



The Ottawa
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Bell Patient Decision Support Laboratory Recognition & Media event Monday, February 2, 2004

INTRODUCTION

The Canadian public will benefit from unique tools called “decision aids”, thanks to the opening of the Bell Patient Decision Support Laboratory – the first in Canada. These tools will help better prepare patients to discuss difficult decisions about their health or that of their loved ones with their health practitioners.

As part of their ongoing commitment to the healthcare sector and to the Ottawa area, Bell Canada has chosen to partner with the Ottawa Hospital Foundation to help launch this exciting initiative, in support of the Ottawa Health Research Institute (the research arm of The Ottawa Hospital). Decision aids will also help to train call center nurses, doctors, and other professionals in coaching and counseling patients facing tough decisions.

The new Bell Patient Decision Support Laboratory will also be the world’s clearinghouse for decision aids and will lead an international team of researchers to set standards in their design and testing.

QUESTIONS AND ANSWERS

What is the Bell Patient Decision Support Laboratory?

The Bell Patient Decision Support Laboratory will identify innovative solutions to support patients making tough, shared, healthcare decisions. Tough decisions may have multiple options, uncertain outcomes, or benefits and harms that people value differently.

When did this research begin?

In 1982, Dr. Annette O’Connor, Director of the new laboratory, began researching ways to help patients and their families facing difficult and emotional decisions, in order for them to feel more confident in their choices. This research led to the development of several ‘decision aids’ on topics such as hormone therapy, breast cancer surgery, prostate cancer treatments, tube feeding, blood transfusions, end of life care, and care facilities for seniors.

What is a decision aid?

Aside from providing the latest scientific information on options, outcomes, and probabilities, decision aids guide people to clarify the personal importance of benefits versus harms and emphasize personal involvement in decision making. Using personal worksheets, patients can communicate to their families and health professionals what they value in balancing benefits and harms and what role they prefer in decision making.

Decision aids do not provide advice nor are they meant to replace professional counseling. Although decision aids usually focus on options for a specific condition, Canadians can also access a decision aid, known as the Ottawa Personal Decision Guide, for any health or social decision (school, child care, employment, retirement). People are coached to assess their decisional needs and build their own 'balance scales' to rate the features of their options.

How will decision aids help Canadians?

Standard care is not enough to ensure quality decision making for tough choices. People who are prepared with decision aids participate more, know more about the alternatives, and are more likely to get options that match their values. Their discussions with health professionals are more satisfying to both parties, in that professionals spend less time presenting facts and more time listening and discussing the personal concerns of the patient and family.

Will this be available for all Canadians?

Canadians can access over 150 decision aids at their convenience through the Web site at: www.ohri.ca/decisionaid. There is also a research database of 500+ decision aids in various stages of development, evaluation measures, and training programs.

How is this Web site different from other medical information sites?

Not all medical information is in the form to help people make tough personal choices. This website compliments others as the world's clearinghouse for decision aids. An international team evaluates each one to determine whether they are based on the latest scientific evidence, balanced, effective in promoting informed values-based decisions, and developed by a credible team.

Are decision aids also available in French?

The bulk of decision aids developed around the world are in English. The Lab is assembling an international team of French speaking researchers to make as many tools as possible available in French.

What are the other features of the Bell Patient Decision Support Laboratory?

- Researchers are working with health care providers to find ways to integrate decision support as part of the process of care.
- A physical lab is located at the Civic Campus of The Ottawa Hospital. There are computer workstations to give patients access to the internet-based decision aids.
- TV/VCRs give patients access to video-based tools;
- Audio and video recording hardware evaluate how patients interact with decision aids on the Web;
- Computer servers maintain the online portal, to provide linkages and share data with call centres and information services throughout Canada and the U.S.;

- Meeting rooms for focus groups and interviews with patients, practitioners, and policy-makers.

What has been the cost and what is the total funding for this project?

The cost to build the laboratory and develop the online portal was \$300 000 (provided by Federal Government– CFI and Province of Ontario– OIT)

Bell Canada is investing \$500 000 over three years to cover operational costs

Why has Bell chosen to partner with The Ottawa Hospital Foundation on this initiative?

Bell's investment in the first Patient Decision Support Laboratory in Canada reflects their ongoing commitment to the healthcare sector and patients through the use of innovative technologies. This partnership with The Ottawa Hospital builds on their continued involvement in the Ottawa area following their recent announcement as a founding sponsor of the pediatric palliative care facility at CHEO.

Who are decision aids developed for?

- Anyone facing a tough choice regarding their health or that of their loved ones
- Any healthcare practitioner that is presenting a difficult choice to their patient
- Researchers
- Students

Interesting statistics

- In a recent survey, 65% of Canadians reported making tough healthcare decisions, commonly about medical or surgical treatments or birth control.
- More Canadian women (73%) report making difficult decisions than men (56%).
- Most Canadians prefer to take an active role when facing difficult healthcare decisions, often sharing their decisions with family members
- 59% of Canadians report experiencing uncertainty when facing tough decisions, especially females, or those who feel uninformed, pressured to select one option, or unskilled in decision making. The highest rates of stress and decision delay are those deciding about placing a relative in an institution.
- When choices depend on personal values, over 90% of Canadians endorse the notion that a 'good' decision is one that is informed, consistent with personal values and enacted.

Source: O'Connor AM, Drake ER, Wells GA, Tugwell P, Laupacis A, Elmslie T. A survey of the decision-making needs of Canadians faced with complex health decisions. Health Expectations 6(2):97-109, 2003