

Advancing Health Equity by Design: Identifying and Addressing Disparities in Patient Access

December 5, 2024

ASTP Annual Meeting



Moderator

- ❑ **Melinda Kidder, DHA, MSN, RN**, Office of the Assistant Secretary for Technology Policy, US Department of Health and Human Services

Speakers

- ❑ **Chelsea Richwine, PhD**, Office of the Assistant Secretary for Technology Policy, US Department of Health and Human Services
- ❑ **Robert W. Turer, MD**, UT Southwestern Medical Center
- ❑ **Gerardo Lazaro, PhD, CHI**, Office of Minority Health, US Department of Health and Human Services
- ❑ **Dana Schinasi, MD, MSHI**, Ann & Robert H. Lurie Children's Hospital of Chicago

What does “Health Equity by Design” mean?

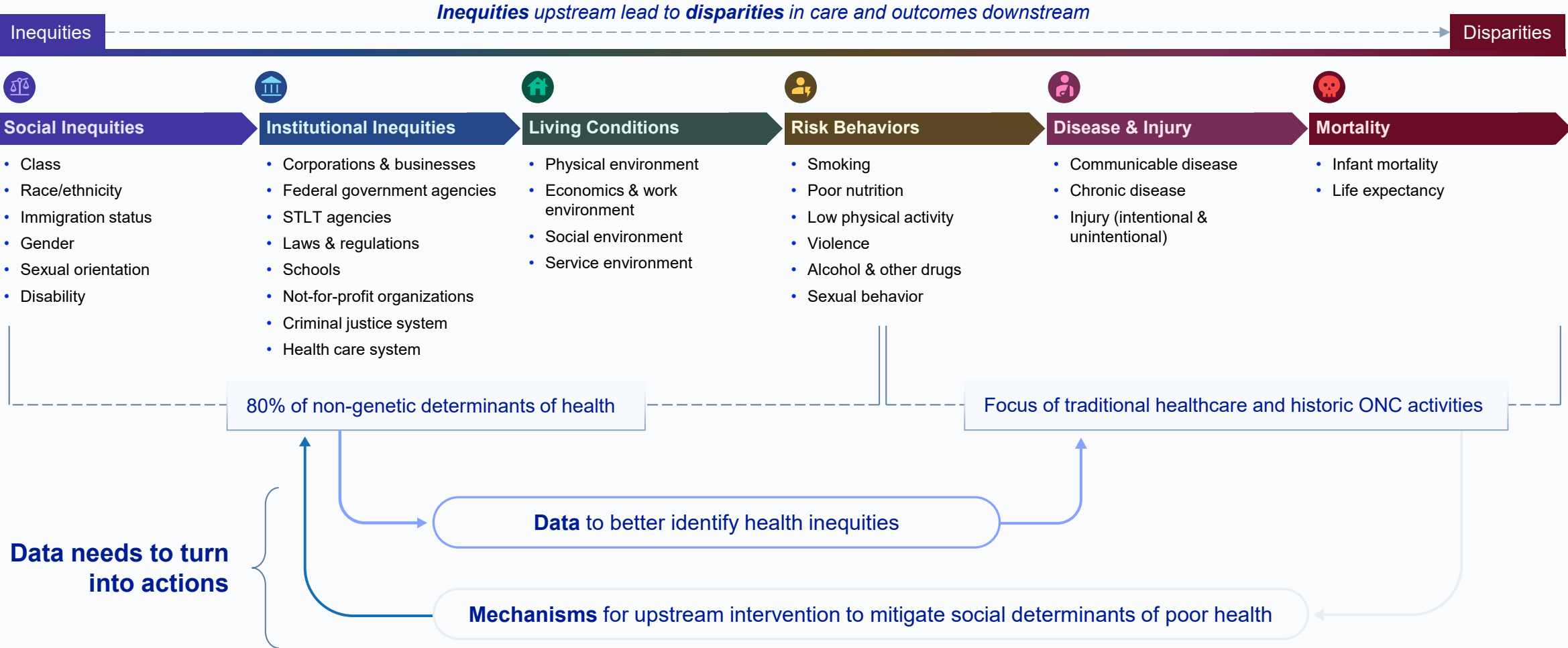
What is it?

- Equity considerations identified and incorporated as early as possible in design, build, implementation process
- Health IT products and capabilities are designed to be foundationally equity enforcing – making the implicit explicit
- Strategies, tactics, and patterns are guiding principles for developers and enforced by architecture and built into the system at every layer

What is ASTP doing to promote health equity by design?

- Data and standardization efforts to address health inequities
 - USCDI: Added SDOH and SOGI data
 - Identify levers for adoption of standards for race, ethnicity, language (REL) data
 - Ensures existing technology (EHRs, patient portals) can be leveraged to collect, share, and use data to improve patient and population health
- Programmatic efforts to address health inequities
 - Referrals for social services: Awarded LEAP grant to UT Austin
- Finalized policies focus on the use of AI and predictive algorithms that optimize for clinical decision-making and methods that build transparencies into these technologies to help guard against discrimination.

Causal Chain of Health Disparities



Progress and Persistent Disparities in Patient Access to Electronic Health Information

Chelsea Richwine, PhD

Economist, Office of Standards, Certification,
and Analysis, ASTP

ASTP Annual Meeting

December 5, 2024

Enhancing patient access to electronic health information

Importance

Patient access to electronic health information (EHI) contained in online medical records and patient portals has been shown to help individuals make informed decisions about their health and lead to better health outcomes.

Background

Patient access has been on the rise for nearly a decade as federal efforts have sought to empower individuals to make informed decisions about their health by increasing patient access:

- [The CMS EHR Incentive Programs \(now Promoting Interoperability\)](#), supported by ASTP's Health IT Certification Program, required eligible hospitals and clinicians to adopt certified EHR technology with patient engagement capabilities
- [The ONC Cures Act Final Rule](#) sought to make EHI more easily accessible to patients through secure, standards-based APIs that can be leveraged to create applications (apps) that help patients manage their health information.

Despite substantial progress in patient access, growth has not occurred equitably. Studies have identified racial/ethnic disparities in patients being offered portal access by their health care provider (HCP), which has negative downstream implications for patient access and use of EHI.



Leveraging national data to track progress and persistent disparities in patient access

Study Objectives

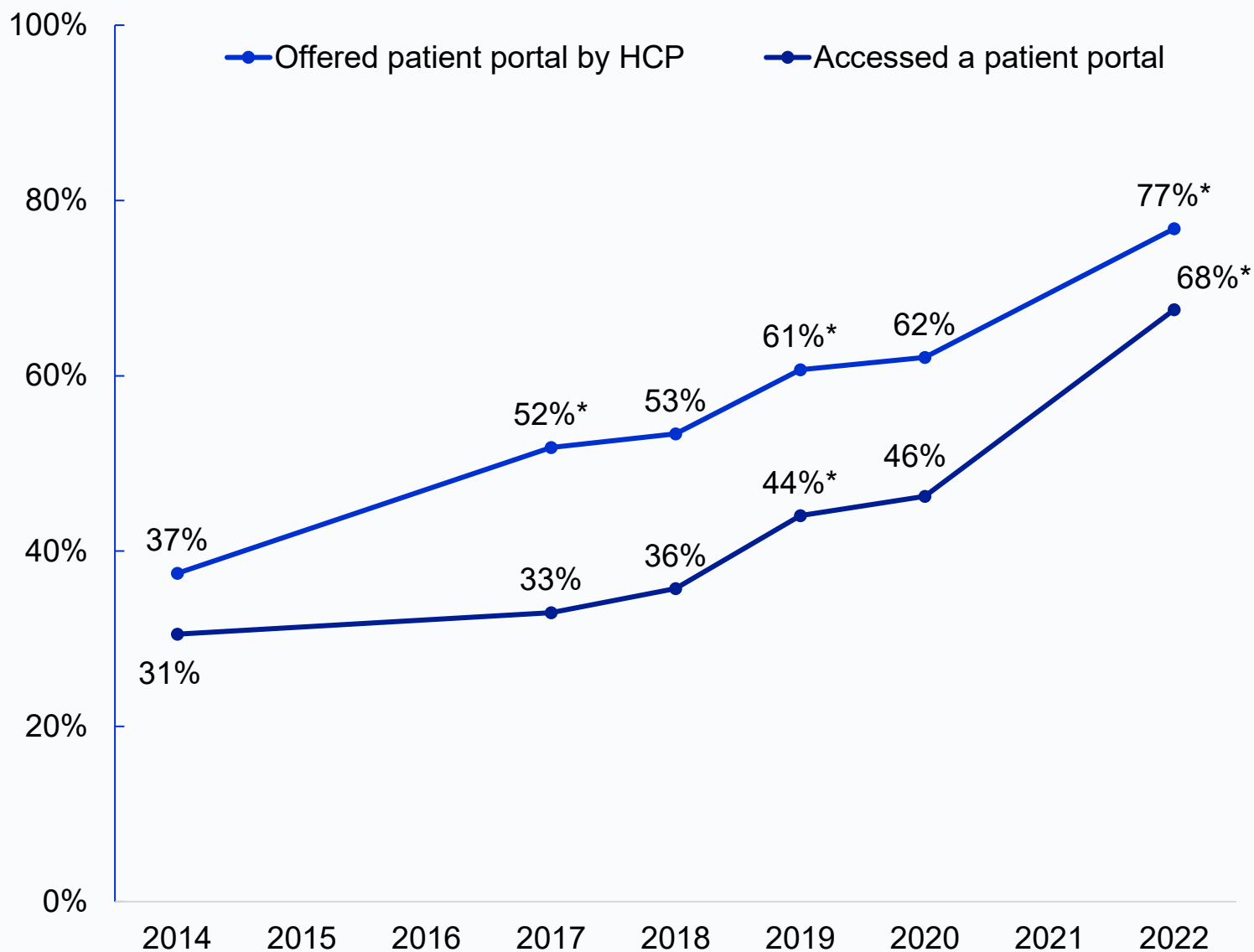
1. **Assess progress towards equitable patient access** to EHI two years after the start of the COVID-19 pandemic—which may have increased demand for access to EHI—by examining trends in individuals being offered & accessing their patient portal between 2014 and 2022.
2. **Identify persistent racial and ethnic disparities in patient access** by examining differences in individual reports of being offered and encouraged by their HCP to use patient portals in 2022, as well as differences in patient-reported access, use, and understanding of information contained in portals.

Data

- Data come from 6 waves (2014, 2017-2020, 2022) of the [Health Information National Trends Survey \(HINTS\)](#), a nationally representative survey of U.S. adults that tracks individuals' access and use of health-related information.
- Trended key outcomes related to individuals' engagement with their online medical records or patient portal (“henceforth patient portal”)
- Sample was restricted to respondents who had a healthcare visit in the past 12 months, and thus, had a reason to access their patient portal
- All analyses employed survey weights developed by HINTS to adjust for non-response and account for the complex survey design.

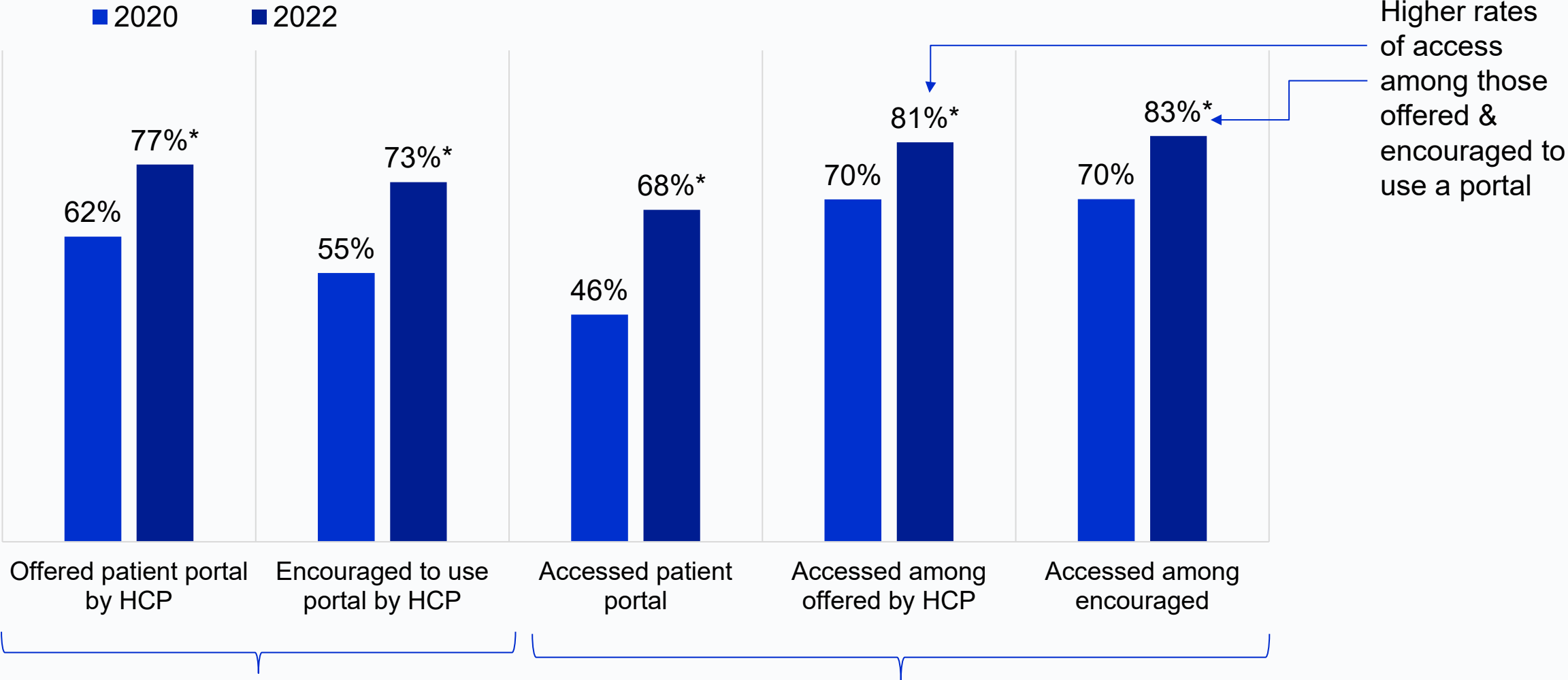
Patient access increased steadily between 2014-2019 and accelerated between 2020-2022

- The share of **patients offered a patient portal increased 24%** between 2020-2022
- **Patient access increased 48%** between 2020-2022—likely reflecting increased demand for access to online medical records during the pandemic



Source: [Progress and Persistent Disparities in Patient Access to Electronic Health Information | Health Policy | JAMA Health Forum | JAMA Network](#)

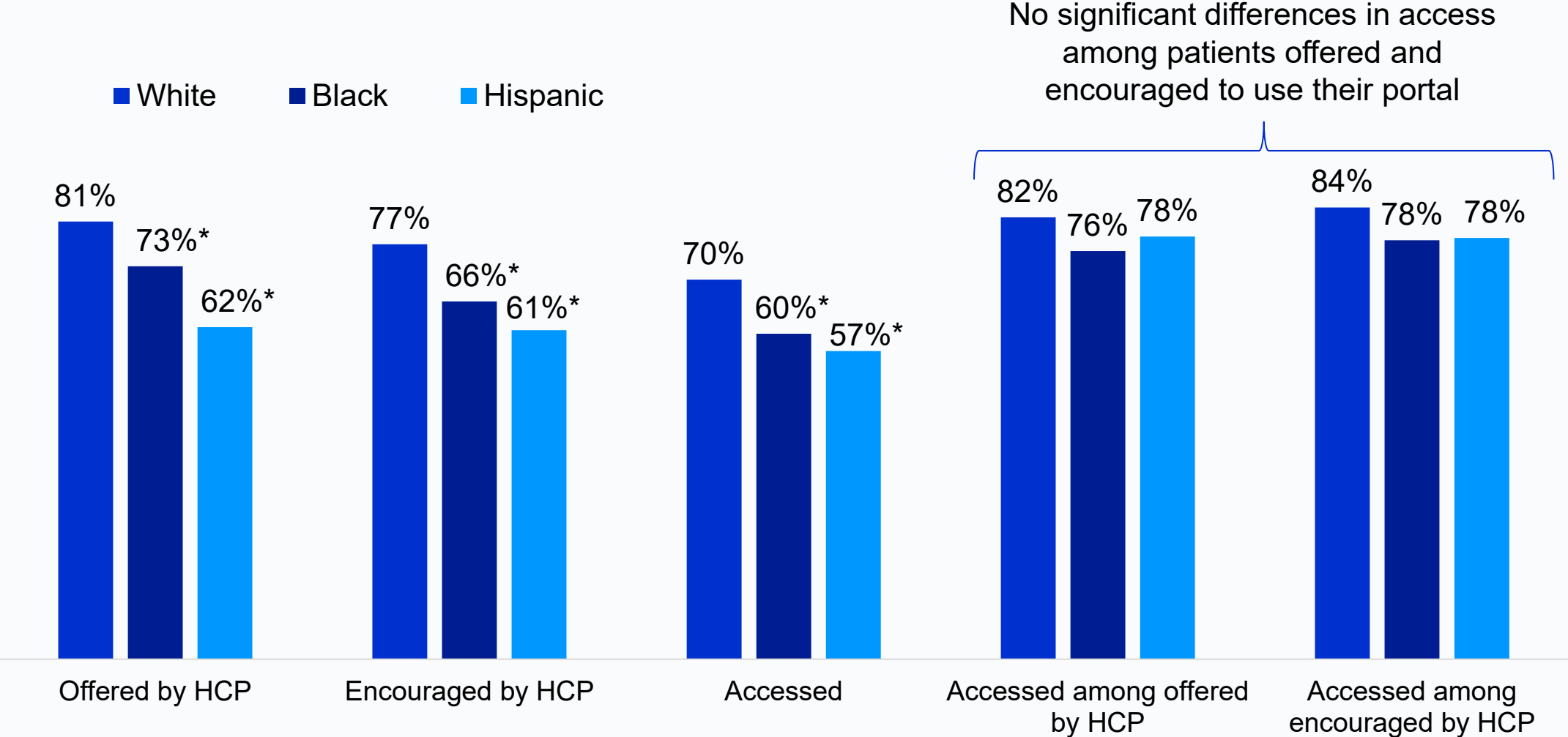
Growth in access may be due, in part, to an increase in providers offering patient portals and encouraging their use



Increased HCP engagement

Increased patient engagement

Growth in patient access has not occurred equitably – disparities persist in 2022



Notes: Differences in patient access measures were examined among three racial/ethnic groups: Non-Hispanic White, Non-Hispanic Black or African American, and Hispanic, Latino/a, or Spanish origin (referred to here as White, Black, and Hispanic). * Indicates statistically significant difference between Black or Hispanic relative to White (reference group) ($p < .05$).



No differences in use or understanding of information in patient portal among those who had the opportunity to access them

Patient portal use among those who accessed, by race and ethnicity, 2022

	White	Black	Hispanic
Look up test results	91%	89%	89%
Download health information	28%	41%*	43%*
Send information to a 3rd party	19%	24%	24%
View clinical notes	72%	75%	67%

Increased slightly from 2019-2020. Black and Hispanic individuals still more likely to download their health information

Understanding of information in portals among those who accessed, by race and ethnicity, 2022

	White	Black	Hispanic
Very or somewhat easy	91%	90%	88%
Very or somewhat difficult	9%	10%	12%

Remained stable over time (2017-2022)

Key Takeaways

- Patient access to and engagement with patient portals increased significantly between 2014 and 2022, but racial and ethnic disparities persist
- No significant differences in use or understanding of information contained in online medical records among those who were able to access them
- Findings suggest efforts to promote equitable opportunities to access EHI would be successful in increasing patient access.

Implications for Use

- HINTS is the primary data source used by ASTP to monitor the potential impact of policies designed to make it easier for individuals to access and use their EHI
- A key benefit of the HINTS is that it offers patients' perspective on their experiences using health IT to manage their health and care
- Opportunity to track emerging topics of interest including methods of access, satisfaction, caregiver/proxy access
- Ongoing measurement is essential to enabling continued assessment of progress in patient access for *all* individuals and can support the development of solutions to achieve equitable access and use.

Digital Health: An Opportunity to Achieve Health Equity

ASTP2024

Gerardo Lazaro, PhD, CHI

December 5, 2024

Conflicts of Interest

- No Conflicts of Interest to declare

The Digital Health Access Landscape



- We envision connectivity, access, and flow of information through infrastructure and protocols
- Although the existing infrastructure does provide those capabilities...

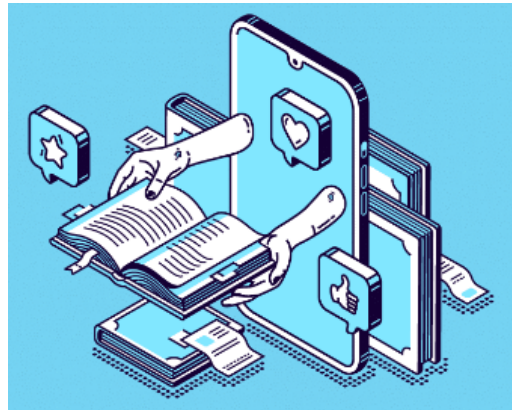
*Is digital health access
the same for all?*

The Digital Health Access Landscape

I will present the digital landscape focusing on three aspects:



Access

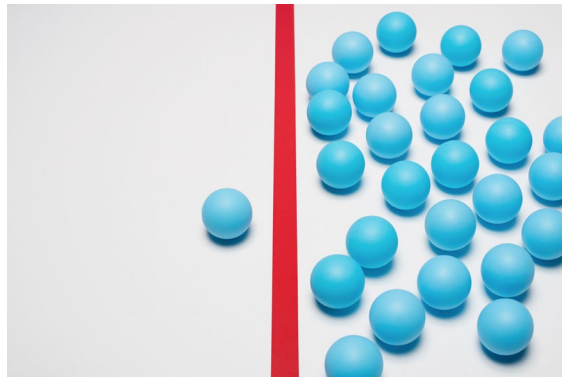


Literacy



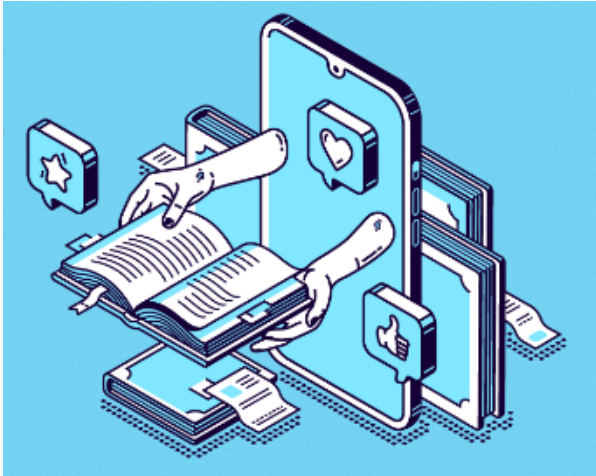
Context

The Digital Health Access Landscape: **Access**



- Access, or lack thereof, exists in different ways for people.
- Effective access, as a form of effective communication, involves addressing several factors:
 - Literacy (e.g. health, digital, numeracy)
 - Language preference
 - Cultural factors

The Digital Health Access Landscape: **Literacy**



- Gaining access and navigating digital settings demand *digital literacy*
- Information is mostly presented in *narrative* above 6th grade level (recommended)
- Understanding healthcare and public health reports and communications demands a good domain of *numeracy*

The Digital Health Access Landscape: **Context**



- *Human-centered design* should replace “one size fits all” approaches
- *Contextualization* helps people understand complex information
- Language preference and cultural factors add up to inequitable access and low literacy: *compounded effect?*

Digital Health: An Opportunity to Achieve Health Equity

How prepared are your apps and sites to address access, literacy and context?

Are your apps and sites implementing Culturally and Linguistically Appropriate Service (CLAS) Standards?

How ready are your apps and sites to address patients' needs from a human-centered design approach?

Culturally and Linguistically Appropriate Service (CLAS) Standards

Principal Standard

Provide effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs.

**Governance,
Leadership, and
Workforce**
3 Standards

**Communication and
Language
Assistance**
4 Standards

**Engagement,
Continuous
Improvement, and
Accountability**
7 Standards

Digital Health: An opportunity to achieve Health Equity

How prepared are your apps and sites to address access, literacy, context, language factors, and cultural preferences?





Thank you for your attention.

Gerardo Lazaro, PhD, CHI

Public Health Analyst

Office of Minority Health

U.S. Department of Health and Human Services

Online access: <https://bit.ly/4evu3ca>

Low health literacy: <https://bit.ly/4evxkZ8>

Context: <https://bit.ly/40Mwrlg>

Patient-centered design: <https://bit.ly/4ftR8Nx>

Image Credits

Every Patient, Every Time: A Digital Transformation for Equity

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Dana Schinasi, MD MSHI
on behalf of the Lurie Children's Digital Health Team



Our Digital Equity Mission

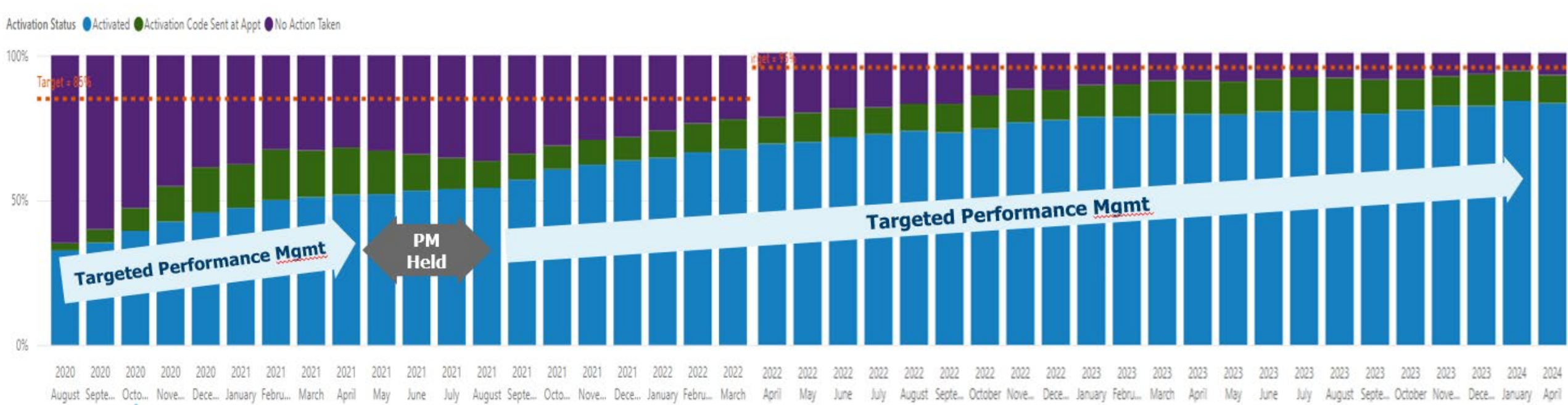
We seek to advance equity and access for all through our digital health tools by ensuring that every individual, regardless of background or circumstance, has seamless and inclusive access to high-quality, personalized healthcare



We are committed to innovating and implementing solutions that bridge gaps in accessibility, foster inclusivity, and empower patients and providers alike to achieve optimal health outcomes through equitable digital health solutions.

Activation success: structured performance management yielded improved patient portal enrollment

Patient Portal Activation Rates by Encounters



27%
Activated

85%
Activated

- Encounters not offered or not activated on our tethered patient portal shrunk from 72% to 6% from April 2020 to April 2024
- Active and engaged performance management provided an opportunity for improvement, but any pauses released the pressure causing stagnation

Five steps to an effective performance management structure for improving patient portal enrollment

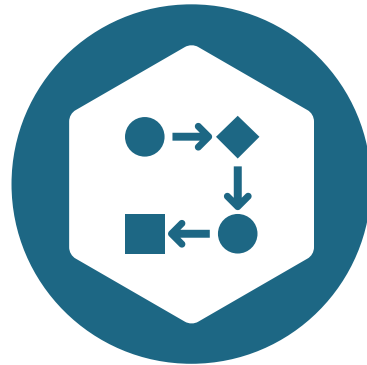
Optimize the Workflow

Optimizing staff and patient/proxy workflow inefficiencies through the use of existing resources



Simplify the Metrics

Creating simple, actionable metrics digestible by end-users with varying degrees of data literacy



Develop an Effective Dashboard

Visualizing KPIs with functional filters, targeted to end-users for consumption and action



Define and Deploy the MVP

Driving immediate action while prioritizing future options



Administer with Effective Governance

Creating accountability structures to ensure effective action-oriented performance management



Create an effective dashboard with actionable KPIs targeted at the correct audience

Leverage Actionable KPIs

- Using simplified KPIs with **clear action items** associated with each category

Operational Functionality of Data

- Viewing the data in the **correct graphic formation with functional filters** is critical for effective comparison

Optimize for the Audience

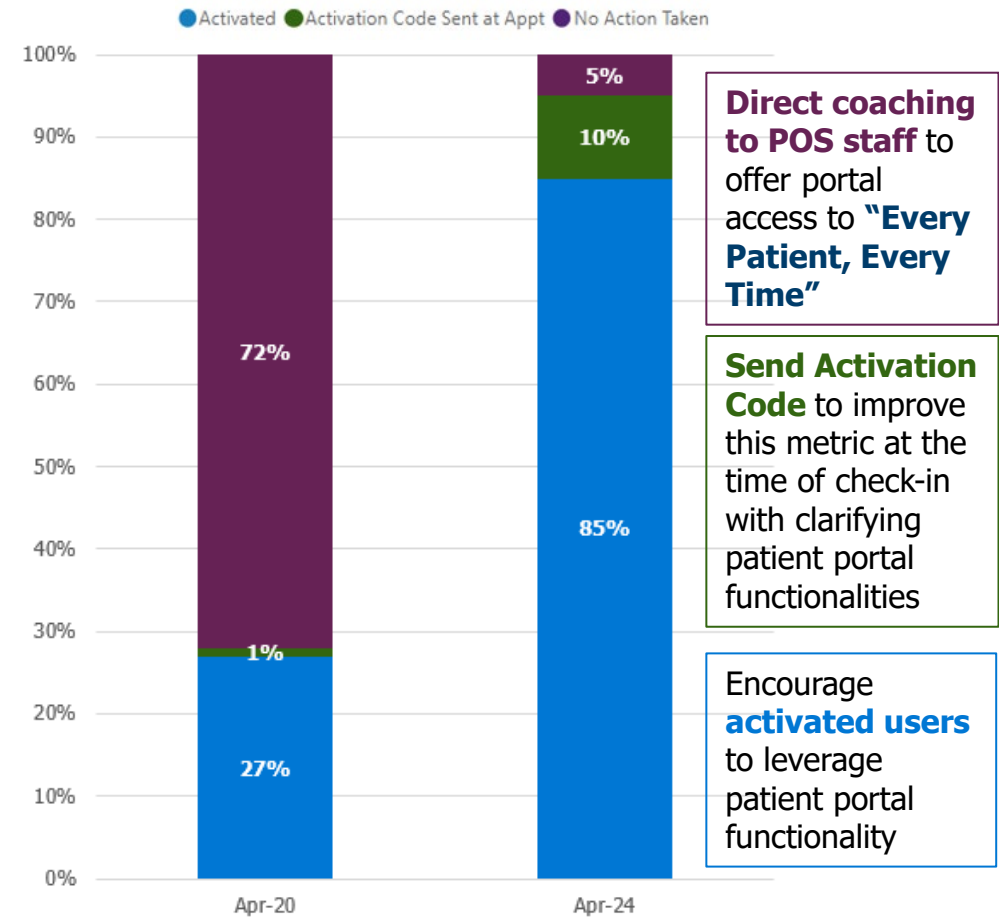
- Target the data to views that **allow all end users and their respective leaders to drive action**

Balancing Measures

- Demonstrate balancing measures to **ensure equitable approach** without negative impact on performance goals



Patient Portal Activation Rates by Encounters with Action Item

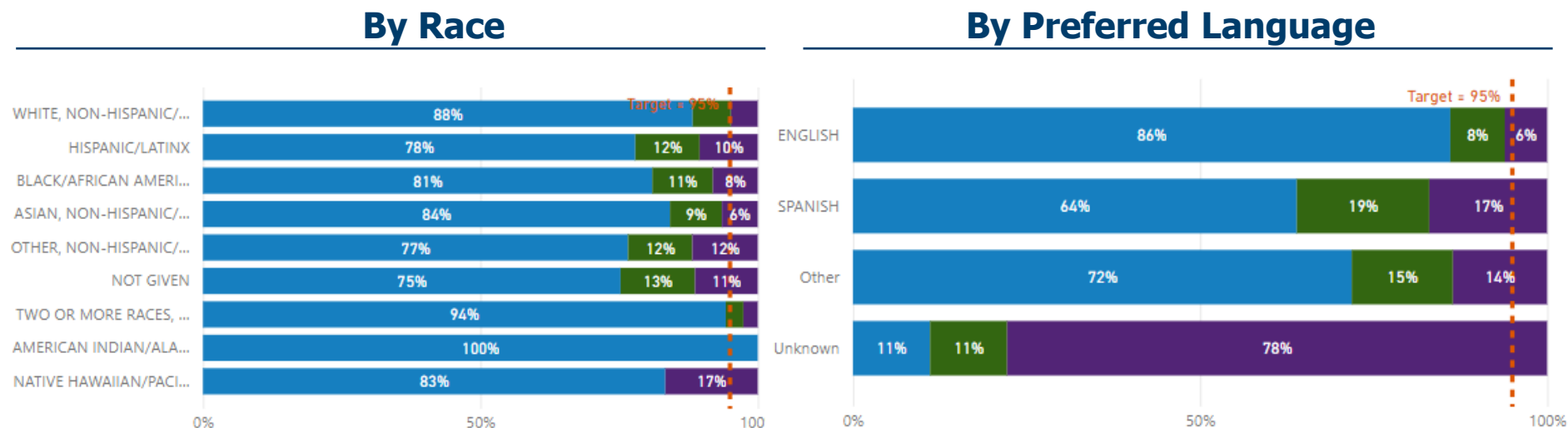


Create a dashboard with actionable KPIs targeted at the correct audience

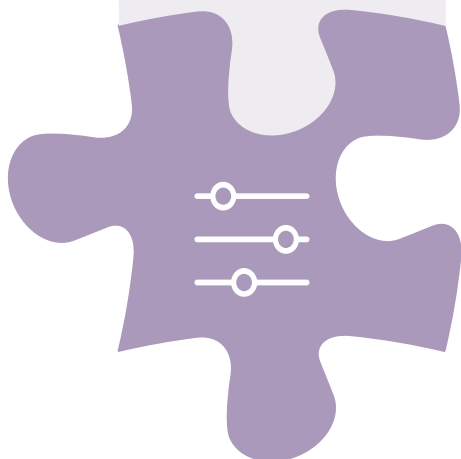
Balancing Measures

- Demonstrate balancing measures to ensure equitable approaches without negative effects on other perf. goals

Patient Portal Activation Rates by Encounters (Last 30 days)



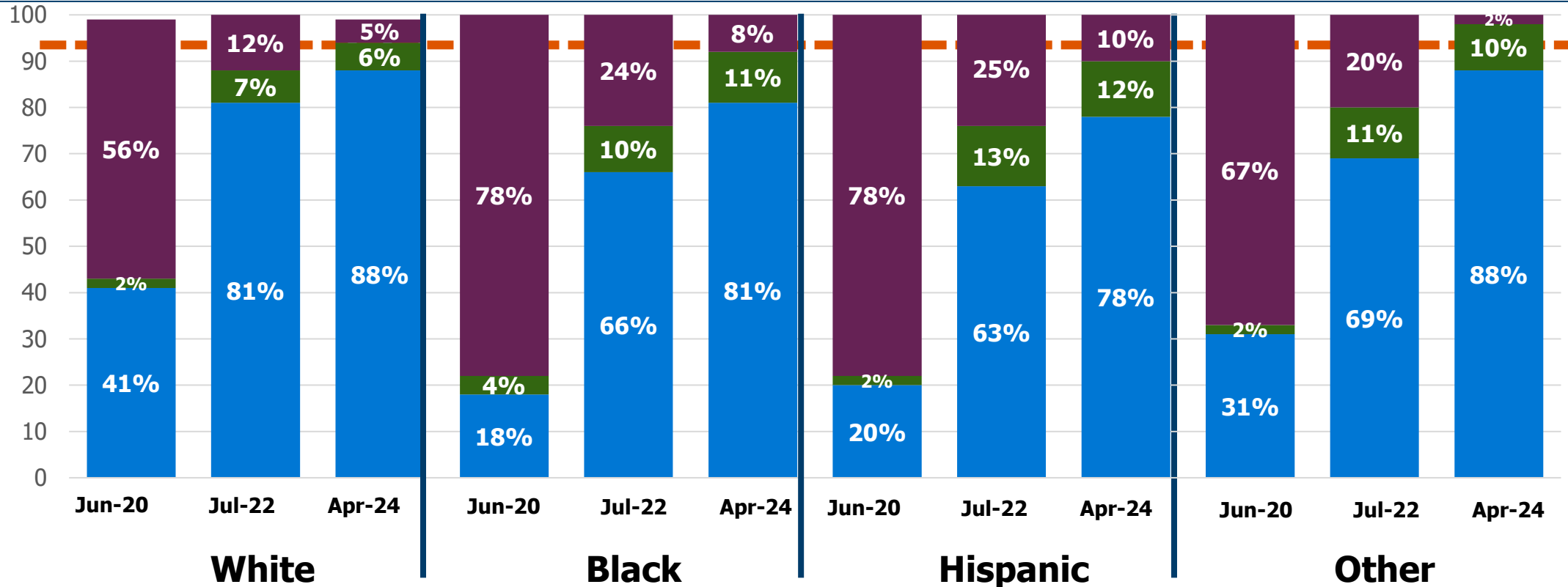
- **Ensuring equitable approaches for *Every Patient* to receive a portal activation code *Every Time*** was a clearly visible, primary objective during the development of the dashboard
- All filters available on the dashboard allow the ability to demonstrate the impact by race, ethnicity and preferred language



Every Patient, Every Time approach helped to close the gaps in racial and ethnic equity

Patient Portal Activation Rates by Race/Ethnicity

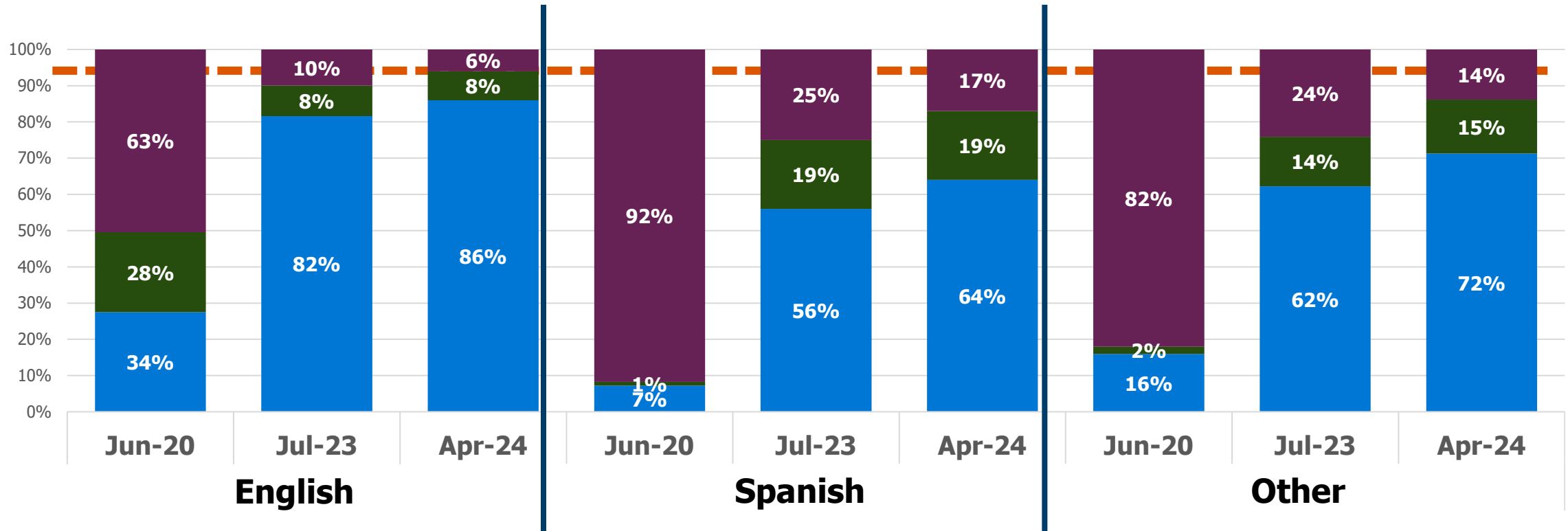
Activated Activation Code Sent at Appt No action taken Target "No action taken"



- Ensuring MyChart was offered to *Every Patient, Every Time* helped close the gap in activation between the White population and other races

Every Patient, Every Time approach helped to close the gaps in language equity

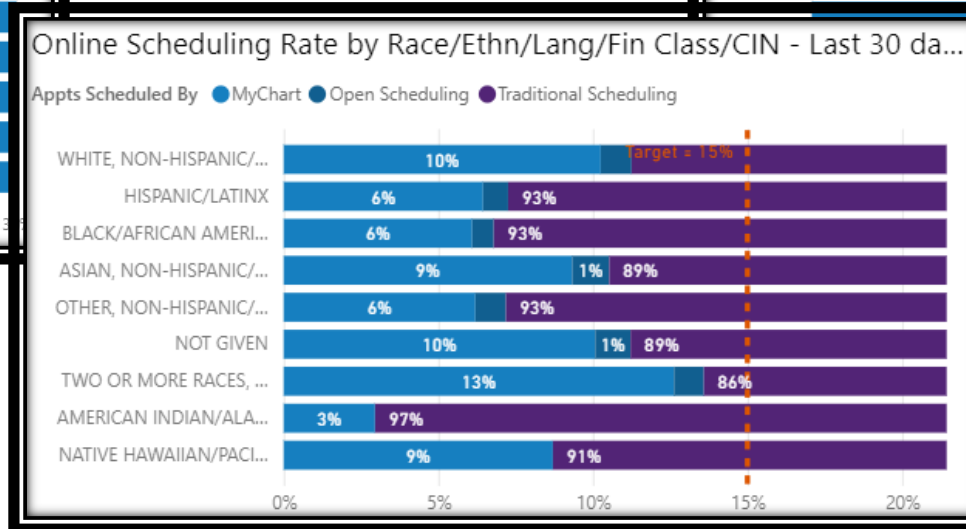
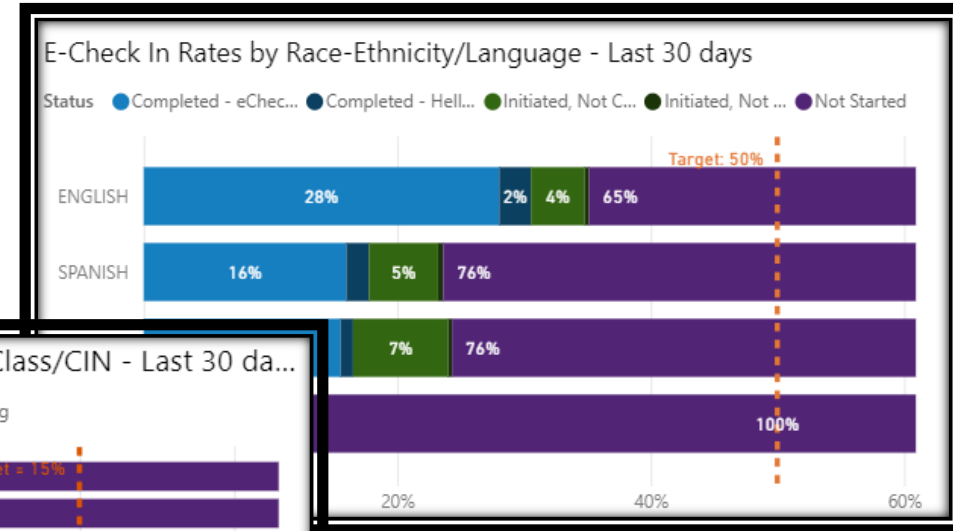
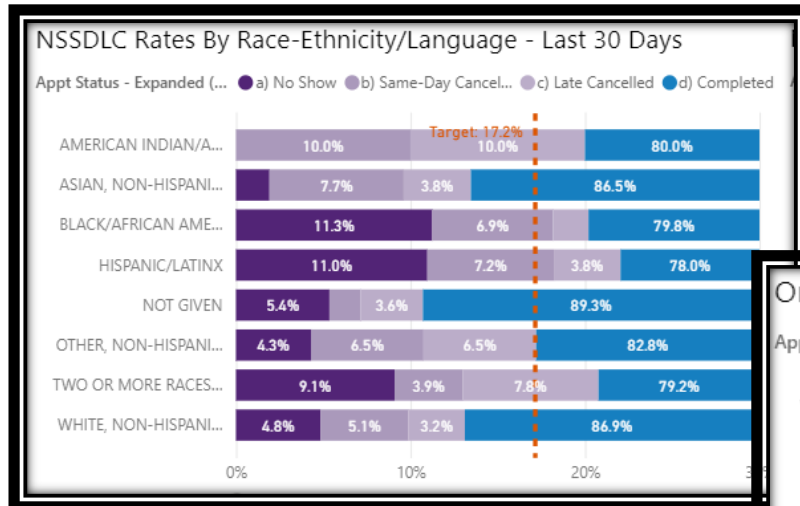
Patient Portal Activation Rates by Preferred Language ■ Activated ■ Activation Code Sent at Appt ■ No action taken --- Target "No action taken"



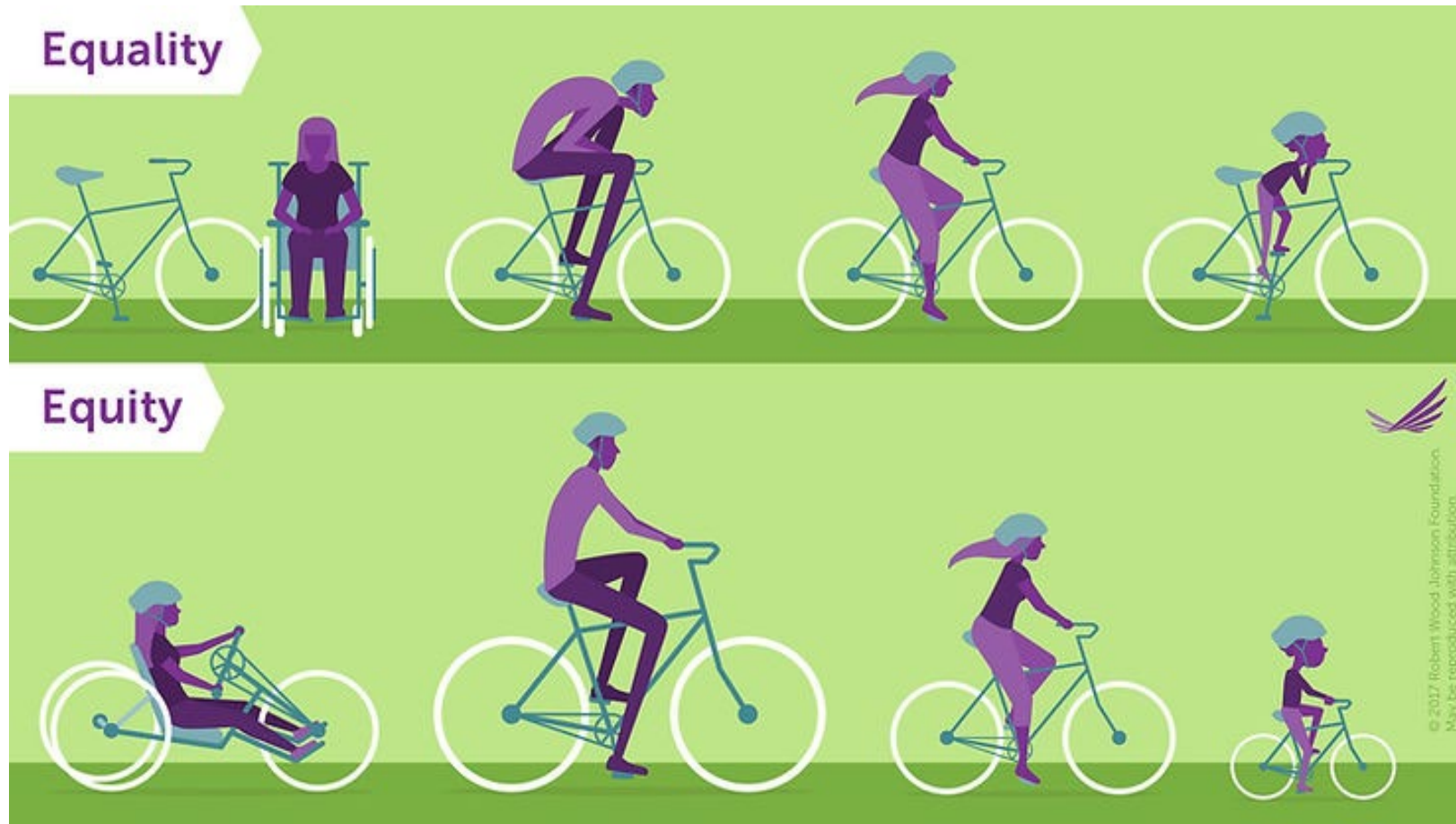
- Patients with a preferred language other than English have also started to adopt the portal when given an equal opportunity to leverage the platform, demonstrating **the need to think upstream from technology/internet access**
- **Previously, non-English speakers were preemptively dismissed** and not given an opportunity to leverage the platform due to perceived language barriers

We instilled an equity lens into every effort

Recognizing that unconscious bias is a pervasive factor despite our *Every Patient, Every Time* approach, we instilled an equity lens into all reporting dashboards, accounting for **language, race/ethnicity, and financial class** for all metrics.



Equal does not necessarily mean *Equitable*



RE-FRAMING OUR QUESTION: Do populations *desire* to utilize digital tools at the same rates?

A survey of > 50k patients with any digital interaction indicates that patient preferences vary across populations, providing actionable insight for future work



Across race/ethnicity and preferred language, 94% of patients report very good experiences with our patient portal

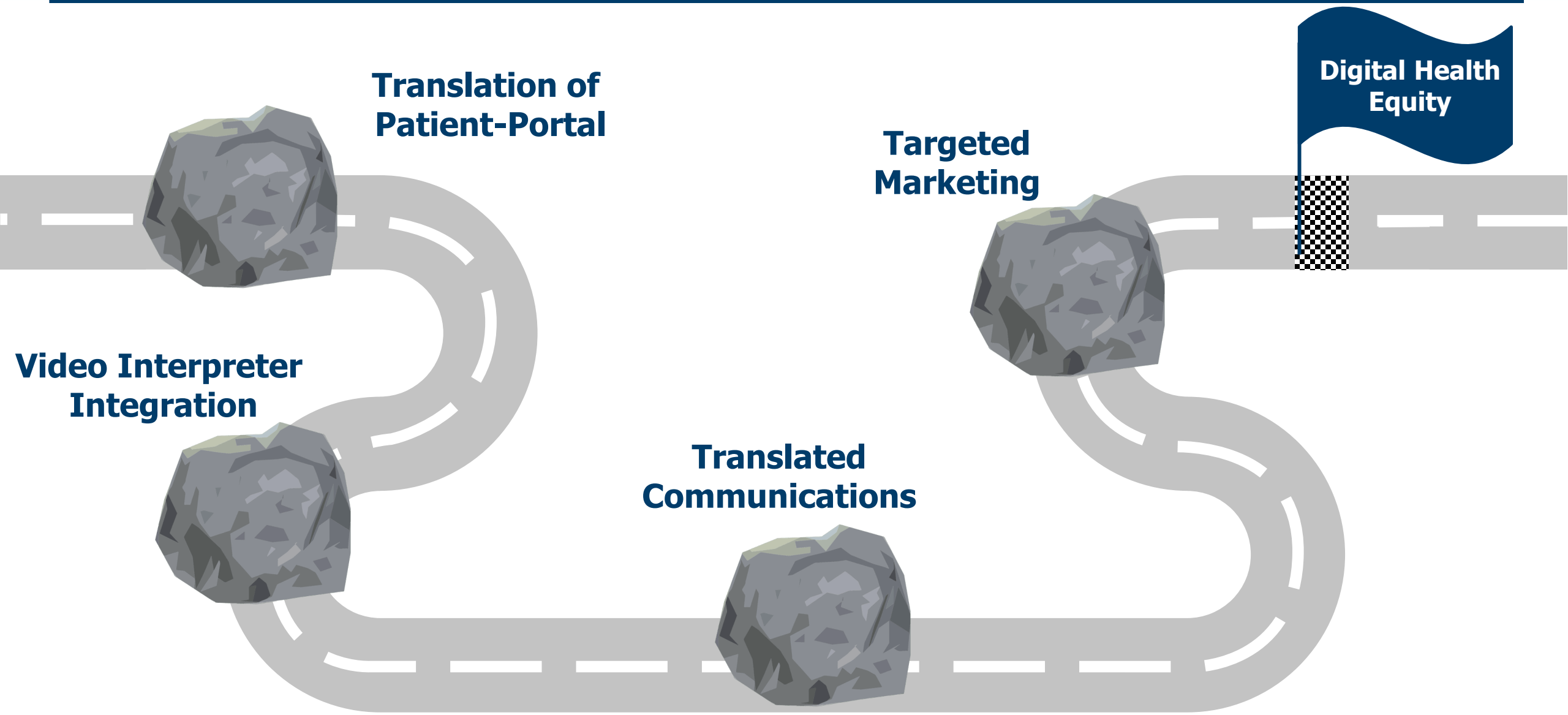
Telemedicine was perceived by patients to be offered at equal rates across populations

There is a pervasive belief that an in-person visit is better than a virtual video visit

Spanish-speaking patients are 40% less likely to prefer a video visit compared with English-speaking patients, if the clinician offered both

13% of Hispanic patients report difficulties using their device for telemedicine appointments compared to 9% of the overall population

Removing barriers according to patient preferences is the next step to achieving equitable access across digital tools



Key Takeaways to Systematically Closing the Equity Gap for Patient Portal Engagement



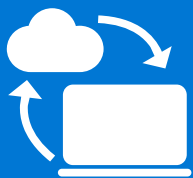
- **Unconscious biases within the workforce can create an equity gap** in offering digital tools to patients
- Awareness of implicit bias is critical, but must be **reinforced with data**



- **Effective performance management** with improved activation workflows, defined goals, and a transparent and easily accessible monitoring dashboard for end users and managers
- Clear accountability to a **simple set of actionable metrics** is critical



- Understand **patient perceptions on digital health care** compared with in-person care
- Leverage **targeted marketing** to influence preferences and behavior in the long-term



- By assuring an **opportunity for digital engagement** for *Every Patient, Every Time*, the stage is set to identify and address systemic infrastructure challenges

Thank you

This presentation showcases the vision and strategy thoughtfully developed and executed by the following individuals and teams:

Ravi Patel, MD

CJ Lilly, MBA

Rebecca Stephen, MD MS

Lurie Children's Digital Health Team



Questions?





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