# CPATH Ethical Guidelines for Research Involving Transgender People & Communities

The Canadian Professional Association for Transgender Health (CPATH) is a national, multidisciplinary, professional organization working to support the health, wellbeing, and dignity of trans and gender diverse people. Among the professionals included in our membership are family physicians, endocrinologists, paediatricians, surgeons, social workers, psychologists, psychiatrists, speech therapists, educators, researchers, and lawyers, as well as organizational members who provide front line services and support to trans people across Canada.

In 2015, CPATH began to work toward generating ethical guidelines for research involving transgender people and communities. While language use can vary, in these guidelines we use the word *trans* as an umbrella term for anyone whose gender identity differs from their sex assigned at birth. This will include individuals with a wide range of identities (e.g., transgender, two-spirit, non-binary, or simply man or woman). Members of CPATH's Research Committee have taken responsibility for moving this process forward and are pleased to formally present these guidelines.

## Need for Guidelines

It is apparent to trans community members, practitioners, and researchers that interest in researching trans experiences has increased exponentially with greater public awareness of trans lives. An increase in attention to communities that experience marginalization can be positive, but also raises some serious ethical questions. While many of these questions are not unique to trans communities (e.g., how to navigate the problem of small communities becoming over-researched, histories of research exploitation), the trans-specific aspects of ethical considerations may not be immediately apparent to researchers, even those who are not new to this area or are themselves members of trans communities.

In Canada, all research involving trans people and communities should adhere to the research guidelines articulated by the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, in addition to addressing considerations specified in these CPATH guidelines.[1] The Tri-Council Policy Statement is guided by three principles: respect for persons, concern for welfare, and justice. However, research projects may obtain formal Research Ethics Board approval but still be experienced as stigmatizing, oppressive, and/or unethical by trans individuals and communities, particularly in a context of prior pathologizing research.

CPATH recognizes the need to create an ethical framework for research that addresses concerns not specifically included in the Tri-Council policy. Some additional concerns have already been articulated regarding ethical issues in community-based research with marginalized communities. Challenges may include, for example, wasting resources, advancing academic careers at the expense of communities, neglecting to share results, over-researching certain communities, failing to give back to communities, and stigmatizing communities by releasing results out of context.[2] The creation and implementation of alternative, or supplemental, ethical frameworks have been pursued by advocacy groups for other populations, including people living with HIV/AIDS,[3] children,[4]

1    TCPS2. (2014). Retrieved from: http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf
2    Flicker, S., Travers, R., Guta, A., McDonald, S., Meagher, A. (2007). Ethical dilemmas in community- based participatory research: Recommendations for Institutional Review Boards. Journal of Urban Health, 84(4), 478-493.
3    UNAIDS. (2007). The Greater Involvement of People Living with HIV (GIPA). Retrieved from: http://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_gipa.pdf
4    International Charter for Ethical Research Involving Children. Retrieved from: https://childethics.com/wp-content/uploads/2013/10/ERIC-compendium-Charter-section-only.pdf

lesbians and gay men,[5] and people who use illegal drugs.[6] The OCAP™ (Ownership, Control, Access, and Possession [7]) Principles developed by the National Aboriginal Health Organization in Ottawa in 2004 are likely the most prominent set of supplemental guidelines designed for a specific population with a documented history of having been subject to unethical research. Additional ethical challenges may be trans-specific.

In this document, we provide guidance for student, academic, community or clinical researchers who are working with, or considering working with, trans communities. These principles and guiding questions are not prescriptive. However, as the professional organization most closely invested in working with trans people in Canada, CPATH strongly recommends that researchers give these issues serious consideration before and while proceeding.

## Process for Development of Guidelines

The following overarching principles and guiding questions are based on a two-year developmental process. The initial draft was based on summary notes and flip chart records from a brainstorming workshop conducted with approximately 45 community and/or professional participants at the 2015 Canadian Professional Association for Transgender Health (CPATH) Conference in Halifax, Canada. The draft principles were further revised after a consultation session at the 2016 World Professional Association for Transgender Health (WPATH) meeting in Amsterdam, Netherlands. Discussions were then held at the Two Spirit and Queer People of Colour Call to Conversation with LGBT & Allies Conference in Winnipeg in 2017. The draft guidelines were then translated into French for online consultations and feedback within Canada. Additional commentary was sought in an online feedback form, with invitations circulated to the CPATH membership, and distributed broadly to trans community members and researchers engaged in trans research in Canada.

# Six Overarching Principles for Transgender Research

## 1

### Attentiveness to Issues of Legitimacy and Impacts on Communities

- Consult trans communities potentially impacted by the research when determining the significance of a research project, and consider the balance of benefit and impact of research projects on trans communities as well as on participants.

- Learn the history of research involving trans people, so as to understand the potential for suspicion of research, the effects of research fatigue on an over-researched minority population, and the necessity of building and maintaining trust.

- Ensure that impacts on communities are considered with regard to other communities to which trans people belong. Community impact may include positive impact (e.g., producing community-specific knowledge in conjunction with communities) as well as negative impact (e.g., presenting results in ways that uncritically reinforce stereotypes).

## 2

### Engagement with Communities

- Understand and use accessible and culturally relevant language to explain the approach to research methods and consultation processes and to define concepts such as community consultation, community engagement, community participation, community review and community control so that the relevant communities can have clear expectations with regard to the process.

- Be deliberate and transparent about which individuals and organizations are selected to represent trans communities and on what grounds. This includes attention to multiple identities such as race and class, as well as attention to gender

5    Ontario Public Health Association. (2002). Ethical Research and Evidence-based Practice for Lesbians and Gay Men. Retrieved from: https://www.opha.on.ca/OPHA/media/Resources/Position-Papers/2002-01_res.pdf?ext=.pdf
6    Canadian HIV/AIDS Legal Network. (2005). "Nothing About Us Without Us" Greater, Meaningful  Involvement of People Who Use Illegal Drugs: A Public Health, Ethical, and Human Rights Imperative. Retrieved from: http://www.aidslaw.ca/site/wp-content/uploads/2013/04/Greater+Involvement+-+Bklt+-+Drug+Policy+-+ENG.pdf
7    First Nations Information Governance Centre. (2016). The First Nations Principles of OCAP. Retrieved from: https://fnigc.ca/ocap

diversity including people who identify as on the transfeminine or transmasculine spectra, non-binary, agender or other similar identities.

- Assess the need to offer participation incentives with sensitivity to motivational socio-economic drivers to participate. Provide fair compensation for knowledge and work contributed by community members on research teams, in situations where their engagement is not part of paid employment or educational opportunities.

- Recognize that community members may have different vulnerabilities with regard to working on research teams. Develop processes that attend to privacy concerns and the potential for vicarious trauma in the process of researching difficult topics.

- Meaningfully engage trans communities at all stages of the research process, where feasible, including identification of research questions, study design, implementation, data analysis, interpretation of results, and knowledge translation.

- Recognize the expertise and contributions of community members to research through team membership, and appropriate authorship, acknowledgement and compensation.

## 3
### Consent and Confidentiality

- Ensure that informed consent (written or otherwise) has been obtained for the use of case reports, photographs, personal health information, video and audio recordings, and clinical data. Best research practices suggest that individuals included in case reports be given a reasonable opportunity to review the content before they are publicly presented or published.[8]

- Consider carefully that information that may seem anonymized to clinicians or researchers may not be anonymous when it involves trans people, particularly those in smaller cities or where ethnicity, age, multiple diagnoses, or family details are disclosed in combination. In these contexts, trans people can be particularly vulnerable to privacy breaches that can put people at risk.

- Require the ongoing assent of child participants in instances where parental or guardian consent is required. Ensure that children and youth do not feel compelled to participate by those in a position of power, including researchers, health care providers, family members or guardians.[9]

- Consider a waiver of parental or guardian consent from the Research Ethics Board to allow for the participation of youth who have not disclosed their gender identity to their parents, or who have unsupportive parents or guardians.[10]

- Build safeguards to protect data privacy in the event of court challenge, wherein confidentiality is decided on a case-by-case basis.[11]

## 4
### Consideration of Diversity, Power, Marginalization and Representation

- Respect gender-diverse Indigenous participants and Indigenous approaches to understanding gender. Indigenous ownership of research involving Indigenous people and communities must follow First Nations Principles of Ownership, Control, Access and Possession of data (OCAP[TM 12]).

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8    See BMJ Instructions for Authors (retrieved from: https://casereports.bmj.com/pages/authors/#consent ), and Journals' Best Practices for Ensuring Consent for Publishing Medical Case Reports: Guidance from COPE (retrieved from: https://publicationethics.org/files/Best_Practices_for_Ensuring_Consent_for_Publishing_Medical_Case_Reports_guidance_from_COPE.pdf )

9    See the International Charter for Ethical Research Involving Children. Retrieved from: https://childethics.com/wp-content/uploads/2013/10/ERIC-compendium-Charter-section-only.pdf

10   See Taylor, C. G. (2008). Counterproductive effects of parental consent in research involving LGBTTIQ youth: International research ethics and a study of a transgender and two-spirit community in Canada. Journal of LGBT Youth, 5(3), 34-56

11   For an example, see http://www.universityaffairs.ca/news/news-article/another-case-involving-research-data-confidentiality-hits-courts/

12   First Nations Information Governance Centre. (2016). The First Nations Principles of OCAP. Retrieved from: https://fnigc.ca/ocap

- Attend to issues of who is being included or excluded in studies, taking into account gender diversity, racialization, sex work, Indigenous identity, immigration status, age, ethnicity, ability status, geographic location, religion, poverty and other vectors of difference. Focus on reducing or removing barriers to participation, and on the relevance of research to different groups within trans communities.

- Consider, in situations involving trans researchers, whether researcher disclosure of trans identity or history may be beneficial with regard to representation and power, and reducing potential for harm.

- Design and analyze research in ways that recognize the wide range of gender identities trans people hold, including non-binary and culturally specific identities, and the heterogeneity of lived genders and gender expressions. Consider methods for outreaching to and including those who have not disclosed their gender or who are isolated and not connected with community organizations.

- Frame research design and questions in ways that take into account the diversity of trans anatomies and physiologies. In quantitative research, this may require revisions to 'validated' study measures and designing study flow (skip patterns) that do not make biological assumptions based on gender.

- Consider a life-course approach to study trans people at life points beyond a focus on social or medical transition. If focusing on transition is relevant, consider whether it may be appropriate to include the voices of those who transitioned long ago, or those who know they are trans but are living in their assigned gender.

- Conduct analysis to make intersectional heterogeneity visible, rather than just painting a picture of an 'average' trans person.

- Design research to reflect that intersecting vulnerabilities require intersecting expertise. Developing theoretical frameworks and analysis plans for research on sub-groups that are multiply marginalized, for example, may require drawing on the lived experiences of those at these intersections, particularly in areas where existing research is scarce.

## 5
### Accountability to Participants and Trans Communities

- Engage with communities about strategies for disseminating results and data sharing. Ensure that study results with potential to reinforce stereotypes or contribute to stigma are presented in context, and that it is made clear not only what results mean, but what they do not mean.

- Commit to open public dissemination of results beyond closed-access traditional academic venues. Provide results in forms that are understandable and usable by members of trans communities and other stakeholders. Establish mechanisms (e.g., a website) through which participants can access the results of research to which they have contributed. Ensure results are available for specific community sub-groups, and not just overall results.

- Promote sustainability in research by providing training opportunities and employment to members of trans communities and groups who may want to undertake research on their own behalf.

## 6
### Reflexivity on the Part of Researchers and Research Teams

- Maintain awareness that no researcher is 'unbiased' or neutral on issues of gender.

- Reflect on researchers' social location (i.e., gender, class, race, etc.) and the impact this may have on research design, research questions, analysis and conclusions.

- Include self-reflection in written reports on the research, if working in research traditions where this is appropriate.

# Seventeen Guiding Questions for Transgender Research

This section contains 17 questions, each followed by further considerations to support researchers to engage in self-reflection. In some cases, researchers will need to seek more information from trans communities to determine whether these important issues have been adequately attended to.

## 1
### Why is it important to do your research, and why at this time?

To whom is your research study useful, and in what ways? Is there a need to document community experiences where there is little or no existing research? Does your research answer important clinical questions? Does it inform policy or practice? Is your research well designed to produce the results that are intended? Has the current body of evidence been thoroughly considered? Have you considered whether a new body of evidence will make a significant contribution, or are there opportunities to synthesize existing studies through scoping or systematic reviews? Will all the data collected be used? How will the data be used? Is this work the work that is needed now? How will it impact actual trans lives? Have you engaged trans communities (see below) to help determine if your proposed research addresses an appropriate priority?

## 2
### What is the role of trans communities in your research project?

Is your research project community-informed? Community-engaged? Community-driven? Community-owned? Who represents trans communities or trans issues? Have you involved a diverse group of trans people with respect to race, class and other identities or social positions? How will community knowledge be drawn on? Has your team developed a terms of reference with regard to decision-making power over different aspects of the project? Is there trust between community members and researchers (including researchers who are part of trans communities)? Is there community engagement in all aspects of the project, including interpretation of results and knowledge translation? If secondary analyses are being conducted on already-collected data, are trans communities involved in shaping the theoretical framework, analysis, interpretation, and translation of results? Will trans community members be fairly compensated for their labour and expertise? Are there measures to ensure that trans research team members do not bear a disproportionate burden for any possible negative community reactions to aspects of the project?

## 3
### Has your team considered whether processes traditionally considered 'ethical' by research ethics boards are inappropriate in this context? Whether processes traditionally considered 'unethical' may be ethical in this context?

Might requiring parental consent for participation put trans youth at risk of harm? Might sending letters directly to potential participants' homes put trans people at risk if they have not disclosed their gender to others in their homes? Could a focus group design potentially strain relationships between community members if there are already existing tensions? Might there be situations (particularly in transphobic international contexts) wherein researcher distance from trans communities is more desirable than researcher involvement in communities?

## 4
### Have the burdens on trans communities been minimized?

Will all original data collected actually be used, particularly if questions are about sensitive experiences? Have you been transparent about how data will be used? What commitments of time, personal information, etc. are being asked of trans participants, and of trans research team members? Are research team members compensated for their time and expertise, particularly those who are not involved as part of paid employment or educational programs? Can these costs be incorporated in the budget in the planning phase? If trans staff are hired (e.g., peer research associates), has support been provided for situations of vicarious trauma? If trans or other community organizations are involved, has the research been designed in such a way that it will not detract from their primary missions? Are the burdens placed on trans communities by your research appropriately aligned with the potential benefits to trans communities?

## 5
### Does your research build capacity within trans communities?

Is your research designed in such a way as to provide opportunities for learning, experience, and employment for trans community members? Are there opportunities for trans students to do project, practicum, or thesis work on the project? Are there ways of prioritizing the

hiring of trans research staff, particularly more marginalized members of trans communities? Will trans research team members have opportunities to speak on behalf of the project, to present at conferences, or do other knowledge translation work? Does the knowledge translation phase expand community capacity?

## 6
### If original data are being collected, which trans people are included or excluded?

Beyond *a priori* inclusion/exclusion criteria, are certain groups indirectly preferentially included, or indirectly excluded? Have barriers to participation (cost, transportation, etc.) been reduced or removed where possible? Will the research address the needs of different sub-groups within trans communities, especially those who experience multiple marginalization? Will there be enough participants who are racialized, Indigenous, immigrants, living in poverty, sex workers, or other sub-groups to present results at these intersections of social position or experience? Will there be enough variation in gender identity, lived gender, or other sex/gender factors to present a realistically complex picture of trans issues and trans lives? Have you considered using sampling methods that can increase inclusion of more groups (e.g., purposive sampling in qualitative research, or oversampling of smaller groups in quantitative research)?

## 7
### Are you using an intersectional approach in your research?

Will your results reflect heterogeneity within trans communities? Is there attention to power dynamics and interacting oppressions? Are inequalities identified not only between trans and cisgender groups, but inequalities within trans communities as well? Do statistical methods allow for interactions, and is your study sufficiently powered to detect them if they exist? Are the processes through which advantages and disadvantages may interact explored? Will your research design be able to surface and account for interactions between forms of oppression (e.g., racism, misogyny, sex-work stigma, transphobia) that may drive inequities?

## 8
### Are survey or clinical measures appropriate for trans participants?

If original data are being collected, are the measures used appropriate for trans experiences, trans identities, and trans bodies? Have you included a developmental phase to the project to adapt existing measures that may not be appropriate? Have survey measures been validated in trans samples? Has community knowledge been used to ensure that survey response options are appropriately worded, and sufficiently comprehensive? Have you insured the questions are appropriately and sensitively worded? Are clinical measures (e.g., laboratory tests with sex-based reference ranges) used in ways that make sense for trans anatomies and physiologies? Have trans-specific measures been developed where needed (e.g., HIV-related risk assessments that work for trans people, measures of trans-specific stigma or transphobia)? For data that include cisgender as well as trans participants, have skip patterns been examined to ensure that participants receive appropriate questions, i.e., those not based in cisnormative assumptions regarding identity, anatomy and physiology?

## 9
### Are interview or focus group questions appropriate for trans participants?

Are questions free of cisnormative assumptions regarding concordance between anatomy/physiology and gender identity? Do questions allow for culturally specific and non-binary identities and experiences? Are open and inclusive wordings used that allow space for trans experiences to be voiced?

## 10
### Have you considered the impacts of survey or interview questions on participants?

Are participants aware in advance of the type of questions they will be asked? Given that researchers often want to know about difficult experiences, what types of messages do your questions communicate to research participants regarding what you or your research team may think of them? Does the research participation process promote stigma, engender pride? Is there a process for hearing from participants, or for finding out whether participation was emotionally difficult? What might be the unintended consequences of your research?

## 11
### How will dual roles be dealt with?

In situations where researchers are also clinicians or service providers, how will the conflicting needs of these two roles be handled? Given difficulties that trans people often have in finding knowledgeable service providers, how can your research team ensure that participants do not feel coerced or obligated to participate, and that they may fully contribute their personal research data, or decline to, without impacting their clinical care or their relationship with their providers? Have you made a clear distinction in your research materials between consent to research and consent to clinical care so as to avoid any impression that research participation is expected?

## 12
### If 'LGBTQ' research is conducted, how will data from trans participants be used?

Will the analysis allow for different effects for sexual minorities (LGBQ) and gender minorities (T), acknowledging that some participants will be both? Will separate data on trans participants be presented, so they may be used in trans advocacy, education and other work?  Is there sufficient trans participant in your research or would it be better characterised LGBQ?

## 13
### If general population or clinical research is conducted, how will data from trans participants be used?

Will there be enough trans participants to analyze? If not, on what dimension of sex or gender (e.g., lived gender, gender identity) will trans participants be grouped with cisgender participants for analysis? If data relate to clinical outcomes, have the appropriate data on anatomy and/or hormonal milieu been collected to allow for accurate interpretation of clinical care needs, disease risks, and health history? Has it been made clear to participants why this information is needed and how it will be used?

## 14
### How will difficult or potentially stigmatizing results be handled?

How will your results be presented? Can this be done in ways that may guard against misinterpretation of results? Could your research results be misused by groups with hostile objectives?  Can findings that may reinforce stereotypes or stigma (e.g., high levels of substance use) be contextualized? Does the study clearly explain what results *do not* mean?

## 15
### For student/trainee research projects, is the supervisor prepared to take accountability?

What will happen if your student or trainee does not complete a project? What provisions are put in place to ensure that intended knowledge translation work is completed? How will situations be handled where academic processes (e.g., recommendations of supervisory committee members) may run counter to community processes or needs? Have terms of reference been developed with the research team, student, and supervisors as to how these situations will be handled without jeopardizing either the student's education or community needs?

## 16
### Who owns and controls the data?

How will access to the personal data be determined? How will decisions be made regarding which analyses are conducted with qualitative or quantitative data? Who owns photos or artwork produced as part of a research project? What will happen if there is disagreement over data use? Where student projects or theses are conducted, can the supervisor or student use that data for other purposes? If the research is conducted with Indigenous communities, how will their ownership, control, access and possession of data be established? In all projects, what institution will formally own the data, and what are the implications of this? How will the confidentiality of data be protected over the data life cycle during collection, transfer, storage, use archiving and destruction?

## 17

### Is there a well-designed, but flexible plan for knowledge translation?

Have relevant groups who will use the results of this study been identified, and are they involved in planning the knowledge translation strategy? How will results be returned to participants and to trans communities in a timely fashion? Who else will use the results? (Health care providers? Policy makers? Educators?) In what form will study results be most useable to members of these groups? Can some of the findings be released quickly as accessible brief reports? Since knowledge translation plans may change based on study findings, is there flexibility in the budget and plan to adapt? Can academic publications be made available open access?

# Publication Information

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