

Session 1:

# Moving from research participant to research collaborator



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# Objectives

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- To gain knowledge and skills in engaging patients throughout the research enterprise
- To gain knowledge and skills in engaging patients in research priority setting

# Developing the research agenda

- Priority setting exercises
  - James Lind Alliance
    - <http://www.jla.nihr.ac.uk/>
  - WHO approach – checklist for health research priority setting
    - <http://www.health-policy-systems.com/content/8/1/36>

# Developing the research agenda

- Developing the steering committee
- Identifying the scope
- Identifying areas of uncertainty/research gaps
- Verifying research gaps/uncertainties
- Interim priority setting
- Final priority setting
- Dissemination
- Evaluation

# Designing the study

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- Establishing participant characteristics
- Developing recruitment strategies
- Designing the intervention
- Ensuring vulnerable groups are represented
- Developing data collection strategies

# Conducting the study

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- Collecting data
- Recruiting participants
- Participating in the DSMB
- Interpreting data

# Disseminating the study results

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- Developing key messages
- Identifying audiences for dissemination
- Functioning as knowledge brokers

# Evaluating engagement

- Respect
- Trust
- Fairness
- Legitimacy
- Competency
- Accountability
  - Deverka et al, J Compar Eff Res 2012;397



# Reporting stakeholder engagement

- Engagement purpose
- Stakeholder orientation information
- Stakeholder recruitment
- Methods of engagement
- Prioritisation methods
- analysis
  - J Clin Epi 2013;66:666-74

# RESEARCH MINUTE

December

http://odprn.ca/research/research-impacts/

Research Impacts | ODPRN

odprn.ca



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## Blood glucose test strips

Blood glucose test strips are typically prescribed to patients with diabetes, but have limited clinical benefit among certain groups of individuals, leading to potential overuse and significant costs to the healthcare system. The ODPRN analyzed potential cost avoidance related to hypothetical scenarios involving changes the quantity of blood glucose test strips dispensed. Research findings identified between \$26 and \$300 million CAD in potential cost savings over 5 years. The Ontario Public Drug Programs considered this research, in addition to considering information on clinical benefit, when moving to introduce quantity limits for blood glucose testing strips in 2013.

**Find Out More:** [Publications](#), [Knowledge Exchange](#)

## Pulmonary Arterial Hypertension

Pulmonary arterial hypertension (PAH) is a rare and potentially life-threatening condition. Prior to 2010, the Ontario Public Drug Programs only funded PAH monotherapy (i.e. one drug at one time) due to the lack of evidence on the effectiveness and safety of PAH combination therapy (i.e. multiple drugs at one time). Clinicians and patients advocated to the MOHLTC that this was an impediment to optimal care. The ODPRN conducted multiple studies on the prescription and utilization of PAH drugs in Ontario; this information contributed to PAH drug funding changes, which were enacted in June 2010. Funding was expanded to include combination therapy of selected PAH drugs, and PAH drug initiation was restricted to Ontario's five Centres of Excellence.

**Find Out More:** [Publications](#), [Knowledge Exchange](#)

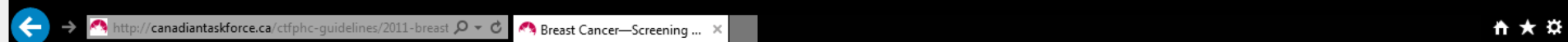
**The Ontario Drug Policy  
Research Network**  
St. Michael's Hospital  
30 Bond St.  
Toronto, ON Canada  
M5B 1W8

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# ABSOLUTE BENEFIT OF SCREENING WITH MAMMOGRAPHY

If we screened 2,100 women, aged 40–49 years, at average risk of breast cancer every two



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ENGLISH French · Français

PRIMARY CARE PRACTITIONERS Switch to General public



Canadian Task Force  
on Preventive Health Care

SEARCH

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## CTFPHC Guidelines

Overview  
Obesity in Children  
Obesity in Adults  
Prostate Cancer  
Depression  
Cervical Cancer  
Hypertension  
Type 2 Diabetes  
**Breast Cancer**

### UPCOMING GUIDELINES

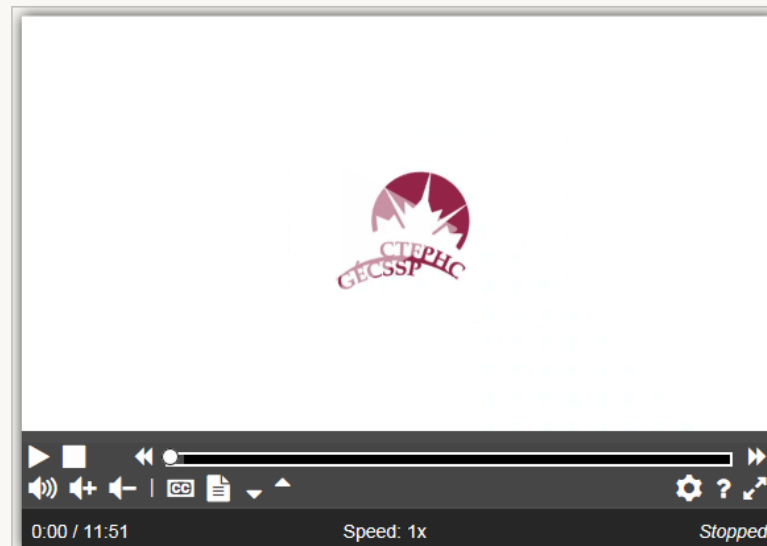
Cognitive Impairment  
Colorectal Cancer  
Lung Cancer  
Developmental Delay

### ADDITIONAL PUBLICATIONS

The Red Brick  
Other guidelines (1979–2006)  
Other documents (1979–2006)

## Breast Cancer—Screening Guideline Video

### VIDEO



The Canadian Task Force on Preventive Health Care has released a video to aid in facilitating the doctor-patient discussion around breast cancer screening.

## Guideline documents

Overview  
CMAJ Publication  
Clinician CBE/BSE Recommendation  
Clinician Mammography Recommendation

## Tools

Patient Algorithm  
Patient FAQ  
Risks & Benefits, Age 40–49  
Risks & Benefits, Age 50–69  
Risks & Benefits, Age 70–74

## Additional documents

Systematic Review  
Protocol  
Screening Guideline Video  
Guideline Presentation

## I AM A WOMAN BETWEEN THE AGES OF 25 AND 69. WHY SHOULD I BE SCREENED EVERY 3 YEARS?

- Among women who do not screen, the lifetime risk of dying from cervical cancer is about 1 in 100
- Among women who screen every 3 years, the lifetime risk of dying from cervical cancer is about 1 in 500
- Among women who screen annually, the lifetime risk of dying from cervical cancer is about 1 in 588

After the age of 25, the likelihood of being diagnosed with cervical cancer increases dramatically. 86% of women who get cervical cancer are between the ages of 25 and 69. Screening with a Pap test improves a woman's chances of survival from cervical cancer. However, screening more often than every 3 years may not add any additional benefits and may expose women to more frequent "false positive" or abnormal Pap test results. About 3% of women over the age of 30 will have an abnormal Pap test result, which may lead to additional unnecessary tests ([see "What else should I know about cervical cancer screening?" below](#)).

## I AM A WOMAN 24 YEARS OF AGE OR YOUNGER. SHOULD I BE SCREENED FOR CERVICAL CANCER?

- About 1% of women who get cervical cancer are 24 years of age or younger
- Women 20 to 24 years of age have a less than 1 in 500 000 chance of dying from cervical cancer

Because there is such a small risk of being diagnosed with and dying from cervical cancer, young women are very unlikely to benefit from cervical cancer screening. Additionally, about 10% of young women have an abnormal Pap test result. This makes young women 24 years of age or younger more likely than older women to be exposed to additional testing that may be unnecessary ([see "What else should I know about cervical cancer screening?" below](#)).

## WHAT ELSE SHOULD I KNOW ABOUT CERVICAL CANCER SCREENING?

Sometimes a Pap test shows abnormal cells in the cervix. An abnormal test result does not mean

# Engaging patients in systematic reviews

- Question formulation
- Search
- Appraisal
- Data collection – selection of outcomes
- Interpretation
- Dissemination of results
  - Examples

# Exercise

- You are working with a team to establish research priorities for older adults (aged 65 years and older) with 2 or more chronic diseases (including the 10 commonest chronic diseases, namely cardiovascular disease, stroke, hypertension, diabetes, COPD/asthma, depression, arthritis, osteoporosis, cancer, dementia) and their caregivers.
  - This is envisioned to be a national initiative and will include frail elderly and their caregivers, as well as those who speak English and French.
- Small group discussion:
  - How would you engage patients and caregivers in this?
  - What are potential challenges to their recruitment and involvement in this exercise?