



Fall Retreat 2023 Report

Edmonton, AB
September 28 & 29

Managed by



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INTRODUCTION

The ARECCI (A pRoject Ethics Community Consensus Initiative) program recently marked its 20th anniversary by hosting a two-day retreat in Edmonton, Alberta. The event brought together the ARECCI community, past and present. This retreat was a commitment to keep the ARECCI community engaged and informed following the previously held ARECCI SORers meeting in October 2022. From that retreat, discussions were had on the importance of ARECCI, why it matters and how it must evolve to meet the growing demands for ethics reviews in quality improvement and evaluation projects in health and human services. The journey together continues to advance the work and ARECCI.

The September 28 and 29th retreat was structured around several objectives. The first objective was to provide an update on ARECCI's modernization activities and to explore their potential impact on various facets of the program. These included the ARECCI Community of Practice, ARECCI Courses (ARECCI Project Ethics course and ARECCI Second Opinion Reviewer Training), and ARECCI Reviews (which comprise the ARECCI SOR Process and ARECCI Organizational Recognized Review).

The second objective was to facilitate networking opportunities for the ARECCI Community. Attendees had the chance to interact with their peers, share experiences and provide feedback on the work-to-date. These discussions laid the foundation for potential enhancements and improvements within ARECCI.

Finally, the retreat was a celebration of ARECCI's remarkable 20-year journey. The success of the program was recognized and celebrated, along with the dedicated members (former and current) who play a vital role in ARECCI's growth and development.

The retreat achieved its objectives through a combination of presentations, workshops, and feedback from the participants. It provided a unique opportunity to explore human and health system challenges from an ethical standpoint and fostered collaboration and knowledge sharing among the ARECCI community. The insights gained from this retreat will contribute to ARECCI's ongoing modernization and growth, and the program's commitment to promoting ethics reviews of quality improvement and evaluation projects in health and human services.

Retreat: Day One

The first day of the ARECCI retreat featured a series of engaging presentations and activities that provided valuable insights into the program's history, current initiatives, and strategic future direction. As the retreat officially began, Tim Murphy, Vice President of Alberta Innovates delivered the opening remarks that set the tone for the day's discussions and presentations. He opened with a land acknowledgment recognizing the land that we gathered on and the many First Nations and Metis Settlements in Alberta, respecting the Knowledge Keepers and Elders, and acknowledging their histories, languages and cultures that continue to enrich our vibrant community.

Opening Remarks: Tim Murphy

What we heard

Tim covered a range of topics related to healthcare and innovation in Alberta. He emphasized the importance of having robust knowledge networks, a thriving competitive marketplace, and inspired leadership with open dialogue and trust as key ingredients for a successful life sciences organization. He also highlighted the significance of open dialogue with society and a social contract in the context of health and life sciences. He recognized the importance of ARECCI with its 20-year history of reducing harm. Tim described changes over the last 20 years within Alberta Innovates, formerly the Alberta Heritage Foundation for Medical Research (AHFMR).

Alberta Innovates is proud to be a supporter of ARECCI going forward, as it is perfectly positioned as an enabler in innovation and research. Alberta Innovates funds good ideas, provides technical expertise for entrepreneurs and companies, and helps move those ideas from discovery to market by offering investments and services on those platforms. Alberta Innovates has three roles - funder, partner and collaborator, and convener and connector. As a funder, they do more than simply write a cheque. They work with their clients (coaching, advising) to enable their success and provide technical expertise. ARECCI is part of the service offering. As a partner and collaborator, they work with companies, subject matter experts (SMEs), researchers, and innovators to help them get the right resources at the right time and for the right reason. They help move products to market and companies to fail fast, without creating dependency on their money. Finally, as

a convener and connector, they help stimulate partnerships and collisions among innovators, thought leaders, and industry experts. The presentation outlined the organization's focus on innovation priorities, including artificial intelligence, digital health, clean energy, low-carbon resources, and smart agriculture.

Tim addressed the challenges in harnessing health data for innovation, including technical factors such as data standards and human factors in governance, regulations, culture, and data literacy. He mentioned the importance of applying ethical principles to research projects and highlighted the role of ethical considerations in non-research projects. Tim also emphasized the need to shift from acute care to promoting healthy communities, driven by factors like cost efficiency, the impact of social determinants of health, the role of technology, and consumer preferences for personalized care. The exponential growth of data and the challenges associated with managing and utilizing healthcare data were also discussed, focusing on the importance of quality and trust in data. Tim sees an increase in ARECCI's role in the interplay of data, health communities and the goal of high-quality care.

Finally, he highlighted the importance of transforming health services to address fragmentation, silos, interoperability, and coordination issues within the healthcare system. The presentation concluded with an emphasis on embracing new technologies, mobilizing knowledge, and the importance of a social contract between the healthcare system and citizens. ARECCI has an integral part in helping with the social contract.

Tim's presentation illuminated Alberta's challenges and opportunities in healthcare and innovation. The role of ARECCI was noted as significant in this context, highlighting the importance of ethical considerations in healthcare research and innovation. He concluded by congratulating everyone in the room for their 20-year success.



PRESENTATION SUMMARIES

20 Year Look Back.

A Strategic Analysis: Striking a Balance

Robin Lau

What we heard

Robin delivered an informative and detailed presentation that covered various aspects of the program's history, the evolution of healthcare ethics, good strategy, stakeholder concerns, and the program's strategic plan. He began his presentation by discussing the origin story of ARECCI, emphasizing the importance of conducting a strategic analysis to understand the program's genesis and evolution. He provided valuable insights into the program's early motivations and development, highlighting the contributions of Kathy GermAnn, who is involved in a series of ARECCI papers. These papers are drawn from Kathy's interviews, older research and writings that contribute to the knowledge base of ARECCI.

Robin introduced the concept of a "good strategy" and explained its three essential elements: diagnosis, guiding policy, and coherent action. He emphasized that a diagnosis is central to identifying critical factors in a situation and coordinating actions to address those factors effectively. He also highlighted the distinction between good and bad strategy, stressing the importance of defining the challenge, simplifying complexity, and providing a clear direction for action. With this framing in mind, he describes the history of bioethics, which emerged from two parallel traditions: the clinical tradition focused on patient-physician relationships and the public health tradition centred on community welfare, sometimes at the expense of individual interests. He underscores the need for robust research ethics and highlighted several historical ethical breaches, including the Tuskegee Syphilis Study, Nazi experimentation in concentration camps, and the Milgram study.

Robin discusses the development of research ethics oversight, such as the introduction of Research Ethics Boards (REBs) and the Tri-Council Policy Statement TCPS. The context in Alberta at the time (early 2000s) included the Health Information Act (HIA), nine health

regions, two provincial health authorities and six research ethics boards. Ethics oversight under the HIA is designated to the REBs for research projects. However, a gap remained for ethics oversight in quality improvement and evaluation projects (QI/E) as TCPS did not require these projects to undergo ethics review. There is growing concern among stakeholders that QI/E projects could have significant ethics risks. Key issues of:

- no clear criteria to differentiate research from QI/E
- no clear guidelines to review QI/E projects
- no agreement on what an ethics review for QI/E would look like
- fear that projects with ethics risks could result in harm
- fear that researchers bypass the REB process by deeming their projects as QI/E
- capacity, feasibility and acceptability of REBs undertaking additional reviews
- lack of QI/E methodology expertise in REB
- a REB-like process and a lengthy review time could impact practice improvement and decisions

The diagnosis of Alberta's situation with QI/E projects led to the establishment of ARECCI in 2003 for knowledge-generating projects. Robin explained the second element of good strategy is guiding policy, and in 2004, ARECCI's five primary goals were developed through consultation and collaboration involving key stakeholders from various sectors. These goals include:

- Develop a common understanding and broad consensus on issues of ethics review.
- Increase the clarity, consistency, transparency and efficiency of ethics review processes in Alberta.
- Recommend an approach to answering the questions:
 - What kind of investigation or project is it?
 - What ethics review process should be used for each kind of project?
 - What level of review is appropriate for a particular project – full or expedited?
- Develop guidelines and tools to support the implementation of the recommendations by Alberta's health and human services researchers, managers, ethics boards and other stakeholders.
- Inform health authority, provincial and federal policy related to ethics review processes.

To address these goals, ARECCI's operational and enabling recommendations are:

- Screen all projects to determine the need for ethics review
 - Assess the primary purpose (research or QI/E)
 - Assess the level of risk and determine the appropriate review process
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- Build capacity and build on existing practices (spread throughout province)
 - Progressive Implementation (implement in organizations engaged in knowledge-building projects)

Those involved with ARECCI's development specifically identified capacity building needs to occur at the system's level and implementation to build onto existing structures. Three enabling components were identified:

- structural (organization support policy and processes, defined roles and responsibilities and technology infrastructure)
- resources (financial, human, education and ongoing professional development)
- networking (enabling environment, formal/informal collaborations and formal/information communication mechanisms)

The final element of good strategy is coherent action, and between 2005 and 2010, ARECCI developed a suite of products and services. Each product and service addressed a specific need or strategic issue, improving ethics oversight and decision-making in QI/E projects. ARECCI's guiding policy, products and services remain relevant today in the evolving landscape of healthcare ethics and research ethics oversight. The original concerns from stakeholders on the ethics risks in QI/E still apply currently. He concludes his presentation by discussing the following steps as set by ARECCI's strategic plan to build on its foundations (guiding policy), strengthen its products and services (coherent action) and focus on the enabling components (structural, resources, networking).

Robin's presentation provided a valuable systems perspective on ARECCI, highlighting the enduring importance of ethics in healthcare and research and the ongoing need for strategy, action and improvements. The modernization of ARECCI progresses with constant attention and active maintenance to ensure stakeholders' needs are addressed.

"Ethics is where people decide what kind of society they live in."



ARECCI Program Overview & Decision-Making Tammy Fraser-Mah



What we heard

Tammy provided insights into ARECCI's current vision, mission, and the path forward. She gives an overview of the current state of ARECCI and discusses the challenges and opportunities ahead. Tammy provided a summary of the three main components of ARECCI's work: screening, capacity building, and oversight. Specifically, she explained that ARECCI gives ethical screening to projects involving people, information, and knowledge generation. They also provide capacity building through ethics courses and second opinion reviews. Finally, they offer organizational recognition of ethical review through their oversight component with the ARECCI program.

Tammy described ARECCI's original vision, which was to be a vital resource for ethics review for all projects protecting individuals and their information. She discussed the driving forces that support ARECCI's work, such as the demand for courses, project design and learning, reducing silos, and addressing emerging areas such as data and new methodologies. Also mentioned are the restricting forces, including awareness, the optional nature of participation, concerns about disrupting current practices, resource allocation and getting started with ARECCI. She noted the program's progress by stabilizing its screening tool, moving to a learning management system for consistent course materials, and fostering a community of practice. The program aims to pilot an oversight and recognition framework.

ARECCI's new vision is to become an enabling learning system that fosters learning and improvement through every project it engages with. We have an opportunity to build the learnings by being part of an ecosystem. The mission is to enable system learning and collaboration, bringing together various stakeholders in the field of quality and evaluation in health and human services. Tammy provides an overview of ARECCI's core strategies, which include scaling, capacity building, connecting stakeholders, and providing oversight. She also discusses the core values that guide ARECCI's work and the strategy we will work through during the two days of the retreat. She identified that it is essential to scope what ARECCI is doing as many interdependencies are impacted by the three constraints of time, resources, and money. From a strategic position, she explained how ARECCI would proceed

in two phases: elevating its current activities and adjusting to emerging areas and needs. She emphasizes the importance of consultation and decision-making processes within ARECCI. She shared an illustration with the details of the consensus method for ARECCI. She explained that complete consensus is sought for critical decisions, while consultations and focus groups are used for specific projects. Operational and tactical decisions are made within the organization, but she expresses that she would like to hear back from the community on the consensus illustration and the new ARECCI program vision and mission.

She acknowledged that communication has been a big theme they could address, but they need the community to tell us how to do it better. She emphasized that she looked to everyone in the room working together on stakeholder engagement. Communication has been difficult as the ARECCI program has moved forward on multiple fronts and the interdependencies from the many projects. She stresses the importance of the retreat as an opportunity to hear the community's opinions as they are valued. She hoped that the process of decision-making and consultation would continue to work.

Tammy concluded her presentation by emphasizing the importance of feedback and inviting stakeholder input. She encouraged stakeholders to provide feedback on the mission and consensus process to help ARECCI improve and achieve its mission.

Introduction to ARECCI's QI/E Project Ethics

Online Course

Marilynne Hebert

What we heard

Marilynne showcased the progress made on the learning management system (LMS) and migration of the Project Ethics course to the Thinkific platform. She demonstrated system features and how they enhance the participants' learning experience. LMS benefits included a variety of content delivery methods such as presentations, videos, quizzes, surveys, and discussion boards. Learners can also download some resources for offline access. Additional features can be included in the LMS as you need them such as using AI software to convert text to voice to create voice-overs.

She described the course organization which included chapters and lessons to help learners navigate the content. The intended target audience for the course has remained the same as the previous in-person version which has largely been individual project

managers involved in quality improvement and evaluation projects. A variety of course resources support learner interaction with the content and other learners including: project plan template, project scenarios, guideline tool for addressing ethics considerations in project planning, and the use of a fillable PDF template for project planning.

Marilynne noted over the past 20 years QI/E projects have increased in complexity, including ethics considerations. For example, evolving concepts and vocabulary in ethics such as equity, diversity and inclusion (EDI) required updates in the course. Stakeholder input contributed to reorganizing and streamlining content for clarity. Opportunities to improve terminology and language consistency in the course were provided, and considerations were raised for keeping required changes current.

Learning outcomes and objectives of the online course were discussed with possible suggestions to adapt or tailor the content for different audiences and organizations to make it practical and applicable. Examples and context could be customized to make the course more relevant to specific groups. The course includes a variety of scenarios reflecting a range of health and human service contexts, with some being outside the personal experience of learners. These scenarios are intended to help learners apply ethical principles to unfamiliar situations, enhancing their understanding of ethical concepts. Some example scenarios mentioned include increasing cervical cancer screening for immigrant women, EMS and paramedic distribution of carbon monoxide detectors, and a community support program to keep students in school.

Marilynne emphasizes the importance of learners' personal accountability in completing coursework and commitment to small group assignments and presentations. The facilitator's role was to guide learners through the course, answer questions and help them develop a deep understanding of ethics. The facilitator also ensured that the course maintained its integrity and was conducted consistently. The course could follow a cohort-based approach that provided specific timelines and activities for participants to stay on track with their projects and interact with their peers. For example, a cohort of 12 would start and finish at the same time. While this approach is very structured, it supports manageable group sizes, essential for effective online learning and successful course completion. The number of cohorts and the division of learners among them can be adjusted based on available resources. The course is completed in 20 hours over four weeks, including individual course work, small group meetings to share what they have learned, two guest presentations, completion of their project proposals and meeting with an SOR to review and revise their proposals.

Technical challenges can be a barrier to learning success, and Marilynne suggested a dedicated technical support hotline could assist learners with technical difficulties during the course. She also emphasized the importance of evaluating the course and collecting feedback. The learning management system allows for monitoring learner progress and identifying areas where learners may be struggling.

Throughout her presentation, Marilynne encouraged questions, comments and feedback.

Feedback During the Presentation

- Are the key ethics principles retained as part of the analysis process?
- Fidelity to ethical principles and ARECCI content and learning is essential, and the core content and principles of ethics must remain consistent across different adaptations for various audiences.
- Include family physicians, clinicians, non-healthcare roles and the universities.
- Clarify the intended audience and their learning outcomes.
- There should be a confidential agreement as projects are brought forward during the course.
- Is there programming to develop facilitators? The response from the ARECCI program is that the train-the-trainer model approach is part of the conversation.
- Implementing a community of practice for regular updates and language changes in the field.
- There is a need for a sustainability assessment tool to evaluate the long-term impact of a project. The tool MUSIQ was shared.
- The question of accreditation and the validity of certificates is raised. It's suggested that the course could be accredited in the future, but there should also be a system in place to ensure that learners refresh their knowledge periodically. This would ensure that the course remains relevant in a rapidly changing ethical landscape. Include a date that the certification expires.
- It was suggested to make transcripts available for the videos, catering to different learning preferences.
- Using real people for voice-overs in a project rather than AI.
- Is there an ability for technical support?

Workshop Activity

The group provided additional feedback following the presentation with the Rose Bud Thorn activity which involves people sharing positive aspects (roses), potential areas for growth or improvement (buds), and challenges or concerns (thorns) on a topic. Participants were asked to discuss their thoughts on the QI/E Project Ethics Course in the LMS.

Some participants found it difficult to provide detailed feedback as they needed time to navigate through the online platform and course contents. Those who expressed interest in reviewing the course were asked to provide their names and email addresses, which would be sent to Marilynne to set up their access.

Rose Bud Thorn Participant Feedback

Rose

- Learning objectives
- Benefits of course
- Staff given time to do course
- Questions and answers at the end of each module
- Spread over 4 weeks
- ARECCI light version
- Standardizing content knowledge for broad audiences
- Course without facilitators
- Size of cohort
- Based on adult learning principles
- Course length 5-8 hours
- Learning tools are available, accessible and well laid out, nice Consistent approach as other PD opportunities e.g. LinkedIn learning *familiar process
- Discussion boards provide excellent opportunity for reflection, dialogue and learning
- Moving the course to online LMS is great. Self-scheduling learning makes courses accessible
- Ability to copy course/make a copy
- Well-organized
- Very scalable
- Accessible
- Cost-effective
- Facilitators - great idea - number? training? time commitment?
- I like that the guidelines tool is integrated with project description form. Is the guideline tool still going to exist?

Bud

- Ability to go back and forth between modules
- What is the main purpose/problem of the course?
- Scenarios with own project is a lot
- 20 hours seems long
- Resourcing and finding course facilitators
- If PE course exists online for everyone, it still does not address organizational support to ARECCI
- Length of course may discourage/limit uptake
- Course still optional for folks doing QI/E projects
- The need for a project might preclude participation for those without projects
- Who is the course facilitator? Sounds like a big role - who is going to lead the course in an ongoing sustainable way

Thorn

- Composition of cohort
- Who is the audience
- Consultation service for next project
- Need to market ARECCI to journals
- Marketing to whom?
- Consider sub-courses that are context-specific
- Need foundational info on what is QI, Evaluation and Research
- Different types of delivery modes (hybrid, asynchronous)
- Confidentiality: option to work on the same projects/same team
- Is there continued access to the course?
- Adapt/modify course to other areas (less health care focused)
- Make the project plan more user-friendly
- Learning objective? Value of ethical considerations for a successful project
- What is "official" documentation vs educational material? Branding of course
- Add transcripts
- What is the cost? who is paying? will there be a cost for an ORR process? Fees could be detrimental to uptake
- How are the two separate methodologies accommodated? QI and Eval
- Office hours - set time each week
- Does the project need to be current or can it be completed previously?
- Can there be a fundamentals course with principles and no need for project?
- Who is the gatekeeper? intake?
- Management of course
- Control copies of course - central
- How many facilitators, trained trainers will we need for this?
- Process for KT/wisdom sharing

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- How context specific is this LMS? will it be or should it be useful for someone from another province or course
 - Need clarity about timelines, when will course be accessible for public use? e.g. build awareness and build capacity to take full course e.g. grad student
 - Consider accessibility e.g. screen reader compatibility
 - Is your project going to actual SOR or do you have to submit it separately?
 - How will sustainability of course facilitation be developed?
 - There is a risk of losing great depth and expertise (retirement table)
 - If course is accredited, should facilitator be accredited? Will SORs be facilitating?

Feedback Takeaways

- Course facilitation, role of facilitators and sustainability is a concern to be addressed.
- Include foundational information on methodologies of quality improvement, evaluation, and research.
- Cater to diverse learners and different contexts (less health focus).
- Offer a lite version that is less time intensive and without a project.
- Confidentiality and continued access to the course should be ensured.
- LMS has good features but consider additional ones such as transcripts and accessibility (screen reader).
- Management and maintenance of the course is a concern especially with copies; expectation for content fidelity.
- Explore accreditation of ARECCI and re-certification process for learners.
- Potential limitations and barriers include course length, project information, charging for course.



ARECCI SOR Redevelopment Status Update Birgitta Larsson & Silvia Koso



What we heard

Birgitta and Silvia shared their learnings from their engagement of Second Opinion Reviewers (SORs). They gave an overview of their work on the Second Opinion Reviewers training model and sought feedback with a "World Cafe" discussion style.

In their presentation, they note their involvement in the Second Opinion Reviewer (SOR) program, which has existed since 2010. They stress the significance of considering the ethical implications of community projects and the need to bring a community perspective to the program. The primary purpose of their presentation is to provide an update on the SOR program while also seeking valuable feedback from the retreat participants.

Birgitta and Silvia engaged Second Opinion Reviewers or community, both active and inactive, to understand what was happening. What are their concerns? What are they facing? What are their challenges? What are the good things? What are the benefits? And what is happening? Before considering revamping the training model, we should determine what is needed. They heard that more resources and time are required to conduct SOR reviews. Quality improvement and evaluation projects are much more complex and intrusive, with risks we didn't know about 20 years ago. There is a need to determine how to share stories and get them into the institutions, organizations and communities.

An iterative approach was used to gather data from the SORs, and the data was analyzed, which helped inform the development of focus group questions. They invited people who had time to join for a focus group. Twelve people participated in the focus group, and upon analysis of the data, some of the themes required further exploration with key informant interviews. Five individuals completed the interviews.

Through an iterative process that included a survey, focus groups and key informant interviews, they learned that SORs have been involved for many years, with a quarter of the current SORs doing this work for over ten years. Most SORs are doing 2-3 reviews per year. They continue to do the reviews, but it's an add-on, not part of their regular work or recognized by their organization. There is an absolute commitment, a professional

commitment to do the right thing because they believe in the ethical review process. Even though organizations may not recognize the work, SORs know the benefits to their organizations. Another benefit of doing this work is continuous learning and professional development.

Time was the biggest challenge identified by SORs, the scarcity of time available as it is not part of regular duties, with many doing this as volunteers. There is a lack of recognition and support for SOR work by peers and within organizations. They also heard that SORs do not feel connected to a Community of Practice or the ARECCI Program Office. There is a necessity for a more cohesive and active community of SOR practitioners. A community of practice to share, learn and bring forward things SORs are struggling with.

They introduce the proposed SOR training model with the emphasis that the training is not aimed at teaching project ethics, but the training teaches how to use those principles when reviewing a project. The training has four components:

- SOR candidate requirements
 - candidates must possess a deep understanding of project ethics with experience applying the principles in their own project work
- Self-study course
 - key concepts are reviewed with decision-support tools
 - candidates are guided through a scenario to review
- Synchronous SOR training
 - focusing on processes and structure (approximately 6-8 hours either online, in-person or both) and includes SOR role and review process
 - constructive feedback is also emphasized as a crucial element of the training
- Guided mentoring of approximately 3-6 months
 - the mentoring process is detailed, with three phases:
 - observation
 - collaborative reviews
 - independent reviews
 - tailored to individual's needs and organizational context

The logistics of training groups are discussed, recommending no more than six participants per group for effective interaction and learning. The recruitment of mentors and trainees is considered, with questions raised about whether specific individuals should be targeted as mentors or if an open-call approach is more suitable.

They explain that they foresee minimal changes to content but a format change as it moves to an online version. Assistance is required for realistic scenarios that reflect the complexity and need to consider artificial intelligence, equity, diversity and inclusion, and other sectors beyond healthcare or health and human services. The need for ongoing support for SORs is highlighted, along with the importance of demonstrating the program's value to potential donors, organizational leaders, and decision-makers.

Birgitta and Silvia conclude by outlining the next steps for the SOR program and inviting the participants to actively contribute to its success and provide feedback with a World Cafe. A collaborative effort is needed to enhance the SOR program's impact and sustainability.

World Cafe Activity

A World Cafe is an interactive method for dialogue and engagement to elicit ideas, thoughts, and insights on questions that matter. Five tables with questions pertaining to the SOR training is arranged. Participants travel from one table to the next providing input into the questions. A table host remains at each table as the historian to share the previous discussion and to stimulate new thoughts, ideas and conversation.

How can the ARECCI Program Office and SORs jointly build a well-functioning Community of Practice (roles, type of engagement, frequency of engagement, contributions, topics, professional development)?

- More SOR's/subsections by context (different methodology) e.g. acute care/PCNs
- Body of ethics knowledge – broad exposure to different projects because cause/risk is different
- High risk = research, economies between REB and ARECCI
- Retreat – education
- Ethics forum -come and meet Capstone e.g. fall meeting upcoming techniques; sharing Alberta Evaluation Network, mentorship; emerging trends e.g. diversity and racial equity, AI
- One intake -centers of excellence, FAQ projects, knowledge repository, e.g. Newsletters, recent projects

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- Program office – regular functions e.g. social – build relationships; practices – difficult scenarios; feedback/pass review; pass to someone else, sharing with greater community
 - Chat forum/discussion board
 - Recognition -ongoing e.g. letter to manager annually
 - Question expectation reviews/education
 - Broaden to anyone interested in QI/Evaluation; subsection SOR
 - Showcases – this worked well, this was a challenge
 - Linkages to other CoP -present
 - Need scope – start small then build connections
 - Know what ARECCI is doing and where it is at
 - Contact list -self updated
 - Virtual learning session -presentation of review; EDI; recreate review – virtual simulation
 - Survey of topics – quarterly session, hear different partners perspectives (jurisdictions)
 - Balance push – responsibility of ARECCI to pull people together/ tech may not allow to log into system. Challenge -time to log in and look for something
 - Platform needs to be a good functioning platform, easy to access/user friendly
 - Short professional development opportunities – presentation 1 hour - value added
 - Regularly updated – strong link CoP & ARECCI

Feedback Takeways

- Exposure to different projects and scenarios to develop a body of knowledge that can be applied to various ethical challenges is needed to improve practice.
- Increase opportunities for sharing knowledge and connection through contact list, regular functions, social events, retreats, knowledge repository, shorter professional opportunities and learning events (in-person and virtual) to discuss emerging trends such as diversity, racial equity and artificial intelligence.
- Create linkages with other groups in different sections/jurisdictions) and open CoP to anyone interested in QI/E
- Provide regular updates and recognition through annual letters to managers, newsletters and virtual learning sessions.

As an SOR, what would be the most meaningful way to be recognized by Alberta Innovates/ARECCI Program Office?

- Credential/letters behind name/formalization
- Letter of recognition/summary of activity
- Regular get-together (ideally in-person) to facilitate connections (attractive venues – Banff?) -Ask organizations to donate space
- Some sort of tiered recognition (extra recognition for those who have done more or for longer)
- Award for outstanding contributions – community of practice
- Tangible/financial – honorarium? gift card? Donation in SOR name?
- SOR directory (not public? Or public?) – ecard (about the gesture)
- Thanks from AI/ARECCI to SOR's organization/employer
- Advocacy for recognition by organizations/raising public profile
- Encourage ministries to formally see it as valuable/important work/job duty
- ARECCI email address
- SOR of the month
- Start by doing what we can now -long service profile/award/honour
- Provide SORs with pitch package to explain value-add to managers
- Food, personal thanks
- Recognition for being a mentor
- Facilitate education opportunities
- Swag (keep up the nice pens and books) Pick your own?
- Recognition event (real or virtual) (nice restaurant)
- Peer recognition/nominations program

Feedback Takeways

- Offer credentials, regular get-togethers, tiered recognition, recognition events for mentors and long service awards, and tangible rewards.
- Facilitate education opportunities and provide letters to employers/organizations.
- Raise the public profile of ARECCI to advocate its value.
- Provide pitch resources to help SORs explain the value-add to managers.

What is your feedback on the proposed SOR Training model (applicant requirements, self-study content, workshop content, mentoring process)?

Requirements

- Minimum number of projects/SORs? (at least 1 otherwise limit pool of candidates)
- TCP training (Tri-Council Policy to start) core training
- Recommended? Required?

Mentoring

- 2 reviews vs 3; observe, joint lead, lead
- Mentor evaluation of mentee – are they ready? What happens if not ready? Formalize process? Criteria?
- Self-reflect or “readiness” – do more “joint leads” until comfy
- Does mentor have to be SOR? (active SOR) = YES!
- Availability of ongoing mentoring – have some go to leads
- Expectation to become a mentor after SOR training
 - After a certain number of SORs
- Requirement to mentor others before SOR certification?

Self-study

- Requirements for submission after self study
- Documents/length/level of detail
- Self study submission deadline/length of study completion window (30-60 days prior)
- Where to get scenarios? (applies to workshop as well)
- Do you really need to bring a project of your own? Tap into database?
- Attendees submit
- Existing SORs
- QI consultants?
- Evaluation experts
- Use attendee projects
- Choice of scenarios
- Build a database
- Upskilling of current SORs – ongoing training
- QI/Eval

Workshop

- Flexible with format (full day/ 2x3 hours etc.); online, F2F – richer experience; same number of hours
 - Include more people and offer different formats so people can choose
- Cover common/important stuff
- Can we combine scenarios (composite) to get more complexity?
- 4 scenarios seems like a lot; QI and evaluation
- 6-8 hours may be too much for some? Could some of the current content be included in self-study?

Feedback Takeaways

- Consider additions to training, including TCP training and composite QI/E scenarios to reflect complexity.
- A database for SOR to access different scenarios and continuous learning opportunities to upskill.
- Mentor and mentee expectations and processes should be clearly defined, including suitability, access, experience and sustainability.
- The workshop format should be flexible with different options to allow for choice in delivery and times.
- Keep the certification process straightforward and less complex to avoid discouraging people from completing it.
- Training details such as number of scenarios, course hours, length of self-study are concerns.

What evidence needs to be tracked to demonstrate the value of the SOR activities (who should track what)?

- Applicant's/SOR's assessment – agree
- Risk level of projects to that go to SOR
- Types of risks that trigger SOR
- Types of risk that are surfaced in an SOR – marketing
- Applicant vs SOR assessment of risk – agree or disagree and why
- Post – areas in which mitigation/strengthen recommendations are made
- Follow up – did you use/not use/partially use recommendation (close the loop)
- Number of SOR submissions/requests, missing info, SOR that can't be done (ARECCI office gatekeeper)
- Risk assessment needs to be reassessed
- Track the number of SORs done by each SOR to be able to recognize efforts/identify senior SORs
- SOR retention/recruitment
- Survey SORs – is doing an SOR a worthwhile activity?
- Canadian Evaluation Society – do other bodies recognize ARECCI and SOR process
- Centralize process required to track and document values e.g. within an organization – AHS
- Number of SORs who give back as facilitator, mentors, etc.
- Process time tracking – time from request to review, receive letter
- Question how to track project time saved by applying ARECCI process up front

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- Track the number of SORs done by each SOR to be able to recognize efforts/identify senior SORs
 - SOR retention/recruitment
 - Trends overtime – risks identified, mitigation strategies
 - Identify new risks we didn't consider before
 - Quantify/record “what doesn't happen”
 - Risks eliminated by the review
 - Catalogue all recommendations made in review letters “output” vs “outcome”, value to project lead
 - Pre-post survey of project leads and project sponsors
 - Input/output tracking
 - Number of projects reviewed vs number times high risk is triggered by the online tool
 - Ask organizations about the value of SOR
 - Risk management (should be) is value to organization
 - Sectors requesting SOR – who is using and not using ARECCI process, track location -urban vs rural; teams – acute, primary care, health care, community services, human service
 - Accreditation Canada Professional Association – leverage to expand
 - Track SOR capacity building
 - Who needs what evidence of value?
 - Number applicants – candidates – course component completed – SORs with certification- number of SOR reviews completed per SOR – retention
 - Number of journals that accept ARECCI review

Feedback Takeaways

- Capacity building, retention, and recruitment of SORs, as well as the number of applicants, candidates, and SORs with certification should be tracked.
- Important to track risks over time and identify any trends and the number of risks that were mitigated or avoided as a result of a review.
- Assess the type of risks that are triggering reviews and track the effort spent for specific activities.
- Conduct output and outcome measures including whether recommendations were implemented, and survey project leads and sponsors pre and post.
- Consult with organizations to obtain data on the value received.
- Identify which sectors request a SOR, including those that are not using the ARECCI process.
- Track the number of citations and journals that mention ARECCI reviews.

What needs to be in place for the SOR program to be sustainable (recruitment, retention, Alberta Innovates and other organizational supports, program structure, workload expectations)?

- More SORs
- Workload -reasonable -project complexity
- # requests and complexity – balance/equitable; tracking (AHS. ARECCI); documents in shared format
- Remind clients of zero methodology review – refer to other groups (i.e. AbSPORU)
- Standard of project info – pre-screen; clients need to take PE course
- Peer SOR support
- Meet/open forum – learn from each other
- Call other/list of SORs (content expertise)/sharing
- Best practice – common themes
- Training ie. data use, collection, destruction/management
- Who do you need to protect?
- Regulations – HIA, research, TCPS2 (knowledge)
- Feeling connected – 1/yr. meeting
- Independents -sustainable/Honorarium
- ORR -micro-units (ie. dept level, non-profits)
- Partner Metis/First Nations – ethical principles of research; BIPOC (AHS DARE); Vulnerable Populations
- PE Course
- HIA/FOIP – tie-in/organizational learning
- Reporting into ministry requirement
- Multi-prong Organizations to create funded positions; within org have dedicated QI/Eval resources but zero PE, formalize job descriptions; all just QI/Eval
- Smaller org and community needs structure/mechanisms – pool; on-call
- People on call 2-3 weeks plus central management/coordination; QI/Eval
- Funders attaching a requirement, i.e. zero REB approval = zero funding
- Good will of other organizations/senior leadership buy-in/champions
- Embedded in multiple organizations - policies; all QI/E projects must have approval from _____
- Accreditation requirement? Organization recognition – HQCA, CARF (independent, nonprofit accreditor for health and human services)
- Infrastructure -platform; SORs come together; emails; recognition to come together; community -SOR
- Raise profile of ARECCI -broadly; awareness, market value-add, annual report
- SOR Course completion – expectations do # reviews – accountability; micro-credentials, milestones # reviews/pin
- HIA refresh – strengthen policy/procedures – requirement, consequences/individual level; how about the community?

-
- What is mandate, requirement, consequence, accountability? Starts with education i.e. students doing research, also QI/Eval; university level
 - Ensuring appropriate collaboration with organizations (i.e. UofA, UofC, HREBA)
 - Professional associations – nursing, dietician, College of physician and surgeons (CPSA)– target audience?



Feedback Takeaways

- Recruitment and retention strategies, organizational support, program structure, and reasonable workload expectations need to be in place.
- The workload needs to be managed by balancing the number of requests and their complexity, tracking them in a shared format, and reminding clients that methodology review is not part of the SOR program.
- Develop relationships or partnerships with other groups to refer reviews not applicable to ARECCI, such as AbSPORU.
- Training in data use, collection, destruction, and management must be provided, and regulations such as HIA, research, and TCPS2 must be followed to protect all stakeholders involved.
- Fostering a sense of community and connectedness among SORs is essential for sharing knowledge, best practices, and experiences.
- Independent SORs can be sustainable through honorariums, while ORR micro-units can be created at the department level or non-profit organizations.
- Partnerships with Metis/First Nations can ensure ethical principles of research are followed, and vulnerable populations are protected.
- Accreditation requirements, policy/procedures, and infrastructure can improve organizational recognition and support.
- Collaboration with organizations, education institutes and professional associations can support the SOR program.

DINNER CELEBRATION

The first day of the retreat finished with a transformation of the room for an evening dinner and celebration. The remarkable accomplishments of ARECCI and all the people involved were recognized with a keepsake - a beautiful piece of artwork from Red Deer, Alberta.

As part of the evening celebration, the participants heard how ARECCI is being used with the preliminary results of a scoping review demonstrating the value that ARECCI has outside Alberta.

ARECCI in Academic Literature: Preliminary Results

Jennis Jiang

What we heard

Jennis presented the preliminary results of a scoping review that explores how ARECCI is being cited in academic literature and how it is applied to quality improvement and evaluation projects in health and human services that do not require REB review. Jennis began her presentation with a brief background on the importance of quality improvement and evaluation in healthcare, as well as ethical oversight in research. She reiterated that these projects currently do not require any research ethics board (REB) oversight or approval and that there is growing consensus that clear guidelines, protocols, and ethical oversight should be required.

Jennis offered a detailed explanation of the scoping review's methodology. The Population, Concept, and Context (PCC) framework was used to set clear objectives and eligibility criteria, ensuring a rigorous and transparent review. Jennis and Robin consulted with Liza Chan – a librarian at Alberta Innovates – who previously worked on an informal scoping review on ARECCI. Lisa helped to modify the search terms and conducted the search primarily in the Dimensions database for primary literature, and other sources for grey literature. The inclusion criteria for articles included:

- full-text articles or documents;
- mention of ARECCI and/or how it was being cited in the literature;
- year range between 2003-2023; and
- publication in English.

The exclusion criteria included: wrong intervention, context, publication format, timeframe, language, and no mention of ARECCI. For study selection, the abstracts and titles of articles were independently assessed and screened using Covidence – an online management software – by two members using the inclusion/exclusion criteria. Conflicts between the two reviewers were resolved by a third reviewer and exclusion reasons were recorded. Once full agreement was reached for abstract and title screening, the studies would be moved forward to full-text screening and the same process was followed.

Following study selection, data extraction began with the co-development of an extraction spreadsheet in Microsoft Excel. One member of the team reviewed each article. Extracted information from the articles included: study details; study context; study design; country/province of publication; ethics process details; which ARECCI tools, guidelines, or services were used; and aspects of the ARECCI tools.

The preliminary results focused specifically on descriptive statistics of articles that used ARECCI for ethics approval in academic literature. Articles that focused on the theoretical application of ARECCI have not yet been analyzed. At the beginning of the data selection process, there were 481 articles, which included both primary and grey literature. After abstract and title screening, 320 articles remained. Following the full-text screening, 289 were left and included in the scoping review. Among the 289 articles, 249 studies used ARECCI for ethics approval while the 33 articles focused on the theoretical application of ARECCI, and 7 articles were grey literature. Jennis spoke to the 249 articles for the rest of the presentation.

The greatest number of articles ($n = 52$) were published in 2021, with a rise in 2015/2016 and then a decrease in the number of articles published in 2022 and 2023. She mentioned how this decrease could be due to the impact of COVID-19 and how priorities in research may have shifted away from quality improvement and evaluation. The decline could also be attributed to publication delays. Presenting the results, she shared that the median year was 2020, with a mean number of articles of 17.785 and a median number of articles of 14.5. As for published papers by country, Canada overwhelmingly published 241 articles, with other countries such as Italy, the Netherlands, the United States, and others utilizing ARECCI in their projects.

By Canadian province, Alberta yielded a total of 182 articles followed by British Columbia ($n = 29$), Ontario ($n = 21$), Nova Scotia ($n = 6$), Manitoba ($n = 1$), Saskatchewan ($n = 1$), and Quebec ($n = 1$). The majority of projects were quality improvement studies ($n = 183$) followed by evaluation projects ($n = 58$). Other project types included health/human

services, needs assessments, quality assurance studies, lab validation studies, and case studies. The BMJ Open Quality journal had the greatest number of publications ($n = 9$), and Jennis explained that this could be due to their publication requirements and availability of a template for quality improvement projects, potentially making it easier for researchers to utilize. Among the list of journal types, many articles were published in oncology and cancer journals, which also happened to be the number one project topic or area of intervention that articles focused on ($n = 32$). Cancer topics included breast cancer/reconstruction, cervical and colorectal cancer, colon cancer, head and neck cancer, and prostate cancer. Other areas of intervention included but were not limited to mental health and addiction, virtual care, COVID-19, and screening programs or tools. Jennis showed a table that illustrated the different variables for ethical oversight and the use of ARECCI tools; 236 projects did not require REB review, and 222 projects submitted their proposals to REB for initial review. Only 34 projects clearly mentioned that they used ARECCI to manage project risks, while 177 said no, and 38 projects were unclear (the article mentioned a level of risk or provided an ARECCI score but did not specify if risks were mitigated). 193 projects used the ARECCI tool, 81 used the guidelines, and 16 used the SOR process. There were 32 and 39 projects that were categorized as 'unclear' for ARECCI screening tool and guideline use respectively, which indicated that ARECCI was used but had no mention of these tools.

Jennis concludes that there is work towards publishing the scoping review on ARECCI use in academic literature. A separate data extraction spreadsheet for the remaining grey literature and articles on the theoretical application of ARECCI will be co-developed and used to inform parts of the discussion and publication of a second paper. These results are expected to inform policy decisions, such that researchers may be more transparent in project ethics risks and ways to manage risks, as well as the possibility to provide recommendations for learning health systems, policies, and ethical oversight of quality improvement and evaluation projects in health and human services. Finally, this scoping review and future work will contribute to the ongoing improvement of the ARECCI program.



Retreat: Day Two

Participants are welcomed back to the second day of the retreat and asked to reflect on the first day and their celebration dinner.

Valuable thoughts on the facilitator role in the project ethics course were shared. Discussion included whether the facilitator needed to be an experienced Second Opinion Reviewer or someone skilled in adult learning principles. Consensus was reached that a facilitator was required for the online training; however, it was identified that perhaps a lite version of the course could be developed and offered in parallel that did not require an SOR facilitator.

The first day had the history, discussion of current state and the celebrating of the great activity and progress made. The final day of the retreat is about the journey forward and the work ahead for the ARECCI community which included a few more presentations and workshops to engage and obtain feedback.

PRESENTATION SUMMARIES

Organization Recognized Review Project

Andrew Ross

What we heard

In Andrew's presentation, he discussed the importance of the Organization Recognized Review (ORR) and its role in risk management. He began by acknowledging the common challenge in their field with projects that exhibit a greater than minimal level of risk, which stems from the lack of a clear understanding of the ORR process.

To address this issue, a working group was formed, consisting of small to large-sized organizations, to create a comprehensive ORR framework that could be applied by organizations within the community. The framework aimed to standardize the approach for high-risk projects, mitigate risks, and ensure ethical practices in project management.

Andrew provided the background on the co-development of the framework with the diversity of the working group members. The working group had their first meeting in November and held the final meetings in April. A consultant supporting this work was instrumental so that the working group could focus on content and not be distracted by the administrative aspects. He continued to explain the timelines and the activities with the vision and the definition of an ORR achieved in December. What is an ORR or what isn't was a harder question to answer than we realized. However, a consensus was reached which was a milestone accomplishment. In January, the group determined why this matters with the development of the value proposition.

Andrew highlighted the potential benefits of the ORR process, which included reduced organizational risk, ethically designed projects, time and resource savings, and the opportunity to learn from the wider community. He then presented the framework, which consisted of several key components, such as training, monitoring, risk mitigation, partnerships, guidelines, accountability, leadership and a value proposition. He pointed out that the framework is in a circle with no arrows because everything is interdependent.

He emphasizes the importance of an ORR in navigating complex project landscapes, managing risks effectively, and promoting ethical practices. We want to enhance the knowledge base surrounding projects and ethical risks. The vision is for organizations to build their own capacity for ethics reviews. The value proposition is the heart of ORR: a systematic process for ethical reviews that would safeguard organizations and individuals.

We are proud of this work, it is needed and we want to promote and engage leaders on the importance of ethics review of projects. We encourage everyone to read the details in the ORR framework.

Workshop Activity

Following the ORR presentation, the group participated in the Six Thinking Hats to consider the implementation of an ORR pilot from the specific perspective or style of thinking denoted by the hat colour.

The six hat colours:

- red hat (emotions, feelings)
- blue hat (controlling process)
- black hat (downsides, risks, worst-case)
- yellow hat (positivity, benefits, opportunities)
- green hat (creativity)
- white hat (information, data)

Red Hat (emotions, feelings)

- Finally, long overdue – thumbs up
- Excited
- Ethics is in an organization
- Cautious regarding implementation (magnitude)
- Happy to see the value
- Sh** not another hoop to jump through
- Huge project to find ability to do this
- Now the real work starts
- “Risk language motivates action
- Dry topic (i.e. hard to sell)
- Confusion in language differences
- Optimism
- Fatigue
- Relief – expectations of organization clear, sharing responsibilities

Blue Hat (controlling process)

- Policy and procedure templates
- Responsible manager sign off
- Who does the reviews? SME, resources, multiple SORS vs committee, multidisciplinary
- Coordination/tracking
- Who provides the education?
- Quality control
- Determination of acceptable level of risk before going to ORR
- Process for the review
- How many projects go beyond first/second cycle or make a change in a program

Green Hat (creativity)

- Build awareness
- Build a desire
- Create knowledge/education/workshop for leaders e.g Canadian College of Health Leaders
- Find ability
- Need a QI/Program evaluation review pathway/panel for community
- Publishing -emphasize/clear that you can use ARECCI for review and meeting publication needs
- Look to existing ORR processes (interior Health)
- Go where current SORs are
- Selling the value -add/telling the story
- Consortium of small/independent project leaders? (CVD, ECVO, United Way?)
- Continuing education credit for clinicians
- Blue seal = external recognition

White Hat (information, data)

- Number of projects; number going to SOR, number going to ORR
- Allow for localized operation of the principles of the ORR, organization needs to decide who is involved
- What comes out of the review, how to share learnings
- Evaluation of pilot
- Requirements by professional colleges that QI/PE is reviewed (ARECCI) Education needs for future leaders (Certification and diploma programs)
- Number of projects; number going to SOR, number going to ORR
- Allow for localized operation of the principles of the ORR, organization needs to decide who is involved
- What comes out of the review, how to share learnings
- Evaluation of SOR
- 5 Safes Model

Black Hat (downsides, risks, worst case)

- Non-compliance
- Conflict of Interest
- Context – nuances of different settings, organizations
- Third parties – internal/external – liabilities
- Risk of complacency
- Sufficient understanding by management? Need leadership support resources
- Lack of outside perspective
- How to ensure competence/quality of review
- Time demands
- Smaller scope – manage capacity
- People don't understand the process/purpose
- Explanation of process too complex for people to understand
- Awareness (hire professional marketer)
- Credibility ARECCI/SOR/ORR
- Suitability of ARECCI for different contexts

Yellow Hat (positivity, benefits, opportunities)

- Accountability
- Building trust
- Due diligence
- Expert-built
- Ethics review already defined -adapt into own organization
- People-centered
- Builds a culture of ethics consideration embedded
- Badge/external recognition
- Defined value proposition
- Protection of participants/institutions
- Slick graphics
- Putting in resources for ORR = support
- Customers/clients/participants should experience a more ethical process
- Possible more expeditious process within organization
- Creates culture of respect with ethical conduct and standards
- Risk mitigation – awareness that even QI/Evaluation can have
- Decrease costs of rework

Feedback Takeaways

- Excitement, relief and optimism about ORR implementation despite concerns about challenges.
- Recognition that ethics should be a shared responsibility within an organization.
- Resources to support the implementation of an ORR is needed to embed within organizations a culture of ethics and standards.
- Promote the value proposition and benefits including decrease cost of rework, expedited process, protection of participants and institutions, and meeting publication standards.
- Create quality improvement and evaluation review pathways for community and develop a consortium of small/independent project leaders.
- Allow for organizations to make the decisions on the operations of an ORR and their acceptable level of risk before an ORR.
- Management should have sufficient understanding of purpose and processes, and leadership support and resources are required.
- Promote ARECCI and increase awareness, credibility and value through a professional marketer.

Following the activity, participants were asked if their organizations would be willing to be part of a pilot. Several organization expressed interest in piloting an ORR.

Quality Improvement, Evaluation, and Alberta Privacy Legislation

Brian Hamilton

What we heard

Brian began the presentation by thanking the audience for inviting him and acknowledging the familiar faces from the previous year's discussion. Brian has worked in the health privacy field in Alberta for many years and discussed his various roles, including working with Alberta Innovates, the Health Quality Council, Alberta Health, and others. Brian's presentation is an intersection of quality improvement and evaluation with Alberta's privacy laws, primarily the Health Information Act (HIA) and the Freedom of Information and Protection of Privacy Act (FOIP). He emphasized that the challenges and concerns regarding privacy and security in this context have remained relatively consistent since the early 2000s, even though there has been an increased demand for such work.

He addressed the common pain points that organizations often encounter when engaging in quality improvement and evaluation projects. These pain points included issues related to information-sharing agreements, the use of privacy impact assessments, the availability of in-house privacy and security expertise, and the challenges of working with external organizations that have different rules and risk tolerance levels. Brian introduced his report, which provided an in-depth analysis of quality improvement and evaluation under both HIA and FOIP. It highlighted the need to consider both acts since the organizations that participate in ARECCI are regulated under one or both of these laws.

Brian delved into the specifics of how quality improvement and evaluation activities can be conducted within the framework of HIA and FOIP. Under HIA, there is explicit mention of quality improvement and evaluation, making it clear that these activities are permitted. However, the scope varies for different types of custodians, with provincial-level organizations having a broader mandate compared to individual providers. Under FOIP, public bodies can use or disclose personal information for purposes directly connected to their original mandate, which can include evaluation. The challenge lies in differing interpretations of what is considered "consistent" with a public body's mandate, which can lead to discrepancies when working with external parties.

He places emphasis on the importance of understanding the nuances of conducting quality improvement and evaluation within the framework of Alberta's privacy laws. Brian

provided an overview of the checklist aimed to provide practical guidance for organizations in navigating the complex landscape of privacy and security in their projects. He covered the main points and highlighted that organizations should address these when embarking on quality improvement and evaluation initiatives.

Brian stressed the significance of starting with non-identifying and aggregate data whenever possible. Using anonymized data helps minimize privacy concerns and simplifies the approval process. He also notes that organizations are advised to ensure they have explicit authority under the applicable privacy laws, such as the Health Information Act (HIA) or Freedom of Information and Protection of Privacy (FOIP) for conducting quality improvement and evaluation activities. This means understanding the specific provisions within these laws that grant permission for such activities. Also identified within the checklist, is a need to conduct Privacy Impact Assessments (PIAs) for projects involving the use of health information. PIAs are essential tools for identifying and mitigating potential privacy risks.

Organizations are encouraged to establish clear information-sharing agreements and obtain any necessary consent from individuals or other organizations involved in data sharing. These agreements should outline the scope of data usage, security measures, and the purpose of data sharing. It was stressed that organizations should collect only the minimum amount of personal information required to achieve the goals of quality improvement and evaluation projects. Minimizing data collection helps protect individuals' privacy.

Brian highlighted security and safeguards and the importance of implementing robust security measures to protect the data being used in quality improvement and evaluation activities. This includes encryption, access controls, and auditing mechanisms. Another checklist element is ensuring consistency in how the data is handled and transparently . communicating privacy practices to all parties involved in the projects was deemed crucial. Consistency and transparency build trust, lowering the likelihood of privacy complaints.

Organizations should establish clear policies for retaining data only as long as necessary and securely dispose of it when no longer needed. Proper data lifecycle management is a key aspect of privacy protection. In addition to data retention and disposal policies, organizations should establish mechanisms for reporting data breaches and privacy incidents. Brian also discussed the accountability for privacy breaches which helps organizations respond effectively in case of privacy violations. The presentation stressed

the importance of conducting regular audits and reviews of privacy practices within the organization as these ongoing assessments help identify and rectify issues promptly.

Brian urged organizations to use this checklist as a practical tool to guide their quality improvement and evaluation initiatives. By systematically addressing each point in the checklist, organizations could not only ensure compliance with privacy laws but also build a stronger foundation for effective and secure data-driven projects.

In addition, Brian discussed the importance of developing common definitions, standards, and templates to streamline privacy practices across organizations, especially those that work together on quality improvement and evaluation initiatives. By adopting consistent materials, it would be possible to mitigate many of the challenges and pain points identified from the checklist, making the process more efficient and compliant with privacy regulations. He addressed how to resolve the pain points discussed earlier by focusing on practical approaches, and he acknowledged that changing the law might not be a realistic or desirable solution.

The practical measures discussed include the development model agreements and policies that organizations can use as templates. These templates could be tailored to specific quality improvement or evaluation projects while ensuring legal compliance. This approach could help streamline the administrative aspects of data sharing among multiple parties. Common definitions of terms related to quality improvement and evaluation are another practical measure emphasized. Brian highlighted the importance of organizations, such as the Alberta Real-World Evidence Consortium (RWE), taking a leadership role in developing and promoting common definitions within the community. This would provide clarity and consistency in communication and understanding. It was acknowledged that agreeing on acceptable risks could be challenging, and having common definitions in place would be a crucial first step. Once organizations share a common understanding of terms and concepts, they can work together to determine what risks they are willing to accept in the context of data sharing.

In summary, Brian mentioned the legal authority under both HIA and FOIP to conduct quality improvement and evaluation activities. While there is legal authority, practical challenges, including differences in policies, procedures, and expertise among organizations, can make it difficult to navigate privacy and security requirements. To address these challenges, he suggested the development of common definitions, standards, and templates that can be used across organizations to ensure a more consistent approach to privacy and security.

Questions Arising from Presentation

- What is the responsibility of public organizations when faced with a request for data by an external consultant or media who has not gone through the standard administrative channels but instead resorts to a Freedom of Information (FOI) request?

This could be an indication that the standard channels are not working well. Also, this may not meet the requestor's QI needs as responses must be handled in accordance with FOIP regulations, potentially involving redaction and adhering to specific timelines.

- What is the relationship between these two laws, are there other laws that cover QI projects in non-profits?

Working with non-profits can be tricky as they may not have an established privacy program, though they may follow ethical guidelines or conventions informally. Non-profits do not have the funds to have professional privacy and security resources. If they are under contract with the government or a healthcare organization, they have to follow the policies and procedures of who they are working for. Large organizations and their legal and security departments often want information-sharing agreements and may question the non-profit's IT security.

- As an evaluator with a contract to a publicly funded NGO, I have raw data and identifiable information; I don't have to provide the data if there is a FOIP request, do I?

The public body needs to respond to the request and may apply some exemptions to disclosure. The FOIP office will take care of processing the information and they have to go through their normal FOIP response process, which could involve consultations with contractors.

- How often should you review PIA?

There is no regulated timeframe but a good rule of thumb is 18-24 months.

Workshop Activity

After discussing these practical approaches, the participants were divided into four groups to focus on the pain points and generate ideas to advance privacy and security practices in the context of quality improvement and evaluation. The first group session focused on the development of common definitions for terms related to quality improvement and evaluation. Participants were encouraged to discuss who should be involved in this effort, the required resources, and the authority responsible for establishing these definitions.

The second group session discussed standards related to data de-identification, data security, and other aspects relevant to quality improvement and evaluation. Participants were expected to consider which standards are needed and how to implement them effectively. The third group focused on the different types of agreements required for data sharing in the context of quality improvement and evaluation. This included discussing information-sharing agreements and information manager agreements and understanding the distinctions between them. The fourth group was dedicated to Privacy Impact Assessments. Participants were encouraged to explore various aspects of PIAs, including their purpose, procedures, and how to ensure that they are conducted effectively.

This interactive approach was designed to encourage collaborative problem-solving and generate practical solutions to address the pain points and challenges in the field of quality improvement and evaluation within the framework of Alberta's privacy laws.

Participant Feedback -Common Definitions

- Could we agree to a common definition, yes if kept high-level
- In use – ORR definition
- Look to other organization with definitions already. Eg. IHI, NHS
- Players involved REB, ARECCI, Institutions
- Authority under TCP2
- AI/ARECCI, REBS, GoA
- CES needs to be involved for evaluation
- AH/AHS as custodians
- QI/QA – HQCA, CPSA, AH/AHS, professional associations
- Other: monitoring needs assessments – Accreditation Canada, Professional associations/colleges (all health professionals)
- ARECCI has ability to bring people together to come to consensus. The result of the work would be the credible definition
- Moral – ARECCI community (preference to waiting for Government to do it)

Standards

- Need a data management person to help with standards – understanding systems and how they connect to make things identifiable again
- Need methodologists as well
- Consider amount of indirect identifiers when reported together
- Cell size include when cross tab
- Unique experience – often frequently removed but still use the learning “needs to swim in an ocean”
- Non identifying info: De-identified vs anonymized
- Identifying info: Single elements vs sets

Agreements

- ARECCI to bring together custodians to develop model agreements plus public plus security/privacy experts plus data managers and lawyer
- NFP (nonprofits) are missing from the HIA
- NGO
- Institutional offices
- Sponsors of the project
- Dedicated team with knowledge, expertise
- Careful

PIAs

- Good idea model PIA
- Consistent between in-house and contracted provider
- Privacy department
- Principles and best practices
- Remove research specific language
- Prepopulate form with Qi/E specific responses and then have the applicant remove those responses that don't apply to their project
- What's housed
- How accessed
- Use/who
- Control
- Confirmation of PIA needed
- Date last time -frequency changes of time/law changes

Feedback Takeaways

- ARECCI has the ability to bring people together (REB, Institutions, Canadian Evaluation Society, AHS, community) to develop a consensus and create a credible definition: a common definition.
- ARECCI has the ability to bring custodians and other stakeholders together to develop model agreements.
- A team with knowledge and expertise in data management, standards and privacy is required.
- A model PIA template is a good idea.

Close of Day Two

Before the final goodbyes and closing of the retreat, further feedback was sought on some topics that required closure including communication and the next steps.

For communication, the group expressed that a quarterly newsletter with high-level information would be beneficial as it would be something to share with their leadership. Include in the communication any updates on the LMS. Other ideas include holding an annual meeting, but that shared ownership and planning could occur, so the onus was not on the ARECCI program office. It was suggested that one of the organizations may be able to offer a location to host.

Further ideas were incorporating SOR training into bigger conferences or events with Universities as this may help increase the pool of SORs. An online Community of Practice would be helpful to provide updates, discussion boards or in-services that are co-designed. Expanding the community by inviting leaders from Universities and Colleges.

Finally, consensus was reached on the terminology in the ORR Framework as the term ethical review was problematic. The group agreed that ethics review was the appropriate term that should be revised in the ORR Framework.

Key Takeaways

The key takeaways are group according to responsibility.

Alberta Innovates/ARECCI Program Office

- The vision and strategic direction for ARECCI will advance the program to meet the community's needs in quality improvement and evaluation projects in health and human services.
- There is promising potential and benefits with the transition of the project ethics course to an online platform, but resources, support, and processes to ensure sustainability are concerns that must be addressed as many interdependencies are tied to the availability and access to education and training.
- Recommendation for a "lite" course that teaches the foundations (principles and QI and evaluation methodologies without project-specific requirements).
- Continuous communication and engagement with the community, including a robust and sustainable community of practice.
- ARECCI's work is valuable, and the work and practice must be recognized, promoted and accredited.
- Develop partnerships and leverage opportunities with the Canadian Evaluation Society (CES), Accreditation Canada, REBs, Universities, Associations and Regulatory Bodies.
- The ARECCI program is well positioned to convene the community and others for consensus building on common definitions, standards, and agreements.
- Attract second-opinion reviewers, facilitators and mentors by engaging with Universities, CES and others.
- The value proposition is critical, and building capacity within organizations to conduct their own reviews is vital in the long term.

SORs and ARECCI Community

- Organizations should use the privacy and data security checklist tool for quality improvement and evaluation projects. This practical tool will help guide them in ensuring compliance with Alberta's Privacy Legislation.
- Interest in the ORR framework and its importance in building capacity.
- Caution advised on making things too complex, too much time, or burden in the ARECCI program, processes and training.
- The ARECCI community is passionate about ethics and invested in advancing ethics reviews in quality improvement and evaluation projects, as the level of engagement and input from the retreat was substantive.

Actionable Next Steps

- Access to be given to those who volunteered to review the LMS.
- All feedback collected from the reviewers of the LMS would be collated and discussed with a small working group to finalize any further changes in the course.
- The group to provide any feedback on the vision and consensus building documents shared by Tammy.
- ARECCI program to discuss collaboration with REBs on process and a development of a pathway.
- ARECCI program to communicate regularly with SORs and community.
- Volunteers for the ORR pilot to be contacted for follow-up.
- ORR Framework to be updated to reflect ethics review and not ethical review.

Conclusion

The retreat was a success with high levels of engagement, discussions, and insights. The ARECCI community was celebrated and recognized for their valuable contributions. Members had the opportunity to connect and build relationships over two days, which will undoubtedly strengthen the community moving forward.

Overall, the retreat was helpful in fostering rich collaboration and receiving feedback that contributed to takeaways and learning. ARECCI will continue to evolve to meet the needs of ethics review in QI/E projects in Alberta, as it becomes an enabling learning system. The next celebratory milestone will come sooner than expected through relationships, networks, and core strategies.

List of Participants

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