United States Senate

WASHINGTON, DC 20510

June 22, 2022

Alon Matas Founder and President BetterHelp 990 Villa St Mountain View, California 94041

Dear Mr. Matas,

As telehealth services, especially online mental health platforms, grow in popularity, it is increasingly important for consumers to understand whether their personal health data is being shared with third-parties, and if so, how and why this is done. We are particularly concerned about your company's data privacy and security policies¹ and whether they are leaving the patients you serve vulnerable to exploitation from large technology platforms and other online actors. Multiple studies highlighting data sharing between mental health apps and Big Tech giants like Google and Facebook reveal that patients and regulators alike may not understand the full extent of your company's relationship with these businesses.² To address these concerns, we are seeking information on: (1) the type and breadth of data that BetterHelp's apps shares with third parties, including Big Tech companies like Google and Facebook; (2) methods that BetterHelp is using to protect clients' information, such as anonymization and data storage; and (3) processes BetterHelp has developed to inform potential clients and current users about your privacy policies and the risks of data sharing.

Mental health apps, which have exploded in popularity during the COVID-19 pandemic, have been touted as low-cost therapy alternatives that can drastically expand access to mental health services.³ First-time downloads of the top 20 mental wellness apps in the U.S rose 29 percent between January and April 2020.⁴ The popular app Talkspace doubled its new user count between mid-March and May 1, 2020 compared to the same

²CNBC, "Mental health apps draw wave of new users as experts call for more oversight," Kira Herzog, May 24, 2020, https://www.cnbc.com/2020/05/24/mental-health-apps-draw-wave-of-users-as-experts-call-for-oversight.html.

¹ BetterHelp, Privacy Policy, website accessed June 17, 2022, https://www.betterhelp.com/privacy/.

² Consumer Reports, "Mental Health Apps Aren't All As Private As You May Think," Thomas Germain, March 2, 2021, https://www.consumerreports.org/health-privacy/mental-health-apps-and-user-privacy-a7415198244/; JAMA Network Open, "Assessment of the Data Sharing and Privacy Practices of Smartphone Apps for Depression and Smoking Cessation," Kit Huckvale, John Torous, Mark E. Larsen, April 19, 2019, https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2730782.
³ CNBC, "Mental health apps draw wave of new users as experts call for more oversight," Kira Herzog, May 24, 2020, https://www.cnbc.com/2020/05/24/mental-health-apps-draw-wave-of-users-as-experts-call-for-oversight.html; New York Times, "How to Find a Mental Health App That Works for You," Christina Caron, April 13, 2022, https://www.nytimes.com/2022/04/13/well/mind/mental-health-apps-therapy.html.
⁴ CNBC, "Mental health apps draw wave of new users as experts call for more oversight," Kira Herzog, May

period in 2019.⁵ Meanwhile, your platform, BetterHelp, saw a 60 percent increase in downloads from January to April 2020, reaching 80,000 downloads in just one month.⁶

However, there is mounting evidence that platforms marketing themselves as a "cost-effective alternative to traditional therapy" are collecting, mining, and disseminating private information about their clients. BetterHelp advertises that your services are "100% private" and operate in accordance with the *Health Insurance Portability and Accountability Act of 1996* (HIPAA), but several facets of your services are not covered by HIPAA, and your company appears to be taking advantage of the "regulatory gray area" in which mental health applications operate to juice your profits. A February 2020 investigation found that BetterHelp was sharing analytics with Facebook about how often users opened the app and metadata from every message shared on the platform – giving the company a sense of when, for how long, and where users were using mental health services. Description of the services of the platform is a sense of when, for how long, and where users were using mental health services.

Mental health apps' widespread use of user data raises additional concerns. Even though you claim this data is anonymized, it can still provide third parties with important and identifying information. Both BetterHelp and Talkspace were sharing anonymized information with the research and analytics panel MixPanel, allowing MixPanel to see "where [users] were and what device [users] were using; approximately how old [users] were, whether [users] considered [them]selves spiritual or religious, [their] financial status, and [their]sexual orientation," as well as information about where and when users had used therapy. In addition, a 2019 study reported that even anonymized data could be used to reidentify individuals, finding that with just a zip code, gender, and date of birth, companies could reidentify an "anonymized" person 81% of the time. In the content of the state of the

Nicole Martinez-Martin, Assistant Professor for Biomedical Ethics at Stanford University, noted that even fully anonymous information shared from mental health platforms raised significant concerns about whether third-party apps, including Facebook, could use BetterHelp's information to target "patients as a class [...] and treat them a

⁵ *Id*.

⁶ *Id*.

⁷ Daily Beast, "Inside Travis Scott's Strange Post-Astroworld Partnership With BetterHelp, the 'Tinder of Psychotherapy,'" Cheyenne Roundtree, November 11, 2021, https://www.thedailybeast.com/inside-travis-scotts-strange-partnership-with-betterhelp-the-tinder-of-psychotherapy.

⁸ Jezebel, "The Spooky, Loosely Regulated World of Online Therapy," Molly Osberg and Dhruv Mehrotra, https://jezebel.com/the-spooky-loosely-regulated-world-of-online-therapy-1841791137.

⁹ Consumer Reports, "Mental Health Apps Aren't All As Private As You May Think," Thomas Germain, March 2, 2021, https://www.consumerreports.org/health-privacy/mental-health-apps-and-user-privacy-a7415198244/.

¹⁰ Jezebel, "The Spooky, Loosely Regulated World of Online Therapy," Molly Osberg and Dhruv Mehrotra, https://jezebel.com/the-spooky-loosely-regulated-world-of-online-therapy-1841791137.

¹¹ Jezebel, "The Spooky, Loosely Regulated World of Online Therapy," Molly Osberg and Dhruv Mehrotra, https://jezebel.com/the-spooky-loosely-regulated-world-of-online-therapy-1841791137.

¹² MIT Technology Review, "You're very easy to track down, even when your data has been anonymized," Charlotte Jee, July 23, 2019, https://www.technologyreview.com/2019/07/23/134090/youre-very-easy-to-track-down-even-when-your-data-has-been-anonymized/.

certain way." This would allow third-parties to target clients through advertising and exploit people who are already at a "vulnerable point." ¹³

We have long been concerned about the misuse of personal data by Big Tech companies and unscrupulous data brokers, especially for the purpose of microtargeting vulnerable populations. ¹⁴ Unfortunately, it appears possible that the policies used by your company and similar mental health platforms allow third-party Big Tech firms and data brokers, who have shown remarkably little interest in protecting vulnerable consumers and users, ¹⁵ to access and use highly confidential personal and medical information. Given these concerns, we are requesting answers to the following questions no later than July 6, 2022:

- 1. What information does your company provide to third parties, including advertisers, data brokers, research and analytics firms, and social media sites including Meta? What are the circumstances under which this data is shared?
 - a. Please provide a specific list of third parties with whom data is shared, including which data elements are shared with each.
 - b. Does BetterHelp limit how shared data can be used by third parties?
 - c. What financial arrangements for data sharing does BetterHelp have with third parties? Please provide a specific list of all contracts or agreements, and the amount that BetterHelp is paid by entities in exchange for sharing data.
- 2. What steps are taken to anonymize data shared externally? Have these processes changed as re-identification techniques have become more effective and widespread?
- 3. How are transcripts from mental health sessions or communications between a user and their counselor used within the company?
 - a. What are your company's policies around the use of data derived from transcripts from mental health sessions or communications between a user and their counselor?
 - b. Has your company used data derived from transcripts from mental health sessions or communications between a user and their counselor to improve ad targeting or to microtarget vulnerable populations?
 - c. Can users opt out of allowing your company to use transcripts from mental health sessions or content of communications with their counselor for non-treatment-related purposes?
- 4. Can users access or delete their medical records from your company's database following the retention time required by federal laws governing medical records?
- 5. How are users informed that data will be shared either internally by BetterHelp or with third parties for research or marketing purposes?

https://www.wired.com/story/opinion-data-brokers-are-a-threat-to-democracy/.

¹³ Jezebel, "The Spooky, Loosely Regulated World of Online Therapy," Molly Osberg and Dhruv Mehrotra, https://jezebel.com/the-spooky-loosely-regulated-world-of-online-therapy-1841791137.

¹⁴ Elizabeth Warren, "Warren, Wyden, Murray, Whitehouse, Sanders Introduce Legislation to Ban Data Brokers from Selling Americans' Location and Health Data," press release, June 15, 2022, https://www.warren.senate.gov/newsroom/press-releases/warren-wyden-murray-whitehouse-sanders-introduce-

<u>legislation-to-ban-data-brokers-from-selling-americans-location-and-health-data</u>.

15 Wired, "Data Brokers Are a Threat to Democracy," Justin Sherman, April 13, 2021,

6. Do you enable users to opt out of having their data collected using cookies, tracking pixels, and other tracking technologies for marketing and ad tailoring purposes?

Sincerely,

Elizabeth Warren

United States Senator

Cory A. Booker

United States Senator

Ron Wyden

United States Senator

United States Senate

WASHINGTON, DC 20510

June 22, 2022

Douglas Braunstein Talkspace Chairman and Interim Chief Executive Officer 2578 Broadway #607 New York, NY 10025

Dear Mr. Braunstein,

As telehealth services, especially online mental health platforms, grow in popularity, it is increasingly important for consumers to understand whether their personal health data is being shared with third-parties, and if so, how and why this is done. We are particularly concerned about your company's data privacy and security policies¹ and whether they are leaving the patients you serve vulnerable to exploitation from large technology platforms and other online actors. Multiple studies highlighting data sharing between mental health apps and Big Tech giants like Google and Facebook reveal that patients and regulators alike may not understand the full extent of your company's relationship with these businesses.² To address these concerns, we are seeking information on: (1) the type and breadth of data that Talkspace shares with third parties, including Big Tech companies like Google and Facebook; (2) methods that Talkspace is using to protect clients' information, such as anonymization and data storage; and (3) processes Talkspace has developed to inform potential clients and current users about your privacy policies and the risks of data sharing.

Mental health apps, which have exploded in popularity during the COVID-19 pandemic, have been touted as low-cost therapy alternatives that can drastically expand access to mental health services.³ First-time downloads of the top 20 mental wellness apps in the U.S rose 29 percent between January and April 2020.⁴ Your platform, Talkspace, doubled its new user count between mid-March and May 1, 2020 compared to the same period in 2019.⁵ Meanwhile, the popular

¹ Talkspace, Privacy Policy, June 14, 2022, https://www.talkspace.com/public/privacy-policy.

² Consumer Reports, "Mental Health Apps Aren't All As Private As You May Think," Thomas Germain, March 2, 2021, https://www.consumerreports.org/health-privacy/mental-health-apps-and-user-privacy-a7415198244/; JAMA Network Open, "Assessment of the Data Sharing and Privacy Practices

of Smartphone Apps for Depression and Smoking Cessation," Kit Huckvale, John Torous, Mark E. Larsen, April 19, 2019, https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2730782.

³ CNBC, "Mental health apps draw wave of new users as experts call for more oversight," Kira Herzog, May 24, 2020, https://www.cnbc.com/2020/05/24/mental-health-apps-draw-wave-of-users-as-experts-call-for-oversight.html; New York Times, "How to Find a Mental Health App That Works for You," Christina Caron, April 13, 2022, https://www.nytimes.com/2022/04/13/well/mind/mental-health-apps-therapy.html.

⁴ CNBC, "Mental health apps draw wave of new users as experts call for more oversight," Kira Herzog, May 24, 2020, https://www.cnbc.com/2020/05/24/mental-health-apps-draw-wave-of-users-as-experts-call-for-oversight.html. ⁵ *Id*.

mental health app BetterHelp saw a 60 percent increase in downloads from January to April 2020, reaching 80,000 downloads in just one month.⁶

However, there is mounting evidence that platforms marketing themselves as a "cost-effective alternative to traditional therapy" are collecting, mining, and disseminating private information about their clients. Apps like Talkspace advertise that their services are "100% private" and operate in accordance with the *Health Insurance Portability and Accountability Act of 1996* (HIPAA), but several facets of online mental health apps are not covered by HIPAA, and your company appears to be taking advantage of the "regulatory gray area" in which mental health applications operate to juice your profits. Talkspace does not allow users to delete their transcripts, essentially preventing clients from removing and protecting their records from their services. In an even more troubling allegation, former employees of the company claimed that "treatment transcripts [were treated] as another data resource to be mined," and revealed that "individual users' anonymized conversations were routinely reviewed and mined for insights" to help the company with research and marketing tactics.

Mental health apps' widespread use of user data raises additional concerns. Even though you claim this data is anonymized, it can still provide third parties with important and identifying information. Both Talkspace and BetterHelp were sharing anonymized information with the research and analytics panel MixPanel, allowing MixPanel to see "where [users] were and what device [users] were using; approximately how old [users] were, whether [users] considered [them]selves spiritual or religious, [their] financial status, and [their][sexual orientation," as well as information about where and when users had used therapy. ¹² In addition, a 2019 study reported that even anonymized data could be used to reidentify individuals, finding that with just a zip code, gender, and date of birth, companies could reidentify an "anonymized" person 81% of the time. ¹³

⁶ *Id*.

⁷ Daily Beast, "Inside Travis Scott's Strange Post-Astroworld Partnership With BetterHelp, the 'Tinder of Psychotherapy,'" Cheyenne Roundtree, November 11, 2021, https://www.thedailybeast.com/inside-travis-scotts-strange-partnership-with-betterhelp-the-tinder-of-psychotherapy.

strange-partnership-with-betterhelp-the-tinder-of-psychotherapy.

8 Jezebel, "The Spooky, Loosely Regulated World of Online Therapy," Molly Osberg and Dhruv Mehrotra, https://jezebel.com/the-spooky-loosely-regulated-world-of-online-therapy-1841791137.

⁹ Consumer Reports, "Mental Health Apps Aren't All As Private As You May Think," Thomas Germain, March 2, 2021, https://www.consumerreports.org/health-privacy/mental-health-apps-and-user-privacy-a7415198244/.

¹⁰ The Verge, "Breakdown," Cat Ferguson, December 19, 2016,

 $[\]frac{https://www.theverge.com/2016/12/19/14004442/talkspace-therapy-app-reviews-patient-safety-privacy-liability-online.}{}$

¹¹ New York Times, "At Talkspace, Start-Up Culture Collides With Mental Health Concerns," Kashmir Hill and Aaron Krolik, August 7, 2020, https://www.nytimes.com/2020/08/07/technology/talkspace.html.

¹² Jezebel, "The Spooky, Loosely Regulated World of Online Therapy," Molly Osberg and Dhruv Mehrotra, https://jezebel.com/the-spooky-loosely-regulated-world-of-online-therapy-1841791137.

¹³ MIT Technology Review, "You're very easy to track down, even when your data has been anonymized," Charlotte Jee, July 23, 2019, https://www.technologyreview.com/2019/07/23/134090/youre-very-easy-to-track-down-even-when-your-data-has-been-anonymized/.

Nicole Martinez-Martin, Assistant Professor for Biomedical Ethics at Stanford University, noted that even fully anonymous information shared from mental health platforms raised significant concerns about whether third-party apps, including Facebook, could use mental health information to target "patients as a class [...] and treat them a certain way." This would allow third-parties to target clients through advertising and exploit people who are already at a "vulnerable point."

We have long been concerned about the misuse of personal data by Big Tech companies and unscrupulous data brokers, especially for the purpose of microtargeting vulnerable populations. ¹⁵ Unfortunately, it appears possible that the policies used by your company and similar mental health platforms allow third-party Big Tech firms and data brokers, who have shown remarkably little interest in protecting vulnerable consumers and users, ¹⁶ to access and use highly confidential personal and medical information. Given these concerns, we are requesting answers to the following questions no later than July 6, 2022:

- 1. What information does your company provide to third parties, including advertisers, data brokers, research and analytics firms, and social media sites including Meta? What are the circumstances under which this data is shared?
 - a. Please provide a specific list of third parties with whom data is shared, including which data elements are shared with each.
 - b. Does Talkspace limit how shared data can be used by third parties?
 - c. What financial arrangements for data sharing does Talkspace have with third parties? Please provide a specific list of all contracts or agreements, and the amount that Talkspace is paid by entities in exchange for sharing data.
- 2. What steps are taken to anonymize data shared externally? Have these processes changed as re-identification techniques have become more effective and widespread?
- 3. How are transcripts from mental health sessions or communications between a user and their counselor used within the company?
 - a. What are your company's policies around the use of data derived from transcripts from mental health sessions or communications between a use and their counselor?
 - b. Has your company used data derived from transcripts from mental health sessions or communications between a user and their counselor to improve ad targeting or to microtarget vulnerable populations?
 - c. Can users opt out of allowing your company to use transcripts from mental health sessions or content of communications with their counselor for non-treatment-related purposes?

¹⁴ Jezebel, "The Spooky, Loosely Regulated World of Online Therapy," Molly Osberg and Dhruv Mehrotra, https://jezebel.com/the-spooky-loosely-regulated-world-of-online-therapy-1841791137.

¹⁵ Elizabeth Warren, "Warren, Wyden, Murray, Whitehouse, Sanders Introduce Legislation to Ban Data Brokers from Selling Americans' Location and Health Data," press release, June 15, 2022, <a href="https://www.warren.senate.gov/newsroom/press-releases/warren-wyden-murray-whitehouse-sanders-introduce-murray-whitehouse-murray-murray-murray-whitehouse-murray-murray-whitehouse-murray-murray-murray-murray-murray-murray-murray-

<u>legislation-to-ban-data-brokers-from-selling-americans-location-and-health-data</u>.

16 Wired, "Data Brokers Are a Threat to Democracy," Justin Sherman, April 13, 2021,

¹⁶ Wired, "Data Brokers Are a Threat to Democracy," Justin Sherman, April 13, 2021. https://www.wired.com/story/opinion-data-brokers-are-a-threat-to-democracy/.

- 4. Can users access or delete their medical records from your company's database following the retention time required by federal laws governing medical records?
- 5. How are users informed that data will be shared either internally by Talkspace or with third parties for research or marketing purposes?
- 6. Do you enable users to opt out of having their data collected using cookies, tracking pixels, and other tracking technologies for marketing and ad tailoring purposes?

Sincerely,

Elizabeth Warren

United States Senator

Cory A. Booker

United States Senator

Ron Wyden

United States Senator