

# Health Research Portal Style Guide & Content Requirements

## Welcome to The New Normal™ Campaign

The New Normal™ Campaign's goal is to increase awareness of and participation in health research using proven techniques to communicate, connect, and engage. The campaign audience is the general public.

About The New Normal™ Campaign

The New Normal™ Campaign works to shorten the average 14-year wait for cures, new treatments, and discoveries that could help you and your friends and family. We make health research easily accessible by matching you with opportunities in the areas you care about the most and by sharing the breakthroughs you and your loved ones can use to live a healthier, longer life. Join the movement and learn more at BeTheNewNormal.org.

The New Normal™ Campaign is championed by the Institute for Translational Medicine (ITM), a partnership between the <u>University of Chicago</u> and <u>Rush</u> in collaboration with <u>Advocate Health Care</u>, the <u>Illinois Institute of Technology (Illinois Tech)</u>, <u>Loyola University Chicago</u>, and <u>NorthShore University HealthSystem</u>, as well as the <u>Northwestern University Clinical and Translational Sciences (NUCATS) Institute</u> and the <u>University of Illinois at Chicago Center for Clinical and Translational Science (CCTS)</u>. The ITM, NUCATS, and CCTS are fueled by nearly \$80 million from the <u>National Institutes of Health (NIH) National Center for Advancing Translational Science (NCATS) Clinical and Translational Science Awards (CTSA) Program.</u> The New Normal™ movement is also supported by the <u>Chicago Department of Public Health</u> and other regional and national partners who believe in empowering everyone to get involved in making discoveries to improve human health.

## Welcome to The New Normal™ Study Style Guide

This writing guide governs the content appearing on the Chicagoland health research portal to ensure consistent study descriptions suitable for a nonscientific, general audience.

This guide gives you a rundown of requirements for your study description content to appear in the portal. These guidelines were created in collaboration with leaders in communications, research, Institutional Review Boards, and patients and community members.

The New Normal™ Review Committee uses these factors to review and approve all study description content prior to it being published on the matchmaking site called TNN Match. The Committee has the authority to reject any study descriptions that do not meet these guidelines. Teams can edit and resubmit studies for Committee review. Once the Committee approves the content, study teams can submit it to their respective IRB if their IRB requires pre-approval.

### Why It Matters

Only about 30% of Americans say they have a clear understanding of what it means when they hear or read the term "scientific study," <u>according to the National Science Foundation</u>.

User testing shows people do not interact with studies that are complex, have jargon, and are not approachable. First impressions are everything, and the portal is only as useful as the study descriptions. If people can't understand them, they won't use the portal to match with your research study or any others. This portal only helps you and other study teams if the public can understand and engage with the content to get involved and join studies.

This is the first time the public and researchers and study teams are coming together at a huge scale! In order to set everyone up for success, all study descriptions must be accurate, easy to understand, welcoming, and approachable.

Portal users must also be committed to the interactive nature of the tool - if someone asks questions or expresses interest in your study, just make sure to respond within 5 business days. There are templates and batch-mailing functions in TNN Match to make responding fast and easy.

Keep in mind: The style and approachable tone of this portal content will likely be different from what you're used to writing. It may feel different to write or read. That's OK. That's a good sign, because this is not formal academic writing!

## **GENERAL GUIDELINES**

## 7th Grade Reading Level

- The portal won't work for you if the public can't understand your study! All descriptions must be at a maximum reading level of 7th grade.
  - Use this tool to check the Flesch-Kincaid reading grade level of your descriptions for each field.
  - Use the Flesch-Kincaid Grade Level box in the Readability Score in the right column.
  - This free online tool was created by a PhD in Computer
     Science who has worked for Google, Microsoft, and Yahoo.

The below guidelines will help your writing meet the 7th-grade reading level requirement.

## **Keep it short. Descriptions Will Not Contain All Study and Consent Information**

#### • This is:

- A short, high-level overview of what you're doing. There are character counts.
- A welcoming front door for people to interact, match, and learn more.

#### • This is not:

- A consent form. You'll consent interested participants separately using your IRB-approved consent process.
- A deep-dive into every part of your study and all potential outcomes.

Welcome and direct specific questions for full study details to your study team and its established consent process.

# Descriptions Will Have An Approachable, Welcoming, Clear Editorial Voice

#### • Write in a conversational, welcoming tone.

- Picture yourself talking to a friend or family member. Our data shows people want more approachable, welcoming content.
- Avoid formal writing. Formal writing creates distance. The goal is to make connections between you and the public.

#### Use contractions.

- "You'll" instead of "you will."
- o "It's" instead of "it is."
- **Use second person (you)** when referring to potential study participants.

- Avoid using third person and referring to volunteers in jargon that creates distance, like "human subjects" or "research participants."
- Example:
  - Yes You'll visit our clinic.
  - No Human subjects/research participants will visit our clinic.
- Use short, simple sentences.
  - Short sentences keep the reading level below 7th grade.
    - Example: See Spot run. Spot runs fast.
  - Avoid several clauses in one sentence. Break long sentences into two or three simple sentences.
- Write in an active voice to be clear, transparent, and empower participants.
  - The person in the sentence (subject of the sentence) is doing something and in control, as opposed to having something done to them.
  - Makes clear the public is in control and collaborating as part of a team with researchers.
  - o Instead of:
    - Volunteers will be asked questions.
    - Volunteers will have their blood pressure taken.
  - Use:
    - You'll answer questions.
    - Your study team will measure your blood pressure.

# Write a Strong Headline & Description - It May be the Only Thing People Read

Headline and Description are the two shortest and most important fields in the portal. People will read your headline and short description first, and then decide if they want to click to read more. Tips for success:

#### Headline

- Use an action verb. What's the big picture and goal?
  - Examples: Track, predict, evaluate, help, explore
- Use strong, simple keywords for your study. Avoid jargon.
  - Keywords will often include the health concern, problem you're trying to address, or solution.
- Get straight to the point.
  - Readers can get the rest of the details in the other description sections.
- · Give a high-level overview
  - What problem are you trying to solve?
  - What are YOU most excited about?
     Example:

Finding ways to build better inhalers to treat asthma

#### Description

- · Second thing people will read
- 300-character limit
- What are you exploring
- Why should anyone care? What good could come from this study?
- Include a statistic when possible.

## **Explain Why Your Study Matters**

How is your study tied to the shared public/researcher goal of improving human health? People want to understand what greater good they're contributing to by participating in your study.

Include a sentence about the end goal of the research. Is it working toward a new possible treatment or cure? Is it to better understand how the heart works to find ways to prevent heart disease?

- Always be accurate and transparent.
- Explain the current state and how your study might improve it.
- Include a key statistic.
  - Example: Heart disease is the leading cause of death in the U.S.
- Don't overpromise.
- Do connect the dots to the end goal of your work using clear, conditional words.
  - Examples of conditional words: Might, could, potential, maybe, etc.
- Communicate that the result of the study isn't guaranteed, but whatever is learned brings everyone one step closer to answers and that shared end goal.
- Examples:
  - o Exploring new possible treatments for heart disease.
  - Learning how (X) works to bring us one step closer to treating (Y.)

### **Don't Make People Do Math**

- Be clear in your time and money descriptions.
  - Time
    - Instead of 52 weeks say one year
    - Instead of 14 weeks say about 3.5 months
  - o Money tally up the total. Put this in the Compensation section.
    - Instead of "You'll receive \$25 per visit."
    - Say "You could receive up to \$500 total. You'll earn \$25 per visit."
  - Gift Cards

- Specify if it's to a specific store or if it's general money that can be spent anywhere
- Transportation/Parking Costs
  - Include information in every study description about whether transportation/parking costs will be covered. If so, specify what exactly will be covered.
- Always include this line in your study description: Any questions? Just ask your study team!

# **Keep Descriptions Simple. For Complicated Acronyms, etc., Use Last "Optional" Field**

- Complex jargon and abbreviations don't mean anything to your audience: the general public.
- Study names and abbreviations will not be used in the headlines and primary descriptions of studies. It eats up limited character counts and there isn't space to explain what they mean.
- Include this content in the bottom optional field for additional information.
- Empowers people to search for more information if they would like. Avoids burying most important information.
  - Examples:
    - Modeling the Epidemiologic Transition Study
    - ENGAGE-2 study
    - · Complex full name of a specific medicine

Remember: It's Not All About You. What's in it For The Public?

The New Normal™ Campaign is connecting and matching the public to study teams at a large scale for the first time in history. Write about what's in it for the public through the lens of joining with them as a team to explore and make advancements together. "Let's do this together" instead of "I want to do this."

#### Examples

- o Instead of:
  - We want to figure out which one helps people.
- Use:
  - Let's figure out which one helps people.
- Instead of:
  - Immigrants may experience a decline in health the longer they're in the U.S. due to the stress of adapting to a new place. This is particularly true of Asian women. We want to better understand the connection between stress and the risk of developing type 2 diabetes in Chicago's Filipina community.
- Use:
  - If you're an immigrant, your health may <u>decline</u> the longer you're in the U.S. from the stress of adapting to a new place. Let's work together to understand the connection between stress and the risk of developing diabetes in Chicago's Filipina community.
- Instead of:
  - We're recruiting women from Mexico.
- Use:
  - Are you a woman from Mexico? Partner with us to do X.
  - Are you a woman from Mexico? Team up with us to do Y.
  - Let's team up.
  - Join the team!

#### **Avoid Getting Lost in Details**

Remember that the portal is a welcoming front door. Include general, relevant information. Send specific questions for full study details to the study team and its established consent process.

#### Example:

 Instead of: 100 shots. (Detail that requires more explanation, defer to study team interaction and their consent process.)
 Use: Many shots. (Accurate, will filter out anyone who wants to avoid shots.)

# **Explain Why Certain Steps Matter and What Will Be Done for Volunteers**

- Explain why something is important.
- Put yourself in the readers' shoes and explain what the experience will be like, especially if it involves shots, biopsies, painful procedures, etc.

#### Examples:

- We'll numb your leg before you get your shots.
- You'll get multiple shots to make sure your leg gets enough X.
- o A skin sample the size of a dime.

# **Avoid Complicating Information that Could Create Confusion**

The portal Descriptions and Additional Information field are not consent forms. This is not the place for deep dives into data protections, study design about whether/when/how people will find out results to tests, etc. The place for that information and those conversations is during your IRB-approved consent process and answering any questions interested participants may have.

If participants will receive test results as a motivating factor for joining in the study, that information will be included. General educational information about health research, how it's done, data protections, etc., will be highlighted as part of The New Normal™ Campaign.

## Be Transparent: Encourage Questions and Give Answers

Because the portal is just a first touchpoint to open the door for awareness and participation - and it's not the place for deep dives into things like the above - questions are encouraged! You can answer using the simple, mobile portal interface.

Since the portal descriptions are a high-level overview, the below line will be a routine sentence at the end of every What Is Involved? section so people know that any detailed questions they may have can be answered.

 Any questions? Just email or call your study team at the below contact information!

#### Simple Reference First, Then Medical Name

When explaining something complex, describe it first. Then use a comma and refer to it by the medical term. The public then knows what you're

talking about and won't stop reading because of a scary word they don't understand.

- Example:
  - o An X-ray to see your blood vessels, called an angiogram.

A growing list of synonyms to help keep within the required approachable reading level is below for easy reference:

Instead of This	Use This
Approximately	About
Free	At no cost
Therapy or therapeutics	New potential treatment, medicine, etc.
	If in reference to cognitive behavioral therapy, OK to use "therapy."
Join registry	Crowdsource information Sign up for a list of X Help build a library of X
Investigator	Researcher, doctor, study team
Evidence-based	Proven, a treatment that worked for others
Agent	Avoid this unless you're a secret agent or spy. Say what kind of specific agent it is for biomedical science - a substance, chemical, molecule, etc.
Angiogram	An X-ray to see your blood vessels
Additional	More
Drugs	Medicine, treatment
Cardiac catheter/catheterization	When a small tube goes through a big vein to see your heart
CT scan, PET scan, other acronymed scans	Images of the (insert body part here.) An MRI scan to make a picture of your insides or (insert organ here)
Angioplasty	When a tiny tube opens a blocked vein

Generic "activities" Be specific as to what kind of activity,

such as exercise, diet, walking, etc.

Procedure Test, exam or process

You'll get general anesthesia You'll be asleep under anesthesia

Participate Take part, join us, help out, team up

Qualify Be a good fit for, if you're a match

Females and males Women and men

Physician Doctor

Communicate Talk, write, be specific

Conducting Doing

Menstrual cycle Period

Inflammation Swelling and irritation

Potential participants or patients You

You'll be compensated You'll earn/get

Gene abnormalities and variants Differences in your genes

Sputum Lung mucus

Eight weeks About two months

Spirometry to measure your lung function | Test your breathing

Prolong life Live longer

Saliva Spit

We will take Your study team will collect or You'll give

Rehab	Physical therapy. If referring to addiction/drugs, rehab is fine.

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