## Consumer Generated & Controlled Health Data Seminar Tweets

On May 7, 2014, the FTC hosted a seminar titled: <u>Consumer Generated & Controlled Health</u>
<u>Data</u>. The seminar was the third in its Spring Privacy Series. OPA staff live-tweeted the 2-hour seminar from the @FTC Twitter account and used the hashtag: #FTCpriv.

The following is a transcript of the tweet. All tweets in their original order and without redaction remain publicly available on the agency's Twitter account for as long as Twitter allows.

## **Seminar Tweets**

Happening at 10am ET: FTC examines consumer generated health data. Watch live, send us your ?s: <a href="http://go.usa.gov/kukk">http://go.usa.gov/kukk</a> #FTCpriv #privacy

Hi, please note there will be webcast archive & you can send us questions online today & file comments until June 9. #FTCpriv

Our #privacy series seminar on consumer health data starts in 25 mins! Direct webcast link: <a href="http://bit.ly/1bgdyNZ">http://bit.ly/1bgdyNZ</a> Tweet ?s using #FTCpriv.

Please note, there's been a change to #FTCpriv health data agenda today: <a href="http://go.usa.gov/kuN4">http://go.usa.gov/kuN4</a> // Heather Patterson will not be here.

The FTC's #privacy seminar is starting! Watch: <a href="http://bit.ly/1bgdyNZ">http://go.usa.gov/kuN4</a> #FTCpriv

Greater consumer involvement in generating, using health data exciting, but poses sig #privacy & security risks. - @JulieBrillFTC #FTCpriv

Health data some of most sensitive personal info, says @JulieBrillFTC, yet amount of data outside of HIPAA is quickly increasing. #FTCpriv

Comm'r @JulieBrillFTC gives opening remarks at #FTCpriv #privacy seminar on consumer health data in DC. https://twitter.com/FTC/status/464045598295859202

Looking forward to today's overview of new health data devices, services, & exploring bens & risks to consumers. - @JulieBrillFTC #FTCpriv

Now up: Chief Technologist Latanya Sweeney, @TechFTC, discusses health data flows. #FTCpriv https://twitter.com/FTC/status/464046685937614848

Learn more about CTO Sweeney's health data flows presentation in her @TechFTC blog post: <a href="http://go.usa.gov/kJGh">http://go.usa.gov/kJGh</a> #FTCpriv

33 states sell or share personal health data, says @TechFTC. Only 3 adhere to HIPAA. #FTCpriv

Next up: Data Sharing By Select Health & Fitness Apps presentation by FTC's Jared Ho. #FTCpriv

Jared Ho: Users provide health & fitness apps w/wealth of info: running paths/ habits; eating habits; weight & other personal info. #FTCpriv

The panel discussion is now starting. Speaker bios: http://go.usa.gov/kJAF #FTCpriv

Moderator: #HIPAA doesn't cover all health data. But consumers might not know that. #FTCpriv

#HIPAA and #HITECH give patients the right to their own health care records, says Joy Pritts, CPO, HHS. #FTCpriv

Moderator: What are some of the apps/products & their benefits that put health care data in consumers' hands? #FTCpriv

Medical measurement tools: wireless scales to upload weight; wearables to record daily habits to track health/wellness, says Hall. #FTCpriv

Reminder: You can tweet your questions for moderators if you're watching health care data webcast. Use #FTCpriv & we will submit.

Fed gov't working to allow individuals to safely & securely receive their health data through Blue Button initiative, says Burrow. #FTCpriv

Burrow: There's 37 million medical beneficiaries that can now use Blue Button. #FTCpriv

The FTC's #privacy seminar on health data will continue until 12pm EDT. Watch here: <a href="http://bit.ly/1bgdyNZ">http://bit.ly/1bgdyNZ</a> #FTCpriv

If you pay for an app, you're the client. If you're not paying for the app, you're likely not the client, says Burrow. #FTCpriv

Many third parties resell the data to other entities, says Pritts. #FTCpriv

People are willing to share data to better understand their own experiences - & to help others, says PatientsLikeMe's Sally Okun. #FTCpriv

Divide of how people use social tools: either willing to share only w/people they know, or only w/people they don't. - Hall #FTCpriv

We won't see the benefits of consumer generated health data unless we protect the data, says Pritts. #FTCpriv

Burrow: Data shows with just gender, date of birth, and zip code, 50% of people in U.S. can be identified. #FTCpriv

Panelists agree that there are different definitions of what de-identified means. #FTCpriv

Panelists at FTC #privacy health care data seminar provide their final thoughts. #FTCpriv https://twitter.com/FTC/status/464072991664795648

Comment period for health care data #privacy seminar open until June 9. Learn more here: <a href="http://go.usa.gov/kuNP">http://go.usa.gov/kuNP</a> #FTCpriv

Thanks to everyone tweeting with us for #FTCpriv. Have a great day.

Hi, the transcript & webcast archive will post to http://www.ftc.gov/videos .
Usually within 24/48 hours. #FTCpriv

Thanks, Corey! #FTCpriv