Turning Knowledge into Action: Practical Guidance on How to Do Integrated Knowledge Translation Research

Edited by:
Ian D. Graham
Jacqueline M. Tetroe
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Lippincott-Joanna Briggs Institute Synthesis Science in Healthcare Series: Book 21

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The Lippincott-Joanna Briggs Institute Synthesis Science in Healthcare Series

Series Editor: Professor Alan Pearson AM

This series of concise texts is designed to provide a “toolkit” on synthesizing evidence for healthcare care decision-making and for translating evidence in action in both policy and practice. The series seeks to expand understandings of the basis of evidence-based healthcare and brings together an international range of contributors to describe, discuss and debate critical issues in the field.

Incredible developments have occurred in the synthesis and use of evidence in healthcare over the last several years, but the science and emerging practices that underpin evidence based healthcare are often poorly understood by policy makers and health professionals. Several emerging and exciting developments have much to offer health professionals. First, new, deeper understandings of the nature of evidence and of ways to appraise and synthesize it have led to the development of more sophisticated methodologies for synthesis science. Second, the realization that the rapid increase in the availability of high quality evidence has not been matched by increases in the translation of this evidence into policy and/or clinical action has spurred on developments in the science of knowledge implementation and practice improvement.

The burgeoning publications in this area – particularly books on evidence based healthcare – can go only so in informing responsible and conscientious policy makers and healthcare practitioners. This new series Lippincott/Joanna Briggs Institute, “Synthesis Science in Healthcare,” is devoted to communicating these exciting new interventions to researchers, clinicians on the frontline of practice and policy makers.

The books in this series contain step-by-step detailed discussions and practical processes for assessing, pooling, disseminating, and using the best available international evidence. In all healthcare systems, the growing consensus is that evidence-based practice offers the most responsible course of action for improving health outcomes. All clinicians and health scientists want to provide the best possible care for patients, families and communities. In this series, our aim is to close the evidence to action gap and make that possible.

About the Editors

Ian D. Graham PhD, FCAHS, is a Professor in the Department of Epidemiology and Community Medicine at the University of Ottawa and Senior Scientist at the Ottawa Hospital Research Institute. His research program focuses on studying the use of evidence in practice. Between 2006 and 2012 he was on an interchange with the Canadian Institutes of Health Research where he served as the Vice President of Knowledge Translation and Public Outreach. He is co-originator of the Ottawa Model of Research Use, the Practice Guideline Evaluation and Adaptation Cycle, the ADAPTE process and the Knowledge to Action Cycle. He is co-editor of Knowledge Translation in Healthcare (2013, 2nd edition) and Evaluating the Impact of Implementing Evidence-based Practice (2010).

Jacqueline M. Tetroe BA, MA, RP, recently retired from the Canadian Institutes of Health Research, Canada's primary health research funding agency, where she was a senior advisor in knowledge translation. She has worked in health research for twenty years, with a particular interest in population health, evidence based medicine, clinical practice guidelines, organizational change, aboriginal health, and the theory and practice of moving knowledge into action. Jacqueline is co-editor of Knowledge Translation in Healthcare published by Wiley Blackwell BMJ Books (2013, 2nd edition).

Alan Pearson AM, MSc, PhD, FCNA, FAAG, FRCN (UK), FAAN, is Professor and Director of the National Health and Medical Research Council Centre of Research Excellence for Aboriginal Chronic Disease Knowledge Translation and Exchange (NHMRC CREATE), Joanna Briggs Institute, School of Translational Health Science at The University of Adelaide, Australia. He was the founder and Executive Director of the Joanna Briggs Institute and Head of the School of Translation Health Science until December 2013. Professor Pearson is Editor-in-Chief of the International Journal of Nursing Practice.

Chapter 2-5 are revisions, modifications, or updates of knowledge translation learning modules developed for the Canadian Institutes of Health Research and the editors would like to thank all who have provided input and feedback on the learning modules as well as these chapters.

About the Authors

Sarah Bowen, BA, MSc, PhD, is an Applied Research and Evaluation Consultant, with extensive community and health system experience in promoting evidence-informed action. Previously an Associate Professor, School of Public Health, University of Alberta she designed and taught specialized courses for PhD students in Engaged Scholarship/Knowledge Translation. As the founding director of the Winnipeg Regional Health Authority Research and Evaluation Unit, she developed an interdisciplinary team with expertise in promoting and facilitating use of evidence in policy, planning and practice. Her research interests focus on collaborative approaches to evaluation research; promoting action on issues of disparity and diversity; and organizational change to promote knowledge utilization.

Sandy Campbell, MA, is a Knowledge Translation Specialist currently based in New Mexico, USA. He has been active in the field of KT since 2003, first with Canada's International Development Research Center, and, since 2008, as an independent consultant. His specialties include the development of Knowledge Translation Platforms in Low and Middle Income Countries, KT strategic planning, and communications. His clients include EVIP Net of the World Health Organization, the Canadian Coalition for Global Health Research, and he is currently part of a research project investigating priority setting within Zambia's Ministry of Health.

Sonia Angela Castiglione, RN, MSc (A), is an Evidence-informed Decision-Making Advisor in the Nursing Research-Centre for Knowledge, Innovation and Action at the McGill University Health Centre (MUHC), Montreal, Canada. Sonia is a knowledge broker and facilitates evidence implementation.

Ann C. Macaulay, CM, MD, FCFP, is Professor of Family Medicine and Inaugural Director of Participatory Research at McGill University. She has been honored with lifetime achievement awards in family medicine and primary care research from the College of Family Physicians of Canada and the North American Primary Care Research Group; was named College of Family Physicians of Canada Family Medicine Researcher of the Year (2008) for contributions to participatory research; was inducted to the Order of Canada for contributions to Aboriginal Health; and is a foreign member of the Institute of Medicine of the US National Academies. Ann has practiced community-based medicine since 1969 and has been engaged in community-based participatory research since the early 1990s.

Robert K. D. McLean, MSc, is a Senior Program Specialist at the International Development Research Centre and an Evaluator at the Canadian Institutes of Health Research, Ottawa, Canada. His research interests focus on the intersection of knowledge translation and evaluation.

David Parry, BA, LLB, BCL, is a Research Associate with Participatory Research at McGill University. He is a lawyer with specific interests in criminal law and bioethics. David has served on the National Task Force on Ethics Reform at the Canadian Institutes of Health Research and as ethics advisor to both university and hospital ethics review boards. David has also worked on a project with the Kazakh Government and World Bank to develop capacity and governance structures for technology transfer and institutional reform in Kazakhstan's health research system.

Judith Anne Ritchie, PhD, is Professor Emerita at McGill University, MontreaL, Canada where her research focused on ways to improve patient outcomes by changing nursing practice, work organization and nurses' work environments by studying the effect of efforts to implement evidence-based guidelines, approaches to care organization, involving patients in re-design of care, and ways of sustaining practice changes so as to make care safer for patients. Judith is currently a consultant in Translating Knowledge into Practice.

Jon Salsberg, MA, PhD(c), is Associate Director of Participatory Research at McGill University. He is a qualitative researcher with a background in public health promotion and the anthropology of development, with over thirteen years of experience working in community and academic participatory research and integrated knowledge translation. Jon has undertaken partnered research involving a broad range of stakeholders including patients, health practitioners, community organizations, policy makers and health service decision-makers, and has worked with both northern and southern Indigenous communities. Jon currently teaches introductory and advanced participatory research in the McGill University Faculty of Medicine.

Contents

CHAPTER 1

Some Basics of Integrated Knowledge Translation Research

By Ian D. Graham, Jacqueline M. Tetroe, and Robert K. D. McLean

Learning Objectives

- To understand what integrated knowledge translation research (iKTR) is and is not
- To learn about the benefits and challenges of conducting integrated knowledge translation research

What is knowledge translation?

Many terms are used to refer to the concept of turning knowledge into action or translating research into practice and policy. Over a hundred terms for this concept were identified in one study looking at the literature published in 2006 (McKibbon et al, 2010) and over 80 terms describing the concept are located on the What Is KT wiki McKibbon, Lokker, & Mathew, 2014). Common terms used to refer to this general notion of moving knowledge into products, practice, programs and policy including include: dissemination, adoption, research use; knowledge mobilization; knowledge transfer; knowledge exchange; knowledge translation; research transfer; research translation; commercialization; knowledge to action; implementation, Translation 1 (T1), Translation 2 (T2) and translational research (Graham et al.; 2006, McGibbon et al., 2010; Tetroe et al., 2008).

The Canadian Institutes of Health Research, Canada's health research funding body defines knowledge translation as:

> *a dynamic and iterative process that includes* ***synthesis, dissemination, exchange and ethically sound application*** *of knowledge to improve health, provide more effective health services and products and strengthen the healthcare system. This process takes 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.*
>
> (adapted Canadian Institutes of Health Research, 2014)

There are four key elements that delineate the scope of translation described in Canadian Institutes of Health Research's definition. **Knowledge synthesis** is the contextualization and integration of research findings from individual studies within the larger body of knowledge on the topic. This is an important step in determining when the strength of the evidence is sufficient to warrant wide spread dissemination and application. Without synthesis, there is risk of diffusion and adoption of unproven innovations and/or potentially harmful ones.

Dissemination involves identifying the appropriate audience for research findings, and tailoring the research message and the medium to the audience to ensure optimal awareness and understanding of the message. The rational for this is that potential audiences must be aware of the research and innovations if they are to be able to act on them.

The concept of **knowledge exchange** refers to the interaction between knowledge-users (those who can inform their decision-making with research) and researchers (the knowledge producers) that result in mutual learning and knowledge use. **Ethically sound application of knowledge** refers to the iterative process by which knowledge is actually considered, adapted and put into practice and used to improve health and the health system. Implicit in this concept is the notion that all KT activities must be consistent with ethical principles and norms, social values, as well as legal and other regulatory frameworks (Canadian Institutes of Health Research, 2012; Graham & Tetroe, 2007; Graham & Tetroe, 2009a).

While there are differences and nuances between the definitions of the various terms outlined above, what most have in common is that the essence of translation is to close the gap between research and practice/policy by turning knowledge into action. This involves making sure that the proposed research is not focused solely and primarily on advancing knowledge, but addresses key issues and challenges of knowledge users. The findings from research must be accessible to potential knowledge users and the findings should potentially facilitate improved health outcomes.

What Are the Types of Knowledge Translation?

There are essentially three related but different types of knowledge translation that need to be differentiated. There is end of project knowledge translation (also known as dissemination), the science of knowledge translation (often referred to as implementation science) and integrated knowledge translation research (iKTR).

Diffusion, dissemination and application (Canadian Institutes of Health Research, 2012; Lomas, 1993) typically all occur after research findings become available and so can be thought of as end of project KT. Historically, researchers were only expected to encourage the **diffusion** of their findings by publishing or presenting them. Diffusion therefore is a passive process whereby knowledge is acquired by the end-user seeking it out via attending conference presentations or finding the publication or website posting. **Dissemination** is slightly more active and involves activities that tailor the message and medium to a specific audience, such as providing summaries/briefings of the findings to stakeholders, engaging knowledge-users in developing and executing the dissemination plan, engaging the media and the use of knowledge brokers. Finally, **application** of knowledge, which is quite active, involves moving research into practice or policy in cases where the strength of the evidence is sufficient to warrant its implementation. This may require understanding the context in which the research is to be used, adapting the knowledge for use, identifying barriers and supports to using the knowledge, developing and deploying interventions to facilitate knowledge use, monitoring knowledge use and measuring its impact. Ultimately though, implementation is the responsibility of those who would benefit from using the findings not researchers (unless the research findings were generated with an integrated knowledge translation research approach to address a problem identified by a knowledge user – this will be discussed below). Funding agencies traditionally expected their researchers to diffuse their research results, but are increasingly expecting them to disseminate their findings to target audiences (especially when these audiences are beyond the research community) and when possible to facilitate the application of their findings.

The science of knowledge translation (implementation science, implementation research) is*"…the scientific study of methods to promote the systematic uptake of clinical research findings and other evidence-based practices into routine practice, and hence to improve the quality (effectiveness, reliability, safety, appropriateness, equity, efficiency) of healthcare. It includes the study of influences on healthcare professionals and organizational behavior"* (Eccles et al., 2009, p.2). Knowledge translation research includes studying the determinants of knowledge use in clinical, community and policy contexts as well as developing and studying interventions designed to hasten knowledge use.

Integrated knowledge translation research is a way of approaching research to increase the chances that the results will be applicable to the population under study. It is a paradigm shift that focuses on engagement with end users and the context in which they work. Essentially it is a collaborative way of conducting research that involves researchers and knowledge-users, sometimes from multiple communities (e.g. clinicians, managers, policy makers, patients) working together as partners in the research process. Similar to concepts such as co-production of knowledge, participatory research, linkage and exchange, Mode 2 knowledge production, engaged scholarship, and community based research (Bowen and Graham, 2012; Denis and Lomas, 2003; Gibbons et al., 1994; Jogash et al., 2012; Macaulay et al., 1999, Salsberg et al., 2014), integrated KT research requires a collaborative approach to the research process that is action oriented and focused on solutions and impact.

This approach to research involves conducting research of direct relevance to stakeholders be they patients and the public, policy makers, health system managers, healthcare professionals, industry or others inside or outside of the healthcare system by engaging them in meaningful ways in the actual research enterprise. It starts with ensuring that the knowledge-user is involved with the researcher in shaping the research question. It can also include collaboration on decisions about study methods and outcome measures, data collection and interpretation of the findings, crafting messages around the findings, applying the findings in the real world, and widespread dissemination of the findings (Canadian Institutes of Health Research, 2012; Graham & Tetroe, 2008; 2009a; 2009b; Tetroe et al., 2011). Integrated knowledge translation researchis about finding solutions to knowledge-users problems so that they can apply the solutions in the real world. IKTR can also be considered to be implementation science in cases where generalizable knowledge has been created about how to facilitate research use.

Increasingly, integrated knowledge translation research protocols (Cummings et al., 2012; Rosella et al., 2014) and studies (Camp et al., 2013; Driedger et al., 2010; McGrath et al., 2009; Moodie et al, 2011; Munce et al., 2013) are being reported in the literature. Integrate knowledge translation approaches are also being used for conducting knowledge syntheses (Boote, Baird, & Roy, 2011; Higg in bottom et al., 2013), setting research agendas (Kothari et al., 2014), developing grant proposals (Henderson et al., 2013) and to guide quality improvement processes (Simunovic et al., 2013). Papers are also appearing describing how knowledge users (e.g. nurses) can be engaged in various phases of research (Abdullah & Stacey, 2014). There are also articles advocating for this approach or describing the potential benefits of conducting collaborative research (Bucknall 2012; Estabrooks, Teare, & Norton, 2012; Kothari & Wathen, 2013; Lapaige, 2010; Martens 2011; Michalak et al., 2012; Roberts & Burton, 2013). For descriptions of a number of IKTR studies see the Canadian Institutes of Health Research Knowledge to Action: Knowledge Translation Casebook (Canadian Institutes of Health Research, 2008).

How does Integrated Knowledge Translation Research Differ from the Traditional Approach of Knowledge Transfer?

Table 1 lays out some of the differences on the translation continuum by contrasting the knowledge transfer approach at one end of the continuum and integrated knowledge translation approach at the other. The typical or traditional approach of knowledge transfer is for researchers to conduct curiosity driven research and then release (diffusion) or disseminate the findings (pushing them) to potential knowledge-users (i.e. end of project knowledge translation). It is expected that research findings move from researchers to end users in a unidirectional fashion. On the other hand, an integrated knowledge translation research approach is about collaboration between researchers and knowledge users and answering the research questions of interest to the knowledge users. IKTR focuses on partnerships, respect, knowledge exchange, mutual learning and co-production of knowledge. As Table 1 reveals, the different approaches have implications for the purpose of the research; who is involved; when and how the research is conducted and the goal of knowledge translation.

Table 1: The KT Paradigms

The Knowledge Transfer Paradigm	The Integrated KTR (Engagement) Paradigm
Biomedical roots	Social science roots
Researcher unilaterally makes decisions about: ▪ the research question ▪ study design ▪ data collection approaches ▪ outcome measures ▪ analysis of results ▪ relevance of findings ▪ dissemination of findings	Coproduction of knowledge: researchers and users collaboratively make decisions on: ▪ the research question ▪ study design ▪ data collection approaches ▪ outcome measures ▪ analysis of results ▪ relevance of findings ▪ dissemination of findings
Users are subjects or collaborators to achieve researchers' goals	Researchers and users share decision- making power: they are equal partners
Research skills needed	Research and other professional and people skills and experiential knowledge needed and equally valued
Recipients may or may not use research results	Collaborative engagement between researchers and users facilitates assessment of results and their applicability
Focus on generic findings, applicable in all contexts	Recognition of non-research sources of evidence; importance of synthesis and application of research results in context
KT Goal: more availability of research	KT Goal: increased application of research through better quality, relevant research, ultimately improved health outcomes
Focus on communication and dissemination ▪ Information transmission – one way transfer from expert to users	Focus on partnership, power sharing and mutual respect ▪ Knowledge exchange – mutual learning
Focus on single issue/topic	Focus on multiple issues and change in how business done (research and health organizations)
Focus on content	Focus on process
Emphasis on dissemination of findings and perhaps increasing user capacity to use results	Emphasis on implementation and change management

(Adapted from Straus, Tetroe, & Graham, 2013; Bowen & Graham, 2013)

To be clear, there will always be an important role for researcher/curiosity driven research, especially where fundamental knowledge needs to be generated. In contrast, the emphasis of integrated KT research is on the more immediate application of research to address health and societal needs. The two approaches should be seen to be complementary rather than in opposition. As Louis Pasteur noted, *"There does not exist a category of science to which one can give the name applied science. There are sciences and the applications of science, bound together as the fruit of the tree which bears it"* (Wiki quote, 2014).

What Are the Benefits and Challenges of Using the Integrated Knowledge Translation Research Approach?

Evidence is emerging about the potential benefits and challenges of doing research using an integrated knowledge translation research approach. We will focus on four sources: a realist review that focused on participatory research, a study conducted on the benefits of stakeholder engagement in systematic reviews (Cottrell et al., 2014), Project RESTROSIGHT which studied the impact of cardiovascular and stroke research (Wooding et al., 2011; Wooding et al., 2013), and an evaluation of the Knowledge Translation Funding Program at the Canadian Institutes of Health Research (Canadian Institutes of Health Research, 2013; McLean et al., 2012).

Jagosh and colleagues (2012) have conducted the most comprehensive realist review of the participatory research (PR) literature to date and identified mechanisms by which PR adds value to the research process. The synthesis comprised twenty-three PR partnerships reported in 276 publications. They noted that the link between process and outcome in these partnerships was best explained using the middle-range theory of partnership synergy, which demonstrates how PR can (1) ensure culturally and logistically appropriate research, (2) enhance recruitment capacity, (3) generate professional capacity and competence in stakeholder groups, (4) result in productive conflicts followed by useful negotiation, (5) increase the quality of outputs and outcomes over time, (6) increase the sustainability of project goals beyond funded time frames and during gaps in external funding, and (7) create system changes and new unanticipated projects and activities.

Cottrell and colleagues (2014) in the United States conducted a review of the literature to examine the benefits and challenges of engaging stakeholders in the process of developing and performing systematic reviews and complemented their literature review with interviews with 34 key informants. In this study, the term **stakeholder** was inclusive of patients, caregivers, clinicians, healthcare organizations, government agencies, purchasers and payers, healthcare industry representatives, healthcare policy makers at all levels and healthcare researchers and research institutes. The literature review identified six potential roles for stakeholders engaged in developing systematic reviews:

- refining the scope of the review;
- improving the quality of the review;
- suggesting and locating relevant literature;
- interpreting the review findings and putting them into perspective;
- improving the readability and clarity of the reports; and
- contributing to wider dissemination and utilization of the findings.

The key informants identified the following contributions from engaged stakeholders:

- establishing credibility for the systematic review and buy-in;
- anticipating controversy that may be generated by the systematic review;
- ensuring transparency and accountability;
- improving relevance and enhancing quality of the systematic review; and
- increasing dissemination and uptake of the systematic review findings.

Several challenges related to engaging stakeholder were also identified in the literature:

- need for additional time and resources;
- concerns about representativeness of stakeholder perspectives;
- the ability of stakeholders to participate throughout the review process; and
- the potential for tokenistic involvement.

The key informants also identified the following challenges:

- engagement takes more time, training and resources;
- finding the right people;
- balancing multiple inputs; and
- understanding how to match the right type of stakeholder to the right time in the systematic review process.

The RETROSIGHT Project was a researcher-driven project focused on identifying the impact and payback from research funding. The study involved an international consortium of funders and collaborators from Australia, Canada and the United Kingdom. The design was a multinational case study comprised of 29 detailed case studies of research grants funded 15-20 years earlier. The focus of the case studies was on research proposals that had been awarded funding in the areas of cardiovascular and stroke research. The cases included both basic biomedical and clinical (including health services) research projects. Based on the PAYBACK framework, impact was assessed in terms of what the authors labeled academic impact (knowledge production, research targeting, capacity building), and wider impact (informing policy and product development, health and health sector benefit and broader economic benefit). When comparing the basic biomedical research cases with the clinical research cases, the basic biomedical research had greater academic impact. On the other hand, clinical research had wider impact on health policies, practice, and generating health gains. Project RETROSIGHT failed to find any correlation between knowledge production and wider impacts.

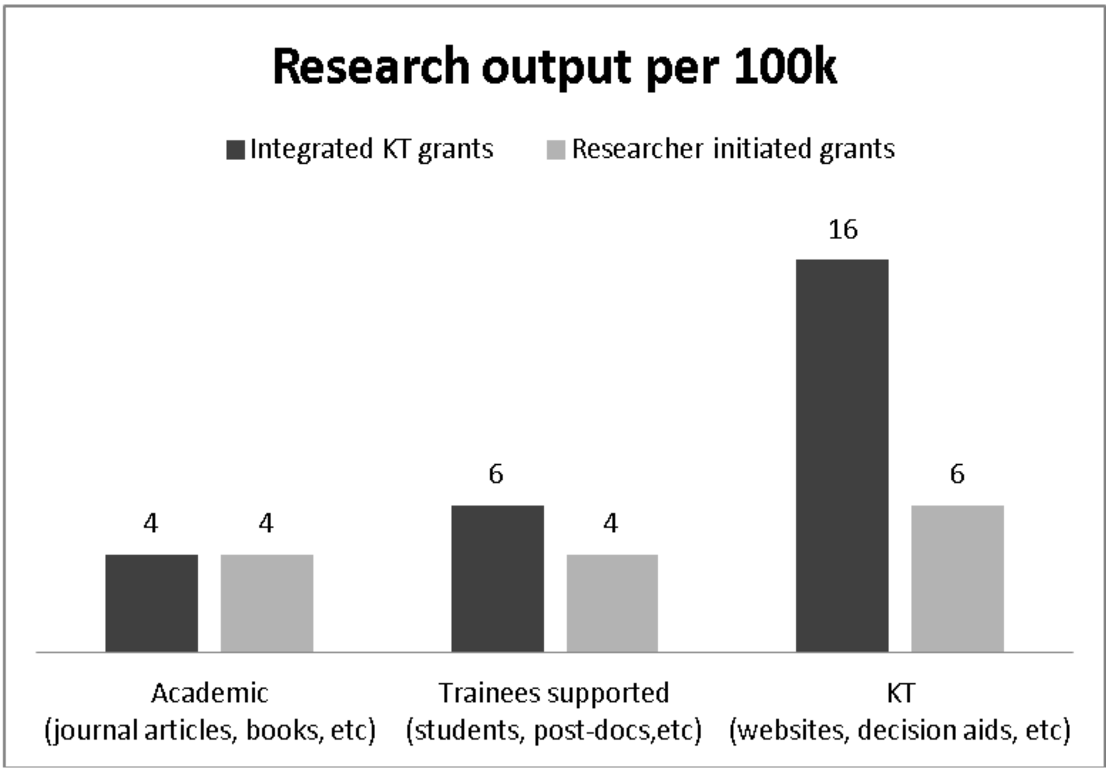
Two factors that correlated with higher impact, demonstrating the benefits of integrated knowledge translation research were: 1) “engagement with practitioners and patients [which was] associated with high academic impacts and high wider impacts,” 2) “basic biomedical research with a clear clinical motivation [was] associated with higher academic impacts and higher wide impacts”(i.e. biomedical research focused on addressing a clinical problem and often involving clinician-researchers)(Wooding et al., 2013, p.7).

In 2011, the Canadian Institutes of Health Research undertook an evaluation of its knowledge translation funding program (McLean et al., 2012). Included in the evaluation was an assessment of three integrated KT funding opportunities: the Knowledge Synthesis Funding opportunity (KS FO), the Partnership for Health System Improvement (PHSI FO) Funding Opportunity and the Knowledge to Action Funding Opportunity (K2A FO). All three require knowledge users (stakeholders) to be co-applicants on the grant proposal, and to demonstrate how: the research questions is addressing an important research need of the knowledge user, knowledge users are meaningfully engaged in the research process, and what their plans are for implementing the findings. In keeping with the philosophy of engagement, the grant proposals are subjected to merit review- a peer review process that includes both researchers and knowledge users on the panel (Canadian Institutes of Health Research, 2011). Each proposal is scored on potential impact/relevance as well as scientific merit by the researchers and knowledge users, and to be funded must score high on both criteria.

As a part of the evaluation, 344 Principal Applicants who had received funding for the KS FO the PHSI FO and the K2A FO were surveyed to gather information about program performance. The response rates by funding opportunity were: KS FO 61% (n=89), PHSI FO 35% (n=47) and K2A FO 43% (n=28). 591 Principal Applicants funded through Canadian Institutes of Health Research's open grants competition (researcher-driven research with no requirement to engage knowledge users) served as a comparison group. Twenty-nine funded KT researchers and knowledge users were also interviewed as part of the evaluation.

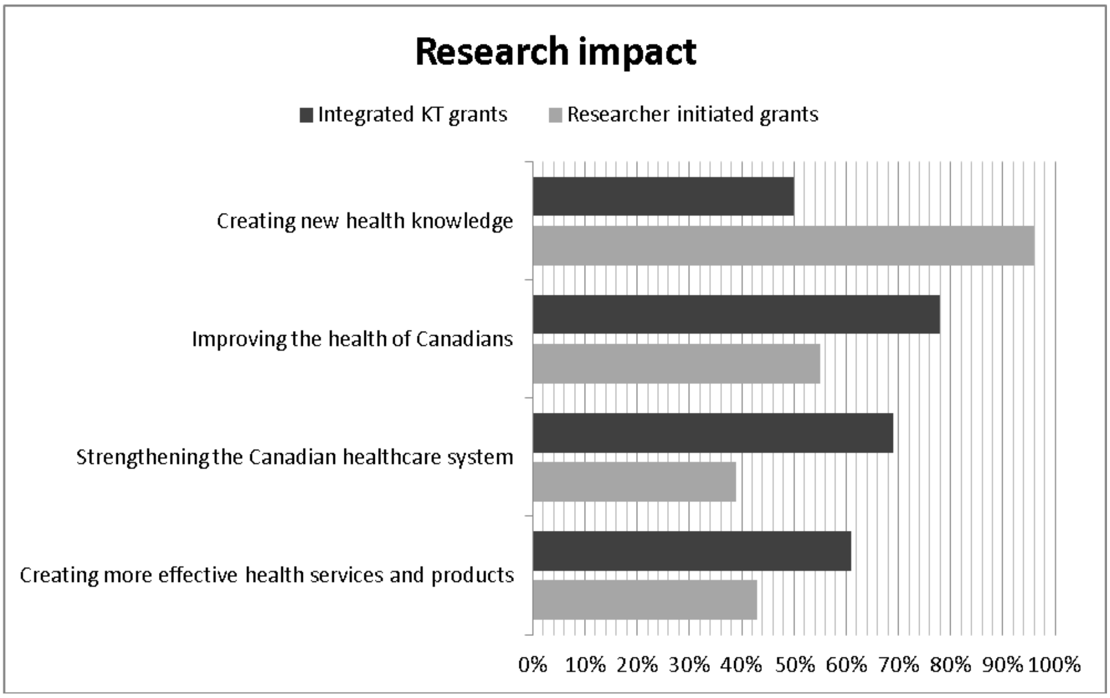
The evaluation study (Canadian Institutes of Health Research, 2013) revealed that for the same financial investment ($100,000), grants using an integrated KT approach produced the same number of publications, engaged more individuals in training, and had nearly three times the number of dissemination outputs as researcher initiated grants (see Figure 1).

Figure 1. Outputs Per $100,000 Investment in Research Grants



The Principal Applicants were also asked to what extent their study contributed to Canadian Institutes of Health Research's legislated mandate. Figure 2 presents the percentage of grants where the respondent indicated that their grant had contributed to each element of Canadian Institutes of Health Research's mandate. As the data reveal, Principal Applicants of the iKT grants were more likely to report improving the health of Canadians, creating more effectives health services and/or products and strengthening the Canadian healthcare system while Principal Applicants of researcher initiated grants were more likely to report creating new health knowledge.

Figure 2: Percentage of Principal Applicants Who Indicated Contribution to Each Area of Canadian Institutes of Health Research's Mandate



The interview component of the evaluation provided insight into the significance of researcher-knowledge user partnerships. The following quotes from one set of partners illustrate how the partnership played an important role in turning the research project into an impactful event.

"The most significant thing was that we ended up with a tool that practitioners can use. Too often research happens and then nobody knows what is going on; nobody hears about it. It's like a dinner party where you create a feast and then you don't invite anyone to the party." K2A FO knowledge user (Canadian Institutes of Health Research, 2013, p. 14)

"I think these partnerships have made me a better researcher. I am less naive. The greater the contact we have with non- researchers, the more we understand the world we are working in, and the problems that exist." K2A FO researcher (Canadian Institutes of Health Research, 2013, p. 14)

The qualitative findings further revealed that for those using an iKTR approach, meaningful partnerships were characterized by: *"mutual learning, mutual respect, mutually agreed upon roles and responsibilities, mutual recognition of efforts, and mutual exchange of information"* (Canadian Institutes of Health Research 2013; p15). The respondents also reported that 'mutual' means negotiating roles and not everyone needs to or should be equally involved in all aspects of the research process. As the report notes, "*meaningful partnerships are negotiated based on many factors including, but not limited to: resources, external commitments, technical skills, and epistemology"* (Canadian Institutes of Health Research, 2013, p. 15).

While considerably more research is needed on the benefits, challenges and impact of using an iKTR approach, the emerging evidence would appear to support the commonly held belief that through partnerships with knowledge users, research is strengthened and the application of research findings accelerated. Knowledge user/stakeholder engagement in the research process contributes to research being more solutions-based and relevant; increases knowledge user confidence in the results and the researchers; and because of knowledge user readiness to move the results into practice produces greater impact (improved healthcare and outcomes).

The chapters that follow offer practical guidance on how to: conduct collaborative (iKT) research (Chapter 2), undertake deliberative dialogue priority setting for research (Chapter 3), move research into action (Chapter 4), and conduct evaluation (Chapter 5). Each chapter identifies learning objectives, describes the key issues and relevant research, uses examples to illustrate concepts and ends by providing summary points.

In Chapter 2, Jon Salsberg, Ann Macaulay and David Parry provide a guide to integrated knowledge translation research. This chapter describes how the basic principles of participatory research support integrated knowledge translation research.

Sandy Campbell in Chapter 3 offers a guide to undertaking deliberative priority setting for research. He presents different approaches to deliberative priority setting that have been used and offers direction on how to undertake such a process in an iKT fashion.

In Chapter 4, Sonai Castiglione and Judith Ritchie provide guidance on how to promote the implementation of evidence by healthcare providers and organizations. Using the Knowledge to Action Cycle, they illustrate how to engage knowledge users, plan for and implement change in clinical settings.

In the last chapter, Sarah Bowen offers a guide to evaluation and illustrates how evaluation can enhance knowledge translation. This chapter defines evaluation, discusses it relationship with research, and reviews three major evaluation traditions, including the utilization tradition which focuses on engagement.

CHAPTER 2

Guide to Integrated Knowledge Translation Research: Researcher and Knowledge-User Collaboration in Health Research

By Jon Salsberg, Ann C. Macaulay, and David Parry

Integrated Knowledge Translation and Participatory Research

Learning objectives:

- Be able to define and distinguish knowledge translation and integrated knowledge translation research.
- Understand basic principles of participatory research and how they support Integrated knowledge translation research.
- Know when integrated knowledge translation research may not be appropriate.

What is knowledge translation? What is integrated knowledge translation research?

Health, its acquisition and maintenance, endure as pressing social and political priorities. The effectiveness and efficiency of the behaviors, practices and policies that support health have become key areas of research, with a modern focus on assuring that these are supported by best available evidence. Nevertheless, it has become clear that evidence is not being used to its best advantage (Straus, Tetroe, & Graham, 2013). This is often due to the fact that emergent knowledge does not reach those who must apply it in a timely fashion. One study strikingly demonstrates that it takes on average 17 years to turn 14 per cent of original research to the benefit of patient care (Weingarten S, Garb CT, Blumenthal D, Boren SA, & GD, 2000). Conversely, there is increasing awareness by researchers (but old news to clinicians) that much so-called best evidence is not deemed contextually relevant or suitable by those who must apply it (Lugtenberg, Burgers, Besters, Han, & Westert, 2011; Lugtenberg, Zegers-van Schaick, Westert, & Burgers, 2009).

As has been described in Chapter 1, knowledge translation (KT) is the attempt to bridge the gap between what we know (best evidence) and what we do (health behavior, practice and policy) (Straus, et al., 2013). It has been defined as *a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services, products and systems* (Canadian Institutes of Health Research, 2010). Knowledge translation then, in its most general form, can be described as getting the best knowledge into the hands of those who need it and facilitating their use of it. And for the most part, KT science has been about discovering and testing the best ways to do so. This has led to various KT models and action cycles for identifying action gaps, adapting evidence to local context, selecting, tailoring and implementing strategies to apply suitable evidence, monitoring and evaluating use and outcomes, sustaining knowledge use (Straus, et al., 2013). Best practice in this type of implementation research is participatory: the appropriate end-users of the evidence should be fully implicated in identifying the action gap, and in all the subsequent phases required to make the right evidence work for them (Jagosh et al., 2011; Straus, et al., 2013). This is *participatory implementation*. Knowledge users are involved in adaptation and application of the evidence, but not in the original studies that created it.

However, what if – as is increasingly the case, selection and tailoring of existing evidence is not enough? In other words, what if *no* evidence can be found by knowledge users that adequately and appropriately meets their action needs because the original research questions that led to the existing evidence were not, from their perspective, the relevant ones? Is there a different way to approach knowledge creation from the beginning that will anticipate and ameliorate this problem? As has been pithily commented, "if it is an evidence-based practice, where's the practice-based evidence?" (L. W. Green, 2008).

Integrated knowledge translation research. In contrast to standard KT – moving existing evidence into practice – *integrated KT* Research (IKTR) involves engaging and integrating those who will need to act on the findings, the knowledge users, into the research (knowledge creation) process. IKTR 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 application. By integrating knowledge users at every stage, KT becomes woven into the process and researchers minimize the possibilities of unanticipated barriers that may occur when attempting to act upon results with stakeholders (Bowen & Graham, 2013).

IKTR is most appropriate within the framework of action- or solution-oriented, as opposed to purely researcher initiated and 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 IKTR is that researchers and knowledge users make joint decisions to 1) shape the research questions; 2) interpret the results; and 3) craft messaging to move the research findings into practice. In some situations, this partnership is deepened so that knowledge users also participate in decisions on research methodology, tools development, data collection and analysis.

The significant advantages of IKTR are that the knowledge users understand their action needs (clinical, policy or otherwise), bring different expertise and skills to the research team, have an application-based insight into the interpretation of the results (which may differ from that of researchers), and are well positioned to move these results into practice. Researchers provide an expert skill-set for conducting research and accessing funding; they also 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, 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, briefing to stakeholders, educational sessions with health organizations, patients, practitioners and/or policy makers, creation of tools, commercialization 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.

IKTR relies on a partnered approach to research founded on an ever-growing body of experience encapsulated within the literature of *participatory research*. Participatory research has been defined by the Royal Society of Canada as *systematic enquiry with those affected by* *the issue under study to effect action or change* (L. W. Green et al., 1995), and is increasingly recognized as a highly effective method of enhancing relevance and value in health research (Israel, Schulz, Parker, & Becker, 1998; Jagosh et al., 2012; Macaulay et al., 1999). The equally important goals of participatory research are to undertake quality research, provide benefit to the local knowledge users while developing knowledge that is applicable to other settings (Macaulay, et al., 1999). Scientific rigor should not be sacrificed. Indeed, one systematic review of participatory research noted that the strongest projects were the most scientifically rigorous (Viswanathan et al., 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 and applying results. There is general agreement that participatory research includes a wide spectrum of partnership scenarios and knowledge users may choose not to be involved in all stages, especially in developing tools and collecting and analyzing data. As mentioned above, at a minimum participatory research, like IKTR, requires the co-development of the research question; interpretation of results; and the crafting of messages and dissemination of findings.

What is challenging for researchers who may be used to making all the decisions, is learning how to work as a member of a team, how to respect other viewpoints, the sharing of power and authority, developing positive relationships, understanding different agendas and timeframes, and developing the flexibility required to accommodate the course of events, to build trust and find mutually beneficial solutions. Knowledge users face similar challenges such as the need to understand the importance of research designs, research timeframes and the university requirements faced by academic researchers.

Table 1(fd): Comparing the Roles of Researchers and Knowledge-User Partners in Participatory Research and IKTR

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, outcomes
▪ 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
Based on: Macaulay AC, Gibson N., Freeman W, et al. Participatory Research Maximizes Community and Lay Involvement. BMJ 1999;319:774 -778		*from http://www.Canadian Institutes of Health Research-irsc.gc.ca/e/33747.html; Knowledge Translation at Canadian Institutes of Health Research - Dr. Ian D Graham; February 28 , 2007*

Principles of Participatory Research

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

- 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

Although evidence around the effectiveness of individual aspects of the participatory approach are still emerging, a recent systematic review (Jagosh, et al., 2012) demonstrated the following benefits of taking a participatory approach to research:

- PR generates culturally and logistically appropriate research characteristics related to
  - Shaping the scope and direction of research.
  - Developing program and research protocols.
  - Implementing program and research protocols.
  - Interpreting and disseminating research findings.
- PR generates capacity to recruit
  - Community members to advisory boards.
  - Community members for implementation (specifically for lay health worker programs).
  - Study enrollees (i.e., study participants or intervention targets).
- PR generates the capacity of both knowledge-user and researcher partners
- PR generates disagreements between the partnering stakeholders during decision-making processes, sometimes having negative consequences for the research process, but if resolved leading to strengthened partnerships and positive outcomes for subsequent research and programming.
- Partnership synergy accumulates in cases of repeated successful outcomes in partnering, thus increasing the quality of outputs and outcomes over time.
- Partnership synergy accumulates capacity to sustain project goals beyond funded time frames and during gaps in external funding.
- PR generates systemic changes and new unanticipated projects and activity.

Should *every* researcher be involved in IKTR 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 often true for basic science, but even here there is opportunity to partner with knowledge users. Generally however, just as intense knowledge translation efforts should only take place when there is a strong evidence base that justifies application, IKTR is most justified when there is a clearly identified action gap for which there is no clear evidence-based guidance. 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 supporting funding opportunities. However we strongly recommend that each researcher 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 IKTR help to achieve those goals?

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

Here are some points to consider when deciding whether or not to undertake an IKTR 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 IKTR project.

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

- Are your personal goals (e.g. professional, tenure), perspective and interpersonal style (e.g. team player, good listener) compatible with and IKTR 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 IKTR 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 IKTR 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 IKTR 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 organization 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 IKTR 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 IKTR process can often be time consuming and administratively burdensome?

Identify and recruit research partners

Learning objectives:

- Learn the steps and skills necessary to successfully develop appropriate partnerships.
- Learn how to achieve partner buy-in and engage in preliminary steps towards fostering a genuine collaborative partnership.

Assessing the environment around you

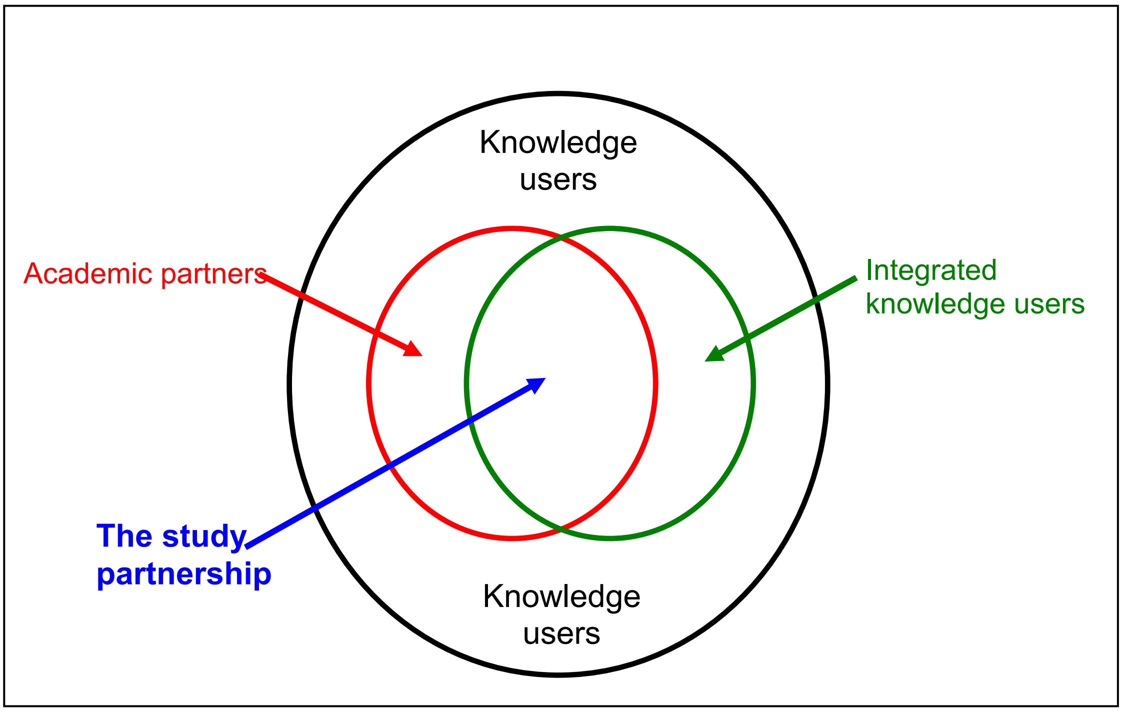
An immediate distinction must be made between the potential knowledge users of the research results at large, and the integrated knowledge users who will become partners for this specific research project. The study partnership is situated within the larger environment of knowledge users, which are all 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.

Table 2(a): 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 center)	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 and social care systems are organized and/or funded
Other researchers (e.g. researchers from other disciplines/fields	Biomedical researchers linking with clinicians or clinical researchers or health services researchers working with clinician scientists
Institutions/organizations (e.g. hospitals, primary care clinics, schools)	Starting a new outpatient health programme targeting a particular disease or problem

Potential knowledge user	Example types of projects
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
Note that a particular research project may involve one or more of these potential knowledge users, and thus overlap should be expected.	

Figure 2(a): The Study Partnership and its Situation



The first and perhaps most important step in any IKTR 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 organizations, 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 enlightenment).

- 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. Indigenous 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 (impromptu) meetings/discussions with knowledge users.

Table 2(b): Practical tips for identifying knowledge users

Type of research	Strategy
I: Biomedical research	▪ Contact clinical researchers to ask if there is a need for more basic science to better inform their clinical research ▪ Approach leaders or organizations from a community with an identified pre-disposition to a particular disease
II: Clinical research	▪ Contact regional health authorities to reach physicians' communities of practice ▪ Ask departments in the Faculty of Medicine at your university to send out information about the project on their email lists ▪ Approach advocacy groups for the target disease of the project
III: Health services/systems research	▪ 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, Population and Pubic Health	▪ 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 ▪ Approach leaders or organizations from a community with an identified pre-disposition to a particular disease

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, Cosby, Swan, Moore, & Broekhoven, 1999). Other possibilities include analyzing 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).

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

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 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 & Gutierrez, 2001): Is the research topic important to this knowledge user (as distinguished from whether it *should* be important) and 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 and thus has 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. time, 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'?

A positive answer 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(a): Pediatric palliative care

This research team undertook two studies that are included in one article: i) to document implementation of a new home based pediatric palliative care program; and ii) two years later to describe the living conditions of families in the program; to analyze 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 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 pediatric 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' (Edwards, Jumper-Thurman, Plested, Oetting, & Swanson, 2000; Salsberg et al., 2008) and openness towards research (Levy, Baldyga, & Jurkowski, 2003; Straub et al., 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 select 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

Making first contact and achieving partner buy-in

Attaining complete partner involvement – i.e., knowledge users becoming *integrated* knowledge users – is a process and as such might not be obtained instantaneously, not the least because developing new partnerships requires building trust. 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). 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.

Case study 2(b): 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 knowledge users 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, et al., 1998).

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 organization dedicated to promoting academic-community engagement. These are approached, and those who accept participate in refining and finalizing 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 (Jagosh et al., 2011).

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 communicates 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 and the associates helped to finalize 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, Cave, Doering, Ortiz, & Harms, 2005).

Example 4 – Professional Organization Initiation: The Canadian Pharmacists Association

(CPhA) publishes an online resource 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. The CPhA used the findings from this study to improve the way they deliver evidence to clinicians and incorporate user feedback (Budzinski et al., 2012).

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 summary document in hand whenever meeting potential integrated knowledge users, as people tend to notice these things

Even though one of the fundamental tenets of IKTR 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 emphasize is that this is only a draft plan which is presented for discussion and input from knowledge users. Another option, where geographically possible, and which 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, for example outside of office hours, including a light meal and, if appropriate, also offering to compensate for expenses.

Then follow-up communication should 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 IKTR principles and why their participation in the research process is crucial to its success; and 4) start a 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 unmet 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. In other words, distinguish between support for the IKTR process you are proposing from support for the project you have in mind. It is the former (i.e. support for the process) you should be seeking at this point. Such support is considered partner buy-in with respect to IKTR projects, even though the specific research questions and methods may not yet be finalized. Although, it should not be assumed that researchers have the support of the knowledge users, and vice versa, merely after the preliminary meeting (although in some cases this may be true). 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 formalized 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 of the research project

Getting to know one another

A critical part of any IKTR process is getting to know one another. This means familiarity with the backgrounds, stories, institutions, etc., of the 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 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 these cases, this process may be quite brief as the relationship may be seen in strictly business terms of collegiality. Care, however, must be taken 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.

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 topics other than just business may be discussed

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.

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

Taking stock of barriers and facilitators

Learning objectives

- Learn the importance of assessing barriers to integrated knowledge user participation.
- Learn how to identify some of the most common barriers with examples of strategies for overcoming them.
- Learn how to identify and build on partnership facilitators.
- Learn about possibilities in mobilizing the resources of integrated knowledge users (e.g. social capital).

Working together to overcome barriers to integrated knowledge user participation

Many barriers, foreseen and unforeseen, to meaningful integration of knowledge users in to the research must be expected, especially given the inherently social and collaborative nature of IKTR projects. It is absolutely essential that these barriers are 1) identified and openly acknowledged, 2) given due consideration, and 3) jointly addressed through a solution-based approach. In order to do so, all participants should be prepared to engage in critical reflection on the research process, including the status of researchers and the status of the integrated knowledge users. Identification of barriers can be carried out in a formal or informal manner. Examples of the former could include administering anonymous questionnaires to partners (for example after meetings), asking everyone to write down what is working well and what is not (a full discussion of evaluation tools is to be found below in the section on maintaining partnerships). Alternatively, or in conjunction, informal discussions could be held with partners to gauge the different aspects of the relationship. Generally, you will develop a sense of where tensions lay. You should never ignore these feelings, hoping they will just go away if unaddressed. They rarely do. In any collaboration, conflicts arise; experience has demonstrated that when these are addressed and resolved to everyone's satisfaction, partnerships flourish and research productivity increases (Jagosh, et al., 2012).

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 partners 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
Job mandates of knowledge users	
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.	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. Researchers can often budget stakeholder release time funds in to grant applications; these funds can be given to partners' organizations to cover locums or other means of covering work.
Scheduling	
It is important to accommodate, as much as possible, the schedules of integrated knowledge users when arranging meetings. This is particularly important for both clinician and community-based partners, who may only have time to dedicate to your project outside of clinic or work hours, especially when research is not part of their job or organizational mandates.	Scheduling meetings and other project-related events during the evenings or weekends, or having lunch or dinner meetings, can help integrated knowledge users to have the adequate time to become actively engaged in your project. Catering these meetings can win much favor, 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.
Compensation	
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 weekends). Researchers should not assume all partners will volunteer their time without paid compensation or expenses.	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 and are allowed by most funding agencies.

Language/culture	
Especially when working on multicultural or international research projects, issues of language and culture may arise that can negatively impact upon a knowledge user's ability to effectively participate in the IKTR 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.	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.
Power differentials	
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 or implied hierarchy between disciplines can lead to feelings of unease among partners.	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, 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. Some projects alternate meeting chairmanship between partners, or even intentionally cede the chair permanently to a non-academic partner.
Knowledge	
Non-academic integrated knowledge users may often lack the scientific or methodological training to fully understand aspects of the research design or the language of research. Conversely, researchers often lack knowledge of the contextual realities of practice or application settings.	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, however, be discussed openly and agreed upon. Researchers, nevertheless, must take care to explain things 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, that all partners are equal by definition, and everyone brings their own valid and valuable expertise to the process. In particular, researchers have much to learn from the insights of integrated knowledge users about the context in which the knowledge will be applied.
Geography	
It may be difficult for researchers and integrated knowledge users to meet face-to-face or travel times may be quite long, particularly in national projects. 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.	Thus, 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 Skype, video- and teleconferencing technologies, as well as online meeting services where presentations and text documents can be jointly viewed and edited (e.g. wikis, Web Ex, etc.). 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.

Critical to overcoming these and other barriers, is for researchers to develop skills other than strictly methodological ones (Haggman-Laitila & Rekola, 2014; Israel et al., 1998; Minkler & Wallerstein, 2003). 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, ability to admit one’s errors, and, most importantly, humility. Humility does not mean to undervalue your own knowledge and expertise. But you must be willing to learn from integrated knowledge users and be able to recognize that others may have knowledge and experiences that, though very different than yours, will make valuable contributions to the research and its ability to have an impact.

Summary points:

- 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 want to learn from integrated knowledge users, and develop others skills to augment their methodological and scientific ones in order to partner effectively

Jointly building on the facilitators of knowledge user involvement

While there may be many barriers when engaging in an IKTR process, there are also many facilitators to integrated knowledge user participation. It is very important to explicitly identify and assess these facilitators and then constantly build and expand upon them. Identification of facilitators can be accomplished through either the formal or informal means mentioned in the previous section. 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.

Table 3(b): Practical Tips for Facilitating Effective IKTR Process

- Hire members of the integrated knowledge users' community (even professional community of practice) to work as coordinators of the project or RAs in data collection and analysis
- Make use of email 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 location of meetings between research settings (e.g. university, hospital) and integrated knowledge user settings (e.g. community centers, 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, even printing. This both aids to alleviate some of the administrative workload of the researcher, which can be higher for IKTR projects, fosters co-ownership of the project, and also promotes empowerment and capacity building of individual knowledge users. It is important to try to ascertain what would be least burdensome for all partners, and divide up tasks in a way that benefits all and, importantly, benefits the goals of the partnership.

Case study 3(a): 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, nor should they be expected to. While researchers will contribute the bulk of the scientific know-how and their institutions will often contribute the bulk of administration, 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 such a way that 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 organizational infrastructures in place and can make in-kind contributions to project administration, from clerical support through tool development.

Example 1 – Administrative Support: Although most federal funding agencies transfer funds to universities to cover the 'indirect costs' of research (infrastructure and administration), these often get lost in the bureaucracy and researchers often never see the benefits for their individual projects (e.g., one departmental research secretary for 25 faculty members in your division means you won't get your meeting minutes typed up any time soon). An IKTR project partnering researchers with, for example, 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 organization or community where the research is being undertaken.

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

Example 3 – Intervention Funding: In an IKTR project with intervention and evaluation components, funding the intervention can be a challenge as most funding mechanisms only allow for research and evaluation salaries (assistants, collaborators, etc.). Integrated knowledge-user partners can sometimes 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 IKTR 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). Time spent up-front fomenting strong, respectful trust relationships is never wasted.

Summary points:

- Facilitators to an effective IKTR 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

Engaging in collaborative research design

Learning objectives

- Learn how to identify and merge issues that are important to both researchers and integrated knowledge users.
- Learn how to operationalize these issues into viable research questions.
- Learn how to choose appropriate, clear and feasible priorities for each research project based upon these questions.

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 identify specific issues that are important to the integrated knowledge users and 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 IKTR 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. Essential skills in this process include:

- Becoming an active listener to points raised by researchers and integrated knowledge users, taking a genuine interest and asking 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 show willingness to compromise and move beyond your initial ideas.
- An ability to provide everyone with equal opportunity.

It is appropriate to here reiterate: humility does not mean to undervalue your own knowledge and expertise. But you must be able to recognize that others may have knowledge and experiences that, though very different than yours, will make valuable contributions to the research and its ability to have an impact. 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 photo voice or organizing walking tours when researchers have the opportunity to see the community of interest and meet people relevant to the project (Wang, Anderson, & Stern, 2004; Wang & Burris, 1997).

Table 4(a): Practical Tips for Jointly Identifying Issues

- The *nominal group technique* (Moore, 1994) can be employed with a large group of people, which first involves the use of small groups to brainstorm their ideas and, second, bringing all the small groups together to see overlap, synthesize ideas, 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. Web Ex) which allows everyone at remote locations to view PowerPoint slides and jointly edit 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' skills can be particularly valuable and may be a good opportunity to introduce partners without an academic background to some appropriate methodology. 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 while maintaining methodological rigor required to create effective evidence and successfully garner funding. In other words, questions must fill a gap in the literature and a gap ‘on the ground’.

The questions that you develop should have broad support from researchers and integrated knowledge users alike. If all parties to the project cannot come to an agreement or feel 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 IKTR approach is a good fit for the research team. 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 IKTR 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, using the scientific expertise of the researchers

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 its own grant. Therefore, of all the points raised, it is advisable to focus on one main topic, especially for those starting out with IKTR 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 winnowing 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 (Community-Campus Partnerships for Health, n.d.):

- Is the priority unifying or divisive?
- Is there strong potential for application of the findings?
- 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 in to, 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 of 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 (Turoff & Hiltz, n.d.). 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, 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 (Norman et al., 2013).

ii) 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 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 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 et al., 2007).

The overarching goal of this exercise of selecting priorities is to clarify expectations between all parties 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 IKTR process in that transparent benchmarks are set against which the long-term progress of the partnership can be judged.

Summary points:

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

Governance

Learning objectives

- Learn about the different models of joint governance and various decision-making processes.
- 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.
- Learn how to enable successful group practices based upon open communication and equitable participation.

Joint governance and decision-making

All research requires leadership and governance. In its simplest form this would entail a single principal investigator unilaterally making all the decisions. This PI may solicit input from others, but still makes all the final decisions. More typically, decisions are made by a team of researchers, each contributing an area of expertise to the protocol. There may still be one nominated principal investigator, but by agreement the governance is more diffuse and collaborative, recognizing the value of each team member's input. The same process holds true for IKTR; what changes however is that you define the research team to include not only traditional researchers, but the integrated knowledge users as well. In order to ensure that the principles of IKTR are truly put into practice, formal mechanisms are needed that support the team approach and create 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. 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.

There is no one size fits all solution for joint governance in IKTR projects. Various governance models are available, and 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 (if research activities are not part of their jobs, they may not be able to contribute regularly). Key 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 in order 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 to maintain ongoing translation of knowledge throughout the process. Table 5(a) summarizes some of the various ways with which to formalize this.

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	Very small projects (e.g. pilot studies) with relatively few	Limited administrative bureaucracy, thus speeding along the	Can be heavy on researcher control, as they decide when to bring in	▪ Keep all integrated knowledge users up-to-date through

	individual basis, according to the issues at hand.	researchers and integrated knowledge users involved.	decision-making process. Enables one-on-one relationships to develop.	integrated knowledge users. Partnership not formalized.	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.	▪ 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	An Advisory	Larger projects	This	Can be	▪ Make sure

Committee	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, and budget).	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.	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.	administratively burdensome and it may take longer to make a decision, especially if back-and-forth is required between the Committee and the researchers.	that the Advisory Committee has a very clear mandate that is written into any partnership agreement (see Partnership Agreements below). ▪ 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.

These three alternative models of shared governance are not exhaustive, nor are they meant to be mutually exclusive. Rather, they are meant to be combined, mixed and matched depending upon the type and needs of the project and all its partners.

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. By 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, Israel, & Allen, 2005). This can be applied in two ways. First, rather than a simple majority vote (such as 51%), a super-majority 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.

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 integrated knowledge users should be jointly agreed upon. It is important that these are made as explicit and clear as possible. Be creative and flexible when deciding upon project leadership, not just because IKTR is built upon shared governance and decision-making, but also because responsibilities and burdens can be shared amongst all parties to maximize individual expertise. 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 generally require a nominated principal investigator (and historically, this has been someone with an academic appointment), it should not be assumed that this person is the sole leader with ultimate authority. Today, certain funding opportunities allow a nominated integrated knowledge user to serve as principal investigator and to hold the research funds at their eligible non-academic institutions. Even where this is not the case, 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 they choose to take on such a role or not. For example, when recruiting research participants 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. 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 integrated 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 (CCPH, 2006):

- Develop project, processes, procedures and policies that support the IKTR initiative.
- Identify an implementation 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 constituents 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 though its various stages.
- Integrated knowledge users can assume many innovative roles beyond a traditional 'advisory' capacity.

Group dynamics

The group dynamics for any IKTR project should be influenced by the principles of open communication and equitable participation (Becker, et al., 2005). 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 results for organizations or communities) and pragmatics (e.g. funding cycles, slow diffusion of knowledge amongst communities of practice) of both researchers and integrated knowledge users. Written operational norms or codes of ethics also play a crucial role.

Open communication. The over-arching principles of open communication must be honesty and transparency. This means: discuss important decisions and only make a decision when the group is ready to do so; talk frankly through any disagreements or conflicts that may arise; keep one's word and avoid making promises that cannot be kept; be realistic about goals and outcomes from the outset; make decisions according to agreed-upon norms; and never exclude any of the partners from this process even if you feel that they may impede it.

Table 5(b): 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 meeting minutes with actions and decisions clearly highlighted so everybody is on the same page, and provide an opportunity for comments/amendments
- 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
- Maintain a common project website for timely communication and sharing of documents
- Be available to all partners by email and phone, and respond to messages in a timely manner

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

Table 5(c): Practical Tips for Equitable Participation

- Use group facilitators to run meetings and ensure everybody has a chance to speak and no one person (or group) dominates meetings
- Rotate meeting chairs between researchers and integrated knowledge users so all partners have the chance to set the agenda and pace of a meeting
- Ask for written feedback on issues or documents, in order for partners who may not feel comfortable participating in large groups to provide input
- Divide the partners up into sub-committees, 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 IKTR process. 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 IKTR processes are built upon the principles of open communication, and equitable participation.
- Think outside the box when devising ways to put these principles into practice.

Ethics and partnership agreements

Learning objectives:

- Understand the ethical considerations inherent in IKTR projects, beyond traditional research ethics.
- Learn that IKTR 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.
- Learn the advantage of written partnership agreements, and some models/examples for developing them.
- Learn how Research Ethics Boards (REBs) may approach IKTR projects, and strategies for working with REBs to ensure an adequate and timely ethics review.

The need for ethics specific to IKTR

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. 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.

However, IKTR projects involve partners with differing backgrounds and divergent agendas, shared governance and decision-making, co-creation/ownership of knowledge, and joint dissemination and publication. Furthermore, 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 include among the issues that will frame ethical conduct between parties 1) *building trust* between researchers and integrated knowledge users, and 2) *mutual respect*. IKTR projects also require an expanded ethical discourse that includes both the rights of the individual as well as rights of the collectivity (e.g., community or organization) represented by some or all of the integrated knowledge users. Communal consent in important because the potential *impact* of research results on targeted organizations or groups can continue beyond the scope of one project (i.e. positively though 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 exploitation in the context of IKTR 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 IKTR Projects

Although by no means an exhaustive list, the following five issues are of paramount concern when engaging in an IKTR project. Flexibility and the ability to adapt are key, as not every IKTR context will need to address each of them 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 marginalized communities)

Researchers and integrated knowledge users need to have a heightened awareness of the potential ethical challenges characteristic of IKTR, 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 suffered harm or stigmatization from negative research experiences. Researchers' diligence in creating complex ethical agreements should be a function of the culture of knowledge users (even when it is a professional culture), and the nature and context of the research project.

Summary points:

- Building trust, mutual respect, community consent, benefit sharing and avoiding exploitation are five ethical principles of central concern in IKTR projects, in addition to central notions of informed consent, confidentiality, etc.
- IKTR may require protection of both individuals and collectivities
- 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 nature and context of the research

Rights and responsibilities of researchers and knowledge users

Standard conceptions of research ethics tend to view 'the researched' as having rights and the researchers as having responsibilities (e.g. to not exploit, to treat with respect). In IKTR, the integrated knowledge users *represent* research stakeholder groups, but may or may not be themselves participants in the traditional sense (i.e., data sources). Yet because IKTR equally protects collectivities along with individuals, the ethics of IKTR sees integrated knowledge users and researchers as having both rights and responsibilities. Table 6(b) provides examples (Macaulay, et al., 1998).

Table 6(b): Some rights and responsibilities

	Researchers	Integrated knowledge users
Rights	▪ 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.	▪ To have opportunities for meaningful involvement 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> be able to meaningfully express dissenting opinions regarding interpretation of research results
Responsibilities	▪ To actively engage knowledge users in the project rather than consider passive acceptance sufficient ▪ To provide reasonable resources to the knowledge users to facilitate their collaboration ▪ 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 and research results, and thus involve them in decisions on secondary analysis ▪ To address any health or social issues raised as a result of research	▪ 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 constituencies ▪ To offer advice, at a minimum, on the research questions, and interpretation and dissemination of results ▪ To offer constructive input rather than negative criticism, and work with the researchers to modify the project as needed

These rights and responsibilities are context specific and should be discussed, negotiated and agreed upon before the project begins. Time is spent on this process is valuable for getting to know one another and understanding 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. Trust serves to make the project more feasible because it helps mitigate concerns between researchers and integrated knowledge users regarding potentially conflicting agendas.

Moreover, by positing both researchers and integrated knowledge users as having rights and responsibilities, the 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

Negotiating written partnership agreements

We highly recommend the development of partnership agreements, which will be distinct to each IKTR project depending upon its nature, context and partners. Some helpful guides to what may go into an agreement include:

- Reliability-Tested Guidelines for Assessing Participatory Research Projects, (Mercer et al., 2008) also available at http://www.lgreen.net)
- Community-Campus Partnerships for Health (CCPH) Research Ethics (http://ccph.memberclicks.net/index.php?option=com_content&view=article&id=30:research-ethics&catid=26:focus-areas&Itemid=111)
- Canada Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/Default/)
- Canadian Institutes of Health Research Guidelines for Health Research Involving Aboriginal People (www.Canadian Institutes of Health Research-risc.gc.ca/e/29134.html) focuses on partnership research, include a useful template, and are highly adaptable to other contexts.
- Example of a community-specific agreement: Kahnawake Schools Diabetes Prevention Project (KSDPP) Code of Research Ethics (http://www.ksdpp.org/elder/code_ethics.php).

Table 6(c): What Goes in to a Partnership Agreement?

- The principles on which the partnership is based
- The research project's objectives and goals
- How roles will be divided between the various partners
- The structure of the project's shared governance and methods for joint decision making and operating norms
- Partner rights and responsibilities
- Mechanisms for conflict resolution and ongoing evaluation of the partnership process
- 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 many partners are involved, and is extremely valuable in research with historically marginalized, underserved, or ill-served communities. It can also be useful in multicultural environments, where a written document can serve to minimize cultural misunderstandings. Very rarely, a written agreement may be culturally inappropriate such as with some Aboriginal communities.

Case Study 6(c): Written Agreements in Practice (Gibson, 2005)

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. Community members were also willing to discuss how genetic research discoveries could ultimately serve their interests and benefit 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 genetic research. 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 et al., 1998).

Example 2 – Statement of principles: The following is a list of the principles used by the tuberculosis project presented in Case study 2(b). 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. Honor 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.

Agreements 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 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
- For large projects with community-based partners, a formal code of ethics is recommended; for smaller projects with a community of practice, the research protocol can fulfill this role

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 many institutions for REBs to include members of the public to review research projects – particularly members of communities identified in study protocols under review.

As IKTR projects and more participatory approaches to research increase in frequency, REBs will need to become familiar with the additional ethical principles outlined above, and develop the competencies required to evaluate IKTR proposals. There remains a wide spectrum of REB attitudes toward this research approach and many ethics review forms checklists and guidelines were developed strictly for a biomedical clinical research framework, focusing on the principle of assessing risk to individuals not collectivities. Groups in the United States, Canada, and Europe are currently developing REB/IRB training curricula addressing the particular exigencies of partnered research (Community-Campus Partnership for Health, n.d.).

Some of the additional challenges for REBs include: scarce guidance to evaluate degree of meaningful knowledge user engagement; processes for evaluating incomplete or evolving protocols where the partners need further discussions to finalize details; and joint jurisdiction over research with community or organizational ethics boards.

We recommend taking a participatory approach with REBs not accustomed to reviewing partnership IKTR projects, through an early and ongoing dialogue with them. The content of these early discussions can include: informing them early on of intention to submit an IKTR project; providing the REB with resources to help with ethics review (e.g. guidelines mentioned above); 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; particularly with respect to research involving vulnerable populations, 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 ethics 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 IKTR 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.

Summary points:

- Some REBs may not be familiar with an IKTR approach to research, and hence may lack the capacity to assess the protocols
- 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

Maintaining partnerships over time

Learning objectives:

- Learn that partnerships require maintenance, and about some of the issues that may need to be addressed.
- Learn basic steps to resolving partnership conflict.
- Learn the value of ongoing partnership evaluation and some strategies for doing so.

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 mentioned in module 6. These mechanisms must recognize and help to mitigate the fact that project politics 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 – researchers, knowledge users and 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 towards 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.

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 IKTR 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 has already been mentioned that participatory research regularly leads to productive conflict that, when successfully resolved, creates increased trust, partnership synergy and research productivity (Jagosh, et al., 2012). However, it is incumbent upon researchers and integrated knowledge users alike to develop conflict resolution skills, and processes.

Conflict can be divided into the following types (Forsyth, 1999): 1) personal, conflict between individual personalities; 2) substantive, disagreements over opinions or ideas; 3) conflict over procedural, strategic or operating norms; and 4) competition amongst members. The best way to anticipate and resolve conflict is to build conflict resolution processes in to the partnership agreement (Becker et al., 2005). That way, jointly agreed upon procedures are incorporated that help assure everyone that it is acceptable to openly acknowledge conflict, prevent ad-hoc or arbitrary solutions and ensure that no one is left out of the discussion. These should be based upon a *non-adversarial* approach to resolving conflict, that is, based upon negotiation (Johnson & Johnson, 1998). If a resolution to the conflict cannot be found, consider an appeal to a third party mediator. This person should be mutually agreed upon by all parties and their scope for finding a resolution clearly delineated. 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 can be an opportunity for growth and improving the partnership.
- Conflict needs to be openly acknowledged to 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
- Accept that you may need to agree to disagree.

Ongoing evaluation

A crucial element to maintaining successful IKTR partnerships is ongoing evaluation of the partnership process. Partnership evaluation, as distinct from evaluating the success of the project's goals overall, serves as a means to continually improve and strengthen the day-to-day and overall 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 is little sense in continuing a partnership that ceases to function adequately to achieve its goals, and ongoing evaluation can not only help prevent such a state, but identify ways 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.

Partnerships accrue many benefits for both researchers and knowledge users along the way to fulfilling their ultimate research and action goals. These are often relegated as process outcomes but can be equally valuable, often lead to system change within the knowledge use setting and are often unplanned or unanticipated (Haggman-Laitila & Rekola, 2014; Jagosh et al., 2012). Perhaps the simplest means to evaluate the partnership is documenting these 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 of which they may take stock.

Table 7(a): 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. 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. Questionnaires of this type need not only assess the partnership as a whole; they are also useful with respect to specific issues or aspects as well. For example, a questionnaire could 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 many formal instruments available for evaluating perceived partner influence, group dynamics and partnership function (Andersen, El Ansari, Rasmussen, & Stock, 2010; Andrews, Cox, Newman, & Meadows, 2011; Baur, Abma, Boelsma, & Woelders, 2013; Birch, Tuck, Malata, & Gagnon, 2013; Blevins, Morton, & McGovern, 2008; Bowen & Martens, 2006; Brooks, 2010; Butterfoss, 2009; Cargo, Delormier, Levesque, McComber, & Macaulay, 2011; Cargo et al., 2003; Cramm, Strating, & Nieboer, 2011; El Ansari, Oskrochi, & Phillips, 2009; Haggman-Laitila & Rekola, 2014; Jason, Davis, Olson, Ferrari, & Alvarez, 2006; Jolley, Lawless, & Hurley, 2008; Jones & Barry, 2011a, 2011b; Kihl, Tainsky, Babiak, & Bang, 2014; King et al., 2009; Parker et al., 2003; Parkinson, 2009; Patsios & Carpenter, 2010; Reed & Jernstedt, 1997; Rutter et al., 2013; Sanchez, Carrillo, & Wallerstein, 2011; Savitz, 2007; Tomioka & Braun, 2013; Van Olphen et al., 2009; Wagemakers, Koelen, Lezwijn, & Vaandrager, 2010; Wells et al., 2013). 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 are most useful for evaluating large or complex, multi-level partnerships spanning diverse stakeholder groups.

Irrespective of method, researchers and integrated knowledge users should be committed to implementing evaluation results to improve the partnership function. As such, action plans should be developed based upon these results outlining what, if anything, needs to be changed 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 reiterated to stress the distinction between evaluating the project's success (i.e., outcomes) versus the partnership's success. Even if projects fail to meet all its objectives or the research undertaken 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 create a platform for future, fruitful research collaboration or may lead to other spin-off projects (Jagosh et al., 2012).

Summary points:

- Ongoing partnership evaluation is crucial to partnership maintenance and improvement – and it is on these terms that the success of the IKTR 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 exist and may benefit large or complex partnerships

End of Project KT: Dissemination

Learning objectives:

- Reflect on dissemination goals that include both increasing knowledge and action.
- Agree on audiences to reach.
- How to craft the central messages and the importance of the messenger.
- Assess facilitators and barriers to uptake of results.
- Evaluate the dissemination process (when appropriate).

An integrated knowledge translation research dissemination plan

Before dissemination can occur, researchers and integrated knowledge users need to jointly interpret the results, agree on findings 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 IKTR project, to advance knowledge and promote its use for change, while identifying team member responsibilities for reaching the different dissemination audiences. By definition, the IKTR project starts with the participation of integrated knowledge users as representatives of one or several stakeholder groups) that could use or be impacted by the research results. Furthermore, many partnership research grants now require a detailed description in the proposal of how, by whom and to whom the dissemination will be carried out. Thus, even at the initial planning stage the partnership should have a well-established dissemination path within integrated knowledge users' own organizations and to other key individuals, organizations or communities.

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 (Canadian Institutes of Health Research, 2012).

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, 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 together crafted a 20 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 organizations 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 soliciting recommendations for future KSDPP interventions. The lessons learned included: the importance of joint community-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. After seeking both community and institutional ethics approval, the community feedback was used to improve future interventions and finalize interpretation of the results before submitting a scientific paper for publication (Macaulay et al., 2007; Paradis et al., 2005).

Summary points:

- A dissemination plan, developed collaboratively by researchers and integrated knowledge users, is a key component to all IKTR projects
- The preliminary dissemination plan, developed at the project's outset, should be reviewed and revised as needed once the results have been produced

Goals of dissemination

Dissemination goals include the traditional objectives of increasing knowledge amongst the research community, including researchers from different disciplines, teams and countries. As IKTR involves a partnership, researchers should consider inviting integrated knowledge users to share in delivering any presentations – and this includes scientific conferences. One activity specific to IKTR, is joint authorship between researchers and integrated knowledge users. This will be very familiar to anyone who has jointly authored papers before 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.

What differs in the IKTR case is that several of the co-authors may have little or no experience in writing scientific articles. Furthermore, what constitutes meaningful contribution to the study might differ 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. However, integrated knowledge user authorship should not be used as a rubber stamp of authenticity, especially in the context of research with marginalized or disempowered groups. All partners should ensure that listed authors have in fact made a real contribution to the study or paper. This process may include sitting down with integrated knowledge users and helping them write, or even providing them with a temporary research assistant. This should be done with respect and acknowledgement that the integrated knowledge user has a unique contribution to make to the final product.

In most joint authorship cases, one of the researchers will take the lead for articles targeted at scientific audiences. This is 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 writing for articles aimed at community-based audiences (e.g. in the local media). However, there is often value in cross-germination, and care should be taken in each case that the appropriate messengers *for your study* are delivering the message to each target audience. Often patients may be more persuasive than researchers with policy makers or clinicians!

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 organization. Other potential groups to reach (if not already integrated into the partnership) include policy makers, service managers, 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 websites, videos and DVDs, tools appropriate for various audiences, handouts in lay language, etc.

Summary points:

- As equal partners, integrated knowledge users should be invited to be co-authors on all publications and co-presenters at conferences
- Standard authorship guidelines should still be respected
- Integrated knowledge users may take the lead in disseminating results within their own context and community, but can be valuable voices to other audiences as well

Summary

What are the key integrated KT research lessons?

- An IKTR 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, IKTR involves a *partnership* between researchers and integrated knowledge users at all crucial stages of the research process.
- *Integrated knowledge users* can include: practitioners, patients, caregivers, communities, community-based organizations, healthcare 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 IKTR project, and need to be identified early on and overcome/enhanced.
- Research needs must be *jointly identified and valued* 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.*
- IKTR projects may require a different *ethical framework,* especially when being review by Research Ethics Boards.
- *Written partnership agreements* can provide clarity and serve to build trust between partners.
- IKTR projects require *ongoing partnership maintenance.*
- Integrated knowledge users should play an equal part in any *dissemination and implementation planning.*
- Do not engage in an IKTR project if the *readiness factor* is just not there.

CHAPTER 3

Deliberative Priority Setting for Research

By Sandy Campbell

Introduction

Learning Objectives

- An understanding of how deliberative priority setting – a primary tool in integrated knowledge translation research – can help determine a society's, a system's, or an institution's research priorities, ultimately contributing research evidence to the creation and implementation of policies that address core societal issues.
- An understanding of the role that multi-stakeholder deliberation can play in priority setting, including an appreciation of how to identify relevant stakeholders and then convene for a that gives each stakeholder the same opportunity to participate.
- An understanding of other priority setting for research models.

In this *Chapter*, we review the concept of priority setting for research, ultimately advancing a new (yet amalgamated) methodology for arriving at priorities reflecting the knowledge needs that have been identified by an inclusive group of stakeholders. The Chapter is divided into four sections: the first surveys the literature to provide an overview of knowledge translation – in particular integrated knowledge translation research – priority setting (PS), the values underlying a PS process, along with the role of stakeholders. The second section moves into an overview of participatory PS methods, reviewing the literature on each, while presenting their basic functions and discussing their logical flow, strengths and limitations. The third section describes and analyzes key deliberative dialogue concepts, from ways of identifying and analyzing relevant stakeholders (including different types of stakeholder analysis tools) to means of eliciting multi-stakeholder input. The final section features some observations and conclusions on how to fuse deliberative techniques with any priority-setting process. This includes remarks on implementing priority-setting processes in low- and middle-income countries (LMICs); areas for future research; how institutions and systems (e.g. national health research systems) can increasingly inform their priority-setting work with deliberative techniques; and some key evaluation considerations.

In its ideal interpretive form, priority setting selects the right people to brainstorm on the right issues to determine what a society's, a system's, or an institution's research priorities are. Doing so enables health research systems to accurately target genuine knowledge needs and ultimately contribute research evidence to the creation and implementation of policies that address urgent or core societal issues.

Section 1: An Overview of Priority Setting

Learning Objectives

In this Section, major learning objectives include an understanding of:

- the evolving field of knowledge translation, with specific reference to integrated knowledge translation research;
- the philosophical, political and economic undertones of any priority-setting exercise;
- the value of the PS process and not the final PS product: for any PS exercise, the actual setting of priorities is less important than the deliberation around the priorities;

- the ethical complexities of priority setting, along with an evaluative framework for assessing any PS exercise's fairness and legitimacy;
- the role of criteria in fairly assessing competing priorities or research options;
- how to determine the right stakeholders to deliberate on priorities; and
- how priority-setting processes have unfolded at the national level to help shape a national research agenda.

Throughout this Chapter, we consider priority setting to be a connected – yet discrete – set of activities within the broader discipline of iKTR. Priority setting for research is in many ways the first step in connecting research evidence with policy-making: if policy-makers can identify the knowledge they require to devise or modify policies, and researchers can then fill these knowledge needs, the resulting policies will be strongly evidence-informed, and stand a much higher chance of effectively addressing issues or problems within the health sector.

Considering PS as part of an integrated KTR approach allows us to draw upon a range of connected concepts and processes, with particular reference here to the idea of a deliberative dialogue, where an inclusive mix of stakeholders meet to discuss both explicit (i.e. scientific) and tacit (i.e. best practice, experience) knowledge in order to inform policy development. In this first sub-section, we review iKTR in order to frame PS within much wider and very dynamic currents connecting research and policy processes.

Knowledge Translation and Integrated Knowledge Translation Research

In theory, health researchers and health policy-makers both work to the same end of addressing societal ills and solving collective problems. In practice, researchers and policy-makers are often pitted on opposite sides of a great rift – the know-do gap, where what a society knows and what it does fail to align (WHO, 2004). Working towards scientific truth, researchers often see policy-makers as unable to understand or apply their work. Working towards consensus, policy-makers often see researchers as just another group trying to influence their decisions (Choi et al., 2005; Greenhalgh & Russell 2005; Lomas 1997). Only rarely do their worlds converge.

Since its formal introduction at the 2004 Ministerial Summit in Mexico, the concept of knowledge translation (KT) has emerged as a leading approach in narrowing this rift between research and policy (Hamid et al., 2005; Pablos-Mendez et al., 2005). Often misunderstood as a technique to transfer research findings directly to policy – of putting research into the "right language" to ensure its policy uptake – KT is more properly imagined as a series of steps bringing together the research and policy *processes*. While there are many definitions of KT in the literature that reflect this (somewhat abstract) merging of processes (see, for instance, Graham et al., 2006), we prefer here the simplest: KT is "an ethos connecting contextualized knowledge with its application to improve health and well-being" (Campbell, 2012, p. 25).

KT treats both the research and policy as non-linear, richly complex and continually evolving processes that are so often opaque to the outsider. Importantly, these processes are not products (a research paper; a policy statement): research, for instance, is "not a retail store … [with] researchers busy filling shelves of a shop front with a comprehensive set of all possible relevant studies that a decision-maker might someday drop by to purchase" nor is policy a one-off event – instead, it's a highly complex and often irrational process akin to making sausage (Lomas, 1997, p. 7).

Integrated knowledge translation research emphasizes the co-production of knowledge, bringing together the creators and users of research (among others) to take knowledge from question to findings to application. In iKTR, the distinctly different research and policy processes are able to effectively influence the other. Through the spirit of mutual understanding that must underpin iKTR, where researchers come to understand policy pressures and policy-makers the rigorous requirements of research, research stands a much better chance of informing policy, and policy a much better chance of influencing research.

The ultimate goal of iKTR is a constantly turning cycle of policy-informed research leading to evidence-informed policy which, in turn, creates more policy-informed research. To do this, iKTR relies upon strong relationships and open dialogue, upon trust, respect and the achievement of shared goals (Ginsburg et al., 2007; Innvaer et al., 2002; Jackson-Bowers et al., 2006; Dobbins et al., 2007; Golden-Biddle et al., 2003). As deliberative priority setting so too is iKTR a fundamentally social process.

Priority Setting: An Overview

Priority setting (PS) represents the first movement of this iKTR cycle. By identifying policy needs and research options, priority setting can unite policy-makers and researchers before the research begins. A priority-setting process might ask: what are the research and evidence needs of policy-makers? And how might those needs inform and ultimately shape the research agenda?

There are two major types of priority-setting processes: priority setting for research (determining, weighting and ranking specific research topics and/or research questions) and priority setting for service delivery (determining, weighting and ranking the interventions a healthcare institution offers – also called rationing or intervention priority setting). To date there has been much more attention in the literature on priority setting for service delivery. While there is some cross-over between these two types of PS processes, they are notably distinct, with few synergies explored thus far (see Ranson & Bennett, 2009). In this Chapter, we have included much of the thinking, logic and experience from priority-setting for service delivery, but our focus is primarily on priority setting for research – at the national level (e.g. setting priorities for a national research agenda), and at a theme- or issue-based level (e.g. prioritizing and ranking different researchable issues or research questions). This Chapter does not fill the literature gap linking together these two major types of priority-setting processes, but does attempt to make some models of priority setting for service delivery (e.g. Program Budgeting and Marginal Analysis) relevant to priority setting for research.

Priority setting is by its nature a philosophical and economic act. It is philosophical in the questions it poses – how does a society decide which topics are urgent, relevant and under-researched? – and economic in the guidance it can offer investors – how does a society align its financial resources with its knowledge needs? Ultimately, however, priority setting is a political act. Even the term itself – *priority setting* – carries with it a finality: one has assessed a society's current gaps, anticipated its future needs, and decided what needs to be done, in what order and to what effect. For most societies, this kind of decision-making is a very high-level process that an elected representative (a Minister of Health, for instance) may see as their own distinct purview (see Makundi et al., 2007; Makundi, Kapiriri & Norheim, 2007). No matter how inclusive or representative a priority-setting process may be the mechanism of where and how a society's needs are identified and how its resources are allocated in addressing those needs is inherently political.

To that end, we argue here that what is important is less the actual *setting* of priorities and more the *deliberating* around those priorities (where an inclusive, representative group gathers to discuss collective needs). *It is the process and not the product that ultimately matters* (WHO 2003). Dialogue may not solve a problem or set actual priorities, but it will build the social relationships, trust and interactions critical to iKTR and any health system. Though we use priority setting throughout this Chapter in recognition of the accepted terminology, a better term capturing this spirit of deliberation and interaction may be priority identification.

Priority Setting for Research: Theoretical Frameworks

In its ideal interpretive form, priority setting selects the right people to brainstorm on the right issues to determine what a society's, a system's, or an institution's priorities are. It is a transparent, fair, legitimate and accountable process designed to guide decisions, a rational means to determine how resources are invested to address societal needs and to steer researchers towards topics of national interest and priority (Lenaway et al., 2006). Within such political and philosophical dynamics, there are a number of different priority-setting approaches, exercises and processes. Each is typically distinguished by level (global, national, and institutional), comprehensiveness (research priorities for the health sector; research on specific issues; determining precise research questions), the balance between technical and interpretive approaches, and stakeholder involvement (Ranson & Bennett, 2009). Each is a complex, value-driven process.

By far the most cited framework in providing and assessing the ethical complexities of priority setting is that of Daniels and Sabin (1998; 2000; 2002; 2008). Their Accountability for Reasonableness (AFR) framework for priority setting describes a fair process that allows stakeholders to determine the legitimacy, fairness, and context-specificity of values and priorities that ought to combine and ultimately inform decisions. AFR establishes a moral underpinning that emphasizes the principles of democratic deliberation (Bruni et al., 2007; Kapiriri & Martin, 2007). It prescribes four necessary conditions for any priority-setting process:

It must be **relevant** to the local context as determined by accepted criteria

Its eventual decisions – and the reasons behind them – must be **publicized**;

It must include **appeal mechanisms** for challenging, revising, and reversing decisions;

Its leaders must be able to **enforce** the above three conditions (see Byskov et al., 2009; Daniels, 2000; Peacock et al., 2009; Kapiriri, Norheim, & Martin, 2007).

AFR rotates around the principles of social justice, and as such describes the idealized value core of priority setting processes (i.e. fair, just, deliberative, legitimate, transparent, accountable, enforceable). However, as Sibbald and colleagues (2009) explain, because priority-setting processes depend upon the adjudication *between* those values, they set the stage for conflict as stakeholders will necessarily and fundamentally disagree about the importance of different values. And precisely because of this constant, context-driven adaptability, there can be no normative approaches (Menon, Stafinski, & Martin, 2007) nor agreement on the required elements for a successful process – despite the desire of some authors to find a replicable algorithm that can rank and weight priorities in any given situation (Rudan et al., 2007a; Baltussen & Niessen., 2006; Ghaffar et al., 2004). While some priority-setting processes will involve a relatively simple judgment on whether an issue or argument advances equality of opportunity for a given population in many others the process will generate more questions than answers (Hasman & Holm, 2005).

Given the context-specificity of values, arriving at criteria for a specific priority-setting exercise is a crucial step (Working Group 2000; COHRED 2006). There are many ways to determine criteria, from considering how any given issue correlates to a laundry list of philosophical concepts to responding in *realpolitik* fashion to the desires of those with power and influence (Rudan et al., 2007a; Baltussen & Niessen, 2006). In general though, there seem to be a set of criteria that are increasingly useful and used, with specific attention to:

- magnitude, relevance and urgency – will the research be needed within the next 3-5 years (El-Jardali, 2010; Working Group, 2000)? Will the issue at hand still be a priority in five years' time (Alliance for Health Policy and Systems Research, 2009)?
- applicability, deliverability, affordability, sustainability (Rudan et al., 2007a)
- maximum potential to reduce disease burden equitably (Rudan et al., 2007a; Baltussen & Niessen, 2006)
- originality – is the issue researched or is there an existing knowledge base (El-Jardali, 2010, Working Group, 2000)?
- research capacity and feasibility: do the skills exist to do the research? Is it feasible financially, technically, socio-culturally and ethically (Working Group, 2000; COHRED, 2006; Rudan et al., 2008)?
- policy relevance (El-Jardali, 2010); and
- expected impact of the research – will its impact be greater than its relative cost (COHRED, 2006; Rosenstock, Olenec & Wagner, 1998; González-Pier et al., 2006)?

Priority Setting and the Right Stakeholders

No matter the criteria, the priorities arrived at depended upon those involved in the process (Commission on Health Research for Development, 1990). Slum dwellers will have differing priorities than physicians (Sitthi-amorn, 1989 cited in Lomas et al., 2003), and researchers typically have different ideas than policy-makers. But what of the needs and preferences of other stakeholders, including funding agencies, healthcare practitioners, street-level bureaucrats within the health system, civil society and/or the private sector (Kapiriri et al., 2007)? Involving an *inclusive set of stakeholders* reinforces priority setting's value as, among other things, a vehicle to entrench and enrich democracy (Charles & DeMaio, 1993; Abelson et al., 2003; Bruni et al., 2007; Bruni et al., 2008; Mshana et al., 2007; Martin, Abelson, & Singer, 2002). The involvement of multiple stakeholders confers legitimacy and fairness (Bruni et al., 2008), evidence of a society openly debating and advancing the social-justice values necessary for a strong health system, while also allowing decision-makers to gauge whether their perceptions of constituent needs are in fact accurate (Smith et al., 2009).

Box 1: Stakeholder Definition

A stakeholder is defined here as "any individual, group, organization, department, structure or network with a vested interest in a particular issue. They stand to gain or lose if conditions stay the same or if conditions change. As they have a stake in those conditions, they have rights, possibly ownership and, very likely, information that is critical to the successful creation or implementation of any policy or policy change. The term variously includes the ideas of participant, involved/responsible party, and recipient" (Campbell, 2012, p. 91).

Determining exactly who those right stakeholders are to involve in an inclusive process can be a certain challenge. A range of stakeholder analysis tools – from simple stakeholder sheets to more complex sector-stakeholder mapping – can help to determine who needs to be involved, along with some of the power dynamics that may exist among them. There is little in the literature to date on the subject of a stakeholder analysis, though a comprehensive overview of available approaches is available in Campbell (2012) and Bryson (2004).

Balancing the different voices within a priority-setting process is another tall challenge. Most of the literature on this focuses on the role of the wider public (Working Group, 2000), studying whether the public's voice has been co-opted by the professionals (Abelson et al., 2003), muted by louder wheels squeaking for grease (Teng et al., 2007), or ignored by those with real policy-making power (Wait & Nolte, 2006, Rudan et al., 2007a). The priority-setting literature on service delivery is much more concerned with public involvement as the public is in fact the primary receiver of those services and thus deserves a voice in how those services are prioritized and ultimately delivered. When it comes to research priority-setting, however, the public may be more effectively represented by civil society organizations or global entities (such as WHO, UNICEF), with the research community more engaged in the often technical nature of the deliberations. This is not to downgrade the public voice but to recognize the inherent specializations within health research and the training required to identify and analyze knowledge gaps, needs and priorities. Such issue specialization, however, demands even closer attention to balance – since, as Kapiriri and colleagues observe, the values and criteria deemed essential by technical experts may not reflect those of other important stakeholders (2007).

Priority Setting as a Deliberative Dialogue

From a theoretical perspective, the concept of the deliberative dialogue offers a variety of ways to involve multiple stakeholders in any decision-making process and to balance their different opinions, values, needs and criteria. We define a deliberative dialogue here as a process of collective and procedural discussion where an inclusive and representative set of stakeholders consider facts from multiple perspectives, converse with one another to think critically about options, and through reasoned argument refine and enlarge their perspectives, opinions, and understandings (Gregory, Hartz-Karp, & Watson, 2008; McCoy & Scully, 2002; London, 2005; Lavis et al., 2009b). A deliberative dialogue creates joint meaning and shared understanding (Franco, 2006); it is a unique and effective problem-structuring tool (McDonald, Bammer, & Deane, 2009) that represents the soul of democracy itself (Dryzek, 2000). Unlike any other mechanism, a deliberative dialogue adds both scientific and social credibility to the decision-making process, as it unites and empowers those who will be affected by the eventual decision (CHSRF, 2006). A deliberative dialogue can open new windows of understanding, particularly for those whose views are not yet fully formed or informed (London, 2005).

A deliberative dialogue is not intended to solve problems (Lavis, 2009a) but rather to create open discussion on the nature and complexity of the problem (Abelson et al., 2003), and to frame it within its wider, systemic framework. In short, it is not in itself an end goal but rather a point within a much longer process of decision-making – much as priority setting is simply one point in the much longer process of creating and applying relevant knowledge.

The literature on multi-stakeholder deliberative dialogues suggests careful consideration of how each stakeholder is *selected*, and how each stakeholder actually *functions* in the dialogue. Of these two elements, there is little evidence about what works in selecting participants (Abelson et al., 2007). Rowe and Frewer's (2005) useful typology of public engagement mechanisms makes rough divisions between dialogues that have no control over who is selected to participate (such as public hearings, study circles, hotlines, open spaces, town meetings – where participants self-select) and those that do have some degree of control over who participates (e.g. opinion polls, consultation documents, citizen panels/juries, consensus conferences, task forces, planning cells) (McDonald, Bammer, & Deane, 2009; Start & Hovland, 2004; National Cancer Institute, 2007; Martin, Abelson, & Singer, 2002). Beyond descriptions and case studies of these dialogue types, however, there is simply little evidence for what works in multi-stakeholder processes, including the impact the deliberative processes have on those stakeholders, on decision-makers and on decision-making; and on how different context can, in turn, shape these processes (Abelson et al., 2007). Research is, however, currently emerging on the policy brief and dialogue methodology, suggesting that for knowledge translation platforms (KTPs) around the world, this method successfully capitalizes on the strengths of a deliberative dialogue to inform policy development (Moat et al., 2014; el-Jardali et al., 2014).

When it comes to the *function* of stakeholders in a deliberative dialogue, the evidence is scarce. If all relevant stakeholders participate in a deliberative dialogue, will they all have the same ability to contribute? Given the fundamentally technical core of a priority-setting exercise, how does a deliberative dialogue handle differing levels of expertise? Clearly, there is much to understand and evaluate, particularly in assessing the links between priority-setting processes and decision-making, and between stakeholder involvement and the types of priorities identified (Ranson & Bennett, 2009; Smith et al., 2009). Helpfully, Abelson and colleagues (2003) suggest four components to apply in evaluating any deliberative process, which we might certainly advance (along with AFR) for evaluating any priority-setting process. These include *representation* (what demographic, geography or political affiliation did participants represent?), *procedures* (were the procedures governing the dialogue open, reasonable, understood, responsive, legitimate and fair?), *information* (what information was selected, presented and interpreted?), and *outcomes* (was multiple stakeholder input incorporated into the decision-making process?).

Priority-Setting Processes at the National Level

Of central concern here is priority setting at the national level, particularly as a function of national health research systems. While the literature here is relatively scarce, there is nonetheless a strong global enthusiasm for creating priority-setting processes – particularly in LMICs. This enthusiasm arises partly from efforts to establish governance systems for health research that can accurately allocate research funding to understand and eventually solve urgent or core societal ills (Ghaffar et al., 2004; Nuyens, 2007). Unfortunately, the literature reveals very little about actual priority-setting processes, focusing instead on the many challenges to implementing any sort of priority-setting process. Such challenges include: the general dearth of available information; disconnections between who actually sets vs. who should set priorities, and the values that do set vs. those that should set priorities (Kapiriri & Martin, 2007); how national priority setting could inform sub-national levels and how those sub-national levels might adapt national priorities to their own needs (Nuyens, 2007); how the process itself may affect identified priorities (Makundi, Kapiriri, & Norheim, 2007); how to move priority-setting from the realm of researchers to a broader composition of stakeholders (Kapiriri et al., 2007; Rudan et al., 2007a; Rudan et al., 2007b; Tomlinson et al., 2007); how to push the discussion past disease-specific issues to the systemic (el-Jardali, 2010; Walker et al., 2009); and how to move beyond the simple cost-effective analyses that have long dominated various priority-setting initiatives (Mshana et al., 2007). All of these challenges – particularly in LMICs – are punctuated by governance institutions often too weak to make lasting or enforceable decisions, and subject to the very real and considerable pressure of research funders to align with their own perception of priority.

Box 2: International research funders and priority setting

"Paradoxically, it is the international donor community which has helped governments avoid making difficult resource-allocation decisions. Donor agencies have traditionally financed and supported separate projects based on their own priorities. These priorities may be expressed in terms of particular geographic areas, particular diseases, particular levels of healthcare (e.g. primary care and public health, rather than hospital services), particular types of interventions (e.g. immunization or contraceptive supplies), particular management systems (e.g. drug supply), or particular parts of the population (e.g. pregnant women, children under five). This has to some extent undermined aid-receiving governments' ability to develop coherent sectoral policies and allocate resources accordingly" (WHO, 2003).

On top of the above concerns, incorporating the views and voices of multiple stakeholders to make priority-setting processes fair and legitimate is an additional challenge. The Working

Group (2000) suggests “sequential patterns of consultations, analyses and priority setting at the community and district levels, and aggregation and synthesis of these outputs at the provincial and national levels” (p. 132) going through several iterations to achieve some sort of consensus. However, despite the rubric of many national health reforms to advance a participatory, multi-stakeholder process in health policy, this type of participation depends upon a genuine willingness of decision-makers to cede some of their power (Wait & Nolte, 2006), which is often better phrased on paper than seen in action. As Nuyens (2007) observes, “the strategies and methods necessary to achieve a participatory process have not been developed or implemented systematically. There is no body of knowledge about how and when various stakeholders should be involved or what their functions and responsibilities should be….priority setting has often been handled as an isolated, one-off event that has little impact on, or relation to, other essential components used to construct a health research system” (p. 320).

In applying the AFR framework to Uganda, Norway and Canada, for instance, Kapiriri, Norheim and Martin (2007) find no obvious mechanisms for achieving publicity, relevance or revisions of priority-setting processes, with no apparent leadership for ensuring a fair process. Likewise, Sabik and Lie’s 2008 study of national processes in the Netherlands, Sweden, New Zealand, Oregon, the United Kingdom, Denmark and Norway reveal that the act of priority setting had a negligible effect on the actual issues that had been prioritized, funded and researched. They, as others, conclude that priority-setting processes at the national level – in countries of any income level – require strong decision-making abilities to determine, oversee and enforce what is (or is not) eventually funded or implemented (Peacock et al., 2006; Rudan et al., 2008; Sabik & Lie, 2008), and also to ensure that the right stakeholders are at the table.

Despite the lack of evidence or evaluations at the national level, there are some strong recommendations in the literature for the way forward. These range from countries creating advisory panels of key stakeholders who are first trained in the principles of priority setting and can then assist various bodies in its execution (Peacock et al., 2006) to finding a priority-setting algorithm or model that can be safely adapted or replicated country-by-country (e.g. the Child Health and Nutrition Research Initiative PS model as outlined in, among others, Rudan et al. [2007a] and explained in *Section Two* below). Perhaps the most important contribution to the field at this time though is the documentation of national experiences in setting priorities, with particular attention to the actual criteria developed to assess respective research priorities. Martin and Singer (2002) advance this as a *describe-evaluate-improve strategy*: describe priority setting in its context; evaluate it using an ethical framework like AFR; and use the evaluation to improve the act of priority setting. To this we would add a fourth component: disseminate. As it will be some time before the formal evidence base reflects national experiences, we nonetheless need to learn from the many priority-setting projects and experiments underway – to adapt, apply, and ultimately refine these crucial deliberative acts.

Summary Points

- PS is a core tool in influencing policy and in influencing the research agenda.
- Every PS process must be fair and legitimate, have context-specific values, and ultimately result in priorities that can inform decision or guide research investments.
- Every PS process determines the criteria that can helpfully distinguish among priorities. Typical criteria used in determine a research agenda include magnitude, relevance and urgency; applicability, deliverability, affordability, sustainability; originality; research capacity and feasibility; policy relevance; and expected impact of the research.
- PS processes must be evaluated- first to ensure their legitimacy and ethics and second to ensure that robust learning occurs and PS processes worldwide can improve. The

global knowledge base in PS for research remains scan, and this the more we can learn from each process, the better PS exercises collectively become.

Section Two: Priority-Setting Processes

Learning Objectives

In this Section, major learning objectives include an understanding of:

- ideal interpretive PS, and how it selects the "right" stakeholders to brainstorm on the "right" issues to determine the priorities of a society, a system, or an institution. There are seven connected steps in performing an interpretive PS exercise.
- how the health research option can allow PS exercises to identify knowledge needs including a vision for how that knowledge might be effectively implemented in reducing disease burden.
- concrete interpretive PS exercises in dissimilar contexts, with different methods yielding varying results.

Introduction

There are many different priority-setting processes possible, with each typically distinguished by level (global, national, and institutional), comprehensiveness (research priorities for the health sector; research on specific interventions), the balance between technical and interpretive approaches, and stakeholder involvement (Ranson & Bennett, 2009). In this section, we shift into very specific consideration of five different priority-setting approaches. This includes an overview of an ideal interpretive priority-setting process; participatory priority-setting methods; the Canadian Health Services Research Foundation's Listening for Direction (LfD) model; the Global Forum for Health Research's Combined Approach Matrix (CAM); and Program Budgeting and Marginal Analysis (PBMA). In this section, we'll review the literature on each, provide an overview of their logical flow with flowcharts and graphs, and provide a brief discussion of their strengths and limitations.

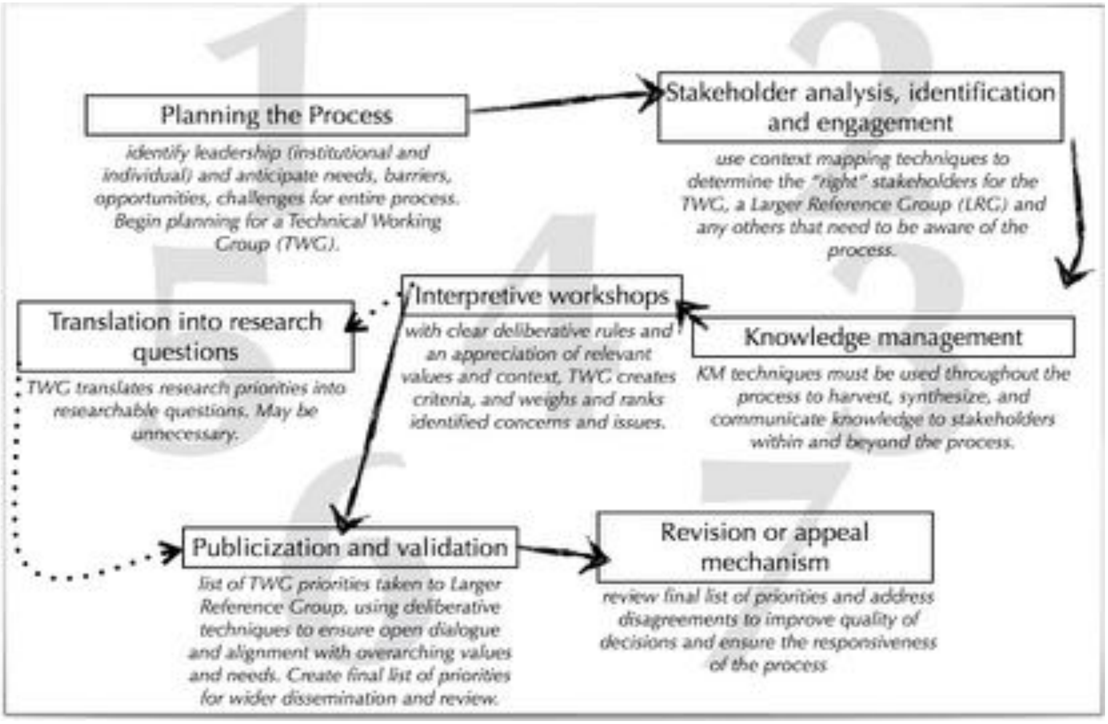
Ideal Interpretive Priority Setting

In its ideal interpretive form, priority setting selects the right stakeholders to brainstorm on the right issues to determine what a society's, a system's, or an institution's research priorities are (Sibbald et al., 2009; COHRED, 2006; Alliance for Health Policy and Systems Research, 2009; Rudan et al., 2007a; Rudan et al., 2007b). While there is little consensus on what marks a successful priority-setting process (Sibbald et al., 2009), we can nonetheless identify, from a theoretical perspective, an iterative list of seven ideal elements within a priority-setting process for research that satisfy Daniel's (2000) Accountability for Reasonableness conditions – one that is fair, legitimate, relevant, public, subject to appeal, and enforceable. Figure 1 below outlines the seven steps of this ideal interpretive priority-setting process.

Planning the Process

This step is crucial in anticipating the needs, barriers and challenges for all of the remaining steps. At this planning stage, the process needs to identify leadership, with particular attention to the central individuals and institutions. This may coalesce into a Technical Working Group (TWG) (variously called a Senior Advisory Team, a Council of Elders, etc.) of individuals representing major institutions. The TWG will need to determine the timing of the process, its logistics, budget (including funding possibilities), dissemination plan, etc., without unduly influencing or corrupting the many details. Members of the TWG may need to be identified using some of the stakeholder analysis techniques detailed in step two (and in *Section Three*).

Figure 1: The Seven Steps of the Ideal Interpretive Priority-Setting Process



Stakeholder identification, analysis and engagement

As discussed in the *Introduction*, few priority-setting processes pay sufficient attention to how their stakeholders are actually selected: who are the right people and how do they come to sit around the same table? How can a priority-setting process ensure a balanced representation of different institutions, interests, and levels? As discussed in much greater detail in *Section Three*, a stakeholder analysis is a critical tool in determining who should sit at the table. It can help the leaders of a priority-setting process identify:

- the importance, influence and interests of stakeholders in relation to the research agenda or particular research theme/issue. This could include identification of both primary and secondary stakeholders.
- the layers and levels within complex stakeholder institutions – e.g. entities like a Ministry of Health, a community, or the World Health Organization can all be treated as a single or as a multiple actor depending upon the nature of the issue at hand (Varvasovszky & Brugha 2000). One institution may in fact turn out to be several different stakeholders.
- the "level" of stakeholder to involve – local, regional, national, and/or international.
- potential conflicts, conflicts of interest, or risks that could jeopardize the process;
- opportunities and relationships that can be built on during the process;
- groups that should be encouraged to participate in different stages of the process; and
- appropriate strategies and approaches for stakeholder engagement (WWF, 2005).

Performed by the Technical Working Group (TWG) (or a consultant hired for the purpose), a stakeholder analysis may well identify members of the TWG itself, and potential members of a Larger Reference Group (see *Section 2.2.6* below), with each acting as a filter and adding layers of context, depth and legitimacy to the process. The TWG may also complete or commission a situation analysis as a way of further understanding the actors relevant to a domain, theme or question; the actual information needs of the process; and/or the relevant aspects of the overall health research system.

Knowledge management

The flow of knowledge throughout the process is also of critical importance. Mechanisms to guarantee a circular flow must be in place from the outset to ensure that all stakeholders have the same information, with provisions made to ensure that the less technically skilled participants can interact with the more technically advanced input. Before the process begins, a range of relevant information must be made available to stakeholders (e.g. systematic reviews, peer-reviewed and grey literature, and national health research policy documents). The availability of knowledge – and the knowledge selected to be available – has a direct influence on the priorities chosen, and thus there must be a balance of the rigorous with the spontaneous (Working Group, 2000).

Clearly, any priority-setting process requires the development of a knowledge management strategy to satisfy the above concerns and needs. Such a strategy should coalesce around three broad areas:

- what knowledge and information needs do the stakeholders in the process have? Do they all have a similar educational background? Can they all read the same language? Do they all have similar access to knowledge resources?
- how will knowledge influence the priority-setting process? Where will it need to be introduced in the process? How will the leaders ensure that information is available to stakeholders during and after the process? How will it be disseminated to ensure the transparency and accountability of the process?
- how should people, processes and technologies – in terms of specific tools and practices – be used? How will people share and access knowledge and information?

Interpretive workshops

This may be one workshop among a select group of stakeholders (i.e. the TWG), or it may be several; it may also be a sequence of workshops among different groups or levels of stakeholders. In any case, an interpretive workshop sees stakeholders gathering to discuss criteria for assessing priorities; to establish the means to weight or rank the criteria; to apply the criteria to identified priorities (Working Group, 2000); or to determine broader health research options (Rudan et al., 2007b). These workshops are open, deliberative and iterative – conflicting priorities may trigger some consensus-building techniques, or the leaders may decide the nature of the conflict to be an important element that need not be resolved. Workshops may flow from:

- reactions to the pre-circulated material (which may include a comprehensive list of priority research issues or questions)
- a brainstorm on the big, pressing or contentious research issues or questions
- a discussion of criteria that should be used to rank the research issues or exact questions
- agreement on a formal set of criteria, and means of weighting that criteria (i.e. some may be more/less important than others)
- applying that criteria to research issues or questions to arrive at a scored or ranked list of issues or questions
- a discussion of the types of research that could best illuminate the issues or questions.

Note the three possible levels of deliberation. The interpretive workshops may discuss particular research issues (e.g. malnutrition), a specific research question (e.g. the role of Vitamin A supplementation coverage in three regions in Tanzania in reducing nutritional deficiencies) or a broader health research option (e.g. health system barriers and opportunities for increasing Vitamin A supplementation coverage in Tanzania).

Box 3: The Health Research Option

"The major conceptual advance in this [CHNRI] initiative is the recognition that there should be a broader definition of 'health research option' as an activity that is not only limited to producing new knowledge, but also has a vision of implementation of this knowledge, which ultimately should help to reduce disease burden. From this recognition it follows that it is important not to consider the endpoint of research as 'generating new and interesting knowledge or insight,' because this might favour more fundamental research. Rather, the process of research priority setting should have a clear theoretical framework based on multiple endpoints coupled to a systematic process of scoring and ranking competing research options" (Rudan et al., 2007b, p. 57-58).

Translation of issues into research questions

While some interpretive workshops may discuss precise research questions, it's more likely that they will identify policy concerns, research issues and/or research options that may then (context depending) be translated into actual questions. The TWG should lead this process, and may then wish to convene another interpretive workshop to discuss the list of questions and their respective priority.

Publication and validation

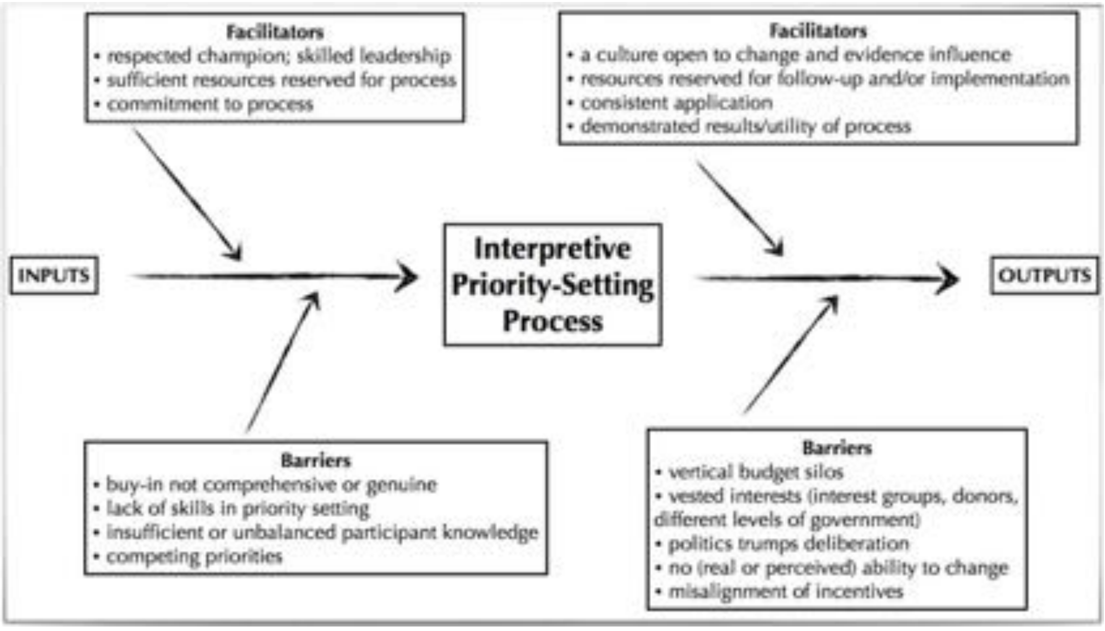
The final list of ranked issues, questions and/or options must now be made available to a larger group of stakeholders (a Larger Reference Group [LRG]), ensuring that the list aligns with the values and needs of all concerned, with clear definitions of the expected outcome of its work – from broad lists of priority health (system) problems or issues to a detailed list of priority research questions. The TWG should provide each LRG member with all necessary information sufficiently ahead of time. The TWG will then lead the LRG meeting itself, which might be initiated virtually but will conclude either with a complete list of validated priorities or with a set of criteria ranked for a specific context (i.e. rather than determining precise priorities, the LRG validates which elements (e.g. equity, maternal-child health) is of the greatest concern to them). Ballots and voting may be the easiest process for arriving at some sort of consensus on criteria ranking or priority listing. More information on using an LRG to validate PS criteria and/or priorities can be found below and in Rudan and colleague's (2008) work.

Revision or appeal mechanism

Following publication and larger discussion of the list of priorities, there needs to be a mechanism in place to address disagreements comprehensively and constructively. Such a revision process would "1) improve the quality of decisions by providing opportunities for new information to be brought forward, errors to be corrected, and failures in due process to be remedied; and 2) operationalize the key ethical concept of responsiveness" (Sibbald et al., 2009, p. 16).

Figure 3 provides a visual representation of some of the barriers and facilitators at different stages of this process, adapted here for the ideal interpretive model.

Figure 3: Facilitators and Barriers to an Ideal Interpretive Priority-Setting Process (Peacock et al., 2009)



Participatory Priority-Setting Methods

Recognizing the dearth of viable and tested priority-setting mechanisms for the national level, particularly in LMICs, recent research and experience have focused on a new set of approaches, with most being variants on the above ideal interpretive process. Involving a range of stakeholders, these approaches identify existing policy concerns and research priorities; assess the extent to which current research addresses these concerns and priorities; develop a list of core priorities for future research; and then widely disseminate those priorities for discussion and revision. Such approaches have led to context-sensitive, evidence- and stakeholder-informed priorities, and critically revitalized the act of priority setting at national, regional and even global levels with particular relevance for health systems research and for strengthening national health research systems.

In this section, we explore specific examples of participatory priority-setting models and lessons from the regional level on a particular global health research issue and for a national-level institute (sub-section 2.3.3). It is important to note that each of these models has a different number of steps in moving from the start to the finish of the process. This reflects the ability of each exercise to tailor the process to its specific needs – in some processes, for instance, stakeholders may be more difficult to identify or to convene, and may need to be treated as discrete groups.

Participatory Priority-Setting at the Regional Level: Latin America, East Asia, South-East Asia and the Middle East/North Africa

The WHO's Alliance for Health Policy and Systems Research has pioneered this method of priority setting in three health-research themes – the role of the non-state sector; financing; and human resources for health – involving twenty-four LMICs in four regions (Latin America, East Africa, South-East Asia, and the Middle East/North Africa). The process featured key-informant interviews, literature reviews and thematic papers all done by four different LMIC organizations. With this regional identification and synthesis of existing policy concerns and research topics, a validation and ranking consultation workshop of regional experts created criteria for sorting those concerns and priorities, and ranked them according to the following questions: a) can the research question be answered? b) how large is the impact on social welfare likely to be? (intended to include both health and equity impacts); and c) is there a lack of research on this topic? They then discussed in some detail the kinds of research that could best address the four resulting research questions that ranked highest. Dissemination of the results and products of the validation workshops ensured that the loop closed with policy-makers receiving priority lists in answer to their initial concerns (Alliance for Health Policy and Systems Research, 2009; El-Jardali et al., 2010; Walker et al., 2009; Ranson & Bennett, 2009).

From a meta level, Figure 4 demonstrates the four key steps in this approach. Figure 5 shows detail on a specific regional process.

Figure 4: The Four “Big-Picture” Steps in Participatory Priority-Setting Methods at the Regional Level

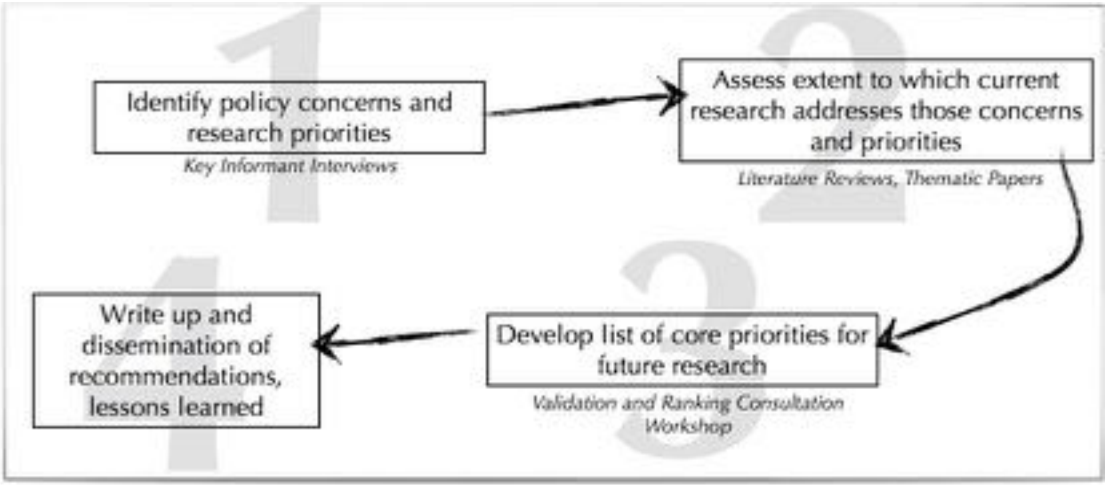
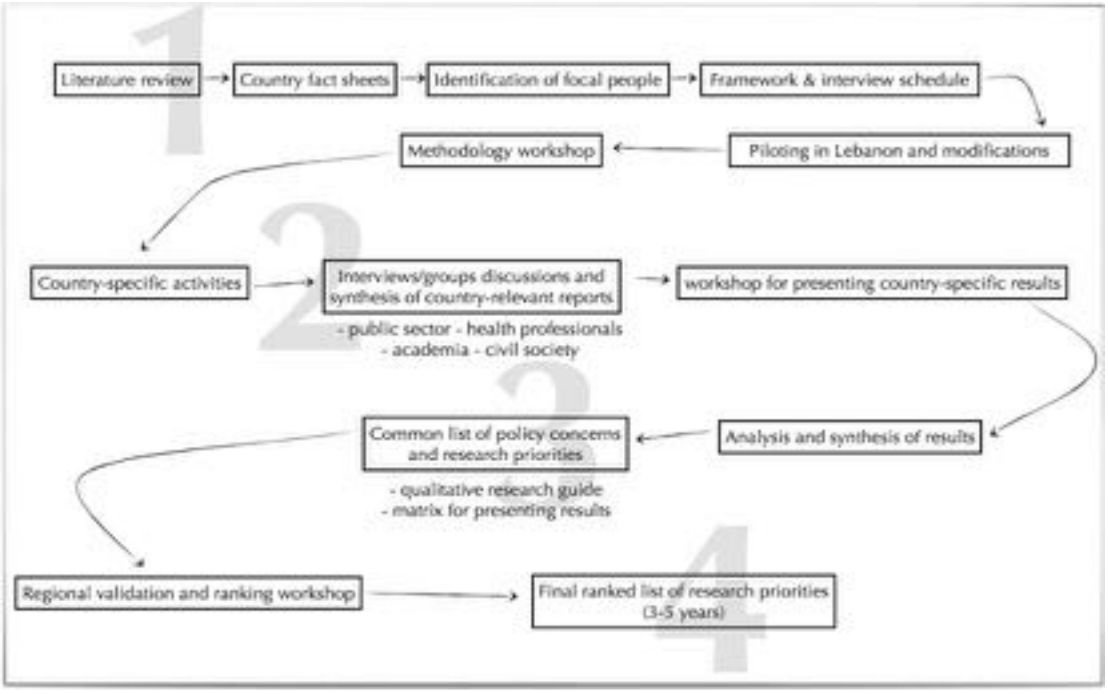


Figure 5: The Regional Priority-Setting Process in the Middle East and North Africa (el-Jardali et al., 2010)



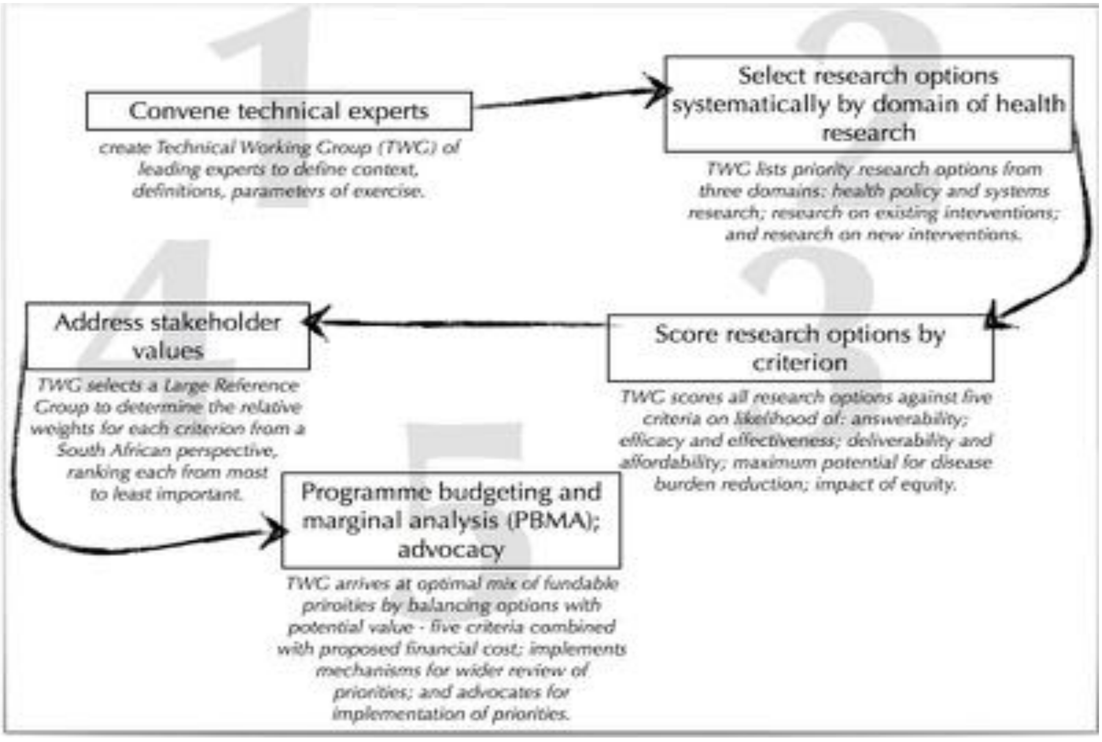
Child Health and Nutrition Research Initiative

One particularly innovative participatory priority-setting process was led by the Child Health and Nutrition Research Initiative (CHNRI) (Rudan et al., 2008; Tomlinson et al., 2007; Rudan et al., 2007b) and used for the first time at a country level in South Africa in 2006. As a participatory priority-setting process, it made two major contributions to the field: by concentrating less on the creation of new knowledge and more on the health research option and its vision of implementation (Rudan et al., 2007b); and by focusing on ways of incorporating societal values and principles through an LRG. The CHNRI method is a hybrid of technical and interpretive approaches, principally by ensuring that technical experts provide opinions and input anonymously, with the end ranking of each research option done in an open, systematic fashion for transparency, replicationm and validation (Rudan et al., 2008).

As Rudan and colleagues (2008) comment, the CHNRI priority-setting methodology results in seven strong outcomes: a better understanding of the context; an agreement on expectations and acceptable risks; a definition of main criteria for priority setting; a listing of the many different research investment options; a transparent assessment of each option; adjusting each options according to social values; and combining this adjustment with "predicted cost, expected profits and risk preferences to decide on the optimal investment strategy" (p. 316). It is systematic, it limits the influence of technical experts, has a final quantitative output (research priority score), can evaluate and rank different types of research and, critically, through the involvement of the LRG "incorporates an efficient means of considering the voice of stakeholders and the wider public, who are given the power to place thresholds and weights upon intermediate scores (which are based on the collective opinion of technical experts) and in this way considerably shape the final outcome" (Rudan et al., 2007b, p. 59).

In 2006, this methodology was tested for the first time at a country level, in South Africa (Tomlinson et al., 2007). Figure 6 shows the steps employed during that exercise.

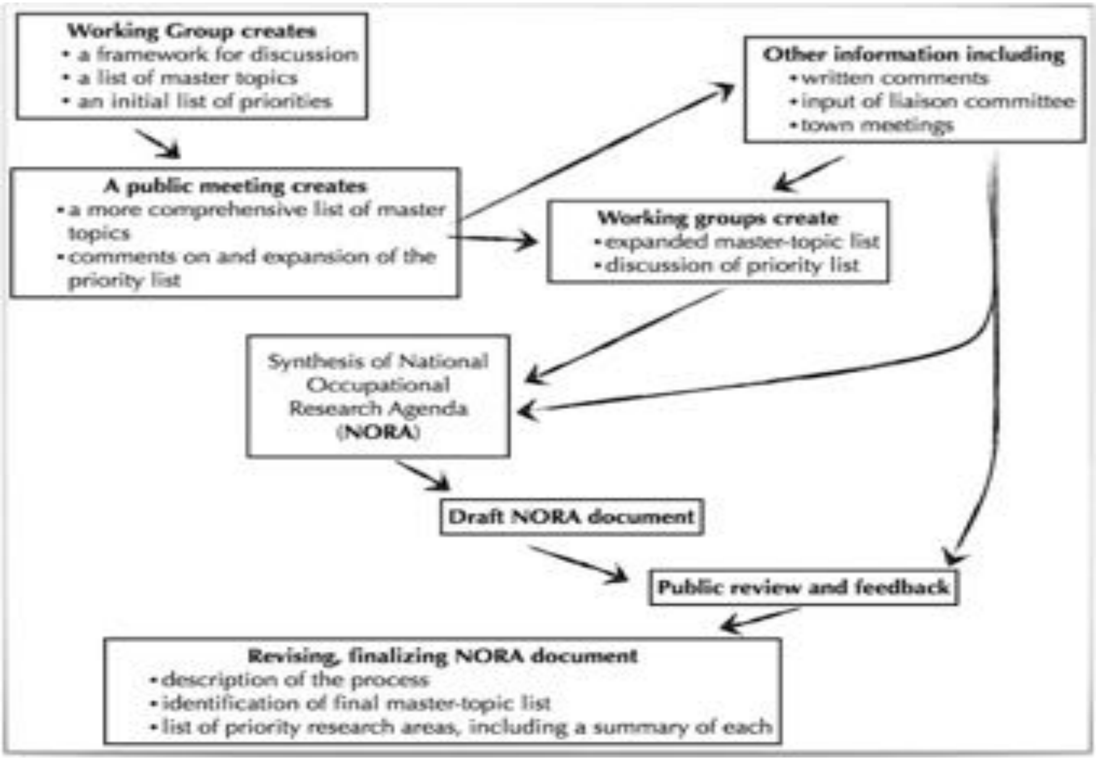
Figure 6: Setting Priorities in Child Health Research Investments for South Africa (Tomlinson et al., 2007)



The National Institute for Occupational Safety and Health

Slightly different than the above models, the National Institute for Occupational Safety and Health (NIOSH) in the United States developed their own participatory priority-setting process (Rosenstock et al., 1998). This was a consensus-building process revolving around input from working groups and open town meetings to arrive at final research priorities. With the working groups – one comprised of researchers, one of other stakeholders, one of health professionals, and one of internal NIOSH staff – identifying initial priority areas, an iterative process whittled this list down to 23 topics, using criteria on the seriousness of hazard, numbers of works exposed, potentials for reducing risk, etc. Public town meetings then contributed to and further refined this master list of priorities for a National Occupational Research Agenda (NORA), with comments and criticisms leading to the development of a public process for shaping the research agenda. Figure 7 shows how the steps link one to the next.

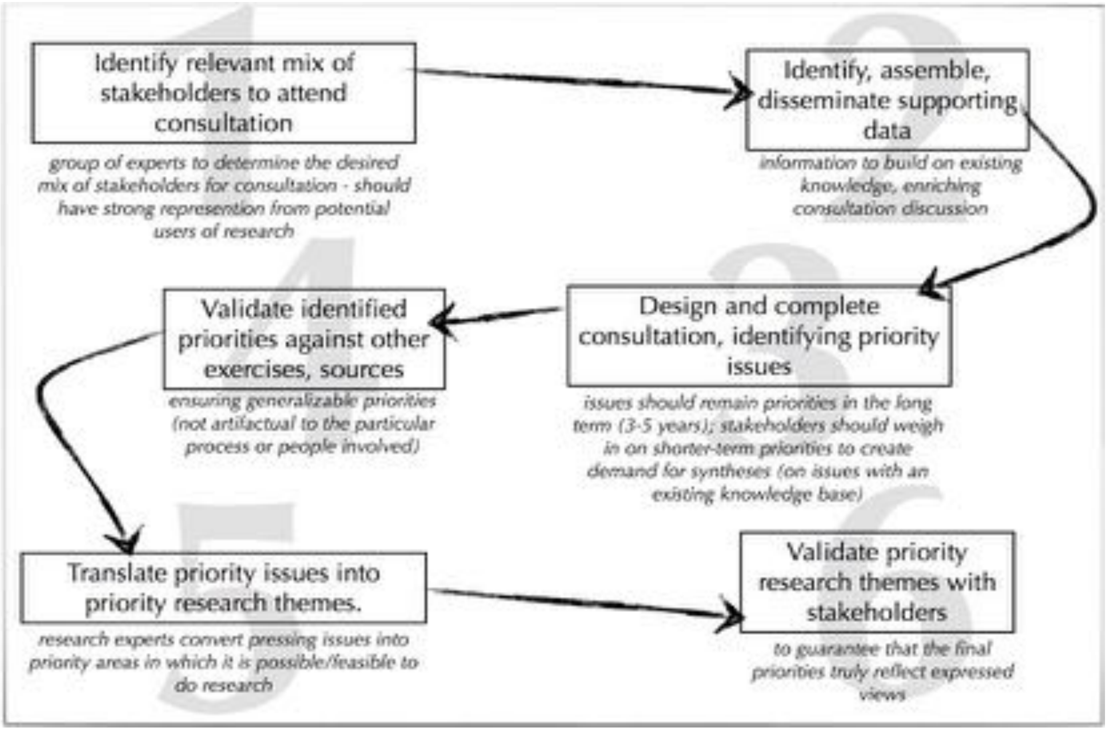
Figure 7: Determining a National Occupational Research Agenda (Rosenstock, Olenec, & Wagner, 1998)



Listening for Direction

Pioneered by the Canadian Health Services Research Foundation (CHSRF), Listening for Direction (LfD) is a strong interpretive priority-setting process that does not deviate greatly from the ideal described above. It creates a situation in which a range of stakeholders can present their opinions on the big issues. “Based on the principle of linkage and exchange between research funders and researchers on the one hand and the research’s potential users on the other,” LfD moves from environmental scan to regional workshops to national workshops “with invited participants, focused on pressing issues that decision-makers expected to encounter in the medium-term (3-5 years)” (Smith et al., 2009, p. 3). It ultimately wants to create and promote the production of timely, relevant evidence to inform healthcare decision-making with both sides actively listening to the other, ultimately creating priorities relevant to researchers, to decision-makers, and to practitioners (Lomas et al., 2003). Figure 8 provides the graphic progression among the steps.

Figure 8: The Six Steps of Listening for Direction (Lomas et al., 2003)



Box 4: Listening for Direction

“The LfD model builds on the respective areas of expertise of research funders, researchers and research-users. All groups participate in the process with varying degrees of intensity throughout its various phases. Representatives from the partner organizations (primarily research funders whose roles include knowledge transfer and research use) oversee the consultation process, listen to the discussions and, with the aid of expert researchers, use the concerns identified by decision-makers and other research-users to derive research questions. During the consultation workshops, research-users identify priority issues that would benefit from being informed by research. Researchers ‘translate’ those priority issues and concerns into research questions that are likely to provide evidence to help address those issues…

The CHSRF has tested this model in three different rounds to date. Critically, Listening for Direction II distinguished two sorts of researchable questions from the identified priorities: syntheses of existing evidence – where there was felt to be a sufficient body of knowledge which could be synthesized within 6 to 24 months; and primary research – where new evidence was required which could be produced over the next 2 to 5 years…

For the 2007 LfD process, the objectives were to identify health-system priorities for the short term (one-to-two years) and the longer term (3 to 10 years). These results would be analyzed by researchers who would identify questions suitable for syntheses of existing research, and questions that required original and perhaps longer-term research” (Law, Flood and Gagnon 2008, p. 5).

As described in Smith and colleague’s (2009) work, LfD was used to bring together a range of listening stakeholders in the Canadian province of British Columbia. The organizers followed the below seven steps:

1. key individuals from each of BC’s six health authorities were recruited as research partners.

2. a priority-setting for a invited these research partners, select decision-maker partners (or their substitutes), and individuals from different sectors and job positions (e.g. finance managers, vice presidents, a CEO).

3. various priority-setting for a discussed potential research questions.

4. each for a produced a set of notes capturing the discussion and the context.

5. a summary of these notes – including potential questions – was circulated to decision-makers to ensure their ideas and opinions were adequately captured.

6. the study's lead author analyzed these notes to group possible research questions or comments into themes, with the second author providing another layer of analysis and review of the findings; all authors gave their own commentary (Smith et al., 2009).

7. Following these for a, researchers had face-to-face meetings with decision-makers to discuss these findings and chart out possible areas for partnership.

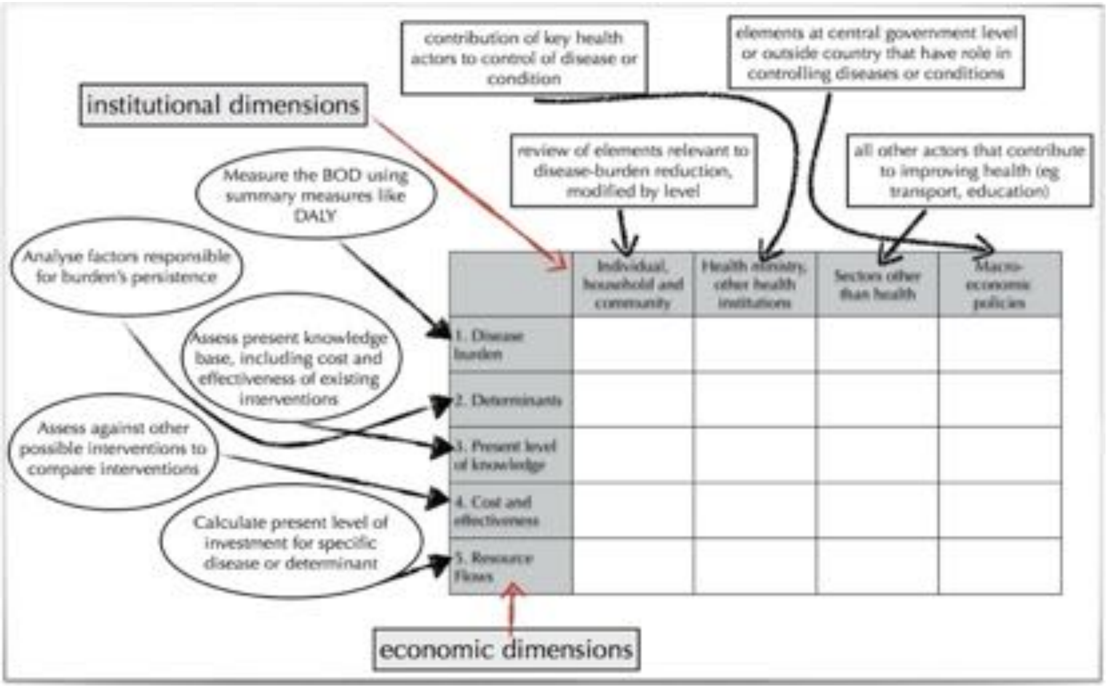
The Combined Approach Matrix

The Combined Approach Matrix (CAM) was developed by the Global Forum for Health Research in 2004 and then updated in 2009. Its objective is to incorporate both economic and institutional aspects into a single tool – a combined approach – for priority setting. The advantage of this tool is that it helps:

> *…organize, summarize and present all available information on one disease, risk factor, group or condition, and facilitate comparisons between the likely cost-effectiveness of different types of interventions at different levels. The information may be partial, and possibly even sketchy in some cases, but it will improve progressively, and even limited information is sometimes sufficient to indicate promising avenues for research. The CAM seeks, above all, to summarize the evidence base for particular diseases or risk factors, thus highlighting gaps that require further research and action.* (Ghaffar et al., 2004, p. 28)

Figure 9 shows the type of table critical to executing the CAM.

Figure 9: The Combined Approach Matrix (Ghaffar et al., 2004)



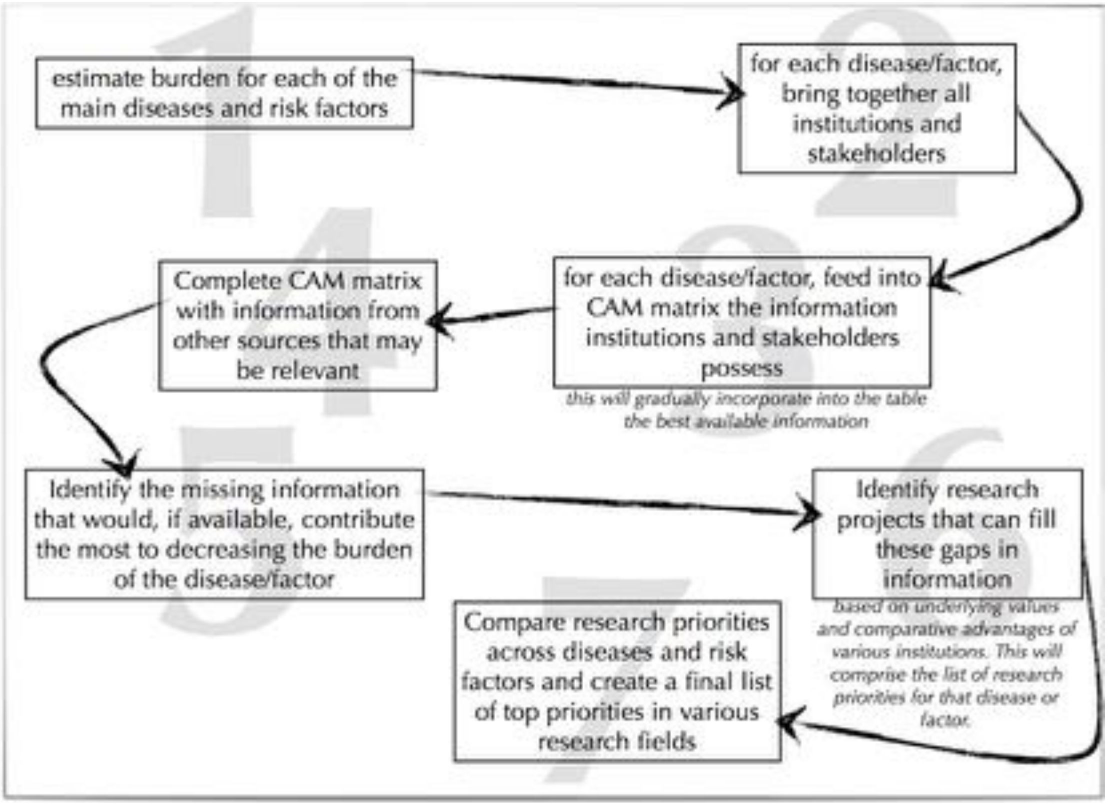
The Matrix helps to organize and summarize information about a particular disease and the interventions available to combat it. As shown in the above chart, the Matrix categorizes this information according to five economic dimensions (e.g. disease burden and cost-effectiveness of interventions) and four institutional dimensions representing the various levels at which interventions can be implemented.

“Information gathered in a priority-setting exercise conducted at country, regional and global levels could be introduced into the CAM as a common framework to organize and present the collected information (as a basis to identify gaps in health research and health research priorities). As we can see in filling in the above matrix, the CAM:

- brings together in a systematic framework all information (current knowledge) related to a particular disease or risk factor
- identifies gaps in knowledge and future challenges
- relates the five-step process in priority setting (economic axis) with the actors and factors (institutional axis) determining the health status of a population
- permits the identification of ‘common factors’ by looking across the diseases of risk factors
- is applicable to priority setting in the field of:
    - national, regional or global problems
    - both diseases and risk factors
- permits the linkage of priorities in the field of health and health research
- enables the rapid identification of the effect of a change in one of the ‘boxes’ of the matrix on the others
- permits taking into account the large number of factors outside the health sector that have an important impact on people’s health.” (Ghaffar et al., 2004, p. 32)

Figure 10 shows the steps distilled into graphic form.

Figure 10: The Seven Steps of the Combined Approach Matrix (Ghaffar et al., 2004)



As various authors note, though, the CAM has some shortcomings, from a non-inclusivity to a disease-driven orientation.

> *Although it is an extremely helpful tool for gathering and organizing information needed for priority setting, it does not in itself represent an algorithm for making the decisions on the priorities by ranking or separating the competing investment options. Therefore, in the absence of reliable information, which is usually very scarce for developing countries, most of the decisions will still be based on discussions and agreements within the panels of experts.* (Rudan et al., 2007a, p. 601)
>
> *It is a predominantly disease-driven approach to priority setting that does not serve the health system level well. Many health systems research questions stand to provide benefits for multiple different diseases. Linking health systems research questions to specific diseases, rather than seeing them in total, results in these topics being systematically de-prioritized and contributes to the fragmentation of health systems research*. (Ranson & Bennett, 2009, p. 3)

Program Budgeting and Marginal Analysis (PBMA)

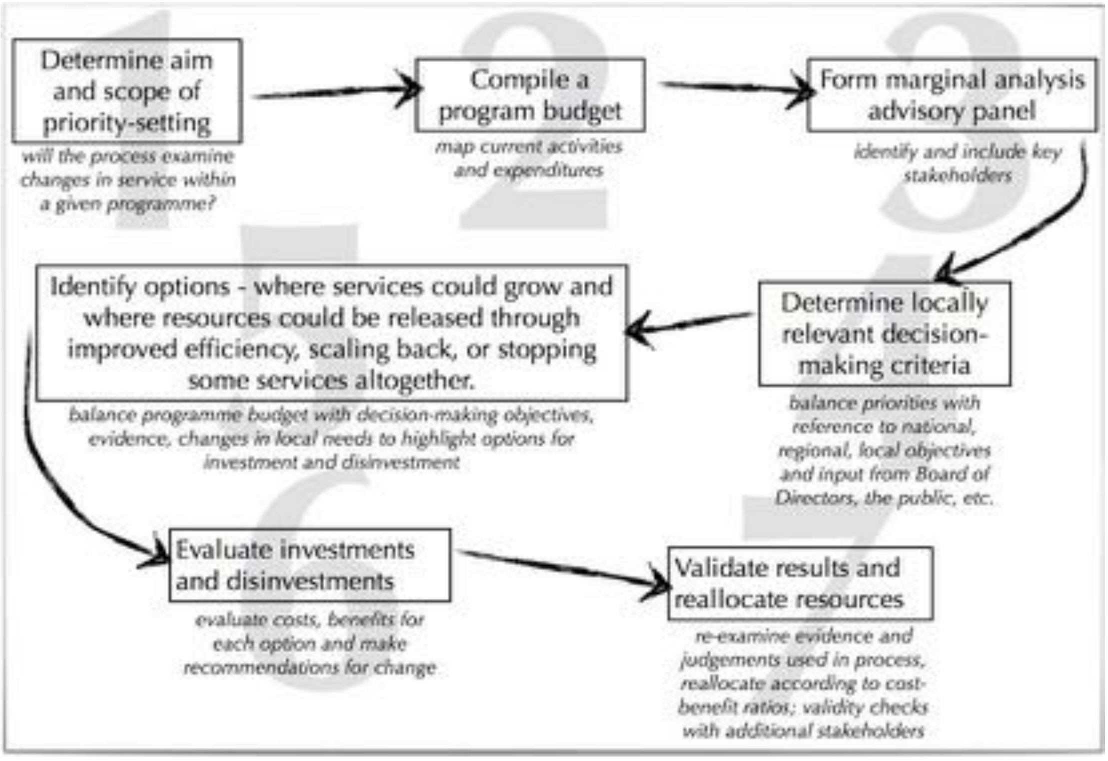
PBMA is most often used at the organizational level (typically by service-delivery institutions) to decide among competing services, or to determine a feasible basket of services. It is above all a priority setting for interventions model, but has strong applicability for priority setting for research. “The basic principle is that to do more of some things we have to take resources from elsewhere, by either doing the same things at less cost or reallocating resources from other areas of care. This requires accurate measurement of the costs and benefits of healthcare programs” (Peacock et al., 2006, p. 482). While PBMA differs from the above priority-setting tools in that its focus is on service delivery, it has been effectively incorporated into priority setting for research – most notably by Tomlinson and colleagues (2007) in South Africa, where PBMA was used to help cost out respective research options. Indeed, this function – of assessing a true cost of a question or option – may be the strongest contribution PBMA can make to priority setting for research.

As Mitton and Donaldson (2004) and Mitton and colleagues (2003) explain, PBMA embraces two key economic underpinnings.

> *The first is that of opportunity cost, which carries with it the understanding that in investing resources in one way, some opportunity for benefit, through investing those resources elsewhere, has been lost. One of the keys in setting priorities, then, is to measure or weigh out the costs and benefits of doing one thing vis-à-vis another… The other principle is that of the margin, which is about shifting or changing the resource mix. If the budget increases, one could reasonably ask how best the additional resources should be spent. Conversely, if the budget decreases, one would likely want to take resources from areas which are producing the least benefit. Lastly, if the budget was neither increasing nor decreasing, at least not continuously, the questions remains as to whether resources should be re-allocated (with some areas cut back so that others can expand) so as to improve benefit to the population being served. The concept of the margin is crucial to this development of an economic approach to priority setting.* (Mitton & Donaldson, 2004, p. 2)

Figure 11 Sets Out the Seven Different Steps of the Process.

Figure 11: The Seven Steps of PBMA (Mitton & Donaldson, 2004; Mitton et al., 2003)



Section Two: Summary Points

- The ideal interpretive PS process illustrates an iterative list of the seven ideal elements within a priority-setting process for research that, as a result, can be fair, legitimate, relevant, public, subject to appeal, and enforceable.
- Specific participatory PS processes have identified existing policy concerns and research priorities; assessed the extent to which current research addresses these concerns and priorities; developed a list of core priorities for future research; and then widely disseminated those priorities for discussion and revision.
- The CHNRI PS model has become very effective in different contexts around the world, a hybrid of technical and interpretive approaches resulting in a ranked list of research options done in an open, systematic fashion for transparency, replication and validation.

Section Three: Deliberative Processes

Learning Objectives

In this Section, major learning objectives include an understanding of:

- Major approaches in identifying and analyzing stakeholders, particularly through an understanding of the power, involvement and interests of those stakeholders; the degree of any stakeholder's support for a particular position, ideology or political perspective; the dynamics that exist between various stakeholders; and underlying policy networks and influencers.
- Major means for eliciting stakeholder input through virtual, collective and/or confidential techniques.
- Leading deliberative dialogue models that can convene many different types of stakeholders to discuss and debate priorities.

Introduction

A critical gap in the priority-setting literature lies at the outset of the process – with the stakeholder. What is a stakeholder exactly? How are stakeholders identified and analyzed? How can one be deemed relevant to a priority-setting process and another irrelevant? And what are some tools for analyzing the relationships and dynamics that exist among stakeholders?

Added to these questions are issues around elicitation. Clearly, not all mechanisms for eliciting stakeholder input – from, for instance, a structured stakeholder interview to a chance meeting in the corridors – are equal. In the interests of fairness and legitimacy, every priority-setting process must not only identify the right stakeholders, it must also grant those stakeholders the time and space to speak, or the loudest – the squeakiest wheels – may well dominate the discussion. And building on this, deliberative processes then shape, weigh and synthesize the opinions and concerns of each stakeholder to ensure an objective balance – between the "rigorous and the spontaneous," the technical and the general, and among stakeholders themselves.

To that end, this section is divided into three. Here we explore a range of practical tools for:

- identifying and analyzing stakeholders;
- eliciting stakeholder input; and
- convening deliberative dialogues.

Identification → **Elicitation** → **Deliberation**

Stakeholder Identification and Analysis

Identifying the right stakeholders for any priority-setting process is much more than simply creating a list of individuals. While the identification process may start with this type of brainstorming, the greater the process can identify and analyze not only the relevant institutions, networks, and individuals but also the underlying assumptions, the forces for and against change, and the critical dynamics among stakeholders, the better any priority-setting process will prepare itself for understanding and grappling with complexity. Some processes may be relatively straightforward, but most involve a tangled web of stakeholders – such as in setting priorities for research in health financing, which actors need to be involved? and how do they need to be involved, and when?

In any priority-setting process, the leaders need to understand:

- the different stakeholders in any given research or policy environment;
- the power, involvement and interests of those stakeholders;
- the degree of any stakeholder's support for a particular position, ideology or political perspective;
- the dynamics that exist between various stakeholders; and
- underlying policy networks and influencers.

Analyzing the Stakeholder

What is a stakeholder? And how do we distinguish the key variables of *power*, *involvement* and *interest* among different stakeholders?

Stakeholders are defined here as any individual, group or institution with a vested interest in the prioritization process. Their vested interest includes something they stand to win or lose, or the rights or ownership they may possess (WWF, 2005; Bourne & Walker, 2006). As Bryson (2004) concludes, a stakeholder gains relevance "if they have information that cannot be gained otherwise, or if their participation is necessary to assure successful implementation" (p. 27).

A stakeholder analysis is, then, a multi-step tool to identify and analyze relevant stakeholders, the dynamics among them *and* between them and their environment. It typically maps the nature of stakeholders' interests; the extent to which stakeholders' interests converge or overlap; the stakeholders' importance or influence with regard to the issue at hand; the dynamics at play among various stakeholders; and how a shifting context can modify any of the above variables.

As the WWF (2005) concisely states, "the goal of a stakeholder analysis is to develop a strategic view of the human and institutional landscape, and the relationships between the different stakeholders and the issues they care about most" (p. 1). It is neither possible nor desirable to involve or satisfy all possible stakeholders (Bryson, 2004). Instead, a stakeholder analysis typically identifies and focuses on the *key* stakeholders – sometimes referred to as the primary and secondary stakeholders. Primary stakeholders have a direct interest in the issue at hand; secondary stakeholders may have a lesser interest or may be influenced indirectly – for instance by the actions of the primary stakeholder. This reflects the cascade effect that may exist among stakeholders: their dynamics are not static, and their relationships are subject to constant shift and change.

Critically, the very act of determining who is primary – and who is not – turns a stakeholder analysis into a political act with certain ethical consequences (Bryson, 2004) and reinforces the fundamentally political nature of the overarching priority-setting process. To mitigate this, stakeholder analyses are often done by teams of individuals, which can reduce or neutralize biases and assumptions (Varvasovszky & Brugha, 2000).

In summary, a stakeholder analysis can help the leaders of a priority-setting process identify:

- the importance, influence and interests of both primary and secondary stakeholders;
- the layers and levels within complex institutions – e.g. entities like a Ministry of Health, a community, or the World Health Organization can all be treated as a single or as a multiple actor depending upon a closer analysis of their positions and needs;
- the "level" of stakeholder to involve – local, regional, national, and/or international.
- potential conflicts, conflicts of interest, or risks that could jeopardize the process;
- opportunities and relationships that can be built on during the process;
- groups that should be encouraged to participate in different stages of the process; and
- appropriate strategies and approaches for stakeholder engagement (WWF, 2005).

Box 5: Complex Stakeholders

"The Ministry of Health may be treated as a single actor in the case of an inter-sectoral national policy on road injuries; or as a group of units or interest groups in developing a policy on health-services decentralization, where different divisions (e.g. hospital services, manpower, vertical disease control programs etc.) have different interests and concerns about the outcome." (Varvasovszky & Brugha, 2000, p. 340)

Stakeholder Analysis: Components, Approaches and Tools

There are various different ways of conducting a stakeholder analysis, as evidenced in the literature (see, for instance, Campbell, 2012). Below is an amalgam of these approaches, distilled here into nine separate components. Some are sequential steps; some are stand-alone tools. Some depend upon facilitated group work, and some rely upon scientifically rigorous data collection.

- Planning the process

- Identifying (and possibly training) a working or expert group
- Developing a plan and timeline
- Identifying the issue or problem (types or priorities)
- Research tools for identifying stakeholders
- Facilitating a brainstorming session
- Power versus Interest Grid
- Stakeholder Influence Mapping
- Stakeholder-issue interrelationship diagrams

Planning the process

This first step helps to define the overarching purpose of the stakeholder analysis, while identifying the potential users of the information and creating a plan for using that information. A leader should be identified and then assume ownership of the entire process. This leader should ensure that a consensus exists on the purpose of the process, and on who will use the information and how (Schmeer, 2005).

Identify (and train) a working/expert group

The leader should assemble an inclusive working or expert group (e.g. a Senior Advisory Team, a Task Force, a Technical Working Group) to oversee the analysis. As Schmeer (2005) notes, this group should in effect be a team representing different organizations and interests to avoid biases and mitigate power and personality dynamics, with ideally at least one individual considered neutral and/or independent. A training session could go over the entire priority-setting process and discuss the specific role of stakeholder analysis within that process, as well as specific tools and techniques the group's members will oversee and themselves use.

Note that for a priority-setting process, there may already be a Technical Working Group in place; it would obviously take ownership and leadership of the analysis.

Develop a plan and timeline

The working/expert group should create a timeline by listing the specific steps in the process. There should be ample time allocated to meetings, interviews, presentations, and so on (Schmeer, 2005).

Identify and discuss the issue at hand

Every issue – from the national to the thematic – has its own layers and components. A stakeholder analysis must capture and understand these, as they may further identify a set of relevant stakeholders that might be hidden at first glance (Varvasovszky & Brugha, 2000).

Research tools for identifying and analyzing stakeholders

As Varvasovszky and Brugha (2000) outline, there are several different methods for designing a comprehensive list of stakeholders. Choosing the right method depends entirely upon the issue at hand – some will require relatively simple brainstorming techniques, while those of great complexity will require a much more thorough and scientific approach to ensure the right stakeholders are identified and not omitted. Brainstorming may begin with some familiar research tools to get a better handle on the issue itself, which in turn reveals various stakeholders and essential variables, as Varvasovszky and Brugha (2000) detail:

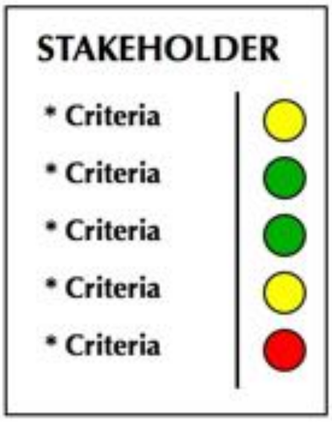
> *Face-to-face interviews using checklists, semi-structured interviews and structured – often self-administered – questionnaires can all be used to collect data from primary*

> *sources. Usually these are individual respondents, though groups of stakeholders may also be interviewed, e.g. through focus group or informal group discussions. Secondary sources include published and unpublished documents, reports, policy statements, internal regulations of organizations, etc. Interviews provide opportunities to access additional secondary sources, e.g. internal documents not obtained in the initial literature search. Semi-structured interviews can help structure data collection while keeping the focus sufficiently broad to allow for hidden or emerging themes. When analyzing complex issues, especially for policy analysis, qualitative approaches are essential so as to preclude premature focusing on a limited number of aspects of the issue, to the neglect of others which may emerge during the process of data collection and analysis.* (p.341)

Following the data collected with these research tools, the working/expert group would make some strong evidence-informed decisions about the stakeholders relevant to their issue, setting the stage for some deeper analysis of their dynamics and relationships.

Facilitated Brainstorming Session

Bryson (2004) describes this type of group-based facilitated approach for identifying and analyzing stakeholders. In this brainstorming session, the working/expert group assembles, potentially adding to its numbers with some invited members, for a facilitated session or sessions to fully brainstorm out all possible stakeholders. At such a meeting, the facilitator would:



- Use a flipchart, white board or computer software (e.g. mind mapping or word processing) to identify each stakeholder
- For each stakeholder, create a separate sheet/document and place their name at the top of the page
- Create a narrow column down the right side of each page/sheet and leave the column blank
- For each stakeholder, in the area to the left of the narrow column, list the criteria the stakeholder would use to judge the project, policy or policy reform.
- Use colored dots to indicate a stakeholder judgment of good (green), fair (yellow) or poor (red).
- Identify and record what can be done quickly to satisfy each stakeholder.
- Identify and record longer-term issues with individual stakeholders and with stakeholders as a group.

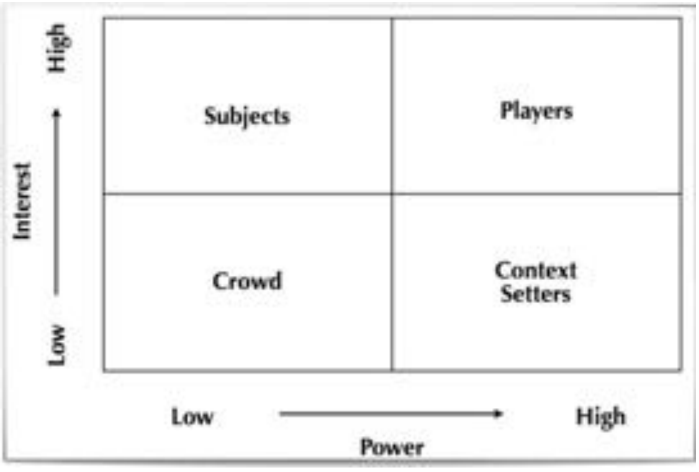
Additional steps that might be included here:

- Specify how each stakeholder influences the issue at hand
- Decide what the issue needs from each stakeholder.
- Rank the stakeholder according to their importance to the issue, with considerations of the stakeholder’s power, legitimacy and influence. This can help to create the categories of primary and secondary stakeholders (with the possibility of adding a third category of special or key stakeholders potentially not captured in the primary or secondary categories, or to highlight particularly important members of the primary category).

Complete a Power vs. Interest Grid

These grids (as described in Bryson 2004) array stakeholders on a matrix where the axes are the stakeholder's interest in the issue, and the stakeholder's power to affect it. This results in four different types of stakeholder: *players* who have both an interest and significant power; *subjects* who have an interest but little power; *context setters* who have power but little direct interest; and the *crowd* which consists of stakeholders with little interest or power. Figure 12 shows a completed grid.

Figure 12: Power vs. Interest Grid (Bryson, 2004)



Power versus Interest grids can indicate which stakeholders must by all accounts be involved in addressing the issue at hand. "They also help highlight coalitions to be encouraged or discouraged, what behavior should be fostered and whose 'buy-in' should be sought or who should be 'co-opted'. Finally, they provide some information on how to convince stakeholders to change their views" (Bryson, 2004, p. 31).

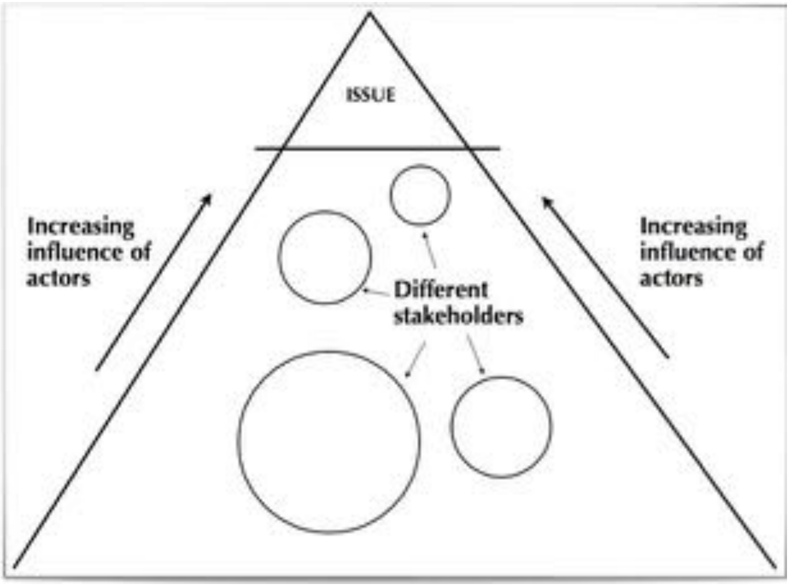
Stakeholder Influence Mapping

Upon completing a Power vs. Interest grid, the next step visualizes relationships and influence between and among the stakeholders. With a facilitator, the working/expert group can:

- chart lines of influence from one stakeholder to another
- highlight two-way influences (with every attempt to identify the primary direction of any influence)
- discuss which influence relationships exist, their relative importance and primary directions (Bryson, 2004).

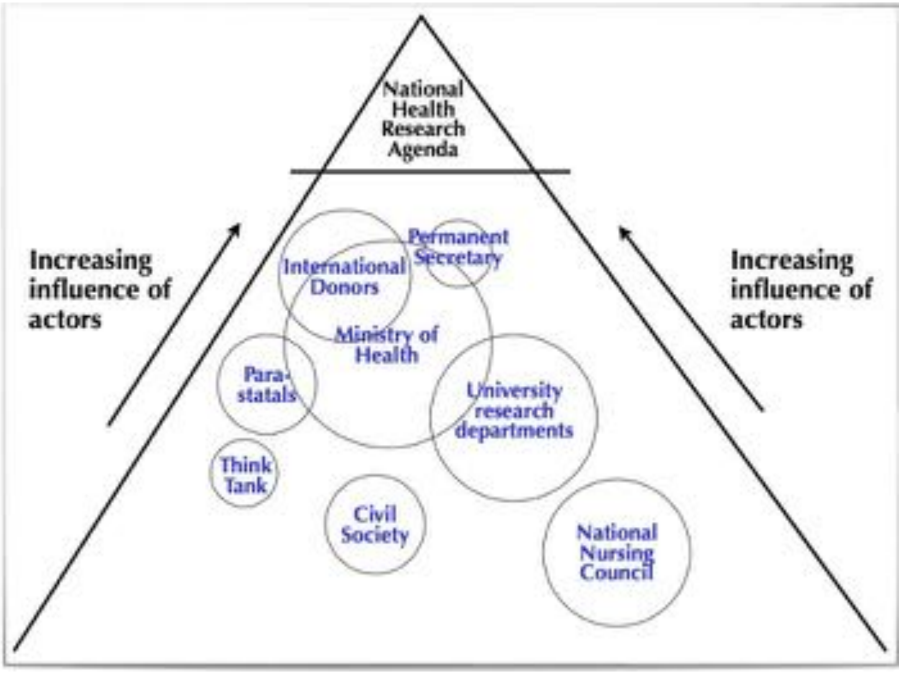
The International Institute for Environment and Development ([IIED] 2005) adds a different dimension to stakeholder influence mapping, preferring instead a pyramid that arranges different stakeholders. The closer a stakeholder is to the issue at the top of the pyramid, the more influence they have. Moreover, this type of diagramming allows the working/expert group to visualize the relative size of stakeholders (in terms of numbers or of power) as well as the connections among stakeholders. Figure 13 demonstrates this.

Figure 13: Stakeholder Influence Mapping (IIED, 2005)



IIED (2005) suggests following nine steps to preparing such a triangle, which are very similar to those for the Power versus Interest Grid. Figure 14 shows a hypothetical example of a triangle relevant to setting national health research priorities.

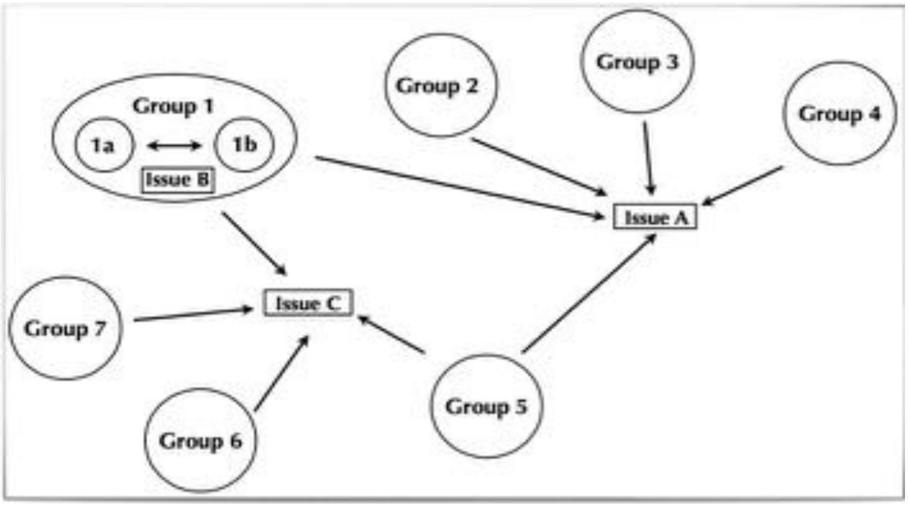
Figure 14: Stakeholder Influence Mapping for a National Health Research Agenda



Stakeholder-issue interrelationship diagrams

Expanding on stakeholder influence mapping are diagrams that link particular stakeholders to particular issues; this can reveal connections to other stakeholders who also have a link with the same issue. As Bryson (2004) notes, “the resulting diagrams help provide some important structuring to the problem area, in which a number of actual or potential areas for cooperation – or conflict – may become apparent. Group work should start with a Power vs. Interest grid and/or a stakeholder influence diagram, brainstorm the issues at hand, and then how stakeholders array around the issues” (p. 37). Figure 15 below illustrates this tool.

Figure 15: Stakeholder-issue Interrelationship Diagram (Bryson, 2004)



Eliciting Stakeholder Input

With a better awareness of who the primary and secondary actors in any given priority-setting process may be, we can turn now to mechanisms for eliciting their input. Recognizing that each stakeholder will have different levels of knowledge, different interest in the priority-setting process, and different means of expression, exactly how their insights and concerns are elicited is of high importance. Moreover, as stakeholder elicitation efforts are both costly and time-consuming, the question of *whom to involve and how* – particularly as research issues and questions become more technical in nature – is particularly relevant.

This sub-section highlights three tools particularly useful for eliciting stakeholder input in the lead up to a deliberative dialogue. These tools can provide the raw data or information for the dialogue itself (especially in contributing to pre-circulated materials); shape the contents and structure of the dialogue; provide a platform for those who cannot participate in the dialogue (due for instance to financial or geographic constraints); provide anonymity on sensitive issues; and indicate how various stakeholders might best participate in the dialogue.

Concept Mapping

Sometimes referred to as “structured conceptualization,” concept mapping is a participatory tool that combines organized brainstorming with statistical analysis to create a visual aide that can be used to kick-start, plan, inform or even evaluate deliberation (Novak & Cañas, 2008, National Cancer Institute, 2007). The tool begins with a focus question or focus prompt that isolates the problem or concern a concept map can address. As Novak and Cañas (2008) observe, “every concept map responds to a focus question, and a good focus question can lead to a much richer concept map” (p. 10). Organizers can send this focus question to a range of stakeholders for their own private deliberation; or can convene a facilitated dialogue to discuss the focus question. Either way, this can be a strong tool to elicit stakeholder input and then synthesize that input visually.

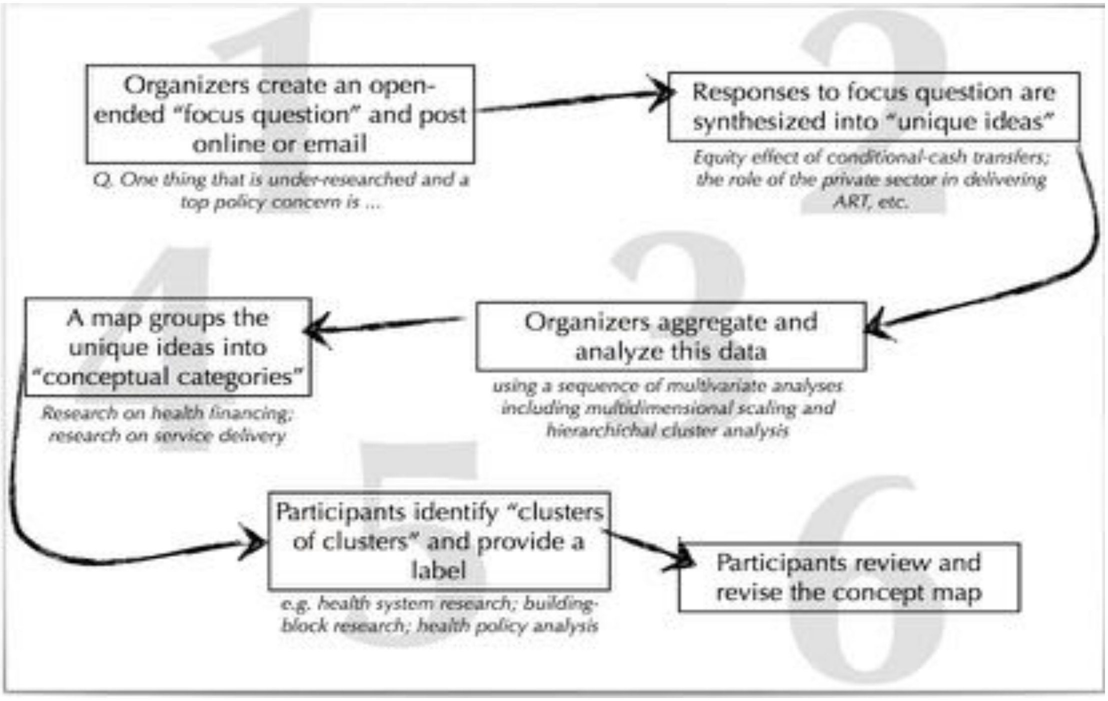
Following the initial elicitation – such as stakeholder responses to the focus question – organizers group those responses into 15-25 concepts.

> These concepts could be listed, and then from this list a rank ordered list should be established from the most general, most inclusive concept, for this particular problem or situation at the top of the list, to the most specific, least general concept at the bottom of the list. Although this rank order may be only approximate, it helps to begin the process of map construction. We refer to the list of concepts as a *parking lot*, since

> we will move these concepts into the concept map as we determine where they fit in. Some concepts may remain in the parking lot as the map is completed if the map-maker sees no good connection for these with other concepts in the map. (Novak & Cañas, 2008, p. 11)

A preliminary map should reveal linkages between the concepts, and suggest ways that ideas might be combined or further contrasted. This map can be the visual aid brought to the deliberation, or it may, for instance, be posted online for further revision and concept re-positioning, with a final map ultimately informing the priority-setting work. Figure 16 shows some of the steps involved in creating a map.

Figure 16: Concept Mapping Flowchart

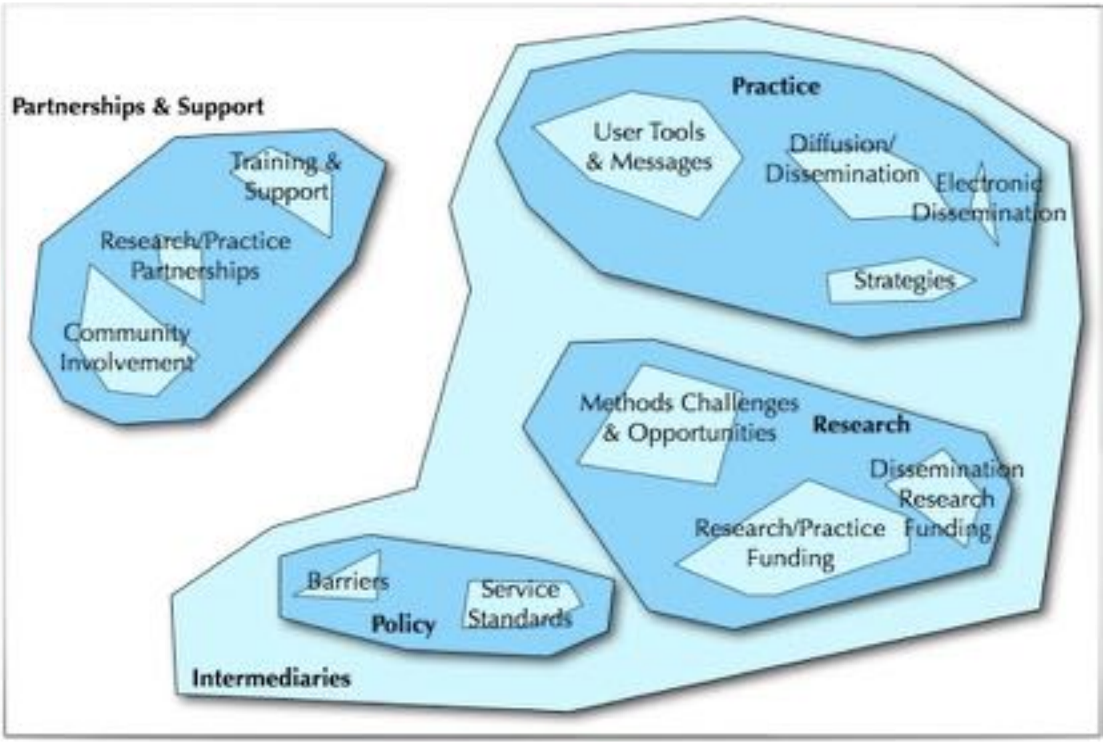


Below is a case study from the National Cancer Institute (2007) outlining how concept mapping provided critical stakeholder input to the focus prompt.

Box 6: Case Study: Concept Mapping in Tobacco Control

A monograph by the National Cancer Institute (2007) used concept mapping to generate stakeholder input to the focus prompt: *one thing that should be done to accelerate the adoption of cancer-control research discoveries by health service delivery programs is…* "Approximately 55 people contributed (by email) more than 200 answers to the focus prompt, which were subsequently synthesized by the steering committee into 98 unique ideas. The data were aggregated and analyzed with a sequence of multivariate analyses that included multidimensional scaling and hierarchical cluster analysis. The resulting map grouped the 98 ideas into 12 conceptual categories. The participants also were asked to identify clusters of clusters that seemed to belong together and provide a label for each such region of the map. Participants identified four major regions: 1) policy, consisting of policy issues that would enable more integration of research and practice, as opposed to policy that results from such efforts; 2) research; 3) practice; and 4) partnerships and support" (National Cancer Institute, 2007, p. 87). See Figure 17 for a concept map used in this tobacco-control work.

Figure 17: Concept Mapping (National Cancer Institute, 2007)



Used in a priority-setting context, the above concept map could provide a good starting point for a deliberative dialogue. Particularly useful features of a concept map for priority setting include:

- anonymous, scientific elicitation of stakeholder input that equalizes each voice and eliminates power differentials among the stakeholders;
- can be done at a distance, which can both lower meeting costs and secure the input of a wider range of individuals (e.g. the time pressed or those in distant, rural communities);
- thematic grouping of stakeholder input, including connections among the themes and relative size of themes, depicts stakeholder interest and thus sets some thematic parameters for the dialogue;
- short, visual summary of issues to inform and influence deliberative dialogue (an ideal piece of pre-circulated material for the dialogue).

Delphi Technique

This is a well-used methodology for the systematic elicitation and synthesis of opinions and judgments on a topic, issue or theme through a flow of sequential questionnaires, information summaries, and feedback (Delbecq et al., 1975). While typically used to integrate the judgments and feedback of a small expert group, the Delphi Technique can be used in advance of a deliberative dialogue to better understand issues and to begin the preliminary synthesis of ideas, concerns and priorities (McDonald, Bammer, & Deane, 2009). As with Concept Mapping, it is often done anonymously – potentially a critical factor in its success.

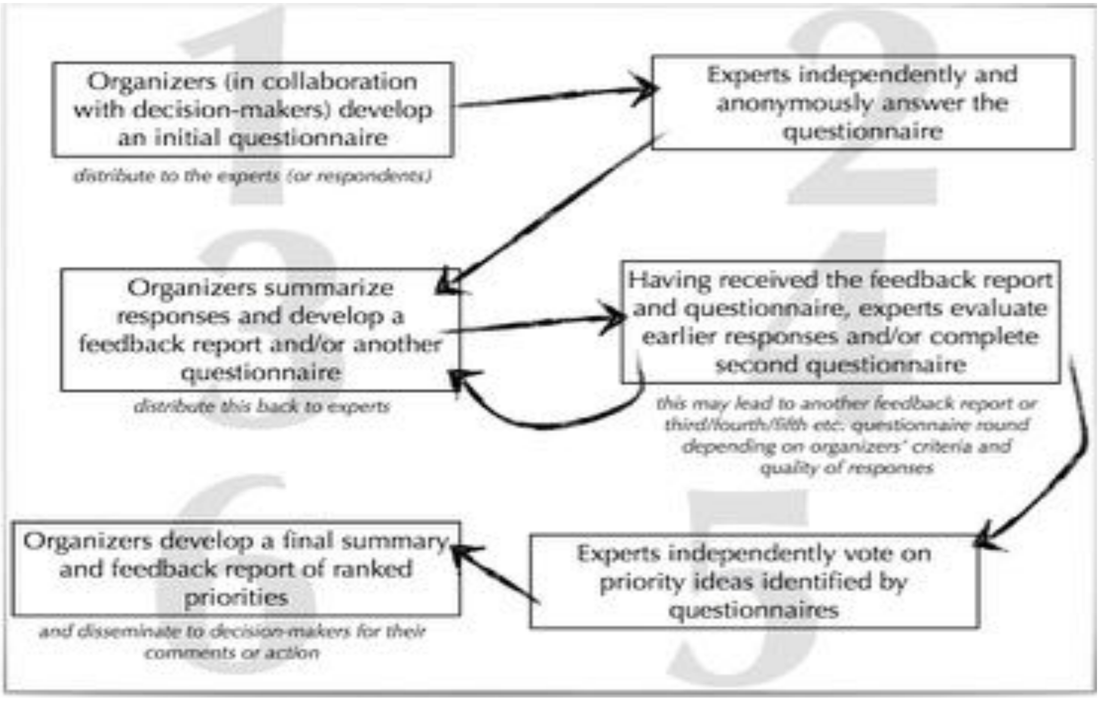
Box 7: The Delphi Technique

"The Delphi Method [or Delphi Technique] is a systematic, interactive forecasting method which relies on a panel of experts. The experts answer questionnaires in two or more rounds. After each round, a facilitator provides an anonymous summary of the experts' forecasts from the previous round as well as the reasons they provided for their judgments. Thus, experts are encouraged to revise their earlier answers in light of the replies of other members of their panel. It is believed that during this process the range of the answers will decrease and the group will converge towards the "correct" answer. Finally, the process is stopped after a pre-defined stop criterion (e.g. number of rounds, achievement of consensus, stability of results) and the mean or median scores of the final rounds determine the results."(Wikipedia, 2014a)

The Delphi Technique typically involves three groups:

- *organizers* who design the overarching questions and approach, summarizing responses and preparing subsequent questions;
- *experts* or *respondents* who offer judgments and answers to the organizers' questions; and
- *decision-makers* who may act upon receiving a consensus statement or recommendations produced by the technique. See Figure 18 for a flowchart demonstrating the major steps.

Figure 18: The Delphi Technique (McDonald, Bammer, & Deane, 2009)



As an early phase of a priority-setting process, the Delphi Technique can be particularly useful at:

- eliciting input from a range of different stakeholders anonymously and repeatedly – this may help to amplify and strengthen the voices of those who might not ordinarily participate due to power differentials and dynamics;
- incorporating "virtual participants": as with Concept Mapping, can be done at a distance, both lowering meeting costs and securing the input of a wider range of individuals (e.g. the time pressed or those in distant, rural communities)
- refining that input through rounds of feedback, evaluation and revision – particularly helpful for highly complex or technical research issues/options/questions

- providing a strong starting point for a deliberative dialogue, with some of the issues or complexities already resolved.

Nominal Group Technique

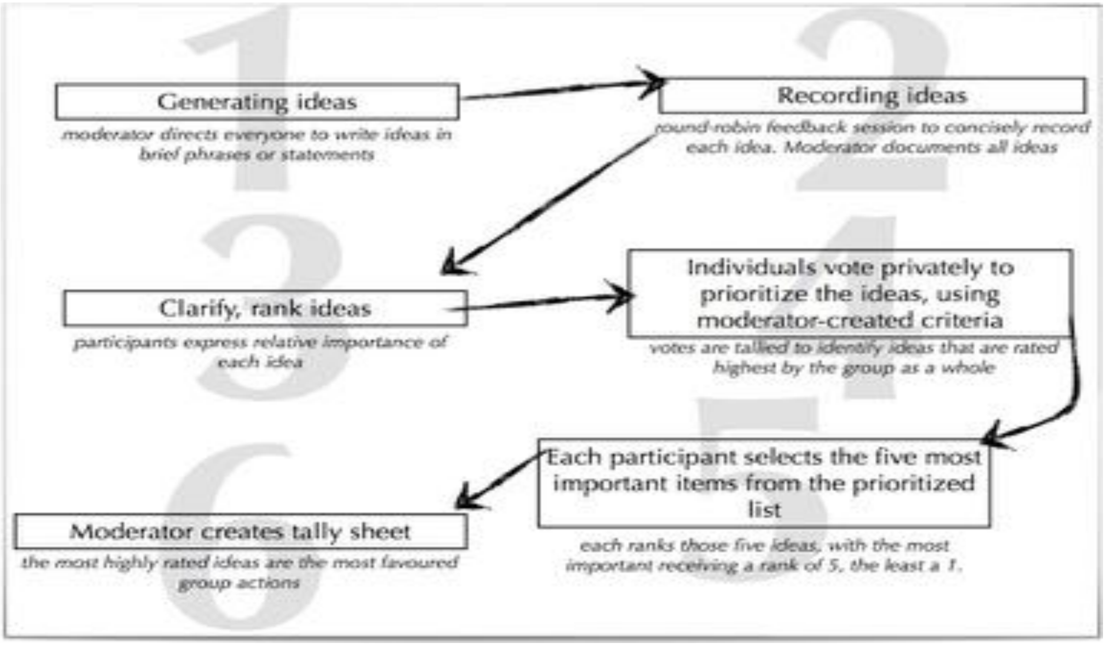
This is a tool typically used to pool knowledge and arrive at a ranked list of ideas, concerns and/or priorities that is accepted and considered legitimate by the group (McDonald, Bammer, & Deane, 2009). It is highly structured and thus best in a facilitated situation; unlike the Delphi Technique or Concept Mapping, it is not an anonymous, at-a-distance tool, which can be both a strength and a weakness. It can be applied "in two phases: knowledge exploration (a search for major conceptual frameworks and broad insights) and solution exploration (the refinement of broad insights by specifying components which should be included in the solution program)" (McDonald, Bammer, & Deane, 2009, p. 65).

Box 8: The Nominal Group Technique

"The nominal group technique (NGT) is a decision making method for use among groups of many sizes, who want to make their decision quickly, as by a vote, but want everyone's opinions taken into account (as opposed to traditional voting, where only the largest group is considered). The method of tallying is the difference. First, every member of the group gives their view of the solution, with a short explanation. Then, duplicate solutions are eliminated from the list of all solutions, and the members proceed to rank the solutions, 1st, 2nd, 3rd, 4th, and so on. The numbers each solution receives are totaled, and the solution with the lowest (i.e. most favored) total ranking is selected as the final decision. There are variations on how this technique is used. For example, it can identify strengths versus areas in need of development, rather than be used as a decision-making voting alternative. Also, options do not always have to be ranked, but may be evaluated more subjectively." (Wikipedia, 2014b)

Like the Delphi technique, the Nominal Group Technique (NGT) gives each participant an equal voice, thus minimizing or eliminating the potential power differentials among stakeholders. Additionally, the face-to-face nature of NGT provides a range of opportunities to better understand the opinions and judgments of others. See Figure 19 for the steps involved in a nominal group technique.

Figure 19: The Nominal Group Technique (McDonald, Bammer, & Deane, 2009)



As a tool within the priority-setting process, the Nominal Group Technique is particularly adept at:

- arriving at consensus on highly complex issues
- amplifying participation and creativity, while also expanding perceptions of key points in defined areas
- determining and dissecting initial priorities (McDonald, Bammer, & Deane 2009).

Convening Deliberative Dialogues

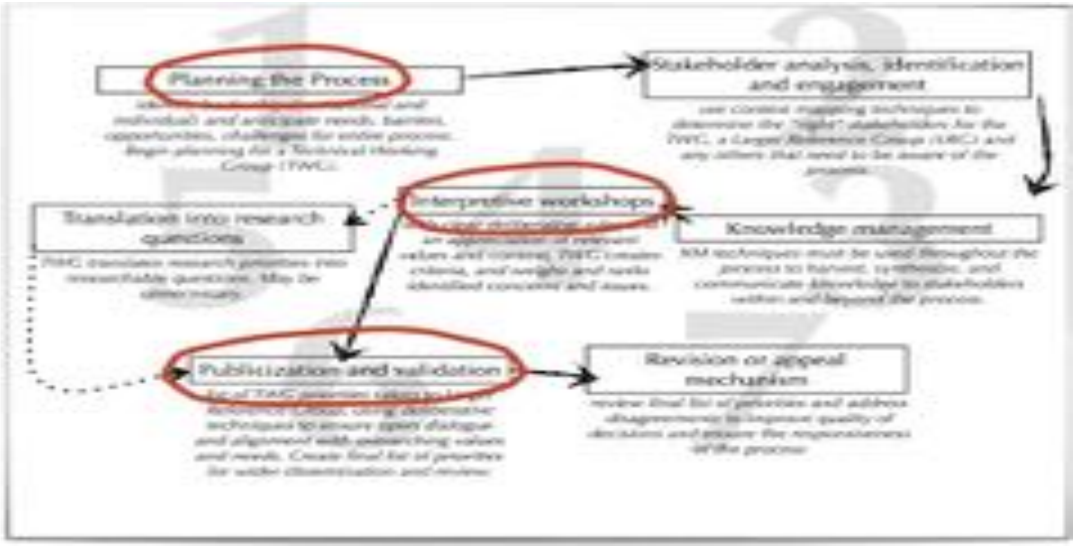
There are many ways to convene a deliberative dialogue. For some priority-setting situations, the best way may also be the simplest: a neutral chair presiding over a meeting of the "right" stakeholders (identified through a stakeholder analysis), each having read the pre-circulated material (with some of these materials informed by any of the above elicitation techniques) and arriving at a list of weighted, ranked priorities for broader dissemination, review and revision. Depending on context and the stakeholders involved, however, certain dialogue mechanisms may prove superior to balancing and synthesizing different voices, and ultimately creating a comprehensive list of priorities to further influence decision-making.

Any multi-stakeholder deliberative dialogue should embrace the following principles:

- the process should encourage a multiplicity of voices, with listening as critical as speaking, and the conversation more horizontal than vertical (i.e. among equals);
- a range of views should be heard and discussed before any decision or resolution is made;
- the discussion should emphasize analysis and reasoned argument. "The powerful work that occurs in dialogue – identifying the connections between personal and public concerns, creating mutual understanding, and building relationships based on trust – is necessary for solving complex public problems" (McCoy & Scully, 2002, p. 124).

In reviewing the ideal, interpretive priority-setting process outlined in *Section 2* of this Chapter, we find (at minimum) three different areas where a deliberative dialogue might be convened: at the beginning of the process (step 1), where a small group comes together to plan the process through its various steps; during the interpretive workshops, where the small group drafts an initial list of priorities (step 4); and during the larger publication and validation workshop, where the initial list of priorities is submitted to a larger reference group for validation, dialogue and revision (step 6) (see Figure 20).

Figure 20: Stages That Can Involve Deliberative Dialogue



As the Technical Working Group will use different deliberative dialogue techniques than the Larger Reference Group in a priority-setting process, we've divided the discussion below by group, with several deliberative techniques suited to each.

The Technical Working Group – Formation, leadership, ownership

At the heart of the ideal interpretive priority-setting processes is a small group of leaders – sometimes called a Senior Advisory Team, Advisory Committee, or Group of Elders – charged with overseeing the entire process. But how do these groups form and how might they effectively lead an actual priority-setting process?

Visualization in Participatory Planning (VIPP)

Visualization in Participatory Planning (VIPP) is one such tool extremely useful in creating and bonding disparate groups and bringing out the best of each individual member. VIPP embraces these group dynamics through the use of diagrams, cards and photographs to express main ideas, with the less talkative participants finding a means of expression, and the group arriving at an effective and genuine consensus. VIPP depends upon an expert facilitator to guide the group through its structuring.

It derives from educational processes in both Germany and Latin America, but was originally developed as its own approach by UNICEF in Bangladesh (McKee et al., 2009). It is a unique methodology for group processes – putting people at the center "of solving development and social problems and coming to new, collective visions of the future. It is unique in that it provides a creative combination of different participatory approaches which emphasize visualization techniques" (McKee et al., 2009, p. 2). It builds in turn upon Bruce Wayne Tuckman's 1965 work describing how groups come together and weather conflict to become a cohesive whole able to make broad, consensual decisions. As Smith (2005) explains of these group dynamics, "it is clear, for example, that people tend to want to know something about the other members; have to develop a degree of interdependence in order that the group or team may achieve its tasks and be satisfying to its members; and has to learn at some level to deal with conflict if it is to survive" (p. 1). Illustrating this, Tuckman's five steps or stages of group development include:

a) **Forming**. Here, groups "concern themselves with orientation accomplished primarily through testing" (Tuckman, 1965, p. 78). This orientation and testing allows group members to understand "interpersonal and task behaviors" while also establishing relationships with other members, and becoming increasingly comfortable with the group's leader.

b) **Storming**. In this stage, groups are often "characterized by conflict and polarization around interpersonal issues" (Tuckman, 1965, p. 78). There can be some resistance to the group at this stage as personalities battle to determine the course and activities of the group.

c) **Norming**. Here, groups tend to overcome the earlier conflict and develop an in-group feeling and cohesiveness with new roles, standards, and a warmer atmosphere for expressing opinions.

d) **Performing**. At this stage, with roles established yet flexible and the group's work understood and clear, the structure of the group "can now become supportive of task performance" (Tuckman, 1965, p. 78) and the central purpose of the group can be meaningfully and lastingly fulfilled.

e) **Adjourning**. While not part of Tuckman's earlier identification of the stages involved, this last stage necessarily concerns the dissolution of the group, with central tasks complete, and a roadmap for the future drawn and awaiting implementation. See Figure 21 for some photographs of a VIPP process from Zambia.

Box 9: VIPP Processes

"In VIPP processes… those who usually dominate cannot control the process and are forced to let others contribute. Through visualization, repetition and circularity in discussion are reduced while new ideas are highlighted and processed. This adds to the creativity of group processes and the practicality of their outputs." (McKee et al., 2009, p. 2)

Figure 21: VIPP Photographs by Cole Dodge (2009), from a Technical Working Group Meeting in Zambia Determining Priorities in the Formation of the National Health Research Council of Zambia.

The Expert Witness Panel

Once the TWG has achieved some coherence – with clarity of purpose, of teamwork, and of the scope of the problem or issue at hand – there are a number of participatory techniques that can be employed to add critical elements to the group's brainstorming. The Expert Witness panel is one such participatory tool highly successful in incorporating the voices of individuals who have particular insights but who, because of time constraints or institutional conflict, cannot or should not serve on the Technical Working Group. To convene an Expert Witness panel, the TWG brainstorms on experts of relevance to their discussions; invites a select number of experts to come to a TWG meeting at specific times; the experts then sit individually before the TWG, with two TWG members at a time sitting in front of the expert and asking specific questions (to inform the TWG's wider thinking); once a TWG member has asked his/her question, s/he returns to the wider group and is replaced by another TWG member. Following all expert witness interviews, the TWG summarizes and synthesizes their input and uses these insights to assist its decision-making processes.

For priority-setting processes, the Expert Witness panel can be of great assistance as a prelude to the formal interpretive workshops, getting advice on criteria to weigh priorities, on further priorities to consider, on the overall process itself, and a general tool to expand the TWG's approach and thinking. The panel has further utility in disseminating its work to a select audience (i.e. the take-away messages each expert will return to his/her institution), which will expand the collective ownership of the process as those whose voice is incorporated into the process are typically more likely to accept its outcomes.

Box 10: The Chatham House Rule

This technique can be added to any deliberative dialogue, assuring those present that nothing will be attributed, thus opening up discussion to areas that some may deem sensitive, or may be hesitant to comment on for fear of misrepresenting or exposing an institution. "The Chatham

House Rule is a principle that governs the confidentiality of the source of information received at a meeting. Since its refinement in 2002, the rule states: 'when a meeting, or part thereof, is held under the Chatham House Rule, participants are free to use the information received, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed'. The rule allows people to speak as individuals and to express views that may not be those of their organisations, and therefore, encourages free discussion. Speakers are free to voice their own opinions, without concern for their personal reputation or their official duties and affiliations. The Chatham House Rule resolves a boundary problem faced by many communities of practice, in that it permits acknowledgment of the community or conversation, while protecting the freedom of interaction that is necessary for the community to carry out its conversations. Meetings, or parts of meetings, either may be held *on the record*, or, *under the Chatham House Rule*. In the latter case, all participants are understood to have agreed that it would be conducive to free discussion that they should be subject to the rule for the relevant part of the meeting. The success of the rule may depend upon it being considered morally binding, particularly in circumstances where a failure to comply with the rule may not result in sanction. Sometimes the rule is half-jokingly summarized as, 'You may be quoted, but you cannot be fired.'" (Wikipedia, 2014c)

For more on deliberative techniques at interpretive workshops, see *Section Two's* discussion of the ideal, interpretive priority-setting process.

Larger Reference Group – wide multi-stakeholder deliberation

Taking initial priorities to a wider pool of stakeholders to ensure alignment with their values and needs is a critical step in the interpretive process. This "Larger Reference Group" (LRG) brings with it a host of components critical to deliberative dialogues. They are representative in ways that the TWG likely cannot be due to their larger size; can include wider members of the public and thus further democratic ideals; create shared meaning and open new windows of understanding; are critical to disseminating both the list of priorities and the process of priority-setting itself; and can add both scientific and social credibility to wider decision-making processes.

As Kapiriri and colleagues 2007 observe, "the actual size and composition of the [LRG] would depend on the research options to be considered and the available resources including time. Stakeholders can be represented by a reasonably small or very large reference group, depending on the context. For example, the group may comprise of only 10 persons (e.g. main individual donors to a private charity who want to participate in decision-making on how their money is invested) or more than a thousand people (e.g. in the case of addressing research to avert global child mortality, where everyone from members of [the] public in developing countries, public and private donor foundations, to the UN, World Health Organization (WHO) and UNICEF officials represent the potential stakeholders)" (p. 7-8).

Box 11: Larger Reference Groups in Priority Setting – two examples

"To ensure that the assessment of the research priorities is combined with a view of the wider society, the relative weights for each criterion were measured from 30 stakeholders' representatives from the larger reference group. LRG members included academics from three Cape Town universities, members of the public, government representatives, clinical psychologists, and other professionals. In choosing LRGs, we used a convenience sample attempting to secure a diverse mix of researchers, clinicians, professionals, academics, and members of the public and allowed them to express their opinions through an interview and as a quantitative score. LRG members were first told the elements of the process, then asked for feedback, and eventually asked to rank those five criteria from the most important within the South African context (rank 1) to the least important (rank 5)." (Tomlinson et al., 2007, p. 1295). "To ensure involvement of the wider society in directing research investment priorities, we collected opinions from a larger reference group, comprising 43 stakeholders' representatives… The reference group comprised nine psychiatrists, four psychologists, two social workers, three government employees, six non-governmental organization representatives, six researchers, six users of mental health services and seven members of the public. We contacted members of the group by e-mail and asked them to express their opinions through an electronic questionnaire that described the elements of the process. We asked them to rank the five criteria used for setting priorities."(Tomlinson et al., 2009, p. 439).

The Nominal Group Technique and Delphi Model are two strong deliberative tools that might assist the functions of the LRG, given that the core function of the LRG is to rank – be it criteria or priorities. They can be initiated virtually and concluded at a physical meeting.

Other Deliberative Dialogue Models

There are a variety of other models for convening a deliberative dialogue. Some may not be ideally suited to priority setting, but may accord well with other discussions within any national health research system. Such models are discussed in detail in McDonald, Bammer and Deane (2009), and include:

- *Consensus Conferences.* "This is a highly structured event designed to involve the non-expert, non-partisan citizens in deliberating on important (and typically complex) social, technological, planning and/or policy issues, and through doing so to integrate judgements. Their objective is to 'bridge the gap between the general public, experts and politicians'… Its chief characteristics include: a representative sample of participants in small numbers (12-25); a skilled facilitator; participants provided with written evidence before they meet; participants decide who to call in as an expert witness; interactive; preparatory weekend; deliberative meeting of 2-4 days; recommendations published in a formal report; either the recommendations are implemented or sufficient grounds must be provided publicly to explain why they will not be implemented" (McDonald, Bammer and Deane 2009).
- *Consensus Development Panels*. "The purpose of these panels is to provide guidance in areas of medical and broader health practice, particularly in areas in which controversy exists and a body of scientific evidence is available that can be scoped, explored, assessed and synthesized to produce a consensus statement on the issue. The consensus development panel process developed and used regularly by the National Institutes of Health in the USA is a highly structured approach for integrating scientific research evidence emanating from different disciplines. At the core of the process is judging the evidence and reaching a consensus position that is then communicated to the health professions and the public in non-technical language" (McDonald, Bammer, & Deane, 2009).
- *Town Meetings*. "To date the most successful Town Meeting format is a day-and-a-half meeting that includes a scientific symposium and an open forum for community members. The full meeting is open to community involvement, although the most active participants during the scientific symposium are researchers, healthcare providers, and public health officials who want to hear about the latest research findings in this particular field. The open forum is designed specifically to encourage and facilitate comments and questions from residents. To this end, the forum is set at a time and location that allows for the greatest level of community participation, and panelists give brief comments on research, policy and public health before the floor is opened to the public. The expert panel addresses the comments and questions raised.

Sometimes the host organization will have a local or federal politician, a popular local television news anchor, or a communications expert facilitate the meeting. This strategy often results in a more interesting meeting and attracts a larger audience" (O'Fallon et al., 2003, p. 1857).

- *Future Search Conferences*. These are large-group planning conferences, using face-to-face dialogue to develop plans, including the identification of action steps. Future search conferences are particularly useful in situations of rapid change (for e.g. changes in knowledge, society, technology, the environment) when various stakeholders can be expected to make different judgements about the implications of change for the future. They begin with a focus on visions and use these to guide the proposals for action. The implementation methods vary. Some proponents of this technique argue for limiting the number of future search conference participants to about 60-80, all meeting in one room and in active dialogue, on the grounds that more than this number means that productive dialogue is not feasible. Others are comfortable with far more participants. In these instances, participants are broken up into smaller groups. The tasks of the conferences are expressed as 'The future of X is Y…' Conditions for success include:
  - getting the 'whole system' into the room; invite a significant cross-section of all parties with a stake in the outcomes of the conference
  - exploring the 'white elephant' before seeking to fix any part; get everyone talking about the same world; explore the global context before focusing on local issues
  - emphasizing common ground and future focuses, while treating problems and conflicts as information, not action items
  - encouraging self-management and responsibility for action by participants before, during and after the conference. (McDonald, Bammer, & Deane, 2009).
- *Open Space Technology (OST)*."This tool can assist groups of people to identify and explore issues, identify opportunities for change and identify and set priorities among action steps to achieve desired goals. The approach is based on the theories of complexity, self-organization and open systems… The key elements of the setting are one or more circles of chairs, with circles being seen as the 'fundamental geometry of human communication'. The room has to be large enough to have a number of small groups sit in circles, and to change the configuration of circles as the process unfolds. The facilitator explains the process: whoever comes is the right people; whatever happens is the only thing that could have; whenever it starts is the right time; when it's over, it's over… The facilitator then asks people to come to the center of the circle, introduce themselves and tell everyone else of one aspect of the session's theme about which they are passionate. The person records this aspect on a large sheet of paper along with their name and a suggested time and place for discussing the issue, before attaching the sheet to the wall. In this way, a first-draft agenda evolves… When all the issues for discussion have been posted, participants sign up for the groups with which they wish to be involved. At this stage, topics can be combined. Once this step is completed, the facilitator announces that he is departing; inviting the groups to get to work…OST is effective in situations where a diverse group of people must deal with complex and potentially conflicting material in innovative and productive ways. It is particularly powerful when nobody knows the answer and the ongoing participation of a number of people is required to deal with the questions. The process requires participants to shed their power roles in organizational hierarchies and interact as equals… The underlying philosophy is that synthesis will occur through small-group discussions among people self-selected to address a topic about which they are

passionate. Integration is taken to be an emergent property of the group process" (McDonald, Bammer, & Deane, 2009, p. 70).

- *Citizens' Jury*. Connected to the idea of an Expert Witness panel is the citizens' jury. Here, a randomly selected group (18-24 individuals) of lay citizens convene to interview witnesses and collectively deliberate on an issue. They are "representative – selected by a recognized sampling method; informed – witnesses present to the jury a variety of facts, information and opinions on the matter under consideration, and are questioned by the jury; impartial – those organizing the process select witnesses whose evidence is carefully balanced to ensure fair treatment to all sides of the issue; and deliberative – the jury deliberates in a variety of formats and is given sufficient time to ensure that all of the jurors' opinions are considered" (McDonald, Bammer, & Deane, 2009, p. 20). A citizens' jury typically concludes with the jury issuing recommendations for the way forward. Several authors (such as Price [2000] and Lenaghan et al.[1996]) have explored the use of citizens' juries in priority setting for service delivery.

Section 3: Summary Points

- The goal of a stakeholder analysis is to gain an overhead view of the human and institutional landscape, including relationships among stakeholders and the core issues that can define those relationships.
- As each stakeholder will have different levels of knowledge, different interest in the priority-setting process, and different means of expression, exactly how their insights and concerns are elicited is of tremendous importance.
- Depending on context and the stakeholders involved, certain deliberative dialogue mechanisms may prove superior to balancing and synthesizing different voices, and ultimately creating a comprehensive list of priorities to further influence decision-making.

Section Four: Priority Setting and the Deliberating Stakeholder

Learning Objectives:

In this Section, major learning objectives include an understanding of:

- the value of the "deliberating stakeholder" in priority-setting processes. Stakeholder values and criteria drive the entire priority-setting process; any process that seeks to gauge and address a society's knowledge needs must then focus on *who* is involved and *how* they participate in the process.
- how a three-pronged approach – from the identification of stakeholders, to means for eliciting their input, to guiding collective deliberation – is critical to the success of any interpretive priority-setting process.
- the strong need need to experiment and pilot in PS in order to understand what techniques work, for whom, and under what circumstances – particularly in assessing the links between specific deliberative techniques and identified priorities.

How can deliberative techniques improve research priority-setting processes? What steps can institutions and systems take to increasingly infuse their priority-setting processes with deliberation?

The concept of the deliberative dialogue offers a variety of ways to determine and involve the right stakeholder in priority setting – not only as those who are consulted, but as those who play an active role in the process. Much as Rudan and colleagues (2007b) identify the health research option as an essential addition to priority-setting theory, we advance here the concept of the deliberating stakeholder as a missing or glossed-over component of priority-setting processes. Stakeholder values and criteria drive the entire priority-setting process; any process that seeks to gauge and address a society's knowledge needs must then focus on *who* is involved and *how* they participate in the process. Failure to do so will leave this critical function to the technical experts and scientists, who often have significantly different values and criteria than other relevant stakeholders (Kapiriri et al., 2007). Priority setting must begin with a comprehensive identification and analysis of relevant stakeholders, understanding their values, interests and dynamics; it must then implement platforms to elicit their input (especially virtual or distance platforms); and by appreciating overarching context, values and stakeholder dynamics, then balance and synthesize their input through appropriate deliberative techniques.

This three-pronged approach – identification, elicitation, and deliberation – is critical to the success of any interpretive priority-setting process. As with other iKTR techniques, such an approach recognizes and values the social nature of priority setting, one that is based on relationships and trust. The better any priority-setting process can be cast in this light – as an iterative, deliberative, and fundamentally social mechanism – the greater chance a society's priorities can align with its values, and its resources with its needs.

Identification → Elicitation → Deliberation

Experimenting, Piloting, Evaluating

That said, there is still a great deal we don't know about priority setting. We need to experiment and pilot, we need to understand what techniques work, for whom, and under what circumstances – particularly in assessing the links between deliberative techniques and identified priorities, between stakeholder involvement and the types of priorities identified (Ranson & Bennett, 2009), and between priority-setting processes and decision-making itself (Smith et al., 2009). We already have good evaluative frameworks for priority setting (e.g. the fair, just, deliberative, legitimate, transparent, accountable and enforceable elements of Daniels' [2000] Accountability for Reasonableness) and for deliberative processes (e.g. around representation, procedures, information and outcomes as suggested in Abelson et al.[2003]). Given the need to understand, assess and document the complex dynamics within priority-setting processes, it is imperative that innovative and strong evaluations capture this experimentation and piloting in priority-setting.

Incorporating deliberative dialogue techniques into priority-setting processes

Not every priority-setting process needs to rotate around a costly series of meetings bringing in stakeholders from across a country. There are tremendous opportunities for refining and advancing virtual tools – such as Concept Mapping and the Delphi Method – to elicit multi-stakeholder input and kick-start deliberations among a wider, more inclusive pool of stakeholders. If priority setting to date has been an expert-driven process, it is the increasing use of these kinds of deliberative tools that will bring out new perspectives and different ideas. In many cases, this stage of stakeholder value and opinion elicitation is too often ignored or minimized in priority setting, but there has never been a better time to learn how other contexts have used such tools, and to apply them in priority setting, at a national level, a regional level, a provincial/state level, even an organizational level.

Applying this type of innovation is even more crucial for the interpretive workshops that lie at the heart of most priority-setting processes. The literature brims with interpretive workshops that depend upon an equality of scientific understanding, on an acceptance of scientific rationale and method. If the leaders of a national health research system are serious in bringing more stakeholders to the priority-setting table, it must combine deliberative approaches and mechanisms to level the playing field, blending the rigorous with the spontaneous, the quantitative with the qualitative. This does not mean that every interpretive workshop should be akin to a Town Meeting, but that among the medley of deliberative techniques discussed in this chapter, various elements might come together to identify, elicit and synthesize the valuable contributions from across the stakeholder spectrum.

Emphasis on process

As has been emphasized throughout this Chapter, it is the process and not the product that ultimately matters (WHO, 2003). Dialogue may not solve a problem or set actual priorities, but it will build the social relationships, trust and interactions critical to the functioning of any health system. If a priority-setting process fails to arrive at a ranked list of priorities but does strengthen a system now able to diagnose and discuss its weaknesses and opportunities, then it will have more than achieved its objectives. After all, a deliberative dialogue is not intended to solve problems (Lavis, 2009a) but rather to create open discussion on the nature of the problem itself, working to reveal the true complexity of the problem (Abelson et al., 2003), or to frame it within its wider, systemic framework. The point is not to solve: it is to deliberate.

And it is to evolve. We've shifted our vocabulary from "the Third World" to "the developing world" to "the South"; we've incorporated gender as a fundamental research lens to perceive a society's often hidden power relationships. Along these lines, we may need to recast research "priority setting" as "informing research priorities" to soften the rigidity and finality of the term. We must recognize that the political actors of any given setting may not yet be ready to cede or share their priority-setting powers (no matter who participates in a Technical Working Group), and that this is a battle likely not worth fighting: *it is the process, not the product – or the name – that matters*. After all, any Minister can set a priority, but much more valuable are those situations where an inclusive range of voices can discuss a society's values, needs and concerns.

Re-imagining knowledge generation and application

Lastly – and absolutely critically – we must start to re-imagine how knowledge is generated and applied. For far too long, the research agenda has been controlled by researchers and research funders, and the policy formulation/implementation agenda by local, national and global policy-makers. To achieve any progress in bridging the knowledge-to-action divide, these two camps must converge, and must do so by adopting an integrated KTR approach that involves a range of concerned stakeholders. If there is to be any real progress in having research inform policy to strengthen national health research systems, we must increasingly treat knowledge as a multi-faceted public good: demanded, shaped and used by the many stakeholders it has always claimed to serve.

CHAPTER

4

Moving Into Action: We know what practices we want to change, now what? An implementation guide for healthcare practitioners

By Sonia Angela Castiglione and Judith Anne Ritchie

Introduction

Learning objectives

- Learn what is meant by practice change based on evidence in a healthcare setting
- Gain a basic understanding of the Knowledge to Action Framework and how it applies to the implementation process.

You may have already encountered this scenario or one similar: You are concerned about a specific practice that exists in your clinical setting involving a unique patient population. Your concern leads you to search the literature – an approach that you've used numerous times before. You find a clinical practice guideline and other types of evidence dealing with the issue, and you think "Eureka! Now I know exactly what we should be doing!" This excitement slowly turns to concern again. You think: "I know what I want to change, but now what? How do I get all the staff to adopt this change? How do I get the organization to support this change?"

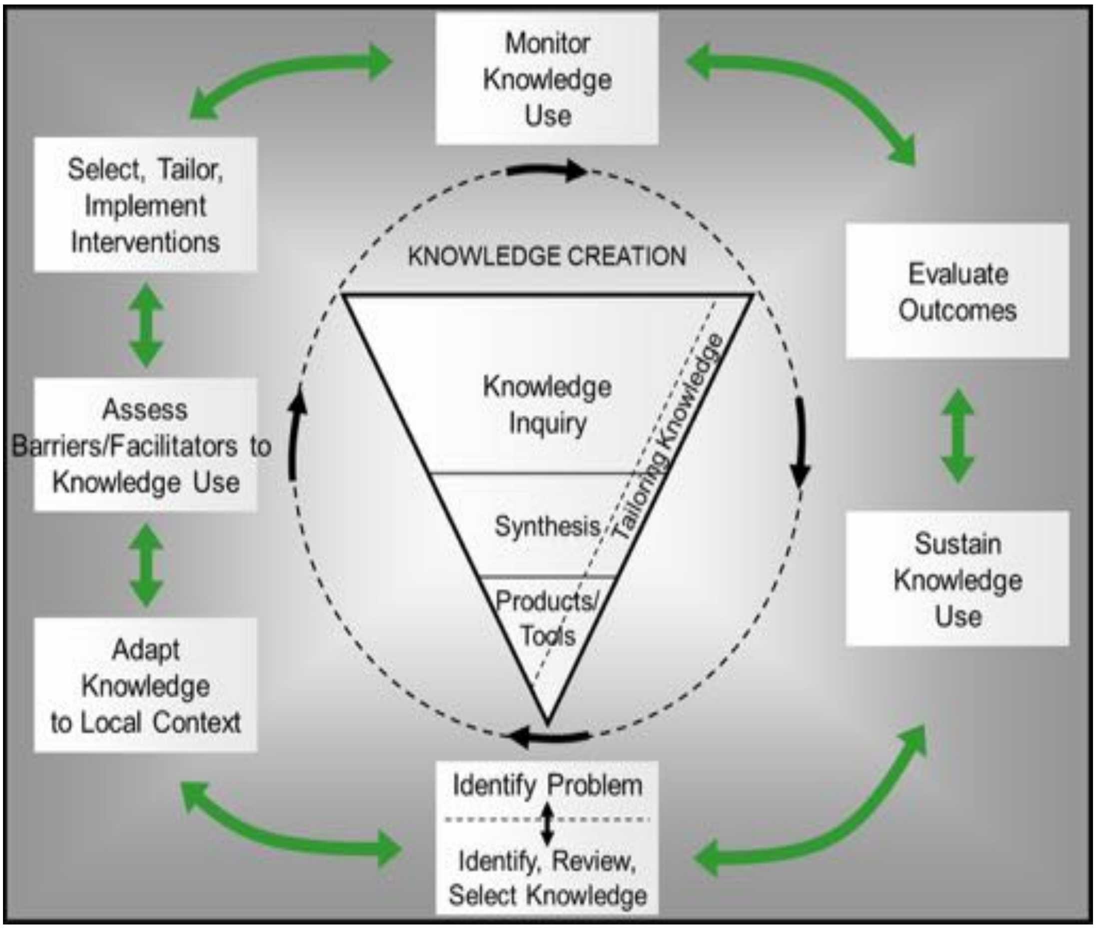
Many healthcare practitioners encounter these questions as they consider the challenges involved in changing healthcare practitioner behavior. It was thought at one time that simply presenting the recommendations for change, circulating a memo or providing education would change behavior. If only it was that easy! Rather, translating evidence into practice can be a complex and daunting process. We know now that it requires careful thought and systematic planning from the innovation itself to the organizational policies and politics.

This chapter is intended for all healthcare professionals as a resource tool for implementation of a practice change based on evidence. A practice change can include: A recommendation or recommendations from clinical practice guidelines or a systematic review of research, a change in a practice routine, and/or a new technology or tool (such as patient decision aids, algorithms, and so on) Often healthcare practitioners find that recommendations for a practice change in a clinical practice guideline, for example, are not easily applicable in their setting. An integrated knowledge translation approach advocates for a collaboration between researchers and knowledge users in the research and development process to help ensure that tools informing best practice are useful and take into account contextual issues (Canadian Institutes of Health Research, 2014).

There are a number of models in the literature to guide us as we try to successfully move evidence into practice. One useful framework is the Knowledge to Action (KTA) Framework (Graham et al., 2006) that outlines the relationship between knowledge creation and the seven action phases in implementation. The entire process is complex and dynamic. Each phase influences the other. The process can take place within different contexts or work environments and these contexts influence the process as well. Implementation is not a linear process, and therefore we suggest that you read through the entire chapter before embarking on a practice change project.

This chapter guides the professional through three phases of implementation that parallel three phases of the KTA Framework (Figure 22): Adapting the evidence to the local context, assessing barriers and facilitators to knowledge use, and selecting, tailoring and implementing strategies. These phases are not sequential but, for purposes of clarity in this chapter, we will label the sections by phase number.

Figure 22: Knowledge to Action Framework (Straus, Tetroe, & Graham, 2006; 2013)



You will have an opportunity to think more deeply about the factors influencing different phases of implementation using the reflection boxes throughout the chapter. At the end of this chapter, we have listed resources that can help guide you through the other phases of the KTA Framework (such as developing goals and evaluating the implementation process). These will not be discussed in detail here.

Summary points

- Implementation of a healthcare practice change is a complex process that involves careful though and systematic planning.
- A practice change in healthcare must be based on evidence.
- The KTA Framework is useful in guiding healthcare professionals in the various phases of implementation of a practice change.

Section 1: Important Considerations when Planning to Implement a Practice Change

Learning objectives

- Learn about the initial stages of implementation

- Learn what elements need to be considered when implementing a practice change.
- Understand the importance and role of stakeholders in the implementation process.

Sometimes, we want to jump right into making a change when we've discovered an innovation that may improve practice and patient outcomes in our setting. Though this enthusiasm is critically important, it is crucial that we go through the initial stages of implementation by carefully organizing and clarifying:

- What is the current state of practice?
- What is the evidence that supports that a change should happen?
- What is our purpose in making the change (exactly what is the goal)?
- Why do we need this change and who (what stakeholder) wants it to happen?
- Who are the stakeholders that are directly and indirectly affected or implicated by the practice change?

Each phase in the implementation process is important and requires an investment of time and resources. For some practices, change may be accomplished in a very short time while others need longer.

Consider whether the following activities have occurred before continuing with the implementation process:

- A question or concern came up in my practice or practice setting either from an evaluation of practice, incident report, etc…. OR
- Evidence for an innovation or practice change was found
    - The highest level and best available evidence was sought for this practice change.
    - The strength of the evidence was appraised.
- Stakeholders were identified and informed about the practice change.
    - A communication plan was made with stakeholders.
    - Input from stakeholders is sought on an ongoing basis.
- The gaps between the evidence (about what should be happening) and the current practice in my setting have been identified through observation or measurement.
    - Baseline data was collected in my practice setting about the actual state of practice at present by identifying and measuring practice sensitive indicators.
    - A decision was made whether this concern is relevant and important enough to warrant moving to implement a change, based on the findings.
- Goals for the practice change were written, and are specific and measurable.
    - The target for the behavior change has been determined. (Who? Where? When? What? How long?)
    - E.g.: *Within 24hrs of admission, all patients admitted to the unit will be assessed for their risk of pressure ulcers using the specified scale.*

Implementation is not an individual endeavor. A team of individuals should be assembled to prepare and work through the implementation process. The team can be composed of stakeholders who have a vested interest in improving outcomes for patient care. The members of your group can vary over time depending on the issues you are working through. It is important to identify a leader within this group who will act as the spokesperson and project manager. See Appendix A for an algorithm to support the implementation of practice changes.

Summary Points

- The initial stages of implementation include understanding the current state of practice,

  - acquiring evidence that a change should happen, outlining a goal for practice change to address the evidence-practice gap, involving and developing a plan for communication with stakeholders.

Reflection Box 1

The initial phases of implementation require ongoing reflection about the decisions made and those that will need to be made. Consider the following questions at this point in the implementation process:

- Is my goal clearly stated? How will I know I have achieved it?
- Is the goal for practice change specific, achievable and measureable? How will it be measured or observed?
- Is the goal realistic? Is it time-limited?
- Have I included the relevant stakeholders and knowledge users in this process? Do I need to involve stakeholders from all levels of the organization? What can I do to ensure that I have not missed a crucial stakeholder or knowledge user?
- Where do my stakeholders and knowledge users stand on the proposed practice change?

Section 2. Planning for Implementation: Adapt the Knowledge to Your Local Setting

Learning objectives

- Learn about the various processes to adapt recommendations from research evidence to fit your local practice setting.

Whether you are aiming to change practice based on evidence from a clinical practice guideline or recommendations from another source (e.g. a systematic review), you need to consider the “fit” of the recommended practices within your setting. Many issues may influence your decision about “fit”.

Findings from research evidence are based on samples of populations that may or may not resemble your local practice setting. Similarly, recommendations from any source may not match with the values and beliefs of your population of patients or staff or may require the use of equipment or other resources that are not readily available. Some recommendations may be vague or unclear about the desired approaches. Therefore, it may be necessary to adapt the recommendations in order to ensure a good fit with your setting, while at the same time, making sure that you only make changes that are consistent with the evidence. Adapting the recommendations to your local practice setting is a necessary step to successful implementation.

Adapting the Evidence

Adapting recommendations from evidence to fit the local setting is a crucial exercise to improve your chances for success when trying to make a change. At this point, you have developed goals for changing behavior based on the best available evidence. These can be:

- Clinical practice guidelines,
- Synthesis of research literature (systematic reviews, series of individual studies, etc…),
- Research projects developed in your setting, (requires appropriate attention to quality and generalizability),
- Local consensus in your setting with validation (by healthcare professionals or patients and families), or
- A combination of sources.

The next step would be to adapt recommendations from the evidence to make it user friendly in your setting. The process of adaptation needs to be a systematic and participatory process that takes into account a number of considerations.

This phase involves looking at the realities of your setting. This will also be helpful in the next phase of implementation as you formally assess the barriers and facilitators to implementing a practice change.

Reflection Box 2

Consider local evidence from your setting when adapting guideline recommendations for implementation (Harrison, Légaré, Graham, & Fervers, 2010). In my setting:

- Are there relevant, specific practice problems relevant? What evidence do I have that there is/could be a problem?
- What are our specific needs and priorities?
- What legislation, policies or resources could hinder or facilitate our implementation of the guideline recommendations?
- What is the scope of practice of our target group? (E.g.: nurses, physiotherapist etc…) Do the recommendations fit?
- Do the recommendations fit with our delivery care models?
- Could the practice changes be sustained over time based on our priorities and target population(s)?

To make implementation easier and expectations more concrete and clear, create a tool to support the practice change such as a protocol or procedure, an algorithm that outlines the steps and clinical decision points for patient care, or new or adapted documentation tools. The final product in the adaptation process requires creativity and an understanding of what will be useful in your setting.

A manual and toolkit, called the ADAPTE process (2009), was created to guide healthcare practitioners and policy makers in adapting existing clinical practice guidelines. A subsequent resource guide, called the CAN-IMPLEMENT © (Harrison & van den Hoek, 2012; Harrison, van den Hoek, Graham, & Tufunarau, 2014), was then developed in response to a study that evaluated the ADAPTE process (Harrison et al., 2013). In the first phase of CAN-IMPLEMENT ©, the practice issues or problem is identified and clarified, where a customization of the guideline occurs to meet the realities of the local context. Phases 2 & 3 of the CAN-IMPLEMENT © process, proceed through the next phases of implementation as described in the Knowledge to Action Framework, and in this guide, using a practical approach. The end result in guideline adaptation can include:

- Rejection of the entire guideline
- Adoption of the entire guideline unchanged,
- Reject the recommendations of the guideline, but accept the evidence base.
- Accept some of the recommendations of the guideline.
- Modification and update of single recommendations,
- Production of a customized guideline (this can include adoption of a portion or sections of a guideline.)

In general, the process for adapting a clinical practice guideline or other types of tools to fit the local setting is as follows:

- Evaluate the guidelines or tool for quality, currency (evidence is up-to-date) and consistency of the recommendations with the underlying evidence (such as appraise the source and/or the primary research behind each recommendation.)The AGREE II tool can be useful here for evaluating clinical practice guidelines (Brouwers et al., 2010).

- Adapt the document to meet the needs and priorities of the local setting, if necessary, while still being consistent with the evidence. This could include selecting some recommendations with strong evidence and that can be implemented locally, modifying the recommendations (based on new evidence), or taking the best recommendations from several guidelines and creating a local guideline.
- Format the recommendations or tool so that they include a statement about targets for quality improvement. (i.e.: goals for evaluation of the practice change.)
- Consider implementation activities (like designing prompts, modifying documentation forms and securing resources) when adapting guidelines. These considerations will help you in the next phases of the implementation process.
- Finalize the adapted document based on feedback from stakeholders and in some cases, developers of the original guidelines.
- Write the final guideline and establish a process for updating.

Other groups have also developed processes for adapting evidence based knowledge in specific population groups that can be useful in attaining a good fit between the evidence and the setting for successful implementation. For example, The CDC Division of HIV/AIDS Prevention developed guidelines on adapting recommendation into unique areas of practice (McKleroy et al., 2006).

Moving into Action

Here is an example of the process to follow when adapting the evidence to fit the local setting:

1. Identify the source(s) of evidence you are planning on implementing. Such as clinical practice guideline, systematic review etc…
2. Communicate and involve stakeholders in this process. A subcommittee can be formed to work on adaptation.
3. Adapt the recommendations from the evidence by following a standardized process, for example the CAN IMPLEMENT © for clinical practice guidelines.*Note: depending on your needs, it may not be necessary to follow the entire process. You may also review the local evidence in your setting and tailor the practice change to fit the setting.
4. Create a written document of the adapted guideline or practice change that will include the final format and language. This can be an algorithm, spreadsheet, protocol etc.*Note: using the CAN Implement process will lead you to this step.
5. You may need to revisit the adaptation issues in later phases of the implementation process. For example, if unanticipated challenges arise or clinicians find the recommendations/practice change tool unclear, you may need to refine or revise the final product.

Reflection Box 3

Think about the decisions made so far. Consider:

- Are we still on track to achieve the set goal? Does this goal need to be modified?
- Do we need to go back and rethink any decisions made?
- What assumptions have we made? Do they still hold true?
- Are the members of the team still the right ones?
- Is there an individual or a group in the organization that can facilitate the adaptation phase?
- As a project leader, what is my role at this stage?
- As a leader within the organization, what can I do to support the practice change at this step?

Examples of Adaptation in a Real Setting

Example 1: Adapting a skin care guideline to prevent diaper dermatitis in a paediatric oncology population (Espirito, Santo, & Choquette, 2013).

Nurses in a paediatric oncology unit were concerned about the high incidence of diaper dermatitis in infants and toddlers receiving chemotherapy. The advanced practice nurses, in consultation with the staff nurses, were interested in implementing a change in practice to prevent diaper dermatitis. In reviewing the literature they found a clinical practice guideline pertaining to diaper dermatitis that had been prepared in another children's hospital for infants.

Using the recommendations from, the ADAPTE process, and while consulting the stakeholders (e.g.: nurses families and physicians), the local children's hospital adapted the Pittsburgh guideline to the local oncology setting. This new guideline outlined the recommendations dealing with prevention of diaper dermatitis, as well as an algorithm that was posted at the bedside as a guide and reminder for nurses as well as parents.

Example 2: Adapting a clinical practice guideline based on the feasibility of implementing a specific recommendation.

A working group that was focused on reducing the hospital's rate of pressure ulcers decided to implement a specific clinical practice guideline. However, one of the guideline recommendations was, in an acute care hospital, to repeat patients' risk assessments every 48hrs. The evidence supporting the recommendation was weak (the personal opinion of a leading researcher in the field, but not based on any research study). The stakeholders in the situation (clinical nurses on busy in-patient units) raised many serious questions about the feasibility of repeating the assessment every 48 hours. The working group decided not to require that step in its local policy and protocol given the lack of supporting research evidence.

Example 3: Adapting a clinical practice guideline to improve success in achieving the overall goals.

A working group that was focused on reducing the hospital's rate of pressure ulcers selected a specific published clinical practice guideline for implementation. Their review of the guideline revealed that there were more than 30 recommendations. Several of those were vague or general and were not based on strong research evidence. Some of the recommendations pertained to practices that would be more complex to change or for which the outcomes would not be immediately visible. The working group decided to begin their implementation work with a focus on the specific recommendations pertaining to assessment and to translate the intervention recommendations into an algorithm that summarized the steps to take in the situation of a particular assessment. These were then made into pocket guides and posters for practitioners and patients to use for reference or reminders.

Summary points

- Adapting recommendations from evidence or tools (clinical practice guidelines) is the process of making them user friendly in the local setting.

- CAN-IMPLEMENT © is a practical resource guide that supports the process of adapting clinical practice guidelines as well as the next phases of the implementation process.
- The final adapted product can be the recommendations in their original form or a medication of this.
- Adaptation is a collaborative and systematic process and should involve key stakeholders.

Section 3: Planning for Implementation: Identify Barriers and Facilitators of Implementation in the Local Setting

Learning objectives

- Gain an understanding of the possible factors that might help or create challenges for implementation in your setting,
- To systematically identify these in order to build a plan of action.

Whether you are planning to implement a small scale practice change within your clinic, or you are implementing clinical practice guidelines across multiple practice areas, having a clear picture of the important issues or complexities of the setting will shape your approach to selecting strategies for implementation. Strategies for implementation can be more effective when they are tailored to address specifically the barriers or when they make use of the facilitators identified in the setting (Baker et al., 2010). Therefore, identifying these factors prior to selecting the strategies can contribute to successful implementation.

Identifying Barriers and Facilitators

A barrier in the context of implementation can be defined as any factor that may inhibit or pose challenges to the implementation process. Conversely, a facilitator to implementation is seen as any factor that may enable the process. Keep in mind that many factors can be a barrier and a facilitator.

Barriers and facilitators for implementation can be identified by examining characteristics of the (Ploeg, Davies, Edwards, Gifford, & Miller, 2007):

- innovation or practice change,
- individual care providers,
- local practice setting, and
- organization.

Each has unique factors to consider. Barriers and facilitators for sustaining the practice change are also identified at multiple levels, but they are not necessarily the same as those that influence implementation.

Characteristics of the innovation or practice change.

Characteristics of the innovation or practice change could be perceived as barriers and/or facilitators to implementing a practice change. This perception can shape the attitudes and opinions of the individual care providers that are involved in implementation. For example, when practitioners perceive the recommended change to have no added benefit, it will require different or perhaps more intense implementation strategies to influence the practice change.

Rogers (2003) argues that the ease with which an innovation is adopted is related to people's perceptions about 5 main attributes of the innovation (Table 1). Different people may have different opinions about any of the attributes. Greenhalgh and colleagues (2004) reported that there is moderate to strong direct evidence that perceptions about such attributes influence use of evidence in healthcare situations.

A recent systematic review (Kapoor, Dwivedi, & Williams, 2014) of studies that have cited Rogers' innovation attributes showed that relative advantage, compatibility and complexity were statistically associated with the adoption of an innovation, While the attributes of trialability and observability also positively influenced adoptions, the relationships were not significant.

Other researchers describe attributes that are specifically related to the adherence to recommendations from clinical practice guidelines (Grol et al, 1998; Cabana et al., 1999).

Table 1: Attributes of the innovation to consider as a barriers and facilitators to implementation.

Attribute	Definition	Example
Relative advantage or benefit	The perception of whether the innovation is better than the practice it will replace. *"Will it be better than what I'm already doing?"*	As part of a hospital wide initiative, a clinical practice guideline for the prevention of pressure ulcers was implemented on a nursing unit with 0% prevalence of pressure ulcers at baseline. The practice was not sustained over time as the nurses stated it was "not relevant" for their population.
Compatibility	The perception of whether the innovation is consistent with the values and beliefs of the setting (culture). Recommendations that are non-controversial are more likely to be followed. *"Will it fit with my beliefs about dealing with this issue?"*	In implementing a practice change to promote family centered care, nurses who valued the input of families might be more invested in making the changes than the nurses who did not value families' involvement in care. It is a common practice to continuously and electronically monitor the fetal heartbeat during normal labor and delivery despite published clinical practice guidelines to the contrary. Many practitioners oppose this recommendation due to medical-legal concerns (Qian, Smith, Liang, Liang, & Garner, 2006)
Complexity	The perception of the degree of difficulty and ease of the innovation. *"Will it require too many steps and just feel like more work?"*	The reduction of the use of a "sitter" and/or restraints forelderly patients following surgery may be complex because it may require multiple types of changes by many and different types of providers. For example, the physicians may need to change and harmonize their medication orders. Nurses may need to develop new skills in assessing and intervening for delirium.

Attribute	Definition	Example
Trialability	The degree to which an innovation can be experimented with and tested. *"Will it be too difficult to just try out?"*	Nurses were skeptical about a change of practice that would require independent double checks in administering high-risk medication to improve patient safety. Two volunteers were asked to try the practice for a month. The results were clear that patient safety had improved significantly and other nurses were more on board in adopting the new practice.
Observability	The degree to which the outcome of the innovation is visible. *"Will it be easy to see the results?"*	An innovation to improve pain management is more visible than an innovation to promote family centered care.
Evidence-based	Recommendations based on research evidence are more likely to be followed. *"Is the proposed change based on research evidence? Is that important to me?"*	A study evaluated the factors that influenced surgeons' consideration of applying a novel needle suspension technique with mesh in patients suffering from urogenital prolapse. Their decision was most strongly influenced by the level of scientific evidence underlying the technique. (Hinoul, Goosens, & Roovers, 2010).
Clarity	Recommendations that are specific and not vague are more likely to be followed. *"Do I understand what I am being asked to do?"*	The following is a recommendation in a clinical practice guideline dealing with crisis intervention: *"The delivery of crisis intervention is based on an integrative framework."* (RNAO, 2002). It does not provide any clear action steps for users and may be less likely followed.
Change in routine	Recommendations that do not call for a change in routines are more likely to be followed. "*Will this easily fit into my current routine?"*	Strong evidence exists for the administration of antibiotics prophylaxis preoperatively and at specific intervals thereafter in patients undergoing gastrointestinal surgery. In one hospital, although adherence to the hospitals' prophylactic antibiotic protocol was below optimal, surgeons requested the purchase of antibiotic soaked sponges use during surgery. It appeared that this type of practice would involve less change in routine. However, the request was denied and it was urged that the surgeons follow the existing protocol (Pan & Dendukuri, 2010).

Individual care providers.

Individuals across healthcare disciplines and settings may be influenced differently by their perceptions about specific attributes of the innovation or practice change. For example, physicians may place a higher importance on whether recommendations are evidence based compared to other disciplines (Langley & Denis, 2011; Goosens, Bossuyt, & de Haan, 2008).

Individual care providers include any provider within your setting who will be targeted in the practice change. The providers' attitudes, knowledge and skills can influence the culture of a practice setting and will influence their adoption of the desired change. For example, if the practice change involved the process of patient transfers, nurses could be directly implicated in changing their behavior. As well, unit coordinators and orderlies would be affected by the change and may have differing perspectives.

Reflection Box 4

Perceived characteristics of the innovation also factor into the attitudes and opinions of individuals. Consider:

- Is the innovation perceived as better for the patient and/or for the clinician than what is already in place?
- Is the innovation consistent with existing values, past experiences of change and the needs of the individuals?
- Is the innovation complex? How difficult will it be to understand?
- Can the innovation be tested on a small scale?
- Will the outcomes of the innovation be clearly observable?
- Is the practice change based on research evidence? Or another type of evidence?
- Is the recommendation for practice change stated clearly?
- Can the recommended practice change fit into the existing work flow processes, or does it require a major change in routine?

Here are examples (Table 3) of factors to consider with individual care providers when assessing barriers and facilitators for implementation (Wensing, Bosch, & Grol, 2013a):

Factor	Definition	Example
Competence	The knowledge or skills that are needed to implement the innovation.	The innovation may require learning how to use a piece of technology or may require understanding a disease process.
Attitudes and opinions	Individuals may have varying attitudes and opinions about the innovation itself, or about changing existing practices.	A culture can exist where any change is seen as disruptive. The attitude of maintaining the status quo can impede the implementation of practice change.
Motivation for change	The motivation to change behavior can depend on the individuals' level of satisfaction with their own performance. This can be a gradual recognition, or may depend on a specific event.	A negative incident where a patient's health was compromised because of a lack of knowledge with a disease process can signal to the practitioner areas of improvement.

Factor	Definition	Example
Individual characteristics	Individual characteristics of the healthcare professional have been shown to affect the utilization of evidence in their practice.	systematic review identified individual characteristics that positively influence nurses’ use of evidence, include having: ~~in their practice~~: Positive attitude to research, conference attendance,, a post-graduate degree, a leadership or advanced role, clinical specialization and job satisfaction (Squires, Estabrooks, Gustavsson, & Wallin, 2011)

Table 3: Factors of individual care providers

Reflection Box 5

Social cognitive theories can help to better understand health professionals’ behavior and offer insights to help you decide on the barriers and facilitators of implementation. They can be used to better inform the implementation process.

Godin, Bélanger-Gravel, Eccles, and Grimshaw (2008) found that the Theory of Planned Behavior (Ajzen, 1991) was appropriate in examining the attitudes and beliefs in health professional behavior. Michie, van Stralen and West (2011) developed the Behavior change wheel from a review of behavior change frameworks that linked factors to behavior change and the interventions and policies that have an impact on these factors.

See appendix D for the above models.

Practice setting.

The practice setting includes individuals and characteristics of the patients that make up the local practice area or areas where the innovation will be implemented. This also includes the size of the setting (which usually cannot be changed), local resources, and the presence of transformational leaders.

Here are examples of factors to consider in the practice setting that could be barriers and/or facilitators to implementation (Table 4):

Table 4: Factors Related to the Practice Setting

Factor	Definition	Example
Patient characteristics	Patient and family preferences or capacities can be a barrier or facilitator to the change process. Preferences to be involved in certain care activities, treatment goals or healthcare outcomes can be influenced by the patients' culture, beliefs and previous experiences. Care providers' beliefs about patient characteristics such as age, gender, illness type and acuity can influence their care routines. (Wensing et al., 2013a)	Young adults with significant cognitive delays may be unable to participate in self-management even if the recommended practice is to foster these skills. Beliefs that a specific patient demographic has overall better literacy skills can influence the practitioners' approaches to teaching this group.
Champions	Champions are appointed individuals who promote the implementation process by encouraging, coaching and/or convincing others to accept the innovation. Champions are facilitators that can come from different levels of the organization, including executive, managerial and, most commonly, clinical levels. Clinical champions generally do not hold formal leadership roles who have a realistic understanding of their setting. Champions can be resource persons and mentors, and participate in tailoring implementation strategies to the setting (Greenhalgh, Macfarlane, Bate, & Kyriakidou, 2004)	Key activities of champions include: Educating peers about the innovation, advocating for the innovation, building positive relationships with users of the innovation and communicating with and reaching out to other professionals and practice settings. They can also facilitate through coaching, reminding and doing audits and feedbacks. In implementing a falls prevention guideline, the nurse manager on a surgical unit appointed two champions to support the implementation: A junior and senior nurse because there were trusted by different groups within the nursing staff.

Factor	Definition	Example
Other care providers	The opinions of colleagues across or within disciplines about the innovation can greatly influence whether a new practice is implemented. Sometimes different disciplines use language differently. This can lead to miscommunication of the goal. (Wensing et al., 2013a)	Reusable dialysis filters were implemented with prudence as there were differing opinions about the benefits of adopting this new technology. Nephrologists had varied opinions: some saw little clinical benefit; some felt it could be unsafe for patients and they would be held liable; some felt that it could benefit the department by saving money. Technicians, who would be responsible for sterilizing the filters, were concerned about the added use of formaldehyde on their own health (Denis, Hebert, Langley, Lozeau, & Trottier, 2002.)
Opinion leaders	These include individuals within a setting who are seen as important, trustworthy and influential among their peer group. They often have high levels of expertise and well inter-connected. An opinion leader often is an informal leader that can be a facilitator or barrier to change (Rogers, 2003.)Opinion leaders may not remain over time, therefore it important to reassess this in the local context (Doumit, Wright, Graham, Smith & Grimshaw, 2011).	A change in the model of care required physicians to communicate with each patient's primary nurse, rather than the assistant head nurse for all patients on the unit. Most of the attending physicians disagreed with the change. The chief of service, who was an active member of the team, was in favor of the change. He supported his medical colleagues but promoted the change in model of care.

Reflection Box 6

Think about possible opinion leaders who can be influential in the change process.

- Who can be included? (Educators, clinical leaders, local managers?)
- Why they are leaders? (Expertise/experience, trusted, often involved in evaluation of services, strong presence, etc…)
- Is their opinion of the innovation positive or negative?
- Can they be considered barriers or facilitators to implementation? What lessons can we learn from their perspectives?
- What could be done to change their position if they are perceived as a barrier?

The Registered Nurses of Ontario (RNAO) have developed a process for identifying, analysing, and engaging stakeholders, including opinion leaders in their Implementation toolkit. See the resources section for more information.

Most practice changes are not adopted universally at the same time. Some people will be more willing and ready to engage in a particular change than others; some may give reasons for resisting a particular change. For instance, they may fear how the change will affect them personally or worry that the change is not feasible. This pattern is so common that researchers have described 5 different adopter categories (Rogers, 2003).40% of individuals within a setting usually fall into the first three groups described below. In healthcare, for example, medical faculty who are ‘early adopters’ had different characteristics, adoption patterns and perceptions about instructional technology than others (Zayim, Yildirim, & Saka, 2006). Because of this pattern, it is useful to consider which members of the group fall within the various categories for a particular change and to begin initial work for change with them.

1. *Innovators* are risk takers being the first to adopt a new idea from outside of the setting. They are the ones always full of ideas.
2. *Early adopters* are next to adopt an idea, but have a careful approach. They are respected members of the setting who provide advice to others about the innovation. They often hold positions of opinion leadership.
3. The e*arly majority* adopt new ideas just before the average individual in the setting. They may consider the innovation for a significant period of time and raise questions before adopting it.
4. The *late majority* adopt an innovation or practice change because of necessity or peer pressure. They are usually skeptical and cautious about new ideas.
5. *Laggards* are last to adopt an innovation or practice change. They hold traditional values, tend to be suspicious of change and must be certain that a new idea may not fail if they are to adopt it. Laggards may never come to adopt a change unless specific actions are taken.

Individuals can move between categories depending on the innovation. The people who regularly fall into the different adopter categories are usually well known in a work setting! You may be able to recognize which individuals falls into which adopter group as you proceed with implementation. You can also survey (informally or formally) individuals in your setting to see how they stand on the practice change.

It is important to respect and listen to all groups. Begin working with the innovators and early adopters but always pay close attention to the issues raised by the late majority and laggards.

Even the nay-sayers have very relevant concerns about the innovation or practice change. Being attentive to each group's concerns can help you to identify barriers to implementation and to select implementation strategies to deal with these barriers. You can consider implementation strategies for each adopter category. Try not to be slowed down or stopped because of negativity!

Organization.

The organization reflects the larger setting structure or healthcare system (i.e.: higher order than the individual). This includes characteristics and procedures by leadership and management groups of the hospital system, community, and government bodies to support change.

Here are examples of factors in the organization when considering barriers and facilitators in implementation (Table 5):

Table 5: Factors Related to The Organization

Factor	Definition	Example
Philosophy and mission	The philosophy of an organization, where priorities for improved care have already been established can be a barrier or facilitator to the implementation of a specific innovation.	The dacare Center has articulated a vision to develop new models of care in order to improve quality. They have clearly outlined targets for improvement to reduce waste and to improve value to users. They are recognized as being leaders in innovation and excellence.(The dacare Centre for Healthcare Values, 2011).
Formal Leadership	Formal leaders (such as program directors, managers and advanced practice leaders) are responsible for creating a culture that is receptive to innovative change. However, this influence may differ between healthcare disciplines, where the social structure varies (e.g.: medicine compared to nursing.)Individual leaders and leadership styles can be a barrier or facilitator to change.	Key behaviours to enable a culture of innovation include creating and sustaining a clear vision, role modelling the change, commitment to the vision, developing supportive relationships, mentoring and aligning actions and priorities with the stated vision (Gifford, Davies, Edwards, Griffin, & Lybannon, 2007).

Factor	Definition	Example
Resources and structure	Facilities, space, materials, technology, staffing, and work design adequacy in the organization can influence implementation. This can also include accessibility to new technology and developing new service programs. As well, existing formal procedures can be conducive or not to the implementation process.	The availability of specific imaging services on site, referral procedures to the clinic, staffing mix and levels on care units, the rate at which patients are seen, documentation procedures and forms, etc, are examples of specific resource and structure issues that affect implementation. Nurses' self-report of use of research in practice was higher when they also perceived that they had a positive work context (Cummings, Hutchison, Scott, Norton, & Estabrooks, 2010).
Financial resources	Financial resources to support implementation can include available existing funds, opportunities to apply for special funding through grants or a re-allocation of funds.	Monetary support can be used for the purchase of new equipment, salary support for education days if necessary, hiring of experts in the field for coaching or demonstration, adding extra staff during a brief transition period, a printer for documentation sheets or patient education pamphlets, etc…
Beyond the organization	Services or requirements beyond the organization or institution such as a health administration or insurance body or the ministry of health may have regulations or resources that serve as barriers or facilitators	Documentation regulations, role definitions, medical-legal issues and scope of practice, standards of care, etc…

Reflection Box 6

Think about the innovation you would like to implement:

- What materials, people, services, or facilities are needed?
- Are these resources available in your setting? Are there too many implementations at once? Is there a way to combine or bundle these?
- How can resources be mobilized? With whom do you need to speak to get these resources? Consider creating a business case (see implementation strategies)
- Are there financial implications to acquire resources? What sources of funding are available? (e.g.: Professional associations? Inter-organizational networks?)
- Are there resources available to sustain the practice change over time? (e.g. materials needed to initiate the practice change are available indefinitely.)
- How can formal leaders in your organization be involved to facilitate implementation?
- What ethical issues to consider when implementing the innovation? Does the change project require ethical approval?
- What broader system level issues may have an impact on implementation and sustainability of the innovation? (e.g.: staff shortages, changes in leadership, new patient populations etc…)

Moving into Action

1. Organize yourself! Create a spreadsheet to visualize barriers and facilitators for implementation and sustainability OR use and adjust the one provided in Appendix B.
2. There are several ways of teasing out barriers and facilitators. Before embarking on this process, consider the following (in deciding your approach):
    a) This process can be time consuming. Think of your time commitment to this phase. Dedicate time and resources. Keep in mind that taking time up front will save you time later!
    b) Decide who will be involved (and available) in this process. Consider members of your taskforce to aid in choosing and conducting assessments for barriers and facilitators. Think of stakeholder inputs from frontline to administration level.
    c) Keep in mind the goals and outcomes of the practice change. Consider your target group. Are your goals realistic?
    d) Be sure to consider the barriers and facilitators to sustainability in addition to implementation. The factors may or may not be similar. Having an idea early in planning will help you communicate resources for the long-term.
3. Consider one or more of the various strategies to identify barriers and facilitators. There are several methods:

Reflection Box 7

These questions can be used to assess barriers and facilitators with individual practitioners or formal leaders through:

- Informal discussions or conversations with individuals
- Semi-structured individual interviews or focus groups
- Following a presentation to introduce the innovation and group discussion
- A paper based survey

The answers will help you consider and plan which implementation strategies that will map to identified barriers and facilitators. Adapt the questions so that they are specific to your innovation and health practitioner (adapted from Brett, 1989):

1. Have you heard or read about the innovation?
2. Have you observed this innovation in use?
3. What do you know about the innovation?
4. Do you already use this innovation? Or have you seen it in use?
5. What are your beliefs about this innovation fitting in the setting? How does this innovation fit with your role (as a nurse, physician, physical therapist etc…)?
6. How will the innovation lead to improved patient or practitioner outcomes?
7. What skills do you have or need to carry out the innovation?
8. What resources (time, financial, space, and personnel) are needed to carry out the innovation? How accessible are these?
9. Is this innovation important to you? To your colleagues? To the leadership group? To your organization? To the patients and families?

a) Use a prepared list of barriers and facilitators. Taxonomies of generic barriers and facilitators already exist. For example, see Appendix C. Or use frameworks to guide brainstorming sessions on possible factors such as PARIHS (Rycroft-Malone et al., 2004) or the Behavior Change Wheel (Michie et al., 2011). Others can be found in the resource list at the end of this chapter.

b) Survey individual care providers, patients and/or others (this can include the stakeholder group) at various levels using approaches such as:

   - Survey questionnaire on barriers and facilitators about practice change in general,
   - Questionnaire on barriers and facilitators about the actual innovation or practice change to be implemented,
   - Case specific questionnaire that assesses barriers and facilitators after a specific event. For example, surveying physicians after ordering a specific diagnostic test to indicate their reasons for ordering it. (Grol et al., 2013).
   - Standard questionnaire on determinants of change to evaluate motivations for change.
   - You can create or adapt standardized questionnaires (see Squires et al., 2011; Brett, 1989; Coyle & Sokop, 1990 for useful tools such as the Nursing Practice Questionnaire (NPQ).

c) Interview individual care providers, patients and/or others through:

  - Individual interviews using a semi-structured format or informal conversations.
  - Group interviews using a semi structured format. These can be informal. This could include brainstorming activities, the Delphi method or focus groups.

d) Collecting and analyzing observations of current practice through:

  - Self-registration of behaviors whereby individual practitioners complete a form, or a diary of their behaviors.
  - A review of medical records that identifies the frequency and context of selected behaviors or tasks.
  - Participant and non-participant observation involving a trained observer that records specific events or activities.
  - Reviewing routinely collected data from pre-existing databases.

4. Select strategies to identify barriers and facilitators of implementation in your setting. Consult Table 6 below for advantages and disadvantages of the various methods:

Table 6: Comparison of Strategies to Identify Barriers and Facilitators

Strategy	**Advantage**	**Disadvantage**
Consulting a prepared list of barriers and facilitators	Less time commitment. Factors most commonly observed are listed. Discussion starting point.	Unique factors overlooked if it is the only approach used. Factors still need to be validated in your setting.
Surveying individual care providers, patients and/or others using questionnaires	Most efficient if assessing a large sample. Standardized questionnaires are psychometrically tested.	Self-assessment is usually not very accurate. Piloting may be necessary. Developing a questionnaire is complex and time-consuming. More useful in a research project or large scale implementation.
Interviewing and/or discussions with individual care providers, patients and/or others	Efficient in a small sample. Can go into more depth than a questionnaire. Elicits issues that may not have been brought up using a questionnaire. Follow up and feedback are more feasible. Increased accessibility to forums where groups may already be assembled (e.g.: rounds, departmental meetings, etc…)	Can be a challenge to organize (especially group interviews). Time consuming.

Strategy	**Advantage**	**Disadvantage**
Observation	Can be relatively easy to collect, especially in a small sample. May be more reliable than other methods as it captures what is actually happening.	Some types of behavior often go unreported (e.g.: education interventions) whereas others are reliably reported (e.g.: medication administration.) Having an observer present can influence behavior.

Reflection Box 8

How much is enough? Who and how many people do I need to survey? Unfortunately, there is no exact number. Think about these points when planning to survey individuals to assess for barriers and facilitators:

- The number of individuals to survey depends on the type of innovation and the reach of implementation. For example, implementing a pain management clinical practice guideline in several clinical areas of a hospital, may require you to interview more individuals of varying disciplines, than if you were implementing a new practice technique for physical therapists working with paediatric orthopaedic patients.
- Remember, this is not a research study. You just want to identify specific factors in your setting.
- Ask yourself: How many individuals do I need to survey in order to feel confident? For decision-makers to feel confident?
- When considering with whom to implement, be sure to survey people from all adopter categorization groups, and stakeholder groups. This often includes patients and families as well.

5. Begin assessing your barriers and facilitators of implementation and sustainability using the strategies you selected.
   - Keep a timetable.
   - Keep your stakeholders informed of the process and results.
   - Organize your results in a spreadsheet.
6. You may uncover several barriers and facilitators in your setting! As you analyze the barriers and facilitators, consider the implications of your conclusions:
   a) Is it wise to modify your goal?
   b) Which barriers or facilitators are the most important to carry forward and plan implementation strategies around? Think about the overall goals of your local practice area and organization, the needs of the patients and families and the values of the practitioners.
   c) Are there different or additional strategies that are needed for some individuals or units?

Examples of Barriers and Facilitators in Real Life Settings

Example 1: Strategies to assess the barriers and facilitators of implementation of a clinical practice guideline related to falls prevention.

In developing a plan to implement a falls prevention clinical practice guideline, the working group used a number of different strategies to assess the barriers and facilitators. For example, they:

- Assessed the status of unit equipment that would be required for nursing staff to implement the injury prevention recommendations. Two members of the group surveyed the unit managers to determine their inventory (if any) of the specified equipment.
- When it became apparent that there were major gaps between what existed on the units and what would be required (a major barrier!), the Senior Administration member of the working group prepared a business case (discussed in detail in the next section) that noted the estimated annual cost of a patient incurring a falls injury while hospitalized and compared that cost to the costs of the required equipment. The business case showed that the expenditure for equipment would result in an overall budget saving by year two. The Senior Administrator then worked with the Department of Finance and other hospital decision-makers to obtain a budget allocation for equipment purchase. The barrier was converted to a facilitator as the clinicians were impressed that 'the Administration' had paid attention and that if 'they' had put actual financial resources into equipment purchase, then this must be a 'really important issue.'
- The working group translated the guideline recommendations into an easy-to-use tool to help clinicians be more specific about a particular patient's falls risk and choose the related prevention interventions. When they pilot tested this tool with clinicians on 3 units, the clinicians pointed out many 'glitches' and features of the tool that they felt were 'unfriendly.' The working group interpreted the clinician's reactions as a major barrier to successful implementation and revised the tool based on their feedback.

Example 2: The importance of assessing and not assuming what the barriers are prior to investing resources in further implementation strategies.

We often assume that the barrier to changing practice is the lack of the clinician's knowledge. However, several research studies in the field of pain care have shown that often, even when the clinicians score very well on tests of knowledge about pain and pain management, the related clinical practices are not implemented. A study in neonatal intensive care nurseries found that the barriers and facilitators of nurses implementing evidence-based pain care was related more to their relationships with physician members of the care team and some features of the infant (Latimer, Johnston, Ritchie, Clarke, & Gillin, 2009) than with a lack of knowledge.

Summary Points

- Identifying barriers and facilitators for implementation is crucial in choosing implementation strategies that will be most effective in your setting.
- Barriers and facilitators can be found by examining unique characteristics of the practice change, individual care providers, the local practice setting, and the organization.

- There are several ways to identify barriers and facilitators. Consider the resources available in your setting and your target group when deciding how to identify these factors.

Section 4: Planning for Implementation: Select, Tailor and Implement Strategies

Learning objectives

- Gain an understanding of the different approaches to take when selecting and tailoring implementation strategies.
- Learn how to create a plan and put the plan into action.

Selecting and tailoring strategies that will enhance the success of implementing a practice change can be a creative and challenging process. It requires careful thought, collaboration with stakeholders, a deepened understanding of the setting and project management skills. We need to choose strategies that fit the specific situation: such as strategies that address knowledge are useful only if lack of knowledge is the barrier!

Selecting Implementation Strategies

Traditional ways of promoting change in practice, such as written memos and conferences are insufficient (Wensing, Bosch, & Grol, 2013b). These can be helpful to increase knowledge, but are less successful in actually changing behavior.

Approaches that have been shown to promote a change in behavior (mainly in medicine) include (Wensing et al., 2013b):

- A multi-strategy approach that is tailored to the specific barriers and facilitators found in the setting,
- Strategies that target multiple factors (facilitators and barriers related to the innovation, individual care providers, practices setting and organization), and
- Strategies that actively involve professionals, patients/clients and formal leadership.

Strategies for implementation have been categorized and conceptualized in a number of different ways. Those categories might help you to think systematically about the types of issues to consider in your plan. Regardless of the way they are organized, it is important to choose strategies for implementation that:

- are effective,
- are targeted toward addressing the barriers and engage the facilitators of implementation in your setting, and
- do not exceed the resources available in your setting (for the implementation process and for sustainability.)

Table 7 will give you some *examples* of implementation strategies that target practitioners and patients. These have been shown to be effective in a healthcare setting to promote behavioral change among healthcare professionals. For a more complete list of strategies, see KT Clearinghouse or see the resources at the end of this chapter.

Table 7: Implementation Strategies

Type	Details	What does the research say?	Examples of Targeted Barriers
Audit and feedback	A means of changing individual practitioner or team behavior by: ▪ Demonstrating the gap between desired and actual clinical performance. ▪ Encouraging ongoing success in implementation.	A Cochrane Collaboration review indicated that Audit and feedback generally lead to improvements in practice (Ivers, Jamtvedt, Fottorp, Young, Odgaard-Jensen et al., 2012). The methods of doing and audit and feedback for success are in need of future research. This strategy is often underused or not properly used in some professions (Dulko, 2007).	▪ Lack of awareness of or attention to indicators of quality ▪ Lack of awareness of reality of current practice ▪ Low momentum in implementation
Educational outreach visits (a.k.a. academic detailing)	Trained individuals visit the practice setting to provide face-to-face information on practice change. Information provided could be: ▪ Educational, ▪ Feedback on individual performances, and/or ▪ Problem solving about obstacles to change.	According to a review by The Cochrane Collaboration educational outreach appeared to improve the care delivered to patients for a number of different practitioner behaviors with small to moderate changes in practice (O'Brien, 2007).	▪ Lack of knowledge ▪ Culture/Beliefs ▪ Poor communication channels ▪ Complex innovation
Engage local opinion leaders	Practitioners perceived as important, trustworthy and influential could be called upon to encourage a change in practice. This can be done: ▪ Informally through modeling, information discussions. Formally through active learning sessions or mentoring.	The evidence suggests that engaging local opinion leaders can promote evidence-based practice (Flodgren, Parmelli, Doumit, Gattellari, O'Brien, Grimshaw, and Eccles, 2011). The literature is variable in describing how opinion leaders were used, with what frequency, as well as how they were identified.	▪ Disbelief, or negative attitudes ▪ Misperceptions about social norms ▪ Lack of knowledge or skills

Type	Details	What does the research say?	Examples of Targeted Barriers
Interactive educational meetings & workshops	A workshop where professionals are actively engaged in learning through didactic lectures, discussions, and role playing for problem solving in small group sessions. This has the purpose of increasing knowledge, changing practitioner behavior and subsequently, patient outcomes.	According to a review by The Cochrane Collaboration (Forsetlund, Bjørndal, Rashidian, Jamtvedt, O'Brien and Wolf, 2009), educational meetings were most effective when they combined interactive and didactic education methods. These were shown to change practitioner behavior as well as patient outcomes.	▪ Lack of knowledge ▪ Lack of skills ▪ Challenges to modify current work organization ▪ Poor communication skills and channels
Local consensus	Discussions about the relevance of the issue, as well as the proposed innovation with practitioners who will be directly involved in the implementation process. This requires involving practitioners at the beginning. These practitioners could also be included in the taskforce of stakeholders.	A Cochrane review is underway to determine whether local consensus processes improve healthcare outcomes or professionals' practice (Nasser, Oxman, Paulsen and Fedorowicz, 2007). This strategy has been advocated in a number of guidelines for implementation (Bero, Grili, Grimshaw, Harvey, Oxman & Thomson, 1998; RNAO, 2012). There have been conflicting reports about its effectiveness in clinical guideline implementation.	▪ Disbelief around the issue ▪ Lackof knowledge or awareness ▪ Disparity of opinion or controversy over the evidence
Patient mediated Interventions	Provides patients with information or guides to help change practitioner behavior. This can include: ▪ Educational material such as pamphlets, posters or audiovisual information in waiting rooms, hospital rooms or delivered to patients homes.	Coulter and Ellins (2007) advocate for enhancing the involvement of patients in their care through strategies that improve health literacy. In their review of patient engagement strategies, they place an emphasis on providing patients as well as healthcare professionals with the resources needed to work collaboratively. Patient decision aids can	o Providers' information overload o Providers' sense of "what matters" ▪ Lack of respect for or lack of partnership with patients and/or families. ▪ Poor shared decision making

Type	Details	What does the research say?	Examples of Targeted Barriers
	▪ Reminder systems for patients such as telephone calls. ▪ Counseling or education initiatives given by healthcare professionals to patients.	improve decision quality, communication with providers, and service use (O'Connor, 2009; Légaré, Ratté, Stacey, Kryworuchko, Gravel et al. 2010.)Patient reminder systems have also been shown to increase immunization rates (Jacobson Vann & Szilagyi, 2005)	
Reminders (paper or electronic)	Prompts set up to alert to the healthcare practitioner to perform a clinical action. These can be delivered electronically or manually. For example: ▪ Computerized decision support systems that provides prompts and reminders from patient specific data. ▪ Enhanced reports (i.e.: lab reports) that provide suggestions for follow up actions when an abnormal result is found. ▪ Stickers, posters or paper reminders in charts or on communication boards for practitioners.	Grimshaw, Thomas, MacLennan, Fraser, Ramsay, Vale, et al (2004) emphasized the importance of using paper based or computerized reminders whenever possible in guideline implementation. Also, computer reminders specifically showed variable improvement in physician behavior in a systematic review (Shojania, Jennings, Mayhew, Ramsay, Eccles and Grimshaw, 2010). Computer generated reminders delivered on paper to healthcare professionals showed moderate improvement in the processes of care (Arditi, Rège-Walther, Wyatt, Durieux, and Burnand, 2012)	▪ Information overload ▪ Multiple demands ▪ "Forgetting" ▪ Inaccessible information

Here are some examples of other important implementation considerations:

Champions.

Individuals who demonstrate leadership qualities in the local setting or organization can be developed as champions to lead change. Champions are key people who are part of the network usually as part of the "front line" in the local setting, such as an in-patient unit, and support the proposed change (Greenhalgh et al., 2004; Ploeg et al., 2010) Engaging and developing champions in a setting involves an investment of resources for training of a champion (on the innovation and strategies to facilitate implementation), and to allow the champion protected time to promote implementation. Champions can be involved in the implementation process through (Woo, Berta and Baker, 2009):

- Dissemination of the information about the practice change to their staff. Specifically by:
    - Leading interactive educational meetings or workshops,
    - Engaging local opinion leaders,
    - Participating in audit and feedback, and
    - Being resources in the setting.
- Persuasion of other staff through local and interdisciplinary committees
- Being involved in planning and tailoring implementation strategies to the local setting.

Facilitators.

Facilitators can be an individual or group role that supports individuals or teams to change their practice (Dogherty, Harrison, Baker and Graham, 2012). Often facilitators have other roles in the organization such as clinical educators, practice developers (Dogherty, Harrison, & Graham, 2010.) Some refer to facilitation roles by other labels such as ‘change agent’, ‘knowledge brokers’, ‘champions’, etc (Harvey, Loftus-Hills, Rycroft-Malone, Titchen, Kitson, McCormack, and Seers, 2002). Individuals who facilitate practice changes can be either internal or external to the unit or agency and have specific skills in helping others to accomplish change processes (Stetler, Legro, Rycroft-Malone, Bowman, Curran, Guihan et al., 2006). Using the role of facilitator has been effective in achieving complex practice changes (Kauth, Sullivan, Blevins, Cully, Landes, Said et al., 2010).

Facilitators may engage in different activities at different levels; that may be related to individual differences in the facilitators but is also guided by the nature of the practice change, the phase of change and the practice context. In one recent study (Dogherty et al., 2012) across 4 stages of the process, facilitators performed a total of 51 activities that fell into the following groupings:

- Increasing awareness
- Developing a plan
- Knowledge and data management
- Recognizing the importance of change
- Administrative and project-specific support
- Project Management
- Fostering team-building/group dynamics
- Problem-solving
- Providing support
- Assessment

The use of multiple strategies has been associated with successful implementation examples (Dogherty, Harrison, Graham, Digel Vandyk & Keeping-Burke, 2013.)

Formal leaders.

Individuals holding formal leadership roles (e.g. programme directors, unit managers) also need to be engaged in supporting specific implementation projects or to create a culture that supports change and innovation (Gifford et al., 2007; Grol, et al., 2005; Stetler, Ritchie, Rycroft-Malone, Schultz and Charns, 2009). Formal leaders should also be involved in the planning phases of the implementation process, in particular with the assessment of barriers and facilitators.

In facilitating a specific implementation project (e.g. A clinical practice guideline), formal leaders can:

- Provide ongoing support by addressing individual concerns, encouraging staff and creating opportunities for education and problem solving. This also includes providing and allocating resources to support implementation and sustainability.
- Be accessible and visible in bringing the specific recommendations to be implemented and the evidence supporting these to the staff and interdisciplinary and administrative groups.
- Communicating clearly, consistently and regularly about the importance of the change, the expectations for action and the consequences of not meeting expectations.
- Communicate effectively to raise awareness of the innovation using multiple communication tools and to acknowledge the efforts of the staff to implement the recommendations. This can contribute to improving motivation and sustainability.
- Being part of the implementation team.
- Celebrating small achievements and successes.

In contributing to an overall culture that supports innovation and change, whether that is related to a context of 'routine' or pervasive evidence-based practice (Stetler, et al., 2009) or to a specific practice change (Gifford, Davies, Tourangeau and Lefebre, 2011) leaders can:

- Work within leadership groups in an organization to create a shared vision to support innovation. This can include a vision of promoting evidence- based care.
- Incorporate the vision of evidence-based care into expectations of professionals by changing job descriptions.
- Allocate human and material resources to support and develop a culture of change and innovation.

Marketing and mass media strategies.

Marketing and mass media strategies are impersonal channels that create an awareness of the innovation or practice change to occur (Greenhalgh et al., 2004). Creating posters, publishing articles in organizational newsletters or an intranet webpage are examples of strategies that can bring a new innovation to the forefront of the minds of healthcare practitioners in an organization. As well, these strategies can also be useful to inform patients and families of new policies or practices in the organization or clinic area and to discourage services of proven ineffectiveness (Grilli, Ramsay, & Minozzi, 2002).

Mass media strategies, such as television and radio advertisement are useful in promoting public health policy, to provide health related information and to create expectation in care services. These strategies can be effective in practice change only if they are used in combination with other implementation strategies, as described above.

The resources required for these strategies can vary considerably depending on the reach and media used to market the innovation.

Business case.

Resources are needed to implement every practice change. Resources can include financial, space, personnel and time demands. Creating a business case can be a useful tool to persuade leadership groups to supply the resources needed to implement the innovation, especially financial resources. You should have a good idea of the resources needed to implement your innovation based on the assessment of the barriers and facilitators. For example, if you have identified a major gap in knowledge and plan to address that through learning activities, then you might need such resources as:

- Time (salary compensation for the facilitator),

- Freed time for staff,
- Room rentals,
- Refreshments,
- Audiovisual rentals,
- Learning tools such as handouts (printing), reminder cards, writing instruments, etc.

Outlining a business case does not need to be complex or long. You must include clear statements about what resources you will require to implement and sustain the change. Your institution may have a template for developing a business case which could be helpful. Otherwise, when outlining the resources you need, be sure to include the following:

- **Vision statement and/or problem statement**: Outline why this practice change is important, and how it will contribute to the overall goals of the practice setting or organization.
- **Resources needed**: Specifically outline what exactly is needed. Include the amount of money needed and for what purpose, the space needed, the time needed to plan, implement and sustain the practice change over time and the dedicated personnel needed to move the plan forward. This can be outlined in a table for clarity.
- **The amount of resources that will be used if the practice change is not implemented**: It can be a convincing argument to outline what costs could be avoided if implementation of the practice change is properly supported.
- **Outline what has been done and what is left to do in the implementation phase**: Expanding on what has been done and what is the next step demonstrates the motivation and commitment to the project.

A business case is useful to present to leadership once an assessment of the barriers and facilitators to implementation has been done. It is important to be adequately aware of what is needed, otherwise you risk seeming ill-prepared and less likely to receive the resources you need.

Tailor Implementation Strategies

Keep in mind that strategies should be tailored to your setting, for example, by adapting the strategy to the healthcare professionals, patient population and resources available in the setting. This will require creativity and insight from the stakeholder group, and an understanding of the barriers and facilitators in the setting.

Tailoring strategies in any change effort involves testing them out with small risk to the setting. One method of making change manageable is to aim for small tests of change, using the PDSA (Plan Do Study Act) cycle (IHI, 2014). This model advocates for:

- A quicker implementation process that begins on a small scale (e.g.: with a small number of clinicians, for a few days, etc.),
- Iterative testing of the plan,
- A redevelopment of the plan without a major impact on the setting, and
- Demonstrating whether the implementation will actually produce an improvement or change.

Reflection Box 9

The PDSA cycle can be used with any implementation strategy to bring about change. Plan to use effective evidence-based implementation strategies first when embarking on the cycle.

The PDSA cycle is widely used in healthcare quality improvement with success, but the outlined process is not frequently followed (Taylor et al., 2013)

The PDSA method proposes the following steps (Table 8):

Table 8: PDSA Method

Plan	**Identify the change including the related evidence** **Make a prediction about the outcome** **Plan to carry out the cycle: Who, what, when & where**
Do	**Execute the plan** **Document problems and unexpected observations** **Start data analysis**
Study	**Complete data analysis** **Compare the data with predictions** **Summarize what was learnt**
Act	**Tailor the change based on what was learnt** **Plan the next cycle**

As confidence in implementation and resources permit, PDSA cycles of multiple changes can be run at the same time. As well, the target group and goals for behavior change can increase in scope as success is achieved over time.

Reflection Box 10

- Be practical and action oriented. Don’t waste time! Start small to get things off the ground.
- Change spreads! It is very challenging to target all practitioners at the “get go”. Focus on one or a manageable number of eager individuals to implement a practice change.
- Be flexible. You will have planned on using strategies that seemed appropriate or effective until actually applied in your setting. Expect that you will go back and redevelop the plan. This process is far from linear.
- Change takes time, for some longer than others.
- You will need to evaluate your change after the implementation process. This is a good time to think about how you might go about that.

Moving into Action

1. Review the most relevant and influential barriers and facilitators.
2. Carefully consider which implementation strategies to use in your setting to implement a practice change by:
    a) Thinking about your overall goals for change,
    b) Engaging stakeholders,
    c) Aiming to overcome the important barriers,
    d) Choosing strategies that are shown to be effective in the literature,
    e) Making use of your facilitators,
    f) Considering the feasibility of the strategies in terms of resources such as financial, personnel, time and space.
    g) Considering whether the strategies can be sustainable over time.
3. Use a pre-existing list of implementation strategies to review, and build on. Or consider strategies that have been used in the past in your setting and are effective. A resource list at the end of this chapter can be helpful.
4. Once you've considered which implementation strategies to use, organize them in a spreadsheet, outlining the consideration and decision making process (Appendix D).
5. Make a concrete and written implementation plan. For each strategy:
    a. Secure the resources needed to make it happen.
    b. Plan to start small and where you will likely have more success. Use the PDSA cycle to tailor the strategies for success. Try it, assess it, modify the plan if necessary and move forward!
    c. Build in methods of monitoring, feedback and ongoing support during the trial period.
6. Build on your success by expanding your implementation (to the goals initially set out.)

Reflection Box 11

Think about what has been achieved so far. It may be important to reconsider some of the questions from Reflection Box 3.

- Are we still on track to achieve the set out goal?
- Do we need to go back and rethink any decisions made?
- What assumptions have we made? Do they still hold true?
- Is there someone or a group in the organization that can assist in following through on the plan so far?
- As a project leader, what is my role at this stage?
- As a leader within the organization, what can I do to support the practice change at this stage?

Examples of Selecting and Tailoring Implementation Strategies in Real Settings

Example 1: Implementing a documentation tool to improve communication and practice of effective pain management.

As part of a hospital wide implementation of a clinical practice guideline for pain assessment and management, the birthing centre and post-partum units in the hospital received feedback from their staff nurses that communication around pain was difficult and unclear between nurses and other health professionals. Normally, pain scores were documented on the vital signs sheet. A pain management flow sheet was available, but used routinely only for more complex patients (e.g.: Those who had had caesarean-sections.) The Assistant Nurse Managers (ANMs) and the champion on the unit decided to implement the existing pain management flow sheet for all patients to improve clarity of pain management in documentation and to improve communication with staff and other professionals.

The ANMs and champion informally evaluated the facilitators and barriers to implementing the use of the documentation tool. Some examples of facilitators included:

- Effective pain management was becoming an increasing priority among staff, as they were part of a hospital wide implementation project for pain assessment and management.
- A new law mandating a change in the documentation of pain had been recently put into place.
- Turnover of staff on the maternal child care unit was low.
- Nursing staff and other health professionals were already familiar with the pain management flow sheet documentation tool, as it was used for more complex patients on the unit.
- Modification of the pain management flow sheet was not needed.
- Leadership supported this initiative.

Some examples of barriers included:

- Knowledge and effective communication about pain management was not fully updated (but ongoing) as per larger implementation project.
- The maternal child care unit is composed of the birthing centre and post-partum care areas. Beliefs about pain management differed in these areas; one area was less consistent about practicing with current evidence-based knowledge.

The ANMs and champions proceeded to implement the tool over a 4 month period using the following strategies:

- As part of the existing individual or small group workshops already in place for increasing knowledge in pain management, they included teaching around the pain management flow sheet.
- They made a change in the medication orders sheet to facilitate the use of the new documentation tool.
- The ANMs first targeted eager nurses, and then let change spread!
- They performed regular audits and feedback to individual nurses.
- They placed visual reminders on the unit to promote the use of the documentation tool. For example, posters, flags in the medical chart, verbal reminders directed at specific individuals or during unit meetings or rounds.
- They included the new documentation tool in the orientation binder (a resource for new staff) in the post-partum unit.

The ANMs, champion and leadership team noted the following outcomes in the post-partum area:

- Pain was an increasing priority for nurses; they witnessed the nurses advocate for pain control through improved communication with other staff members.
- Communication of pain issues with physicians was clearer and more consistent.
- An appropriate use of narcotics was observed.
- Communication of pain continued to be difficult within the areas of the maternal child care unit, as the documentation tool was more effectively implemented and in use in one area compared to the other.

Examples of Selecting and Tailoring Implementation Strategies in Real Settings

Example 2: Implementing a new protocol for treatment of hypo-glycemia.

As part of a hospital-wide initiative to improve patient safety for patients with diabetes, an inter-professional team that included nursing, medicine, nutrition services, logistics services and pharmacy developed a new protocol and algorithm for nurses to follow when a patient's capillary blood glucose was below a set level. The documents were approved and an implementation plan was adopted with the appropriate collective orders, documentation requirements, etc. The new protocol was similar to a protocol that had been in place in one area for some years. The team decided that the nursing staff would need more knowledge about the protocol and the underlying evidence and that 90% of the staff on all in-patient units would need to be taught.

The team worked with the educators and developed a systematic, detailed educational programme to be delivered during in-service sessions. Their plan included consideration of the feasibility of releasing staff to participate in the education session and the demands on educators to provide the teaching. Within the timeline designated in the action plan, 90% to 100% of Registered Nurses on all units participated in the education session.

Six months later, an evaluation was done that included assessment of the amount of use of the designated products as per the protocol and interviews with nurses on some units. Overall, the results showed that most nurses were not adhering to the new protocol; on some units the old protocol was partially implemented but not consistently. Furthermore, the interview data showed that, in general, the experienced nurses did not believe that they needed the protocol as they knew what to do based on their experience, and the newer nurses found the protocol extremely helpful. However, the newer nurses also commented that, once they had more experience, they would be able to use their judgement just as their more experienced colleagues did!

0The team met again to consider the next steps and, in their planning, they considered the lessons learned through the first attempt at practice change and modified the plan. They planned for a more diverse array of strategies in the next phase so as to address the lessons:

- Long standing, entrenched work practices existed (how we do things now) and had not been assessed prior to choice of education as the only implementation strategy.
- Some nurses did not believe that their entrenched practices really caused undesirable variations in blood glucose and were harmful to the patient.
- Nurses had little explicit understanding of the difference between a 'guideline' and a 'protocol'.
- The nurses felt they had other, competing and more important priorities and reported that their unit-based leaders did not emphasise this particular change.
- No attention had been paid to whether there were some clinicians who were more ready than others to make the change and whether they might be prepared to 'try out' the new protocol.

Summary points

- Implementation of a practice change is more effective when multiple strategies are used to target the barriers and facilitators of implementation in a setting and that actively involve stakeholders.

- There are many effective strategies that can be considered when looking at the available resources in the setting.
- Strategies need to be tailored to fit the realities of the setting. The PDSA cycle is a useful process to test and adapt implementation strategies.

Section 5: Later Phases- Monitor, Evaluate, and Sustain the Practice Change

Learning objectives

- Learn about the later phases in the implementation process.

Once the implementation process is underway, the next phases in the process include:

- Monitoring the practice change: Is the innovation being used/implemented? Have the barriers been overcome?
- Evaluating the practice change on health provider and patient outcomes: Has there been an improvement in care and management of the patient?
- Sustaining the practice change over time: what active processes need to happen to keep this practice going and evolving? Do some areas need more help than others to achieve and sustain the change?

This chapter will not discuss in detail these phases of implementation. However, monitoring the implementation outcomes, evaluation and sustaining practice change are crucial to the process. As you proceed through implementation, plan for how you will evaluate and sustain your practice change, and how you will assess whether your changes are having a positive effect on patient, provider and/or system outcomes. These steps require additional planning and resources.

Summary points

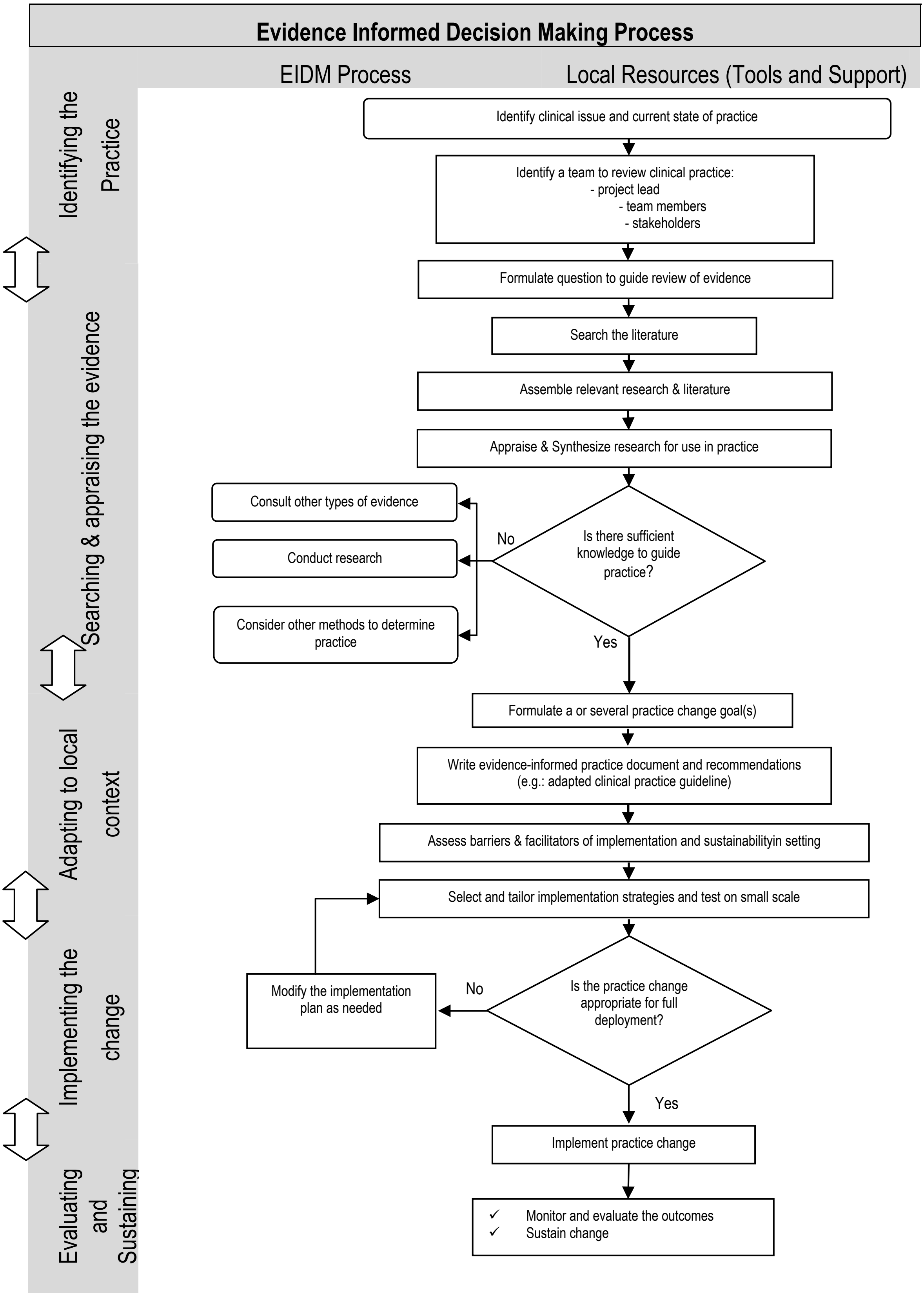
- Monitoring the implementation, evaluating the practice change on patient and health provider outcomes, and sustaining the practice over time are crucial phases in the implementation process.
- Sustaining a practice change needs to be considered at throughout the entire implementation process.

Conclusions

- Healthcare practitioners are regularly faced with the challenge of making simple and complex practice changes in their settings. Careful thought and systematic planning involving stakeholders from the setting are key to successfully implementing these changes.
- The Knowledge to Action Framework is useful in helping healthcare practitioners understand the process of implementation and its complexities.
- In the initial stages of implementation, it is important to identify the current state of practice, and establish the gap that exists with recommendations from the best available evidence. This needs to be accomplished with the support and involvement of stakeholders and knowledge users who are impacted by the proposed practice change. Having a clearly stated goal will improve communication between various groups and will keep the implementation process on the right track.
- The best available evidence to support practice changes, including recommendations from clinical practice guidelines, need to be adapted to fit the resources and characteristics of the patients and healthcare setting. The CAN-IMPLEMENT is a guide that can support a systematic and participatory adaptation process.

- Identifying the barriers and facilitators related to the practice change, healthcare practitioner, local setting and larger organization and system will support which strategies will be most effective in implementation.
- Implementation strategies are selected to deal with the barriers and make use of the facilitators. These strategies can be tailored to improve their effectiveness in the local setting by using the PDSA Cycle to test and improve the strategy on a small scale.
- Monitoring and evaluating the practice change are after implementation are crucial in ensuring that the implementation was successful and improved patient and health provider outcomes.
- Strategies to support the sustainment of practice change over time need to be considered at the start of an implementation process and require active and deliberate processes.

Appendix A: Implementation Algorithm (Adapted from the MUHC EIDM process)



Appendix B: Action Plan Table

Overall Goal Statement:						
Targeted Barrier/ Facilitator	Goal as it relates to barrier/ facilitator	Implementation Strategy	Resources needed for implementation	Timeline and person/ group responsible	Sustainability strategy	Sustainability resources needed

Appendix C: Examples of Barriers and Facilitators

Knowledge	Lack of Awareness
	Lack of Familiarity
	Forgetting
Attitudes	Lack of agreement due to: ▪ The scientific value of the evidence ▪ The rigidity of the guideline ▪ The threat to professional autonomy ▪ The perceived bias of the author ▪ The lack of clarification and impracticality of the guideline
	Lack of applicability due to: ▪ The characteristics of the patient ▪ The clinical situation ▪ The perception that knowledge implementation is not cost-beneficial ▪ The lack of confidence in the individuals who are responsible for developing or presenting knowledge implementation
	Lack of expectancy due to: ▪ The perception that implementation will not lead to improved outcomes for either the patient or the healthcare process ▪ the negative feelings that may be provoked by the new behavior resulted from knowledge implementation, and/or not having taken into account existing feelings around the process of implementation ▪ the lack of self-efficacy ▪ the lack of motivation to use knowledge or to change one’s habits.

External Barriers	Factors associated with the patient: ▪ the inability to reconcile patient preferences with the use of knowledge
	Factors associated with knowledge use as an innovation: ▪ the perception that the innovation cannot be experimented with on a limited basis ▪ the perception that the innovation is not consistent with one's own approach ▪ the perception that the innovation is difficult to understand and to put into use (▪ the lack of visible results in using the innovation ▪ the perception that the innovation cannot be created and shared with one another in order to reach a mutual understanding ▪ the perception that the use of the innovation will increase uncertainty (for example, the lack of predictability, of structure, of information) ▪ the perception that the innovation lacks flexibility to the extent that it is not changeable or modifiable by a user in the process of its adoption and implementation
	Factors associated with environmental factors: ▪ insufficient time to put knowledge into practice ▪ insufficient materials or staff to put knowledge into practice ▪ insufficient support from the organization ▪ inadequate access to actual or alternative healthcare services to put knowledge into practice ▪ insufficient reimbursement for putting knowledge into practice ▪ perceived increase in malpractice liability if new knowledge is put into practice.

Resources

Initial stages

Canadian Institutes of Health Research: More about Knowledge Translation at Canadian Institutes oF Health Research. http://www.Canadian Institutes of Health Research-irsc.gc.ca/e/39033.html

Canadian Institutes of Health Research: Introduction to Evidence-Informed Decision Making. http://Canadian Institutes of Health Research-irsc.gc.ca/e/45245.html

Registered Nurses Association of Ontario: Toolkit: Implementation of Clinical Practice Guidelines.

http://ltctoolkit.rnao.ca/resources/pain%20-%20Planning-Implementation-Tools

Canadian Institutes of Health Research: Overview and Examples of Knowledge Translation throughout Canada. http://www.Canadian Institutes of Health Research-irsc.gc.ca/e/41594.html

The AGREE Collaboration: Appraisal of guidelines for research and evaluation (AGREE II) instrument. http://www.agreetrust.org/resource-centre/agree-ii/

Canadian Institutes of Health Research: Critical Appraisal of Intervention Studies. University of Kent: Critical Appraisal of the Journal Literature. http://www.Canadian Institutes of Health Research-irsc.gc.ca/e/45235.html

KT Clearinghouse: Identifying the knowledge to action gaps. http://ktclearinghouse.ca/knowledgebase/knowledgetoaction/action/identify

Canadian Medical Association Journal: The knowledge-to-action cycle: Identifying the gaps. http://www.ncbi.nlm.nih.gov/pubmed/19948812

National collaborating centre for methods and tools: Introduction to evidence informed decision making. http://www.nccmt.ca/learningcentre/index.php?lang=en#main2.html

Adapting

Canadian Medical Association Journal: Adapting Clinical practice guidelines to local context and assessing barriers to their use. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2817341/

ADAPTE: Guideline adaptation: A resource toolkit. http://www.g-i-n.net/document-store/working-groups-documents/adaptation/adapte-resource-toolkit-guideline-adaptation-2-0.pdf/view?searchterm=adapte

CAN-IMPLEMENT: Canadian Partnership Against Cancer. http://www.cancerview.ca/cv/portal/Home/TreatmentAndSupport/TSProfessionals/ClinicalGuidelines/GRCMain/GRCGDGuidelineAdaptation?_afrLoop=809952732641000&jsessionid=4qvfTddJJLbTqZTy2jJdf5vGqhvKb1NFp2ZyrhX5dm2vnnyb6L4q%21586379035&lang=en&_afrWindowMode=0&_adf.ctrl-state=gidxwhscl_4

Barriers and Facilitators

Journal of Clinical Nursing: An exploration of the factors that influence the implementation of evidence into practice. http://www.ncbi.nlm.nih.gov/pubmed/15533097

Implementation Science: Barriers and facilitators to implementing shared decision-making in clinical practice. A systematic review of health professionals' perceptions. http://www.implementationscience.com/content/1/1/16

Implementation Science: Individual determinants of research utilization by nurses: A systematic review update. http://www.implementationscience.com/content/6/1/1

Implementation Science: Healthcare professionals' intentions and behaviours: A systematic review of studies based on social cognitive theories. http://www.implementationscience.com/content/3/1/36

KT Clearinghouse: Examples of barriers to knowledge use. http://ktclearinghouse.ca/knowledgebase/knowledgetoaction/action/assess

Implementation Science: A checklist for identifying determinants of practice. http://www.implementationscience.com/content/8/1/35

A guide for applying the PARIHS framework. http://www.implementationscience.com/content/6/1/99

Alberta Context Tool. http://www.biomedcentral.com/1472-6963/9/234

The Delphi method: Techniques and applications. http://is.njit.edu/pubs/delphibook/

Implementation Strategies

KT Clearinghouse: Implementation Strategies. http://ktclearinghouse.ca/knowledgebase/knowledgetoaction/action/interventions/strategies

Plan Do Study Act (PDSA). http://www.ihi.org/resources/Pages/HowtoImprove/ScienceofImprovementTestingChanges.aspx

Monitoring, Evaluating and Sustaining

Canadian Institutes of Health Research: Monitoring knowledge use and evaluating outcomes of knowledge use. http://www.Canadian Institutes of Health Research-irsc.gc.ca/e/41945.html

Canadian Medical Association Journal: Monitoring use of knowledge and evaluating outcomes.

http://www.cmaj.ca/content/182/2/E94.long

British Medical Journal: Methods for evaluation of small scale quality improvement projects. http://qualitysafety.bmj.com/content/12/3/210.long

Nursing Best Practice Units: Determinants of the sustained use of research evidence in Nursing (SURE) study. http://nbprc.ca/projects/determinants-sustained-use-research-evidence-nursing-sure-study

CHAPTER 5

Evaluation as KT

By Sarah Bowen

Introduction

Previous chapters have emphasized the importance of knowledge translation in ensuring a better health system, and healthier communities. The knowledge to be transferred, however, is not limited to knowledge generated by research that is peer-reviewed and generalizable to all settings. Much of the most useful knowledge to aid in decision-making comes from evaluation of existing services and programs, or of pilots of new interventions.

In response to the myriad of challenges facing the health system, both researchers and health system managers are proposing significant changes to current clinical, management and public health practice. This requires timely and rigorous evaluation of current programs and innovations. However, many researchers and health system managers have limited evaluation knowledge and skills, with the result that evaluation as a tool for health system improvement is often neglected. Many changes are made with little or no planned evaluation, limiting our ability to guide effective implementation, identify problems early in the change process, or establish systems for data collection that will facilitate eventual outcome evaluation. The potential of evaluation *research* (in contrast to program evaluation) is also often not realized: carefully planned evaluation can, in addition to generating knowledge that can be immediately applied in a specific context, create transferable knowledge useful to the broader health system.

Evaluation, however, can be more than a strategy for *generating* knowledge that needs to be translated into action. The *process of evaluation* itself can serve as an effective knowledge translation strategy. The focus of this chapter, therefore, while intended to build knowledge and skill in the area of evaluation, will emphasize approaches to evaluation that are consistent with integrated knowledge translation. It will also provide practical guidance on how to design and conduct an evaluation in a way that will encourage evidence use, optimize the potential of evaluation to support consensus-building, and build organizational capacity to move knowledge into action.

While the chapter is informed by various evaluation approaches (theories), the primary purpose is to serve as a practical guide to conducting collaborative evaluations. Because of increasing evidence of the benefits of including knowledge users as partners in evaluation activities, the chapter focuses on strategies for conducting evaluation in collaboration with health system or other partners.

It does not attempt to address all the important topics in evaluation design (e.g. how to minimize and control bias, develop a budget, or implement the evaluation plan). There are many excellent resources that focus on these topics. Rather, the chapter is intended to provide guidance on the *process* of developing an evaluation plan in such a way as to promote knowledge translation.

This chapter is divided into five sections. Following this introduction, Section 1: ***Evaluation: A Brief Overview*** provides a short overview of evaluation, addresses common misconceptions, and defines key terminology that will be used in the chapter. This is followed by Section 2, ***Getting started,*** which provides guidance for the preliminary work that is required in planning an evaluation, and Section 3, ***Designing an Evaluation***, which will lead you through the steps of developing an evaluation plan. Section 4, ***Special Issues in Evaluation*** discusses some of the ethical, conceptual and logistical issues specific to evaluation. This is followed by Section 5: ***Resources,*** which includes references, a checklist for evaluation planning and a sample evaluation planning template.

Throughout the chapter, concepts will be illustrated with concrete examples – drawn from case studies of actual evaluations. While based on real-life evaluations, they have been adapted in order to maintain confidentiality. A summary of these cases is found below.

Case Studies

Case Study 1: Unassigned Patients

A provincial health department contracts for an evaluation of three different models of care provided to hospitalized patients who were without a family physician to follow their care in hospital (unassigned patients). In addition to wanting to know which models 'work best' for patients, the province is also interested in an economic evaluation, as each of the models has a different payment structure and overall costs are not clear.

Case Study 2: Computerized Decision Support

There is a decision to pilot a commercially developed software program that will combine computerized order entry and physician decision support for test ordering. The decision-support module is based on evidence-based guidelines adopted by a national medical association. Funders require an evaluation of the pilot, as there is an intention to extend use across the region and into other jurisdictions if the results of the evaluation demonstrate that this is warranted.

Section 1: Evaluation: A Brief Overview

Learning Objectives

- Define evaluation, and discuss its relationship to research
- Identify and discuss common misconceptions about evaluation
- Review three major evaluation traditions

The current field of evaluation has emerged from different roots, overall purposes and disciplines, and includes many different approaches (theories and models) (Owen, 2007). Various authors *define* evaluation differently, *categorize* types of evaluation differently, *emphasize diverse aspects* of evaluation theory and practice, and (because of different conceptual frameworks) *use terms* in very different ways.

This section will touch on some of the various approaches to evaluation and highlight some differences between them. However, the focus of this chapter is to provide a *practical* guide for those with some research experience, but perhaps limited exposure to evaluation. There are a myriad of evaluation handbooks and resources available on the internet sponsored by evaluation organizations, specific associations and individuals. Both the evaluation *approaches* used and the quality and usefulness of these resources vary significantly (Robert Wood Johnson Foundation, 2004). While there are excellent resources (many of which offer the benefit of framing evaluation for a specific sector or issue); far too many evaluation guides offer formulistic approaches to evaluation – a template to guide the uninitiated.

This is not the approach taken here. Rather than provide a template that can be applied to any initiative, this chapter aims to provide the necessary background to understand the concepts and alternatives related to evaluation, and to creatively apply these to a specific evaluation activity.

Similarities and Differences between Research and Evaluation

The similarities and differences between research and evaluation have long been the subject of intense debate: there are diverse and often conflicting perspectives on this topic (Levin-Rozalis, 2003). It is argued by some that evaluation and research are distinctly different. Proponents of this position cite such factors as the centrality of 'valuing' to evaluation; the inherently political nature of evaluation activities; the limited domain of application of evaluation findings (local and specific rather than transferable or generalizable); and the important role of theory in research compared to evaluation activities. It is also argued that the political and contextual framing of evaluation means that evaluators require a unique set of skills. Some describe evaluation as a *profession*, in contrast to research, where researchers belong to specific *disciplines*.

This sense of differentness is reinforced by the fact that evaluators and researchers often inhabit very different worlds. Researchers are largely based in academic institutions and are most often engaged in research that is described as curiosity-driven. Many have no exposure to evaluation during their academic preparation. Evaluators (many of whom are not PhD prepared) are more likely to be working within the health system or established as consultants. In most cases, the two belong to different professional organizations, attend different conferences, and follow different (though overlapping) ethical guidelines.

Taking an alternative view are those who view evaluation as a form of research – using research methodology (and standards) to answer practical questions in a timely fashion. They argue that the commonly cited differences between evaluation and research do not apply to all forms of research, only to some of them. It is noted that the more engaged forms of research have many of the same characteristics and requirements as evaluation and similar skills are needed – skills in communication and collaboration, political astuteness, responsiveness to context, and ability to produce timely and useful findings. It is noted that the pragmatic use of diverse perspectives, disciplines and methods is not limited to evaluation, but applied by many researchers as well. Many evaluators stress the knowledge-generating aspects of evaluation (Preskill, 2008), and there is increasing interest in theory-driven evaluation (Coryn et al, 2010). This interest reflects increasing criticism of what is often called black box evaluation (the simple measurement of effects of interventions with little attention to how the effects are achieved). Findings from theory-driven evaluations can potentially be applied to other contexts – i.e. they are transferable. It is also argued that not all forms of evaluation are focused on determining value or worth; that there may be other purposes of evaluation. Many writers highlight the benefits of 'evaluative thinking' in planning and conducting research activities.

Why is it Important that Researchers and Knowledge Users Understand How to Conduct an Evaluation?

The first reason to focus on developing evaluation skills is that the urgency of the problems facing the health system means that many new solutions are being tried, and established processes and programs questioned.

Discussions with healthcare managers and executives highlight the reality that many of the 'research' questions they want addressed are, in reality, evaluation questions. They want to know whether a particular strategy is working, or will work, to address a known problem. They want accurate, credible, and timely information to inform decisions *withinthe context* in which they are working. Consequently, there is growing recognition of the need for evaluation expertise to guide decisions. Evaluation can address these needs and evaluation research, conducted by qualified evaluation researchers, can ensure the rigor of evaluation activities and optimize the potential that findings will be useful in other settings.

Research skills are required to ensure that such evaluations (which inform not only decisions about continuing or spreading an innovation, but also whether to discontinue current services, or change established processes) are well designed, implemented and interpreted. Poorly designed and overly simplistic evaluations can lead to flawed decision making – a situation that can be costly to all.

A second reason is that that there are increasing expectations from both program and research funders that initiatives will be evaluated. For example, there are an increasing number of funding opportunities that result in researchers proposing pilot programs to test new strategies. For these proposals, a rigorous evaluation plan is an essential component. KT researchers are also urged to evaluate their knowledge translation interventions (Bhattacharyya et al., 2007).

Finally, as mentioned earlier, collaborative approaches to evaluation can also contribute to, or serve as, effective knowledge translation strategies – in fact they are very closely aligned with integrated KT theory. Collaborative evaluation brings the potential of promoting appropriate evidence use in real time, and applied to a concrete situation.

Two of the often-stated frustrations of decision-makers are that a) there is often insufficient published research available to inform the challenges they are facing, and b) there is a need to incorporate contextual knowledge with research in order to inform local decisions. In turn, researchers often express concern that decision-makers are not familiar with research concepts and methods.

Early stages of well-designed and well-resourced evaluation research begin with a *critical review* and *synthesis* of the literature with local and contextual data. This can inform both evaluators and the program team on what is known about the issue, and about current leading practices. The process of designing an evaluation plan, guiding implementation of the evaluation, interpreting data, and making decisions on the data as the evaluation evolves can *promote use of evidence* throughout the planning/implementation/evaluation cycle. Even more importantly, a collaborative evaluation approach that incorporates key stakeholders in meaningful ways will help build *evaluative thinking capacity, a culture that values evaluation* and *research literacy* at the program/organizational level. These skills can then be transferred to other organizational activities. An evaluation can be designed to provide some early results that may *inform ongoing decision-making*. And finally, because a collaboratively-designed evaluation reflects the questions of concern to decision-makers, evaluation can *increase the likelihood that they will trust the evidence identified through the evaluation, and act in response to it.*

Defining Evaluation

It has been observed that “evaluation — more than any science — is what people say it is, and people currently are saying it is many different things” (Glass, 1980, p. 211). This chapter will adopt the following definition, adapted from a commonly used definition of evaluation (Patton 1997, page 23):

> *The systematic collection of information about the activities, characteristics, and outcomes of program, services, policy, or processes, in order to make judgments about the program/process, improve effectiveness, and/or inform decisions about future development.*

The definition, like many others, highlights the *systematic* nature of quality evaluation activities. For example Rossi et al., define evaluation as “... *the use of social research methods to systematically investigate the effectiveness of social intervention programs”* (2004, p. 28). It also highlights a number of other points that are often a source of misunderstandings and misconceptions about evaluation.

Common Misconceptions about Evaluation

There are a number of common misconceptions about evaluation, misconceptions that have contributed to the limited use of evaluation by both health researchers and decision-makers. Some of these are described in more detail below:

Evaluation = program evaluation

As the above definition illustrates, in addition to programs, evaluation can also focus on policy, products, processes or the functioning of whole organizations. Nor are evaluation findings limited to being useful to the particular program evaluated. While *program evaluation* activities are designed to inform program management decisions, evaluation *research* can generate knowledge potentially applicable to other settings.

Evaluation is about determining the value or worth of a program

The concept of valuing is central to evaluation. In fact, some authors define evaluation in exactly these terms. Scriven, for example, defines evaluation as "*the process of determining the merit, worth, or value of something, or the product of that process"* (1991, p. 139). Data that is simply descriptive is not evaluation. (For example, "*How many people participated in program X*?" is not an evaluation question, although this data may be needed to answer an evaluation question). However, there are other purposes for undertaking an evaluation in addition to that of making a judgment about the value or worth of a program or activity (summative evaluation). Evaluation may also be used to refine or *improve* a program (often called formative evaluation) or to help support the design and *development o*f a program or organization (developmental evaluation). Where there is limited knowledge on a specific topic, evaluation may also be used specifically to *generate new knowledge*. The appropriate selection of evaluation purpose is discussed in more detail in Section 2, Step 1.

This misconception is related to the previous one: if evaluation is only about judging the merit of an initiative, then it seems to make sense that this judgment should occur when the program is well established. The often-heard comment that it is too soon to evaluate a program reflects this misconception, with the result that evaluation – if it occurs at all - happens at the end of a program. Unfortunately, this often means that many opportunities have been missed to use evaluation to guide the development of a program (anticipate and prevent problems and make ongoing improvements), and to ensure that there is appropriate data collection to support end-of-project evaluation. It also contributes to the misconception that evaluation is all about outcomes or impact.

Evaluation is all about outcomes

In recent years, there has been an increasing emphasis on outcome, rather than process, evaluation. This is appropriate, as too often what is measured is what is easily measurable (e.g. services provided to patients) rather than what is important (e.g. did these services result in improvements to health?). The emphasis on outcome evaluation can, however, result in neglect of other forms of evaluation and even lead to premature attempts to measure outcomes. It is important to determine whether and when it is *appropriate* to measure outcomes in the activity you are evaluating. By measuring outcomes too early, one risks wasting resources and providing misleading information.

As this chapter will illustrate, much useful knowledge can be generated from an evaluation even if it is not appropriate or possible to measure outcomes at a particular point in time. In addition, even when an initiative is mature enough to measure outcomes, focusing *only* on outcomes may result in neglect of key program elements that need policy maker/program manager attention (Bonar Blalock, 1999). Sometimes what is just as (or more) important is understanding what factors contributed to the outcomes observed.

There are two types of evaluation: summative and formative.

Some writers (and evaluation guides) identify only two purposes or types of evaluation: summative and formative. Summative evaluation refers to judging the merit or worth of a program at the end of the program activities, and usually focuses on outcomes. In contrast, formative evaluation is intended as the basis for improvement and is typically conducted in the development or implementation stages of an initiative. Robert Stake is famously quoted on this topic as follows: "*when the cook tastes the soup, that's formative; when the guests taste the soup, that's summative*" (Scriven, 1991, p. 169). However, as will be covered in later sections of this chapter, the evaluation landscape is more nuanced and offers more potential than this simple dichotomy suggests. Section 2, Step 1, and Section 3, Step 8provide more detail on evaluation alternatives.

Evaluation = performance measurement

A common misconception among many healthcare decision-makers is that evaluation is simply performance measurement. Performance measurement is primarily a planning and managerial tool, whereas evaluation research is a research tool (Bonar Blalock, 1999). Performance measurement focuses on results, most often measured by a limited set of quantitative indicators. This reliance on outcome measures and pre/post measurement designs poses a number of risks, including that of attributing any observed change to the intervention under study without considering other influences; and failing to investigate important questions that cannot be addressed by quantitative measures. It also contributes to a common misperception that evaluation must rely only on quantitative measures.

> *Tending to rely on a narrow set of quantitative gross outcome measures accessible through Management Information Systems, performance management systems have been slow to recognize and address data validity, reliability, comparability, diversity, and analysis issues that can affect judgments of programs. Performance management systems usually do not seek to isolate the net impact of a program – that is, to distinguish between outcomes that can be attributed to the program rather than to other influences. Therefore, one cannot make trustworthy inferences about the nature of the relationship between program interventions and outcomes, or about the relative effects of variations in elements of a program's design, on the basis of performance monitoring alone* (Bonar Blalock, 1999, p. 134, 146-147).

It is important to be aware of these common misconceptions as you proceed in developing an evaluation plan; not only to avoid falling into some of these traps yourself, but in order to prepare for conversations with colleagues and evaluation stakeholders, many of whom may come to the evaluation activity with such assumptions.

Evaluation Approaches

Evaluation can be described as being built on the dual foundations of a) accountability and control and b) systematic social inquiry (Alkin & Christie, 2004). For good reasons, governments (and other funders) have often emphasized the accountability functions of evaluation, which is one of the reasons for confusion between performance measurement and evaluation. Because the accountability focus usually leads to reliance on performance measurement approaches, a common result is a failure to investigate or collect data on the question of *why* the identified results occurred (Bonar Blalock, 1999).

There are dozens, even hundreds, of different approaches to evaluation (what some would call *philosophies* and others *theories*). Alkins and Christie (2004) describe an evaluation theory tree with three main branches: a) methods; b) valuing; and c) utilization. Some authors exemplifying these three branches are Rossi (methods) (Rossi et al, 2004), Scriven (valuing) (1991), and Patton (utilization) (1997). While some authors (and practitioners) may align themselves more closely with one of these traditions, these are not hard and fast categories – over time many evaluation theorists have incorporated approaches and concepts first proposed by others, and evaluation practitioners often take a pragmatic approach to evaluation design.

Each of these branches includes many specific evaluation approaches. It is beyond the scope of this chapter to review all of them here, but some examples are outlined below.

Methods

The methods tradition was originally dominated by quantitative methodologists. Over time, this has shifted, and greater value is now being given to incorporation of qualitative methods in evaluation within the methods theory branch.

The methods branch, with its emphasis on rigor, research design, and theory has historically been closest to research. Indeed, some of the recognized founders of the methods branch are also recognized for their work as researchers. The germinal paper *Experimental and Quasi-experimental Designs for Research* (Campbell and Stanley, 1966) has informed both the research and evaluation world. Theorists in this branch emphasize the importance of controlling bias and ensuring validity.

Of particular interest to researcher-evaluators is *theory driven* evaluation (Chen & Rossi, 1984). Theory-driven evaluation promotes and supports exploration of program theory – and the mechanisms behind any observed change. This helps promote theory generation and testing, and transferability of new knowledge to other contexts.

Valuing

Theorists in this branch believe that what distinguishes evaluators from other researchers is that evaluators must place value on their findings – they make value judgments (Shadish et al., 1991). Michael Scriven is considered by many to be the primary mainstay of this branch: his view was that evaluation is about the *science of valuing* (Alkins & Christie, 2004). Scriven felt that the greatest failure of an evaluator is to simply provide information to decision-makers without making a judgement (Scriven, 1983). Other theorists also stress valuing, but rather than placing this responsibility on the evaluator, see the role of the evaluator as helping facilitate negotiation among key stakeholders as they assign value (Guba & Lincoln, 1989).

In contrast to those promoting theory-driven evaluation, those in the valuing branch may downplay the importance of understanding *why* a program works, as this is not always seen as necessary to determining its value.

The centrality of valuing to evaluation may present challenges to researchers from many disciplines, which often deliberately avoid making recommendations; cautiously remind users of additional research needed; and believe that 'the facts should speak for themselves'. However, with increasing demands for more policy and practice relevant research, many researchers are grappling with their role in providing direction as to the relevance and use of their findings.

Utilization

A number of approaches to evaluation (see for example Patton, Stufflebeam, Cousins, Pawley, add others), have a utilization focused orientation. This branch began with what are often referred to as decision-oriented theories (Alkin & Christie, 2004), developed specifically to assist stakeholders in program decision-making. This branch is exemplified by, but not limited to, the work of Michael Q. Patton (author of Utilization-focused evaluation (1997)). Many collaborative approaches to evaluation incorporate principles of utilization-focused evaluation.

The starting point for utilization approaches is the realization that, like the results of research, many evaluation reports end up sitting on the shelf rather than being acted on – even when the evaluation has been commissioned by one or more stakeholders. With this in mind, approaches that emphasize utilization incorporate strategies to promote appropriate action on findings. They emphasize the importance of early and meaningful collaboration with key stakeholders and build in strategies to promote 'buy in' and use of evaluation findings.

Authors closer to the utilization branch of evaluation find much in common with knowledge translation theorists and practitioners: in fact, the similarities in principle and approach between integrated knowledge translation (iKT) *(*Canadian Institutes of Health Research, 2014b) and utilization-focused evaluation (UFE) are striking.

Both iKT and UFE:

- Keep utilization (of evaluation results or research findings) prominent through all phases of the process.
- Promote research and evaluation conducted in response to stakeholder identified needs.
- Promote early and meaningful involvement of the intended users of the research or evaluation activity. Utilization-focused evaluation urges identification of the specific individuals who will be expected to act on results and focus on evaluation questions of concern to them.
- View the evaluator/researcher as a member of a collaborative team, with respect for the experience, insights and priorities of users.

While it is helpful to have knowledge of the different roots of, and various approaches to, evaluation, it is also important to be aware that there are many common threads in these diverse evaluation approaches (Shadish, 2006) and that evaluation societies have established agreement on key evaluation principles.

Summary points:

- There are many misconceptions about evaluation: these misconceptions often prevent appreciation of the potential contribution of evaluation research
- While there are diverse traditions in evaluation, there is agreement on key evaluation principles.
- Evaluation traditions that emphasize utilization are closely aligned with integrated knowledge translation research.

Section 2: Getting Started

Learning objectives

- Outline the initial steps in preparing to undertake an evaluation
- List and describe the potential purposes of an evaluation
- Describe the importance of clearly identifying intended knowledge users, and of ensuring effective processes and structures to support collaboration
- Identify issues in, and strategies for, building an effective evaluation team
- Describe options for describing the program/service to be evaluated.

The previous section provided a brief overview of evaluation concepts. This section will provide a step-by-step guide to preparing for and developing an evaluation plan.

While the activities outlined in this section are presented sequentially, you will likely find that that the activities of a) considering the evaluation purpose, b) identifying stakeholders, c) assessing evaluation expertise, d) gathering relevant evidence, and e) building consensus are iterative. Depending on the evaluation, you may work through these tasks in a different order.

Step 1: Consider the Purpose(s) of the Evaluation

One of the first steps in planning evaluation activities is to determine the *purpose* of the evaluation. It is possible, or even likely, that the purpose of the evaluation may change – sometimes significantly – as you undertake other preparatory activities (e.g. engaging stakeholders, gathering additional information). For this reason, the purpose is best finalized in collaboration with key stakeholders. However, as an evaluator, you need to be aware of the potential purposes of the evaluation and be prepared to explore various alternatives.

As indicated earlier, there are four broad purposes for conducting an evaluation:

To make a judgment about the worth or merit of a program or activity

This is the form of evaluation (summative evaluation) most people are familiar with. It is appropriate when a program is well established, and decisions need to be made about its impacts, continuation or spread.

Example 1: Program X has been piloted in Hospital Y. A decision must be made about whether to continue the program.

Example 2: A new therapy is being trialed on physiotherapy patients. The evaluation is intended to determine what impacts the therapy has on patient outcomes.

Pilot studies (small studies to determine the feasibility, safety, usefulness or impacts of an intervention before it is implemented more broadly) also require a form of summative evaluation. The purpose of these studies is to determine whether there is enough merit in an initiative to develop it further, adopt it as is, or to expand it to other locations. Pilot studies, therefore, require some level of summative evaluation – there is a need to make a judgment about one or more of these factors. What is often overlooked, however, is that an evaluation of a pilot study can do more than assess merit – in other words, it can have more than this one purpose. A well-designed evaluation of a pilot can also identify areas for program improvement, or explore issues related to implementation, cost effectiveness, or scaling up the intervention. It may even identify different strategies to achieve the objective of the pilot.

To improve a program

If a program is still getting up and running it is too soon for summative evaluation. In such cases, evaluation can be used to help guide development of the initiative (formative evaluation). However, an improvement-oriented approach can also be used to assess an established intervention. A well-designed evaluation conducted for the purpose of program improvement can provide much of the same information as a summative evaluation (e.g. information as to what extent the program is achieving its goals). The main difference is that the *purpose* is to help improve, rather than to make a summative judgment. For example, program staff members often express the wish to evaluate their programs in order to ensure that they are doing the best possible job they can. Their *intent* (purpose) is to make program improvements. One advantage of improvement-oriented evaluation is that, compared to summative evaluation, it tends to be less threatening to participants and more likely to promote joint problem-solving.

Example 1: Program X has been operating for several years. Staff are confident it is a useful and needed program but want to ensure that it is 'doing the best it can' for its clients.

Example 2: Program Y has undergone major redesign in order to promote greater self-management by patients of their chronic disease. The sponsors want to ensure that this redesigned initiative is implemented appropriately, and that any necessary changes to processes are made before patient outcomes are measured.

To help support the design and development of a program or organization

Developmental evaluation uses evaluation processes, including asking evaluative questions and applying evaluation logic, to support program, product, staff and/or organizational development. Reflecting the principles of complexity theory, it is used to support an ongoing process of innovation. A developmental approach also assumes that the measures and monitoring mechanisms used in the evaluation will continue to evolve with the program. A strong emphasis is placed on the ability to *interpret* data emerging from the evaluation process (Patton, 2006).

In developmental evaluation, the primary role of the evaluator, who participates as a team member rather than an outside agent, is to develop evaluative thinking. There is collaboration among those involved in program design and delivery to conceptualize, design and test new approaches in a long-term, on-going process of continual improvement, adaptation and intentional change. Development, implementation and evaluation are seen as integrated activities that continually inform each other.

In many ways developmental evaluation appears similar to improvement-oriented evaluation. However, in improvement-oriented evaluation, a particular intervention (or model) has been selected: the purpose of evaluation is to *make this model better*. In developmental evaluation, in contrast, there is openness to other alternatives – even to changing the intervention in response to identified conditions. In other words, the emphasis is not on the model (whether this is a program, a product or a process), but *the intended objectives* of the intervention. A team may consider an intervention, evaluated as ineffective, a success if thoughtful analysis of the intervention provides greater insights and direction to a more informed solution.

> Example 1: Agency X has designed intervention Y in an attempt to prevent youth-at-risk from becoming involved in crime. While they believe that the intervention is a good one, there is little evidence in the literature on what would be effective in this context. Agency staff members are open to discovering, through their evaluation, other strategies (besides the intervention) that would achieve the goal of reduced youth crime.

Developmental evaluation is appropriate when there is a need to support innovation and development in evolving, complex, and uncertain environments (Patton, 2011; Gamble 2006). While considered by many a new (and potentially trendy) evaluation strategy, it is not appropriate in all situations. First, evaluation of straightforward interventions usually will not require this approach (e.g. evaluation of the implementation of an intervention found effective in other settings). Second, there must be an openness to innovation and flexibility of approach by both the evaluation sponsor and the evaluators. Third, it requires an ongoing relationship between the evaluator and the initiative to be evaluated.

To create new knowledge

A final purpose of evaluation is to create new knowledge – evaluation research. Often, when there is a request to evaluate a program, a critical review of the literature will reveal that very little is known about the issue or intervention to be evaluated. In such cases, evaluators may design the evaluation with the specific intent of generating knowledge that will potentially be applicable in other settings – or provide more knowledge about a specific aspect of the intervention.

While it is unusual that evaluation would be designed solely for this purpose (in most cases such an endeavor would be defined as a research project), it is important for researchers to be aware that appropriately-designed evaluation activities can contribute to the research literature.

As can be seen from the potential evaluation questions listed below, an evaluation may develop in very different ways depending on its purpose.

Examples of evaluation purpose: Case Study #1 Unassigned Patients

- **Judgment oriented questions**: Are the models of care meeting their objective? Should we continue to fund all of them? Is one model better than another?
- **Improvement oriented questions:** How can current models be improved?
- **Developmental oriented questions:** What is the best strategy to achieve our objectives of continuity of patient care and decreased patient length of stay?
- **Knowledge oriented questions:** Are the theorized benefits of each of these models of care found in practice?

Examples of evaluation purpose: Case Study #2: Computerized Decision Support

- **Judgment oriented questions**: Should the software program be adopted across the region? Should it be promoted / marketed more widely?
- **Improvement oriented questions:** How can the software program be improved? How should implementation of these process and practice changes be facilitated?
- **Developmental oriented questions:** What is the best strategy to achieve appropriate test ordering?
- **Knowledge oriented questions:** What can be learned about physician test ordering practices and barriers and facilitators to changing such practice?

Case Study # 1: Unassigned Patients: A real life example

In our case study example, a provincial department of health was originally looking for a summative evaluation (i.e. they wanted to know which model was ‘best’). There was an implication (whether or not explicitly stated) that results would inform funding and policy decisions (e.g. implementation of the ‘best’ model in all funded hospitals).

However, in this case preliminary activities determined that:

- there was no clear direction from a systematic review of the literature on which model would be advised in this particular context, and;
- there was a great deal of anxiety among participants about the proposed evaluation activity, which was viewed by the hospitals as an attempt to force a standard model on all institutions.

There was also concern that the focus on ‘models of care’ may avoid consideration of larger system issues believed to be affecting the concerns the models were intended to address, and little confidence that the evaluation would consider all the information the different programs felt was important.

As a result, the evaluators suggested that the purpose of the evaluation be improvement oriented (looking for ways each of the models could be improved) rather than summative. This recommendation was accepted, with the result that evaluators were more easily able to gain the support and participation of program staff in a politically-charged environment. By also recognizing the need to generate knowledge in an area where little was at that time known, the evaluators were able to design the evaluation to maximize the generation of knowledge. In the end, the evaluation also included an explicit research component, supported by research funding.

While an evaluation may achieve more than one purpose, it is important to be clear about the main intent(s) of the activity. As the above discussion indicates, the purpose of an evaluation may evolve during the preparatory phases.

Step 2: Identify Intended Users of the Evaluation

The concept of intended users (often called key or primary stakeholders) is an important one in evaluation. It is consistent with that of 'integrated knowledge user' in integrated knowledge translation research (Canadian Institutes of Health Research, n.d; Salsberg, Macaulay, Perry, 2014). In planning an evaluation it is important to distinguish intended users (those you are hoping will take action on the results of the evaluation) from other stakeholders (interested and affected parties who may or may not actually use the evaluation results) in general. Interested and affected parties are those who care about, or will be affected by the issue and your evaluation results. In healthcare, these are often patients and families, or sometimes staff. Entire communities may also be affected. However, depending on the questions addressed in the evaluation, not all interested or affected parties will be in a position to act on findings. For example, the users of an evaluation of a new service are less likely to be patients (as much as we may believe they should be) than they are to be senior managers and funders.

The experiences and preferences of interested and affected parties need to be incorporated into the evaluation if the evaluation is to be credible. However, these parties are often not the primary audience for evaluation findings. They may be appropriately involved by ensuring (for example) that there is incorporation of a systematic assessment of patient/family or provider experience in the evaluation. However, depending on the initiative, these patients or staff may – or may not – be the individuals who must act on evaluation findings. The intended audience (those who need to act on the findings) may not be staff – but rather a senior executive or a provincial/state funder.

It is important to keep in mind the benefits of including, in meaningful ways, the intended users of an evaluation from the early stages: this is a principle of integrated knowledge translation. As we know from the literature, a key strategy for bridging the gap between research and practice is to build commitment to (and ownership of) the evaluation findings by those in a position to act on them (Cargo & Mercer, 2008). This does not mean that these individuals need to be involved in all aspects of the research (e.g. data collection) but that, at a minimum, they are involved in determining the evaluation questions and interpreting the data. Many evaluators find that the best strategy for ensuring this is to create a steering/planning group to guide the evaluation – and to design it in such a way as to ensure that all key stakeholders can, and will, participate.

Funders (or future funders) can be among the most important audiences for an evaluation. This is because they will be making the decision as to whether to fund continuation or scaling up of the initiative. Take, for example, a pilot or demonstration project that is research-funded. It may not be that difficult to obtain support from a health manager (or senior management of a health region) to provide the site for a pilot program of an innovation if the required funding comes from a research grant. If, however, it is hoped that a positive evaluation will result in adoption of the initiative on an ongoing basis, it is wise to ensure that those in a position to make such a decision are integrally involved in design of the evaluation of the pilot, and that the questions addressed in the evaluation are of interest and importance to them.

Step 3: Create a Structure and Process for Collaboration on the Evaluation

Once key stakeholders have been identified, evaluators are faced with the practical task of creating a structure and process to support the collaboration. If at all possible, try to find an existing group (or groups) that can take on this role. Because people are always busy, it may be easier to add a steering committee function to existing activities.

In other cases, there may be a need to create a new body, particularly if there are diverse groups and perspectives. Creating a neutral steering body (and officially recognizing the role and importance of each stakeholder by inviting them to participate on it) may be the best strategy in such cases. Whatever structure is selected, be respectful of the time you ask from the stakeholders – use their time wisely.

Another important strategy, as you develop your evaluation plan, is to build in costs of stakeholders. These costs vary depending on whether stakeholders are from grassroots communities or larger health/social systems. What must be kept in mind is that key stakeholders (intended evaluation users), like integrated knowledge users in research, do not want to simply be used as ‘data sources’. If they are going to put their time into the evaluation they need to know that they will be respected partners, their expertise will be recognized, and that there will be benefit to their organization. A general principle is that the costs of all parties who are contributing to the evaluation should be recognized – and as much as possible – compensated for. This compensation may not always need to be financial. Respect and valuing can also be demonstrated through:

- Shared decision-making, including determining the purpose, focus and questions of the evaluation.
- A steering committee structure that formally recognizes the value given to partners in the evaluation process.
- The extent to which there is multi-directional communication between the evaluation team and the initiative to be evaluated.

If key stakeholders are direct care staff in the health system, it will be difficult to ensure their participation unless the costs of ‘back-filling’ their functions are provided to the organization. Similarly, physicians in non-administrative positions may expect compensation due to lost income.

You may be wondering about the time it will take to set up such a committee, maintain communication, and attend meetings. This does take time, but it is time well spent as it will:

- Reflect respect for the intended users of the evaluation;
- Contribute to a more credible (and higher quality) evaluation; and,
- Significantly increase the likelihood that the results of the evaluation will be acted upon.

It is particularly important to have a steering committee structure if you are working in a culture new to you (whether this is an organizational culture, an ethno-cultural community, or in a field or on an issue with which you are unfamiliar). Ensuring that those with needed cultural insights are part of the steering/planning committee is one way of facilitating an evaluation that is culturally competent and recognizes the sensitivities of working in a specific context.

It may not be feasible to have all those on a collaborative committee attend at the same time, particularly if you are including individuals in senior positions. It may not even be appropriate to include all intended users of the evaluation (e.g. funders) with other stakeholders. However, all those that you hope will take an interest in evaluation findings and act on the results need to be included in a minimum of three ways:

- Providing input into the evaluation questions.
- Receiving regular updates on progress. A well-thought-out communication plan (that ensures ongoing two-way communication as the initiative develops and as findings emerge) is needed.
- Participating in interpretation of evaluation results and implications for action.

It is also essential that the lead evaluators are part of this steering committee structure, although – depending on your team make-up (Step 4) – it may not be necessary to have all those supporting the evaluation attend every meeting.

Step 4: Assess Evaluation Capacity, Build an Evaluation Team

A key challenge is to ensure that you have the evaluation expertise needed on your team:

- To design the evaluation component of your proposal;
- To negotiate the environment and stakeholder communication; and,
- To guide and conduct the evaluation activities.

A common mistake is to assume the existing team planning the evaluation has the required evaluation skills. Thoughtful assessment will often reveal either limited evaluation expertise, or a lack of specific evaluation skills needed for the proposed evaluation plan. For example, an evaluation plan that relies on assessment of staff/patient perspectives of an innovation will require a qualitative researcher on the research team. Remember that there is a need for knowledge and experience of the culture in which the evaluation takes place, as well as generic skills of communication, political astuteness and negotiation. Ensuring that you have, on the team, all the expertise that is needed for the particular evaluation you are proposing, will strengthen your evaluation plan. Do not rely simply on contracting with an evaluation consultant who has not been involved to date.

Reviewing your evaluation team composition is an iterative activity – as the evaluation plan develops, you may find a need to add evaluation questions (and consequently expand the methods employed). This may require review of your existing expertise.

The issue of internal vs. external evaluators

The evaluation literature frequently distinguishes between internal and external evaluators. Internal evaluators are those who are already working with the initiative – whether health system staff or researchers. External evaluators do not have a relationship with the initiative to be evaluated. It is commonly suggested that use of internal evaluators is appropriate for formative evaluation, and external evaluation is required for summative evaluation.

The following table summarizes commonly identified differences between internal and external evaluation.

	Internal	**External**
Advantages	▪ Less expensive (uses existing resources) ▪ Less threatening to program/ organizational staff ▪ Can be integrated with continuous Quality Improvement activities ▪ Can build internal evaluation	▪ More objective ▪ May be more credible to external stakeholders ▪ Bring specialized evaluation and research expertise ▪ Can provide additional resources, particularly important if time is limited

	capacity; support evaluative thinking by program staff ▪ Potential of more credibility and ownership by program staff ▪ Increased potential for knowledge translation	▪ May bring in new perspectives
Disadvantages	▪ Existing staff often lack evaluation expertise ▪ There may be a conflict of interest when those responsible for design, implementation and management of an initiative are asked to evaluate it ▪ Those involved in the initiative may lack the time to conduct a rigorous evaluation ▪ The evaluation may lack credibility externally (e.g. funders)	▪ External evaluators (e.g. consultants) vary significantly in skill level ▪ External evaluators may lack knowledge of context, history and players ▪ Significant time is often required to orient external evaluators, help them identify data sources, & assist with evaluation activities ▪ Costs are increased ▪ Beliefs that “he who pays the piper, calls the tune” may detract from credibility of evaluation findings

This dichotomy, however, is too simplistic for the realities of many evaluations, and does not – in itself - ensure that the evaluation principles of competence and integrity are met. Nor does it recognize that there may be other, more creative solutions than this internal/external dichotomy suggests. Three potential strategies, with the aims of gaining the advantages of both internal and external evaluation, are elaborated in more detail below:

A collaborative approach, where evaluators participate with stakeholders as team members, as is done in integrated knowledge translation research. This is standard practice in many collaborative evaluation approaches, and a required element of a utilization-focused or developmental evaluation. Some evaluators differentiate between objectivity in evaluation (which implies some level of indifference to the results) and neutrality (meaning that the evaluator does not ‘take sides’) (Patton, 1997). Collaborative approaches are becoming more common, reflecting awareness of the benefits of collaborative research and evaluation.

Identifying specific evaluation components requiring external expertise (whether for credibility or for skill), and incorporation of both internal and external evaluators into the evaluation plan. Elements of an evaluation that require external evaluation (whether formative or summative) are those:

- That will explore the perspectives of participants (such as staff and/or patients). For example, it is not recommended that staff or managers associated with a program interview patients about their satisfaction with a service. This is both to ensure evaluation rigor (avoiding the risk of patients or staff giving the responses expected of them – social desirability bias), and to ensure that ethical standards are met. The principle of voluntariness may not be met if patients feel obligated to participate because they are asked by providers of a service on which they depend.
- Where there is potential (or perceived) conflict of interest by the evaluator. While the reasons for not using a manager to assess his/her own program are usually self-evident, the potential for bias by researchers must also be considered. If they are the ones who have designed and proposed the intervention, there may be a bias, whether intended or not, to find the intervention successful.

- Where there is not the internal expertise for a particular component.
- Where use of a certain person/group would affect credibility of results with any of the key stakeholders.

Activities that may be well suited to evaluation by those internal to the initiative are those where there are the resources in skill and time to conduct them, and participation of internal staff will not affect evaluation credibility. One example might be the collection and collation of descriptive program data. In some situations it may be appropriate to contract with a statistical consultant for specialized expertise, while using staff data analysts to actually produce the data reports.

Use of internal expertise that is at arm's length from the specific initiative. A classic example of this would be contracting with an organization's internal research and evaluation unit to conduct the evaluation (or components of it). While this is not often considered an external evaluation (and may not be the optimal solution in situations where the evaluation is highly politicized), it often brings together a useful combination of:

- Contextual knowledge, which brings the benefits of both time saved, and greater appreciation of potential impacts and confounding factors.
- Commitment to the best outcomes for the organization, rather than loyalty to a specific program (i.e. may be able to be objective).
- Potential to promote appropriate use of results, both directly and – where appropriate – by making links to other initiatives throughout the organization.

Step 5: Gather Relevant Evidence

The program, product, service, policy or process you will be evaluating exists in a particular context. Understanding context is critical for most evaluation activities: it is necessary to undertake some pre-evaluation work to determine the history of the initiative, who is affected by it, perspectives and concerns of key stakeholders, and the larger context in which the initiative is situated (e.g. the organizational and policy context). How did the initiative come to be? Has it undergone previous evaluation? Who is promoting evaluation at this point in time and why?

In addition, a literature review of the issue(s) under study is usually required before beginning an evaluation. Identifying, accessing and using evidence to apply to an evaluation is an important contribution of research. Such a review may focus on:

- Current research on issues related to the initiative to be evaluated. Many interventions developed organically, and were not informed by research. Even if the initiative was informed by research at one point in time, program staff may not be up to date on current work in the area.
- Evaluations of similar initiatives.

If an evaluation is potentially contentious, it is also often a good idea to meet individually with each of the stakeholders, in order to promote frank sharing of their perspectives.

Case Study #1: Unassigned Patients

The first step in this evaluation was to undertake a knowledge synthesis. While it was hoped that a systematic review would provide some guidance as to a recommended model, this was not the case – almost no literature on the topic addressed issues related to the specific context. Presentation of this finding at a meeting of stakeholders also indicated that there were a number of tensions and diverse perspectives among stakeholders.

One of the next steps proposed by the evaluators was to make a site visit to each of the sites. This included a walk-through of the programs, and meetings with nursing and physician leadership. These tours accomplished two things: a) additional information on 'how things worked' that would have been difficult to gage through other means, and b) development of rapport with staff – who appreciated having input into the evaluation and describing the larger context in which the services were offered.

Case Study #2: Computerized Decision Support

A review of the research literature identified a) key principles predicting effective adoption, b) the importance of implementation activities, and c) limited information on the impacts of computerized decision-support in this specific medical area. This knowledge provided additional support for the decision to a) focus on implementation evaluation, and b) expand the original plan of pre/post intervention measurement of tests ordered to include a qualitative component that explored user perspectives.

Step 6: Build a Shared Level of Consensus about the Evaluation

As indicated in earlier sections, evaluation is subject to a number of misconceptions, and may have diverse purposes and approaches. It is usually safe to assume that not all stakeholders will have the same understanding of what evaluation is, or the best way to conduct an evaluation on the issue under consideration. Some are likely to have anxieties or concerns about the evaluation.

For this reason, it is important to build shared understanding and agreement before beginning the evaluation. Many evaluators find that it is useful to build into the planning an introductory session that covers the following:

- Definition of evaluation, similarities and differences between evaluation, performance management, quality improvement, and research.
- The range of potential purposes of evaluation, including information on when each is helpful. If there is anxiety about the evaluation, it is particularly important to present the full range of options, and help participants to recognize that evaluation – rather than being a judgment on their work – can actually be a support and resource to them.
- Principles and benefits of collaborative evaluation.
- How confidentiality will be maintained.
- The processes you are proposing to develop the evaluation plan.

This overview can take as little as 20 minutes if necessary. It allows the evaluator to proactively address many potential misconceptions – misconceptions that could present obstacles both to a) support of and participation in the evaluation and to b) interest in acting on evaluation findings. Additional benefits of this approach include the opportunity to build capacity among evaluation stakeholders, and to begin to establish an environment conducive to collaborative problem-solving.

It is also important to ensure that the parameters of the evaluation are well defined. Often, the various stakeholders involved in the evaluation process will have different ideas of where the evaluable entity begins and ends. Reaching consensus on this at the outset helps to set clear evaluation objectives and to manage stakeholder expectations. This initial consensus will also help you and your partners keep the evaluation realistic in scope as you develop an evaluation plan. Strategies for focusing an evaluation and prioritizing evaluation questions are discussed in Steps 8 and 9.

Case Study #1: Unassigned Patients

In this example, the introductory overview on evaluation was integrated with the site visits. Key themes were reiterated in the initial evaluation proposal, which was shared with all sites for input. As a result, even though staff from the three institutions had not met together, they developed a shared understanding of the evaluation and agreement on how it would be conducted.

You may find that consensus-building activities fit well into an initial meeting of your evaluation partners. In other cases, such discussions may be more appropriate once all stakeholders have been identified.

Special issues related to collaborative evaluation

In collaborative evaluation with external organizations, it is also important to clarify roles and expectations of evaluators/researchers and program staff/managers, and make explicit any in-kind time commitments or requirements for data access. It is particularly important to have a clear agreement on data access, management and sharing (including specifics of when and where each partner will have access) before the evaluation begins.

Before embarking on the evaluation it is also important to clarify what information will be made public by the evaluator. Stakeholders need to know that results of research-funded evaluations will be publicly reported. Similarly, staff needs to know that senior executives will have the right to see the results of program evaluations funded by the sponsoring organization.

It is also important to proactively address issues related to speaking to evaluation findings. It is not unknown that a sponsoring organization may – in fear that an evaluation report will not be what it hoped for – choose to present an early (and more positive) version of findings before the final report is released. In some cases, they may not want results shared. For this reason it is important to be clear about roles, and to clarify that the evaluator is the person who is authorized to speak to accurately reflect the findings, accept speaking invitations or publish on the results of the evaluation. (Developing and presenting results in collaboration with stakeholders is even better.) Similarly, it is for the program/organization leads to speak to the specific issues related to program design.

Funding proposals for evaluation projects are strengthened by clear letters of commitment from research and evaluation partners. These letters should specifically outline the nature and extent of partners in developing the proposal; the structure and processes for supporting collaborative activities; and the commitments and contributions of partners to the proposed evaluation activities (e.g. data access; provision of in-kind services).

Step 7: Describe the Program/Intervention

Special Note: While this activity is placed in the preparation section of this guide, many evaluators find that, in practice, getting a clear description of the program, and the mechanism of action through which it is expected to work, may not be a simple activity. It is often necessary to delay this activity until later in the planning process, as you may need the active engagement of key stakeholders in order to facilitate what is often a challenging task.

Having stakeholders describe the program is useful for a number of reasons:

- It may be the first opportunity that stakeholders have had for some time to reflect on the program, its rationale, and evidence for its design.
- Differences in understanding of how things actually work in practice will quickly surface.
- It provides a base for ‘teasing out’ the program theory.

However, you may find that those involved in program management find the process of describing their program or initiative on paper a daunting task. An important role of the evaluator may be to help facilitate this activity.

Case study #1: Unassigned Patients

One deliverable requested by the provincial health department was a description of how each of the different models worked. This early activity took over 6 months: each time a draft was circulated for review, stakeholders identified additional information and differences of opinion about how things actually worked in practice.

The issue of “logic models”

Many evaluators place a strong emphasis on *logic models*. Logic models visually illustrate the logical chain of connections showing what the intervention is intended to accomplish. In this way, a logic model is consistent with theory-driven evaluation, as the intent is to get inside the black box, and articulate program theory. Researchers will be more familiar with conceptual models or frameworks, and there are many similarities between the two. However, a conceptual framework is generally more theoretically-based and conceptual than a logic model, which tends to be program specific and include more details on program activities.

When done well, logic models illustrate the ‘if-then’ and causal connections between program components and outcomes, and can link program planning, implementation and evaluation. They can be of great benefit in promoting clear thinking, and articulating program theory. There are many different formats for logic models ranging from simple linear constructions to complex, multidimensional representations. The simplest show a logical chain of connections under the headings of inputs (what is invested in the initiative), outputs (the activities and participants), and the outcomes (short, medium and long-term).

Other logic models are more complex, illustrating complex, multi-directional relationships. See, for example, various templates developed by the University of Wisconsin, Extension: www.uwex.edu/ces/pdande/evaluation/evallogicmodel.html

In spite of the popularity of logic models, they do have potential limitations, and they are not the only strategy for promoting clarity on the theory behind the intervention to be evaluated.

Too often, logic models are viewed as a bureaucratic necessity (e.g. a funder requirement) and the focus becomes one of “filling in the boxes” rather than articulating the program theory and the evidence for assumptions in the program model. In other words, rather than promoting evaluative thinking, the activity of completing a logic model can inhibit it. Another potential downside is that logic models tend to be based on assumptions of linear, logical relationships between program components and outcomes that do not reflect the complexity in which many interventions take place. Sometimes logic models can even promote simplistic (*in the box*) thinking. Some authors advise that logic models are not appropriate for evaluations within complex environments (Patton, 2011).

Whether or not a graphic logic model is employed as a tool to aid in evaluation planning, it is important to be able to articulate the program theory: the mechanisms through which change is anticipated to occur. A program description, advised above, is one first step to achieving this. Theory can sometimes be effectively communicated through a textual approach outlining the relationships between each component of the program/process. (*Because there is strong evidence on X, we have designed intervention Y*). This approach also brings the benefit of a structure that facilitates inclusion of available evidence for the proposed theory of action.

Summary points

- While presented in a step-wise fashion, activities described in this section are likely to be undertaken concurrently.
- Information gathered through each of the activities will inform (and often suggest a need to revisit) other steps.
- It is important to ensure that these preliminary activities have been addressed before moving into development of the actual evaluation plan.

Section 3: Designing An Evaluation

Learning Objectives

- Practice using an evaluation planning matrix to organize collaborative evaluation planning in a logical sequence
- Give examples of the different potential foci of an evaluation, and the importance of choosing a focus appropriate for the evaluation phase
- Explore strategies for developing consensus on priority evaluation questions.

The steps outlined in this section can come together very quickly if the preparatory work advised in Section 2 has been completed. These planning activities are ideally conducted in collaboration with your steering/planning group.

An Evaluation Planning Matrix

Description of the steps in this section is based on an evaluation planning matrix (Appendix A). This matrix is not meant to be an evaluation template, but rather a tool to help organize your planning. Caution is needed in using templates in evaluation, as evaluation research is much more than a technical activity. It is one that requires critical thinking, assessment of evidence, careful analysis and clear conceptualization.

The first page of the matrix provides a simple outline for documenting a) the background of the initiative, b) the purpose of the planned evaluation, c) the intended use of the evaluation, d) the key stakeholders (intended evaluation users), e) and the evaluation focus. Completion of preparatory activities should allow you to complete sections a-d.

This section will start with a discussion of focus (Step 8, below), and then lead through the steps of completing page 2 of the matrix (Steps 9-11).

Step 8: Confirm Purpose, Focus the Evaluation

Confirming the purpose of the evaluation

Through the preparatory activities you have been clarifying the overall purpose of the evaluation. At this point, it is useful to operationalize the purpose of evaluation by developing a clear, succinct description of the purpose for conducting this *particular* evaluation. This purpose statement, one to two paragraphs in length, should guide your planning.

It is also important to include a clear statement of how you see the evaluation being used (this should be based on the preparatory meetings with stakeholders), and who the intended users of the evaluation are.

Case study 1: Unassigned Patients

Renegotiation of the purpose of the evaluation of hospital models of care resulted in an evaluation purpose that was described as follows:

- To respond to the request of the provincial government to determine whether the models developed by the sites were a) effective in providing care to unassigned patients, and b) were sustainable. (You will note that although the evaluation was framed as improvement-oriented, there was a commitment to make a judgment (value) related to these two specific criteria – which were acceptable to all parties).
- To explore both program specific and system issues that may be affecting timely and quality care for medical patients. This objective reflected the concern identified in pre-evaluation activities, that there were system issues – not limited to specific programs – that needed to be addressed.

In keeping with an improvement-oriented evaluation approach, there is no intent to select one 'best model', but rather to identify strengths and limitations of each strategy with the objective of assisting in improving quality of all service models.

Preliminary consultation has also identified three key issues requiring additional research: a) understanding and improving continuity of patient care; b) incorporating provider and patient/family insights into addressing organizational barriers to effective provision of quality inpatient care and timely discharge; and c) the impact of different perspectives of various stakeholders on the effectiveness of strategies for providing this care.

This evaluation will be used by staff of the department of health to inform decisions about continued funding of the programs; by site senior management to strengthen their specific services; and by regional senior management to guide ongoing planning.

Case Study #2: Computerized Decision Support

This evaluation summarized its purpose as follows:

The purpose of this evaluation research is to identify facilitators and barriers to implementation of decision-support systems in the Canadian health context; to determine the impacts of introduction of the decision-support system; and to develop recommendations to inform any expansion or replication of such a project. It is also anticipated that findings from this evaluation will guide further research.

As these examples illustrate, it is often feasible to address more than one purpose in an evaluation. The critical point is, however, to be clear about the purpose, the intended users of the evaluation, and the approach proposed for working with stakeholders.

Focusing an evaluation

So far, we have discussed the purpose of the evaluation, and, in broad terms, some of the possible approaches to evaluation. Another concept that is critical to evaluation planning is that of **focus.** Whatever the purpose, an evaluation can have any one of dozens of foci (For example Patton [1997] lists over 50 potential foci). These include:

- **Implementation focus:** a focus on the implementation of an initiative. (King et al., 1987). Implementation evaluation is a necessary first step to many evaluations, as without assessment of implementation, it will not be possible to differentiate between failure of program theory (the initiative was poorly thought out, and failure to be expected), and failure to implement appropriately a theoretically sound and potentially successful intervention. While many authors incorporate implementation evaluation into general formative evaluation, it is often useful, in early phases of an evaluation plan, to focus specifically on implementation questions.
- **Goals-based** evaluation is familiar to most readers. The focus is on evaluating the extent to which an initiative has met its stated objectives.

- **Goals-free** evaluation, in contrast, takes a broader view and asks "*what actually happened*?" as the result of the intervention. While it is generally wise to consider the original objectives, goals free evaluation allows assessment of unintended consequences (whether positive or negative). This is of particular importance when evaluating initiatives situated in complex systems, as small changes in one area may result in big impacts elsewhere. These unanticipated impacts may be of much greater importance than whether the stated objectives were met.

Case Study #2: Computerized Decision Support

Through exploring the experience and perspectives of all stakeholders, the evaluation found that those receiving the computerized orders, while finding them easier to read (legibility was no longer a problem) also found that they contained less useful information due to the closed-ended drop down boxes that replaced open-ended physician description of the presenting problem. This question was not one that had been identified as an objective, but had important implications for future planning.

- **Impact evaluation** assesses the changes (positive or negative, intended or unintended) of a particular intervention. These changes may not be limited to direct effects on participants.
- **Outcome evaluation** investigates long term effects of an intervention on participants. Few evaluations are in a position to measure long term outcomes: most measure short term outcomes (e.g. processes), or intermediate outcomes (e.g. behavior, policy change).
- **Cost benefit analysis, or cost effectiveness analysis** explores the relationship between program costs and outcomes (expressed in dollars, or not measured in dollars respectively).

The importance of focus and sequence

It is also important to sequence evaluation activities – the focus you select will depend at least in part on the stage of development of the initiative you are evaluating. A new program, which is in the process of being implemented, is not appropriate for outcome evaluation. Rather, with few exceptions, it is likely that the focus should be on implementation evaluation. Implementation evaluation addresses such questions as:

- *To what extent was initiative implemented as designed?*
- *Were resources, skills, timelines allocated adequate?*
- *Are data collection systems adequate to collect data to inform outcome evaluation?*
- *What obstacles to implementation and uptake can be identified, and how can they be addressed?*

A program that has been implemented and running for some time, may select a number of different foci for an improvement-oriented evaluation.

Many summative (judgment-oriented) evaluations are likely to take a focus that is impact or outcome focused.

It is important to keep in mind that a focus will help keep parameters on your activities. The potential scope of any evaluation is usually much broader than the resources available. This, in addition to the need to sequence evaluation activities, makes it useful to define your focus.

Step 9: Identify and Prioritize Evaluation Questions

Only when preparatory activities have been completed is it time to move on to identifying the evaluation questions. This is not to say that a draft of evaluation questions may not have already been developed. If only the research team is involved, questions may already be clearly defined: if you have been commissioned to undertake an evaluation, at least some of the evaluation questions may be predetermined. However, if you have been meeting with different stakeholders, they are likely to have identified questions of concern to them. The process of developing the evaluation questions is a crucial one, as they form the framework for the evaluation plan.

At this point we move on to page 2 of the evaluation planning matrix. It is critical to start with the question (i.e. with what we want to learn from the evaluation). Too often, stakeholders first focus on the evaluation activities they would like to conduct (e.g. we should conduct interviews with physicians), the data they think is available (e.g. we can analyze data on X), or even the indicators that may be available. But without knowing what questions the evaluation is intended to answer, it is premature to discuss methods or data sources.

Get the questions on the table (Column 2)

In working with evaluation stakeholders, it is often more useful to solicit evaluation questions with wording such as *"what do you hope to know at the end of this evaluation that you don't know now?"* ratherthan as "*what are the evaluation questions?"* The latter question is more likely to elicit specific questions for an interview, focus group, or data query, than to identify questions at the level you will find helpful.

In collaborative evaluation, a useful strategy is to incorporate a discussion (such as a brainstorming session) with your stakeholder group. You will often find that, if there is good participation, dozens of evaluation questions may be generated – often broad in scope, and at many different levels. Scope of questions can often be constrained if there is a clear consensus on the purpose and focus on the evaluation – the reason that leading the group through such a discussion (Section 2, Step 6) is useful.

The next step for the evaluator is to help the group rework these questions into a format that is manageable. This usually involves a) 'rolling up' the questions into overarching questions, and b) being prepared to give guidance as to sequence of questions. These two activities will facilitate the necessary task of prioritizing the questions: reaching consensus on which are of most importance.

Create overarching questions (Column 1)

Many questions that are generated by knowledge users are often subquestions of a larger question. The task of the evaluator is to facilitate the roll-up of questions into these overarching ones. Because it is important to demonstrate to participants that the questions of concern to them are not lost, it is often useful to keep note (in column two of the matrix) of all the questions of concern.

Case Study #1: Unassigned Patients

The stakeholders at the 3 sites generated a number of questions, many of which were similar. For example: "I want to know what nurses think about this model", "I want to know about the opinions of patients on this change", "How open are physicians to changes to the model?'

These questions could be summarized in an overarching question "What are the perspectives of, and experiences with, physicians, nurses, patients, families, and other hospital staff" on the care model?"

Guide discussion of sequence

It is common for knowledge users (and researchers) to focus on outcome-related questions. Sometimes it is possible to include these questions in the evaluation you are conducting, but in many cases – particularly if you are in the process of implementing an initiative – it is not. As discussed earlier, for example, it is not appropriate to evaluate outcomes until you are sure that an initiative has been fully implemented. In other cases, the outcomes of interest to knowledge users will not be evident until several years into the future – although it may be feasible to measure intermediate outcomes.

However, even if it is not possible to address an outcome evaluation question in your evaluation it is important to take note of these desired outcomes. First, this will aid in the development of program theory and, secondly, noting the desired outcome measures is an essential first step in ensuring that there are adequate and appropriate data collection systems in place that will facilitate outcome evaluation in the future.

If it is not possible to address outcome questions, be sure to clearly communicate that these are important questions that will be addressed at a more appropriate point in the evaluation process.

Prioritize the questions

Even when the evaluation questions have been combined and sequenced, there are often many more questions of interest to knowledge users than there is time (or resources) to answer them. The role of the evaluator at this point is to lead discussion to agreement on the priority questions. Some strategies for facilitating this include:

- *Focusing on how the information generated through the evaluation will be used*. Simply asking the question "*When we find out the answer to X, how will that information be used?"* will help differentiate between questions that are critical for action, and those that driven by curiosity. A useful strategy is to suggest that given the time/resource constraints we all face, the priority should be to focus on questions that we know will result in action.
- *Referring back to the purpose of the evaluation, and to any funder requirements*.
- *Addressing feasibility*. There are rarely the resources (in funds or time) to conduct all the evaluations of interest. Focusing on funder time lines and available resources will often help eliminate questions that, while important, are beyond the scope of your evaluation.
- *Revisiting the issue of sequence.* Even though 'early' evaluation questions may not be of as much interest to stakeholders as outcome questions, it is often useful to develop a phased plan, illustrating at what phase it is best to address a particular question. The evaluation matrix can be adapted to include sections that highlight questions at different phases (e.g. implementation evaluation, improvement oriented evaluation, outcome evaluation questions).
- *Exploring the potential of additional resources to investigate some questions.* Some questions generated may be broad research questions. They are important, but there may not be an urgency to answer them. In such cases, there may be interest in investigating the potential of additional research funding to explore these questions at a later date.

If there is time, the steering/planning group can participate in this 'rolling up' and prioritization activity. Another alternative is for the evaluator to develop a draft based on the ideas generated and to circulate it for further input.

It is only when the evaluation questions have been determined that it is appropriate to move on to the next steps: evaluation design, selection of methods and data sources, and identification of indicators.

Step 10: Select Methods and Data Sources (Columns 3 and 4)

Select methods for the specific evaluation questions

Only when you are clear on the questions, and have prioritized them, is it time to select methods. In collaborative undertakings you may find that strong facilitation is needed to reach consensus on the questions, as stakeholders are often eager to move ahead to discussion of methods. The approach of 'starting with the question' may also be a challenge for researchers, who are often highly trained in specific methodologies and methods. It is important in evaluation, however, that methods be driven by the overall evaluation questions, rather than by researcher expertise.

Evaluators often find that many evaluations require a multi-method approach. Some well-designed research and evaluation projects can generate important new knowledge using only quantitative methods. However, in many evaluations it is important to understand not only *if* an intervention worked (and to measure accurately any difference it made) but to understand *why* the intervention worked – the principles or characteristics associated with success or failure, and the pathways through which effects are generated. The purpose of evaluating many pilot programs is to determine whether the program should be implemented in other contexts, not simply whether it worked in the environment in which it was evaluated. These questions generally require the addition of qualitative methods.

Your steering committee will also be helpful at this stage, as they will be able to advise you on the feasibility – and credibility – of certain methods.

Case Study #1: Unassigned Patients

When the request for the evaluation was made, it was assumed that analysis of administrative data would be the major data source for answering evaluation questions. In fact, the data available was only able to provide partial insights to *some* of the questions of concern.

While the overall plan for the evaluation suggested focus groups would be appropriate for some data collection, the steering group highlighted the challenges in bringing physicians and hospital staff together as a group. They were, however, able to suggest strategies to facilitate group discussions (integrating discussions with staff meetings, planning a catered lunch, and individualized invitations from respected physician leaders).

Identify data sources

The process of identifying data sources is often interwoven with that of selecting methods. For example, if quantitative program data are not available to inform a specific evaluation question, there may be a need to select qualitative methods. In planning a research project, if the needed data were not available, a researcher may decide to remove a particular question from the study. In evaluation, this is rarely acceptable – if the question is important, there should be an effort to begin to answer it. As Patton (1997) has observed, it is often better to get a vague or fuzzy answer to an important question than a precise answer to a question no one cares much about. The best data sources in many cases are specific individuals!

Remember that many organizations have formal approval processes that must be followed before you can have access to program data, staff or internal reports.

Identify appropriate indicators (Column 5)

Once evaluation questions have been identified, and methods and data sources selected, it is time to explore what indicators may be useful.

An indicator can be defined as a summary statistic used to give an indication of a construct that cannot be measured directly. For example, we cannot directly measure the quality of care, but we can measure particular processes (e.g., adherence to best-practice guidelines) or outcomes (e.g., number of falls) thought to be related to quality of care. Good indicators:

> *…. should actually measure what they are intended to (validity); they should provide the same answer if measured by different people in similar circumstances (reliability); they should be able to measure change (sensitivity); and, they should reflect changes only in the situation concerned (specificity). In reality, these criteria are difficult to achieve, and indicators, at best, are indirect or partial measures of a complex situation. (*Alberta Heritage Foundation for Medical Research, 1998, p.5)

However, it is easy to overlook the limitations both of particular indicators and of indicators in general. Some authors have observed that the statement *we need a program evaluation* is often immediately followed by *we have these indicators*, without consideration of exactly which question the indicators will answer (Bowen & Kriendler, 2008).

An exclusive focus on indicators can lead to decisions being *data-driven* rather than *evidence-informed* (Bowen et al., 2009). It is easy to respond to issues for which indicators are readily available, while ignoring potentially more important issues for which such data is not available. Developing activities around "what existing data can tell us," while a reasonable course for researchers, can be a dangerous road for both decision-makers and evaluators, who may lose sight of the most important questions facing the healthcare system. It has been observed that "the indicator-driven approach 'puts the cart before the horse' and often fails" (Chesson, 2002, p. 2).

Not all indicators are created equal, and an indicator's limitations may not be obvious. Many indicators are gameable (i.e. metrics can be improved without substantive change). For example, breastfeeding initiation is often used as an indicator of child health, as it is more easily measured than breastfeeding duration. However, lack of clear coding guidelines, combined with pressure on facilities to increase breastfeeding rates, appear to have produced a definition of initiation as, "the mother opened her gown and tried" (Bowen & Kriendler, 2008). It is not surprising then that hospitals are able to dramatically increase 'breastfeeding rates' if a directive is given to patient care staff, who are then evaluated on the results. This attempt, however, does not necessarily increase breastfeeding rates following hospital discharge. This example also demonstrates that reliance on a poor indicator can result in decreased attention and resources for an issue that may continue to be of concern.

The following advice is offered to avoid these pitfalls in indicator use in evaluation:

First determine what you want to know. Don't start with the data (and indicators) that are readily available.

In selecting indicators, evaluate them for validity, robustness and transferability *before* proposing them. Don't just use an indicator because it's available.

Understand what the indicator is really telling you – and what it isn't.

Limit the number of indicators, focusing resources on the strongest ones.

Choose indicators that cannot be easily gamed.

Ensure that those who gather and analyze the data (and are aware of what an indicator is actually measuring, data quality, etc.) are included on your team.

Remember that there may not be an appropriate indicator for many of the evaluation questions you hope to address (Bowen & Kriendler, 2008).

Case Study #1: Unassigned Patients

At the beginning of this evaluation it was assumed that assessment of impact would be fairly straightforward: the proposed indicator for analysis was hospital length of stay (LOS). However, discussions with staff at one center uncovered that:

Health information staff members were being asked to run the data in two different ways, by heads of different departments. This resulted in different calculation of LOS.

Although the LOS on the ward (the selected indicator) showed a decline, the LOS in the emergency department was actually rising. Attention to the selected indicator risked obscuring problems created elsewhere in the system.

Step 11: Clarify Resources and Responsibility Areas (Column 6)

At this point, we are ready to move the evaluation plan into operation. It is necessary to ensure that you have the resources to conduct the proposed evaluation activities, and know who is responsible for conducting them. This final column in the matrix provides the base from which an evaluation work plan can develop.

Step 12: Implement Evaluation Activities

This chapter does not attempt to provide detailed information on project implementation and management, although some excellent resources to support such work are available (Western Michigan University). However, as you conduct the evaluation it is important to:

- **Monitor (and evaluate!) implementation of activities**. Be prepared to revise the plan when obstacles are identified. Unlike some research designs, in evaluation it is not always possible – or advisable – to hold the environment constant while the evaluation is occurring.
- **Ensure regular feedback and review of progress by stakeholders.** Don't leave reporting until the evaluation is completed. As issues are identified, they should be shared and discussed with stakeholders. In some evaluations (e.g. improvement oriented or developmental evaluation) there will be an intent to act on findings as soon as they are identified. Even if there is no intent to change anything as the result of emerging findings, remember that people don't like surprises – it is important that stakeholders are informed not only of progress (and any difficulties with the evaluation), but also alerted to potentially contentious or distressing findings.

Step 13: Communicate Evaluation Findings (ongoing and end-of-project knowledge translation)

Communication is an essential component of knowledge translation: it is certainly important in promoting action on evaluation findings. There are two main categories of communication in evaluation: a) ongoing communication with evaluation partners, and b) final communication of evaluation results.

It is important to ensure that emerging evaluation findings are shared in effective ways with evaluation partners as the project progresses. Determining the best strategies for such communication (whether it is by regular meetings, newsletter, website, monthly reports, etc.) should be a topic of early planning meetings. Regular communication keeps partners involved; it allows for prompt action to address emerging issues; and helps build capacity through interpretation of results. Open communication also builds trust: if there are unexpected or negative findings, partners are more likely to be receptive to them if they have learned of these as the project progresses.

Even though it is recommended that there are regular reports (and opportunities for discussion) as the evaluation progresses, it is often important to leave a detailed evaluation report. This report should be focused to the intended users of the evaluation, and should form the basis of any presentations or academic publications, helping promote consistency if there are multiple authors or presenters. There are many guidelines for developing reports for knowledge users (see for example the 1-3-25 format developed by the Canadian Health Services Research Foundation, n.d.). The specifics will depend on your audience, the scope of the evaluation and many other factors. It is important to leave sufficient time to prepare an effective final report, and to ensure that there is a process for sharing draft findings, and collaboratively developing recommendations and next steps.

Evaluation frequently faces the challenge of communicating contentious or negative findings. Issues related to communication are covered in more detail in Section 4, Ethics and Evaluation.

Summary Points

- An effective evaluation is built around clear questions developed in collaboration with knowledge users. It is important not to get distracted by discussions of potential methods, data sources and indictors before there is agreement on the evaluation questions.
- Like integrated KT research, collaborative approaches to evaluation include knowledge users in identifying priority questions, planning evaluation activities, and interpreting results.
- Communication about findings should be integrated throughout evaluation activities rather than left to an end of project report.

Section 4: Special Issues In Evaluation

Learning objectives

- Identify common ethical issues faced in evaluation, along with helpful resources.
- Discuss the impact of complexity on evaluation activities
- Recognize the special requirements for conducting economic evaluations

Ethics and Evaluation

The ethics of evaluation

Evaluation societies have clearly identified ethical standards of practice. For example:

- The Canadian Evaluation Society (n.d) provides *Guidelines for Ethical Conduct* http://www.evaluationcanada.ca/site.cgi?en:5:4, (competence, integrity, accountability)
- The American Evaluation society (2004) publishes *Guiding principles for evaluators* http://www.eval.org/publications/GuidingPrinciplesPrintable.asp (systematic inquiry, competence, integrity/honesty, respect for people, and responsibilities for general and public welfare).
- The Australasian Evaluation Society publicizes *Guidelines on Ethical Conduct of Evaluation and Code of Ethics* (Revised July 2013) http://www.aes.asn.au/join-the-aes/membership-ethical-guidelines.html.

The ethics of evaluation are an important topic in evaluation journals and evaluation conferences. Ethical behavior is a live issue among professional evaluators. This may not be apparent to researchers as, in many jurisdictions; evaluation is exempt from the ethical review processes required by universities.

In addition to the standards and principles adopted by evaluation societies, it is important to consider the ethical issues specific to the type of evaluation you are conducting. For example there are a number of ethical issues related to collaborative and action research or undertaking organizational research (Alred, 2008; Bell & Bryman, 2007; Flicker et al, 2007; Salsberg, Macaulay, & Perry, 2014).

Evaluators also routinely grapple with ethical issues, which while also experienced by those conducting some forms of research (e.g. participatory action research), are not found in much academic research. Some of these issues include:

Managing expectations. Many program staff welcome an evaluation as an opportunity to ‘prove’ that their initiative is having a positive impact. No ethical evaluator can ensure this and it is important the possibility of unwanted findings – and the evaluator’s role in articulating these – is clearly understood by evaluation sponsors and affected staff.

Sharing contentious or negative findings. Fear that stakeholders may attempt to manipulate or censor negative results has led to evaluators either keeping findings a secret until the final report is released, or adjusting findings to make them politically acceptable. While the latter is clearly ethically unacceptable, the former also has ethical implications. It is recommended that there are regular reports to stakeholders in order to prepare them for any negative or potentially damaging findings. One of the most important competencies of a skilled evaluator is the ability to speak the truth in a way that is respectful and avoids unnecessary damage to organizations and participants. Some strategies that you may find helpful are to:

- Involve stakeholders in interpretation of emerging results and planning for release of findings.
- Frame findings neutrally – being careful not to assign blame.
- Consider a private meeting if there are sensitive findings affecting one stakeholder to prepare them for public release of information.

Issues Related to REB review

Research ethics boards (REBs) vary in how they perceive their role in evaluation. Some, reflecting the view that evaluation is different from research, may decline to review evaluation proposals unless they are externally funded. Other REBs, including institutional boards, require ethical review. This situation can create confusion for researchers. It can also present challenges if researchers feel that their initiative requires REB review (as they are working with humans to generate new knowledge) but there is reluctance on the part of the REB to review their proposal. Unfortunately, there may also be less attention paid to ethical conduct of activities if the initiative is framed as evaluation rather than as research. Some REBs may also have limited understanding of evaluation methodologies, which may affect their ability to appropriately review proposals.

Health organizations can, and will, proceed with internal evaluation related to program management, whether or not there is REB approval. There is an often vociferous debate in the literature about the difference between Quality Improvement and Research – and the role of REBs in QI (Bailey et al, 2007). Evaluation activities are generally considered to be Quality Improvement and there is resistance on the part of the health system in many jurisdictions to the involvement of Ethics Boards in what organizations see as their daily business (Haggerty, 2004).

Unfortunately, this grey zone in REB review often results in less attention being given to the ethical aspects of evaluation activities. In other words, the attention is directed to the ethics review process (and approval), rather than the ethical issues inherent to the project. In some cases, there may even be a deliberate decision to define an activity as evaluation rather than research simply to avoid the requirement of ethical review. This lack of attention to the very real ethical issues posed by evaluation activities can often pose significant risks to staff, patients/clients, organizations and communities – risks that are sometimes as great as those posed by research activities. These risks include:

- *Negative impacts on staff*. There is a risk that difficulties identified with a program may be attributed to specific staff. Some organizations are even known to conduct a program evaluation as a way to avoid dealing with staff *performance* – presenting a potential trap (and ethical dilemma) for the evaluator. This practice is also one reason why evaluation is often threatening to staff. Even if this is not the intent, negative findings of an evaluation can have disastrous effects on staff.
- *Opportunity costs*. Inadequate (or limited) evaluation can result in continuing to provide resources to support a lackluster service, meaning that other initiatives cannot be funded.
- *Negative impacts on patients/clients***.** Not only clinical, but system redesign interventions, can have negative impacts on patients and families – it is essential that the evaluation is designed to assess potential impacts.
- *Impact on organizational reputation***.** Concerns about results of evaluations becoming public may lead to organizational avoidance of external evaluation. As indicated earlier, it is essential to negotiate the terms of any evaluation reporting involving an external partner *before* the evaluation is conducted.

Evaluating in Complex Environments

There is increasing attention directed to the challenge of evaluation in complex environments (Pawson, 2013)– and many initiatives (particularly in the Population Health and Health Services environments) are, by their very nature, complex.

It has been claimed that one of the reasons so little progress has been made in resolving the many problems facing us in the healthcare system, is that we continue to treat complex problems as though they were simple or complicated ones.

Evaluation design must match the complexity of the situation (Patton, 2011). Simple problems reflect linear cause-effect relationships: issues are fairly clear, and it is usually not difficult to get agreement on the best answer is to a given problem. In such cases there is a high level of both a) certainty about whether a certain action will result in a given outcome, and b) agreement on the benefits of addressing the issue. Simple problems are relatively easy to evaluate – evaluation usually focuses on outcomes. An example would be the evaluation of a patient education program to increase knowledge of chronic disease self-management. This knowledge could be measured with a pre/post design. Findings from evaluations of simple interventions may be replicable.

In complicated problems, cause and effect are still linked in some way, but there are many possible good answers – not just one best way of doing things. There is lack of either certainty about the outcome (technically complicated), or agreement on the benefits of the intervention (socially complicated) (Patton, 2011). An example of the latter would be provision of pregnancy termination services or safe injection sites. Evaluation in complicated contexts is more difficult, as there is need to explore multiple impacts from multiple perspectives. There are many, often diverse, stakeholders.

In complex systems it is not possible to predict what will happen (Snowden & Boone, 2007). The environment is continually evolving and small things can have significant and unexpected impacts. Evaluation in complex environments requires a great deal of flexibility – it needs to take place in real time: the feedback from the evaluation itself serves as an intervention. There are no replicable solutions as solutions are often context specific. Evaluation in a complex environment requires identification of *principles that are transferable* to other contexts – where the actual intervention may look quite different. This lack of clear cause-effect relationships (which may be apparent only in retrospect) explains the limitations of logic models in such environments (although their use may help to test assumptions in underlying program theory).

The Complexity of Causation

In research, much attention in research design is directed to identifying and minimizing sources of bias and confounding, and in distinguishing between causation and correlation. These design considerations are equally important in evaluation, and can often be more challenging than in some research projects as there is usually not the opportunity to create a true experiment, where all conditions are controlled. In fact, this inability to control the environment in which the initiative to be evaluated is taking place is one of the greatest challenges faced by evaluators.

A major task in evaluation is that of differentiating between *attribution* and *contribution*. A common evaluation error is to select a simple pre-post (or before and after) evaluation design, and to use any differences in data measured to draw conclusions about the impact of the initiative. In 'real life' situations, of course, there are many other potential causes for the observed change. Commonly, the intervention can be expected to contribute to some of the change, but rarely all of it. The challenge, then, is to determine the extent of the contribution of the intervention under study.

Some authors provide detailed formulae for helping evaluators determine the proportion of effect that can be assumed to be contribution of the specific intervention (see for example Davidson, 2005, Chapter 5). Strategies often used by evaluators to help determine the weight that should be given to the contribution of the intervention include:

- Triangulation. Triangulation refers to use of multiple methods, data sources, and analysts to increase depth of understanding of an issue.
- A focus on reflexivity and evaluative thinking throughout the phase of data interpretation.
- Incorporation of qualitative methods where those directly involved can be asked to comment on other factors potentially contributing to results.

For example, one evaluation of a Knowledge Translation research initiative conducted in collaboration with health regions included interviews with CEOs and other key individuals in addition to assessing measurable changes. Participants were asked directly about factors that had, over the preceding years, contributed to increased use of evidence in organizational planning. Responses included a range of other potential contributors (e.g. changes by the provincial department of health to the planning process; increased access to library resources; new organizational leadership) in addition to the intervention under evaluation. Identification of these factors and the relative impact attributed by stakeholders to each in promoting change, assisted in determining the extent of contribution of the project compared to other events occurring at the time.

The Special Case of Economic Evaluation

Decision-makers are often interested in an economic evaluation of an intervention(s). The purpose of *economic evaluation* (defined as the comparison of two or more alternative courses of action in terms of both their costs and consequences) is to help determine whether a program or service is worth doing compared with other things that could be done with the same resources (Drummond et al., 1997). If, however, only the *costs* of two or more alternatives are compared, (without consideration of the effects or consequences of these alternatives) this is not a full economic evaluation, rather it is a cost analysis.

Unfortunately, those requesting economic evaluation (and some of those attempting to conduct it) often equate costing analyses (assessment of the costs of a program or elements of a program) with economic evaluation, which can lead into dangerous waters. Before drawing conclusions, it is also necessary to know the costs of other alternatives, and the consequences of these alternatives – not only to the program under study but from the perspective of the larger health system or society. One risk in simple costing studies is that a new service often has a separate budget line, whereas the costs of continuing with the status quo may be hidden and not available for analysis.

Case Study # 1: Unassigned Patients

The department of health originally requested an economic evaluation of the various hospital models. Preliminary investigation revealed that the plan was, essentially, to conduct a cost analysis of only one component of the model – the actual physician costs. This is not an economic evaluation, as to demonstrate which of the models was most cost effective would require not only calculation of other costs of each model (e.g. nursing costs, test ordering), but also of the consequences of each (e.g. readmissions, LOS, costs to other parts of the system such as home care or primary care).

While an economic evaluation would have been extremely useful, the evaluators had neither the funds, nor the data readily available to conduct one. Consequently, simply reporting on the physician costs could have led to flawed decision-making. In this situation, the evaluators explained the requirements for conducting a full economic evaluation, and the feasibility of conducting one with the data available.

In responding to a request to undertake an economic evaluation it is important to:

- Ensure that you have health economist expertise on your team
- Undertake a preliminary assessment of the data available (and its quality) to undertake economic analyses
- Be realistic about the resources needed to undertake an economic evaluation. Most small evaluations do not have the resources to undertake economic evaluation, and the data to do so may not be available. Remember that a poorly designed ‘economic evaluation’ can lead to poorer decisions than no evaluation at all.
- Ensure that those who understand the program, and the context within which it is operating, are integrally involved in planning the evaluation.
- Be prepared to educate those requesting the evaluation on what economic evaluation entails, and the limitations of a costing study.

The Concept of the Personal Factor

A useful concept in evaluation is that of the personal factor (Patton, 1997). This concept recognizes that important factors in the success or failure of any initiative are often the individual(s) in key roles in the initiative: their knowledge and skill; their commitment to the initiative; the credibility they have with peers; their ability to motivate others. The best example might be that of a set curriculum: different instructors can result in vastly different student assessments of exactly the same course. Many evaluations require consideration of the personal factor before drawing conclusions about the value of the initiative.

At the same time, it is important to ensure that recognition and assessment of the personal factor does not degenerate into a *personnel* assessment. Nor is it useful for those looking to implement a similar initiative to learn that one of the reasons the initiative was successful was due to the wonderful director/staff. What is needed is clear articulation of *what* personnel factors contributed to the findings and for these to be communicated in a positive way.

Summary points

- Evaluation research often presents unique challenges that may not be encountered in all forms of research.
- Many of the ethical issues in evaluation are similar to those faced in participatory research. There are guidelines and codes of ethics to guide evaluator practice.

Summary

The intent of this chapter has been to provide readers with sufficient background on the topic of evaluation that they will be able to participate in the design of a range of evaluations to respond to a variety of evaluation needs.

Collaborative approaches (particularly utilization-focused approaches) to evaluation are conceptually well-aligned with integrated knowledge translation research. These approaches

- provide a unique opportunity to generate knowledge that can be immediately applied to decision-making,
- can be integrated with, and in themselves serve as, effective KT strategies.

Following the guidelines in this chapter will increase the likelihood of implementing an evaluation plan that has support of key stakeholders, answers questions of concern to these stakeholders, and avoids common evaluation errors. Consequently, it is more likely that findings resulting from these evaluations will be used.

EVALUATION CHECKLIST

EVALUATION CHECKLIST	**Developing an Evaluation Plan**
	Questions to consider:
• **Evaluation plan appropriate for proposed project**	• What are the requirements of the funding opportunity? • What is the relative importance of evaluation to the overall proposal? • How will evaluation contribute the knowledge needed? • What resources are available?
1. Intended evaluation user sclearly identified	• Who do you hope will act on evaluation findings? • Have you clearly differentiated between intended users & affected parties in general?

2. Appropriate collaboration	• Have partners been involved appropriately in design of proposal?
	  • identifying evaluation purpose &focus
	  • developing evaluation questions
	• How will you continue to involve these partners in meaningful ways?
	  • Guiding & monitoring evaluation
	  • Data interpretation
	  • Promoting action on results
	• Have you come to agreement on roles and responsibilities?
	• Are partner contributions recognized in budget?
	• Do letters of commitment for any proposal specify partners past and future contributions?
	• Have publication and other issues been negotiated?
	• What structure and processes will support the collaboration?

3. Evaluation team includes needed expertise	• Does your team have
	  • The methodological expertise needed to conduct the evaluation?
	  • Evaluation experience & knowledge of evaluation context?
	• Do you have interpersonal & negotiating skills on the team?
	• Is an internal, external or collaborative evaluation the best option?
	• Has any potential conflict of interest been addressed?

4. Preparatory work completed	• Have you gathered contextual evidence (history, stakeholders, program design) on the initiative to be evaluated? • Have you conducted a review of the literature appropriate to the evaluation question? • What strategies have you used to explore evaluation alternatives and develop consensus among partners? • Have data management/sharing contingencies been considered?

5. Clear description of initiative to be evaluated	• What format (logic model, textual description) would best describe the initiative & its program theory? • How does evaluation reflect the program theory of action? • Have evaluation partners been involved in developing the description?
• Clearly stated evaluation purpose and focus	• Are the parameters of the evaluation well defined? • Have you developed a clear, concise description of the purpose of the evaluation component? • Is the evaluation focus appropriate for this point of development of the initiative? • How do you see the evaluation being used, and by whom?
• Clear evaluation questions	• Have intended users been involved in developing the questions? • Are questions appropriate for the stage of development of the initiative? • Can the questions be addressed within time frame and resources available?
6. Appropriate methods	• Are methods appropriate for the questions? • Have you identified data sources, and received any necessary approvals? • Are any selected indicators appropriate, valid and robust?
7. Overall quality of design	• Why is the purpose, focus, questions, methods you have selected the most appropriate in this situation? • How will you control bias? Analyze data? Determine the contribution of the initiative to identified results? • Have you identified the specific challenges presented in this evaluation?
8. Expertise and roles clearly articulated	• Have you outlined evaluation roles & responsibilities clearly? • Have you demonstrated that you have the needed team expertise? • Are roles and future involvement of partners clear?
9. Communication plan	• What is your plan for keeping team members informed of progress? • How will you develop a plan for evaluation result dissemination? Why is it appropriate for this evaluation?
10. Ethical issues addressed	• Are you familiar with guidelines and principles for conducting evaluations? • What are the ethical review requirements for this specific evaluation (REB, sponsoring organization?) • What potential ethical challenges will be presented by this evaluation? How will you address them? • Have ethical issues related to collaborative engagement been considered?

APPENDIX A

SAMPLE EVALUTION PLANNING MATRIX

A. Background

Summary of initiative

B. Evaluation Purpose

Why is evaluation being undertaken?

C. Intended Use of Evaluation

How will results be used?

D. Intended Users

Who are intended users of the evaluation?

What other stakeholders should be involved in some way?

E. Evaluation Focus

1. Proposed Evaluation Questions	2. Comments/Notes Sub-questions	3. Possible Methods	4. Data Sources	5. Potential Indicators	6. Responsibility/ Resources
IMPLEMENTATION EVALUATION					
IMPROVEMENT ORIENTED EVALUATION					
OUTCOME/IMPACT EVALUATION					
DEVELOPMENTAL EVALUATION					

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