Patient Priorities on Health Data Access, Sharing, and Patient Matching

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The Pew Charitable Trusts

Patient safety

Interoperability

Who we are

Ben Moscovitch

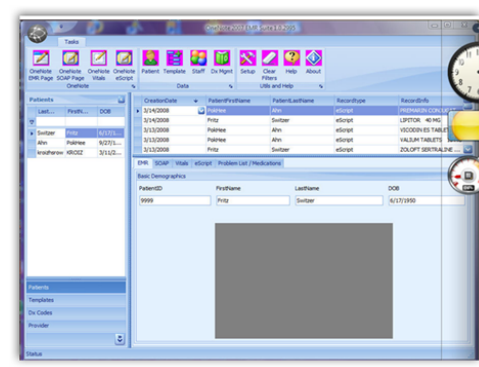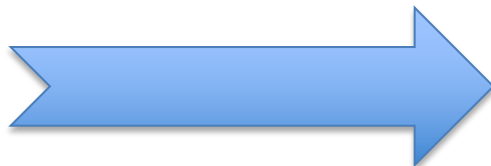**Project Director**

Ashley Ashworth

Senior Associate

Molly Murray

Officer

Setting the Stage

- Goal of EHRs- improve care

- 2016: 21st Century Cures
  - New regulations

Policymakers address challenges

- 21st Century Cures and associated rulemaking
  - More standardized data for patients and providers
  - Advancing application programming interfaces (APIs)
  - More demographics for patient matching
- Renewed interest in removing federal ban on a unique patient identifier

Objectives

Understand individual perceptions about…

Patient access to data

Exchange of health data

Privacy

Patient matching solutions

Methodology

- Public Opinion Strategies and Hart Research Associates conducted a national survey from June 1- July 3, 2020.

- N=1,213 adults ages 18 or older (N=110 by phone and N=1,103 by web).

- Interviews were conducted in English and Spanish

- The survey was conducted using NORC at the University of Chicago's AmeriSpeak panel. AmeriSpeak is a nationally representative, probability-based panel of the U.S. household population.

Patient Access

- A majority (61%) of adults say they would want to be able to download their EHR to different health apps.

- Younger adults are more interested in downloading. 67% of Millennials compared to 53% of Boomers.

- Education also a factor. 76% of post grads compared to 52% of those with a high school education.

- Surprisingly, chronic health and caregiver status not factors.

Benefits Outweigh Risks

The health benefits outweigh the privacy risks	**32%**
The privacy risks outweigh the health benefits	**18%**
The benefits and risks are equal	**28%**
The benefits and risks are unclear	**21%**

Concerns about HIPAA

How concerned, if at all, would you be about the privacy of your medical information and data if you download it to different health apps you selected to use on your smart phone, computer or tablet?

Extremely/Very Concerned	**35%**
Extremely Concerned	**16%**
Very Concerned	**19%**
Somewhat Concerned	**44%**
Total Not Concerned	**20%**
Not Too Concerned	**16%**
Not At All Concerned	**4%**

And how concerned, if at all, would you be about the privacy of your medical information and data if you found out that once it is downloaded to some health apps it may **NO LONGER BE PROTECTED BY FEDERAL LAWS RELATING TO PRIVACY SUCH AS HIPAA** and may instead be subject to the health app's privacy policy or terms of service?

Extremely/Very Concerned	**62%**
Extremely Concerned	**42%**
Very Concerned	**20%**
Somewhat Concerned	**28%**
Total Not Concerned	**10%**
Not Too Concerned	**6%**
Not At All Concerned	**4%**

Provider approval helps

Unapproved apps ⚠️	Approved by and independent certification board 🏅	Approved and recommended by your providers 🏅
Total comfortable: 15% Total uncomfortable: 84%	Total comfortable: 61% Total uncomfortable: 39%	Total comfortable: 76% Total uncomfortable: 23%

Provider Exchange

- More than 8 in 10 adults support enabling health care providers to share patient health information between their EHR systems when treating/caring for the same patient.

- Concerns specific to: insurance billing/claims information, mental health or substance use histories, or social determinants of health.

Access vs Exchange

Ranked by % Net Difference	% Yes, I Want Access	% Yes, I Want My Providers To Share	Net Difference (Share-Access)
Insurance billing and claims information	84%	48%	-36%
Behavioral or mental health history	74%	52%	-22%
Your history of medical conditions and past diagnoses	88%	71%	-17%
Treatment plans	87%	70%	-17%
Physician and clinical notes on your medical care	84%	67%	-17%
Laboratory test results	89%	74%	-15%
Vital signs, such as blood pressure	87%	76%	-11%
Radiology images and reports such as x-rays, CAT scans, MRIs	87%	76%	-11%
Your family medical history	80%	69%	-11%
Substance use history	61%	51%	-10%
Medications and prescription medicines that you are currently taking or have taken in the past	87%	78%	-9%
Immunizations	87%	78%	-9%
Information about you such as exposure to violence or history of physical abuse, hunger or lack of access to healthy food, or homelessness or lack of access to housing	57%	48%	-9%
Advanced care plans or directives such as do not resuscitate orders (DNRs) or end of life care preferences	82%	76%	-6%
Allergies	83%	80%	-3%
Demographic information about you such as gender, age, or ethnicity	58%	63%	+5%

Broad support for at least some

At Least One Of Items In Category – Ranked by Want Personal Access	Personal Access	Health Care Provider Sharing
Basic Clinical Information	96%	86%
Detailed Notes and Plans	91%	83%
Medical History	90%	78%
Insurance and Claims	84%	47%
Mental Health and Substance History	77%	60%
Demographic Information	58%	63%
Social Determinants	57%	48%

Frequent users more

sl

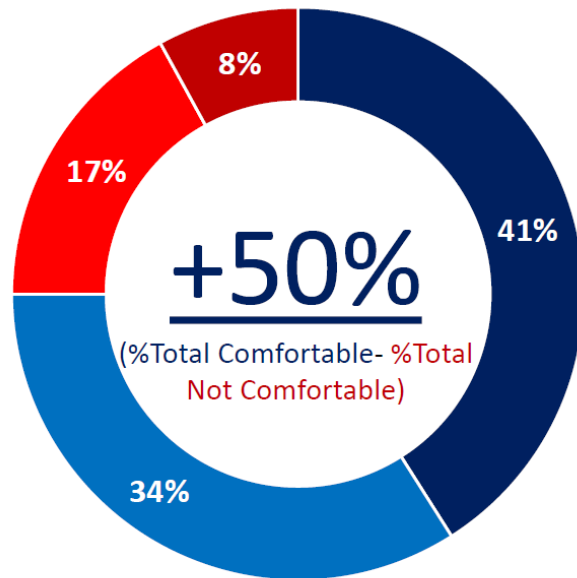| Health Care Provider Sharing *All Items In Category – Ranked by All Adults*	All Adults	See 0-1 Doctors Annually (34%)	See 2-3 Doctors Annually (45%)	See 4+ Doctors Annually (20%)
Demographic Information	**63%**	52%	70%	70%
Medical History	**61%**	46%	71%	69%
Basic Clinical Information	**60%**	46%	68%	70%
Detailed Notes and Plans	**57%**	45%	65%	63%
Social Determinants	**48%**	36%	57%	50%
Insurance and Claims	**47%**	35%	57%	48%
Mental Health and Substance History	**43%**	33%	54%	34%

Collection of SDOH

How comfortable would you be with providing your doctor with the following types of information about you for them to enter into your electronic health record: _exposure to violence or history of physical abuse, hunger or lack of access to healthy food, or homelessness or lack of access to housing_?

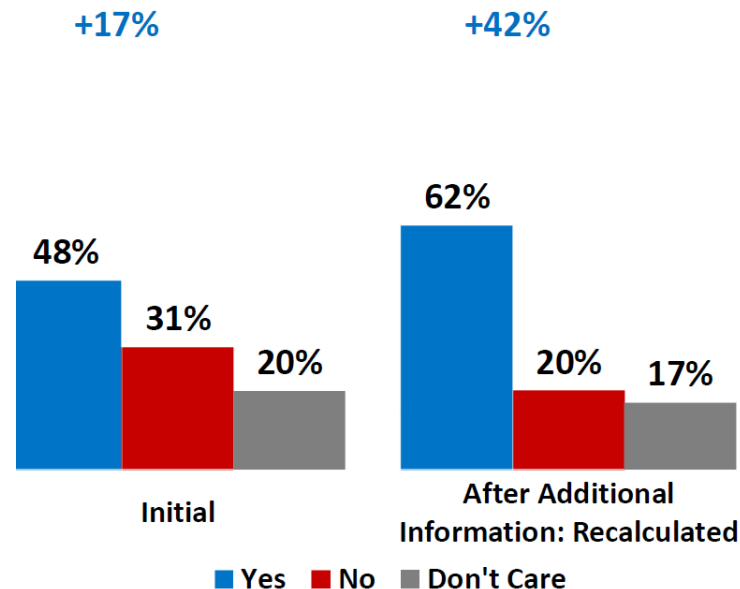|	
Total Comfortable	**75%**
Total Not Comfortable	**25%**

+50%
(%Total Comfortable- %Total Not Comfortable)

8%
17%
41%
34%

- ■ Very Comfortable
- ■ Somewhat Comfortable
- ■ Not Too Comfortable
- ■ Not Comfortable At All

Sharing of SDOH

- Hesitation around sharing- only 48% comfortable initially

- Education helps! When told about the benefits of SDOH, comfort increased 14%

- Comfort increases with education and income
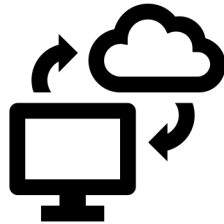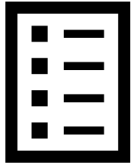
Privacy Concerns

Top reasons for concern:

- Identity theft/blackmail

- Discrimination

- Health apps not covered by HIPAA

- Do not want information shared with tech companies, ie Facebook or Google
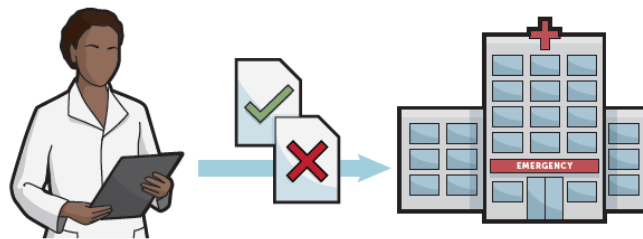
APIs: What's next?

Patients want
access to their data

Want providers
to be able to
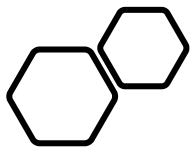communicate

Need privacy
solutions

Patient matching

Patient matching is the ability to accurately link each individual's records from multiple doctors' offices or hospitals.

Up to half of patient records are not matched in transfers—e.g., from a rural doctor to an urban hospital.[2]
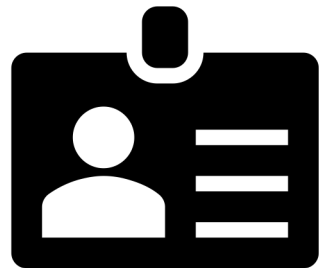
Patient matching: Opportunities

- Universal Patient Identifier
- ONC Report to Congress

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Set national standards

Would you support or oppose the federal government setting national standards to more accurately match up a patient's electronic health records across multiple providers?

Total Support:
74%

Total Oppose:
25%

Spend federal money

2/3 support spending federal money to improve patient matching

Even when broken down by political party, there is majority support:

Republicans (total support): **51%**

Independents (total support): **66%**
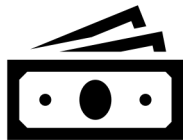
Democrats (total support): **82%**

When asked to choose which one method they would most want to see implemented, scanning a patient's fingerprint is the top choice for the majority of adults.

Ranked by 1st Choice	First Choice	Combined Choice
Scanning your fingerprint	37%	54%
Assigning a unique number or code to each individual patient which the patient would need to remember or bring with them	22%	41%
Scanning your eye	10%	27%
Using your smart phone or a smart phone app	10%	23%
Comparing photos of your face that your health care providers have taken	7%	18%
Do not support any of these being implemented	13%	N/A

Total Biometric*	
54%	69%
First Choice	Combined Choice

*Total Biometric defined as: scanning fingerprint, scanning eye, and comparing photographs of face

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Patient matching: What's next?

Americans want this issue solved

Do not support the current spending ban

Supported methodologies should be part of ONC report

Thank you!

For additional questions or information, please contact:

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