



SECOND OPINION REVIEWER (SORer) MEETING REPORT

Edmonton, Alberta
October 6, 2022

TABLE OF CONTENTS

Introduction	2
Presentation Summaries	
ARECCI: Tammy Mah Fraser	4
Modernizing the ARECCI Tools - The Journey Ahead: Kathy GermAnn	6
Quality Improvement, Program Evaluation and the Health Information Act: Brian Hamilton	13
ARECCI Modernization - ARECCI E/QI Project Ethics Training: Marilynne Hebert	17
ARECCI SOR Process - Building Organizational Buy-In and Capacity: Robin Lau	19
Overall Recommendations and Next Steps	23
Appendix: Questions and Comments from Participants	25
Glossary of Acronyms	27
List of Participants	28

INTRODUCTION

ARECCI: Why it matters and why it needs to change

ARECCI (A pRoject Ethics Community Consensus Initiative) was launched by Alberta Innovates, formerly Alberta Innovates Health Solutions (AIHS), in 2003 to provide ethical oversight to minimize and mitigate risks when interacting with individual information. It addresses the gap in ethical oversight of quality improvement (QI), evaluation and human service projects which may not require research ethics board review. This work supports health system and human service improvement, which builds public trust and strengthens the validity and usefulness of gathered information.

Over the past 20 years, the world has changed dramatically. Information has become digitized, projects have become

riskier and more complex, and the importance of supporting groups without equity is increasingly significant. As we look ahead, ARECCI continues to have an important role to play in ensuring ethics and quality improvement guide and protect the work of ARECCI's broad range of participants and partners.

But to fill that role, ARECCI must evolve to address the needs, challenges, and opportunities of our reality now. Can we continue to fill the ethics gap? How do we adapt to an almost fully digitized world? And can ARECCI adapt to address the evolving demands and restrictions of the projects that need quality improvement and ethical guidance?



Exploring the future of ARECCI

On Thursday, October 6, 2022, 23 partners and participants came together to discuss ARECCI and how it moves forward. This hybrid event, which allowed for in-person and Zoom participation, was the first in-person event since the start of the pandemic and created an opportunity for the community to reconnect, share experiences and discuss emerging issues.

Earlier this year, interviews were conducted with 31 individuals – Second Opinion Reviewers (SORers) and key stakeholders – who shared insights and suggestions for how ARECCI could adapt to move forward. The consensus from those who participated in the interviews and those in attendance at the one-day event is that ARECCI must be modernized to remain relevant and useful. Beginning with that understanding, the one-day event sought to invite questions and encourage discussion on how to undertake that modernization.

Bringing people together allowed for a frank and open discussion about the value of ARECCI and its role going forward. It also allowed for an exploration of the creation of a value proposition that could communicate the value of ARECCI to future participants, partners, and the public.



How to ensure ARECCI remains relevant, useful and sustainable.

Attendees at the one-day event explored several key questions during the discussions, including:

- Is ARECCI sustainable?
- How do we update/improve tools and resources?
- What are the risks and benefits of the use of artificial intelligence?
- What are the ethical issues around informed consent and public health ethics frameworks?
- Do we need supporting materials and targeted key messages? Do we require expedited pathways?

PRESENTATION SUMMARIES

ARECCI: Tammy Mah Fraser

What we heard

We need to understand where ARECCI is going and what is the role of Alberta Innovates. Alberta Innovates sponsored the development of ARECCI and over the years has invested heavily in ARECCI's personnel, training, tools and resources. Alberta Innovates remains committed to ARECCI and its work.

Although partners are coming from many different places, the common thread is ARECCI. ARECCI is more than one sector or one industry, which allows it to bring together participants with a broad range of interests, expertise and challenges.

ARECCI is facing a much different environment than when it was first launched in 2003. One of the major changes is the increased awareness of the importance of social justice issues that came to the forefront during the pandemic. There is a growing urgency to explore the importance of inclusivity and equity among different populations, including the many Indigenous groups. As part of this, there are new power dynamics, sensitivities and risks that

must be considered and must inform how we update ARECCI tools and processes.

We recognize that a one-size-fits-all approach will not work and that it is important to adapt and customize as necessary to address the needs of various populations. The questions that are being asked today are more complex than ever, although quality improvement and ethics must continue to guide how data is collected. The digitization of data has also changed how information is gathered and people's expectations for access to that information. Often, people want immediate access to information and are unwilling to wait for data to be interpreted or analyzed.

Although partners are coming from many different places, the common thread is ARECCI.

Ultimately, the goal is to ensure ARECCI remains relevant, applicable, current and true to the needs of the groups we work with. The aim of this session is to engage

on modernization so we understand the next steps in updating the tools and the guidelines we need to move ARECCI forward and take it where it needs to go.

Recommendations/Takeaways

- ARECCI is sustainable, but only by all of us working together.
- ARECCI needs to be more inclusive and consider all populations with an equity lens.
- It's important to update and improve not just tools and training, but also increase awareness of the value of project ethics.
- ARECCI's new vision and mission focus on how we fit into the broader ecosystem – does this resonate?

- ARECCI contributes to a system of learning and improvement, involving one ethical knowledge project at a time.
- Next year will be ARECCI's 20th anniversary – the time is right to modernize and update.
- Will be looking for ideas and input on how to celebrate that milestone.

Ultimately, the goal is to ensure ARECCI remains relevant, applicable, current and true to the needs of the groups we work with.



Modernizing the ARECCI Tools - The Journey Ahead: Kathy GermAnn

What we heard

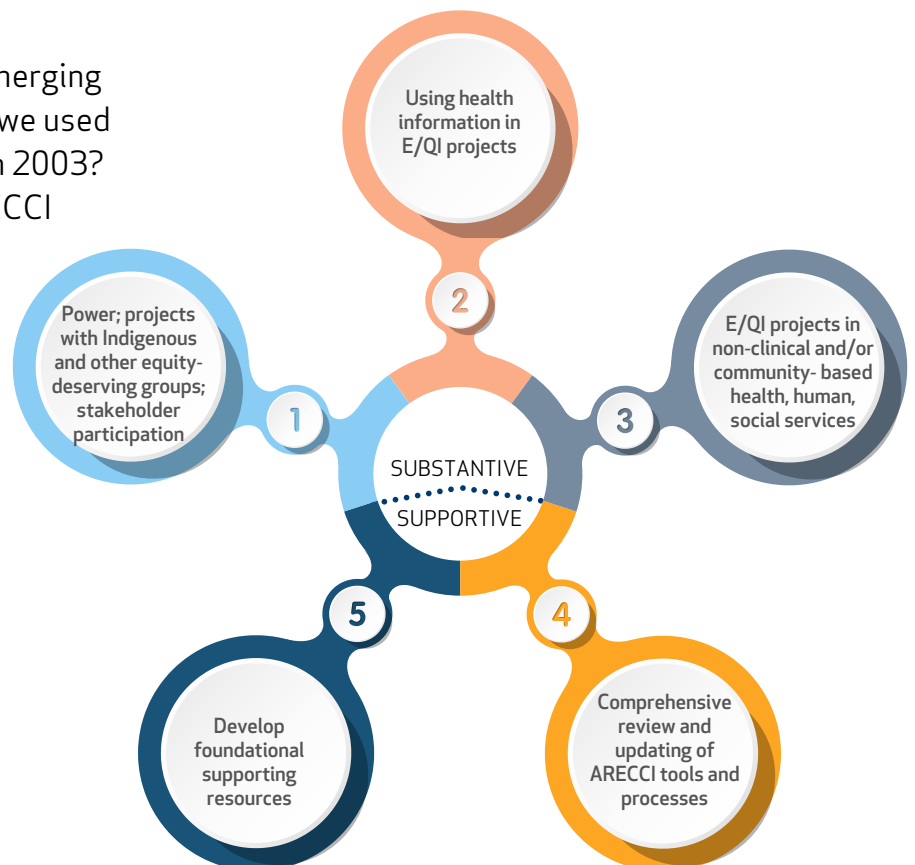
Spoke with many SORers and stakeholders earlier this year, and everyone expressed a desire to get together in person and connect. Last spring, we interviewed about 31 people as part of the discussion around modernization, mostly focusing on the tools.

We asked a number of questions intended to explore the sustainability and the future of ARECCI, including:

- What are you seeing out there?
- What are the trends?
- What kinds of projects are emerging that are different from what we used to do when ARECCI started in 2003?
- Are you happy with what ARECCI does now?

There are two reports that emerged from the interviews that outline the information gathered. Today is about where we're going to go – places where ARECCI could evolve and grow – and how we are going to get there.

During the interviews there was strong agreement on the five areas for modernizing and willingness to support modernization efforts.



Project - Articulating and updating the value proposition of project ethics and ARECCI

While modernization is necessary, participants noted there must be parameters that guide any efforts to update ARECCI:

- Revisions made within the context of the vision, purpose, and audiences for ARECCI.
- Guided by a clear, shared understanding of E/QI project ethics – and underlying ethical principles.
- Grounded in adult learning pedagogy.
- Inclusive language.
- Must be kept succinct and easy to use while explicating ethical risks/mitigation strategies.
- Don't toss out all the good work that's been done. ARECCI has served us well for almost two decades.

In June, the findings of the interviews were presented during a meeting where attendees provided feedback and suggestions, including:

- Link to or develop additional resources to support methodology (e.g., what to include for informed consent, tips for survey development).
- Agreement that the language in the “screening tool” is too clinical.

It is important to remember that ethics doesn't just happen at the beginning of a project, but must be threaded throughout.

- Alignment or reference to OCAP (First Nation Principles of Ownership, Control, Access, and Possession) and patient-centred best practices will be essential moving forward.
- Explore opportunities to support community-based projects that are not health/clinic-based.
- Reduce redundancy in tools.
- Seek feedback from groups who don't use the tools, have stopped using them or disbanded internal ARECCI processes.
- Try to understand the implications of artificial intelligence (AI)/machine learning and the ethics involved in that space.

It is important to remember that ethics doesn't just happen at the beginning of a project, but must be threaded throughout.

With this feedback in mind, participants in the one-day session explored the logistics of how to move ARECCI forward.

How do we establish a foundation for modernizing the tools? And how do we address identified challenges? It was also made clear that whatever modernization looks like, ARECCI must be grounded in a solid, shared understanding of ethical principles. In order to do this, we must answer three key questions:

- Revisiting the case for project ethics and ARECCI: Why are they so important today?
- Revisit/reaffirm the ethical principles of ARECCI: Still good?
- Are the current versions of the ARECCI tools sufficient to address the ethical risks in the broad array of projects we see today?
 - How can we address any challenges/gaps/limitations?


We need to be able to convey why the ethical conduct of projects matter. Even people who employ SORers don't always understand why ethics are so crucially important. People don't know what they don't know, so as a foundation for modernizing ARECCI, this is an important place to start. This will help articulate ARECCI's value proposition, which will assist with marketing and communications to improve awareness of ARECCI.

Project ethics are, in fact, more important than ever. We are increasingly seeing projects involving Indigenous

communities, and the need to consider social determinants of health and mental health. We need to pay closer attention to equity, diversity, and inclusion. We are involved in increasingly complex projects across the spectrum of health and human services. Projects are riskier and come with more consequences for both participants and project leaders. We need to understand if the projects are making a difference. Are equity-deserving groups getting the support they need? In some cases, a breach of confidentiality could be life-threatening. When we first began, we were doing largely patient satisfaction surveys – now projects could involve gangs or human trafficking. The questions we ask are more intrusive and potentially upsetting. There's a strong push for participatory processes, new methodologies, and growth in QI activity. The world has changed, projects have changed, and we need to make sure ARECCI can continue to support the work that needs to be done.

We need to pay closer attention to equity, diversity, and inclusion... Projects are riskier and come with more consequences for both participants and project leaders.

Although there are new challenges that didn't exist when ARECCI was first founded, there is also an opportunity to make system-level changes on the ground here and now through evaluation and quality improvement.



Why is it important that ARECCI continues? Because ethics matter in health and human services projects. It helps protect participants and stakeholders and it's learning-focused.

But what else? Do we need different messages for different groups and how do we craft those?

Before we can answer those questions, we must ask if the six ethical principles underlying ARECCI are still relevant and sufficient. While the principles are embedded in the Screening and Guideline tools, they are not explicitly described in any obvious way outside of the ARECCI training.

- Respect for human dignity
- Respect for free & informed consent
- Respect for vulnerable persons
- Respect for privacy and confidentiality
- Respect for justice and inclusiveness
- Balancing harms and benefits

In reviewing a number of ethical frameworks, while definitions of ethical principles can be found, less common is a description of what those principles might look like in actual practice. Every project and every population is different, so we need to create more examples for people to access.

Project – Exploring the kinds of E/QI/HS projects we are seeing today and what the implications are for project ethics

As we examine and explore what needs to change – or what doesn't, certain areas may require substantive change:

- Projects using health information
- Non-clinical projects and/or community-based projects
- Power, projects with Indigenous and other equity-deserving groups, and stakeholder participation

As we dig into these areas, we need to ask what the ethical risks are associated with these kinds of projects. Is ARECCI able to deal with these risks in its current form and help project leads identify and mitigate these risks? Or are there limitations and gaps in ARECCI and if so, what do we need to do about those?

Interview findings indicated there are a lot of questions about digitization of data. When ARECCI began, surveys were done with pen and paper and were stored in filing cabinets. Respondents also mentioned ethical issues around mixing qualitative and quantitative data, and data sharing through collaborative and intersectoral collaboration. In addition, respondents mentioned emerging issues with artificial intelligence.

When SORers were asked where project leads often stumble, it is in understanding power dynamics in their projects, especially in relation to managers and employees.

Generally, interview participants working in community-based and non-clinical projects reported that the tools were too long with cumbersome clinical questions that make them hard to use. Can they be streamlined to be more useful? As well, we need to consider the nature of the people involved in the projects. For example, when working with groups or communities, what are the ethical issues around getting informed consent from entire groups? A one-size-fits-all tool may not be feasible, but we must be careful not to create too many variations. However, ethics should not vary and basic, standardized ethical principles should be consistent.

There was also discussion around shifting the language in the screening tool to be broader and more community-based, creating expedited pathways through the screening tool, and creating tip sheets to help explain ARECCI to new audiences.

Issues surrounding power relationships within E/QI/HS projects were explored. When SORers were asked where project leads often stumble, it is in understanding power dynamics in their projects, especially in relation to managers and employees. This may require adding examples of power imbalances to the ARECCI tools.

It is important to remember that any modernization of the ARECCI tool should also serve to help streamline processes and create mechanisms for oversight, especially with equity-deserving groups. It is also important to note that ethical considerations must include more than just the participants, as project organizers and interviewers often face risks. This is indicative of the increasingly complex nature of projects.

One big issue that deserves more exploration is working with Indigenous communities and other equity-deserving groups. During the discussion, it became clear that many people don't understand structural inequalities, racism, discrimination and colonization, the impact it has on health, or how it might creep into their own projects. The fundamental guideline must be that we do not cause further harm to anyone as part of our projects. There are many Indigenous

frameworks out there, including OCAP, and we are exploring those at the moment.

There are various opinions on what to do with these projects, with some SORers saying the existing tools work, but that it is important to ask additional questions and ensure members of the community are part of the team. The shift toward stakeholder engagement and interaction helps mitigate risks and is part of good practice. Some SORers indicated they were uncomfortable pursuing those projects and need more support and guidance. Others noted that because Indigenous communities are so unique, they may require an additional screening tool or modified approaches. Do we need to change the tools or be critically reflective in our practice? There are still many questions to be explored.



Recommendations/Takeaways

- SORers and other key stakeholders have identified and agreed upon several substantive areas for modernizing ARECCI, a general updating of tools and development of supporting resources. All these areas will require careful thought and deliberation, but especially the intersecting substantive areas of power; projects with Indigenous and other equity-denied groups; community-based, non-clinical projects; and stakeholder participation in E/QI/HS projects.

The fundamental guideline must be that we do not cause further harm to anyone as part of our projects.

- While E/QI/HS projects are becoming increasingly more complex and involved, we still need to keep the ARECCI tools and processes as straightforward and easy to use. We need to ensure the tools effectively surface potential ethical risks and provide support/guidance regarding possible mitigation strategies.

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- To do our best, we really need the wisdom and expertise of SORers and other key stakeholders – those who review E/QI/HS projects for ARECCI and those who lead and participate in them. Ultimately, we want to reach consensus on the changes made to modernize ARECCI. That means we need to optimize stakeholder participation in the process while recognizing that everyone is busy and their time is precious. We will take whatever time, advice, insight, support you are able to offer!
 - We need to know what are the best ways of engaging you in conversations about what needs to change and how. Emails that outline specific issues and questions for your input and feedback? Online meetings? Collaborative software? Other?
 - We also plan to develop reports and papers for publication to pull needed information together. The paper(s) for publication will help communications and marketing (i.e., making the case for project ethics and ARECCI; peer reviewed publication will lend credibility/legitimacy).
 - As a foundation to modernization, we need to reach consensus on the ethical principles underlying ARECCI. Are the existing ones still good? Or do we need to think about other possibilities? We will be developing an exercise in the near future. Also as a foundation, we need to solidly state the "value-add" of project ethics and ARECCI in particular. This will inform the changes we make to modernize ARECCI, and any communication and marketing efforts. Again, we will be developing an exercise to capture your insights.
 - We will be holding workshops in spring 2023. We want to do a lot of groundwork before then so we can spend time during those in-person workshops sorting through some of the more challenging issues and/or working towards consensus on various pieces of work.
 - ARECCI has served us well for 20 years - we don't want to throw out the baby with the bathwater but we do need to adapt to where the world is going.



Quality Improvement, Program Evaluation and the Health Information Act: Brian Hamilton

What we heard

The main focus today will be on the Alberta Health Information Act (HIA) – background, issues for QI and program evaluation. Much of it involves understanding definitions and common understandings, particularly relating to privacy impact assessments. The audience here today is primarily people who work as custodians under the HIA and we will be discussing health privacy legislation. As a general rule, you should always talk to your own privacy officers and seek their advice.

The HIA covers collecting, using, storing, and disposing of health information. It includes individual rights to request access to your own information, to request corrections, and to limit disclosure. Everything is based on a standard of reasonableness – there is no black-and-white directions in privacy law. Most often you are basing what you are doing on what others in your sector are also doing. The HIA also includes independent oversight through the

Privacy Commissioner’s Office in Alberta.

Generally, the HIA allows quality improvement and evaluation but there are three considerations to keep in mind. You should always:

- Collect, use, and disclose aggregate (non-identifying) information if adequate for the purpose.
- Collect, use, and disclose only the amount of health information essential for the purpose.
- Take reasonable steps to protect health information.

The two hardest questions in privacy are, “who are you?” and “what are you doing?” Under the HIA, you may likely fall into one of four categories:

- Custodian
- Affiliate
- Information Manager
- Researcher

Custodians are the gatekeepers of the information and are responsible for any QI/PE activity with the information in their custody or under their control. They are the decision-makers regarding proposed QI/PE activity, agreements with partners with whom they share information, reasonable safeguards to protect health information and whether information is individually identifying, and whether or not a privacy impact assessment (PIA) is required.

Here in Alberta, custodians include:

- Alberta Health (AH) + Minister
- Alberta Health Services (AHS)
- Covenant Health
- Health Quality Council of Alberta (HQCA)
- Pharmacies
- Nursing Home Operators
- Ambulance Operators
- Advocates, Panels, & Committees, etc.

In addition, regulated members of various health profession colleges and associations may also be custodians. Alberta Health determines who is allowed into the protected arena as a custodian (refer to HIA for complete listing).

Custodians may use non-identifying information for any purpose. Custodians must rely on the HIA and may rely on other laws of Alberta or Canada for legal authority to collect, use and disclose identifying health information. Custodians may also use the information for internal management purposes.

There is also a special mandate for provincial custodians, such as AH, AHS and the HQCA who can use health information for broader, health system management purposes. There is a distinction in the HIA between individual custodians such as physicians, dentists, or pharmacists and large provincial custodians – it is only the larger provincial custodians who can use the information for system-wide purposes.

Affiliates are people who work for the custodians or perform a service for the custodian. This could be a physician exercising their privileges in an AHS facility, an employee, a contractor, a student or volunteer, for example. The simple rule for affiliates is that you can only collect, use, and disclose in accordance with your duties to the custodian.

Information managers are generally IT providers, but could also be a survey company, a data storage company, etc. An information manager can only do what the custodian authorizes.

Researchers are those who intend to do academic, applied, or scientific research that requires the use of individually identifying health information.

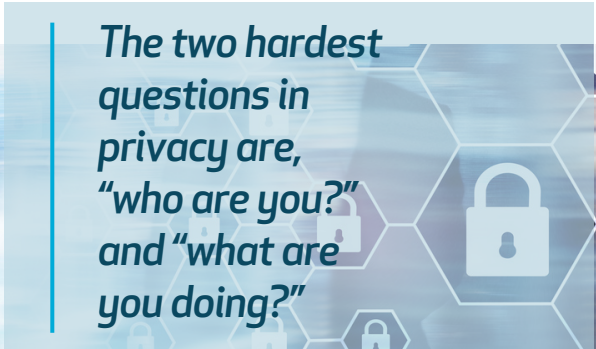
It is important to know who you are and what you will be doing with the information. Also, need to define terms. QI/PE is not defined in the HIA or other Alberta privacy laws, although Alberta Health defines those terms in its guideline manual. Under HIA, when used to describe health information “non-identifying” means: “the identity of the individual who is the subject of the information cannot be readily ascertained from the information.”

Unfortunately, many people do not find that definition helpful. Those that work closely with data will say there is no way to ensure that aggregate data is impossible to re-identify. Whether information is non-identifying is only one consideration, you must also look at who will have access, do you have agreements in place, and are there access controls? If you can get to where you are satisfied with the level of aggregation, it does allow you to use it more broadly.

In Alberta, there are two agreements you are most likely to see – an Information Sharing Agreement and an Information Manager Agreement. There is nothing in the HIA about information-sharing agreements, although they have proliferated in recent years and may have become a bit of a barrier to QI/PE. They are not strictly required, although some will say that an agreement provides an administrative control.

The Information Manager Agreement is a feature in the HIA and has specific requirements listed in the act that must be included in an agreement. Privacy Impact Assessments (PIA) are another important consideration. The PIA requirement is generally triggered by new initiatives, such as a new administrative process or information system that involves health information. In Alberta, you need to write and submit your PIA to the Information and Privacy Commissioner before you implement your new initiative. PIAs are also required for “data matching”, which is a term defined in the HIA.

With any project, consider administrative, physical and technical safeguards. These three safeguards should be part of any collection, use, and disclosure of health information. The HIA and other privacy laws certainly allow for the collection, use, and disclosure of health information for QI/PE with appropriate privacy due. It will require dedicated resources to make sure it is done.



The two hardest questions in privacy are, “who are you?” and “what are you doing?”

Recommendations/Takeaways

- Everything we do is influenced by privacy concerns.
- Important to think about privacy impact assessments.
- With any new project need to consider safeguards.
- Everyone working with QI/PE could benefit from adopting common definitions, checklists, templates, etc.
- It is important to bridge the gap between frontline staff and leadership.
- Challenges are with the lack of understanding of the requirements and different interpretations of the rules and different willingness to accept risk among organizations and leaders.
- We need to explore creating model agreements and policies and information-sharing models.
- In asking about pain points, it was noted that people have concerns with data storage, auditing requirements, documentation requirements, and the role of patient consent. These issues should be explored further.



ARECCI Modernization – ARECCI E/QI Project Ethics Training: Marilynne Hebert

What we heard

What do we want people to learn and take away from taking the course on ethics training? How do we know that you can carry out the skills once you've taken the course?

In advance of today's session, participants were provided with six handouts that include scripts, case studies, and other resources.

The ARECCI Project Ethics course is intensive, with content presented through 110 PowerPoint Slides. How do you build interactivity? How do you build in self-directed adult learning? It has to be more than clicking through slides. It's important to think about how adults learn and what is drives them to learn. Adults want to learn practical skills that help them solve problems and work better. The purpose for completing the training isn't just to do the course, but to learn skills that are applicable to their work.

In order to apply this knowledge to project ethics, it will be important to create relevant examples and case studies that require problem-solving and reasoning. The goal is to engage people – education should be exciting and interesting with examples that really grab your attention. Real-world learning examples are key.

The current ARECCI Project Ethics course has a 20+-year history that requires a review and possible updating to address issues such as:

- Ethics related to Indigenous People's health
- Access to and use of electronic data
- Terminology (do we use vulnerable populations, equity-denied, or equity-deserving?)

Ensuring we use inclusive language throughout all the ARECCI tools will be important, although language may continue to evolve and change.

The findings from the interviews conducted earlier this year are extraordinarily helpful in updating future training. As we look to update the ARECCI Projects Ethics training we need to think about how to ensure the content reflects the realities of increasingly complex projects as well as how we deliver that training. We need to be realistic about relying on volunteers and begin looking at a payment model to sustain the course.

Should future ARECCI training be developed in a limited way so we keep doing the same thing? Or maybe the

training should go online and be more available to broader audiences? There are a lot of possibilities that we haven't been able to explore yet. ARECCI was created to fill a need for QI/PE ethics guidance but needs have changed.

In looking at course management, we need to begin preparing for expansion through development strategies, like using a Learning Management System or a MOOC. We should also consider new models for determining competency in project ethics. Can technologies help with determining those competencies? Should we consider communities of practice, where we can share (examples), ask questions and build a library of resources?

As we look ahead, there are three potential directions to generate discussion on where we are going with ARECCI:

- Convert current content to online.
- Modify current content to include the changes we know need to be made right now. Also incorporate adult learning principles.
- Expand to provide broader content, give context to what ethics are and why they matter.

If we make the decision to expand, there are increased opportunities to market to new audiences and be self-funding. But before we get to that, the second option might be the most feasible.

Recommendations/Takeaways

- We need to have conversations around the intended audience and purpose of ARECCI Project Ethics course.
- We need to consider costs. May never get to a cost-neutral situation but shouldn't be cost-prohibitive.
- Consider separating and not charging for the public sector – do not want cost to be a barrier to understanding ethics.
- Maybe the ethics primer is cost-free? If we expand beyond Alberta, should it be revenue-generating?
- We need to decide what the statement of purpose for ARECCI is – who do we want to use it, what will it do for them, what are the learning outcomes and learning objectives? This needs to be addressed before we can discuss expansion and monetizing the ARECCI tool.

Applying this knowledge to ARECCI, it will be important to create relevant examples and case studies that require problem-solving and reasoning.

Robin Lau: ARECCI SOR Process - Building Organizational Buy-In and Capacity

What we heard

We're currently experiencing delays in the ARECCI peer review process with review times expanding and we are struggling to meet project needs. There is a need for peer reviewers and the Second Opinion Review (SOR) process is still valued, but projects are becoming more complex and more time-consuming.

We are facing a shortage of SORers and the current process is taking too long. In addition, the current review process is very one-dimensional and doesn't support the networking, learning, and professional development the community wants.

Some of the factors contributing to the delay in the SOR process is that we haven't offered any courses for the last two years, due in large part to the pandemic. There has been an attrition of SORers, perhaps caused by a lack of communication with ARECCI over the past two years, as well as competing demands on their time and other opportunities.

People have moved on with their lives and their work, and simply aren't available to work as SORers. As well, because there

are no clear timelines for reviews, SORers are less willing to take on projects.

We need to begin working to relaunch the ARECCI SOR course and training so that we can mentor and train new SORers. As part of that process, we will gather SOR comments and suggestions. What do existing SORers need to train new reviewers and how can we entice people to consider becoming SORers?

Ultimately, we would like to see the ARECCI SOR mentorship program re-energized so that we have a larger pool of SORers to turn to.

There has been some discussion around the ARECCI ORR (Organizational Recognized Review) processes and objectives, including the realities facing the more complex projects in the current ecosystem. We need a high-quality SOR process in order to ensure project success.

With issues around data, consent, and custodian requirements, we've encountered a lot of uncertainty. There are no easy solutions to these constraints or these different stakeholder requirements.

So how do we navigate those different stakeholder requirements in the short term? We need to leverage the community, we need to leverage our partners in the room, and we need to leverage partners in the ecosystem.

It will also be necessary to build the infrastructure – creating the essential IT pieces, including secure online file sharing so we can address issues of auditability. In addition, we need to address essential networking and communications processes, so that people can communicate freely and quickly.

The challenge with the effective coordination of information is that speed will be both our friend and our enemy if you don't organize it properly. There are a lot of considerations to building this structure. People need basic knowledge in project design to ensure that the level of projects going into the review process is at a minimum level of quality – we can't have just everything coming into it because it will further clog the system.

We also need teams of high-quality secondary opinion reviewers that are supported by a robust secondary review course and mentorship program. The sharing of projects helps mentor and train new secondary interviewers.

The inputs to this are going to involve three things – the ARECCI PE course, the ARECCI SOR course/program, and the ARECCI communities of practice. Together, they will support continuous learning, professional development, and networking.

It will also be necessary to build the infrastructure – creating the essential IT pieces, including secure online file sharing so we can address issues of auditability.

Recommendations/Takeaways

- Existing SORers need good candidates to mentor and support from leadership to do that work.
- Define what skills potential SORers should have.
- Mentoring SORers requires executive buy-in so staff can devote necessary time.
- We need a good training package – checklists, resources, and references.
- Funding support for SOR training. Consider a sustainable funding model.
- Create tip sheets for commonly asked questions/issues.
- Update the course for becoming a SOR to address modern realities.

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- Important to build in ongoing skill training/development for existing SORers.
 - We need clear learning objectives for SORers and assisting mentors to develop necessary teaching skills.
 - Compensate or better recognize SORers for their work.
 - Encouraging people to see the personal/professional growth opportunities that come from being a SORer.
 - Emphasize the “pay it forward” altruism aspect.
 - Agreement to proceed with necessary infrastructure.



OVERALL RECOMMENDATIONS AND NEXT STEPS

The one-day session offered an important opportunity for ARECCI stakeholders and partners to reconnect and discuss the important issues surrounding the modernization of ARECCI and determine what should happen next.

Each of the presenters touched on important considerations that will guide any modernization efforts, and participants shared valuable questions that will inform future discussions. It is imperative that these discussions continue. Another in-person session is planned for early 2023 but in advance of that session, it will be important for stakeholders and partners to continue to ask questions, share ideas, and explore challenges and opportunities. It may be beneficial to set up regular touchpoints with interested individuals to gather information and begin developing recommendations that can be shared at the next scheduled session.

During the meeting, some questions arose about ORRs and what they involve. A request was made to have a meeting specifically on ORRs to help better understand what they look like and how they work. This should involve organizations that are currently using ORRs who can speak from first-hand experience.


Participants expressed that time or capacity to take on additional work is a challenge. To avoid overtaxing people, perhaps ARECCI could establish a small modernization working group to begin exploring some of the key recommendations that arose out of the most recent one-day session.

From a logistics standpoint, the hybrid meeting model presented some technology and interactivity challenges. It is recommended that if pandemic considerations allow, meetings are not hybrid but held in-person in a workshop format to get to actionable next steps and progress toward modernization. This will allow for more networking and idea sharing in a more informal, spontaneous way. Some of the best ideas come out of face-to-face conversations among colleagues with a shared commitment and interest.

It is important to remember that ARECCI has a rich history, effective tools, and existing resources that can be built upon. We are not starting from scratch, so while the process of modernization may seem daunting it is achievable.

NEXT STEPS

- 1 It is imperative that these discussions continue.
- 2 Stakeholders and partners need to continue to ask questions, share ideas, and explore challenges and opportunities.
- 3 Set up regular touchpoints with interested individuals.
- 4 Schedule a meeting specifically on ORRs to help better understand what they look like and how they work.
- 5 Create a small modernization working group to begin exploring some of the key recommendations.
- 6 Ensure meetings are not hybrid but held in-person in a workshop format to get to actionable next steps and progress toward modernization.



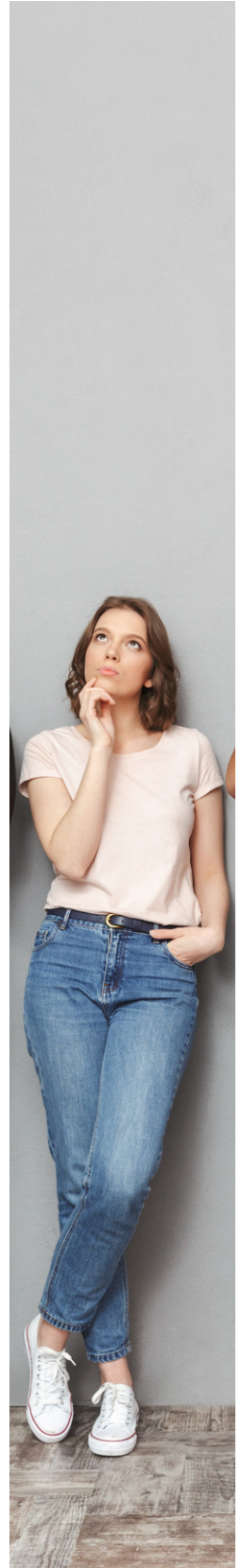
Remember that ARECCI has a rich history, effective tools, and existing resources that can be built upon.

APPENDIX

QUESTIONS AND COMMENTS FROM PARTICIPANTS

- Have a very burned-out health care system, and in that state people are willing to cut corners. It's a difficult time to try to adhere to the processes.
- The problem now is with the overcollection of data – people want to use validated tools but are not using them in the right context. Will get more data than they need for the objectives of the project. If you are asking this, what are you going to do with the data?
- In a hurry to do something, they often don't look at validated tools and will just make up questions. Those questions may not be interpreted by the participant in the way that is intended. Are we thinking about the cognitive process of asking a question that will get valid answers?
- Should the name of ARECCI be refreshed? Some have indicated the acronym makes no sense.
- How are tools evidence-informed? What does this mean?
- Is there a recognition that including the lived experiences of others may create ethical risks? Those collecting the data may be at risk, might be in danger, and may be triggered because they are collecting data in high-risk settings.
- There is a struggle as we partner with Indigenous communities and try to understand their lens, knowing what we need to do from an ethical perspective.
- Could ARECCI go broader and cover all those various communities?
- Is there something clear at the outset of ARECCI as to what it does and why it matters?
- If you are dealing with a lot of sensitive information with vulnerable populations, is ARECCI the right tool?

-
- Does it matter where information is stored? Are there data sovereignty concerns when data is stored outside of Canada?
 - Struggle with accessing auditing requirements when dealing with identifiable data. Need to be able to show who has looked at the data, which can be difficult. Logs need to be kept for 10 years.
 - What does HIA say about the role of patient consent in using data for evaluation?
 - Are there any requirements for people to get into ARECCI and start asking for mentorship? Are there minimum requirements for education, training, or experience?
 - Is it really ARECCI's job to be educating those who want to be mentored? If they don't have the first clue about doing it, whatever they generate won't be worth anything – unless the SOR does all the work for them.
 - If you are working for a smaller organization, perhaps partnering with larger groups that have QI/PE processes may be an option. Do not want those from smaller organizations to be left out.
 - Need more information on ORR to be able to comment. What are they and who uses them?
 - Need to remember the importance of being at arm's length in order to meet the requirements of transparency.
 - Need more clarification on the low-risk classification – is there no level of project that doesn't require additional review?
 - If we make ARECCI too complicated and too difficult to implement, many smaller community organizations may simply choose not to participate.
 - What is the difference between a community of practice and a SOR project network? Worried it might become more complex than necessary.



GLOSSARY OF ACRONYMS

AH	Alberta Health
AHS	Alberta Health Services
AI	Artificial Intelligence
ARECCI	A pRoject Ethics Community Consensus Initiative
E	Evaluation
HIA	Health Information Act
HQCA	Health Quality Council of Alberta
HS	Human Services
IT	Information Technology
OCAP	Ownership, Control, Access, and Possession (First Nation Principle)
ORR	Organization Recognized Review
PE	Program Evaluation
PIA	Privacy Impact Assessment
QI	Quality Improvement
REB	Research Ethics Board
SOR	Second Opinion Review
SORers	Second Opinion Reviewers

LIST OF PARTICANTS

Carol Adair	University of Calgary
Krista Brower	Edmonton O-Day' min Primary Care Network
Shelby Corley	Three Hive Consulting
Dale Dewhurst	Health Research Ethics Board of Alberta (HREBA)
Janine Engelhart	Alberta Health Services (AHS)
Kathy GermAnn	Independent Consultant
Brian Hamilton	BW Hamilton Consulting Inc.
Marilynne Hebert	Write from the Heart, Inc.
Kyle Kemp	Alberta Health Services (AHS)
Silvia Koso	University of Lethbridge
Markus Lahtinen	Health Quality Council of Alberta (HQCA)
Bonnie Lakusta	Three Hive Consulting
Birgitta Larsson	B.I.M Larsson & Associates
Robin Lau	Alberta Innovates
Leah Lechelt	Covenant Health
Tammy Mah-Fraser	Alberta Innovates
Karena Mallet	Health Research Ethics Board of Alberta (HREBA)
Brandi McCormack	Alberta Health Services (AHS)
Erica Phelps	Fraser Health (BC)
Andrew Ross	Alberta Health Services (AHS)
Laura Schattle-Weiss	Alberta Health Services (AHS)
Flora Stephenson	Alberta Health Services (AHS)
Kimberley Stever	Alberta Health Services (AHS)
Alexandra Turcanu	Government of Alberta, Justice & Solicitor General
Eric Worrall	Fraser Health (BC)

CONTACT US

Email: ARECCI@albertainnovates.ca

Website: <https://albertainnovates.ca/strategic-initiatives/a-project-ethics-community-consensus-initiative-arecci/>

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