#### FHIR in the Research Community @UW

Care and

September 12, 2020

SEAN MOONEY Chief Research Information Officer UW Medicine

Professor Biomedical Informatics and Medical Education



#### Welcome!



#### The University of Washington

\$1.579 billion in research awards in 2019 from more than 5,400 awards

In 2017, the UW ranked fifth overall nationally in research expenditures

Ranked 10th overall by US News and World Best Global Universities and the world's most innovative public university by Reuters in 2019



#### Patient care comprises half of UW business

- Four hospitals, 60+ primary care clinics, cancer center, level one trauma center, Airlift NW, School of Medicine
- Greater than 600,000 patients seen in 2019
- Greater than 28,000 faculty and 4,600 trainees
- Enterprise electronic health record system going live in October 2020
- Forward thinking enterprise analytics data platform with more than 30 years of data comprising nearly five million patient lives

|        |                  | Total     | 2019    |
|--------|------------------|-----------|---------|
|        | Count patients   | 4,981,278 | 608,727 |
|        | •                |           |         |
| Age    | 0-20             | 663,436   | 63,719  |
|        | 21-30            | 495,870   | 92,564  |
|        | 31-40            | 574,132   | 98,882  |
|        | 41-50            | 580,900   | 83,788  |
|        | 51-60            | 632,476   | 94,027  |
|        | 61-70            | 649,187   | 93,367  |
|        | 71-80            | 459,552   | 56,554  |
|        | 81-90            | 268,389   | 20,858  |
|        | Over 90          | 608,479   | 4,938   |
|        |                  |           |         |
| Gender | Male             | 2,231,714 | 273,579 |
|        | Female           | 2,277,872 | 334,854 |
|        |                  |           |         |
| Race   | African          | 132,401   | 43,554  |
|        | American         |           |         |
|        | American         | 40,465    | 8,048   |
|        | Indian           |           | 50 500  |
|        | Asian            | 257,707   | 58,503  |
|        | Caucasian        | 2,223,450 | 365,985 |
|        | Hispanic/Latino  | 79,493    | 123     |
|        | Other            | 81,363    | 28,778  |
|        | Pacific Islander | 94,130    | 4,835   |
|        | Unknown          | 1,585,666 | 88,434  |

#### Goals of the presentation

Give perspective of academic health system and preparing to enable next generation of research, investigation and tech development

## UWMedicine

Communicate our strategy and how we are addressing challenges of translation of research using technologies like FHIR to enable investigators



#### The UW FHIR Community

Universities have great ability to convene communities

Started by bright graduate students and interested faculty

Included previous workshop, monthly meet ups (largely pre Covid) and this workshop



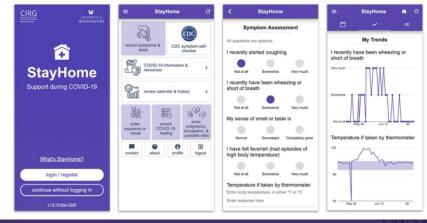


#### Building an ecosystem of developers

Our self organizing community of developers brings a 'bottom up' approach to innovation

Seeing many successes during Covid-19 working with UW Medicine and other entities Hear more about the StayHome App at Panel Session 3 at 1:15pm Pacific

A **reusable**, **mobile-friendly**, **FHIR-native** consumer health application for collecting <u>patient-reported outcomes (PROs)</u> and experiences to support the need for COVID-19 symptom self-monitoring and <u>data sharing with appropriate public health agencies</u>.



#### Hannah Burkhardt

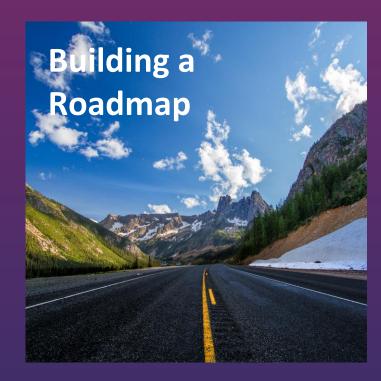


#### **Our Strategy**

Investigators are are always thinking about what's possible 5 years from now

At the UW, we are constantly approached by developers who want to pilot apps, machine learning and other tools that require interfaces to operational systems

Has led to us (research informatics) focusing on a strategy of building in *people/resources*, *technology* and *governance* 



**UW** Medicine

UW SCHOOL OF MEDICINE

BIOMEDICAL INFORMATICS



#### The 'people' resources

The Institute of Translational Health Sciences (ITHS) provides services to investigators in the WWAMI region and is largely funded by NCATS and the Clinical and Translational Sciences Award Program

ITHS, UW Medicine and Biomedical Informatics and Medical Education (BIME) have built a Research IT team to serve investigator needs









ABOUT ITHS The institute of Translational Health Sciences is dedicated to speeding science to the clinic for the benefit of patients and communities throughout Washington, Wyoming, Alaska, Montana, and Idaho. RESEARCH SERVICES ITHS offers resources to researchers that increase the speed at which scientific discoveries can be translated into treatments. that improve health outcomes for patients and communities.

EDUCATION & TRAINING The ITHS Education Program supports investigators and scholars through the development and maintenance of curriculum and career development education.

Institute of Translational Health Sciences

Melissa 'Mel' Habrat, Director of Research IT UW Medicine

#### **Research Information Technology**



UW and other University Faculty We sit between the health system and innovative

faculty





Health System Clinical Systems and Healthcare Delivery

#### **UW Medicine Research IT**





Management of Enterprise Systems (CTMS, etc)



Support for REDCap and EDC



Advanced Computing on Clinical Data



Innovations & Engineering

Leaf Self Service Query Tool



# Nationally and locally, research is increasingly targeting the EHR

Research in the EHR(s) Increasing interest on leveraging APIs to deploy investigational apps and and other tools including SMART on FHIR apps



We are supporting proposal development and helping shepard projects through governance

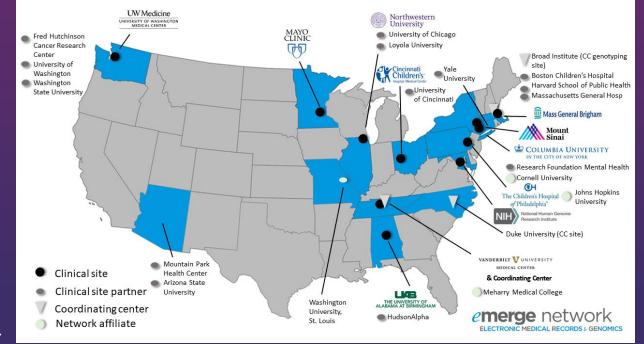
Interest area focuses on apps, decision support and machine learning



#### NHGRI eMERGE Phase IV (https://emergenetwork.org/)

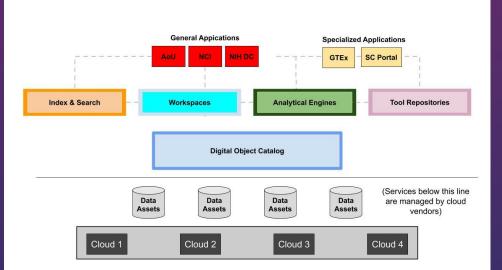
Research in the EHR(s)

Example, the eMERGE Consortium (from RFA funded by NHGRI)): "The eMERGE Genomic Risk Assessment and Management Network will incorporate genotyping information into EMRs using the Fast Health Interoperability Resource (FHIR) standard"



## NHGRI Genomic Data Science Analysis, Visualization and Informatics Lab-space (AnVIL)

- Cloud-based repository to allow access and computing with genomic data sets
  - To replace dbGaP
- AnVIL Phenotyping Working Group
  - Tasked with mapping phenotype data across multiple studies to standards, *including FHIR*
- Includes the Electronic Medical Records and Genomics (eMERGE) Genomic Risk Assessment and Management Network



AnVIL Ecosystem (figure courtesy of Dr. Anthony Philippakis)

#### Slide: David Crosslin

#### FHIR is being leveraged as a data model

National consortia are leaning on FHIR as a data model standard to facilitate data harmonization and sharing

Access to data for research

For example, the Clinical and Translational Sciences Awards and their informatics Coordinating Center CD2H are focusing heavily on leveraging FHIR as a data model (https://cd2h.org/data\_sharing):





National Center for Advancing Translational Sciences



#### FHIR can interface to enterprise applications

Support for REDCap and EDC

- REDCap (Vanderbilt) is widely used nationally for electronic data capture. Epic FHIR / REDCap interface available
- Some sites are leveraging FHIR to support clinical trials such as OnCore CTMS



Institute of Translational Health Sciences

ERATING RESEARCH. IMPROVING HEALTH.

AMIA Jt Summits Transl Sci Proc. 2019; 2019: 54–63. Published online 2019 May 6. PMCID: PMC6568121 PMID: <u>31258956</u>

FHIRCap: Transforming REDCap forms into FHIR resources

Alejandro Metke-Jimenez, PhD and David Hansen, PhD



#### Governance

- 1. Developed enterprise research informatics governance committee
  - a. Multi-stakeholder with faculty and executive representation
  - b. Provides input on data governance, processes and research integration
  - c. Identifies challenges, discusses solutions, escalates complex solutions to other stakeholder leadership

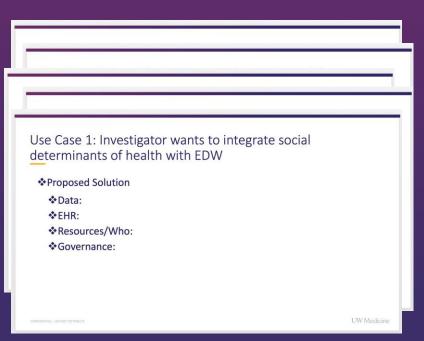
 Embed faculty in BIME associated with Research Informatics in operational governance including patient portal, security, enterprise analytics, IT oversight and other informatics governance.



#### Last thought: The idea file

I spend about 20% of my time as focused on consulting with investigators both at the UW and externally on their challenges

Every time I hear a problem I don't know how to solve, I put it a personal journal (powerpoint slide) of "things we should be able to do but I don't know how to do"





### Final thoughts

Enjoy the meeting

My advice is that aspiring organizations to support researchers:

- ➢ Build a community
- ➢ Set a strategy
- Address people/resources
- Address technology capability
- ➤ Address governance



