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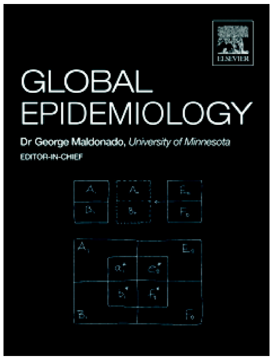

Community-driven Epidemiologic Research: Guiding Principles

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Abstract

Increasingly, public health research standards call for engaging communities who live with health issues under investigation to help ensure that results translate into effective public health measures. Here, we share guiding principles for community-driven epidemiologic research developed over a decade conducting research sought and controlled by participating communities. These principles provide a roadmap for epidemiologic research that effectively addresses community priorities while meeting academic standards: research questions are developed collaboratively in community-university partnerships; knowledge takes shape from information donated by participants through methods that turn information into scientifically useful data and analysis that reveals data patterns that address research questions; thus, knowledge is generated collaboratively by academic researchers and community partners; academic researchers are bound by ethical, professional, scientific, contractual, and other legal standards to be responsible stewards of information donated by participants; community review protocols ensure that interpretation and presentation of research results reflects the voices of all partners; meaningful community review creates the trust needed for open access to research results as required of academic researchers; all partners share credit for achievements. Lacking models for operationalizing these principles, we developed specific guidelines for research project initiation, data use, authorship, acknowledgment, and data dissemination. Conventions in academia present formidable challenges to effective community engagement and are often at odds with calls from community organizations and funding agencies to conduct research driven by community priorities and values. We hope others can benefit from time and effort we have spent crafting solutions that bridge this divide.

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Communities defined by a common identity often recognize collective concerns that need to be addressed to improve quality of life. Many communities have developed their own approaches to generating knowledge that promotes wellness. Academic health research initiatives, however, have had mixed impacts on diverse cultural groups: some with adverse consequences yielding wariness towards academic researchers, others achieving strong community-university partnerships that use academic methods to identify effective strategies for improving community health.[1–5] Here, we share guidelines developed while striving to achieve the latter over a decade conducting community-driven epidemiologic research. These guidelines provide a roadmap for research that effectively addresses community priorities while meeting academic standards.

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Ethical standards governing the conduct of research involving human participants evolved to ensure that research cannot be conducted without individual participants giving informed consent. Increasingly, ethical standards are expanding to include collective consent to protect cultural groups, along with values of equity and justice with respect to who benefits.[6] Health research norms are shifting toward the expectation that academic researchers should limit themselves to research that benefits study populations. In Canada, for example, standards of agencies that govern research on Indigenous Peoples evolved over the past decade, in response to advocacy of Indigenous organizations and individuals to promote research that benefits Indigenous communities:[5,7,8] current standards restrict federal grants for research involving Indigenous Peoples to projects driven by the priorities, values and knowledge-seeking approaches of targeted communities.[9] Current standards arose from attempts to correct historic injustices to Indigenous Peoples inflicted by scientists advancing their own agendas without regard for those contributing data or specimens.[5,10,11] Such standards recognize that benefits to Indigenous communities arise from research designs centered around shared ownership of knowledge generated collaboratively using culturally relevant methods that incorporate Indigenous voices and academic sciences.[12–14] Innovative integrated knowledge translation approaches that include decision makers in community-university research projects aim to ensure that research directly benefits study populations.[15–17] Because adhering to current standards requires resources beyond conventional grant budgets, costs of partnership development and knowledge exchange should be included in proposals.

Research principles that call for engaging people who live with health issues under investigation apply to all demographically defined groups. In the 1990s, leading epidemiologists called for scientific paradigm shifts,[18–21] in response to failures of large-scale efforts of the 1970s and 1980s to intervene on lifestyle risk factors to prevent chronic diseases.[22] While much of the critique centered on limitations of approaches that reduce determinants of health to individual risk factors without regard for socio-ecological factors,[18–20] Schwab and Syme went further, proposing "a 'participatory eco-epidemiology' embracing the experience and partnership of those we are normally content to simply measure".[22(p. 2050)] Pointing to evidence of greater disease prevention effectiveness of interventions informed by community participation, they proposed a scientific paradigm that requires working "with the population itself, in defining variables, designing instruments, and collecting data…that reflect the ecological reality of life in that population, as people experience it".[22(p. 2050)] This paradigm frames research participation as decision-making partnerships that go beyond consultation with token community members and requires academic researchers to have qualities not usually emphasized in the training of health

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scientists: the ability to share power in setting research goals and cultural sensitivity for transcending sociocultural differences between them and the communities they aim to serve.[23–25] It should be emphasized that mistrust of health science research is not confined to socioeconomically disadvantaged groups; for example, the contemporary rise in vaccine hesitancy based on mistrust of health science experts is driven largely by people who are well educated.[26,27]

In a 1998 review, Israel *et al* specified principles that characterize "community-based research": uses community as a unit of identity; builds on community strengths and resources; facilitates collaboration; integrates knowledge and action for mutual benefit; promotes co-learning and empowering that transcends social inequalities; is cyclical and iterative; addresses health from positive and ecological perspectives; and disseminates knowledge gained to all partners.[28] We have encountered public health academics who use this characterization to define "community-based research", which we find unfortunate given that many health scientists use "community-based" to differentiate community research settings from clinic or laboratory research settings. In the 2000s, proponents of the approach described by Israel *et al* began to call it "community-based, participatory research,"[29] which emphasized participation but does not specify who controls or benefits from the research.[30] In Canada, where current Indigenous health research standards require community control over the research process, research that incorporates these standards is being labeled "community-driven" or "community-led"[5,31,32].

Our approach arose in community-university partnerships established with Indigenous communities in northern Canada during 2007-2017.[33] Our collaborative team, the Canadian

North *Helicobacter pylori* (CAN*Help*) Working Group, links community members, health care providers, and academic researchers; it formed in response to concerns voiced by community members and their health care providers about *H. pylori* (*Hp*) infection, a risk factor for stomach cancer,[34] which has a high prevalence in Indigenous residents of the circumpolar north.[35] Our initial community project arose after Billy Archie, mayor of Aklavik, Northwest Territories, Canada during 2004-2006, led community leaders in advocating for research to address concerns about stomach cancer and *Hp* infection.[36] In turn, territorial health officials asked University of Alberta scientists to design research aimed at reducing *Hp*-related health risks. The Aklavik *Hp* Project launched in 2007.[37] Public interest generated media coverage,[38–46] which led nearby communities to seek participation. By 2017, with *Hp* projects in 4 Northwest Territories and 5 Yukon communities, these projects engaged over 70 community residents as planning committee members or research staff.

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Our projects are community-driven: the participating communities sought the research and controlled it from start to finish. While most community-driven health science investigations are limited to qualitative studies of socio-cultural-environmental factors that affect health,[5] our collaboration used knowledge exchange throughout the project to engage communities in shared planning and oversight of biomedical epidemiologic research that addresses their priorities, incorporating local knowledge, approaches to knowledge-seeking, and values. Along with qualitative methods,[47–51] our community-driven projects have included: biologic specimen collection (gastric tissue, hair); diagnostic procedures (endoscopy, pathology); microbial genomics; environmental toxicology; and multivariable statistical models.[50–60] Our research presentations and reports are co-authored by community, health care, and academic partners,[47,56,63–77] integrating approaches from social, biological, clinical and public health sciences.

As our community-university partnerships evolved along with Canadian federal standards for the conduct of research with Indigenous Peoples,[3] we found the need to collaborate on protocols for ensuring that our research methods promoted community-identified goals and values while adhering to academic standards and policies. We eventually crafted a Statement on Stewardship and Dissemination of Knowledge Generated Collaboratively in CAN*Help* Working Group Community Projects,[78] beginning with guiding principles (Table 1). Lacking models for operationalizing these principles, we developed specific guidelines for research project initiation, data use, authorship, acknowledgment, and data dissemination, along with a community-university research agreement template[78–81].

Our approach arose in a setting where advocates from small communities with elected leadership and community organizations sought partnerships with academic researchers. Because our research was not investigator initiated, we did not attempt to persuade communities to engage with us. When asked to do so by regional governance or advocacy organizations, we extended invitations to communities that did not reach out to us and left it up to community leaders to express interest. In settings such as ours, where community self-determination in research is a goal, some form of community consent is required to undertake research. While this standard provides a necessary safeguard for communities to set their own research priorities, communities that lack adequate organization or leadership for setting priorities or have political factions with conflicting priorities may get left out of opportunities for beneficial research partnerships.

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Even where there is sufficient community-level agreement to move forward with a research partnership, forces external to communities can create challenges. We encountered instances where brokers external to communities, whose approval or influence was required for research activities to proceed, used this power in ways that impeded research. In our experience, the most effective solution to such challenges was to have strong support at the community level and strong partnerships with health officials who were accountable to communities and could influence brokers. While our guiding principles apply more fully to communities that are sufficiently organized to engage in research partnerships, and settings where health officials are expected to support community-identified priorities, we believe that the spirit of these principles can be adapted to other settings.

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Guiding Principles (see Table 1)

1. Research questions are developed with input from community project planning committees, who represent research participants. We found the formation of a local project planning committee made up of community residents to be an effective vehicle for engaging community members in the design and conduct of each community-driven research project. We asked the community members who sought research collaborations to constitute such committees based on their own criteria. We came to see this initial step taken by community partners as crucial confirmation that the community was committed to the research partnership. In initial planning committee meetings, academic researchers identified questions community members wished to answer and offered expertise on which questions could be addressed using scientific methods. In this way, the research process started with the collaborative development of research questions that would produce meaningful information for participating communities.

Some communities rose to the challenge of forming a planning committee more readily than others. In some instances, it took several years for priorities to align and for a sufficient number of community members to be available. Circumstances may require approaches other than committees to obtain community input, for example, when working with communities that lack conducive organizational structures or when faced with other logistic constraints. In one of our community projects, funding restrictions required us to begin research activities requested by a regional governance organization before a local committee could be formed, so we sought guidance from the regional partners and the community health representative in the local health center.

Even under the most conducive circumstances, researchers will need to invest time and resources into facilitating community participation, providing logistic support for the formation and operation of planning or advisory committees where this is feasible, or for input from individual community consultants. As well, community participants should not be expected to invest their time in research partnerships without deriving benefit on par with the benefits academic researchers derive. Benefits that participants value will vary across settings and individuals, but should include compensation for time spent, whether this be in the form of social or clinical services, goods, or cash. A complementary approach is to employ community members to coordinate community input.

Communities are heterogeneous and fluid groups of people, even when defined by a narrow set of characteristics. Whether community input comes from a committee of residents in a small hamlet or a collection of individuals in an urban area, the informants cannot be assumed

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to represent the community fully; those who engage with researchers most readily are not likely to be average citizens. In some situations, researchers may need to consult a larger number of community members, or seek out key individuals with relevant perspectives. The goal here is to take perspectives of research participants into account in ways that gain their trust and facilitate research activities. What matters most is careful consideration of how the research can be conducted so as to bring equitable benefits to the target population and whether approaches to obtaining community input are meaningful, transparent, open to those who want to contribute, and perceived to have legitimacy in representing community interests.

2. Research participants donate personal information, including that arising from biological material, to community research projects; knowledge takes shape from information donated by participants through: a) Scientific observation and measurement that turns information into scientific data; b) Analysis that reveals patterns in data; and c) Interpretation of data patterns. Scientists use systematic methods to collect information and other research materials, such as biologic specimens, extract the relevant bits, transform them into or use them to generate useful data, organize the data in ways that reveal patterns, and interpret the patterns to address specific research questions. In scientific research involving contributions from individual participants, knowledge arises from individual contributions combined with scientists' expertise. In our view, knowledge arising from our scientific research collaborations is generated collaboratively by academic and community research partners along with research participants. Consequently, our scientific research results are the intellectual property of all research partners and participants. Collaboratively generated knowledge arising from community-university research partnerships differs from research materials contributed by participants, including material such as personal information, samples of tissue or bodily fluids, culturally inherited knowledge, locally created

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objects, or culturally meaningful natural specimens, which may be individually owned by research participants or collectively owned by communities.

In Canada, the First Nations Information Governance Centre's OCAP®[8,82] standards for how First Nations data should be collected, protected, used, or shared, have been widely adopted for use across Indigenous communities. OCAP® includes four components (Ownership, Control, Access, and Possession) and is intended to "ensure that First Nations own their information and…are stewards of their information, much in the same way that they are stewards over their own lands." [82] OCAP® "also reflects First Nation commitments to use and share information in a way that maximizes the benefit to a community, while minimizing harm." [82] Recognizing that "rights of First Nations communities to own, control, access, and possess information about their peoples is fundamentally tied to self-determination…,"[82] OCAP® is not intended as a doctrine or a prescription; instead, it asserts that First Nations communities have the right to decide why, how, and by whom information is collected, used, or shared. Because the OCAP® components of ownership, control, access and possession can be challenging to operationalize in research collaborations involving universities and funding agencies, each community-university partnership should develop its own explicit statements of why, how, and by whom community members' information will be collected, used, shared or stored. We have found that beginning a research partnership by working collaboratively on an agreement that covers these aspects of research data facilitates the protection of the interests and responsibilities of all partners and creates a foundation of trust in the partnership.

3. Researchers are bound by ethical, professional, scientific, contractual, and other legal standards to be responsible stewards of the information donated by participants; this entails

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using this information for no other purpose than to achieve explicitly shared research goals. This statement casts researchers as stewards of participants' research contributions rather than owners of collected data. It is meant to include all information arising from participant contributions, including data characterizing microbes grown from their tissue or bodily fluids. It addresses the distinction between individually owned contributions of research participants and collaboratively generated knowledge arising from combined individual contributions. Documentation of agreed-upon research aims should be maintained to remind researchers of restrictions on how research materials in their possession can be used and when new lines of inquiry require approval and guidance from community partners. To facilitate this, we established written research agreements between community planning committees and academic researchers[77]. It should be noted that written agreements need not preclude flexibility; for example, an explicitly shared goal could be to allow the academic researchers to store data or specimens to address research questions of relevance to community interests that may arise down the road, provided that individual participants agree to this as part of informed consent.

4. Any member of the CANHelp Working Group who contributes to a particular research project may contribute to the interpretation of the data patterns; when consensus is not possible, different viewpoints will be reported. Meaningful community participation in research requires a mechanism for community partners to participate in interpreting results. At the same time, academic researchers must publish and otherwise disseminate research results to adhere to the policies of universities that employ them and agencies that fund their research. We developed a protocol for community review of results, which functions as a successful solution to these potentially conflicting requirements. This protocol requires academic researchers to share all new

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results with the project planning committees of participating communities and give them the opportunity to ask questions or provide feedback before we disseminate results more broadly within the participating communities or beyond in scientific or media reports. For complex results, academic researchers prepare lay summaries of reports intended for scientific audiences and discuss the lay summaries with planning committees in teleconferences or in-person meetings, with the latter often preferred by community partners. In our experience, this process has allowed us to improve the scientific accuracy of our reports as well as their relevance to participating communities. While our guidelines allow for publication of alternate interpretations of findings if partners disagree, we have not encountered an instance when consensus was not achieved.

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5. All members of the CANHelp Working Group who contribute to a particular research project are entitled to be acknowledged for their contributions (either as a group or individually depending on practical considerations). In community-university partnerships, it is crucial to acknowledge the specific contributions of all partners as essential elements of the research to reflect the collaborative generation of the research results. Acknowledgment can take many forms, such as authorship, published acknowledgments, ceremonial tributes, or simply mentioning partners in public presentations or media reports. To maintain trust, it is crucial that academic partners consistently share credit with community partners for collaborative achievements.

6. In keeping with professional and ethical standards, individuals who make key contributions to specific research reports will be acknowledged as authors. When a collaborative group has too many members to name all as authors, a useful solution is to name the group as a collective author; partners who make key contributions can be named individually, while others can be named collectively.

7. After following CANHelp Working Group guidelines for review of research results by relevant collaborators, results will be made accessible to the public to ensure open access to knowledge generated through the support of public resources, as required by funding agencies and the university. Our community review protocol instills community trust in results and minimizes apprehension about reporting results to the public. While scientific norms of open access could potentially undermine community control, many community partners value contributing to a body of scientific evidence and having an impact beyond themselves. For example, our community treatment trial reports have informed regional and national clinical guidelines.[54,83]

8. The CANHelp Working Group research director, Karen Goodman, has ultimate responsibility for ensuring that these guiding principles are upheld. It is crucial for a research director or panel to assume responsibility for upholding policies that determine how a community-university partnership will function. Because engaging communities in planning research and reviewing results is beyond the training and experience of most academic researchers, strong leadership and rigorous procedures for safeguarding research materials and data may be required to ensure that all academic partners adhere to policies that protect interests of community partners. As our collaboration grew, we found it necessary to develop detailed written protocols for data use and dissemination, as well as authorship and acknowledgement[78,80,81].

Conclusion

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In conclusion, during our decade of experience developing approaches to effective community-driven epidemiologic research, we discovered that conventions in academia presented formidable challenges to effective community engagement and were often at odds with calls from community organizations and funding agencies to conduct research driven by community priorities and values. We encountered the need to spend much time and effort crafting solutions that bridged this divide. We hope that others can benefit from what we have learned.

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Table 1. Guiding Principles for Stewardship and Dissemination of Knowledge Generated Collaboratively in CAN*Help* Working Group Community Projects

1. Research questions are developed with input from community project planning committees, who represent research participants
2. Research participants donate personal information, including that arising from biological material, to community research projects; knowledge takes shape from information donated by participants through:
    a. Scientific observation and measurement that turns information into scientific data
    b. Analysis that reveals patterns in data
    c. Interpretation of data patterns
3. Researchers are bound by ethical, professional, scientific, contractual, and other legal standards to be responsible stewards of the information donated by participants; this entails using this information for no other purpose than to achieve explicitly shared research goals
4. Any member of the CAN*Help* Working Group who contributes to a particular research project may contribute to the interpretation of the data patterns; when consensus is not possible, different viewpoints will be reported
5. All members of the CAN*Help* Working Group who contribute to a particular research project are entitled to be acknowledged for their contributions (either as a group or individually depending on practical considerations)
6. In keeping with professional and ethical standards, individuals who make key contributions to specific research reports will be acknowledged as authors
7. After following CAN*Help* Working Group guidelines for review of research results by relevant collaborators, results will be made accessible to the public to ensure open access to knowledge generated through the support of public resources, as required by funding agencies and the university
8. The CAN*Help* Working Group research director, Karen Goodman, has ultimate responsibility for ensuring that these guiding principles are upheld

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