Real time release of complex labs to patients: What this means to your practice

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### **Land Acknowledgment**

We would like to recognize that we are webcasting from, and to, many different parts of Alberta today. The province of Alberta is located on Treaty 6, Treaty 7 and Treaty 8 territory and is a traditional meeting ground and home for many Indigenous Peoples.









## **Disclosure of Financial Support**

This program has not received any financial or inkind support.









#### **Presenter Disclosures**

- Heidi Fell: AMA-physician contractor, PCN Contractor
- Steven Turner: AHS
- Dave Sidhu: None
- Brad Bahler: AMA-physician contractor
- Julie Lauzon: None
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#### **Session Overview**

- This session will prepare physicians for the planned release of microbiology, pathology, and genetics results to the My Health Record portal; this change is scheduled for August and September 2021.
- This interactive session will include presenters from family medicine, medical genetics, and pathology.
- Presenters will share their experiences and insights on what this change means for your practice, and how to adapt.









## **Learning Objectives**

- Assess the impact of real time lab release to patients and the need for pre-test counselling
- Evaluate the impacts of patient access to labs on physician, clinic and/or hospital workflows









#### **Patient Portals in Alberta**

- Provincial
  - My Health Records
    - My Personal Records (Alberta Health) "MPR"
    - MyAHS Connect (AHS Connect Care) "MAC"
    - Covid-19 Children's Lookup Tool
- Local
  - Physician Electronic Medical Records
  - Local Patient Health Records





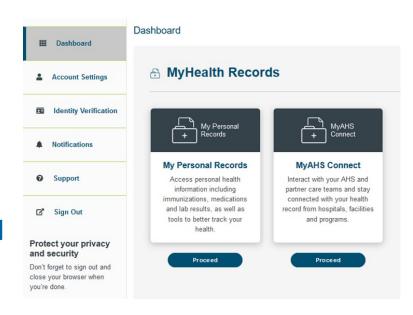




### MyHealth Records

## Universal landing page for both MyPersonal Records and MyAHS Connect

- Any Albertan over 14 years of age
- Must have an Alberta Identity card or Driver's License
- Registration via MADI process
- Interim access confirmed by PIN sent via mail











#### **Patient Portals**

#### What's known already?

- All Albertans 14 and up
- 95% of labs (by volume) present as of Feb 1, 2021
- COVID and other immunization records
- Available to Albertans (14 and up) receiving care from an AHS facility using **Connect Care**

#### What's New or Coming?

- Microbiology released (no susceptibilities) June 15, 2021
- All lab results as of August 23, 2021 including pathology and genetics
  - In province only
  - Exception for neuro predictive genetic testing (done through genetics services)









### **Portal Summary**

#### My Personal Record

- No patient notifications
- Almost all lab results released in real-time (as of August 23)
- No DI results at present (future development)
- New users only will see 18 months of retroactive data
- Brightsquid integration for secure messaging
- Sharing of records by patient control; no proxies





#### **My AHS Connect**

- Patients receive notifications when there is a new result
- All lab results released in real time to align with MPR
- DI results remain available with a five-day delay
- Retroactive view to 2017
- Additional communication tools available to support clinician – patient interactions.
- Proxy access available within identified guidelines





## Important Concepts – Real Time Posting

- Patient will be able to see results as soon as they are available, sometimes prior to the provider
- Some Providers receive results as batch feeds (paper, fax or electronic) rather than in real time
  - Lab data also available to all providers in real time in Netcare
- Strong patient feedback that real time release is desirable, even when the news is bad
- Literature shows reduced anxiety overall among patients with real time release
- These changes were approved by the Health Information Executive Committee
  - Reps: AH, AHS, AMA, CPSA, ACP, ACFP, AARN, PCN









## Important Concepts – Results Context

- Patients may contact a Provider who did not order the test (and not cc'ed that result)- to discuss that result
  - That provider needs to carefully decide how to handle that situation
    - Critical results
    - Results requiring detailed specialist follow-up
    - Need to be clear about the question prompting the test
- Also some appropriate and some inappropriate situations occur where a provider orders test(s) with another provider listed as the primary person ordering that test









# Personal Experience/ Primary Care Perspective

- In general, the number of inquiries from patients is far less than I expected
- A very small number of patients need to be coached on appropriate communication
  - Opportunity to inform patient (benefits/risks, limitations, and potential outcomes)
- If using asynchronous messaging patients need to be clearly notified by the system that this is not for urgent issues
  - i.e. patient should call rather than message the provider for urgent issues









### **Personal Experience**

- Pre-test counselling assists in managing patients expectations
  - Explanation of possible results (positive/negative, secondary or unexpected results)
  - Possibility of further testing (if inconclusive)
  - Managing expectations for next steps following result
  - Potential implications for family members (genetics testing)
  - Patient also have link access to test information on myhealth.alberta.ca
- Educate your patients on how you or your clinic review and act on results
- Patients greatly appreciate seeing results and having the ability to discuss them with you without having to make an inperson appointment









## What about experiences in other portals?

- Community EMR (Telus Wolf) actively posting all lab and reports ~ 5 years
  - Net balance of calls (some patients call less now and some call more)
  - Panel is savvier with meaning of results and better self management, involvement in decisions
  - Use asynchronous messaging to replace "results review" appt.
  - Pre-counselling and planning with patients is key
  - Team "scripting" and process for patients calling for results









- Genetic and Genomics testing
  - Testing performed by
    - Cytogenetics Laboratory
      - Karyotype, Chromosomal Microarray
    - Molecular Genetics Laboratory
      - Single gene testing
      - Next Generation Sequencing ("gene panels")
    - Biochemical Genetics Laboratory
      - Includes Newborn Metabolics Screening (MAC Only)
- Current access to genetic testing will not change
  - Open vs restricted access to specific care providers









#### Pre-test counselling

- Possible outcomes of testing
  - Positive
  - Negative
  - Variant unknown clinical significance (VUS)
  - Incidental findings
  - Carrier status
- Turn around time
- Clinical implications for patient
- Implications for family members
- Social and psychological impact









- A negative genetic test result does not mean it is not a genetic disorder
- A VUS is a VUS cannot make diagnosis based on this result.









- Only in-province genetic testing performed by the Genetics and Genomics Laboratories will be released
  - \*Exceptions
    - Out of Province testing
    - Predictive testing for some disorders









- Predictive testing/Pre-symptomatic testing
  - Testing of asymptomatic patients
  - Results that will be released include
    - Cardiac conditions
      - O Cardiomyopathy, Cardiac arrhythmias, etc ...
    - Cancer predisposition
    - Neurologic conditions

\*Results for neurodegenerative conditions will NOT be released (Huntington disease, ALS, Dementias, Ataxias)









#### **Clinical Genetics and Metabolics Programs**

#### Calgary

#### **General Genetics Clinic (ACH)**

- Phone (403) 955-7373
- Fax (403) 955-2701

#### **Prenatal Genetics Clinic**

(Cambrian Wellness Center)

- (403) 943-8375
- Fax (403) 943-8376

AB Netcare eReferrals
On call Consult Service

#### **Edmonton**

## **General and Metabolic Genetics Clinics** (Stollery)

- Phone (780) 407-7333
- Toll free 1-855-935-7333
- Fax (780) 407-6845

Connect Care Referrals
On call Consult Service

#### **Genetics and Genomics Laboratory Services**

https://www.albertahealthservices.ca/lab/page8667.aspx









# Lab Medicine / Pathology Perspective

- Pathology results peculiarities
- Pathology consults
  - "Patient" on-call service In discussion
- Ordering pathology test advise patient it may take weeks to get results
- Adjuvant testing
- Other change management?



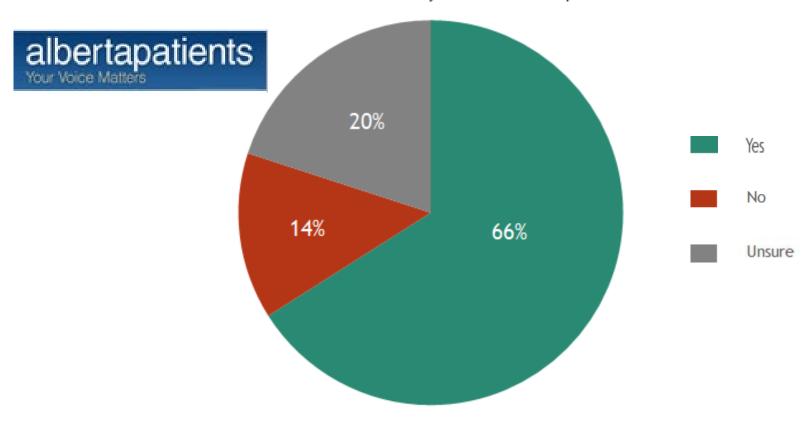






## **Patient Perspective on Interaction with Pathologists**

Do you think it would be valuable to have more interactions between pathologists/laboratory medicine physicians and patients to be able to understand how your lab tests were performed or assessed?











## **Questions and Answers**











## **Evaluation Link & CME Credits**

#### **Evaluation Link:**

https://interceptum.com/s/en/Realti <u>mereleaseofcomplexlabsinpatinetpor</u> tals



#### **CME Credits:**

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