ASTP Assistant Secretary for Technology Policy

Addressing Health Equity with the Leading Edge Acceleration Projects

Dec. 4, 2024

1. Overview of LEAP
2. AllianceChicago's Aligning Housing and Healthcare
3. MedStar Health Research Institute's Equity Engines
4. Discussion
5. Audience questions

LEAP Background

- Address well-documented and fast emerging challenges that inhibit the development, use, and/or advancement of well-designed, interoperable health IT since 2018
- Solutions are expected to further a new generation of innovating health IT and inform the development, implementation, and refinement of standards, methods, and techniques for overcoming major barriers in health information access, exchange, and use
- New Areas of Interest released annually
- One award per Area of Interest up to $1M per award
- Awards are considered cooperative agreements
- Two-year period of performance

AllianceChicago

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MedStar Health Research Institute

- Mike Gillam, MD, FACEP
- Kristen Miller, DrPH, MSPH, MSL, CPPS

Addressing Health Equity

Aligning Health and Housing (AHAH)

Leading Edge Acceleration Project (LEAP)

AllianceChicago

Innovating for better health

Problem

Services addressing SDOH are disconnected and have disparate service providers with individual and disconnected care plans and tracking systems.

Project Plan

- Leverage FHIR-based resources and the experience and capabilities of a strong partnership to enable service providers to break down barriers to integration and coordination of services in order to better address social determinants of health for individuals experiencing homelessness.

- Implementation of a functional shared interoperable care plan that spans the collective domains of needs and services of the two service organizations using disparate information systems/technology.

- Work with the Community Health Center (Heartland Alliance Health) serving homeless patients with complex health problems and needs, and a Homeless Services organization (Chicago House) to
    1. Understand and characterize the elements of a comprehensive care plan bridging the domains of need and services across both organizations
    2. Co-design and pilot test a standards-based, open source, FHIR enabled electronic interoperable care plan accessible to both institutions and the patient, and
    3. Conduct a rigorous evaluation of the pilot and publish findings.

Goals & Objectives Summary

To create a shared care plan that addresses the following,

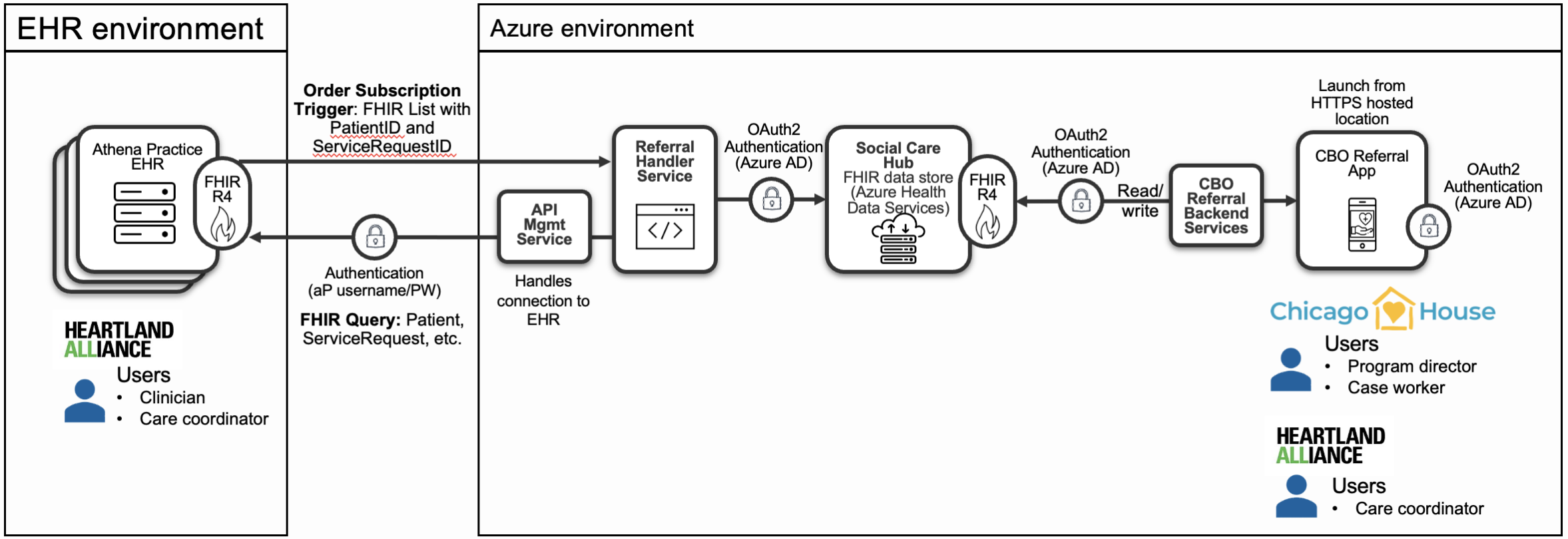
1. Collection and analysis of SDOH data in both EHR and other service provider information systems
2. Facilitation of closed-loop service referrals
3. Sharing of a care plan with patients through patient-facing tech (future goal)

Outcome & Metrics

Co-designed standards-based, open source FHIR enabled e-care plan for institutions and patients

Success determined by evidence-based assessment tool for evaluation – Participant Reported Implementation Update & Score (PRIUS)

Infrastructure Architecture



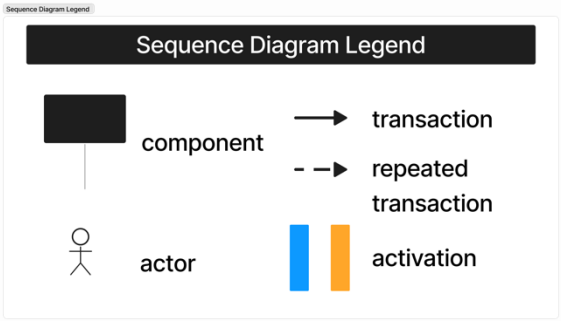
Use Case 1: Housing services referral

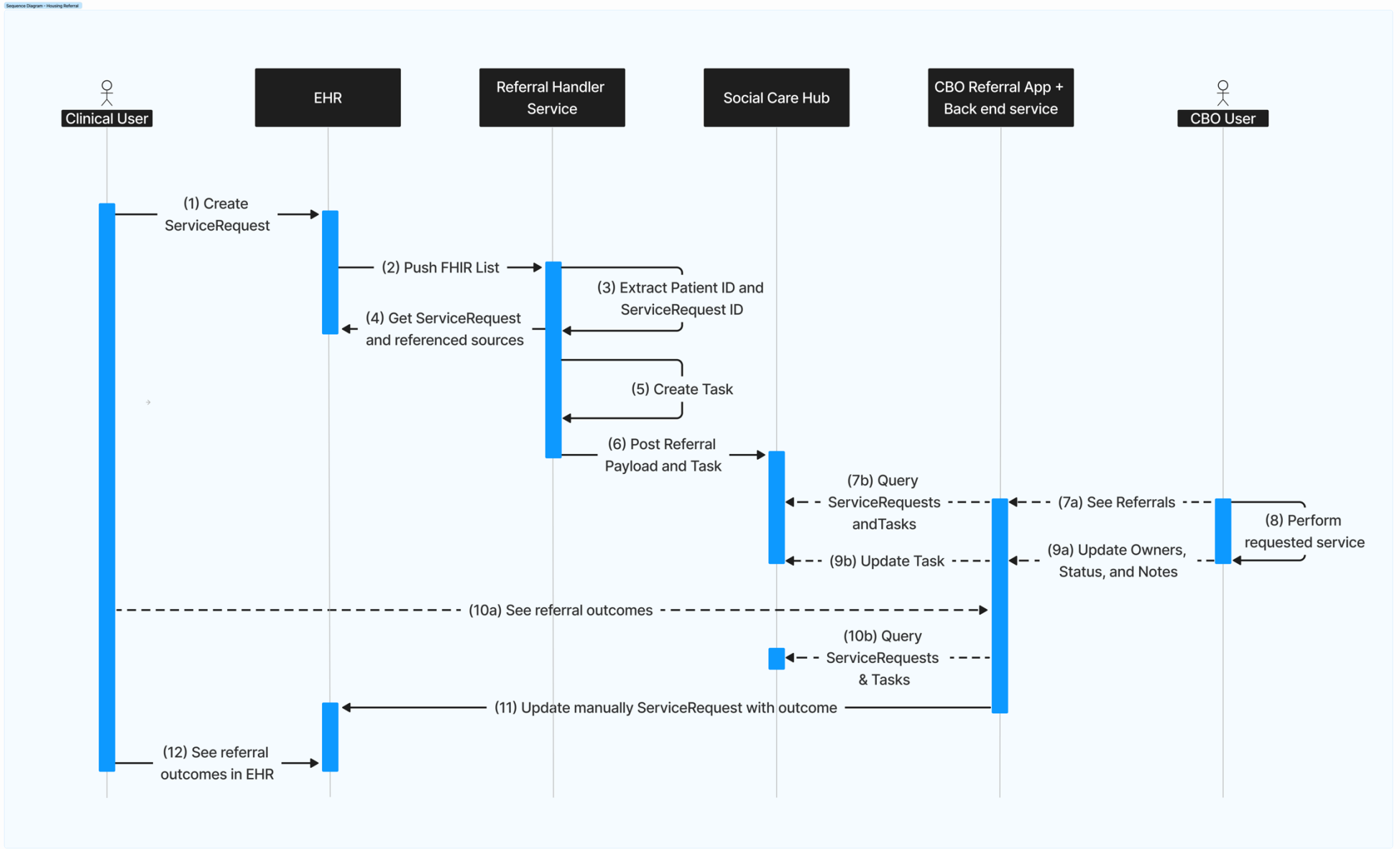
- TransLife Care (TLC)
- Health, Outreach, Prevention and Education (HOPE)

Use Case 1: Referral for Housing Services

WORKFLOWS	1. Create Referral	2. Send Referral	3. Manage Referral	4. Review Referral Outcome
	• Choose referral type • Create referral order • Sign referral order	• Send FHIR IDs for referral and patient • Query Referral bundle • Create Task • Post to Social Care Hub	• View referrals • Assign owner • Change status • Write notes • Close referral	• View Referral outcomes • (Optional) Update EHR with Referral outcome
ACTORS	• HAH clinician • HAH care coordinator	• n/a	• CH case worker • CH program director	• HAH clinician • HAH care coordinator
SYSTEM COMPONENTS	• HAH aP EHR	• HAH aP EHR • Referral Handler Service • Social Care Hub	• Community-based organization (CBO) Referral App	• CBO Referral App • Social Care Hub • (Optional) HAH aP EHR
FHIR RESOURCES	• ServiceRequest	• List • Service Request • Additional FHIR queries (patient, condition, observation etc.)	• Task • ServiceRequest • Practitioner	• Task • ServiceRequest

Sequence Diagram: Use Case 1





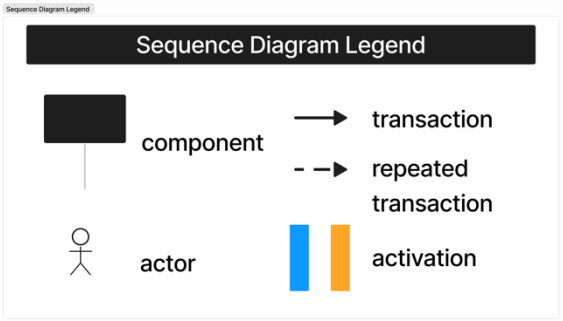
Use Case 2: Medical services referral

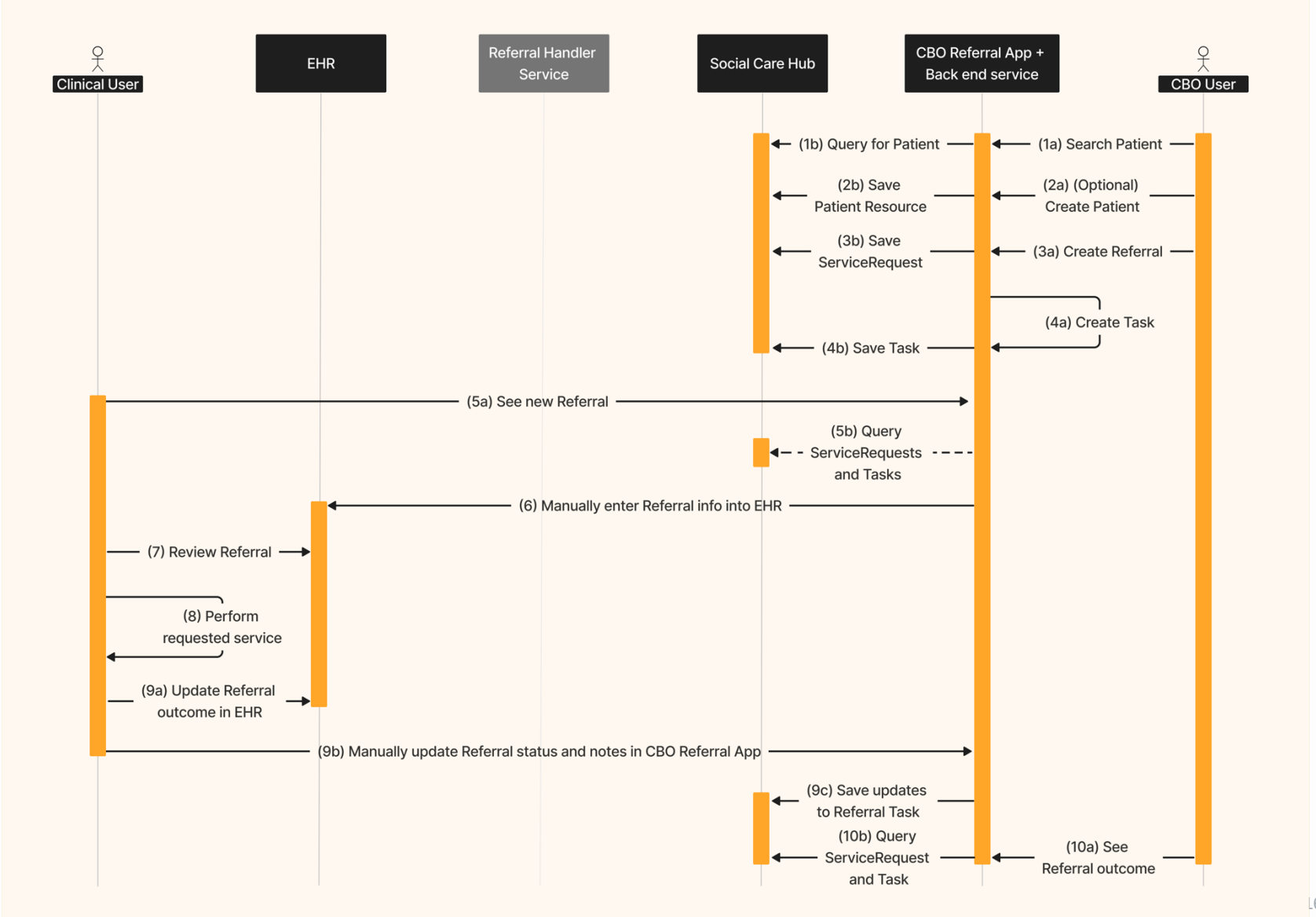
- Pre-exposure prophylaxis (PrEP) referral
- Test or screening
- Physical
- Etc.

Use Case 2: Referral for Medical Services

	1. Create Referral	2. Triage Referral	3. Perform Service	4. Document Outcomes
WORKFLOWS	• Search for patient • Select patient OR Create new patient • Create referral • Save referral	• Enter referral into EHR • Review referral info • Assign clinician	• Schedule appointment • Change status • Document medical appt/ follow-up • Close referral	• Update referral with outcomes in CBO App • View referral outcomes
ACTORS	• CH case worker • CH program director	• HAH care coordinator	• HAH care coordinator • HAH clinician	• HAH care coordinator • CH case worker
SYSTEM COMPONENTS	• CBO Referral App • CBO Referral Backend Services • Social Care Hub	• CBO Referral App • Social Care Hub • HAH aP EHR	• HAH aP EHR	• CBO Referral App • Social Care Hub • HAH aP EHR
FHIR RESOURCES	• Patient • ServiceRequest • Task • Practitioner • Organization	• Service Request • Task • Patient	• Task • ServiceRequest	• Task • ServiceRequest

Sequence Diagram: Use Case 2





Connection Considerations Use Case 1

- EHR limitations may require modified approaches depending on the vendor and their ability to handle different FHIR / API models
  - EHR or local network security policies may require FQDN, or a static IP to limit allowed traffic for the FHIR connection into the EHR system. Azure by default assigns random IP by connection. Static IP can be acquired via Azure at a cost and can take a bit longer to initiate setup
  - Subscription Triggering by referral orders is not available with our system. We used a modified approach with HL7 ORM triggering, then transform the message to match the expected JSON messages which we post to the referral handler to minimize customizations to the referral app

Connection Considerations Use Case 1 (cont.)

- EHR limitations may require modified approaches depending on the vendor and their ability to handle different FHIR / API models
  - Many EHR's do not allow Inbound ServiceRequest updates to update/close existing orders
    - We utilized a DocumentReference FHIR resource to post a txt file containing the summary notes from the referral in the Social Care Hub, routed to the staff member who ordered referral
    - Manual workflow defined to review notes and manually complete pending order in EHR

Connection Considerations Use Case 2

- EHR and workflow limitations may require modified approaches
  - Our EHR does not allow inbound ServiceRequests currently, so evaluated options for notification
    - Inbound Demographics (add Patient) is allowed systematically, however in review it is not best practice for the clinic to allow addition of new patients without proper review/assessment to avoid duplicate charts and ensure all necessary information is collected
      - System checks around add Patient functionality does not account for misspellings, or other incorrect data that frequently leads to the creation of duplicate chats
    - Clinic preference of manual workflow defined to monitor Social Care Hub, as well as continue with current warm handoffs directly between staff in this scenario to notify of new referrals back to the clinic

Key Challenges

- **Policy**: Institutional EHR write-back limitations makes it not possible to close the loop electronically.
- **Human**: Patient populations served in these use cases do not have reliable and consistent access to devices that have internet access; this makes the use of patient-facing technology not feasible.
- **Scalability**: Scaling this interface to more clinics and CBOs will require state-wide agreement and implementation of privacy, consent, patient identity management, patient matching, system-to-system and end user authentication approaches.

AllianceChicago

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MedStar Health

It's how we treat people.

December 4, 2024

Equity Engines: Leveraging Human-in-the-Loop Patient-Generated Health Data

MedStar Health
Center for Diagnostic Systems Safety

Project Goal: To explore and demonstrate the use of equity-enhancing patient-generated health data (PGHD) for clinical care and research

Landscape Analysis
- Environmental scan
- Stakeholder interviews and expert steering committee

Design & Development
- Co-design workshops
- User design feedback sessions

Demonstration & Evaluation
- Implementation across primary care sites
- RE-AIM evaluation

MedStar Health

Scoping Review Key Findings

Objective: Identify tools for PGHD capture and integration with a focus on health equity and patient co-development, addressing social determinants of health and bridging the digital divide.

PGHD Opportunities

- Enhance patient engagement
- Provide a complete picture of patient health
- Help manage chronic conditions with timely, personalized interventions

Barriers to Adoption

- Policy/ coverage challenges
- Digital health literacy
- Access to devices and disparities in broadband access
- Power, trust, equity

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> “EVERYONE IS CAPABLE OF READING OR HEARING EVERY WORD PRESENTED, UNDERSTANDING EACH ONE, AND YET GRASPING NOTHING OF THE MEANING OF THE MESSAGE.”

Wilhelms & Reyna

AMA Journal of Ethics®
Illuminating the Art of Medicine

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Engaging Stakeholders

Phase 1

Semi-structured interviews with patients (n=20) and primary care providers (n=10)

Phase 2

Presented findings to the Equity Engines Steering Committee (8 experts in health equity, patient engagement, digital health solutions, health IT policy)

Content Discussed

- Types of data tracked by patients
- Sharing data/ Integrating PGHD into the EHR
- Use of PGHD in clinical decision making
- Patient empowerment
- Health equity considerations
- Challenges and opportunities

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Why Hypertension (HTN)?

- HTN rates have worsened for racial and ethnic minority groups
  - Burden is higher among Black adults (56%) than non-Hispanic white (48%), non-Hispanic Asian (46%), and Hispanic adults (39%)
  - Worse outcomes including 4-5x HTN-related mortality, 30% higher rate of fatal stroke, 50% higher risk of cardiovascular disease mortality, and more than 4-5x higher risk of end-stage renal disease
- System innovations have shown improved HTN control across different populations
  - Home blood pressure monitoring; telemonitoring; team-based care
  - Interventions must be culturally tailored to be effective
  - 21% of disparities in HTN control explained by lack of treatment intensification and 14% by missed visits among Black patients

Significant risk factors for leading causes of mortality; leading single preventable risk factor

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Co-Design Sessions

Empathy Mapping

- Used to gain deeper insights into a user's experiences, needs, and emotions.
- Fosters user-centered thinking, ensuring that solutions address real needs and behaviors.

Journey Mapping

- Used to Illustrate steps in a process over time and identify top priorities.

Prototype Development

- Used to imagine potential functionalities and features of the proposed solution and platform.

Goals of Co-Design

- Elicit experiences of patients and providers with PGHD
- Identify features and functions that could be incorporated into the Equity Engines solution
- Identify potential benefits and concerns of the demonstration project

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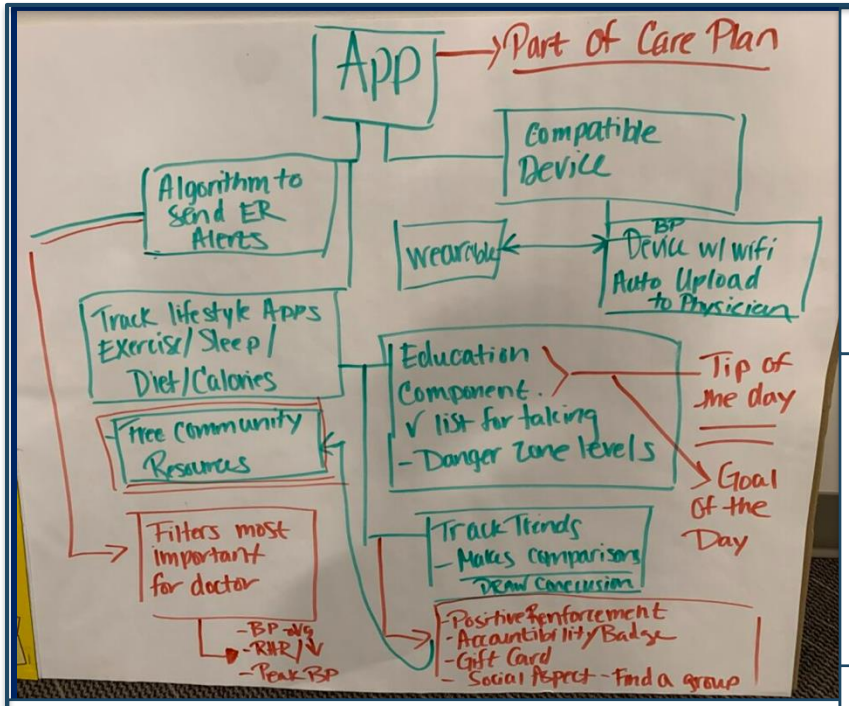
Key Components in Prototype Development



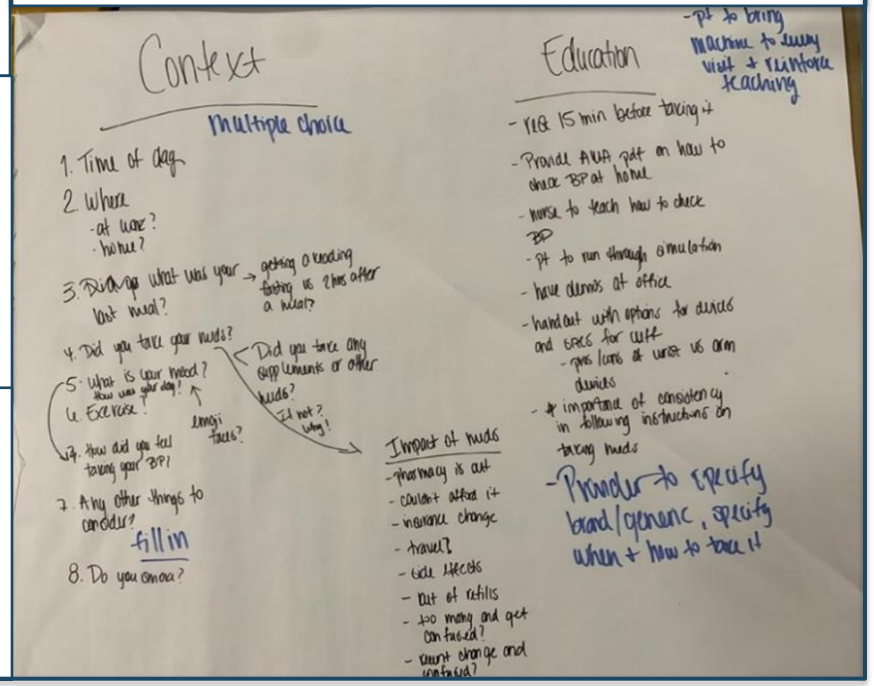
Education about HTN and home monitoring

Motivation and positive reinforcement in managing HTN

Real-time monitoring and triage

Community building, support, and engagement

Communication with the care provider team



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Demonstration Case (Two Part)

Health Metric: Home Blood Pressure (BP) Monitoring	Patient-Reported Outcome: Medication Adherence/ Social Needs
Self-measured BP monitoring • Confirm and manage HTN diagnosis • Empower patients • Increase physician monitoring	Survey patients regarding medication adherence and potential social needs • Monitor medication adherence • Identify social needs • Tailor interventions and strategies

By tracking my BP levels, I know if it's too high or too low and if it's too high, I know what to do and what not to do.

Doctors only ask patients what medications they are taking and if their medication lists are right. They aren't interested in more information we have to share.

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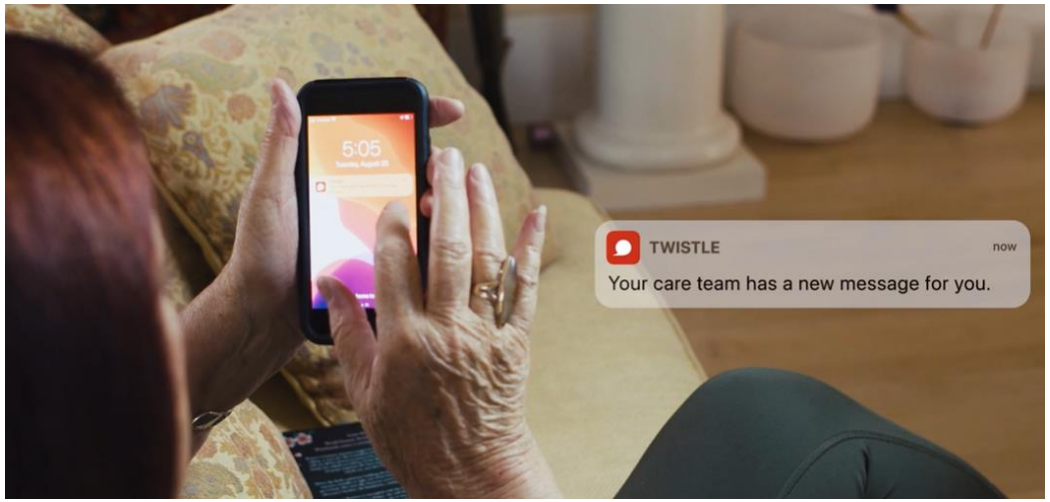
Key Components of Both Demo Projects

- Patients recruited from primary care practices (at providers discretion)
- 21 day care cycle
- Patients provided home BP monitor and batteries
- Anonymous, secure text messages
- Guidance on self-monitoring BP at home
- Assessing and addressing social needs that might affect adherence to HTN control strategies
- Culturally appropriate materials



Patient education, patient empowerment, and patient engagement. Education starts first and foremost because we want patients to be empowered, and we want them to be engaged.

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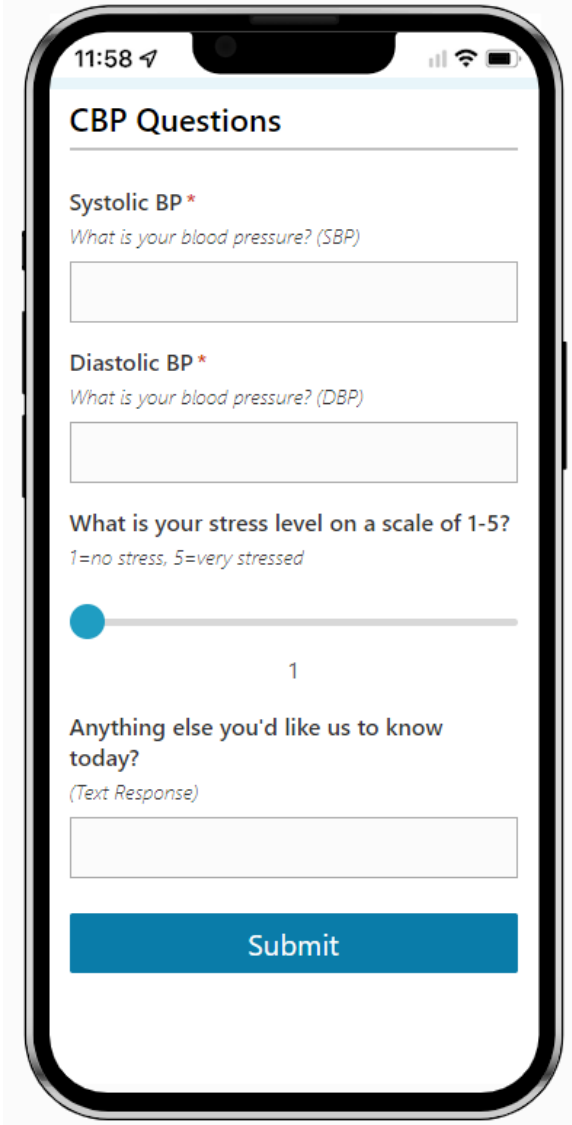
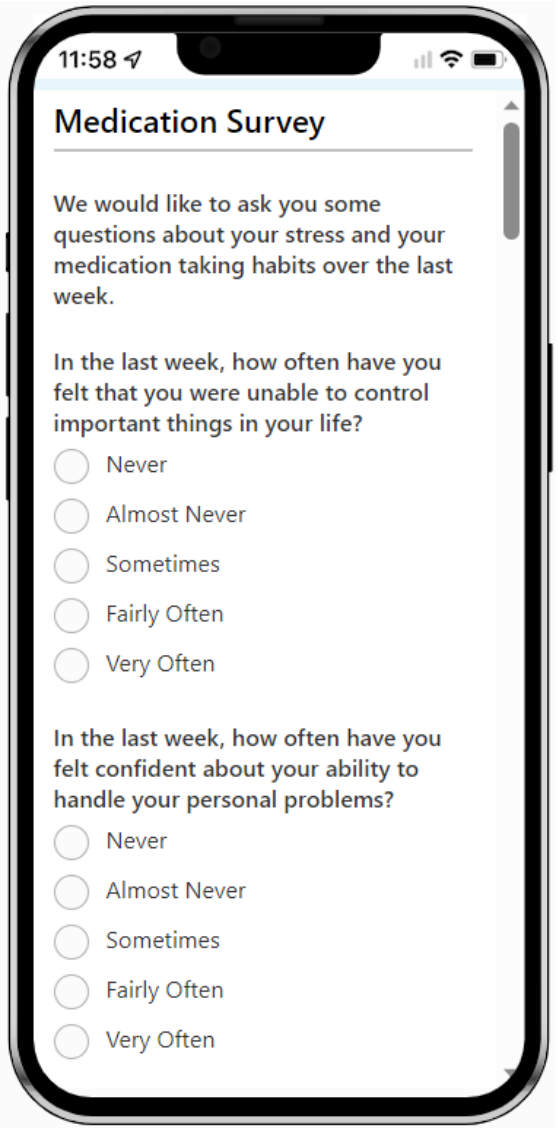
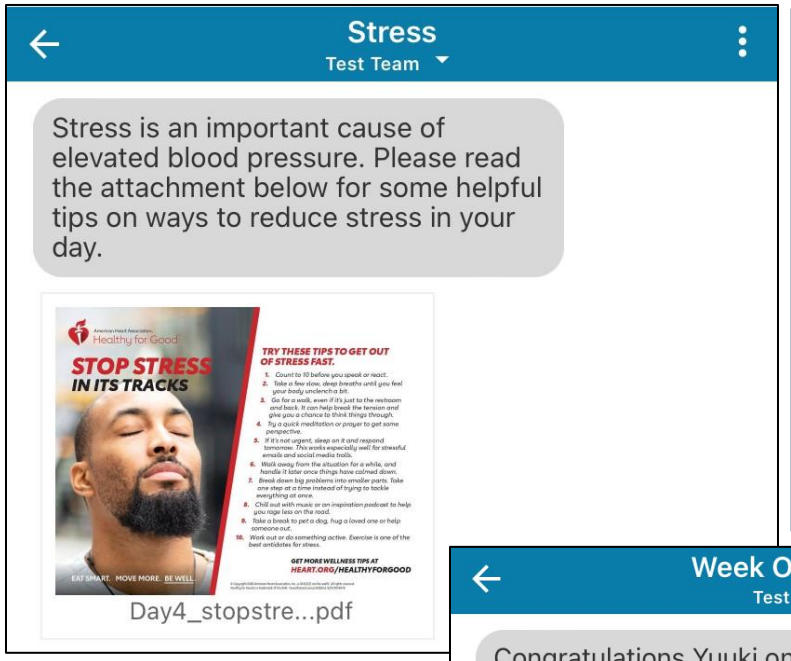
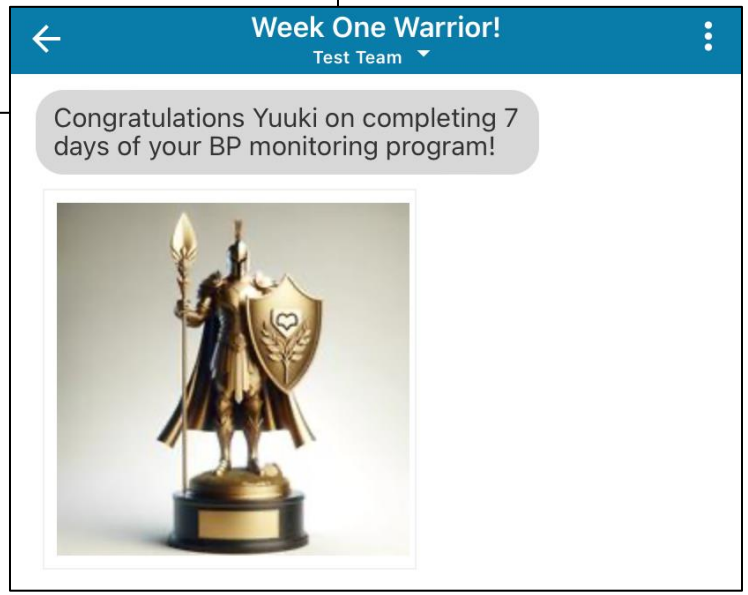






Educational materials on hypertension, stress, diet, exercise, sleep, and medications

Celebrations and achievements on data entry and pathway progress



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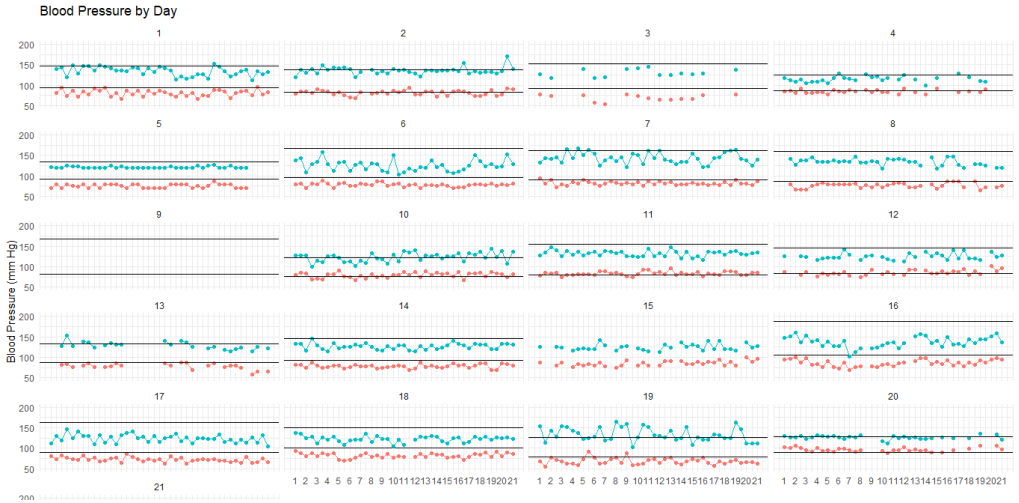
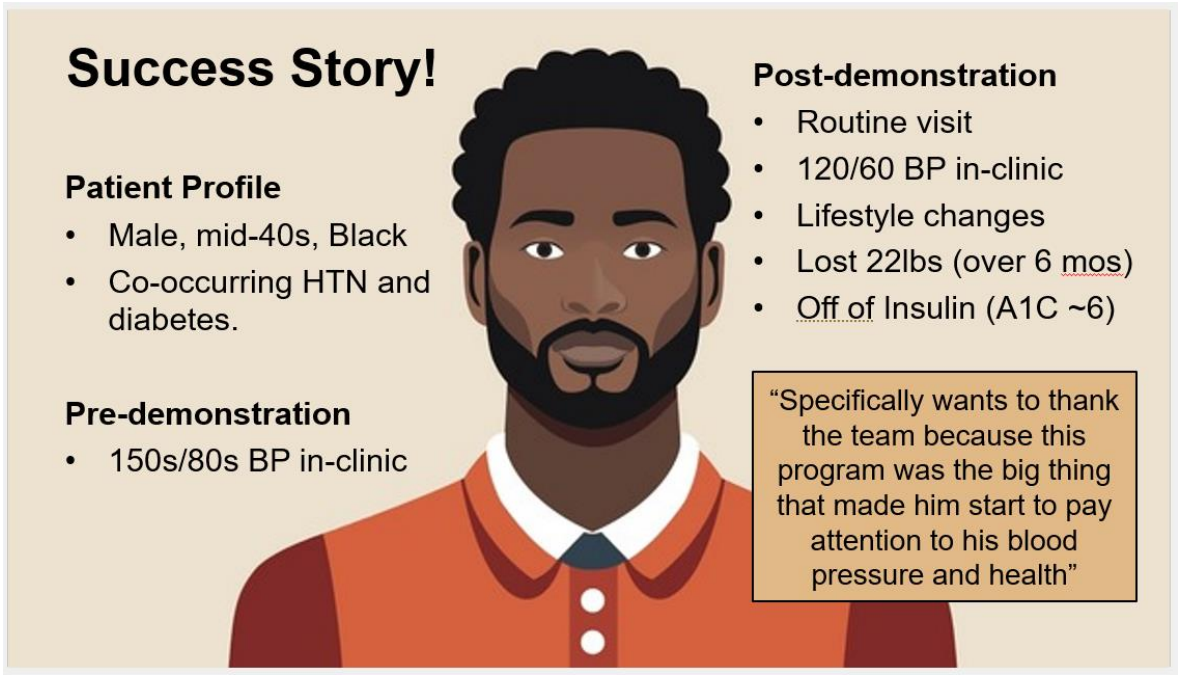
Key Findings

- Clinically significant results
- Improved patient experience
- Improved provider access to data (with context)



> It felt like it held me accountable, having to report my numbers daily. In order to get the numbers that I know you were looking for, it made me want to do the right thing and take my medicine daily.

> I would definitely recommend using it. It got patients to take their BPs and I got to see them. It got patients more invested in something that is of high clinical importance to me, but of probably medium importance to them.



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WASHINGTON D.C.

MedStar Health

EQUITY ENGINES

2024 Final Discovery Report

“You can’t manage what you cannot measure.”
-Peter Drucker

PATIENT AS CEO OF THEIR OWN HEALTH

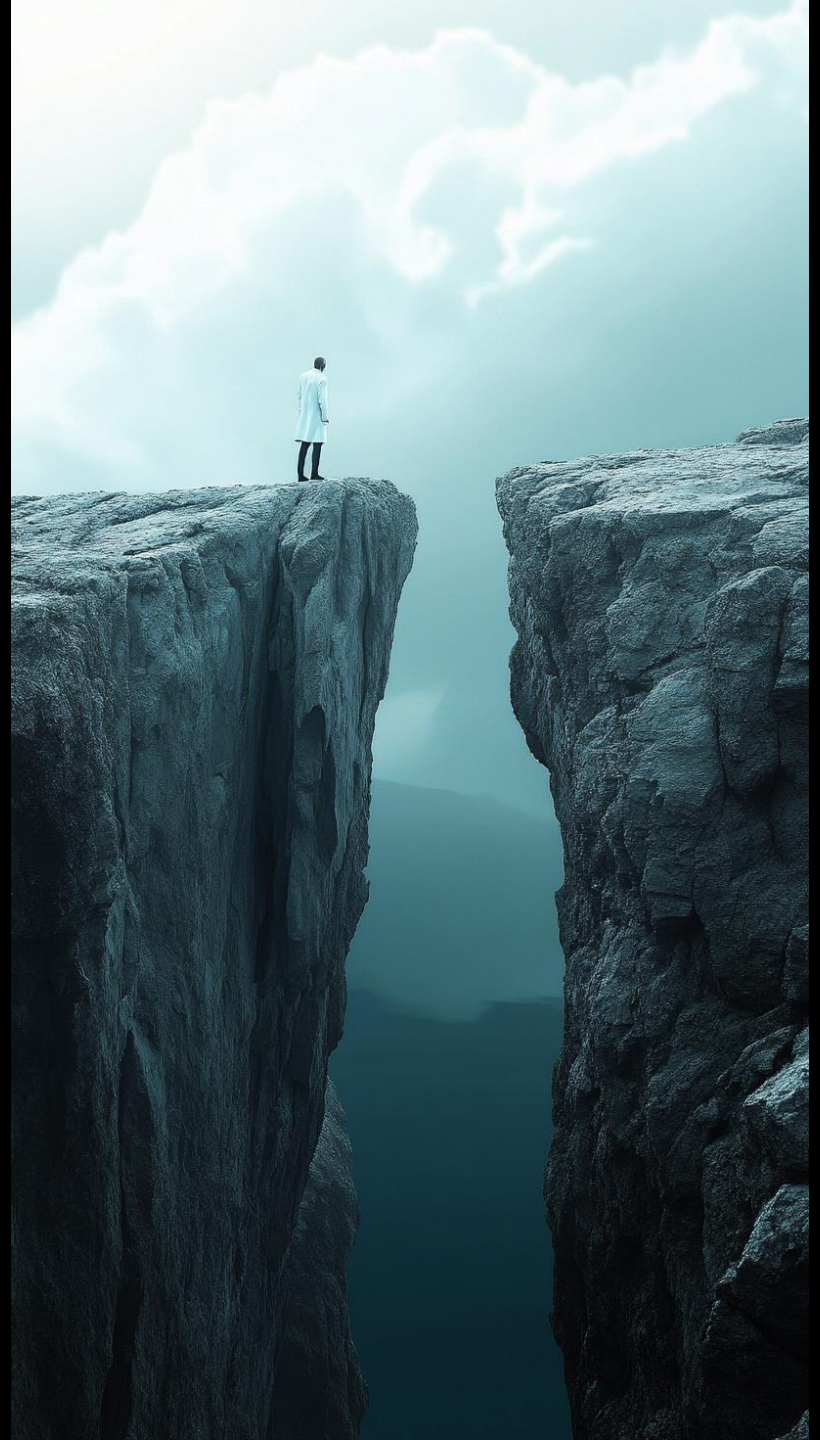
We want to empower our providers and patients with readily accessible data with which they can collaboratively make care decisions.

EMR

PATIENT PROVIDED DATA

WEARABLES

EMR



PATIENT PROVIDED DATA

WEARABLES

EMR

FHIR

DATA STRUCTURES

PATIENT PROVIDED DATA

WEARABLES

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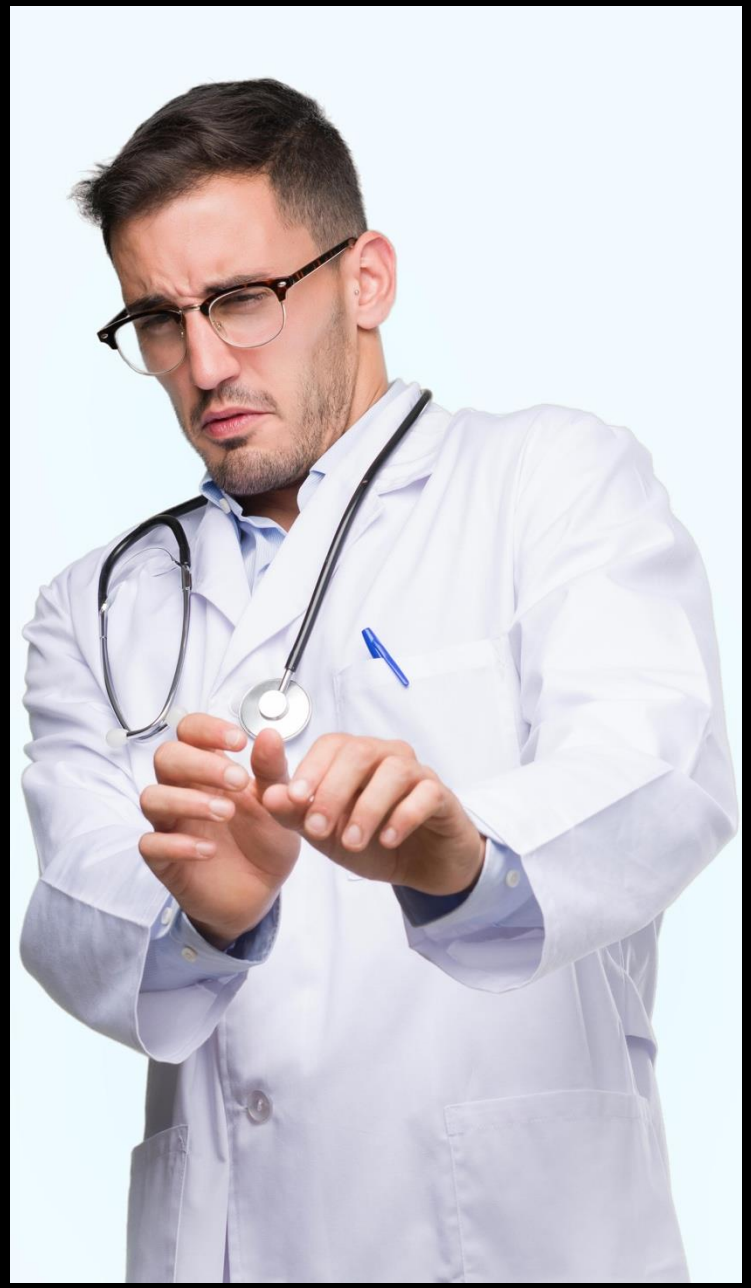
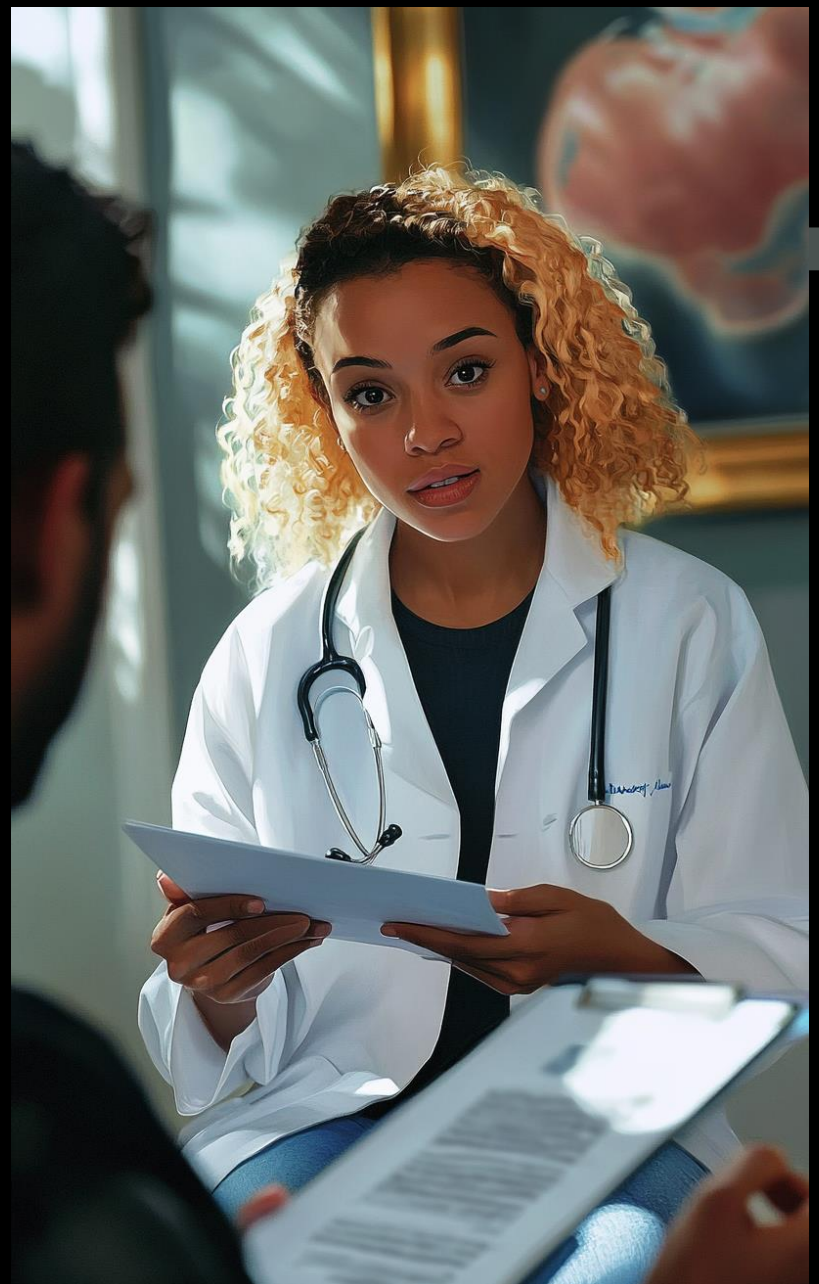


PATIENT PROVIDED DATA

WEARABLES

APPROACH

EMR

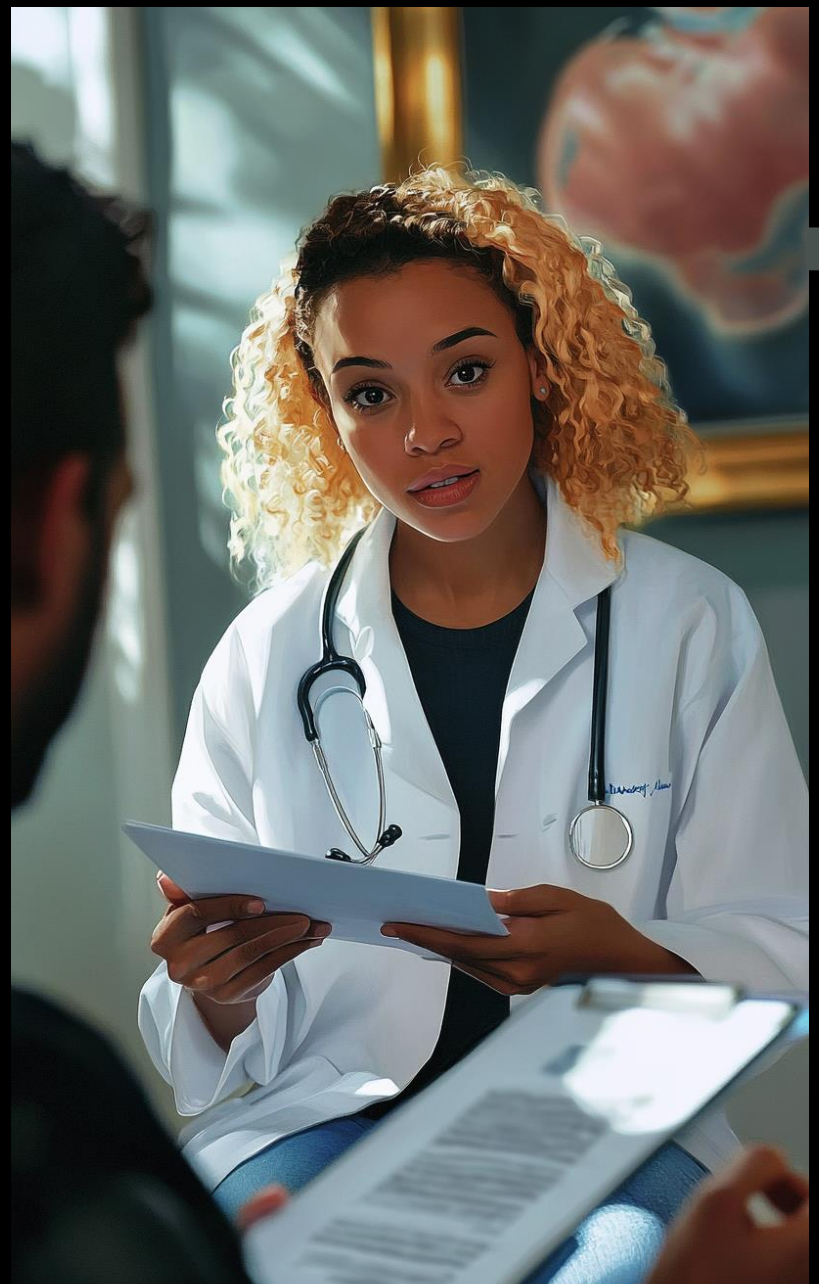


NEUTRAL GROUND

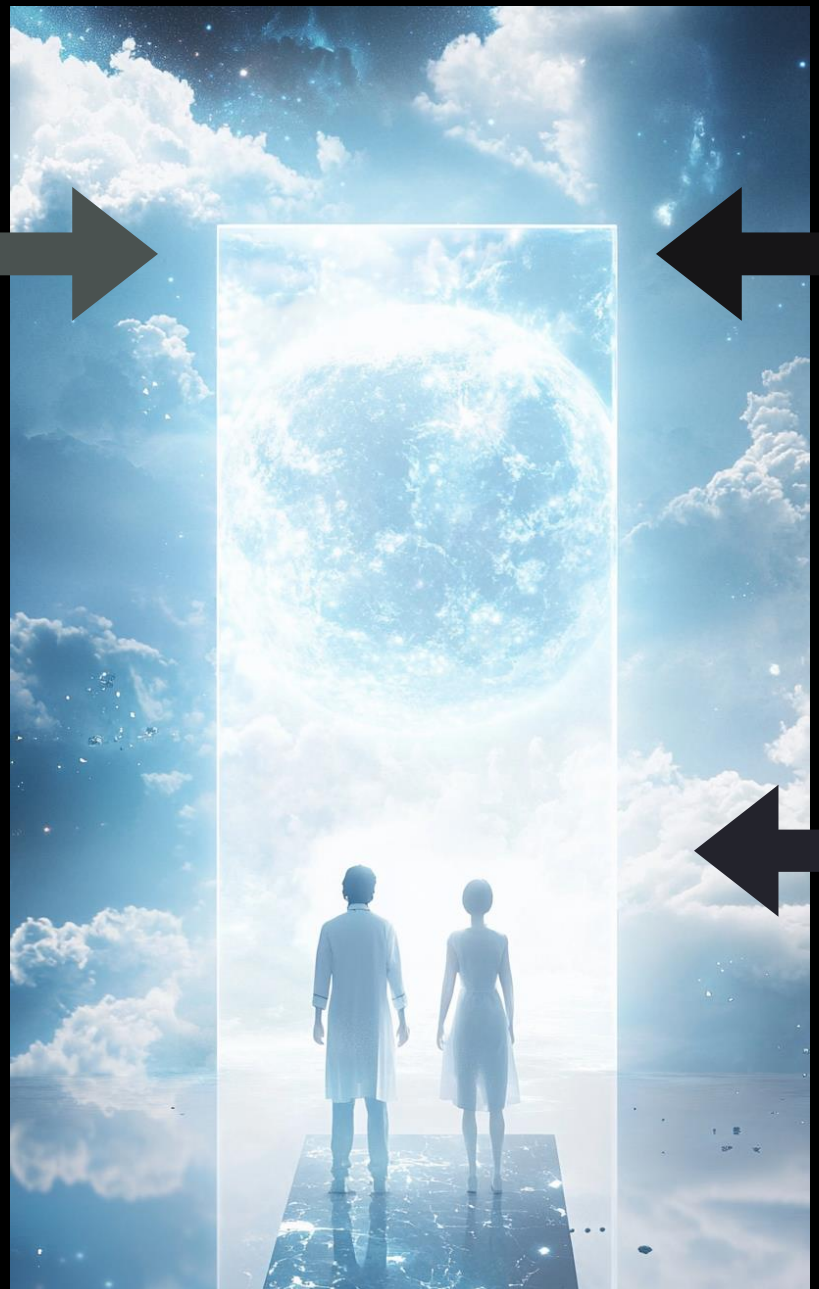
PATIENT PROVIDED DATA

WEARABLES

EMR



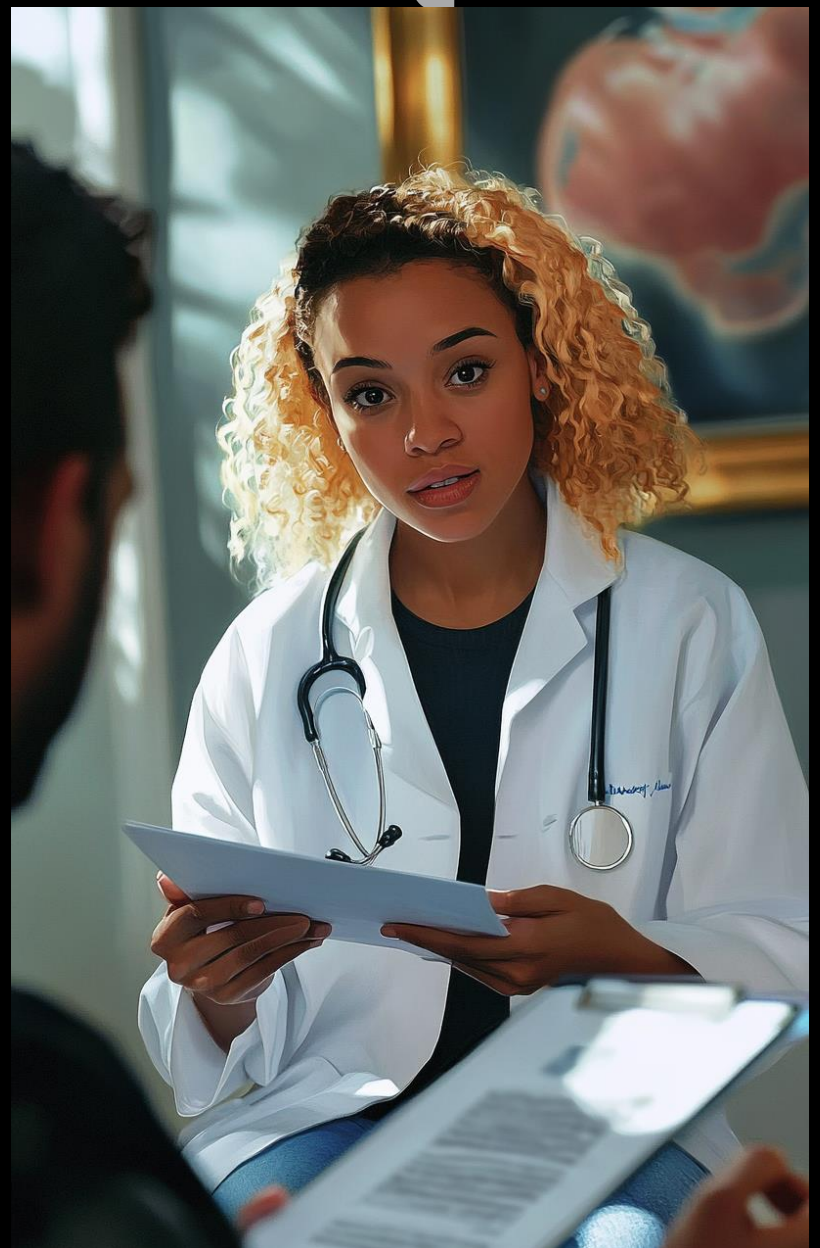
NEUTRAL GROUND



PATIENT PROVIDED DATA

WEARABLES

EQUITY ENGINE: CO-PORTAL



EQUITY ENGINE: CO-PORTAL

1. IMPORT
   - DOCUMENTS
   - LABS
   - WEARABLES
2. SEARCH
   - SEARCH SPEED
   - TRENDS
   - DATES
3. COLLABORATE
   - FAVORITES
   - SORTING
   - JUXTAPOSING

EQUITY ENGINE: CO-PORTAL

1 IMPORT

- DOCUMENTS
- LABS
- WEARABLES

SEARCH

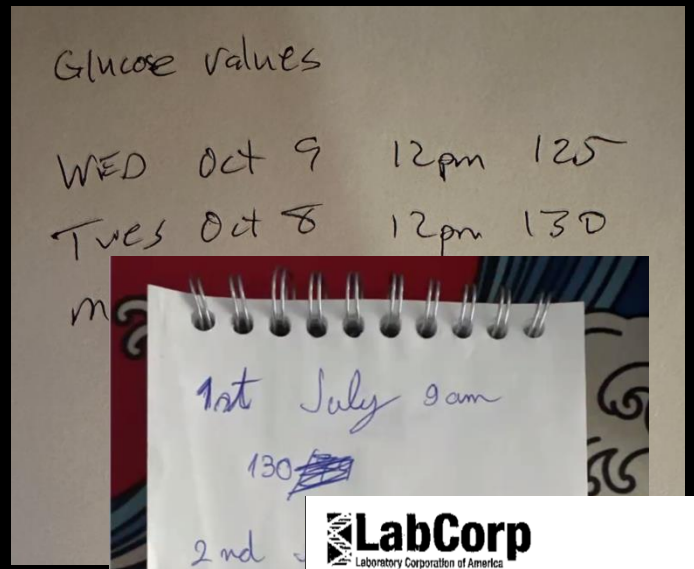
- SEARCH SPEED
- TRENDS
- DATES

COLLABORATE

- FAVORITES
- SORTING
- JUXTAPOSING

❶ CHALLENGE: IMPORT

BEFORE



LabCorp
Laboratory Corporation of America

Specimen Number	Patient ID	Control Number	Account Number	Account Phone Number
-		M223945682		

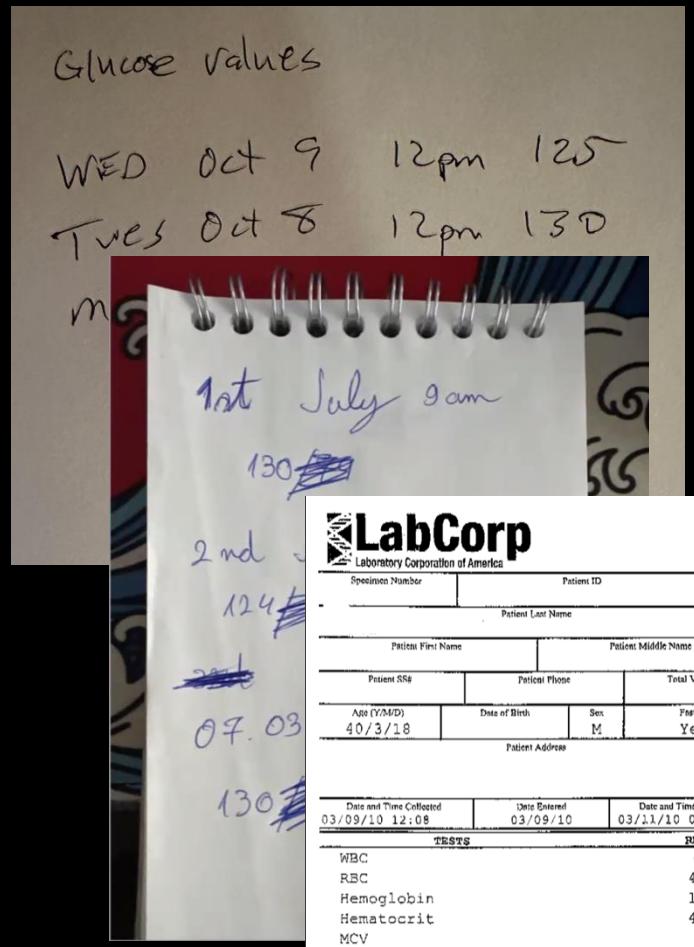
Patient Last Name	Account Address
Patient First Name / Patient Middle Name	
Patient SS# / Patient Phone / Total Volume	
Age (Y/M/D): 40/3/18 / Date of Birth / Sex: M / Fasting: Yes	
Patient Address	Additional Information

Date and Time Collected	Date Entered	Date and Time Reported	Physician Name	NPI	Physician
03/09/10 12:08	03/09/10	03/11/10 05:43ET			1669575

TESTS	RESULT	FLAG	UNITS	REFERENCE INTERVAL
WBC	4.7		x10E3/uL	4.0-10.5
RBC	4.59		x10E6/uL	4.10-5.60
Hemoglobin	14.6		g/dL	12.5-17.0
Hematocrit	42.7		%	36.0-50.0
MCV	93		fL	80-98
MCH	31.7		pg	27.0-34.0
MCHC	34.1		g/dL	32.0-36.0
RDW	13.4		%	11.7-15.0
Platelets	162		x10E3/uL	140-415

CHALLENGE: IMPORT

BEFORE



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Specimen Number	Patient ID	Control Number	Account Number	Account Phone Number
		M223945682		

Patient Last Name

Account Address

Patient First Name | Patient Middle Name

Patient SS# | Patient Phone | Total Volume

Age (Y/M/D)	Date of Birth	Sex	Fasting
40/3/18		M	Yes

Patient Address

Additional Information

Date and Time Collected	Date Entered	Date and Time Reported	Physician Name	NPI	Physician
03/09/10 12:08	03/09/10	03/11/10 05:43ET			1669575

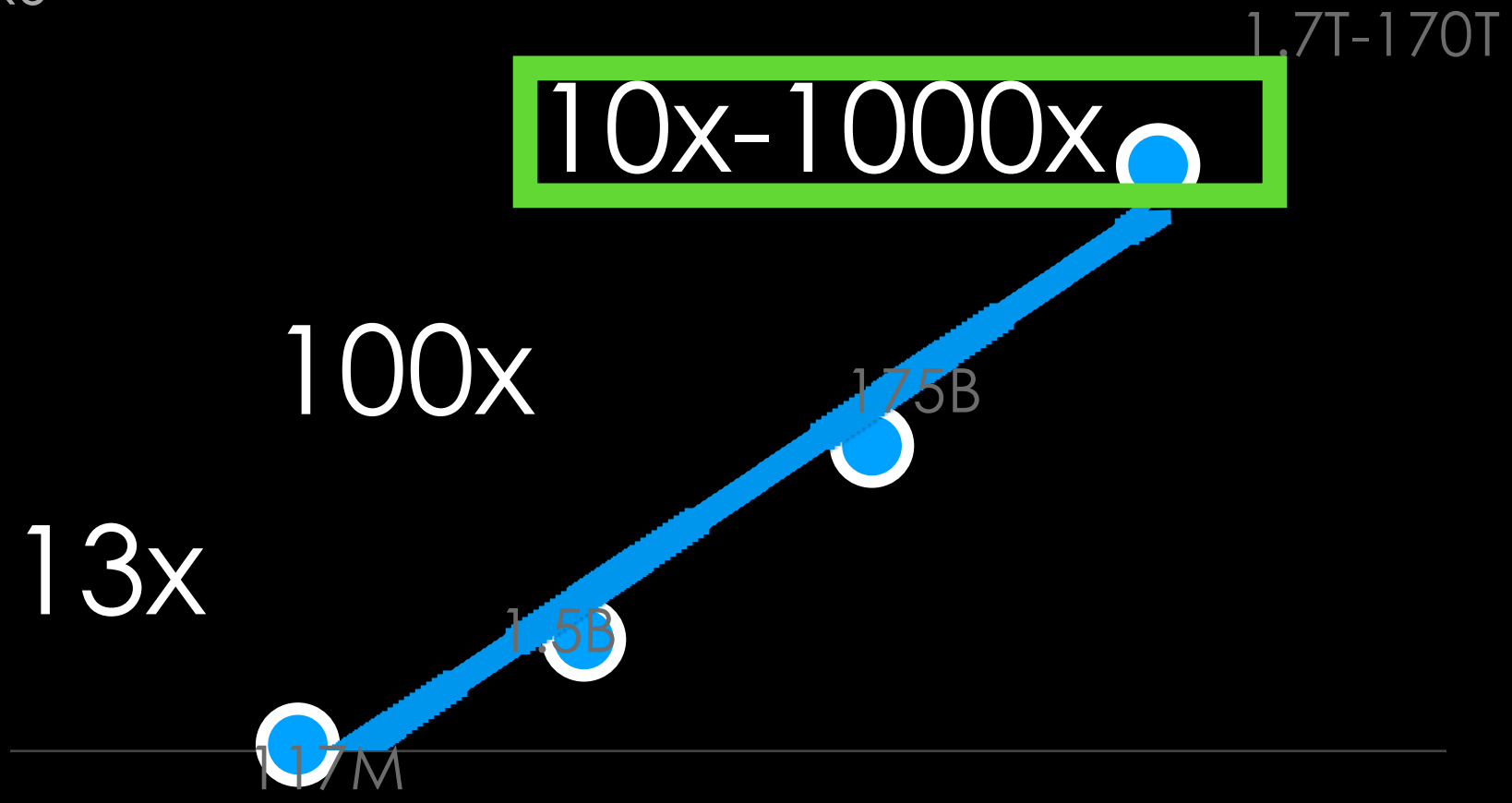
TESTS	RESULT	FLAG	UNITS	REFERENCE INTERVAL
WBC	4.7		x10E3/uL	4.0-10.5
RBC	4.59		x10E6/uL	4.10-5.60
Hemoglobin	14.6		g/dL	12.5-17.0
Hematocrit	42.7		%	36.0-50.0
MCV	93		fL	80-98
MCH	31.7		pg	27.0-34.0
MCHC	34.1		g/dL	32.0-36.0
RDW	13.4		%	11.7-15.0
Platelets	162		x10E3/uL	140-415

"How do we track these over time?"

OPPORTUNITY: IMPORT

LLM PROGRESS

TRAINABLE PARAMETERS



GPT1 GPT2 GPT3 GPT4

SYNAPTIC EQUIVALENTS

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GPT-4 Beats 90% Of Lawyers Trying To Pass The Bar

John Koetsier Senior Co

John Koetsier is a journa
speaker.

0

OpenAI announces GPT-4, claims it can beat 90% of humans on the SAT

PUBLISHED TUE, MAR 14 2023•1:42

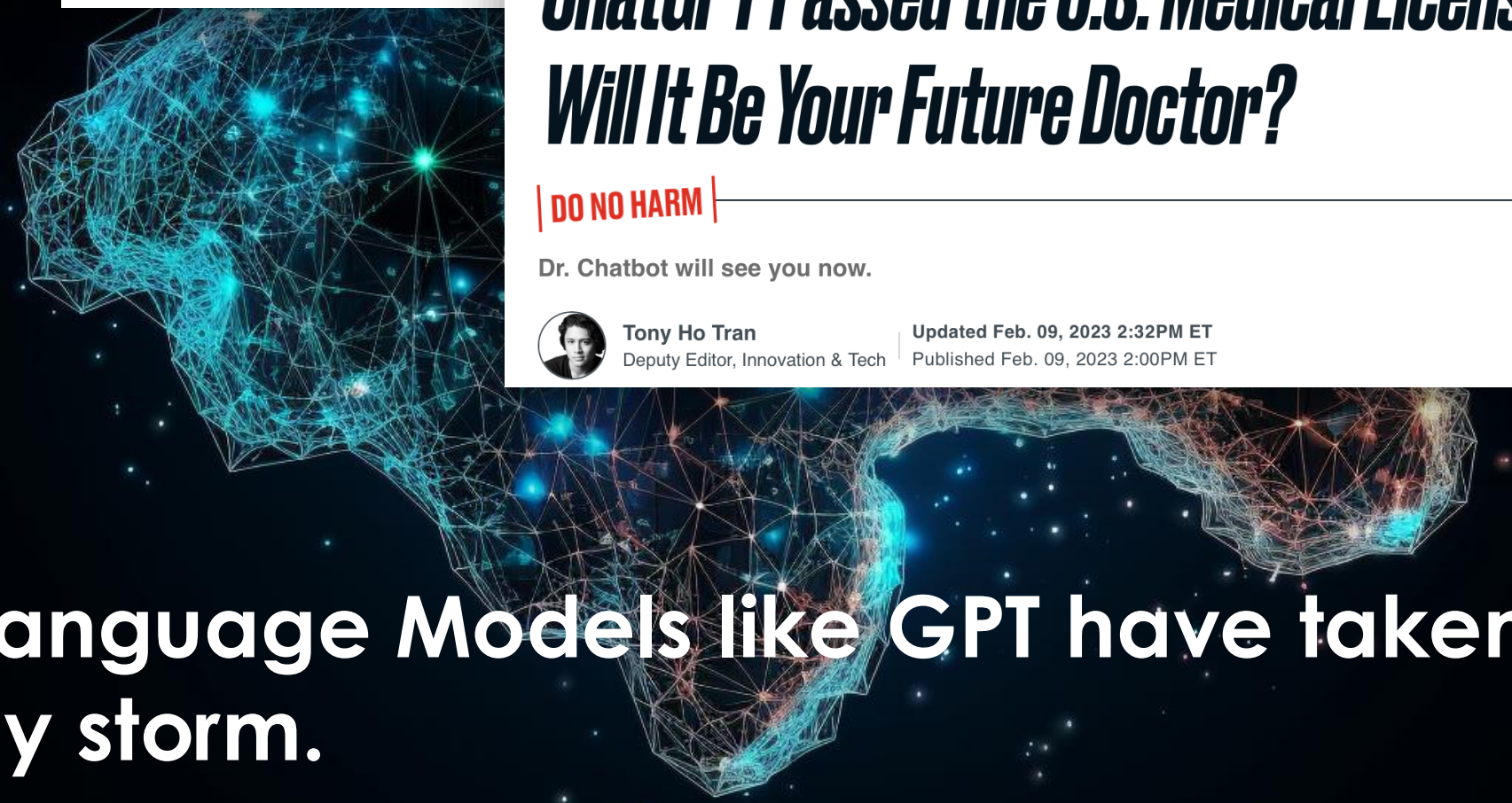
ChatGPT Passed the U.S. Medical Licensing Exam. Will It Be Your Future Doctor?

DO NO HARM

Dr. Chatbot will see you now.

Tony Ho Tran
Deputy Editor, Innovation & Tech

Updated Feb. 09, 2023 2:32PM ET
Published Feb. 09, 2023 2:00PM ET



Large Language Models like GPT have taken the world by storm.

OpenAI

2018

AI and Compute

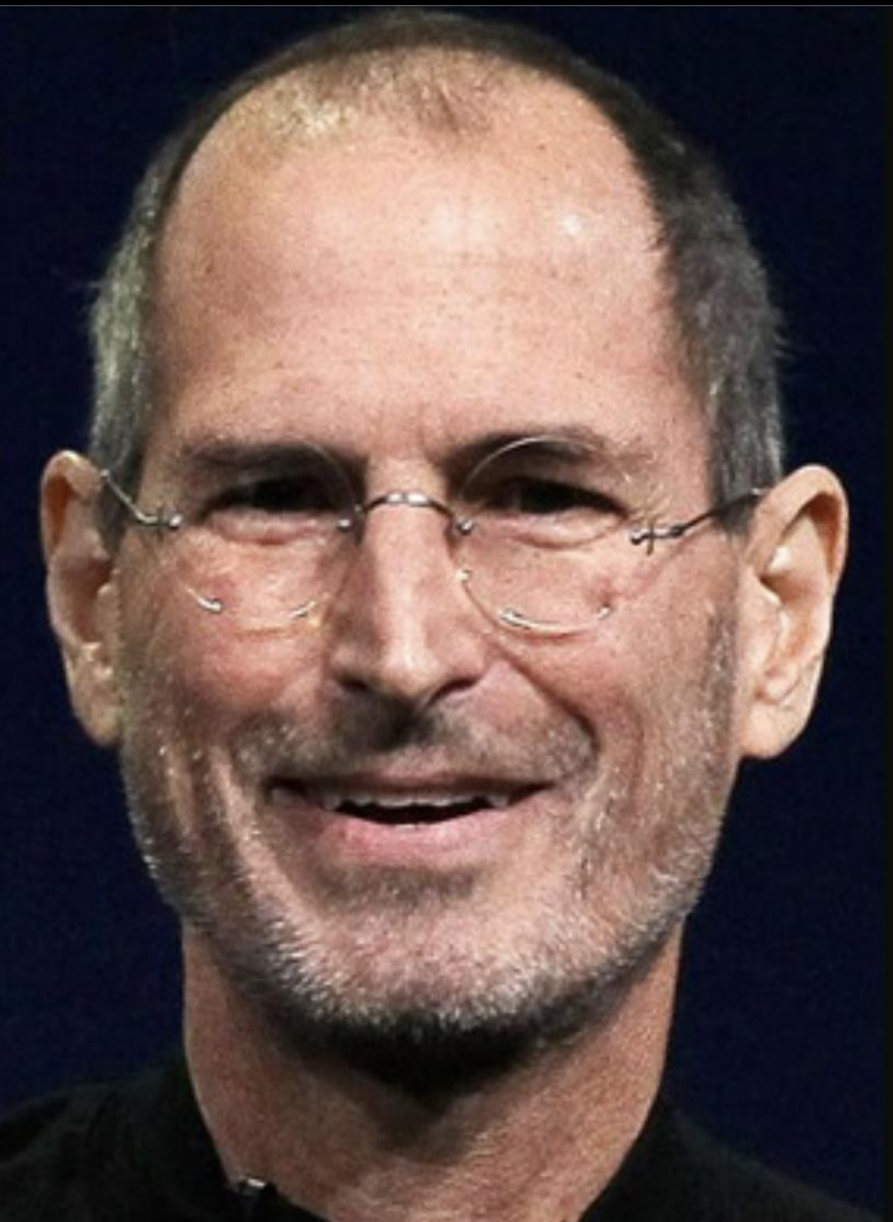
We're releasing an analysis showing that since 2012, the amount of compute used in the largest AI training runs has been increasing exponentially with a 3.4-month doubling time (by comparison, Moore's Law had a 2-year doubling period).[1] Since 2012, this metric has grown by more than 300,000x (a 2-year doubling period would yield only a 7x increase). Improvements in compute have been a key component of AI progress, so as long as this trend continues, it's worth preparing for the implications of systems far outside today's capabilities.

3.4 MOS

3y

GPT3	June 1, 2020	
	September 11, 2020	2
	December 22, 2020	4
	April 3, 2021	8
	July 14, 2021	16
	October 24, 2021	32
	February 3, 2022	64
	May 16, 2022	128
	August 26, 2022	256
	December 6, 2022	512
GPT4	March 18, 2023	**1024**

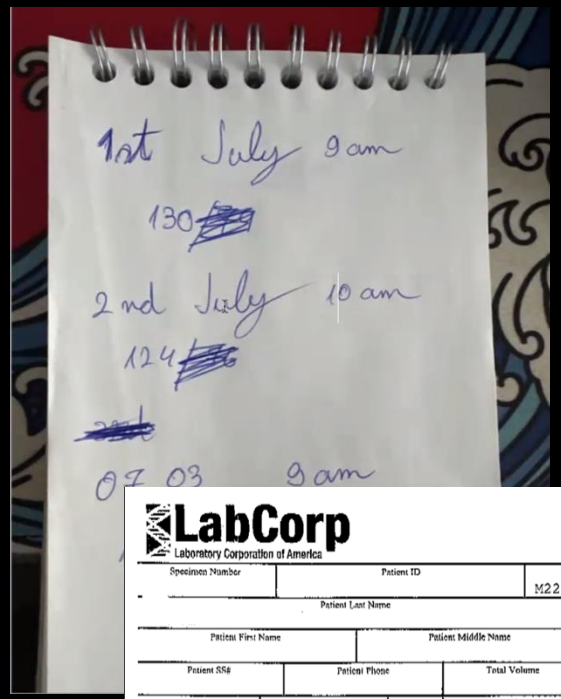
1024x



There's an old Wayne Gretzky quote that I love. 'I skate to where the puck is going to be, not where it has been.' And we've always tried to do that at Apple. Since the very, very beginning. And we always will.

— Steve Jobs —

IMPORT
BEFORE



LabCorp
Laboratory Corporation of America

Specimen Number	Patient ID	Control Number	Account Number	Account Phone Number
		M223945682		

Patient Last Name

Account Address

Patient First Name | Patient Middle Name

Patient SS# | Patient Phone | Total Volume

Age (Y/M/D)	Date of Birth	Sex	Fasting
40/3/18		M	Yes

Patient Address

Additional Information

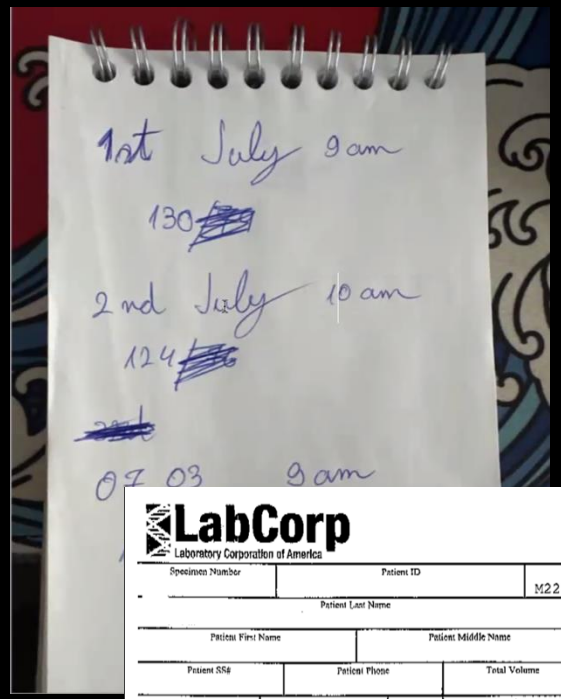
Date and Time Collected	Date Entered	Date and Time Reported	Physician Name	NPI	Physician
03/09/10 12:08	03/09/10	03/11/10 05:43ET			1669575

TESTS	RESULT	FLAG	UNITS	REFERENCE INTERVAL
WBC	4.7		x10E3/uL	4.0-10.5
RBC	4.59		x10E6/uL	4.10-5.60
Hemoglobin	14.6		g/dL	12.5-17.0
Hematocrit	42.7		%	36.0-50.0
MCV	93		fL	80-98
MCH	31.7		pg	27.0-34.0
MCHC	34.1		g/dL	32.0-36.0
RDW	13.4		%	11.7-15.0
Platelets	162		x10E3/uL	140-415

LABS

IMPORT

BEFORE



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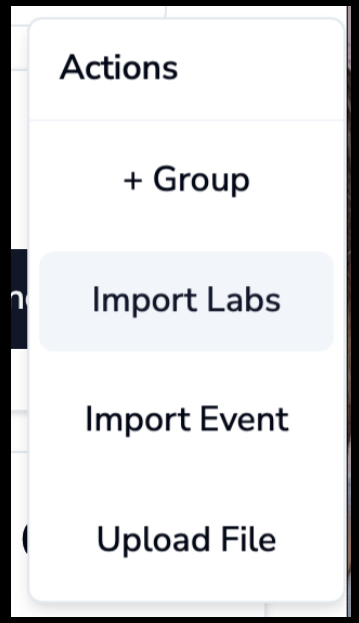
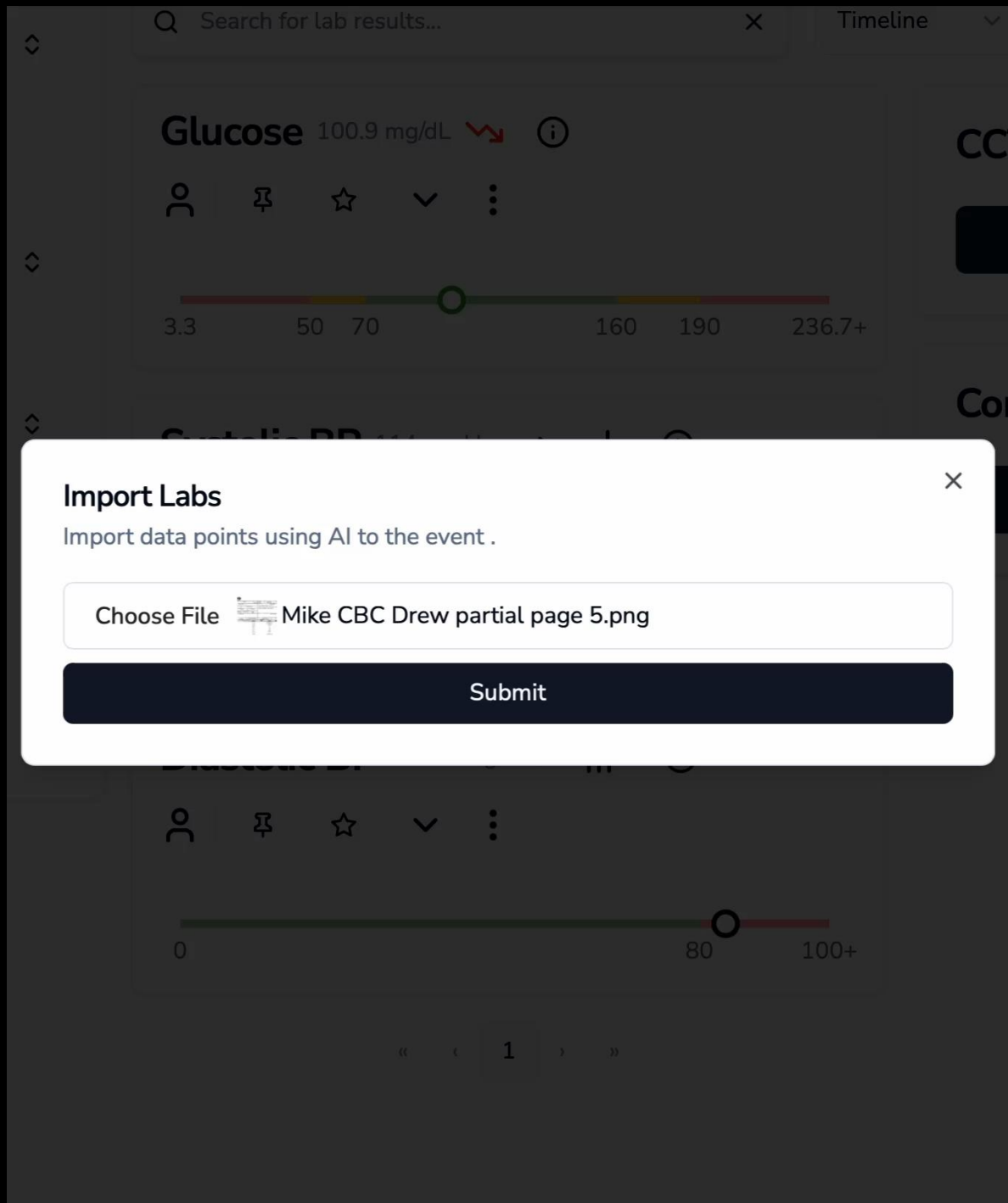
LABS

AFTER





“Where is your last EKG?”

IMPORT
BEFORE

DOCUMENTS

IMPORT

BEFORE

AFTER

document

Timeline

Date

Encounter Notes 1

1.3 months ago

Amoxicillin 2

..3 months ago

1.3 months ag

General Note 5

11.9 months ago

« ‹ 1 › »

DOCUMENT: DATES

IMPORT

BEFORE

AFTER

DOCUMENTS

observation

Timeline

Date

Creatinine 1 mg/dL ↘

0.5 0.7 1.3 1.5+

Mean Arterial Pressure 88 mm/Hg ↘

91 93 99 101+

Hemoglobin 13 g/dL ↘

12.7 13.8 17.2 18.3+

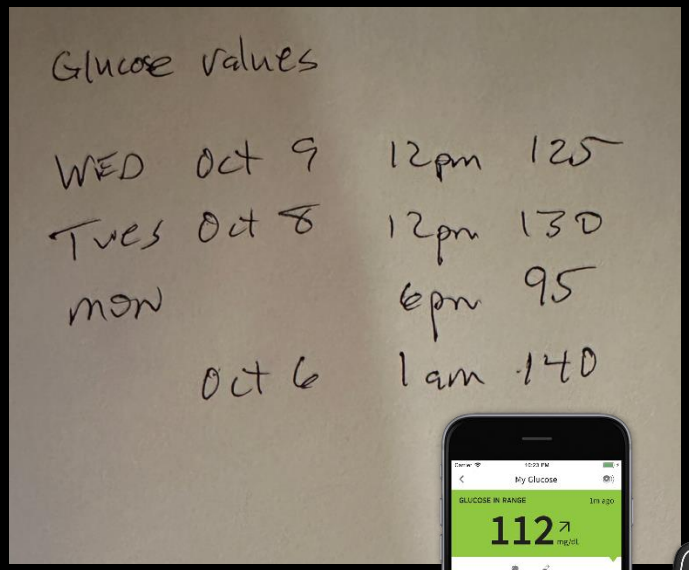
Total Cholesterol 240 mg/dL ↗

-66.7 0 200 266.7+

Hemoglobin A1C 6.5 mm/Hg →

3.5 4 5.6 6.1+

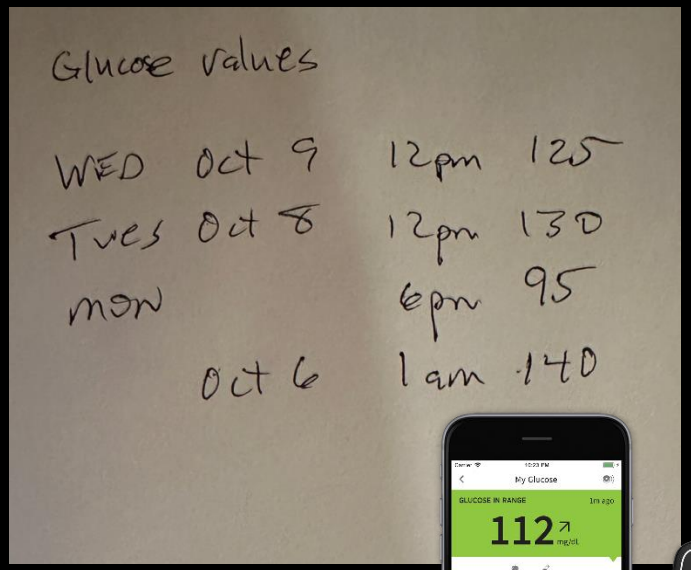
IMPORT
BEFORE



WEARABLES

IMPORT

BEFORE



WEARABLES

AFTER

EQUITY ENGINE: CO-PORTAL

IMPORT
- DOCUMENTS
- LABS
- WEARABLES

② SEARCH
- SEARCH SPEED
- TRENDS
- DATES

COLLABORATE
- FAVORITES
- SORTING
- JUXTAPOSING

“Let’s discuss your latest kidney function. What’s your latest creatinine?”

❷ SEARCH

BEFORE

All Results | Lab | Vital Signs | Radiology | HLA | Microbiology | Assessments | Pulmonology | Cardiology | Pharmacogenomics

Flowsheet: All Results Flowsheet ... Level: Table Group List

October 12, 2022 14:17 EDT - October 15, 2022 14:17 EDT (Clinical Range)

Navigator

Show more results

No Results Found

FIND TREND DATE

Google

Thursday, November 09, 2006

Marissa Mayer at Web 2.0

Google VP Marissa Mayer just spoke at the Web 2.0 Conference and offered tidbits on what Google has learned about speed, the user experience, and user satisfaction.

Marissa started with a story about a user test they did. They asked a group of Google searchers how many search results they wanted to see. Users asked for more, more than the ten results Google normally shows. More is more, they said.

So, Marissa ran an experiment where Google increased the number of search results to thirty. Traffic and revenue from Google searchers in the experimental group dropped by 20%.

Ouch. Why? Why, when users had asked for this, did they seem to hate it?

After a bit of looking, Marissa explained that they found an uncontrolled variable. The page with 10 results took .4 seconds to generate. The page with 30 results took .9 seconds.

Half a second delay caused a 20% drop in traffic. Half a second delay killed user satisfaction.

Marissa Mayer:

0.5 second of delay caused 20% traffic drop-off that never recovered.

What sort of drop-off for conversation & collaboration are we getting in healthcare?

THE CLASSIC ELK STACK*

ELASTIC SEARCH

LOGSTASH

KIBANA

ELK STACK

OPPORTUNITY

* OPEN SOURCE

THE CLASSIC ELK STACK

ELASTIC SEARCH

LOGSTASH

KIBANA

ELK STACK

SERVER FARMS

OPPORTUNITY

THE CLASSIC ELK STACK

ELASTIC SEARCH

LOGSTASH

KIBANA

ELK STACK

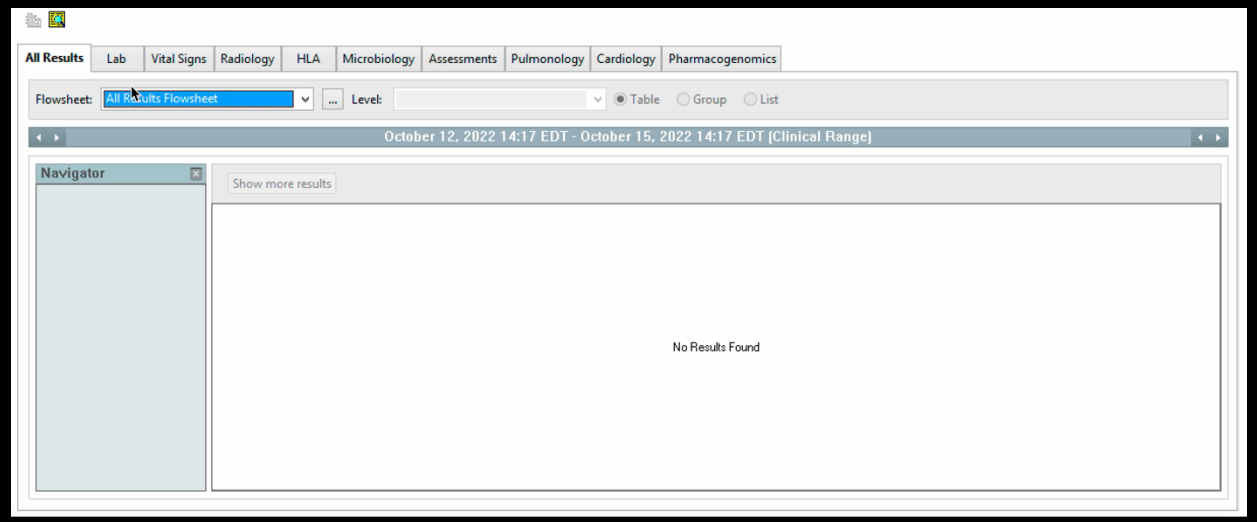
SERVER FARMS

OPPORTUNITY

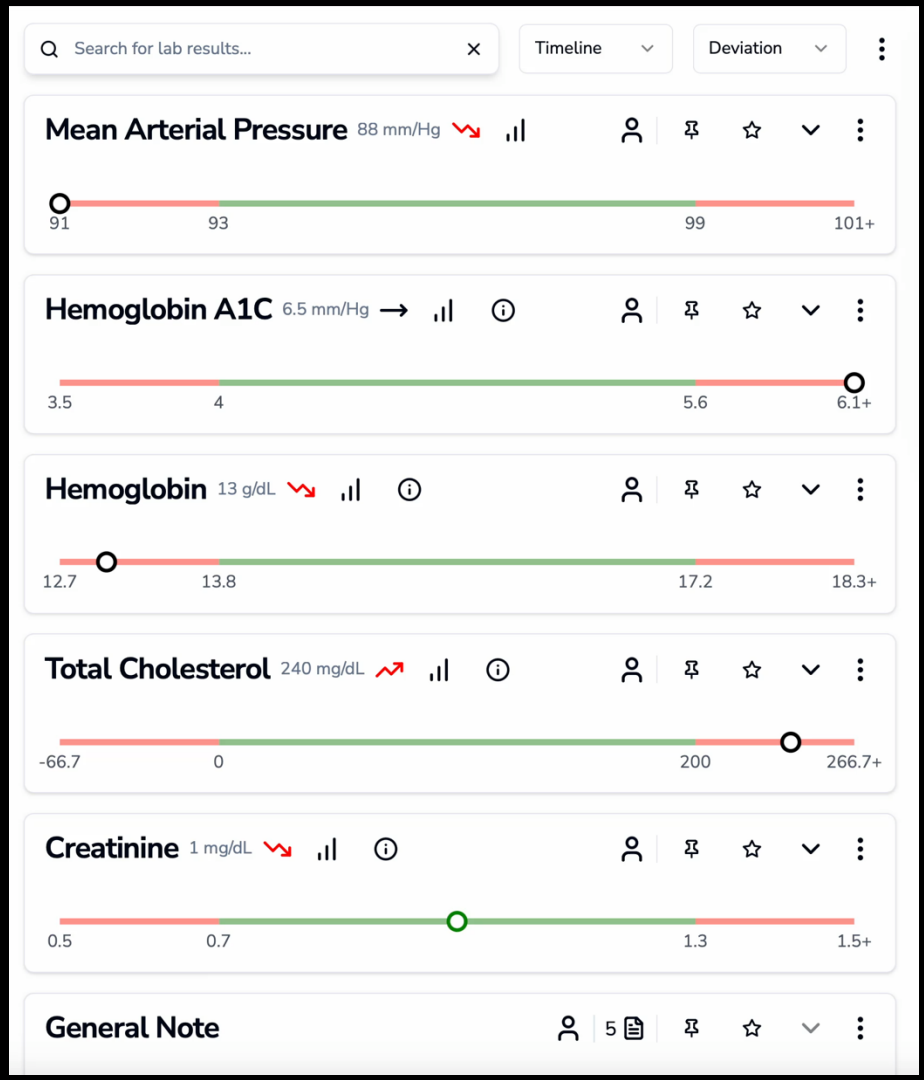
TIME SERIES

SEARCH

BEFORE



AFTER



FIND

TREND

DATE

EQUITY ENGINE: CO-PORTAL

IMPORT
- DOCUMENTS
- LABS
- WEARABLES

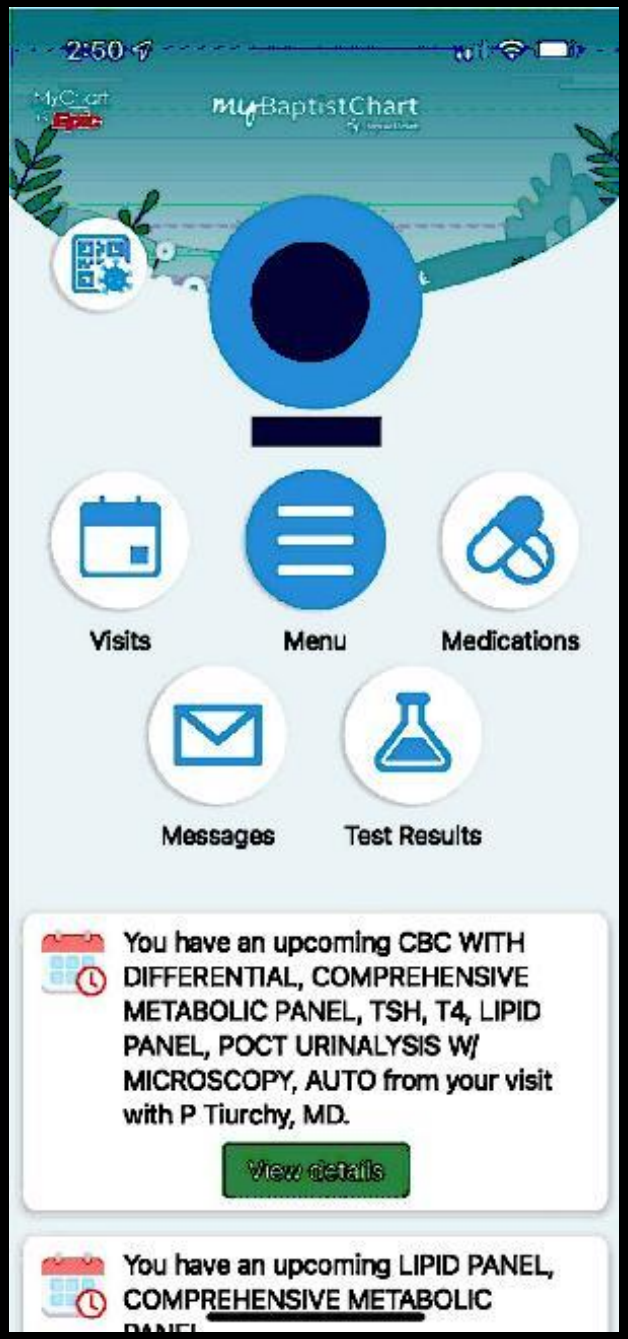
SEARCH
- SEARCH SPEED
- TRENDS
- DATES

❸ COLLABORATE
- FAVORITES
- SORTING
- JUXTAPOSING

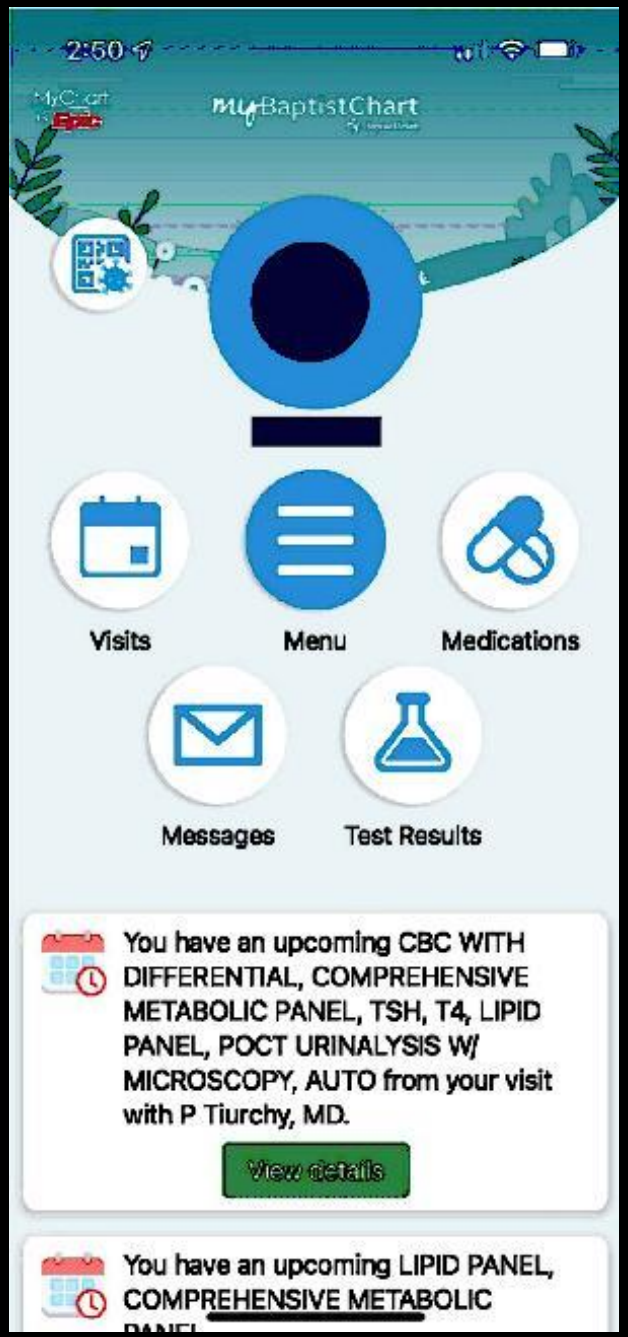
❸ COLLABORATE

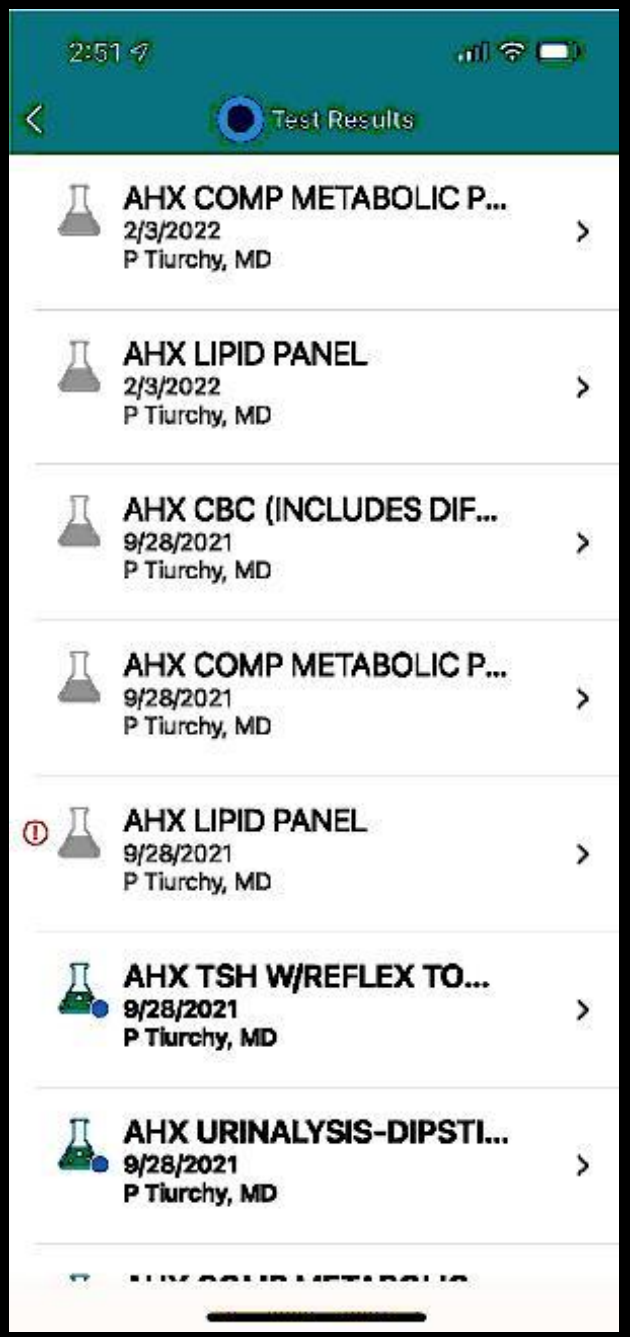
BEFORE

EPIC MOBILE



"What labs do I have that are abnormal?"


2:50
MyBaptistChart
Visits
Menu
Medications
Messages
Test Results
You have an upcoming CBC WITH DIFFERENTIAL, COMPREHENSIVE METABOLIC PANEL, TSH, T4, LIPID PANEL, POCT URINALYSIS W/ MICROSCOPY, AUTO from your visit with P Tiurchy, MD.
View details
You have an upcoming LIPID PANEL, COMPREHENSIVE METABOLIC


2:51
Test Results
AHX COMP METABOLIC P...
2/3/2022
P Tiurchy, MD
AHX LIPID PANEL
2/3/2022
P Tiurchy, MD
AHX CBC (INCLUDES DIF...
9/28/2021
P Tiurchy, MD
AHX COMP METABOLIC P...
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AHX LIPID PANEL
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P Tiurchy, MD
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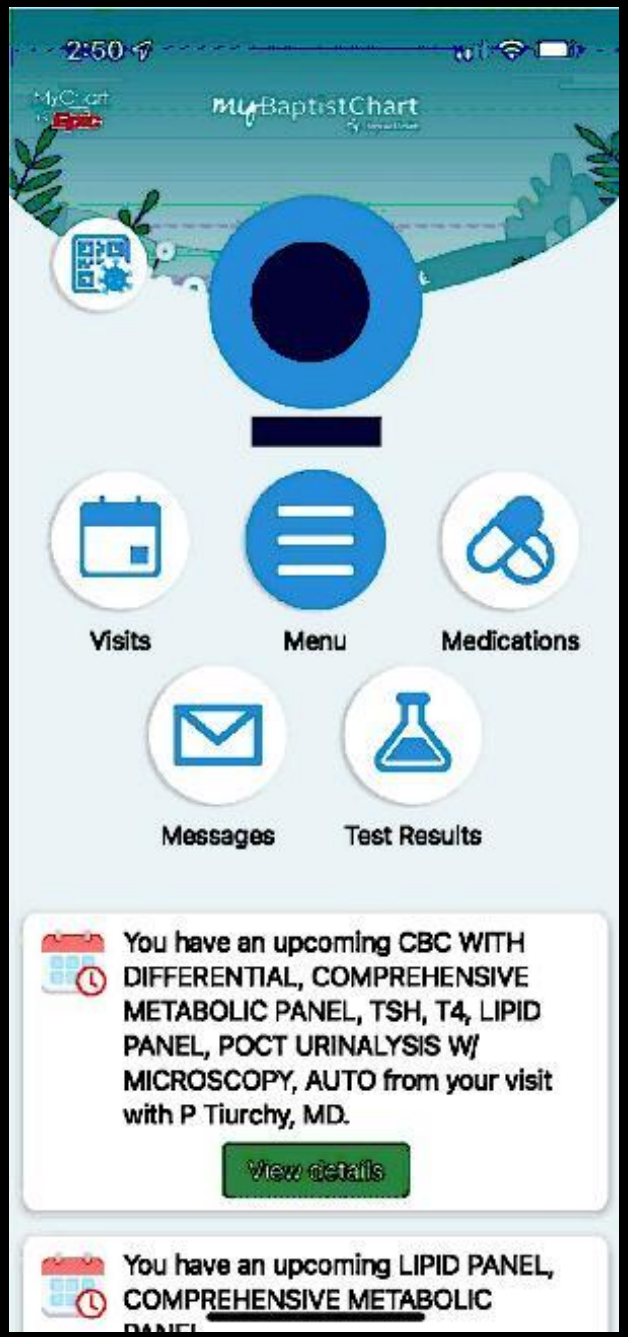
AHX URINALYSIS-DIPSTI...
9/28/2021
P Tiurchy, MD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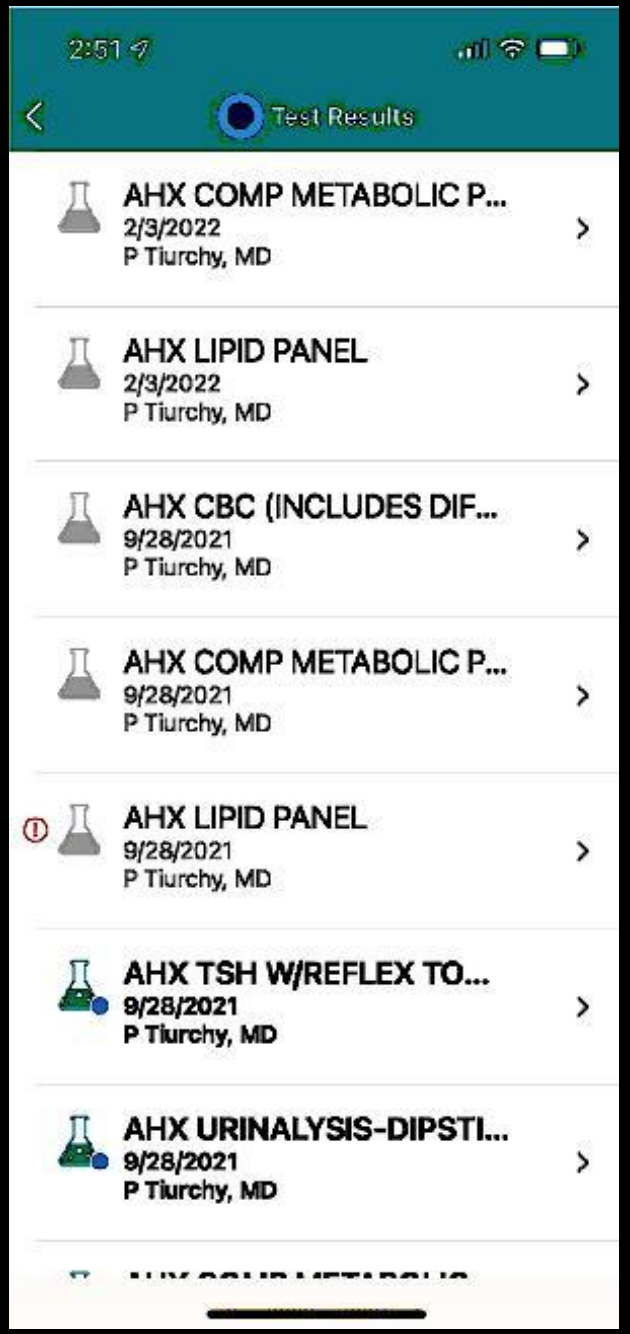
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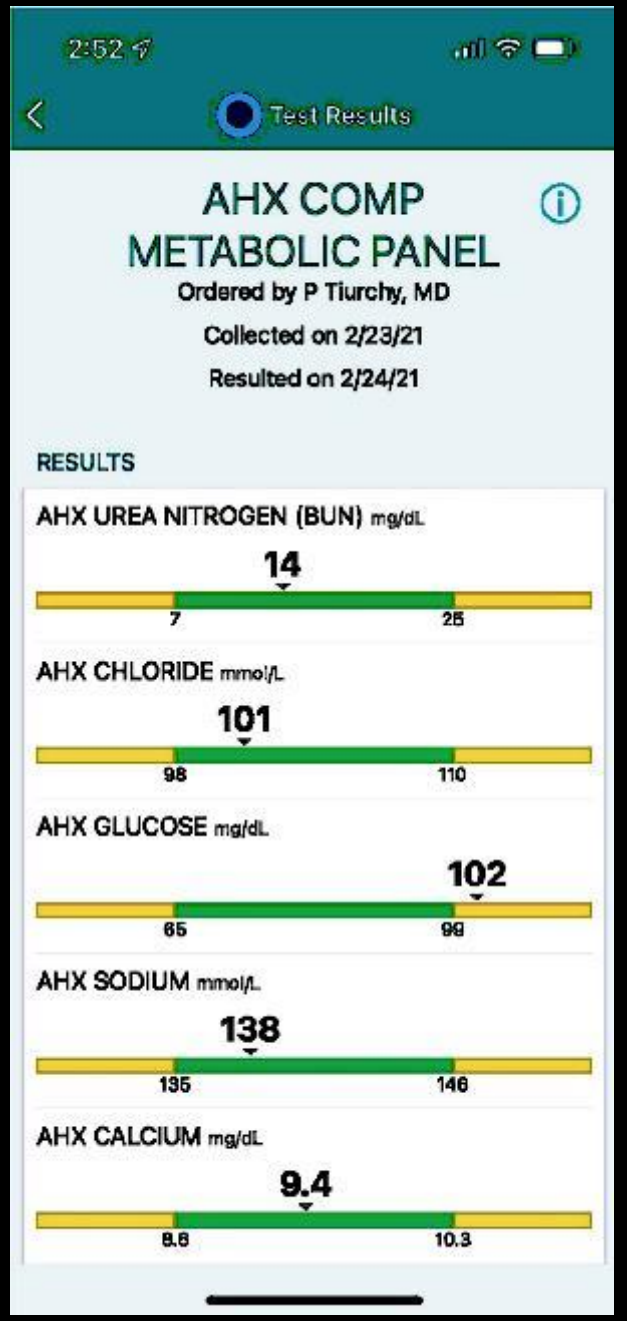
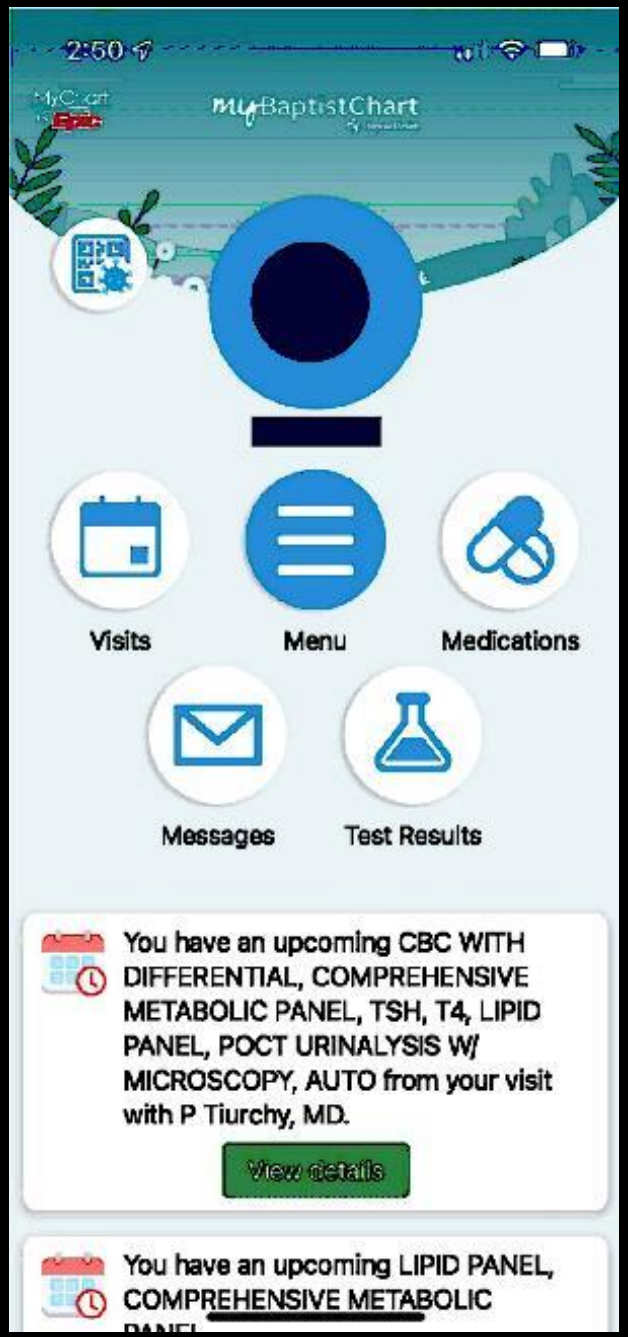

2:52
Test Results
AHX COMP METABOLIC PANEL
Ordered by P Tiurchy, MD
Collected on 2/23/21
Resulted on 2/24/21
RESULTS
AHX UREA NITROGEN (BUN) mg/dL
14
7
25
AHX CHLORIDE mmol/L
101
98
110
AHX GLUCOSE mg/dL
102
65
99
AHX SODIUM mmol/L
138
135
146
AHX CALCIUM mg/dL
9.4
8.6
10.3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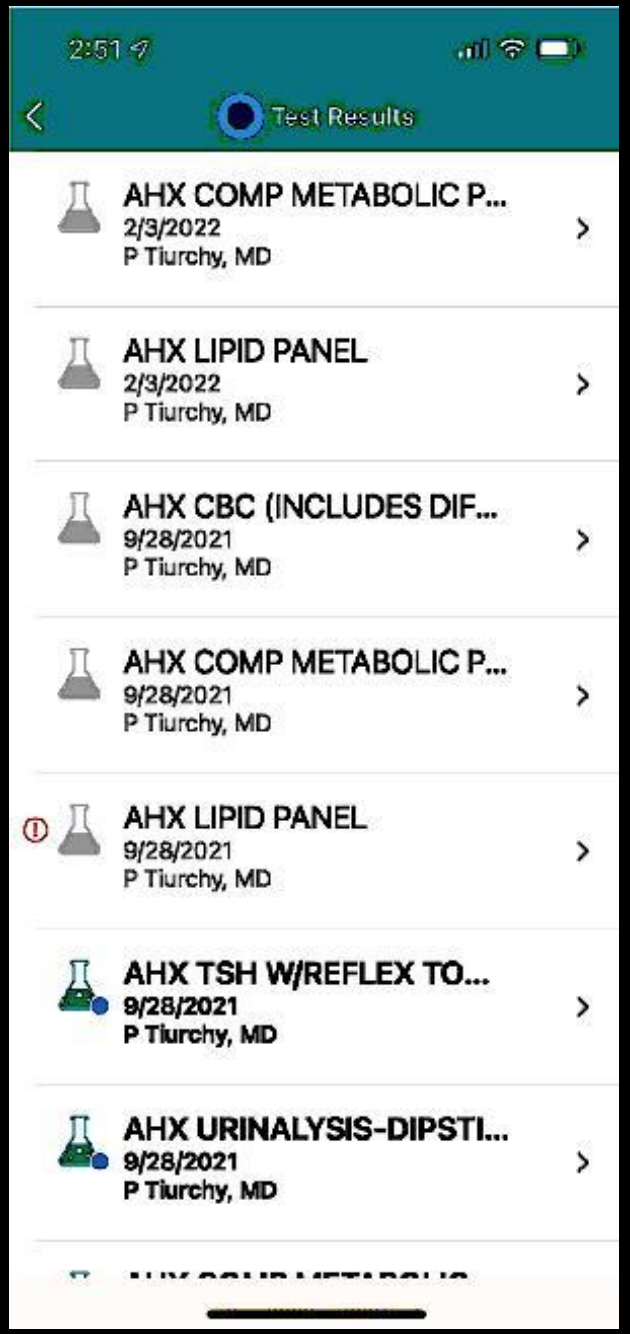
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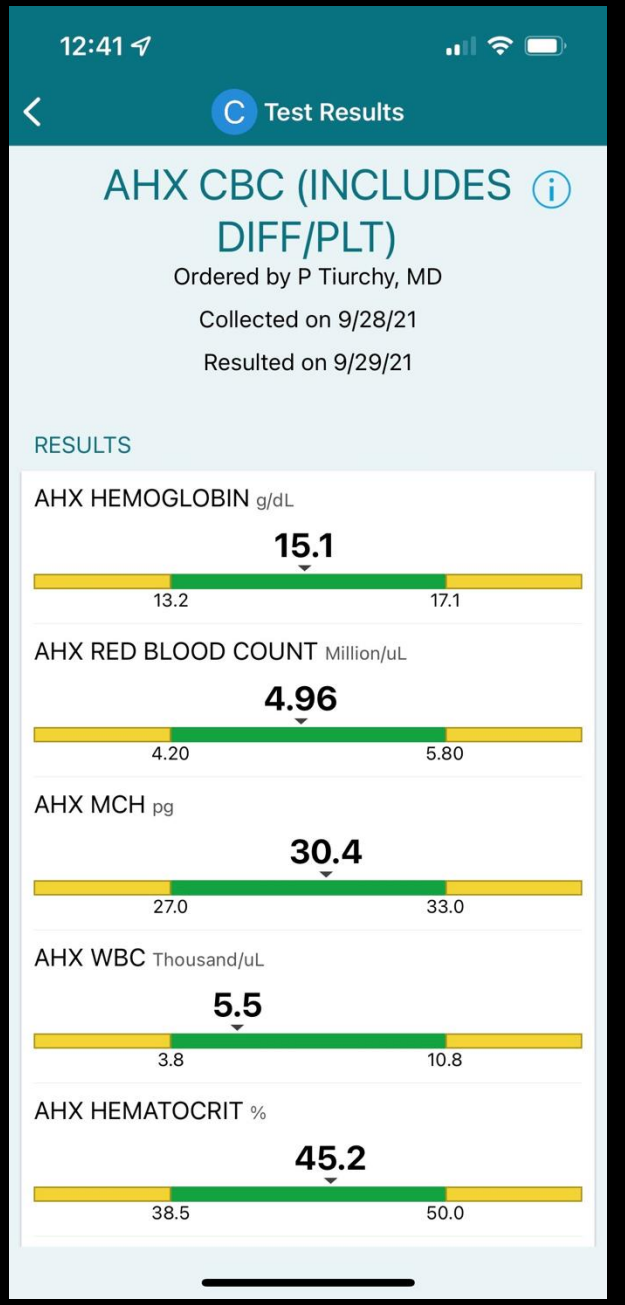
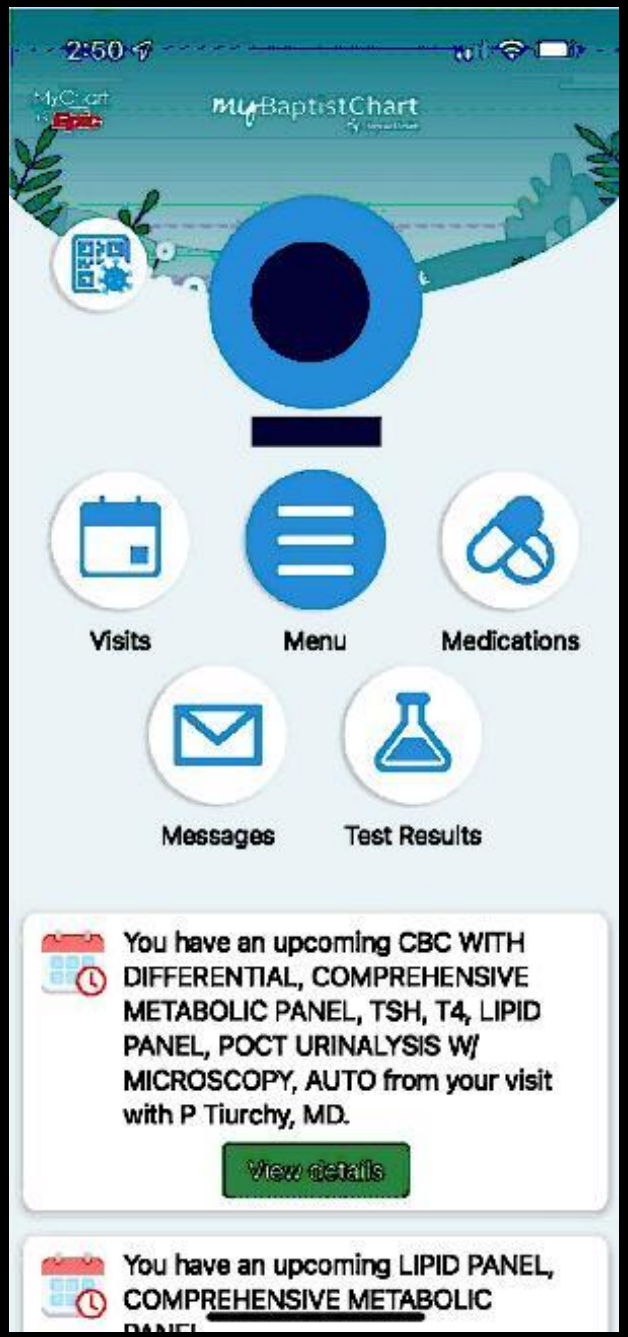

12:41
Test Results
AHX CBC (INCLUDES DIFF/PLT)
Ordered by P Tiurchy, MD
Collected on 9/28/21
Resulted on 9/29/21
RESULTS
AHX HEMOGLOBIN g/dL
15.1
13.2
17.1
AHX RED BLOOD COUNT Million/uL
4.96
4.20
5.80
AHX MCH pg
30.4
27.0
33.0
AHX WBC Thousand/uL
5.5
3.8
10.8
AHX HEMATOCRIT %
45.2
38.5
50.0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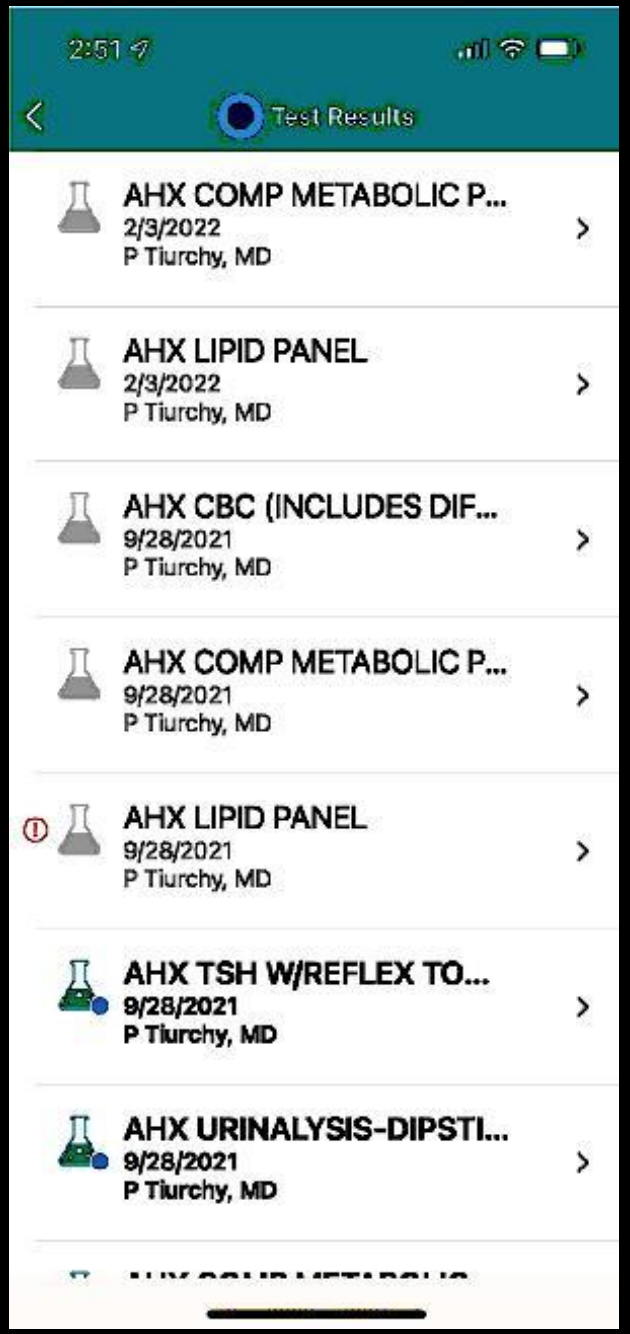
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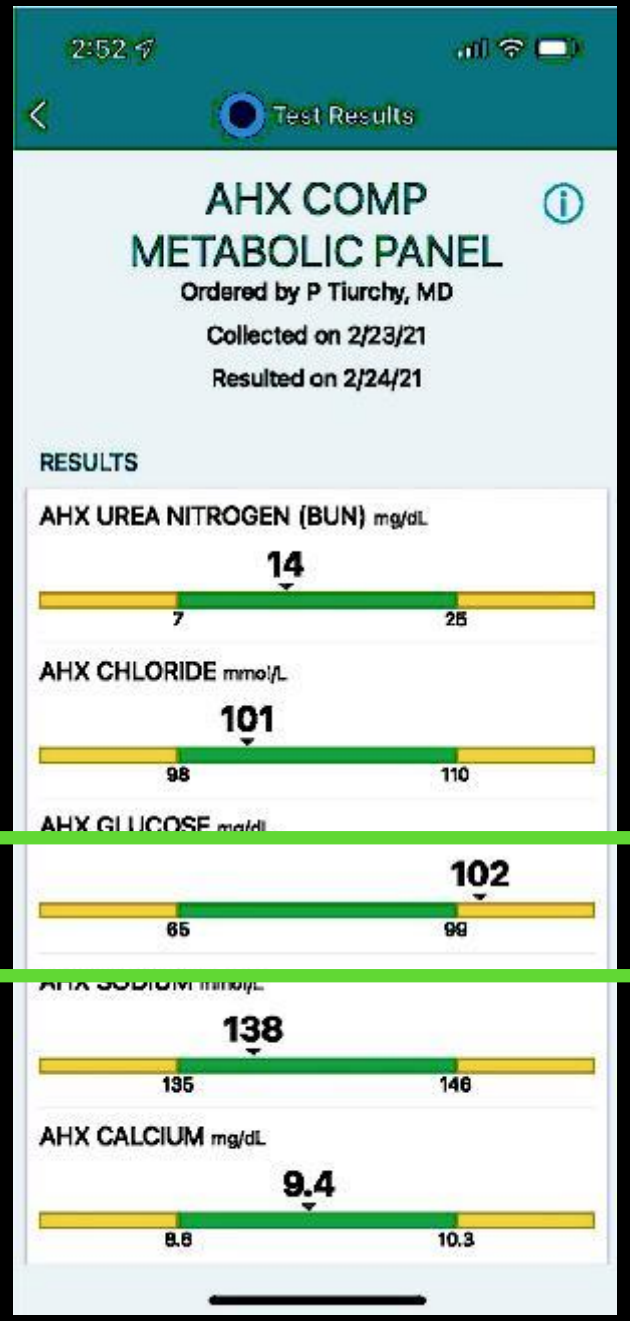
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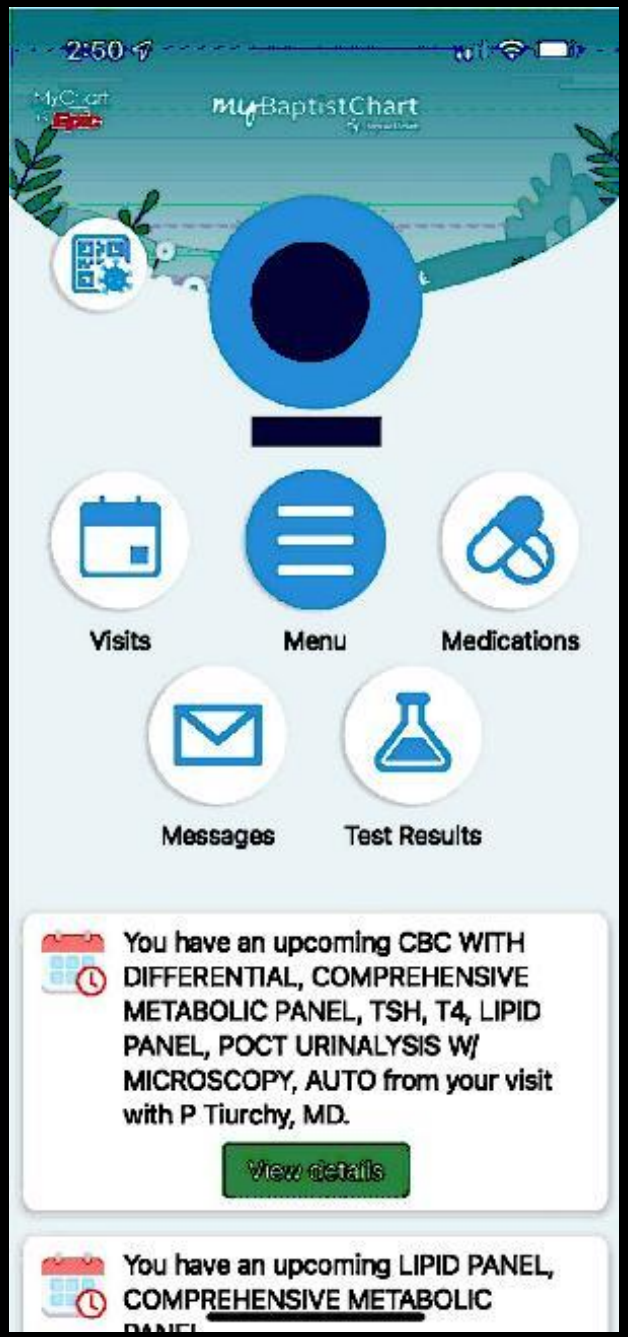
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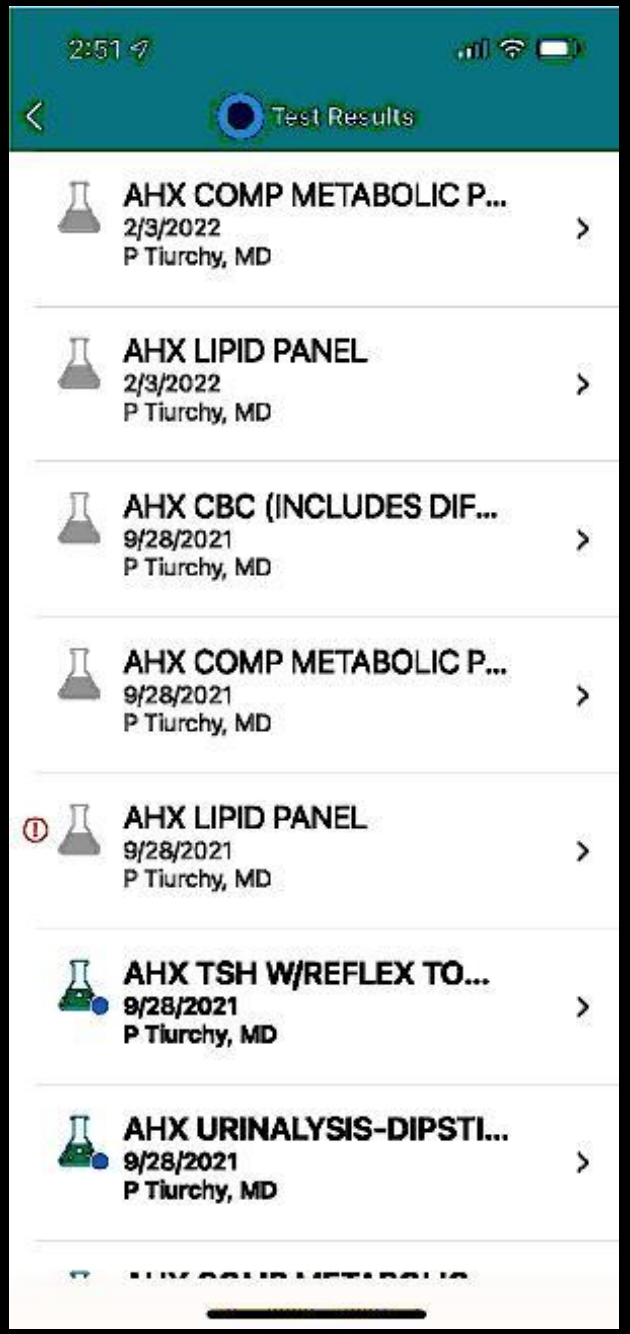
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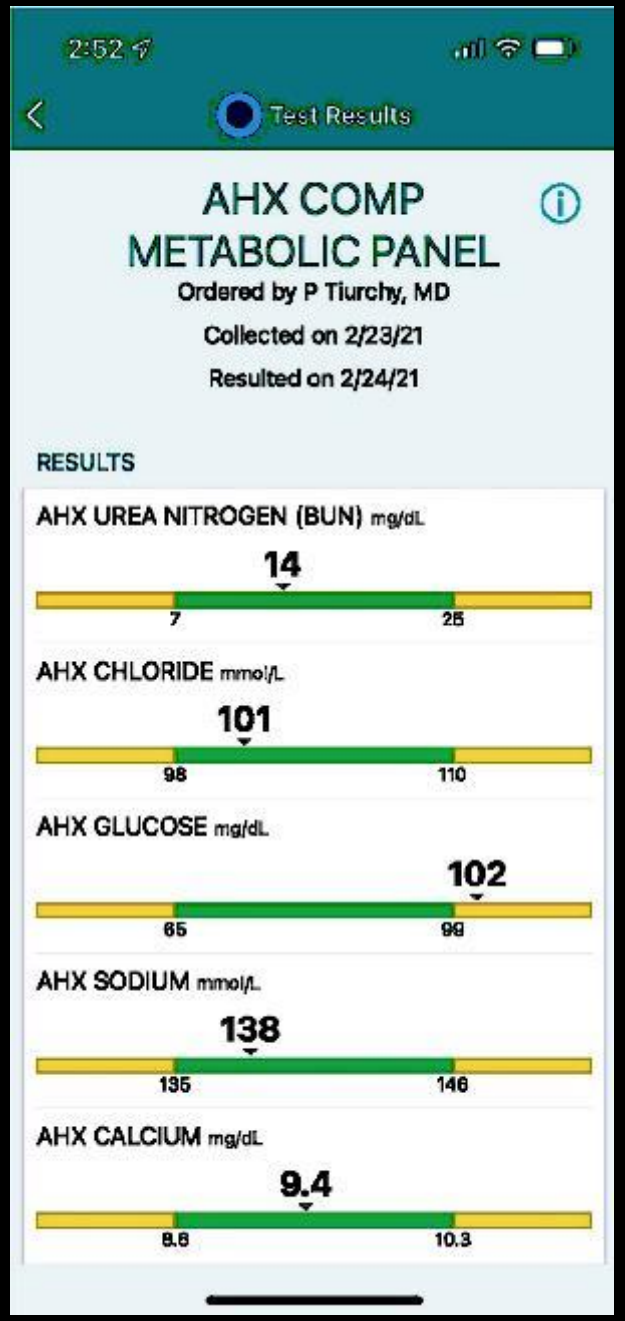
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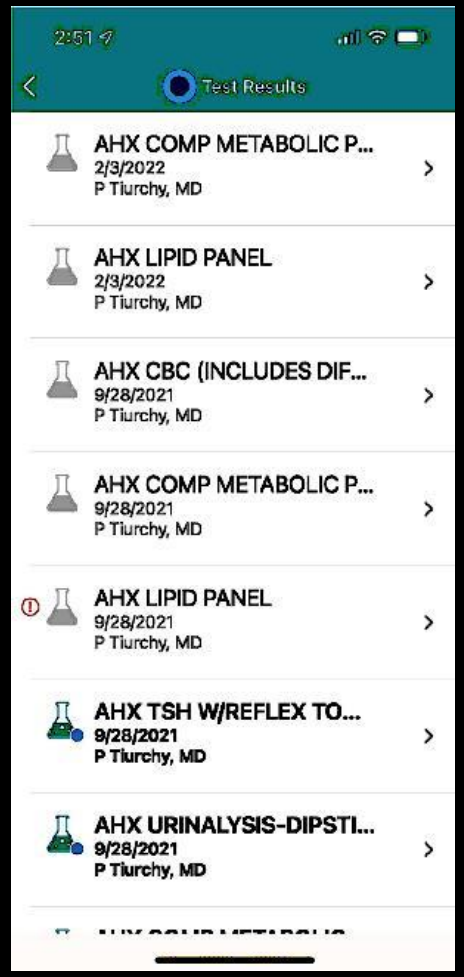
138
135
146
AHX CALCIUM mg/dL
9.4
8.6
10.3

❸ COLLABORATE

BEFORE



"What labs should we talk about first?"

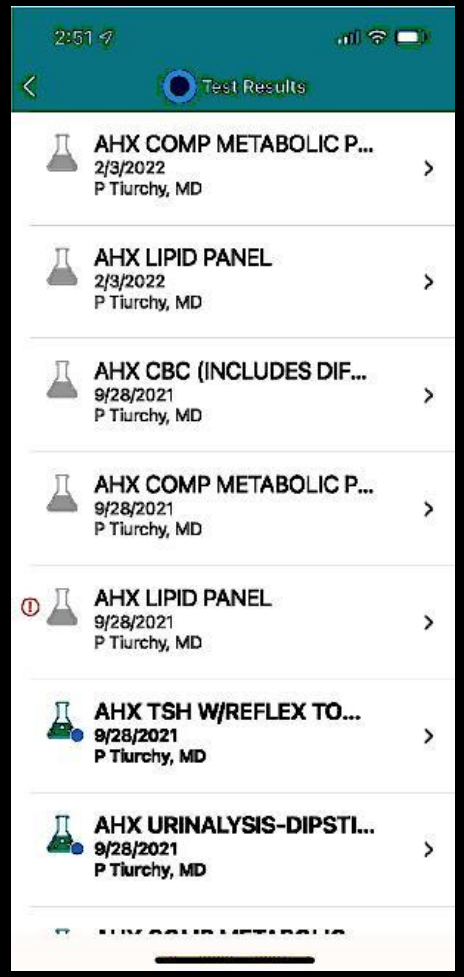
SORTING

FAVORITES

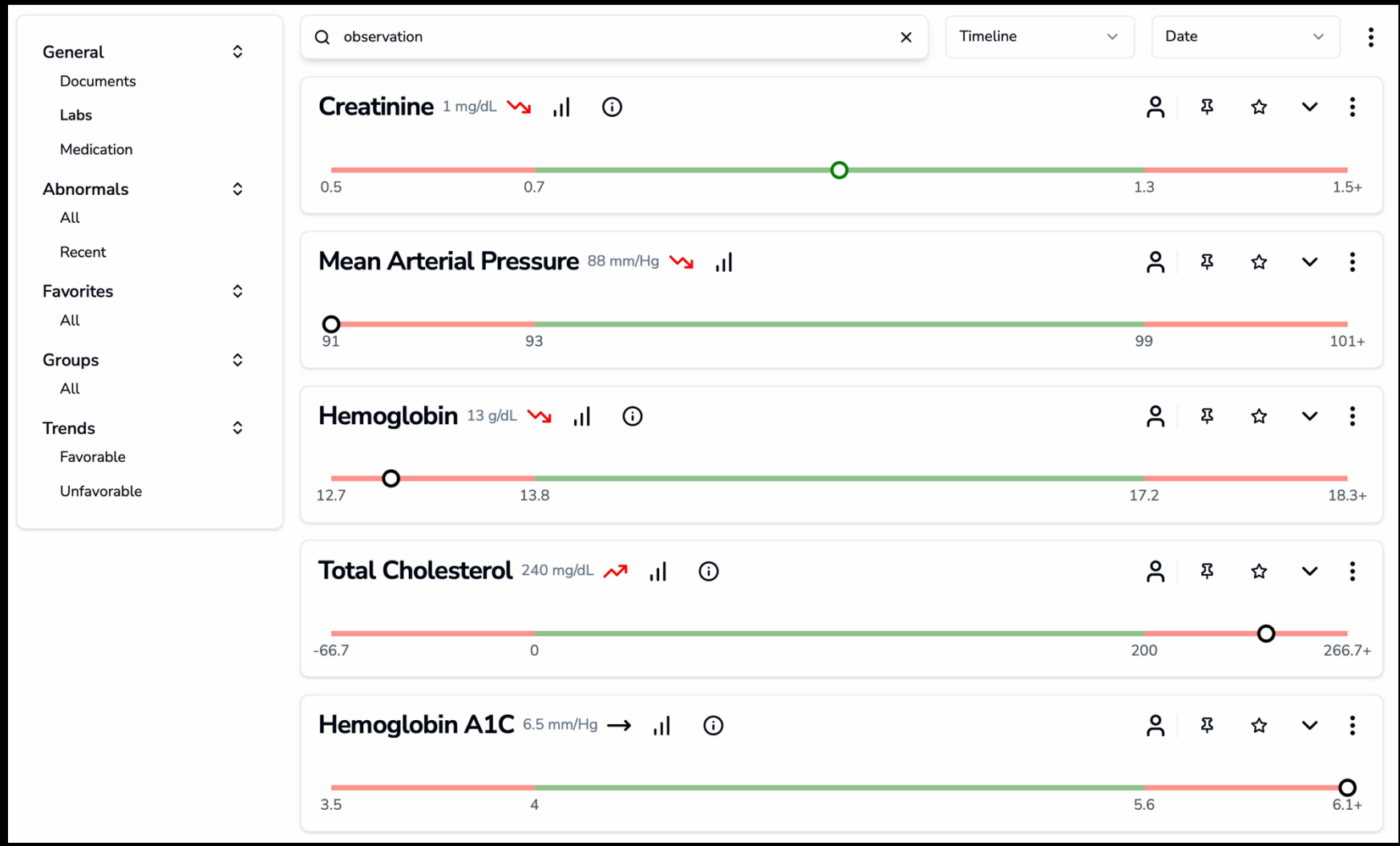
JUXTAPOSING

❸ COLLABORATE

BEFORE



AFTER



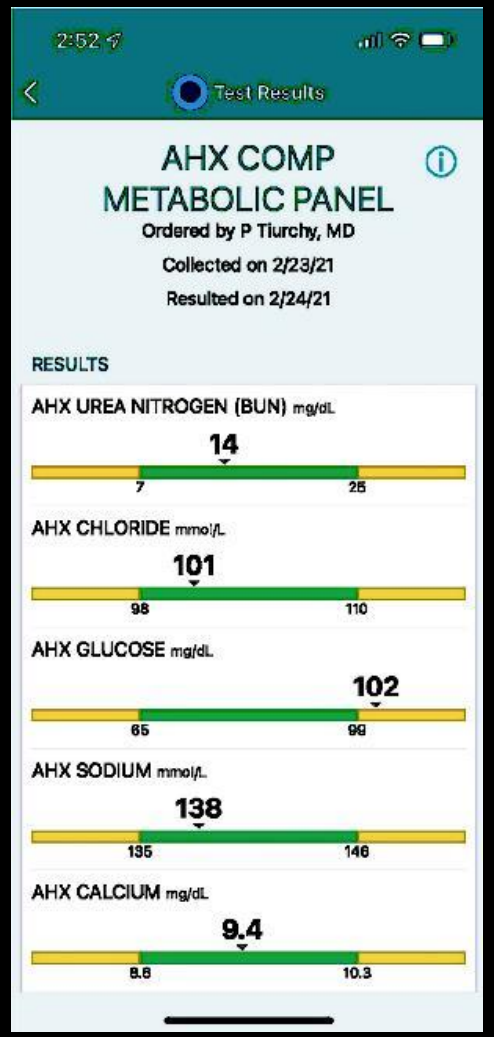
SORTING

FAVORITES

JUXTAPOSING

❸ COLLABORATE

BEFORE



"What did we decide we wanted to track together every time?"

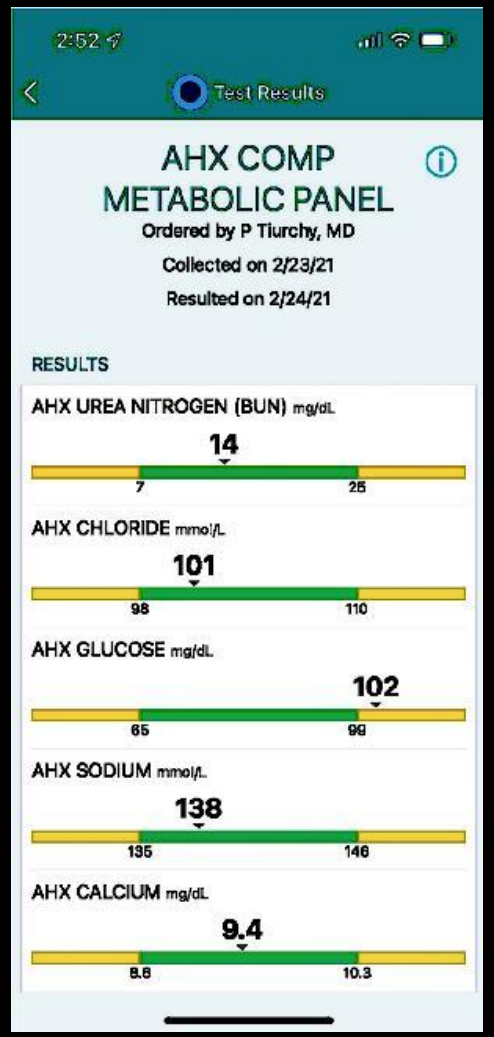
SORTING

FAVORITES

JUXTAPOSING

❸ COLLABORATE

BEFORE



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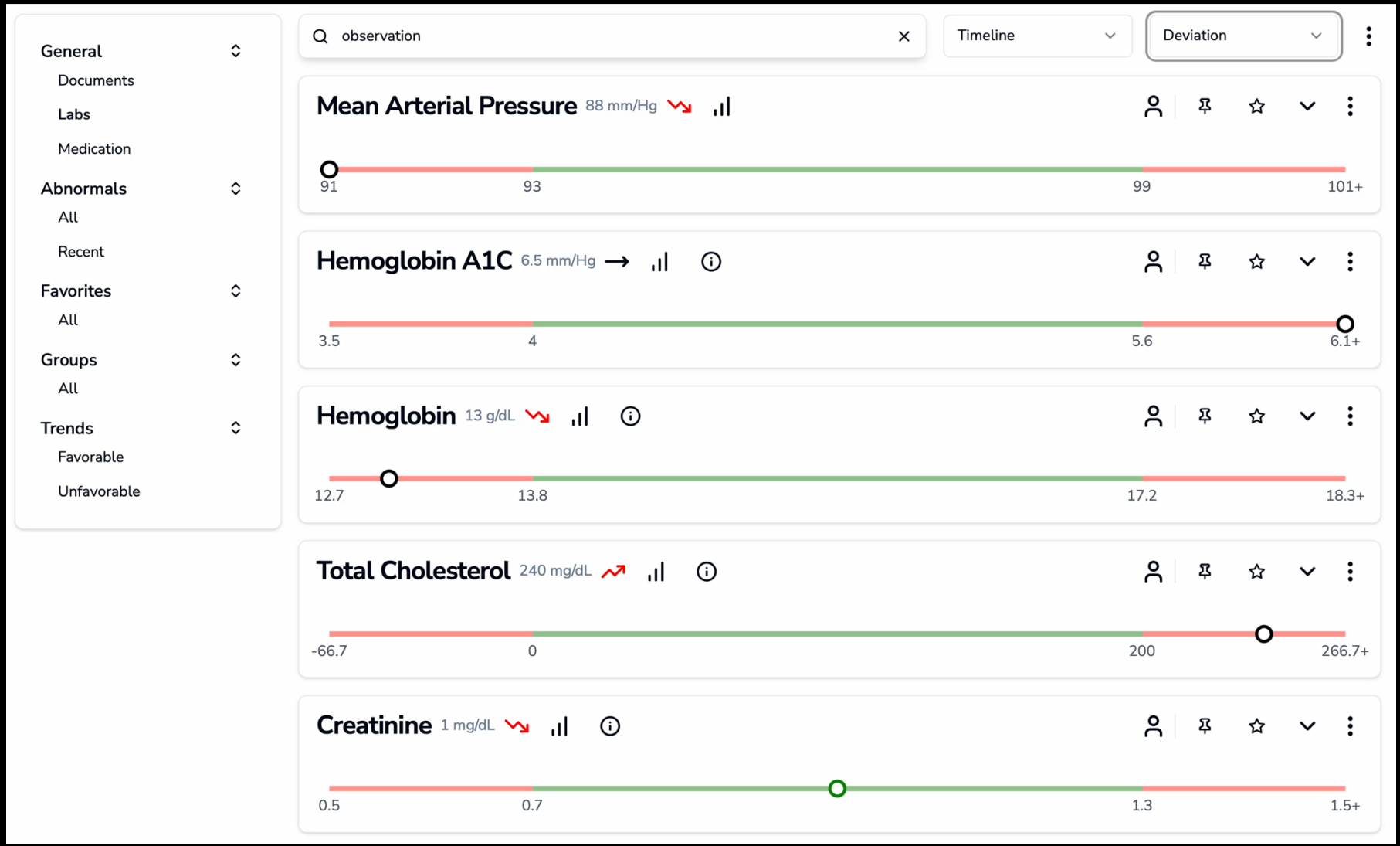


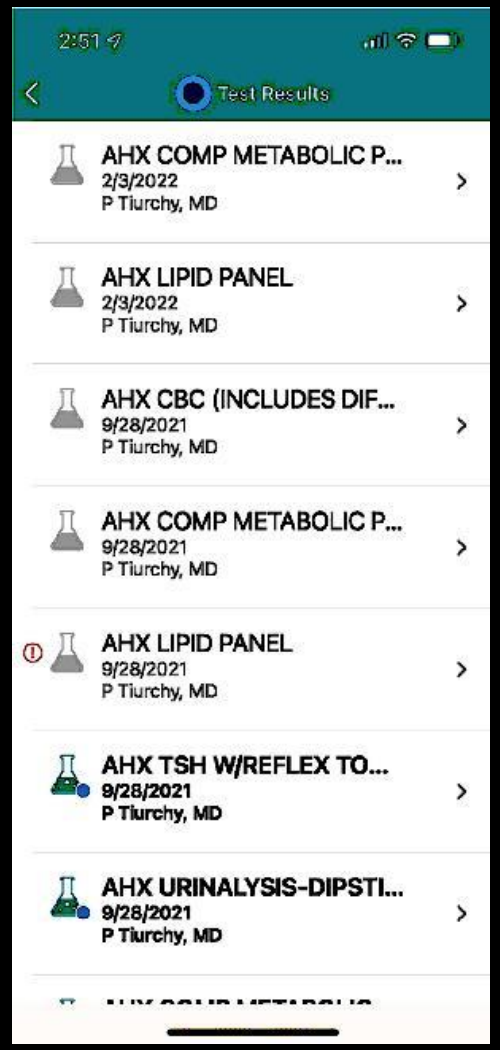
SORTING

FAVORITES

JUXTAPOSING

❸ COLLABORATE

BEFORE



"Let's compare how X (e.g. stress) is affecting Y (e.g. blood pressure)?"

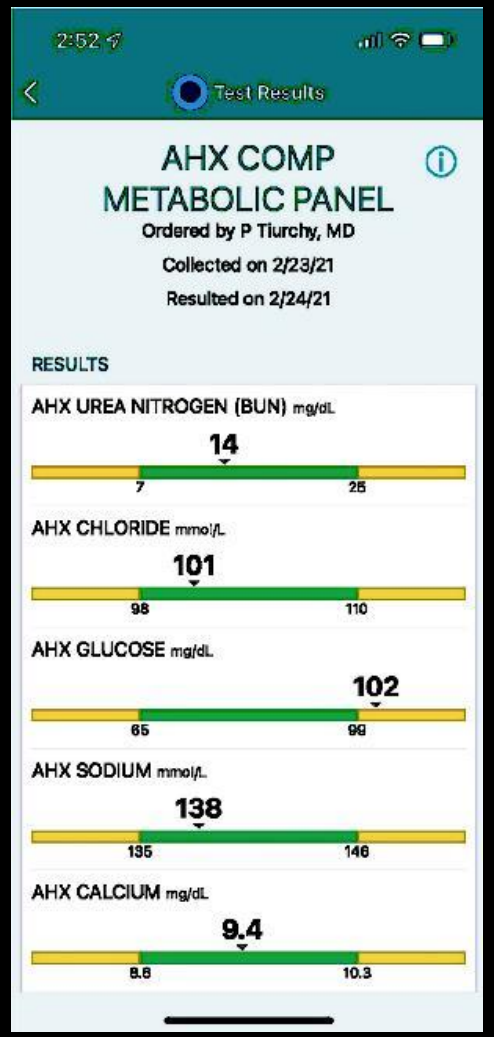
SORTING

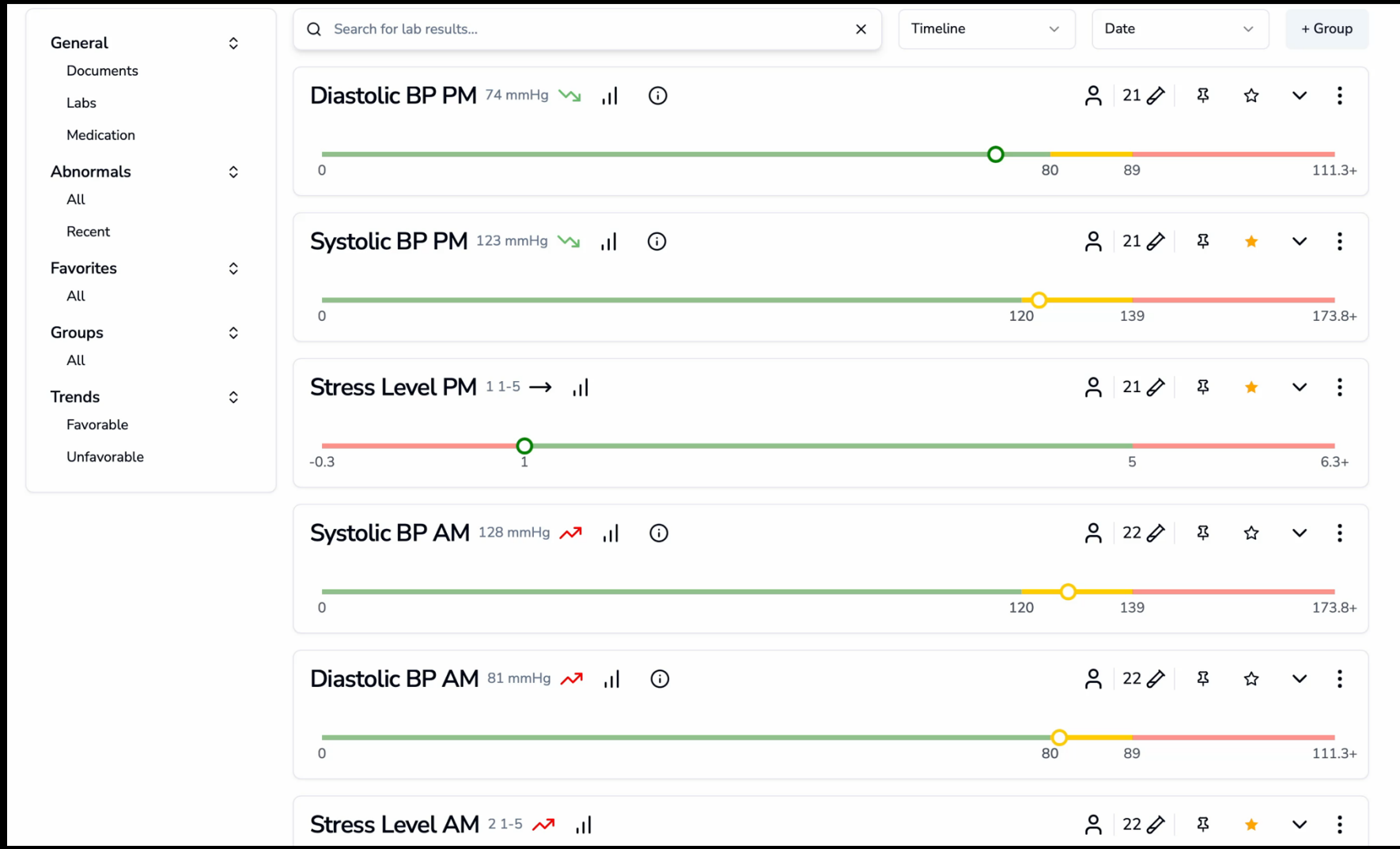
FAVORITES

JUXTAPOSING

❸ COLLABORATE

BEFORE





SORTING

FAVORITES

JUXTAPOSING

EQUITY ENGINES: CO-PORTAL

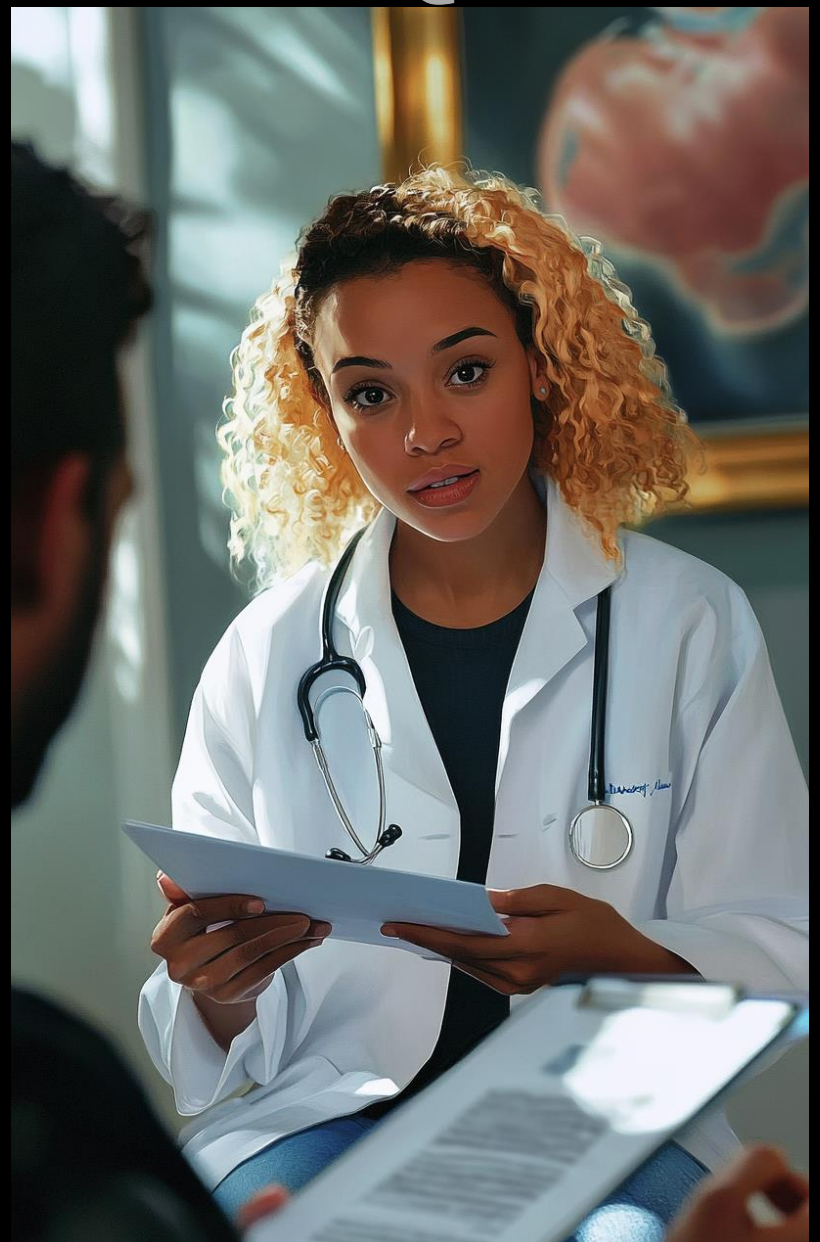
DIGITAL FLUENCY

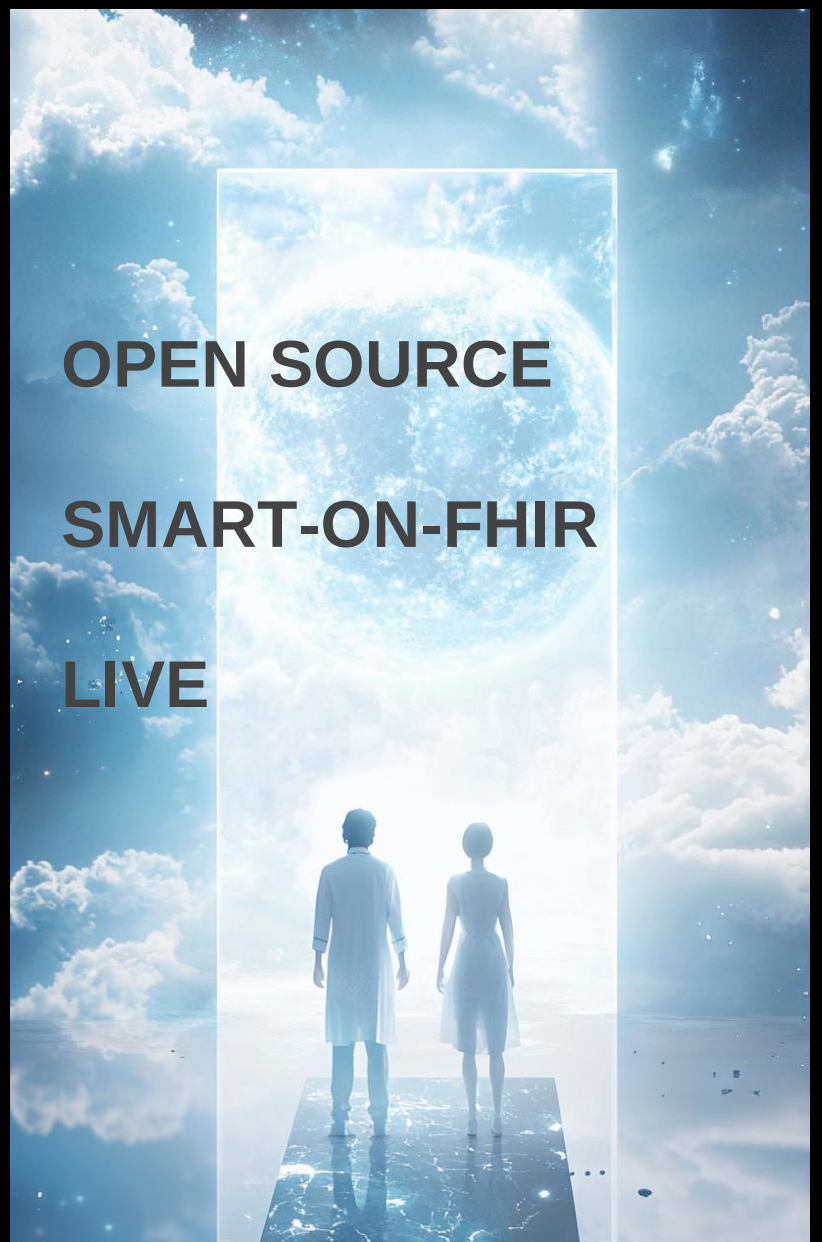
ACCESS

ADOPTION

“You can’t manage what you cannot measure.”
-Peter Drucker

EQUITY ENGINE: CO-PORTAL





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EQUITY ENGINES

Discussion and audience questions

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