Consumer Perspectives on APIs and Privacy and Security

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API Task Force
Virtual Hearing
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national partnership
for women & families

About us

The **National Partnership for Women & Families** is a nonprofit, nonpartisan advocacy group dedicated to promoting fairness in the workplace, access to quality health care, and policies that help women and men meet the dual demands of work and family.

▸ **Key health initiatives:**

- ▸ **Engaging patients, family caregivers, consumers in redesign** of our health care delivery and payment systems

- ▸ Advancing **health information technology** (health IT) as the core infrastructure, in ways that **benefit patients and families**

The **Consumer Partnership for eHealth** (CPeH) is a coalition led by the National Partnership for Women & Families since 2005 of more than 50 consumer, patient, and labor organizations working at the national, state, and local levels to advance private and secure health IT in ways that measurably improve the lives of individuals and their families.

More information is available at www.NationalPartership.org/hit

Consumer Partnership's comments about APIs

▶ **APIs should ensure that all patient-facing functionalities are equally available through the API, such as:**

  ▶ Online access to view, download and transmit health information

  ▶ Share patient-generated health data and non-clinical data

  ▶ Access patient-specific educational information

  ▶ Send and receive secure messages

  ▶ Request appointments and medication refills

▶ **Consumers need and want access to more than the Common Clinical Data Set:**

  ▶ Access and use of the synthesized care plan as well as separate plans of care for a single provider and encounter

  ▶ Items such as referral summaries, discharge instructions, birth plans and advanced directives

Consumer Partnership's comments about privacy and security

- **There are significant privacy and security implications for patients who download their data through APIs or portals and upload it to applications of their choice**

  - HIPAA's privacy and security protections do not apply to many commercial apps and personal health records (PHRs) unless provided by HIPAA-covered entities such as providers, payers or their business associates

  - Applications and devices may have poor privacy policies, weak security controls, or policies that explicitly share data liberally with third parties or allow broad uses

- **Many patients have limited understanding of how privacy and security protections change (or end) when they move health data from a HIPAA-covered entity to a third-party application or device**

  - **Critical issue for preserving and building consumer trust overall—no surprises!**

CPeH's recommendations on privacy and security

- **ONC, OCR and CMS should collaborate on ways to educate consumers about their rights and steps they should take to protect their data, and examine policy options that improve privacy and security for patients using apps and APIs to download and use their data**

- **ONC, OCR and CMS should also educate providers (especially those in small practices), who are likely to receive questions from patients and family members about APIs, such as what they mean, how they work and are they safe**

  - Doctors are a trusted source of guidance for patients

- **API and application developers must communicate their privacy policies clearly, in plain language, to patients and consumers as well as providers**

  - For example, ONC's Model Privacy Notice

- **Access and use through APIs should be available at no cost to the patient**

About GetMyHealthData

- A consumer-led, **national campaign** to help patients **request** their electronic health data and **illuminate** problems in the system along the way.

  - **Advocate** for changes that enable consumer health data download and use to become the norm.

- **Coordinated** by the National Partnership for Women & Families, in **collaboration** with
  - health, consumer and technology groups;
  - individual advocates and experts.
- **Funded** by the Robert Wood Johnson Foundation and individual donors

GetMyHealthData's basic questions for app developers

▸ **Doesn't Release Personal Data—** Most are not HIPAA-covered entities, and GMHD does not list if releases personal data without explicit patient consent

▸ **Uses Model Privacy Notice—** Whether the app uses model privacy notice published by ONC in 2011

▸ **Data Portability—**Whether the app allows you to download your data

▸ **Offers Direct Access—**Whether the app offers a Direct email address

	Use Model Privacy Notice	Doesn't Release Personal Data	Offer Direct Address	Data Portability
ACTIVDOCTORS ONLINE		X	X	X
Andaman7		X	X	
better.		X		X
bluehub health		X		X
carebox	X	X	X	X
caresync medical group		X		X
CORAnet		X		X
genieMD		X	X	X
Get Real Health	X	X	X	X
Health Companion		X	X	X
OSIA MEDICAL		X	X	X
Healthjump		X	X	X
Healthspek		X	X	X
huMETRIX	X	X	X	X

Detail in Appendix

GetMyHealthData

Summary of Product Features and Services	ZibdyHealth	Andaman7	OSIA Medical
What tasks does your product help clients perform?			
Gather and manage their health records	X	X	
Obtain a second opinion		X	
Coordinate care across providers	X	X	X
Let clients contribute their health data to research			X
Price different treatment options and/or providers			
Match clients with clinical trials			
How do you help clients assemble their health data?			
We will contact all their providers and gather their health records		X	
We give them a Direct address so their providers can send information to their accounts		X	X
We will log onto their provider portals using their username and password			X
They can upload their data to our product	X	X	
Our product interfaces directly with EHRs		X	X
What types of data do you accept?			
Clinical summaries	X	X	X
Full health record including notes	X	X	
Radiology images		X	
Claims records		X	
Data from wearable devices	X	X	X

**If available, would you access your health information
from a smartphone or tablet?**

[Base = All qualified respondents: non-Hispanic White (n=1323); Hispanic (n=242);
Black/African American (n=221); Asian (n=218); LGBT (n=167); non-LGBT (n=1878)]
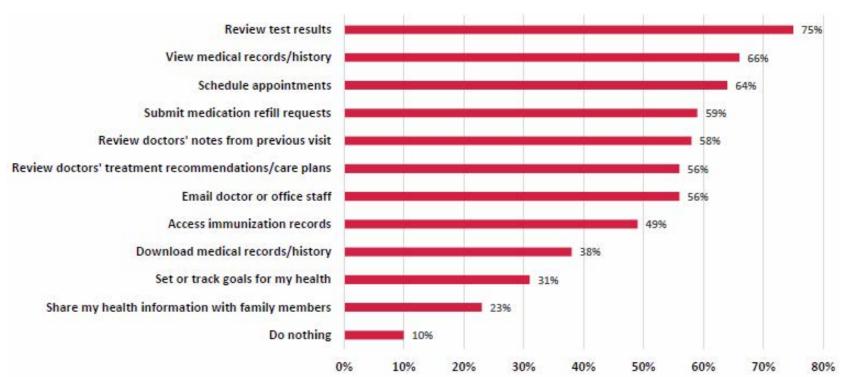
Putting the Apps in APIs:
How Consumers Would Leverage APIs

Which of the following activities would you do with online access to your health information?

[Base = All qualified respondents (n=2045)]

Activity	Percentage
Review test results	75%
View medical records/history	66%
Schedule appointments	64%
Submit medication refill requests	59%
Review doctors' notes from previous visit	58%
Review doctors' treatment recommendations/care plans	56%
Email doctor or office staff	56%
Access immunization records	49%
Download medical records/history	38%
Set or track goals for my health	31%
Share my health information with family members	23%
Do nothing	10%

Appendix:
GetMyHealthData Survey Questions

▸ **Survey questions from www.GetMyHealthData.org**
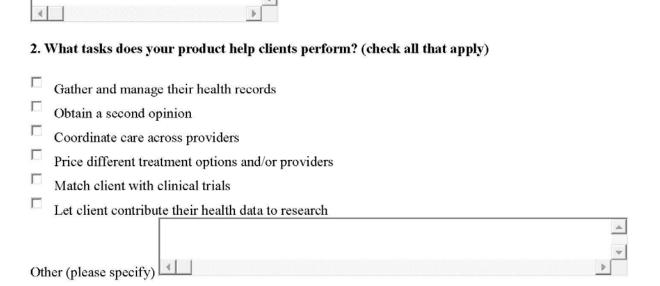
▸ **"Consumers will be asking their providers for electronic copies of their health data. We want to be able to point them to products and services that can help them manage and use their health information. Please fill out this brief survey so that we can learn more about your product and share this information with Data Independence Day participants."**

GetMyHealthData

Data Independence Day Product List

As part of Data Independence Day, consumers will be asking their providers for electronic copies of their health data. We want to be able to point them to products and services that can help them manage and use their health information. Please fill out this brief survey so that we can learn more about your product and share this information with Data Independence Day participants

1. Company/product name, brief description of your product, company/product url and email address of person who completed survey

2. What tasks does your product help clients perform? (check all that apply)

- ☐ Gather and manage their health records
- ☐ Obtain a second opinion
- ☐ Coordinate care across providers
- ☐ Price different treatment options and/or providers
- ☐ Match client with clinical trials
- ☐ Let client contribute their health data to research

Other (please specify)

3. How do you help clients assemble their health data? (check all that apply)

☐ We will contact all your providers and gather your health records

☐ We give you a Direct address so your provider can send information to your account

☐ We will log onto your provider portals using your log-in information

☐ You can upload your data to our product

☐ Our product interfaces directly with EHRs

Other (please specify)

4. What types of data do you accept? (check all that apply)

☐ Clinical summaries

☐ Full health record including notes

☐ Radiology images

☐ Claims records

☐ Data from my wearable devices

☐ Other (please specify)

5. What are the charges and fees for using your product?

6. We will ask every participating company/product to fill out and post the model privacy notice - http://www.healthit.gov/policy-researchers-implementers/your-organizations-phr-data-practices

☐ Yes, we have already posted the model privacy notice

☐ No, we have not yet posted the model privacy notice

☐ If No above - We have not yet posted but we are willing to

☐ If No above - We would like to learn more

If "yes" above, please provide link

7. For what purposes do you release clients' data?

	Marketing and advertising	Medical and pharmaceutical research	Reporting about our company and our customer activity	Your insurer and employer	Developing software applications
We release clients' personal (identifiable) health data for	☐ We release clients' personal (identifiable) health data for Marketing and advertising	☐ We release clients' personal (identifiable) health data for Medical and pharmaceutical research	☐ We release clients' personal (identifiable) health data for Reporting about our company and our customer activity	☐ We release clients' personal (identifiable) health data for Your insurer and employer	☐ We release clients' personal (identifiable) health data for Developing software applications
We release statistical (de-identified) data for	☐ We release statistical (de-identified) data for Marketing and advertising	☐ We release statistical (de-identified) data for Medical and pharmaceutical research	☐ We release statistical (de-identified) data for Reporting about our company and our customer activity	☐ We release statistical (de-identified) data for Your insurer and employer	☐ We release statistical (de-identified) data for Developing software applications

Other (please specify)

8. Do you require limiting agreements that restrict what third parties can do with your Personal Data?

○ Yes

○ No

○ N/A

9. Do you stop releasing clients' personal data if they close or transfer their account?

○ Yes

○ No

○ N/A

10. Can clients download their health data from your site?

○ Yes

○ No

○ If "yes" above, what formats?

For more information

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