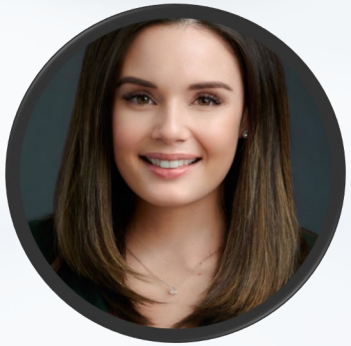
Sensitive Data

Speakers

Nichole Sweeney, J.D.
General Counsel & Chief Privacy Officer
CRISP



Meghan Reading Turchioe, PhD, MPH, RN, FAHA,
Assistant Professor
Columbia University School of Nursing

Consent v. Affirmative Consent

Laws that may impact data availability

Nichole Sweeney, JD
General Counsel and Chief Privacy Officer, CRISP
nichole.sweeney@crisphealth.org

Pop Quiz!

(A) A patient must sign a document to authorize a clinician to share their information with other clinicians and insurance companies.

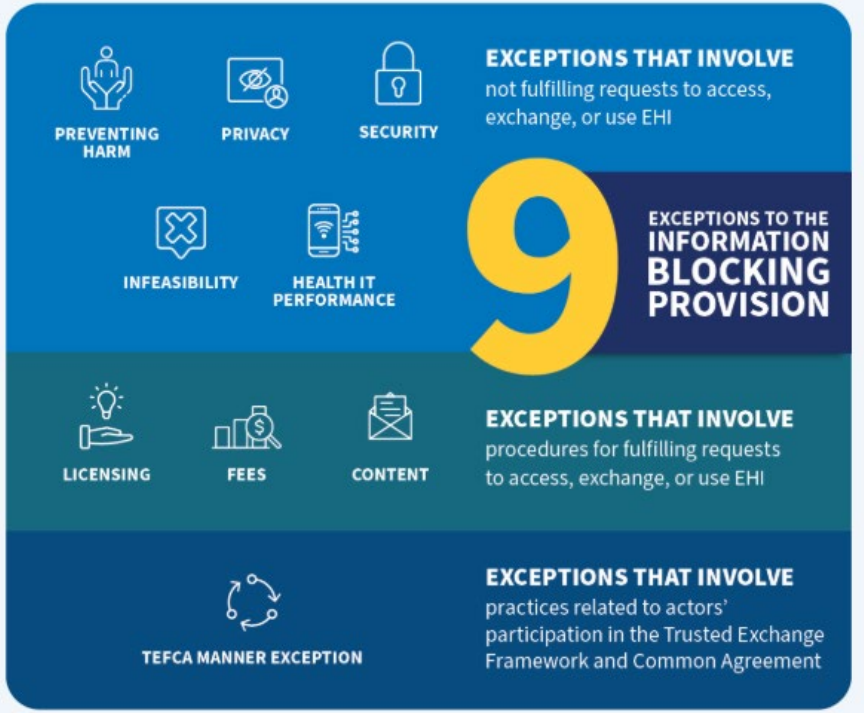
(B) A patient could write “DO NOT SHARE MY INFORMATION” on every document they receive at a clinician’s office, and the clinician could still share their information with other clinicians and insurance companies.

Pop Quiz!

True or False:

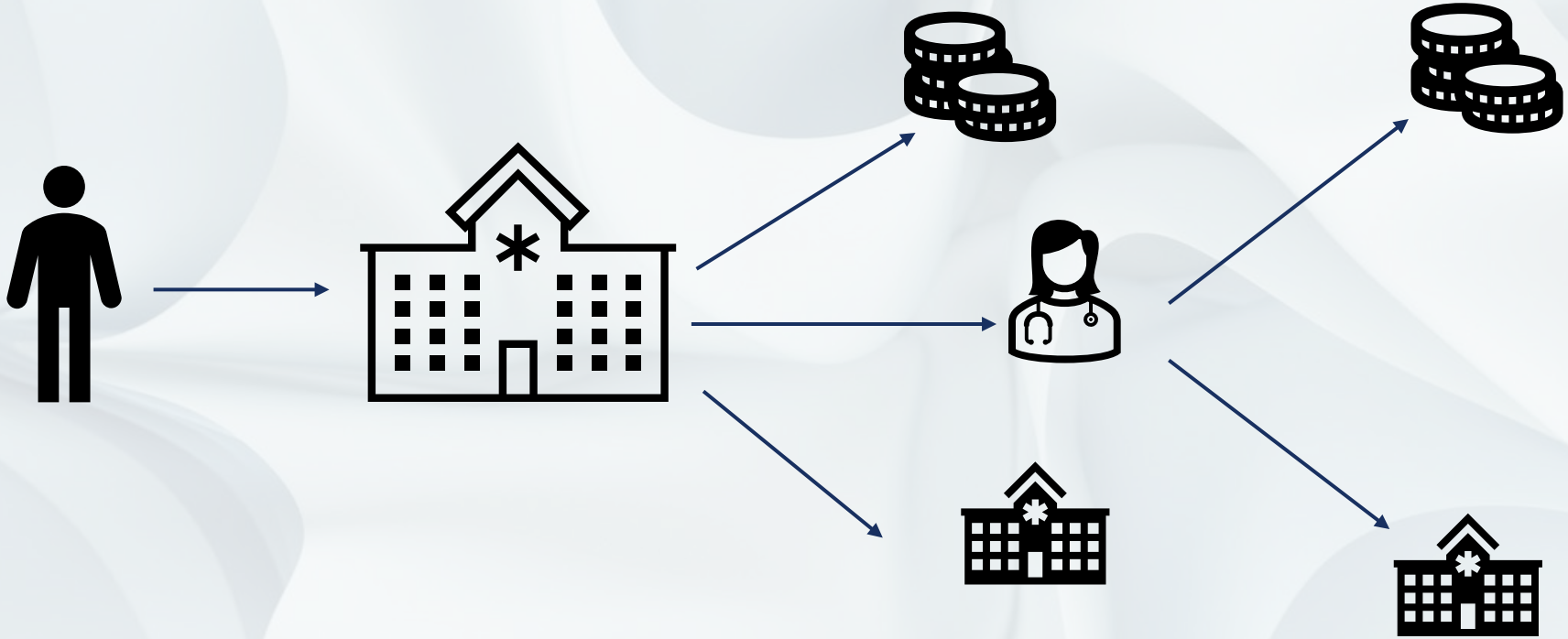
A clinician can decide when and

how to share data about a patient.



Information Blocking | HealthIT.gov

(Most)
HIPAA-Covered Entities and their Business Associates



e/PHI may be shared for treatment, payment, and operations WITHOUT CONSENT

[eCFR :: 45 CFR 164.506 -- Uses and disclosures to carry out treatment, payment, or health care operations.]

*notable exceptions: psychotherapy notes and self-pay

Federal Laws Requiring *Affirmative, Written Consent*

42 CFR Part 2

information

[Disclosure of Substance Use Disorder Patient Records (samhsa.gov)]

entity

"holding itself out" as providing SUD treatment services

receiving federal funding (e.g., Medicare, Medicaid, grants)

Maryland Laws Requiring *Affirmative, Written Consent*

- **Md. Health. Gen. § 4-302.5:**
  - A **health information exchange or electronic health network** may not disclose . . . sensitive health services as determined by the Secretary **without patient consent**
  - "Sensitive Health Services" are certain **code sets** the Secretary determines applicable
    - The Commission has authority to include **additional codes** related to services outside of abortion services
  - Health information exchanges **include electronic health records**

Other State / Territory Laws Requiring *Affirmative, Written Consent*

- Massachusetts, HIV Testing: General Law - Part I, Title XVI, Chapter 111, Section 70F
- California, Reproductive Data: Bill Text: CA AB352 | 2023-2024 | Regular Session | Chaptered | LegiScan
- Many States: Behavioral Health
- Other Restrictions: Adolescent Data

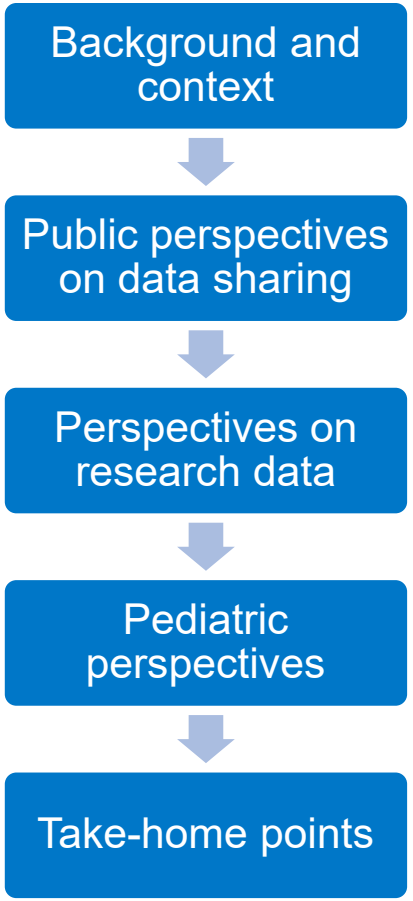
Impact to Data Availability

- Substance Use Disorder treatment information AND other information from 42 CFR Part 2 facilities
  - Medication Assisted Treatment medications
- Codes related to abortion (Maryland)
  - Mifepristone
- Behavioral health diagnoses and psychotherapy notes

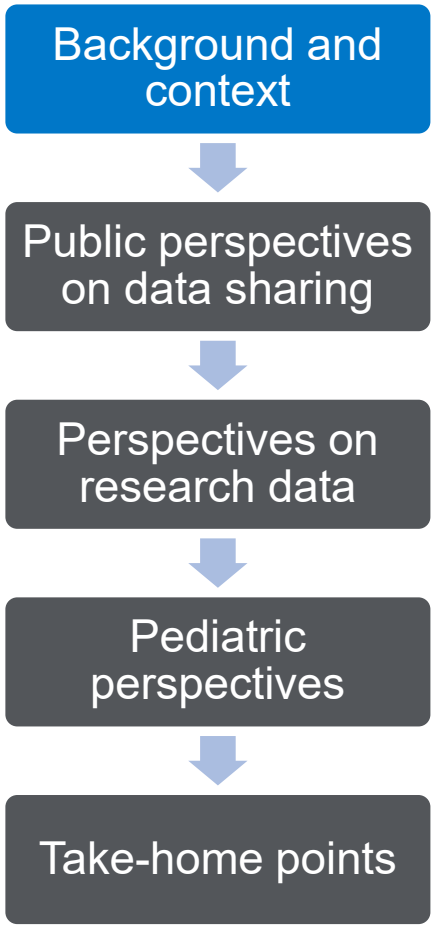
CRISP SUMMIT: SENSITIVE DATA

Meghan Reading Turchioe, PhD, MPH, RN, FAHA
Assistant Professor
Columbia University School of Nursing

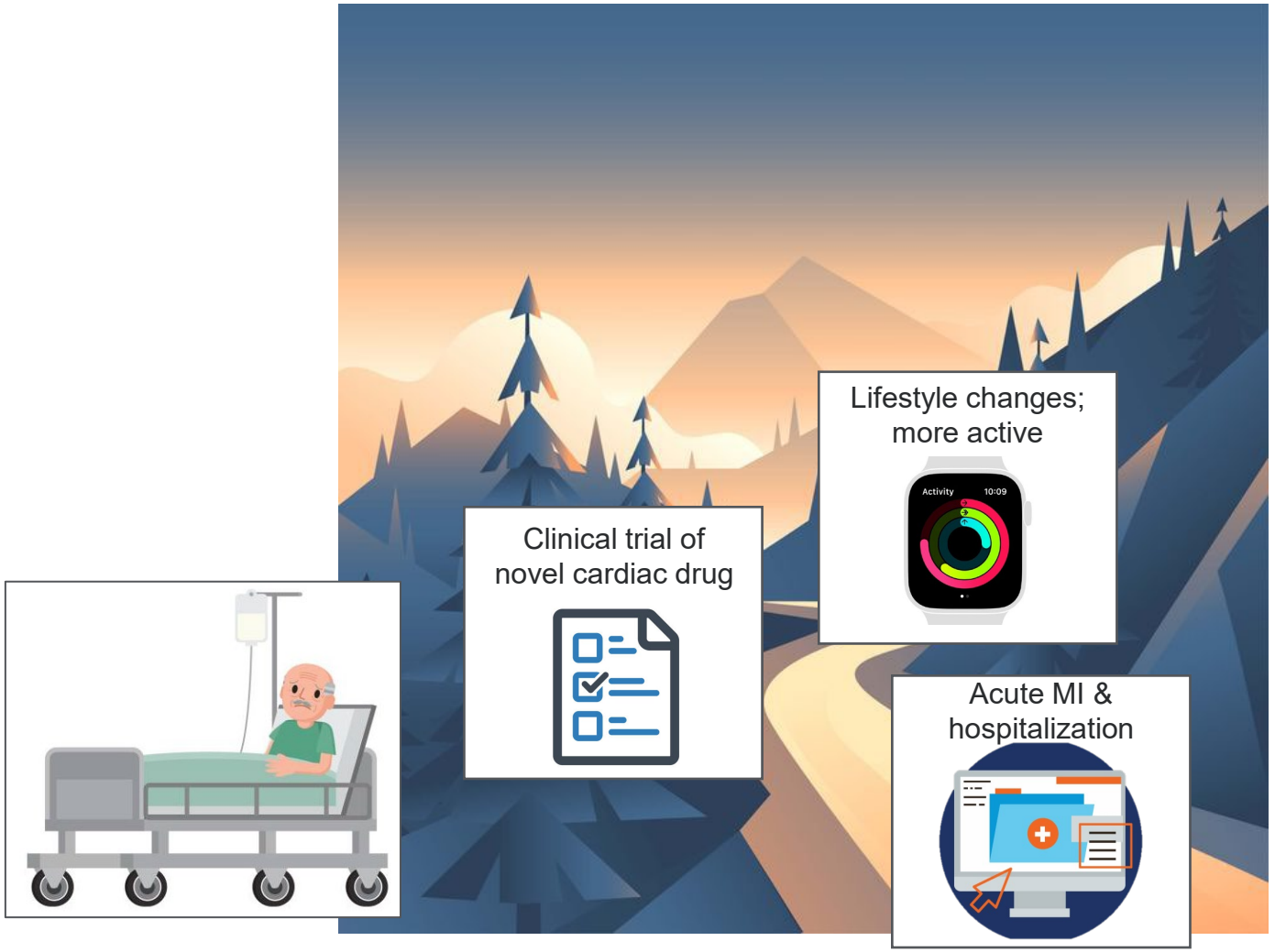
Overview of today's talk



Overview of today's talk

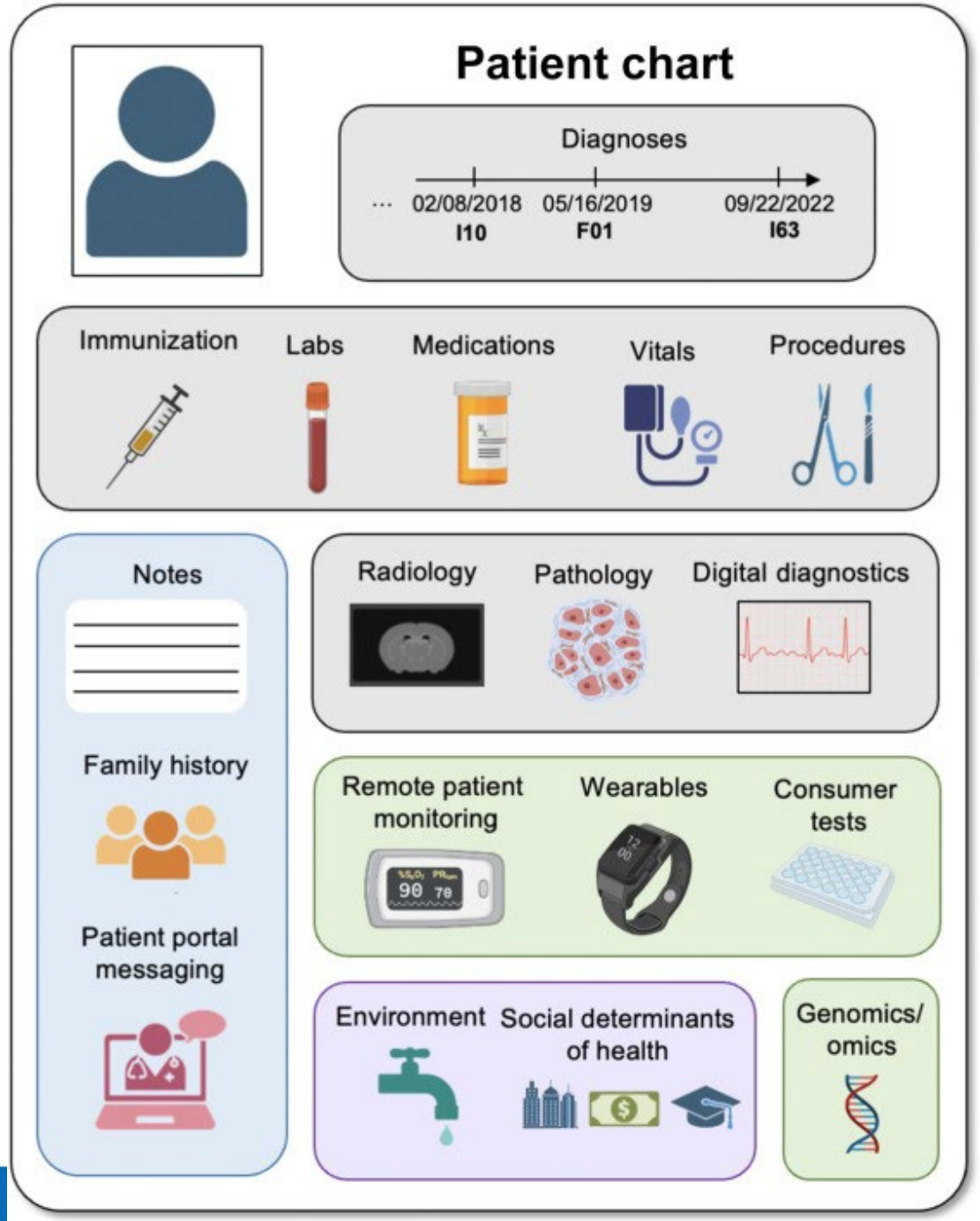


Electronic “breadcrumbs” generated by patients



The value in these “breadcrumbs”

- **Improved patient care**
- Generating disease phenotypes
- Studying behavior change
- Evaluating symptom and quality of life outcomes
- Machine learning algorithms
- Clinical decision support
- Patient decision support and engagement


Patient chart
Diagnoses
02/08/2018
I10
05/16/2019
F01
09/22/2022
I63
Immunization
Labs
Medications
Vitals
Procedures
Notes
Family history
Patient portal messaging
Radiology
Pathology
Digital diagnostics
Remote patient monitoring
Wearables
Consumer tests
Environment
Social determinants of health
Genomics/ omics
Trends in Molecular Medicine

What is Sensitive Health Data?

Definition: Health data that, if disclosed, could cause harm or distress to an individual, such as stigma, discrimination, or legal risk.
(Source: European Union Agency for Fundamental Rights, 2015)

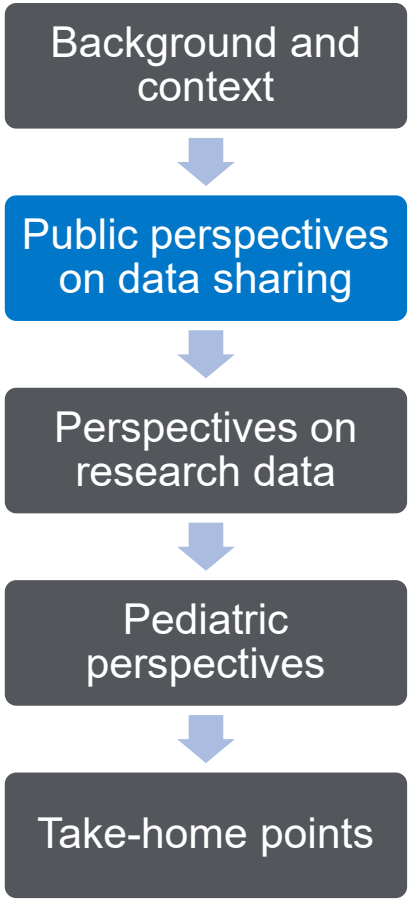
Examples include:

- Sexual and reproductive health information
- Mental health diagnoses and treatment history
- Genetic and biometric data
- Substance use and addiction history
- -Data from health apps and wearables

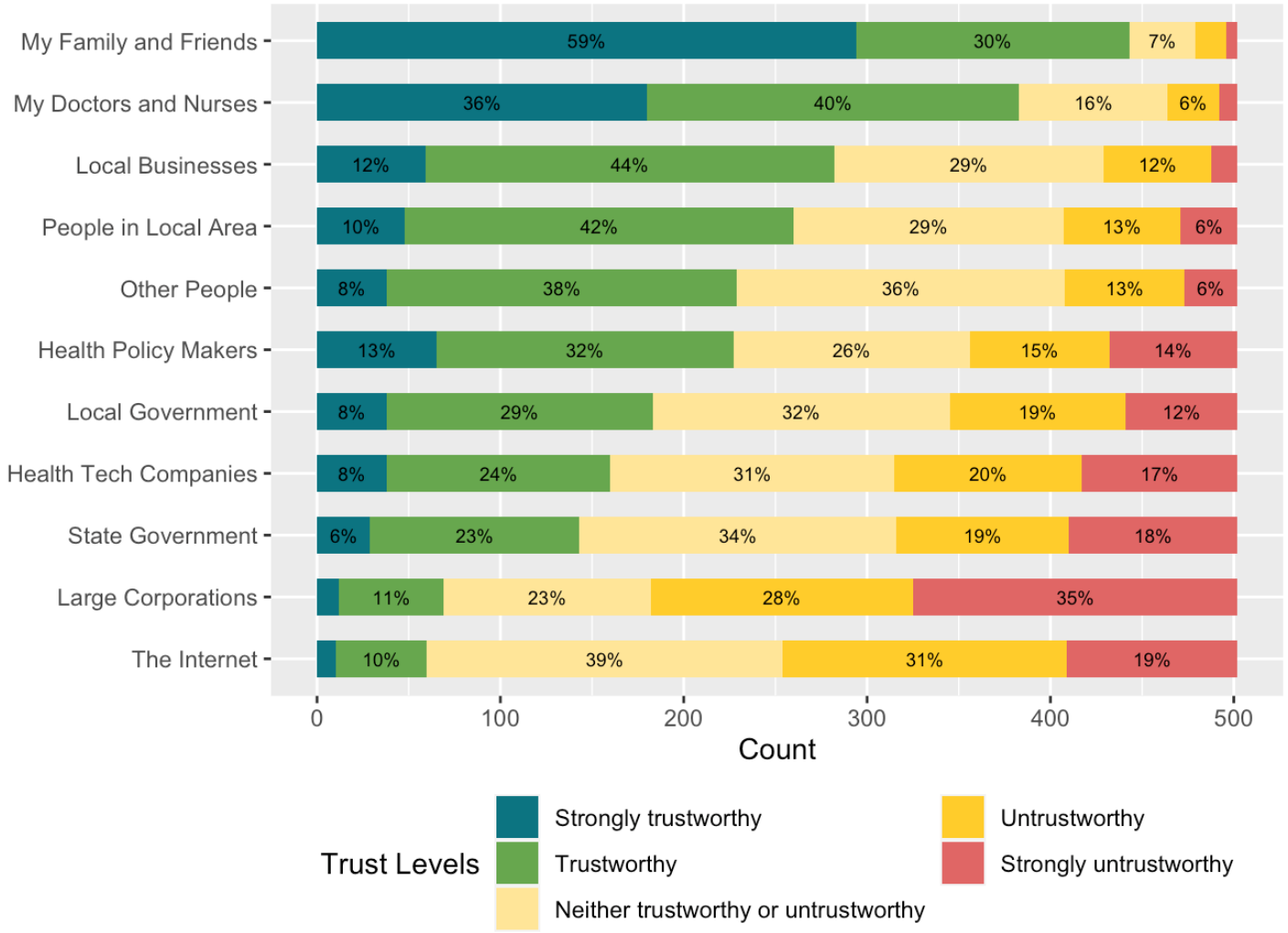
The context for patient concerns

- Prior research shows participants worry about:
  - Misuse of data
  - Re-identification of 'anonymized' datasets
  - Commercial exploitation
- Sensitive data (e.g., reproductive, mental health) evokes additional concern, especially post-Roe v. Wade.
- Underrepresented racial groups may be particularly wary due to historical injustices in research.

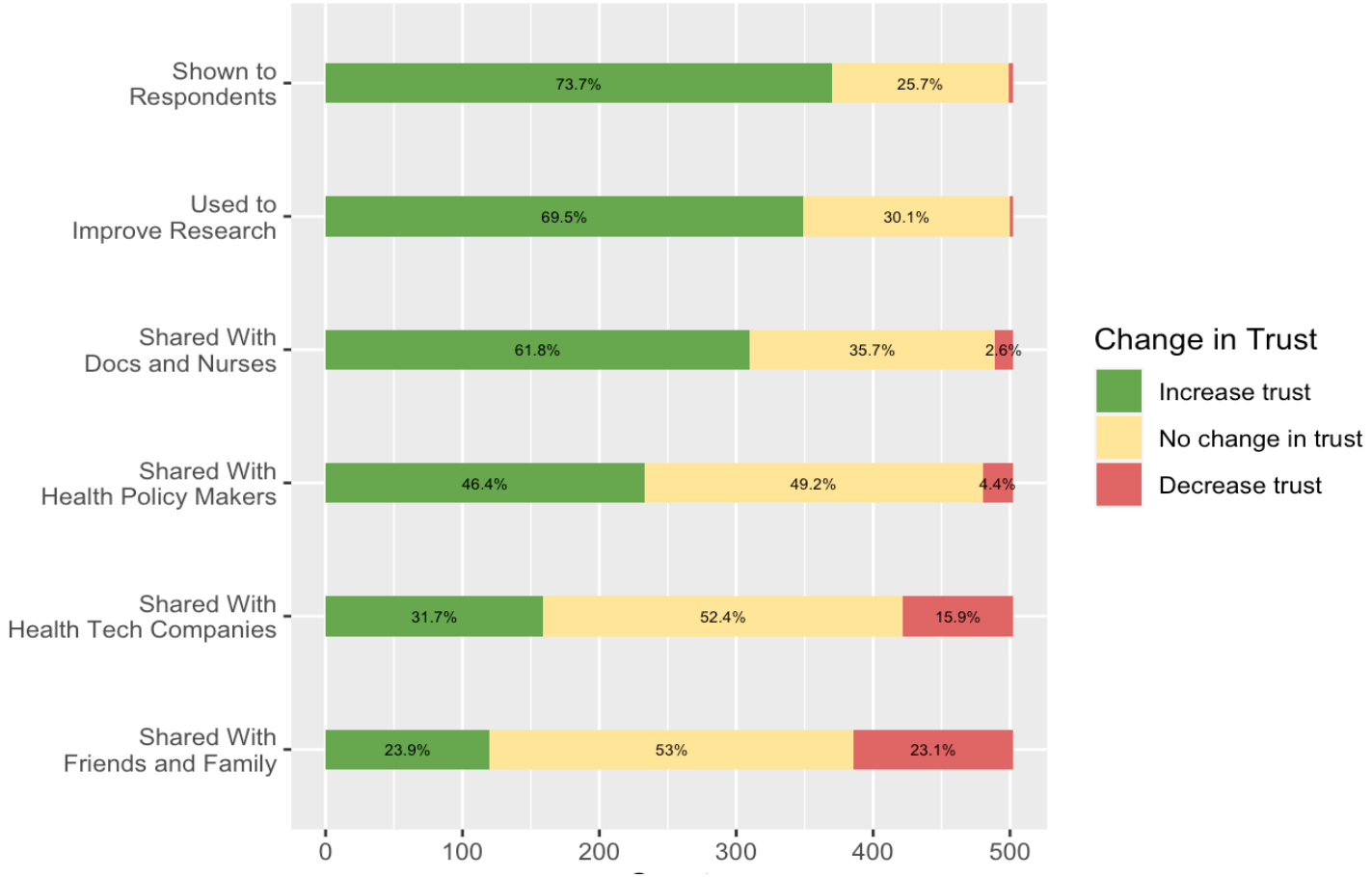
Overview of today's talk



Baseline trust in different recipients varies.



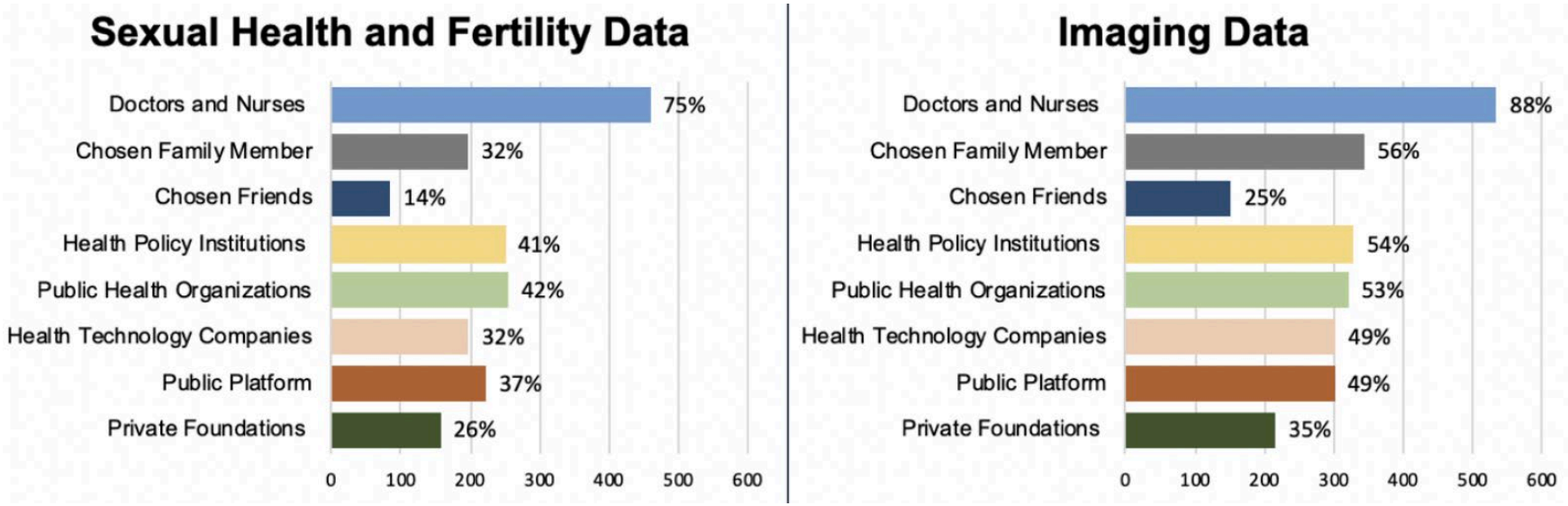
Trust changed depending on who the data was shared with.



All data is not equal.

Sharing preferences vary based on the type and recipients of that data.

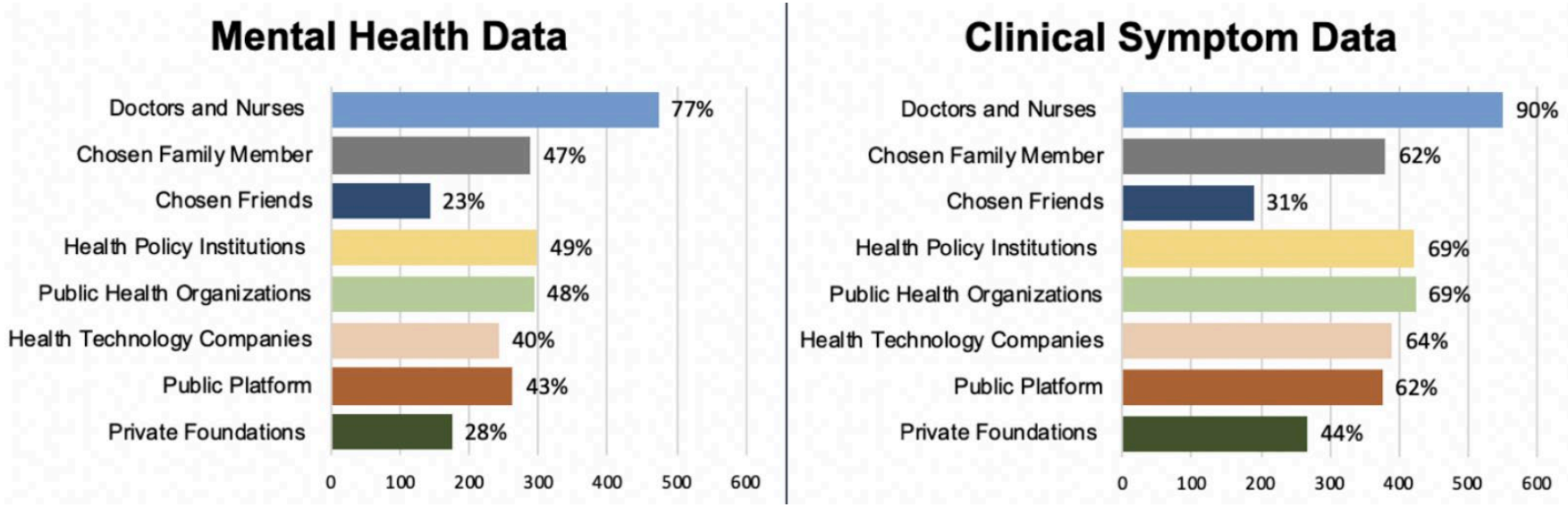
Example 1



All data is not equal.

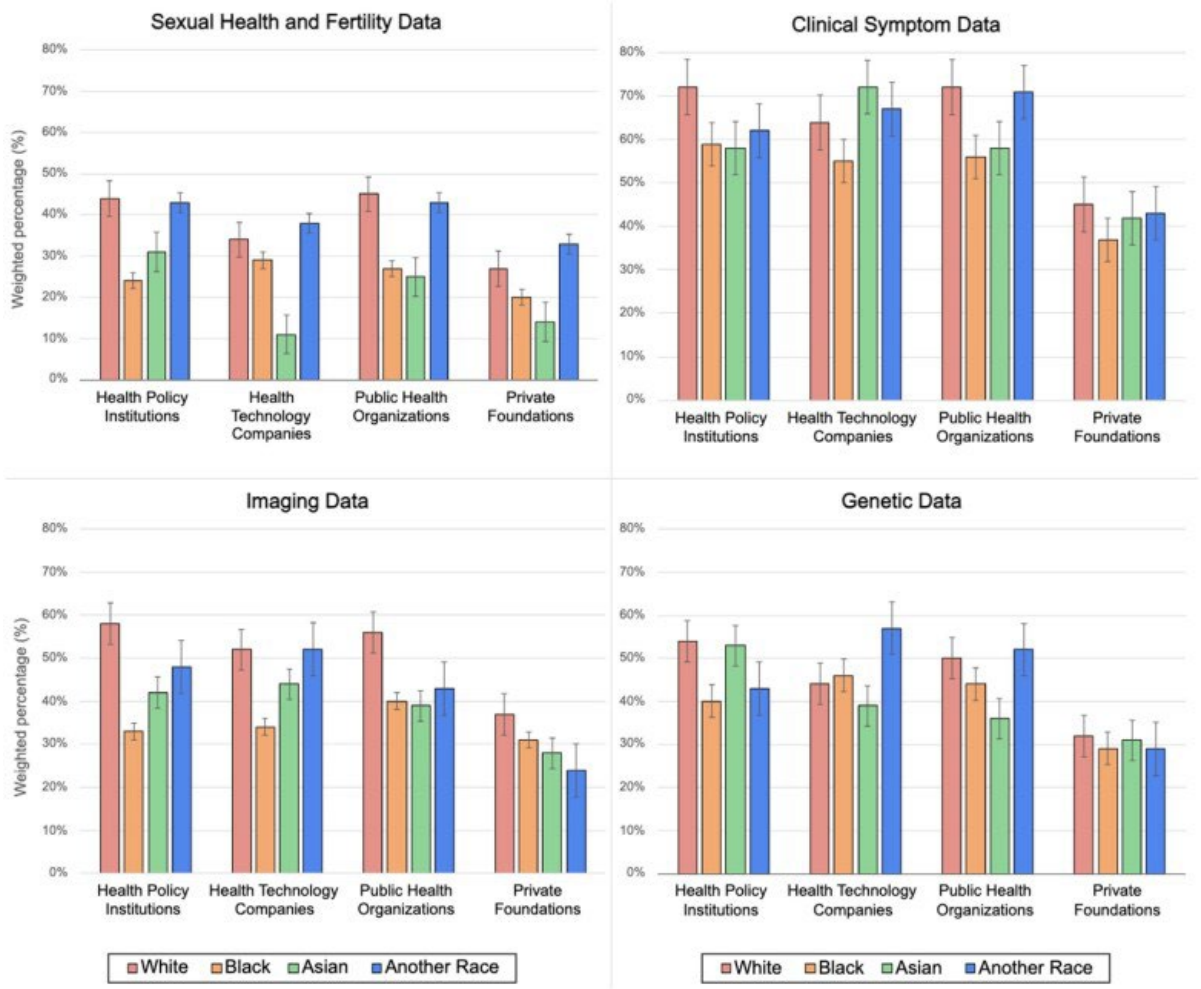
Sharing preferences vary based on the type and recipients of that data.

Example 2



Preferences differ by racial/ethnic group

Sharing preferences for sharing specific types of data (sexual health and fertility, clinical symptom, imaging, and genetic data) with external recipients by different racial groups.



Do you have concerns with increased data sharing practices?

Supported limiting access to data

"While I agree that it can help to make positive changes, I would 100% want to know which outside companies they're talking about before I would be willing...it does decrease my willingness."

Advocated for greater autonomy

"Though I completely understand the positives of what making information public would bring, people still deserve the right to choose to have that type of [data] private."

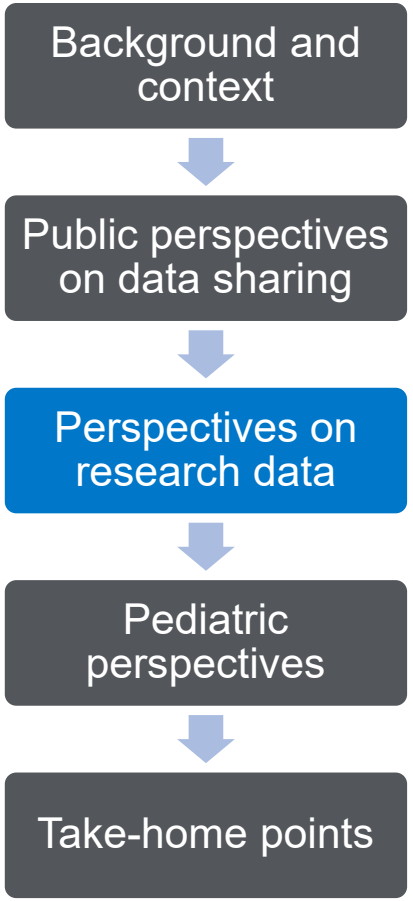
Prioritized remaining anonymous

"By combining information from multiple sources, it is possible to de-anonymize data. If you know my age, zip code and income, you are a long way towards knowing who I am."

Wanted greater transparency

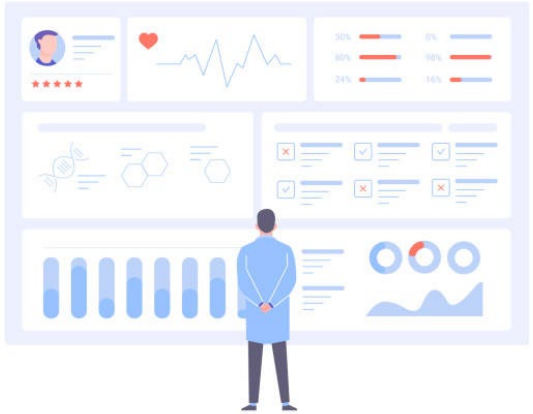
"I would need to know exactly which public groups would have access. Neighbors? Insurance companies?"

Overview of today's talk

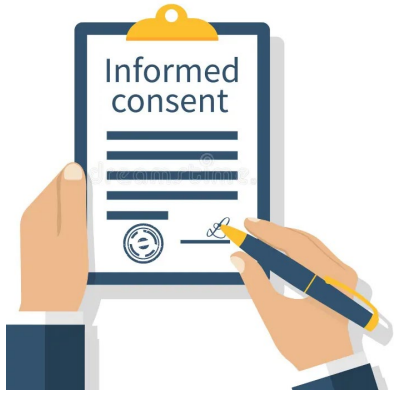


1. Evolving Data Sharing Policies encourage **increased data sharing** (e.g., public repositories)

NIH SCIENTIFIC DATA SHARING



2. Participants usually grant **broad consent** without clear knowledge of future data use.



Evaluated perspectives for sharing specific types of data with specific groups, and strategies to enhance trust in data sharing practices.

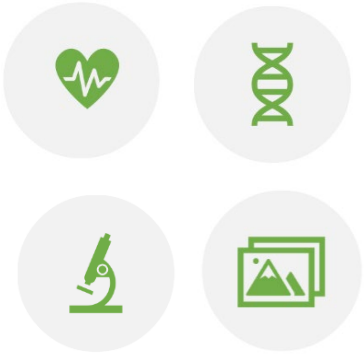
Online survey using Prolific

US representative survey

610 participants

Logistical regression models assessed sociodemographic variances

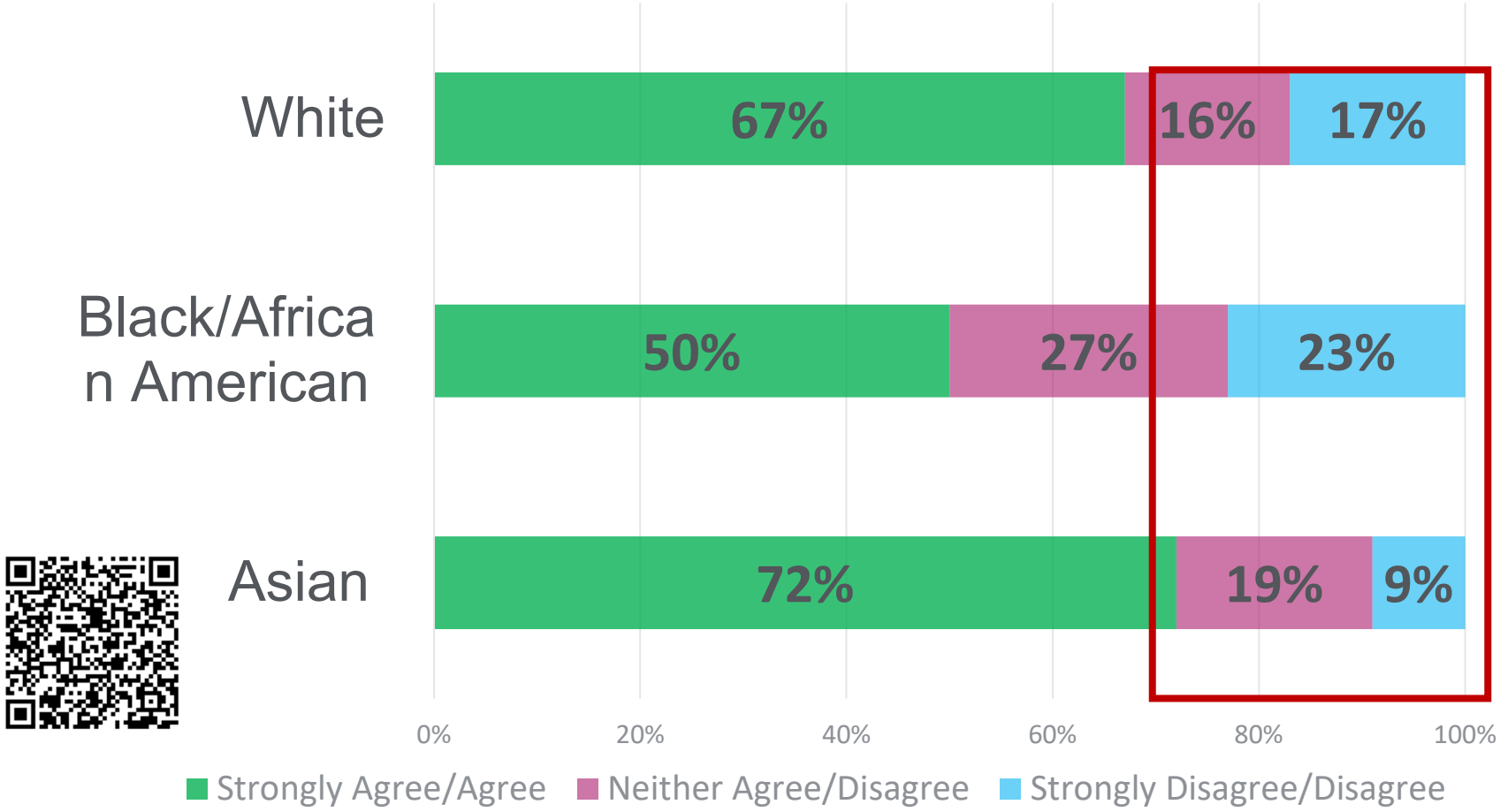
National Institutes of Health Data Management and Sharing Policy (2023)



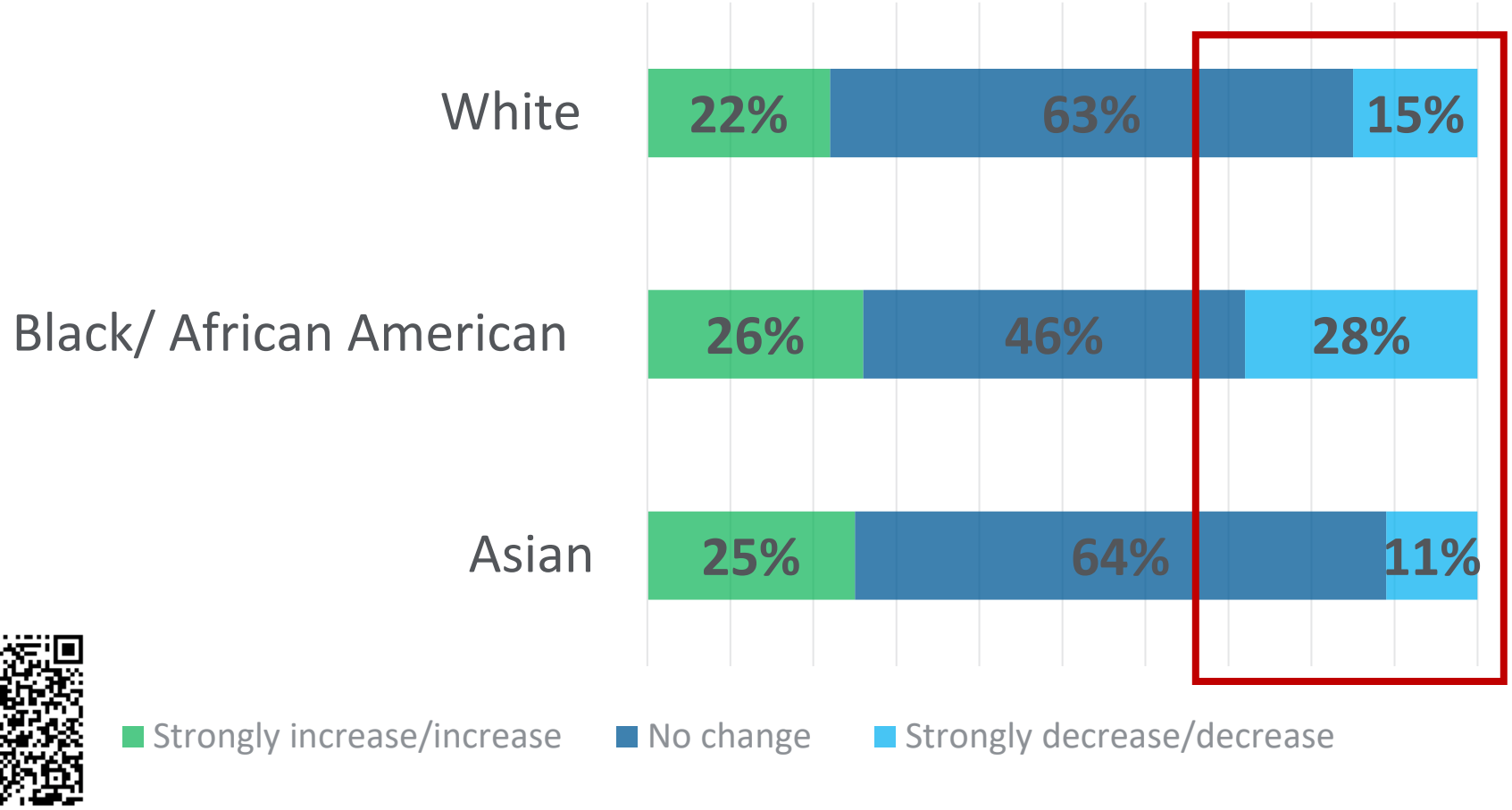
Types of data participants are willing to share

Preferences for data sharing with external groups

Most people agree; yet, 9-23% of participants **strongly disagreed** with the updated NIH policy.



Does the NIH's new efforts **change your willingness** to participate in a research study?



Key Themes from Open-Ended Responses

Support depends on trust, control, and clear communication.

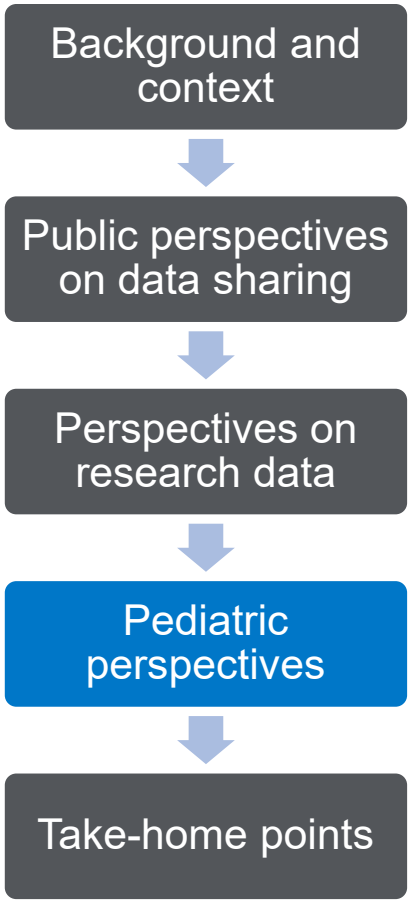
Top qualitative themes from 302 responses:

- Value in advancing research
- Want limits on access, especially for commercial entities
- Prioritized anonymity, autonomy, and transparency

"It is my information, and I should be in charge of where it goes and who can access it."

"All the policies in the world are great, but there is no safe data."

Overview of today's talk



What about sensitive pediatric data?

Research Letter

October 7, 2024

Portal Confidentiality Concerns and Health Information Sharing and Access

Marianne Sharko, MD, MS[1]; Stephanie Niño de Rivera, BA[2]; Natalie Benda, PhD[2]; Meghan Reading Turchioe, PhD, MPH, RN[2]; Xiaoyue Ma, MSc[1]; Ruth Masterson Creber, PhD, MSc[2]; Erika L. Abramson, MD, MS[1]

☐Author Affiliations | Article Information

JAMA Pediatr. 2024;178(12):1373-1375. doi:10.1001/jamapediatrics.2024.3688

Adolescent population - at risk for having sensitive healthcare information

Behavioral health

- Substance use, addiction

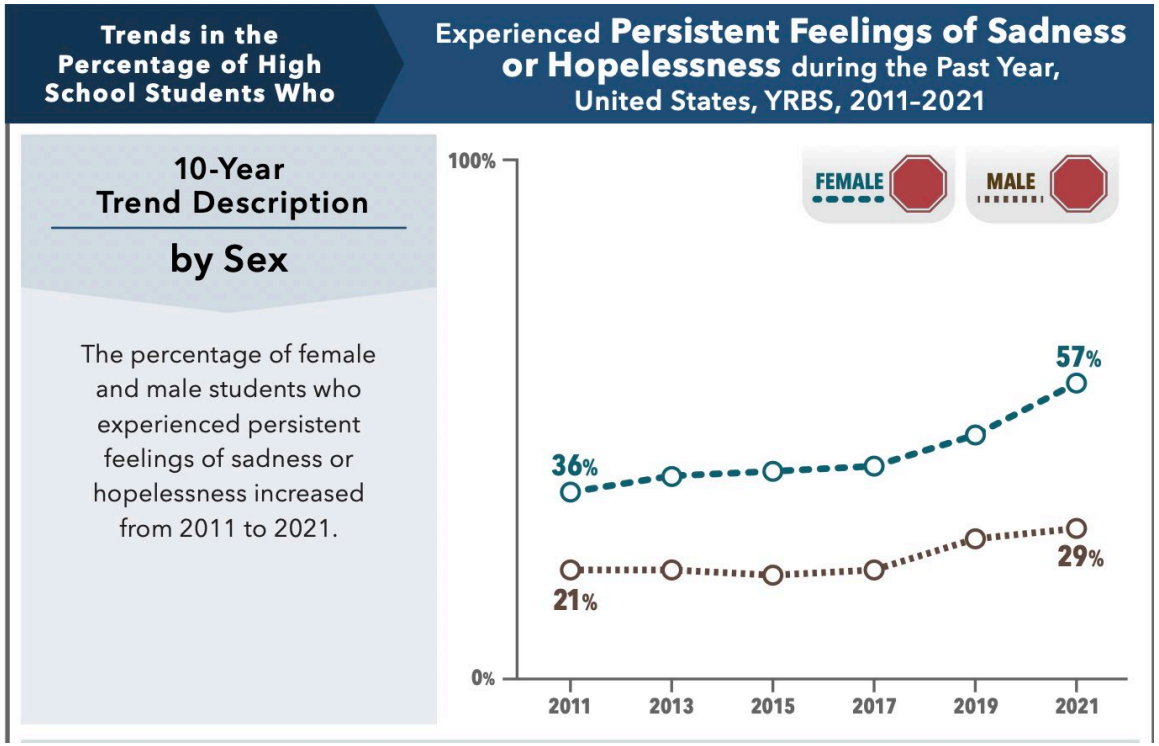
Mental health

- Anxiety, depression, eating disorders

Sexual/reproductive health

- Sexually transmitted infections, unplanned pregnancies

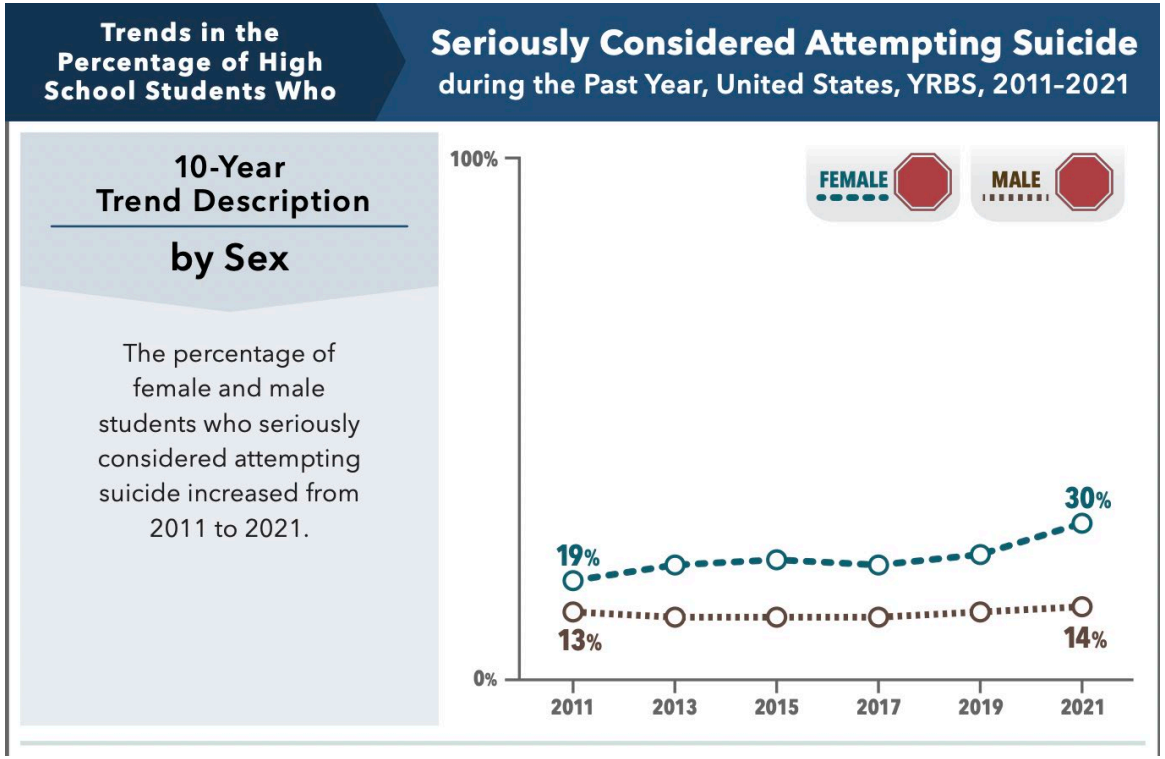
CDC National Youth Risk Behavior Survey 2021



https://youth.gov/feature-article/2011-2021-yrbs-data-summary-and-trends-report

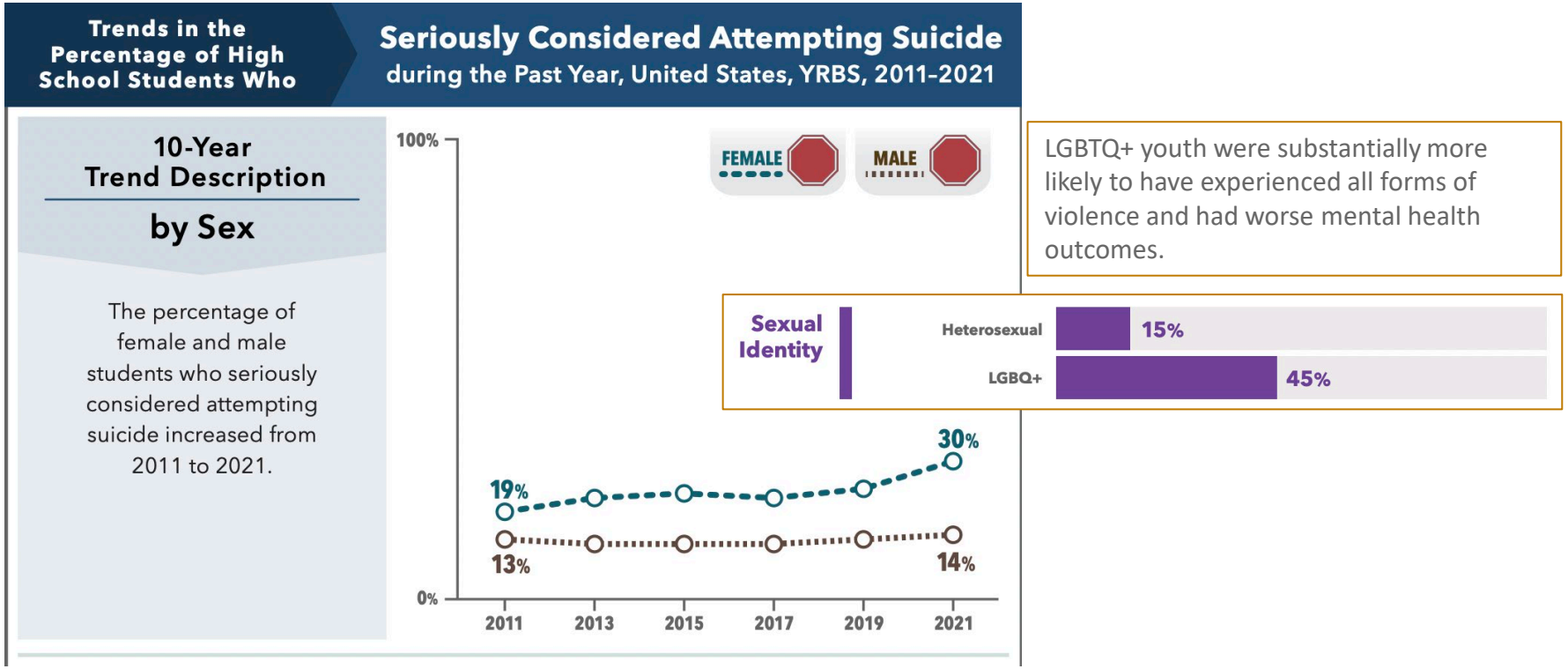
Teens - experiencing increasingly high levels of violence, sadness, and suicide risk.

CDC National Youth Risk Behavior Survey 2021



https://youth.gov/feature-article/2011-2021-yrbs-data-summary-and-trends-report

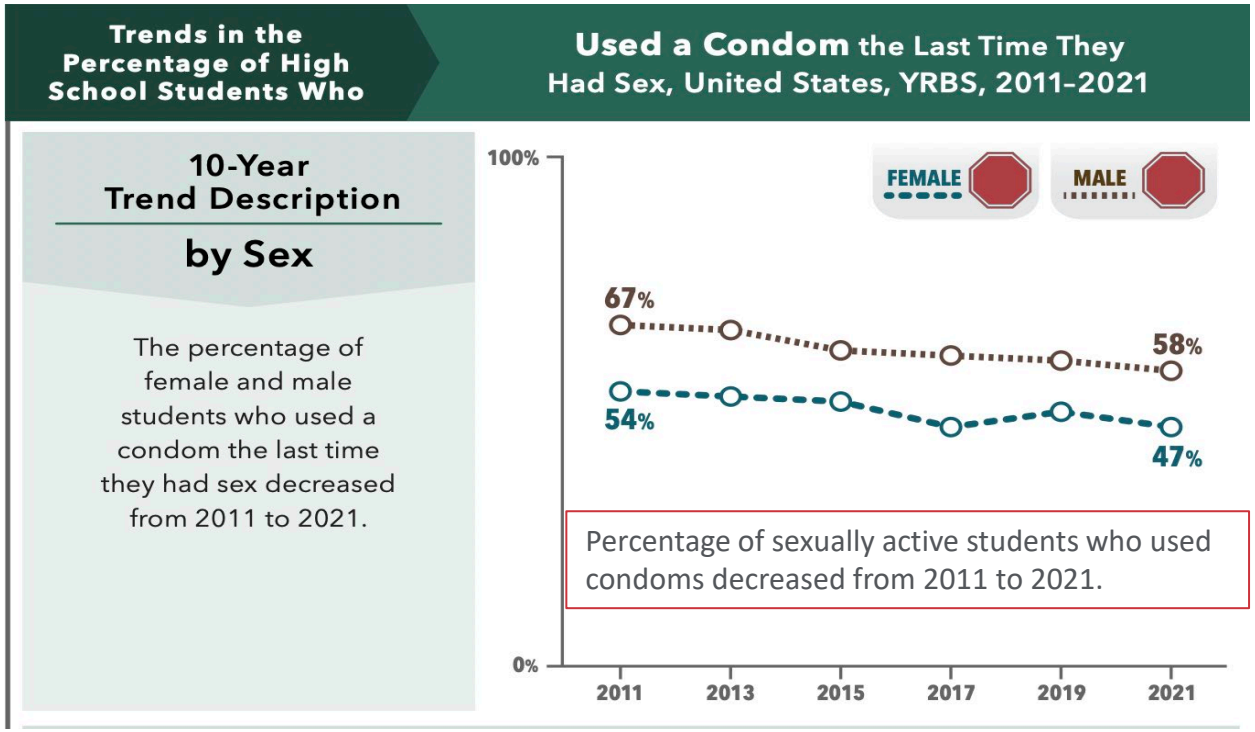
CDC National Youth Risk Behavior Survey 2021



LGBTQ+ youth were substantially more likely to have experienced all forms of violence and had worse mental health outcomes.

https://youth.gov/feature-article/2011-2021-yrbs-data-summary-and-trends-report

CDC National Youth Risk Behavior Survey 2021



Only about half of sexually active students used a condom the last time they had sex.

https://youth.gov/feature-article/2011-2021-yrbs-data-summary-and-trends-report

Adolescents rely on privacy to share sensitive health information

> JAMA. 2002 Aug 14;288(6):710-4. doi: 10.1001/jama.288.6.710.

Effect of mandatory parental notification on adolescent girls' use of sexual health care services

Diane M Reddy [1], Raymond Fleming, Carolyne Swain

> J Adolesc Health. 2007 Mar;40(3):218-26. doi: 10.1016/j.jadohealth.2006.09.015. Epub 2006 Dec 14.

Forgone health care among U.S. adolescents: associations between risk characteristics and confidentiality concern

Jocelyn A Lehrer [1], Robert Pantell, Kathleen Tebb, Mary-Ann Shafer

Affiliations + expand

PMID: 17321421 DOI: 10.1016/j.jadohealth.2006.09.015

JAMA Pediatr. 2018 Mar 1; 172(3): 209–210. PMID: 29309491
doi: 10.1001/jamapediatrics.2017.3927

I Thought You Said This Was Confidential? Challenges to protecting privacy for teens and young adults

Lauren E. Wisk, PhD, Susan H. Gray, MD, and Holly C. Gooding, MD, MSc

Clinical Trial > JAMA. 1997 Sep 24;278(12):1029-34.

Influence of physician confidentiality assurances on adolescents' willingness to disclose information and seek future health care. A randomized controlled trial

C A Ford [1], S G Millstein, B L Halpern-Felsher, C E Irwin Jr

> JAMA. 1995 Jun 28;273(24):1913-8.

Adolescents' perceptions of factors affecting their decisions to seek health care

K R Ginsburg [1], G B Slap, A Cnaan, C M Forke, C M Balsley, D M Rouselle

> Issues Compr Pediatr Nurs. Apr-Jun 2006;29(2):73-88. doi: 10.1080/01460860600677577.

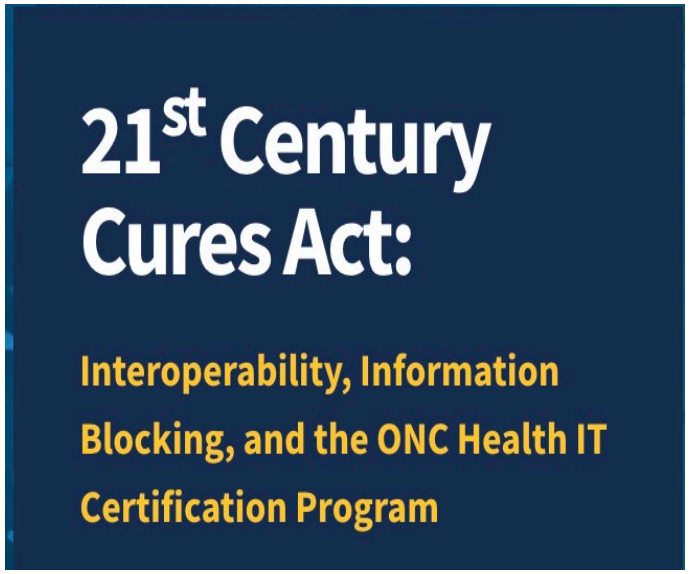
Barriers to sexual and reproductive health care: urban male adolescents speak out

Claire Lindberg [1], Carolyn Lewis-Spruill, Rodney Crownover

Affiliations + expand

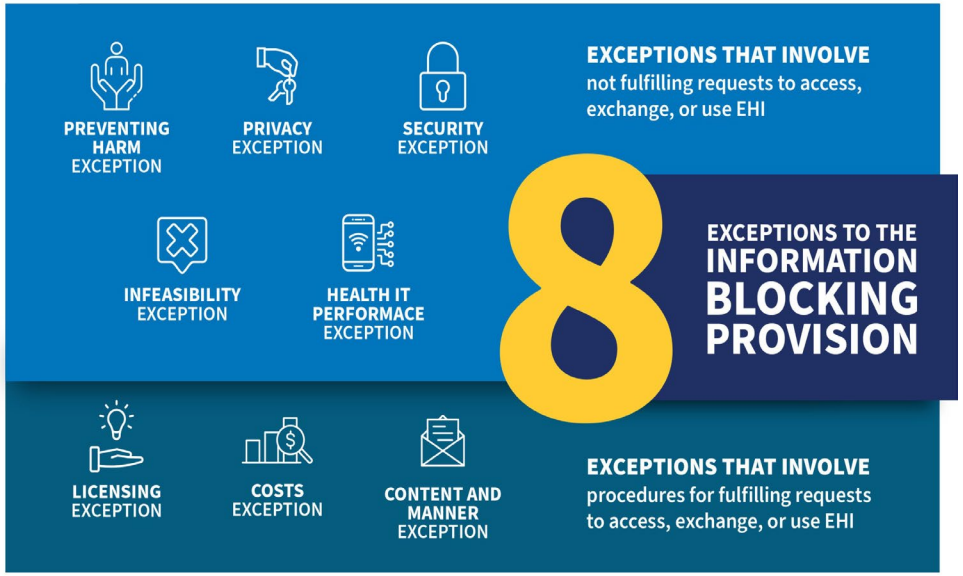
PMID: 16772237 DOI: 10.1080/01460860600677577

21st Century Cures Act



Rule designed to give patients and their healthcare providers secure access to health information.

https://www.healthit.gov/curesrule/



To further support access and exchange of EHI, the rule implements the information blocking provisions of the Cures Act. This rule outlines eight exceptions.

Use case

Maria is 17 years old. She lives with her mom and visits her dad in another state.

In her home state Maria can consent to confidential contraception and has been prescribed oral contraceptive pills (OCPs).

Maria visits her dad, who has a history of violence.

Maria develops painful urination and forgets her OCP's. She tells her father she doesn't feel well, and he takes her to the clinic.

Through an API, her PHI is shared with this clinic.

Laws in this state allow healthcare providers to disclose her OCPs to her parent. However, the pediatrician chooses not to share.

Maria privately discloses her symptoms.

The pediatrician informs her that she can consent without her dad's permission to testing and treatment for a sexually transmitted infection.

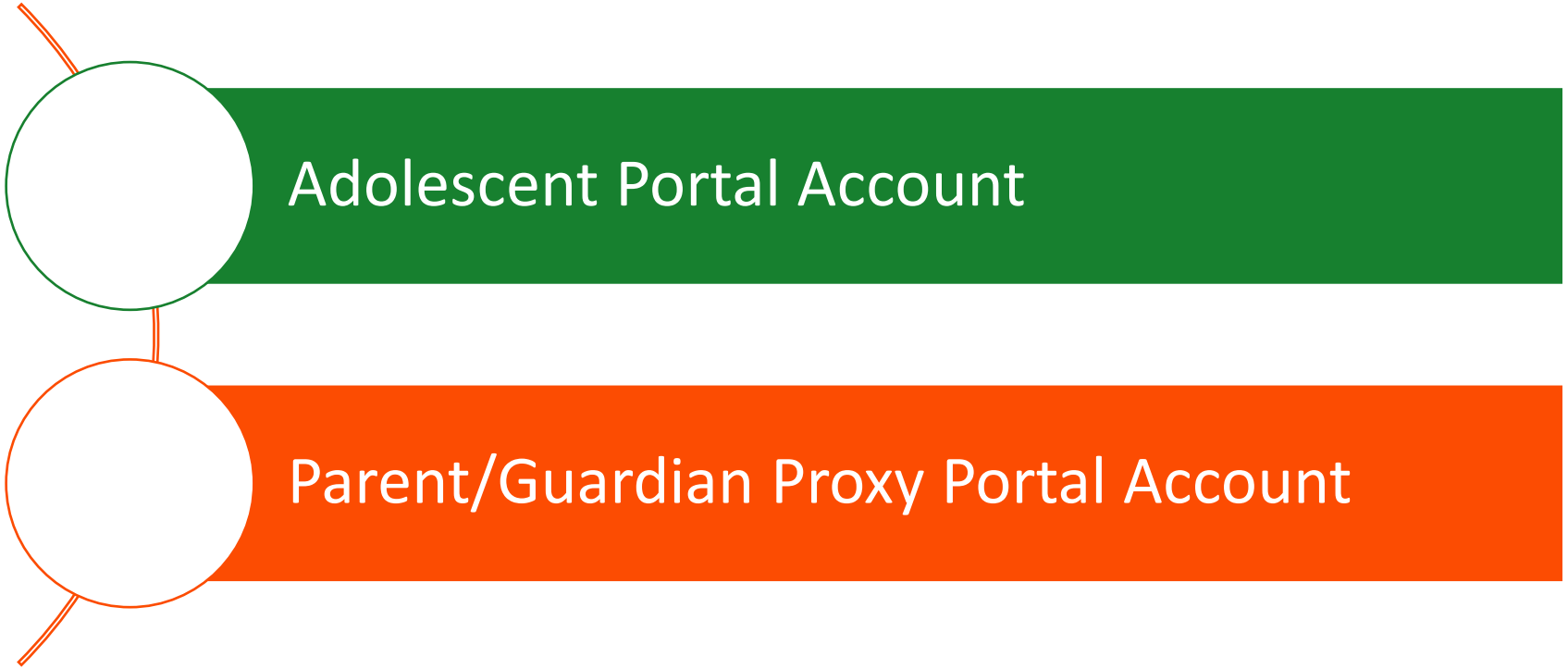
Maria consents to the testing, which comes back positive.

Through a proxy portal account, Maria's father learns about her STI medication and her OCPs.

Information about lab testing is also included in the AVS and the billing EOB.

Maria's father becomes angry, and Maria is now fearful for her safety.

Adolescent and proxy portal accounts



Parental access to adolescent accounts

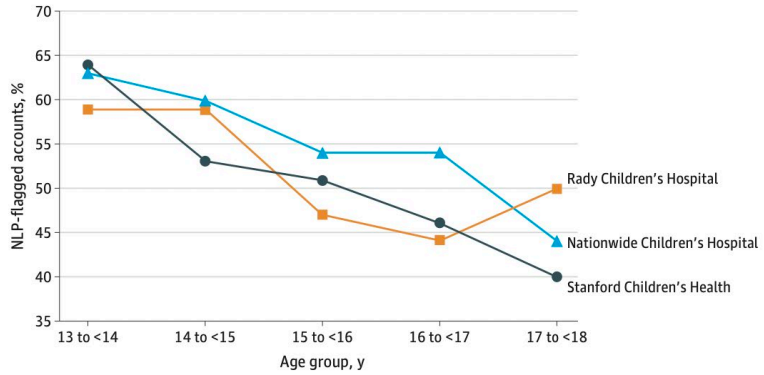
JAMA Network Open

Original Investigation | Pediatrics

Assessment of Prevalence of Adolescent Patient Portal Account Access by Guardians

Wui Ip, MD; Samuel Yang, MD; Jacob Parker, BS; Austin Powell, MS; James Xie, MD; Keith Morse, MD, MBA; Rachael C. Aikens, MS; Jennifer Lee, MD; Manjot Gill, MD; Shravani Vundavalli, MD; Yungui Huang, PhD, MBA; Jeannie Huang, MD, MPH; Jonathan H. Chen, MD, PhD; Jeffrey Hoffman, MD; Cynthia Kuelbs, MD; Natalie Pageler, MD, MEd

Figure. The Percentage of Natural Language Processing (NLP)–Flagged Accounts in Each Age Group



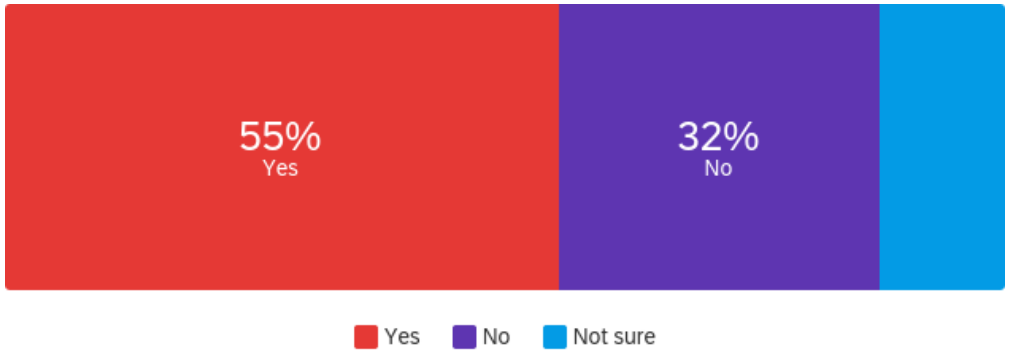
JAMA Network Open. 2021;4(9):e2124733. doi:10.1001/jamanetworkopen.2021.24733

https://pubmed.ncbi.nlm.nih.gov/34529064/

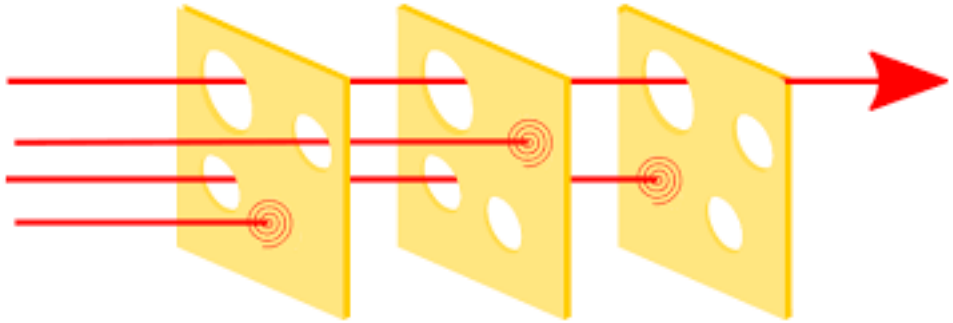
More than half of adolescent accounts with outbound messages were estimated to have been accessed by guardians at least once.

2023 National online survey

If you thought that your parent would look at your portal and see all your health information, would that change how much sensitive information you share with your doctor or nurse?



Holes in confidentiality protection



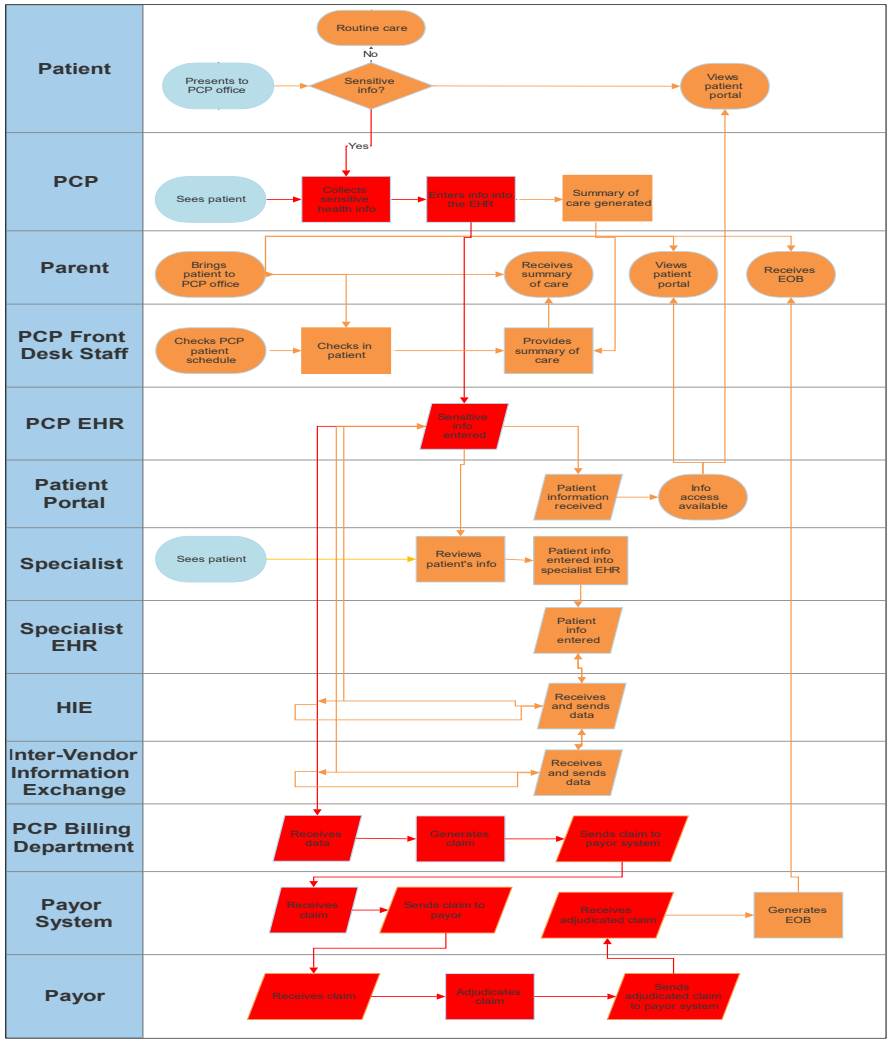
Variability in portal policies
Variability in state laws and regulations
Facets of care that compromise confidentiality

Path of information

- No sensitive information
- Potential sensitive information
- Definite sensitive information

Facets of care that may compromise confidentiality

- Automated appointment reminders
- Automated prescription notifications from pharmacies
- After visit summaries
- Explanation of benefits



State-by-State Variability in Adolescent Privacy Laws (from 2022)

Table 1: State-by-State Laws on the Ability to Consent for the Following Medical Services[a]

State	Age in years for consent for medical health services	Immunizations	Dental care	Sexual assault evaluation	STI testing and treatment	HIV testing and treatment	Contraceptive services	Prenatal treatment	Treatment for abuse of illegal substances	Mental health treatment
Alabama	14 or older Age of maturity is 19	Yes, if 14 or older or graduated from high school	Yes, if 14 and older	No explicit policy	Yes, if 12 or older*	Yes, if 12 or older*	Yes, if 14 or older, married, parent or pregnancy	Yes	Yes	Yes, if 14 or older
Alaska	Varies by service	No	Yes, if a parent or if parent of minor cannot be contacted or unwilling to give consent	No explicit policy	Yes	No	Yes	Yes	No explicit policy	No explicit policy
Arizona	15 years or older and deemed mature enough	No, unless court ordered	No	Yes, if 12 and older	Yes	No	Yes	No explicit policy	Yes, if 12 or older	No explicit policy
Arkansas	Mature minor	Yes, if mature minor	No explicit policy	No explicit policy	Yes*	No	Yes	Yes	No explicit policy	No explicit policy
California	15 or older	Yes, if 12 or older for HPV, HepB and COVID-19	No explicit policy	Yes	Yes, if 12 or older*	Yes, if 12 or older	Yes	Yes	Yes, if 12 years or older*	Yes, if 12 years or older*
Colorado	15 or older	No	Yes, if 15 or older	Yes	Yes, if 13 or older	Yes, if 13 or older*	Yes	Yes	Yes	Yes, if 15 or older*
Connecticut	16 or older for certain services	No	Yes, if married, or emancipated minor, or a parent.	No explicit policy	Yes, physician must report positive result if younger than 12	Yes, physician must report positive result if younger than 12	Yes, if married	No explicit policy for unmarried minors	Yes Outpatient: if 12 years or older Inpatient: 14 or older	Yes
Delaware	12 or older for pregnancy and infectious diseases.	Yes, if 12 and older, except COVI-19	Yes, if married or parent	No explicit policy	Yes, if 12 or older*	Yes, if 12 or older*	Yes, if 12 or older*	Yes, if 12 or older*	Yes, if 12 or older (parental consent for inpatient)	No explicit policy
Florida	16 or older, living apart from their parents and managing own affairs	No	16 or older, living apart from their parents and managing own affairs	No explicit policy	Yes	Yes	Yes, if married, parent or pregnancy	Yes	Yes	Yes, if 13 and older
Georgia	No age mentioned	No	Yes, for emancipated minor	No	Yes*	Yes*	Yes	Yes	Yes*	No explicit policy
Hawaii	14 or older	no	No explicit policy	No explicit policy	Yes, if 14 or older*	No	Yes, if 14 or older*	Yes, if 14 or older*	Yes*	No explicit policy

Sharko M, Jameson R, Ancker JS, Krams L, Webber EC, Rosenbloom ST. State-by-State Variability in Adolescent Privacy Laws. Pediatrics. 2022;149(6).

Variability of adolescent portal features

Type of Medical Center	Is there a patient portal account available during adolescence?	Age at which "adolescence" begins (IT-related)	Can adolescent have a portal account?	Does adolescent require parent permission?	Does adolescent see the same content as what an adult patient would see?	Can parent access adolescent account?	Does parent need adolescent permission to access adolescent account?	(If parent can access adolescent account) Does parent see the same content as the adolescent?	Type of EHR/Portal
Federally Qualified Health Center	Y	10	Y	N	Y	Y	N - restricted access Y - full access, if agreed upon by patient, parent and provider	N Y - if collaborative agreement for full parental access	Epic
Academic Medical Center	Y	12	Y	N	Y	Y	Y in-person with both parties	N	Epic
Academic Medical Center	Y	12	Y	N	Y	Y	N - limited access Y - full access	N - limited access Y - full access	Epic
Academic Medical Center	Y	12	Y	Y	N	Y	N	N	Epic
Academic Medical Center	Y	12	Y	Y	N	Y	Y	Y - except for private messaging with the provider	Epic
Children's Hospital	Y	12	Y	N	N	Y	N	N - medication list allowed if teen signs assent agreement	Epic
Children's Hospital	Y	12	Y	Y	N	Y	N	N	Epic
Integrated County Health System	Y	12	Y	N	Y	Y	N	N	Epic
Community Hospital	Y	12	Y	N	N	Y	Y	Y	Epic
Public Hospital	Y	12	Y	N	N	Y	N	N	Epic
Federally Qualified Health Center	Y	13	Y	N	Y	N	NA	NA	NextGen
Academic Medical Center	Y	13	Y	Y	Y	Y	Y	Y	Home-grown System
Children's Hospital	Y	13	Y	N	Y	Y	Y	Y	Epic
Children's Hospital	Y	13	Y	N	Y	Y except in teen health center	Y	Y	Epic
Children's Hospital	Y	13	Y	N	Y	Y	Y	N	Epic
Integrated Managed Care Consortium	Y	13	N	NA	NA	NA	NA	NA	Epic
Public Hospital	Y	13	Y	N	Y	Y	N	N	Epic
Academic Medical Center	Y	14	Y	N	Y	Y	N	N	Epic
Children's Hospital	Y	14	N Adolescent and parent can share an account.	N	Y	Y	Y	Y	Epic
Children's Hospital	Y	14	Y	N	N	Y	N	N	Epic
Academic Medical Center	Y	Level 1: 12 Level 2: 16	Y	Y if <16	N	Y	Y if >16	Y	Epic
Medical Group Practice	N	12	N	NA	NA	NA	NA	NA	Medent EHR / Relay Health tethered portal
Academic Medical Center	N	12	N	NA	NA	NA	NA	NA	Cerner
Academic Medical Center	N	12	N	NA	NA	NA	NA	NA	Allscripts
Non-profit Catholic Community Hospital	N	13	N	NA	NA	NA	NA	NA	Allscripts for all inpatient Epic in outpatient OB-GYN Department

Age at which adolescence begins (IT-related)

10
12
12
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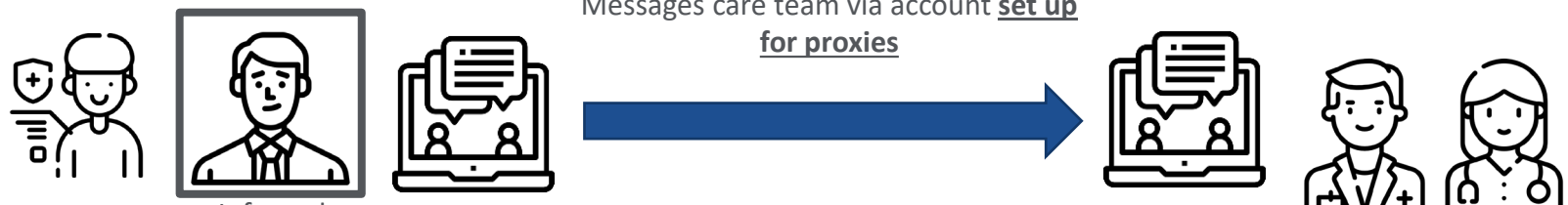
14
Level 1: 12 Level 2: 16

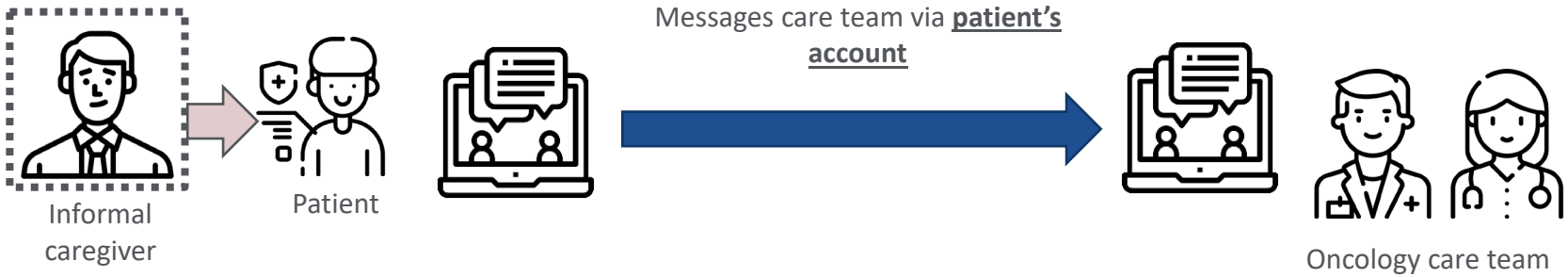
Sharko M, Wilcox L, Hong MK, Ancker JS. Variability in adolescent portal privacy features: how the unique privacy needs of the adolescent patient create a complex decision-making process. J Am Med Inform Assoc. 2018;25(8):1008-17.

The problem of “hidden proxies”

Formal proxy



Hidden proxy



Prevalence and characteristics of “hidden proxies”

NATIONAL CANCER INSTITUTE

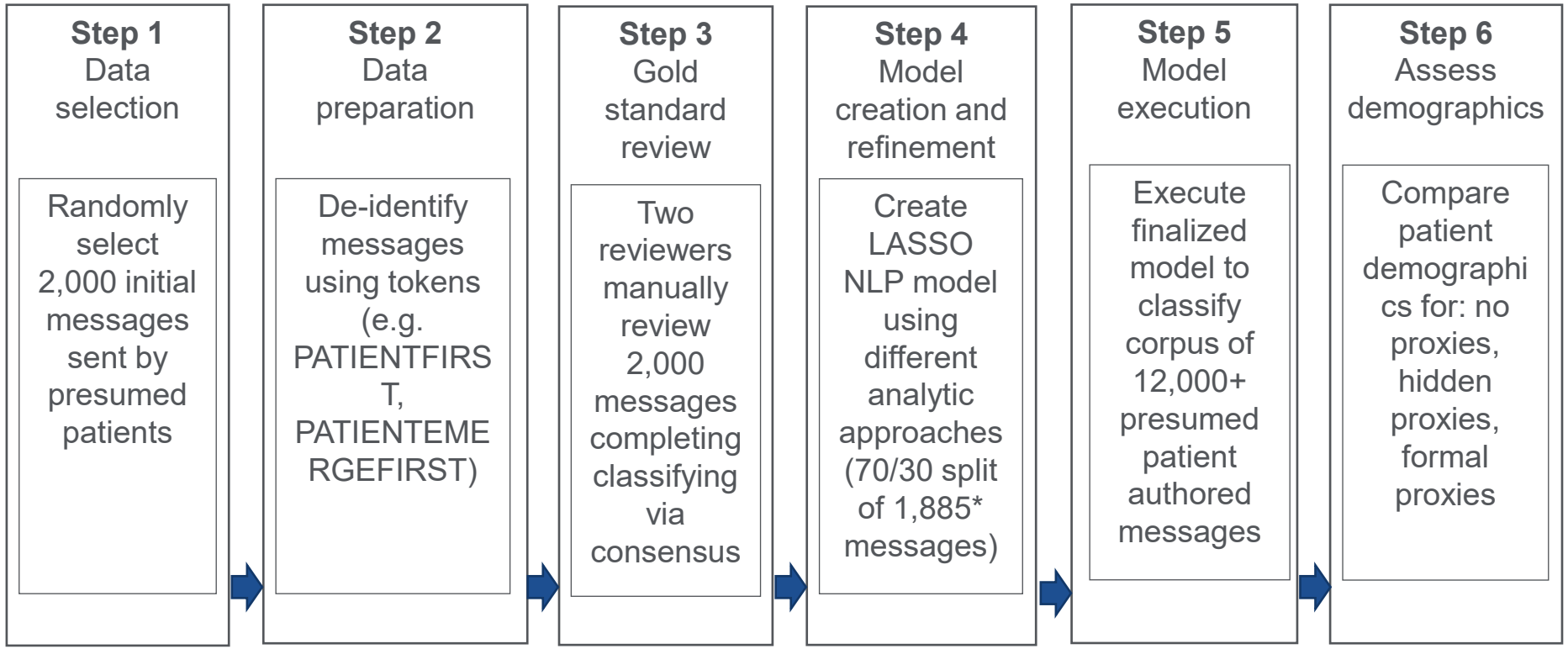
Health Information National Trends Survey®

- Over 10% of respondents reported accessing a family

Our goal: To develop an NLP-based algorithm for patient portal secure messages in oncology to:
1) classify hidden proxy messages in an oncology setting
2) determine demographic differences between patients with formal proxies, hidden proxies, no proxies

- 46% of patients had messages from “hidden proxies”
- High rates of “hidden proxy” messages more likely for older patients, less literate, and those with limited English proficiency

Analysis process



Differences in patient demographics

Of 12,119 patient portal accounts classified, 10.3% labelled as having "unregistered proxy" users

Significant differences based on:

- Sex (Male ↑)
- Race* (White ↓, Asian ↑, Other ↑)
- Language (Non-English ↑)
- Age (median age of 68 in un-registered proxy group vs. 61 in comparison group)
- Insurance* (Public ↑, Other↑)
- Religion* ("Non-spiritual" ↑)

Differences assessed but no significant based on: Ethnicity, marital status

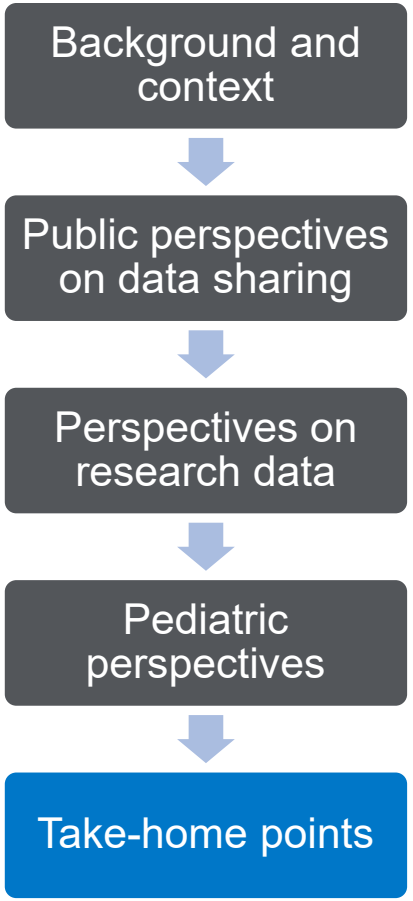
Discussion

- Informal caregivers play an important role in oncology care
- **Oncology patients with unregistered proxies more likely to be male, older, and have non-English preferred language** (additional significant differences based on race, insurance, and religion)
- May indicate who current communication does not support and how electronic communication may be improved
- Shows how manual qualitative analysis can feed creation of larger scale NLP models

JCO CCI Algorithm Dev.

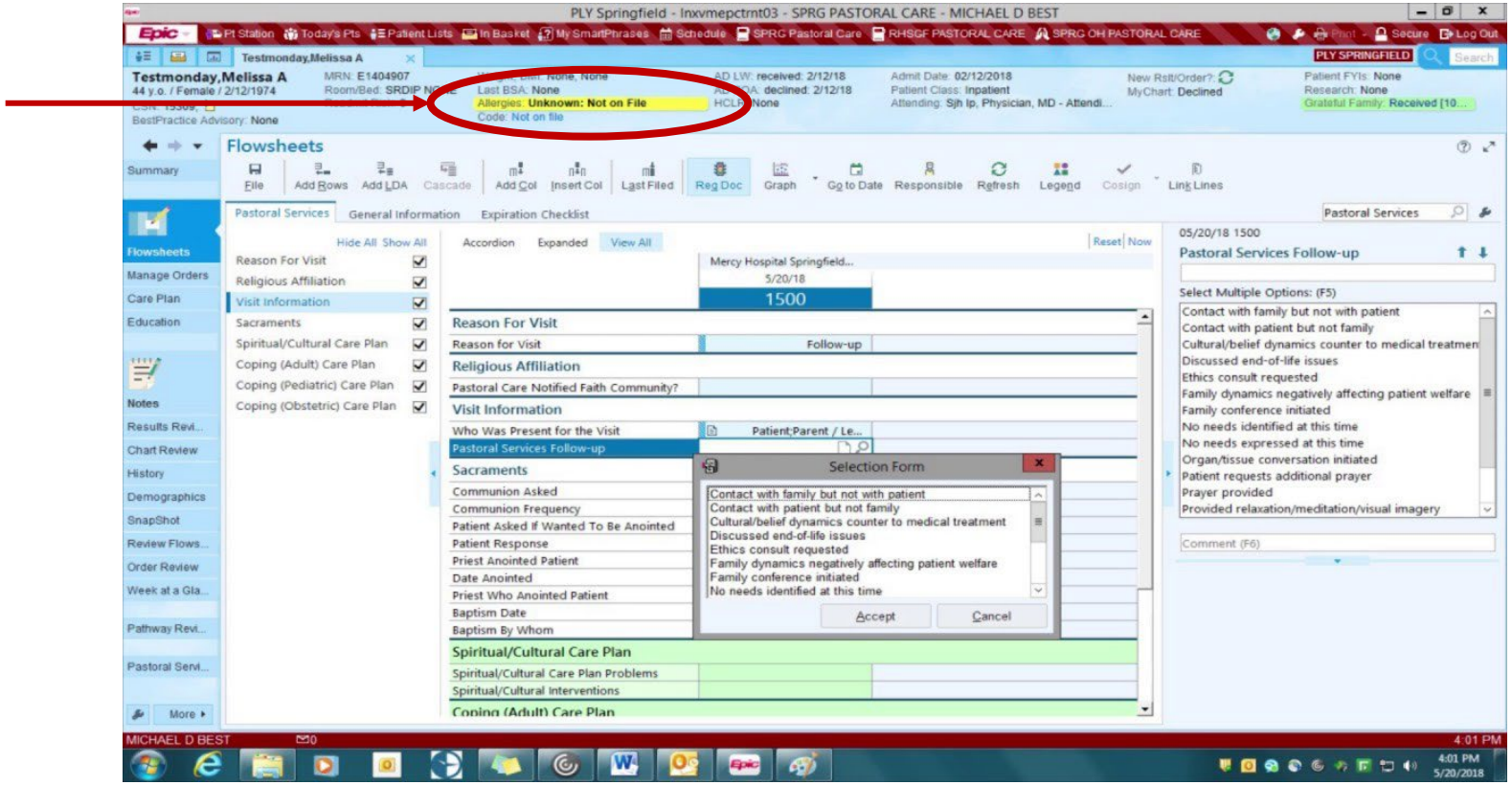
ACI Demographic Diff.

Overview of today's talk



You will never have all the information: Always verify sensitive health data

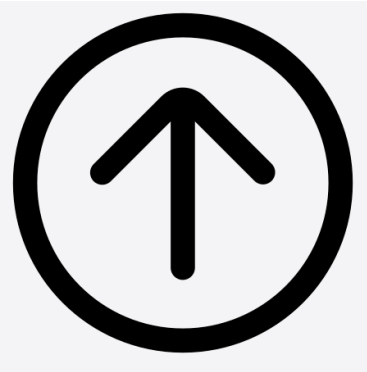
- Patient concerns about sensitive health data sharing → not all information will be in the chart.
- Assume incomplete data and verify sensitive data elements the way you would allergies, medications, or other critical information.



When using digital tools, we must consider the ethics of data ownership, consent, transparency, and the impact on trust.

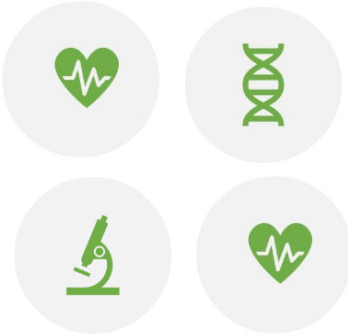
Data ownership	Consent and data sharing	Protecting personal health information	Trust
			

Lessons learned on data sharing for future work

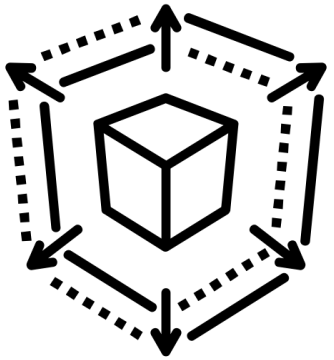


Participants want data returned and that increases trust

Data sharing matters—people care



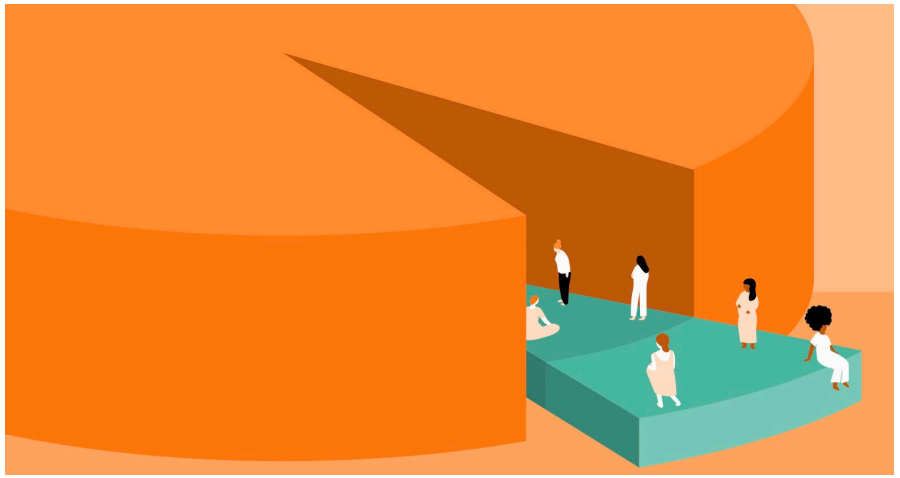
Some data is more sensitive than others



Diverse viewpoints are needed to mitigate risk of distrust and participation

Lack of clarity of the uses of data can erode trust, especially among communities that are already hesitant to participate and are underrepresented

Inclusive and transparent data sharing policies and practices can be a path towards building trust.



Thank you!

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