NEW YORK - Today, Crisis Text Line, a not-for-profit organization, announced they will be making their data available to approved researchers, who must meet stringent requirements, including that research will help more people in crisis.

Currently, the largest open dataset on mental health and crisis is a survey run every other year by the Center for Disease Control (CDC). Over 13 million text messages have been exchanged via Crisis Text Line since its launch in August 2013, qualifying this as the nation’s largest open set of crisis data.

“With this new program, Crisis Text Line is not only making an unprecedented volume of valuable mental health data available to universities and other researchers,” said Peter Salovey, President of Yale University and the Chris Argyris Professor of Psychology, “it is also engaging those researchers in compounding the already significant impact that Crisis Text Line is having on society. As a clinical psychologist, I view this as a significant step forward in the organization’s goal of using ‘data for good’.”

Founder and CEO, Nancy Lublin, is making good on a promise she made publicly from the very beginning: that the data itself could save lives. "From day one, this was the goal: to help
people one-on-one and leverage the data for smart system change on a broad scale,” said Lublin. “I'm pretty darn excited that we're making it happen.”

For the first time, researchers will have access to a large-scale crisis data, which will hopefully lead to more-informed policies, journalism, and interventions across the crisis and mental health space. For example, researchers can answer questions like: what is the relationship between weather patterns and depression? Or, if a texter mentions “bullying,” do eating disorders or other issues arise? This data offers a new perspective that complements existing qualitative and quantitative approaches.

“As an organization of people affected by mental health conditions, we are very grateful to Crisis Text Line for making their data available for innovative research. Every day, we see the consequences of delayed mental health care. We hope research will pave the way for earlier help and brighter futures” said Mary Giliberti, Executive Director of NAMI.

In order to securely distribute this data, Crisis Text Line spent nearly a year establishing an Ethics Committee, creating an IRB process, and preparing a stringent application procedure. Data will not be shared for commercial use; it will only be shared with researchers affiliated with a university or research institution with IRB-approval.

“Crisis Text Line is working to share data with empathy and compassion,” said John Wilbanks, Chief Commons Officer, Sage Bionetworks. “I've been engaged with this application over the last year, and it meets or exceeds the way that most leading research institutions share data.”

Crisis Text Line is offering three levels of data to researchers – conversation, actor and message level – with each level increasing in detail. The conversation level dataset will allow researchers to explore questions such as, “what crisis issues occur most on holidays, such as Christmas and Valentine’s Day?” and “how are bullying and depression related?” The actor level dataset will allow researchers to answer questions like “For a texter experiencing depression, how do issues fluctuate over time?”

The most intricate of the datasets, the message level, will allow researchers to dive deep into interactions, and uncover patterns such as how texters struggling with self-harm describe their experience. All datasets are scrubbed of personally identifiable information. Crisis Text Line’s data sharing guidelines draw from best practices established by the University of Michigan, CDC, and NIH and advisement from the Crisis Text Line Ethics Committee.

The White House Office of Science and Technology Policy, U.S. Department of Health and Human Services, and Department of Veteran Affairs are collaborating with local agencies and technology not-for-profits to support data-driven suicide prevention and mental health initiatives.

"Suicide prevention is a complex topic without easy answers. Open data will help the broad ecosystem of those working on solutions to gain insights and shed new light on patterns and subtleties never before detected. Crisis Text Line's open data release is an example of collaborative, innovative non-governmental action that can save lives," says Megan Smith, the United States Chief Technology Officer (CTO) in the Office of Science and Technology Policy.

Enclave data will build on Crisis Text Line’s existing open data offerings. For the last 18 months, Crisis Text Line has made aggregate data available at www.crisistrends.org. This has already
informed journalism, local policy makers, and community groups taking action to help people in crisis.

Ultimately, Crisis Text Line believes opening this data will lead to better care for people in crisis across the U.S. “We are tremendously excited by the potential of these datasets,” said Lublin, “and we hope it enables researchers everywhere to engage in groundbreaking discoveries.”

Researchers interested in Crisis Text Line’s data enclave can find the application here: http://www.crisistextline.org/open-data/

About Crisis Text Line
Crisis Text Line is free, 24/7 support for people in crisis via text. For more, visit www.crisistextline.org

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What other experts and researchers are saying:

Process and Application
- **Robert J. Levine, MD.** Professor of Internal Medicine, Chair, Executive Committee, Center for Bioethics, Yale University
  “In harmony with the nation’s leading research ethicists, we have created an application that follows best practices for sharing the results of mental health research.”

- **Bob Filbin, Chief Data Scientist, Crisis Text Line**
  “This is one of the largest datasets released by a not-for-profit. We hope the process by which we developed the application will serve as a blueprint for other not-for-profits seeking to increase their impact through open data.”

Privacy
- **David Rousseau, MPH.** Vice President and Executive Director of Health Policy Media and Technology, The Henry J. Kaiser Family Foundation
  “More organizations should consider opening up data to researchers, while maintaining privacy safeguards that protect their users. I applaud Crisis Text Line’s efforts and am hopeful that this new resource will lead to improved ways to help those in crisis.”

- **John E. Marcotte, PhD.** Director, Data Sharing for Demographic Research & Data Security Officer, Inter-university Consortium for Political and Social Research (ICPSR), University of Michigan
  “Crisis Text Line has become part of a vanguard that provides access to impactful data while still protecting individual privacy.”

- **danah boyd, Principal Researcher at Microsoft Research and the founder of Data & Society, Crisis Text Line Board Member**
  “Crisis Text Line is designed to help people. When used right, data can be extraordinarily powerful in that effort which is why Crisis Text Line was built around data. Now the org is positioned to work with researchers to understand and improve mental health.”

The value of the data
- **Tracy Costigan, PhD, Senior Program Officer at the Robert Wood Johnson Foundation**
  “The value of making these data available to researchers will be enormous. The ability to
identify trends and common themes that arise as crises unfold will create myriad opportunities to improve crisis response, mitigation, recovery, and prevention."

• Madelyn Gould, Ph.D., M.P.H., Columbia University Medical Center
  “Crisis Text Line has the volume and variety of data from young people in crisis to uncover insights that were previously inaccessible.”

• Kaja Perina, Editor in Chief, Psychology Today
  “Crisis Text Line forever changed the counseling landscape by offering round-the-clock support to the public via today’s communication platform of choice. This data enclave is an equally significant addition to the research landscape. By anonymizing and sharing data on a huge range of psychological and sociological subjects, Crisis Text Line again meets a critical need. As academics, journalists and policy makers know well, big data sets provide tools to ask and answer the questions that matter most. I’m thrilled that Crisis Text Line’s data can now be harnessed in service of mental health innovation and policy planning.”

• John MacPhee, Executive Director and CEO, The Jed Foundation
  “Crisis Text Line gives young people a means to communicate their emotional well-being in a medium they are familiar with. By examining the trends contained in these organic moments of self-expression, we can see how young adults experience their mental health on their own terms.”

• Alison Malmon, Executive Director, Active Minds
  “By being able to see how people in crisis communicate in their moment of greatest need, researchers will be able to uncover insights that may prevent crises from happening in the first place.”

• Angela Solano Doncel, Programme Manager Americas and The Caribbean, Child Helpline International (CHI) the global network of child helplines
  “Child helplines are crucial drivers of system transformation given that more than any other child protection service, child helplines have direct access to invaluable insights on children’s lives expressed by children themselves, identifying the most important issues in their lives and responding to them. CHI supports the use of this exceptional resource, the knowledge and experience of child helplines to highlight gaps in child protection systems and advocate for the rights of children globally, regionally and nationally, believing in the profound change that well-documented data can achieve. Crisis Text Line’s Enclave Research has the potential to shift child advocacy worldwide to a more data-informed (or evidence-based) approach.”

• Beth Kanter, Trainer & Nonprofit Innovator in networks, learning, and social media
  bethkanter.org, The Networked Nonprofit, Monterey Institute of International Studies
  "This is a great an example of a new wave of not-for-profits, built from the ground up around tech and data, bringing more value to the social sector by working to share data externally."