



# Knowledge Exchange Decision Support (KE-DS) Toolkit for Supportive Cancer Care Final Report, 2009

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## Contents

INTRODUCTION: <i>Why build another Knowledge Exchange Model and Toolkit?</i> .....	2
HOW TO USE THE KNOWLEDGE EXCHANGE DECISION SUPPORT TOOLKIT .....	3
KNOWLEDGE EXCHANGE .....	3
KNOWLEDGE EXCHANGE DECISION SUPPORT MODEL .....	4
TOOLKIT DESIGN & USE .....	5
GOALS AND OUTPUT .....	6
KE-DS TOOLKIT .....	7
MODULE A: Template for outlining an intervention.....	7
MODULE B: Template for creating a site reflection .....	7
MODULE C: Putting it all Together - Reflect and Report .....	9
APPENDIX 1: KE-DS TOOLKIT GRID .....	10
APPENDIX 2: RESOURCES AND REFERENCES OF INTEREST .....	11

## **INTRODUCTION: *Why build another Knowledge Exchange Model and Toolkit?***

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Psychosocial Supportive Cancer Care is an umbrella term for a range of services provided across the cancer-care trajectory, to an individual patient, by a multitude of individuals and organizations within a broadly defined community.

As part of the Canadian Partnership Against Cancer (CPAC) and Cancer Journey Action Group (CJAG), the Supportive Cancer Care Knowledge Exchange Decision Support (KE-DS) model was created to support a large-scale change initiative - changing current clinical and research focus of cancer care from a tumour-centered approach to a person-centered one.

The KE-DS Model is a comprehensive model. It is designed to assess and understand the properties, effects, and impacts of a program or an intervention in the context of supportive cancer care, to facilitate the inclusion of all stakeholders, and provide the opportunity to align local health needs with population health initiatives.

Attached is an information package describing the developing model and the KE-DS Toolkit prototype for use and evaluation. The package is composed of the KE-DS Toolkit Modules including guidance notes. The KE-DS Model is designed to be iterative – to be re-addressed throughout the project process, and has an evaluation component for process assessment. As such, it can be initiated at project inception, or used as a reflective tool during the project timeline. The KE-DS Toolkit contains guidelines with which to apply critical theory to health care interventions by drawing on a number of disciplinary perspectives, epidemiology, sociology, and economics and systems science. More specifically, through a set of modules, the KE-DS Toolkit provides a method for recognizing and engaging stakeholders at multiple levels, identifying and appraising the evidence on effectiveness, efficiency and appropriateness of the intervention; and optimizes decision-making by integrating population, economic, and social contexts.

The implementation of the KE-DS Toolkit across different environments and settings will allow the community developing and implementing Supportive Cancer Care programs across Canada the opportunity to create and pool empirical evidence for supportive cancer care.

# HOW TO USE THE KNOWLEDGE EXCHANGE DECISION SUPPORT TOOLKIT

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The KE-DS Toolkit was designed as a means of operationalizing, formalizing and creating an accurate and detailed progress report of the evidence-based decision-making behind developing and utilizing a site-specific program. It was designed for supportive cancer care but can be used for any project development. It is a means of making transparent the process of program development and implementation.

## KNOWLEDGE EXCHANGE

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Knowledge translation (KT) and Knowledge Exchange (KE) are concepts being used in health services and policy research. The term KE is based on the premise that a gap exists between the production of research knowledge and its implementation as evidence-based practice, planning and decision making. The process of bringing research evidence to practice has yielded various frameworks, models and toolkits for KE in many disciplines. All delineate, in various ways, a complex set of interactions between the creation of new information, synthesis, assessment and evaluation of that information, strategies for dissemination and translation for a broad range of stakeholders, as well as the collection, storage and facilitation of access for all users.

Knowledge exchange (KE) as used in this context derives directly from the current CIHR definition (CIHR, 2009<sup>1</sup>). The Knowledge Exchange Model for Supportive Care is designed to show the complex set of interactions between creation, synthesis, assessment and evaluation of relevant information, strategies for dissemination and translation for a range of stakeholders, and the collection, storage and facilitation of access for all users.

The KE model elaborates how alternative choices may have diverse consequences that often stretch far beyond immediate patient outcomes. The model provides a synthesis of the socio-medical dynamics in policy and practice; it adopts a critical perspective which delineates issues of power and dominance, as well as describing the impact of the intervention (i.e. supportive cancer care). Best practice decisions occur in a series of fairly well-defined stages (that one could also repeat and backtrack): 1) recognition of problem, 2) formulation of possible intervention, 3) generation of alternatives, 4) information search, 5) judgment or choice, 6) action, 7) feedback. This broad “problem solving” approach is the one adopted for the proposed model to ensure a comprehensive

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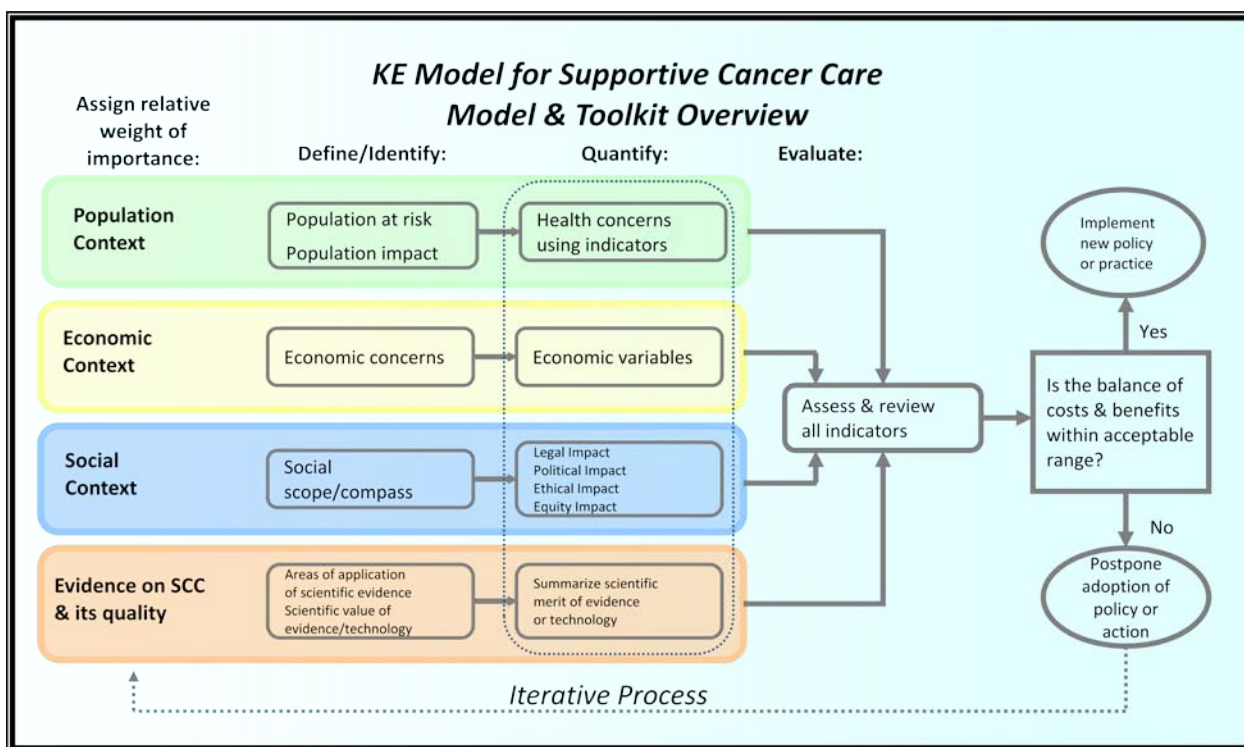
<sup>1</sup> <http://www.cihir-irsc.gc.ca/e/39033.html>, accessed on August, 2009

understanding of the specific problem/deficit as well as a thorough examination of the consequences of alternative courses of action.

In summary, the KE model reflects the Ottawa Model of Research Use (Tetroe & Graham et al. 2008) and has several features of significance. Firstly, by virtue of its comprehensive nature with the coverage of all dimensions of concern, the Framework process assumes the inclusion of all stakeholders, it provides the opportunity to align local (or sub-population, or stakeholders) “wants” with population health needs, and it provides guidelines within which the appropriate information is sought and examined. This is achieved through raising several questions for which the answers may be readily available or may need further elaboration.

## KNOWLEDGE EXCHANGE DECISION SUPPORT MODEL

The KE Model that the KE-DS Toolkit is based on draws on a number of disciplinary perspectives, incorporating theories of epidemiology, sociology, economics and systems science; and applies critical theory to health care evaluation.



## TOOLKIT DESIGN & USE

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The Toolkit is designed as a short set of modules in an action-oriented format designed to facilitate a KE strategy of working through the process of program inception to completion. Guidance notes and issues to consider are incorporated into the modules. Support materials are available as a set of appendices which contain the KE-DS Grid for consolidating information gathered throughout the iterative process of project and population assessment and a selection of References and Resources.

The steps of the Toolkit have been divided into three modules – this is for ease of use and reference. The Modules are designed to serve as an outline for reflecting and reporting. It is important to keep in mind that this is an iterative process, one that will require you to continually revisit components and reconsider information (such as stakeholder members or the population of interest). As such, it can be initiated at project inception, or at the current point in the timeline of your project. Within each module, there are action oriented activities – we encourage you to write things down as this will require you to not only conceptualize the process of planning and implementing the project, but also to articulate it. The goal here is not to come away with new information, but rather to utilize a framework through which to organize and track the issues, supports and barriers that you encounter during the planning and implementation process of your project or initiative. Some steps may be very straightforward; while others may take considerable thought and consideration in order to fully capture the various elements associated with that dimension.

As the impetus for this Model is the facilitation of *knowledge exchange* and the transfer of *knowledge into action*, you may want to consider this Toolkit as a medium through which to share your experiences with other potential project teams who might want to implement your project or initiative in the future. What are the valuable lessons learned and issues that emerged during your experience? The Toolkit can serve as a vehicle to track and organize these issues, both for the purposes of your project team and for other teams in the future.

## GOALS AND OUTPUT

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The intended output of KE-DS Toolkit use is a report from each site that documents stakeholder involvement, the social, economic, and population contexts and evidence underlying program choice. Working through the Toolkit also facilitates documentation of development and implementation of the program. As all of our sites use the Toolkit, and create their reports for their funding bodies and the KE Team, it creates empirical evidence which will be used to inform further research and programming. The KE-DS Grid Template (found in Appendix 1) is designed as a summary tool for consolidation of the knowledge compiled while progressing through the KE-DS Toolkit Modules.

*We look forward to your feedback and questions. Please do not hesitate to contact Arminee Kazanjian [a.kazanjian@ubc.ca](mailto:a.kazanjian@ubc.ca), research coordinator Kirsten Smillie [smilliek@interchange.ubc.ca](mailto:smilliek@interchange.ubc.ca) or graduate research assistant Vivian Chan [vwychan@interchange.ubc.ca](mailto:vwychan@interchange.ubc.ca).*

## KE-DS TOOLKIT

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### MODULE A: Template for outlining an intervention

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#### **SUMMARIZE THE INTERVENTION**

Create an overview of the Intervention (project/program/initiative) that is under consideration (prospective) or provided (retrospective).

#### **ESTABLISH CURRENT NEED/ FRAME PATIENT-CENTRED OUTCOMES**

Define the macro and micro health care policy (Big Picture and Small Picture) and frame the intervention. The goal is to establish that the intervention (program/project/initiative) will contribute to system change (e.g. shift to more patient-focused supportive cancer care).

#### **ESTABLISH THE CURRENT LITERATURE/EVIDENCE TO CONSIDER**

Document the resources, tools, reports in the current literature, experiential knowledge etc. that support the choice of the program, and the relevance of current need.

### MODULE B: Template for creating a site reflection

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#### **IDENTIFY STAKEHOLDERS**

Create a list of current stakeholders: the individuals, organizations or systems that are important (i.e. who will contribute to program organization, implementation and/or will affect the program or be affected by it).

Does your site have a broad-based, balanced stakeholder group that includes people from all these groups<sup>2</sup>, who are available and willing to contribute to development process, and agree on the relevance of the initiative and its relevance to the big picture and small picture?

Are there a decision-making body/team, project timelines, communication strategies and logistical plans in place?

#### **CONSIDER POPULATION CONTEXTS**

##### **A) IDENTIFY SITE SPECIFIC POPULATION OF INTEREST**

Who are the people you are targeting with the program or initiative? Who is the population at risk?

Identify the socio-demographic, geographic, and/or ethnic /cultural factors.

Confirm that this population group is the focus of the current priority in macro and micro Health Care environments.

Consider the logistical issues of targeting this population. What are the barriers you might encounter? What are the supports?

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<sup>2</sup> Service agencies; Community-based agencies; Health Professionals/Practitioners; Cancer Care NGO's; Patients and supports; Cultural representatives; Other



Quantify health concerns using indicators based on the natural history of the disease, the size of the population, the ability to access the population etc.

#### **B) IDENTIFY SITE SPECIFIC POPULATION IMPACT**

What do you hope to accomplish for the population of interest?

Describe anticipated population impact-in terms of population health and health systems research. Describe how it fits with big picture and small picture focus.

#### **C) QUANTIFY HEALTH CONCERS USING INDICATORS**

What are relevant measures to gauge improvement in disability and survivorship? (i.e. potential tools might be a Functional Assessment inventory, a Quality of Well-Being scale or a Social Relationship scale). What are appropriate and relevant program, process, or intermediate outcome measures?

#### **RE-VISIT THE PROJECT/PROGRAM/INITIATIVE**

Assess if the intervention will appropriately serve your specific population of interest, result in the desired population impact, and be acceptable to stakeholders.

Consider the measurement of impact/evidence in conjunction with greater system impacts: consider local system, larger systems.

What are the hard-to-measure impacts of this program (ones that cannot be easily quantified)? How will you acknowledge them?

#### **CONSIDER ECONOMIC CONTEXTS**

Assess economic concerns and variables at individual, community, organizations and other relevant groupings, institutional and systems levels.

Consider:

- Unit costs versus total costs, direct, direct non-health, indirect, intangible care costs
- Potential costs to the individual, community and organization and impact on other services and supporting groups
- Allocative versus distributive costs
- Opportunity costs
- Medical Cost Offset
- Outcome measures: future use of services
- Morbidity
- Mortality

#### **CONSIDER SOCIAL CONTEXTS**

Assess the social scope at an individual, community, organizational level, and other relevant groupings, institutional and systems levels.

Consider:

- Clinicians and hospital/organization staff
- Public (patient population that will benefit) vs. private interests (e.g. how oncologists will benefit, RN's and/or Health Authority)
- Ethical acceptance

Cultural differences  
Public perceptions and/or priorities  
Legal framework  
Power /status and dominance issues  
Personal/public values  
Perspectives people bring to program that will influence the success of the program

### **CONSIDER THE SCIENTIFIC/BEST EVIDENCE CONTEXT**

Reflect on the 'contextualization of knowledge': placing research findings in an appropriate context considering ethical concerns, socio-cultural norms of end users and specific health systems.

Delineate what is known from existing research.  
Delineate what is known from clinical experience.  
Delineate what is the experiential and cultural knowledge.  
Are the interventions or supportive care services identified as best practices or evidence based?  
What is the impact value of evidence for stakeholders?  
What is the area of application of the evidence?  
What is the merit/value of the evidence/technology?

## **MODULE C: Putting it all Together - Reflect and Report**

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### **RE-VISIT THE INTERVENTION: EVALUATE HOW MUCH AND FOR WHOM?**

Assess the intervention in light of all contextual issues (population, economic and social) developed in steps 4-7, and consider documented and experiential evidence in order to confirm goals and uptake.

Analysis:

Will the program improve this population's well-being or quality of life?  
Are methods in place to measure the improvement to this population's well-being or quality of life?  
Will the project have an impact within different social contexts?  
Will the project have an impact within different geographic contexts?  
Will the project have an impact within different demographic contexts?  
Will the project employ norms of utility, (the greatest good and equity to the largest number of people)?

Consolidate material from Steps 1-10.

Conclude as to costs and benefits of program or initiative.

Determine recommendations and next steps for your project.

*What are your recommendations to the KE-DS Team and affiliated sites?*

## APPENDIX 1: KE-DS TOOLKIT GRID

<i>Dimension</i>	<i>Indicators</i>	<i>Target/Goal and Uptake</i>	<i>Evidence considered</i>
<b>1) Population of interest:</b> Identify clearly the population of interest – referred to “population at risk” in epidemiological studies e.g. socio-demographic, geographic, and/or ethnic /cultural group at risk			
<b>2) Population Impact:</b> Describe anticipated population impact – in terms of population health and health systems research.			
<b>3) Economic Concerns:</b> Identify economic issues – comparing the “inputs” of the intervention/practice/policy with some combinations of the “outputs”.			
<b>4) Social Context</b> Understand the social context for : <ul style="list-style-type: none"> <li>• Individuals</li> <li>• Communities</li> <li>• Organizations or other groupings</li> <li>• Institutions and systems</li> </ul>			
<b>5) Scientific Context</b> What is known from existing research/clinical experience? What is the experiential and cultural knowledge? What is the merit/value of the evidence/technology			

## APPENDIX 2: RESOURCES AND REFERENCES OF INTEREST

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Atlantic Health Promotion Research Centre

<http://www.ahprc.dal.ca/kt/prototype/>

BC Cancer

<http://www.bccancer.bc.ca/default.htm>

Canadian Institute for Health Information (CIHI)

[http://secure.cihi.ca/cihiweb/dispPage.jsp?cw\\_page=cphi\\_knowledge\\_exchange\\_e](http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=cphi_knowledge_exchange_e)

Canadian Institute for Health Research (CIHR)

<http://www.cihr-irsc.gc.ca/e/29418.html> <http://www.cihr-irsc.gc.ca/e/7518.html>

Cancer Control Planet

<http://cancercontrolplanet.cancer.gov/>

Community-University Partnership for the Study of Children, Youth and Families: A Handbook on Knowledge Sharing <http://www.cup.ualberta.ca/>

Institute for Work and Health

<http://www.iwh.on.ca/kte/showcase.php>

<http://www.iwh.on.ca/kte/kte.php>

Institute of Medicine - Cancer Care for the Whole Patient

[http://books.nap.edu/openbook.php?record\\_id=11993&page=R1](http://books.nap.edu/openbook.php?record_id=11993&page=R1)

Kellogg Foundation Evaluation Toolkit

[http://www.chsrf.ca/kte\\_docs/Kellogg%20Foundation%20Evaluation%20Toolkit.pdf](http://www.chsrf.ca/kte_docs/Kellogg%20Foundation%20Evaluation%20Toolkit.pdf)

NHS (UK) The gold standards framework: a programme for community palliative care

[http://www.goldstandardsframework.nhs.uk/gsf\\_in\\_practice.php](http://www.goldstandardsframework.nhs.uk/gsf_in_practice.php)

Wellness Community

<http://canada.thewellnesscommunity.org>