# Your Guide to NCHPAD Connect Frequently Asked Questions



# **Background Information**

## What is NCHPAD?

Since 1999, the National Center on Health, Physical Activity and Disability (NCHPAD) has been a pioneering force in inclusive health. Based at the University of Alabama at Birmingham (UAB) School of Health Professions, NCHPAD offers a variety of innovative resources, free health promotion programs, trainings and partnership opportunities designed to empower individuals and communities to engage in health and wellness, champion inclusion and advocate for health equity all across the United States.

# What is NCHPAD Connect?

In 2022, we created NCHPAD Connect to collect and understand the needs, interests and lifestyles of people with mobility limitations across the United States. Within this private wellness database, we use the data to create, evaluate and enhance health promotion programs, develop educational resources and improve inclusion.

Individuals who join and contribute their information to NCHPAD Connect have access to our free evidence-based health and wellness programs, resources and virtual community events, with additional opportunities to participate in and further the development of new resources.

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# What is a wellness database?

A wellness database is our version of a registry that collects and manages information to help improve access to health promotion programs and resources for people with mobility limitations, while also supporting broader goals to help advance inclusion.

# Who is involved in NCHPAD Connect?

NCHPAD Connect is comprised of a collaborative group of disability health experts, public health professionals, healthcare providers, scientists and program coordinators advancing inclusion and developing accessible health promotion opportunities.

# **Does NCHPAD Connect cost money?**

No, it is 100% free!

# Why is NCHPAD Connect free?

NCHPAD Connect is entirely free because it is fully funded grant from the CDC. This funding ensures that all program services and resources are available to participants at no cost, allowing us to focus on providing valuable support without any financial burden on participants.

# Is NCHPAD Connect a research study?

No, NCHPAD Connect is not a research study. While we have scientists and data experts on our team, their role is to design questions that highlight the value of our programs, understand participant lifestyle and health behaviors, and evaluate the impact of our resources. This helps us demonstrate to our funders why ongoing support for our health promotion work is important.

# **Eligibility & Joining NCHPAD Connect**

# How do I join NCHPAD Connect?

You can join NCHPAD Connect by signing up online, contacting our call center or through one of our partners. After signing up, your eligibility will be confirmed, and you'll receive series of surveys and questionnaires. Once those are completed, you'll officially be part of NCHPAD Connect and can enjoy access to our programs, resources and virtual community!

# Am I eligible to join NCHPAD Connect?

To be eligible to join NCHPAD Connect, you must live in the United States or its territories, be 18 years or older, self-report a mobility limitation or physical disability, or use a mobility device or assistive technology. No medical diagnoses or paperwork are required.



# What is disability?

According to the CDC, A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions). We believe that disability exists on a spectrum and can vary greatly among individuals. As people age or encounter different life circumstances, they may experience disability in various forms. At NCHPAD, we are dedicated to understanding the diversity of disability to promote accessibility and wellness for everyone.

## What is a mobility limitation?

A mobility limitation refers to any condition or impairment that affects a person's ability to move freely or perform daily activities. Examples include:

- Chronic pain: Persistent pain in areas such as the back, joints or limbs that makes walking or standing for extended periods challenging.
- Join Inflammation: Joint inflammation that can limit movement and flexibility, impacting tasks like climbing stairs or reaching high shelves.
- Muscle weakness: Experiencing weakened muscles, affecting an individual's ability to lift objects or maintain balance.
- Difficulty walking or not able to walk: Individuals may be unable to walk or have difficulty walking and need the use of assistive devices like canes or wheelchairs to support mobility.
- Limb Difference: Individuals may have differences in limb length or function or use prosthetics to support mobility.

## Do I need insurance to join NCHPAD Connect or participate in a program?

No, you don't need insurance. We only ask for self-reported information, so you don't need to provide any official documentation or medical records – just the details you're aware of and comfortable sharing.

## Will I be paid to join NCHPAD Connect?

No, we do not provide compensation for joining NCHPAD Connect. However, you will receive program materials at no cost, which may include items like resistance bands, water bottles, food choppers, t-shirts and more.

#### Do I need an email address for NCHPAD Connect?

You do not need an email address to join NCHPAD Connect, but you do need one to participate in our wellness programs. An email address is required to create your GetHealthie account.

#### Do I need a phone number for NCHPAD Connect?

You do not need a phone number to join NCHPAD Connect. If you do not have a phone number, you

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can connect with us through email or mail.

#### Do I need to give you my address for NCHPAD Connect?

Yes, we request a reliable mailing address to confirm your eligibility for NCHPAD Connect and to send you program materials and freebies at no cost. If you have any concerns about providing your address, please contact us via email at nchpad@uab.edu or call us at 866-866-8896.

#### What do you do with my contact information?

We use your contact information to send you program materials, inform you of new opportunities, enroll you in programs and check in on you. If you have expressed interest in receiving information about research studies you might qualify for, we may provide you directly with contact details for those studies. However, we will never share, sell or rent your contact information to any third party.

#### Do you need my Social Security Number (SSN)?

No, we will never ask for your Social Security Number (SSN) to join NCHPAD Connect or any of our programs.

#### How often will I be contacted by someone from NCHPAD Connect?

If you request contact, a NCHPAD team member will contact you within 24-48 business hours. If we initiate contact, it will typically be to assist you with enrollment, check in about paperwork, scheduling for programming or share new opportunities if you've opted in. We also send a monthly email to NCHPAD Connect participants with new resources, news and updates – you can unsubscribe from this at any time.

#### Who will be contacting me if I join NCHPAD Connect?

Someone from our NCHPAD Call Center, an Expert Inclusion Specialist (EIS) or other NCHPAD team member may contact you to complete the process of joining NCHPAD Connect or help you enroll into a program and access resources. If you receive a call from 866-866-8896 or email from nchpad@ uab.edu, please know that we are trying to contact you and that this is not spam!

#### What are the benefits of NCHPAD Connect?

The greatest benefit of NCHPAD Connect is the direct impact participants make in helping us continuously develop and improve access to health promotion programs and resources for people with and without disabilities. Additionally, participants gain access to a variety of evidence-based health programs, personalized resource recommendations and opportunities to connect with a community of individuals with similar experiences and goals.



# What are the risks in joining NCHPAD Connect?

There are no risks in joining NCHPAD Connect and adding your information to our wellness database. Our web platforms are safe, secure and HIPAA-compliant.

During a program activity or session, NCHPAD instructors will always guide participants on ways to minimize risk. If at any point you experience discomfort or have concerns, please contact your program instructor.

If you have questions or concerns before you join NCHPAD Connect, please call the NCHPAD Call Center at 866-866-8896 or email us at nchpad@uab.edu. We are happy to answer any questions that you have.

# How do I leave NCHPAD Connect?

If at any point you would like to leave NCHPAD Connect or have your information removed from our wellness database, please contact us via email, phone or mail.

# If I leave NCHPAD Connect, can I rejoin later?

Yes, you can always rejoin by contacting us via email, phone or mail.

# **Participant Experience**

# What is health promotion?

Health promotion focuses on enhancing participant well-being through engaging with healthy behaviors and practices. At NCHPAD Connect, we aim to support participant wellness journeys in a way that fits particular needs and preferences.

# Are your programs and resources evidence-based?

Yes, our programs and resources are evidence-based. NCHPAD Connect programs use methods proven effective by research and are rigorously validated by experts to thoroughly evaluate risks and benefits before implementation. We aim to provide maximum benefits, and your feedback helps us continuously refine and enhance our offerings.

# What types of programs do you have?

We currently offer three online programs with live instruction exclusively through NCHPAD Connect. These programs focus on a range of topics designed to boost your well-being, including mindfulness, exercise, nutrition, resilience, mental health and weight management. We develop two new programs each year based on participant feedback and are working to add asynchronous options (available on demand) to better accommodate participant needs.



#### Will your programs work for me?

Our goal is that anyone can fully participate and benefit from all aspects of our programs! Our programs are designed to accommodate your disability or mobility limitation. Our experienced exercise instructors, registered dietitians, mindfulness instructors and mental health coaches will work with you in a group setting or one-on-one to provide the necessary adaptations and support you want.

#### How do I enroll into a program?

In your NCHPAD Connect interest survey, we ask if you're interested in joining the NCHPAD MENTOR program. If you answer "YES," we'll contact you with enrollment details and share what to expect next. If you selected "NO" but are still interested in other programs or have changed your mind, you can contact our Call Center at 866-866-8896 or email us at nchpad@uab.edu.

#### Who will contact me if I enroll into a program?

A Call Center team member will call you to explain what the program is, go over the times the program is offered, send you pre-program paperwork for you to complete and answer any questions you may have. If you receive a call from 866-866-8896 or email from nchpad@uab.edu, please know that we are trying to contact you and that this is not spam!

#### Do the programs or resources have any additional costs?

No, there are no extra costs to enroll in our programs or access our resources. We provide any necessary materials or equipment at no charge. For our weight management program, we provide the diet plan, but you are responsible for purchasing and preparing your own meals. This may impact your food budget, but you can discuss any concerns with your program coordinator.

## What are the benefits of joining a program?

Joining one of our health promotion programs offers you access to disability inclusive resources, support from experts and opportunities to make improvements your well-being. You'll also benefit from a community of peers, personalized guidance and tools designed to help you support your health and wellness goals.

#### I don't have access to the internet. Can I join NCHPAD Connect or a program?

If you don't have internet access, you can still join NCHPAD Connect's wellness database by requesting our surveys to be mailed to you. Alternatively, you can call us at 866-866-8896 to complete the surveys and questionnaires over the phone with a team member. While reliable internet access is currently needed to enroll in and participate in our programs, we can send resources and other opportunities to your address. We are also currently working on expanding offline options for greater accessibility.



#### What is GetHealthie?

GetHealthie is our program platform that makes it easy for you to connect with your instructors in one secure place and remotely. On this platform, you'll be able to attend your classes, chat with instructors, schedule one-on-ones and access program information taught in your classes. You will need internet access to use the GetHealthie platform and participate in a program.

#### Can my caregiver be involved in and join the programs with me?

Yes! Your caregiver is welcome to join your scheduled classes and assist you with the program content.

#### Are the programs flexible to my schedule?

Flexibility can vary by program, but we understand that conflicts may arise. If you need to miss any sessions, let us know, and we'll try to arrange one-on-one time to help you catch up. We are also working on developing asynchronous options to improve access for those who can't join during our scheduled class times.

# Do I need to tell my healthcare provider that I've joined NCHPAD Connect or a NCHPAD program?

You don't need to inform your provider since NCHPAD Connect is focused on wellness and not healthcare. However, you might find it helpful to mention your participation to your provider, similar to how you'd share that you're going to the gym.

#### How do I leave a program?

If you decide to leave a program, we encourage you to contact the program's coordinator to discuss your options. They can help you with the process and address any questions or concerns you might have.

#### If I leave a program, can I rejoin later?

Whether you can rejoin later depends on the program and why you're leaving. Some programs have long waitlists, so we can't always guarantee a spot. It's best to discuss this with the program coordinator when considering leaving, as they can provide specific details and options.

#### What is an Expert Inclusion Specialist (EIS)?

An Expert Inclusion Specialist (EIS) is a NCHPAD representative who finds or creates resources tailored to your needs and interests. This could include finding local accessible resources like parks or gyms or locating the best articles or videos. If you need specific resources to support your health goals or engage in wellness, contact us at 866-866-8896 or email nchpad@uab.edu to get started.

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#### What are tailored resources?

Tailored resources are designed to fit your specific needs and interests. We personalize the information we share with you, whether by highlighting parts of a resource that may be especially helpful or by having one-on-one conversations to address your individual needs. Our goal is to ensure that the wellness resources you receive are relevant and useful to you.

#### What resources do you have?

We offer a range of resources, including videos, toolkits, infographics, articles, programs and more. These resources cover various topics and are designed to promote health and the inclusion of people with disabilities. Many of these resources can be accessed on our main website nchpad.org.

#### What if I don't want to join a program or receive resources from an Expert Inclusion Specialist?

You can still join NCHPAD Connect! We appreciate individuals who share their lifestyle and health information to our wellness database. By joining, you help us develop and improve health promotion programs and resources for everyone. Even if you choose not to join a program or use our resources, your participation supports our mission to enhance access and inclusion.

# Do you have programs and resources for people with intellectual or developmental disabilities?

Currently, we do not have specific programs for individuals with intellectual or developmental disabilities. However, we are working to enhance our offerings to better meet these needs, in collaboration with Special Olympics International and other community partners and experts.

#### Do you have programs and resources for kids or teens?

Currently, NCHPAD Connect and our programs are available only for adults aged 18 or older. However, if you are 17 or younger, work with or serve children or teens with disabilities, or are a parent of a child with a disability, you can find a wealth of resources on our main website at nchpad. org.

# Who do I contact if I need an alternate format for surveys, resources or program materials?

If you need an alternate format, please contact us by email at nchpad@uab.edu or by phone at 866-866-8896.

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# **Surveys, Personal Information & Data**

# How does NCHPAD Connect use participant information and data to improve its programs and resources?

NCHPAD Connect uses participant information to make data-driven decisions that improve our programs and resources. We analyze feedback and participation data to understand what works best, identify areas for improvement and tailor our offerings to better meet participants' and the disability community's needs. Participant information helps us ensure our programs are effective, inclusive and aligned with evidence-based practices.

#### What is **REDCap**?

REDCap is a secure web application for building and managing online surveys and databases. Participants might receive emails or reminders from REDCap to complete surveys or complete other tasks.

#### What are your surveys asking about?

The surveys you complete to join NCHPAD Connect or enroll into our programs ask about your access to care, quality of life and initial knowledge before starting our wellness programs. Your responses help us understand your healthcare access, lifestyle behaviors and experiences, which is crucial to creating and refining effective programs and resources.

## Why do I need to fill out surveys before joining a program?

Filling out surveys before joining a program helps us establish a starting point to measure progress and ensure the program meets its goals. This information allows us to track your progress throughout the program and identify areas for improvement to enhance future offerings.

## What do you do with the data from the surveys?

We use survey data to develop new programs and improve our current programs, create educational resources and ensure that everything we offer is available for free. The data collected from our surveys and questionnaires helps us evaluate and enhance our offerings, publish insights on health promotion and support communities working to advance inclusion. Personal identifiable information is never shared.

## Why do I need to fill out an annual questionnaire?

The annual questionnaire helps us provide our programs and resources for free and ensures we design them with you – not just for you. Completing the questionnaire is necessary to continue participating in future programs, accessing local and national resources, and staying connected with others.



# Do you need any samples (blood, urine, etc.) from me?

No! We do not collect biological samples from our participants. All the information we collect is selfreported by you without the need to visit a doctor or health professional.

# How long do you keep my personal information?

Your personal information is kept indefinitely. If at any point you wish to be removed from our wellness database, please contact us via email at nchpad@uab.edu.

## How is my personal my information protected?

We protect your information through our HIPPA-compliant secure storage system that has strict access controls and regular security audits.

#### How is my personal information kept secure?

Security is a top priority! This is why we keep your information in a safe HIPPA-compliant system with strict access controls.

## Is my information or data sold to any third-party?

We will never sell, trade or rent your personal identification information. Any information shared with our CDC funders and NCHPAD affiliates can never personally be linked to you (ex. "X amount of our participants live in a food desert").

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