

The feasibility of using a patient-controlled health record

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On behalf of:

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Objective

- To discuss a set of projects that describe the feasibility of a patient controlled health record to improve communication, care and access between patients and health care providers.



Outline

- Background
 - personal health records (PHRs)
 - the MyOSCAR system
- Application for blood pressure management
- Application for drug safety and effectiveness
- Shared care between patients and primary care clinics





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Access to Web-Based Personalized Antenatal Health Records for Pregnant Women: A Randomized Controlled Trial

Elizabeth Shaw, BSc, MD, CCFP, Michelle Howard, MSc, PhD, David Chan, MD, CCFP, MSc, FCFP, Heather Waters, BPE, MD, CCFP, Janusz Kaczorowski, PhD, David Price, BSc, MD, CCFP, Joyce Zazulak, BSc, MSc, MD, CCFP

Journal of Obstetrics and Gynecology Canada. January 2008; 30(1): 38-43.



Personal Health Record / Patient Controlled Health Record

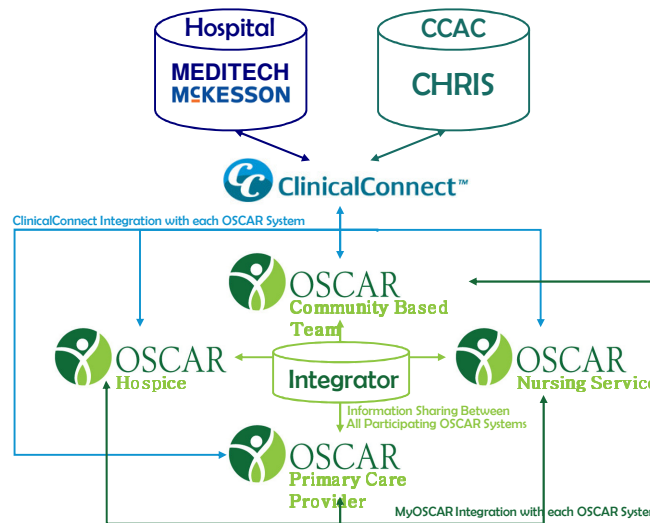
- Designed to give the patient a life-long, standard-based electronic health record that is under the control of the patient.
- Different from a patient portal into a clinic electronic health record. (e.g. Practice Solutions mydoctor.ca – physician driven portal)
- Canada: Telus HealthSpace (Microsoft HealthVault)
- US: various proprietary systems



The **MyOSCAR** personal health record

- Offers patients access to and control of their health records,
- Patients are able to share their record with whomever they choose; health care providers, family members or other selected individuals

A Flexible, Integrated IT Solution to Support Coordinated, Seamless Shared Care



Selected Evidence related to PHR concepts

- Family physicians generally positive about PHRs; concerns relate to data management, practice management, and the patient-physician relationship. (Yau, CFP 2011)
- Patients identify many advantages to PHRs, the need for a PHR system to be user friendly, easy to navigate, have difficulty with interpreting some of their records (e.g. lab tests and radiology) (Wagner 2010; Keselman, AMIA 2007)
- An increased trend in physician-patient communication via email that has the potential to improve health care delivery (Brooks 2006; Kittler 2004)
- Web-centered interventions that involve patient online participation and entry of personal data are effective in the treatment of chronic (Shea 2009; Angeles 2011; Southard 2003)



MyOSCAR is based on FOSS

- uses Free/Open Source Software (FOSS)
 - the software source code is open for peer review and customization
- fosters community support and involvement
- allows for development and contributions from users internationally, and can be freely distributed.



MyOSCAR and other systems

- There are 1500 (800+ in Ontario) physicians across Canada currently using the companion EHR OSCAR (Open Source Clinical Application Resource) system
- MyOSCAR is not linked to any one EMR system

www.MyOSCAR.org

MyOSCAR
Your Connection To Health

Home About MyOSCAR Using MyOSCAR Projects Support

Why Should you get MyOSCAR?
Have You Ever?... Waited on hold just to book an appointment? Misplaced your child's immunization record? Needed to keep track of your blood pressure, etc?

- OSCAR McMaster
- OSCAR Canada
- Implementing an Interoperable Personal Health Record in Pediatrics: Lessons Learned at an Academic Children's Hospital
- Sociotechnical Challenges of Developing an Interoperable Personal Health Record: Lessons Learned

- More timely access to test results
- Receive important health information from your health care provider as it becomes available (e.g. lab)
- Send important health information to your health care provider (e.g. home blood pressure readings)
- Create your own online community of people supporting your health, with ability to give each person access to only the information they need

NEW: MyOSCAR Video
Feature Release Dates
Information Session Schedule
MyOSCAR Adventure Blog

Internet | Protected Mode: On

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Welcome page



My Personal Health Record :

Home Messages | My Account | Access and Sharing | Previous Actions | Sign Out

Health Profile

Appointments

Allergies

Immunizations

Medications

> My List

> Medication Effects

> Coming Soon

Documents

Wellness

> Blood Pressure

> Blood Pressure Chart

> Blood Sugar

> A1C Diabetes Test

> Height and Weight

> Coming Soon

Health Tips and Tools

Surveys

Welcome to MyOscar

MyOSCAR is your secure, private on-line health record. This means that you can store online, the personal health information you choose to add. It is secure because information does not travel on the Web, but instead goes through the main hub of MyOSCAR or to other MyOSCAR account holders you share with. You have total control as to who can put information into your record and with whom you share this information. With MyOSCAR you can do all this from the privacy of your home. All you need is access to a computer, a MyOSCAR account, and the Internet. Some examples of what you can do are:

- manage your prescription medications, vitamins, herbs and alternative therapies
- report how you are feeling before and after using a new medication
- track and manage symptoms
- track health behaviours such as diet and exercise
- access health information about topics of interest to you that have been chosen by health professionals to be reliable

If your doctor or pharmacist has the OSCAR system, you may also be able to:

- communicate securely with your doctor, pharmacist or other health
- request copies of your records such as lab results, prescription profile, or scanned documents
- make appointment requests or cancel appointments

Select an item from the menu to get started.

[For information on MyOSCAR, including information on privacy and security please click here.](#)



MyOSCAR / MyBP Application

Funding: Ontario Ministry of Health and Long Term Care (Enhancing Quality in PHC project) and the Department of Family Medicine, McMaster



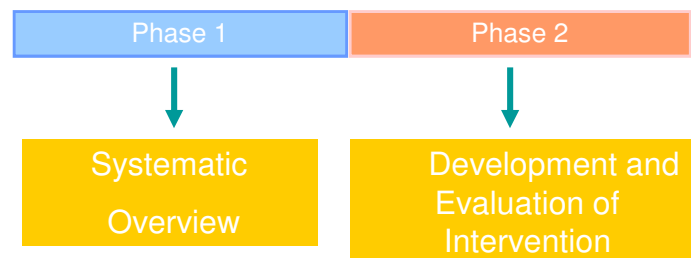
Research Questions

What is the uptake, feasibility and ease of use of the e-health self-management strategy (MyBP Program)?

What is the potential impact of the intervention on processes of care and patient outcomes?



'MyBP' Hypertension Self-Management Program




Study Design & Methodology

Design	Pilot randomized controlled trial; wait list control group Survey: QUAL and QUAN data
Study Length	3 months
Recruitment site	McMaster Primary Health Centre
Inclusion criteria	<ul style="list-style-type: none"> ▪ Between 40 to 79 years of age ▪ Diagnosis of hypertension ▪ Elevated office BP reading in past 12 months (SBP \geq140 mmHg [or \geq130 mmHg if diagnosed with diabetes]) ▪ Regular access to email / internet
Exclusion criteria	<ul style="list-style-type: none"> ▪ Patients with MyOSCAR account

MyOSCAR / MyBP Application

- Enter BP into **MyOSCAR/myBP** and ability to track their BP over time using the graphing tool
- Received weekly feedback on BP readings entered into **MyOSCAR** from clinical assistant
- Access to allied healthcare providers using secure messaging in **MyOSCAR** (pharmacist, dietitian, and nurse practitioner)
- Completed survey to identify personal cardiovascular risk factors
- Ability to create own personalized BP action plan to implement lifestyle changes to target these risk factors
- Access to information about hypertension (mybloodpressure.ca)

Entering Blood Pressure



My Personal Health Record :

Home | Messages | My Account | Access and Sharing | Previous Actions | Sign Out

- Health Profile
- Appointments
- Allergies
- Immunizations
- Medications
 - > My List
 - > Medication Effects
 - > Coming Soon
- Documents
- Wellness
 - > Blood Pressure
 - > Blood Pressure Chart
 - > Blood Sugar
 - > A1C Diabetes Test
 - > Height and Weight
 - > Coming Soon
- Health Tips and Tools
- Surveys

My Blood Pressure Readings

My Blood Pressure Readings allows you to measure your blood pressure. You may enter your systolic and diastolic reading as well as your heart rate. Please indicate the date and time at which you took your reading as well as where you measured it. You may also select the medication you are currently taking to treat your blood pressure.

Add



Sys/Dia: /

Heart Rate: Beats/min


Date:

Measured At:

BP Meds?:

Charting blood pressure



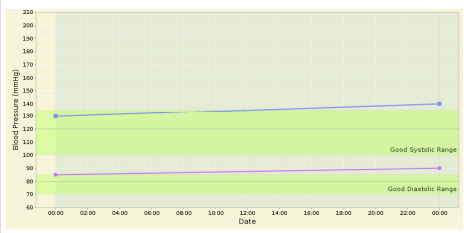
My Personal Health Record : HTN2008 TEST

My Account | Messages | Access and Sharing | Sign Out

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- Documents
- Wellness
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 - > Blood Pressure Chart
 - > Blood Sugar
 - > A1C Diabetes Test
 - > Height and Weight
- Test
- Trackers
 - Other Health Trackers Chart
 - > Health Tips
 - > Surveys



Blood Pressure Chart

From 2011-08-14 To 2011-11-14




myoscar.org | About | User Manual | Report a Problem | Account Audit

Nov, 2011 10:40:07 AM

Messages



My Personal Health Record :

[Home](#) | [Messages](#) | [My Account](#) | [Access and Sharing](#) | [Previous Actions](#) | [Sign Out](#)

Health Profile

Appointments

Allergies

Immunizations

Medications

- > My List
- > Medication Effects
- > Coming Soon

Documents

Wellness

- > Blood Pressure
- > Blood Pressure Chart
- > Blood Sugar
- > A1C Diabetes Test
- > Height and Weight
- > Coming Soon



Health Tips and Tools

Surveys


From: _____

To: _____

Subject: _____

Action Plan Summary





Congratulations on creating your own personal action plan to lower your blood pressure! You're on the right track for making the right changes to your lifestyle!

You have decided to **decrease your salt intake** by:


- Reading the labels of the foods you eat
- Eating more fresh food and less prepackaged food

You have also decided to **increase your physical activity** by:

- Taking a walk after dinner 3 nights a week
- Taking the stairs at work

MyBP: Resources



[site map](#) [accessibility](#) [contact](#)

home | hypertension and you | blood pressure control | medication and adherence | diet and exercise | taking action
log in | join

you are here: home

navigation

- Home
- Hypertension and You
- Blood Pressure Control
- Medication and Adherence
- Diet and Exercise
- Taking Action

log in

Login Name

Password

[Forgot your](#)



Welcome to the 'My Blood Pressure' Resources Site

High blood pressure can be controlled through lifestyle choices as well as adherence to prescribed medication. It is important to understand your treatment and the changes you can make to reduce your risk of cardiovascular disease or stroke. Many people find it challenging to make and maintain lifestyle changes. Because high blood pressure has no symptoms, it can also be hard to remember to take your medication. This site provides a collection of educational resources for patients with high blood pressure. This information can help you to measure your blood pressure on your own and keep track of it over time, understand and remember your medication, and make important changes in your diet and exercise habits to stay healthy. This information and support from your health care providers can help keep your blood pressure under control.

A variety of risk factors can contribute to the development and exacerbation of hypertension. Many of these risk factors are modifiable. Prominent factors such as obesity, diet, alcohol consumption and physical activity can all be modified by making healthy lifestyle choices. The first step toward a healthy lifestyle is through education!

Choose from the following broad categories to get your started on your education:

- Hypertension and You
- Blood Pressure Control
- Medication and Adherence
- Diet and Exercise
- Taking Action

Results: Entering blood pressure

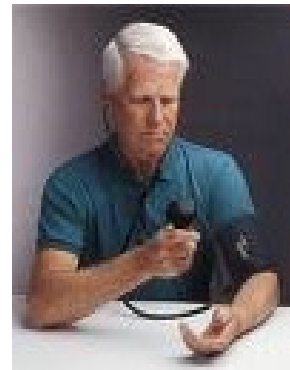
- Nearly all patients in the intervention group entered at least one BP reading into their MyOSCAR record (93%; n=26/28).
- The majority of patients monitored their BP at home (96%), while pharmacies and healthcare centres were also used by 26% and 23% of the patients, respectively.

Results

- 80% (n=21/28) of intervention patients created a Personal Action Plan
- 10 patients sent messages to the allied healthcare professionals.

MyBP Program: all patients wished to continue using application

“I've been pleased with my progress and choices over the past week. I've been able to log most or all of my food intake on most days. I have mostly been meeting my objectives for lots of fruits & vegetables, low-fat foods, and water. My weight is finally dropping a couple of pounds. I've been walking 6,500 - 10,000 steps a day over the past week. And my blood pressure is coming down a few points. Now I'm looking forward to seeing it in the target range. Thanks for this program which is giving me a way to measure my progress, especially in such a visible, tangible way as the BP chart.”



The feasibility of drug safety and effectiveness data collection and monitoring system within a patient controlled health record: the MyMeds pilot study



Funding: Department of Family Medicine, McMaster



Research questions

- Primary: What is the completion rate of the Patient Oriented Symptom Index tool by adult patients (> 18 years of age) within a web based patient controlled health record module before and after starting a new prescription?



Medication effects questionnaire



Personal Health Record: Patient MyMed (Patient)

Access Rights | Change Password | Sign Out

- > Personal/Contact Info
- > Messages
 - Inbox
 - Sent
- > Documents
- > Medications
- > Measurements
- > Blood Pressure
 - Show/Add Measurements
 - Blood Pressure Chart
- > Surveys

1/58 questions

MEDS Reporting How I Feel

Question:
You have just started on a new or changed medication(s). The set of questions will ask you how you feel to help identify if the medication(s) work for you the way it is expected.

Please indicate how you felt by selecting a number from 0 to 3 for each symptom:

- 0- The symptom was absent in the past week
- 1- The symptom was present but was not bothersome
- 2- The symptom was bothersome but tolerable
- 3- The symptom was intolerable

Click on "Next" or press "Enter" to continue.

Answer:

Save and Close Back Next



Medication effects questionnaire

- > Health Profile
- > Appointments
- > Allergies
- > Immunizations
- > Medications
 - My List
 - Medication Effects
- > Documents
- > Wellness
 - Blood Pressure
 - Blood Pressure Chart
 - Blood Sugar
 - A1C Diabetes Test
- Height and Weight
- Other Health Trackers
 - Other Health Trackers Chart
- > Health Tips
- > Surveys

Symptom Questionnaire

Please select the box that best describes how you feel for each symptom. Use the following scale to rate the symptoms.

- 0 - Symptom is absent
- 1 - Symptom is present but is not bothersome (i.e. can be ignored if you don't think about it)
- 2 - Symptom is bothersome but tolerable (i.e. cannot be ignored, but does not stop you from doing things)
- 3 - Symptom is intolerable (i.e. stops you from doing things)

For each symptom, you may select the priority box to indicate if it is a significant concern (this will facilitate discussion with your physician or pharmacist). Please also select the medication box if you feel the symptom will get better with your medication(s).

Symptom	Severity				Priority Concern	Better with Medication
	0	1	2	3		
Pain						
persistent aches and pains in several different part of body	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
eye pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
throat pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
wrist pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
hand pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
chest pain (ache or discomfort in the chest)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
breast pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
abdominal pain (ache, pain, or discomfort in stomach or belly)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
bone pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
joint pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
hip pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
knee pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
General symptoms						
fever (high temperature)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
chills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
night sweats	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
general weakness, fatigue or tiredness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
difficulty walking or moving due to rigidity or stiffness of legs or arms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
tingling or numbness in hands or feet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
tremor, shaking or uncontrolled movements	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
excessive thirst	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
excessive / increased appetite	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
loss of appetite	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
weight gain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
weight loss	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
feeling anxious, tense, frightened or irritable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
feeling depressed, down, unhappy, sad or hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
early morning awakening or interrupted sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>

Done

Internet | Protected Mode: On

100%



Reporting an adverse drug reaction

Personal Health Record: Patient MyMed (Patient)



Access Rights | Change Password | Sign Out

- > Personal/Contact Info
- > Messages
 - Inbox
 - Sent
- > Documents
- > Medications
- > Measurements
- > Blood Pressure
 - Show/Hide Measurements
 - Blood Pressure Chart
- > Surveys

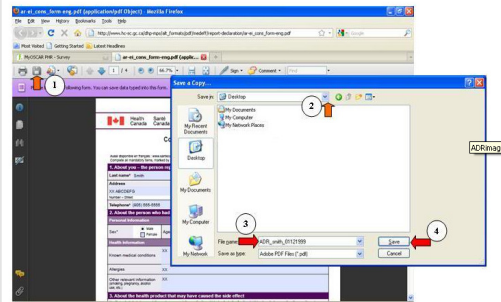
2/4 questions

MEDS Reporting an Adverse Drug Reaction

Question:

Click [here](#) to access and complete the Adverse Drug Reaction report. This will open in a separate window so you can continue with the instructions below.

Once you have completed the report, (1) save the report on your (2) desktop, enter the (3) file name **ADR_lastname_date (DDMMYYYY)** (for example: ADR_smith_01121999) and click (4) Save



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Messages



My Personal Health Record :

Home Messages | My Account | Access and Sharing | Previous Actions | Sign Out

- Health Profile
- Appointments
- Allergies
- Immunizations
- Medications
 - > My List
 - > Medication Effects
 - > Coming Soon
- Documents
- Wellness
 - > Blood Pressure
 - > Blood Pressure Chart
 - > Blood Sugar
 - > A1C Diabetes Test
 - > Height and Weight
 - > Coming Soon
- Health Tips and Tools
- Surveys

From: [dropdown]

To: [dropdown]

Subject: [text box]

[Send] [Cancel]



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Adding Medications generates a list of medications



My Personal Health Record :

Home Messages | My Account | Access and Sharing | Previous Actions | Sign Out

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 > Coming Soon

Health Tips and Tools
 Surveys

Medications

Please enter any prescription, vitamins/supplements, over the counter medications as well as herbal medications/ alternative therapies that you have taken or are currently taking.

Add

Medication Type	-
Drug Name	
Dose	
Strength	
Frequency	
Date Started	
Date Stopped	
Reason for taking	
Prescriber	
Refill Date	
Renew Date	

Add



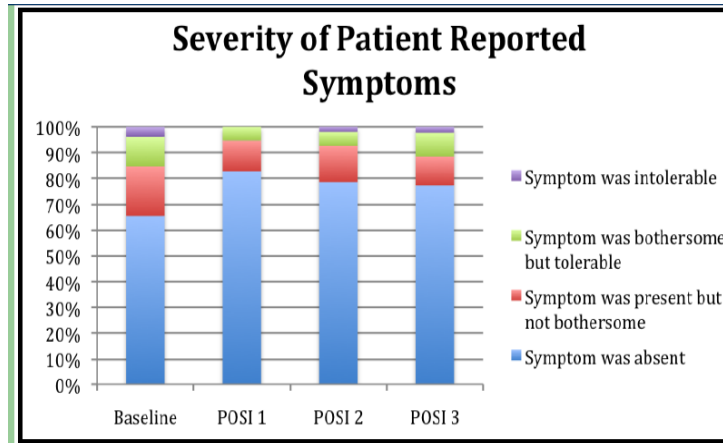
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Results: Use and feasibility

- 10 patients enrolled
- Taking a wide variety of new prescriptions
- 8/10 patients completed at least 1 POSI
- 6/10 of patients completed the MyMeds module from baseline to Time 3



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Symptom changes: case examples

Patient ID	Medication	Symptoms Improved n (%)	Symptoms Worsen n (%)	No Change in Symptoms n (%)
100	Salbutamol	16 (31)	0	36 (69)
600	Lansoprazole	11 (21)	18 (35)	23 (44)
700	hydrochlorothiazide	6 (12)	7 (13)	39 (75)
800	Betamethasone valerate	7 (13)	1 (2)	44 (85)

Patient feedback

- Feedback was obtained from 7 patients. Patients reported being: very satisfied (1), satisfied (3), somewhat satisfied (2), and unsatisfied (1) with the MyMeds program
- Most patients (6/7) understood symptoms in the POSI and found it helpful in describing their symptoms, 6 patients reported verifying their medication list and found that it was a useful tool, 6 reported using the messaging and 5 found that it was a useful tool



Linkage of MyOSCAR with OSCAR clinic EMR

Funding: eHealth Ontario, the Department of Family
Medicine McMaster University, The Department of
Family Medicine, Queens University



Project Overview

Scope:

- Plan, implement and manage PHR functionality for 2,000 patients across the three (3) primary care clinics (SFHC, MFP, Queens FHT);
- Work with each clinic's EMR vendor to configure and deploy the PHR functionality;
- Create and distribute materials and processes required to ensure successful participation of patients, providers and support staff;
- Manage implementation and any mechanisms to ensure the protection of PHI;
- Create mechanisms to capture feedback and key lessons from the participants; and
- Consolidate that feedback into a summary that could be shared with other stakeholders interested in PHRs.



Linkage functions in MyOSCAR

- Messaging with clinic
- Document transfer (labs, diagnostics tests, consultation notes immunisation records)
- On-line Appointment booking



Project description and progress

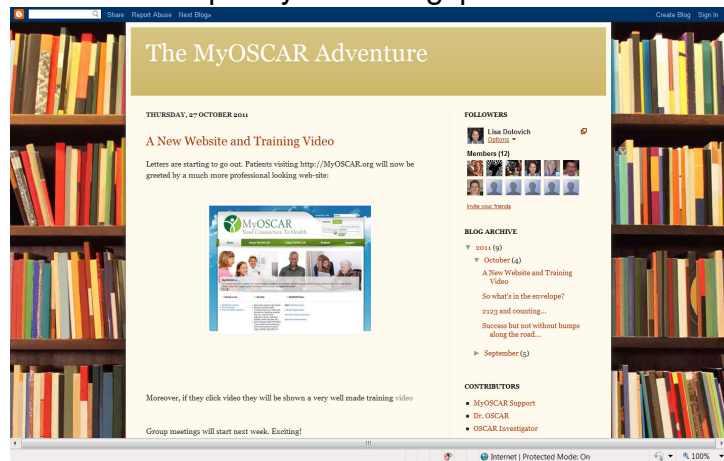
- 10 physicians
- 10,000 patients invited with account
- Large implementation team at each site
 - Hamilton - 9 staff including 1 programmer
 - Australia - 1 programmer
 - Queen's – 3 staff
- Ethics approval at both sites
- Implementation / education and training materials created
 - (<http://www.bizclip.com/download/my-oscar.html>)

Evaluation of Pilot Implementation

- Process: participation rates, buy-in of clinics/staff, success of orientation/video/pamphlet
- Resources: refusal rates, frequency of logins, success of data collection, use of help desk
- Management: readiness and functioning of MyOSCAR, suitability of staffing resources, level of ongoing commitment of clinics, work-load changes in clinics, drop-outs
- Scientific: rates of use of various components, quality of data from surveys and interviews of satisfaction, variability in results

Follow along with our Blog!

<http://myoscar.blogspot.com/>



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Added value of this data

- No other research completed in Canada on feasibility, usefulness, or benefits of actual implementations of a PHR (other types of systems are also conducting studies)
 - Demonstrates proof of concept
 - Numerous challenges and implementation solutions identified through pilots
 - Other projects ongoing
 - Emerging collaborations across Canada and internationally
- Growth in scope from pilots to larger implementation and evaluation

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Limitations / Uncertainty

- Pilots are small relative to possible extent of use
- Limited to those with access to internet and ability to handle software (In the Canadian population of adults aged 65 and older, 65.9 % used the internet at home at least once a day in 2009)
- Adaptation of workflow for primary care clinics and providers
- Health care documents not formatted for exchange with patients



Potential Practice Implications

- Adaptation of workflow for primary care clinics and providers
- New skills for health care providers (communication via email, use of technology)



Potential Policy Implications

- Health care documents not formatted for exchange with patients
- Health care provider payment for services (FFS or FHT) not congruent with electronic communication
- How ehealth primary health care system handles privacy, patient transitions



Questions/ Comments?

