

Evaluation of TellYourContacts.org, a Patient-Initiated Digital COVID-19 Contact Notification Tool

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Abstract

Background: Contact notification is a method used to control the spread of infectious disease by alerting close contacts of possible exposure. Digital contact notification allows for notification via SMS and email.

Objective: This study evaluated TellYourContacts.org, a COVID-19 digital contact notification website that can be used either confidentially or anonymously.

Methods: We performed a descriptive analysis of the feasibility and use of TellYourContacts.org from May 18th to August 17th, 2020. A testing lab and results disclosure service encouraged patients who tested positive for COVID-19 to use TellYourContacts.org through notifications. We collected website data through Google Analytics and used Microsoft Excel to record the data of website users, types of messages sent, and location of the senders.

Results: Over the course of three months, 9,130 users accessed the website and sent a total of 1,952 messages. Of those messages, users sent 1,815 (93%) SMS messages and 137 (7%) emails. Users sent messages from 40 states, with the majority of United States senders from California (49%).

Conclusions: Our findings suggest that TellYourContacts.org is a promising and accessible patient-led digital contact notification method for those who test positive for COVID-19 in the United States. TellYourContacts.org allows for an additional means to assist in contact notification, thereby increasing the overall number of contacts notified of COVID-19 exposure.

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Original Paper

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Evaluation of TellYourContacts.org, a Patient-Initiated Digital COVID-19 Contact Notification Tool

Abstract

Background: Contact notification is a method used to control the spread of infectious disease. In this process, a patient who tests positive for an infectious disease and public health officials work to identify the patient's close contacts, notify them of their risk of possible exposure to the disease, and provide resources to facilitate the decreased spreading of disease. Contact notification can be done physically in person, via phone call, or digitally through the use of media such as SMS and email. When alerts are made through the latter, it is called digital contact notification.

Objective: This study aims to perform a preliminary evaluation on the use of TellYourContacts.org, a COVID-19 digital contact notification tool that can be used confidentially and anonymously, to gather information about the quantity of website users and message senders, the types of messages sent, and the geographic distribution of senders.

Methods: Patients who chose to get tested for COVID-19 and subsequently tested positive for the disease were alerted of their positive results through Curative, Inc., a COVID-19 testing laboratory,

and Healthvana, a results disclosure app. Included in the notification was a link to TellYourContacts.org and a message encouraging the COVID-19 positive patient to utilize the website to alert their close contact of exposure risk. Over the course of three months, from May 18th, 2020 to August 17th, 2020, we utilized Google Analytics and Microsoft Excel to record data on the quantity of website users and message senders, types of messages sent, and geographic distribution of the senders.

Results: Over the course of three months, 9,130 users accessed the website. Of the users, 1,474 unique senders sent a total of 1,957 messages. Of those messages, users sent 1,820 (93%) SMS messages and 137 (7%) emails. Users sent messages from 40 states, with the majority of United States senders from California (49%).

Conclusions: We set out to determine if individuals who test positive for COVID-19 will utilize the TellYourContacts.org website to notify their close contacts of COVID-19 exposure risk. Our findings reveal that, during the observation period, each unique sender sent an average of 1.33 messages. TellYourContacts.org offers an additional method that individuals can and will use to notify their close contacts.

Keywords: patient-led digital contact notification; COVID-19; digital contact tracing; contact notification website

Introduction

The process of contact tracing varies, depending on facility. However, the core concept includes first identifying those with an infection. This is done either when an individual tests positive

for an infectious disease or if there is belief that there is a high probability that an individual has an infection. Then begins the process of determining if there are any close contacts of the infected patient at risk for contracting the disease. With the assistance of the healthcare team, patients can be educated on how to identify their close contacts and notify their contacts themselves. Or, with the patient, public health officials as well as members of the healthcare team can work together to determine and notify the close contacts. The notification of close contacts to tell of their exposure risk can be done in person, via phone call, SMS, email, or any additional form of communication. Lastly, the goal of contact tracing and contact notification is to control and decrease disease spread. As a result, ultimately, when alerting close contacts, resources such as testing for the close contacts, treatments, and educational counselling including the next steps in how to approach suggested guidelines can be supplied to facilitate the goal of avoiding the spread of disease. [1,2].

Digital contact notification is a form of contact notification where technological media such as emails, text messages, and smartphone applications are used to notify the close contacts of positive patients of their exposure risk [3]. It can allow for greater flexibility within the realm of contact tracing when utilized, as opposed to the use of solely in-person or telephone-based contact notification. The use of emails and text messages to notify contacts has been utilized most frequently in partner notification for HIV and other sexually transmitted diseases (STDs) such as gonorrhea, syphilis, and chlamydia [4-11]. Previous studies on both patient initiated-, where the individual positive for disease alerts their contacts, and healthcare provider initiated- digital contact or partner notification have concluded that the use of emails and/or text messages to notify contacts increases the total numbers of contacts alerted when used in addition to traditional in-person, telephone or written, partner notification [5-9]. This method allows for the ability to reach populations that are inaccessible or hard to reach with traditional partner notification [5-7].

However, not all studies have demonstrated a high level of utilization of digital means of

notification. In evaluations of inSPOT.org, a patient-initiated STD partner notification website where those who test positive for a STD can send electronic postcards to their partners, investigators of the project found that <10% of the observed participants sent messages to their partners through the website [12-14]. This, in part, could be due to patients' preference of notifying their contacts in person [12]. Though more recently, TellYourPartner.org, an updated version of inSPOT.org, records a high proportion of visitors to messages sent.

We performed a preliminary evaluation of TellYourContacts.org, a patient-initiated COVID-19 contact notification website where users who have tested positive for COVID-19 have the option of sending either text messages or emails to notify their close contacts, to observe the use of the website over a period of three months. As defined by the Centers for Disease Control and Prevention, a close contact is one who was within 6 feet from the infected, for a cumulative total of at least fifteen minutes over a 24-hour period, starting two days before the positive case started experiencing symptoms or two days prior to specimen collection [15,16]. We determined the frequency of website use and the frequency, types, and geographic distribution of messages sent.

Methods

TellYourContacts.org

Building Healthy Online Communities (BHOC) and Team Klausner Saving Lives (TKSL) collaborated to create and build TellYourContacts.org which officially launched on May 13th, 2020. TellYourContacts.org is a rapid adaptation of TellYourPartner.org, a website in which those positive for a STD can anonymously notify their sex partners [17]. Given the rapid spread of coronavirus and the serious nature of symptoms, a number of BHOC partners requested the adaptation of TellYourPartner.org for COVID-19. With review of Centers for Disease Control and Prevention (CDC)

information as well as input from on-the-ground providers, we developed TellYourContacts.org following quickly evolving best practices on contact notification as they were known at the time.

Many Individuals are first informed of the TellYourContacts.org website when they receive notification of their positive COVID-19 test result from Curative, Inc or Healthvana. Within that notification detailing the positive result, a link to TellYourContacts.org is also provided, encouraging patients to notify their close contacts of their risk of contracting COVID-19. Curative, Inc. is a COVID-19 testing laboratory that supports COVID-19 testing in states throughout the United States and works to send patients an email of their COVID-19 test results. If positive, the email contains a link to the TellYourContacts.org website (Figure 1).

Figure 1. Curative, Inc. email sent to those with a positive COVID-19 test result, with “notify” link to TellYourContacts.org

Hi {{patient_name}},

This is an automatic notification about your recent COVID-19 test result from Curative. Your COVID-19 test was **POSITIVE**, meaning that the virus that causes COVID-19 was detected in the specimen you provided.

You can expect to be contacted by a member of the Florida Department of Health in your county in the coming days.

Many patients experience mild to moderate symptoms similar to the flu. These can be managed with rest, hydration, and appropriate doses of fever-reducing medication. If at any time you experience chest pain, shortness of breath, difficulty breathing, confusion, vomiting that will not stop, or if you feel that your symptoms are worsening in any way, please call 911 or go to your nearest Emergency Room.

Please isolate yourself and minimize any contact with others for at least 10 days. Please [notify](#) anyone with whom you may have been in close contact (> 15 minutes and < 6 feet) starting two days before your symptom onset, or if you asymptomatic, two days before you were tested. You may call, text or email them to advise them that they may have been exposed and should quarantine for 14 days since they last had close contact with you. They should consider getting tested if they develop symptoms. Please visit [this link](#) for isolation guidance and more information from the Florida Department of Health.

Here is information about your test:

Appointment: {{reference_number}}

Patient: {{patient_name}}

Collected at: {{collection_time}}

Result: **POSITIVE**

Released at: {{release_time}}

[Click here](#) to find additional COVID-19 resources for Floridians.

Be well,

Curative

<http://curativeinc.com>

Healthvana, a results disclosure app, works to deliver COVID-19 test results to patients located in California. Within the positive result message, Healthvana sends COVID-19 positive patients the TellYourContacts.org website link [18] (Figure 2).

Figure 2. Healthvana message sent to those with a positive COVID-19 test result, with link to TellYourContacts.org

Positive

If your COVID-19 test result was POSITIVE, this means that the coronavirus that causes COVID-19 was detected. If you have a primary care physician, notify them of your POSITIVE test as soon as possible.

Many patients experience mild to moderate symptoms similar to the flu. These can be managed with rest, hydration, and appropriate doses of acetaminophen (Tylenol). There currently are no specific medications or treatments for COVID-19. Between 85 – 90% of patients with confirmed COVID-19 do NOT require hospitalization.

If, at any time, you experience chest pain, shortness of breath, difficulty breathing, or vomiting that will not stop, please call 911 or go to your nearest Emergency Room.

Please stay away from others. Stay home until at least 14 days have passed after your symptoms first appeared. Recovery means that your fever is gone for 3 days without the use of fever-reducing medications and your respiratory symptoms (e.g. cough, shortness of breath) have improved.

Please visit [TellYourContacts.org](https://www.tellyourcontacts.org) to inform people with whom you may have been in close contact starting 2 days prior to the time you developed any symptoms. Close contact means being within 6 feet of someone for more than 15 minutes. This website sends texts or emails to your contacts completely anonymously. These notifications are critical in our efforts to stem the spread of COVID-19.

Additional information can be found about isolating at home by the [CDC](https://www.cdc.gov).

In addition, the TellYourContacts.org website was also advertised to members of CDC-funded STD organizations as well as through a press release, social media, and word of mouth.

Once on the TellYourContacts.org website, users have the option to either send their notification(s) via email or text message, to up to ten close contacts at a time. Additionally, they have the option to send their message(s) anonymously or confidentially, where the user has the option to enter their name. Users also have the option to create their own custom message or to send a pre-written message. The TellYourContacts.org message alerts the recipient that they may have been exposed to coronavirus and it is recommended for them to home isolate as well as seek testing. They are also directed to the CDC's coronavirus information webpage (Figures 3 and 4).

Figure 3. TellYourContacts.org pre-written and custom messages for SMS

Option 1: Pre-written message

This is an important message about your health.
Please do not reply to this text.

A friend, acquaintance or contact wants to make sure you know you may have been exposed to the coronavirus.

Since you may not have any symptoms, we recommend you follow the CDC's guidelines which currently suggest home quarantine for 14 days.

For more information from the CDC, please go to <https://www.cdc.gov/coronavirus/2019-ncov/index.html> which also contains a self-checker.

For information about testing, check out: <https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/testing.html>

 ENTER YOUR NAME HERE IF DESIRED

Option 2: Custom message

This is where you can write your own personal message if you wish.

Click on the box to start and press the button below to advance to the review and edit section.
Please note, there is an 160 character limit.

 ENTER YOUR NAME HERE IF DESIRED

Figure 4. TellYourContacts.org pre-written and custom messages for email

Option 1: Pre-written message

This is an important message about your health.

A friend, acquaintance or contact wants to make sure you know you may have been exposed to the coronavirus.

Since you may not have any symptoms, we recommend you follow the CDC's guidelines which currently suggest home quarantine for 14 days.

For more information from the CDC, please go to <https://www.cdc.gov/coronavirus/2019-ncov/index.html> which also contains a self-checker.

For information about testing, check out: <https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/testing.html>.

Please do not reply to this email.

TellYourContacts.org — A free and anonymous way to support your contacts' health.



ENTER YOUR NAME HERE IF DESIRED

Option 2: Custom message

This is where you can write your own personal message if you wish.

Click on the box to start and press the button below to advance to the review and edit section. Please note, there is an 160 character limit.



ENTER YOUR NAME HERE IF DESIRED

Lastly, the website provides information about which contacts should be notified and provides direct links to the CDC website for users to learn more about COVID-19 [19,20].

To maintain confidentiality and privacy, TellYourContacts.org does not record the user's contact information unless voluntarily provided. As users access the website and input information such as their contact's email addresses and phone numbers, their connection and data are encrypted and secured via hypertext transfer protocol secured via the third-party service provider

GoDaddy (GoDaddy Inc., Scottsdale, AZ). TellYourContacts.org does not use cookies, though its third-party providers may. Additionally, the website neither stores the email addresses or phone numbers of the user's contacts nor does it link information to an individual. The website also uses services from Mailjet (Mailjet Inc., Paris, France), Twilio (Twilio Inc., San Francisco, CA), and Google Analytics (Google, Mountain View, CA) for email transmission, SMS transmission, and collection of aggregate data that includes the total number of users who access the website, the total number and types of messages sent, and the general location via IP address [21]. These providers have their own respective measures of security which include ISO 27001 Information Security Standard compliance and GDPR-Compliant Email Service Provider Certification [22-24].

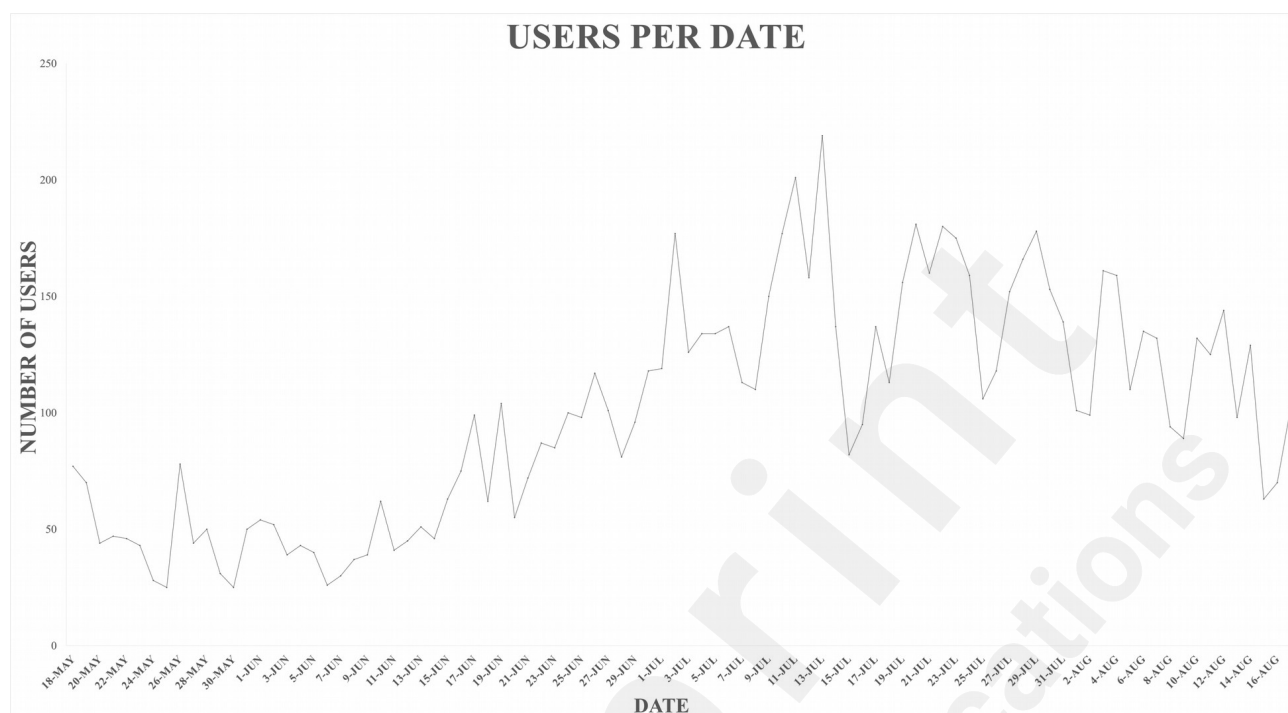
Data Collection and Analysis

We collected data about the total number of emails and messages sent, notifying patients of their positive COVID-19 results, from both Curative, Inc. and Healthvana, respectively. From that, we estimated the number of messages sent to patients observed in our study. Additionally, we collected data regarding TellYourContacts.org website use including message senders, types of messages sent, and approximate geographic location of senders from Google Analytics. We input the data into Microsoft[®] Excel software, version 16.16.12 (Microsoft Corporation, King County, WA) to sum the total quantities of the aggregate website data and used descriptive statistics to determine the mean number of messages sent per unique user within the observation period.

Results

From May 18th, 2020 to August 17th, 2020, Healthvana reported 125,652 COVID-19 positive test results to patients in California. Additionally, from May 18th, 2020 to August 17th, 2020, Curative, Inc. notified 71,866 patients of their positive COVID-19 test results across the United States. During the observation period, from May 18th, 2020 until August 17th, 2020, a total of 9,161 users accessed the TellYourContacts.org website (Figure 5).

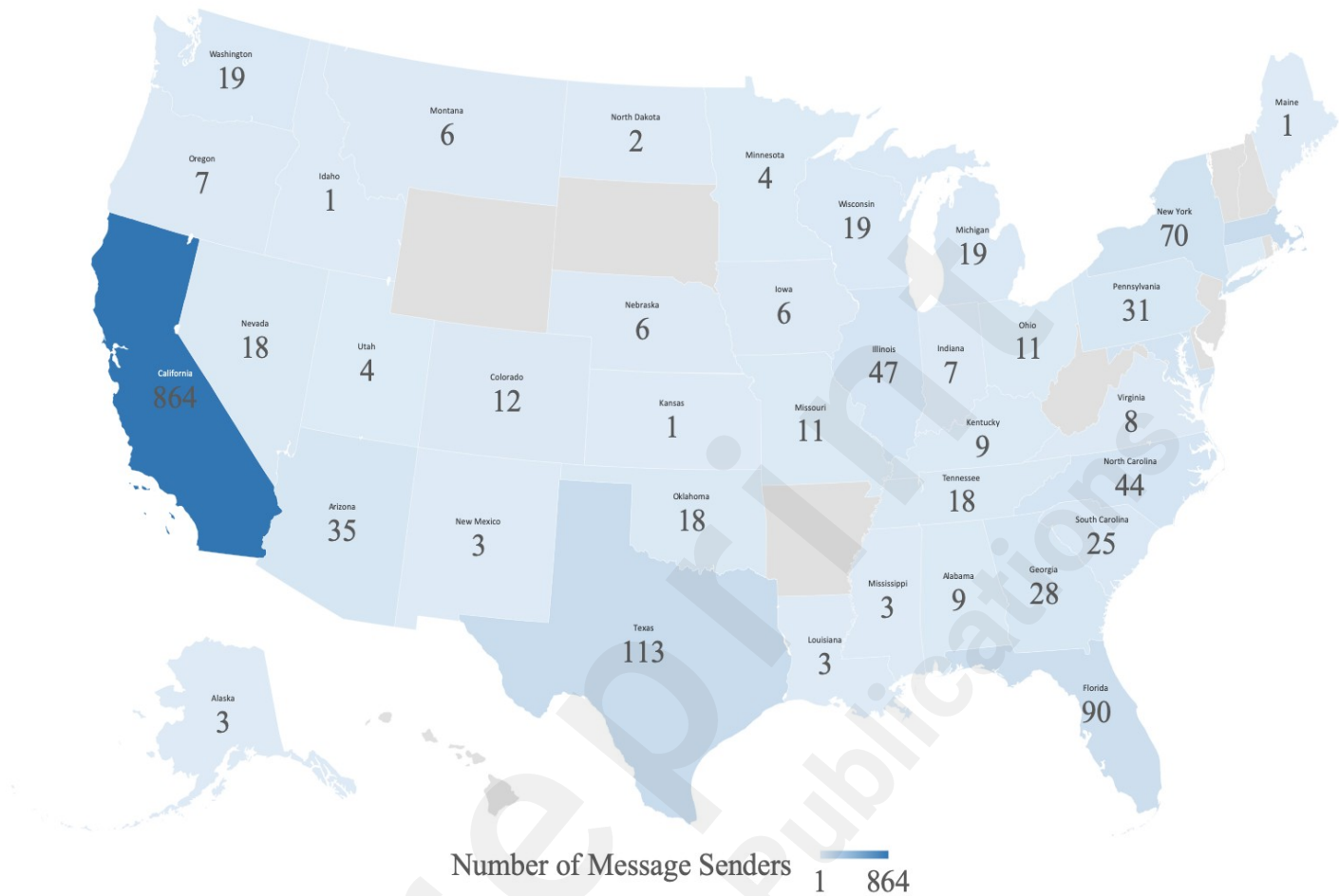
Figure 5. TellYourContacts.org number of users per date, from May 18th, 2020 to August 17th, 2020



Of these users, a total of 1,957 sent messages. We found that users chose to send SMS over email in a 13:1 ratio, 1,820 (93%) via SMS and 137 (7%) via email. Users from 13 countries sent messages – the United States, Canada, Dominican Republic, Mexico, the United Kingdom, South Africa, Japan, Bulgaria, Puerto Rico, French Guiana, the United Arab Emirates, Sweden, Australia, and Morocco. Senders in the United States made up the majority of total senders (97%), representing 40 states. Within the United States, California accounted for the majority of senders with 864 (49%). Texas and Massachusetts accounted for the second-most senders, both with 113 (6%) each (Figure 6).

Figure 6. TellYourContacts.org number of message senders by state, from May 18th, 2020 to August 17th, 2020

SENDERS BY STATE



Discussion

We described the use of a newly created digital notification platform, TellYourContacts.org, and found that in over the course of three months, 9,161 users accessed the website. Of the users, 1,474 unique senders sent a total of 1,957 messages notifying their close contacts of possible COVID-19 exposure risk, from the majority of states in the United States. Our results demonstrate that individuals will use a digital notification platform to notify their contacts.

Currently, there are various modalities in use for digital COVID-19 contact-notification globally such as the smartphone-based contact tracing apps. These apps use either Bluetooth, GPS, or QR (quick response code) to inform individuals that they may have been exposed to a case. Bluetooth-based contact notification apps measure signal strength of nearby smartphones to determine the user's proximity to and duration with those infected. GPS-based contact notification apps geolocate users to determine their proximity to those infected. Lastly, QR-based contact-notification apps utilize QR-barcodes that are scanned upon one's entrance to public spaces to monitor the user's visited locations [3]. In contrast to other forms of COVID-19 contact notification, such as the Apple Inc. and Google Exposure Notification System that uses Bluetooth to automatically notify close contacts that have opted in, TellYourContacts.org offers users the ability to assist them in the process of contact notification while maintaining user agency [25]. It allows users the ability to control how they send their messages by providing them the option to personalize their message or use pre-formed messages and anonymize themselves. This tool can be especially helpful for users who might not feel comfortable or might not know how to directly tell their contacts of their exposure risk, all while providing their contacts with website links to COVID-19 educational resources. Additionally, TellYourContacts.org can be used without having to download and install, continuously update, and authorize additional permissions on their phone or other electronic devices.

Users of TellYourContacts.org chose to send the majority of messages to their close contacts

via text message. This result might be possibly due to the convenience and increasing popularity of text messaging over the past two decades. In 2019, 81% of Americans owned a smartphone, an increase of over 20% five years prior [26]. Geographically, California accounted for the majority of the locations from where messages were sent. This may be because most positive cases observed in our study tested in California.

This study is not without its limitations. First, our evaluation may have underestimated the number of people who may have received information about TellYourContacts.org because those who tested at institutions such as nursing homes and homeless shelters were manually excluded from the total observed count. Second, the TellYourContacts.org website has potential for misuse as messages can be sent for unintended purposes. IP addresses are collected by Google Analytics, a third-party provider, to geolocate and provide relevant COVID-19 related information by region. Currently, an anti-IP address spoofing mechanism is in use to filter out false IP addresses associated with bots. Lastly, due to the nature and privacy policies of the website, data regarding the demographic characteristics of each person tested for COVID-19, the percentage of those who sent anonymous messages, and amount of contacts who read the message and took precautions such as isolation, symptom self-checking, and testing, cannot be obtained and analyzed.

With innovations in technology, 90% of Americans use the internet and 81% own a smartphone [26,27]. As a result, digital means such as emailing, and text messaging are increasingly used to communicate. TellYourContacts.org allows individuals who are positive for COVID-19 the ability to initiate contact notification with tools, such as smartphones and computers, that are already readily in use by them. After the evaluation of TellYourContacts.org, we found supportive evidence that TellYourContacts.org is a viable, low-threshold method that people will use to aid in contact notification for COVID-19. Continued social marketing research is needed to further increase utilization.

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Conflicts of Interest

None declared.

Abbreviations

CDC: Centers for Disease Control and Prevention

IP: internet protocol

QR: quick response code

STD: sexually transmitted disease

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Supplementary Files

Figures

TellYourContacts.org pre-written and custom messages for SMS.

Option 1: Pre-written message

This is an important message about your health.
Please do not reply to this text.

A friend, acquaintance or contact wants to make sure you know you may have been exposed to the coronavirus.

Since you may not have any symptoms, we recommend you follow the CDC's guidelines which currently suggest home quarantine for 14 days.

For more information from the CDC, please go to <https://www.cdc.gov/coronavirus/2019-ncov/index.html> which also contains a self-checker.

For information about testing, check out: <https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/testing.html>



ENTER YOUR NAME HERE IF DESIRED

Option 2: Custom message

This is where you can write your own personal message if you wish.

Click on the box to start and press the button below to advance to the review and edit section.
Please note, there is an 160 character limit.



ENTER YOUR NAME HERE IF DESIRED

TellYourContacts.org pre-written and custom messages for email.

Option 1: Pre-written message

This is an important message about your health.

A friend, acquaintance or contact wants to make sure you know you may have been exposed to the coronavirus.

Since you may not have any symptoms, we recommend you follow the CDC's guidelines which currently suggest home quarantine for 14 days.

For more information from the CDC, please go to <https://www.cdc.gov/coronavirus/2019-ncov/index.html> which also contains a self-checker.

For information about testing, check out: <https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/testing.html>.

Please do not reply to this email.

TellYourContacts.org — A free and anonymous way to support your contacts' health.



ENTER YOUR NAME HERE IF DESIRED

Option 2: Custom message

This is where you can write your own personal message if you wish.

Click on the box to start and press the button below to advance to the review and edit section.
Please note, there is an 160 character limit.



ENTER YOUR NAME HERE IF DESIRED

Curative, Inc. email sent to those with a positive COVID-19 test result, with “notify” link to TellYourContacts.org (Florida).

Hi {{patient_name}},

This is an automatic notification about your recent COVID-19 test result from Curative. Your COVID-19 test was **POSITIVE**, meaning that the virus that causes COVID-19 was detected in the specimen you provided.

You can expect to be contacted by a member of the Florida Department of Health in your county in the coming days.

Many patients experience mild to moderate symptoms similar to the flu. These can be managed with rest, hydration, and appropriate doses of fever-reducing medication. If at any time you experience chest pain, shortness of breath, difficulty breathing, confusion, vomiting that will not stop, or if you feel that your symptoms are worsening in any way, please call 911 or go to your nearest Emergency Room.

Please isolate yourself and minimize any contact with others for at least 10 days. Please [notify](#) anyone with whom you may have been in close contact (> 15 minutes and < 6 feet) starting two days before your symptom onset, or if you asymptomatic, two days before you were tested. You may call, text or email them to advise them that they may have been exposed and should quarantine for 14 days since they last had close contact with you. They should consider getting tested if they develop symptoms. Please visit [this link](#) for isolation guidance and more information from the Florida Department of Health.

Here is information about your test:

Appointment: {{reference_number}}

Patient: {{patient_name}}

Collected at: {{collection_time}}

Result: **POSITIVE**

Released at: {{release_time}}

[Click here](#) to find additional COVID-19 resources for Floridians.

Be well,

Curative

<http://curativeinc.com>

Healthvana message sent to those with a positive COVID-19 test result, with link to TellYourContacts.org.

Positive

If your COVID-19 test result was POSITIVE, this means that the coronavirus that causes COVID-19 was detected. If you have a primary care physician, notify them of your POSITIVE test as soon as possible.

Many patients experience mild to moderate symptoms similar to the flu. These can be managed with rest, hydration, and appropriate doses of acetaminophen (Tylenol). There currently are no specific medications or treatments for COVID-19. Between 85 – 90% of patients with confirmed COVID-19 do NOT require hospitalization.

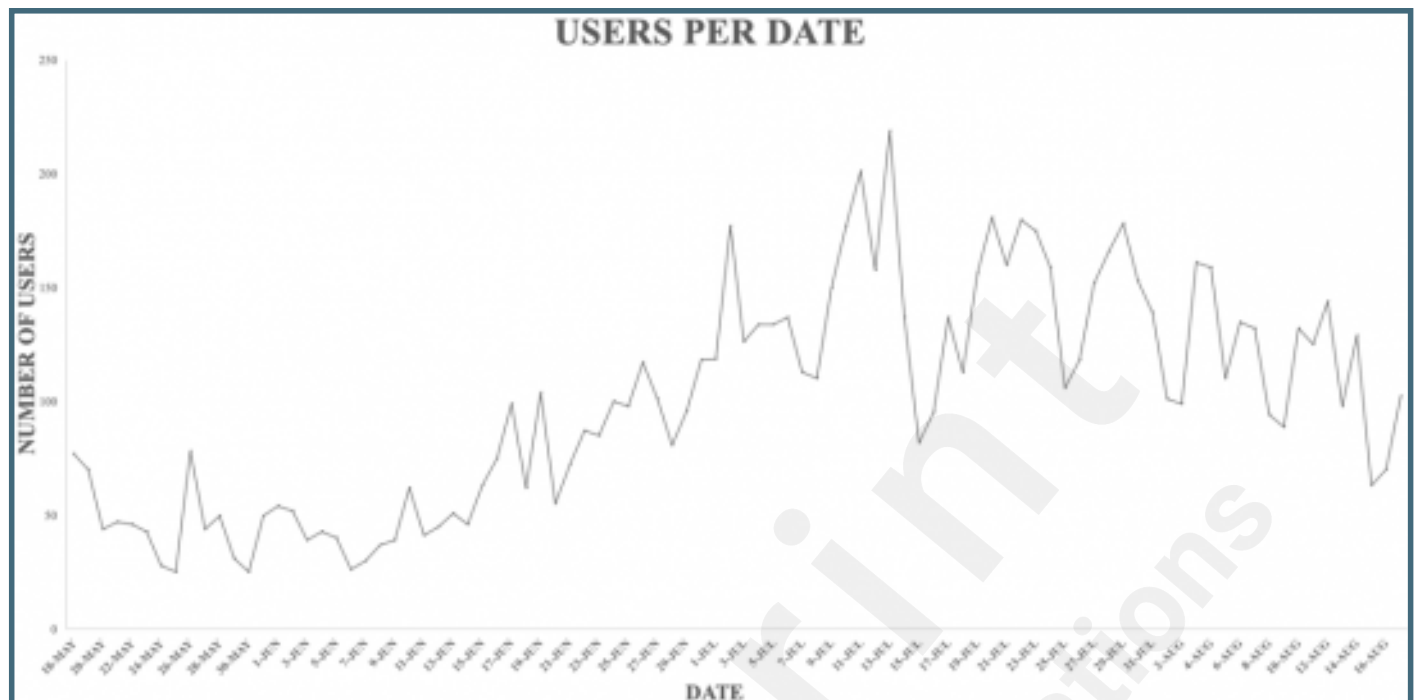
If, at any time, you experience chest pain, shortness of breath, difficulty breathing, or vomiting that will not stop, please call 911 or go to your nearest Emergency Room.

Please stay away from others. Stay home until at least 14 days have passed after your symptoms first appeared. Recovery means that your fever is gone for 3 days without the use of fever-reducing medications and your respiratory symptoms (e.g. cough, shortness of breath) have improved.

Please visit [TellYourContacts.org](https://www.tellyourcontacts.org) to inform people with whom you may have been in close contact starting 2 days prior to the time you developed any symptoms. Close contact means being within 6 feet of someone for more than 15 minutes. This website sends texts or emails to your contacts completely anonymously. These notifications are critical in our efforts to stem the spread of COVID-19.

Additional information can be found about isolating at home by the [CDC](https://www.cdc.gov).

TellYourContacts.org number of users per date, from May 18th, 2020 to August 17th, 2020.



TellYourContacts.org number of message senders by state, from May 18th, 2020 to August 17th, 2020.

