

It's my Data!

How an HIE can Facilitate Patient Engagement

UConn
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CME Series – with CPE sought as appropriate

Health Information Technology for Clinicians:
How to Achieve Optimal Outcomes

Webinars and In-person events



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UConn Health

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Health Information Technology for Clinicians: How to Achieve Optimal Outcomes

Sample Topics

- Medication Safety/ Reconciliation
- Health Data Analytics
- eCQMs (electronic clinical quality measures)
- Telehealth
- Image Sharing
- Precision Medicine
- Health Information Exchange
- Patient Consent models
- Public Health Informatics
- Patient-Generated Data

Learning objectives

1

Discuss the benefits of granting access to health data for patients and their designated surrogates and what elements are required to accomplish this

2

Describe the current status of providing patients/designated surrogates access to their health data at a national level

3

Discuss how a Health Information Exchange can facilitate the safe and effective implementation of patient-facing data sharing

Housekeeping



All participant lines will be muted during the panel discussion



The panelist will address your questions during the Q/A session from the Q/A chat feature



If we are not able to address your question today, we will follow up with you directly using your registered email.



This session will be recorded and available for download along with the slides used today.



Instructions on how to access will be sent after the session to your registered email along with instructions to earn CME and CPE credit.

Presenters

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Education Medical Consultants, LLC
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CT Zebras

Disclosures: All presenters have reported they have no conflicts to disclose

Pat Carroll



Respiratory Therapist



Registered
Nurse



Educator



Voice of
the Patient



My journey from RN to patient

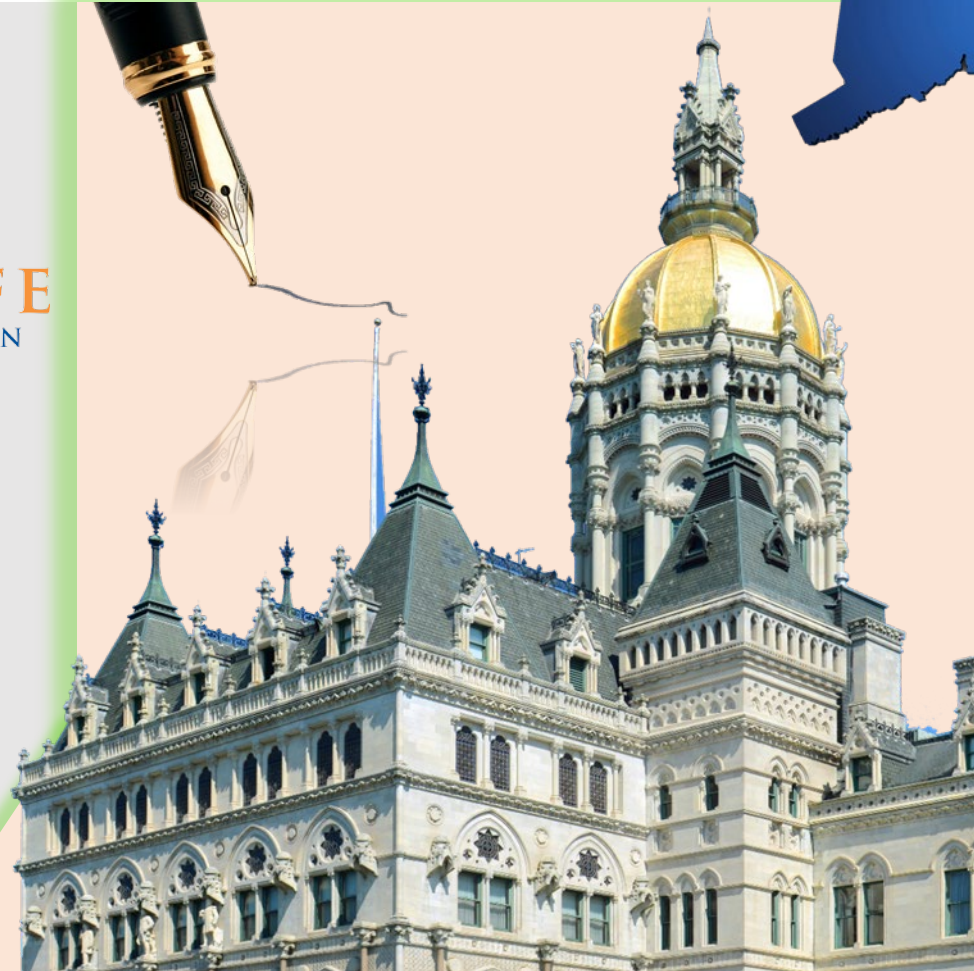


Now what?



PATIENTS
RISING
Delegate

EVERYLIFE
FOUNDATION
FOR RARE DISEASES

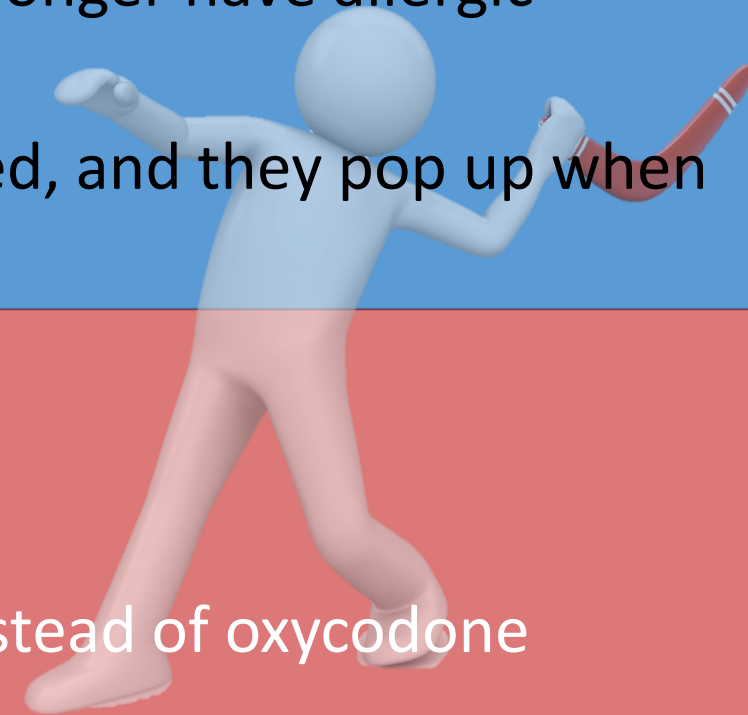


My experience









Medication Errors Introduced

- As a child, diagnosed with penicillin allergy
 - Confirmed with skin tests in college, also positive for allergy to cephalosporins
 - When immune deficiency diagnosed, re-tested & no longer have allergic reaction
 - However, older records have those med allergies listed, and they pop up when records share behind the scenes
- Prescribed oxycodone following spinal fusion
 - Prevented from getting a refill. Why?
 - What changed since my last prescription?
 - A medical assistant at specialist entered oxyCONTIN instead of oxycodone
 - Nobody licensed double-checked
 - I asked for it to be corrected so I could get my refill, but it still follows me



Medication Error Solutions

| Patient Portal | | | | |
|---|---|---|---|---|
|  MY DATA  MY PROVIDERS | Pat Carroll | | | |
| |  |  |  | |
| | MEDICATIONS | ALLERGIES | | |
| Medications | | | | |
| Date Prescribed | Source | Medication | Dose | |
| XX/XX/XX | Specialty Care Physicians | Oxycontin | 10 mg |  |

Ability to flag medication for future review

OR

Submit Notification to Provider

OR

If applicable, ability to fill out correction form to source of data entry



Sharing imaging

- Spine surgeon- ordered x-rays
- Discussed results at office visit
- Requested the CD of the films
- At home- opened the viewer and took screenshots of images
- Tried to share via messaging in MyChart with another specialist
- The images were too large to be attached; only other option was PDF
- Created a Word doc, pasted the images, created the PDF

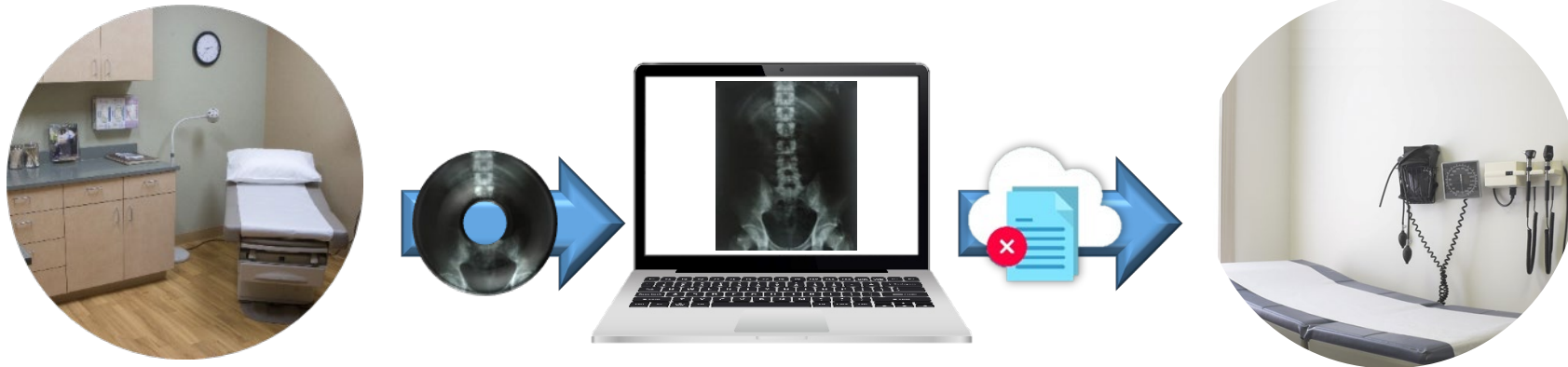
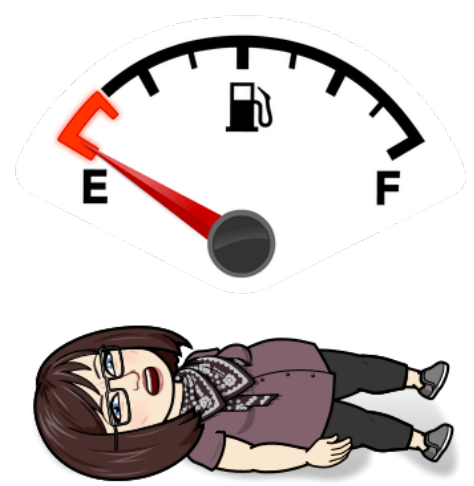


Image Sharing Solution

Patient Portal

Pat Carroll

MY DATA
MY PROVIDERS
MY UPLOADS

MEDICATION

IMAGES

Date Taken
xx/xx/xx

New Image

Date Taken
Image Type
Ordering Provider
Taken at
Comments


FILE UPLOAD

Choose File No File Selected

Cancel OK

ion
associates

WANT



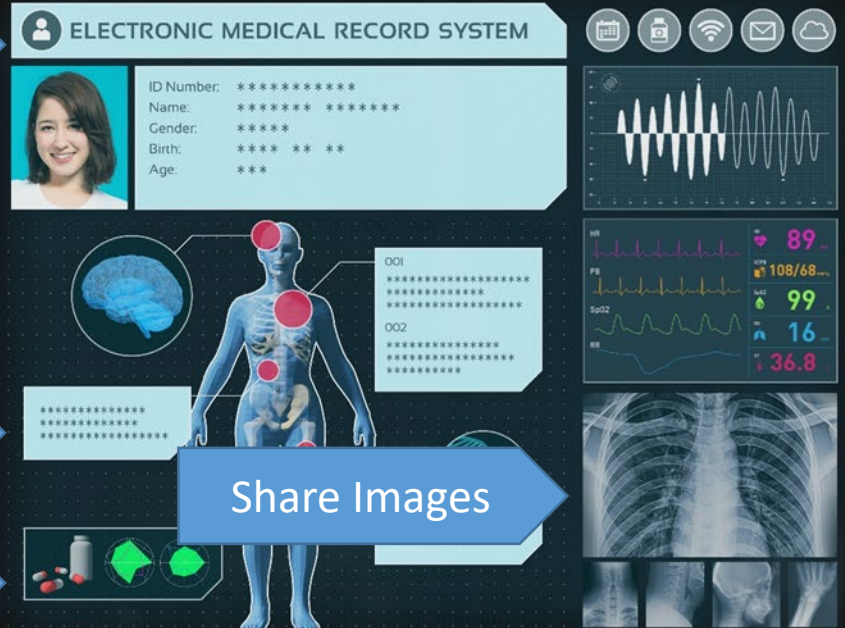
Access to HIE Information

Review

Comment

Notify of Errors

Share Images



Designated Surrogates



Ability to designate a surrogate
with unique login



Decide what they can view

Can be Key to Medication
Reconciliation



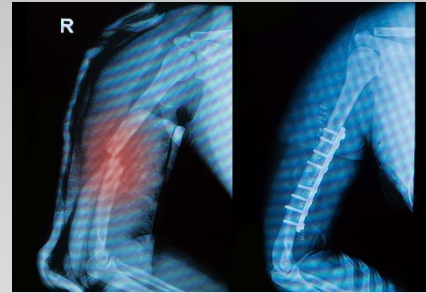
Patient Folder



Insurance companies require original workup to approve coverage



Can print and upload files to facilitate future prior authorizations



Store other information such as imaging



Store our own medication list



Emily Smith

DOB 01/01/1989

Updates 04/08/2019

| Reason | Medication | Details | Status | Reason |
|--------------------------|----------------------------------|---|---------|----------------------------|
| IG Infusion | Hizentra 12 gm Q week | Primary Immune deficiency | ACTIVE | |
| | Diphenhydramine 25mg | premed for infusions w/5mg oxycodone + 1000mg acetaminophen | ACTIVE | |
| Autoimmune | Prednisone 10mg AM± 20mg 1/7/19 | Sjögren's, autoimmune vasculitis 10mg baseline, increased for infection | ACTIVE | |
| | Naltrexone 4mg HS | autoimmune disease | ON HOLD | |
| | Aspirin 325mg QD AM | vasculitis | ACTIVE | |
| | Celebrex 200mg BID | arthritis / autoimmune | ACTIVE | |
| | Levothyroxine 0.05mg QD AM | hypothyroid TSH 6.9 11/2015 3.89 4/2016 w/ replacement | ACTIVE | |
| Pain Management | Lyrica 50mg AM 75mg HS | for muscle spasm and post-op nerve-related pain | ACTIVE | |
| | Sertraline 200mg QD AM | pain management adjunct | ACTIVE | |
| | Diazepam 5mg HS | for muscle spasm | ACTIVE | |
| | Oxycodone 5mg PRN | prn & w/ Ig infusion | ACTIVE | |
| Heart Condition | Nadolol 200mg QD HS | A fib, high blood pressure | ACTIVE | |
| Urinary Tract Infections | Nitrofurantoin 100mg-BID | for prophylaxis hold 1/7/2019 | ON HOLD | Awaiting Culture |
| | Probiotic | Started 9/5/17 for intractable UTI | ACTIVE | |
| Eyes | Lumigan 0.01% 1 drop each eye HS | increased IOP (started 10/25/2013) | ACTIVE | |
| | Restasis 0.05% ophthalmic OU BID | Sjögren's chronic dry eye (started 10/4/2014) | ACTIVE | |
| | TheraTears Nutrition supplement | Sjögren's chronic dry eye (vitamin E, fish oil, flaxseed oil for omega-3) | ACTIVE | |
| | Xiidra 5%-1 drop each eye QD HS | Sjögren's chronic dry eye (started 3/1/17) | ON HOLD | Not Available on Formulary |
| Other | Vitamin D 1000 IU QD AM | low blood levels vit D, normalized with supplement | ACTIVE | |
| | Multivitamin QD AM | | ACTIVE | |

Poll

What do believe is the greatest benefit of granting access to health data for patients and surrogates?

- a) Patient's Coordination of Care
- b) Provider-Patient Communication
- c) Patient Engagement & Adherence
- d) Patient Education
- e) Patient Empowerment
- f) Quality of Care

OVERVIEW

- PGHD: What they are, how they're collected
- Patients' right of access to their data
- Current use cases for PGHD
 - Pediatric remote monitoring
 - Monitoring in oncology care
 - ePROs

PATIENT-GENERATED HEALTH DATA: WHAT IS IT?

- **PGHD** are health-related data—including health history, symptoms, biometric data, treatment history, lifestyle choices, and other information—created, recorded, gathered, or inferred by or from patients or their designees (i.e., care partners or those who assist them) to help address a health concern
- **PGHD** are distinct from data generated in clinical settings and through encounters with providers in that:
 - Patients are primarily responsible for capturing/recording these data
 - Patients direct the sharing of these data to health care providers and other stakeholders

(RTI International, 2012)



PGHD, **THEN** AND NOW

PGHD in 2012

Patient-measured & reported (BP)

Self-reported lifestyle data (steps)

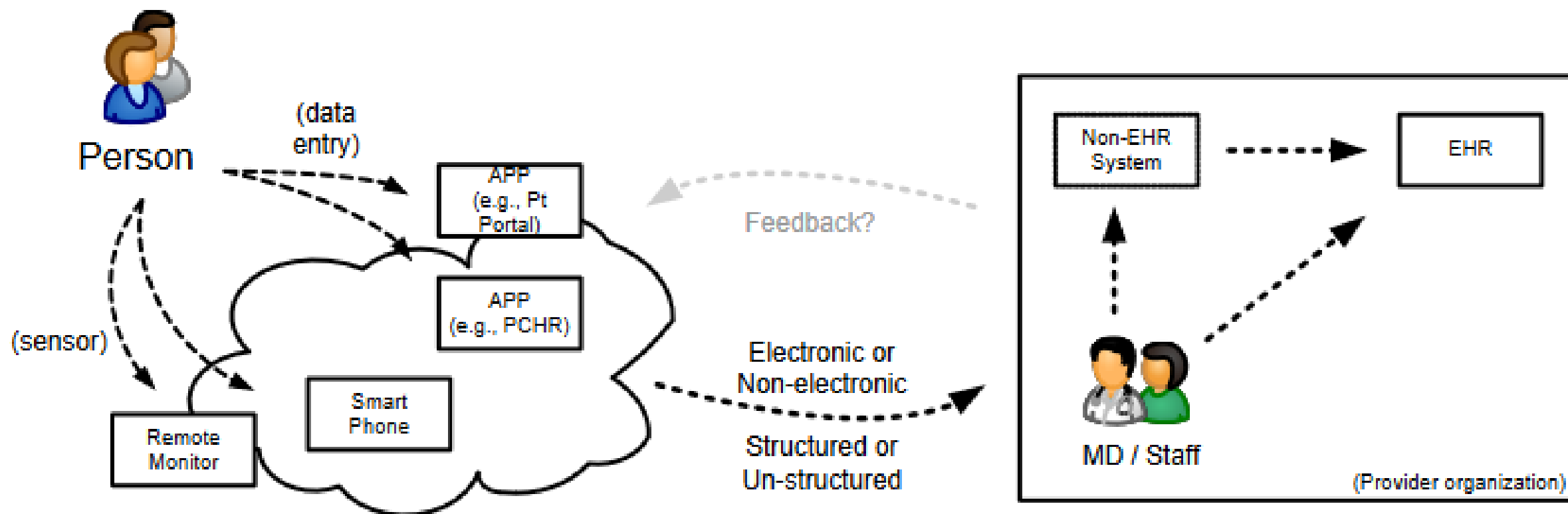
Quality-of-life data (sleep quality)

PGHD today

Patient-reported outcomes (ePROs)

Meds & supplements (Med list)

HOW DOES IT WORK?



Data Capture

Patient* directed / authorized
Sometimes provider-requested

Data Transfer

Patient* directed / authorized
Sometimes provider-requested

Review / Document

Provider directed / authorized

PATIENT ACCESS TO THEIR DATA

- Established by Health Insurance Portability & Accountability Act
- 21st Century Cures Act gives patients the right to access their electronic medical record on demand at no additional cost via apps (APIs)
- Information “blocking” prohibited except for:
 - Harm prevention; Privacy; Security; Infeasibility; HIT performance
 - Content and manner; Fees; Licensing
- 2021: ONC National Coordinator announces that the healthcare system is now in a time of information sharing – info blocking is behind us (?!?!)
 - Sharing is in the eye of the user

USE CASES



REMOTE PATIENT MONITORING IN CHILDREN

- Goals
 - Track child's health during a typical day (e.g., home, school, activities)
 - Support chronic disease management via family-centric approach integrated with care in the clinic
- Examples
 - Real-time continuous glucose monitoring for Type 1 diabetes
 - Childhood asthma symptom and medication use monitoring/reporting
 - Tracker-based activity monitoring for weight management

ONCOLOGY PATIENT MONITORING

- Centers seeking process automation, adherence to best evidence
- Among centers, some variation in content type, extent of integration, maturity of governance
- Challenges: including patients in governance process; instrument selection; incorporating PGHD into clinical workflows; collaboration with vendors
- 2022 recommendations for cancer centers, researchers, EHR vendors

96%

National
Comprehensive
Cancer Network
institutions use
PGHD

90%

Embedded in
EHR

88%

Non-integrated

ELECTRONIC PATIENT-REPORTED OUTCOMES

- Historically used in clinical trials of investigational therapies, though starting to see adoption of ePROs in clinical care
 - Adverse effects, side effects, symptoms, quality of life measures
 - More commonly used in adults
- PROTEUS-Trials Consortium (<https://more.bham.ac.uk/proteus/>)
 - Partnership of clinicians, researchers, regulators, and patients
 - Promote systematic use of ePROs to support decision making
 - Online toolkit that addresses writing PRO protocols, selecting PROs, analyzing PRO data, and reporting and displaying PRO findings
 - Work is expanding in 2022

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Poll

Which of the following patient-related barriers should be the highest priority for the HIE to address?

- a) Comprehension of medical jargon
- b) Connectivity/Accessibility challenges
- c) Privacy/Security concerns
- d) Facilitate inclusion of Patient Generated Health Data (PGHD)
- e) Awareness of health data access rights
- f) Provision of adequate assistance on access/navigation



Connecticut State Statute on Patient Access

Sec. 17b-59d:

- (1) Allow real-time, secure access to patient health information and complete medical records across all health care provider settings;
- (2) Provide patients with secure electronic access to their health information;
- (3) Allow voluntary participation by patients to access their health information at no cost; and
- (4) Promote the highest level of interoperability.

Connie Current Plans



Connie Patient Access Principles Policy

- Patient access is a **read-only service***
 - capabilities such as patient consent, appointment scheduling, prescription refill requests, or referral requests are not applicable
- Patients will be guided to **work with their provider(s)** directly when they:
 - have questions or **concerns regarding the accuracy** of their PHI; and/or
 - want to understand their PHI, e.g., a diagnosis; lab or test results; and x-rays, CT scans or other images.



Connie Patient Access Principles Policy (cont'd)

Accessibility

- Individuals will be provided with multiple methods to access their available PHI
- Patients will not be charged for electronic access
- Where patients have barriers to accessing their data—reasonable accommodations will be provided

***Policy Revision: the Patient Access Principles Policy and procedures will be reviewed (at least every 2 years) and revised as technology and resource capabilities change.**



Poll

Which of the following health care data do you feel would be the highest priority to have available to patients and surrogates?

- a) Lab Results
- b) Problem List
- c) Medication History
- d) Immunizations
- e) Treatment Plans
- f) Radiology Images & Reports
- g) Clinical Notes
- h) Allergies
- i) Advanced Care plans or directives

Questions

- Contact us for further information /
HIELearning@uchc.edu
Or
- Visit us at:
<https://health.uconn.edu/health-interopability-learning/>

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THANK YOU

for your participation