RESEARCH 101

DEVELOPING A “MANIFESTO” FOR ETHICAL COMMUNITY-BASED RESEARCH IN VANCOUVER’S DOWNTOWN EASTSIDE

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Webinar series brought to you by Community-Based Research Canada
Presenters

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WEBINAR RECORDINGS

2016: Canada and Global Community-University Partnerships Part 1

www.communityresearchcanada.ca/webinars
OUTLINE

• Territory acknowledgement
• Background on the DTES
• The pitfalls and potential of research in the DTES
• Introducing “Research 101”
• Manifesto summary
• Next steps
• Q&A
ACKNOWLEDGEMENT

We are here today on the unceded, ancestral, and occupied territories of the xʷməθkwəy̓əm (Musqueam), Skwxwú7mesh (Squamish), and Səl̓ilwətaɁ (Tsleil-Waututh) First Nations.

Context:

• Harmful research practices (from settlers) have long been a source of pain, betrayal, and disrespect in Indigenous communities (Tuhiwai-Smith, 1999)

• We situate this work in the history of Indigenous resistance to colonial research practices (Friesen et al., 2017)
WE NEED TO TELL OUR OWN STORIES.
IF WE DON’T TELL OUR STORIES, PEOPLE WITH POWER WILL TELL OUR STORIES FOR US, AND WE WON’T LIKE WHAT THEY SAY.
WHEN WE TELL OUR STORIES, WE REACH OUT TO EACH OTHER AND BUILD COMMUNITY.
WE SHARE OUR PAIN. WE SHARE OUR HOPE. WE SHARE OUR LAUGHTER, AND OUR DETERMINATION.
WHEN WE TELL OUR STORIES, WE DRAW OUR OWN MAPS, AND WE QUESTION THE MAPS OF THE POWERFUL.
EACH OF US HAS SOMETHING TO TELL, SOMETHING TO TEACH.
WE SPEAK THE LANGUAGE OF THE HEART-
HERE-IN THE DOWNTOWN EASTSIDE-
THE SOUL OF VANCOUVER.
VANCOUVER’S DOWNTOWN EASTSIDE (DTES)
VANCOUVER’S DOWNTOWN EASTSIDE (DTES)
VANCOUVER’S DOWNTOWN EASTSIDE (DTES)

- HEAVILY RESEARCHED NEIGHBORHOOD (DAMON ET AL., 2017)
- IN 2016 ALONE, 60 RESEARCH ARTICLES PUBLISHED ON DTES (67% OF THEM BEHIND PAY WALLS) (MCKAY, 2017)
REPRESENTING THE DTES
REPRESENTING THE DTES
REPRESENTING THE DTES
REPRESENTING THE DTES

These SROs are hell. Inequality is killing us!!
REPRESENTING THE DTES
REPRESENTING THE DTES
RESEARCH CAN BE HELPFUL...
RESEARCH CAN BE HELPFUL...

- CREATE (SOME) JOBS
- EDUCATE & EMPOWER
- PROVIDE EVIDENCE FOR HARM REDUCTION
BUT RESEARCH CAN ALSO HURT
BUT RESEARCH CAN ALSO HURT

EXPLOITATION

I CALL IT OPPORTUNITY, NOT EXPLOITATION!
BUT RESEARCH CAN ALSO HURT

EXPLOITATION

EXTRACTION

I CALL IT OPPORTUNITY, NOT EXPLOITATION!
BUT RESEARCH CAN ALSO HURT

EXPLOITATION

EXTRACTION

EXHAUSTION
BUT RESEARCH CAN ALSO HURT

EXPLOITATION

EXHAUSTION

EXTRACTION

FALSE HOPE

BE IRRELEVANT

DELAY ACTION

PERPETUATE STIGMA...
Research can stigmatize a neighborhood

1. Research links records

Abstract
Background: A subgroup of individuals becomes entrenched in a “revolving door” involving corrections, health, and social welfare services. Little research has investigated the numbers of people that are in frequent contact with multiple public agencies, the costs associated with these encounters, or the characteristics of the people concerned. The present study used linked administrative data to examine offenders who were also very frequent users of health and social services. We investigated the magnitude and distribution of costs attributable to different categories of service for those in the top 10% of sentences to either community or custodial settings. We hypothesized that the members of these subgroups would be significantly more likely to have substance use and other mental disorders than other members of the offender population.
RESEARCH CAN STIGMATIZE A NEIGHBORHOOD

1. Research links records

2. Media picks up the story

SFU study suggests 300 offenders on Downtown Eastside cost $26.5M in services

Researcher says more services targeting people with concurrent health issues are needed.

BC Centre on Substance Use
RESEARCH CAN STIGMATIZE A NEIGHBORHOOD

1. Research links records

High-frequency use of corrections, health, and social services, and association with mental illness and substance use

Abstract

Background: A subgroup of individuals becomes entrenched in a 'revolving door' involving corrections, health, and social welfare services. Little research has investigated the number of people who are in frequent contact with multiple public agencies, the costs associated with these encounters, or the characteristics of the people concerned. The present study used linked administrative data to examine offenders who were also very frequent users of health and social services. We investigated the magnitude and distribution of costs attributable to different categories of service for those in the top 10% of sentences to either community or custodial settings. We hypothesized that the members of these subgroups would be significantly more likely to have substance use and other mental disorders than other members of the offender population.

2. Media picks up the story

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Researcher says more services targeting people with concurrent health issues are needed

3. Columnists use research to support gentrification & displacement

Pete McMartin: The high cost of misery in Vancouver’s Downtown Eastside
“I invite you to join me in re-visioning research in our communities not only to recognize the need to document the effects of oppression on our communities but also to consider the long-term repercussions of thinking of ourselves as broken.” (p.409)

“...The time has come for our communities to refuse to be complicit in our further categorization as only damaged, as only broken” (p.422)
RESEARCH 101

DISRESPECT

un/ethical
RESEARCH 101

Goals:

• Clarify community expectations for respectful, useful and ethical research in the DTES

• Reduce harms associated with research by empowering communities to say “no” or to demand more from researchers
Partnership between SFU Vancity Office of Community Engagement (Am Johal) and Hives for Humanity (Sarah Common). Facilitation support from SFPIRG.

Developed a 6-week workshop series on “Research ethics in the DTES”
COLLABORATORS

PACE

VANDU
Vancouver Area Network of Drug Users

SWUAV
SEX WORKERS UNITED AGAINST VIOLENCE

WAHRS

BCAPOM
British Columbia Association of People on Methadone

Culture Saves Lives

HIVES for HUMANITY

VANCOUVER NATIVE HEALTH SOCIETY

PROVIDENCE CROSSTOWN CLINIC
84 W. Hastings Street
COLLABORATORS

• Engaged with wide array of DTES peer-based organizations to build support, recruit collaborators
• 6-13 weekly workshop participants
• Mostly “peers”, i.e. people with lived experience of substance use, sex work, criminalization, over-research etc.
WEEKLY WORKSHOPS

WEEK 1: INTRO TO RESEARCH IN THE DTES

WEEK 2: WHAT TO ASK RESEARCHERS

WEEK 3: REB VS COMMUNITY ETHICS

WEEK 4: POWER IN PEER RESEARCH

WEEK 5: RECIPROCITY & COMMUNITY FEEDBACK
WEEK 6: CO-AUTHORSHIP

Co-Authored by:

Louise Boilevin, Jules Chapman, Lindsay Deane, Caroline Doerksen, Greg Fresz, DJ Joe, Nicolas Leech-Crier, Samona Marsh, Jim McLeod, Scott Neufeld, Steven Pham, Laura Shaver, Patrick Smith, Martin Steward, Dean Wilson, Phoenix Winter
Research 101

A Manifesto for Ethical Research in the Downtown Eastside
bit.ly/R101Manifesto
MANIFESTO OUTLINE

Four parts of the research process:

1. Getting to Know Each Other
2. Ethical Review
3. Doing the Research
4. Bringing the Research Back
I) GETTING TO KNOW EACH OTHER

Importance of knowing more about researchers themselves

• Social position? Motivation? Experience? Time? Trauma-informed? Politics? Funding/partnerships? Plans for feedback? What you will gain from the research? What will the community gain? What actions are you prepared to take on the basis of your research?

• Researcher reference letter – A past collaborator we can hear from?
2) WHOSE ETHICS?

Limitations of University REBs (Tuck & Guishard, 2013)

- Different understandings of “risk”, “harm”, “benefit”
- No accountability mechanism
- Focused on individuals, not necessarily communities

Critical review of your university ethics application

- Research agreement, accountability mechanism

Developing a Community Research Ethics Board in the DTES

- Lots of ideas and energy for creating a “CREB” or “CREW” in the DTES
- Exploring possible funding and future partnerships...
- Let us know if you have experience or ideas on this!
3) POWER AND PEERS

“Peer” research is crucial, but comes with new challenges...

- Tokenism, given grunt work, used for ‘access’ only, patronized, elitism, not recognizing “peers” as your actual “peers” in the research (with different sets of expertise), attend to power dynamics between peers/academics

- Stop with the entitlement: “Research has been costly for our community, and very rarely has it actually benefitted us. Don’t assume your research is helpful, wanted, needed, or going to be beneficial for our community. We don’t owe you anything.”

- Pay peers fairly for their time (in cash, not gift cards!)

  - “We don’t ask what you do with your money, don’t worry what we do with ours”
4) COMMUNITY FEEDBACK AND RECIPROCITY

At a minimum, come back and tell us what you found...

• Plan to fund, organize, and make accessible whatever community presentation you’re going to do

• That work shouldn’t fall to the community!

Recognize that “knowledge translation” isn’t reciprocity...

• Do the work of prioritizing what is most useful and interesting to the community (e.g. co-write a community report, co-present at conferences)

• Write ACTUAL plain language summaries of your work, with us

• Do something ELSE for the community to show your gratitude and build reciprocity (e.g. volunteer, organize an event, provide $$$ support)
NEXT STEPS

Building support for the Manifesto

- Currently 60 Individual and 21 organizational endorsements
  - Add your name to the list here: bit.ly/R101Support
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• Education and accountability
NEXT STEPS

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  - Education and accountability

Integrating Manifesto with local REBs

Working towards developing a DTES “Community Based Ethics Board” (CREB) or “Community Research Ethics Workshop (CREW)
NEXT STEPS

Replicating the process elsewhere?

- Manuscript published this year in Harm Reduction Journal


Research 101: A process for developing local guidelines for ethical research in heavily researched communities

Scott D. Neufeld1,2*, Jule Chapman3, Nicolas Crier4,5, Samona Marsh3,5,6,7,8, Jim McLeod5,9 and Lindsay A. Deane1
RESEARCH 101...
COMING TO A HEAVILY RESEARCHED COMMUNITY NEAR YOU?

Four Steps To Replicate the Process:

1. Get Organized - Form partnerships, engage community, involve diverse voices
2. Come Together - Tell stories, share resources, dream big
3. Write It Down - Prioritize community ownership, make it representative
4. Share It Out - Websites, leaflets, banner drops, carrier pigeons, petitions, media, endorsements...
THANKS!

Read (and endorse) the manifesto online at bit.ly/R101Manifesto
ACKNOWLEDGEMENTS

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AM JOHAL
LINDSAY DEANE
MICHAEL T. SCHMITT
RYAN MCNEIL

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UBC LEARNING EXCHANGE
SUPPORTING OPEN AND TRANSPARENT RESEARCH ENGAGEMENT AND EXCHANGE (STOREE)

SIMON FRASER PUBLIC INTEREST RESEARCH GROUP (SFPIRG)
BC CENTRE ON SUBSTANCE USE (BCCSU)
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BCCSU
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BRITISH COLUMBIA CENTRE ON SUBSTANCE USE

SSHRC = CRSH
Social Sciences and Humanities Research Council of Canada
Conseil de recherches en sciences humaines du Canada

CIHR IRCSC
Discoveries for life / Découvertes pour la vie
QUESTIONS?

Read (and endorse) the manifesto online at bit.ly/R101Manifesto

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MORE WAYS TO GET INVOLVED WITH CBRC

Sign up for CBRC e-News

Fall 2019 e-News

CBRC Webinars

Share Your News and Events!

info@communityresearchcanada.ca

Bi-Annual C2UExpo

www.communityresearchcanada.ca
PLEASE SHARE YOUR FEEDBACK

Tell us what you think!

Feedback Form:
Research 101: Developing a “Manifesto” for Ethical Community-Based Research in Vancouver's Downtown Eastside

Start press ENTER
THANK YOU!

www.communityresearchcanada.ca