

# Developing a Strategy to Address Uncertainty in Decision-making

Advancing quality in cancer control and cancer system performance

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On behalf of the Uncertainty Project Team



UNIVERSITY  
OF MANITOBA

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# On behalf of: Melissa Brouwers



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# Uncertainty Project Team

## Research Team

- Melissa Brouwers (Co-PI: McMaster University)
- Michelle Driedger (Co-PI; U of Manitoba)
- Mita Giacomini
- Jeffrey Hoch
- Jeff Sisler
- Donna Turner

## Project Staff

- Gary Annable
- Samantha Craigie
- Kimberly Garcia
- Julie Makarski

## Advisory Panel

- Canadian experts



UNIVERSITY  
OF MANITOBA



McMaster  
University

# Funding



- CCSRI
  - breast cancer screening (women 40–49)
  - HPV vaccination
  - PSA screening
- ARCC (funded by the Canadian Cancer Society)
  - funding of expensive cancer drugs
- MS Society/MHRC
  - liberation therapy for the treatment of MS



Manitoba  
Health  
Research  
Council

# Conflicts of Interest

- None to declare

# Presentation Outline

## Overview:

- Statement of Problem
- Study Objectives
- Methods

## Results:

- Framework
- Guide
- External review

## Current status, Next Steps:

- Continuing Work

# Statement of Problem

## Problem:

- Health care, policy decisions in cancer control are often made in an environment of complex uncertainty
  - limited funds; evidence; differences in values; politics
- Sources of uncertainty, strategies to navigate it, and tools to identify it, are poorly understood/studied

## Our study to address gap:

Advancing Quality in Cancer Control and Cancer System Performance in the Face of Uncertainty

(The Uncertainty Project)

(2010 - 2014)

# Study Objectives

1. To identify and categorize sources of uncertainty faced by healthcare, policy decision-makers
2. To understand its impact on decision-making
3. To identify existing tools used to identify, navigate or mitigate uncertainty
4. To develop a draft tool to assist health care decision-makers in managing uncertainty in the decision-making process

# Methods

## Mixed methods approach:

- 1. Integrated Review of Literature
  - Quantitative and qualitative studies
  - 1995–2012
  - Sources, mechanisms, impacts, tools
- 2. Focus Groups & Key Informant Interviews (UMan)
  - Breast cancer screening (40–49); HPV vaccination; PSA screening; Funding of new cancer drugs
  - What are the most relevant, important sources of uncertainty in policy context and how to manage?
- 3. Tool Development and Evaluation
  - Using 1 and 2
  - Target user group: Healthcare, policy decision-makers

# Results: (I) Framework

- Through the literature review, we identified 4 core areas [sources] of uncertainty:
  - i. Scientific – related to the research evidence base
  - ii. Structural – issues of impact within the organization
  - iii. Normative – stakeholder values
  - iv. Inherent – naturally occurring uncertainty

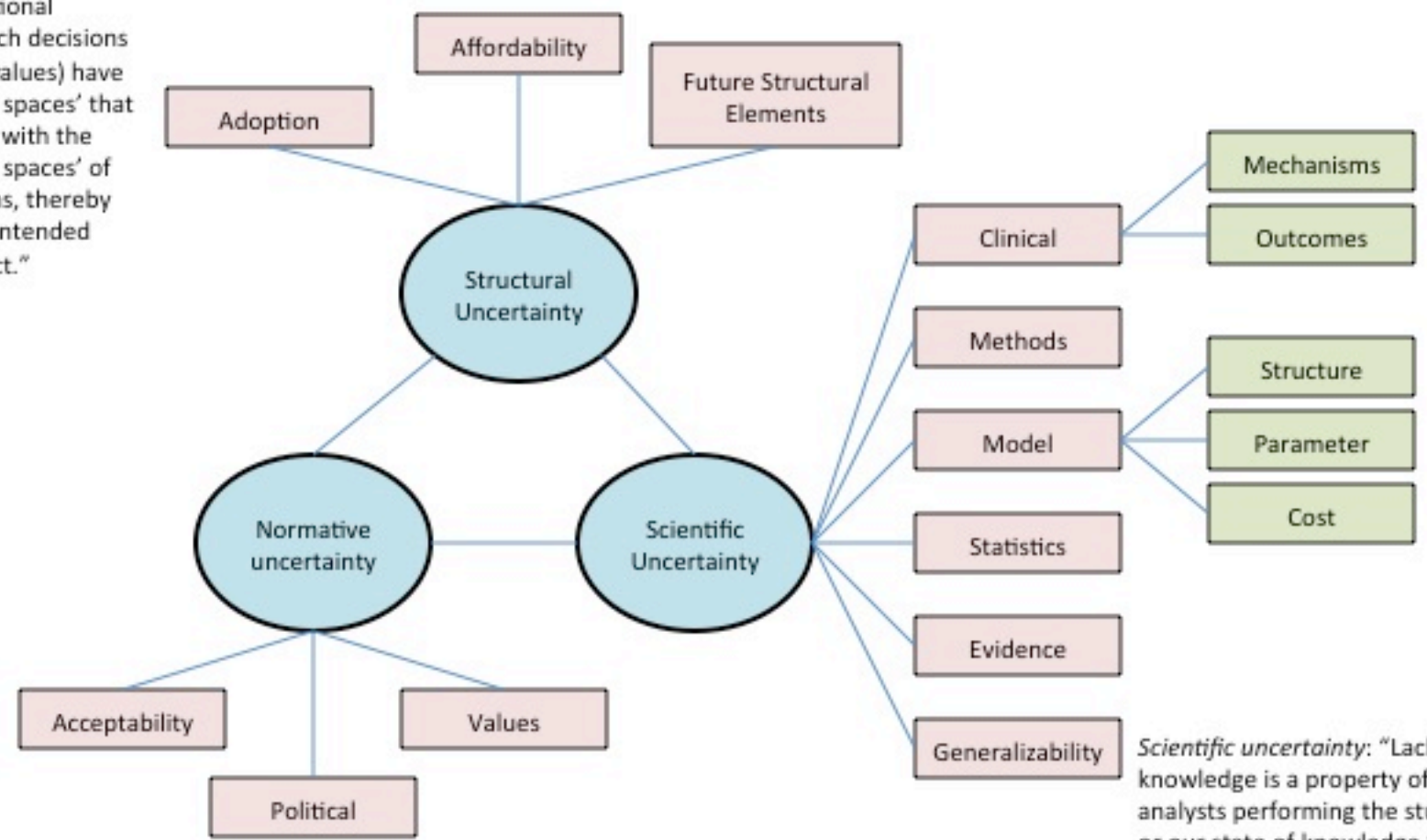


Created a comprehensive  
“Uncertainty Framework”

- 4 “domains”
- 12 “sub-domains”
- Details for each

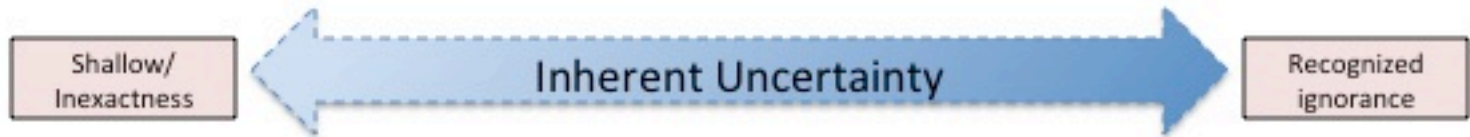
# Proposed framework of Uncertainty

*Structural uncertainty:* "... the impact of related decisions in an interorganizational structure... such decisions (adoption of values) have 'consequence spaces' that may intersect with the 'consequence spaces' of other decisions, thereby limiting their intended rational impact."



*Normative uncertainty:* "The system/process can behave in different ways or is valued differently."

*Scientific uncertainty:* "Lack of knowledge is a property of the analysts performing the study and/or our state of knowledge."



# Results: (II) Decision Guide

→ From the “Uncertainty Framework”



- Developed the “Uncertainty Decision Guide”
  - Objective: to systematically consider sources of uncertainty and impact for a given policy decision during the decision-making process
  - Design:
    - Matrix
    - Each domain/sub-domain (Framework) along left side
    - 6 questions along top
      - To ask for each sub-domain
    - Access to Framework
    - Answer format – Y, N, M, N/A, with room for comments

# Uncertainty Decision Guide

	1. Does uncertainty exist in this domain?	2. Does the uncertainty exist due to a LACK of evidence/information?	3. Does the uncertainty exist due to CONFLICTING evidence/information?	4. Is it possible or feasible to collect the evidence/information needed to resolve the uncertainty?	5. Are considerations relevant to this sub-domain likely to play a role in my decision?	6. Are there any important potential impacts to consider if the uncertainty is not resolved?
<b>SCIENTIFIC UNCERTAINTY</b>						
Clinical mechanisms						
Clinical outcomes						
Methodology						
Statistics						
Model structure						
Model parameter						
Model cost						
Evidence base						
Generalizability						
<b>STRUCTURAL UNCERTAINTY</b>						
Adoption						
Affordability						
Future Structural Elements						
<b>NORMATIVE UNCERTAINTY</b>						
Acceptability						
Political						
Values						

# Results: Evaluation

## External Review:

- Aim = test the Decision Guide with members of the Canadian health policy, decision-making community
- Online, video-based survey
  - Project background, methodology, results
  - Described Decision Guide, how to use
- Opportunity to use the Guide in a mock policy scenario
  - Developed for the purpose of this survey
  - 2 scenarios (randomized to 1)
  - Use Guide to make decision on policy scenario

# Results: Evaluation [cont'd]

## External Review: Survey

- We sought:
  - Feedback on: Framework
  - Feedback on: Decision Guide
  - Feedback on: Experience with Decision Guide
  - Quantitative
    - 7-point Likert scale
  - Qualitative
    - Written feedback
  - ~1.5 hours to complete

# Results: Evaluation [cont'd]

## External Review: Participants

- Invitations to members of Canadian cancer policy and/or research groups:
  - ARCC, OHTAC, pCODR, CCO, our own advisory panel, key informants, trainees in health policy graduate programs
- Surveys distributed: N=64
  - 3 reminders
- Respondents: N=15
  - Response rate=23%

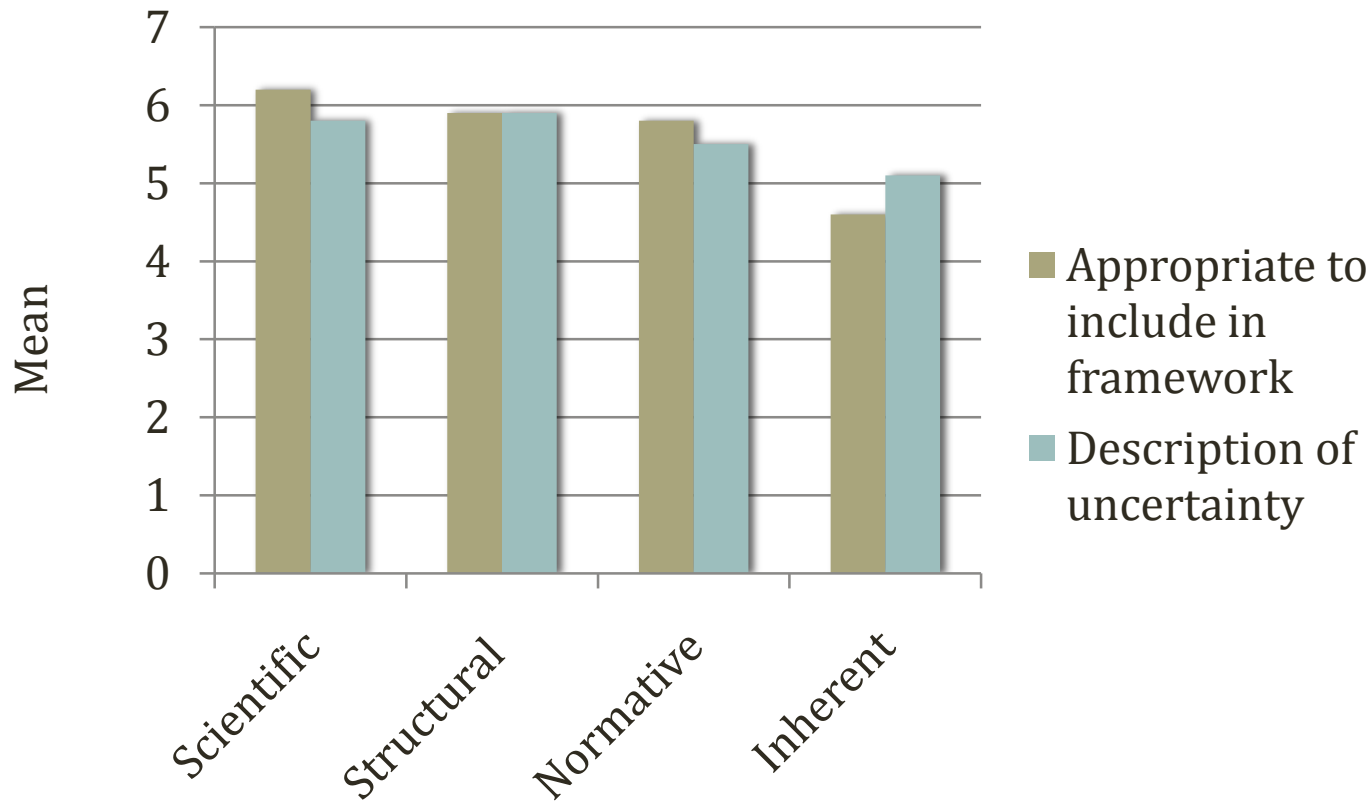
# Results: Evaluation [cont'd]

## External Review: Follow-up Survey

- Sent to: Non-responders
  - N=41
- Main question:
  - “Why didn’t you complete the survey?”
- Respondents:
  - N=15
  - Response rate=37%
- Main reason for not completing:
  - Time

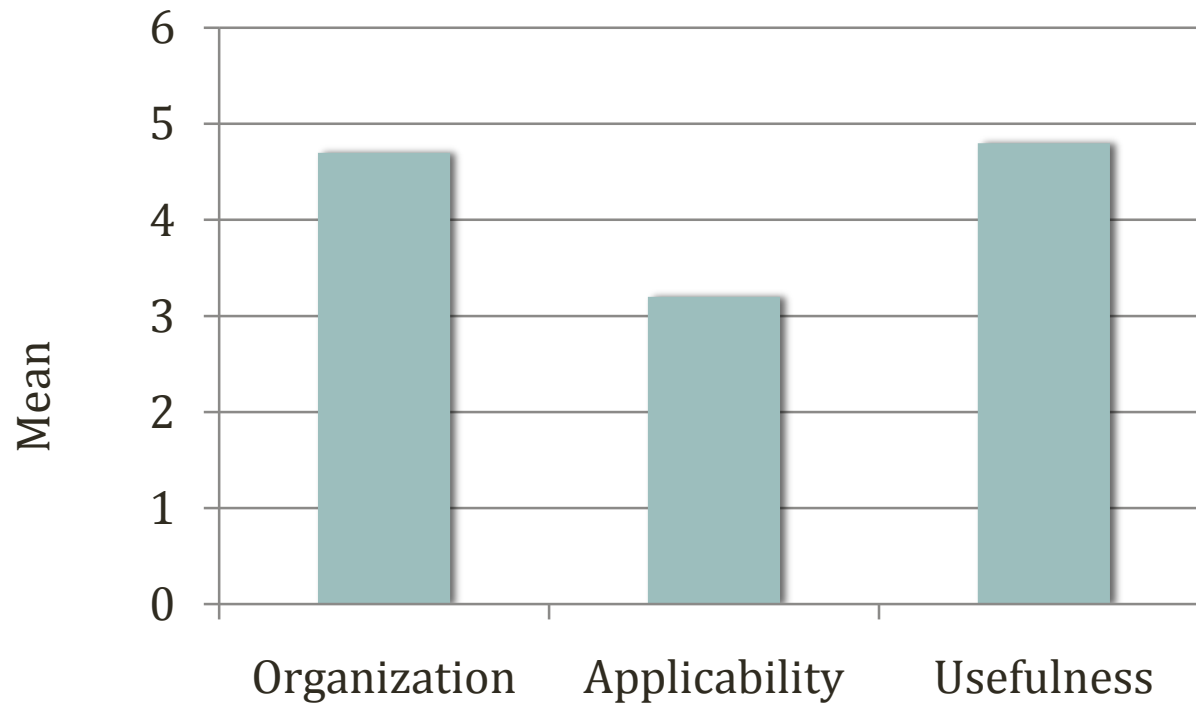
# Results: Framework

Mean Scores for the Uncertainty Framework



# Results: Decision Guide

Mean Scores for the Uncertainty Decision Guide



# Results: Decision Guide

## Key written feedback:

- Survey, process itself – – too long

### Framework –

- Too many categories, overlap
- Language (jargon, e.g., “normative”)

### Decision Guide –

- Not practical for ‘real-world’ use
- Too complex; need to simplify
- Information overload; had to learn too much information to use the tool, not ideal
- “a promising start”

	1. Does the uncertainty exist due to a LACK of evidence/information?	2. Does the uncertainty exist due to a LACK of evidence/information?	3. Does the uncertainty exist due to CONFLICTING evidence/information?	4. Is it possible or feasible to collect the evidence/information needed to resolve the uncertainty?	5. Are there any important potential impacts to consider if the uncertainty is not resolved?
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# Results: Decision Guide

- Revised: Decision Guide based on reviewer feedback
  - “Uncertainty Assessment & Navigation Tool” (U-ANT)
  - 1-pager
  - Simple, self-explanatory
  - Focus = 2 domains: (i) Evidence and (ii) Implementation
  - For each domain:
    - Operational definition
    - Key questions to consider
    - Ask: (i) is the uncertainty *relevant* to the problem? and (ii) is it a *priority for resolution*?
- To Review: with select participants
  - Telephone survey; 20 mins
  - Target of n=8 participants
    - Saturation

## UNCERTAINTY ASSESSMENT AND NAVIGATION TOOL (U-ANT)

**Purpose:** The U-ANT is a resource to help decision-makers consider and work with decisional uncertainty in a systematic and transparent manner.

**Why:** Uncertainty that can influence how, and the type of, decisions made, the credibility and acceptability of a decision, and transparency of a decision. In an ever-increasing environment of public accountability, the U-ANT is an evidence-based strategy designed to help the decision-making process.

**What and How:** Two key sources of uncertainty comprise the U-ANT: evidence and implementation. These sources have emerged from the scientific literature. An operational definition and specific considerations are identified for each source. Users should ask: Is the uncertainty source *relevant to the decision-making context*? Is it a *priority for resolution* during the decision-making process? Resolution considerations are offered.

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### I. EVIDENCE

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This source of uncertainty addresses evidence/information issues related to defining or understanding (i) the clinical or health care problem and/or (ii) the decision option(s). Consider the following:

- Is there a clear understanding of the disease (burden, incidence, prevalence, and trajectory)?
- Is there research evidence regarding the effectiveness and/or efficacy of the decision options?
- Is the quality of research evidence for the decision options acceptable?
- Is the quantity of research evidence for the decision options acceptable?
- Is the research evidence applicable to the context in which the decision is going to be made (e.g. patients or members of the public similar, health care system similar, etc.)?

Relevant		Resolve		Comments
Y	N	Y	N	

Resolution Considerations: Could gathering additional evidence resolve the uncertainty? Is it feasible to gather additional evidence?

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### II. IMPLEMENTATION

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This source of uncertainty addresses issues related to the feasibility, affordability, acceptability and political context of the decision option(s). Consider the following:

- Can the decision option(s) be integrated into the current structures and systems?
- Is/Are the decision option(s) affordable and cost effective (e.g. start-up costs, capital costs, downstream cost, etc.)?
- Is/Are the decision option(s) acceptable to patients/public, providers, decision-makers?
- Do/Does the decision option(s) align with values of the public, patients, clinicians, and/or system leaders?
- Do/Does the decision option(s) integrate with the current political landscape?
- Is there precedence for a decision in another province or jurisdiction? If so, does it impact this decision?
- Is there disagreement between or among stakeholders with respect to the decision options? Are the positions understood?

Relevant		Resolve		Comments
Y	N	Y	N	

Resolution Considerations: Is there a mechanism/is it feasible to prioritize decision options? Is there a means to resolve disagreement? Is there a preferred decision option? Is there a decision option that is less risky?

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# Current Status, Next Steps

- Conduct Telephone Surveys
  - May 2014
- Finalize final version of U-ANT
- Once finalized, publicly release mid-2014

Thank you.



Questions?