



WORLD **PRIVACY** FORUM

Statement of Pam Dixon, Executive Director, World Privacy Forum to the FTC at its Open Commission Meeting

Regarding the need for websites to post clear statements about their regulatory status under HIPAA

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Thank you Chair and Commissioners. The profusion of health apps, websites and digital tools that provide consumers with assistance and insights about their health is a positive development. However, it has come at the cost of increasing privacy risks.

One of these risks is that consumers are confused about when and where federal health privacy protections apply to their health information. Many health-related websites and tools have not been clear about their HIPAA status. Some apps may infer HIPAA coverage in privacy policies with terms such as “we are HIPAA-compliant,” even when they are not regulated under HIPAA. Other times, websites or apps will simply omit disclosing they are not regulated under HIPAA.

As the Commission knows, HIPAA does not generally regulate all health data everywhere; HIPAA generally regulates specific entities such as health care providers which are then obliged to apply HIPAA protections to the data they hold. Many fitness and health-related websites and apps are not regulated under HIPAA; this is true even if they hold an entire medical file a customer has shared with them.

Consumers need to know plainly and simply whether a website or digital service or app is regulated under HIPAA, or not. There needs to be a clear and prominent statement in the privacy policy that says: “We are not regulated under HIPAA. If you share your information with us, it will not have HIPAA protections when we hold it.”

The World Privacy Forum urges the Commission to take action to protect consumers by insisting on a prominent, clear, simple statement regarding the status of whether or not a particular digital tool or service is regulated under HIPAA or not.

Thank you. We look forward to working with you on this important issue.

Respectfully submitted,

Pam Dixon