

Kilala Lelum Health and Wellness Cooperative Charter and Research Application

1. BACKGROUND

Kílala Lelum Health and Wellness Cooperative is a non-profit Indigenous Health organization that has been operating in Vancouver's inner city since 2018. Kílala Lelum Health and Wellness Cooperative offers an inter-professional team based primary care home that includes a balanced partnership of services between traditional Indigenous Elders/Healers and primary care providers. The mandate of Kílala Lelum is to provide culturally safe and effective care to patients of all nations. Specifically, the Kílala Lelum has the mandate to enact the Truth and Reconciliation Commission Calls to Action in Health (Health Actions 19-23) which include establishing measurable goals to identify and close the gaps in health outcomes for Indigenous peoples and to recognize, respect, and address the distinct health needs of the Métis, Inuit, First Nations, and off-reserve Aboriginal peoples. To this end, the Kílala Lelum acknowledges its mandate to participate in research that aims to promote health equity and promote Indigenous Peoples health and wellness.

The purpose of this Charter is to guide the Kílala Lelum Research Committee to (a) promote research that aligns with the philosophy, values and broader mandate of the Kílala Lelum and (b) communicate with potential research partners with respect to the processes of research conducted at the Kílala Lelum Health Centre.

Kílala Lelum's 3-Year Research Vision Statement (2024-2027):

The 3-Year Vision is to be engaged in innovative research that reflects the needs of and provides benefits to our urban Indigenous and non-Indigenous members, the wider community of Indigenous people living in the vicinity and beyond and for Kílala Lelum to be recognized as a model organization in Canada for conducting community-based, culturally safe, participatory research in inner-city healthcare.

2. GUIDING PRINCIPLES

Research conducted at Kílala Lelum must comply with the CIHR (2007¹) ethical considerations for research involving Indigenous people in Canada, and Chapter 9 of the Tri-council Policy Statement on

¹Canadian Institutes of Health Research. (2007). CI7dHR guidelines for health research involving Aboriginal people. Ottawa, ON: Canadian Institutes of Health Research.



Research involving the First Nations, Inuit and Métis Peoples of Canada (2010²). As outlined in this policy, Indigenous Peoples and their communities retain their inherent rights to any cultural knowledge, sacred knowledge, and cultural practices and traditions, which are shared with the researcher (Article 7). Community and individual concerns over, and claims to, intellectual property should be explicitly acknowledged and addressed in the negotiation with the community prior to starting any research project. Expectations regarding intellectual property rights of all parties involved in the research should be stated in the research agreement (Article 8). Researchers should also recognize and respect the rights and proprietary interests of individuals and the community in data and biological samples generated or taken in the course of the research (Article 12.1).

In addition to conforming to these policies, researchers should be familiar with the ethical principles that have been developed specific to research conducted in the Down Town East Side as outlined in the Manifesto for Ethical Research in the Downtown Eastside³. Specifically, Kílala Lelum supports research that is informed by the following principles:

Equity: Research focused on addressing the differences in health status or access to health care that result from inequitable structural and social arrangements. Such research recognizes that Indigenous peoples in Canada have been disproportionately affected by health and social inequities, and that manifestations of these inequities may differ by gender, age, ability, community context, etc.

Action-oriented: Research that aims to generate knowledge that can be used to improve health, health care and health policies for Indigenous peoples and the Kílala Lelum client-population as a whole. Opportunities to capitalize on synergies across research projects should be sought, including opportunities for policy-oriented, social or political actions. Research should endeavor to strengthen relationships between governments, policymakers, other community agencies, funders and Kílala Lelum.

Participatory Approaches: Research that: (a) is conceptualized and designed in partnership with leaders at Kilala Lelum to ensure maximum relevancy, and (b) involves leaders, staff, advisory committees, members, or paid peer workers in aspects of the research. Activities to share and mobilize knowledge

²Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Canada. (2010). Tri-Council Policy Statement: Ethical conduct for research involving humans.http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9/

³https://open.library.ubc.ca/clRcle/collections/ubccommunityandpartnerspublicati/52387/items/1. 0377565



must be integrated throughout the research activities, including for example, engaging staff, members, community advisory committees.

Capacity-Building: Research that contributes to research capacity at Kílala Lelum, for example, providing resources for research assistants, peer workers, or other staff; providing training and support to peer workers employed as research assistants; providing opportunities for client-groups, staff or elders to orient and educate researchers, among other opportunities for multi-way capacity building.

Accountability: Research that integrates accountability mechanisms such as: the use of meaningful engagement of community-advisory committees to guide aspects of research; regular reporting of research activities and findings to Kílala Lelum and the client-population; meaningful knowledge translation activities. This also includes attention to strength-based representations of Indigenous peoples in all communication, reports and presentations. More specifically, any communications that pathologize or stigmatize Indigenous peoples, or that reflect a deficit approach, must be actively avoided. As noted above, knowledge translation and exchange activities must engage staff, patients, community advisory committees, and other groups as appropriate.

These principles will be considered by reviewing any proposed research using the following **key** questions⁴:

- What are the unique benefits of proposing research at Kilia Lelum?
- What kinds of learning opportunities are the researcher/team willing to engage in?
- What are the potential hidden costs and resource requirements that ought to be anticipated?
- How will the researcher/team address the individual and group conflicts and/or anxieties that can sometimes arise when conducting research with decolonizing intentions?

3. RESEARCH COMMITTEE COMPOSITION AND PROCESS

The Kilala Lelum Research Committee shall be composed of a specific balance of members to ensure objective input and adequate community representation. The committee will strive to include community members, Elders, clinical staff, Board representation, and experienced researchers. Researchers with active studies in process or proposed at Kílala Lelum will be asked to declare a conflict of interest to facilitate arm's length review processes. The committee will be led by a Committee Chair and be supported by a staff person in the role of Research Manager.

⁴ Adapted from: Elwood, J., Andreotti, V., & Stein, S. (2019). *Toward Braiding* Handout 1. (2019). Guelph, ON: Musagetes Foundation. https://decolonialfuturesnet.files.wordpress.com/2019/02/towards-braiding-handout-1.pdf



A "consensus" model of decision-making will be employed by the committee. The committee will meet quarterly and at the call of the chair.

Upon submission of the pre-application checklist, the Research Manager and Committee Chair will confer as to whether the application:

- a) does not require an application (is not research, is research conducted elsewhere that requires limited involvement of KL membership and staff)
- b) requires an application which can be reviewed by the committee by email
- c) requires an application and attendance at a committee meeting

Researchers will be notified of the need for an application and meeting attendance. When approval is granted, it will be provisional pending Institutional Board ethics approval. The letter of approval will be issued by the Committee Chair following consensus approval.

4. APPLICATION PROCESS

Application Fee: **Kilala Lelum will collect a NON-refundable (regardless of approval) \$200** application fee (with a sliding scale option) to cover the costs of the review process including the costs of involving Elders. The sliding scale will be considered for those such as unfunded community groups or students, and for requests that requesting minor involvement by KL stakeholders (e.g. invitations to participate posters or e-mail only). Applicants will be notified whether the fee can be reduced once Kilala Lelum processes the application.

Approved multi-year studies will be subject to annual review, coinciding with the research ethics board annual review.



Research Application Form

Please complete the following four sections and submit via email to paula.amaya@kilalalelum.ca

Part 1: Contact Information

Research Applicate Name:					
Email:		Phone:			
Title of Proposed Study:					
Date of Submission:		Proposed Start Date:			
Part 2: Pre-Application Checklist					
Please check all that apply so that we know the scope of your request:					
	☐ To post notices or posters about research being conducted at other locations, which KL staff may wish to participate in.				
•	☐ To post notices or posters about research being conducted at other locations, which KL members may wish to participate in.				
☐ To inv	To invite KL staff to participate in your proposed study.				
☐ To inv	To invite KL members to participate in your proposed study.				
🛚 То со	☐ To conduct research at KL or at any of its program sites.				
🛚 То со	☐ To consult with KL Elders about any aspect of the proposed research process.				
□ То со	To consult with KL Elders about research processes in general.				
☐ Do vo	ou hold research funding to conduct t	his research? (please specify source):			



Are you proposing the research as a student? if so, please specify program and supervisor/supervisory committee members:				
Part 3. Summary of Proposed Research				
Title of Research Project:				
Name of Principal Investigator:				
(please attach copy of CV or resume)				
Name(s) of Co-Principal and Co- Investigators:				
Institutional Affiliation and Position:				

☐ Are you requesting a reduction in the standard \$200 application fee? If yes, please justify:



Summary of research proposal, with objectives and research methods clearly defined (no more than 500 words)	
Please describe the expected resources required from Kílala Lelum (office space, staff time, etc.) and how those costs will be covered	
Ethical Review Board Approval Date: (please attach copy of approval certificate)	



Part 4. Alignment with Guiding Principles

Please describe how your project reflects Kilala Lelum's research principles, and provide brief responses to the key questions listed below (each response can be 200 words or less):

Research Principle	Project Relevance
Equity Oriented:	
Action-oriented:	
Participatory Approaches:	
Capacity-Building:	



Accountability:	



Key Questions:

- What are the unique benefits of proposing research at Kilala Lelum?
- What kinds of learning opportunities are the researcher/team willing to engage in?
- What are the potential hidden costs and resource requirements that ought to be anticipated when engaging with Kilala Lelum in research endeavors?
- How will the researcher/team address the individual and group conflicts and/or anxieties that can sometimes arise when conducting research with decolonizing intentions?