the committee. Colin grew up in Ottawa, ON, but also lived in Nova Scotia and Manitoba before setting down in Alberta. He has a Bachelor of Kinesiology and also earned his Bachelor of Education. Colin is married and has two young boys that keep him quite busy! In his “spare time”, he enjoys traveling and sports. As time permits, he enjoys hitting the ice to play hockey or the courts to play tennis.

Leigh Niwa, MScPT Alberta Health Services

Leigh is a Clinical informatics Lead with Clinical Inquiry and Support in the Chief Medical Information Office. Their clinical practice background is in rehabilitation as a physiotherapist, working in arthroplasty and orthopedics. Leigh is also in progress of their PhD in Rehabilitation Science at the University of Alberta, investigating models of care in osteoarthritis.

