

## To the Federal Trade Commission:

**Introduction and Approach.** My comments are submitted in an open style, not in response to a specific numbered issue or question. I'm telling a story, appealing to individual human goodness within complex systems. At the end of the story, is a call for specific action.

The FTC's supporting information shows a thorough understanding of the issues. I wish to elevate the need to protect persons who are vulnerable. My focus is crisis lines, using the example of Crisis Text Line, from my personal experience.

I volunteered there from the beginning of the pandemic in 2020 until August 21, 2021, when I was terminated.

**Summary.** Crisis Text Line is a Big Data technology company that provides an important service to the public. It's organized as a nonprofit corporation. As many have pointed out, nonprofits operate with few regulations governing data use and storage. More broadly there are few requirements for accountability or transparency, such as public record and open meeting requirements for government entities. I provide examples and offer a near-term tool, which is to develop a set of best practices in federal government for contracting with crisis line providers. This is ripe for implementation with the 988 Lifeline.

**My Time with Crisis Text Line.** This story is told within my August 21, 2021 [opinion paper](#), a culmination of my efforts to encourage reform of Crisis Text Line's data ethics from within. I opposed the existence of their for-profit company Loris.ai, Inc. and was asking for it to be dissolved. Beginning in June 2020 when I first learned of Loris.ai, Inc., I began asking for open dialog within the Crisis Text Line community and questioning its data ethics. Over a year later, my efforts from within ended. Within two hours of sharing the paper, I was unable to login. I had told their vice president I wasn't going to quit, so they ended my volunteer service. It wasn't until shortly after January 28, 2022, when [POLITICO reported on Loris.ai, Inc.](#) that Crisis Text Line publicly acknowledged concerns about its practices and [said it would stop sharing](#) crisis conversations (de-identified) with Loris.ai, Inc. In my view, this represented no actual change or reform, because Loris.ai had already launched its customer service software. It already had the millions of crisis conversations in its possession. Crisis Text Line continued to hold shares in Loris.ai, Inc., along with other private investors. To my knowledge Loris.ai, Inc. has never deleted the de-identified crisis conversation data. Nevertheless, Crisis Text Line's announcement was sufficient for public attention to move on.

**Example 1. There are few guardrails on nonprofits.** There are few restrictions on nonprofits when it comes to data. A [paper](#) titled *Protecting User Privacy and Rights in Academic Data-Sharing Partnerships: Principles From a Pilot Program at Crisis Text Line* (the "2019 JMIR Paper") written in cooperation with Crisis Text Line describes the primary concerns for data sharing as follows:

*“The 2 primary concerns for a company considering sharing data are reputation and cost. Many technology companies holding data that would be useful to science and society are public-facing companies that rely for business success on their reputation or brand, trust from clients or customers, and the loyalty that follows from it. Negative perceptions can spread quickly through modern media and have the potential to cause significant damage in a relatively short period to a company’s image and, by consequence, to its value (as illustrated by recent Facebook scandals).”*

**Example 2. Willingness to license de-identified crisis conversations.** Crisis Text Line describes the conversations it licensed to Loris.ai, Inc. as “anonymized” in its Terms of Service, but there is [significant debate](#) about such claims.

Personally, I know that some conversations have too many details for any algorithm to make them anonymous. Crisis Text Line used deceptive messaging about commercial uses when it stated it never would sell conversation data, and then it did (its license agreement includes monetary consideration). I have documented this in a [letter of concern](#) to the Journal of Medical Research. My letter raised concerns about the paper quoted in Example 1 above. JMIR invited a formal commentary from me, which I submitted in August 2022, and which is pending publication. Please reference the commentary when it’s published for added detail on concerns specific to the Crisis Text Line organization.

**Example 3. Consent.** Crisis Text Line has shared two opposing views about consent. In a January 31, 2022 [blog post](#), Crisis Text Line’s long-time, prominent board member Dr. danah boyd publicly stated that “...A ToS [Terms of Service] is *not* consent...”. Dr. danah boyd’s blog post was [tweeted](#) by Crisis Text Line, so it clearly was aware. I have written more extensively about the problems with Dr. boyd’s statements [here](#), and also in the commentary submitted to JMIR (not yet published).

In contrast, within the 2019 JMIR paper, consent for research is claimed to be provided by the Terms of Service “CTL provides texters with a link to an easy-to-understand Terms of Service[footnote omitted here], including a disclosure of potential future data use, before every crisis conversation”.

In the current [Terms of Service](#) dated October 27, 2022, the following excerpts claim various permissions:

*“We may use and share anonymous and anonymized data with third parties for any reason.”*

*“Using the Services after receiving those text messages will mean that you accept the Terms then in effect.”*

*“We may anonymize personal data that we collect from you so that it cannot be used to identify you or to contact you, by redacting — or ‘scrubbing’ — personally-identifiable details from it, such as name, age, or address that you provide. We may use and share anonymous and anonymized data with third parties for any reason,...”*

*“We retain Personally Identifiable Information for seven years, and then scrub it to render it anonymous, so it can no longer be used to identify you personally. We retain non personally identifiable data — including the data we scrub — indefinitely, so that we may continue to use it to improve our Services.”*

The contradiction between the organization’s written claims about consent and Terms of Service, with the public statements of its board member, remain unresolved. As far as I know Crisis Text Line continues to collect and use the crisis conversations, for example to create algorithms to [triage the queue](#), and to “train” [machine learning models](#).

The conversation around consent generally focuses on persons using the service because of their extreme vulnerability and the sensitivity of the data. I also [asked Crisis Text Line to confirm](#) whether they take the position that *volunteers* have granted consent, but have yet to receive any response.

**Example 4. Crisis Text Line’s Advisory Boards.** I have studied these boards extensively, tracking their membership and attempting to contact every member of the Data, Ethics, and Research Advisory Board. From my experience this [article in Forbes](#) is accurate. While I tried to confirm each advisory member’s experience directly, most members were unwilling to talk with me or did not respond to my requests. Also see my letter of concern to JMIR.

Before Crisis Text Line came under public scrutiny in late January 2022, it [prominently displayed](#) its board of director membership and its advisory board membership (February 1, 2022 capture). By February 4, 2022 it had [removed the advisory board member names](#). By September 13, 2022 it [completely removed](#) mention of the advisory boards. I [asked Crisis Text Line to confirm](#) whether it had disbanded its advisory boards and have yet to receive an answer.

In my view, Crisis Text Line has been deceptive about the existence, purpose, function and influence of its advisory boards. For example, I spoke personally with Dr. Lucy Bernholz, who recalled that while she was serving on the Crisis Text Line Data, Ethics, and Research Advisory Board, Crisis Text Line shared a plan to make their texting service accessible from Facebook Messenger. When she learned of this, Dr. Bernholz communicated with Crisis Text Line’s Chief Data Scientist, and co-founder, Bob Filbin. She informed him this was not acceptable from her perspective, and that Facebook could not be trusted with such sensitive information. Dr. Bernholz told him she was resigning from the advisory board and did so.

Crisis Text Line proceeded with its plan and has a current partnership with Meta/Facebook. The income from Crisis Text Line partners is reported within its federal 990 forms as earned income ([personal communication](#) with Shawn Rodriguez, Vice President and Senior Counsel for Crisis Text Line, June 4, 2021). Bob Filbin left Crisis Text Line for a [position with Meta](#) in October 2021.

**Example 5. Facebook Messenger.** There are security and privacy concerns for individuals texting a crisis conversation with the Messenger app. For reference, some general information about security and privacy for Facebook Messenger is summarized in [this article](#).

As early as 2016 Crisis Text Line was [making plans to integrate](#) the service with a Facebook messaging app.

On March 30, 2020, Crisis Text Line began to offer text access using Facebook Messenger. A prominent [link to the app](#) was added to its home page “Message Us On Facebook”. This page can be compared with the [March 29, 2020 home page](#) with no link.

Presumably in response to criticism, Crisis Text Line removed its “Or message us on Facebook” links from its [website home page](#) as of February 25, 2022, but at that time still accepted SMS from Messenger according to its Terms of Service. On February 24, 2022, the Messenger app was [still offered](#) on the home page.

From my personal notes, Crisis Text Line updated its Terms of Service on July 11, 2022 to remove explicit mention of Facebook Messenger from 3<sup>rd</sup> Party apps. A [previous version of Terms of Service](#) dated April 13, 2022, includes mention of Facebook Messenger. See beginning summary and THIRD PARTY SERVICES.

On November 19, 2022 I tested the system. By following the link to Messenger from the archive, I was sent to an open chat with Crisis Text Line, however in my test the chat window did not accept messages. For the time being it appears Crisis Text Line USA has discontinued use of Messenger. The following language is from the bottom of the Messenger chat window, accessed from an archived link to Messenger:

*“To help personalise content, tailor and measure ads, and provide a safer experience, we use cookies. By clicking or navigating the site, you agree to allow our collection of information on and off Facebook through cookies. Learn more, including about available controls: Cookies Policy.”*

The lack of transparency relating to matters of privacy and security for public users of the service is troubling. I know of no regulatory standards for privacy and security within apps used to access crisis lines, so individuals are left with the task of trying to monitor services.

**Example 6. The reach of Crisis Text Line to international service – what about the data?**

Crisis Text Line has international reach and is growing. Crisis Text Line has a service partnership with Kids Help Phone, which provides crisis texting service in Canada. The Kids Help Phone website still features a link to Facebook Messenger, though my test of the system indicated it was inoperable. The website still has a [blog post](#) from September 30, 2020 titled “Get virtual support with Facebook Messenger”.

Currently, Facebook Messenger is linked within the banner menu above the blog post (select “Get crisis support right now” and the Facebook Messenger option will display in a dropdown

menu). The decision to use Facebook Messenger was highly questionable and is now a potential source of confusion.

Crisis Text Line has recently begun offering Spanish language support. This means they are now accumulating a dataset of crisis conversations in Spanish. In English and in Spanish, Crisis Text Line claims the ability to anonymize data. Is it reasonable to trust this claim?

**Example 7. Institutions support Crisis Text Line.** The American Association of Suicidology [granted accreditation](#) to Crisis Text Line during a time when [the FCC was asking the FTC to investigate it](#) for its consent practices. To my knowledge the evaluation and accreditation reports and standards are not public records, but it is asserted that ethical standards are included. I am currently trying to verify whether SAMHSA has officially accepted Crisis Text Line as a backup provider to 988 Lifeline, with a Freedom of Information Act request pending since August 2022. The example illustrates in the few places where requirements exist, there have been missed opportunities for accountability. Lifeline [claims that data will not be sold](#) (See FAQ answer to “Will chat/text Lifeline services be able to mine my information/user for their company profit?”) but that’s misleading. Crisis Text Line licensed its data to a for-profit, so what controls are there on the individual nonprofits participating in 988 Lifeline? If controls exist, they are not easily found.

**Example 8. Children.** When I was a volunteer, I personally talked to a child who identified themselves as twelve years old to me. Many children’s voices are captured in these transcripts, with no certain way to identify them all—which is as it should be. About one third of children age 13 and below contacted Crisis Text Line multiple times during a [study of conversations](#) between 2017-2018.

About 21% of persons using the service fill out an exit survey which includes the option to give one’s age. Research authorized by Crisis Text Line is listed at their website, and several of the papers report on the demographic of 14 years and younger. Consent for research and other uses of data is a problem, in my opinion. A very recent [report from Crisis Text Line](#) (see pdf page 41), gives some numbers. About 30,000 children each year age 10 or younger filled out surveys during 2019-2021. About 65,000 children age 11 to 13 completed surveys each year during the same time period.

It's not that children should be turned away, but consent, storage and use of data should consider the presence of children who are experiencing crisis within this data.

I do not believe it appropriate to waive consent (I realize that Institutional Review Boards approved many of the studies published through accredited institutions). Regardless, Crisis Text Line cooperates and makes the data available to researchers. Crisis Text Line now appears to be favoring its own inhouse research. Even harder to regulate, and apparently without advisory boards. Crisis Text Line also asserts it is exempt from the Children’s Online Privacy Protection Act of 1998 (reference Terms of Service), but I wonder about the licensing

agreement it has with Loris.ai, Inc. and the fact that it owns shares as disclosed in the most recent (2020) public financial statements.

These examples illustrate the problems caused by a lack of transparency and accountability.

**Recommendation.** As a partial, temporary solution, I recommend that federal contracts be used to require crisis line providers to follow certain minimum standards for data use, storage, consent and to fully disclose practices regarding consent, whether it is for research, data use and storage, or unwanted dispatch of police.

**Model Crisis Line Practices.** A good place to start is [SafeHotlines](#). I would add, for data practices, that crisis conversations should be completely purged after six months' time (if they are recorded at all) with the retention only being for purposes of human quality control. I oppose the use of algorithms to triage the queue because there is no consent to use conversations to "train" algorithms. Crisis Text Line now has the capability to work with the crisis conversations inhouse. There is no public means of control or oversight. Language models could be developed from crisis conversations and sold, for example. This is not isolated to Crisis Text Line. The Trevor Project also uses crisis conversations—regardless of good intentions—without meaningful consent, in my opinion. In addition, The Trevor Project was recently criticized for [partnering with a surveillance company](#) called Gaggle, and they "[trained](#)" [language models](#) to in turn help [train their volunteers](#).

These examples illustrate the magnetism that exists between Big Data, health care, and corporations with profit models and wealth seeking the data and algorithms trained on it. As [Bob Filbin said](#) in 2015

*"Think about the massive juicy data set Crisis Text Line has collected. More than 9 million messages have been exchanged on this free 24/7 text line for people in crisis in just over two years. The volume, velocity and variety of these messages make this data set a very interesting corpus. Better yet? It's real time."*

In my opinion, best practice would be to use human beings to review volunteer work on a spot-check basis and provide training by humans.

**Why I advocate.** I advocate because as a volunteer I am part of the data, I was in the conversations, I am one of the human subjects, and I find the lack of respect to consent or outright waiving of consent deeply offensive and harmful to important public interests in systems of care.

We adults need to protect children. Those of us who are not presently experiencing crisis moments, need to protect those who are.

Who owns these conversations? I've written a lot of words during my advocacy, but my deepest personal feelings are expressed in just a few, within [this poem](#) titled "Some People Want Our Words".

Thank you for the opportunity to comment. I am willing to answer any questions or serve as a resource for any follow-up to these comments.

END COMMENTS