

Optimizing Clinical Health Research in Alberta

Proceedings



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Acknowledgements



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ALBERTA 
INNOVATES

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Background

Active involvement of Canada in clinical health research studies has led to numerous improvements in health, healthcare delivery, and quality of life. Clinical research studies, as part of clinical care, bring the latest diagnostic tools, prevention methods and treatments to Canadians. Additionally, sites that participate in clinical research studies have better patient outcomes, even for patients who do not participate in a trial¹. The sites can also experience economic and social benefits^{2,3}. Clinical health research activities bring economic growth and development through job creation and attract researchers and companies to Canada, leading to a diversified and healthy economy.

Canada represents 4% of global clinical trials and is fourth in the number of trial-hosting sites⁴. There are a number of national and provincial initiatives tasked to increase the attractiveness of clinical health research and keep Canada and Alberta competitive on a global stage: notably the Canadian Clinical Trials Coordinating Centre (CCTCC), Canadian Institutes of Health Research (CIHR), the Alberta Strategy for Patient-Oriented Research SUPPORT Unit (AbSPORU) including the Pragmatic Clinical Trials Platform (PCT), and the Alberta Clinical Research Consortium (ACRC). These initiatives work together with the common goal of strengthening the Canadian clinical trials environment and promoting Canada as a destination for clinical health research. Alberta has a strong ecosystem for clinical health research including an established academic culture, one healthcare system with strategic partners, two medical schools and a diverse population of over four million.

The ACRC and AbSPORU PCT are collaborating and supporting each other on a number of projects that will achieve the goal of optimizing clinical health research in Alberta. Launched in May 2011, the ACRC is a partnership of provincial institutions that bring together academic and community-based researchers and administrators to achieve the vision of high quality, integrated and efficient clinical research in Alberta. With a similar goal, the Alberta SPOR SUPPORT Unit Pragmatic Clinical Trials (PCT) platform aims to create and enhance provincial infrastructure to improve the quality and quantity of patient-oriented research in Alberta. More information on these activities is presented in a General Overview document from December 2016.

Optimizing Clinical Health Research in Alberta

On December 5, 2016, the ACRC and the AbSPORU PCT facilitated a meeting on the topic of optimizing clinical health research in Alberta. The meeting brought together representatives of researchers (academic and community-based) and administrators from Alberta Health Services, Alberta Innovates, the Alberta College of Physicians & Surgeons, Covenant Health, the University of Alberta, and the University of Calgary. The day-long program incorporated both small and large group discussions and activities to set priorities, identify outcomes, and propose actions to optimize clinical health research in Alberta over the next two years. This proceedings document outlines the key priority areas identified by this group of stakeholders and presents the actions proposed to achieve these goals.

¹ Sumit R. Majumdar, MD, MPH ;Matthew T. Roe, MD, MHS ;Eric D. Peterson, MD, MPH ;et al (2008) Better Outcomes for Patients Treated at Hospitals That Participate in Clinical Trials. *Arch Intern Med* .662-657:(6)168;2008 . doi:10.1001/archinternmed.2007.124

² NIHR Clinical Research Network: Impact and Value Assessment. September 2016. KPMG <https://www.nihr.ac.uk/life-sciences-industry/useful-info/Key-commercial-stats.htm>

³ Institute of Medicine (US) Committee on Health Research and the Privacy of Health Information: The HIPAA Privacy Rule; Nass SJ, Levit LA, Gostin LO, editors. Beyond the HIPAA Privacy Rule: Enhancing Privacy, Improving Health Through Research. Washington (DC): National Academies Press (US); 2009.

⁴ Clinical Trials Environment in Canada. https://www.ic.gc.ca/eic/site/lsg-pdsv.nsf/eng/h_hn01774.html Accessed on March 13, 2017.

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The objectives of the meeting were to:

- Build awareness and achieve a shared understanding of, responsibility for, and interest in optimizing clinical health research in Alberta;
- Inform priorities for capacity building and optimization for the ACRC and AbSPORU Pragmatic Clinical Trials initiatives for the next two years;
- Explore and develop action plans, accountabilities, and targets for these priorities;
- Network and build relationships among those who share responsibility for and interest in optimizing clinical health research in Alberta.

Dr. Michael Hill, AbSPORU PCT Lead and ACRC Executive Committee Member, opened the meeting with a reminder that it is our social contract as medical professionals to ensure that new therapies are properly tested. The gold standard for determination of the efficacy and safety of medical interventions are randomized controlled trials (RCTs). Yet, the conduct of RCTs is still a relatively new concept with international guidelines only coming into place 25 years ago. In reflecting upon our provincial progress in this time, Dr. Hill spoke on the evolution of AHS, the adoption of the Health Information Act, and how our health system has partnered in the conduct of clinical health research within our universities. Moving forward with the agenda for the day, Dr. Hill summarized the mandates of the CIHR and Strategy for Patient-Oriented Research, reminding us that the reason we are conducting clinical health research is to *improve patient care*.

The context for action planning at this meeting was presented by first describing the improvements already achieved in Alberta. In 2013, the ACRC collected 131 responses to a baseline survey regarding administrative processes in clinical health research within the province. The results suggested a number of areas for improvement and in the 3 years since then, we have seen success in many of them. For example, clarity and guidance for clinical research is being provided on a provincial level through the “Alberta Clinical Research Roadmap”⁵. Streamlining of processes is being achieved by facilitating centrally accessed approval documents between institutions. Additionally, networking and training opportunities are being offered through the ACRC Clinical Research Conferences, CITI training courses, and the Leadership in Patient-Oriented Research: Pragmatic Clinical Trials Certificate Program. The success of these and other initiatives, beyond the ACRC and the PCT Platform, demonstrates that Alberta is not only capable of thinking provincially but capable of enacting the changes needed to optimize clinical health research in Alberta.

The meeting day additionally leveraged the work and advancements within organizations such as: the University of Calgary’s Clinical, Health Sciences, and Population Health Research Platform Strategy and expanded infrastructure to support clinical health research; the NACTRC-led launch of the Bethecure.ca campaign increasing awareness of clinical trials in collaboration with Alberta Health Services, Government of Alberta Economic Development and Trade and Alberta Innovates; Women Children’s Health Research Institute receipt of \$54 million at the University of Alberta to support grants, recruitment, and expert support teams; Alberta Health Services place as number 16 in Canada’s top research hospitals/health authorities in 2016 and expanded research supports; Covenant Health’s focus on vulnerable populations, development of multi-disciplinary teams, and support of new researchers; and the Strategy for Patient-Oriented Research which puts patients first.

Building on the above success, we began small-group discussions to determine the priority areas for further improvement.

⁵ Online interactive Alberta Clinical Research Roadmap can be found at <http://acrc.albertainnovates.ca>

What were the Priority Areas?

Following small-group discussions on the desired 2-year future of clinical health research in Alberta, five main themes emerged and were set as the priority areas for discussion and action planning:

- **Institutional Collaboration & Integration**
- **Collaboration & Capacity Building**
- **Public Awareness & Engagement**
- **Knowledge Mobilization**
- **Health Systems Engagement**



Institutional Collaboration & Integration

Suggested Leads: Clinical Health Research Administration, Research Services Offices and the ACRC

There was overwhelming agreement that clinical health research in Alberta could be optimized by standardizing processes through institutional collaboration and integration. It is proposed that this activity begin with the creation of an inventory of current support services and resources for clinical health research in Alberta. This inventory will allow for coordination of services, areas for collaboration, and the streamlining of processes that will lead to faster activation times, connecting of researchers, increasing of efficiency and reducing redundancy. It also enables us to streamline, standardize, and create an integrated process map such that all clinical health research projects in Alberta can begin at a single point of entry and be directed accordingly.

In addition to a digital one-stop-shop for clinical health research in Alberta, there exists the potential to establish physical collaborations in the form of regional research coordination offices that fall under the second priority area of Collaboration & Capacity Building.

Collaboration & Capacity Building

Suggested Leads: University Faculties of Medicine and Department Heads

In line with the first priority area, there was also a strong desire to develop the culture and resources needed to encourage researcher collaboration, clinician scientists, and community researchers. It is proposed that this culture shift begin with incentivising and acknowledging contributions to collaborative research rather than the traditional publication-based rewards system. After identifying the Alberta researchers that are championing collaborative efforts, they can be empowered to create cooperatives to share their expertise and contribute to a combined resource base. Such a system could be set up as a hub-and-spoke model, where the cooperatives form spokes out of a central research-coordination hub.



Furthering the effort to create a culture of research, it is also proposed that we engage and educate potential researchers such as medical students, junior trainees, and community health professionals. A standardized curriculum specific to clinical research and clinical trial conduct should be developed and shared between academic institutions in Alberta.

Public Awareness & Engagement

Suggested Leads: Alberta Health Services and AbSPORU

Again following the theme of creating a culture of research, it was felt that clinical health research in Alberta



could be optimized by increasing public buy-in regarding the importance of supporting and participating in research. To facilitate this, a marketing campaign should be launched that not only increases *awareness* of clinical health research in Alberta but ties it to *action* by connecting people to opportunities to learn about and participate in clinical health research. It is proposed that this action begin with an environmental scan of how other

regions are engaging their public and a survey of the Alberta public on how they would like to be engaged. With this information, we can then create tools that allow patients and healthy controls to self-identify and express their interest in being contacted with relevant research opportunities. In addition to this self-manage approach, it is important that the public have access to up-to-date information and educational resources in lay terminology from active researchers. This system of connecting participants to researchers and vice versa will then serve as the action tied to the public awareness campaign.

Knowledge Mobilization

Suggested Leaders: AbSPORU and Strategic Clinical Networks with adoption of best practice by Alberta Health Services

The priority area of knowledge mobilization took on two forms throughout the action planning portion of the meeting. The first form was dissemination of results to participants and the general public. It was felt that sharing results in plain language with research participants and the general public was of the utmost importance, both ethically and in terms of promoting a culture of research. It is proposed that this sharing of results be incorporated from the beginning of a research study with knowledge translation as a part of the granting, ethics application, and informed consent processes.



The second form of the knowledge mobilization priority was effectual adoption of evidence-based research findings. It is proposed that the incorporation of research findings into standard care be a part of AHS' mandate and that a multi-disciplinary approach to protocol development be adopted. Alongside scientific and ethical guidance, health policy makers should be involved in research planning and protocol development so that their view of the utility of the research and methods for implementation of results can be stressed from the beginning.

The infrastructure developed in both the public awareness and institutional collaboration initiatives could easily be leveraged for these knowledge mobilization efforts. The infrastructure created for public awareness could also be used for the sharing of research results in lay terminology. The hub-and-spoke model of research coordination could be used to engage knowledge translation experts and health policy makers in the research planning process.

HEALTH SYSTEMS ENGAGEMENT



Health Systems Engagement

Suggested Leaders: Alberta Health Services

The final priority area discussed was a formal engagement of health systems and other health professionals in Alberta. To truly create a culture of research in Alberta, our health systems need to lead by example and demonstrate

the importance of clinical health research to patient care. To do this, it is proposed that AHS embody this culture of research by providing research orientation to new hires and encouraging clinical staff members to perform some research duties as a part of their job. The advancement of medical care in Alberta is fuelled by research and it should be encouraged and supported in all clinical settings.

Conclusion

Alberta has a distinct advantage in innovation in healthcare in the form of our provincially unified system. However, the application of this advantage to clinical health research is not being realized due to segregated processes and resources. It is our recommendation that the Alberta institutions involved in clinical health research undertake the following initiatives collaboratively:

1. Inventory current resources and processes to create a provincial standard and central hub for research coordination.
2. Share expertise and facilitate collaboration by establishing research cooperatives out of this central hub.
3. Formally educate all levels of healthcare professionals about clinical health research: medical students, junior trainees, primary care physicians, and AHS employees.
4. Connect public awareness of research to opportunities to participate in research and plain language summaries of research findings.
5. Create a pipeline for the adoption of evidence-based research findings by engaging health policy makers in research planning.

By promoting a culture of research at all levels and integrating the many valuable resources already in place, clinical health research in Alberta can take great strides towards optimization in the next two years.

Appendix A: Meeting Participants – December 5, 2016

Attendees:

- Marjan Abbasi
- Yazid Al Hamarneh
- Sharon Appelman-Eszczuk
- Stacey Beck
- Susan Benseler
- Mari Boesen
- Suzette Bremault-Phillips
- Irena Buka
- Jillian Byrne
- Mary-Ann Clarkes
- Veronica de la Rosa Jaimes
- Justin Ezekowitz
- Peter Faris
- Konrad Fassbender
- Leslie Fedorak
- Will Fiebelkorn
- Scott Garrison
- Theresa Griffen-Stead
- Brent Hagel
- Troy Hamilton
- Glen Hazlewood
- Michael Hill
- Scott Jamieson
- Lynn Klein
- Kim Kordov
- Manoj Kumar
- Marc Leduc
- Mark Lowerison
- Donna Manca
- Karine Morin
- Sabine Moritz
- Sheli Murphy
- Suresh Nayar
- Ameen Owaisi
- Lawrence Richer
- Carolyn Robertson
- Lorelee Robertson
- Nicole Romanow
- Dory Sample
- Patricia Steele
- Hude Quan

- Nicole Valade
- Christine Wagoner
- Ron Welch
- Toni Winder
- Becky Wong
- Rose Yeung

For Alberta Innovates:

- Tim Murphy
- Tammy Mah-Fraser
- Trina Johnson
- Tamara Murray
- Ronda Danchak
- Pat Evans (Facilitator)