

# HIC 2009

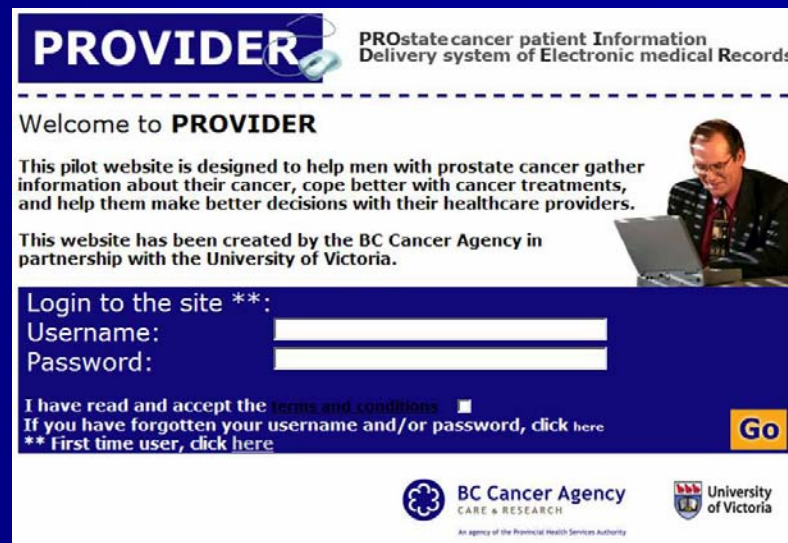
## PROVIDER

### A Personal Health Record for Men with Prostate Cancer

**Howard Pai, MD, FRCPC**

Radiation Oncologist,  
BC Cancer Agency – Vancouver Island Centre  
Victoria, British Columbia, Canada

Univ. British Columbia - Faculty of Medicine  
Univ. Victoria - Health Information Science



**PROVIDER** PROstate cancer patient Information  
Delivery system of Electronic medical Records

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Welcome to **PROVIDER**

This pilot website is designed to help men with prostate cancer gather information about their cancer, cope better with cancer treatments, and help them make better decisions with their healthcare providers.

This website has been created by the BC Cancer Agency in partnership with the University of Victoria.

Login to the site \*\*: ☐

Username:


Password:


I have read and accept the [terms and conditions](#) ☐

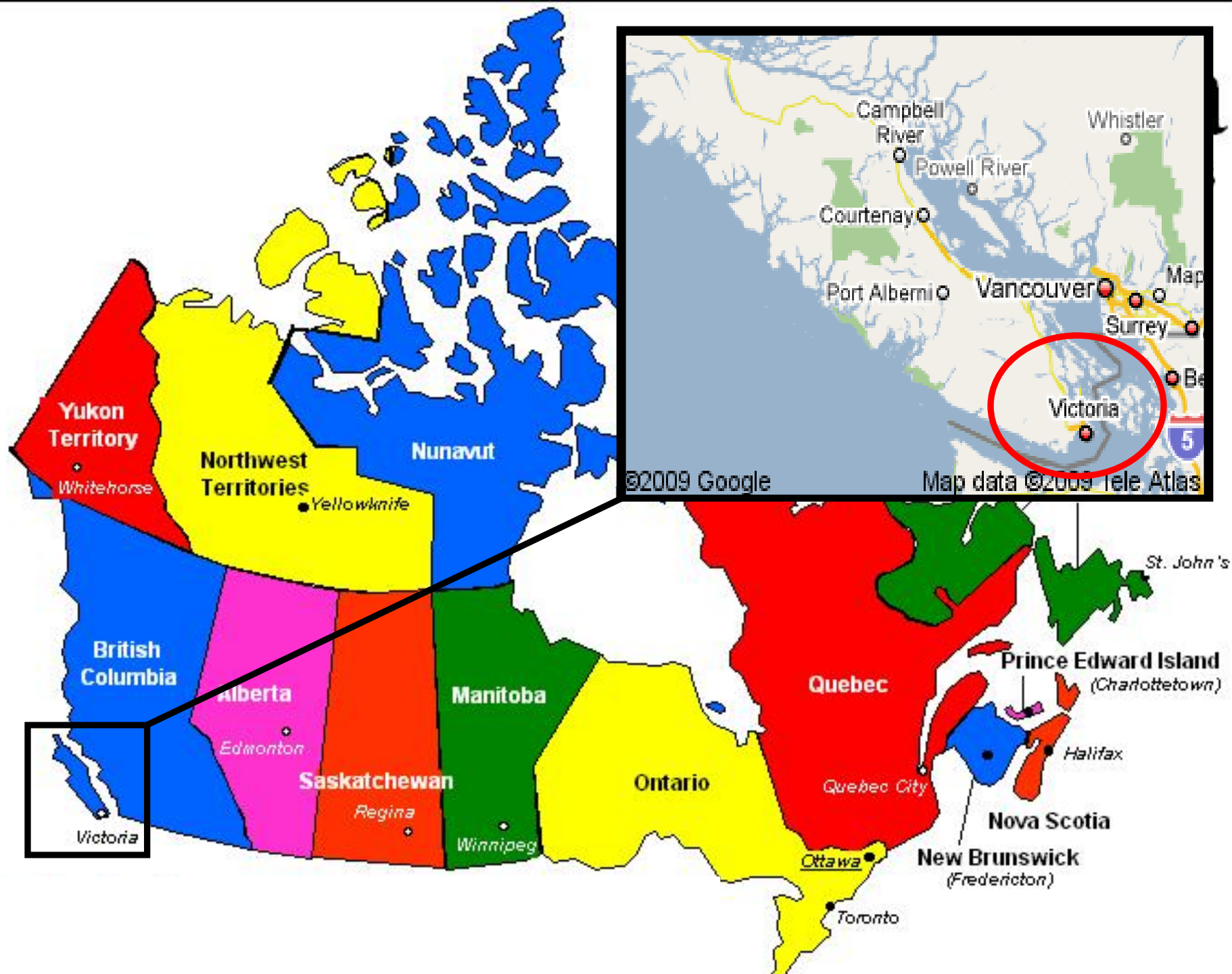
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 **BC Cancer Agency**  
CARE & RESEARCH  
An agency of the Provincial Health Services Authority

 **University of Victoria**







# Rationale for Patient Access to EHR (PAEHR)

- Prostate cancer (PC) fits the common, chronic disease paradigm
- Patients engaged in self-care & medical decision making
- PC patients are information seeking; gaps exist
- Patients use computers (e.g. Internet) to access health information
- Canada healthcare system adopting EHR

# What are the perceived benefits of providing patients access to health information and records?

- Self-management/care
- Empowerment
- Knowledge
- Decision making
- Compliance/adherence
- Navigation
- Communication
- Distress, coping
- Satisfaction
- Health outcomes
- Transitioning (e.g. diagnosis → treatment → survivorship)

# *Web-based electronic health information systems for prostate cancer patients*

Howard H. Pai, MD,<sup>1,2</sup> Francis Lau, PhD<sup>2</sup>

<sup>1</sup>BC Cancer Agency, University of British Columbia, Vancouver, BC, Canada

<sup>2</sup>University of Victoria - School of Health Information Science, Victoria, BC, Canada

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PAI HH, LAU F. Web-based electronic health information systems for prostate cancer patients. The Canadian Journal of Urology. 2005;12(3):0000-0000.

*Introduction:* Providing men with prostate cancer (MPC) timely access to their health records and information (HRI) can enhance their ability to understand their condition and engage in shared medical decision making with their health care provider (HCP). The Internet is a potential means of enhancing such interactions.

*Materials and methods:* Two surveys were conducted at a PC support group in Victoria, BC to identify the health information needs of MPC and the ability to access their HRI. Another objective was to identify the potential role of web-enabled HRI systems at meeting these needs. Sixty-one participants (41 men and 18 spouses/significant others (SS)) completed

then took part in a focus group meeting using a second questionnaire.

*Results:* The majority of men (median age 70 years) were knowledgeable with the computer and Internet. The majority of men (75%) desired the ability to access their HRI through means other than by meeting with their HCP, with the Internet ranking as one of the most desired methods. There was broad interest in accessing various parts of their health record and during different phases of their care. Most men were willing to try a personalized patient web-enabled HRI system. Over 70% of SS desired the ability to access their men's HRI.

*Conclusions:* The surveys indicate that the Internet is a desirable means of accessing electronic HRI and support the potential role of web-enabled HRI systems for PC patients.

**Key Words:** prostate cancer, health information,

# Survey Results

- Most used computers for health information access
- Desired access to all aspects of medical record, during all phases of care
- Electronic means was preferred

# PROVIDER

- **P**rostate Cancer Patient **I**nternet-based **D**elivery System of **E**lectronic medical **R**ecords
- Proof of concept research study
- BC Cancer Agency – Vancouver Island Centre
- Univ. Victoria - Health Information Science & Research Computing Centre
- Grassroots initiative



# What is PROVIDER?

- Personal Health Record (PHR) for PC patients
- Private & secure access over Internet to:
  - Up-to-date EHR
  - e-Health tools
  - PC-related general health information

# Objectives

## ■ Assess:

- Security & integrity
- Usage pattern
- Desired organization of EHR
- Perception of benefits & risks, satisfaction level

# Acknowledgements

- Univ Victoria

- Francis Lau (HIS)
- Francis Ho (HIS)
- Noah Ries (HIS, Law)

- BC Cancer Agency

- Stuart Jones (Med student)
- Sam Christie (Web communications)
- Jeff Barnett (Director Clinical Informatics)
- Stephanie Soon (Pharmacy)
- Maria Cristina Barroetavena (Rehab)
- Charles Ludgate (Rad Onc)
- Paul Blood (Rad Onc)

- Provincial Health Services Authority

- Elaine Sawatsky (Privacy)

# Methods

- 22 PC patients at BCCA
- Median age 64 yr, 75% post-secondary education
- Phases of care:
  - Initial diagnosis/work-up 19%
  - Active treatment 42%
  - Follow-up 10%
  - Recurrence 29%

# Methods

- Eligibility, consent, register patient
- Release of information
- Set up PROVIDER account
- Health Information Services approval for release of records → Print EHR from Cancer Agency → Scan printed records into computer → Convert to PDF format → Upload to UVIC Computing Research Facility
- EHR and appointment info updated every 48 hr
- Tutorial
- Provide access x 6 months
- Patient diary + interview

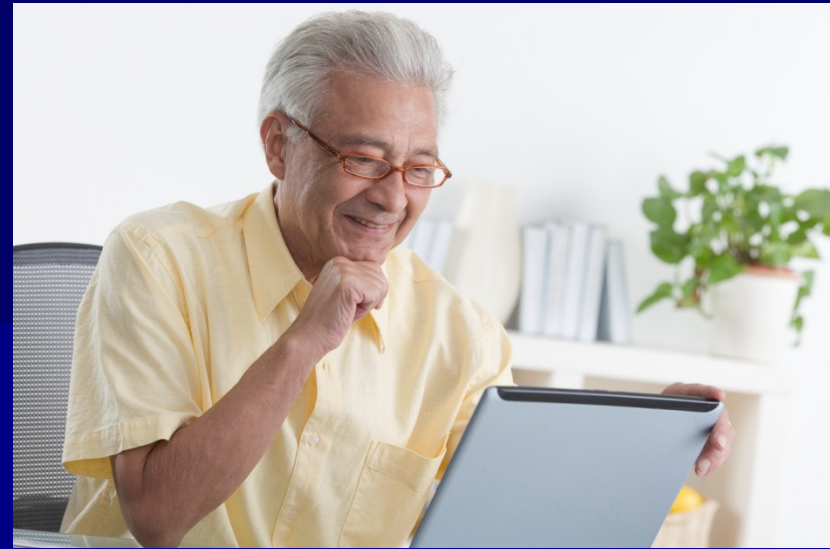


# PROVIDER Features



- Appointment calendar
- Messaging
- PC-related health info, web-links & glossary
- e-Health tools

# e-Health tools



- Hormone therapy teaching tutorial
- Distress monitoring
- Clinical trials eligibility screening tool
- PSA monitoring

# PROVIDER

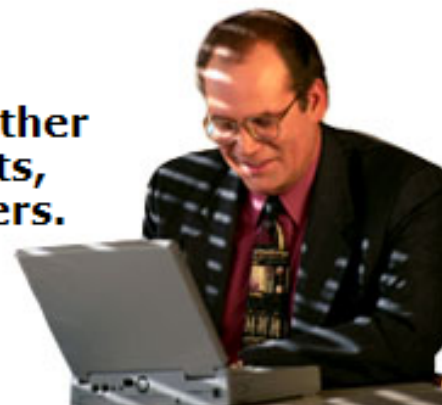


PROstate cancer patient Information  
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## Welcome back Mr. TEST ONE to PROVIDER website

To learn more about this website, please click the "ABOUT US" button at the top left hand side of this page.

The last time you logged on was Oct-06-2008. You have the following new items to review:

### No New Items

You may proceed to other sections of PROVIDER.



[Home](#)  
[Log Off](#)

## Get Profile/Records

- [Your Profile](#)
- [Treatments Received](#)
- [Medications](#)

## By Dates

- [From Oldest Record](#)
- [From Recent Record](#)

## By Record Type

- [From Oldest Record](#)
- [From Recent Record](#)

## By Calendar

- [by Month](#)
- [by Year](#)

## Your prostate cancer profile

[printer friendly](#)

The information provided below is a summary of your medical information regarding your prostate cancer. This information is used by your health care provider to help make decisions regarding management of your cancer and your healthcare. You may find this useful to help understand your cancer and treatment better. We are interested in your feedback. If you come across terms that you are not familiar with, please go the "RESOURCES" section at the top, and then click the "EDUCATIONAL TOOLS" option on the left panel followed by clicking "GLOSSARY". This takes you to a website that provides definitions of terms and words commonly used in prostate cancer.

Age at Diagnosis:	56
Date of Diagnosis (biopsy):	2002-03-03
Cancer Type (histology):	adenocarcinoma
Primary Gleason Grade:	3
Secondary Gleason Grade:	4
Total Gleason Score:	7
Number of Biopsy Cores Taken:	7
Number of Biopsy Cores containing cancer:	7
Percent Positive Biopsies:	100
Clinical TNM stage - T:	T2b
Clinical TNM stage - N:	N1
Clinical TNM stage - M:	M1b
Pathological TNM stage - T:	T2c
Pathological TNM stage - N:	N1
Pathological TNM stage - M:	M1b
Pre-treatment PSA:	7.60
Date of pre-treatment PSA:	2004-01-01



## **Your Medical Records**

**The following is a list of your medical records sorted by type of record (start with most recent record):**

### **Record Type**

- ☐ BC Cancer Agency Doctor notes
  - [08/03/2006](#)
- ☐ Correspondence
  - [08/11/2005](#)
  - [25/10/2005](#)
- ☐ Imaging
  - [03/02/2006](#)
  - [03/02/2006](#)
- ☐ Laboratory & other Investigations
  - [05/01/2007](#)
  - [06/04/2006](#)
  - [08/12/2005](#)
  - [16/05/2000](#)
- ☐ Pathology
  - [12/10/2005](#)
- ☐ Operations & Procedures
  - [12/10/2005](#)

MDS Metro Laboratory Services	
Name: _____	Accession #: _____
Age:    Sex: M	Birth Date: _____
PHN #: _____	Report Date/Time: 07-APR-06 14:40
Patient's Phone #: _____	Postal Code: _____
Collection Date/Time: 06-APR-2006 8:04	Received Date/Time: 06-APR-2006 8:04

(COPY) DR \_\_\_\_\_

(COPY) \_\_\_\_\_

DR \_\_\_\_\_  
BC CANCER AGENCY VICTORIA  
2410 LEE AVE  
VICTORIA BC V8R 6V5

TEST	OUT OF RANGE	WITHIN RANGE	REFERENCE RANGE AND COMMENTS
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This Standing Order will expire on 06-JAN-2007.  
If this Standing Order is still required, please provide your patient with a new laboratory requisition prior to this date.

PSA

0.07    &lt;6.5                    ug/L

Ninety-eight percent of normal males have values within the reference range. Twenty percent of patients with carcinoma of the prostate also have normal values. Most of these patients will have stage A disease.

## Your Support Tools

- **PSA Monitoring Tool**
- Distress Monitoring Tool
- Hormone Therapy Tutorial
- Study Eligibility Tool

[Home](#)  
[Log Off](#)

## Your PSA Profile



printer friendly

We have included your PSA results in a table. You may find this useful to help track your PSA levels.

	Date	PSA
0	2007-01-01	0.01
1	2008-02-02	5.1
2	2008-03-03	6
3	2008-03-09	7.3

## Your Eligible Clinical Studies

- EP0906A (doc)
- GUDEZO (doc)
- BAY43-9006 (doc)
- GUTPPS2 (doc)
- GUPPS2 (pdf)

## Clinical Trials Screening Tool

This section provides you a list of research or clinical studies in prostate cancer currently available at the BC Cancer Agency and in Greater Victoria community that you may be eligible for. These studies have been selected based on your personal profile and cancer.

**What is a research or clinical study?** These studies involve participation by cancer patients to provide information, blood or other tissue samples or to receive a treatment or medical procedure. In fact, by using the PROVIDER website, you are already participating in a research study.

**Why participate in a study?** In order to advance our knowledge on cancer, its diagnosis, treatment and effect on people, we must conduct these studies to scientifically validate their usefulness. Without completing these studies the true effectiveness and safety of many treatments and procedures would be more difficult to confirm. The BC Cancer Agency is committed to cancer care and research. We value your voluntary participation in our studies. All studies are approved by a scientific ethics committee to determine its value, safety and potential risks and benefits to humans.

We encourage you to review the studies located in the left side bar by clicking them and viewing the consent form provided for each study. A consent form is a document that describes the study in detail including the purpose of the study, the potential benefits and harms from participating in the study and the procedures or type of participation expected of you.

If you are interested in learning more about certain studies or participating in them, please contact your physician or nurse at the BC Cancer Agency at 800 670 3322 and they will assist you. Alternatively, you may send a message to Stuart Jones, the research assistant for PROVIDER using our "MESSAGES"

# What are “hormones”?



- Substances that occur naturally in the body
- Prostate cells grow in response to the release of male hormones.





# Usage results

- 3.4 logins / pt-month
- Usage ↓ with time

## Website feature

## % Usage

EHR

94%

Appointments

82%

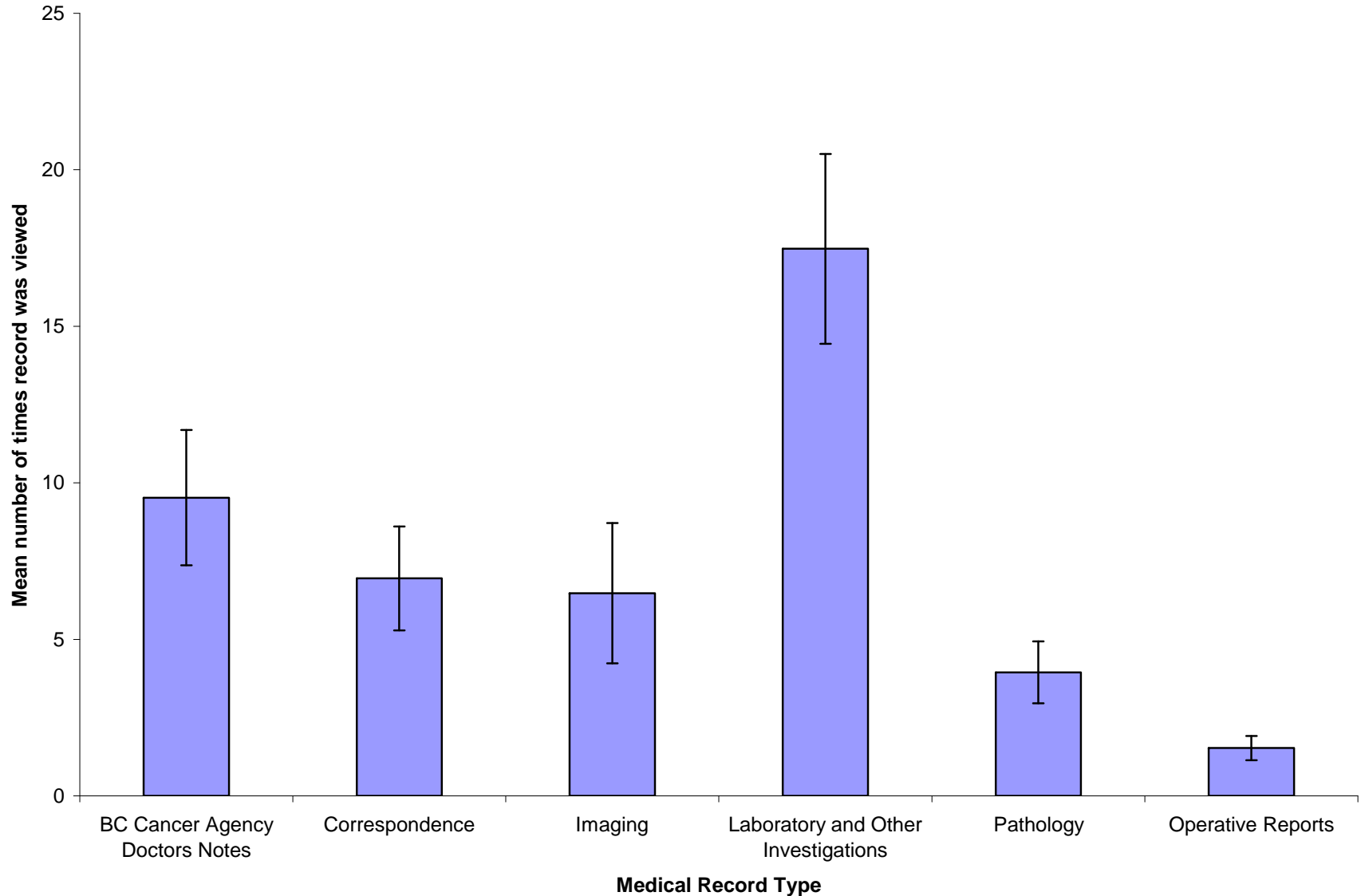
Messaging

59%

PSA monitoring tool

82%

# Medical records



# Survey results

## ■ Patient perceptions:

- 65% Privacy & security preserved
- 75% Communication with doctor improved
- 83% Discovered new info
- 82% Information was useful
- 6% Important info missing
- 67% PROVIDER answered all questions
- 6% Preferred to see doctor instead of PROVIDER

# Survey results

- 88% would use PROVIDER again
- 100% recommend to others
- Overall satisfaction:
  - 12% Good
  - 41% Very good
  - 47% Excellent

# Comments from patients...

- Transparency of medical records using PHR builds trust between doctor & patient
- Patient valued having up-to-date access of his medical records to help with his own research and prepare himself for doctors appointments
- Records helped inform family members because he could answer questions by showing them the reports
- PROVIDER helped remind and reinforce what doctor said during appointment



# Comments from patients...

- Printout of EHR was used for an out-of-province physician looking after patient
- Results from EHR created significant anxiety for patient's spouse, which was later alleviated following meeting with physician
- Found doctor notes very insightful
- Patient felt more involved with his own care
- Government should acknowledge importance of PHRs

# Discussion

- PROVIDER was well received by patients
- Perceived benefits using PHR:
  - Communications
  - Knowledge generation
  - Ease of access

# Discussion

- PROVIDER study support a role for PHR for PC patients
- Significant institutional barriers
- Lack of awareness re: PAEHR & PHR