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Kílala Lelum Health and Wellness Cooperative - Research 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. The Kílala Lelum Health Centre offers an inter-professional team based primary care home that includes a 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/members of all nations. Specifically, Kílala Lelum has the mandate to enact the Truth and Reconciliation Commission Calls to Action in Health (Health Actions 19-23) which includes 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 [VC1] with respect to the processes of research conducted at Kílala Lelum.

Kílala Lelum 3-Year Research Vision Statement (2022- 2025):

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, equity oriented, participatory research in inner-city healthcare.

2. GUIDING PRINCIPLES

Research conducted at Kílala Lelum must comply with the CIHR (2007^[1]) ethical considerations for research involving Indigenous people in Canada, and Chapter 9 of the Tri-council Policy Statement on Research involving the First Nations, Inuit and Métis Peoples of Canada (2010^[2]). 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



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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 Downtown EastSide as outlined in the Manifesto for Ethical Research in the Downtown Eastside^[3]. 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 Kílala Lelum to ensure maximum relevancy, and/or (b) involves leaders, staff, advisory committees, members, or paid peer workers in aspects of the research. Activities to share and mobilize knowledge must be integrated throughout the research activities including, for example, engaging staff, members, and 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.



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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 questions**^[4]:

- 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. GOALS, OBJECTIVES, AND ACTIVITIES

| Goals | Objectives | Activities |
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| 1) Research conducted with Kílala Lelum reflects the needs of the DTES community and is conducted in accordance with the Principles of Research outlined in section 2. | 1) That all research conducted with Kílala Lelum be first approved by the Kílala Lelum Research Committee, and progress/challenges will be reviewed at quarterly committee meetings. | All parties interested in conducting research with Kílala Lelum will complete the pre-application checklist and request form (see appendix) and pay a non-refundable sliding scale administration processing fee. |



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| <p>2) That the outcomes of research conducted at Kílala Lelum be appropriately cataloged and made accessible to the DTES community</p> | <p>2) That all final outcomes of research be collected by the Kílala Lelum research committee and archived on the Kílala Lelum website.</p> | <p>Upon completion of the research process at Kílala Lelum a “final report” (in the form of a poster, manuscript or report) will be submitted to the Kílala Lelum Research Committee Coordinator and will be posted in the “research” section of the Kílala Lelum website, at the discretion of the research committee. Knowledge translation and exchange activities must be completed within a reasonable time frame.</p> |
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4. RESEARCH COMMITTEE COMPOSITION

The Kílala 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, have Board and Member representation, as well as 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 Coordinator”.

A “consensus” model of decision-making will be employed by the committee. Any committee member’s concerns need to be addressed before an approval is granted. Any committee member will recuse themselves if there are conflicts of interest.

The committee will meet quarterly and at the call of the chair.

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



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- 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.

Monitoring Ongoing Research

The Research Committee strives to monitor active research projects to promote sharing of knowledge between research teams and to help with problem solving. Active research groups will be invited to meet with the Research Committee bi-annually. In accordance with CIHR ethical considerations for research involving indigenous people in Canada and Chapter 9 of the Tri-council Policy statement, Kilala Lelum (KL) identifies the following key areas as points of discussion on evaluating a research project's active status.

Consent Procedure: How, when and where participants are approached, and by who. Challenges will be reviewed, and potential solutions discussed.

Privacy & confidentiality: Reviewing current practices related to a participant's personal identification.

Recognizing Elders and Knowledge Keepers: An important aspect of Indigenous-focused research is ensuring research is in partnership with community goals and values, and as such, requires on-going consultation with community Elders or Knowledge Keepers.

Customs & Codes of Practice: Researchers will be asked to share their on-going experience with participants, community members, and other stakeholders.

Conflict of interests

Kilala Lelum has a role in stewarding community-based, Indigenous health research and promoting investigations that are in line with our guiding principles. Purposefully, the Research Committee (RC) membership is composed of diverse individuals with roles as investigators, consultants, practitioners, community- and board members at KL, other allied health services, and research groups. As such, KL recognizes that conflicts of interest (COIs) will arise in



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activities or situations that place an individual or institution in real, potential, or perceived conflicts between the tasks or responsibilities related to research, personal, intra- and inter-institutional, and other interests (enter TCPS 2 citation here). Committee members have the responsibility of being transparent, forthcoming, and consistent in reporting COI information ranging from, but not limited to, personal or professional relationships to financial interests, activities, and other affiliations related to prospective projects. This requires committee members to be aware of their own potential for real or perceived COIs. The diversity of research interests necessitates COIs be assessed on a case-by-case basis through honest and open communication between committee members when reviewing each prospective project.

5. FUNDING

Those parties conducting research with Kilala Lelum will Pay a sliding scale research application processing fee.

Private donations to KL will also be utilized to support the RC activities.

6. RESEARCH COMMITTEE MEMBERSHIP

| Committee Role | Committee Member(s) | Email address |
|-------------------------------------|----------------------------|----------------------------|
| Committee Chair | David Tu | david.tu@kilalelum.ca |
| Board Representative | Annette Browne | annette.browne@ubc.ca |
| Research Committee Coordinator | Paula Amaya | paula.amaya@kilalalelum.ca |
| By virtue of her office (exofficio) | Leah Walker | leah.walker@kilalelum.ca |
| Elder | Elder Sandy | sandylambert2014@gmail.com |



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| Peer Representative | | |
|---------------------|--|--|
| Members at Large | Dr. Colleen Varcoe Jill Fikowski Rory Marck Mathew Fleury Kelsey Lynch | Colleen.Varcoe@ubc.ca jfikowski@changemark.ca rory.marck@kilalelum.ca mfleury@changemark.ca kelsey.lynch@ubc.ca |

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

[2] Canadian 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/>

[3] <https://open.library.ubc.ca/clRcle/collections/ubccommunityandpartnerspublicati/52387/items/1.0377565>

[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>
