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The Ontario HIV Treatment Network
*Promoting excellence and innovation
in HIV research and care*

***Making sense of HIV Research: Using evidence
to inform programs and service delivery***

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Learning objectives

- **During this session we will try to address some questions related to the role of research evidence for informing programs, service delivery and advocacy**
- **Specifically, we will address the following questions:**
 - Why is research an important input into decision-making about programs, services and advocacy? How does this relate to the policy process?
 - What types of situations can research be used and what kinds of research are helpful in each?
 - What challenges do we face when linking research to action and what are some ways to address these challenges?



Why is research evidence important? (1)

- **Stakeholders (CBOs and healthcare managers and policymakers) are increasingly asked to use research evidence to inform their programs, services and advocacy**
- **Emphasis on using practical, scientifically sound and socially acceptable methods in decision-making**
 - Evidence-informed decision-making (research evidence is only one input that needs to be considered)
- **Need to link different sectors**
 - Communities and CBOs need be included as key policy stakeholders
 - Delivery and accountability can be improved through community involvement



Why is research evidence important? (2)

- **Research evidence can play many roles:**
 - Helps identify emerging issues that may require attention or revision of programs or services
 - Helps to garner attention for certain issues (i.e., what challenges should we focus on?)
 - Helps to think about issues and solutions differently (i.e., how should we begin to approach this challenge?)
 - Helps to solve particular issues at hand (i.e., what type of action should we support?)



Why is research evidence important? (3)

- **Research evidence can play many roles (cont.):**
 - Helps to justify a decision already made for other reasons (i.e., how can we sell the position we've taken?)
 - Inform funding proposals for programs and services or for new research
 - Helps identify the potential strengths and weaknesses of current programs and services



How does this relate to the policy process?

- **Government agenda setting is argued to be influenced by three factors:**
 - Problems (i.e., issues)
 - Policies (i.e., solutions to issues)
 - Politics
- **Research evidence can play an important role in informing the problem/issue and policies streams (more on this soon)**
- **Efforts that are cognizant of how research evidence can inform your work and policy decisions are more likely to have impact and generate action.**



Types of research evidence and data (1)

- **There are several types of research evidence and data that I will highlight as being helpful in different situations**
 - Data (raw indicators that have not been statistically manipulated)
 - Administrative database studies and community surveys
 - collection and analysis of data about systems, networks or organizations – e.g., hospital admissions data to determine the rate of re-admission
 - Qualitative research (interviewing)



Types of research evidence and data (2)

Systematic reviews

- **Definition:**
 - “systematic reviews use explicit and rigorous methods to identify, critically appraise, and synthesize relevant studies”
- **What are the key steps for conducting a systematic review?**
 - Develop a specific question
 - Conduct a systematic search for literature (e.g., e-databases, journal hand searches, key contacts, check reference lists, etc.)
 - Develop inclusion criteria (based on review question)
 - Apply inclusion criteria (in duplicate and independently)
 - Appraise the quality of studies that meet inclusion criteria
 - Extract relevant information from included studies (in duplicate and independently)



What types of situations can research be used?

Issue identification and characterization

- Struggles over how to define an issue are a critically important part of the decision-making process
- The outcome of these struggles influence whether and how decision-makers take action to address an issue
 - Need to ‘make the case’ that something warrants attention before action will be taken.
- **For influencing policy** - Efforts at issue definition that are cognizant of concurrent events within the policy and political “streams” of policymaking processes are more likely to generate action



Issue identification and characterization

- **An issue can come to light through several mechanisms**
 - Focusing events
 - A change in an indicator
 - Feedback from operation of a current policy / program
- **An issue can be defined as warranting action by**
 - Comparing current conditions with values concerning more ideal states of affairs
 - Comparing performance with that of other jurisdictions
 - Putting the subject in one category or another (i.e., framing)



Questions to consider when identifying an issue (1)

- **To fully work through identifying an issue, use local data to describe it in terms of whether it relates to one or more of:**
 - a risk factor, disease or condition (e.g., incidence or mortality rates)
 - a program, service or drug currently being used (e.g., what is currently being done and where are there gaps or limitations?)
 - the current health system arrangements within which programs, services and drugs are provided
 - Governance arrangements (i.e., who is allowed to do what)
 - Financial arrangements (i.e., what is covered and how is funding distributed)
 - Delivery arrangements (i.e., how services get to the people who need it)
 - the current degree of implementation of an agreed upon course of action (e.g., a policy)



Questions to Consider When Characterizing an Issue (2)

- **Describe the problem using:**
 - indicators that are available to establish the magnitude of the issue (or the factors that contribute to it)
 - comparisons that are available to establish the magnitude of the issue (or the factors that contribute to it)
 - particular framings of the issue (or the factors that contribute to it) that are likely to help mobilize support among different groups to address the issue



What types of data or evidence can help and what are some key sources? (1)

- **Systematic reviews of administrative database studies or community surveys can provide:**
 1. comparisons of data over time within organizations or settings
 2. comparisons of data between organizations or settings and other appropriate comparators
 - e.g., HIV systematic review clearinghouse (in development)
 - e.g. PPD/CCNC database (www.researchtopolicy.ca/search/reviews.aspx)



What types of data or evidence can help and what are some key sources? (2)

- **Single administrative database studies or community surveys that provide:**
 1. comparisons of data over time within organizations or settings;
 2. comparisons of data between organizations or settings and other appropriate comparators
 3. comparisons of data against plans
 4. comparisons of data against what stakeholders predicted or wanted

For example:

- Locally produced studies (e.g., community-based research)
- PubMed: AIDS or Health Services Research Queries (http://www.nlm.nih.gov/bsd/special_queries.html)
- Public Health Agency of Canada
- Canadian Institute for Health Information (www.cihi.ca)
- Institute for Clinical Evaluative Sciences (ON) (www.ices.on.ca)



What types of data or evidence can help and what are some key sources? (3)

- **Data that would enable you to make the same types of comparisons**
 - Ontario epidemiological data
 - Local epidemiological data
 - Public Health Agency of Canada
 - Canadian Institute for Health Information (www.cihi.ca)



What types of data or evidence can help and what are some key sources? (4)

- **Systematic reviews of qualitative studies that address the meanings that individuals or groups attach to the problem, contributing factors, indicators or comparisons**
 - HIV systematic review clearinghouse (in development)
 - Database of syntheses of qualitative evidence from the Joanna Briggs Institute (<http://www.joannabriggs.edu.au/cqrmg/login.php>)
 - PPD/CCNC database
- **Single qualitative studies that address the same topic**
 - PubMed HSR Queries (select qualitative research on the search page)



Identifying and characterizing 'solutions' to issues (1)

- **Organizations can face 3 situations that require them to characterize or identify policy options**
 1. The decision to act on a particular issue has already been made and the programmatic or policy option already selected
 - need to maximize benefits, minimize harms/risks, optimize impacts and implement a monitoring and evaluation plan
 2. Specific programmatic or policy options are being discussed and the benefits, harms and costs of each need to be weighed
 3. Face a tabula rasa where you can define a problem, identify and characterize programmatic or policy options, and look for the right timing that might allow you to act



Identifying and characterizing 'solutions' to issues (2)

- **Research evidence, particularly evidence about benefits, harms/risks, and costs, can help to inform whether a programmatic or policy option is considered viable**
- **A proposal can be deemed an appropriate solution if it**
 - Is technically feasible
 - e.g., benefits have been shown to be substantial and harms or risks acceptably low; the key elements of a policy are consistent with those elements that have been shown to be critical to success in other settings
 - Fits with dominant values and the current local, provincial or national mood
 - Is acceptable in terms of budget workability and likely stakeholder support or opposition



Identifying and characterizing 'solutions' to issues (3)

- **Identify potential 'solutions' by determining whether it involves confirming/changing:**
 - the program, service or drug currently being used to address a risk factors, disease or condition
 - the current health system arrangements within which programs, services and drugs are provided
 - delivery arrangements
 - financial arrangements
 - governance arrangements
 - the implementation strategies currently being used to support an agreed upon course of action



Identifying and characterizing 'solutions' to issues (4)

- **Describe each of the three options in terms of:**
 - its likely (positive) effects
 - its potential harms or risks
 - its costs and/or cost-effectiveness in relation to the status quo
 - its key elements
 - stakeholders views and experiences (if they are likely to influence a policy option's acceptability)



What types of research evidence can help and what are some key sources? (1)

- **Systematic reviews**

- Cochrane Library (*HIV/AIDS review group)
 - relate to the characterization of the effects of programs, services or drugs and/or implementation strategies targeting clinicians
 - ***All Cochrane reviews are now freely available to all Canadians for a 9-month trial period
- HIV systematic review clearinghouse (in development)
- health-evidence.ca (population and public health)
- PPD/CCNC database (health system arrangements)
- PubMed (AIDS special queries)



What types of research evidence can help and what are some key sources? (2)

What are the alternatives when no review can be found?

- Search for single studies
 - Cochrane Register of Controlled Trials (ignore the name because it contains any type of study of effects, not just controlled trials)
 - PubMed / MEDLINE
 - Locally available studies
 - Grey literature reports



Why focus on systematic reviews? (1)

- **There are approximately 1000 new articles indexed in Medline every day**

Straus S & Haynes B. CMAJ 2009; 180(9): 942-945.

- **Medline search earlier this week:**
 - 'HIV' = 198,010 hits
 - 'HIV' and 'prevention' = 40,564 hits
- **Systematic reviews help synthesize and make sense of this large volume of research evidence for you**



Why focus on systematic reviews? (2)

Systematic reviews offer four advantages over single studies in defining issues and characterizing 'solutions':

- Likelihood of being misled by research is lower (bias is reduced)
- Confidence in what can be expected from an intervention is higher (precision is increased)
- More efficient use of time: literature has already been selected, appraised and synthesized in a rigorous manner
 - Can instead focus on collecting and synthesizing other types of evidence, such as local evidence about the current situation and feasibility and acceptability in terms of stakeholders, community members, budget workability and likely political support or opposition
- Allow public interest or civil society groups, to constructively contest research evidence because it is laid out for them in a more systematic and transparent way



Why focus on systematic reviews? (3)

Systematic reviews can also be conducted for:

- Administrative database studies and community surveys that help to place problems in comparative perspective
- Observational studies that help to characterize a policy option's likely harms or risk
- Qualitative studies that help to understand the meanings that individuals or groups attach to a problem, how and why policy options work, and stakeholders' views about and experiences with particular policy options



Why focus on systematic reviews? (3)

Several constraints have hindered the greater use of systematic reviews beyond the clinical sector

- Misconceptions about them (e.g., only for RCTs, only for effects, only for those working in biomedical paradigms, only if statistical synthesis is possible)
- Poor retrievability – Need 'one-stop shopping'
- Limited understandability – Need user-friendly summaries of systematic reviews



Supporting the use of research evidence (1)

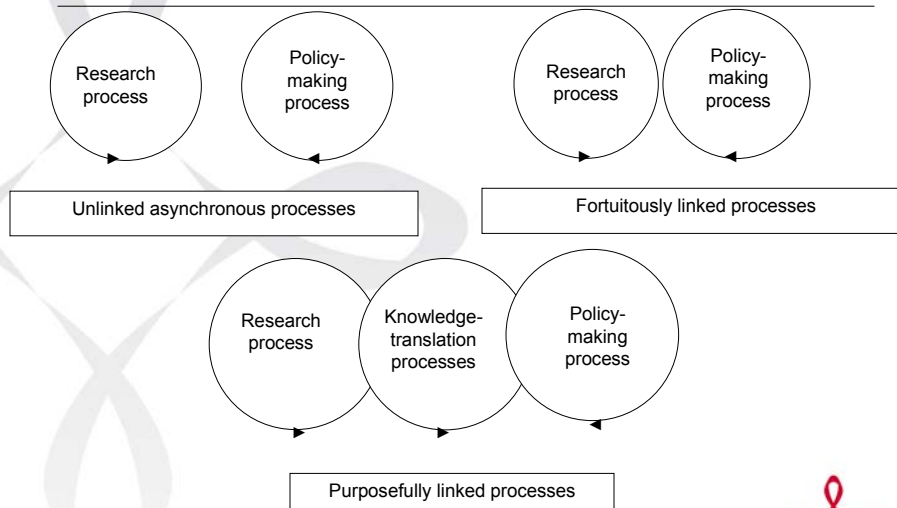
Increasingly efforts to support linking research to action strive to address the two factors that emerged with some consistency in a systematic review of the factors that increased the prospects for research use

- Interactions between researchers and policymakers
 - Engage policymakers in priority-setting, research (including reviews), and deliberative dialogues
- Timing / timeliness
 - Facilitate retrieval of optimally packaged, high-quality and high-relevance systematic reviews and policy briefs (e.g., one-stop shopping, rapid response units)

•ASOs in Ontario indicated through a survey that they generally lack capacity to acquire, assess, adapt and apply research evidence



Supporting the use of research evidence (2)



What is KTE? – Definition

Canadian Institutes of Health Research

Knowledge Translation:

“Knowledge translation is the exchange, synthesis and ethically-sound application of knowledge - within a complex system of interactions among researchers and users - to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system.”



Some core themes...

1. Exchange of knowledge
2. Application of knowledge
3. Interaction or “exchange” between the users and producers of research/collaborative problem solving
4. Occurs through multiple processes
5. Mutual learning
6. Goals: improved health, services and products and health systems
 - ***Evidence-informed decision-making



Challenges in linking research to action and how are we are addressing them (1)

1. Research competes with many other factors in the decision-making processes

- Difficult to address as there are always many factors to consider

2. Research isn't valued as an information input

- Convince stakeholders (policymakers, community-based organizations, etc.) to place value on the use of research by highlighting examples from the past or from other jurisdictions where research made the difference between policy success and policy failure



Challenges in linking research to action and how are we are addressing them (2)

3. Research isn't relevant

- Engage stakeholders periodically in priority-setting processes and communicate the priorities to researchers (including short-term requirements for policy briefs or rapid summaries, medium-term term requirements for systematic reviews, and long-term requirements for new primary research)



Challenges in linking research to action and how are we are addressing them (3)

4. Research isn't easy to use

- a) Research isn't communicated effectively
 - Identify systematic reviews and other evidence on timely topics, identify the key messages arising from the reviews, construct workable options and circulate the 'evidence brief' to relevant stakeholders
- b) Research isn't available when needed and in a form that makes it easy to use
 - HIV systematic review clearinghouse: Develop and maintain a community-targeted website that provides "one stop shopping" for optimally packaged high-quality and high-relevance systematic reviews
 - OHTN Rapid Response Service: ASOs can submit a request for rapid synthesis (2-3 weeks or longer) on an issue they need research evidence for. A succinct synthesis is provided that highlights the key messages from the literature



Challenges in linking research to action and how are we are addressing them (4)

4. Research isn't easy to use (continued)

- a) Lack of prompts for using research in decision-making
 - Revise decision-making processes to have a specific prompt to identify and incorporate research evidence where possible
 - Allow stakeholders to sign-up to receive updates from the HIV systematic review clearinghouse about pre-specified topics of interest
- b) Lack of forums where issues can be discussed with researchers and stakeholders
 - Plan forums at which pre-circulated evidence summaries serve as the starting point for off-the-record deliberations involving community, policymakers, stakeholders, researchers and others (e.g., OHTN Think Tanks, the new McMaster Health Forum)



Challenges in linking research to action and how are we are addressing them (5)

In other words:

1. Foster a culture for research among target audiences
2. Produce relevant research
3. Actively link research to action
 - “Push”
 - Facilitate “pull”
 - “pull”
 - “exchange”



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Questions?

