



Project Report

PROJECT OVERVIEW

PROJECT NAME	KSDPP Community Research Ethics Framework Development (Goal 7)
EXECUTIVE SUMMARY	The KSDPP Community Research Ethics Framework Development project will create a harmonized, community-driven approach to reviewing, approving, and monitoring health research in Kahnawà:ke. Through analysis of existing ethics processes and extensive community engagement, the project will deliver draft framework options, documented community direction, and final reports that support informed decision-making and alignment with the Community Wellness Plan.
PROJECT TEAM	Treena Delormier, Project Owner Coreen Delormier, Project Sponsor Aianóhon Kaylia Marquis, Project Manager Shannon Udy, Subject Matter Expert and Project Technician
SCOPE STATEMENT	<p>The KSDPP Community Research Ethics Framework Development project aims to develop a plan to create a harmonized ethics framework that supports respectful, community-driven health research in Kahnawà:ke. By the end of September 2025, the project will:</p> <ol style="list-style-type: none"> 1. Complete a systematic analysis of the three current ethics processes (KEC, KSDPP, OHSSRC); 2. Conduct meetings, focus groups, and surveys with community members and other stakeholders; 3. Develop and present draft framework options at the KSDPP Research Forum, incorporating community feedback and supporting a collective decision; 4. Develop an implementation plan, and, 5. Produce a final project close-out report for KSDPP and a public-facing report for the community. <p>These activities support alignment with the Community Wellness Plan and aim to clarify and strengthen how health research ethics are reviewed, approved, and monitored in the community.</p>
PROJECT TIMEFRAME	February 2, 2025-September 30, 2025

PROJECT BACKGROUND

ORGANIZATIONAL GOALS MET	<ul style="list-style-type: none"> ▪ This project is the seventh of 7 explicit strategic goals identified as part of KSDPP's Revitalization Strategy.
OPPORTUNITY STATEMENT	<ul style="list-style-type: none"> ▪ Kahnawà:ke currently has three separate ethics review bodies with sometimes overlapping, sometimes confusing policies and codes, and stretched capacity, creating confusion for community members, researchers, and students navigating the health research approval process. This project presents an opportunity to clarify the scope and processes of each policy, reduce unnecessary duplication, and develop a more accessible, coordinated, and community-driven ethics framework. This work is timely and feasible this year because of KSDPP's one-year funding to support this work.
VALUE/BENEFIT	<ul style="list-style-type: none"> ▪ By creating a clear, coordinated, and community-driven ethics framework, this project will make the research approval process more transparent, efficient, and accessible for community members, researchers, and students. The resulting clarity and reduced duplication will save time, strengthen trust, and ensure that health research in Kahnawà:ke is conducted in a way that aligns with community priorities.

INPUTS

KNOWN DEPENDENCIES	<ul style="list-style-type: none"> ▪ Active participation from all three code / policy owners. ▪ Community engagement and feedback ▪ Support from KSDPP Leadership
RISKS	<ul style="list-style-type: none"> ▪ Interested Party Fatigue or Limited Availability or Engagement ▪ Misalignment between ethics bodies ▪ Sensitivity around governance and jurisdiction ▪ Delays in engagement or data collection

KEY OUTPUTS

Key Milestones	Actions & Deliverables	Completed
Project Planning	<ul style="list-style-type: none"> ▪ Set project goals, timeline, and key tasks. ▪ Connected with community stakeholders and shared an introduction to the project. 	2025/04/30
Analysis of 3 Codes/Policies	<ul style="list-style-type: none"> ▪ Reviewed and compared 3 existing codes/policies to understand strengths, differences, areas of overlap, gaps ▪ Mapped out how each one works to understand differences and similarities in processes. 	2025/06/30
Engagement Activities	<ul style="list-style-type: none"> ▪ May/June: Introductory Presentations: KSDPP Community Advisory Board and Research Team; Onkwata'karitáhtshera; Education Center Operations Team. ▪ August 12: Community Consultation Session ▪ September 10: Research Forum Presentation 	2025/09/25
Draft Framework Options and Community Decision	<ul style="list-style-type: none"> ▪ Drafted options for a community-led framework. ▪ Prepared materials to support decision making. September 25: Community Decision Session ▪ The community members present provided modest support for changes to: initiate a single starting point and advisory point for those that need to navigate these codes/policies, with an eventual goal of combining the three codes/policies into one. 	2025/09/25
DECISION	<ul style="list-style-type: none"> ▪ Community was uncomfortable making a decision on a topic they didn't feel that they understood well. Ultimately, the community decision session yielded modest support for creating a single starting point and advisory point to help navigate the three health research ethics policies/codes between the three organizations that currently hold them. They expressed that this could be an initial change with an eventual goal of combining the three codes/policies into one. 	
Project Close Out Reporting	<ul style="list-style-type: none"> ▪ Shared final reports with KSDPP and the community. ▪ Ensured all project records are safely stored. 	2025/11/14

COMMUNITY DECISION

Results of September 25, 2025 Decision session	Community was uncomfortable making a decision on a topic they didn't feel that they understood well. Ultimately, the community decision session yielded modest support for creating a single starting point and advisory point to help navigate the three health research ethics policies/codes between the three organizations that currently hold them. They expressed that this could be an initial change with an eventual goal of combining the three codes/policies into one.
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LESSONS LEARNED & KEY TAKEAWAYS

What Went Well	<ul style="list-style-type: none">▪ Structured milestones, activities, and reporting▪ 40% of community members surveyed heard about our events from posters around the community
Challenges	<ul style="list-style-type: none">▪ Initially unclear decision-making authority▪ Limited availability or engagement with code / policy owners▪ Long lead times to meet/discuss with code / policy owners▪ Lack of awareness of the topic within the community▪ Limited engagement and feedback with community members
Feedback	<ul style="list-style-type: none">▪ Community members shared that they did not feel that they had a strong enough understanding of the issue to be comfortable making decisions.▪ Community members without a background in research asked for documents to be in simpler terms.▪ Students that had proposed projects through these codes felt that the process had been difficult to navigate and, in some cases, jeopardized their project's completion before their program's deadline.▪ There is some interest in aligning the separate codes and policies, however, this would require focused work to change the documents to clarify limits, definitions, and to agree on the responsibilities each will undertake.
Lessons Learned	<ul style="list-style-type: none">▪ Ensure that all components are included when using borrowed equipment▪ Provide more public reporting through social media
Best Practices	<ul style="list-style-type: none">▪ Longer lead times ahead of community consultations▪ Budget for extensive promotion, including social media reach.

WHAT'S NEXT?

Phase II Planning	<p>Pursue Phase II planning with the Project Team.</p> <p>Actions to consider:</p> <ul style="list-style-type: none">Raising Community Awareness (including results of Phase I)Conduct a focused Improvement Session with the three Code/Policy holdersReport to the community
Stay Informed	<ul style="list-style-type: none">@ info@ksdpp.org📞 450-635-4374🌐 www.ksdpp.org