Agenda

• Development of centralized recruitment registry
• 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 patient centric allowing potential participants:

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

• ability to choose a study or studies that best fits their personal preferences for engagement

• Ability to spread the word about research opportunities within their networks
How it works

HOW IT WORKS

- Participant completes the HOPE Registry survey on REDCap
- Participant is provided opportunity to select studies they are interested in
- Study team determines the participant’s eligibility and recruits participant if applicable

We recruit participants via social media, online advertisements, phone calls, MyChart, emails and text messages

The survey uses branching logic to determine which studies the participant may be eligible for

Participant selection triggers email notification to appropriate study team
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

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
Recruitment Methods

- MYCHART MESSAGES
- E-MAILS
- TEXT MESSAGES
- PHONE CALLS
Community engaged recruitment

- Social media campaigns
- Community based organizations
- Day@TheMarket events
- Maryland Department of Health
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.
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

https://sway.office.com/KQbnRMvu9PrIzz5v?ref=email&loc=play
How the registry works

1-Person consents and enrolls answering questions about themselves

2-Branching logic is built to match with studies that they maybe eligible for

3-Study teams gets alert and can then reach out to do a through screening to determine eligibility
How the Registry Works

Study 1: This study is testing the use of an investigational drug Lambda Interferon (not FDA approved for any purpose) in the prevention of SARS-CoV-2 infection in people who have been exposed through household contact. Lambda is an injection into the skin that is given two times, one week apart. The length of study participation is 28 days, with a phone or remote contact on day 84. Participants will receive $50 for completing all visits.

Study 2: This study will test whether a transfusion of plasma containing antibodies from persons who have recovered from COVID-19 can prevent others from getting COVID-19 after exposure. This is a randomized, double-blind trial. Participants will receive plasma containing SARS-CoV-2 antibodies or plasma without antibodies.
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_firstname]
Last Name: [c19ri_lastname]

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_hcw_worker_yn]
If healthcare worker, are they exposed to COVID patients:[c19ri_hcw_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 to join the Registry

• Contact us and we will work with you to Submit a Change in Research (CIR) to IRB to utilize the registry

• We work with you to craft a lay-friendly study description to be listed on website and build logic branching for your study inclusion
Recruitment Innovations Unit
HOPE Registry Enrollment

**HOPE Registry Dashboard**

Total Participants: 4117

- **MyChart** Response Rates:
  - Email: 14.85%
  - Phone Call: 34.72%
  - Text: 6.96%
  - Message: 6.81%

- **Email Response Rates**:
  - 6.96%
  - 6.81%
  - 14.85%
  - 34.72%

**How participants Heard About the Registry**

- MyChart Message: 76%
- Email: 7%
- Social Media/Website: 6%
- Phone Call: 1%
- Postcard from Testing Site: 1%
- Text Message: 3%
- Sway Advertisement: 6%

*Some participants may have been contacted via multiple methods

**Mean Age**
- 53.4

**COVID-19 +**
- 371

**Demographics**

- White: 80%
- Black or African American: 9%
- Asian: 4.70%
- Native Hawaiian or Pacific Islander: 0.10%
- American Indian or Native Alaskan: 0.30%
- Other: 5.00%
Questions & Contact

• Cassie Lewis-Land- Clewis4@jhu.edu
• Johnshopkinshope.org
• “HOPINSHOPE” 474747
• hoperegistry@jhu.edu