



List of resources and process suggestions to help NGOs deal with data requests from researchers

Anne Bergen | October 2014



Community First: Impacts of Community Engagement (CFICE), a major SSHRC-funded project, aims to strengthen Canadian communities through action research on best practice community campus. We ask how community campus partnerships can be done to maximize the value created for non-profit, community based organizations in four key areas: poverty, community food security, community environmental sustainability, and reducing violence against women.

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List of resources and process suggestions to help NGOs deal with data requests from researchers

e.g., how does research work, what should they expect from researchers, how they can best protect their clients, how to address issues of access to their data, etc...

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Background

These resources were sent in response to requests sent to the KTECOP.ca listserv (exchange@ktecop.ca), the CBPR mail list (cbpr@u.washington.edu) and recommendations from the [CFICE project](#). The request was for “resources aimed at community partners/NGOs that are struggling to deal with data requests from researchers.” ([original request appended at the end of this document](#))

There was a strong response to this request – over 20 respondents provided diverse resource and process suggestions, and stories of dealing with similar issues. Although there are resources available, there are also gaps and a need to adapt resources to different contexts and sectors. There was also interest in exploring collaboration from a few people working in this area.

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Best Practice Process Suggestions

- Get the researchers to sign some sort of Non-Disclosure Agreement or some sort of contract stipulating their privacy rules, things you have final say on, things that can be published, media interviews, etc. They may want to reach out to other local NGOs, universities, hospitals to see if they have policies around data sharing. Having a lawyer involved is also usual practice.
- The data should be de-identified and follow whatever patient privacy laws are in place
- Ask the researchers to provide IRB approvals for the study
- Ask the researchers to provide a research proposal, outlining the purpose, goals, timelines, etc
- Ask the researchers to provide background information on their past research in this area, eg publications, grants, etc
- Stipulate things like, having final say on publications, that the researchers cannot 'walk away' with the data but can only access it on site, you can insist on having at least one person from your organization as a co-author on the work so that you are kept in the loop about the project's progress and where it is being disseminated.
- Think about a partnership where a student or a team, working with a prof teaching research methods, could get credit for assisting with reviewing applications and presenting options to staff.
- **There is absolutely nothing wrong with charging for data access.** This is common practice for many small health centres and NGOs; provides a way to backfill when they needed to have a staff person pull and assemble charts and so forth. NGO retains clear ownership and were custodians for the information (and in a way the clients). If a researcher wanted something questionable and got it through an IRB/ERB it must be remembered it's not like a police raid. NGOs are not **required** to hand over everything.
- If you don't have a data request review committee, consider setting one up. This would be most helpful to if it featured some experts in research in your area and probably a legal and ethical advisor.
- If funds are available, some organizations hire their own research director, an in-house scientist who reviews applications and oversees data sharing.
- Demand a common structure to the applications so can ensure concerns are consistently addressed. This covers gaps in the research approval processes from IRBs.

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Resources

Toolkits and Resources Collections

- Pacific AIDS Network compiled:
 - CBR toolkit – contains page with resources to support organizations “when researchers come knocking” and includes principles for collaboration and terms of reference examples.
 - <http://pacificaidnetwork.org/what-to-do-when-researchers-come-knocking-resource-page/>Resources for research partnerships:
 - <http://pacificaidnetwork.org/resources/cbr/cbr-toolkitresources/researchpartnerships/>
- Urban Indian Health Institute compiled:
 - resources for data use and sharing as well as partnerships (MOUs), designed for community-based health-centered American Indian populations, but can be adapted to other contexts
 - <http://www.uihi.org/projects/health-equity/partnership/>
 - Collection of Information for guidelines, sample data use agreements and other information
- <http://www.uihi.org/projects/health-equity/health-equity-project-partnership-links/> Vancouver Native Health Society (VNHS) materials -
<http://www.vnhs.net/about-us/research>
- Online system via Alberta Innovates Health Solutions called [ARECCI](#)
 - both supports the development of a proposal, and screens it for higher risk areas.
- [Vibrantcommunities.ca](#) - good resource generally for community organizations.
- Community ToolBox: <http://ctb.ku.edu/en/toolkits>
- CBPR training curriculum- Unit 1 Section 1.3: Ethics and CBPR
 - <https://depts.washington.edu/ccph/cbpr/u1/u13.php>
- <http://www.sas2.net/>
- Community Research Ethics Office in Waterloo region -
<http://www.communityresearchethics.com/>

Government-Developed Research Ethics Policies and Guides

- [CIHR's Guidelines for Health Research Involving Aboriginal People](#) [former CIHR policy] and [Ethics of Health Research Involving First Nations, Inuit and Métis People](#) [current policy]
- Canada's Tri-Council has clear statements and guideline regarding ethical conduct of health and social research & free online tutorial - these are harmonious with international guidelines on ethics (see also UN & WHO guidelines)
 - www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf
 - <http://www.pre.ethics.gc.ca/eng/education/tutorial-didacticiel/>
- Resource developed by a Working Group at the CDC – *Release Guidelines and Procedures for Re-release of State-Provided Data* - available at
<http://stacks.cdc.gov/view/cdc/7563>

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Example Policy Templates

- Canadian Aboriginal AIDS Network. (2013). Principles of research collaboration - template. Available at <http://caan.ca/wp-content/uploads/2010/03/Principles-of-Research-Collaboration.doc>
- Canadian Neuromuscular Disease Registry. Research Data Request policies. Available at <http://www.cndr.org/overview.cfm>

Example Data Management & Support Organizations

- **ELOKA - <https://eloka-arctic.org> - provides data management services and support to Arctic communities.** The Exchange for Local Observations and Knowledge of the Arctic (ELOKA) was launched during the 2007-2009 International Polar Year. The purpose of ELOKA is to provide data management services and support to Arctic communities and others who are working with local and traditional knowledge (LTK) or who are gathering community-based monitoring data and information.

Example Ethical Guidelines

- First Nations Principles of **OCAP™** (ownership, control, access, and possession) - <http://fnigc.ca/ocap.html> - means that First Nations control data collection processes in their communities. First Nations own, protect and control how their information is used. Access to First Nations data is important and First Nations determine, under appropriate mandates and protocols, how access to external researchers are facilitated and respected.
- Community research guidelines: http://www.pace-society.org/wp-content/uploads/2014/04/Community_Research_Guidelines.pdf.

Brief/ Standalone Resources and Guides

- Participant's perspective - Your Rights in Research: A Guide for Women - http://bccewh.bc.ca/wp-content/uploads/2012/05/2009_YourRightsinResearchAGuideforWomen.pdf
- When Researchers Come Calling: A Guide for Organisations that Work with Women - http://bccewh.bc.ca/wp-content/uploads/2012/05/2009_WhenResearchersComeCalling.pdf
- Barnsley, Jan. (1992). Research for Change. Participatory Action Research for Community. Available Women's Resource Centre. [hardcopy only – but available in some libraries]
- Montgomery, M. (2013). *Fast Facts about Responsible Research Partnerships with Indigenous Communities*. University of Washington. Available at https://depts.washington.edu/ceeh/downloads/FF_Responsible.pdf
- Pacific AIDS Network (2014). *CBR Tips: Compensating Peer Researchers*. Available at <http://pacificaidnetwork.org/cbr-musings/cbr-tips-compensating-peer-researchers/>

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Longer Articles & Reports

- Dickert, N., & Sugarman, J. (2005). Ethical goals of community consultation in research. *American Journal of Public Health, 95*(7), 1123–1127. Available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1449329/>
- Commission for Research Partnership with Developing Countries (1998). Guidelines for Research in Partnership with Developing Countries. Available at http://www.kfpe.ch/key_activities/publications/guidelines/guidelines_e.php
- Grignon, J., Wong, K. A., & Seifer, S. D. (2008). Ensuring Community-Level Research Protections. Proceedings of the 2007 Educational Conference Call Series on Institutional Review Boards and Ethical Issues in Research. Available at <https://ccph.memberclicks.net/assets/Documents/FocusAreas/finalresearchethicscallseriesreport.pdf>
- Ray, N., Wang, K., & Yale Robert Wood Johnson Clinical Scholars Program. (2014). *Making research work for your community: a guidebook to successful research partnerships*. Community Foundation for Greater New Haven. Available at http://www.cfgnh.org/Portals/0/Uploads/Documents/Public/Publications/TCF_MakingResearchWorkForYou_R6web.pdf
- Sullivan, T. P., Hunter, B. A., & Fisher, B. S. (2013). *Strategies for Successfully Developing and Disseminating Useful Products from Researcher-Practitioner Partnerships Study (RPPS)*. National Criminal Justice Reference Service. Available at <https://www.ncjrs.gov/pdffiles1/nij/grants/243913.pdf>
- Sullivan, T. P., Khondkaryan, E., & Fisher, B. S. (2013). *Recommendations for Collaborating Successfully With Academic Researchers, Findings from the Researcher-Practitioner Partnerships Study (RPPS)*. National Criminal Justice Reference Service. Available at <https://www.ncjrs.gov/pdffiles1/nij/grants/243911.pdf>
- Sullivan, T. P., McPartland, T., & Fisher, B. S. (2013). *Guidelines for Successful Researcher-Practitioner Partnerships in the Criminal Justice System, Findings from the Researcher-Practitioner Partnerships Study (RPPS)*. National Criminal Justice Reference Service. Available at <https://www.ncjrs.gov/pdffiles1/nij/grants/243918.pdf>
- Sullivan, T. P., Willie, T. C., & Fisher, B. S. (2013). *Highlights and Lowlights of Researcher-Practitioner Collaborations in the Criminal Justice System, Findings from the Researcher-Practitioner Partnerships Study (RPPS)*. National Criminal Justice Reference Service. Available at <https://www.ncjrs.gov/pdffiles1/nij/grants/243914.pdf>
- The Clinical and Translational Science Award (CTSA) Consortium's Community Engagement Key Function Committee and the CTSA Community Engagement Workshop Planning Committee (2011). *Principles of Community Engagement (2nd Ed)*. National Institutes of Health. Available at http://www.atsdr.cdc.gov/communityengagement/pdf/pce_report_508_final.pdf

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The Clinical and Translational Science Award (CTSA) Consortium's Community Engagement Key Function Committee and the CTSA Community Engagement Workshop Planning Committee (2008). *Researchers and Their Communities: The Challenge of Meaningful Community Engagement*. Available at https://www.dtmi.duke.edu/about-us/organization/duke-center-for-community-research/TheChallengeMeaningfulCommunityEngagement-monograph6_30.pdf

Appendix: Original Request

I have a request for resources on behalf of a colleague doing postdoc work with an NGO in Cape Town, South Africa.

We're looking for resources aimed at community partners/NGOs who are struggling to deal with data requests from researchers.

Something that would be helpful for them in terms of understanding a bit more about research, what they ought to expect from researchers (including what kind of ethical conduct they should be upholding), how they can best protect their clients, how to address issues of access to their data, etc.

Any specific recommendations come to mind?

I'll be compiling a summary of our findings and will report back to this listserv.

Context:

This NGO is struggling with questions of how to deal with the research requests it receives, largely, though not exclusively from overseas researchers.

Even vetting these requests take time and the director does not always feel confident in terms of how to assess the requests they receive, since they cannot take them all on due to limited capacity.

She is also struggling with how to deal with researchers asking for access to the organization's data, including 4 databases the organization keeps.

The population this NGO serves is a very vulnerable one, and in her experience researchers do not always come with the sensitivities one would require.

Within the organization, there is limited knowledge of research ethics processes and protocols.

Even terminology and concepts we researchers take for granted are not always understood at the NGO level.

The result of all this is that while this particular NGO wishes to support research and researchers, the leadership feels very vulnerable and unsure of how to do this while sufficiently protecting itself and its clients.

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