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## What It Means to Use the Portal - Welcome to the User Agreement

### General Information

The purpose of BeTheNewNormal.org/Match | BeTheNewNormalMatch.org is to connect people like you who are interested in participating in health research to studies in the Chicagoland area. We refer to you as participants in this description and as Very Important Participants (VIPs) on the portal, children and adult participants who may be unable to make their own healthcare decisions are referred to in this agreement as “loved ones.”

If you’re interested in participating in research yourself or on behalf of your loved one(s), BeTheNewNormal.org/Match | BeTheNewNormalMatch.org allows you to create your own account, as well as accounts for your loved one(s), so that you can find out about studies you may be a good match for in the health research areas you may care about the most.

This software application is hosted and administered by the University of Michigan on behalf of the The New Normal™ Campaign institutions.

The Institute for Translational Medicine (ITM), a partnership between the University of Chicago and Rush in collaboration with Advocate Health Care, the Illinois Institute of Technology (Illinois Tech), Loyola University Chicago, and NorthShore University HealthSystem, as well as the Northwestern University Clinical and Translational Sciences (NUCATS) Institute and the University of Illinois at Chicago Center for Clinical and Translational Science (CCTS). The ITM, NUCATS, and CCTS are fueled by nearly \$80 million from the National Institutes of Health (NIH) National Center for Advancing Translational Science (NCATS) Clinical and Translational Science Awards (CTSA) Program.

### Information About Using BeTheNewNormal.org/Match | BeTheNewNormalMatch.org

1. Participation in BeTheNewNormal.org/Match | BeTheNewNormalMatch.org is voluntary. People join to team up with researchers for finding ways to improve human health faster. But neither you nor your loved one have to participate.
2. At any time, you can deactivate your account to revoke all access to the information you provided to match with studies. (See “Account Deactivation” section for more details).
3. Your information in BeTheNewNormal.org/Match | BeTheNewNormalMatch.org is confidential.
4. Participating in BeTheNewNormal.org/Match | BeTheNewNormalMatch.org is something you can do at no cost to yourself or your health insurance.
5. Health research in general improves healthcare, leads to the discovery of new treatments and cures, and ultimately benefits humanity. This portal directly benefits you and your loved ones by making health research opportunities easy to find and understand, as well as connecting you with the study teams working on topics you may care about the most.

This matchmaking portal is not health research itself, but it does connect you with health research studies. Because each health research study listed in the portal is different, we can’t predict or guarantee how each study could impact your or your loved ones’ health. Your study team will explain all the benefits and risks for your specific study of interest - ask them any questions you may have!

6. You or your loved one may be invited to participate in current or future research studies because of the information you entered and the interest you expressed. The corresponding research team will explain to you the benefits and risks of these for yourself or your loved ones before you decide whether or not to participate.
7. Researchers are looking for that ‘perfect match’ for each study. We use the phrase ‘perfect match’ to drive home how each study is built in a very specific way to test a specific thing and answer a very specific question. This helps to make the science stronger. If a researcher invites you or your loved one to discuss participation, there is no guarantee that you’ll be eligible for that study. Some studies may require additional tests, like a blood sample, in order to determine eligibility. Don’t worry if you don’t qualify for a specific study. Health research is for everyone - even healthy people - so you’ll likely find a perfect match soon. And new studies are added regularly. Learn more in our FAQ section [here](#).
8. Even if you or your loved one match to a study, you or they are under no obligation to participate. You’re the boss.

## Information Collected

BeTheNewNormal.org/Match | BeTheNewNormalMatch.org captures information about both the participants and the research studies in order to match you with health research opportunities.

If you choose to join BeTheNewNormal.org/Match | BeTheNewNormalMatch.org, some of the information you’ll provide to help make those matches includes:

1. Descriptive information: your name, date of birth, race and ethnicity
2. Medical History
3. Contact Information

If you show interest in a specific study on behalf of yourself or your loved one, you may need to answer additional questions from the study team to make sure you are a good match for the study.

## Information Access

All users of BeTheNewNormal.org/Match | BeTheNewNormalMatch.org, can access health research study descriptions posted by recruiting research studies within the application. You do not need to create an account in order to see information about research studies listed in BeTheNewNormal.org/Match | BeTheNewNormalMatch.org. However, you can not match to studies without an account.

You control how study teams can view your or your loved one’s information, and you can change those settings anytime in your profile.

There are two ways you can control access:

1. Profile Visibility: You can choose your and/or your loved one(s)’ information to be:
  - o Visible to all study teams.
  - o Visible to only study teams whose studies you show interest in.
2. Deactivate account: You can deactivate your or your loved one’s account. Once deactivated, nobody can access your profile information. See “Account Deactivation” section for more details.

Outside of study teams that you allow to view your information, your profile can be viewed by a system administrator. System administrators only use this access to make sure the system is working properly.

## Communication

1. When you express interest in a study for yourself or a loved one, then the study team knows you'd like more information. So when you express interest in a study, you're also expressing an interest in having that study team communicate with you.
2. You'll receive email notifications from BeTheNewNormal.org, such as letting you know when you've matched to studies or that you have messages waiting for you in the portal.

## Account Deactivation

Once you enter your or your loved one's information, researchers can continue to view it and connect with you until you choose to deactivate your or your loved one's information (see "Information Access" section above). You can deactivate your or your loved one's account at any time by logging into the system and choosing the option "Deactivate account." Researchers can't see any profiles that have been deactivated. Your or your loved one's record will remain stored in case you'd like to reactivate in the future, so you can pick up right where you left off. But your personal information will not be available to researchers while your account is deactivated. If you had started to **communicate** with study teams within the application, **they**'ll lose the ability to **communicate with** you within the application once you deactivate. If you choose to restore your account, you will have access to those communications again. Information shared with researchers prior to deactivation cannot be retracted. For example, if you expressed interest in a study, shared your profile with that study team, and answered specific study questions - such as you drink soda three times a week - we can't erase the study team's memory from knowing your age and that you drink soda three times each week. But we can prevent that information from being seen by any study teams in the future.

If you'd like to reactivate your account, just reach out to us at [ask@bethenewnormal.org](mailto:ask@bethenewnormal.org).

## Agreement to Release Information

By choosing "I Agree" at the end of this form, you authorize the The New Normal™ campaign, its agents and employees to release information about you to:

1. The BeTheNewNormal.org/Match | BeTheNewNormalMatch.org team to maintain the portal.
2. Researchers and study teams using BeTheNewNormal.org/Match | BeTheNewNormalMatch.org to connect with potential participants like you for health research studies.

When you express interest in a study, the information you provide will be shared with that study team so they know that you're interested. This information can't be retracted. For example, if you expressed interest in a study, shared your profile with that study team, and answered specific study questions - such as you exercise five times a week - we can't erase the study team's memory from knowing your name, age, and how often you exercise. While we can't control everyone's actions outside of the portal, please know that researchers and study teams are held to high standards and they sign agreements not to disclose information just like your doctors and care teams.

The information you enter into BeTheNewNormal.org/Match | BeTheNewNormalMatch.org may be used for things in addition to recruitment efforts. For example, exploring how many people of different ages use the portal or other general metrics to track usage and improve the platform. Information like those metrics about BeTheNewNormal.org/Match | BeTheNewNormalMatch.org could be published in an article, but would never include any information that reveals you or your loved one's identity.

This agreement is active when you click agree and allows you to create your profile for the platform. You can choose to deactivate your account at any time by reaching out to us at [ask@behtenewnormal.org](mailto:ask@behtenewnormal.org). Your user agreement would come to an end with that deactivation because you would no longer be using the platform.

That's what it means to use the portal and how you match to health research studies! Just click "I Agree" below to make it official and continue setting up your account on BeTheNewNormal.org/Match | BeTheNewNormalMatch.org. Thanks for joining the movement!