

The Personal Health Records in the Rural Context

WL Clifford, OBC, MD, MScF, FCFP November 20th, 2025

Learning Objectives

- Identify the key components and functionalities of a good personal health record (PHR)
- Demonstrate how patients and their families / caregivers, providers and the health system can benefit from PHRs
- Examine how the amplification of health care challenges in rural settings helps to identify priorities for development and implementation of system capabilities for the benefit of all

Disclosures

- I am a consultant to government and non-profit organizations including the RCCbc and DoFPs on matters relating to primary care and health information standards
- I have no financial or other relationship with for profit companies including the pharmaceutical industry

Personal / Patient Health Record (PHR)

- Is it just a record?
 - Providers already have a record; do we need another?
 - Why can't patients just use portals?
- Is it just for patients?
 - How will they understand or not be alarmed at what they are seeing?
 - Are patients at increased risk for suicide?
 - How much extra work will this require for providers?
 - Will providers get any benefit such as getting access to the patient's record when needed?
 - Will there be more lawsuits?
- Does this just add cost to the already overburdened health system?
 - Who's going to pay for the patient version? I'm even paying for each SMS from my EMR to patients!
 - What is the benefit for the health system?

The Answers to These Questions and More Lie in the Big Picture

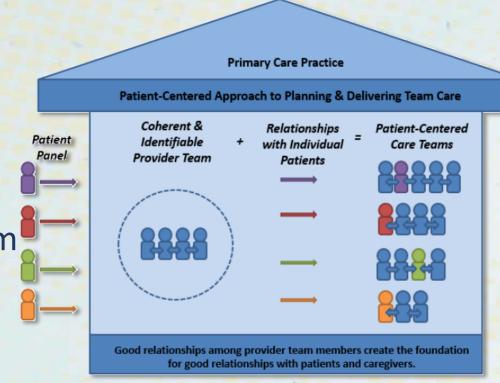
- What are the patient requirements for health and wellness?
- What needs are currently not being met for patients and their families, providers and the health system?
- The rural setting amplifies many health care challenges can that amplification put a spotlight on opportunities for better care for those "on the edge" while also helping everyone?

History

- Boston Children's Hospital, Indivo 1999 (formerly PING Personal Internetworked Notary and Guardian) which continues as MyChildren's portal. Open Source and designed to integrate records across digitally accessible digital health solutions / databases. Supports messaging but appointment scheduling can only be done with 3rd party API
- Beth Israel Deaconess Medical Center, PatientSite 1999
- Microsoft Health Vault, 2007 2019. Was the backbone of the US Blue Button initiative
- Google Health, 2008 2012
- OpenNotes, 2010
- Apple HealthKit, 2014

Scope of Function - What Are The High-Level Competencies For Persons & Their Families In Health Care?

- Plan and manage my health
 - Maintain or improve wellness
 - Manage chronic conditions
 - Understand my risks
- Interact / participate with my health team
- Manage my health information
- Find health care resources and services
- Get access to care
- Improve my health and IT knowledge (health and technology literacy)







Wellness

Health Information Management

Health & Digital **Health Literacy**

Strategic

Plan personal and family health and wellness in the context of life stages

Identify values and preferences

Identify unmet needs

Choose tools

Identify knowledge gaps

Manage condition(s)

Manage risk(s)

Manage care plan

requested

information

Manage learning plan

Collaborate with my team

Manage benefits

Manage tasks, reminders

Comprises completeness, accuracy, timeliness etc.

Manage access

Schedule screening

> Maintain record quality

Access learning resources

New medical problems

> Reduce unnecessary risk

Healthy lifestyle

(prevention)

Coaching & Document mentoring observations &

Follow care plan

Respond to reminders, alerts, notifications



Operational

Tactical



 Providers bear the burden of record accuracy, often manually sharing /re-entering information

Challenges

- Patients are unable to interact with a complete version of their electronic health records
- The rural health care journey is complex with disconnected information and barriers to interaction



Ineed a DIGITAL tool that gathers my information from multiple places and puts it in ONE place - for the people I choose to share it with, and ME



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Sometimes trying to manage everything gets overwhelming,

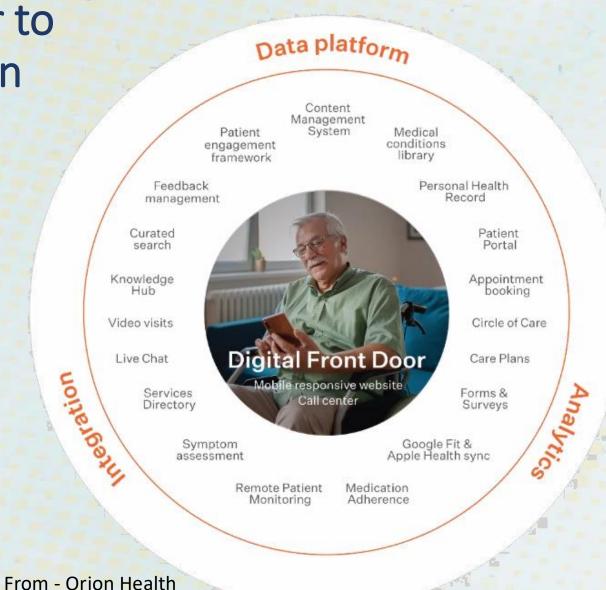
It should be easy to share information with people Who help with my care.



Avoid the "Digital Front Door to Nowhere" and Fragmentation ("polyportalitis")



From - Princeville Global

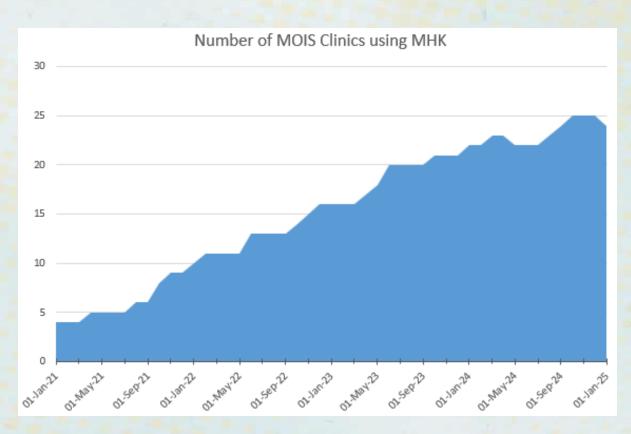


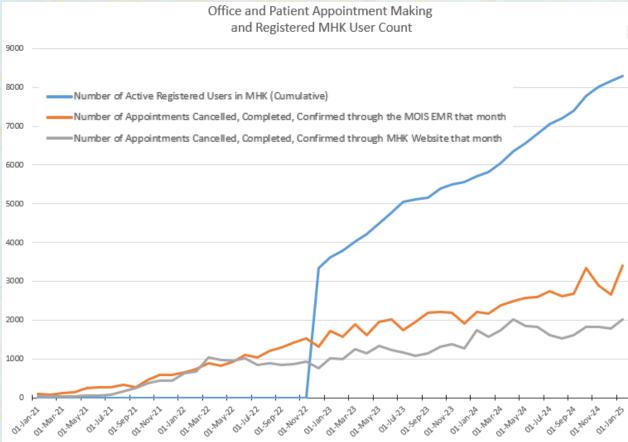
The rPHR Project: Engaging Patients, Providers & Vendors to Prototype or Adjust Development Priorities

- 2 vendors and 3 geographic areas initially interested in participating in the rPHR project
- Ultimately only one vendor (Bright Health Solutions Society) with a PHR product (MyHealthKey) already oriented to standards continued to participate. Pre-existing direct receipt of laboratory and medical imaging results into PHR, rudimentary messaging and scheduling











Measurements

Select Date Range:

YYYY-MM-DD - YYYY-MM-DD

Show All

Show 10 ✔ entries

PDF

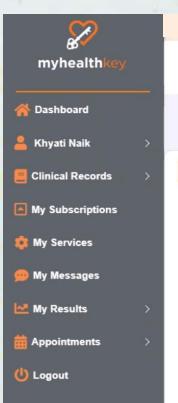
Print

CS

Search:

Collection Date ▼	Test Name ▼	Result	Flag	Reference Range	⊕ Test Information	View Report
2022-02-07 09:04:00 AM	CO2	22		22-29	Learn more about CO2	View
2016-12-26 09:04:00 AM	Potassium LvI	4.0		3.5-5.1	Learn more about Potassium Lvl	View
2016-12-22 09:04:00 AM	Sodium LvI	138		136-145	Learn more about Sodium LvI	View
2016-12-22 09:04:00 AM	Chloride LvI	100	<i>₽</i>	98-107	Learn more about Chloride Lvl	View
2016-12-22 09:04:00 AM	AGAP	20		10-20	Learn more about AGAP	View







? Need Help

What is a Blood Glucose Test?

A blood glucose test measures the glucose levels in your blood. Glucose is a type of sugar. It is your body's main source of energy. A hormone called insulin helps move glucose from your bloodstream into your cells.

Too much or too little glucose in the blood can be a sign of a serious medical condition. High blood glucose levels (hyperglycemia) may be a sign of diabetes, a disorder that can cause serious, long-term health conditions.

High blood sugar may also be caused by other conditions that can affect insulin or glucose levels in your blood, such as problems with your pancreas or adrenal glands.

Low blood glucose levels (hypoglycemia) are common among people with type 1 diabetes and people with type 2 diabetes who take certain diabetes medicines. Certain conditions, such as liver disease, may cause low levels of blood glucose in people without diabetes, but this is uncommon. Without treatment, severe low blood sugar can lead to major health problems, including seizures and brain damage.

Other names: blood sugar, self-monitoring of blood glucose (SMBG), fasting plasma glucose (FPG), fasting blood sugar (FBS), fasting blood glucose (FBG), random blood sugar, glucose challenge test, oral glucose tolerance test (OGTT)

What is it used for?

A blood glucose test is used to find out if your blood sugar levels are in a healthy range. It is often used to help diagnose and monitor diabetes.

Why do I need a blood glucose test?

Your health care provider may order a blood glucose test if you have symptoms of high glucose levels or low glucose levels.

Symptoms of high blood glucose levels include:

Increased thirst and urination (peeing)

Blurred vision

Fatigue

<<

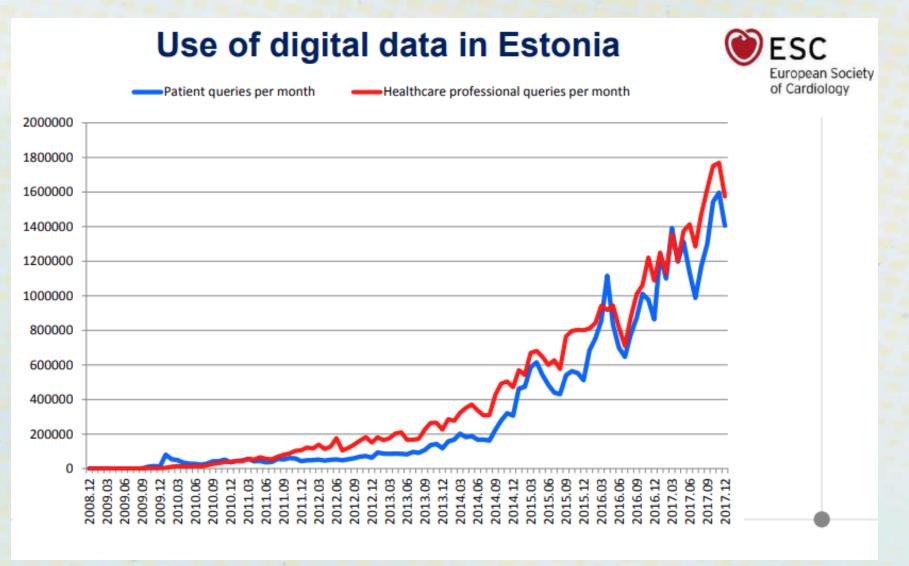
Sores that don't heal

Weight loss when you're not trying to lose weight

Numbness or tingling in your feet or hands



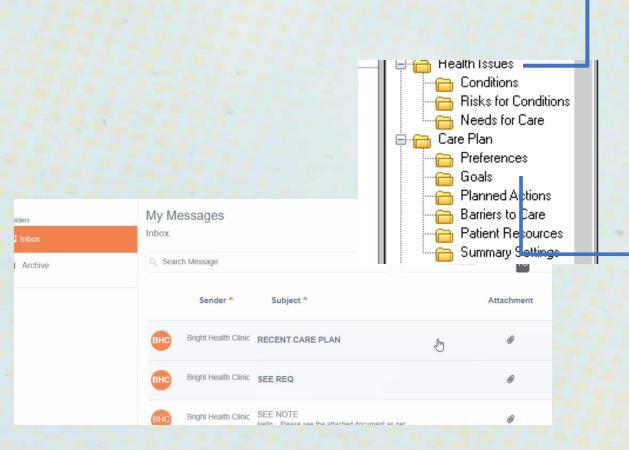
Estonia – Patient and Provider Queries Approximately Equal

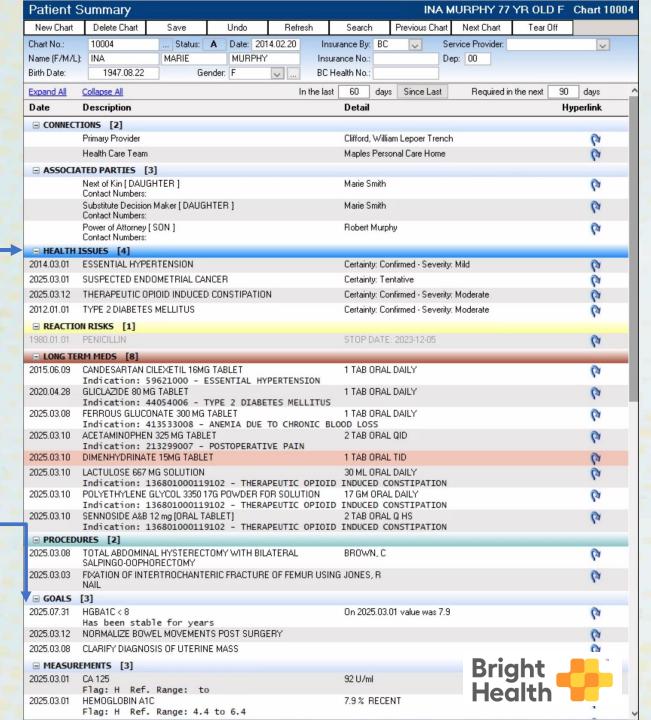


- Supports self-added data
- Patients can track and control who accesses their record
- Patients can manage and request rectification of errors and omissions

M. Viigimaa, European Society of Cardiology, 2019

International Patient Summary with Care Plan Shared with Patients



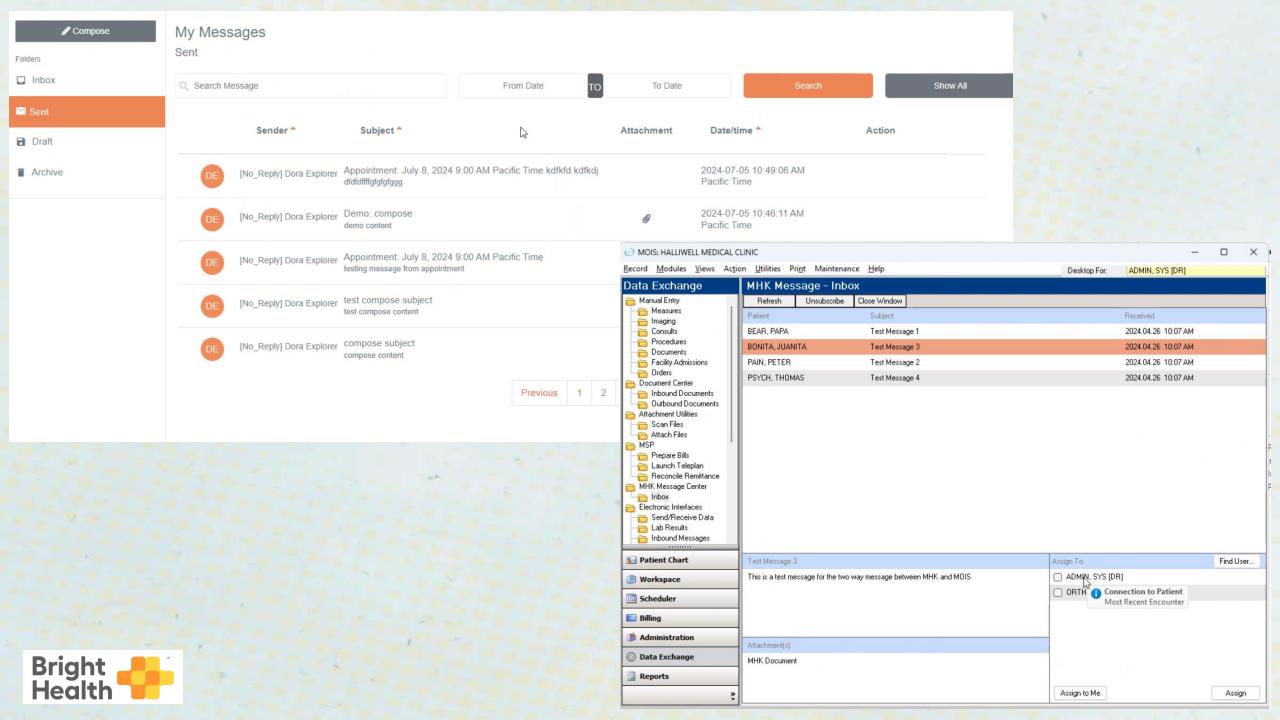


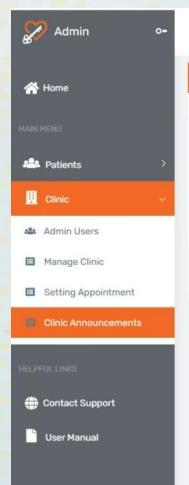
Personal Health Records Improve Communication

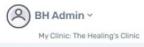




Patients need to be able to participate in their care planning - and know what to expect next







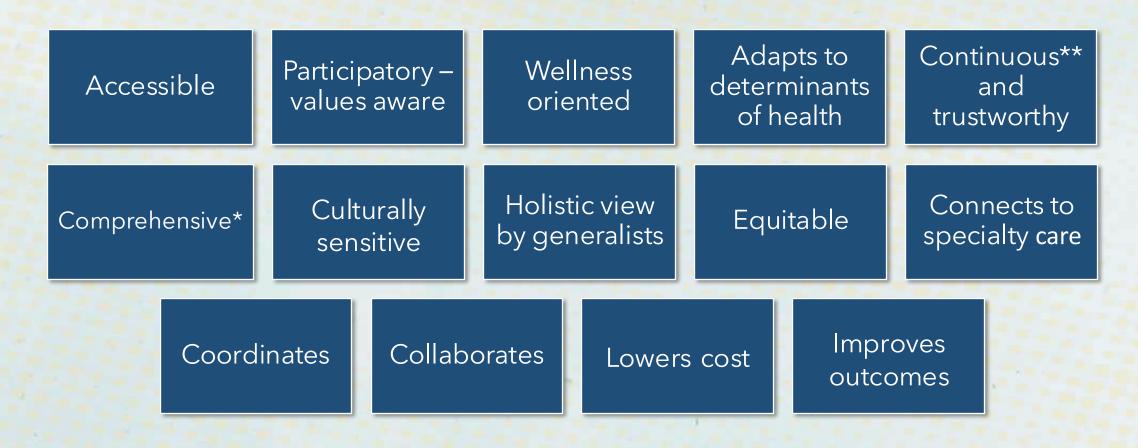
Manage Announcements

O ADD NEW ANNOUNCEMENT

Heading	Content	Announcement Type	Active	Last Modified (PST)	Last Modified By	has attachment	attachments	Actions
Clinic announcement	testing permission	clinic	False	24/04/2025 12:13:18 PM	knaik+bhadmin@brighthealth.ca	False		/ Edit Delete
Adding first clinic announcement	first clinic announcement	clinic	False	22/04/2025 2:16:13 PM	knaik+bhadmin@brighthealth.ca	False		∕ Edit Delete



Good Health Care – The Primary Care Value Proposition





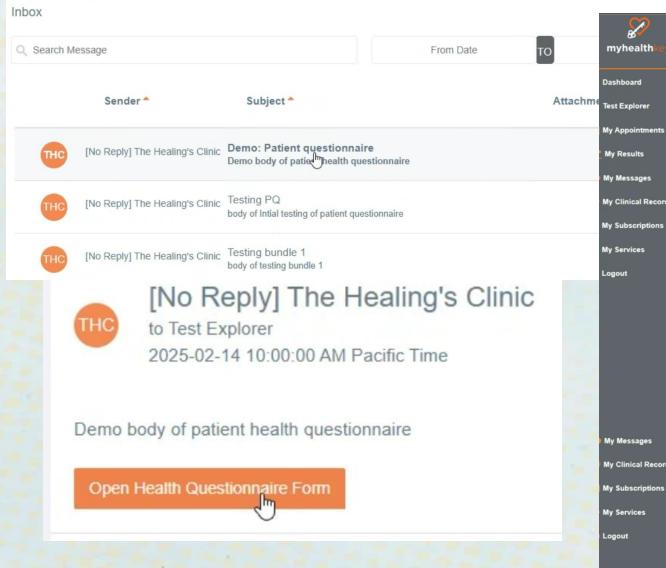
^{*}Especially first contact for new health concerns

** Longitudinal relationship and information

PHRs improve manual tasks and workloads



My Messages



myhealth

My Results

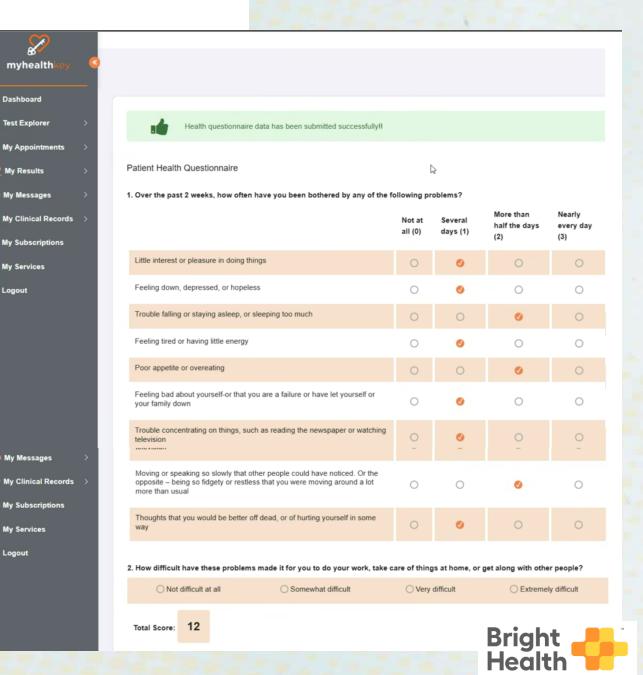
My Messages

My Subscriptions

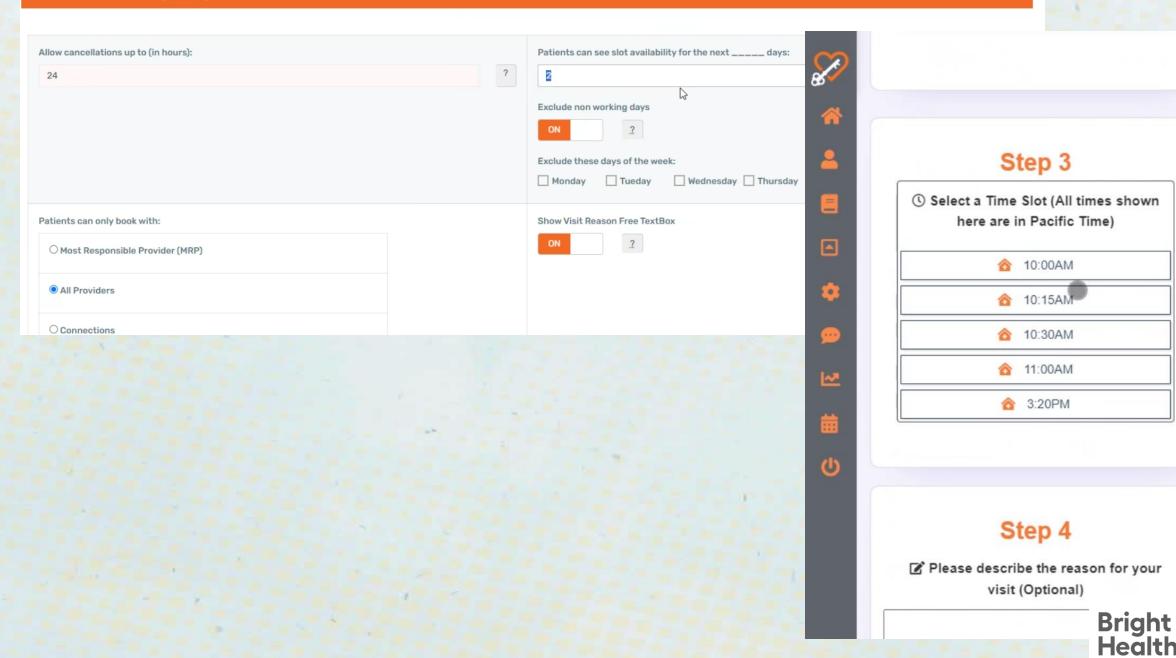
My Services

My Messages

My Services Logout



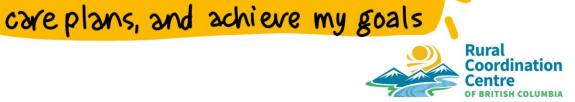
Appointment Scheduling Settings



Personal Health Records Increase Safety



I need to have confidence that there are not any gaps in my care



Report





Notice Something Wrong

≭ Close

Disclaimer: While every reasonable effort has been made to ensure that all information presented here is accurate and up to date, the information presented here represents data sent by systems that are beyond our control and we make no representation or warranty of the accuracy, reliability, or completeness of the information. All medical information presented should be discussed with your healthcare professional as failure to seek timely advice can have serious ramifications.

IMPORTANT: If this result is not yours, please notify your clinic immediately.



Name: ZZZTEST, TEST

Age: 32 years Sex:

Date of Birth: 1991-05-28 PHN: 9806545268 Patient Phone: (250)555-1234 Sending Facility: Pr George RH MRN#:

11122222

Lab

LDL, Chol, Trig, HDL

Collection Date/Ti Ordered By:	me: 2018-04-26 09:38:00 Dora Explorer	Reported Date: 2018-04-26 02:53:25 Accession #: 11-18-116-0332	Specimen: Blood Report Status F
Test	Flag	Result	Reference Range - Units
Chol		6.02	mmol/L
Trig		1.11	mmol/L
HDL		2.07	mmol/L
LDL		3.45	mmol/L
HDL Ratio		2.9	

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Report



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onor nor		Download Print an incorrect result. Please che	Notice Something Wrong ★ Close one of the options below:	ose
	It has my name on it but I don't recogni		<u> </u>	
LDL,Chol,Ti Collection Ordered B	Cancel Submit			
Test				
Chol		1.11		
HDL		2.07		
DL		3.45	mmol/L	
HDL Ratio		2.9		
				ems that are beyond our

PHRs and Patient Safety

BC'S PATIENT SAFETY STRATEGY

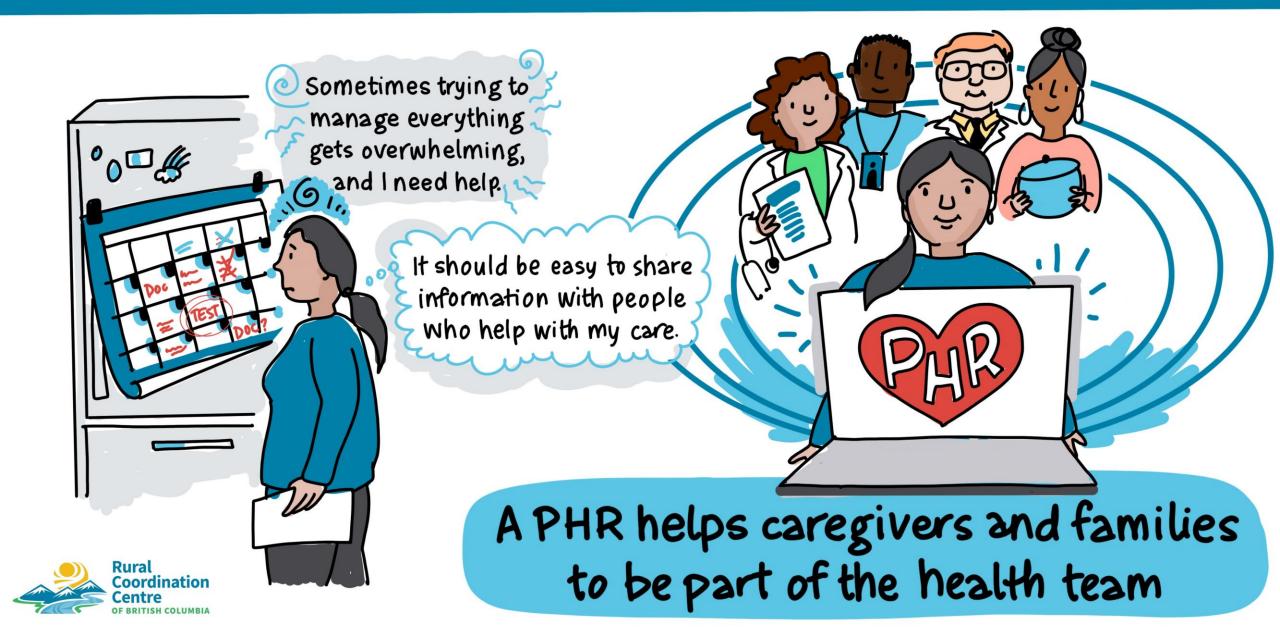
Your Care, Our Commitment



Strategy 1.2: Enhance patient and family agency to promote active engagement in care planning ACTIONS:

- Ensure patient access to their health care information and health records leveraging the Rural Personal Health Record and BC Health Gateway projects as prototypes
- Implement strategies in primary, acute and long-term care settings for patients and families to feel safe to speak up and/or raise concerns with their care
- Implement strategies in primary, acute and long-term care settings for Indigenous patients and families to feel safe to speak up and/or raise concerns with their care

PHRs enable shared access with caregivers and loved ones



Use of Proxy Access

"Among patients with diabetes, informal proxy SM use is more common than registered use and prevalent among socially and medically vulnerable patients. Future research should explore whether proxy portal use improves patient and/or caregiver outcomes and consider policies that integrate caregivers in portal communication".

Secure Messaging with Physicians by Proxies for Patients with Diabetes: Findings from the ECLIPPSE Study. Semere et al, J Gen Intern Med, 2019

Public Engagement 2019

THE FUTURE OF CONNECTED HEALTH CARE

REPORTING CANADIANS' PERSPECTIVE
ON THE HEALTH CARE SYSTEM

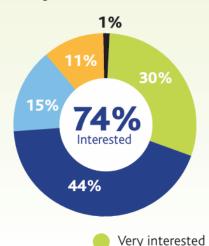
August 2019 – A CMA / Ipsos collaboration

The demand for connected patient portals

A patient portal is a secure online website that gives users 24-hour access to their personal health information and connects them to their family doctor/health team. Users may also be able to book appointments and have secure conversations with their doctors online.

Interest in patient portals

Three-quarters of Canadians are interested in using patient portals, with 3 in 10 being very interested.



Somewhat interested Not very interested Not at all interested

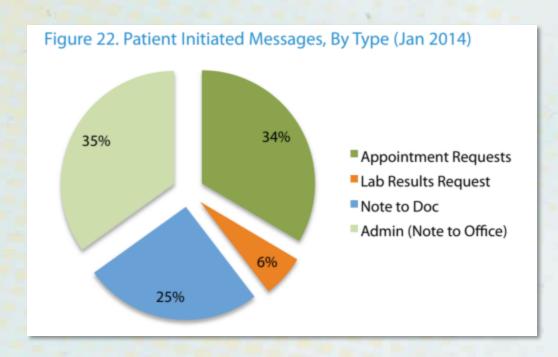
I already use a patient portal

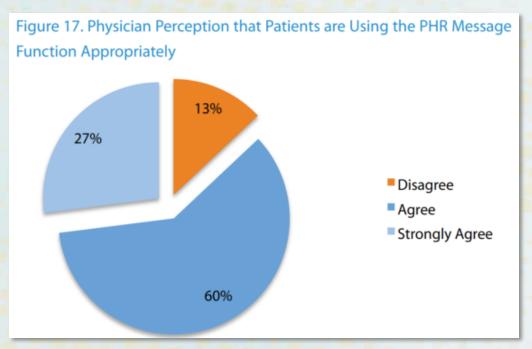
While younger Canadians show greater interest in patient portals (**79%** 18-34, **75%** 35-54), 7 in 10 (**68%**) of those 55+ are interested.

Patient Engagement with PHRs - The Nova Scotia Experience: Messaging

Table 5. Likelihood of Opening Messages Received Through PHR

	Likely or very likely	Unlikely or very unlikely	Not sure
Information about a test result	98%	1%	1%
Upcoming appointment reminder	95%	2%	1%
Forms to complete before an appointment	95%	3%	2%
Public health advisory	94%	3%	2%
Cancer screening reminders	91%	5%	3%
Invitation to an upcoming clinic	88%	5%	2%
Disease-specific information	88%	5%	2%
Tips on how to use your PHR	83%	6%	2%
General healthy living tips	77%	7%	2%



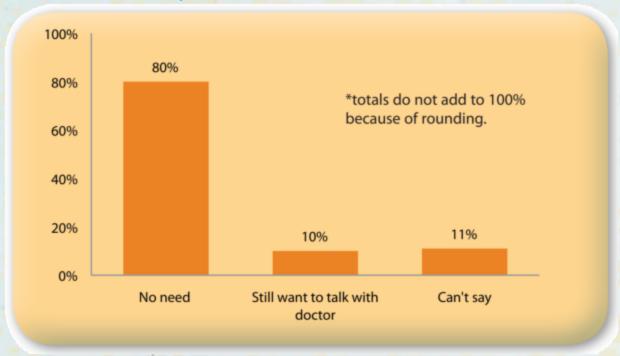


Patient Engagement with PHRs – The Nova Scotia Experience: Test Results

Table 4. Patient Perceptions of Electronic Test Results

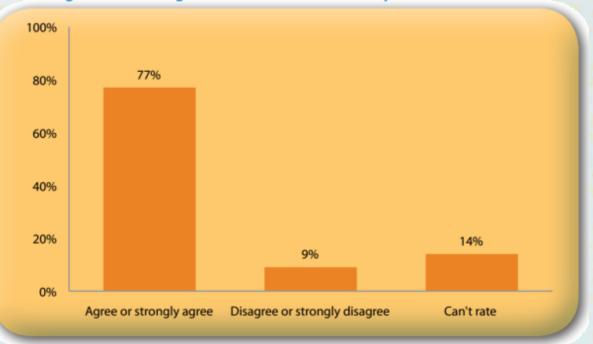
	Agree or strongly agree	Disagree or strongly disagree	Can't rate
I have confidence in the information presented in my test results	98%	1%	1%
Having online access to my test results increases the amount of information I have about my health	95%	3%	1%
I would like to continue to receive my test results electronically	99%	1%	0%
I find online test results confusing and difficult to understand	15%	81%	4%
I like the screen layout of my test results in my PHR	81%	10%	9%

Figure 12. Patients Wanting Doctor Follow-Up After Routine Test Result that Says Normal (PHR)*



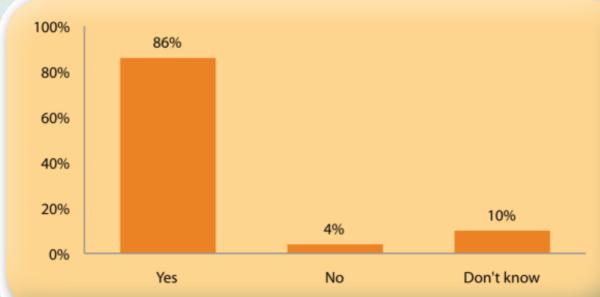
Patient Engagement with PHRs – The Nova Scotia Experience

Figure 11. Feeling of More Involvement in My Health Care



Patient empowerment – "conditions that make patients 'willing and able' to play an active role in their care". Patient empowerment and its neighbours: Clarifying the boundaries and their mutual relationships. Health Policy 2015

Figure 16. Patients Who Would Recommend PHR to a Friend



Provider Fears

A Piece of My Mind

June 30, 2023

Death by Patient Portal

Michael Stillman, MD1

Author Affiliations | Article Information

JAMA. 2023;330(3):223-224. doi:10.1001/jama.2023.11629



What's behind physicians' administrative pile-up

"Doctors don't go into medicine for the paperwork. But from charting, third-party forms and sick notes to managing an office, tracking down lab results and following up from patient appointments, physicians' administrative load can be relentless"



Information Blocking

Regulatory and Policy Affairs Division

Office of Policy

Office of the National Coordinator for Health Information Technology (ONC)

An Act respecting the interoperability of health information in Canada and the prohibition of data blocking by health information technology vendors.

Charter Statement Bill C-72

JUSTICE.GC.CA

Canadä'

INTEROPERABILITY SAVES LIVES

HEALTH DATA INTEROPERABILITY WORKING GROUP

A report from the Alberta Virtual Care Coordinating Body October 2023

DATA DISARRAY

A ROOT CAUSE ANALYSIS OF HEALTH DATA DYSFUNCTION IN CANADA

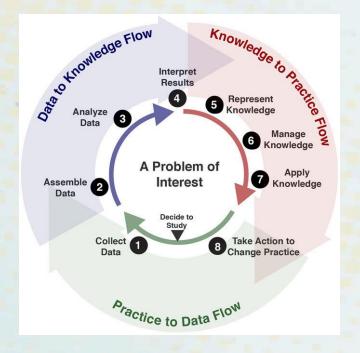
ALBERTA VIRTUAL CARE COORDINATING BODY
NOVEMBER 2024

Digital Health Interoperability

Task Force Report

November 2024

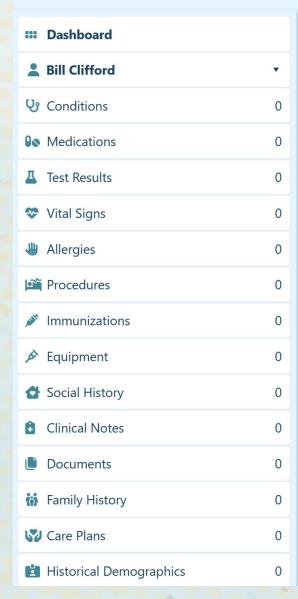


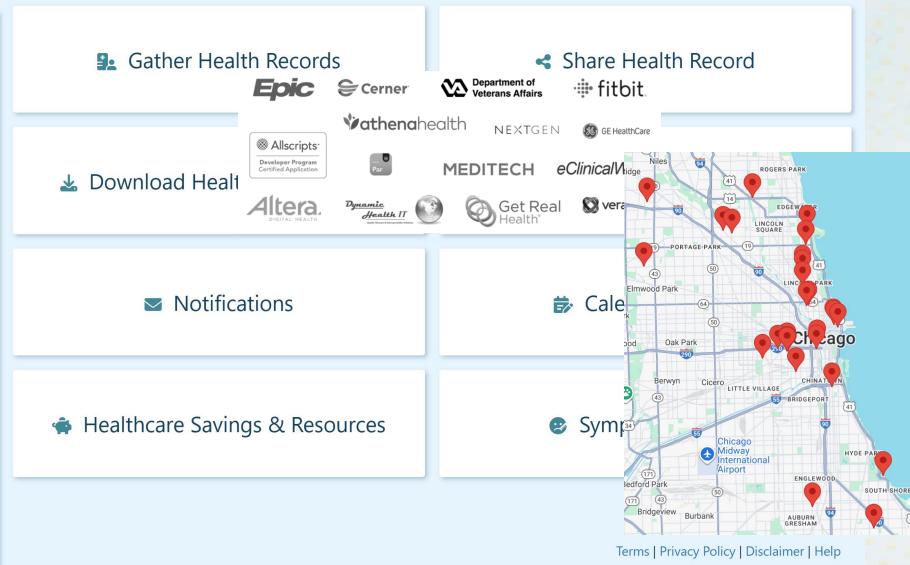


FROM: The Knowledge Object Reference Ontology (KORO)... Flynn et all 2018

© 2024 MyLinks

Profile has been saved.





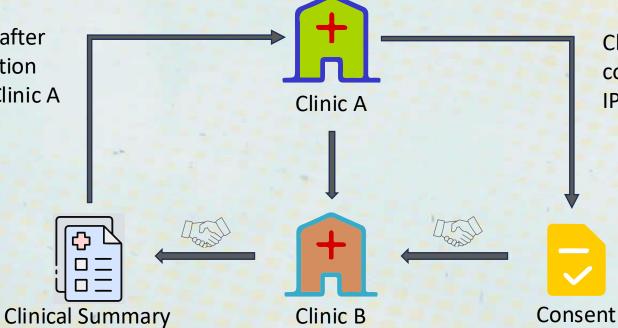
"In the exciting period that lies just ahead, more will be needed than simply connecting patients to clinicians, and clinicians to each other. The health care systems that will be most effective in meeting patients' needs will be those that can actually design their 'human-ware' around that purpose" - Information technology for patient empowerment in healthcare. Lee et al, Book, 2015

Access Information From Another Clinic



Goes to Clinic A and provides consent to obtain International Patient Summary (IPS) from Clinic B

Clinic B receives request and after checking provider authentication and consent, returns IPS to Clinic A



Clinic A records consent and connects to Clinic B API to retrieve IPS



RCCbc Personal Health Record (rPHR): Empowering Patients with Integrated Digital Health Solutions



Providers bear the burden of

record accuracy, often manually

sharing /re-entering information

Challenges

- Patients are unable to interact with a complete version of their electronic health records
- The rural health care journey is complex with disconnected information and barriers to interaction

Personal Health Record Opportunity

To help patients, providers, and the health system enable safer, more accessible care

Improve communication

 PHRs promote shared decision-making and participation in treatment

Increase safety

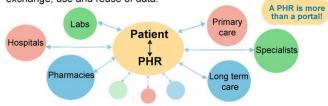
 PHRs enhance safety by ensuring accurate and up-to-date health information is available to providers and patients

Improve manual workloads

 PHRs streamline patient and provider workflows and care transitions while reducing administrative burden

A PHR Supports a Digital Health Ecosystem

- PHRs integrate information and workflows across many systems
 PHRs can leverage interoperability to enable seamless access,
- exchange, use and reuse of data.



 A standards-based approach that leverages open application program interface (API) standards is a critical success factor



Empower access to health information

 PHRs improve patients' access to complete electronic health information, including medications, plans of care and notes



Findings and Lessons Learned

Providers: Critical need for provider incentives, change management support, peer support, educational benefits, and time to enable change Patient/Provider Partnerships: Focus on relationships to co-create health records that support continuity of care; less focus on portals Standards and Usability:
Successes achieved when using open standards-based integrations and usability of data is considered

Visit this QR code for more details and resources:

Benefits Reported: Improved collaboration with patients and families/caregivers; reduced risk of missed or inaccurate information; increased safety

For more information: Rural Coordination Centre of British Columbia www.rccbc.ca rphr@rccbc.ca