

COVID-19 HOPE Registry



JOHNS HOPKINS
INSTITUTE *for* CLINICAL &
TRANSLATIONAL RESEARCH

Cassie Lewis-Land, MS, CCRP

Recruitment Innovation Unit (RIU)

Agenda



- Development of centralized recruitment registry tool
- Recruitment methods used to engage participants
- Workflow of registry process
- How to gain access to utilize registry

Objective of HOPE Registry

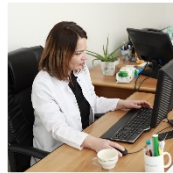
The registry is designed to be participant centric allowing for volunteers to be matched with researchers and building a community around COVID -19 research and information



Participant

- ability to choose a study or studies that best fits their personal preferences and gives them autonomy in choosing

to stay informed of study opportunities that they may be eligible to join



Research Teams

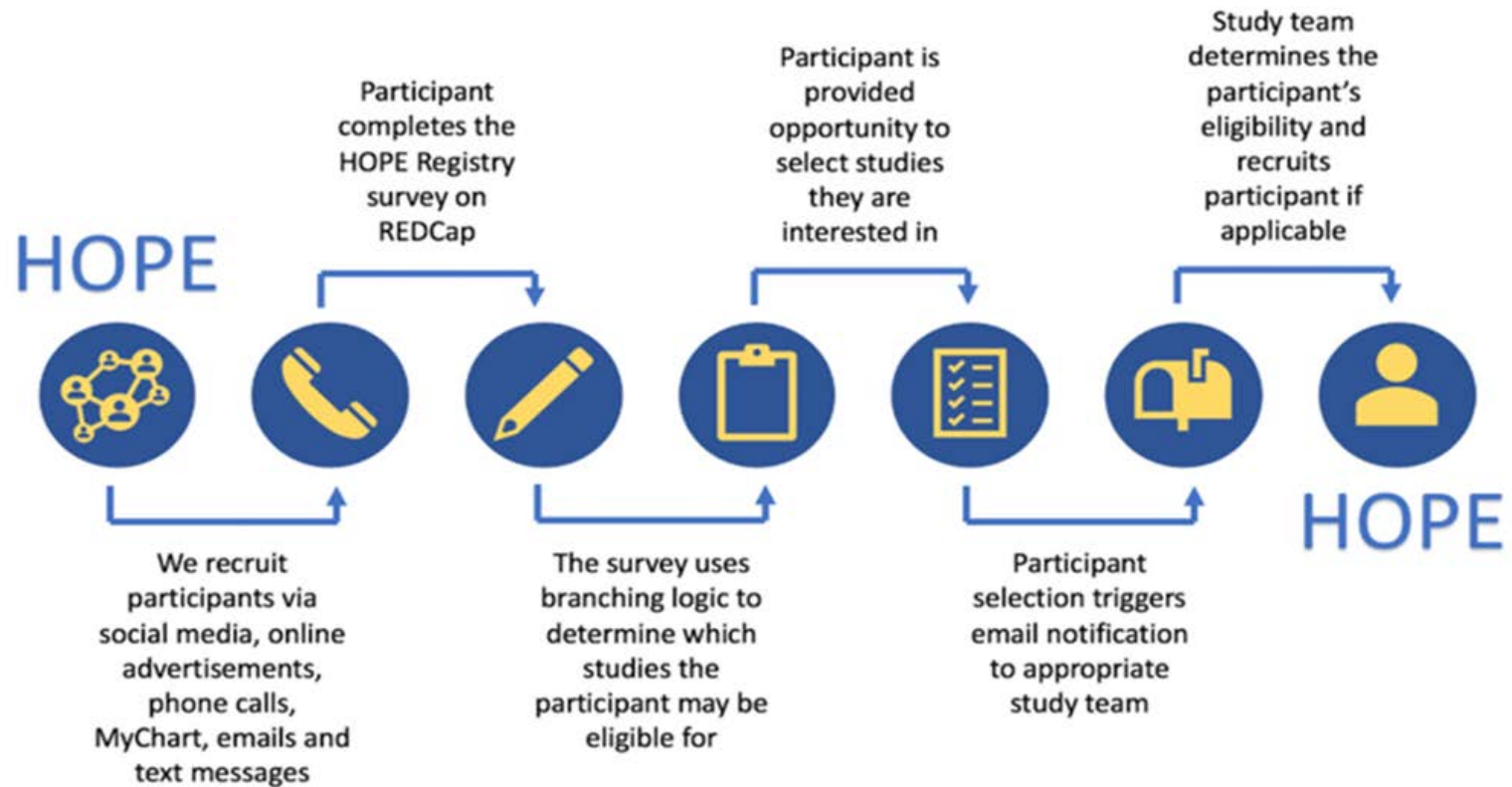
- Provides ability to directly contact individuals who have expressed interest in participating in COVID-19 research and their project
- Creates a organized tool for tracking and documenting recruitment efforts



HOPE Community

- Allows for a diverse community of individuals who through engagement can become ambassadors promoting research participation
- Serves as information center about COVID-19 research opportunities, general information and resources

How it Works



Recruitment Card

Patients at JH testing sites will be given a recruitment post card informing them of the registry and asking them to self enroll, and be on the lookout of our staff calling to help them enroll



Johns Hopkins is Conducting COVID 19 Research



JOHNS HOPKINS
MEDICINE

The COVID-19 pandemic is impacting the lives of nearly everyone throughout the world. Johns Hopkins is working with many research teams to **understand how** the COVID-19 virus causes disease, how we might **fight** the virus, and how to **develop better treatments and vaccines**. We would like you to join us in this effort. There are research studies that you or people in your household might qualify to join. Joining these research studies is voluntary. You can always say no and still be a patient at Johns Hopkins.

We invite you to go to <https://tinyurl.com/hope-registry> to complete a brief survey about your willingness to participate in COVID-19 research.

For some of our studies, you need to start right away, so we may contact you over the next few days to tell you more about these studies. We also may ask if people that you live with are interested in joining studies for preventing COVID-19. We may call, e-mail, or text you, and, if you have MyChart, you may receive a MyChart message. If we call you and you do not wish to participate just let us know and we will not contact you again.

Thank you again for helping us learn more about COVID-19 disease.

Daniel Ford, MD, MPH
Vice Dean for Clinical Research
Johns Hopkins School of Medicine
IRB: IRB00251151



JOHNS HOPKINS
INSTITUTE for CLINICAL &
TRANSLATIONAL RESEARCH

Recruitment Methods



MYCHART
MESSAGES



E-MAILS



TEXT
MESSAGES



PHONE CALLS

Community Engaged Recruitment

Hopkins
Opportunities for
Participant
Engagement

Please consider participating in research related to **COVID-19** prevention, diagnosis, or treatment.

<https://tinyurl.com/Johns-Hopkins-Hope>

Text
HOPKINSHOPE
To **474747** for
more information or visit
JohnsHopkinsHope.org

 **JOHNS HOPKINS**
INSTITUTE for CLINICAL &
TRANSLATIONAL RESEARCH

- Social media campaigns
- community based organizations
- Day@TheMarket events
- Maryland Department of Health
- Centro SOL



Johnshopkinshope.org



ESPAÑOL

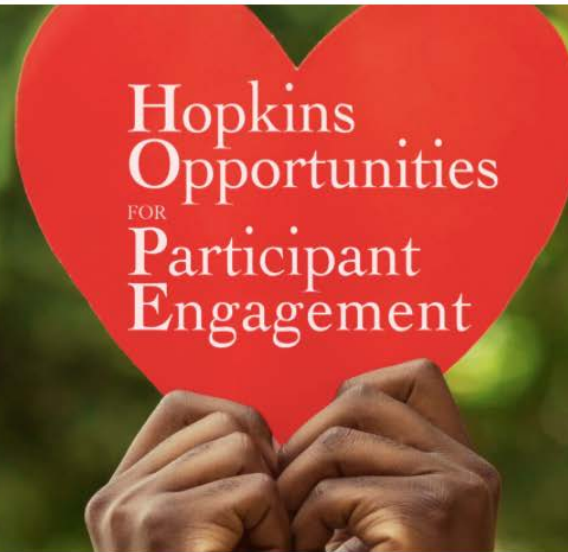
HOPE is in your hands.

Johns Hopkins HOPE brings volunteers, patients and researchers together as partners in clinical research to deliver the promise of medicine.

We want to improve healthcare by studying how we can better prevent disease, treat conditions and improve people's well-being.

Join us in HOPE.

VOLUNTEER FOR COVID-19 STUDIES →



Johnshopkinshope.org

REPAIR COVID

Recovering Patients Informing Research
about COVID-19 (REPAIR COVID)

PI: Hanan Aboumatar, MD, MPH
IRB00258286

Did you have COVID-19? Share your experiences with researchers! The COVID-19 pandemic has affected millions of people. We are looking to partner with people with a pre-existing condition (such as heart disease, diabetes, COPD) who had COVID-19. We need your help to identify:

- Important topics for COVID-19 research studies
- Questions that you want researchers to answer

- Age:** 18+
- Duration:** 6 months
- Visits:** 90 minutes online or phone conversation
- Transportation assistance:** not applicable
Compensation: \$50 check
- Language:** English, Spanish
- Location:** No in-person contact/Remote only

COVID CS5C-001 and COVID CS5C-004 Studies

Consent Form to Stem Cell Research (COVID CS5C-001) and the Coronavirus Plasma to Stem Cell Research (COVID CS5C-004) studies

Have you been tested for COVID-19? The study will involve collection of plasma containing antibodies for persons who have recovered from COVID-19 to prevent others from getting COVID-19 after exposure. The plasma will be used to develop a vaccine. The study will involve plasma collection only and will not involve any other procedures. Compensation is provided.

- Age:** 18 years and above
- Duration:** 2 months
- Visits:** 1 - 7 visits
- Location:** Johns Hopkins Hospital East Baltimore Campus Johns Hopkins Green Spring Station

PROTECT study

Register for the study to be part of a longitudinal study to understand the progression of COVID-19 infection in people who have been exposed through household contact, public settings, or other close contact with someone who has been infected. The length of study participation is 60 days after exposure. Compensation is provided.

- Age:** 18-80 years
- Duration:** 60 days with a single assessment on day 58
- Visits:** 4 visits and one phone or remote contact
- Location:** Johns Hopkins Green Spring Station

Qualification of donors for convalescent plasma

Have you been tested for COVID-19? The study is looking for people who have recovered from COVID-19 to prevent others from getting COVID-19 after exposure. The study will involve plasma collection only and will not involve any other procedures. Compensation is provided.

- Age:** 18 years and above
- Duration:** 1 day
- Visits:** 1 visit
- Location:** Johns Hopkins Hospital East Baltimore Campus Suburban Hospital

HERO-HCO Trial

Are you a healthcare worker? The HERO-HCO trial is looking for healthcare workers who have been exposed to COVID-19 to prevent others from getting COVID-19 after exposure. The study will involve plasma collection only and will not involve any other procedures. Compensation is provided.

- Age:** 18+
- Duration:** 4 weeks
- Visits:** 4 visits and one phone or remote contact
- Location:** Johns Hopkins Hospital East Baltimore Campus Suburban Hospital

REPAIR COVID

Recovering Patients Informing Research about COVID-19 (REPAIR COVID)

Did you have COVID-19? Share your experiences with researchers! The COVID-19 pandemic has affected millions of people. We are looking to partner with people with a pre-existing condition (such as heart disease, diabetes, COPD) who had COVID-19. We need your help to identify:

- Important topics for COVID-19 research studies
- Questions that you want researchers to answer

- Age:** 18+
- Duration:** 6 months
- Visits:** 90 minutes online or phone conversation
- Transportation assistance:** not applicable
Compensation: \$50 check
- Language:** English, Spanish
- Location:** No in-person contact/Remote only

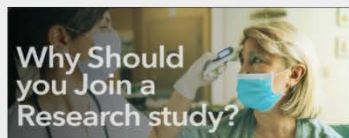
Adapt out COVID

Adapt out COVID-19 study to understand the progression of COVID-19 infection in people who have been exposed through household contact, public settings, or other close contact with someone who has been infected. The length of study participation is 60 days after exposure. Compensation is provided.

- Age:** 18+
- Duration:** 60 days
- Visits:** 4 visits and one phone or remote contact
- Location:** Johns Hopkins Hospital East Baltimore Campus Suburban Hospital

COVID-19 Information Center

Visit any of these pages to arm yourself with all the information you need about the pandemic.



How the Registry Works



1-Individuals consent and enroll into registry answering questions about themselves

2-Branching logic is built to match with studies that the individual maybe eligible for given responses

3-Study teams get immediate alerts of interest and can then reach out to do a complete screening to determine eligibility of individual



How the Registry Works

From: "scarey@jhmi.edu" <scarey@jhmi.edu>
Reply-To: Scott Carey <scarey@jhmi.edu>
Date: Thursday, July 16, 2020 at 9:50 PM
To: covidplasmatrial <covidplasmatrial@jhmi.edu>
Subject: COVID Study Interest Response

A patient has expressed interest in your study. Please use the link below to review the available information and document the outcome.

[Covid19 Study Interest - Study Coordinator Follow Up](#)

If the link above does not work, try copying the link below into your web browser:

<https://mrprcbcw.hosts.jhmi.edu/redcap/surveys/?s=QoZRmRTs4X>

This link is unique to you and should not be forwarded to others.

How the Registry Works

A recruitment response was received from:

First Name: [c19ri_fname]

Last Name: [c19ri_lname]

Demographics:

Biologic Sex: [c19ri_sex]

Race: [c19ri_race]

Ethnicity: [c19ri_ethnicity]

Age: [c19ri_age_yrs]

Contact Information:

Phone Number: [c19ri_phone]

Email Address: [c19ri_email_address]

Exposure Information:

Has this patient been exposed to someone with COVID: [c19ri_exposed_to_others_yn]

Was this exposure great than 24 hours: [c19ri_exposure_length]

How recently was the exposure: [c19ri_last_exposure]

Is this patient a healthcare worker: [c19ri_hc_worker_yn]

If healthcare worker, are they exposed to COVID patients: [c19r_hcwr_exposed]

Symptoms and Testing:

Has this patient experienced symptoms: [c19ri_symptomatic_yn]

When was the first date of symptoms: [c19ri_symptom_start_date]

Has this patient taken medication to prevent or treat COVID: [c19ri_trt_covid]

What medication has this patient taken: [c19ri_trt]

Has this patient been tested for COVID: [c19ri_lab_tested]

What was the date of testing: [c19ri_lab_test_date]

What was the testing result: [c19ri_lab_test_result]

What was the reason for testing: [c19ri_lab_test_reason]

Has this patient been hospitalized for COVID: [c19ri_hospitalized]

Study Interests:

This patient is interested in a study that involves medication to prevent COVID: [c19ri_interest_med_tx_yn]

This patient is interest in a vaccine trial: [c19ri_interest_vaccine_yn]

This patient is interested in donating plasma: [c19ri_donate_plasma_yn]

This patient would travel to a research center: [c19ri_travel_to_fac]

This patient would volunteer for multiple visits: [c19ri_multi_visit]

This patient would volunteer for a single visit: [c19ri_single_visit]

This patient would volunteer in a remote study: [c19ri_remote]

How Researchers Can Join the Registry

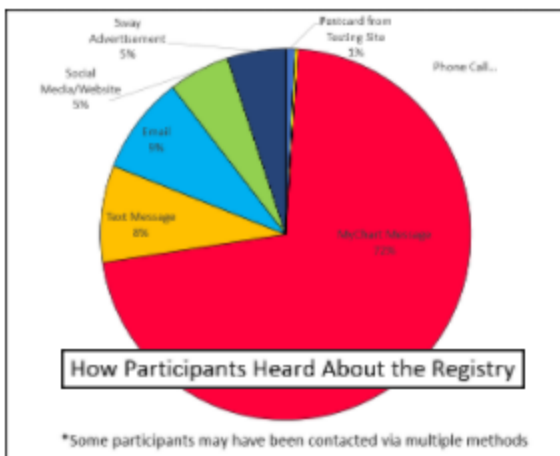
- Contact RIU and we will work with teams to help them submit a Change in Research (CIR) to IRB to utilize the registry
- We work teams to craft a lay-friendly study description to be listed on website and build logic branching for your study inclusion

HOPE Registry Dashboard

Hope Registry Dashboard

Total Participants

11769



Mean Age

52.94

COVID Positive

18.80
%

Response Rates

MyChart

9.27%

Email

11.36%

Text Message

11.30%

Phone Call

12.92%



JOHNS HOPKINS
INSTITUTE for CLINICAL &
TRANSLATIONAL RESEARCH

HOPE Metrics via Recruitment Method

Metrics as of 2/17	Total Sent	Total Enrolled From	Response Rate
MyChart	89,102	8261	9.27%
Email	8,687	987	11.36%
Text	8,645	977	11.30%
Call	240	31	12.92%

Demographics of Registry	Number	Percentage of Total
Female	5247	64.50%
Male	2283	35.80%
Other	15	0.20%
Not Hispanic or Latino	7486	93.20%
Hispanic or Latino	442	5.80%
Other	76	1.00%
American Indian or Native Alaskan	29	0.40%
Asian	389	4.80%
Black or African American	767	9.40%
Native Hawaiian or Pacific Islander	10	0.10%
White	6556	80.40%
Other	354	4.90%
Mean Age	52.94	
Health Care Worker	1729	21.60%
Have tested positive for COVID 19	1425	18.80%

RedCap Metrics as of 2/17	Responses	Percentage of Total
Postcard from Testing Site	95	0.90%
Phone Call	31	0.30%
MyChart Message	8261	71.30%
Text Message	977	7.80%
Email	987	8.50%
Social Media/Website	618	5.30%
Sway Advertisement	590	5.80%
Spanish Outreach	13	0.10%
Total in Registry	11769	

Next Steps

- Focusing efforts on further increasing diversity among participants in COVID-19 research
- ICTR Community Collaboration Core working with community leaders in African America community to promote COVID research awareness
 - Legacy Series Community conversations around COVID
 - Development of Social Media campaign focused on trust in science
- RIU has hired a Community Outreach Specialist to increase diverse community engagement
- Centro Sol has formed a Community Leaders Advisory Council (CLAB) to help guide Latinx engagement
 - Spanish Townhalls
 - Outreach in South, South East , and South West Baltimore neighborhood

Special Thanks

- Dr. Ford, Dorothy Damron, Rox Stambaugh
- Maithilee Mitra and CCDA Team
- Scott Carey
- Cyd Lacanienta
- Crystal Williams
- Liz Martinez
- Sumati Murli
- Social Innovation Team (students from Fashion Institute of Technology)
- Hailey Miller
- Cheryl Himmelfarb
- Bunmi Ogungbe
- Anna Peeler

Questions & Contact

- Cassie Lewis-Land- Clewis4@jhu.edu
- Johnshopkinshope.org
- hoperestry@jhu.edu
- “HOPKINSHOPE” – Text 474747