



Guide to Researcher and Knowledge-User Collaboration in Health Research

Developed by Participatory Research at McGill (PRAM)

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PREAMBLE

Consider the following case:

Interdisciplinary Network for Excellence in Patient Treatment (INEPT)

The INEPT team has spent the past five years developing, testing and validating a new tool for assessing the nutrition level of patients presenting to primary care clinics. INEPT researchers envision that family physicians will administer this ten-minute tool to all their patients during their annual check-up visit. Furthermore, they propose that personalized recommendations should be made to patients who are assessed as having a poor level of nutrition and referrals made to nutritionists as appropriate. The scientific properties of this tool are excellent: very good sensitivity and specificity, as well as validation in a range of clinics across the country. The INEPT team results have been published in high-impact peer-reviewed journals and presented at academic conferences, with very warm receptions from the scientific community. They predict, conservatively, that poor nutrition rates could drop by 50% if the tool was systematically used. Now, at the end of their CIHR grant, the INEPT researchers are wondering why their finding is not being widely applied. They are further frustrated at a lack of will on behalf of health planners, public policy makers, family physicians and even patients to implement this tool. Health planners say it will be too expensive and that they would rather focus their limited resources on encouraging good nutrition habits in the general populations, by public awareness campaigns. Family physicians say it is too long and they just don't have time to squeeze it into their already jam-packed appointments. Patients say that being identified as having poor nutrition would leave them not knowing what to do, unless they are willing and able to pay a nutritionist or spend hours pursuing nutrition websites.

The above is a hypothetical example of a well-conceived, rigorous study with solid outcomes whose investigators find themselves at a loss for why they cannot move its findings into practice. Is there a way that they could have approached their study from the beginning that could have anticipated some of these barriers? Is there a way that they could have identified and approached potential users of the knowledge to be gained through the study (i.e., “*knowledge users*”) before they even began? These are some of the framing questions that move knowledge translation, from its traditional place at the end of research (‘end of grant’ knowledge translation), to its *integration* throughout all stages of the research process (“integrated knowledge translation”; IKT). This learning module will lead those engaged in research – researchers *and* knowledge users alike – through many of the key issues that should be considered when taking an integrated approach to creating knowledge and translating it to action. Knowledge users, or those making use of the research results, can include other researchers, defined communities, health professionals, health organisations and institutions, policy makers, industry, the media and the general public.

This learning module has been created primarily with a researcher audience in mind, but care has been taken throughout to ensure that the language and content is meaningful and accessible to non-academics looking for guidance. The sections are written in every-day language and have been kept as jargon-free as possible, and the text has been broken up with many examples and case studies, illustrating points discussed in each section. We hope that all knowledge users who choose to partner with researchers, including communities and community members, clinicians and professional associations, government agencies and policy makers, service planners and providers, and the general public, will find the material valuable.

Also, we rely heavily on the *participatory research* literature for references, theoretical guidance, and case studies. This is both a reflection of the nascent stage of the IKT-specific literature and of the authors' expertise. The two, nevertheless, share many commonalities in process and goals (see section 1), so this approach seems appropriate.

This module material was developed by *Participatory Research at McGill (PRAM)*, a McGill University-based centre that opened in fall 2006 and is dedicated to furthering the scholarship, understanding and use of a partnered approach to health research (<http://pram.mcgill.ca>). PRAM is dedicated to the idea that, by integrating knowledge users into and throughout the research process, better health outcomes can ultimately be achieved. The tutorials were created by drawing on years of combined experience in partnered research, joined with a critical mining of the current literature to create a practical how-to guide for on-the-ground research partnerships to follow.

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Acknowledgements

All of the tutorial material underwent peer review by researchers working in all four CIHR pillars, and were reviewed by CIHR's Knowledge Synthesis and Exchange Branch.

We would like to gratefully acknowledge the following peer reviewers:

Gillian Bartlett-Esquilant (McGill)

Kaberi Dasgupta (McGill)

Larry Green (University of Colorado)

Robert Hegele (UWO)

Carol Herbert (UWO)

Jane McCusker (McGill)

Baijayanta Mukhopadhyay (McGill)

Amardeep Thind (UWO)

Cara Tannenbaum (U de Montreal)

And we thank CIHR for input and support, particularly:

Ian Graham, Vice President, Knowledge Translation Portfolio

Jacqueline Tetroe, Senior Advisor, Knowledge Translation Portfolio

Michelle Gagnon, Director, Knowledge Synthesis and Exchange Branch

And

Geneviève Dubois-Flynn, Acting Director, Ethics Office
Vardit Ravitsky, Senior Ethics Policy Advisor, Ethics Office

For detailed advice and comment on Chapter 6 (Ethics).

The following projects or researchers graciously allowed us to use their studies as case examples:

Canadian Pharmacists' Association with Pierre Pluye and Roland Grad (McGill)
Kahnawake Schools Diabetes Prevention Project (<http://www.ksdpp.org>)
Ann C. Macaulay (McGill)
Ruth Elwood Martin (UBC)
Vivian Ramsden (University of Saskatchewan)
Sandy Lake Health and Diabetes Project (<http://sandylakediabetes.com>) with
Stewart Harris, Anthony Hanley, Bernard Zinman, Robert Hegele, Roderick
Fiddler
Jack Westfall (University of Colorado)
Point St. Charles YMCA and Paula Bush (McGill)

We are grateful to Kelly Banister, Faculty of Human and Social Development, University of Victoria, for graciously allowing us to include her compilation of ethical guidelines and codes for research involving Indigenous and Aboriginal Peoples.

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WEB LINKS:

- Participatory Research at McGill (PRAM) <http://pram.mcgill.ca/>
- Lawrence Green: Guidelines and Categories for Classifying Participatory Research Projects in Health <http://lgreen.net/guidelines.html>

- Journal Progress in Community Health Partnerships : Research, Education and Action
http://muse.jhu.edu/demo/progress_in_community_health_partnerships_research_education_and_action/
- CIHR Guidelines For Health Research Involving Aboriginal People (2007)
http://www.cihr.ca/e/documents/ethics_aboriginal_guidelines_e.pdf
- Community-Campus Partnerships for Health (CCPH)
<http://depts.washington.edu/ccph/index.html>
- WHO Ethical standards and procedures for research involving human beings
<http://www.who.int/ethics/research/en/>

OTHER LINKS AND REFERENCES:

- Glass, KC and Kaufert, J. Research Ethics Review and Aboriginal Community Values: Can the Two Be Reconciled? Journal of Empirical Research on Human Research Ethics, June 2007.
- Community Health Scholars Program
<http://www.sph.umich.edu/chsp/program/index.shtml>
The goal of the Community Health Scholars program (CHSP) is to increase the number of faculty at health professional schools, with an emphasis on schools of public health, who possess the capacity to carry out community-based participatory research and teaching and who understand determinants of community health and how to build the capacity of communities, health-related agencies and academic centers to function as equal partners in community-based research, service and education
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<http://www.fmdrl.org/index.cfm?event=c.beginBrowseD&clearSelections=1&criteria=Stevenson#879>
NOTE: This bibliography is a useful tool for those wishing to get an overview of some of the key issues in CBPR. However, it is limited to items indexed in Medline and the authors limited themselves to the search term “community-based participatory research”, which therefore precludes results where this phrasing was not to be found.

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SECTION 1: INTRODUCTION

Learning objectives:

1. Understand the history of knowledge translation at CIHR
2. Understand the differences between end of grant knowledge translation (KT) and integrated knowledge translation (IKT)
3. Learn how IKT is supported by the principles of participatory research
4. Understand basic principles of participatory research
5. Know when IKT is not appropriate

a) History of Knowledge Translation at the Canadian Institutes of Health Research

The objectives of the Canadian Institutes of Health Research (CIHR) goals are to *both* develop new research knowledge *and* ensure that new knowledge is translated into practical results. CIHR was created on June 7, 2000 under Bill C 31 with the mandate, "To excel, according to internationally accepted standards of scientific excellence, in the creation of new knowledge *and its translation into improved health for Canadians, more effective health services and products and a strengthened Canadian health care system.*" At CIHR, knowledge translation (KT) is about: 1) making *knowledge users** aware of new knowledge and actively facilitating the use of knowledge to improve health, health services and health care systems through evidence-based, but also practice-based, results; 2) closing the gap between what we know and what we do (reducing the know-do gap); and 3) moving research knowledge into concrete action. (* *Knowledge users* are all those who might use, benefit from, or be impacted by the results of research, but are not necessarily involved in their production.)

CIHR defines KT as "*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*" (www.cihr-irsc.gc.ca/e/29418.html). This statement recognizes that KT is complex, requiring an interactive and dialectic process between researchers and knowledge users.

b) Different forms of knowledge translation

CIHR divides KT into two broad categories: *end of grant knowledge translation* and *integrated knowledge translation* (<http://www.cihr-irsc.gc.ca/e/29418.html>), defined below. In both cases, the goal is to ensure that new knowledge generates action to improve health or health care services, through the "Knowledge to Action Cycle" (Graham 2006 & 2007; <http://www.cihr-irsc.gc.ca/e/29418.html>) that requires: 1) identifying the problem and selecting the relevant knowledge; 2) adapting the knowledge to the local context; 3) assessing barriers to knowledge use; 4) selecting, tailoring and implementing interventions; 5) monitoring knowledge use; 6) evaluating outcomes; and 7) sustaining knowledge use, which completes and reinitiates the cycle. The CIHR Knowledge Synthesis and Exchange Branch is dedicated to supporting all forms of KT; KT strategies and activities may be multi-faceted and will vary according to the type of research to be translated and the audience of knowledge users.

End of grant KT is the classic way that researchers are accustomed to disseminating their research results by discussing results with peers, presenting at conferences, and publishing findings, generally once the bulk of the study has been completed.

In contrast to end of grant KT, *integrated knowledge translation (IKT)* involves engaging and integrating those who will need to act on the findings, the *knowledge users*, into the research process. IKT requires researchers and knowledge users to develop partnerships and engage in a collaborative process with the overarching goal being the co-production of knowledge, its exchange and its translation into action. By integrating knowledge users at every stage, KT becomes woven into the process and researchers minimise the possibilities of unanticipated barriers that may occur when attempting to act upon results with stakeholders.

IKT is most appropriate within the framework of problem-based, as opposed to curiosity-driven, research. Furthermore, the impetus for the study may often originate from a knowledge user who has identified a problem or need for action and approached academic partners for ideas as to how this can be addressed.

The minimum requirement for IKT is that researchers and knowledge users 1) make joint decisions to shape the research questions, 2) interpret the study findings, 3) craft messaging around the results and move the research results into practice. In some situations, this partnership is extended so that knowledge users also partner in deciding on the research methodology, tools development and data collection (see section 4).

The very significant advantages of IKT are that the knowledge users bring different knowledge, skills and insights to the research team, have a unique understanding of the results (which may be different than that of the researchers), and are well positioned to move these results into practice. Researchers have a refined and specific skill-set for conducting research and accessing grants and they possess their own network of contacts. Equally, knowledge users possess an expertise derived from being members of their organizations, communities or professional fields, and have much to contribute throughout the research. Knowledge user strengths include an understanding of the problem, the context and environment where the research results are to be applied, the ability to readily identify potential facilitators and barriers to the uptake of the findings, positioning to adopt new knowledge, capacity to tailor messages and interventions, and capability to evaluate the implementation process and outcomes. Knowledge users can be essential in developing and executing a dissemination plan, which may include the end-of-grant report to funding agencies, briefings to stakeholders, educational sessions with health organizations, patients, practitioners and/or policy makers, creation of tools, commercialisation efforts, use of knowledge brokers and media engagement. These are all areas where researchers are frequently lacking in time, contacts or academic reward to pursue. It is very important to recognize and respect all different forms of expertise – the strength of the overall team results from the combined voices and varied knowledge, experiences and viewpoints of everyone around the table.

c) Overlap of IKT and participatory research

IKT relies on a partnered approach to research founded on an ever-growing body of experience encapsulated within the literature of *participatory research*. Because of the nascent state of IKT literature, we have drawn on this rich participatory research knowledge base to develop these modules.

Those researchers familiar with participatory research will recognise its overlap with IKT. Participatory research has been defined by the Royal Society of Canada as “the systematic enquiry with those affected by the issue under study to effect action or social change” (Green, 1995) and is increasingly recognized as a highly effective method of enhancing relevance of and adding value to health research. The equally important goals of participatory research are to undertake quality research with a high level of scientific rigour; provide benefit to the knowledge users working in partnership with the researchers; and develop knowledge that is applicable to other settings. Scientific rigour should not be sacrificed! Indeed, the one systematic review of participatory research noted that the strongest projects were the most scientifically rigorous (Viswanathan, 2004). Participatory research is an *approach* to research – as opposed to a methodology – and, therefore, uses qualitative, quantitative or mixed methods as appropriate. In its fullest expression, participatory research involves researchers and end users as a team for decision making throughout the process from developing the research question; developing tools; collecting, analyzing and interpreting the data; developing conclusions and a dissemination strategy; and disseminating results. There is general agreement that participatory research includes a wide spectrum of partnership scenarios and knowledge users may not be involved in all stages, especially in developing tools and collecting and analyzing data. As mentioned above, CIHR recommends that, as a minimum, IKT includes developing the research question, interpreting the data, crafting the messages and disseminating results. (These would be the same minima for a participatory research project.)

What may be challenging for researchers who are typically accustomed to making all the decisions, is:

- learning how to work as a member of a team
- how to respect other viewpoints
- sharing of power and authority
- developing positive relationships
- understanding different agendas and timeframes
- developing the flexibility required to accommodate the course of events, to build trust and find the ‘win-win’ solutions.

Knowledge users may face similar challenges, in addition to the need to learn more about the timeframes of research and academic requirements of researchers.

Table 1(d): Comparing the Roles of Researchers and Knowledge-User Partners in Participatory Research and Integrated Knowledge Translation (IKT)

Participatory Research Partner Roles		Integrated Knowledge User Roles
• Setting research goals and objectives	→	• Shaping the research questions
• Deciding on methods and duration of projects	→	• Deciding on the methodology
• Setting strategy and content of evaluation; • Data collection	→	• Helping with data collection and tools development
• Interpretation of data	→	• Interpreting the study findings
• Joint dissemination of results in community language and scientific terms to communities, clinicians, administrators, scientists, and funding agencies	→	• Crafting the message and disseminating the research results • Moving the results into practice
<i>Based on: Macaulay AC, Gibson N., Freeman W, et al. Participatory Research Maximizes Community and Lay Involvement. BMJ 1999;319:774 -778</i>		<i>from http://www.cihr-irsc.gc.ca/e/33747.html; Knowledge Translation at CIHR - Dr. Ian D Graham; February 28 , 2007</i>

d) Principles of Participatory Research

The following principles are identified in the participatory research literature and have been adapted for IKT partnerships (Israel 1998; Minkler & Wallerstein 2003; Macaulay 1998 & 1999; Green & Kreuter, 2005):

- All partners play an equal role in decision-making and shared governance
- All partners are experts in their own contexts, with different experiences that are equally valuable
- Power differentials among partners are acknowledge and sensitively addressed
- All stakeholders discuss potential harm as well as potential benefits of research
- Knowledge is co-created and thus co-owned
- All partners contribute appropriately to the interpretation of results
- All partners contribute appropriately to the crafting of messages
- All partners contribute appropriately to dissemination of results

e) Should every researcher be involved in IKT and/or the application of their research findings?

For many researchers, dissemination of research results to the appropriate audience (this includes other researchers) is usually sufficient. This is especially true of CIHR pillar 1 researchers,† but even here there is opportunity to partner with knowledge users. Generally, however, more intense knowledge translation efforts should only take place when there is a strong evidence base that justifies application – i.e., in changing a clinical practice or modifying health services. Not every researcher needs to become an application or implementation expert – as there are now specialists and knowledge brokers in KT who can help with the process and

support funding opportunities (section 8). († Pillar 1 is biomedical research, Pillar 2 is clinical research, Pillar 3 is health services and policy research, and Pillar 4 is population and public health research.)

We strongly recommend that each researcher should consider the potential use of their work and how their results could have a wider range of impact if they were jointly produced, disseminated, discussed and understood by appropriate knowledge users. The fundamental question is: could IKT help to achieve those goals?

Table 1(e): Is IKT Appropriate for Me?

Here are some points to consider when deciding whether or not to undertake an IKT project. These questions are not meant to serve as a checklist, and thus an answer of ‘yes’ is not required for each of these questions. They are intended to encourage self-reflection while introducing some of the things that need to be considered when contemplating an IKT project.

Some other questions the researchers should ask themselves before engaging in an IKT process include (adapted from Alvarez 2001):

- Are your personal goals (e.g. professional, tenure), perspective and interpersonal style (e.g. team player, good listener) compatible with and IKT approach?
- Are you open to a problem-oriented approach, as opposed to purely curiosity-based research? I.e., are you most interested in affecting change with regard to a concrete, real world problem?
- Are you willing to put the effort into developing partnerships with knowledge users and sustaining an IKT process?
- Are you prepared to be flexible in your project objectives and potentially have your proposed project turned down by knowledge users?
- Are you prepared to engage in shared decision-making at all the important stages in the research process and enter into joint governance of the project?
- Are you aware that an IKT process can often be time consuming and administratively burdensome?
- Are you willing to learn from and maximize the expertise of the knowledge users, even if that expertise is non-scientific?
- Are you willing to openly acknowledge power differentials between researchers and knowledge users, especially with regards to community-based research?
- Would your institution and/or department head value and support an IKT approach?

Knowledge users considering partnering with researchers may ask themselves:

- Is the area of research important to your context and in line with the needs of the community or organization you represent?
- Are you and your organisation or community willing to accept research results that may be other than you imagined?
- Does your job description include building linkages with researchers and, if not, is there openness to expanding it as such?
- Are you aware of the realities of research, including funding timelines and limitations, the need to produce scientifically rigorous results and publish in academic journals?
- Are you willing to put the effort into developing partnerships with researchers and sustaining an IKT process?
- Are you prepared to be flexible in your project objectives and potentially have your proposed project adjusted by researchers?
- Are you prepared to engage in shared decision-making at all the important stages in the research process and enter into joint governance of the project?
- Are you aware that an IKT process can often be time consuming and administratively burdensome?

f) Introduction to module sections

The sections within these modules were developed based on the principles of participatory research and the writings of partnership research to introduce researchers and knowledge users to the strategies of developing effective IKT research partnerships.

This is IKT 101! Seasoned IKT and participatory research researchers may find relevant reminders, references and useful case studies. However, a recent needs assessment of faculty working in health indicated that, although everyone was interested in all stages of the partnership, needs vary between newer and more experienced participatory researchers (Salsberg, 2008). For example, those who self-identified as having ‘none or some participatory research experience’, were most interested in topics about *engaging partners* and *jointly formulating the research design*. While those who self-identified as having ‘significant participatory research experience’ expressed strongest interest in *how to influence policy*, *participatory research issues with IRBs*, and *grantsmanship skills specific to participatory research*.

Some points – especially sections 2 and 7, which focus on developing and maintaining researcher/knowledge user partnerships – are based on recommendations learned from experience and documented in a review of select participatory research literature. This was achieved by applying the evidence-based participatory research guidelines developed by the Royal Society of Canada (Green 1995) to articles by leading authors in this field: B Israel, M Minkler, N Wallerstein, and AC Macaulay (four current leading authors identified using [CiteSpace](#)). The modules sections include many web-based references because they are useful and allow for ease of access by partners. We also recommend that readers review very useful casebooks of examples of knowledge translation projects using both end of grant and IKT from the CIHR Knowledge

Translation Portfolio, the Institute of Population and Public Health and the Institute of Health Services and Policy Research (available at <http://www.cihr-irsc.gc.ca/e/29484.html>) and the CIHR KT Portfolio web pages at <http://www.cihr-irsc.gc.ca/e/29418.html>.

SECTION 2: IDENTIFYING AND RECRUITING RESEARCH PARTNERS

Learning objectives:

- 1) Learn the steps and skills necessary to successfully develop partnerships that are appropriate for the research project.
- 2) Learn how to achieve partner buy-in and engage in the preliminary steps towards fostering a genuine collaborative partnership.

a) Assessing the environment around you

An immediate distinction must be made between the potential knowledge users of the research results at large and the integrated knowledge users who will become partners for this specific research project. The study partnership is situated within the larger environment of knowledge users, which are all those who might use, benefit from, or be impacted by the results of the study, but are not necessarily involved in their production. Integrated knowledge users are those knowledge users who are actively involved in the knowledge production process of the given study. Note that the diagram situates the academic partners as a subset wholly within the realm of knowledge users.

Figure 2(a): The study partnership and its situation

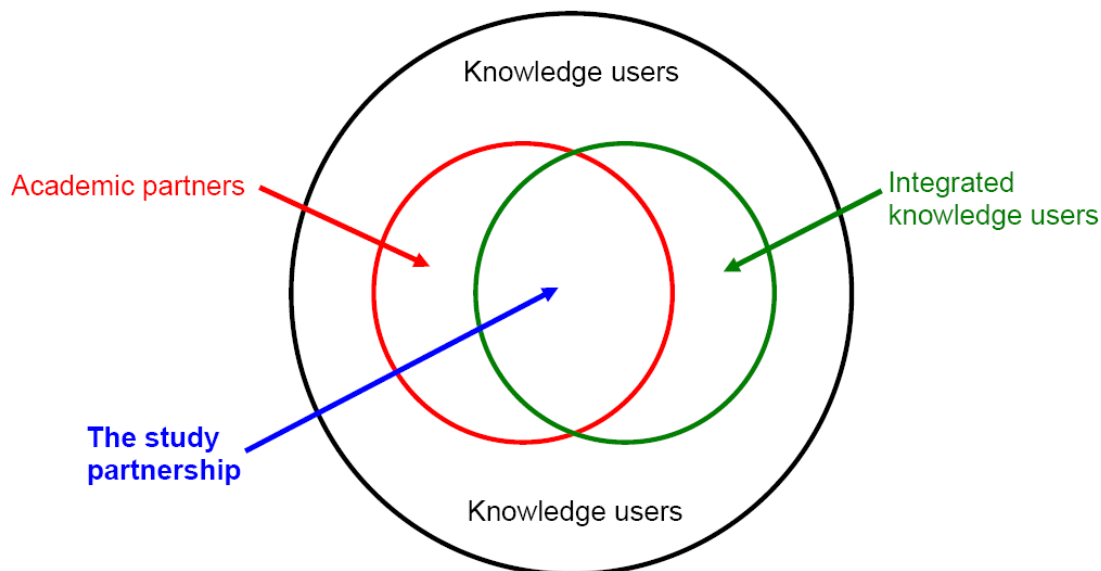


Table 2(a)i: Types of knowledge users

Potential knowledge user	Example types of projects
Practitioners (e.g. MDs, RNs, PTs, OTs, Pharmacists)	Research questions arising from researchers or health professionals, or a research project aiming to develop new treatment modalities intended to be used by them
Patients (e.g. those patients attending a health centre)	Research questions arising from researchers or patient concerns about the care they are receiving, or a research project aimed at improving patient care
Patient organizations (e.g. disease specific)	Assessing the daily problems faced by individuals with that disease
Their caregivers	Developing new treatment or adaptive strategies for community-dwelling patients with a particular disease
Whole communities	Collecting baseline data, evaluating interventions (e.g. for promoting healthy lifestyles)
Decision makers (e.g. program managers)	Evaluating how care is delivered by staff within the organization
Policy makers	Creating an intervention that necessitates changing the way the health care system is organized and/or funded
Institutions/organizations (e.g. hospitals, primary care clinics)	Starting a new outpatient health programme targeting a particular disease or problem
Professional colleges/associations	Evaluating implementation of treatment guidelines developed by members of a professional group
Research funders	Research that involves new approaches that do not fit well with existing funding models
Industry	Formally testing off-label use of an existing medication
<i>Note that a particular research project may involve one or more of these potential knowledge users, and thus overlap should be expected.</i>	

The first and perhaps most important step in any IKT project is to engage in critical examination and reflection of the context and environment in which the research could take place. Some issues to think about include:

- Do you already have working partnerships with potential knowledge users from some other aspect of your research, your university position or your life (e.g. for health professionals this could be with patients, patient advocacy groups, health organisations, administrators, etc.)?
- Learning about any pre-existing relationships that researchers at your institution may have with knowledge users.
- Assessing how/if research results are currently being utilized and implemented by the knowledge users, and how they would like to do so in the future.

- Determining how knowledge users conceptualize research and understand its purpose/ultimate ends (i.e. research will most probably be seen as a basis for action as opposed to purely inquisitive).
- The history of past knowledge user – researcher relations (this is particularly important to consider when working with past or present underserved or ill-served communities, e.g. aboriginal communities, as previous experiences may have been positive or negative).
- The level of organization of the knowledge users – i.e. whether they form a cohesive community, are represented by a professional body or lobby group, or are heterogeneous mix of individuals and/or institutions.
- Becoming aware of the existing mechanisms for knowledge creation and dissemination amongst the partners or community of interest (e.g. social knowledge).
- Who are the major players – i.e. which individuals or organizations are respected amongst the knowledge users?
- Who are the natural leaders?
- Reflection on the power structures inherently in place amongst the knowledge users or between groups thereof.

This environmental assessment can be conducted in either an informal or systematic manner. Informal methods include asking colleagues about prior working relationships with the knowledge users of interest. Other options include perusing websites of potential partner organizations, attending community events or meetings, and informal ‘off the cuff’ meetings/discussions with knowledge users.

Table 2(a)ii: Practical tips for identifying knowledge users

CIHR pillar	Strategy
I: Biomedical research	<ul style="list-style-type: none"> • Contact clinical researchers to ask if there is a need for more basic science to better inform their clinical research • Approach leaders of a ethnicity-based community with an identified pre-disposition to a particular disease
II: Clinical research	<ul style="list-style-type: none"> • Contact the regional Director of Medicine or Regional Health Authorities (e.g. CSSS in Quebec, LIHN in Ontario, RHA in British Columbia) to reach physicians’ communities of practice • Ask departments in the Faculty of Medicine at a local university to send out information about the project on their email listservs • Approach advocacy groups for the target disease of the project
III: Health services/systems research	<ul style="list-style-type: none"> • Contact lobby groups in order to learn about and be introduced to key government policy makers • Approach the Director of Professional Services of local health agencies and ask who their boss is or to whom they report
IV: Social, Cultural, Environmental and Population Health	<ul style="list-style-type: none"> • Contact local public health boards and ask for the person responsible for area of focus of the project • Ask social workers to identify community organizations who work in the project’s area of interest

Examples of systematic methods of assessment are to conduct a comprehensive ‘community analysis’ consisting of focus groups or structured individual interviews of knowledge users (Anderson 1999). Other possibilities include analysing existing data sets or undertaking chart reviews in your area of interest so that you have some baseline information when making initial contact with potential partners. One thing to keep in mind is that there may be multiple knowledge users germane to your research project, each representing completely different stakeholder groups with relatively little cross-over between them. The overarching goal of this assessment process is to get a better idea of who the potential knowledge users are and where they are coming from, as well as identify the main actors who could be solicited for participation (i.e., the integrated knowledge users).

Table A of the preamble shows the variation in characteristics of various types of communities. It can sometimes be easier to form a partnership with groups that already have common culture and traditions or shared history and experiences.

Summary points:

- Knowledge users are anybody who may benefit or be otherwise affected by the research results (including other researchers), whereas integrated knowledge users are partners in generating those results
- Find out what research is currently going on around you by talking to colleagues, community leaders and organizations, government agencies and local health boards
- Learn about the context surrounding the knowledge users, who its leaders are, how it generates and diffuses knowledge, and the history of research within it

b) Choosing partners wisely

After conducting the environmental assessment, you should have a basis for who the key knowledge users are in your research context. This does not mean, however, that all of these key people or organizations are an appropriate partner for your proposed research project. The following questions should be considered when deciding upon which knowledge users would be the best fit as a partner (Alvarez 2001):

- Is the research topic important to this knowledge user (as distinguished from whether it *should* be important) and does it reflect the reality of needs ‘on the ground’?
- Is the knowledge user knowledgeable about the research context – i.e., its culture, norms of practice, and mechanisms of knowledge creation/diffusion?
- Is the knowledge user well-respected within the research context, therefore possessing the potential to influence other knowledge users, stakeholders or decision-makers?
- Is there the possibility for congruence of plans – i.e., that the knowledge user is open to research and you are willing to be flexible and accommodate their needs?

- Is there the potential for a truly synergistic relationship to develop – i.e., that the partnership will be mutually beneficial for both parties through the sharing of resources, expertise and energy?
- Does the knowledge user have the capacity (e.g., human resources, technical skills, etc.) to engage in an effective partnership?
- Will effective communication be possible, given geography, language and cultural factors as well as availability of IT resources?
- What is the overall ‘readiness factor’?

An answer of ‘yes’ to each of these questions is not required; rather they should be weighed and balanced in accordance with the nature of your research endeavour (e.g., some projects may require more cultural competence from researchers, even if the community in question is a professional *community of practice*).

Case study 2(b): Paediatric palliative care

This research team undertook two studies that are included in one article: 1) to document implementation of a new home-based paediatric palliative care program, 2) two years later to describe the living conditions of families in the program to analyse the program’s action process and the development of the participants who had participated in the program (terminally ill children, parents, siblings and volunteers). The research team included researchers together with the palliative care team – director and coordinator of the home care program and later also the volunteer coordinator and her assistant. Parents and volunteers were interviewed to voice their concerns and to propose solutions. Due to their time pressures from caring for their terminally ill children, parents were not fully involved in all of the decision making, but one parent helped in developing the questionnaire and many parents participated in interpreting the results and making recommendations for future care. The challenges documented by the researcher- palliative care team included: establishing trust, meeting of two different cultures, application of the democratic process, time requirements, organizational constraints (personnel turnover in the palliative team), extra requests for the research team - i.e., assisting the organization with grant applications and adapting to needs of paediatric palliative care - requiring researchers to be flexible i.e., postponing interviews due to children worsening situations. The successful partnership led to a third research grant.

As with the environmental assessment, both informal and systematic methods can be utilized to identify appropriate partners. Informal methods include speaking on a casual basis with knowledge users and then ‘snowballing’ to identify more potential partners (e.g., have knowledge users nominate more partners, and so on). Informal methods work well to identify the pre-existing natural networks of knowledge users in their context.

More systematic methods can include developing specific criteria for selection of partners (e.g. main focus of activities in line with your area of interest, history of prior research

experience, etc.), circulating a standardized questionnaire based upon these criteria to potential partners in order to judge how well they meet them, and/or conducting comprehensive interviews with potential partners to judge more inter-personal factors and gauge the ‘readiness factor’ (Salsberg 2007) and openness towards research (Levy 2003, Straub 2007). These systematic methods work well for large projects that involve many different partners, but if the readiness factor is low then it is not appropriate to continue any discussions.

Summary points:

- Integrated knowledge users (i.e. partners on the project) should be selected on the basis of best fit for the project
- Informal or formal methods to partner selection can be adopted, ranging from casual discussions to circulating comprehensive questionnaires or conducting interviews with potential integrated knowledge users

c) Making first contact and achieving partner buy-in

Attaining complete partner involvement – turning knowledge users into *integrated* knowledge users – is a progressive process, and as such might not be obtained instantaneously. Rather, there are multiple steps along the way that may happen in a short period of time (for instance, with other academic researchers/institutions) or over several weeks/months (such as may be the case with many community-based partners).

Case study 2(c): It doesn’t matter who asks who to dance...

Some researchers are concerned that their project cannot be truly participatory and integrated if the question did not originate from their knowledge user partners. While it is certainly true that if the research question comes from the end user group then you can be guaranteed that they have an interest in the project and the results, this does not always have to be the case. The impetus can just as easily arise from the researcher, and will be successful as long as it resonates meaningfully with the knowledge users. Sometimes researchers, familiar with the current state of their field are better situated to identify an issue as needing investigation, and can bring this to the attention of those who may need to know.

Example 1 – Knowledge User Initiation: An Aboriginal community is concerned about high rates of type 2 diabetes.

Elders in the community asked the local physicians to “do something about it” and to focus on young children. So the physicians initially discuss this request with a small group of community leaders from health and education and, with their support, invite researchers with expertise in health promotion and evaluation to join the team. The researchers propose an evidence-based intervention and evaluation project, which is then very significantly modified by community input. As per the elders’ requests the intervention focuses on children attending elementary schools in the community, with supporting programs for parents, extended families and the entire community. The final proposal combines a high level of scientific rigour combined with community values, traditions and relevance, and becomes a sustained joint partnership project. This long-standing project is governed by a community advisory board and guided by a Code of Research Ethics jointly developed by community members and researchers. (Macaulay, 1999)

Example 2 – Researcher Initiation: A researcher wishes to conduct a systematic review of the literature on “the benefits of using participatory research.” She first assembled a team of co-investigators, including experts in all the areas needed to strengthen the review. The team then imagines the possible end users of the knowledge they hope to produce and forms a list of possible decision-maker partners who include research granting agencies, a university ethics review board, public health agencies and an organisation dedicated to promoting participatory research with both community and academic members. These are approached, and those who join partner in refining and finalising the study design for the grant application and commit themselves to partnering on the research and disseminating the results to their own and other agencies.

Example 3 – Health Professional Initiation: A nurse is very concerned that many patients, especially those from various ethnic and Aboriginal communities, are not completing their therapy for tuberculosis (TB). She tells her concern to a researcher who suggests partnering with representatives from these communities. The end result is a research team which includes research associates from seven ethnic communities and three Aboriginal communities, with goals to identify and understand socio-cultural factors, and improve practices for prevention and treatment of TB. The team developed guiding foundation principles (see module 6), and the associates helped to finalise the questions, interviewed their community members for information, helped to interpret the results and disseminated the findings back to their communities. Outcomes included six one-page information sheets in languages of participating communities, which were also printed in local newspapers and featured on a local radio call in show; an educational video; and a nurse educator to visit high risk communities with new research-based knowledge and community-specific TB prevention strategies. The trained community research associates gained new skills useful for further employment. (Gibson 2005)

Example 4 – Professional Organization Initiation: The Canadian Pharmacists Association (CPhA) publishes an online resource called e-Therapeutics® that provides treatment recommendations from an electronic textbook and other pharmaceutical databases. In December 2005, the Editor-in-Chief attended a research workshop on a new Information Assessment Method (IAM). In March 2006, CPhA bought a license of this method for collecting users’ feedback on the resource; and in June 2006, researchers visited CPhA to enable the IAM implementation, and the idea of a collaborative analysis of data collected by the organization emerged. Then researchers contacted CPhA in November 2006 to plan a joint grant application.. Researchers proposed an outline, which was improved by CPhA key members including the Editor-in-Chief, a representative of Editors, the Director of Application Development & Support, and the Director of Product Management. In 2007, a full proposal was jointly submitted by researchers and these organizational members, and funded by federal and provincial agencies: Assessing and Improving Electronic Knowledge Resources in Partnership with Information Providers. (Pluye, in press)

An invitation to participate should be extended in a culturally appropriate manner. For example, an email may suffice for clinicians or health administrators, but a face-to-face meeting with community-based partners may be required.

Table 2(c): Practical tips for making first contact

-
- Attend knowledge user events (e.g. department seminars/grand rounds for communities of practice) in order to get to know faces and start talking to people
 - Get involved in knowledge user causes and issues (e.g. help them with another research project, making linkages to other people in your network, assisting with literature reviews) as a way to get to know people and show a willingness to do something for them (v. them always doing something for you)
 - When contacting busy policy makers, adjust to their schedule and location (even if this means travelling) for meetings and propose ways in which you can support their policy initiatives (e.g. making a link with a key person at your institution)
 - Have a nicely-formatted document in hand whenever meeting potential knowledge users, as people tend to notice these things
-

Even though one of the fundamental tenets of IKT is to jointly shape research questions, it is often helpful – for the sake of clarity – to circulate a draft of your proposed research idea and plan in writing in order for the knowledge users to become acquainted and assess whether or not they wish to participate. It is important to emphasise that this is only a draft plan that is presented for discussion and input from knowledge users. Another option, where geographically possible, and that may also be more suitable for knowledge users without an academic background, is to organize one or more information sessions that potential partners can attend where, for example, a presentation is given outlining the proposed research plan and there is significant time for

questions and discussion. To increase attendance, it is often helpful to organize such sessions to suit the knowledge users, i.e., outside of office hours, including a light meal and, if appropriate, also offering to compensate for expenses.

Follow-up communication should then be conducted to:

1. Acknowledge that everyone at the table will bring different knowledge and skills (researchers are not the overarching experts – rather what they bring is the technical skill to undertake scientific enquiry)
2. Answer any questions about the proposed research plan;
3. Explain IKT principles and why their participation in the research process is crucial to its success; and
4. Start a two-way dialogue by taking a genuine interest in partner activities, initiatives or ongoing research. Questions that may be useful to ask potential partners during this follow-up communication include:
 - What are some of the needs you encounter on a day-to-day basis?
 - Have you ever thought about getting involved with research or starting your own research project?
 - What are some of your or your institution's priorities for the next few years?
 - How large is your institution? How many staff members work there? What is its target population?

It is important to not misinterpret any sign of support from the knowledge users at this stage as a blanket endorsement of your research plan, i.e. to distinguish between support for the IKT process you are proposing from support for the project you have in mind. It is the former (i.e., support for the process) that you should be seeking at this point. Such support is considered partner buy-in with respect to IKT projects, even though the specific research questions and methods may not yet be finalized. It should not be assumed, however, that researchers have the support of the knowledge users, and vice versa, merely after the preliminary meeting (although in some cases this may be correct). Indeed, either party should be prepared to receive and accept 'no' for an answer, and realize that this is an acceptable answer that needs to be respected. Clarification is thus essential.

This buy-in into the process can either be an informal oral understanding between you and the knowledge users or formalized into a letter of intent to partner signed by all parties. An informal understanding is likely sufficient for smaller projects and need not duplicate the declaration of partner roles which will be set out in the eventual grant application or research protocol. Large projects, such as those comprised of national networks of researchers and knowledge users, might benefit from a formalised letter of intent even before the grant application process is initiated.

Summary points:

- Having knowledge users become *integrated* knowledge users is a progression and may sometimes take significant time
- Invitations to participate should be extended in a manner that is appropriate to the context of the integrated knowledge users, ranging from email to information seminars to face-to-face meetings
- Follow-up communication is essential after first contact has been made, which should consist of a two-way dialogue between researchers and integrated knowledge users
- Both researchers and integrated knowledge users alike should understand that it is acceptable for either to say ‘no’ if they do not like the direction

d) Getting to know one another

A critical part of any IKT process is getting to know one another. This means to get to know the backgrounds, ‘stories’, institutions, etc. of these specific integrated knowledge users with whom you are partnering. The overall goal of this process is to begin establishing trust, building commitment and to see how the context of each knowledge user can uniquely influence the entire research project (which includes jointly finalizing the research questions, methodology, interpretation and dissemination). How this is accomplished will depend on the type of integrated knowledge user. For more academically-inclined integrated knowledge users, it may consist of an exchange of CVs and circulation of a draft study protocol with the partner providing his/her feedback and ideas in writing. For decision-makers or professional bodies, this process may consist of a series of face-to-face meetings or teleconferences to discuss the ‘next steps’ of the collaboration to a high level of detail. In both of these cases, this process may be quite brief, as the relationship may be seen in strictly ‘business’ terms of collegiality. Care must be taken, however, with more community-based integrated knowledge users, who may not have an academic background or any experience working with academics. In this case, the ‘getting to know one another’ phase may be lengthier and consist of activities such as ‘meet and greet’ functions, attendance at important community events, collective meals together, etc.

The key here, in any respect, is for researchers to reach out to the integrated knowledge users in their own environments, rather than always expecting the partners to meet them on their ‘turf’.

Table 2(d): Practical tips for getting to know one another

- Jointly organize a health fair on an issue that is of concern to the community of interest, providing, for example, information, screening and referrals
- Invite integrated knowledge users to give a presentation (e.g. at departmental seminars) on their organizations and any research or other key activities that they may be undertaking
- Schedule a dinner or potluck between researchers and integrated knowledge users, where just business may not be strictly discussed

Summary points:

- Time must be dedicated in which researchers and integrated knowledge users can get to know one another in order to establish trust
- This process should be mediated and modified by the type of integrated knowledge user partnered with

Suggested reading for section 2:

- Anderson, 1999
- Kramer, 2005
- Levy, 2003
- Straub, 2007
- Thompson 2001

SECTION 3: TAKING STOCK OF BARRIERS AND FACILITATORS

Learning objectives:

1. Learn the importance of assessing barriers to integrated knowledge user participation.
2. Learn how to identify such barriers, some of the most common barriers with examples of strategies for overcoming them.
3. Learn the importance of building upon the facilitators of the partnership and how to expand upon them.
4. Learn about possibilities in mobilizing the resources of integrated knowledge users (e.g. social capital).

a) Working together to overcome barriers to integrated knowledge user participation

Many barriers – both foreseen and unforeseen – to integrated knowledge user participation must be expected, especially given the inherently social and collaborative nature of IKT projects. It is absolutely essential that these barriers are: 1) identified and openly acknowledged, 2) given due consideration, and 3) jointly addressed through a problem-based approach. In order to do so, all participants should be prepared to engage in critical reflection on the project, including the status of researchers and the status of the integrated knowledge users (see also section 2). Identification of barriers can be carried out in formal or more informal manners. Examples of the former could include administering anonymous questionnaires to partners (e.g., after meetings) or asking partners to write down what is working well and what is not. Alternatively, or in conjunction, informal discussions could be held with partners to gauge the different aspects of the relationship.

An ideal solution may not be possible for all barriers encountered for every type of project, but the key is for partners to discuss them and work together to overcome them as best as possible. Again, barriers may vary according to the type of integrated knowledge users involved with the project. Some barriers that might arise and possible ways to mitigate them are summarized in the table below:

Table 3(a): Potential barriers for partnerships and practical tips for solutions

Barrier	Possible Solution
<i>Job mandates of knowledge users</i>	
<p>The mandates of both partner individuals and organizations may not include research. This may be particularly frustrating when an individual is keen to partner, but there are organizational hurdles to his/her involvement.</p>	<p>Dialogue with integrated knowledge users and their institutions is perhaps the most effective means to overcome this barrier, in order to possibly bring about small changes in job mandates. Offers to work with partners to overcome their organizational hurdles to participation should be made, rather than expecting them to sort it out themselves. Such offers may include contacting senior management to advocate their case (only with consent of the partner). For example, agreements on 'flex-time' could be negotiated whereby partners could make-up hours missed during the day resulting from their attendance at research activities.</p>
<i>Scheduling</i>	
<p>It is important to accommodate, as much as possible, the schedules of integrated knowledge users when arranging meetings. This is particularly important for more community-based partners, who may only have time to dedicate to your project outside of office hours, especially when research is not part of their job or organizational mandates. This is also important for professional partners with demanding practices.</p>	<p>Scheduling meetings and other project-related events during the evenings or weekends, or having lunch meetings, can help integrated knowledge users to have the adequate time to become actively engaged in your project. Catering these meetings can win much favour and increase attendance. For professionals, it is important to work around their practice schedules. Some grants provide for professional release time and this should be budgeted at the time of application.</p>
<i>Compensation</i>	
<p>Many integrated knowledge users may have to work above and beyond their normal job requirements both intellectually and physically (e.g., if meetings are held during evenings or on weekends). Researchers should not expect partners to volunteer their time without paid compensation or expenses.</p>	<p>Many grants may permit budgeting for 'salary release time' for partners. This money is paid to partner institutions in order to free up paid time of employees to participate in research projects to compensate for loss of productivity or work time or to hire replacement staff. If salary compensation is not possible, then out-of-pocket expenses (e.g., parking, gas stipends, babysitters, etc.) should be provided.</p>

<i>Language/culture</i>	
<p>Especially when working on multicultural or pan-Canadian (with francophone/anglophone partners) research projects, issues of language and culture may arise that can negatively impact upon a knowledge user's ability to effectively participate in the IKT process. For example, some partners may have difficulty reading or speaking in their second language and, thus, may not be able to express themselves fully at meetings, leading to frustration.</p>	<p>If your project involves partners from more than one linguistic group, then effort should be made to provide translations of key documents. Such translations can be built into budgets. During meetings, effort should be made to give ample time for members speaking in their second language to speak and complete their thought before interjecting. Regarding culture, it can be useful to be aware of one's own academic culture and modify it when necessary. For example, non-academic partners may not be used to long research meetings with a packed agenda and many discussion points.</p>
<i>Power differentials</i>	
<p>Power differentials – including gender/race/age/education – may deter knowledge users from being able to fully speak their mind. This may be particularly acute for community-based partners (especially those from minority and/or marginalized communities) who may be intimidated at the prospect of working with academics from a university setting. But power differentials may also be present within the health field and an imagined hierarchy between disciplines can lead to feelings of unease among partners.</p>	<p>While it is not possible to make long-entrenched power differentials disappear overnight, it is important to be aware of them and takes steps to minimize their impact upon knowledge user participation. This can be accomplished by ensuring that everyone is respectful at all times and that partners are provided with equal opportunity to participate without being interrupted by those in position of higher power. For example, meetings can be structured so that each partner has a set amount of time in which to speak during which other members are not allowed to talk. Additionally, input can be sought in writing before meetings and these comments circulated to other members and then discussed sequentially at the meeting.</p>
<i>Knowledge</i>	
<p>Non-academic integrated knowledge users may often lack the scientific training and methodological training to fully understand the 'lingo' of the researchers.</p>	<p>It may not always be appropriate to involve all integrated knowledge users in the nitty-gritty technical design of a research project, but this must be discussed openly and agreed upon. Researchers, nevertheless, must take care to explain concepts in a non-technical lay language to partners lacking an academic background and be ready to answer questions that may be posed. Additionally, researchers should remember that, while they may have the technical knowledge, all partners are equal by definition, and everyone brings their own valid and valuable expertise to the process.</p>

Geography	
<p>Particularly given the geographic scope of Canada and national scale of modern research, it may be difficult for researchers and integrated knowledge users to meet face-to-face or travel times may be quite long. The literature, nevertheless, stresses the importance of face-to-face contact in developing collaborative relationships. This may be particularly important for non-academic or non-institutional integrated knowledge users.</p>	<p>If possible, travel costs (e.g., airfare) can be built into grant submissions for face-to-face meetings at project outset and wrap-up. Information technology resources should also be exploited, including video- and teleconferencing technologies, as well as online meeting services where presentations and text documents can be jointly viewed and edited (e.g., www.webex.com). Care should be taken, however, when using these to ensure that people 'on the other end of the line' are included in meetings and given ample opportunity to interject with their comments. In cases of long travel time (e.g., with rural communities), it is important for researchers to not always expect partners to come to their university, but make the effort to hold meetings with the partners in their own community. Use can also be made of common national conferences where many or all partners attend.</p>

Critical to overcoming these and other barriers, is for researchers to develop skills other than strictly methodological ones (Israel, 1998). These may include: active listening skills, lay communication skills, nominal group processes, negotiation and conflict resolution skills, ability to work in multicultural environments (including multidisciplinary cultures), self-reflection skills, able to admit one's errors, and, most importantly, humility.

<i>Summary points</i>
<ul style="list-style-type: none"> • Barriers should be expected and acknowledged, discussed and given due consideration, and then mutually tackled in order to overcome • Identification of barriers can be accomplished through formal means, such as anonymous questionnaires, or informal means, through frank discussion • Researchers must learn others skills to augment their methodological and scientific ones

b) Jointly building on the facilitators of knowledge user involvement

While there may be many barriers when engaging in an IKT process, there are also many facilitators to integrated knowledge user participation. It is very important to: 1) explicitly identify and assess these facilitators and 2) constantly build and expand upon them. Identification of facilitators can be accomplished through either the formal or informal means mentioned above. Once facilitators have been identified, a concerted effort should be made by everyone to build upon them. For example, if questionnaires indicate that partners found a particular way of running meetings to be useful (e.g., having a designated chair, consensus rather than majority decision making), then that method should be utilized in future meetings. These facilitators can be incorporated into any research agreement between the researchers and knowledge users (see section 6).

Table 3(b): Practical tips for facilitating effective IKT process

- Hire members of the integrated knowledge users' community (even professional community of practice) to work as coordinators of the project or research assistants in data collection and analysis
- Make use of e-mail to circulate, on a regular basis, news about the project and solicit integrated knowledge user participation on any special issues that may arise (e.g., low recruitment rates)
- Encourage face-to-face contact by 'piggy-backing' on other events that may bring partners together (e.g., conferences, clinical team meetings)
- Cycle the location of meetings between research settings (e.g., university, hospital) and integrated knowledge user settings (e.g., community centres, group practices, local health agencies)
- Rotate meeting chairs on a regular basis, so that everyone feels included in the running of the project

It is also important to explore other facilitators that might be underutilized. This especially pertains to the resources the partners could bring from their own organizations. In particular, making the most of partner social capital, such as existing human resources, not just in terms of intellectual input into the project, but in helping with some of the 'leg work' activities such as organizing meetings, preparing agenda/minutes, contacting fellow partners about follow-up issues, etc. This both aids to alleviate some of the administrative workload of the researcher, which can be higher for IKT projects, fosters co-ownership of the project, and also promotes empowerment and capacity building of individual knowledge users.

Case study 3(b): Dividing up the work

While all partners should have equal say in the governance of the study, not all partners will make the same contributions. While researchers will contribute the bulk of the scientific know-how, knowledge users will contribute important knowledge and contacts from the contexts in which the results will be used. This will help assure that the question is formulated and the research is structured in a way such that it increases its relevance to end users and that results will need less “translating” after the fact in order to put them to action.

But what else can the integrated knowledge users contribute? Industrial or commercial partners probably have well-developed, organisational infrastructures in place and can make in-kind contributions to project administration, from clerical support through tool development.

Example 1 – Administrative Support: An IKT project partnering researchers with a pharmaceutical company can avail itself of the latter’s administrative support for such items as advertising for participants and the taking and transcribing of research team minutes. The partner can also provide office space outside the university to facilitate meetings within the organisation or community where the research is being undertaken

Example 2 – Technical Support: An IKT project partnering researchers with a health professional association to investigate professional use of digital decision-making devices, can use the latter’s information technology department to create the data tools needed to poll its members and track usage across practice networks.

Example 3 – Intervention Funding: In an IKT project with intervention and evaluation components, funding intervention can be a challenge as most funding mechanisms only allow for research salaries (assistants, collaborators, etc.) . Integrated knowledge-user partners can provide salary support or in-kind human resources to fund the intervention team.

One final comment should be made to stress the importance of initial face-to-face time, where feasible, as perhaps the most important facilitator of IKT projects. Rather than being a disembodied voice on the phone, face-to-face meetings go a long way to establishing trust and a positive working relationship with new knowledge users who you may not know (especially for community-based partners).

Summary points:

- Facilitators to an effective IKT project should also be expected, and accordingly identified and built upon to make the process even better
- The resources of the integrated knowledge users (e.g. human resources) should be examined and utilized as appropriate
- Face-to-face contact is key

Suggested reading for this section:

- Israel, 1998
- Jones, 2007
- Minkler, 2005

SECTION 4: ENGAGING IN COLLABORATIVE RESEARCH DESIGN

Learning objectives:

1. Learn how to identify issues that are important to the researchers and integrated knowledge users alike and mesh them together.
2. Learn how to operationalize these issues into viable research questions.
3. Learn how to choose appropriate, clear and feasible priorities for each research project based upon these questions.

a) Identify the issues that need to be addressed and jointly develop research questions

Now that all researchers and integrated knowledge users relevant to the research project are around the table, a genuine process of collaboration must be embarked upon in order to both: 1) identify specific issues that are important to the integrated knowledge users and 2) develop research questions based upon this input and the researchers' scientific expertise. It is important during this stage to not force the research plan of the researchers upon the knowledge users. It should also be stressed at this point that IKT does not by any means entail that the researchers' research plan should be flatly rejected in deference to that of the integrated knowledge users. Rather, the idea is to turn this plan into a *collaborative* one that both incorporates the researchers' own interests and proposals as well as the needs identified by the integrated knowledge users who will actually use the results of the research in practice. That is, to reflect upon the needs of the integrated knowledge users and to see how these needs can be successfully merged with those of the researchers to come up with research questions important to all. Essential skills in this process include:

- Becoming an active listener of the points raised by researchers and integrated knowledge users, which means to take a genuine interest and ask follow-up questions to explore the issue even further.
- Becoming open to alternative ways of knowing or framing issues in non-medical or scientific terms that may better capture the 'lived experience' of the knowledge users.
- Recognizing that each member brings his or her own expertise to the table, and that no one person's input should be valued over another's.
- Being flexible in one's goals and showing willingness to compromise and move beyond one's initial ideas.
- An ability to provide everyone with equal opportunity by, for example, not relegating a partner to the sidelines due to non-proficiency in language.

Once again, there are systematic methods and more informal ways of learning about integrated knowledge user issues. The use of either will depend on the type of integrated knowledge users involved. Systematic, formal methods may consist of structured qualitative interviews or focus groups with integrated knowledge users, followed by joint interpretation of the data to abstract and discuss the main themes identified. Informal methods may include group discussion(s) or having integrated knowledge users write out their own ideas of what issues need to be addressed in their own context. More creative methods are particularly useful when partnering with individuals or organizations from different cultural groups. These may include,

for example, using the ‘photovoice’ technique where participants take pictures that they feel reflect the realities of their communities or organizing walking tours when researchers have the opportunity to walk through their community of interest and meet people relevant to the project (Wang 1997, 2004).

Table 4(a): Practical tips for jointly identifying issues

- The Nominal Group Technique (Moore, 1994) can be employed with a big group of people, which first involves the use of small groups to brainstorm their ideas and, second, the bringing of all the small groups together to see overlap and generate a final list.
- A professional group facilitator can be employed in the early stages to bring the group together and catalyze the identification of research issues in an equitable and systematic manner
- Organizing a day-long workshop that brings together researchers and knowledge users to brainstorm in a neutral location, with meals in order for everyone to get to know each other
- If not all partners can be brought together, use an online meeting system (e.g., www.webex.com), which allows everyone at remote locations to view PowerPoint slides and jointly edit Word documents

Now that issues have been identified, the task now is to collaboratively turn these issues into a realistic research project. The challenge, accordingly, is to turn the many issues identified by the researchers and the integrated knowledge users into questions that can be addressed by a research project. This is where the researchers’ scientific skills can be particularly valuable and may be a good opportunity to introduce partners without an academic background to the scientific method. The idea is that there is an exchange of expertise here between researchers and integrated knowledge users, so that the questions that develop reflect the needs of the partners with the scientific rigour required for academic research and for success in funding. That is to say, develop questions that do not just fill a gap in the literature, but also a gap ‘on the ground’.

Case Study 4(a): A partnership with policy makers for women's health

The Women's Health Surveillance Report (WHSR) was a multi-sectoral initiative aimed at making a significant contribution to the understanding of gender-related health disparities in important areas of women's health. The project was a collaborative effort between the Canadian Population Health Initiative (CPHI), Health Canada, CIHR, Statistics Canada, Status of Women Canada, the Centres of Excellence for Women's Health, university departments and experts and practitioners in women's health across Canada. International collaborators were also involved in the development and review of the report. Funding was provided by CPHI and Health Canada. The WHSR represented a significant knowledge translation effort, involving an interdisciplinary systematic review of existing research, the development of recommendations for improving health surveillance activities, setting policy for women's health priorities and the use of a variety of dissemination strategies to reach diverse audiences. Significant uptake of the report's findings and recommendations, by practitioners, policy makers, researchers and the general public, was achieved.

The interdisciplinary input used to develop the WHSR was essential to the policy development cycle of a sustainable women's health surveillance system. The external consultation provided many good ideas on the content, dissemination and use of the report: some of these were used and others noted for future reports. For instance, there were suggestions for research on different women's health issues, but reliable data on those topics were not always available. It was also suggested that more consensus around a conceptual framework should have been obtained at the beginning of the research to guide the choice of topics for the report.

While the collaborative and consultative processes employed in the preparation of the WHSR were invaluable, it was occasionally challenging to reconcile the intended quantitative/statistical approach to the WHSR – i.e., analyzing the available data and attempting to make recommendations on the basis of evidence of effectiveness – with the disciplines and expertise more often found in gender and health research, such as social sciences. In retrospect, further steps could have been taken to better prepare the authors, such as short training sessions in the appropriate methods and distribution of a “model chapter” for guidance.

(DesMules, 2004)

The questions that you develop should have broad support from all researchers and integrated knowledge users alike. If all parties to the project cannot come to an agreement or feel as the project has strayed for the worse from the original interests of any of the parties, then consider whether you have chosen the wrong partners for the project (i.e., perhaps they are not the appropriate integrated knowledge users for the research question) or whether the IKT approach is a good fit for the research team (see section 1). This issue can be turned on its head in the case of integrated knowledge user questions: disagreement might indicate that they have approached the wrong academic disciplines or the wrong individual researcher(s). Other interpretations include the fact that the researchers and integrated knowledge users are – for

whatever reasons – not ready for this IKT project at this point in time. In such cases, the project should not be started as commitment is an absolute requirement from all of the partners.

Summary points:

- Research needs must be jointly identified by integrated knowledge users and researchers alike
- All partners must be good listeners, flexible in goals, open to alternative ways of knowing and doing things, and recognize/respect each other's expertise
- These needs must be turned into researchable questions, especially with the scientific expertise of the researchers

b) Selecting priorities that are realistic, feasible and important to all parties

The above process may leave one with an unmanageable plethora of issues, each important in their own right, and research questions, each worthy of a grant in themselves. Therefore, of all the points raised, it is advisable to focus on one main topic, especially for those starting out with IKT projects. Again, it is important to stress that this should not just be the researchers' priorities, but the priorities of the integrated knowledge users as well. This narrowing-down can be a complicated process, fraught with the potential for conflict given the competing demands placed upon integrated knowledge users (e.g., for practical results that they can apply in their context, in line with government policy) and researchers (e.g., for time commitment, to submit grants and publish papers). Some issues to consider when selecting priorities include (CCPH 2006, DUITT 2005):

- Is the priority unifying or divisive?
- Will it have real benefits for the knowledge users?
- Does it have the support of all knowledge users and researchers involved?
- Could it constitute a cohesive, do-able research project?
- What barriers might such a priority run into and could they be sufficiently overcome to ensure the success of the project?
- Would it enable the knowledge users to utilize their own resources for the project?
- Does the project offer opportunities for capacity building?
- Are there funding opportunities?

No quick consensus or vote should be made when selecting priorities; extensive discussions are required in order to ensure that no one partner feels as though their own priorities are being marginalized. With large numbers of integrated knowledge users where extensive meeting time is prohibitive, as in the case of national research networks, the [DELPHI](#) technique is often used to select priorities through written text and email. In any case, this collaborative process might necessitate adding some short-term deliverables for the integrated knowledge users who will not be used to the long time frames of many research grants. This helps to both maintain

their interest, justify their participation in the research process (especially to their respective organizations), support co-learning, facilitates capacity building and aids in the iterative process inherent to most partnership projects.

Case Study 4(b): Engaging in collaborative research design

i) Aligning projects with realities of funding

There is a research funding opportunity in colon cancer requiring that the researchers partner with patients or communities. A family medicine research group has a high level of the necessary expertise, but the Community Advisory Committee (CAC) from a practice-based research network has identified their priority to be research into illicit drug use. One researcher drives in trepidation out to the CAC meeting and informs the group of the funds and available expertise, whilst acknowledging that he knows that this subject is not one of their interests. However, during the CAC meeting, one member needs to leave to visit her father terminally ill with colon cancer, and another expresses great frustration that her husband will not go for colonoscopy after his father had been diagnosed with the illness. What was the end decision? The CAC voted to partner with the researchers and apply for funding (it was successful), and the researchers promised to try to find expertise and funding for a future project in illicit drug use.

(Westfall, 2004)

ii) Developing a research project with women prisoners

A family physician has cared part-time for women prisoners in a minimum/medium security prison for ten years. Her research questions were to: 1) determine whether it was feasible to engage women inside prison utilizing participatory research, and 2) identify the health concerns that participatory health research could address inside a women's prison. In the summer of 2005, women in prison and prison staff (correctional officers, contracted health and inter-professional staff) were interviewed. The questions included: "Tell us what you think are the major health concerns for women in prison that the prison participatory health research project should address?" Data analysis showed five major categories from both prisoners and prison staff: addictions and mental health; HIV, hepatitis and infections; health care in prison; life skills and re-entry into society (including homelessness and housing); and children, family and relationships. In the fall of 2005, all women prisoners, prison staff, management, and researchers participated in a one day meeting in the prison gym to discuss the interview findings, brain storm ideas for potential health research interventions, and invite women and staff to assist in writing a research grant. The ecological health concerns of life-skills, re-entry and family became the priorities of the ensuing funded prison participatory health research project.

(Martin, under review)

iii) Realities of the partnership

A researcher knows of a situation where students are travelling from great distances to attend junior college, and where the drop out rate each year is high, but many students eventually return and finish their courses, sometimes years later. He has significant discussions with the director of the college and some students resulting in strong interest to form a partnership of students, college staff and researchers to better document the actual numbers eventually completing college, and to interview students to understand their challenges. The end goal is to use results to develop programs to support students complete their training. However, there is a change in leadership at the college and the new director does not see this proposed research as a high priority. The proposed research agenda fails to materialize.

iv) Coming to a common understanding

Researchers were interested in evaluating ‘adverse events’ that had occurred to patients and proposed this idea to clinicians in a practice-based research network and its Community Advisory Council (CAC). The CAC proposed that a patient survey, parallel to the survey of network providers, to identify community perceptions of adverse events, would provide a more complete picture of this issue. The CAC members felt very strongly that ‘adverse events’ were better described as ‘medical mistakes’. The group also believed that using local newspapers would distribute the survey to a high number of patients in a short period of time. Researchers understood and agreed with the CAC’s suggestions. In the questionnaire, which was jointly finalized by researchers, clinicians and patients participants were asked to report “any event you don’t wish to have happen again that might represent a threat to patient safety”. The research findings resulted in a system to make reporting medical errors easy, safe and reliable: interventions designed to reduce error. The CAC assisted with data analysis and interpretation, co-authored a manuscript, and presented findings at local and national meetings. They also ensured that study results were shared with communities by writing an article about the study and results for publication in local newspapers throughout the network region.
(Van Vorst, 2007)

The overarching goal of this exercise of selecting priorities is to clarify expectations between all parties – i.e., to make sure that everyone is on the same page – in order to mitigate conflict or disappointment down the line. Detailed discussions also help in team building as everyone comes together and learns more about each other. Furthermore, it aids in ongoing evaluation of the IKT process in that transparent benchmarks are set against which the long-term progress of the partnership can be judged.

Summary points:

- Limit oneself to one main priority for the research project, which must be jointly agreed upon from all the issues identified previously
- Consider the fit of this priority with the research partnership, the reality (in terms of funding and time) of the situation and capacity building
- For large groups, employ a systematic technique for selecting a priority (e.g. DELPHI)

Suggested reading for this section:

- CCPH 2006, Unit 2
- Martin 2008

MODULE 5: GOVERNANCE

Learning objectives:

1. Learn about the different models of joint governance and various decision-making processes.
2. Learn how to share leadership of projects and the different roles that integrated knowledge users can play in order to put their expertise to good use.
3. Learn how to enable successful group practices based upon open communication and equitable participation.

a) Joint governance and decision-making

In order to ensure that the principles of IKT are truly put into practice, formal mechanisms are needed that support the team approach and solidify the channels for everyone's participation in the project. Indeed, the discussions needed to develop these mechanisms frequently serve as a crucial way of increasing the understanding and trust between the various parties. To accomplish this, potential modes of joint governance and decision-making of the project must be reviewed and mutually agreed upon – i.e. negotiation on how the project is to be governed and the setting out of procedures for how decisions are to be made. Once again, care should be taken to engage the integrated knowledge users in this process to jointly arrive at a framework. They should not just be asked to agree to the proposed framework put forward by the researchers, but all team members should have the opportunity to contribute intellectually to developing agreements that respect the nature of the research project and their own particular context. The first paragraph and table of this section deal with joint governance, and the second deals with shared decision-making.

There is no 'one size fits all' solution for joint governance in IKT projects. Various governance models are available. The one selected should depend upon the scale of the project (for instance, larger projects of a national scale may require more administrative layers) and type of integrated knowledge users involved (for example, busy institutional practitioners and community members may not be available to contribute on a day-to-day project management basis). That is, the complexity of the governance model is a function of the size of the project and the culture of the integrated knowledge users (whether professional or ethnicity-based). The key theme in any model agreed upon, regardless of its structure, is equitable representation of integrated knowledge users at the highest or ultimate level of governance and decision-making of the project. Such equitable representation is meant to ensure genuine shared control and equitable participation from integrated knowledge users at all important junctures of the project - not only to inform design and methodology, but also to maintain ongoing translation of knowledge throughout the process. Summarized in the table below are some of the various ways with which to formalize this. The table represents a spectrum, with more researcher-controlled projects on the left and more integrated knowledge user-controlled on the far right. We advocate the middle, which maintains a good balance in terms of genuine shared decision-making.

Table 5(a): Types of Joint Governance

Type	Description	Suitable for:	Advantages	Disadvantages	Practical tips
Ad-hoc	Bringing in integrated knowledge users as needed on and individual basis, according to the issues at hand.	Very small projects (e.g. pilot studies) with relatively few researchers and integrated knowledge users involved.	Limited administrative bureaucracy, thus speeding along the decision-making process. Enables one-on-one relationships to develop.	Can be heavy on researcher control, as they decide when to bring in integrated knowledge users. Partnership not formalized.	<ul style="list-style-type: none"> • Keep all integrated knowledge users up-to-date through emails or newsletters, so no one feels left out. • When a crucial decision needs to be made for the project, inform all partners and provide them with the opportunity to take part in the decision-making process. • Ask for written feedback from integrated knowledge users if a face-to-face meeting is not planned.
Integrated	Incorporated integrated knowledge users into the researcher/investigator committee – i.e. making them ‘part of the research team’ along with other co-investigators.	All projects, though very large projects might want to consider mixing this with an Advisory Committee.	Integrated knowledge users and researchers make joint decisions together, as all are part and parcel of the same team or working group.	Some integrated knowledge users (especially patients or community-based partners) may feel uncomfortable discussing complex scientific issues, and feel it an unproductive user of their time.	<ul style="list-style-type: none"> • Consider forming a sub-committee to deal with nitty-gritty scientific issues. • Maintain an equal balance of research and integrated knowledge users at the high level of decision-making. • If sub-committees are formed, ensure that integrated knowledge users area afforded the opportunity to participate.

Advisory Committee	An Advisory Committee can be formed consisting of integrated knowledge users (but with some researchers if appropriate). It can offer input and advice on the general direction of the project at pre-determined frequencies, or researchers can defer to it specific issues before final decisions are made (e.g. methods, publications, staffing, budget).	Larger projects with multiple integrated knowledge users, or projects of a national scale. Works especially well for community-based projects, in particular in communities previously harmed or otherwise disenfranchised by research). Also useful for communities of practice.	This Committee can serve to provide the integrated knowledge users with a place to freely discuss their concerns semi-independently – or in some cases independently – of the researchers, thus enhancing their participation.	Can be administratively burdensome and it may take longer to make a decision, especially if back-and-forth is required between the Committee and the researchers.	<ul style="list-style-type: none"> • Make sure that the Advisory Committee has a very clear mandate that is written into any partnership agreement (see section 6). • Consider setting up a small subset of the Committee that can deal with more administrative issues and thus offer a faster turnaround on decisions between meetings of the Committee at large.
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These three alternative models of shared governance are not meant to be mutually exclusive. Rather, they are meant to be combined, mixed and matched depending upon the type and needs of the project.

The most common ways of approaching joint decision making are: 1) majority vote, 2) consensus building and 3) the 70% rule. The first may be the easiest of all the methods, but it is also fraught with the greatest chance for conflict to arise. Using a simple majority, especially when making very important decisions about the project’s direction, can lead to a sizeable number of participants (the ‘other’ 49%) becoming disenfranchised and feeling as though their voices do not count. Also, decisions can be biased if there are more researchers around the table than integrated knowledge users and vice versa. (As mentioned above, equal representation and quorum when decisions are made are crucial.) Consensus building, on the other hand, does help to generate a genuine sense of inclusion within and joint ownership of the project, but can be a time-consuming and often frustrating process. Furthermore, consensus may not always be possible on all issues and is not always necessary when making more administrative decisions. One intermediary between these two approaches is the 70% rule (Becker 2006). This can be applied in two ways. First, rather than a simple majority vote (i.e. 51%), a majority vote of 70% of members must be obtained before a decision is made. Alternatively, if consensus is desired, members do not all have to 100% agree with the decision, instead they can each agree only 70% with the decision. That is to say, everybody must agree that the final decision is one that they can live with – even if it is not their preferred choice. One final thought should be kept in mind: joint decision-making can become unwieldy in very large group, where everybody has a different set of priorities and agendas. Accordingly, it can be useful to decentralize decision-making to sub-committees that are charged with meeting a specific set of the project’s goals.

Summary points:

- Integrated knowledge users should always be afforded the opportunity to participate in the highest levels of governance and decision-making.
- There are many ways of going about sharing governance and decision-making, and the various options need to be discussed and mutually agreed upon by researchers and integrated knowledge users.
- The complexity of the governance model and decision-making procedure should reflect the scale of the project and the culture of the integrated knowledge users involved.

b) Deciding upon leadership and roles

In order to reduce later confusion or potential conflict down the road, the project leadership and roles of both researchers and knowledge users should be jointly agreed upon. It is very important that these are made as explicit and clear as possible. It is important to be creative and flexible when deciding upon project leadership, not just because IKT is built upon shared governance and decision-making, but also because responsibilities and burdens can be shared amongst all parties and their expertise put to effective use. Moreover, flexibility is required as the roles of partners may fluctuate over time according to the tasks that need to be done at various stages of the research project.

Even though funding agencies often require a nominated principal investigator to be listed on their grants, it should not be assumed that this person is the sole leader with ultimate authority. (In the past, this was always someone with an academic appointment.) Today, some CIHR grants allow a nominated integrated knowledge user to serve as principal investigator and to hold the research funds at their eligible non-academic institutions. Integrated knowledge users should have the opportunity to assume leadership roles for the project as a whole or for parts that are most relevant to their expertise, whether or not they choose to take on such a role. For example, when recruiting research subjects from a specific community, it may be appropriate for members from that community to lead the development of a recruitment strategy and oversee its implementation. Additionally, an integrated knowledge user will often be the best person to act as the primary advocate disseminating the research results (see module 9). When regular meetings are held, researchers and integrated knowledge users can take turns chairing meetings and share the administrative load of preparing agendas and minutes.

Crucial decisions should also be made on the roles of the researchers and knowledge users during the various stages of the research project. For instance, it may be jointly decided that the researchers will be solely responsible for the scientific aspects of the project (e.g., methodological design, statistical analysis, etc.) and knowledge users for active dissemination (e.g., be the ‘face’ the project to community at large, academic detailing, advocacy for change, meeting with health planners, etc.). If there is to be a Steering Committee or Advisory Committee, then its role in the project and the scope of its authority should be clearly set out. Some other sample roles that knowledge users can play include (adapted from CCPH 2006):

- Develop project, processes, procedures and policies that support the IKT initiative.

- Identify an intervention plan for research results appropriate for their members or context.
- Develop and/or review grant proposals, scientific journal articles and presentations.
- Where more than one data collection method exists (often with no ‘gold standard’), the knowledge users can identify the methods most appropriate or acceptable for their members or context.
- Facilitate two-way communication between the project and the overall knowledge users of the research results (e.g., the professional colleges, community organizations, the media, etc.).
- Recruit new integrated knowledge users to the project as needed.
- Summarize group discussions and show appreciation for everybody’s participation.
- Integrated knowledge users can be hired as research coordinators and/or assistants for the project.

Summary points:

- Roles of researchers and integrated knowledge users alike need to be entirely clear and result from discussion.
- Flexibility in these roles is essential, as they may change over time as the project develops and moves through its various stages.
- Integrated knowledge users can assume many innovative roles beyond a traditional ‘advisory’ capacity.

c) Group dynamics

The group dynamics for any IKT project should be influenced by the principles of: 1) open communication and 2) equitable participation (Becker, 2006). Key for the success of both is to set, at the outset, clear and realistic goals that suit the needs (e.g., promotion and tenure issues amongst younger academics, desire for rapid change to answer organization questions or address health disparities in a community) and pragmatics of both researchers and integrated knowledge users (e.g., funding cycle periods, slow diffusion of knowledge amongst communities of practice). Written operational norms or codes of ethics also play a crucial role (see section 6).

1) Open communication: The over-arching principles of open communication must be honesty and transparency. This means to:

- discuss important decisions and only make a decision when the group is ready to do so;
- frankly talk through any disagreements or conflicts that may arise;
- keep one’s word and never make promises that cannot be kept;
- be realistic about goals and results from the outset, and;
- make decisions according to the agreed upon operating norms, and never exclude any of the partners from this process even if you feel that they may impede it.

Table 5(c)i: Practical tips for open communication

- Distribute agendas in advance of meetings so participants know the issues to be discussed and can think about them ahead of time
- Promptly circulate the minutes to meetings with the decisions made clearly highlighted so everybody is on the same page and provide an opportunity for corrections/modifications if needed
- Make an effort to communicate with partners who were absent at important meetings to ensure they are up-to-date and obtain their input on any important decisions
- Be available to all partners by email and phone and respond to messages in a timely manner

2) Equitable participation: The intention of equitable participation can be understood as two-fold. First, it is to acknowledge and seek to rectify the power differentials that exist between researchers and some knowledge users (e.g., academic qualifications, gender, ethnic origin and age). Second, it is to adopt strategies that actively encourage participation and strive to create an environment that is conducive to such participation.

Table 5(c)ii: Practical tips for equitable participation

- Use group facilitators to run meetings and ensure that everybody has a chance to speak and that no one person (or group) dominates meetings
- Rotate meeting chairs between researchers and integrated knowledge users so that all partners have the chance to set the pace of a meeting
- Ask for written feedback on issues or documents circulating in order for partners who may not feel comfortable participating in large groups to provide input
- Divide the partners up into sub-committees of 8-9 people, each charged with a certain task or meeting a certain goal (e.g., writing a consent form, developing a dissemination strategy)
- Assigning individual work to partners who are interested

Be creative in how you choose to implement these two principles that enable a successful IKT process – i.e., don't be afraid to think 'outside the box'. Moreover, these principles highlight the point that researchers should not assume that integrated knowledge users are not interested in a certain task, responsibility or otherwise (e.g., statistical analysis, data collection) and vice versa. Every partner must be afforded with equal opportunity to engage, even if that opportunity is not taken up on.

Summary points:

- Effective IKT processes are built upon the principles of 1) open communication and 2) equitable participation.
- Think 'outside the box' when devising ways to put these principles into practice.

Suggested reading for this module:

- Becker 2006
- CCPH 2006, Unit 3
- Quinn 2004
- Wallerstein 2006

SECTION 6: ETHICS AND PARTNERSHIP AGREEMENTS

Learning objectives:

1. Learn about the ethical considerations inherent in IKT projects that necessitate a discussion that goes beyond the principles traditionally underlying research ethics.
2. Learn that IKT ethics endows both researchers and integrated knowledge users with clearly defined rights and responsibilities, and understand the value of jointly negotiating these with respect to trust and mutual respect.
3. Learn the advantage of written partnership agreements, and some models/examples for developing them.
4. Learn how Research Ethics Boards (REBs) may approach IKT projects, and strategies for working with REBs to ensure an adequate and timely ethics review.

a) The need for ethics specific to IKT

The basic premise of the ethics of research involving humans is to ensure protection for individuals who agree to take part in a research project. In Canada, the Tri-Council Policy Statement (TCPS): Ethical Conduct for Research Involving Humans (Tri-Council 1998, which incorporates the fundamentals of the Belmont Report and Declaration of Helsinki) is the main Canadian guideline for research involving human participants¹, and it is based on the moral imperative of ‘respect for human dignity’. This means that researchers should only conduct research that leads to acceptable *ends* (i.e., the creation of beneficial and generalizable knowledge for society) and using morally acceptable *means* (i.e., never treating the subject merely as a means, but rather as having intrinsic moral worth and dignity). From this overarching principle of *respect for human dignity*, central ethical obligations are derived to protect participating individuals. These are: Respect for Free and Informed Consent; Respect for Vulnerable Persons; Respect for Privacy and Confidentiality; Respect for Justice and Inclusiveness; Balancing Harms and Benefits; Minimizing Harm; Maximizing Benefit.

IKT projects involve partners with differing backgrounds and divergent agendas, shared governance and decision-making, co-creation/ownership of knowledge and joint dissemination and publication. Because there is the potential that the research process and its results will affect many people, each choice can have complex ethical implications. As such, one must look beyond - while not forgetting - the traditional issues as outlined above and also consider issues that will frame ethical conduct between parties: 1) *building trust* between researchers and integrated knowledge users and 2) *mutual respect*. IKT projects also require an expanded ethical discourse that includes both informed consent of individuals *and* the additional group or communal consent of the organization or community of integrated knowledge users (including communities of practice). Communal consent is important because the potential *impact* of research results on targeted organizations or groups can continue beyond the scope of one project (i.e., positively through additional research projects or negatively through stigmatization caused by publishing negative results). In addition, mutually-agreed upon mechanisms for benefit sharing should be in place to prevent inequalities so that both researchers and knowledge users have access to the real, concrete benefits of their work. Finally, it is important to prevent

¹ The TCPS is currently being revised. This module may be updated to reflect any relevant changes in the final version of TCPS.

exploitation in the context of IKT by ensuring the protection of vulnerable populations and by ensuring that communal consent is genuine and not used as a rubber stamp.

Box 6(a): Main ethical issues to consider in IKT projects

Although it is by no means an exhaustive list, the following five issues are of paramount concern when engaging in an IKT project. Flexibility and the ability to adapt are key, as not every IKT context will need to address each of these issues to the same degree.

1. Building trust between researchers and knowledge users
2. Maintaining mutual respect amongst all parties
3. Obtaining communal consent
4. Agreeing on mechanisms for benefit sharing
5. Preventing exploitation of knowledge users (especially when working with traditionally marginalized communities)

Researchers and integrated knowledge users need to have a heightened awareness of the potential ethical challenges characteristic of IKT and openly discuss them to reach agreements outlining how they will be addressed. This is especially important when partnering with vulnerable communities that have previously been subjected to top-down researcher-driven projects, where dissemination of results did not occur within the community, or where external dissemination occurred without community knowledge. There are many examples of researchers who published negative results in named communities without consent (e.g., high rates of alcoholism and suicide), which resulted in stigmatization of those communities. This notion can also be important when partnering with communities of practice where, in the past, research has served to further entrench biases about certain professional groups and its members. Researchers' diligence in creating complex ethical agreements should be a function of: 1) the culture of knowledge users (even when it is a professional culture) and 2) the nature of the research project.

Finally, ethical principles should be considered within specific contexts. It is, therefore, important to apply sound judgement as to what is the best approach and to determine which ethical principles are most relevant and salient in a given situation.

Summary points:

- Building trust, mutual respect, community consent, benefit sharing and avoiding exploitation are five ethical principles of central concern in IKT projects, in addition to central notions of informed consent, confidentiality, etc.
- How these principles are put into practice must be openly discussed and jointly negotiated amongst researchers and integrated knowledge users at the beginning of the project
- The complexity of any ethical agreement depends upon the culture of the integrated knowledge users and the essence of the research carried out

b) Setting the rights and responsibilities of both researchers and knowledge users

Standard conceptions of research ethics tend to view ‘the researched’ as having rights and the researchers as having responsibilities to them (e.g., to not exploit, to treat with respect). The ethics of IKT, however, sees integrated knowledge users and researchers as having *both* rights and responsibilities to one another and to the research subjects. Examples of each are summarized in the table below (Macaulay 1998):

Table 6(b): Rights and responsibilities of partners

	Researchers	Integrated knowledge users
Rights	<ul style="list-style-type: none"> ▪ To conduct scientifically rigorous research that meets established standards of excellence ▪ To publish research results, as long as it has been jointly interpreted and everyone has come to consensus <u>or</u> to include a dissenting opinion. 	<ul style="list-style-type: none"> ▪ To be consulted and involved, if desired, in all aspects of the research project and all important decisions ▪ To benefit from research results, both in terms of new knowledge gained and increased capacity to address any problems identified ▪ To come to consensus <u>or</u> to be able to have, and write about, dissenting opinions regarding interpretation of research results
Responsibilities	<ul style="list-style-type: none"> ▪ To actively engage knowledge users in the project rather than consider passive acceptance as sufficient ▪ To provide resources to the knowledge users to facilitate their collaboration (e.g., travel/parking costs) ▪ To provide scientific explanations to knowledge users in lay and culturally-appropriate language, if needed ▪ To recognize the knowledge users as co-owners of the data 	<ul style="list-style-type: none"> ▪ To meet regularly with the researchers in order to discuss any issues that may have arisen and offer prompt feedback ▪ To promote the objectives of the project and actively disseminate its results within their institutions, professional bodies and/or community ▪ To offer advice, at a minimum, on the research questions, and interpretation and dissemination of data ▪ To offer constructive input rather

and research results, and thus involve them in any secondary analysis

- To help address any health or social issues raised as a result of research

than negative criticism, and work with the researchers to modify the project as needed

These rights and responsibilities should be discussed, negotiated and agreed upon before the project begins. They should reflect the unique realities of IKT projects and the specific individual contexts. Valuable time is spent getting to know one another through this process of negotiation that helps clarify what needs to be done to promote the success of the project. Such negotiations not only help avoid confusion and misunderstanding down the line, but also serve as a *trust-building* exercise between parties. Trust serves to make the project more feasible because it diminishes potential concerns between researchers and integrated knowledge users regarding potentially conflicting ‘agendas’.

Moreover, by positing both researchers and integrated knowledge users as having *both* rights and responsibilities, the additional and aforementioned principle of *mutual respect* is fulfilled – researchers do not take a paternalistic attitude to protecting the research subjects and integrated knowledge users are empowered to take an active and engaging role in the project.

Summary points:

- Researchers and integrated knowledge users are endowed with *both* rights and responsibilities
- These rights and responsibilities must be discussed and mutually agreed upon, which is a trust-building exercise in itself

c) Negotiating written partnership agreements

We highly recommend the development of partnership agreements, which will be distinct to each IKT project depending upon its nature, the context and the partners. When negotiating these agreements, it can be helpful to review previous agreements and guidelines (Boser, 2006).

Examples of such guidelines include:

- Royal Society of Canada 1995 guidelines for assessing participatory research projects (see section 1, available at <http://www.lgreen.net/>).
- New Reliability-Tested Guidelines for Assessing Participatory Research Projects, Appendix C in *Community-Based Participatory Research (Second Edition)*. Editors Minkler M and Wallerstein N. Jossey-Bass (2008). Guidelines will also be available [here](#).
- Centres dedicated to participatory research such as the [Detroit Urban Research Centre](#)
- [Community-Campus Partnerships for Health](#) offers many other examples
- [Center for Minority Health - Community Research Advisory Board](#)

- [CIHR Guidelines for Health Research Involving Aboriginal People](#) focus on partnership research, include a useful template, and are highly adaptable to other contexts.

For research with Aboriginal Communities:

- [CIHR Guidelines for Health Research Involving Aboriginal People](#) are mandatory for all CIHR research funded after July 2008
- Some specific projects have published their own codes of ethics i.e., the [Kahnawake Schools Diabetes Prevention Project](#)
- See Appendix for a broader list of Aboriginal and Indigenous ethics statements and guidelines

For the sake of clarity and for future reference, it is recommended to develop a *written partnership agreement*. Its writing process is a worthwhile endeavour that allows both parties to think about the rights, responsibilities and roles of all those involved in the project. A written agreement can serve to bring together many of the points that have been discussed in the previous modules.

Table 6(c): Practical tips for content of written partnership agreement

- The principles on which the partnership is based
- The research project’s objectives and goals (section 4)
- How work will be divided between the various partners (section 3)
- The structure of the project’s shared governance and methods for joint decision making and operating norms (section 5)
- Roles of each of the partners (section 5)
- Rights and responsibilities of partners (section 6, especially Table 6(b))
- Mechanisms for conflict resolution and ongoing evaluation of the partnership process (section 7)
- Conflicts of interest and how they will be managed

Preparing a written partnership agreement is perhaps most desirable in large-scale or national projects, where multiple partners are involved, and is extremely valuable in community-based research, where the community has historically been disadvantaged and thus hesitates to agree to further research. It can also be useful in multicultural environments, where a written document can serve to minimize cultural misunderstandings as all parties have agreed to it. (Very rarely, a written agreement may not be culturally appropriate, such as with some Aboriginal communities.)

Different teams have developed different levels of agreements that vary from more general foundation principles, through agreements outlining specific administrative procedures, to very detailed Codes of Research Ethics (see above websites).

Case study 6(c): Written agreements in practice

Example 1 – Written memorandum of understanding: The Sandy Lake Health and Diabetes Project (SLHDP) is a community-based participatory research project investigating all levels of cause, impact, complications, management and prevention of type 2 diabetes. The Oji-Cree community of Sandy Lake, Ontario, had the 3rd highest documented prevalence of this disease in 1992. Community leaders and Elders wanted to know why, as well as how they could alleviate the burden on future generations. One component of research was a proposed genetic study to investigate the prevalence of a 'thrifty gene' in this community of 2,100 that encourages the efficient storage of fat in lean times; something that was once advantageous, but today ill-serves this population. Despite a well-earned modern history of Aboriginal mistrust of genetic research, founded on many cases of abuse by other researchers, Sandy Lake was quite eager to learn more about the genetic aspects of diabetes in their community. This was due to the firm trust relationships built between the community and both the regional medical director who became the Principal Investigator of the SLHDP intervention/evaluation study and the study coordinator who later became its key epidemiologist. Community members were very willing to discuss and discover how further research discoveries could ultimately serve their interests and benefit many other Indigenous communities. The community and academic partners crafted a research memorandum that included an agreement on sharing of any revenue that might result from this research program. This memorandum included Sandy Lake First Nation, the University of Toronto, the University of Western Ontario, St Michael's Hospital and Mt. Sinai Hospital, Toronto.
(Hegele, 1998)

Example 2 – Statement of principles: The following is a list of the principles used by the tuberculosis project presented in Case study 2(c). Although these are oriented towards community-based integrated knowledge users, they are highly adaptable to other types of projects (even communities of practice).

1. Plan the code of ethics / foundation principles in conjunction with the Community Advisory Committee, community associates and cultural communities.
2. Honour the life circumstances of people we are working with and be guided by mutual respect and appropriate confidentiality.
3. Be sensitive and responsive to the values, cultures and priorities of the individuals and communities.
4. Promote sustainability of community networks and research capability.
5. Research is to be responsive to identified community needs.
6. Research is to be educational.
7. Primary commitment should be to those who are at risk and to enhance possible coping strategies for those most challenged.
8. Advocate for equity to support those who have barriers/challenges.

(Gibson, 2005)

Such a formal, written spelling out of these issues can be done either in a formal or an informal manner. The most formal manner of a written partnership agreement is a Code of Research Ethics or Statement of Principles signed by all parties (e.g., the [Detroit Urban Research Center](#), the [Kahnawake Schools Diabetes Prevention Project](#), or the sample agreement provided by the [Centre for Indigenous People's Nutrition and Environment \(CINE\)](#) with clauses that specifically address all these points. A more informal approach, particularly with smaller projects or with communities of practice, is for a grant proposal or research protocol to stand as the written agreement. If this latter approach is taken, there should be explicit mention of the partnership and the topics listed in Table 6(c) should be addressed in the protocol. In both cases, the integrated knowledge users should not just agree to the documents, but be actively engaged in writing and reviewing them because adequate opportunity must be given to everyone. The process can, therefore, be quite lengthy.

Summary points:

- Written partnership agreements, jointly developed by researchers and integrated knowledge users, are advantageous for the sake of clarity and future reference
- When drafting such agreements, refer to a set of externally-developed guidelines to direct this process
- For large projects with community-based integrated knowledge users, a formal code of ethics is recommended; for smaller projects with a community of practice, the research protocol can fulfil this role

d) Obtaining Research Ethics Board approval

All health research requires ethics approval by a recognized Research Ethics Board (REB), for which the majority are university or hospital-based. It is now common practice in Canada that all REBs include members from the general community to review all research projects. Community members were added to REBs in order to bring a different perspective and support research of increased relevance to the public at large.

As IKT projects and more participatory approaches to research increase in frequency, REBs will need to become familiar with the additional ethical principles outlined above and be in a position to evaluate proposals coming in from projects with researchers and integrated knowledge users partnerships. There exists at present a wide spectrum of REB attitudes toward this research approach. Some boards are very supportive and others still focus on the model of traditional researcher-driven projects. In the case of the latter, many of the ethics review forms checklists and guidelines were developed strictly for a biomedical clinical research framework, focusing on the principle of assessing risk to and informed consent of individuals and, thereby, not including assessment of risk to the knowledge user group or whether consent has been obtained from that group as a whole. This will have to be addressed in the future through education of REB members and revisions to review forms, checklists and guidelines. In fact, groups in both Canada and the US are currently undertaking to develop REB/IRB training curricula addressing the particular exigencies of partnered research.

Some of the additional challenges for REBs include: 1) little guidance to evaluate partnership proposals, (addressed somewhat by the recent release of the “New Reliability-Tested

Guidelines for Assessing Participatory Research Projects” in Minkler & Wallerstein 2008); 2) evaluation of research proposals where the partners need further discussions to finalise details such as data collection tools; and 3) allowing for decisions or negotiating with community-level or local ethics boards.

We recommend taking a ‘participatory’ approach with REBs not accustomed to reviewing partnership IKT projects, through an early and ongoing dialogue with them. The content of these early discussions can include 1) informing them early on of intention to submit an IKT project, 2) resources available to the REB to help with ethics review (e.g. guidelines mentioned above), 3) demonstration of the team’s willingness to answer any questions that the REB may have and even attend a meeting to do so, if requested, and 4) in some cases, particularly with respect to research involving vulnerable groups, encouraging the REB to bring in a representative from that group to offer their perspective on the project, and requiring REBs to respect any community-level ethical review boards. Ongoing dialogue between the project and the REB can be held at the time of interim review and further facilitated by the use of amendments in order to keep its members updated with modifications made as the IKT partnership evolves.

It is also important that researchers explain the ethics review process to any integrated knowledge users unfamiliar with research ethics and the review process. The online [Tri-Council Policy Statement tutorial](#) (produced by the Interagency Advisory Panel on Research Ethics) is a good resource for this purpose².

Summary points:

- Some REBs may not be familiar with an IKT partnership approach to research and, hence, may lack the expertise and tools to assess the proposed project.
- An ongoing dialogue with the REBs, even before submission of protocol for review, can be helpful in overcoming some of these challenges.
- The ethics review process must be explained to integrated knowledge users who are not already familiar with it.

Suggested reading for this module:

- Boser, 2006
- Emanuel, Wendler and Grady, 2000
- Fadem, 2003
- NAPCRG, 1998
- Weijer and Emanuel, 2000

Links:

- [Declaration of Helsinki](#)
- [The Belmont Report](#)

² Again, the TCPS is currently being revised. This module may be updated to reflect any relevant changes in the final version of TCPS.

SECTION 7: MAINTAINING PARTNERSHIPS OVER TIME

Learning objectives:

1. To learn that partnerships require maintenance and about some of the issues that may need to be addressed through such maintenance.
2. To learn the basic steps to resolving conflict in the partnership.
3. To learn the importance of ongoing evaluation of the partnership process and some strategies for doing so.

a) Maintaining partnerships requires ongoing effort

Effective partnerships require constant work between integrated knowledge users and researchers, with everyone making an active effort to keep the lines of communication open, ensure a sustained and smooth progression of the project, and address conflict promptly before it gets out of hand. In addition to individual motivation, specific mechanisms can be explicitly put into place or built into the partnership agreements, as mentioned in section 6. These mechanisms must recognize and help to mitigate the fact that the ‘politics’ of the project may change over time as priorities shift and personalities change. Some other issues to consider when maintaining partnerships include:

- How member turnover will be addressed – i.e., members leaving and bringing new researchers and knowledge users into the team, as well as students.
- Maintaining regular communication between all partners by, for example, circulating regular newsletters or memos updating everyone on progress.
- Providing interim results to integrated knowledge users on an ongoing basis, while stressing that they should not jump to conclusions based upon incomplete data (i.e., that preliminary data may not equal conclusions).
- If the research results are a long way off, researchers can consider providing immediate services to the integrated knowledge users – i.e., information seminars on the existing state of knowledge of the research topic or research methodology.
- Working toward overcoming some of the institutional and structural barriers to integrated knowledge user involvement – e.g., finding salary release funds or getting research activities written into their job descriptions.
- Recognizing that partnership maintenance is a two-way street, requiring effort from researchers and knowledge users alike.
- Periodically, re-affirming the project’s goals and objectives.

Case study 7(a): Maintaining partnerships over time – An example from Saskatchewan

In 2004, the University of Saskatchewan Department of Family Medicine and Saskatoon Health Region began to create West Winds Primary Health Centre (WWPHC) to be located in under-served Saskatoon communities. WWPHC would provide primary health services, a Residency Training Program, and engage in primary health care research including a community-based participatory research (CBPR) project that resulted in the development of evidence-informed prevention and treatment programs.

The Community Participation Working Group began in the fall of 2004, with membership from each of the Community Associations that WWPHC was to serve: the Department of Family

Medicine, Saskatoon Health Region and individuals that had participated as Peer Researchers in an earlier participatory research project in downtown Saskatoon. In 2005, this group negotiated a set of values around *respect, trust, communication, and empathy*.

Project goals were to: 1) engage the communities being served by WWPHC in program development, and 2) better understand the strengths and opportunities for change in the communities.

Peer Researchers (community members) received orientation prior to implementing the CBPR project, covering interviewing, data collection and facilitation skills that included transforming conflict. From September 2005 to June 2006, Peer Researcher teams collected data from six WWPHC communities and team meetings (Peer Researchers and Principal Investigator) occurred weekly at a local community hospital until April 2006 and then at WWPHC. At these team meetings, successes and challenges of the past week were discussed and thoughtful solutions to the challenges were developed. Although these meetings could be seen as being very repetitive, it is what kept and what continues to keep the team together. These research projects have also facilitated praxis which resulted in personal healing. Some Peer Researchers have worked with the Principal Investigator for nearly ten years on various research projects and program development; thus, maintaining partnerships takes time but is very humbling and rewarding.

(Government of Newfoundland and Labrador, 2006)

The remainder of this module is dedicated to two of the most important elements of IKT partnership maintenance: 1) conflict resolution, and 2) ongoing evaluation.

Summary points:

- Effective partnerships require constant maintenance with all partners making an active effort
- Mechanisms should be put in place in the partnership agreement to support this activity

b) Conflict resolution

Whenever large groups of people work together, conflict is inevitable. Indeed, it would be naïve to believe that conflict will not arise given the inherently social and collaborative nature of IKT projects. Nevertheless, it should be addressed in a timely and appropriate manner to prevent long-term negative effects that impair the ability of the partnership to complete the project. The best solution is turn conflict and its resolution into something *productive* and *positive* to further strengthen the partnership. It is hence incumbent upon researchers and integrated knowledge users alike to develop conflict resolution skills, above and beyond their respective traditional field of expertise.

Conflict can be divided into the following types (Forsyth 1999): 1) personal, conflict between individual personalities; 2) substantive, disagreements over opinions or ideas; 3) procedural, strategies or operating norms may conflict; and 4) competition amongst members. By far the best way to both expect conflict and resolve it is to build in conflict resolution structures

or norms of conflict to the partnership agreement (Becker 2006). That way, jointly agreed upon procedures are incorporated that 1) help assure everyone that it is perfectly acceptable to openly talk about conflict, 2) prevent ad-hoc or arbitrary solutions and 3) ensure that no one is left out of the discussion. These should be based upon a *non-adversarial* approach to resolving conflict; that is to say, they should be based upon negotiation (Johnson 1994). The following points summarize typical steps in negotiated resolutions to conflicts (Johnson 1994):

1. Jointly defining the conflict: The resolution of a conflict depends upon the way it is defined, as do the feelings of the parties involved. When defining a conflict, it is best to take time to reflect with a ‘cool’ head and in two steps: 1) defining the conflict to yourself, and 2) agreeing with the other parties on a definition. Other helpful rules include:

- Describe the other party’s specific actions that have led to the conflict, and not their personality or character flaws that may have done so.
 - Define the conflict as a mutual problem to be solved collaboratively that will result in a win-win situation – by framing issues in terms that will not lead to one party emerging victorious over the other.
 - Take a narrow and specific definition to the conflict, without including the larger ‘political’ background issues.
 - Be clear about your thoughts and feelings – i.e. do not assume that the other party understands how you feel or can read your mind.
 - Reflect and describe upon what actions you currently do, or neglect to do, that have given rise to this conflict and may sustain it – after all, one only has control over your own actions.
2. *Exchanging proposals and feelings:* Set out the needs and hopes of both parties, so a better picture of what a sustainable solution must look like can be developed. Be an active listener to the other’s thoughts and feelings, and leave time for them to speak before interruption (e.g. by designating specific times when parties ‘have the floor’). Be sure to ask questions of the other’s point of view for the sake of clarity and to offer critical feedback. Finally, remain flexible to the needs and goals of the other party when proposing collaborative solutions.
3. *Understanding the other’s perspective:* Put yourself into the other party’s shoes and make a concerted effort to understand how they view the conflict and what the main issue is. This is helpful in devising a resolution that meets the needs of the other partners and allows them to ‘save face’. Recognize that blame can be counter-productive and result in defensive posturing.
4. *Inventing options for mutual gain:* The five steps are: 1) focus on the needs and goals of all parties in finding a solution, and not on trying to change their positions; 2) ensure that all differences are brought to light and clarified before focusing on the commonalities between the parties’ concerns; 3) make the other person feel empowered through the conflict resolution process and not feel as though they are coming out the loser; 4) avoid obstacles to finding a resolution, such as jumping to conclusions, looking for quick-fix solution and focusing too much on your own needs and goals; and 5) be creative in finding a resolution.

5. *Reaching a wise agreement:* A wise resolution is one that has 1) concrete strategies for overcoming the conflict, 2) a feasible implementation strategy, and 3) a means to monitor and re-asses it. It is crucial that both parties not just agree to the resolution, but show commitment to abide by it. Also recognize that there may be ‘after-shocks’ to the conflict and ‘slip-ups’ to the implementation of the resolution. How to deal with these, should they arise, can also be discussed.

If a resolution to the conflict cannot be found, consider an appeal to a third person or *mediator*. This person should be mutually selected and agreed upon by all parties, and their scope for finding a resolution clearly delineated (e.g. if both parties agree to be bound by results of this arbitration or not, timeframe for finding a resolution, etc.). A final note, one of the most important attitudes everyone can adopt when conflict arises is ‘agreeing to disagree’. This is especially true for large teams with multiple partners, and can take some of the pressure off trying to reconcile all differences through recognizing and validating multiple perspectives.

Summary points:

- Conflict is an opportunity for growth and improving the partnership, and not just difficulty.
- Conflict needs to be openly talked about so that it can become such an instrument for enhancing the partnership.
- A step-wise plan for addressing conflict should be developed and put into any written agreement, with recourse to a mediator made an option or simply ‘agreeing to disagree’.

c) Ongoing evaluation

A crucial element to maintaining successful IKT partnerships is ongoing evaluation of the partnership process. Evaluation of the partnership process specifically, as distinct from evaluating the success of the project’s goals overall, serves as a means to continually improve and strengthen the overall and day-to-day functioning of the partnership, identify problems early before they potentially turn into a larger conflict, and ensure that all partners feel comfortable with and able to contribute to the partnership. There may be little sense in continuing a partnership that is going badly, and ongoing evaluation can help to not only prevent such a state, but also identify ways with which to fix it. These range from very simple and informal approaches to formal evaluation tools and instruments. Ideally, the various options should be discussed and agreed upon in the beginning, and then incorporated into the written research agreement.

Perhaps the simplest means to evaluate the partnership is documenting its achievements through time. Too often, minor achievements along the way can be forgotten in lieu of obtaining the project’s major objectives. Therefore, by documenting them, researchers and knowledge users have a readily available list of the partnership’s achievements when they sit down to ‘take stock’ of it.

Table 7(c): Practical tips for ongoing simple evaluation

- Create a timeline containing milestones for the partnership (e.g. finalize research agreement, secure funding, begin study recruitment) so that everybody knows where the partnership has to be and its progress easily tracked.
- Use the research agreement itself as a reference point, with integrated knowledge users and researchers alike regularly reviewing it ('spot checks') in order to ascertain how well partners are abiding by it (especially with respect to operating norms)
- Devote time at the end of project meetings to have a free, unstructured discussion of how everyone thinks the partnership is going and offer recommendations for improvement (take care, however, to make sure that everyone appreciates and respects this exercise and comments are kept constructive)
- Conduct a similar exercise to above by having all partners anonymously write down one thing they would like to see in the partnership, and then have one person read out to the group at large for discussion

More formal approaches can include circulating non-scientific questionnaires to all partners on a regular basis. Such questionnaires should be anonymous, and ideally an impartial third party should review and synthesize them for the group. Questions could include (Portland State University 2008):

- What's working well in our partnership?
- What's not working well in our partnership?
- What do we need to proceed?
- What expectations have been met so far?
- What expectations have not yet been met?
- What are the sources of satisfaction for you?
- What are the sources of frustration for you?

Note that asking these questions is different from taking stock of barriers and facilitators (module 3). Whereas the latter's intent is to identify the barriers and facilitators to the partnership *before* it begins, this evaluation process is meant to provide an ongoing means to enhance an existing partnership (even after several years of operations).

Case study 7(c): Developing a partnership with a local YMCA to promote physical activity among teenagers in an underserved community: A doctoral participatory research project

I am a PhD student who wants to develop, implement and evaluate a physical activity promotion program for teenagers in an underserved neighbourhood. To begin, I initiated a collaboration with the community YMCA, thus facing the hurdle of gaining access to the organisation. In my initial contact with the director, I stated my research goals, my desire to work with employees in a “bottom-up” fashion, and I suggested various degrees of collaboration framed around the YMCA’s community orientation. Subsequently, the director, youth programmes coordinator and I met to discuss means and feasibility of collaboration, and it became clear that we had common goals and a common vision.

One idea discussed during this meeting was to implement a Double Dutch skipping programme. Hence, I immediately arranged to have a Double Dutch demonstration. The rapidity of my actions, and success in implementing this activity, helped to establish my credibility and led to the employees’ confidence in my intentions. Although I took full initiative for this activity, I kept the YMCA abreast of all developments so as they could take over the planning or repeat the event at a later date. Furthermore, asking employees’ consent and feedback on every planning detail demonstrated that I respected them and also valued and needed their expertise. The time and energy I devoted to organising this event confirmed my commitment to helping them to achieve some of their goals.

Over the year since the initial contact, several hurdles developed due to personnel changes at all levels. I have had to be patient and flexible. When a new director was hired, the processes of gaining access, developing trust, and establishing credibility began anew. I did this by listening to her perceived needs and goals, and by presenting the work I had accomplished and how it had benefited the YMCA. I also provided resources unrelated to my own research. Given the personnel and managerial changes, the research design is continually evolving so as to remain relevant. Time delays have also resulted and, although frustrating, they have been very valuable, allowing for more complete assessment of the organisation, and a better understanding of the personalities and work ethic of employees. Finally, as an outsider, I have had to overcome communication difficulties. Reaching employees by phone or email is not always possible, nor efficient. Getting involved in programs, being present in the organisation, and engaging in informal, informative hallway discussions has helped me to maintain contact, and increased my relationships with employees. Employees recognise my continued presence and also my patience, and perseverance to navigate through the changes and their trust in me has strengthened.

I can afford this time as I am supported by a 3 year research scholarship. I have kept detailed notes throughout this process, to be incorporated into the project’s process evaluation, documenting the barriers and facilitators to achieving my ultimate research goals.

Paula Bush, doctoral candidate, McGill University Department of Kinesiology and Physical Education

Questionnaires of this type need not be to only assess the partnership as a whole; they are also useful with respect to specific issues or aspects as well. For example, project meetings where all integrated knowledge users and researchers get together are extremely important to the IKT initiative's success. But because they can be comprised of a large group, they may be difficult to facilitate and some may feel that they have not had their chance to speak fully. A questionnaire could thus be circulated at the end of project meetings to assess how well the meetings are working and whether everybody feels they have the chance to equitably participate. Questions could include:

- What worked well in this meeting, in terms of how it was run?
- What did not work well?
- Was there anything that you wanted to say going in, but didn't feel as though you had the opportunity to during the meeting?

Finally, there are very formal instruments available for evaluating the perceived influence of different partners on a project (see Cargo 2008) or the group dynamics of a partnership (see Schulz 2003). These instruments tend to be evidence-based, grounded in a conceptual framework for partnerships, require scientific or statistical analysis in order to interpret the results, and useful only for very large partnerships with many different parties, or when external evaluation is required (e.g. for a funding application).

Irrespective of the evaluation methods, researchers and integrated knowledge users should be committed to implementing the results to improve the functioning of the partnership. As such, *action plans* should be developed based upon these results outlining what needs to be changed (if anything) and how to go about doing so. In some cases, the original research agreement may have to be modified or the project's objectives scaled back. For example, if the questionnaire circulated at the end of project meetings indicates that all parties may not feel as though they had their adequate say when a decision was made, then the discussion and decision-making procedures should be reviewed and revised accordingly. As such, it is very important that researchers and integrated knowledge users alike exhibit flexibility in modifying the original agreement.

One final note should be added to stress the distinction between an evaluation based upon the project's success versus the partnership's success. Even if projects fail to meet all its objectives or the research undertaken (e.g. for a new intervention) has mixed or negative results, researchers and integrated knowledge users may still consider the partnership between themselves to be a resounding success in terms of co-learning, individual and team capacity building, and personal connections. This is an important success, which can also pave the way for an ongoing, fruitful collaboration.

Summary points:

- Ongoing evaluation in terms of the partnership itself (v. the research objectives) is crucial to partnership maintenance and improvement – and it is on these terms that the success of the IKT process is determined
- Study timelines and the partnership agreement serve as excellent measures, and thus should be reviewed (and modified according) on a frequent basis
- More formal evaluation techniques include circulating questionnaires to researchers and integrated knowledge users asking them to rate certain aspects of the partnership

Suggested reading for this module:

- Johnson 1994
- Naylor 2002
- Schulz 2003

MODULE 8: IDENTIFY IKT FUNDING OPPORTUNITIES

Learning objectives:

1. To learn potential strategies for obtaining research funds.
2. To learn what funding opportunities are right for the partnership.
3. To learn what to consider and what needs to be included when applying for an IKT-specific funding opportunity.
4. To learn about current potential funding opportunities for IKT projects.

a) Potential strategies to obtaining research funds

We envisage a two-step process to securing an IKT research grant. Current funding mechanisms may not account for the significant time required to develop a new researcher-integrated knowledge user partnership before a grant can be submitted. Indeed, it can take many months to identify integrated knowledge users, identify research questions and set the project's priorities – all required before even thinking about the actual content of a grant submission. This development time is crucial and partners should only apply for large-scale project funding once they feel as though the partnership is strong enough. Obviously, resources are required in order to carry out these partnership formation activities. Thus, as the first step to seeking any sort of large-scale IKT funding, we recommend, if possible, seeking '*seed*' or '*start-up*' funding for the partnership in order to conduct these activities and do them well.

CIHR now offers some funding for development work. In particular, the "Meetings, Planning and Dissemination grant" is offered through each of the 13 Institutes as well as the KT Portfolio. This grant awards a maximum of \$25,000 for one year to develop a research project and prepare a funding application. Additionally, "Team Grant" funding opportunities require a two-step application process: 1) submission of a letter of intent and 2) of those selected, submission of a full application. Once a letter of intent is approved, \$10,000 is awarded in development funds. Finally, many private foundations are open to providing seed funding for partnerships and are not bound by traditional funding models of government agencies. Once the partnership has been adequately developed, ideally through this seed funding, then you can move onto the second step: securing a full-fledged IKT grant.

b) Determining which funding opportunities are right for the partnership

Some of the issues to consider when deciding what opportunities are good to apply to for an IKT project include (adapted from CCPH Handbook, 2006):

- Does the opportunity fit with the priorities and common agenda that the partnership has established?
- Does the funding agency or organization appear supportive of collaborative research?
- Does the funding agency or organization appear knowledgeable about partnership, IKT or participatory research?
- Does the opportunity's deadline allow for adequate time to receive input from all researchers and integrated knowledge users in the partnership?
- What is the opportunity's funding timeframe – i.e., for how many years is funding given?
- Does this allow for the additional time that IKT projects can potentially take?

- Does the opportunity provide sufficient financial resources for the success of the IKT project? Is salary release time available for integrated knowledge users?
- How will the grant proposals be reviewed? Will there be sufficient knowledge user involvement in the review process?
- Does the opportunity allow for integrated knowledge users to act as co-applicants or, in some cases, as principal applicants on the grant?

Although most funding opportunities are geared toward researchers, many agencies now allow knowledge users or community-based, not-for-profit organizations to apply for grants. Indeed, many private foundations have this explicit objective in giving out money. However, it remains essential for researchers and integrated knowledge users to partner in applying for funding. Integrated knowledge users will bring additional strengths and insights to the grant application and researchers can provide support and training to knowledge users to increase their acquaintance with funding agencies and the grant applications process.

c) Issues to consider when applying to an IKT-specific funding opportunity

CIHR, among other agencies, offers various funding opportunities that require a partnership of researchers and integrated knowledge users. In cases where the initial research questions or identified needs arise from the researchers, care must be taken in approaching and integrating knowledge users who can adequately and meaningfully translate the study's ultimate finding. This means that the knowledge user organisations integrated in the study need to be well situated to turn the results into effective action to "improve the health of Canadians" (in the CIHR context). However, it also means that the actual individual sitting on the study's team representing their organisation, has meaningful ability (i.e. authority, distinction, credentials, etc.) to translate the results *within* their organisation, and to the wider audience that the organisation serves. This includes the authority to propose changes in the organisation's policy and practice to successfully move the research results from knowledge to action. CIHR formalises these concepts by inviting co-applicants (researchers and integrated knowledge users alike) to consider a number of questions when deciding on a collaborative partnership:

- To what degree does the question respond to a knowledge gap identified by knowledge user partners?
- What is the commitment and capacity of the knowledge user partners to use the synthesis in their decision-making?
- What is the likelihood that the project will have a positive and substantive impact on health outcomes, practice or policy?
- What is the overall quality and feasibility of the end-of-grant knowledge translation plan
- How relevant is the proposal to themes identified in this funding opportunity?

Here are some practical considerations when developing an IKT grant with integrated knowledge users included as co-applicants:

- It is generally the researchers' role to write the grant application. But how can integrated knowledge users share the costs of preparing the grant application? The burden need not rest solely on the researchers and their team of research assistants and staff. The integrated knowledge users' organisations can offer in-kind contributions in the way of clerical support and other technical services.

- Keep in mind that integrated knowledge users (i.e., *Decision Makers* in CIHR web-form parlance) will need to have CIHR agency personal identification numbers (PINs). Individual integrated knowledge users can [apply for PINs](#) themselves or, alternatively, research assistants can apply on their behalf (but certain information is required; please view the above webpage for details).
- CV requirements for integrated knowledge users vary depending upon the funding competition. In some cases, the full Common CV is not required of them and, rather, a shortened (3-page) decision-maker CV is necessary. In other cases, no CV whatsoever is required. As standards have yet to emerge, it is best to check with the officer administrating the funds for which you are applying.
- For integrated knowledge users who decide not to become co-applicants (i.e., not take an intellectual role in the project, but still want to be involved in a particular aspect), letters of support should be appended to the grant application.
- In the grant proposal, there should be a detailed account of why each integrated knowledge user partner is involved and how they will contribute to each stage of the study. At minimum, this must include a description of how integrated knowledge users will contribute to shaping the research questions, interpret the research findings and craft the message around them, and move the results into practice. Other considerations include integrated knowledge users' time commitment, if/how they will be involved in methodological considerations and if/how they will be involved in data collection. These descriptions should be as specific as possible. We recommended creating a table and including it as an appendix (see example below). This table is not only helpful to the reviewers, but can serve as a good exercise for the partnership itself in that it forces partners to think about who will do what.

Table 8(b): A good appendix to include

For grants where integrated knowledge users do not require CVs or are brought in as collaborators (and not co-applicants), we recommend including a table similar to the one below that outlines who the integrated knowledge users are, where they come from, their expertise, and their role in the project. This is hypothetical example of a study looking at cardiology patients released from hospital and followed-up in community.

Name	Position & Affiliation	Expertise	Involvement in project	Letter Enclosed
Mike Orlando	Coordinator, Clarkdale Community Clinic, Clarkedale, BC	Community-based clinics, primary care, community organizing	Recruitment of study subjects, recruitment of participating family physicians, dissemination to community	Y
Juspaga Golan, MD	Physician (Cardiology), Clarkdale General Hospital, Clarkedale, BC	Cardiology, patient-centred care, continuity of care, medical education	Designing appropriate data collection methods at hospital, dissemination at cardiology conferences	Fax
Carey Milosa, MD, MBA	Director, Clarkdale Health Authority, Clarkedale, BC	Health planning/policy, programme management, primary care	Advisory Committee	Y

Some other important things to include in the grant proposal include (which could constitute sub-headings in an IKT protocol):

- Timeline for the project that includes milestones for the research project as well as for the partnership (e.g., finalization of written partnership agreement, formation of Advisory Committee, etc.).
- A detailed dissemination plan that has been jointly developed by all partners, including very specific measures that will be taken by the integrated knowledge users to help implement results and any concrete assistance the researchers will provide in doing so.
- A section that describes the governance of the project and how decision will be made, including a diagram/organigram to be appended.
- For grants that do not require CV documents from integrated knowledge users, a brief synopsis from key people outlining their respective organizations/communities and previous work they have done in the field (whether research or not).

d) Funding opportunities

Below are some examples of funding opportunities and mechanisms that require a partnership component to be built into the research process. A link is provided to allow for the search of CIHR opportunities. Select opportunities that require a specific research partnership are listed from SSHRC, other Canadian funding agencies, some provincial agencies and US opportunities. These opportunities have been identified from the agencies' respective websites and are in no specific order. It must be stressed that, although many of these competitions and mechanisms are ongoing, many others are unique, one-time funding opportunities or have only one or fewer funding cycles per year. Furthermore, additional opportunities specific to IKT may be added in the near future and other opportunities updated. Thus, for a comprehensive list of which opportunities are at present, please consult the website of the funding agency in question.

i) Canada

The two largest funding agencies open to IKT initiatives on a Canada-wide level are the Canadian Institutes of Health Research (CIHR) and the Social Sciences Humanities Research Council (SSHRC). Summarized in the tables below are some of their main funding initiatives with a partnership focus. *These opportunities have been identified by searching their online funding databases with the keyword 'partnership'.*

CIHR

To find funding opportunities made available by CIHR, see their [Funding Opportunity Database](#). The Operating Grant Program has now been expanded to include provisions for researcher-knowledge user partnerships as well as targeted knowledge translation projects. Examples of funding opportunities with a specific focus on partnerships include:

- Meetings, Planning and Dissemination Grants
- Partnerships for Health System Improvement
- Knowledge to Action
- Knowledge Synthesis

SSHRC

The list includes all grants with a specific partnership focus. Check frequently with [SSHRC](#) and individual institutes for special Funding Opportunities.

- *Aboriginal Research: Development Grants:* To help teams of Aboriginal community organizations and university-based researchers develop research partnerships and proposals to investigate issues of concern to Aboriginal peoples.
- *Aboriginal Research: Research Grants:* To support university-based researchers and Aboriginal community organizations to conduct research on issues of concern to Aboriginal peoples.
- *Capturing the Outcomes and Impacts of Publicly Funded Research:* To support research that will develop more effective ways to identify and assess the impact of Canadian research.
- *Community-University Research Alliances (CURA):* To support research projects jointly developed and undertaken by postsecondary institution-based researchers and organizations from the community.
- *International Community-University Research Alliances (CURA)—in Partnership with the International Development Research Centre (IDRC):* To support research projects jointly developed and undertaken by community organizations and postsecondary institutions in Canada and low- and middle-income countries.
- *International Opportunities Fund: Project Grants:* To support projects that secure Canadian participation in international research initiatives or networks.
- *Northern Research Development Program:* To support research in and about the Canadian North, with emphasis on involving local stakeholders.

Canadian Health Services Research Foundation (CHSRF)

[CHSRF](#) has two funding opportunities targeted specifically toward partnership initiatives that must involve knowledge user integration. Note that CHSRF uses the term ‘knowledge exchange’ rather than CIHR’s preferred ‘knowledge translation’. These two opportunities are summarized below:

- *Decision Support Synthesis Program:* The Decision Support Synthesis program aims to contribute the best available evidence to decision-making in a particular policy or management context. Decision support syntheses are driven by the information needs of decision makers and produce recommendations for policy and management through a deliberative process that involves key stakeholders. These syntheses incorporate different types and sources of evidence, including research results and promising practices. (1 year, maximum \$65 000 from CHSRF (matching funding, cash or in-kind, must be found from a partner))
- *Research, Exchange and Impact for System Support (REISS) Competition :* Developed in consultation with researchers, decision makers, and funders across Canada, the REISS competition combines elements known to fuel collaborative, evidence-based support for

the organization, management, and policies of the Canadian healthcare system. The result is a unique funding model that goes beyond traditional research funding to promote high-potential-impact research, high-quality capacity-building initiatives, and effective dissemination and implementation of results. (4 years, maximum \$500 000 split over the course of the project)

ii) Provincial

Most provinces offer research funding through provincial agencies. Please visit the websites for your province.

iii) United States

Most US grants must be held at an American institution. However, many have international collaborative components and most can include international (i.e., Canadian) co-investigators. Most governmental grants are administered through the National Institutes of Health (NIH). For a comprehensive, continually updated list of US funding opportunities, please consult the [Community-Campus Partnerships for Health's website](#).

Key Funding Opportunity Websites:

- [Community-Campus Partnerships for Health \(CCPH\)](#)
- [Canadian Institutes of Health Research \(CIHR\)](#)
- [Fonds de la recherche en santé du Québec \(FRSQ\)](#)
- [Social Science and Humanities Research Council of Canada \(SSHRC\)](#)
- [National Institutes of Health \(NIH; USA\)](#)
- [Centers for Disease Control and Prevention \(CDC; US\)](#)

MODULE 9: DISSEMINATION AND KNOWLEDGE TO ACTION

Learning objectives:

- Reflect on the goals of disseminating results that include both increasing knowledge and using results for ‘knowledge to action’.
- Agree on who are the audiences to reach, how to craft the central messages and the importance of the messenger; understand the differences between passive and active dissemination.
- Assess facilitators and barriers for and against uptake of results.
- Evaluate the dissemination process (when appropriate).

a) A dissemination plan

Before dissemination can occur, researchers and integrated knowledge users need to jointly interpret the data, agree on the final results and key points and craft the messages for different audiences. This process culminates with the development of a *dissemination plan*, a crucial component of any IKT project that will advance knowledge and promote using that knowledge for change in addition to identifying which team members will be responsible for the different milieux of dissemination. By definition, the IKT project starts with the participation of integrated knowledge users as representatives of one or several stakeholder groups (e.g., professional bodies) that could use or be impacted by the research results. Furthermore, many partnership grants now require a detailed description in the research proposal of how, by whom and to whom the dissemination will be carried out (section 8). Thus, even at the initial planning stage, the partnership should have a well-established dissemination path within their own organization and to other key individuals, groups or organizations.

Once results of the project have been produced, the partners must review their initial plans to ensure they are still appropriate and achievable. Actual results may necessitate new or additional dissemination strategies and partners may have changed along the way. Strategies may depend upon such considerations as the strength of the findings, if results are new or if they add to existing knowledge, their potential applicability or, if they are too preliminary or contradictory, whether widespread dissemination would be beneficial. Furthermore, the actual results may implicate further knowledge users who were not identified at the outset (see figure 2[a] in section 2).

Case study 9(a): Dissemination for KSDPP

The Kahnawake Schools Diabetes Prevention Project (KSDPP) started in 1994 as a partnership between the Mohawk community of Kahnawake (population 7,500 people), represented through a Community Advisory Board (CAB), and researchers. Its goals are to improve healthy lifestyles to reduce the high rates of type 2 diabetes. In 2002, follow-up data of children in grades 1-6 showed improved nutrition and stable physical activity levels, but increased weights. These results were first jointly interpreted by CAB and researchers and then shared with the entire community. A team of six people, including CAB members, local nutritionists and researchers, crafted a twenty minute presentation in everyday language. This included the known risk factors for developing type 2 diabetes, the rationale for improving lifestyles and the eight-year KSDPP results. The same presentation was made by 2-3 people (CAB and

researchers) to 14 organisations and at two open community meetings. Notes were taken of the wide ranging discussions followed each presentation and attendees completed a short questionnaire regarding their satisfaction with the presentation and recommendations for future KSDPP interventions were solicited. The lessons learned included: the time needed to develop and make the presentations; the importance of joint CAB-researcher presentations; using community knowledge to guide the experience and ways of attracting an audience; the difficulty of reaching men; the importance of feedback from those attending the presentations; and the need to plan prospectively for analyzing attendee feedback. The community feedback was used to improve future interventions and finalize interpretation of the results before submitting a scientific paper for publication. (Macaulay, 2007 and Paradis, 2005)

What is the most effective way of reaching and interacting with knowledge users? Much has been written about dissemination, so the following is a summary of key points identified in the literature. Readers are encouraged to learn more from the references and, visit websites and resources dedicated to knowledge translation and knowledge to action activities.

Summary points:

- A dissemination plan, developed collaboratively by researchers and integrated knowledge users, is a key component to all IKT projects
- The preliminary dissemination plan, developed at the project's outset, should be reviewed and revised as needed once the results have been produced
- There are many web-based resources for knowledge translation and knowledge to action, see *suggested reading* at the end of this module

b) Goals of dissemination

Dissemination goals include the traditional objectives of increasing knowledge within the research community, including researchers from different disciplines, teams and countries. As IKT involves a partnership, researchers should consider inviting integrated knowledge users to share in delivering any presentations, including at scientific conferences. One activity specific to IKT is joint authorship between researchers and integrated knowledge users. This will be very familiar to anyone who has previously jointly authored papers based upon team efforts; the lead author is generally responsible for the bulk of the writing, with some others contributing specific content, and all authors being responsible for reviewing and accepting the final draft. Standard authorship guidelines should still be enforced, with authorship only going to those who have contributed meaningfully to the project in some accepted way (see CIHR's authorship guidelines).

What differs in the IKT case is that several of the co-authors may have little or no experience, not only in writing scientific articles, but also in being familiar with their style and format. Furthermore, what constitutes 'meaningful' contribution to the study might be a bit different from cases where all team members are researchers. Integrated knowledge users should be encouraged to actively participate in authorship and many will find the experience rewarding and even empowering. Integrated knowledge user authorship should not, however, be used as a

‘rubber stamp’ of authenticity, especially in the context of research with marginalised or disempowered groups. All partners should ensure that listed authors have, in fact, made a real contribution to the study or paper. This process might include sitting down with integrated knowledge users and helping them write, or even providing them with a temporary research assistant. In all cases, this should be done with respect and acknowledgement that the integrated knowledge user has a unique contribution to make to the final product. (See the [Kahnawake Schools Diabetes Prevention Project Code of Research Ethics \(2007\)](#) for authorship guidelines addressing contribution of community members.)

In most joint authorship cases, one of the researchers will take the lead for articles targeted at scientific audiences. This is both for reasons of writing experience and for more pragmatic reasons such as better ‘marketing’ of the article in fields where the author’s name is known. Furthermore, it should be acknowledged from the project’s outset that academic publication is one of the key outputs that the researchers require from the partnership. Integrated knowledge user partners may lead writing teams as well. In any study, there will likely be room for several publications. Integrated knowledge user partners should appropriately serve as lead author for publications to professional journals in their communities of practice and community members should appropriately lead the writing of articles aimed at community-based audiences (e.g., in the local media). Also consider writing articles about the process in addition to the outcomes.

Research results will also increase the knowledge of all the other team members who are well-positioned to decide how to inform their own group or organisation. Other potential groups to reach include policy makers, decision makers, funding agencies, health professionals, industry, the public and the media. Remember to think *creatively* in the dissemination process – e.g., would it be appropriate to create videos and DVDs, tools appropriate for various audiences, handouts in lay language, etc. See the CIHR website for [an example](#) of how theatre performances were used for dissemination.

Summary points:

- As equal partners, integrated knowledge users should be invited to be co-authors on all publications and co-presenters at conferences
- Authorship should be determined based upon the typical guidelines of level of contribution to the project and manuscript preparation
- Integrated knowledge users should take the lead in disseminating results within their own context and community

c) Knowledge translation as ‘knowledge to action’

CIHR [defines knowledge translation](#) “as *taking place within a complex system of interactions between researchers and knowledge users, which may vary in intensity, complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user*”. This recognizes that knowledge translation is not just the transfer of information, but requires multifaceted interactions between those who create knowledge and its potential users. Although there is need for more information as to how new knowledge is adopted into practice, the literature shows that new knowledge is socially constructed, negotiated and adopted: 1) through both communication and by people of influence,

and through social networks that link peers and similar organizations; 2) by the presence of peers, opinion leaders and champions; and 3) especially by tailoring the message to the language, values and needs of the organization (Greenhalgh 2004).

It is important to choose the right team member as ‘the messenger’, since people learn best from their peers, opinion leaders and champions. If an integrated knowledge user – as the most appropriate ‘messenger’ – feels diffident in explaining complex research results, this person could ask a researcher to be present as a back up in order to provide the scientific knowledge. If possible, the person disseminating the information should first make contact with a leader or champion in the other organization or group in order to understand their experiences, information needs, appropriate language and values, to adapt the results for the organization and, finally, to decide on the format of the knowledge translation activities together with the organizational leader. It is important to allow for extensive dialogue to discuss new knowledge and its potential applicability.

Knowledge translation processes are diverse, distinct and linked to local structures, geography, history and culture. For example ‘...understanding local Indigenous processes of knowledge creation, dissemination, and utilization is a necessary prerequisite to effective KT, including health promotion practice in Indigenous contexts” (Smylie et al. 2008). This overall philosophy applies to all groups and cultures. It is just as important to understand how knowledge is generated, understood and utilized in communities of practice as it is for ethnicity-based communities.

Knowledge translation activities include both passive and active ways of transmitting information. These methods have been [described](#) as:

1. Diffusion is the passive and most broadly aimed strategy and often does not result in changing behaviour (e.g., peer and non-peer reviewed publications, including open access journals, websites, social networks, use of mass media)
2. Dissemination is more active and targeted to individuals and organizations with shared interests (e.g., summaries/briefings to stakeholders, educational sessions with patients, practitioners and/or policy makers)
3. Implementation is active, targeted and involves ‘systematic efforts to encourage adoption of the results’ (e.g., educational activities, identifying and overcoming barriers).

Case study 9(c): Using diffusion of innovations theory to guide implementation of a diabetes management program: an illustrative example

This article is worth reading in its entirety as a good example of how an excellent two year pilot project with end of grant knowledge translation activities was unable to secure continued funding. Further funding was needed to continue the intervention, which included additional nurses to coordinate the care of patients with type 2 diabetes. The authors of this paper make suggestions as to how this project and other projects could use the principles of integrated knowledge translation to increase the chances of ‘sustaining long term implementation into real world settings’. This includes the ‘Who’, ‘What’ and ‘How’ of the knowledge to action plan. ‘Who’ starts with forming early strong partnerships with government departments and community organizations, health planners, administrators and patients for their greater understanding of the need for improved services and their advocacy role in continuing to provide continued funding. ‘What’ includes clear communication of risks and benefits associated with the values, interests and power of the stakeholders in addition to identifying the champions and opinion leaders. Finally the ‘How’ recommends that the entire team evaluate barriers, hold regular working group meetings of all the stakeholders, ensure stakeholders are regularly updated and have a real say in all the decisions.

(De Civita, 2007)

It is always worth the time and effort needed to assess facilitators and barriers for and against uptake of results. Here, the varied expertise of everyone at the table, especially the integrated knowledge users, will be of great use. The factors found to be associated with a successful knowledge translation strategy include dissemination among peers by the different members of the research team, adaptation of research results for users, acquisition efforts by the users, pre-existing formal and informal linkage mechanisms, source of funding, type of research results, and the contexts of users and research team Please visit “[Knowledge Utilization – Utilisation des Connaissances \(KUUC\)](#)” for an excellent summary of KT recommendations and examples of adapting research results for very different groups.

If possible, it is always useful to track evidence of useful initial dissemination and sustained knowledge use by evaluating the outcomes. Documentation of the short- and long-term outcomes would also add to the literature on KT activities. In summary – in the words of Jacqueline Tetroe, [Knowledge Translation at CIHR: A Primer](#) – “Generally, the intensity of knowledge translation should depend on factors such as the potential importance/impact of applying the findings; the amount and strength of the evidence supporting the findings (often determined only by synthesis); the target audience(s); what is known about effective strategies to reach the audience(s); and what is practical, ethical, and feasible to do under the circumstances”.

Summary points:

- Knowledge to action requires a multifaceted approach to bringing together creators of knowledge with its intended users
- The messenger is key, and should be a leader or champion within the context in which the message is being disseminated
- Assessing the facilitators and barriers to implementation of research results in bring knowledge to action can be helpful in modifying the message and making it more likely to be integrated into practice

Key resources and references

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<http://kuuc.chair.ulaval.ca/ctci/>

MODULE 10: EPILOGUE

Recall the hypothetical case study presented at the outset of these training modules. The INEPT team was struggling to implement their new tool for assessing nutrition level – i.e., to move their *knowledge into action*. What are the main lessons they can learn from the IKT approach after reading these modules?

- An IKT approach to research increases the *relevance* and *pertinence* of its results, thus making them more likely to be implemented into day-to-day practice
- To accomplish this, IKT involves a *partnership* between researchers and integrated knowledge users at all crucial stages of the research process
- *Integrated knowledge users* include: practitioners, patients, caregivers, communities, community-based organizations, health care institutions, decision-makers, policy makers and other stakeholders in the research results
- All partners in this partnership are *equal* and each brings their own *expertise* to the table
- *Barriers and facilitators* are present in any IKT project and need to be identified early on and overcome/enhanced
- Research needs must be *jointly identified* by both researchers and knowledge users, and then turned into researchable questions
- *Governance* of the project should be shared and a procedure agreed upon for joint *decision-making*
- IKT projects may require a different *ethical framework*, especially when being reviewed by Research Ethics Boards
- *Written partnership agreements* can provide clarity and serve to build trust between partners
- IKT projects require *ongoing partnership maintenance*
- Integrated knowledge users should play an equal part in any *dissemination plan*
- Do not engage in an IKT project if the *readiness factor* is just not there

With this in mind, the INEPT team has decided to re-brand itself as the ‘Experienced Partnership-Engaged Research Team’ (EXPERT). They are now going to apply for a *new* research grant in order to re-work their nutrition tool using an IKT approach.

Experienced-Partnership Engaged Research Team (EXPERT)

First, the EXPERT team thought about the potential knowledge users of their tool. They decided that there are four main groups: 1) health care planners, who will be responsible for wide-scale adoption of the tool through setting policy and procedures; 2) family physicians, who will actually use the tool during their patient appointments and counsel their patients based upon its results; 3) nutritionists with both nutrition knowledge and expertise in counselling patients; and 4) patients, who will have to act upon the results to change their eating habits and lifestyle choices.

With this in mind, the EXPERT researchers decided to target representatives from each of

these groups. They first asked their colleagues if there are any pre-existing linkages between themselves and/or their university and representatives from these groups. One colleague replied that she had previously worked with a Patient Committee at a local hospital, so the EXPERT team contacted them in writing and then attended one of their meetings to solicit their participation. Another colleague had a neighbour who was a nutritionist and also suggested asking the Department of Family Medicine at the university to send around an email on their listserv network. Without any pre-existing linkages with health care planners, the EXPERT researchers decided to contact the Director of Professional Services at their local health agency, present their case, and then ask with whom they should get in contact (i.e., snowballing).

From these preliminary contacts, they then decided upon the exact individuals with whom to partner – i.e., which knowledge users to ‘integrate’. They considered a number of factors of ‘fit’, including how well-placed these knowledge users are to bring about change, whether their agendas can be made congruent with those of the researchers and the ‘readiness factor’. These individuals were invited to become members of the EXPERT research team, which is now a partnership.

Then the EXPERT partnership decided to hold a one-day workshop that brought together all the partners. There, the researchers presented the results of the previous study and their goal for developing a shortened tool with high scientific psychometric properties. However, most of the time was dedicated to having the integrated knowledge users present their needs for nutrition and its assessment. Issues identified included: health planners expressed the need for a comprehensive and very specific action plan detailing the steps necessary for implementing the tool in practice (i.e., what human resources are needed, who will act as the ‘messengers’ in health care centres); patients expressed issues like the need for follow-up care, financial concerns and monitoring if the tool shows inadequate nutrition (e.g., through referral to already-existing community resources, key educational materials they would require); nutritionists were concerned about how the rigidity of a standardised tool could be balanced with individual client goals; and family physicians expressed concerns about time (e.g., shortening the tool through reliability analysis). The partnership then set about designing a new research project, based upon these identified needs, that also brings together the researchers’ previous project experience, with strict and rigorous scientific standards.

Together, the partners developed a series of research questions based upon discussions in the workshop. A few of these were designated as priorities for a research project through further discussion, via teleconference and web conferencing as some partners could not travel to the researchers’ university on a regular basis. Then, the partnership set about jointly writing a research grant. The researchers were able to contribute their knowledge of the literature and scientific expertise and the integrated knowledge users were able to contribute their day-to-day experiences of being people who could potentially benefit from the knowledge to be gained. The policy makers worked to develop a comprehensive dissemination plan with exactly what other policy makers would look for in such a plan if they were to be convinced enough to implement the tool on a wide-scale basis. The patients and nutritionist offered to help develop a patient-friendly guidebook to be circulated in case of a ‘positive’ test. Finally, the family physicians suggested that rather than having them administer the tool, try adapting it for use by

nurses who typically already take blood pressure, height, weight, etc. As such, it was decided to bring a nurse in as a partner on the research team.

In jointly working on this grant submission to develop, test and implement the revised and shortened tool, the partners also discussed their roles, rights and responsibilities. The integrated knowledge users would become co-applicants on the grant, and one of them would be nominated as Co-Principal Investigator. They would have the right to be equally involved in all major decisions during the research process and have their name attached in any documents sent for external dissemination, including co-authorship on scientific articles. Their responsibilities would include providing timely responses to the researchers when important decisions had to be made and disseminating results within their milieu. The researchers' rights would be to be able to publish the results of this new study. Their responsibilities would be to ensure the fair and equitable participation of the integrated knowledge users throughout the project, and to get their consent before any publications are submitted or conference presentations made.

This led to more general discussions concerning governance and decision-making. The EXPERT partnership decided against setting up a formal Community Advisory Board and, instead, decided to make all integrated knowledge users part of the investigator or research team so that they would be involved in all crucial decisions during the course of the project and especially during the analysis phase. They also felt that consensus might not always be entirely possible and too time-consuming, so jointly decided that, as long as 70% of the members agreed with a decision, then it would be taken. All this, including the roles/rights/responsibilities, was written down in a short document constituting a partnership agreement and submitted as an Appendix to the grant.

The partnership also engaged in some critical reflection at this development stage to determine what some of the barriers/facilitators might be to integrated knowledge user involvement. Nutritionists and family physicians expressed concern that they did not have dedicated research time apart from their clinical duties, thus it was decided to make use of CIHR's mechanism for providing salary release time to partners. Patients felt as though they needed some travel expenses, such as mileage and parking, to attend meetings, and this was duly added to the grant's budget module. The main suggested facilitator was to rotate research team meetings between the university and some of the offices of the integrated knowledge users.

Finally, the EXPERT researchers and integrated knowledge users devised a preliminary dissemination plan that included joint authorship on any study publications (which implies integrated knowledge user support of the findings) and presentation of results at conferences relevant to their professional domain by partner family physicians and nutritionists. These clinicians also were willing to become 'champions' of the new tool within their institutions and beyond as the 'public face'. The patients would push the Patient Committee of the hospital to devise an awareness campaign to encourage other patients to get assessed and provide the nutrition guidebook free of charge if they screened 'positive'.

As the partners look back on this whole grant-writing exercise, they feel as though they have gotten much more out of it than a funding application. Critically, trust has been developed

between the integrated knowledge users and researchers and a general feeling of co-ownership of the research project has been fostered. They are now optimistic that they can create a good nutrition assessment tool, in terms of scientific reliability and feasibility for moving it from knowledge to action.

We thank you for taking the time to read these modules and sincerely hope that you have found some useful information contained therein. We wish you the best of luck with your IKT projects!

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