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Consumer Health Informatics Summit

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ASSOCIATION CANADIENNE
D'INFORMATIQUE DE LA SANTÉ



October 30, 2007 – Ottawa, Canada

OCRI

Program

Registration	8:15 – 8:45
Welcome	8:45 – 9:00
Opening Keynote Chaired by Khaled El Emam Consumer Health Informatics: Supporting the high-touch Alex Jadad	9:00-10:00
Break	10:00-10:30
Session 1 Chaired by Michael Martineau Will the Consumer Please Stand Up Matt Anderson The Chronic Need for Connectivity: Helping today's aging health care consumers help themselves Garry Folker Joint Q&A/Discussion	10:30-12:00 10:30-11:05 11:05-11:40 11:40-12:00
Lunch	12:00 – 13:00
Session 2 Chaired by Gunther Eysenbach Using Web Based Tools to Help Patients Achieve Optimal Clinical Outcomes Jay G. Mercer Electronic Personal Health Records: Challenges for Development and Adoption Tom Jones Joint Q&A/Discussion	13:00-14:30 13:00-13:35 13:35-14:10 14:10-14:30

Break	14:30-15:00
Session 3	15:00 – 16:30
Chaired by William Pascal	
The Internet Changes Everything: Lessons from other industries Michael Martineau	15:00-15:35
Extreme Makeover: Consumerism, the EHR and the transformation of health care Shelagh Maloney	15:35-16:10
Joint Q&A/Discussion	16:10-16:30
Closing Remarks	16:30 – 16:45

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Introduction

In today's business environment it is commonly accepted that information and communications technology will be deployed to improve service delivery and reduce costs. How will this model be integrated into Canada's healthcare system? How can technology improve healthcare delivery, patient participation and the patient experience? This Consumer Health Informatics Summit, the first of its kind in Canada, addresses these issues and explores the technical, social and professional implications of consumer empowerment.

Consumers, who are not necessarily suffering from any illness, are increasingly playing a more active role in their health care. This means that they are better informed about life style choices, disease etiology, treatment options, available drugs and their side effects, providers, and coping strategies. These are empowered consumers.

Information Technology can play an important role in supporting and facilitating such empowerment by providing access to reliable information, allowing communication with peers and professionals, making available information and access to tools for disease management and decision making, and providing access to electronic medical records. To the extent that such technologies are adopted, financial and capacity pressures on the overall health care system can also be eased.

New players outside the health care system are helping provide this technology. These intermediaries are bringing in knowledge and expertise from other domains to define the future of consumer informatics and facilitate its adoption.

This outcome of the presentations and discussions at this Summit will be a report that we hope will guide policy making and help define a research agenda. We are looking forward to your input at the Summit and feedback on the report.

Biography of Chair: Opening Keynote

Khaled El Emam, CHEO RI and University of Ottawa

Dr. Khaled El Emam is an Associate Professor at the University of Ottawa, Faculty of Medicine and the School of Information Technology and Engineering. He is also a Canada Research Chair in Electronic Health Information at the University of Ottawa. Previously, Dr. El Emam was a Senior Research Officer at the National Research Council of Canada, and prior to that he was head of the Quantitative Methods Group at the Fraunhofer Institute in Kaiserslautern, Germany. In 2003 and 2004, he was ranked as the top systems and software engineering scholar worldwide by the Journal of Systems and Software based on his research on measurement and quality evaluation and improvement, and ranked second in 2002 and 2005. He holds a Ph.D. from the Department of Electrical and Electronics, King's College, at the University of London (UK). His lab's web site is: <http://www.ehealthinformation.ca/>.

Consumer Health Informatics: Supporting the high-touch

Alex Jadad, Chief Innovator and Founder, Center for Global eHealth Innovation

Abstract:

One of the greatest fears for the public regarding the use of information and communication technologies (ICTs) is the risk of de-humanization of the health system. This fear is well founded, as the introduction of ICTs have led to reduced levels of direct human interaction in almost any other sector of society, from grocery shopping to banking. As every health system struggles to meet increasing demand for services with limited resources, the relationship with the public has already suffered. In this presentation, Dr. Jadad will illustrate opportunities for ICTs not only to empower consumers, but also to re-vitalize their relationship with health professionals and to meet needs that go beyond those that could be addressed through face-to-face interactions.

Bio:

Dr. Jadad's mission is to help improve health and wellness for all, thorough information and communication technologies (ICTs).

Born and educated in Colombia, he obtained his medical degree in 1986, specializing in anesthesiology. By the time he was 20 years of age and still a medical student, he became a leading medical expert on cocaine in Colombia and an internationally sought after speaker. In 1990 he joined the University of Oxford (Balliol College and the Oxford Pain Unit), where he obtained a doctorate in pain management, knowledge synthesis and meta-analysis.

In 1995, he moved to Canada and joined McMaster University, where he was Chief of the Health Information Research Unit; Director of the McMaster Evidence-based Practice Centre; Co-Director of the Canadian Cochrane Network and Centre; Associate Medical Director of the Program in Evidence-based Care for Cancer Care Ontario and Professor in the Department of Clinical Epidemiology & Biostatistics.

In 2000, Alex moved to Toronto, where he led the creation of the Centre for Global eHealth Innovation, a setting designed as a simulator of the future, to study and optimize the use of ICTs before their widespread introduction into the health system and society at large. He is also spearheading the development of the Global eHealth and eWellness Network Initiative (GENI, pronounced as "genie"), a unique group of individuals, organizations, tools and facilities working in harmony to promote research, development, education, policy, funding, recognition and commercialization activities related to the uses of ICTs to promote optimal levels of health and wellness, worldwide. He is developing virtual clinical tools to transform the encounter between patients and health professionals, new methods to evaluate the impact of ICTs in society, interactive tools to promote knowledge translation and mentorship of health professionals and the public, and a platform to support virtual communities, to respond to major public health threats (e.g., obesity, pandemics) and to enable the public (particularly young people) to shape the health system and society.

Dr. Jadad's numerous awards, including a 'National Health Research Scholars Award', by Health Canada (1997), one of 'Canada's Top 40 Under 40' awards (1998), a 'Premier's Research Excellence Award' (1999), the New Pioneers Award in Science and Technology (2002). In 2001 and 2002, he was featured by Time Magazine as one of the new Canadians who will shape the country in the 21st century, and as one of the leading medical researchers in the country. In 2004, he received the Canadian Latin Achievement Award, as one of the people who have made

important contributions to the relationship between Canada and the Hispanic world. In 2005, he was selected by the Top 40 Under 40 alumni as one of "The Best of the Best" for achievements in Health and Science, and by his peers in Colombia as the scientist who probably has had the greatest impact in the country's history.

Contact info:

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Bringing back the high touch in the age of social networks

Alex R. Jadad, MD DPhil FRCPC

Chief Innovator and Founder, Centre for Global
eHealth Innovation

Canada Research Chair in eHealth Innovation

Rose Family Chair in Supportive Care

Professor, Health Policy, Management and Evaluation,
Public Health Sciences and Anesthesia

University Health Network and University of Toronto

Social networks fueled our development



Our main source of support for ages!

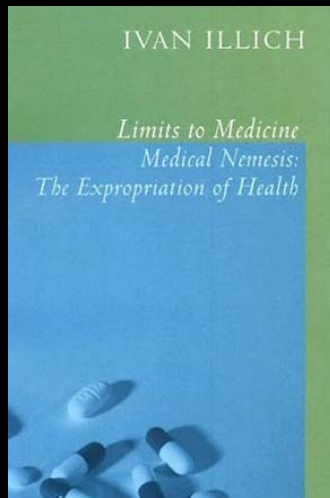


A best seller for 200 years

The art of
living well and
dying well



Where are we now?



"Health, or the autonomous power to cope, has been expropriated down to the last breath"

Hitting roadblocks!



October 16, 2007

The New York Times

In Diabetes, a Complex of Causes

By AMANDA SCHAFER

An explosion of new research is vastly changing scientists' understanding of [diabetes](#) and giving new clues about how to attack it.



A tsunami is coming!



Longer lives, greater expectations!

- 30-40% of people (>90% of seniors) live with at least one chronic disease
- They consume more than 70% of health resources
- Most of the services available were designed to deal with acute conditions
- Needs are exceeding rate of economic growth
- This is happening all over the world

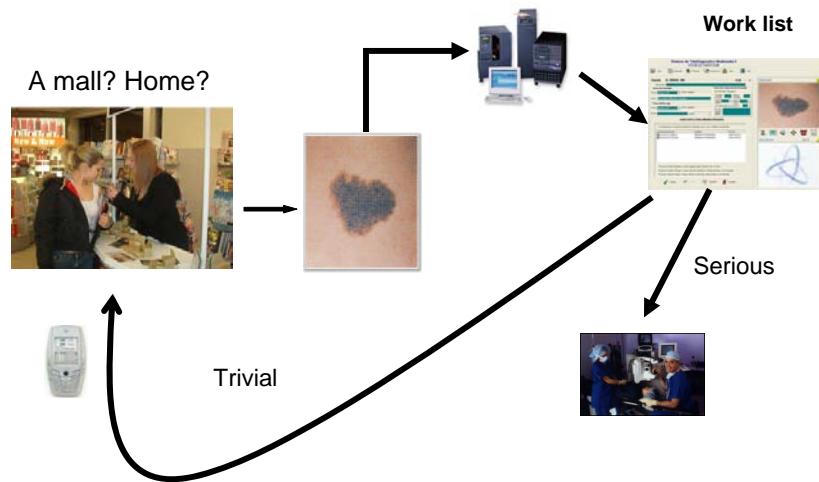
How could we minimize the impact?



Making hospitals the last resort!

- Major surgery or complex procedures
- Major emergencies
- Intensive care
- Short-term management of acute conditions or exacerbations of chronic conditions
- Experimental interventions

The point of care, anywhere?



Hospitals at home?



Paternalism is
passé!



A technological tsunami?



People are
voting with
their
keyboards!

Global Top 500
Updated Daily

- 1. Yahoo!**
www.yahoo.com
Site info for yahoo.com
- 2. Google**
www.google.com
Site info for google.com
- 3. Microsoft Network (MSN)**
www.msn.com
Site info for msn.com
- 4. YouTube**
www.youtube.com
Site info for youtube.com
- 5. Windows Live**
www.live.com
Site info for live.com
- 6. Myspace**
www.myspace.com
Site info for myspace.com
- 7. Facebook**
www.facebook.com
Site info for facebook.com
- 8. Wikipedia**
www.wikipedia.org
Site info for wikipedia.org
- 9. Orkut**
www.orkut.com
Site info for orkut.com
- 10. Hi5**
www.hi5.com
Site info for hi5.com

**1st in Canada
5th in the USA**



Losing mindshare... fast!


• WebMD	1,648
• American Cancer Society	2,205
• Mayo Clinic	3,998
• World Health Organization	4,543
• American Diabetes Association	30,013
• Medline Plus	52,348
• Canadian Cancer Society	154,098
• Canadian Diabetes Association	264,347

Patients are self-organizing...

  BMJ Masterclasses for GPs • General Update 28.09.06, London and 08.11.06, Manchester • Cardiology & Diabetes 29.10.06, London and 08.12.06, Manchester		Author <input type="text"/>	Keyword(s) <input type="text"/>
		Vol <input type="text"/>	Page <input type="text"/>
Home Help Search Archive Feedback Table of Contents		[Advanced] Search	

- The Breast Cancer Mailing List has been active since 1994
- Its members (over 500 in 2006) have sent more than 250,000 messages in the past decade
- More than 99% of 4,600 messages analyzed in 2005 were accurate
- 7 of 10 misleading messages were corrected within 10 hours (4.5 hours on average)

Filling a gap...



My name is Allee, this is the second time i am trying to add to this subject. the first time it said it wouldn't send so i am going to try again. I am 11 years old not a teen but i hope that is ok. my dad died on new years day which was his birthday. he was talking with my mom me and my sister. he just fell over dead. the doctors said his heart just stopped. he was never sick how can his heart just stop? i miss him so bad. i want him to come back. i am so mad at everyone. how come my sister got to grow up with him she is 24 years old and i dont get to. i hate that everyone else has a dad but i dont. i hated that at fathers day i had to go and visit him at the cemetary and take him flowers. i cant talk to anyone cause i am afraid it would make my mom so sad. she is trying so hard to make everything alright. but she just cant do it all. i want to cry all the time but i dont cause i dont want anyone to think i am stupid. when will the hurt stop? my mom used this site to talk to people so she said i could do the same. thanks to anyone who is listening to me....allee

Beyond
Changing the world

• Home • Message

Search

Subject Go

CHANNELS

- Children & Grief
- Grief Support
- Death & the Spirit
- Funerals & Customs
- Healing from all Loss
- Sudden & Violent De
- Caregiving & Illness

TOP 5 SUPPORTS

- Find a Buddy Now
- Light a Candle

What is our role?

Editorial |

Web 2.0: Could it help move the health system into the 21st century?

| Amol Deshpande and Alejandro R. Jadad

How it is

Amol Deshpande, MD, MBA
Centre for Global Health
Innovations, University
Health Network and
University of Toronto,
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ajr

Online 11 October 2008

112 | JGIM | Vol. 23, No. 4, pp. 112-116, November 2008

Using multiple online images similar to his lesion, he concluded that the most likely diagnosis was prostate cancer. Daniel was prompted by his PIR to answer a questionnaire and upload images of his lesion for review by his family physician. Following instructions sent to him automatically by the Personal Health Coaching System, Daniel sent his household digital camera to take samples of his lesion, uploadable from his record and sent an alert to his family physician's office for urgent processing. Images were acknowledged within a minute. A reply the next morning indicated the digital samples had been forwarded to a dermatologist and an urologist for review. A provisional diagnosis of squamous cell penis cancer was made within 24 hours and Daniel was automatically pre-validated with the names and locations of the two most experienced and available urologists closest to him. After receiving information about their profiles, consultation styles and satisfaction ratings provided by other patients, Daniel chose the urologist most suitable for him. After sending an electronic confirmation, Daniel was scheduled for surgery within 3 days in the emergency clinic. His personal schedule was checked in advance for availability by the intelligent booking agent at the clinic. The procedure was performed uneventfully as a day case, and he was informed that the lesion was so limited that there was no anticipated impact on his sexual life. Upon discharge, the urologist who performed the surgery had a conversation during which subsequent treatment options were addressed. As Daniel requested time to think about them, he had an information prompt in the recovery room with the urologist, that included links to online support groups of men his age with squamous cell penis cancer and to multimedia resources on treatment options. After Daniel logged out of the PIR, he was automatically provided with alerts for two more modules published in the

Caring Voices

patientslikeme™

OrganizedWisdom™
Health Data

revolutionhealth™
Your home for health and balance

Healthline™
Connect to Better Health

DailyStrength

OutHealthCare
Together for life.

Microsoft HealthVault™
BETA

Could we close the gap?

Tracking the journey...

TODAY ← hourly daily weekly **monthly** →

80kg	78kg	75kg	9.2	7.0	How are you feeling ...
8.5	7.8	74kg		74kg	Add data to your tra...
	77kg				
	78kg				
Diabeta	Diabeta	Diet	Exercise routine	Add note	
Exercise routine	Exercise routine	Exercise routine	Add appointment		
Exercise routine	Diabeta	Add activity			
What happened during...	Exercise routine	Have you had your 3 ...			
Welcome to Wellociti...	Results of medical a...				
Diabetes Symptoms	Medications	Bookmark a web page			
Blood sugar monitori...	Add data to your tra...				

Sep Oct Nov Dec

zoom +

Feelings and data

My Account | Logout | Tell a friend | Feedback | Help

Welcome deshy

Home Messages Friends Blogs Group Talk Trackers

My Blog My News

Overall, how is your well-being today?

Choose an icon.

Excellent Good Fair Poor

Tell us about your day:

Had a great lunch and blood sugars stable

You have 159 characters available

Blood Sugar

Blood Sugar: 6.9 Time of Reading: AL Units Insulin: 3 Units

Comments:

Need to readjust daily insulin dose

Weight:

Weight: Metric Imperial

Save Remind me later

Contextualized

The screenshot shows the Wellocities website interface. At the top, there's a navigation bar with links like 'Home', 'Messages', 'Friends', 'Blogs', 'Group Talk', and 'Trackers'. Below this is a search bar with the text 'diabetes' entered. The main content area is titled 'Doctors' and features a map of the M5C region in Toronto. A text box on the map states: 'There are 10 Doctors in the M5C region. Please find your results displayed below the map.' Below the map, there's a detailed profile for Dr. Gillian Booth, including her address (6F-61 Queen St E, Toronto, ON M5C 2T2), phone numbers, fax, sex, graduation year (1993 University of Toronto), degree, major language (English), other languages, hospital (St Michael's Hosp), specialty (Internal Medicine FRCPC), and specialty (Endocrin/Metabolism). To the right of the profile is a smaller map showing the location of St Michael's Hospital.

Well informed...

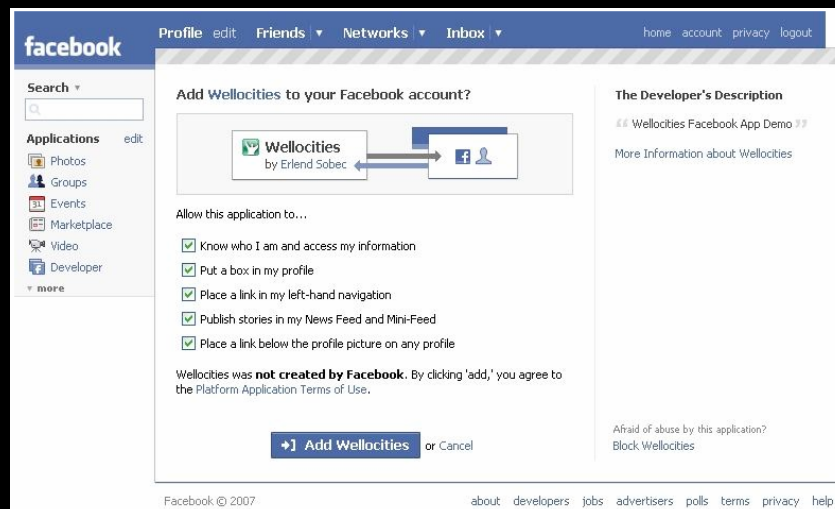
The screenshot shows the Wellocities website interface with search results for 'diabetes'. The top navigation bar includes links like 'Login', 'Join now', 'New password', 'Tell a friend', 'Feedback', and 'Help'. Below the navigation bar is a search bar with the text 'diabetes' entered. The main content area is titled 'Search results' and features a list of search results. The results are categorized into 'Health topics' and 'Medications'. Under 'Health topics', there are 69 results, with 54 being 'Health Topics' and 7 being 'Medical Tests'. Under 'Medications', there are 8 results. The search results are listed as follows:

- 1. Diabetes [Learning Center]
- 2. Diabetes-Related High and Low Blood Sugar Levels
- 3. Gestational Diabetes
- 4. Sick-Day Guidelines for People With Diabetes
- 5. Type 1 Diabetes

Supported and supporting others...



As part of daily life...



Fully integrated...

The screenshot shows a Facebook interface with a custom application titled "wellocities" (Connect Now. Live Well.). The application is integrated into the Facebook layout, appearing as a post on a user's profile. The main content area contains a "Manage Your Glucose Log" form. The form has the following fields and controls:

- Glucose level:** A text input field containing "10.5".
- mmol/L measured:** A dropdown menu currently set to "before lunch".
- Insulin units:** A text input field containing "5".
- Comments (200 characters max):** A large text area containing the text "No comment."
- Submit To Log:** A button at the bottom of the form.

The Facebook navigation bar at the top includes links for Profile, edit, Friends, Networks, Inbox, home, account, privacy, and logout. The left sidebar shows the search bar and a list of applications: Photos, Groups, Events, Marketplace, Video, and Developer. The footer of the page includes a link to "Page built by Wellocities" and a set of links: about, developers, jobs, advertisers, polls, terms, privacy, help.

Fully in control...

The screenshot shows a Facebook profile page for a user named "Erland Sobec". The profile is fully integrated with the Facebook interface, showing a profile picture, cover photo, and various sections for user information and activity. The profile sections include:

- Profile Information:** Networks (Toronto, ON), Sex (Male), Interested In (Women), Relationship Status (Unknown), Birthday (January 1, 1900), Hometown (Toronto, Ontario).
- Mini-Feed:** A section for recent updates.
- Information:** A section for user details.
- Education and Work:** A section for educational and professional background.
- Travel Map:** A section for travel history.
- Quizzes:** A section for quizzes.
- Cities I've Visited:** A section for visited locations.
- Wellocities:** A section for the Wellocities application, showing a "My Glucose Level" bar chart.

The Facebook navigation bar at the top includes links for Profile, edit, Friends, Networks, Inbox, home, account, privacy, and logout. The left sidebar shows the search bar and a list of applications: Photos, Groups, Events, Marketplace, Video, and Developer. The footer of the page includes a link to "Page built by Wellocities" and a set of links: about, developers, jobs, advertisers, polls, terms, privacy, help.

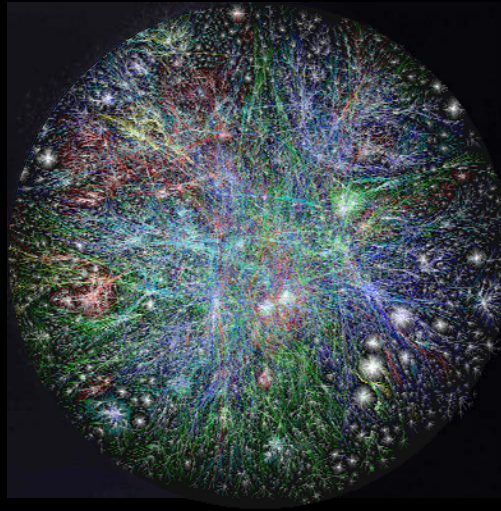
In Spain...



If we do not move fast, others will come...

- 3 accounts, with no filter, received 4153 messages (November 2006)
- 83% of the messages were spam
- 32% offered health products
- Most messages came from the US, China and Congo
- One third of purchase attempts were successful
- We received controlled substances for pain and anxiety relief, and sexual function enhancement

Transcending our boundaries...



We must not disappoint them!



Biography of Chair: Session 1

Michael Martineau, Vice President, Public Sector Research & eHealth Practice Lead, Branham

As one of Canada's Internet pioneers, Mr. Martineau was a founding executive with two of Canada's leading Internet Service Providers and witnessed first hand the initial reluctance and eventual embrace of the Internet by clients in a variety of industries. Mr. Martineau is now Vice President, Public Sector Research and eHealth Practice Lead with Branham Group Inc., a Canadian market research and strategic planning firm serving IT vendor. In his current role, Mr. Martineau is responsible for defining Branham's eHealth research agenda and translating this agenda into a variety of information services for Branham clients. Most recently, Mr. Martineau authored Branham's second annual syndicated study on the current and future use of IT by the Canadian health sector.

Will the Consumer Please Stand Up

Matt Anderson, Vice-President, University Health Network; Chief Information Officer, SIMS Partnership; eHealth Lead, Toronto Central LHIN

Abstract:

With the emergent technology of the personal health record, consumers are transforming health care. One way many organizations are beginning to address patients' demands for access to information is through the creation of Patient Portals. Structured similar to an online banking website, a portal is a web based tool that integrates with an electronic health record to support patients in the management of their own health care. This approach shifts away from traditional practice, empowering the patient to be a member of his/her own health care team.

While a patient portal provides a single touch-point that unifies the continuum of care, what cost befalls the organization? Can health care organizations who often struggle to achieve an electronic environment, respond and provide patients access? This session explores the rise of consumerism and the financial, legal, technological and other challenges faced by health care organizations to respond to and provide patients access.

Bio:

Matthew is vice-president and chief information officer for University Health Network (UHN), Canada's largest acute-care teaching hospital. In this role, he is responsible for leading the organization's information management strategy, which aims to improve the patient experience, achieve the best clinical outcomes and ensure accountability through information and technology. He is also charged with leading the organization's complement of information services.

In May 2004, Matthew began to serve as chief information officer for the Toronto Community Care Access Centre (CCAC) as part of a joint initiative integrating UHN with the Toronto CCAC at the information systems level. This initiative was later expanded to include St. John's Rehabilitation Hospital, Bridgepoint Health and the North York Community Care Access Centre. While developing an information systems operating plan for the partnership, Matthew drives collaboration, consistency, standards and cooperation to facilitate the electronic sharing of key referral information among community providers and partner hospitals.

In May 2005, Matthew received Canada's Top 40 Under 40 award.

Contact info:

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Will the Consumer Please Stand Up

Matthew Anderson

Vice President, University Health Network
CIO, SIMS Partnership
e-Health Lead, Toronto Central LHIN

October 30, 2007



“the rise of ‘user-generated content’- spurred by sites such as YouTube, Facebook and Wikipedia - has also **infected health care.**”



Source: *The Economist*, Sept 2007

A Growing Trend

3

Home | Add to my favorites | Sign in or Create an account

Welcome to HealthVault

Be well. Protected.

When it's your job to protect your family's health, you need every advantage. Imagine if you had a way to collect, store, and share the health information critical to your family's well-being.

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3. You decide who can see and use your information on a case-by-case basis.
4. We do not use your health information for commercial purposes.

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Google Health

Profiles | Medical contacts

unnamed

[Services and health guide](#)

[Conditions & symptoms](#)

[Medications](#)

[Allergies](#)

[Surgeries & Procedures](#)

[Test results](#)

[Immunizations](#)

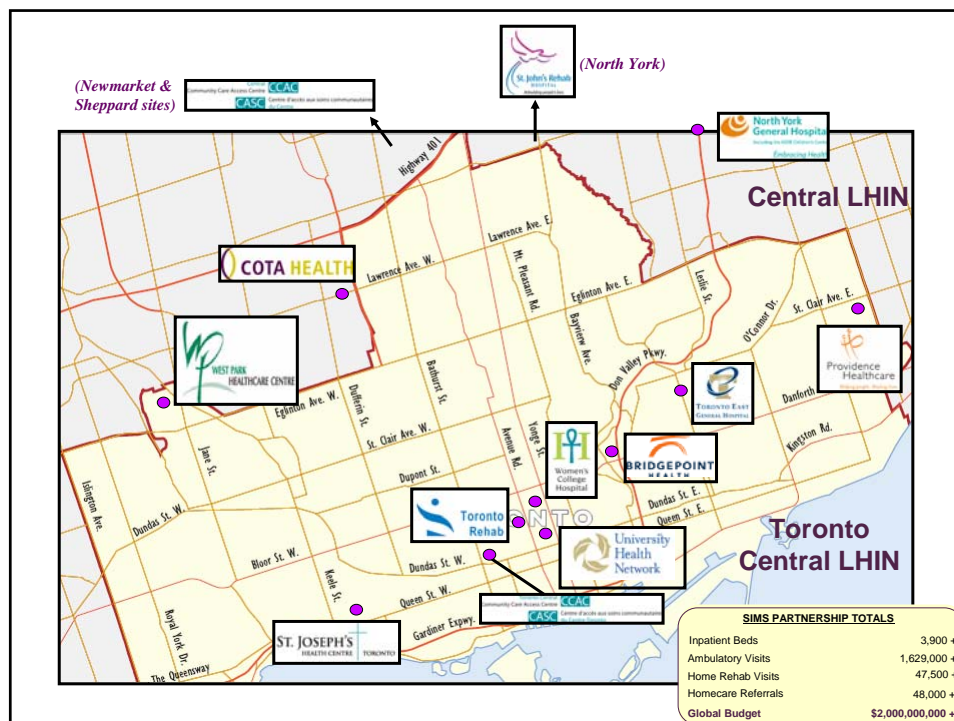
Conditions & symptoms

Add a condition:

head

- Head and Neck Angioedema
- Head and Neck Carcinoma
- Head Injury
- Head Pain
- Head Sensation Disturbance
- Severe Head Pain
- Presence of Head Lice
- Cancer Involving the Head or Neck
- Prevention of Seizure after Head Trauma or Brain Surgery
- Disturbance of Any of the Senses Affecting the Head

The SIMS Partnership
Transforming health care delivery



SIMS Partnership CDM Program

5

• Chronic Disease Management (CDM):

- High incidence and impact of chronic disease management in Canada:
 - 16 million Canadians suffer from chronic diseases
 - 67% of total direct & 60% of indirect health care costs

• CDM is challenging in our current environment:

- System is:
 - currently designed around acute care
 - highly fragmented
- Information silos
- Long wait times
- Lack of primary care infrastructure for CDM



- 1 CDM as a Priority Program
- 2 Disease Registry
- 3 Client/Patient Portal for Self-Management
- 4 Primary Care Integration and Support
- 5 CDM Care Plan Management Model
- 6 Care Coordination Centre/Call Centre

The SIMS Partnership
Transforming health care delivery

SIMS Partnership Patient Portal

6

• Patient Portal:

- A secure, web-based information system that supports patient education, patient-provider communication, and the achievement of self-management goals.

• Improves the patient experience by providing:

- Personalized information and care
- Treatment plans
- Education
- Clinical data
- Links to community programs



• Transforms health care service delivery:

- Empowers patients with 24/7 access to information and tools
- Enables patient participation in decision-making processes
- Encourages self-management behaviours that lead to improved outcomes

The SIMS Partnership
Transforming health care delivery

SIMS Patient Portal Projects

- Breast Cancer Survivorship (Princess Margaret Hospital) – Pilot Site
- Diabetes - Type 2 (SIMS Partnership)
- Tri-LHIN Chronic Kidney Disease: University Health Network, Grand River Hospital, LHIN 4 (Hamilton Niagara Haldimand Brant)



The SIMS Partnership
Transforming health care delivery

New Medium Reveals New Issues

- Technology is not necessarily the challenge
- Providing the consumer the opportunity to become more engaged in monitoring their health and volunteering health information
 - New patient expectations for treatment and care
 - New practice standards
 - Potential future medico-legal risks
- Pushing the envelope
- No precedent
- Role of the provider changing
- Workflow changes
 - Help Desk (clinical vs. technical)
- Who pays



The SIMS Partnership
Transforming health care delivery

Will the Consumer Please Stand Up

Matthew Anderson

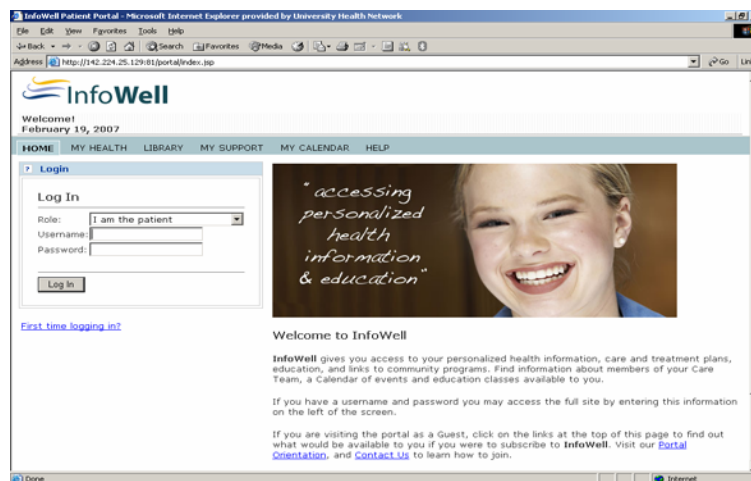
Vice President, University Health Network
CIO, SIMS Partnership
e-Health Lead, Toronto Central LHIN

October 30, 2007



Patient Portal Interface

10



InfoWell Patient Portal - Microsoft Internet Explorer provided by University Health Network

File Edit View Favorites Tools Help

Address http://142.224.25.129-81/portal/index.jsp

Welcome Laura!
February 16, 2007

Site Home Suspend Logout My Account My Colours

HOME MY HEALTH LIBRARY MY SUPPORT MY CALENDAR HELP

Enhanced Features Available

Our records show that you have access to enhanced features of this site:

- To access your test results and reports, click on "My Results", found under the "My Health" section of this site.

7 Edit Message Center

Personal (2) Requests Broadcasts Reminders

Display Archived and Current Messages

Sender	Subject	Received
<input type="checkbox"/> University Health Network	Enhanced Features Now Available	Monday January 29, 2007 5:25 PM
<input type="checkbox"/> University Health Network	Welcome to InfoWell	Monday January 29, 2007 5:25 PM

Archive

Section Descriptions

Section Descriptions

My Health

- Learn about your condition and get tailored information about your specific treatment or care plan
- View your test results and find information on how to understand them
- See who is on your care team
- Update your personal profile

Library

- Search our patient library catalogue or browse for brochures
- Bookmark your favourite pages for your next visit

Done Internet

The SIMS Partnership
Transforming health care delivery

InfoWell

Welcome Fredi
February 14, 2007

Site Home Suspend Logout My Account My Colours

HOME MY HEALTH LIBRARY MY SUPPORT MY CALENDAR HELP

My Diagnosis
Breast Cancer
Stage & Status
My Treatment
My Team
My Medications
My Profile

What Is Breast Cancer

What Is Breast Cancer?

Breast cancer occurs when cells grow abnormally in the cells of the breast causing a malignant (cancerous) tumor. The disease occurs mostly in women, but men can get breast cancer as well. The information here refers only to breast cancer in women. There is separate information about [breast cancer in men](#).

A woman's breast is made up of glands that make breast milk (lobules), ducts (small tubes that connect lobules to the nipple), fatty and connective tissue, blood vessels, and lymph vessels. The majority of breast cancers begin in the ducts (ductal carcinoma), some begin in the lobules (lobular carcinoma), and the rest in other tissues.

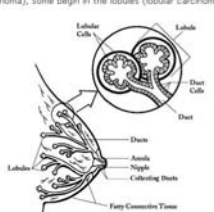


Image Source: National Cancer Institute, www.cancer.org

Many patients with early stages of breast cancer experience no symptoms and the tumour can continue growing for months or years without causing any symptoms. Detection of a lump or cancer cells is usually detected through breast self-exam or through

Breast Cancer Related Links

Breast Cancer Related Links

- Inflammatory Breast Cancer
- Male Breast Cancer

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Transforming health care delivery

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InfoWell Patient Portal - Microsoft Internet Explorer provided by University Health Network

File Edit View Favorites Tools Help

Address http://142.224.25.129:81/portal/index.jsp?epi_menuItemID=120fe458fe7fc896ef1915618910ee88epi_menuID=90bac54eb8feab327eb94805b031bb88epi_baseMenuID=bf

My Diagnosis
My Treatment
My Results
My Team
My Medications
My Profile

My Results

My Results allows you to see test results and/or reports from your electronic patient record. See [list of test results and reports](#) available.

Your information will display below in a few moments. If you have questions, concerns, or corrections regarding your information or your test results and reports, please contact a member of your health care team or discuss this with them at your next appointment.

My Results
You are here: [My Results](#) >> [Labs](#)

Platelets (Plt)

Platelets are very small, sticky fragments that circulate in the blood. They are produced in the bone marrow from cells called megakaryocyte (means large cell). Platelets are an essential part of a complex blood clotting process. When there is an injury to a blood vessel, platelets are needed to help clot the blood to prevent blood loss. ([learn more](#))

Showing: Last 6 months 160

Test	Latest	Feb-14 11:00	Jan-29 11:00	Normal Range
Platelets (Plt)	Low	149	166	150.00 - 400.00
Hemoglobin (Hb)	Normal	140	155	120.00 - 160.00
Leukocytes (White Blood Count)	Low	3	5	4.00 - 11.00

Platelets (Plt)
Your last Platelets (Plt) test was performed on 14-Feb 11:00

↓ Your value is below normal range for your sex

This is called thrombocytopenia. The causes of thrombocytopenia are many but can generally be divided into two broad areas: a defective construction process (genetic disorders, bone marrow damage from cancer or a variety of drugs including chemotherapy,) or too much loss to the system (chronic bleeding due to autoimmune disorders, drugs). The most common causes for thrombocytopenia are: idiopathic (means of unknown origin), a side effect of drugs, or a part of other bleeding disorders.

Trend of result values for Platelets (Plt)

Done Internet

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InfoWell

Welcome Laura!
February 16, 2007

Site Home Suspend Logout My Account My Colours

HOME MY HEALTH LIBRARY MY SUPPORT MY CALENDAR HELP

My Diagnosis
My Treatment
My Results
My Team
My Medications
My Profile

Reference Guide
Adriamycin and Cyclophosphamide (AC) CEF Protocol

Laura's Adriamycin and Cyclophosphamide (AC) for Breast

Your doctor has recommended the following plan: [Adriamycin and Cyclophosphamide \(AC\)](#) [How do I use this tool?](#)

Previous | Cycle 1 of 4 | Next

Cycle 1, Week 1

- Appointment with Medical Oncologist
- Pharmacy Teaching
- Prescription for Medication
- Medications before Chemotherapy
- Lab work before beginning treatment
- Chemotherapy Medications
- What can I do while receiving chemotherapy?
- Possible Immediate Side Effects

Cycle 1, Week 2

- Possible Early Side Effects
- Other Reminders

February 2007

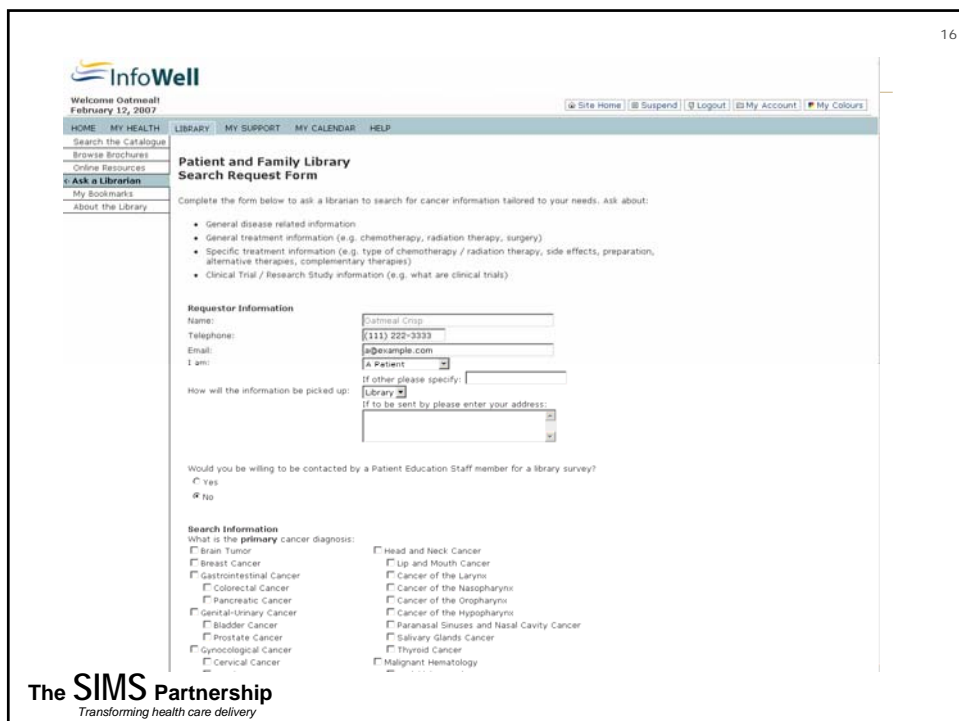
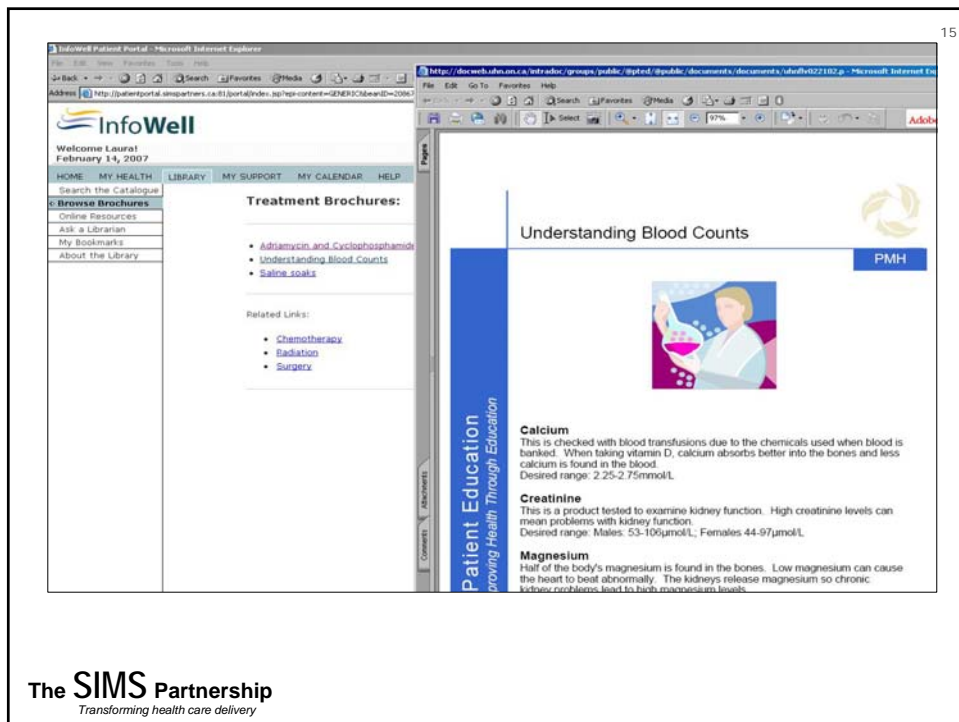
S	M	T	W	T	F	S
			1	2	3	4
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28			

February 2007

S	M	T	W	T	F	S
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28				

Done Internet

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The screenshot shows the InfoWell Patient Portal interface. On the left, a navigation menu includes 'My Diagnosis', 'My Treatment', 'My Team', 'My Profile', 'My Food Diary', 'My Blood Pressure', and 'Content Test'. The main content area is titled 'My Medication List' and includes a table of medications:

Drug Name	Started	Dosage	How Often
Acyclovir (Glucobay®), previously called Brandase®	May 18, 2007	10 mg	bic
Acyclovir	May 17, 2007	100 mg	tic
Chlorambucil	May 21, 2007	11 mg	od

Below the table are buttons for 'Add a Medication' and 'Print'. To the right, a 'MEDICATION INFO SHEET' for CHLORAMBUCIL (Klor-AM-byoo-sill) is displayed, providing details on appearance, usage, and precautions.

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The screenshot shows the 'My Diary' section of the InfoWell Patient Portal. It includes a 'My Diary' header with a description of journaling as a pathway to healing. Below this, a 'Personal Diary' section provides instructions on how to use the diary. A calendar for February 2007 is shown, with the 16th highlighted. The entry for February 16, 2007, is displayed, detailing a patient's experience with a mammogram and a biopsy.

February 2007

S	M	T	W	T	F	S
		1	2	3		
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28			

February 16, 2007

I almost skipped my second mammogram. When I got the letter saying they had to do a follow-up, I assumed they'd just messed up the film. But I began to get nervous when the technician took three rounds of pictures, sending me back to the waiting room after each set. I felt myself slip into shock when the radiologist showed me what they were filming: a bicycle-spoke-like pattern emanating from a central point in my left breast. No lump, just these lines in the tissue. I could barely see them. He said he is nearly 100 percent sure that it is nothing. But I should have it biopsied, "just to be 120 percent sure."

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InfoWell Patient Portal - Microsoft Internet Explorer provided by University Health Network

Welcome Guest221
May 24, 2007

[Site Home](#) | [Suspend](#) | [Logout](#) | [My Account](#) | [My Colours](#)

HOME MY HEALTH LIBRARY MY SUPPORT MY CALENDAR HELP

Caring Voices
Finding Support
My Diary

Support Can Help!

It is important to determine what kind of support will best meet your needs. For some attending a lecture, accessing the Internet, individual counseling or talking with a nurse is what helps most. Some people find a number of things important including finding a support group.

Attending a support group can be a lot of help. You may be interested in learning more about how a support group can help you. You may never have needed to consider attending a support group before. A support group is not for everyone but can be a very valuable form of support to help you during your journey. Support groups are an opportunity to come together with other people that are living with the same condition. As a group they can provide information and strategies that may be helpful to you in managing your own experience.

Finding Support - Survivorship

Survivorship Support Group

Why should I join a support group?

Who better to talk with than others who have personal experience in living with this disease? It's a tremendous opportunity to learn from each other. Learn strategies on how to best cope with cancer, how to talk with your family, children and co-workers. A great deal of energy goes into caring for those who are close to you, making it a challenge to talk about some difficult issues. A support group can provide an opportunity to share some of your thoughts in a supportive environment where anything you want to talk about is ok. What you decide to talk about or share is up to you and based on your own

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InfoWell Patient Portal - Microsoft Internet Explorer provided by University Health Network

Calendar

Use your calendar to keep track of your appointments, and upcoming Patient Education events and classes that you wish to attend.

My Calendar

Today is Friday, February 16, 2007

LIST DAY WEEK MONTH YEAR Add Event | Search for Events | Category Filter

February, 2007

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
				01 Chemotherapy Introduction	02 Diversional Activities	03
04	05 Diversional Activities	06 Chemotherapy Introduction	07 Diversional Activities	08 Chemotherapy Introduction	09 Diversional Activities	10
11	12 Diversional Activities	13 Chemotherapy Introduction	14 Diversional Activities	15 Chemotherapy Introduction	16 Diversional Activities	17
18	19 Diversional Activities					
25	26 Diversional Activities					

Event [Edit Event](#) | [Delete Event](#) | X

Event: Mammography Appointment
Category: Personal
When: Fri, February 16, 2007 08:00AM - 09:00AM
Where: Princess Margaret Hospital
Description: Dr. Smith
See: <http://www.uhn.ca>
[Terms of Use](#) | [Privacy Policy](#) | [Contact Us](#)

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Infoweb Patient Portal - Microsoft Internet Explorer provided by University Health Network

Address: http://142.224.25.129:8130/infoweb/infowebContent.do?method=showProfile&id=1127372026&id=0=0&id=0

Welcome Guest??
February 19, 2007

Site Home | Suspend | Logout | My Account | My Colours

HOME | MY HEALTH | LIBRARY | MY SUPPORT | MY CALENDAR | HELP

My Engagements
My Treatment
My Results
My Team
My Medications
My Profile

Health Profile for Dafany Duck

This health profile was last updated: February 9, 2007 7:41 AM

Demographic Information	
Date of Birth:	January 1, 2004
Gender:	F
Blood Type:	A+
Height:	5 feet 4 inches
Weight:	100.0 pounds
Health Card Number:	1234567
Family Physician: Dr. Jones	
Contact Information	
Address Line 1:	123 Main Street
Address Line 2:	
City:	Toronto
Province:	ON
Postal Code:	M1G 1C4
Home Phone:	123-567-7890
Business Phone:	123-567-7890
Mobile Phone:	123-567-7890
Fax:	123-567-7890
Email Address:	
Family Members	
Family Member #1:	Daffey (Spouse)
Family Member #2:	Joe (Child)
Insurance Information	
Name of Insurance Company:	Acme Insurance Company
Name of Policy Holder:	Daffey Duck
Relationship to You:	Spouse
Carrier Number:	1234567
Policy Number:	1234567
Certificate (Personal ID) Number:	1234567
Insurance Number:	1234567
Health Information	
Allergies:	Cross, Wheat
Immunizations:	Flu Shot
Past Illnesses:	
Inpatient Admissions:	
Surgery Dates:	January 1, 2004
Special Considerations:	

Edit | Print | Delete | Cancel

The Chronic Need for Connectivity: Helping today's aging health care consumers help themselves

Gary Folker, xwave

Abstract:

Canada's population steadily ages, and alongside that collective aging process comes the steady increase of Canadians suffering from chronic illness—a figure now estimated around 16 million. At the same time, Canada is confronted with imminent shortages of doctors and nurses, certain to put continued mounting pressure both on healthcare professionals and on their patients. This combination of an older, needier population and increasingly scarce resources is prompting a nation-wide re-evaluation and reform of our healthcare system. Governments are looking for ways to improve public access to care, reduce wait times for treatment, and better manage the seemingly exponential growth of expenditures. Providers, meanwhile, are seeking solutions that will help manage chronic disease and, with it, help control the tremendous cost of treating it. Among the major concerns for patients are the worsening of disease and the prevention of complications. Healthcare professionals know that actively engaging patients is key to effective chronic disease management and enabling the best possible outcomes.

Thus a growing number of professionals in this sector are recognizing that pivotal to its reform will be a shift in our healthcare paradigm, from a traditional focus on treatment to a system that actively promotes prevention and the improved management of chronic illnesses. Studies show that many chronic illnesses can be prevented or delayed by altering unhealthy behaviors at an early age. It's through improved education and self-care that consumers will be equipped to make the kinds of choices that help prevent chronic disease or minimize its effects.

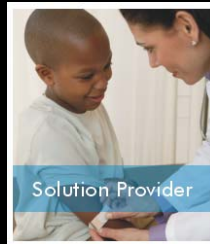
Add to this the fact that today's baby boomers, often caring for aged parents and beginning to face age-related conditions themselves, want to be more involved in their healthcare decision-making and, moreover, have access to an ever-widening array of online services and network infrastructure that form the foundation for remote healthcare communication and personal health management.

Bio:

Gary Folker is Managing Director of Business Development for xwave, a division of Bell Aliant and one of the largest providers of healthcare information and communications technology in Canada. He is playing an integral role in xwave's consortium for Quebec's provincial electronic health record (EHR) project. With additional experience that includes helping to implement Canada's first fully-integrated electronic patient chart and creating the largest document-capture facility in North America, Gary offers his perspective on individual-centric health information and education, outlining some of the components—bidirectional communication; home-based telehealth; an individual health record (IHR)—that are necessary to both foster and support the management of healthcare information on the part of today's increasingly aware healthcare consumer.

Contact info:

Email: gary.folker@xwave.com



The Chronic Need for Connectivity:
Helping today's aging consumers help themselves



Canada's aging population



- ❑ The number of Canadians aged 65 and over increased 11.5% in the five years leading up to the 2006 census.
- ❑ Senior citizens made up a record 13.7% of the total population in Canada.
- ❑ Never before has Canada had so many people 80 years and over: They topped the one-million mark for the first time in 2006.
- ❑ Baby boomers – aged 41 to 60 in 2006 – make up almost one in three Canadians.

A healthcare perspective



In the last 10 years, healthcare spending has almost doubled, increasing to more than \$100B

- 1. Health authorities:**
→ manage or direct 70% of total spending
- 2. Hospitals:**
→ consume 30% of total healthcare spending: \$42B
- 3. Primary care:**
→ represents the third-largest spending component: \$25B
- 4. Consumers:**
→ are becoming an increasing focus of healthcare spending



Why focus on consumers?



Trends in aging and the emergence of technology have made it both necessary and feasible for consumers to become more actively involved in their own healthcare.

Consumers are now driving changes in the provision of healthcare services, and the control of and access to health records.

Chronic disease management (CDM) is one of the key drivers behind this move toward consumer-centric care.

By providing patients with the tools to help them manage their chronic disease, we can help them stay healthier while easing the burden on providers.

The cost of chronic disease



The cost of illness, disability and death due to chronic disease in Canada is estimated at \$85B annually.

Almost three quarters of all healthcare spending is dedicated to treating chronic disease.



The health implications



- ☐ Eighty percent of physician visits are related to chronic disease.
- ☐ About 16 million Canadians are living with it.
- ☐ In Canada, about two thirds of total deaths are due to:
 - cardiovascular disease
 - cancer
 - bronchitis and emphysema
 - diabetes
- ☐ About half of adults over the age of 65 are being treated for five or more chronic conditions.
- ☐ Canadians, on average, live the last dozen years of their lives with one or more chronic illnesses.

Defining chronic disease



A chronic disease...

...is a non-communicable disease typically characterized by:

- ☐ uncertain etiology
- ☐ multiple risk factors
- ☐ long latency
- ☐ prolonged affliction
- ☐ a non-infectious origin
- ☐ impairment or functional disability

Examples:

- ☐ cardiovascular disease (CVD)
- ☐ diabetes
- ☐ cancer
- ☐ asthma
- ☐ arthritis

Example: CVD



- ☐ Cardiovascular disease accounts for 38% of deaths (more than any other disease) in Canada.
- ☐ CVD accounted for almost 75,000 deaths in 2002.
- ☐ Only 4% of Canadians aged 18 to 74 have no major risk factors for CVD.
- ☐ CVD is a leading cause of hospitalization.
- ☐ It costs the Canadian economy over \$18B annually.

Example: diabetes



- ❑ Diabetes is among the most prevalent age- and obesity-related diseases.
- ❑ It affects over two million Canadians, and one-third of sufferers are undiagnosed.
- ❑ Forty percent of these people will develop long-term complications.
- ❑ Diabetes is controllable.

Imagine...



- ...an electronic health record (EHR) for every person in Canada
- ...all of a patient's health, medical and drug history contained in the EHR
- ...the ability of all a patient's providers to access and update the EHR
- ...providing patients with controlled online access to their health information, helping them stay well rather than communicating with them only when they're sick
- ...linking patients and providers at all points of care

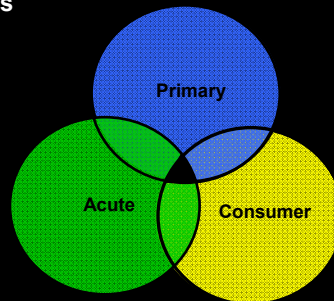


The need for connectivity



By connecting the various practitioners and systems that provide care to a single patient, we improve:

- ❑ the accuracy and availability of that patient's information
- ❑ the chances of successful treatment and a positive outcome
- ❑ the allocation of resources caring for patients with chronic disease



Primary care



- ❑ Primary-care providers, such as family doctors, are the entry point for almost three quarters of people accessing the healthcare system.
- ❑ Seventy percent of patient information is contained in the files of primary-care practices.
- ❑ Most of these medical records are paper-based.
- ❑ About 23% of Canadian doctors use electronic medical records. This compares, for example, with 98% of doctors in the Netherlands.



Acute care



- ❑ Acute-care facilities are hospitals, ambulatory clinics or other short-term-stay facilities from which patients are ideally discharged when they are well.
- ❑ These are generally where patients' electronic health records are housed, for access by other providers such as family doctors, pharmacists and lab technicians.
- ❑ Vast range of strategies currently in process to capture, store and utilize electronic patient information.



Consumer care



- ❑ Consumers are current and prospective patients.
- ❑ Research shows that 60% of Canadians have indicated a strong desire to take a more active role in managing their own health.
- ❑ Overall population health has been cited as a key factor in healthcare reform by the Health Council of Canada.
- ❑ Of the four healthcare sectors listed earlier:
 - health authorities
 - hospitals
 - primary care
 - consumers

...it is consumers who have the greatest potential to effect positive healthcare change.



How IT brings it all together



- ☐ healthcare portals
- ☐ home healthcare
- ☐ community care
- ☐ interoperable electronic health records (iEHRs)
- ☐ electronic medical records
- ☐ client and provider registries
- ☐ next-generation voice solutions, kiosks, patient terminals, inter-hospital communications
- ☐ wait-time and eReferral systems



Moving from EHR to IHR



- ☐ The individual health record (IHR) is an inherently patient-centric EHR.
- ☐ It fosters a collaborative approach to patient care by allowing all providers and patients themselves to access and update personal health information.
- ☐ It draws from existing data sources and doesn't necessarily require extensive installation of new hardware and software.
- ☐ It provides clinicians with only the relevant information they need to care for patients.
- ☐ It encourages patient involvement in and responsibility for personal healthcare.

Portals: helping consumers help themselves



Portals serve as secure Internet gateways that, via a patient's EHR / IHR, enable access to a wide range of healthcare resources such as:

- ☐ personal health profiles and diaries
- ☐ decision support and discussion boards
- ☐ treatment plan information
- ☐ symptom and side-effect monitoring
- ☐ caregiver contact information
- ☐ appointment requests
- ☐ prescription-ordering from the hospital pharmacy

Portals allow patient records to be used as effective, interactive tools for continuing care rather than simply repositories of information.

How portals support CDM



Portals are effective in chronic disease management because:

- ☐ They support the timely delivery of information to patients – for example, treatment and prescriptions.
- ☐ They enable asynchronous communication among providers.
- ☐ Patients get a near real-time view of their disease status through, for example, the receipt of lab results as they become available.
- ☐ Patients can report self-monitoring results such as glucometer and blood-pressure readings to their doctors (who in turn can see when this information has not been provided).
- ☐ Patients can share their information with other physicians and family caregivers.

How portals support CDM



- ❑ Portals can be used anytime, anywhere Internet is available.
- ❑ They save patients and doctors the effort and expense of in-office visits.
- ❑ Patients, meanwhile, stay healthier and at home longer, avoiding hospitalization and nursing homes.



Some current CDM portals



- ❑ The Bell Patient Decision Support Lab
The Ottawa Hospital
- ❑ My Care Source for cancer patients
Grand River Hospital, Kitchener
- ❑ Breast-cancer portal
University Health Network (UHN), Toronto
- ❑ Kidney-disease portal
UHN, Grand River, Hamilton Health Sciences and Canada Health Infoway
- ❑ My Chart
Sunnybrook Health Sciences Centre (Toronto) and OntarioMD
- ❑ Caregiver portal
VON Canada and Canada Health Infoway



More technology-enabled CDM Heart & Stroke Foundation of Ontario



- ❑ HSFO has launched a Hypertension Management Initiative in Ontario to provide physicians with tools and protocols to help effectively manage their patients with hypertension.
- ❑ The information collected will be used to develop tools, interventions and processes to help healthcare practitioners better detect and control this condition.
- ❑ **xwave** created hypertension data-capture forms for its clinical management system, and an interface enabling users to submit the data to a central Heart & Stroke repository.

More technology-enabled CDM Passport to Health



- ❑ Pharmacists are an 'untapped resource' in the healthcare sector.
- ❑ Yet they play a significant role in CDM and are the 'gatekeepers' of patients' medication profiles.
- ❑ **xwave** is helping to develop the electronic version of Passport to Health, which connects physicians with community pharmacists to:
 - involve pharmacists more actively in patient monitoring
 - 'close the loop' between the writing and actual filling of prescriptions, improving treatment targets
 - minimize the incidence of severe drug interactions, responsible for the hospitalization of 25% of Canadians over 50

xwave's partners in CDM



- ❑ **Kryptiq** streamlines healthcare communications among patients, providers, pharmacies and health plans with secure messaging, electronic prescribing, disease management and contract management technologies.
- ❑ By integrating these solutions with existing systems and applications, **Kryptiq** enables the trusted transport of health information where and when it is needed.
- ❑ **CentriHealth** provides Individual Health Record applications, providing consumers with timely access to their personal health information and the tools to help them effectively manage their health care.



The need for home-based CDM



- ❑ Using technology to connect providers with patients at home will become increasingly important in managing chronic disease and helping sufferers live independently as long as possible.
- ❑ Provincial technology-enabled CDM programs could save millions of dollars in healthcare costs.
- ❑ Such programs could provide patients with web-based access to clinical expertise and their IHRs / EHRs.
- ❑ A 'virtual coach' – an online doctor – could guide individual patients through the process of self-monitoring and reporting symptoms.
- ❑ Patients would remain at home longer, which in itself would improve overall morale and health.

The need for home-based CDM



IT-based programs could be supplemented by medical technologies such as:

- ❑ **Motion detectors**, which can alert caregivers and family members to a potential problem
- ❑ **Wearable ECG devices**, which enable wireless, 24/7 transmission of heart rates
- ❑ Devices designed for consumer data input
- ❑ Video capability



Healthcare IT: a snapshot



- ❑ Healthcare IT:
 - is a \$2.1B market in Canada (2006)
 - represents 1.4% of healthcare spending
 - is expected to be 4% of total healthcare spending by 2010
- ❑ Hospitals represent over half – 56% – of total healthcare IT spending.
- ❑ The iEHR is acknowledged by industry professionals to be one of the top healthcare-IT priorities in Canada.

In conclusion...



- ❑ Information technology is an essential component in chronic disease management.
- ❑ By investing in technology-enabled CDM, we won't necessarily decrease the cost of healthcare spending but will spend more preventatively.
- ❑ For example: The VON-Infoway caregiver portal, scheduled for launch in March 2008, will support the three million Canadians who provide two billion hours of care to loved ones. The time they give saves the healthcare system an estimated \$5B per year.

Our healthcare practice



- ❑ Is one of the largest practices of its kind in Canada
- ❑ Comprises 250 consultants: clinical, technical, business
- ❑ Offers customized applications through to enterprise optimization
- ❑ Works to connect providers and patients at key points of care
- ❑ Earned *Company of the Year* at the 2006 Canadian Health Informatics Awards



Biography of Chair: Session 2

Gunther Eysenbach, MD, MPH, Centre for Global eHealth Innovation Senior Scientist

Gunther Eysenbach is a Senior Scientist at the Centre for Global eHealth Innovation at the Toronto Research Institute/Toronto General Hospital and Division of Medical Decision Making and Health Care Research. He also holds an academic appointment as Associate Professor at the Department of Health Policy, Management and Evaluation, University of Toronto. He is one of 4 members of the management committee of the Centre. Dr. Eysenbach and the research group are pursuing projects from a wide area of disciplines including consumer health informatics, population health technology, usability of eHealth systems, electronic and Open Access publishing, knowledge synthesis and knowledge translation.

Dr. Eysenbach studied medicine in Munich and Freiburg in German, and obtained a Master in Public Health from Harvard University. He is recognized by many as one of the leading researchers in the field of eHealth and Internet & Medicine.

He is author of a textbook for computers in medicine (which he wrote at the age of 24), editor of a loose-leaf book on computers for physicians, founding editor and editor-in-chief of the Journal of Medical Internet Research, a leading global eHealth journal. Dr. Eysenbach has authored more than 120 publications, including almost 40 book-chapters as well as several pioneer studies and comments on cybermedicine, e-health and Consumer health informatics, published in respected international journals such as JAMA, BMJ, and the Lancet.

He founded and headed the first research group on cybermedicine and eHealth worldwide at the University of Heidelberg between 1999 and 2001, where his main research interest was consumer health informatics, and came to Canada in March 2002 to help building up the Centre for Global eHealth Innovation in Toronto.

Dr Eysenbach has received numerous awards and distinctions. He has been called "one of the most productive researchers, editors, and publishers in the online health field." (Ferguson Report's Distinguished Achievement Award) and in 2004 received the Janssen-Cilag Future Award, referred to as the German "health care nobel prize".

Using Web Based Tools to Help Patients Achieve Optimal Clinical Outcomes

Jay G. Mercer, MD, FCFP, Medical Director, Practice Solutions Web Services Inc.

Abstract:

Tools to help patients manage chronic disease information are becoming more prevalent on the web. However, there are numerous questions about whether or not they will be used by seniors and if they will change outcomes. Using examples from tools that he has helped to develop and deploy, Dr. Mercer will discuss how vital it is to integrate the tools into the provider's practice to achieve optimal outcomes, and he will relate his experience that demonstrates that the age of the patient is certainly no barrier. He will also describe some of the other tools that are being prepared for deployment and how they are likely to impact the care partnership.

Bio:

Dr. Jay Mercer divides his time between being a family physician in a fully automated office in Ottawa and as Medical Director of cma.ca, the Canadian Medical Association's Internet portal. In these roles he has been able to champion the development of several innovative web based chronic disease management tools and to deploy them in the clinical setting. He also lectures and writes on the use of technology in direct patient care, as well as teaching residents in the University of Ottawa Family Medicine program.

Contact info:

Email: jay.mercer@sympatico.ca

Using Web Based Tools to Help Patients Achieve Optimal Clinical Outcomes

- Dr. Jay Mercer MD, CCFP, FCFP
- Medical Director
- Practice Solutions Web Services

30 October, 2007

TECHNOLOGY | CONSULTING | TENANT LEASING

PRACTICE SOLUTIONS
A CMA COMPANY

Overview

- What we have done so far
- Practice integration
- Which patients will participate
- What we have in the pipeline
- Key lessons learned

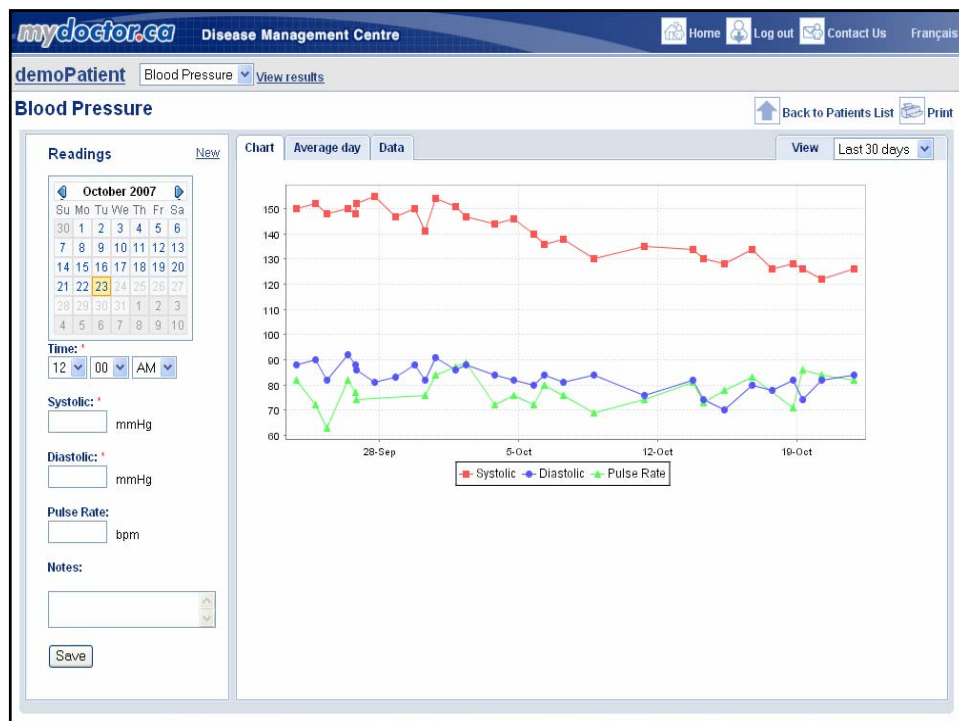
TECHNOLOGY | CONSULTING | TENANT LEASING

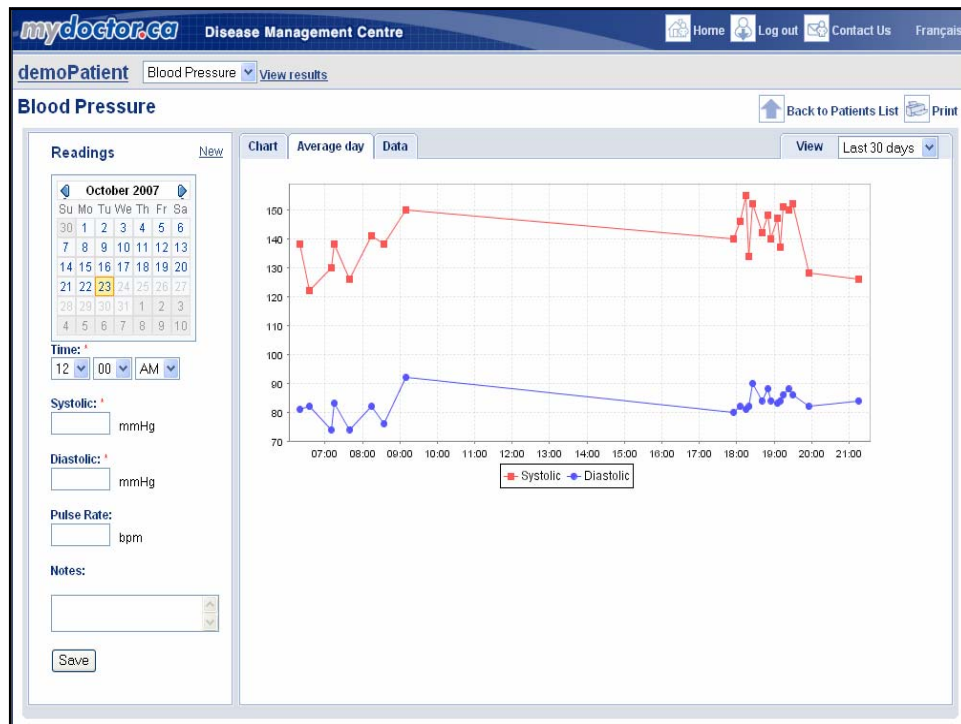
PRACTICE SOLUTIONS
A CMA COMPANY

Blood Pressure Tool

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mydoctor.ca Disease Management Centre Home Log out Contact Us Français

demoPatient Blood Pressure View results

Blood Pressure

Back to Patients List Print

Readings New

October 2007

Su	Mo	Tu	We	Th	Fr	Sa
30	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31	1	2	3
4	5	6	7	8	9	10

Time: 12:00 AM

Systolic: mmHg

Diastolic: mmHg

Pulse Rate: bpm

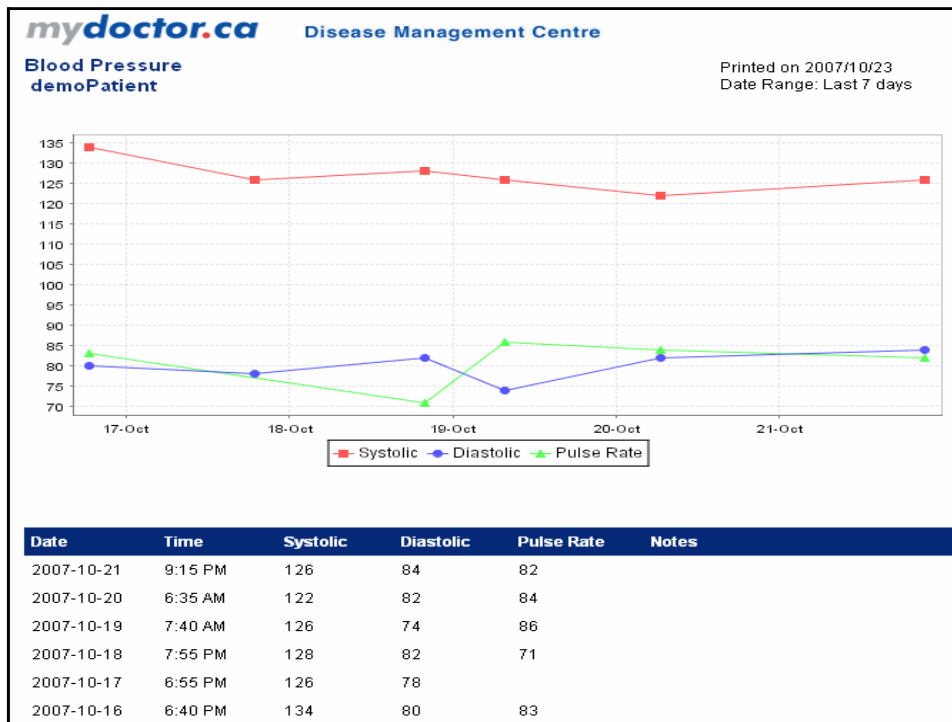
Notes:

Save

Chart Average day Data View Last 30 days

Dropdown menu options: Last 24 hours, Last 7 days, Last 30 days, Last 60 days, Last 90 days, All data

Edit	Date	Time	Systolic	Diastolic	Pulse Rate	Notes
<input type="radio"/>	2007-10-21	9:15 PM	126	84	82	
<input type="radio"/>	2007-10-20	6:35 AM	122	82	84	
<input type="radio"/>	2007-10-19	7:40 AM	126	74	86	
<input type="radio"/>	2007-10-18	7:55 PM	128	82	71	
<input type="radio"/>	2007-10-17	6:55 PM	126	78		
<input type="radio"/>	2007-10-16	6:40 PM	134	80	83	
<input type="radio"/>	2007-10-15	8:35 AM	128	70	78	
<input type="radio"/>	2007-10-14	7:10 AM	130	74	73	
<input type="radio"/>	2007-10-13	6:20 PM	134	82	81	
<input type="radio"/>	2007-10-11	8:15 AM	135	76	74	
<input type="radio"/>	2007-10-08	7:10 PM	130	84	69	
<input type="radio"/>	2007-10-07	6:20 AM	138	81	76	
<input type="radio"/>	2007-10-06	7:15 AM	136	84	80	
<input type="radio"/>	2007-10-05	5:55 PM	140	80	72	
<input type="radio"/>	2007-10-04	6:05 PM	146	82	76	



Usage to Date

- Total number of data points – 3243
- User age range 21-96
- Total number of patients - 147
- Total number active - 66
- Total number of physicians - 9
- Percentage of systolic values ≥ 140
- (863/3222) 29%
- Number of comments - 458

Practice Integration

- Register the patient
- Enter the appropriate settings
- Engage the patient
- Monitor the tool
- Integrate into clinical encounter / patient record

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The screenshot shows the login interface for the mydoctor.ca Disease Management Centre. The header includes the mydoctor.ca logo, the text 'Disease Management Centre', and navigation links for Home, Contact Us, and Français. The main content area is titled 'Login' and contains a welcome message, a note for physicians, and a login form with fields for Username and Password, an Enter button, and a link for forgotten passwords. The footer contains links for Privacy Policy, Licence Agreement, and Terms and conditions, along with a copyright notice for Practice Solutions Web Services.

mydoctor.ca Disease Management Centre Home Contact Us Français

Login

Welcome to the mydoctor.ca Disease Management Centre. This section is reserved for physicians who have subscribed to the Disease Management Centre and for their patients.

Note to physicians: Access the Disease Management Centre by using your cma.ca login information. Not yet [registered](#) to cma.ca?

Username:

Password:

Forgot your password? [Click here to retrieve it.](#)

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mydoctor.ca

Disease Management Centre

Messages (4)

Home

My Profile

Log out

Contact Us

Français

Patient Management for Dr. Lastname

You have (4) new [messages](#)

Filter by last name:

Filter by tool: All Tools

Submit

[New Patient](#)

[Subscribe](#)

⚠ One or more patients have [active alerts](#)

Patient	Date of Birth (yyyy/mm/dd)	View Results	Last Updated	Status
<div>francis beaudoin</div> <div> Edith Profile Messages </div>	1977/02/19	Blood Pressure	2007/10/23	⚠
<div>Marc Graveline</div> <div> Edith Profile Messages </div>	1981/07/27	Asthma Blood Pressure Weight Tracker	2007/10/10	
<div>testMarc testMarc</div> <div> Edith Profile Messages </div>	1987/07/27	Asthma Blood Pressure Weight Tracker		

mydoctor.ca

Disease Management Centre

Home

Log out

Contact Us

Français

Add a patient

Please type the following information and then click on Add.

Your patient will receive an email with a personalized link to be able to create a username and a password to have access to the tool.

First name:

Last name:

Email address:

Date of Birth: YYYY-MM-DD

Gender: ☐ Male ☐ Female

This patient may have access to the following tools:

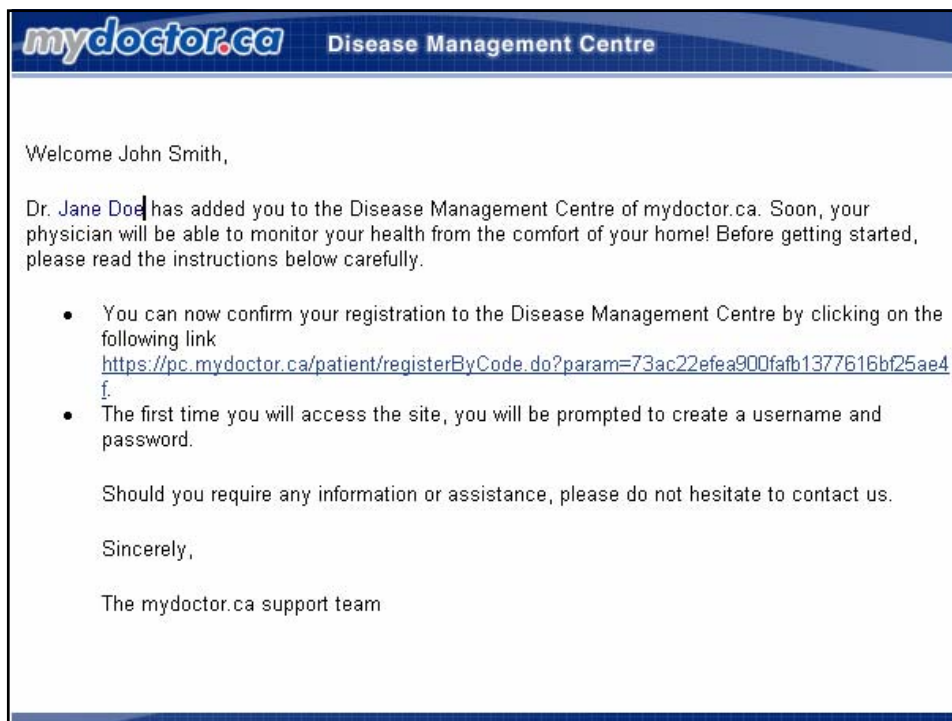
☐ Asthma

☐ Blood Pressure

☐ Weight Tracker

Add

56



The image is a screenshot of the mydoctor.ca website, specifically the "Disease Management Centre" section for a user named Francis Beaudoin. The page has a blue header with the mydoctor.ca logo and navigation links: Messages (4), Home, My Profile, Log out, Contact Us, and Francis. Below the header, the user's name "beaudoin, francis" is displayed, along with a "Back to Patients List" link. A navigation bar contains links for "Disease Management Values", "Details", "Update Password", "Tool Access", and "Delete Account". The "Disease Management Values" section is active, showing tabs for "Imperial" and "Metric". Under the "Imperial" tab, there are input fields for "Target weight" (0.0 kg) and "Height" (0.0 cm), with a "Save Values" button below them. The "Details" section is also visible, containing fields for "First name" (francis), "Last name" (beaudoin), "Date of birth" (1977-02-19), "Gender" (Male selected, Female unselected), "Member since" (2007-10-11), "Email address" (Francis.Beaudoin@globalmedic.com), and a "Notes" field with a "Save details" button.

mydoctor.ca Disease Management Centre Messages (4) Home My Profile Log out Contact Us Français

Alert me when any of my patient enters a reading that is not within the following limits. These settings may be overridden by individual patient profiles.
Email alerts will be forwarded to your cma.ca email address which is currently griffin@cma.ca

Activate Email Alert

<input checked="" type="checkbox"/> Blood Pressure	The systolic value is not within	<input type="text" value="120"/>	and	<input type="text" value="130"/>
	The diastolic value is not within	<input type="text" value="0"/>	and	<input type="text" value="0"/>
	The pulse rate is not within	<input type="text" value="0"/>	and	<input type="text" value="0"/>
<input type="checkbox"/> Weight Tracking Tool	BMI value is not within	<input type="text" value="0.0"/>	and	<input type="text" value="0.0"/>
<input type="checkbox"/> Asthma Tool	PEF value is not within	<input type="text" value="0"/>	and	<input type="text" value="0"/>

Practice Integration

- Register the patient
- Enter the appropriate settings
- Engage the patient
- Monitor the tool
- Integrate into clinical encounter / patient record

Practice Integration – No EMR

- Use front desk staff
- Use computer at home
- Patient responsible for data delivery

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Appropriate Patients

- Motivation
- Basic web skills
- Access to a computer
- Access to someone with time, basic web skills and a computer

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What does not matter...

- Age
- Typing ability
- Computer ownership

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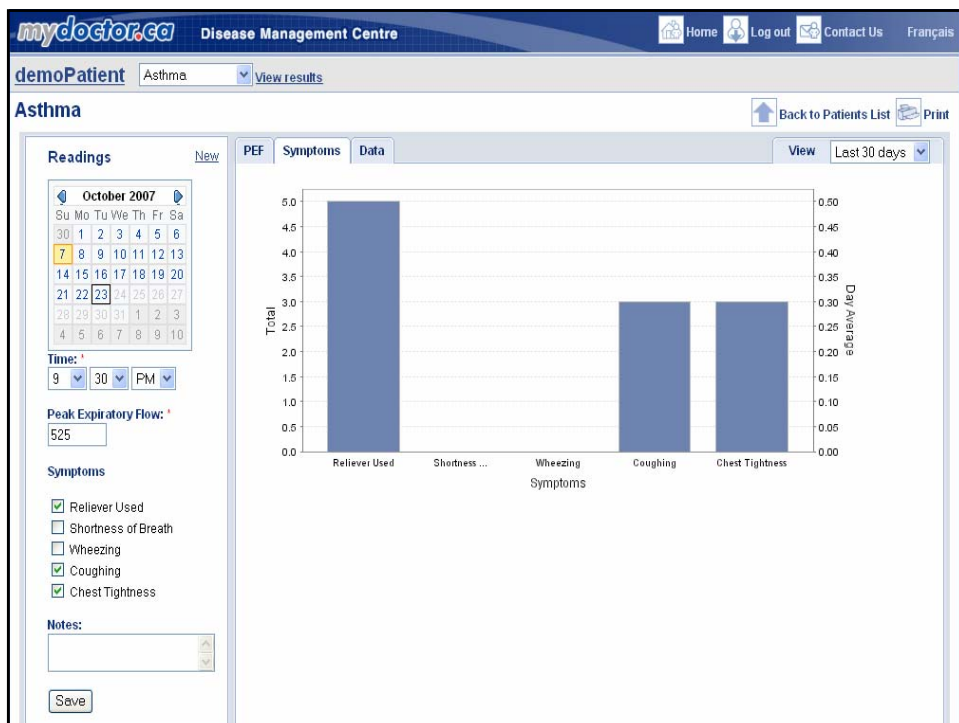
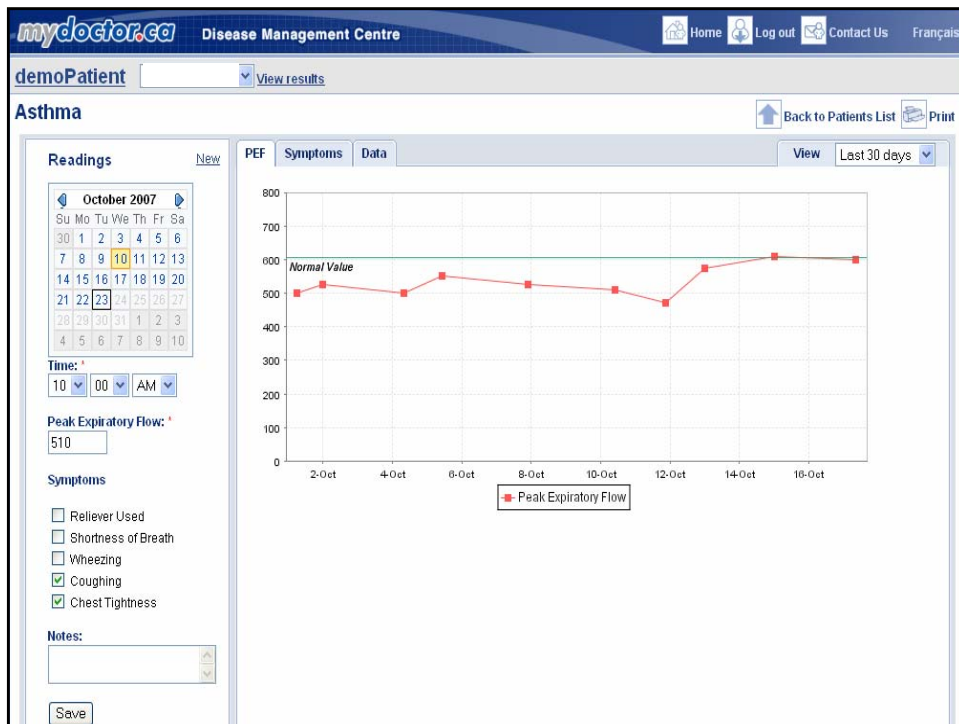
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Tools in the pipeline...

- **Asthma**
- Weight tracker
- Active Alerts
- Secure Messaging
- Diabetes

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mydoctor.ca

Disease Management Centre

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demoPatient

Asthma

[View results](#)

Asthma

[Back to Patients List](#)
[Print](#)

Readings

New

October 2007

Su	Mo	Tu	We	Th	Fr	Sa
30	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31	1	2	3
4	5	6	7	8	9	10

Time:

9

30

PM

Peak Expiratory Flow:

525

Symptoms

☒ Reliever Used
☐ Shortness of Breath
☐ Wheezing
☒ Coughing
☒ Chest Tightness

Notes:

Save

PEF

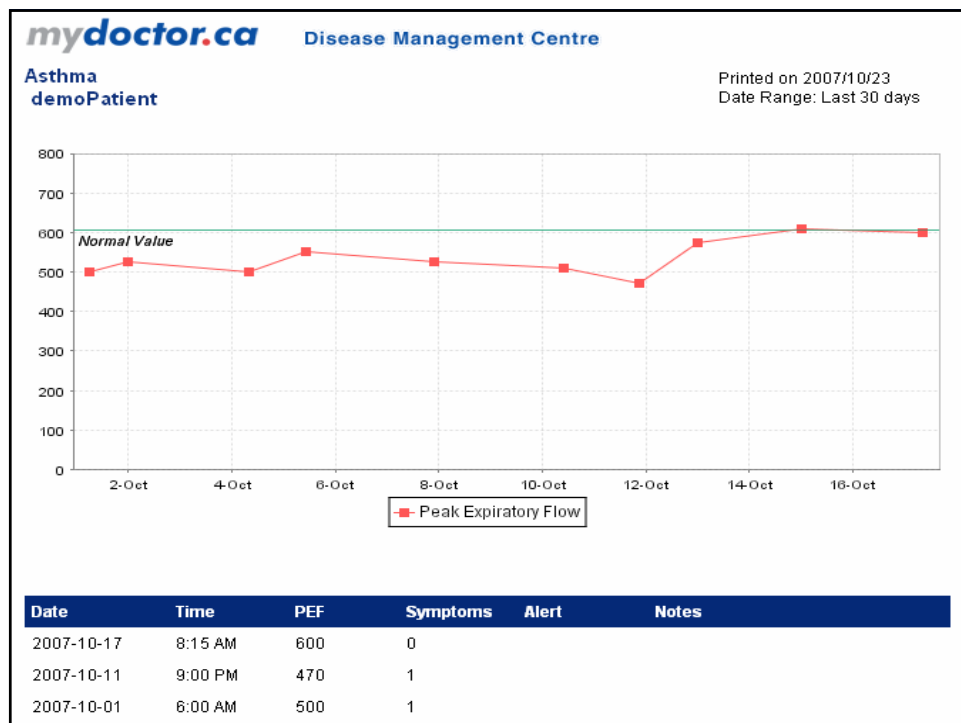
Symptoms

Data

View

Last 30 days

Edit	Date	Time	PEF	Symptoms	Alert	Notes
<input type="radio"/>	2007-10-17	8:15 AM	600	0		
<input type="radio"/>	2007-10-11	9:00 PM	470	1		
<input type="radio"/>	2007-10-01	6:00 AM	500	1		
<input type="radio"/>	2007-10-05	10:00 AM	550	0		
<input type="radio"/>	2007-10-15	12:00 AM	610	0		
<input type="radio"/>	2007-10-07	9:30 PM	525	3		
<input type="radio"/>	2007-10-13	12:00 AM	575	0		
<input type="radio"/>	2007-10-02	12:00 AM	525	2		
<input type="radio"/>	2007-10-04	8:00 AM	500	1		
<input type="radio"/>	2007-10-10	10:00 AM	510	3		



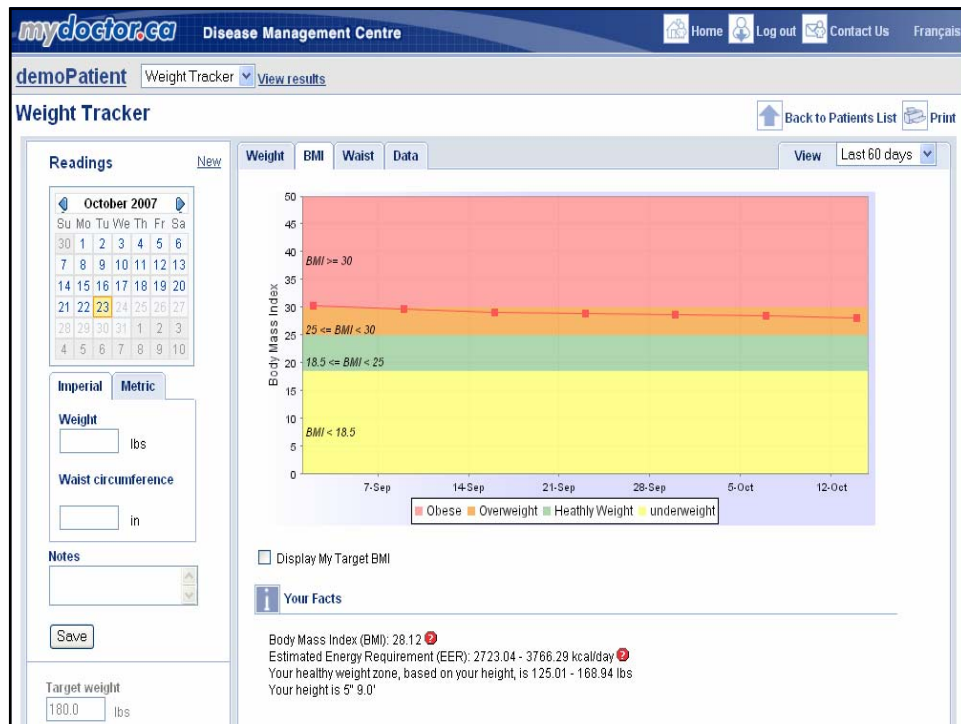
Tools in the pipeline...

- Asthma
- **Weight tracker**
- Active Alerts
- Secure Messaging
- Diabetes

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Disease Management Centre

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[Français](#)

demoPatient
Weight Tracker
View results

Weight Tracker
Back to Patients List
Print

Readings
New

October 2007

Su	Mo	Tu	We	Th	Fr	Sa
30	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31	1	2	3
4	5	6	7	8	9	10

Imperial
Metric

Weight
 lbs

Waist circumference
 in

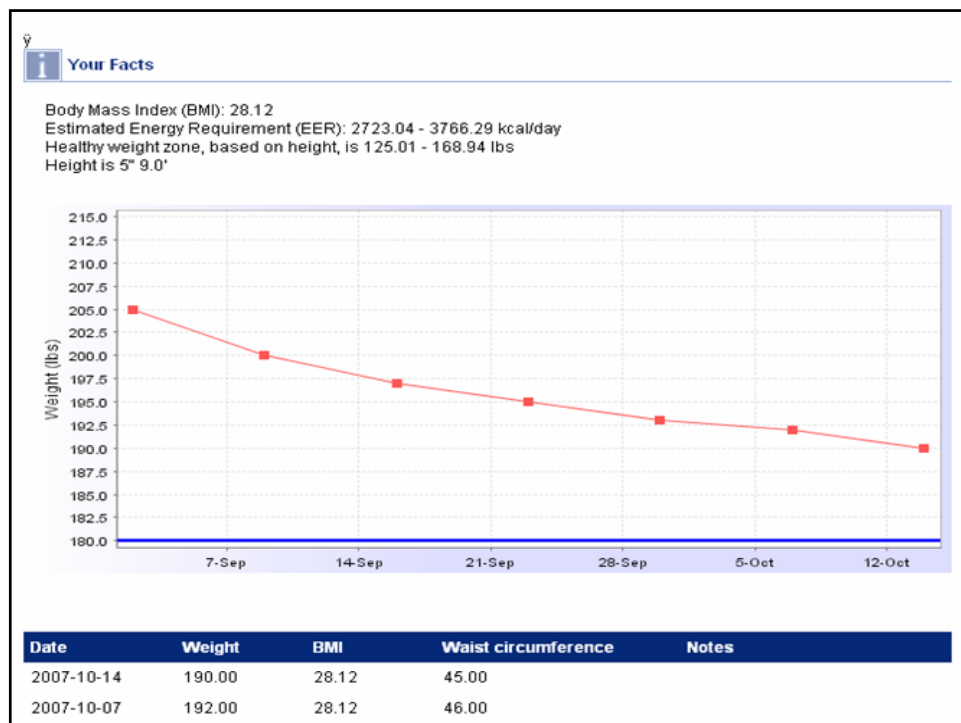
Notes

Save

Weight
BMI
Waist
Data

View
Last 60 days

Edit	Date	Weight	BMI	Waist	Notes
<input type="radio"/>	2007-10-14	190.00	28.2	45.00	
<input type="radio"/>	2007-10-07	192.00	28.5	46.00	
<input type="radio"/>	2007-09-30	193.00	28.65	46.00	
<input type="radio"/>	2007-09-23	195.00	28.94	47.00	
<input type="radio"/>	2007-09-16	197.00	29.24	47.00	
<input type="radio"/>	2007-09-09	200.00	29.68	48.00	
<input type="radio"/>	2007-09-02	205.00	30.43	50.00	



Tools in the pipeline...

- Asthma
- Weight tracker
- **Active Alerts**
- Secure Messaging
- Diabetes

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Update Password

New password:

Retype new password:

Change Password

Tool Access

This patient may have access to the following tools:

☒ Blood Pressure

Save Tool Access

Personalized Alerts

Alert me when the patient enters a reading that is not within the following limits (These settings will overwrite the global alert limits for each tool.)
Email alerts will be forwarded to your cma.ca email address which is currently: griffin@cma.ca

Activate Email Alert

☐ Blood Pressure

The systolic value is not within and
The diastolic value is not within and
The pulse rate is not within and

☐ Weight Tracking Tool

BMI value is not within and

☐ Asthma Tool


PEF value is not within and

Save

Delete Account

Active Alerts

 [Back to Patients List](#)

 The following table displays readings that exceed the alert limits.

Select	Patient	Date	Time	View Results	Details
<input type="checkbox"/>	Apu Nahasapeemametil	2007/06/20	12:00 AM	Asthma Tool	PEF is less than 300
<input type="checkbox"/>	Homer Simpson	2007/06/28	10:00 AM	Blood Pressure Tool	Systolic is less than 50 Systolic is 75
<input type="checkbox"/>	Homer Simpson	2007/06/28	04:00 PM	Weight Tracking Tool	BMI is higher than 30

Tools in the pipeline...

- Asthma
- Weight tracker
- Active Alerts
- **Secure Messaging**
- Diabetes

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Disease Management Centre
Messages (4)
Home
My Profile
Log out
Cont...

Inbox
Sent Messages
Compose a message

- Select -


[Mark as unread](#)
[Mark as read](#)
[Delete](#)

1 2 Next

	To:	Subject:	Delete
<input type="checkbox"/>	francis beaudoin 2007-10-23 17:40:07.0	One Super	x
<input type="checkbox"/>	francis beaudoin 2007-10-23 12:10:21.0	rt555 ghrtyty	x
<input type="checkbox"/>	francis beaudoin 2007-10-23 11:43:36.0	<no subject> retret	x
<input type="checkbox"/>	francis beaudoin 2007-10-23 11:43:28.0	<no subject> retretert	x
<input type="checkbox"/>	francis beaudoin 2007-10-23 11:00:37.0	re:<no subject> dfgsdfdsf	x

Licence Agreement

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Disease Management Centre
Messages (3)
Home
My Profile
Log out
Cont...

Inbox
Sent Messages
Compose a message

One

Messages between you and francis beaudoin

Physician Lastname 2007-10-23 17:37:21.0	How are you today?
francis beaudoin 2007-10-23 17:40:07.0	Super

Reply:

Submit

Cancel

[Mark as unread](#)
[Delete](#)

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mydoctor.ca Disease Management Centre

Messages (3) Home My Profile Log out

Inbox Sent Messages Compose a message

To: ---
Subject: ---
Message: All
Myself
francis beaudoin
testMarc testMarc

Submit Back to Inbox

Privacy Agreement

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mydoctor.ca Disease Management Center

Hello Dr. Jay Mercer,

You have new messages in your Disease Management Centre inbox.
To read the messages, follow the link below:
<http://pc.mydoctor.ca/patient/welcome.do>

Tools in the pipeline...

- Asthma
- Weight tracker
- Active Alerts
- Secure Messaging
- **Diabetes**

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Key Lessons Learned

- Age is not a barrier
- Computer skills are not a barrier
- Design simplicity is vital
- Appropriate practice integration is essential
- Improves patient engagement in health management

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Electronic Personal Health Records: Challenges for development and adoption

Tom Jones, Chief Medical officer, Tolven Healthcare Innovations

Abstract:

In July 2000, the NCVHS (National Committee on Vital and Health Statistics) prepared a document for the US Secretary of Health and Human Services entitled Report on Uniform Data Standards for Patient Medical Record Information. Although this report is mostly concerned about the importance of standards for healthcare information, it contains important statements that are relevant to Personal Health Records (PHRs). Among them are the following:

Patient medical record information (PMRI) is information about a single patient. Healthcare professionals generate this information as a direct result of interaction with the patient, with individuals who have personal knowledge of the patient, or with both. PMRI includes patient demographics, health history, details of present illness or injury, orders for care and treatment, observations, records of medication administration, diagnoses/problems, allergies, and other healthcare information. PMRI facilitates the creation of a lifetime health record for individuals.

In a later report (Personal Health Records and Personal Health Record Systems, February 2006), the NCVHS catches the thread of a “lifetime record for individuals” and weaves a useful fabric for PHRs and underlines both the potential for and the challenges for PHRs in the following statement.

The greatest opportunities for improving health and health care lie in enabling information exchange between the three dimensions (*patient care, population health, and personal health*) of the national health information infrastructure. The full potential of PHR systems will not be realized until they are capable of widespread exchange of information with EHRs and other sources of personal and other health data.

A recent statement by HIMSS (HIMSS Personal Health Records Definition and Position Statement, June 2007) appears to reflect these same principles. There is a growing consensus around the functionality of PHRs.

HIMSS supports the development of interoperable ePHRs which are interactive and use a common data set of electronic health information and e-health tools. HIMSS envisions ePHRs that are universally accessible and layperson comprehensible, and that may be used as a lifelong tool for managing relevant health information that is owned, managed and shared by the individual or his or her legal proxy(s). The ideal ePHR would receive data from all constituents that participate in the individual's healthcare; allow patients or proxies to enter their own data (such as journals and diaries); and designate read-only access to the ePHR (or designated portions thereof).

Many other organizations including the Markle Foundation and the California Healthcare Foundation have issued important white papers regarding PHRs; all have encouraged their development and use. All have lamented the laggardly implementation of PHRs.

In this presentation, we will review the key functions of PHRs that appear to have widespread endorsement. We will then discuss the obstacles that have prevented widespread adoption of PHRs. We will conclude by analyzing the key requirements for interoperability and discuss why those requirements have proved to be among the most difficult to meet.

Bio:

Following his graduation from medical school at Stanford University, Dr. Jones joined the University of Chicago and was there from 1969 until 1995, first as a house staff officer and then as a member of the faculty of the Department of Medicine. As part of the development of the infrastructure for primary care education and clinical activity, Dr. Jones and his colleagues at the University developed the Centennial Patient Care Workstation, a model for allowing clinicians to enjoy the benefits of new information technology. This project was very important in shaping his beliefs that sensitive deployment of commercially available software could provide great benefit to, and enhance the efficiency of practicing clinicians. Dr. Jones' clinical expertise was recognized when, in 1995, he was named by Chicago area physicians as one of the 35 most outstanding general internists in Chicago (The Best Doctors in America, Woodward and White). His interest in clinical informatics grew out of both his clinical practice experience and his teaching experience. He received the Quantrell award for excellence in teaching in 1992; this award is the nation's oldest teaching award and is given by the students at the University of Chicago.

In 1995, Dr. Jones joined Oacis Healthcare Systems where his role allowed him to focus more deeply on the clinical functionality of applied informatics. During his 5 years at Oacis, he had the opportunity to work closely with some of the founding members of the HL7 organization. Over the course of his years of teaching and subsequently at Oacis, he developed sensitivity regarding how clinicians make critical decisions based on clinical information. Understanding how clinicians communicate with one another led to an appreciation of how the standardization of clinical information fostered more rapid and accurate communication.

In 2000, Dr. Jones joined Oracle where he provided the clinical leadership for Oracle's Healthcare Strategy group, including the development of Oracle's Healthcare Transaction Base. During his 5 years at Oracle, Dr. Jones met with provider organizations, payor organizations, academic institutions, healthcare informatics standards organizations, government representatives and pharmaceutical firms in 34 countries. He has been active in deliberations of the European Commission's Directorate-General Information Society and has written major white papers for the EC.

In 2004, Dr. Jones began his participation in the Interoperability Consortium (IC) where he worked with colleagues from Accenture, CSC, Cisco, Hewlett-Packard, IBM, Intel and Microsoft. He chaired the Technical Committee of the IC and was responsible for the technical and architectural sections (including the discussions of standards) of the IC's response to the ONCHIT RFI. He also participates in the CalRHIO (California Regional Health Information Organization) as a member of the Clinical Working Group.

In February 2006, Dr. Jones left Oracle to become a founding partner and Chief Medical Officer of Tolven Inc., a start-up company dedicated to furthering the development and use of open source software for healthcare.

Contact info:

Email: tom.jones@tolvenhealth.com

Electronic Personal Health Records

Challenges for Development and Adoption

Consumer Health Informatics Summit
Ottawa, October 30, 2007

Thomas M Jones, MD, CMO Tolven
tom.jones@tolvenhealth.com

www.tolvenhealth.com

www.tolven.org

<http://wikiHIT.org>

Discussion Points

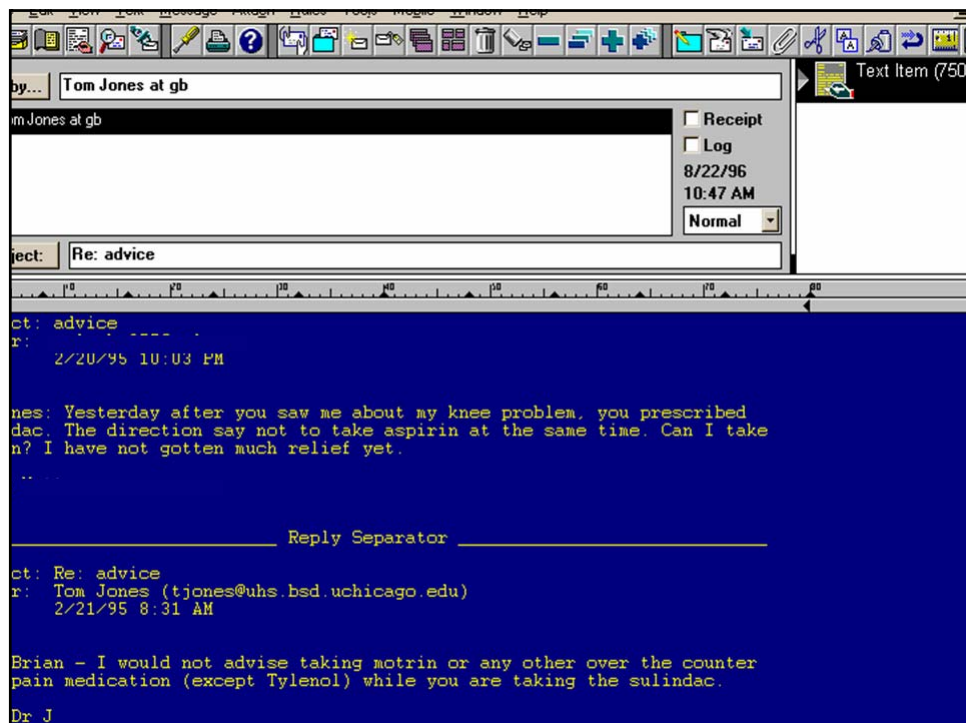
- Early days – My Own Experience
- Personal Medical Record Information
- Evolution of PHR concept
- Today's PHR Landscape
- Challenges in Adoption and Development
- Suggested Resolutions

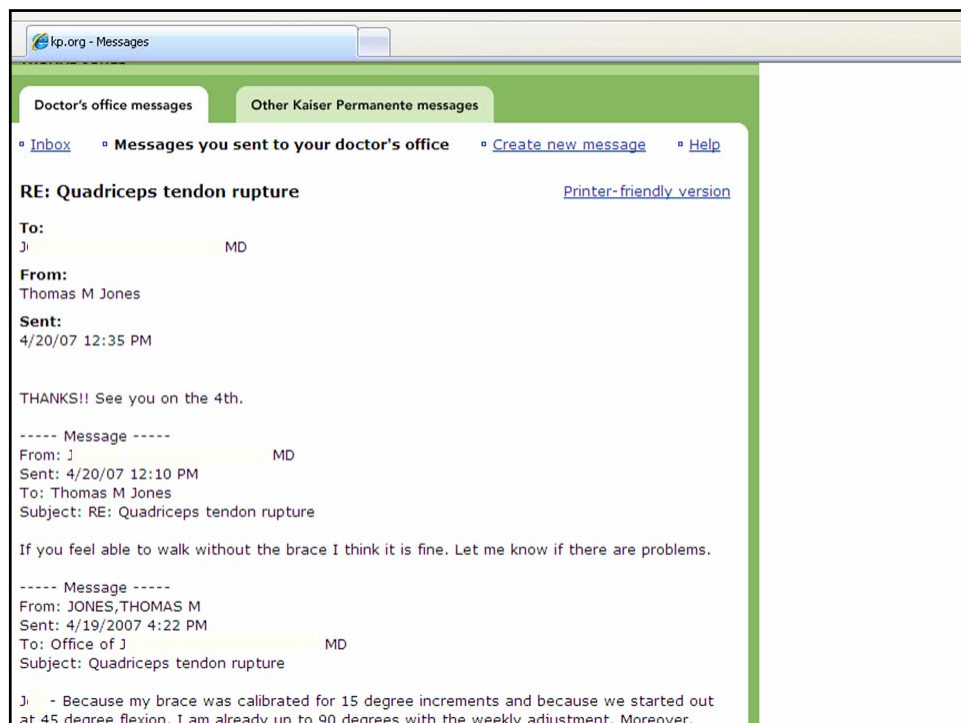
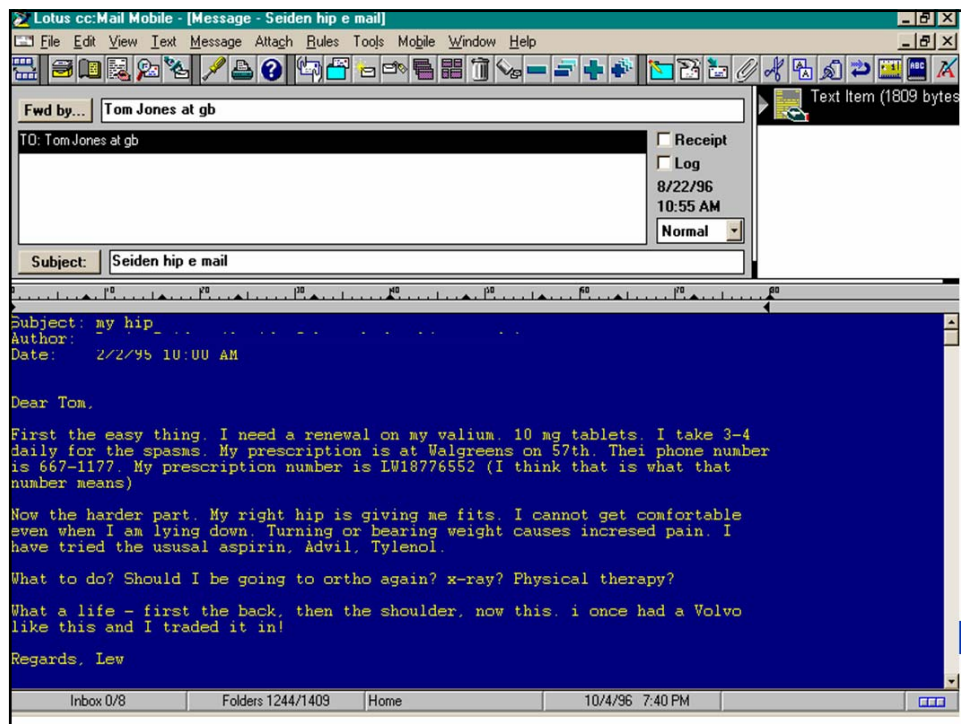
Personal experience



- The allure of email
- Secure messaging
- Patient portal
- My PHR

3





NCVHS 2000: PMRI



- Patient medical record information (PMRI) is information about a single patient.
- Healthcare professionals generate this information as a direct result of interaction with the patient, or with individuals who have personal knowledge of the patient, or with both.
- PMRI includes patient demographics, health history, details of present illness or injury, orders for care and treatment, observations, records of medication administration, diagnoses/problems, allergies, and other healthcare information.
- PMRI facilitates the creation of a lifetime health record for individuals.

Standards and other Issues



- Noted that the lack of complete and comprehensive standards is a major constraint on the ability of our healthcare delivery system to enhance quality, improve productivity, manage costs and safeguard data.
- Recommended accelerating the development, adoption, and coordination of PMRI standards.
- Addressed the related issues of:
 - protecting the confidentiality of PMRI
 - reducing barriers to the electronic exchange of PMRI caused by diverse state laws
 - coordinating the development of PMRI standards within the broader context of the National Health Information Infrastructure.

Impediments to Exchange



- It found that the major impediments to electronic exchange of patient medical record information are:
 - limited interoperability of health information systems, limited
 - comparability of data exchanged among providers, and the need for better quality
 - accountability
 - integrity of data.

Benefits of Standards



- When complete and comprehensive standards for PMRI are available, vendors and users will be able to develop information systems that will:
 - Capture clinically specific information more accurately, more quickly, and less expensively
 - Facilitate the ability to construct and maintain a comprehensive, lifelong healthcare record that enables continuity of care
 - Facilitate low-cost information exchange between patients and providers via the Internet
 - Enable authorized caregivers to access this information from many different locations
 - Prevent adverse events and other potential problems
 - Provide more complete and comprehensive clinical data for outcomes analysis
 - Improve the ability to monitor and protect the confidentiality of healthcare information.

NCVHS 2006: Goals for PHRs



- Support wellness activities
 - Improve understanding of health issues
 - Support timely, appropriate preventive services
- Increase sense of control over health
 - Increase control over access to personal health information
 - Support healthcare decisions and responsibility for care
 - Support home monitoring for chronic diseases
 - Support understanding and appropriate use of medications
 - Reduce adverse drug interactions and allergic reactions

NCVHS 2006: Goals for PHRs



- Strengthen communication with providers
 - Increase access to providers via e-visits
 - Verify accuracy of information in provider records
 - Support continuity of care across time and providers
 - Reduce hassle through online appointment scheduling and prescription refills
 - Avoid duplicate tests

Importance of Information Exchange



- The greatest opportunities for improving health and health care lie in enabling information exchange between the three dimensions (areas) of the national health information infrastructure.
- The full potential of PHR systems will not be realized until they are capable of widespread exchange of information with EHRs and other sources of personal and other health data.

Interoperability and PHRs



- HIMSS supports the development of interoperable ePHRs which:
 - are interactive
 - use a common data set of electronic health information
 - are universally accessible
 - may be used as a lifelong tool for managing relevant health information that is owned, managed and shared by the individual or his or her legal proxy(s)
 - receive data from all constituents that participate in the individual's healthcare
 - allow patients or proxies to enter their own data (such as journals and diaries)
 - designate read-only access to all or some of the ePHR

Interoperability: Raising the Bar



- Semantic interoperability provides common interpretability, i.e., information in the fields within the message can be used in an intelligent manner.
- At the highest level, semantic interoperability takes advantage of both the structuring of the message and the codification of the data so that the receiving computer can interpret the data.

Today's Landscape



- Current PHRs are generally not interoperable
- They vary in how they handle security, authentication, and other technical issues
- While consumers or patients always have access to their own data, they do not always determine who else may access it
 - For example, PHRs that are “views” into a provider’s EHR follow the access rules set up by the provider
 - In some cases, consumers do have exclusive control

Burning Issues



- Data standards
 - Terminology, messaging, content
 - Clinicianspeak vs consumerspeak
- Consumer control - privacy
 - Selectivity of data sharing
 - Agency and family access
- Security
- Operational considerations
 - Affordability
 - ROI
 - Sustainability
 - Consumer/clinician access technology

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Issue Resolution – 1



- Interoperability
 - Common information platform
- Data Standards
 - Terminology
 - Using standard vocabularies
 - Clinical data definitions
 - Changing terminologies
 - User preferences
 - Messaging
 - Accommodating a variety of standard formats
 - Using rules for processing messages
 - Content
 - Continuity of Care Record (CCR)

20

Issue Resolution - 2



- Consumer control – privacy
 - Establishing family accounts
 - The concept of agency
 - Voluntary exchange of data
- Security
 - Security standards
 - Obscurity is not security
 - Encryption in transit
 - Encryption at rest

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Issue Resolution - 3



- Operational considerations
 - Affordability
 - Open Source components
 - Web based deployment
 - ROI
 - Consumer service
 - Sustainability
 - Open architecture
 - Enable voluntary participation in data mining
 - Consumer/clinician access technology
 - Fixed and mobile devices

22

Summary



- While there is growing agreement that personal health records (PHRs) have the potential to engage consumers in the business of managing their healthcare, major obstacles have prevented widespread adoption and continuing use of PHRs.
- Difficulties in exchanging clinical information between consumers and clinicians, failure to incorporate information model and vocabulary standards, trivialization of consumer input, inadequate technology, concerns about privacy, and clumsy financial models have all combined to retard usage.
- The evolution of open source software components that are specifically tailored to healthcare information should contribute to a resolution of these issues.

Biography of Chair: Session 3

William Pascal, Technology Officer for the Canadian Medical Association

As Chief Technology Officer, Mr. Pascal is responsible for shaping the strategic direction and policy for the CMA's e-Health agenda. He has worked in the economic policy and social policy sectors at the Federal government level as well as run operations in regional and headquarter environments.

Over the years, Mr. Pascal has developed air, railway and marine transportation policies as well as built airports throughout the north and negotiated ferry service contracts on both coasts of Canada. He has been responsible for communications policy while at the Privy Council Office and in Health Canada. He has developed health policies and managed the Central Region operations for Health Canada which included Ontario, Manitoba and Saskatchewan. He has managed several large projects, most notably, the Federal government's involvement at Expo 86 in Vancouver and at the 1988 XV Olympic Winter Games in Calgary. Most recently he was the Director General, Office of Health and Information Highway which had responsibility for coordinating, facilitating and managing health infostructure-related activities both within Health Canada, with other Federal government departments, with all the provinces and territories and other stakeholders. His work led to an agreement on Information Technology investments in the health care sector in Canada with all provinces and territories and the creation of Canada Health Infoway.

Mr. Pascal is an electrical engineer, certified management accountant and urban planner by academic training. In 2001 he received the Lieutenant Governor's Medal of Distinction in Public Administration for his work as Chair of the Federal Council in Ontario.

The Internet Changes Everything: Lessons from other industries

Micheal Martineau, Vice President, Public Sector Research & eHealth Practice Lead, Branham

Abstract:

While we may take banking on-line, printing our boarding passes at home, and submitting our taxes electronically for granted, it wasn't that long ago that most of the organizations with which we now conduct business on-line scoffed at early attempts by their competitors to do so. Despite what their marketing campaigns may suggest to the contrary, many of these organizations did not willingly embrace the Internet. Rather, they were pushed to do so by their clients. Like dominoes, these organizations quickly fell into line when it became apparent that consumers were eagerly embracing the on-line services developed by early innovators.

Mr. Martineau's presentation describes how the Internet, the personal computer, and consumerism have combined to transform the manner in which organizations in various industries interact with their clients. The presentation will explore how these organizations have aggressively examined their business processes to determine which ones involve their clients and, having identified these processes, used information and communication technologies to improve service delivery while reducing costs. Lessons learned by these organizations will be identified and offered for consideration by the health sector.

Contact info:

Email: mmartineau@branhamgroup.com



My Background

Branham

- **Founding Exec NSTN Inc. – 1989**
 - One of the first commercial ISPs
 - First Canadian ISP to offer dial Internet access
- **Founding Board Member CA*net – 1990**
 - Original Canadian Internet backbone network
- **Founding Exec iSTAR internet inc. – 1995**
 - Merger of NSTN Inc. and fONOROLA internet

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Musings on Consumer Choice

Branham



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Internet Use

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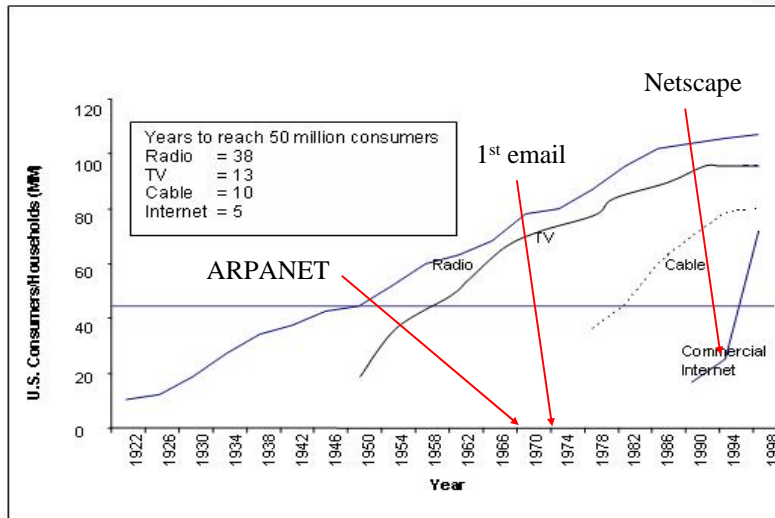
- How many use the Internet at home?
 - 61% Canadian households
- How many bank on-line?
 - 35.2% / 59.9%
- How many book / research travel on-line?
 - 38.5% / 63.1%
- How many look up health / medical information on-line?
 - 35.3% / 59.9%

Source: 2005 StatsCan Canadian Internet Use Survey

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Rise of the Internet

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Source: Goldman Sachs, Morgan Stanley Technology Research

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Branham

"The health care system lags behind other industries in adopting IT by at least 5-7 years but perhaps by as much as 10-15 years."

Final Report of the Health IT Leadership Panel to the U.S. National Coordinator for Health IT

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Good News, Bad News

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Good News

Other industries have trained consumers to use on-line services

Bad News

Other industries have trained consumers to use on-line services

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Consumer On Line Services in Other Industries

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Similarities



Banking

- Confidentiality
- Real-time transactions
- Heavily regulated
- Multiple sites (branches)
- Multiple companies delivering similar services
- High consumer quality expectations

Automotive

- Large complex parts catalog
- Many suppliers and producers
- Process complexity
- Intense cost pressure
- Rising consumer quality expectations

Airlines

- Heavily regulated
- Complex scheduling and logistics
- Intense cost pressure
- High consumer safety expectations

Retail

- Diverse product space
- Complex product space
- Real-time transactions
- Consumer choice – wants options

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В Р А Н Х А М Г Р О У П И Н К

Banking



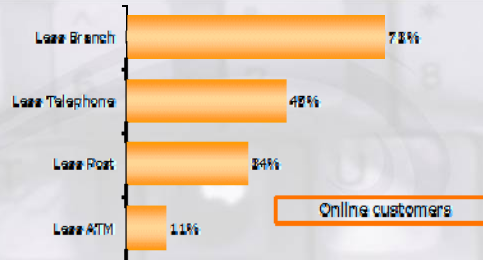
“Usage of the Internet has grown very rapidly amongst the business community with a large proportion of our business customers having access to the Internet and many now having broadband. This has driven demand from customers to be able to use the Internet for the more straight-forward banking needs The result is that Business Internet banking has grown from a relatively marginal channel into virtually an equal partner now with the branch and telephone channels.”

Mervyn Northam, Head of Electronic Services
HSBC Commercial Banking

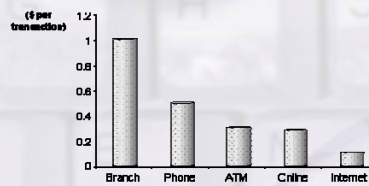
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Banking – Reduced Costs

Branham



Source: The Impact of online banking on customer loyalty, Virtual Surveys

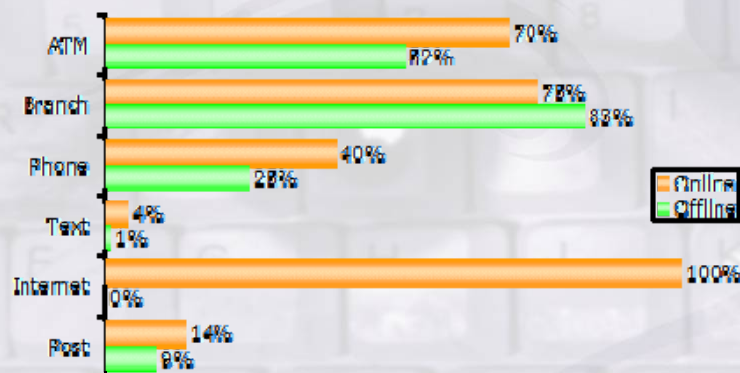


Source: Booz-Allen & Hamilton, JP Morgan (2003)

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Banking – Still Use Multiple Channels

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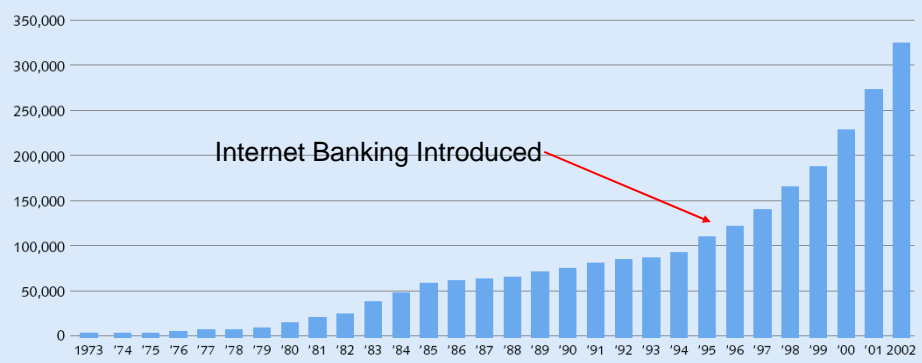


Source: The Impact of online banking on customer loyalty, Virtual Surveys

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Banking – Increased ATM Use

Branham

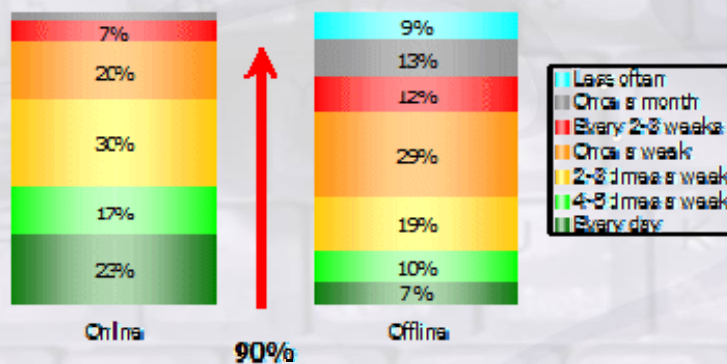


SOURCE: CARD INDUSTRY DIRECTORY, 2003 EDITION

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Banking – Increased Frequency

Branham



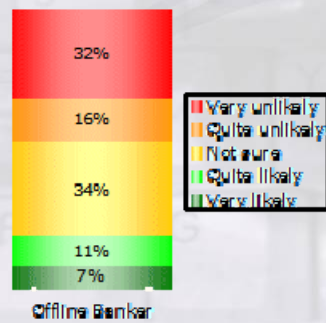
Source: The Impact of online banking on customer loyalty, Virtual Surveys

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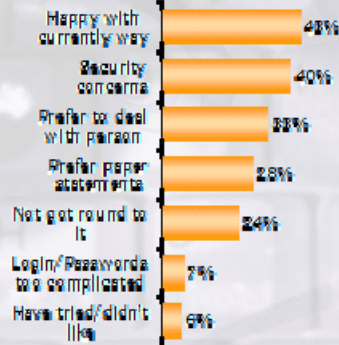
Banking – Barriers to Overcome

Branham

Intentions to Bank Online



Barriers to Online Banking



Source: The Impact of online banking on customer loyalty, Virtual Surveys

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Financial Services – New Entrants

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PayPal

E*TRADE
FINANCIAL

ING DIRECT
save your money

President's Choice
FINANCIAL

MY BANKING
DIRECT
a service of New York Community Bank • Member FDIC

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Airlines

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CHECK-IN CONFIRMATION

TRAVEL DOCUMENT VERIFICATION REQUIRED AT NWA.COM CHECK-IN COUNTER AT AIRPORT

NORTHWEST **INTL** **E-TICKET**

GATE: 28A Subject to Change
Verify gate assignment at airport

FLIGHT: NW21
DEPART: 6:30PM
FROM: Tokyo, Japan (Narita)
TO: Taipei, Taiwan

SEAT: 25-F
Coach Class
25NOV2003

CONF: 72VGM2
ETKT: NW0129636

PLEASE PRESENT THIS DOCUMENT AT NWA.COM CHECK-IN COUNTER AT THE AIRPORT. THIS DOCUMENT WILL NOT BE ACCEPTED BY IMMIGRATION AUTHORITIES AND WILL NOT BE VALID FOR BOARDING. ONLY YOUR TRAVEL DOCUMENTS HAVE BEEN VERIFIED BY A NWA AGENT AT THE AIRPORT COUNTER.

If your travel plans change you must contact Northwest Airlines Reservations prior to flight departure. You must arrive at the airport check-in counter at least 60 minutes prior to departure. Reservations are subject to cancellation if you are not on board the aircraft at least 30 minutes prior to departure.

"[Self-Service] is right up there because volumes of people and flights mean that self-services is the best way to go. Banks went there some time ago with ATMs. People like self-service."

Ed Nicol
Director of Information Management, Cathy Pacific

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Airlines – IT Spending

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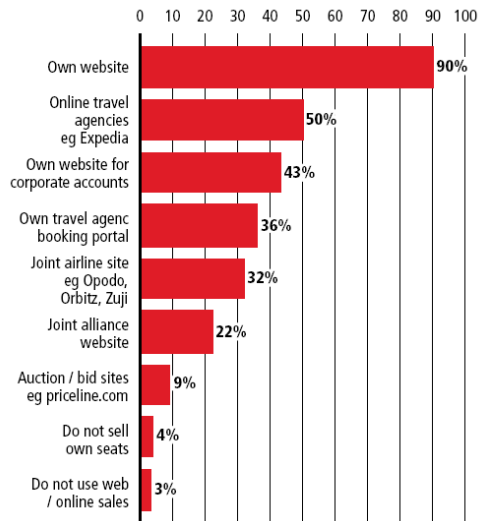
- 2.1% of revenues
- Down from 2.3% in 2005
- 55% of top 25 carriers spent 2.6% or more compared with only 10% of low-cost carriers
- North American carriers are highest spenders at 2.2%, up from 1.95% in 2006

Source: 2007 Airlines Trends Survey

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Airlines – On Line Channels

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Source: 2007 Airlines Trends Survey

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Airlines – On-Lines Sales

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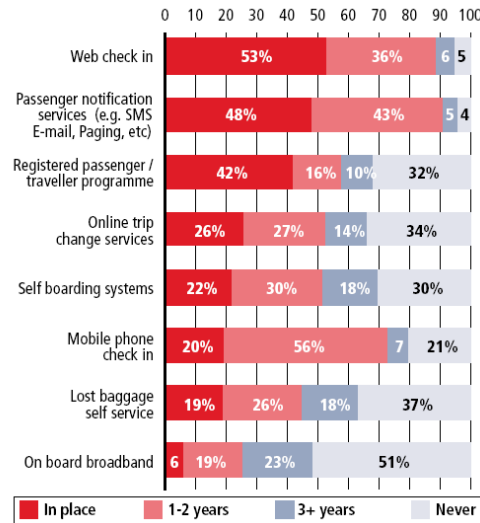
Proportion of all tickets sold				
Percentage of total seat sales	Own airline website	All online sales	Call centres	e-tickets issued
None	1%	6%	3%	6%
2% or less	2%	3%	4%	1%
2% - 10%	17%	10%	44%	3%
11% - 20%	27%	23%	44%	2%
21% - 30%	29%	6%	1%	1%
31% - 40%	7%	17%	3%	7%
41% - 50%	1%	9%	3%	1%
51+%	20%	30%	3%	80%
Average 2007	26.6%	35.2%	13.4%	71.5%
Average 2006	24.4%	32.4%	18.6%	60.3%
Average 2005	16.4%	20.1%	20.3%	26.6%
Average 2004	11.0%	14.5%	17.1%	19.1%
Average 2003	9.7%	15.8%	-	14.7%
Average 2002	5.1%	10.1%	-	11.1%

Source: 2007 Airlines Trends Survey

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Airlines – Customer Self Service

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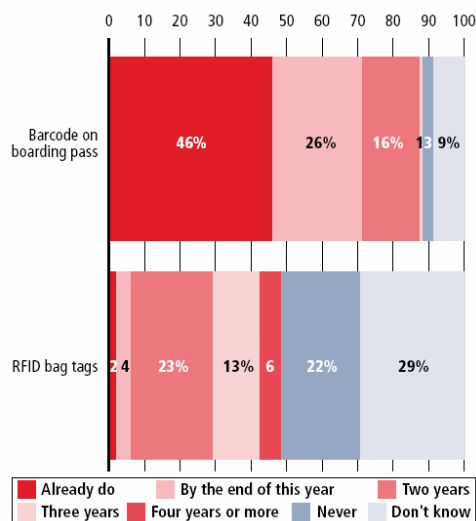


Source: 2007 Airlines Trends Survey

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Airlines – Automated Check-in

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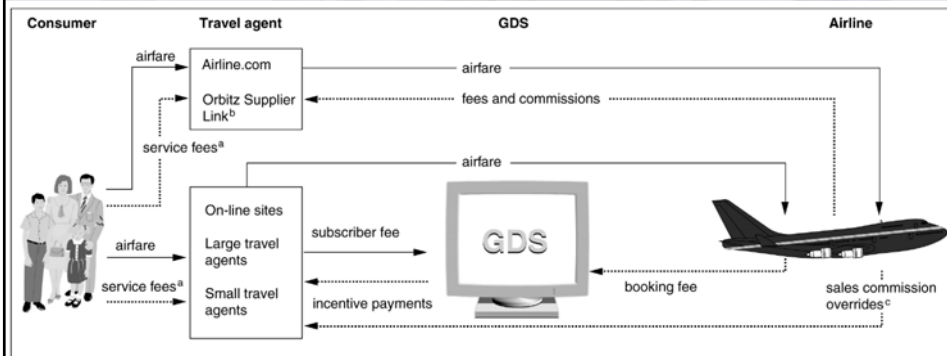


Source: 2007 Airlines Trends Survey

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Airlines - Fall and Rise of Intermediaries

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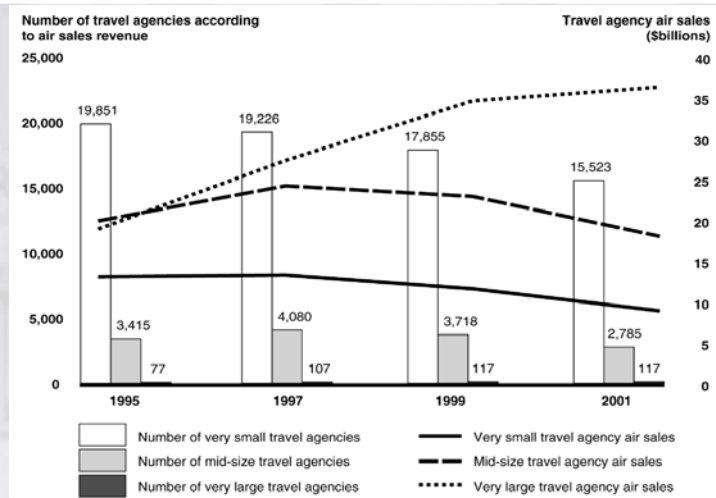


Source: US. Government Accounting Office

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Airlines - Fall and Rise of Intermediaries

Branham



Source: US. Government Accounting Office

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Airlines – Travel Agent Evolution

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- Airline web sites suitable for short-haul and simple flights
- Agencies are specializing in more complex travel arrangements, specialized packages, and business travel
- Two classes arising:
 - Large agencies dealing in volume
 - Smaller agency specializing in niche travel (e.g. family reunions, vacation of a

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Airlines – New Entrants

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What is Personal eHealth?

- **eHealth** is the **digitization and integration** of **healthcare processes** using Information and Communications Technology
- **Personal eHealth** focuses on those **processes** in which the **individual receiving care** or **making decisions about the care** that they will receive **plays** or can play an **active role**

Personal eHealth examples



- Booking an appointment
- Checking a lab result
- Researching a disease
- Examining treatment options
- Vital signs monitoring
- ~~➤ Surgery~~

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Necessary Ingredients



- Consumer Power
 - Canadians rely on others for goods and services
 - Fosters sophisticated consumer society
- Widespread Computer Literacy
 - High level of Internet use
- Escalating Costs
 - Year over year increase in Canadian healthcare costs have outpaced growth in GDP
- Back Office Automation

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Patient vs. Consumer

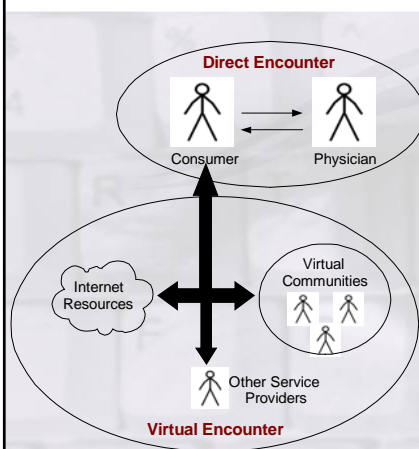
Branham

- Same person, different roles
 - Two sides of the same coin
- Consumer:
 - Evaluates options and make choices
 - Use services outside traditional health sector to assist in decision making
- Patient:
 - Has made a choice
 - Is receiving services

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В В Ч И Н Н В В Е Р О Н Ь И С

Healthcare Consumer

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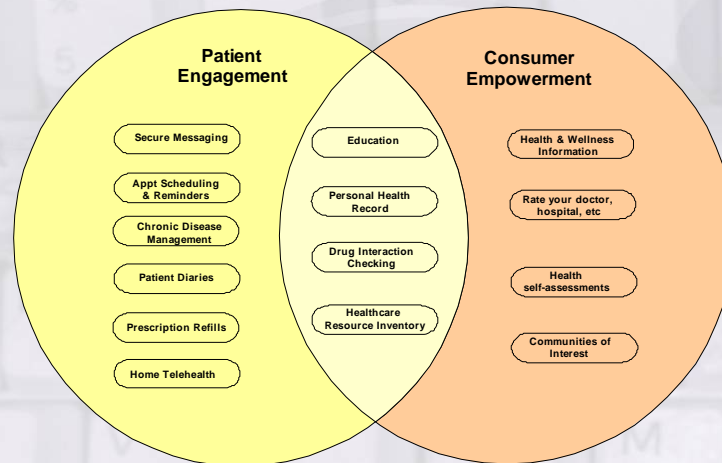


- 58% of users stated that the information that they found in their last search **affected a decision** about how to treat an illness or condition
- 54% of users stated that the information they found on the Internet led them to **ask a doctor new questions or to get a second opinion from another doctor**

Source: Pew Internet & American Life "Online Health Search, 10/6"

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Personal eHealth Applications



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Consumer Empowerment



- Consumers are going online for additional information in droves, and in many cases challenging their physician
- In the past 2 years, consumers have become much more satisfied with the health information they find online
 - They are becoming less satisfied with the information they get from their physician
- Consumers are becoming very comfortable with researching health information online – perhaps too comfortable.
 - Nearly half of the consumers researching health info online are almost exclusively reliant on search engines to find that information

Source: Cybercitizen® Health

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Patient Engagement



<i>Application / Functionality</i>	<i>Yes, Would Like</i>	<i>No, Would Not Like</i>	<i>Not sure</i>
<i>An electronic medical record to capture medical information</i>	64%	18%	19%
<i>Email to communicate directly with my doctor</i>	74%	14%	13%
<i>The ability to schedule a doctor's visit via the Internet</i>	75%	14%	11%
<i>Receiving the results of diagnostic tests via email</i>	67%	22%	11%
<i>A home monitoring devices that allows me to send medical information – like blood pressure readings or blood tests – to the doctor's office via the telephone or email</i>	57%	21%	22%
<i>Reminders via email from my doctors when you are due for a visit or some type of medical care</i>	77%	13%	9%

Source: September 2006 Wall Street Journal Online/Harris Interactive Health-Care Poll

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Patient Engagement



<i>Application / Functionality</i>	<i>I use it now</i>	<i>It's available to me but I don't use it</i>	<i>It is not available to me</i>	<i>Not sure</i>
<i>An electronic medical record to capture medical information</i>	2%	3%	73%	22%
<i>Email to communicate directly with my doctor</i>	4%	4%	73%	19%
<i>The ability to schedule a doctor's visit via the Internet</i>	3%	4%	75%	18%
<i>Receiving the results of diagnostic tests via email</i>	2%	3%	76%	19%
<i>A home monitoring devices that allows me to send medical information – like blood pressure readings or blood tests – to the doctor's office via the telephone or email</i>	2%	3%	76%	19%
<i>Reminders via email from my doctors when you are due for a visit or some type of medical care</i>	4%	3%	74%	19%

Source: September 2006 Wall Street Journal Online/Harris Interactive Health-Care Poll

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PHR – Confusion Reigns



- A PHR can be either:
 - “the patient’s interface to healthcare provider’s electronic record (EHR)”
 - “any consumer/patient-managed health record”
- “It is quite possible now for people to talk about PHRs without realizing that their respective notions of them may be quite different”
- “It is not possible, nor even desirable, to attempt a unitary definition at this time”

Source: US National Committee on Vital and Health Statistics

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Summary

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Consumers not willing to wait



- According to Toronto study published in European Journal of Emergency Medicine
- 95% said that equal access to healthcare based on need was important
- However, to jump the queue:
 - 29% would consider a gift or donation
 - 36% agreed that patients should be allowed to pay extra
 - 71% willing to ask neighbor who was a medical secretary at an MDL clinic

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Summary



- Focus on similarities, not differences
- Embrace new entrants
- Consumers are not patient(s)

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Extreme Makeover: Consumerism, the EHR and the transformation of health care

Shelagh Maloney, Executive Director, External Liaison at Canada Health Infoway and President, COACH

Abstract:

Reduced wait times, increased patient participation in health care, efficient chronic disease management, improved access to care in remote and rural communities, fewer incidents of adverse drug interactions, better prescribing practices: This is the future of health care in Canada. Through a national stakeholder engagement by Canada Health Infoway, a roadmap has been developed to advance Canada's next generation of health care. Patient access to quality care features prominently in this vision of the future.

Ms. Maloney's presentation will look at the foundational elements of 2015: Advancing Canada's next generation of health care and the five key priorities. The presentation will focus on the role of the consumer and how Infoway's approach is addressing an evolving healthcare environment that will include greater involvement of the healthcare consumer.

Bio:

Shelagh Maloney is Executive Director, External Liaison at Canada Health Infoway. In this capacity she leverages national and international partnerships and alliances with both the private and public sectors to identify and develop new business opportunities and raise the profile and impact of Canada Health Infoway.

Prior to joining Infoway, Shelagh held a number of senior management roles in both the private and public sector. She was instrumental in establishing Canada's first remote health information management services organization. In her role as Director of Information Management at the Canadian Institute for Health Information (CIHI), Shelagh was responsible for the development and maintenance of CIHI's national databases in addition to leading the Institute's national and international health information technology standards projects including the *Partnership for Health Informatics Standards*. She was founding chair of HL7 Canada and responsible for coordinating Canada's contribution to the International Standards Organization (ISO) Technical Committee on Medical Informatics.

Shelagh is currently the President and Board Chair of COACH, Canada's Health Informatics Association.

Contact info:

Email: smaloney@infoway-inforoute.ca

Consumerism, the EHR and the transformation of health care



Consumer Health Informatics Summit | Shelagh Maloney, Canada Health Infoway and COACH | October 30, 2007

Agenda

- Three perspectives of consumer health informatics
 - Canada Health Infoway
 - COACH: Canada's Health Informatics Association
 - Consumer
- What is being done
- What's next

Canada Health Infoway



- *Infoway's* mission and goal
- Leveraging the Electronic Health Record
- Making a difference
- Vision 2015
- *Infoway's* role

3

Canada Health Infoway

- Created in 2001
- \$1.6 billion in federal funding to date
- Independent, not-for-profit corporation
- Equally accountable to 14 federal/provincial/territorial governments

Mission:

To foster and accelerate the development and adoption of electronic health information systems with compatible standards and communications technologies on a pan-Canadian basis with tangible benefits to Canadians.

Goal:

By 2010, every province and territory and the populations they serve will benefit from new health information systems that will help modernize their healthcare system. Further, 50 per cent of Canadians will have their electronic health record readily available to their authorized professionals who provide their healthcare services.

4

Identifying information for patient and GP

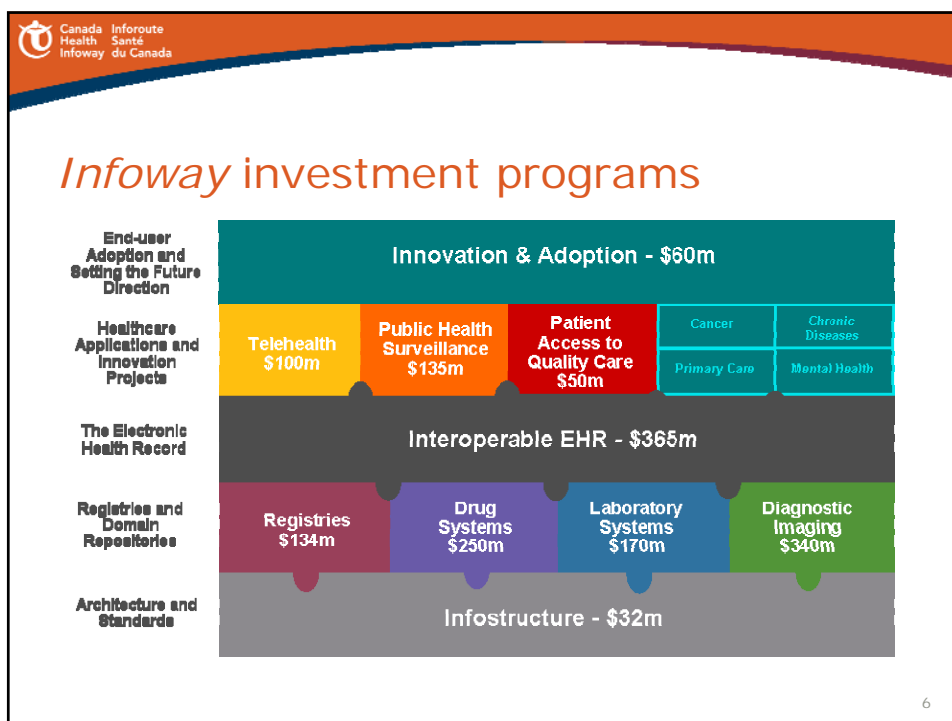
Patient's allergies to food and medications

Patient's medication history, including appropriate dosage recommendations

Patient's lab results and diagnostic images

Patient's medical history/problem list

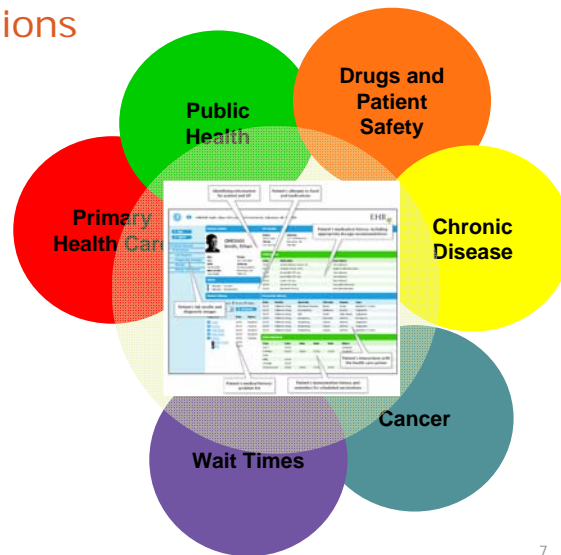
Patient's immunization history and reminders for scheduled vaccinations



Supporting national health care directions

Electronic health record systems can help improve patient health outcomes, decrease duplication, error and costs; and reduce waits. Without electronic health records, national directions to improve primary health care, public health, drugs drug and patient safety, chronic diseases, cancer and wait times will not be successful.

Electronic health record systems form the foundation for a health information and communications infrastructure that can enable modern health care delivery.



7

Leveraging EHRs

Sherbourne Health Centre:
Mobile EHR for inner city communities

Group Health Centre:
Link primary care providers and pharmacists

Vancouver Island Health Authority:
EHR-based clinical decision support tools for Mental Health & Addiction Services

Scarborough Hospital:
Emergency department touch-screen kiosk

Quebec MSSS:
Electronic patient evaluation & service planning solutions

PRIMARY
HEALTH
CARE

WAIT
TIMES

EHR

CANCER

Cancer Care Ontario:
CPOE and decision support

PATIENT
SAFETY

CHRONIC
DISEASE

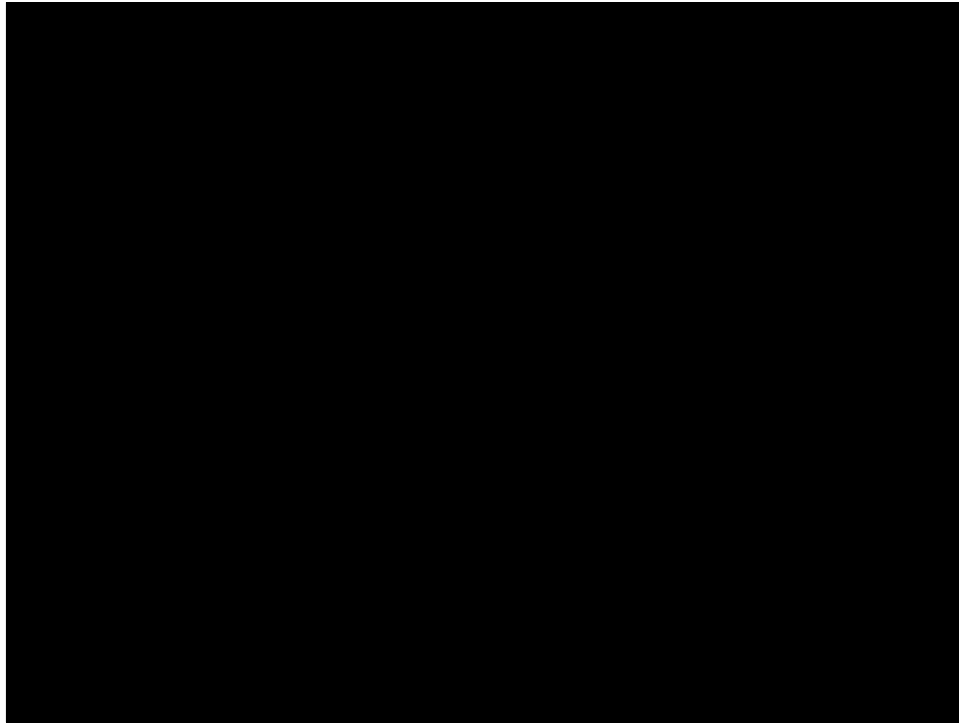
BC Ministry of Health; NFLD Eastern Health:
Pilots for province-wide adverse events reporting, analysis and management

Alberta Capital/Calgary Health Regions:
Extend iEHR and CDM solutions to primary care teams

Grand River Hospital:
Patient portal for cancer and renal patients

Canadian Nurses Association:
Capture of health outcomes for planning/evaluation of care

VON Canada:
Web portal to support family and friend caregivers in the delivery of health care





Update

- Considerable progress has been achieved in the drive to create a pan-Canadian electronic health record since *Infoway's* inception in 2001.
- Implementation is well underway across Canada with over \$1 billion of approved investments. Every jurisdiction has some components of the infostructure in place.
- In 2006, *Infoway* initiated a process to develop a comprehensive health IT strategy for Canada to guide the next 10 years of investment. Deputy ministers, health region executives, hospital executives, clinicians, patients, health associations and government agencies were engaged.

10

Vision 2015

A Jurisdictional Consensus: 5 priorities

At the request of Deputy Ministers of Health, *Infoway* commissioned the development of Vision 2015, an e-health road map for the next 10 years. It represents a consensus among the provinces and territories as to the future direction for e-health across Canada.



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Toward Vision 2015, *Infoway* will:

- Invest in projects that will demonstrate how enabling technologies support clinicians to reduce patient wait times
- Execute an engagement strategy that will create increased awareness of the benefits of the EHR
- Conduct public opinion research (EHR, Privacy)
- Facilitate collaboration to leverage investment
- Advocate for additional funding for e-health

12



- Mission
- Strategic direction
- Supporting consumer health informatics

About COACH

- COACH is a national organization that was established in 1975
- An association of individuals interested in advancing the practice of health informatics in Canada
- Members include IT professionals, care providers, vendors, consultants, governments and students
 - Significantly membership growth in last few months
- Governed by a volunteer Board of Directors

COACH mission and vision

COACH's mission

- To promote the understanding and adoption of health informatics within the Canadian health system through professional development, advocacy, and a strong and diverse membership

COACH's vision

- Taking health informatics mainstream

15

COACH Strategic Goals

- Four Strategic Goals
- Strengthen the membership of COACH
- Enhance the Practice of Health Informatics as a Profession
- **Be an advocate for health informatics**
- Ensure COACH has the resource capacity to meet future challenges and seize opportunities

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Supporting consumer health informatics

- Provide a national platform for consumer health informatics initiatives
 - Alliance with CCPAEHR
 - e-Health conference – themes/tracks
 - COACH journal and other publications (Backbone)
- Advocate for health informatics in general
 - Provide consistent messaging to and for our membership
 - Promote information sharing and best practices
- Create awareness of and recognize achievements in the field of health informatics
 - Canadian Health Informatics Awards Gala

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Consumer/Prosumer



Mission

- Shelagh's Mission
 - Keep my children, my husband, my aging parents and myself well. Support and assist my family through any episodes of ill health.
- Shelagh's Vision
 - Be healthy, be happy.

19

Strategies

- Educate friends and family about the benefits of e-health
- Encourage the use of enabling technologies by my health care team
- Ensure that personal health information is available and accurate/develop a "PHR"
- Lobby my local politicians about e-health funding

20

The Potential

- Increased patient participation in care
- Well-managed chronic illness
- Improved access to care in remote and rural communities
- Fewer adverse drug events
- Better prescribing practices
- Reduction in duplicate or unnecessary tests
- Reduced wait times



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Thank you!

