

CHAMBER OF COMMERCE
OF THE
UNITED STATES OF AMERICA

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June 9, 2014

VIA ELECTRONIC FILING

Mr. Donald S. Clark
Secretary
Federal Trade Commission
600 Pennsylvania Ave., NW, Room H-113 (Annex J)
Washington, DC 20580

Re: *Spring Privacy Series: Consumer Generated and Controlled Health Data, Project No. P145401*

Dear Mr. Clark:

The U.S. Chamber of Commerce (“Chamber”)¹ is pleased to submit these comments to the Federal Trade Commission (“Commission”) in response to the agency’s request for comments on issues raised during the Commission’s May 7, 2014, seminar on “Consumer Generated and Controlled Health Data.”² Given the benefits of this technology to consumers, the Chamber urges the Commission to exercise restraint as it examines this issue.

I. Background on Consumer Generated and Controlled Health Data

As explained during the seminar, consumers are taking an increased interest in managing and generating their own health data.³ Consumers are researching their health issues, educating themselves on possible diagnoses and remedies, learning how to live a healthier lifestyle, and using this information to engage in better informed discussions with their doctors and other health care providers. Consumers are uploading their health information into applications, Web sites, and products that allow users to control and study their data.

¹ The U.S. Chamber of Commerce is the world’s largest business federation, representing the interests of more than three million businesses of all sizes, sectors, and regions, as well as state and local chambers and industry associations, and dedicated to promoting, protecting, and defending America’s free enterprise system.

² Federal Trade Commission, *Spring Privacy Series: Consumer Generated and Controlled Health Data*, May 7, 2014, available at <http://www.ftc.gov/news-events/events-calendar/2014/05/spring-privacy-series-consumer-generated-controlled-health-data>.

³ *Id.*

Increasingly products are combining wireless connectivity with mobile computing, cloud services, and sensors.⁴ For example, devices and applications (i.e., fitness activity trackers) enable consumers to monitor their health and fitness stats via smartphone and Web-based applications.⁵ Unlike single-use or event-centric devices, activity trackers “monitor multiple characteristics of the human body including movement, calories burned, body temperature, and sleep tracking.”⁶ However, as evidenced by constant announcements regarding new and innovative services and products in this area, this technology is ever-evolving. Wearables will be in a variety of forms including headpieces, skin patches, and clothing-based sensors, and the associated applications will be just as varied.⁷

To manage their personal health, 81% of consumers say they would use a wearable health device.⁸ Consistent with this sentiment, ABI Research’s recent assessment of the mobile health care market found that revenues from wearable wireless devices will increase to over \$6 billion in 2018.⁹ In particular, activity trackers are expected to grow at a compound annual growth rate (CAGR) of 40%.¹⁰ Though ownership of dedicated wearable fitness devices tripled from 2012 (3%) to 2013 (9%),¹¹ this market is clearly still in its infancy and ready to take off. Motivation, monitoring fitness goal progress, and tracking physical activity levels or intensity are the top three reasons cited by individuals for using a wearable fitness device.¹²

The number of new health and fitness applications increased by 19% in 2013 compared to 2012, according to mobile analytics platform Localytics.¹³ According to a recent Mobiquity survey, 70% of “people use these apps daily or several times a day” and 63% “plan to use health and fitness apps even more over the next five years.”¹⁴

⁴ Rajiv Kapur, MD, “Understanding the Role of Wearable Technology in Healthcare,” *PC Quest*, May 16, 2014, available at <http://www.pcquest.com/pcquest/interview/214794/understanding-role-wearable-technology-healthcare>.

⁵ *Id.*

⁶ Press Release, “Led by the Sports, Fitness, and Wellness Segment, Wearable Wireless Device Revenues to Exceed \$6 Billion in 2018,” ABI Research, Sept. 30, 2013, available at <https://www.abiresearch.com/press/led-by-the-sports-fitness-and-wellness-segment-wea>.

⁷ “Understanding the Role of Wearable Technology in Healthcare,” *PC Quest*.

⁸ Press Release, “90% of Americans Ready to Share Personal Health Data with Strong Privacy Controls,” Makovsky Health, Apr. 24, 2014, available at <http://www.businesswire.com/news/home/20140424005203/en/90-Americans-Ready-Share-Personal-Health-Data>.

⁹ “Led by the Sports, Fitness, and Wellness Segment, Wearable Wireless Device Revenues to Exceed \$6 Billion in 2018,” ABI Research.

¹⁰ *Id.*

¹¹ Press Release, “Consumer Interest in Purchasing Wearable Fitness Devices in 2014 Quadruples, According to CEA Study,” Consumer Electronics Association (CEA), Dec. 11, 2014, available at <https://www.cea.org/News/News-Releases/Press-Releases/2013-Press-Releases/Consumer-Interest-in-Purchasing-Wearable-Fitness-D.aspx>.

¹² “Consumer Interest in Purchasing Wearable Fitness Devices in 2014 Quadruples, According to CEA Study,” CEA.

¹³ Nicole Kwan, “Health apps, new tech continue to help users live a healthy lifestyle,” FoxNews.com, Jan. 24, 2014, available at <http://www.foxnews.com/health/2014/01/24/health-apps-new-tech-continue-to-help-users-live-healthy-lifestyle>.

¹⁴ Mobiquity, *Get Mobile, Get Healthy: The Appification of Health and Fitness*, Apr. 2014, available at <https://mobiquity.box.com/shared/static/tw3bhxv5iijbrgsj66k.pdf>.

II. The Benefits of Consumer Generated and Controlled Health Data Are Just Starting to be Realized

In the Mobiquity survey, 53% people reported that that they discovered that they consumed more calories than they thought after they recorded intake with their health and fitness apps and 23% found they took fewer steps than they thought.¹⁵

According to the same survey, 60% of health and fitness app users have not shared their progress, achievements or discoveries with a health professional.¹⁶ The majority claim they never thought about it, while 11% thought their doctors would not take them seriously. However, slightly over one-third of users said they would be more likely to use apps to track their health and fitness if their doctor actually recommended it.¹⁷ Therefore, it is interesting to note that more than a third of U.S. physicians recommended that a patient use a health app, according to the recent Manhattan Research's *Taking the Pulse* survey.¹⁸

Sally Okun—Vice President for Advocacy, Policy, and Patient Safety at PatientsLikeMe—said on the panel at the FTC seminar, that people are generally willing and interested in sharing their health data for two important reasons.¹⁹ First, consumers want to know if their experience is normal.²⁰ They want to share their experiences with people like themselves to determine if others are experiencing similar issues.²¹ For example, Okun said that her company learned early on that one-third of the people with epilepsy on their site had never talked to or met another person with epilepsy before.²² Second, people share their information out of a sense of altruism.²³ They want to share their experiences for the benefit of others.²⁴

Similarly, according to a recent Makovsky Health/Kelton survey, 90% of Americans would share personal health information to help researchers understand a disease or improve care or treatment options.²⁵ This same survey found that “26% would share regardless of whether data were anonymous; 23% would share if they could control which data were anonymous; and 40% would share if promised that all data would remain anonymous.”²⁶

¹⁵ Mobiquity, *Get Mobile, Get Healthy: The Appification of Health and Fitness*.

¹⁶ *Id.*

¹⁷ *Id.*

¹⁸ Press Release, “Stethoscopes and Smartphones: Physicians Turn to Digital Tools to Boost Patient Outcomes,” May 29, 2014, available at <http://www.prnewswire.com/news-releases/stethoscopes-and-smartphones-physicians-turn-to-digital-tools-to-boost-patient-outcomes-261089461.html>.

¹⁹ Rough Transcript, FTC Spring Privacy Series: Consumer Generated and Controlled Health Data on May 7, 2014, p. 46, available at http://www.ftc.gov/system/files/documents/public_events/195411/ftc_spring_privacy_series_-_consumer_generated_and_controlled_health_data_-_transcript.pdf.

²⁰ *Id.*

²¹ *Id.*

²² *Id.*

²³ *Id.*

²⁴ *Id.*

²⁵ “90% of Americans Ready to Share Personal Health Data with Strong Privacy Controls,” Makovsky Health.

²⁶ *Id.*

III. Businesses Depend More Than Ever on Having Beneficial Trusted Relationships With Their Customers

In this tough economy, businesses depend more than ever on having beneficial and trusted relationships with their customers. Successful companies work to ensure that their products and services are deemed trustworthy by their customers. If a company has failed to meet customers' privacy and security expectations, then oftentimes the marketplace and public relations consequences will be swift and decisive, forcing the company to quickly align its business practices with consumer expectations.

Given the range of technologies and market participants involved in consumer generated and controlled health data, the Chamber believes that self-regulation and best business practices—that are technology neutral—along with consumer education serve as the preferred framework for protecting consumer privacy and security while enhancing innovation, investment, and competition.

Therefore, policymakers should restrain from acting unless there are specific, identified harms that cannot be addressed by the myriad of existing laws and regulations governing the use of information collected about consumers. The Chamber notes that most of the concerns expressed at the seminar were highly speculative, and that there was a dearth of any actual examples of such harms occurring now (let alone evidence of such harms being wide spread). Federal policy should recognize that differing risks of harm are caused by different types of data usage. For example, the risks associated with non-personally identifiable data are less, especially when anonymized or aggregated, than with data that identifies a user. Similarly, encrypted data also results in reduced risk.

The Commission should, instead, focus its attention on promoting policies that help foster the fast-growing, but nascent, area of consumer generated and controlled health data. The Commission should work to ensure that there is not duplicative government oversight or regulation regarding consumer generated and controlled health data.²⁷

The Chamber also would encourage the Bureau of Consumer Protection's Division of Privacy and Identity Protection to work closely with the Bureau of Economics and the Bureau of Competition on this examination. As Commissioner Wright said in his speech last month at the Chamber, "[As] an economist, I strongly believe in the implementation of thorough cost-benefit analyses across many areas of the agency's consumer protection mission, but particularly when

²⁷ See, e.g., Jonathan E. Nuechterlein, *Antitrust Oversight of an Antitrust Dispute: An Institutional Perspective on the Net Neutrality Debate*, 7 J. on Telecomm. & High Tech. L. 19, 55 (2009) ("[W]here two peer agencies exercise redundant jurisdiction, the government (writ large) will intervene frequently in the market, even though, in a range of cases, one of the two government decision-makers will have concluded that intervention is inappropriate and harmful").

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the agency...makes policy recommendations. To that end, it has been one of my priorities to engage the Bureau of Economics in evaluating these matters.”²⁸

Protecting individuals’ sensitive personal information from theft or illegal uses has been and will continue to be a top priority for the business community. Failure to appropriately safeguard this data can have tremendous reputational, financial, and legal consequences.²⁹ Therefore, companies have a compelling incentive to “continually assess, reassure, evolve, rework and innovate to ensure that consumer privacy...[and security are] protected in the connected world of tomorrow.”³⁰

IV. Conclusion

As the Commission studies the issue of consumer generated and controlled health data, the Chamber strongly urges you to exercise restraint given that the benefits of this technology and its implementation will be guided by consumer reaction to it. Thank you for the opportunity to provide comments on this matter.

Sincerely,

William L. Kovacs

²⁸ *The View from 600 Pennsylvania Avenue: Recent Developments in Law Enforcement and Policy at the Federal Trade Commission*, Remarks of Commissioner Joshua D. Wright, U.S. Chamber of Commerce, at 4 (May 16, 2014), available at:

http://www.ftc.gov/system/files/documents/public_statements/310531/140516chamberofcommerce.pdf.

²⁹ See, e.g., Press Release, *Ponemon Institute Releases 2014 Cost of Data Breach: Global Analysis*, May 5, 2014, available at <http://www.ponemon.org/blog/ponemon-institute-releases-2014-cost-of-data-breach-global-analysis>.

³⁰ Comments of Consumer Electronics Association to the FTC, *In the Matter of Privacy and Security Implications of the Internet of Things*, p. 18 (filed July 12, 2013), available at http://www.ftc.gov/sites/default/files/documents/public_comments/2013/07/00027-86193.pdf.