

Guidance for research ethics considerations in patient- and community-oriented knowledge dissemination:

A tool for researchers

April 2024

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Introduction

Purposeful knowledge translation (KT) planning is a central tenet of a patient-oriented or community-based approach to research. KT – also known by other names such as knowledge-to-action, knowledge exchange, knowledge mobilization, and knowledge dissemination – is ultimately about the mechanisms used to put research evidence into practice. KT is a common term used by [Michael Smith Health Research BC](#) (Health Research BC), to refer to the activities used to close the gap between research and implementation by improving the use of research evidence in practice, policy and further research. Refer to the glossary of terminology in [Appendix IV](#) to better understand the distinct definitions of some of these concepts.

Knowledge dissemination (KD) specifically is considered multiple times in the [Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 \(2022\)](#). For the purposes of this tool, we will refer to these knowledge-to-action activities as “knowledge dissemination” to align with TCPS 2 language. Knowledge dissemination is defined as the “purposive distribution of information and intervention materials to a specific audience, with the intention to spread information about research findings” (National Institutes of Health, n.d.). Typical knowledge dissemination activities could include peer-reviewed publications, conference presentations, policy briefs or media engagement.

Granting agencies and research ethics boards are becoming increasingly more attentive to the ethical considerations that exist alongside knowledge dissemination (KD) work, which has resulted in a need for support for many researchers who might have less experience in this area. This guidance tool is designed to assist researchers and trainees in creating ethical knowledge dissemination plans to support them in sharing back research findings with knowledge users and partners.

Purpose

The purpose of this tool is to strengthen knowledge dissemination planning early, at the research planning stage, to prompt discussion about what makes an ethical knowledge dissemination plan, and to encourage researchers to think more deeply about disseminating the results of their work. For example, this tool can guide researchers in completing the knowledge dissemination sections of their research ethics applications. Additional resources are linked below for more in-depth support with knowledge translation or knowledge dissemination planning. However, this tool serves as an introductory educational resource that explores the ethical considerations that should be considered in knowledge uptake activities.

Using this guidance tool is at the discretion of the researcher. It was designed with patient-oriented and community-based projects in mind, but it could apply to many types of projects, including clinical trials. Ultimately, if a researcher feels that a project would benefit from a stronger knowledge dissemination plan, this guidance tool exists to support that team.

Contextual considerations

The level and type of knowledge dissemination applicable to your project are contextual and may require adjustment based on the type of project, timeline, resources and team’s experience. **Doing any knowledge dissemination within the confines of your resources is better than doing none, as long as it is informed and thoughtful.** Before applying this tool, it may be helpful for researchers to consider the following questions, as these considerations will dictate the feasibility of various KD strategies:

Questions	Guidance
<p>Is this a patient-oriented or community-based research project?</p> <p>As in: was it done in partnership with patients or communities?</p>	<p>Patient partners can help inform the selection of KD strategies.</p>
<p>Is this a clinical or behavioural research project?</p>	<p>Depending on the scope and type of research, certain KD strategies may be more effective.</p>
<p>Who leads this project?</p> <p>For example: student, experienced academic researcher, clinician with limited research experience?</p>	<p>Expectations for KD planning would be higher for experienced researchers.</p>
<p>Is this project funded? What level of funding is it?</p> <p>For example: no funding, student stipend, funded by non-profit, Tri-Council grant, industry-funded or other?</p>	<p>Expectations for KD planning would be higher for funded projects.</p>
<p>Has the project been peer-reviewed?</p>	<p>Peer review in this context could include grant applications, other internal research review or consultation, or review from supervisors in the student context. Projects that have been peer reviewed will have the benefit of additional perspectives in informing KD planning.</p>
<p>What is the timeline?</p>	<p>Projects with shorter timelines, like student projects, may not have the capacity for in-depth KD planning.</p>
<p>What is the size of the team?</p>	<p>Expectations for KD planning would be higher for larger teams with more resources.</p>

Equity, diversity, and inclusion considerations

The research community has an ethical imperative to embed considerations of equity, diversity and inclusion in research projects. Compared to a patient or community member, researchers often hold institutional power regarding research and knowledge generation. At a minimum, the commitment to share back findings with patients or the community can encourage the balance of power, increasing equity. These considerations apply to any priority population, particularly those communities that have been historically underserved or harmed in research. Researchers have an opportunity to use both wise and best practices in engaging with priority populations, including Indigenous communities. This allows researchers to collaborate closely with Knowledge Keepers, community partners and people with lived experience who can provide invaluable guidance and leadership in shaping these knowledge dissemination strategies. Refer to [Appendix III](#) for resources and additional information.

How to use this guidance tool

1. The primary question is the overarching, guiding question for consideration. Refer to the sub-questions under the “Sub-questions and considerations” heading as a framework to help answer the primary question.
2. Refer to the “Examples” column for suggestions and ideas to answer the questions.
3. Refer to the “Tips” column for helpful information and additional external resources that may be useful for deeper consideration of the issues raised by the questions presented in this tool.
4. Refer to the “Case studies” in [Appendix I](#) to dive into examples of innovative knowledge dissemination strategies.
5. [Appendix II](#) offers deeper, more focused questions about potential ethical issues in knowledge dissemination and mobilization planning. Use this as an optional support to prompt thought and discussion about these specific areas.
6. Refer to the “Resources” in [Appendix III](#) for additional external resources that can be used for more in-depth knowledge mobilization planning.

Acknowledgments

The team behind this tool includes Brittney Schichter, Alia Januwalla, Kristie Nicol, Nikita Aistov and Sarah Flann. We also acknowledge Samar Hejazi for her research methods expertise. Thank you to the Fraser Health Department of Evaluation and Research Services, Magdalena Newman, Kathleen Inglis, Hanna Jones-Eriksson, Jaime Flamenbaum and other REB expert reviewers for providing feedback at various stages, as well as the UBC Children’s and Women’s Research Ethics Board for sharing their proviso language.

The BC SUPPORT Unit Fraser Centre initiated this project. The BC SUPPORT Unit is part of Health Research BC and is funded by the governments of Canada and British Columbia. The work is funded under Canada’s Strategy for Patient-Oriented Research (SPOR), led by the Canadian Institutes of Health Research (CIHR).

Questions or feedback for the team?

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Guidance for research ethics considerations in patient- and community-oriented knowledge dissemination: A tool for researchers and research teams

Primary Question: Have you provided sufficient information about: a) what the dissemination plan is and; b) how your research team will execute the plan?			
Sub-questions and considerations		Examples	Tips
Sharing results with community (TCPS 2 Article 2.11 , Article 4.8 and Article 9.17)	Have you consulted with the relevant knowledge users or participants in regard to sharing results in a way that is culturally appropriate, accessible and meaningful to their community or communities?	Website with accessibility features, video explaining findings, magazine articles, presentations to community groups. See case examples 1–8 .	Engage knowledge users as early as possible. Ask knowledge users how they would like to receive results.
	How will you share results in plain language?	See case examples 2 and 5 .	Invite knowledge users to help create plain language summaries. Refer to the BC SUPPORT Unit Plain Language guide .
	How will you inform participants and knowledge users about how they can access research results?	Provide options for receiving results and updates, including by phone, letter, email, meeting or web. Include knowledge users who did not participate in your study but might be interested in the results by informing community groups and organizations via their own media outlets, such as newsletters, websites, forums or other channels. See case examples 6 and 7 .	Ask for permission to contact participants to share results and future research opportunities.

<p>Sharing results with other knowledge users, such as academics, clinicians or decision makers</p> <p>(TCPS 2 Ch.1)</p>	<p>How will you consult and collaborate with community representatives, patient partners or peer researchers to co-create or inform the development of additional dissemination materials aimed at other types of knowledge users?</p>	<p>Co-create publications and presentations, invite knowledge users to conferences, engage someone new at this time if community or patient and family partners were not already engaged.</p> <p>See case examples 2, 3, 5, 6, and 8.</p>	<p>Build dedicated funding into grant applications to pay for knowledge users to attend conferences and participate in other dissemination activities.</p>
<p>Limiting and mitigating factors</p> <p>(TCPS 2 Article 6.24 and Ch.7)</p>	<p>Are there any existing conflicts, barriers, limitations or competing priorities that could impede the timely sharing of results? Are you able to mitigate those limitations? If not, why not?</p>		<p>Multi-site trials have limitations on altering protocols, but local investigators can still communicate results back to their local participants in creative and meaningful ways.</p> <p>Refer to the Clinical Trials BC Resource Toolkit.</p>

Appendices

Appendix I: Case studies

These case studies demonstrate innovative approaches and practices of knowledge dissemination or translation that exemplify the principles of ethical patient-oriented and community-based research. They were selected to showcase a diversity of strategies, audiences and research topics in British Columbia.

Example 1	
Project name	Support, Education, Networking & Sustained Engagement (SENSE): Knowledge-to-Action with Families of the Frail Elderly Living in Residential Long-term Care
Research team	Baumbusch, Jennifer et al.
Purpose	Conduct a knowledge-to-action pilot project to foster family members' inclusion and improve their involvement in the care of long-term care residents.
KD activities	Co-developed a workshop series with families to provide education, peer support and networking opportunities for families of residents living in residential long-term care facilities. The knowledge-to-action process was embedded in the research plan, which included participant observations, surveys and focus groups to assess the effect of the SENSE workshop series on family members' inclusion and optimal involvement.
Website	https://gero.nursing.ubc.ca/research/completed-projects/sense-study/

Example 2	
Project name	New animation makes cancer genomics understandable for everyone
Research team	BC Cancer's Personalized OncoGenomics (POG) Knowledge Translation working group.
Purpose	Create a video to help patients and healthcare practitioners understand the process and benefit of using genomic data for precision cancer treatment planning and the POG program.
KD activities	Co-developed an animated video explaining cancer, genomics, precision medicine and the POG program in plain language with engaging graphics in 6 languages. Cancer researchers and cancer patient partners with no prior knowledge of the program collaborated on the project, which included several rounds of review and revisions, and took about one year.
Website	https://www.bcgsc.ca/news/new-animation-makes-cancer-genomics-understandable-everyone

Example 3	
Project name	Debunking Desire
Research team	Brotto, Lori et al.
Purpose	Share evidence-based information about low sexual desire in women to create and amplify lasting dialogues with women, their partners, their healthcare providers and the media.
KD activities	Co-designed with a person with lived experience, evidence-based resources and toolkits about sexual desire were disseminated through a social media campaign.
Website	https://www.debunkingdesire.com/resources

Example 4	
Project name	Sexual Health & HIV/AIDS: Longitudinal Women's Needs Assessment (SHAWNA) study
Research team	Deering, Kathleen et al.
Purpose	Understand the interpersonal, social and structural factors shaping women's HIV outcomes and experiences navigating healthcare through their lifetime.
KD activities	Co-created information products including infographics, animated videos, policy briefs, digital storytelling and Photovoice projects. Women with lived experience have played a key role since the project's inception as research staff, members of the Positive Women's Advisory Board or Community Advisory Board, and co-authors and collaborators on many information products. Partners and collaborators have included: Oak Tree Clinic at BC Women's Hospital, YouthCO, Afro-Canadian Positive Network of BC, Canadian Alliances and Networks, Positive Living, AIDS Vancouver, PAN, BCC3, Dr. Peter Centre, Kílala Lelum, STOP HIV/AIDS, BCCDC, Options for Sexual Health, Canadian HIV Legal Network, Positive Haven/Lookout, and McLaren House, among others.
Website	https://www.cgshe.ca/research/community-based-cohorts-social-policy-research/shawna/

Example 5	
Project name	What gynecologic cancer patients want to know about gynecologic cancer research: Disseminating timely research evidence through recorded conversations between patients and research experts
Research team	Hanley, Gillian et al.
Purpose	Co-create a series of short videos providing patients with gynecologic cancer information about research on prevention, diagnosis, treatment and living well with gynecologic cancer, and the opportunity to access the stories and experiences of other patients.
KD activities	Co-created four short videos on gynecologic cancer. These videos were conceptualized by the patient partner and were either recorded, structured conversations between a gynecologic cancer patient and a gynecologic research expert or informational videos that were centered around the patient's experience and questions.
Website	https://healthresearchbc.ca/award/what-gynecologic-cancer-patients-want-know-about-gynecologic-cancer-research-disseminating-timely/ https://gynecancerinitiative.ca/beyond-the-stories-video-series/

Example 6	
Project name	Autism Community Connects: A co-design web platform to facilitate the uptake of research evidence by families
Research team	Lewis, Suzanne et al.
Purpose	Co-design a web platform that provides best practices, new research, evidence-based treatments and support to families, so they can decide what services are most beneficial for their child and best direct their funding in a timely manner.
KD activities	Co-designed a web platform that curates credible autism spectrum disorders (ASD) research for families and disseminates it through diversified and accessible communication methods. The Health Design Lab at Emily Carr University designed and prototyped a web platform, based on input from researchers and research users that was gathered during workshops with the ASD community.

Website	https://healthresearchbc.ca/award/autism-community-connects-co-design-web-platform-facilitate-uptake-research-evidence-families/ https://aidecanada.ca/
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Example 7

Project name	Addressing sexual health-related anxiety among sexual health service users
Research team	Salway, Travis et al.
Purpose	Develop resources to assist sexual health service providers in identifying and responding to sexual health anxiety, including how and where they can refer clients for mental health support.
KD activities	Developed an infographic to support service providers in recognizing and responding to sexual health anxiety among its service users, and also developed an online database of accessible mental health services and supports to help providers connect clients with trusted, reliable and accessible mental health services. BCCDC STI Services nurses, physicians, other sexual health and mental health professionals, patient partners and peer researchers created the activities.
Website	http://smartsexresource.com/resources/supporting-and-addressing-anxiety-in-sexual-health-care-a-resource-for-providers/ https://www.mindmapbc.ca/

Example 8

Project name	Sex, pain & endometriosis: Promoting awareness of a new evidence-based patient-centred website
Research team	Yong, Paul et al.
Purpose	Co-design a website for people living with endometriosis and painful sex plain-language explanations of pain etiologies.
KD activities	Co-designed a patient-centred website for people with endometriosis experiencing pain with sex. The website has interactive images, video explanations, actionable ways to self-manage pain and descriptions of current treatment options. The Endometriosis Pelvic Pain Laboratory co-designed the website with patients, clinicians, web developers and endometriosis advocacy groups.
Website	https://endopain.endometriosis.org/

Appendix II: Supplementary considerations and guiding questions*

Activity	Guiding questions
Identify the knowledge gap, knowledge creation opportunity or research question	<ul style="list-style-type: none"> • What are the socio-political and economic contexts of the knowledge? • How did the process of agenda-setting occur? • What powers and voices are represented in defining the question? • What are the implications, consequences and potential uses of this knowledge?
Engage stakeholders and rights holders	<ul style="list-style-type: none"> • Who are the project partners? How are knowledge users (KUs) engaged? How is research evidence made accessible to KUs? • Is there evidence of authentic engagement? Are resources set aside to support this?
Review and select knowledge, assess local context and needs	<ul style="list-style-type: none"> • How is knowledge being contextualized? • How are results being interpreted? Is this representative of the knowledge that the community holds? • Is there selection bias in the way that knowledge is selected? • Whose voice is being centred? • Is local, Indigenous or traditional knowledge honoured?
Apply knowledge and develop intervention	<ul style="list-style-type: none"> • How are resources allocated and distributed? • Is knowledge being applied in an equitable manner? • Is there a responsible stewardship of funds? • What is the potential of the KT or KD activities? Is there potential for this to improve healthcare systems, practices or policies?
Monitor and evaluate knowledge use	<ul style="list-style-type: none"> • Is there an ongoing assessment of knowledge use? • Is there an ongoing reflection on the social, cultural and economic implications of this knowledge use?
Sustain knowledge use	<ul style="list-style-type: none"> • Is there capacity building in place to sustain knowledge use? • Are there other sustainability concerns?

This conceptual framework, developed by the CIHR and colleagues, presents the Knowledge-to-Action Ethics cycle. As a conceptual framework, this cycle illustrates the iterative relationship between knowledge creation and action, and some potential ethical considerations. It builds upon the Knowledge-to-Action Framework¹, developed to define the dynamic and complex processes behind generating knowledge and moving knowledge into action (Graham et. al, 2006). The framework addresses the complete life cycle of scientific knowledge relevant to researchers funded by CIHR and includes a wide variety of elements from data collection to sustaining knowledge use. [Learn more about the Knowledge-to-Action Ethics Cycle.](#)

This tool offers a pragmatic approach to ethical considerations that may be encountered at various stages of the Knowledge-to-Action Framework². We have highlighted some important guiding questions for common knowledge dissemination activities typical to patient- and community-oriented research contexts. These questions prompt reflection related to power and context and offer an approach to embedding this ethical lens in broader applications of knowledge translation beyond research ethics proposals.

^{1,2} Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: time for a map? *Journal of continuing education in the health professions*, 26(1), 13-24.

* [Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 \(2022\)](#)

Appendix III: Resources

We have provided links to additional resources and toolkits to support you in developing an ethical knowledge dissemination or translation plan. These resources will also provide you with a more comprehensive understanding of the knowledge dissemination/knowledge translation considerations you can embed in ethics applications, funding proposals and study designs.

Knowledge dissemination and translation resources

Resource	Details and links
KT Pathways: A digital assessment and learning tool	Developed through a Health Research BC initiative, with support from academic and health system partners across BC, KT Pathways is designed to help you assess your current KT strengths and areas for development and provides tailored training materials and support based on the results. Access the tool.
Consider local health authority, academic or provincial research and KD/T resources	<ul style="list-style-type: none">• Fraser Health• Island Health• Interior Health• Northern Health• Vancouver Coastal Health Research Institute• Michael Smith Health Research BC• UBC Knowledge Exchange and Innovation• SFU Knowledge Mobilization
Menu of Knowledge Dissemination Approaches	This infographic has been created to serve as a quick resource to outline some common strategies for sharing health research findings and activities with your intended audience to increase awareness and promote change. Access the infographic.
How We Work Together – The Integrated Knowledge Translation Research Network Casebook	The Integrated Knowledge Translation Research Network (IKTRN) is a CIHR-funded network that aims to build the science base and capacity of trainees, researchers, and knowledge users to study and use integrated KT (iKT) approaches. The Casebooks (6 volumes) demonstrate exemplary ways that researchers and knowledge users work together to generate impactful research. These cases document a diversity of iKT experiences across Canada, including the challenges, benefits and impacts of working collaboratively. Access the Casebooks.

Research communication and plain language resources

Resource	Details and links
Best practice recommendations for communicating results with clinical trials participants	Developed by the Clinical Trials BC Provincial Working Group, this online toolkit is available to support the awareness and implementation efforts to better communicate results with participants of clinical trials. Access the tool.

BC SUPPORT Unit Plain Language guide	This interactive practical guide to plain language walks you through the process in plain language, providing tools, resources and best practices to shape clearer, more concise and more accessible writing. Using this Plain Language Guide should prepare you with a summary ready to share with the world. Access the guide.
Plain Language Result Summary for Pediatric Clinical Trials	This resource supports researchers in sharing back pediatric clinical trial results with participating youth and their families. The team worked directly with Canadian youth and parents to adapt a Clinical Trials Plain Language Results Summary template to meet the needs of sharing pediatric research results with youth and their families. Access the tool.

Research ethics considerations for Indigenous research

Resource	Details and links
Consider the following resources for support on research ethics considerations involving Indigenous communities	<ul style="list-style-type: none"> • BC Network Environment for Indigenous Health Research • First Nations Health Authority • Indigenous Community Research Partnerships Training • TCPS 2 - Chapter 9: Research Involving the First Nations, Inuit, and Métis Peoples of Canada • UBC Behavioural Research Ethics Board Indigenous Research and Ethics Review

Appendix IV: Glossary of terminology

Terminology	Definition
Dissemination	Purposive distribution of information and intervention materials to a specific audience. The intent is to spread information. ³
Knowledge mobilization	Knowledge mobilization is an umbrella term encompassing a wide range of activities relating to the production and use of research results, including knowledge synthesis, dissemination, transfer, exchange, and co-creation or co-production by researchers and knowledge users. ⁴
Knowledge translation	A dynamic and iterative process that includes synthesis , dissemination , exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system. ⁵
Knowledge user (KU)	An individual: <ul style="list-style-type: none"> • who is likely to be able to use the knowledge generated through research in order to make informed decisions about health policies, programs and/or practices; • whose level of engagement in the research process may vary in intensity and complexity depending on the nature of the research and their information needs; • who can be, but is not limited to, a practitioner, policy maker, educator, decision maker, healthcare administrator, community leader, or an individual in a health charity, patient group, private sector organization or media outlet.
Patient-oriented research	Research that engages patients as partners, focuses on patient-identified priorities to improve patient-centred outcomes, is conducted by multidisciplinary teams in partnership with relevant stakeholders, and aims to apply knowledge generated to improve healthcare systems and practice ⁶
TCPS 2	Tri-Council Policy Statement Guiding Ethical Conduct for Research Involving Humans

³ Glasgow RE, et al. National Institutes of Health approaches to dissemination and implementation science: current and future directions. *American Journal of Public Health* 2012; 102: 1274–1281.

⁴ Government of Canada, Social Sciences and Humanities Research Council. *Social Sciences and Humanities Research Council*, 29 Nov. 2012, <https://www.sshrc-crsh.gc.ca/funding-financement/programs-programmes/definitions-eng.aspx#km-mc>

⁵ Government of Canada, Canadian Institutes of Health Research. “Glossary of Funding-Related Terms.” *CIHR*, 21 July 2023, cihr-irsc.gc.ca/e/34190.html

⁶ Government of Canada, Canadian Institutes of Health Research. “Strategy for patient-oriented research - patient engagement framework.” *CIHR*, 2019 <https://cihr-irsc.gc.ca/e/48413.html>