

Empowering Patients: Enhancing Patient Access and Navigation in Cancer Care

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Access and Use of Electronic Health Information by Individuals with Cancer: 2020-2022

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Importance of Patient Access for Cancer Care Navigation

- In early 2024, as part of the [Cancer Moonshot initiative](#), the White House reaffirmed their commitment to enhancing patient navigation in cancer care. Ensuring patients and caregivers have easy access to information they need to manage their health and care is critical to enabling patients to navigate a recent cancer diagnosis or cancer survivorship.
- For cancer survivors and those navigating a recent diagnosis, having [access to online medical records](#) via patient portals or smartphone-based health apps can enable patients to more easily:
 - Manage complex health needs
 - View clinical notes or lab results from different visits, immediately upon release
 - Communicate with providers
 - Share information with caregivers and other providers involved in their care
- This [data brief](#) leverages data from the National Cancer Institute's [Health Information National Trends Survey](#)—a nationally representative survey of U.S. adults—to examine the access and use of health information by individuals with cancer in 2020-2022.

Over 6 in 10 individuals with a recent cancer diagnosis were offered and accessed their online medical records in 2020-2022, a significant increase from 2017-2018

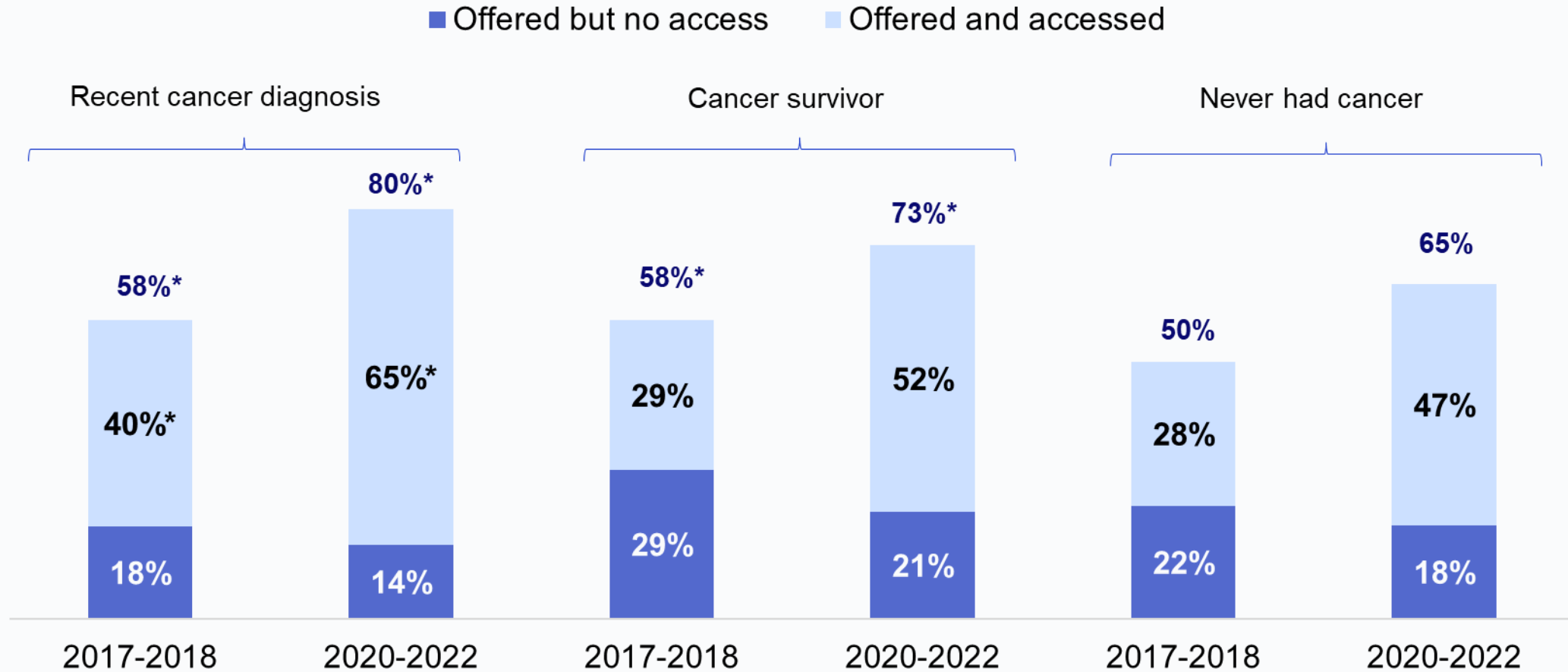


Figure 1. Individuals offered access to their online medical records by cancer status, 2017-2018 vs. 2020-2022.

40% of individuals with a recent cancer diagnosis accessed their records 6+ times in the past year – nearly 2x the rate of those who have never had cancer

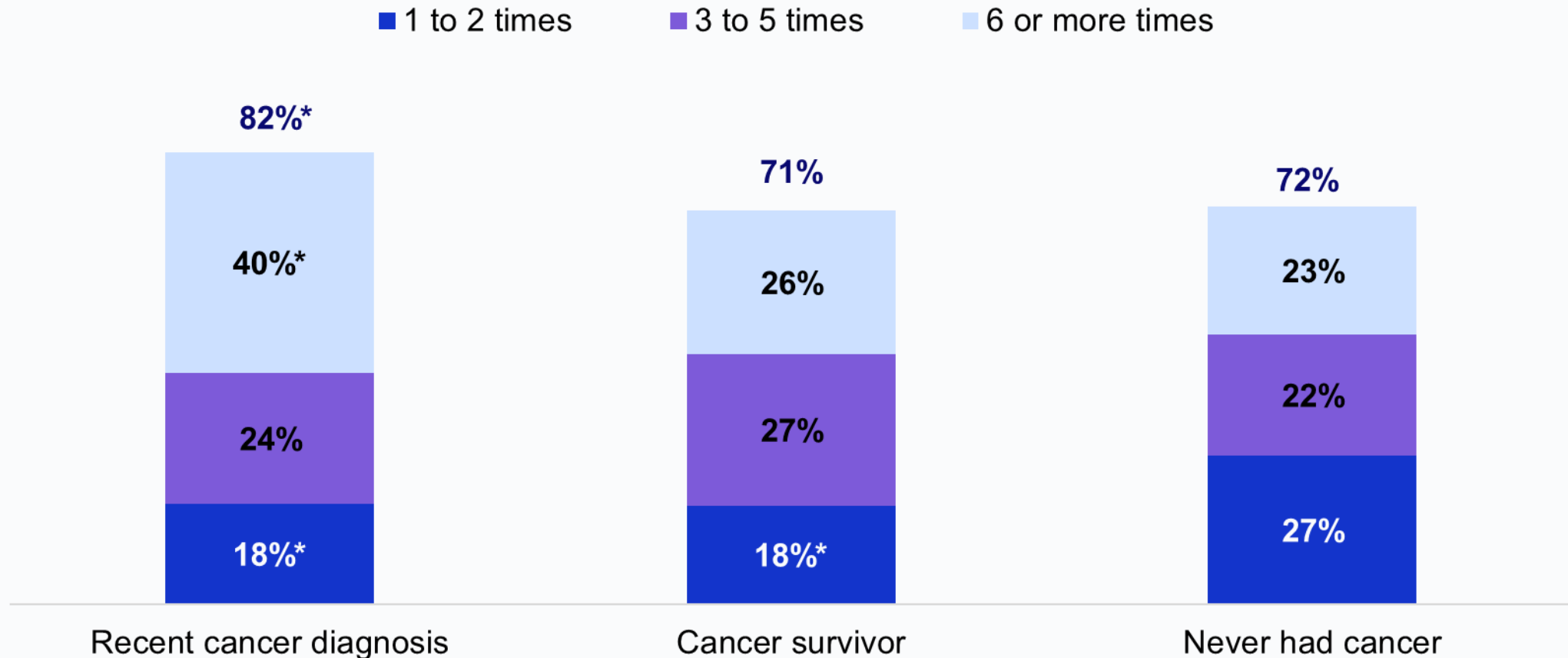
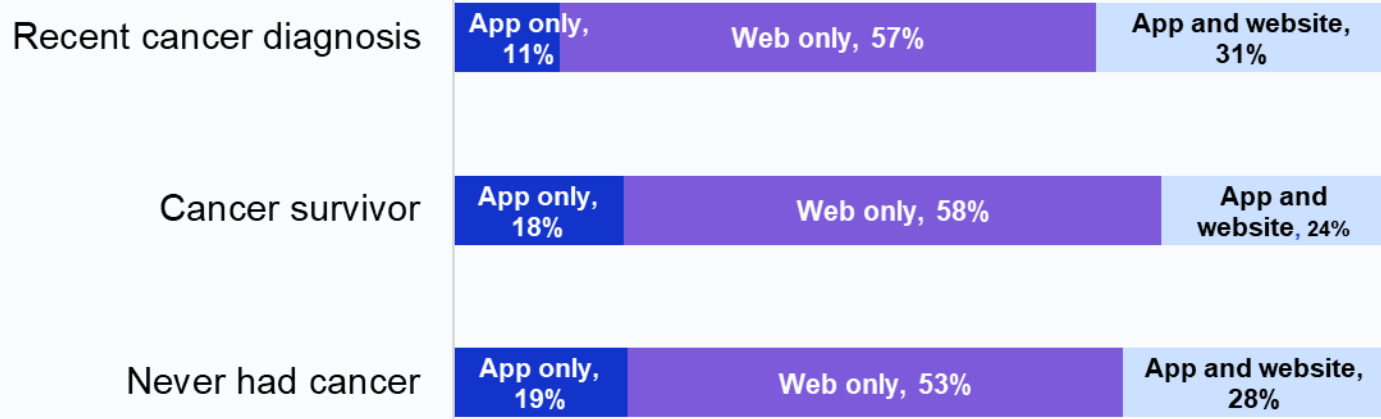


Figure 2. Frequency of access within the past year among those offered a portal by cancer status, 2020-2022

Frequent users and individuals with a recent cancer diagnosis had higher rates of using multiple methods to access their information electronically

A. Cancer Status



- Web-only access still the most common method of access
- Use of multiple methods was higher among those with a recent cancer diagnosis
- Frequency of access is a bigger driver of using multiple methods

B. Frequency of access

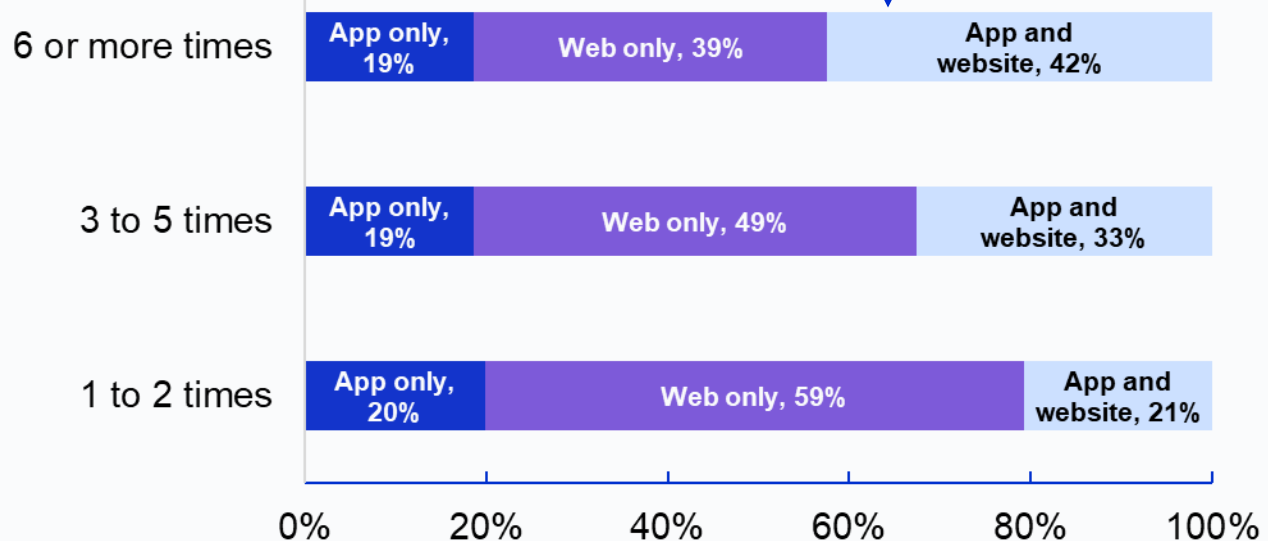


Figure 3. Methods individuals used to access their online medical records by cancer status and frequency of access, 2020-2022.

Nearly all users with a recent cancer diagnosis used their access to view test results, and many used their access to view clinical notes

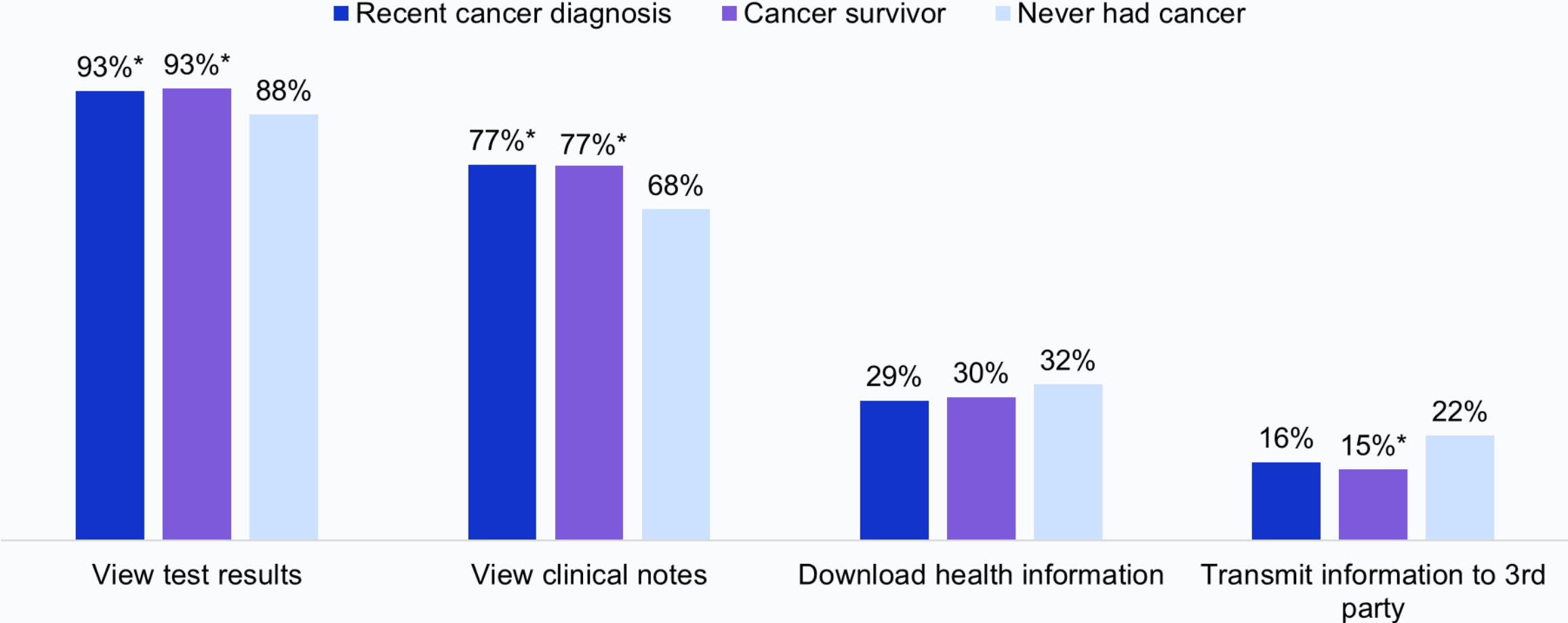


Figure 4. Individuals' use of online medical records or patient portal to view, download, or transmit information by cancer status, 2020-2022.

More than half of individuals with a recent cancer diagnosis reported having multiple patient portals or online medical records.

	Recent cancer diagnosis	Cancer survivor	Never had cancer
Have multiple portals (44%)	59%*	48%	43%
Primary care (63%)	75%*	72%*	61%
Other provider (e.g., specialist) (32%)	51%*	37%	31%
Insurer (29%)	35%	25%	29%
Clinical laboratory (26%)	32%	28%	26%
Pharmacy (23%)	26%	20%	24%
No portal (22%)	12%*	18%	22%
Mean number of portals (1.73)	2.20*	1.82	1.7
Use 3rd party app to organize info (5%)	8%	4%	5%

Table 1. Organization or provider types with which individuals have an online medical record or patient portal and use of 3rd party apps to organize information from multiple records or portals, 2022.

Key Takeaways

- Cancer is one of the most prevalent chronic diseases in the US. Nearly 40% of individuals will be diagnosed with cancer at some point during their lifetimes. Thus, it's important to ensure all individuals—especially those navigating a recent diagnosis or cancer survivorship—have easy access to tools to navigate their health and care.
- Our findings indicate that individuals with cancer, particularly those with a recent cancer diagnosis:
 - Are frequent users of patient portals & online medical records
 - Leverage multiple methods of access (although web-based is still most common)
 - Often use their access to view results and notes, but infrequently to download or transmit information
 - Tend to have multiple online medical records with different providers (yet few use 3rd party apps to organize info from different records or portals, despite their potential utility)
- Together findings indicate the importance of continuing targeted efforts to improve patient access and simplify patient navigation which can help promote patient-centered communication, empower patients to make informed decisions about their health and care, and aid delivery of person-centered care.
- **Looking forward:** More work to be done to identify gaps in access and opportunities to meet patient navigation needs (e.g., making it easier to share information with other providers and caregivers) as well as understand provider perspectives on the benefits and challenges to greater patient engagement

Promoting Engagement through Information Sharing

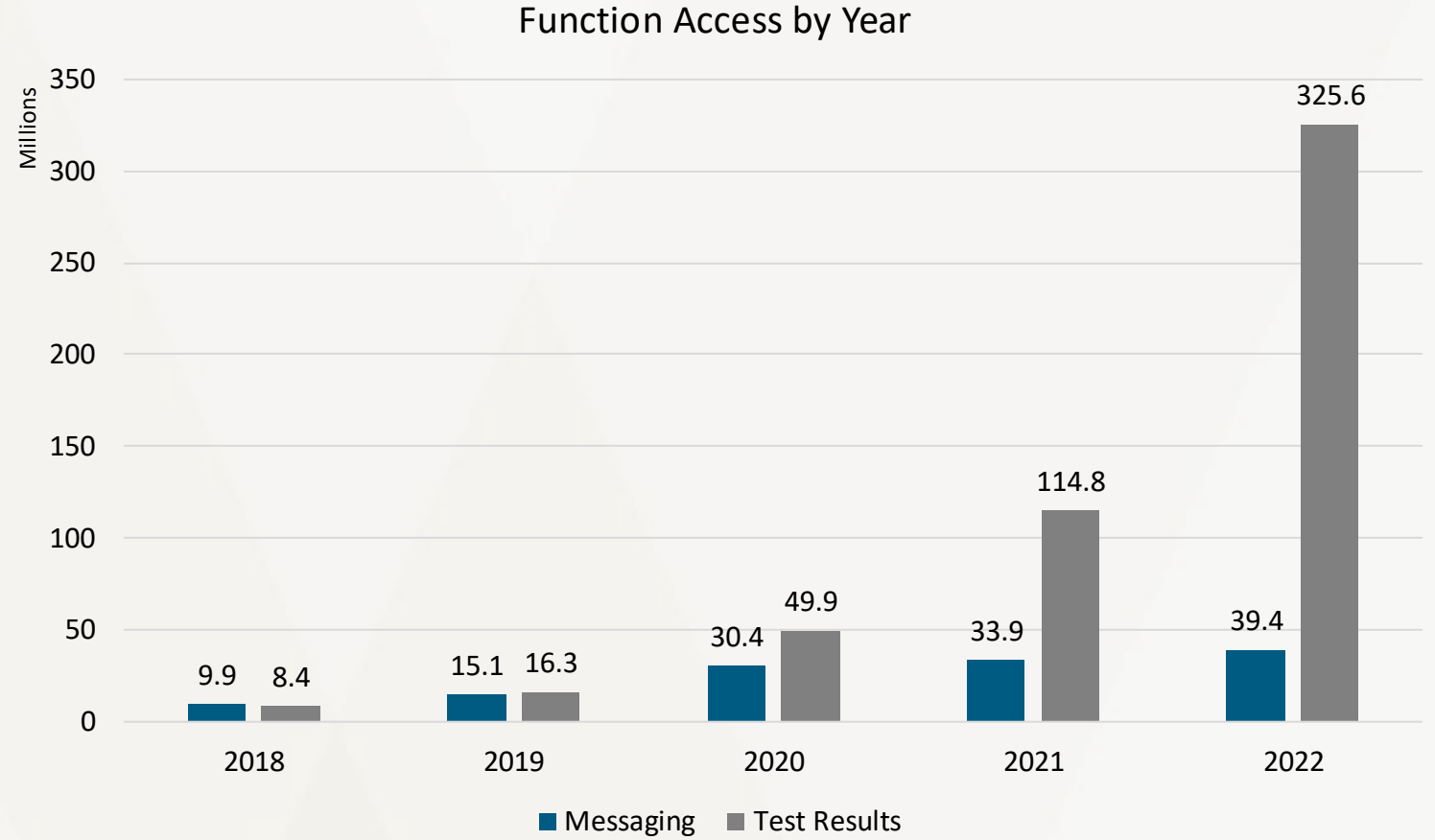
Trends in Patient Access and Review of Cancer-Related Test Results

Bryan Steitz, PhD

Health result review is among the most utilized patient portal function

Most accessed functions

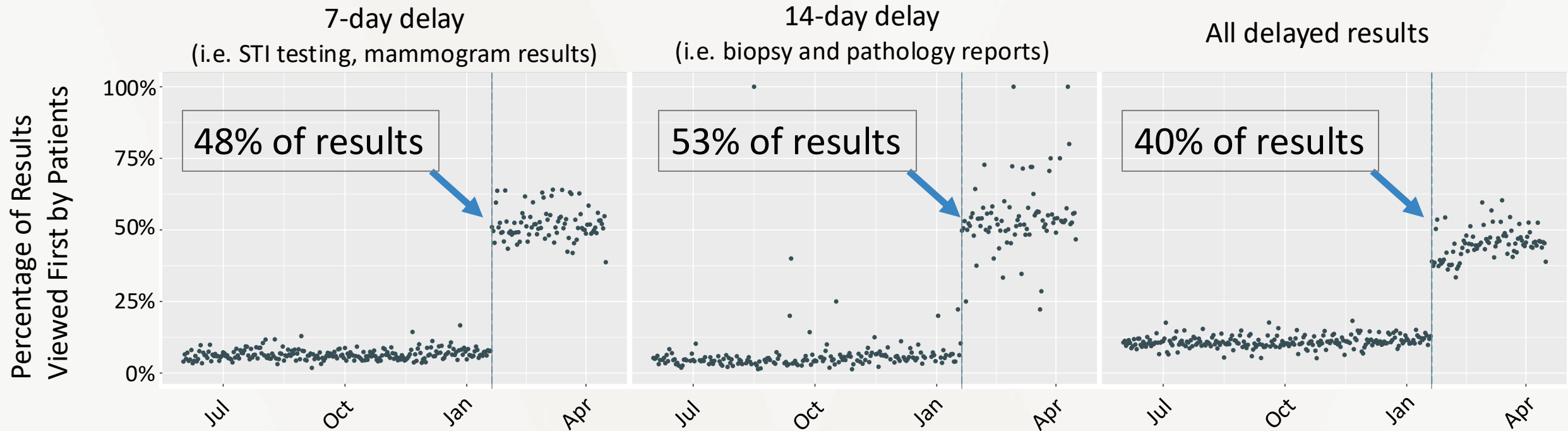
1. Test Results
2. Review Visits
3. Messaging
4. View Provider List



VUMC began Cures Act compliance in January 2021

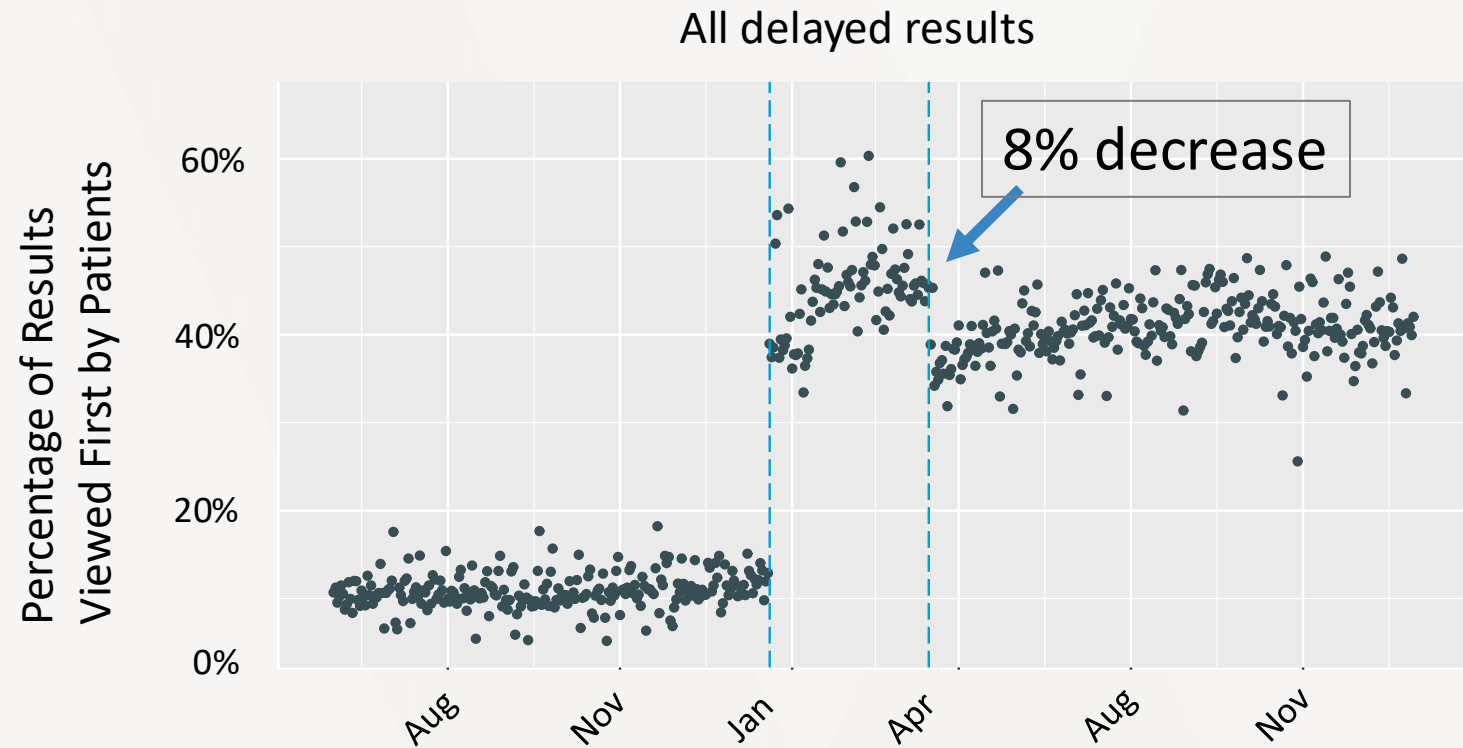
- Cross sectional study of all health results released to the patient portal between July 1, 2020 and December 31, 2021
- Measured the rates at which patients reviewed their test results in the patient portal before their clinician reviewed them
- Stratified analyses by result sensitivity

Patients now see sensitive results before their clinicians



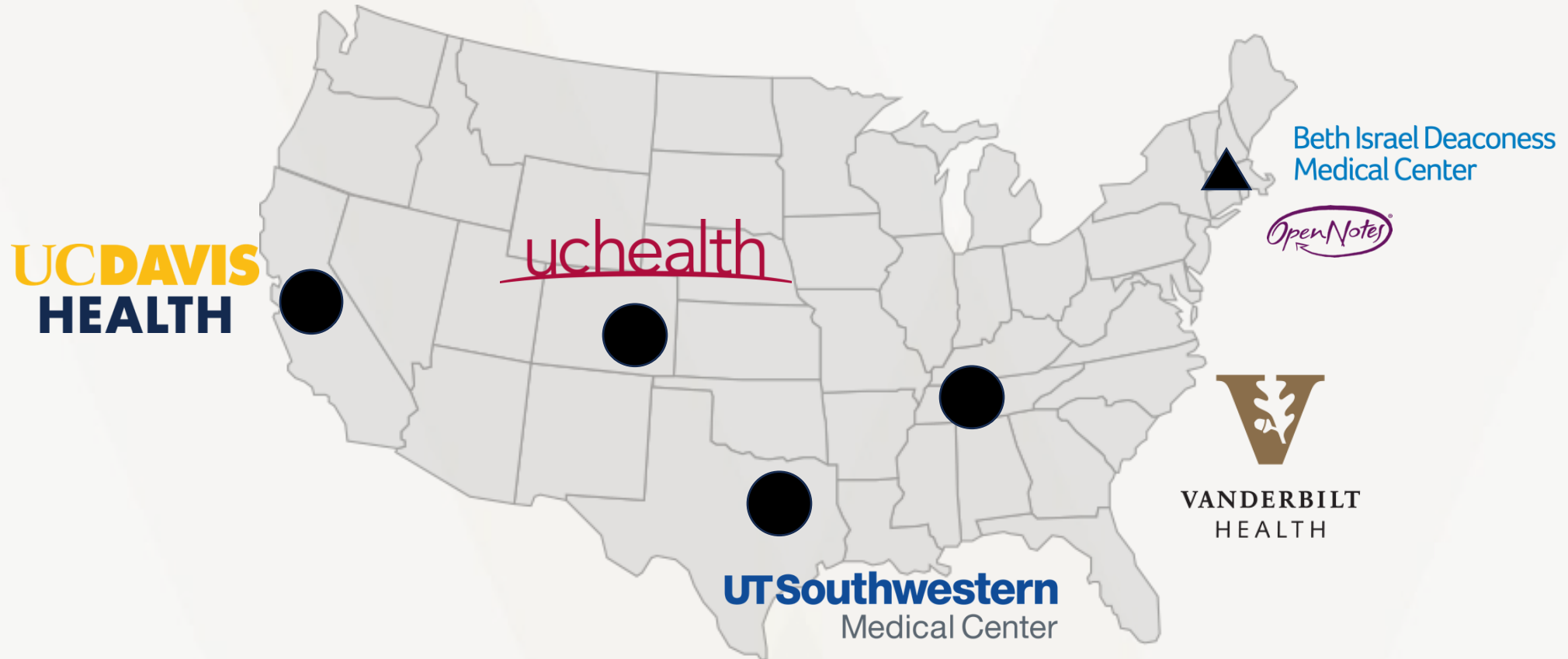
Steitz et al. (2021) Association of Immediate Release of Test Results with Implications for Clinical Workflow. JAMA Netw. Open

Opt-In notification policy associated with decrease in patient-first review



Steitz et al. (2023) Impact of notification policy on patient-before-clinician review of immediately released test results. JAMIA

Surveyed 8139 across 4 medical systems about their preferences toward result release



96%

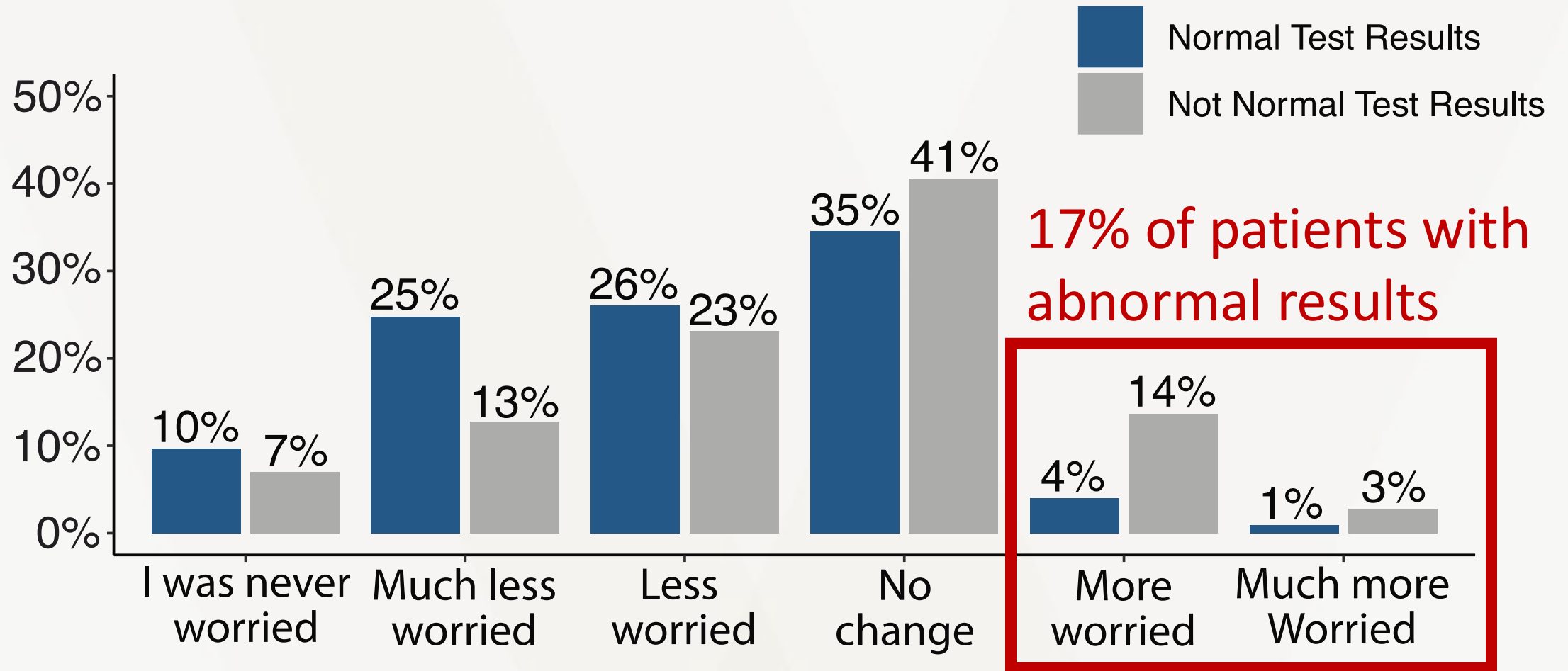
of surveyed patients want to see their
results immediately

Steitz et al. (2023) Perspectives of Patients About Immediate Access to Test Results Through an Online Patient Portal. JAMA Netw. Open

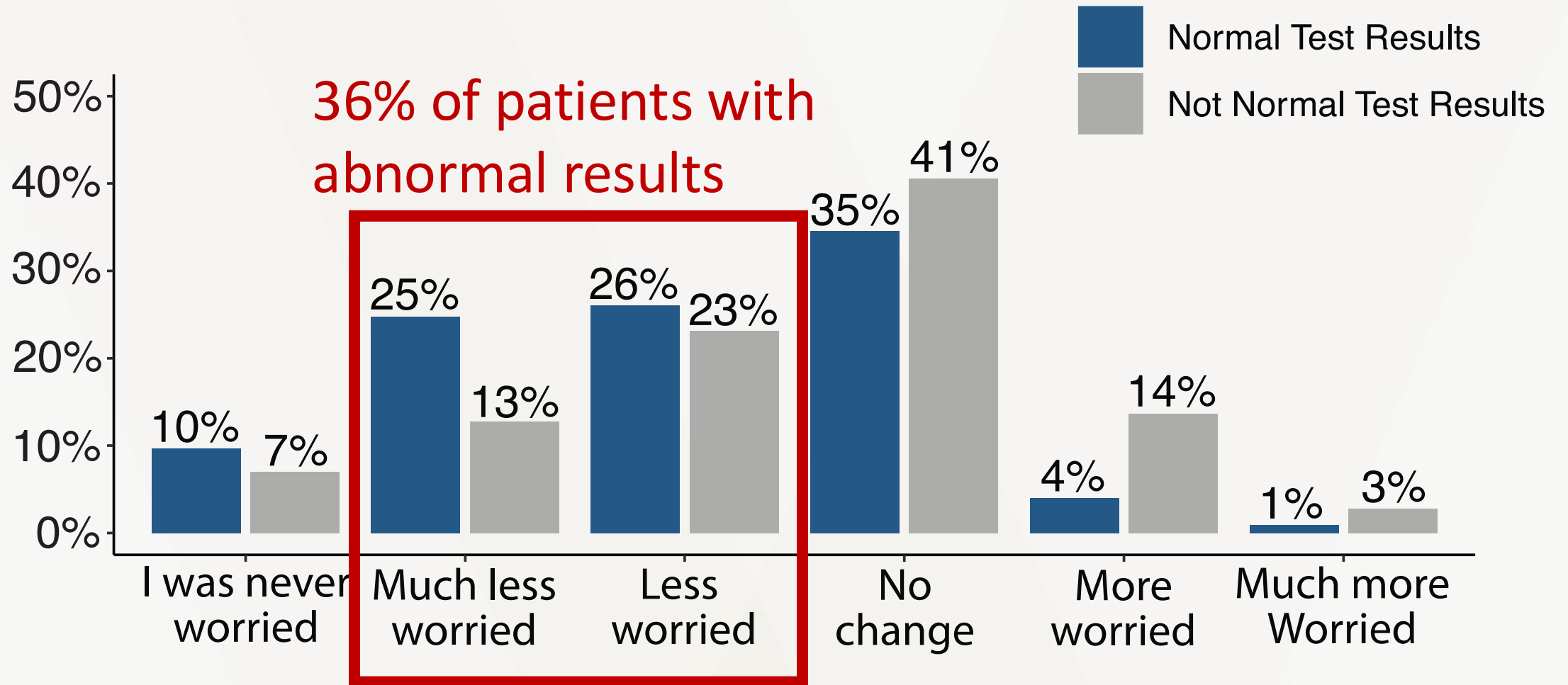
8%

of surveyed patients experienced increased worry

Patients with abnormal tests worried more

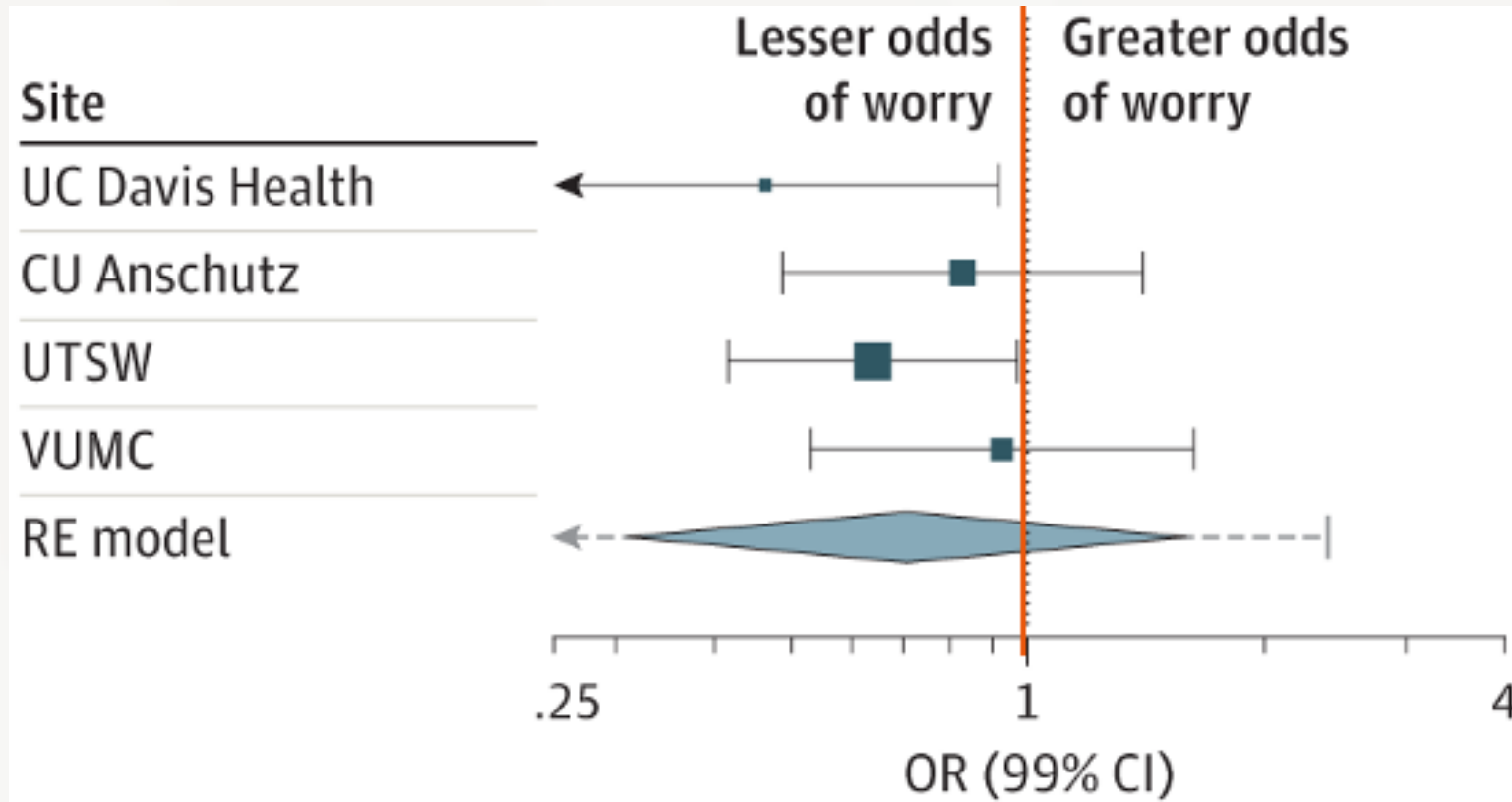


Patients with abnormal tests worried more



...but pre-counseling may help

Association between pre-counseling and reported worry



Additional work is necessary to improve result release

Research Community

- Better understand nuance in result release preferences
- Establish best practice pre-counseling
- Support patients to better understand and use their health information

EHR Vendors

- Allow patients to control their *release* preferences
- Allow patients to control their *notification* preferences

Thank you!

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Policies and Procedures Governing Patient Portal Use at an Academic Medical Center



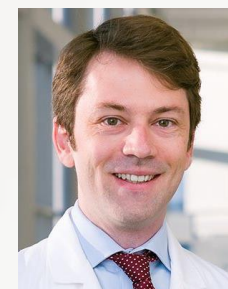
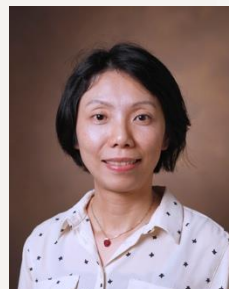
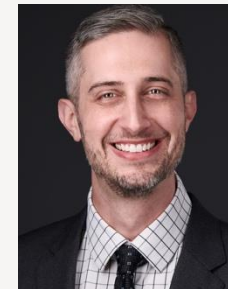
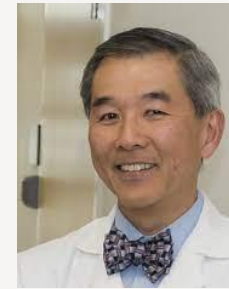
Association of Immediate Release of Test Results to Patients with Implications for Clinical Workflow



Impact Of Notification Policy on Patient-Before-Clinician Review of Immediately Released Test Results



Perspectives of Patients About Immediate Access to Test Results through an Online Patient Portal



Panel Discussion

Empowering Patients: Enhancing Patient Access and Navigation in Cancer Care

Moderator: Stephen Konya



Stephen Konya serves as the Senior Advisor to the Deputy National Coordinator, and Innovation Portfolio Lead for the Assistant Secretary for Technology Policy (ASTP), U.S. Department of Health and Human Services (HHS). In addition to shaping the Agency's long-term strategy, he also serves as the primary liaison to the White House Office of Science and Technology Policy (OSTP) and the external healthcare startup and investor community.

Panelist: Grace Cordovano



Dr. Grace Cordovano, BCPA, founder of Enlightening Results and co-Founder of Unblock Health, is dedicated to providing personalized patient advocacy services, specializing in the oncology space. With over 25 years of advocacy experience, she strategically guides patients through survivorship or end-of-life care planning with empathy, ensuring they are armed with the most pertinent, medically credible, easy to understand information to make informed decisions about their care. Dr. Cordovano is an advocate for leveraging digital technologies to enhance treatment of the whole person in the context of life-altering diagnoses as well as for digital health to give patients a competitive advantage over their diagnosis.

Panelist: Rochelle Prosser



Rochelle Prosser is an Army Mom and a dedicated healthcare founder who has turned her family's struggles with cancer into a mission to help others. This experience led her to create the Prosser Cancer Treatment Library, a comprehensive database of cancer treatment options aimed at reducing the stress and information gaps for other families. Through her company, Orchid Healthcare Solutions, Rochelle provides a Nursing dedicated EHR, cancer education, resources, and healthcare system navigation to patients, oncology providers, and industry partners. Her work focuses on removing health disparity barriers and improving survivorship rates within the African American community.

Audience Q&A

