Community Engagement Learning Hub Plain Language and Design

June 16, 2022

https://vimeo.com/721551922

RECOVER
Researching COVID to Enhance Recovery

An Initiative Funded by the National Institutes of Health

Agenda

1	Welcome	2 minutes	Janelle Linton
2	Learning Hub Guidelines	3 minutes	Shonna Yin
3	Introductions	5 Minutes	Shonna Yin
4	Presentation	30 minutes	Catina O'Leary, HLM Leila Burr, TonicGroup
5	Q&A Session	15 minutes	Shonna Yin
6	Closing Remarks	5 minutes	Janelle Linton

Engaging in Learning Hubs: guidelines

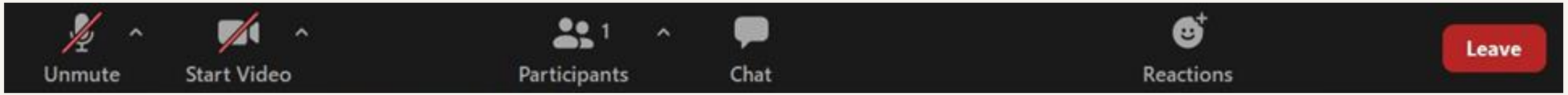
- The session will be recorded
- Use the raise hand function
- We welcome you to turn on your video, if comfortable
- Please remain muted when you are not speaking to minimize background noise
- During the Q&A session, please introduce yourself by name and organization (if applicable)

Tips for using Zoom

Select to turn on/off your video cameras

Select to chat with others and ask questions in the meeting

Select to exit meeting



Select to unmute/mute yourself

Select to view those attending the meeting

Select to raise hand to speak

Moderator

H. Shonna Yin, MD, MSc

CSC Faculty, Health Literacy Lead
Associate Professor of Pediatrics
and Population Health
NYU Grossman School of Medicine

Presenter

Catina O'Leary, PhD, LMSW

President & CEO
Health Literacy Media

Presenter

Leila Burr

Managing Director
TonicGroup

What is Health Literacy?

Defining health literacy

Textbook definitions

Personal health literacy

The degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

Organizational health literacy

The degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

Social determinants perspective

Health literacy is associated with where people get their information

- Economic stability
- Education access and quality
- Neighborhood and built environment
- Social and community context

Healthcare access and quality
- Including health literacy

Cycle of misinformation

Health literacy influences the level of information someone can understand

Health education materials are written beyond most people's ability to understand

People are less likely to use quality sources and turn to social media, TV, etc.

Health disparities and system barriers worsen, leading to more hospitalizations and higher mortality rates

People may not have the ability to find, understand, and use health information and services

Health literacy and research studies

Using clear communication throughout the full study process

Recruitment

Health literate recruitment materials engage everyone and encourage diverse representation

Examples
- Social media
- Website design
- News releases
- Tip sheets

Consent

An understandable consent process is essential to true and legal informed consent

Examples
- ICF templates
- Child assent forms

Retention

Clear data collection forms ensure accurate data – no matter if the study is local or decentralized

Examples
- Patient information
- Data collection forms

Results

Patient-friendly summaries help patients understand their role and encourage future participation

Examples
- Trial summaries
- Journal articles
- Website synopses

Evaluation

Constant collection of insights ensures all research is grounded in the patients' values

Examples
- Focus groups
- Interviews
- Surveys
- Reports and plans

Communication

Staff communication strategies can facilitate meaningful participation for all involved

Examples
- Newsletters
- Blogs
- Web content

Health literacy and regulatory guidelines

Clear and accurate science content that addresses all requirements

Health literacy principles

- **Plain, clear language**
- **Numeracy principles**
- **Structure**
- **Behavior focus**

Requirements and guidelines

- **Accurate, factual, objective**
- **Balanced risk information**
- **Understandable**
- **Actionable and applicable**

Why is health literacy important?

What we know about health literacy

93 million American adults lack the health literacy skills or support to:

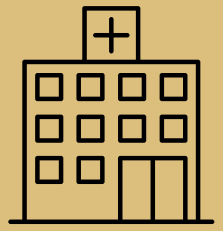
Understand health information written (often written at 11th grade or above)

Calculate dosage and timing through the course of a day

Make decisions about risk, such as whether to get a vaccine

Manage a chronic condition such as diabetes

Get and keep health insurance and access care



Navigate the healthcare system – literally and figuratively

Comprehend jargon-filled diagnoses or medical instructions from providers

Some populations are more affected

Health literacy has a big impact

Mental Illness

Low Income

Older Adults

Low Education

Limited English

How we apply health literacy to RECOVER

We follow a proven process

We use health literacy to meet people where they are with what they need

Understand
the health, science, and risk information

Apply clear
communication best practices

Design
engaging print and digital materials

Audience test
and revise print and digital materials

We decide how best to support our audience

We ask ourselves a few simple, but important questions to inform the content strategy, copy and design of each material we produce:

- Who is the target audience and what specific needs do they have?
- What is the purpose of the material we need to produce?
- Is there a specific outcome we are after?
- How will we deliver our message to our target audience? (For instance, is it a flyer, brochure, billboard, email, advertisement, etc.?)

How we apply plain language principles to RECOVER

We use fundamental approaches

Every element of our work includes these 2 fundamental health literacy best-practices

Plain language

Full health literacy reviews of existing materials using the most current and evidence-based health literacy best-practices and plain language principles, or new materials developed with the principles as a guide

Universal precautions

Using plain language with everyone – in written and verbal communication – because anyone can misunderstand complex information and everyone prefers easy-to-understand information

We define plain language

Plain language involves a range of characteristics, including:

- Word choice and explanations
- Line length and spacing
- Structure and flow
- Numeracy
- Behaviors and action

We develop a glossary of terms and editorial style guide to ensure consistency across RECOVER

Glossary of words used in RECOVER

Use this glossary to learn the meaning of words used in RECOVER.

RECOVERcovid.org

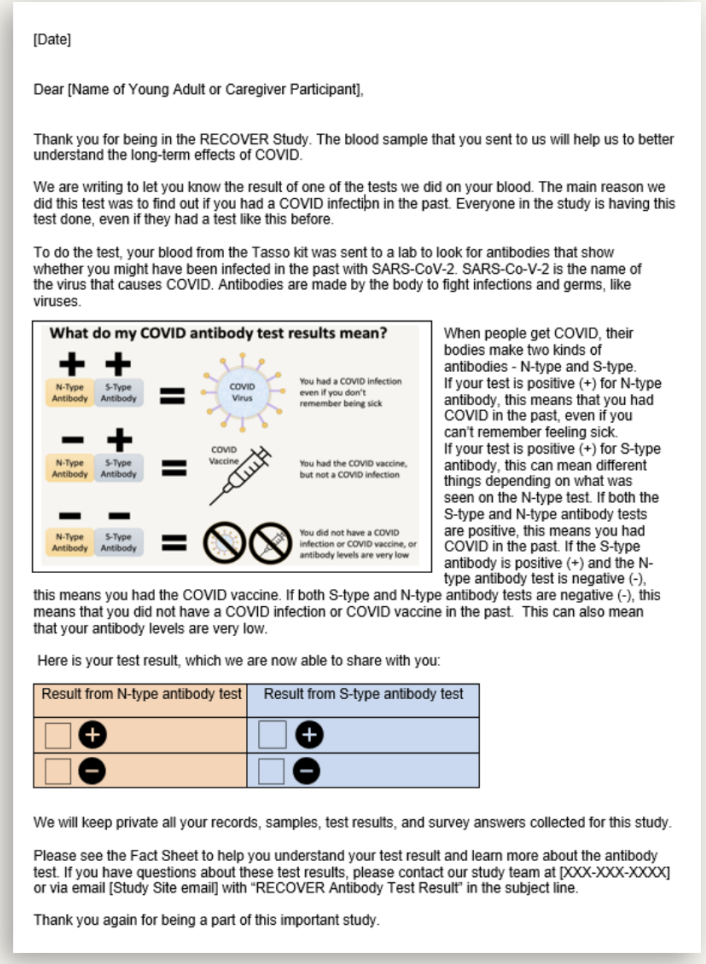
Term to define	Definition
A	
Accountability	Refers to a person or group being responsible for goals and actions.
Adaptive	Able to change to meet a certain situation, such as the needs of a certain group of people.
Acute	A short-term, often severe health problem.
Acute infection	When you first get an infection. Acute COVID infection starts when the virus enters your body and lasts until you can't spread it to others, usually about 2 weeks.
Adjudication Oversight Committee	The RECOVER group that helps RECOVER leaders decide how to put study participants into different groups depending on their COVID symptoms and other tests. They also look at study results and help decide what the results mean in real life. They help decide if harmful events have happened to any study participants, and if so, whether the events are because of the study. If they are, they help decide how those events will be reported. The group is made up of researchers, health care professionals, patients, caregivers, and community members.
Adjuvant	An ingredient in vaccines that helps boost your body's immune system response.
Administrative Coordinating Center (or ACC)	The RECOVER group that supports communication and administrative needs.
Adult cohort	A group of participants in RECOVER who are ages 18 years and older.

RECOVER | Glossary of Words Used in RECOVER 3

We use words that are direct and focused on outcome

BEFORE → AFTER

We structure content in an easy-to-follow way



[Date]

Dear [Name of Young Adult or Caregiver Participant],

Thank you for being in the RECOVER Study. The blood sample that you sent to us will help us to better understand the long-term effects of COVID.

We are writing to let you know the result of one of the tests we did on your blood. The main reason we did this test was to find out if you had a COVID infection in the past. Everyone in the study is having this test done, even if they had a test like this before.

To do the test, your blood from the Tasso kit was sent to a lab to look for antibodies that show whether you might have been infected in the past with SARS-CoV-2. SARS-Co-V-2 is the name of the virus that causes COVID. Antibodies are made by the body to fight infections and germs, like viruses.

What do my COVID antibody test results mean?

N-Type Antibody + S-Type Antibody = COVID Virus — You had a COVID infection even if you don't remember being sick

N-Type Antibody − S-Type Antibody = COVID Vaccine — You had the COVID vaccine, but not a COVID infection

N-Type Antibody − S-Type Antibody = You did not have a COVID infection or COVID vaccine, or antibody levels are very low

When people get COVID, their bodies make two kinds of antibodies - N-type and S-type.
If your test is positive (+) for N-type antibody, this means that you had COVID in the past, even if you can't remember feeling sick.
If your test is positive (+) for S-type antibody, this can mean different things depending on what was seen on the N-type test. If both the S-type and N-type antibody tests are positive, this means you had COVID in the past. If the S-type antibody is positive (+) and the N-type antibody test is negative (-), this means you had the COVID vaccine. If both S-type and N-type antibody tests are negative (-), this means that you did not have a COVID infection or COVID vaccine in the past. This can also mean that your antibody levels are very low.

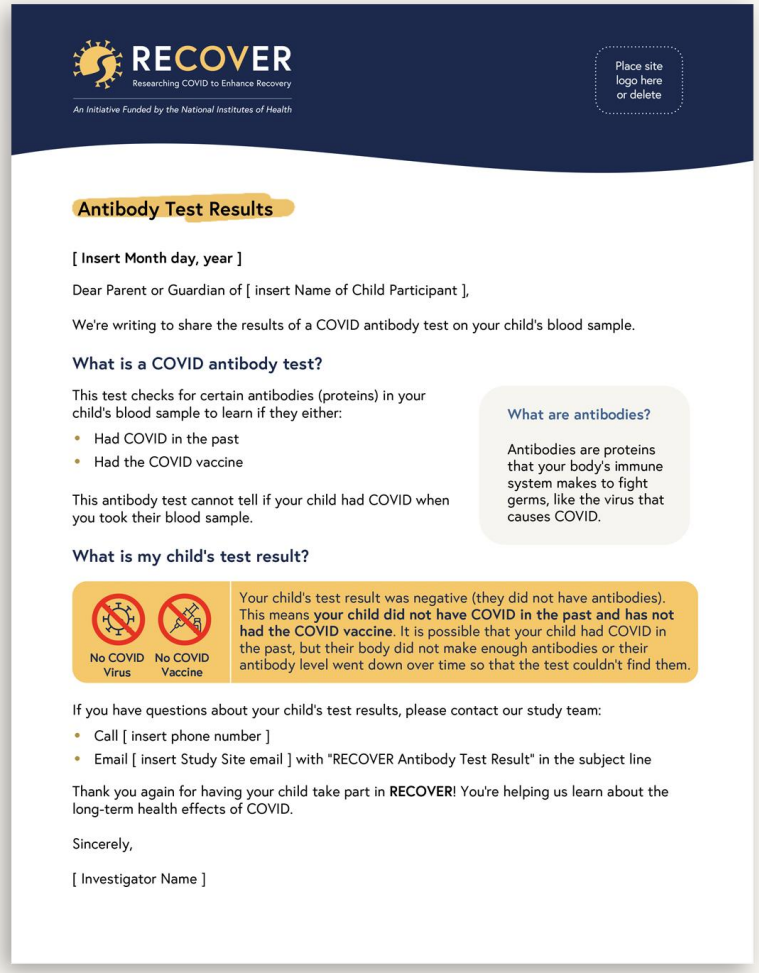
Here is your test result, which we are now able to share with you:

Result from N-type antibody test	Result from S-type antibody test
☐ +	☐ +
☐ −	☐ −

We will keep private all your records, samples, test results, and survey answers collected for this study.

Please see the Fact Sheet to help you understand your test result and learn more about the antibody test. If you have questions about these test results, please contact our study team at [XXX-XXX-XXXX] or via email [Study Site email] with "RECOVER Antibody Test Result" in the subject line.

Thank you again for being a part of this important study.



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Place site logo here or delete

Antibody Test Results

[Insert Month day, year]

Dear Parent or Guardian of [insert Name of Child Participant],

We're writing to share the results of a COVID antibody test on your child's blood sample.

What is a COVID antibody test?

This test checks for certain antibodies (proteins) in your child's blood sample to learn if they either:

- Had COVID in the past
- Had the COVID vaccine

This antibody test cannot tell if your child had COVID when you took their blood sample.

What are antibodies?

Antibodies are proteins that your body's immune system makes to fight germs, like the virus that causes COVID.

What is my child's test result?

No COVID Virus · No COVID Vaccine

Your child's test result was negative (they did not have antibodies). This means **your child did not have COVID in the past and has not had the COVID vaccine**. It is possible that your child had COVID in the past, but their body did not make enough antibodies or their antibody level went down over time so that the test couldn't find them.

If you have questions about your child's test results, please contact our study team:

- Call [insert phone number]
- Email [insert Study Site email] with "RECOVER Antibody Test Result" in the subject line

Thank you again for having your child take part in **RECOVER**! You're helping us learn about the long-term health effects of COVID.

Sincerely,

[Investigator Name]

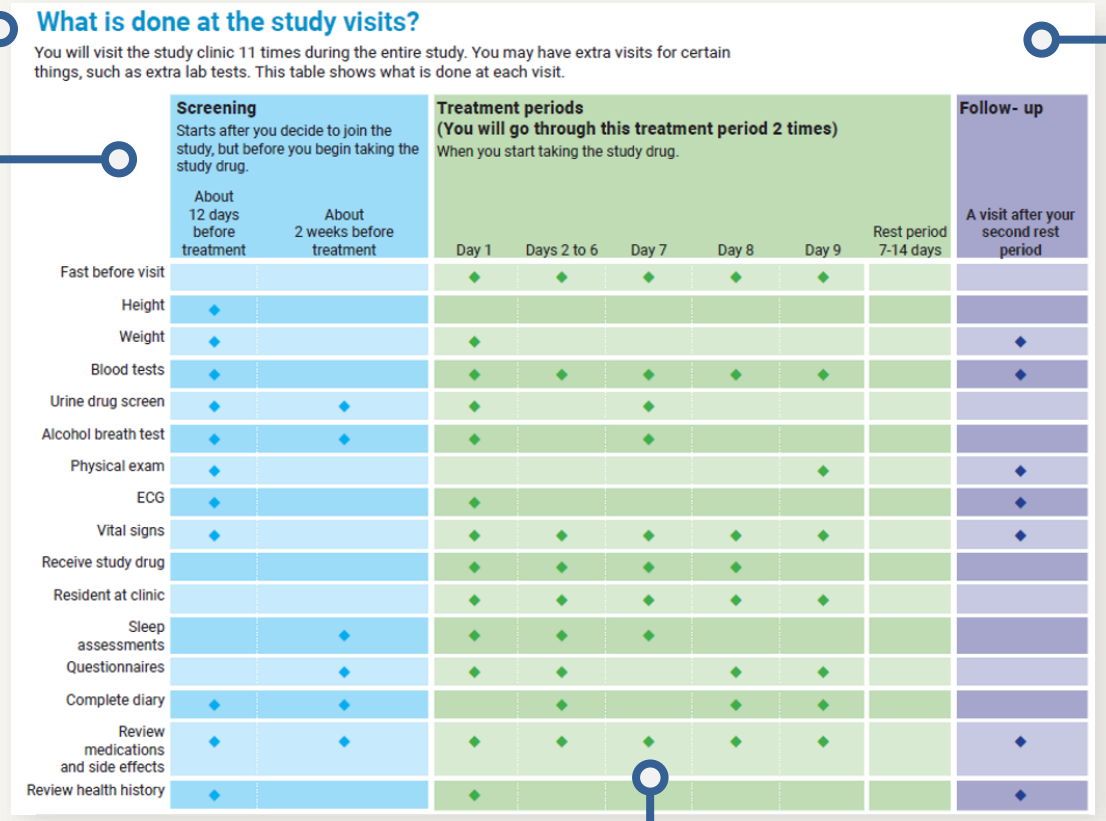
BEFORE → **AFTER**

- Content is streamlined and prioritized
- Clear headers, sub-headers and bulleted lists organize content into easy-to-read blocks
- Important takeaways are highlighted

We custom-tailor materials to the program

Clear heading

Plain language descriptions



What is done at the study visits?

You will visit the study clinic 11 times during the entire study. You may have extra visits for certain things, such as extra lab tests. This table shows what is done at each visit.

	Screening Starts after you decide to join the study, but before you begin taking the study drug.		**Treatment periods (You will go through this treatment period 2 times)** When you start taking the study drug.						**Follow- up**
	About 12 days before treatment	About 2 weeks before treatment	Day 1	Days 2 to 6	Day 7	Day 8	Day 9	Rest period 7-14 days	A visit after your second rest period
Fast before visit			◆	◆	◆	◆	◆		
Height	◆								
Weight	◆		◆						◆
Blood tests	◆		◆	◆	◆	◆	◆		◆
Urine drug screen	◆	◆	◆		◆				
Alcohol breath test	◆	◆	◆		◆				
Physical exam	◆						◆		◆
ECG	◆		◆						◆
Vital signs	◆		◆	◆	◆	◆	◆		◆
Receive study drug			◆	◆	◆	◆			
Resident at clinic			◆	◆	◆	◆	◆		
Sleep assessments		◆	◆	◆	◆				
Questionnaires		◆	◆	◆		◆	◆		
Complete diary	◆	◆		◆		◆	◆		
Review medications and side effects	◆	◆	◆	◆	◆	◆	◆		◆
Review health history	◆		◆						◆

Study visits broken down by period

Indicators for activities

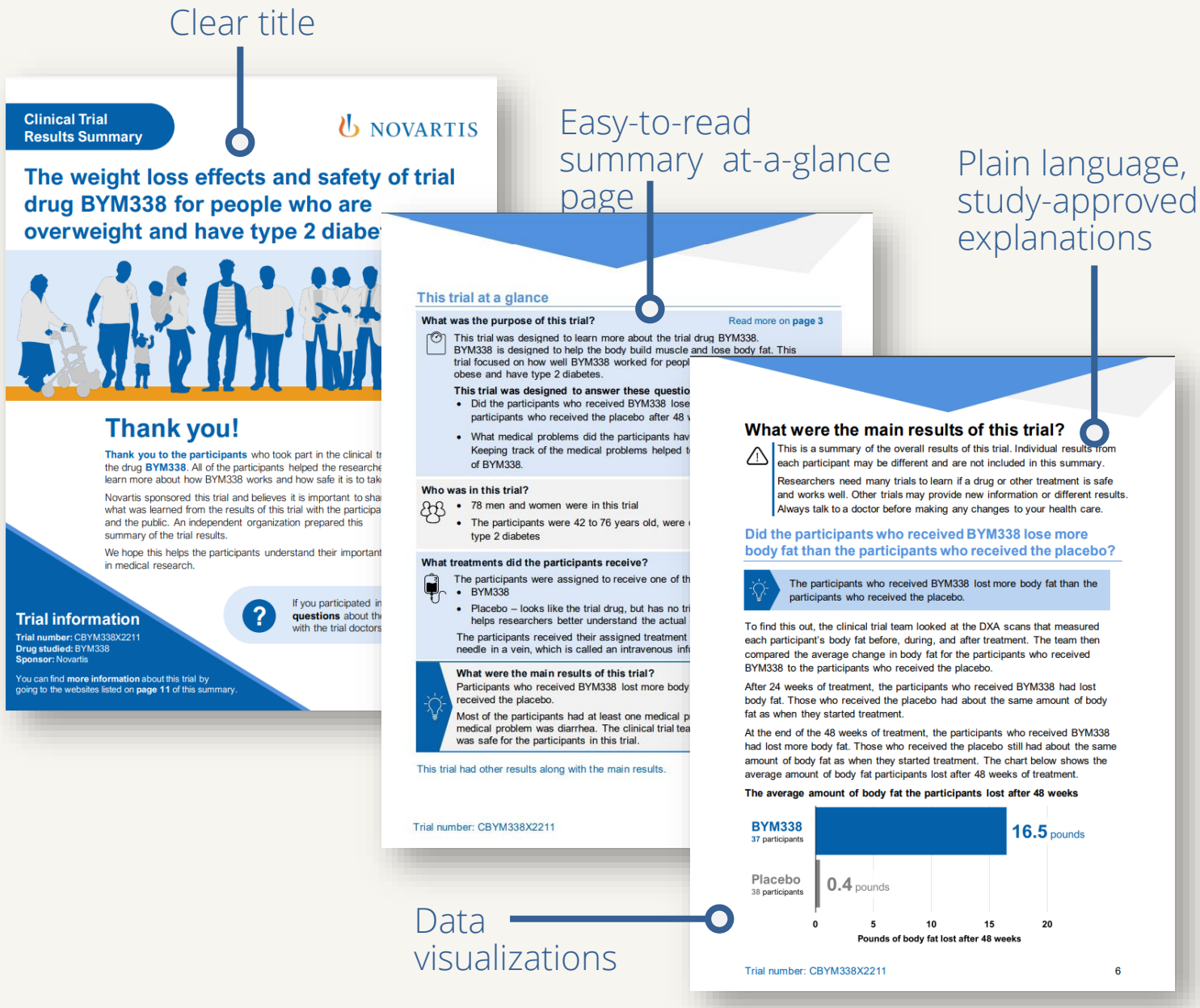
Clear informed consent forms

Helps potential participants understand study information, including what is done at study visits

We deliver results participants can understand

Plain language summaries

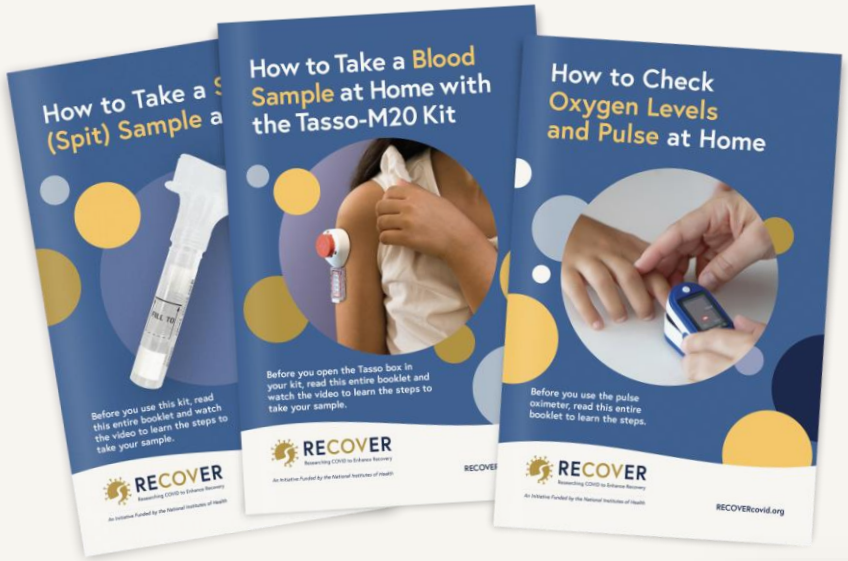
Helps patients, family members and communities understand trial results

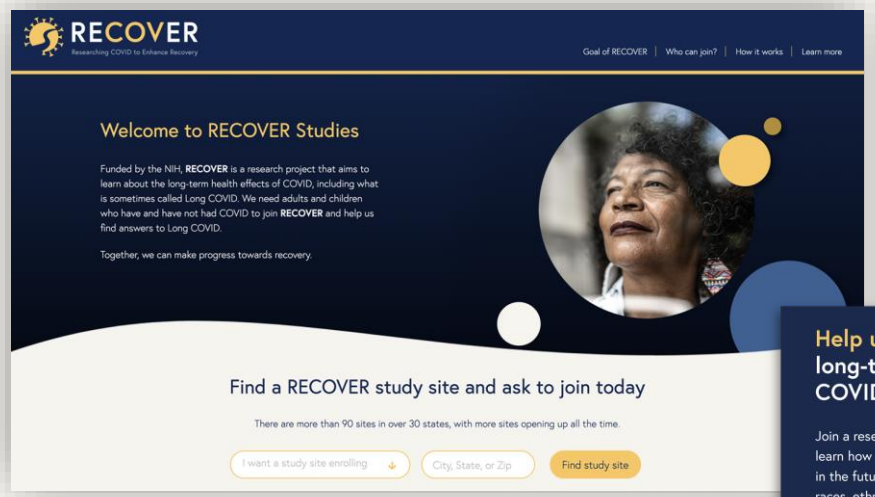


How we apply design principles to RECOVER

We use a style guide to unify the graphic identity

- Consistent visual vocabulary to unify look and feel
- Visual cues participants learn and come to expect
- Framework to operate efficiently
- Accessibility guidance on colors and type styles for contrast and legibility


How to Take a (Spit) Sample a
How to Take a Blood Sample at Home with the Tasso-M20 Kit
Before you open the Tasso box in your kit, read this entire booklet and watch the video to learn the steps to take your sample.
RECOVER
How to Check Oxygen Levels and Pulse at Home
Before you use the pulse oximeter, read this entire booklet to learn the steps.
RECOVERcovid.org


RECOVER
Researching COVID to Enhance Recovery
Goal of RECOVER | Who can join? | How it works | Learn more
Welcome to RECOVER Studies
Funded by the NIH, RECOVER is a research project that aims to learn about the long-term health effects of COVID, including what is sometimes called Long COVID. We need adults and children who have and have not had COVID to join RECOVER and help us find answers to Long COVID.
Together, we can make progress towards recovery.
Find a RECOVER study site and ask to join today
There are more than 90 sites in over 30 states, with more sites opening up all the time.
I want a study site enrolling
City, State, or Zip
Find study site


Help us learn about the long-term health effects of COVID (called Long COVID)
Join a research study and get paid to help us learn how to prevent, test, and treat COVID in the future. Children and adults from all races, ethnicities, and backgrounds can join, including:
• People who currently have COVID
• People who had COVID in the past
• People who have never had COVID
Visit RECOVERcovid.org to learn more about RECOVER and join today.
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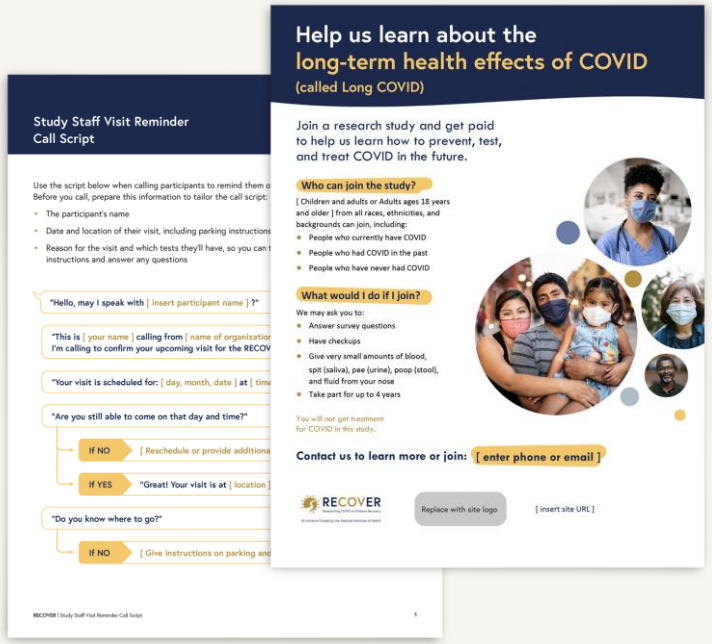
Study Staff Visit Reminder Call Script
Use the script below when calling participants to remind them
Before you call, prepare this information to tailor the call script:
• The participant's name
• Date and location of their visit, including parking instructions
• Reason for the visit and which tests they'll have, so you can
instructions and answer any questions
"Hello, may I speak with [insert participant name] ?"
"This is [your name] calling from [name of organizatio
I'm calling to confirm your upcoming visit for the RECOV
"Your visit is scheduled for: [day, month, date] at [time
"Are you still able to come on that day and time?"
If NO
[Reschedule or provide additiona
If YES
"Great! Your visit is at [location]
"Do you know where to go?"
If NO
[Give instructions on parking and
RECOVER | Study Staff Visit Reminder Call Script
1

Help us learn about the long-term health effects of COVID (called Long COVID)
Join a research study and get paid to help us learn how to prevent, test, and treat COVID in the future.
Who can join the study?
[Children and adults or Adults ages 18 years and older] from all races, ethnicities, and backgrounds can join, including:
• People who currently have COVID
• People who had COVID in the past
• People who have never had COVID
What would I do if I join?
We may ask you to:
• Answer survey questions
• Have checkups
• Give very small amounts of blood, spit (saliva), pee (urine), poop (stool), and fluid from your nose
• Take part for up to 4 years
You will not get treatment for COVID in this study.
Contact us to learn more or join: [enter phone or email]
RECOVER
Replace with site logo
[insert site URL]


RECOVER is a national project
Up to 40,000 people of all ages and races and ethnicities, in almost every state
United States
Ottawa
Montreal
Toronto
Chicago
Las Vegas
Los Angeles
San Diego
Mexico
Guadalajara
Mexico City
Cuba
Gulf of Mexico
Honolulu
Lahaina
Kailua-Kona
Hilo


Why are some people sick months after having COVID?
Join a study to help us find answers. Get paid for your time.
(504) 568-2266
LSU Health NEW ORLEANS
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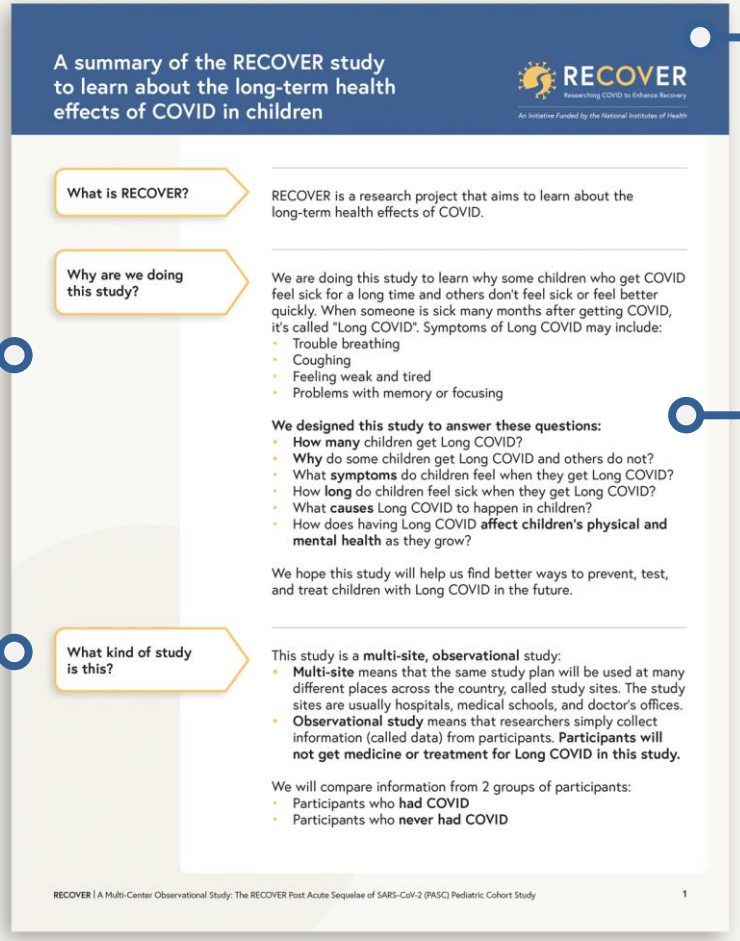
We use design elements to clearly present information

Muted background adds texture and makes primary content pop

Questions are set off on their own to easily identify and read them



A summary of the RECOVER study to learn about the long-term health effects of COVID in children

RECOVER
Researching COVID to Enhance Recovery
An Initiative Funded by the National Institutes of Health

What is RECOVER?

RECOVER is a research project that aims to learn about the long-term health effects of COVID.

Why are we doing this study?

We are doing this study to learn why some children who get COVID feel sick for a long time and others don't feel sick or feel better quickly. When someone is sick many months after getting COVID, it's called "Long COVID". Symptoms of Long COVID may include:

- Trouble breathing
- Coughing
- Feeling weak and tired
- Problems with memory or focusing

We designed this study to answer these questions:

- **How many** children get Long COVID?
- **Why** do some children get Long COVID and others do not?
- What **symptoms** do children feel when they get Long COVID?
- How **long** do children feel sick when they get Long COVID?
- What **causes** Long COVID to happen in children?
- How does having Long COVID **affect children's physical and mental health** as they grow?

We hope this study will help us find better ways to prevent, test, and treat children with Long COVID in the future.

What kind of study is this?

This study is a **multi-site, observational** study:

- **Multi-site** means that the same study plan will be used at many different places across the country, called study sites. The study sites are usually hospitals, medical schools, and doctor's offices.
- **Observational study** means that researchers simply collect information (called data) from participants. **Participants will not get medicine or treatment for Long COVID in this study.**

We will compare information from 2 groups of participants:

- Participants who **had COVID**
- Participants who **never had COVID**

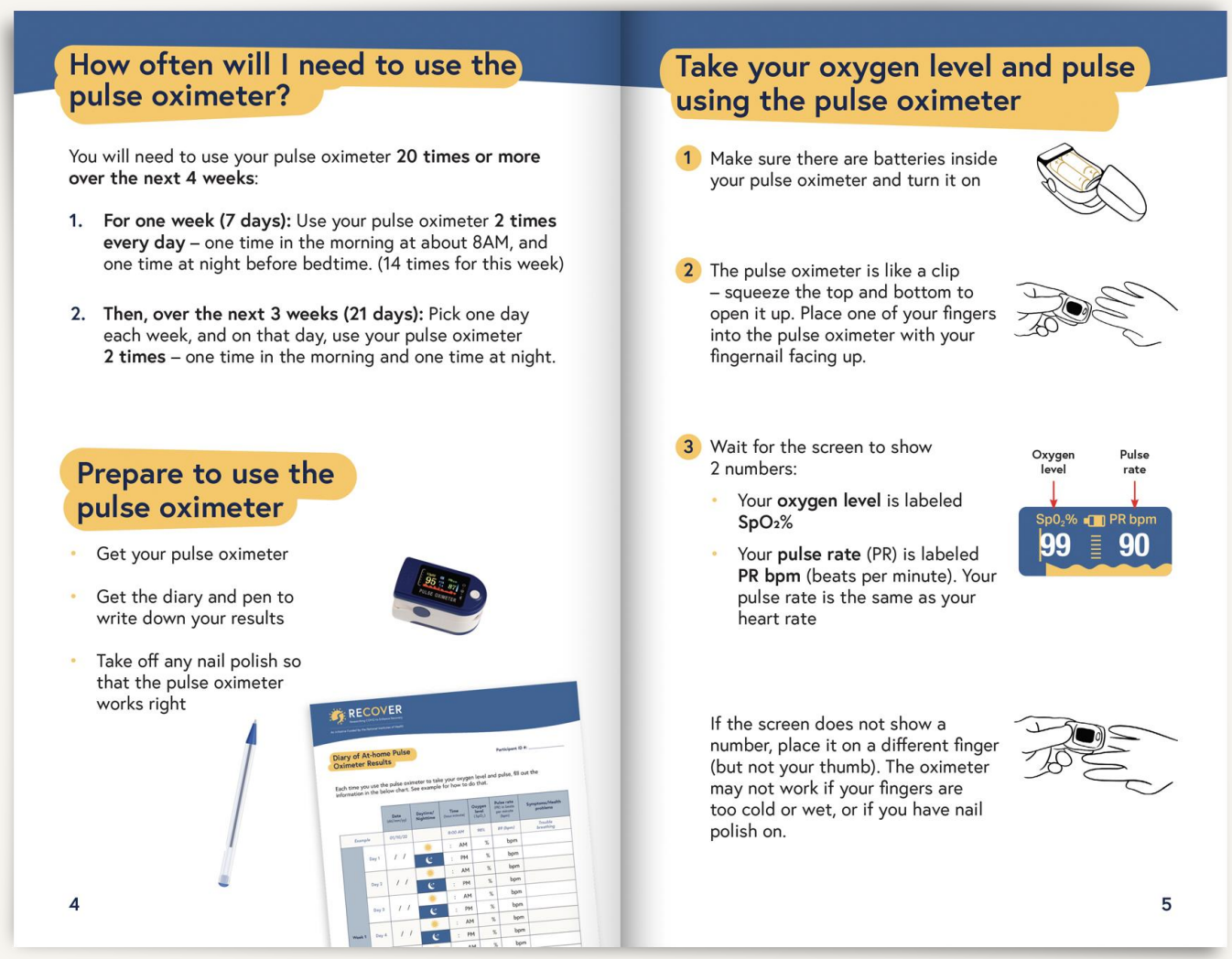
Solid-colored headers house purpose of the document

Main content is set on white for legibility

We use visuals to reinforce key messages

- Visuals can be photographs or illustrations
- They are an important part of instructional text, they aid understanding
- Visuals add interest to engage and invite reader to spend time with content
- They lighten the page content and lessen the visual burden

We embrace “open space”



How often will I need to use the pulse oximeter?

You will need to use your pulse oximeter **20 times or more over the next 4 weeks**:

1. **For one week (7 days):** Use your pulse oximeter **2 times every day** – one time in the morning at about 8AM, and one time at night before bedtime. (14 times for this week)
2. **Then, over the next 3 weeks (21 days):** Pick one day each week, and on that day, use your pulse oximeter **2 times** – one time in the morning and one time at night.

Prepare to use the pulse oximeter

- Get your pulse oximeter
- Get the diary and pen to write down your results
- Take off any nail polish so that the pulse oximeter works right

Take your oxygen level and pulse using the pulse oximeter

1. Make sure there are batteries inside your pulse oximeter and turn it on
2. The pulse oximeter is like a clip – squeeze the top and bottom to open it up. Place one of your fingers into the pulse oximeter with your fingernail facing up.
3. Wait for the screen to show 2 numbers:
   - Your **oxygen level** is labeled **SpO2%**
   - Your **pulse rate** (PR) is labeled **PR bpm** (beats per minute). Your pulse rate is the same as your heart rate

If the screen does not show a number, place it on a different finger (but not your thumb). The oximeter may not work if your fingers are too cold or wet, or if you have nail polish on.

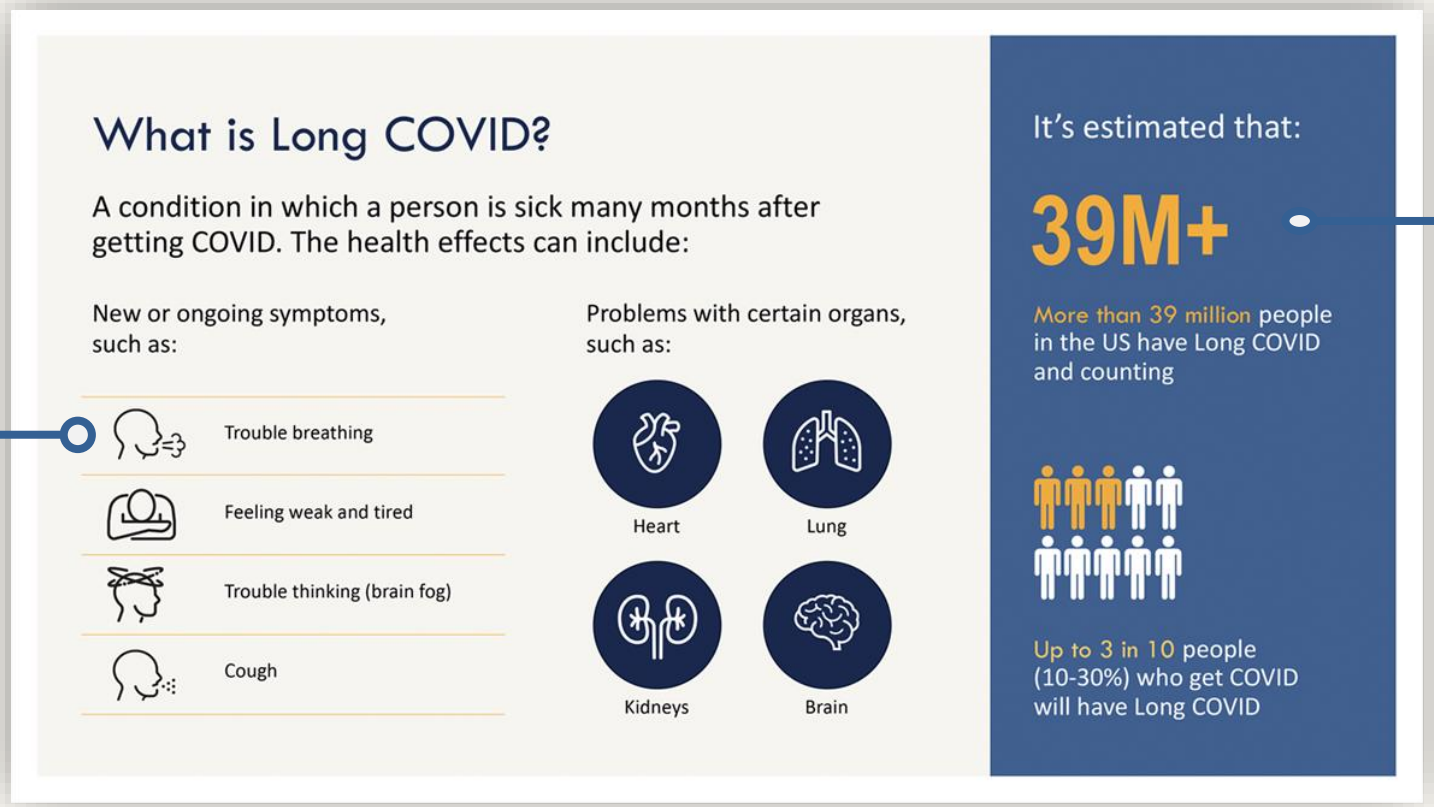
- Don’t fear the “open space”
- Blank space reduces visual burden on the eyes, adding “breathability”
- It allows content and visuals to be easily traced and parsed
- It forces a prioritization of content
- It’s a main consideration for making designs accessible

We use photography to represent our audience

- Photography represents diversity of audience
- Forms connection with audience that helps them relate
- Provides visual interest and breaks up content
- Sets tone – is it serious, playful, happy, sad?

We use iconography and infographics for quick “reads”

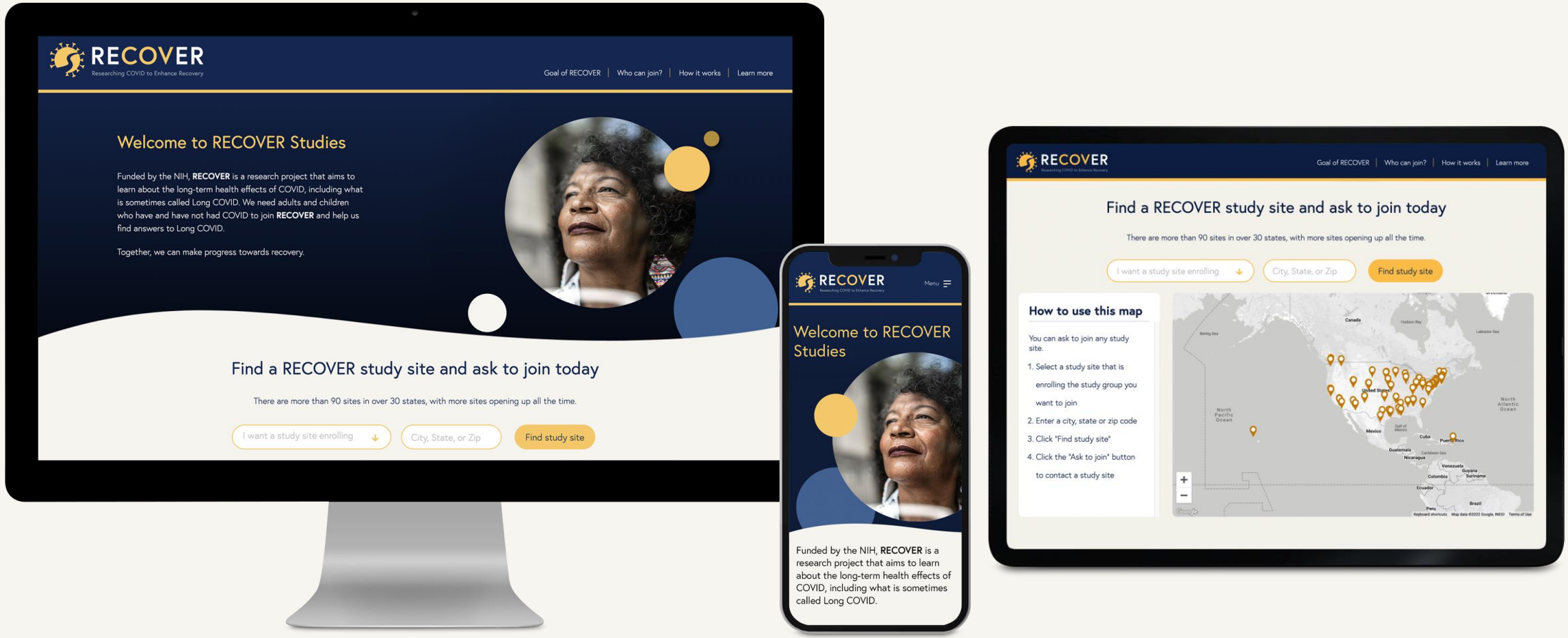
Iconography provides a visual way to absorb content



Infographics reinforce concepts in copy

Together, these elements make a page of content easier to digest

We have a multimedia design strategy



Materials are translated into multiple languages

Accessibility matters

Electronic materials are made to be accessible

RECOVER follows **508 compliance standards**

Document **alt text and tags** are optimized for screen readers

Accessibility standards are met for persons with disabilities, including vision and hearing impairments

Q & A Session

Coming Soon

Building Diversity and Inclusivity through Engagement

A Learning Hub by the National Community Engagement Group and the Community Engagement Team

Featuring Al Richmond and Melvin Jackson

Thursday July 21 at 6:00 pm EST

Register today – Link in the chat

Featured Speakers

Al Richmond
MSW

Melvin Jackson
MSPH

Reach out to us

RECOVER CSC: recover_csc@nyulangone.org
Health Literacy Media: coleary@healthliteracy.media
TonicGroup: leila@tonicgroup.com

Tell us what you thought

The link to complete a brief survey will be shared in the Learning Hub's chat

Thank you

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