

NCAB NEWS FOR MWCCS Participants

Spring 2021



NEW NATIONAL COMMUNITY ADVISORY BOARD (NCAB) BEING FORMED

In the most recent studies' renewal efforts, two independent studies, WIHS and MACS, have been merged into one single multi-cohort study called MWCCS. MACS has been the study investigating the natural history of treatment and prevention of HIV among men, while WIHS has the same focus but was a study among women. MWCCS is the new acronym for the MACS-WIHS Combined Cohort Study.

Over the years, both MACS and WIHS have had their own Community Advisory Boards (CAB) at the site level and separate National Community Advisory Boards (NCABs) at the national level. These boards represent participant interests at both the local site and national level.

An NCABs Merger Task Force consisting of the leadership of both the existing MACS and WIHS NCABs has been working for the past 10 months to determine the process for the merger of the two NCABs. To-date, a new Bylaws document for the MWCCS NCAB has been drafted and approved by both the existing NCABs.

The Task Force has also developed an NCAB merger timeline and is planning for a merger in May, 2021. There are many tasks to accomplish to make this happen. Communications to you, the study participants, is the start of this process. We have also defined the election process for membership on the new combined MWCCS NCAB. This flyer is intended to provide study participants information on the upcoming actions and processes.

The new MWCCS NCAB Bylaws will be available on the MWCCS NCAB website.

LOOKING TO CONTRIBUTE MORE?

As participants, our contribution to the science by participating in this study is hugely important and truly appreciated. Wanting to do more? Consider joining a local CAB or the NCAB, or a committee. Find out more in this flyer.

STUDY SIZE & PARTICIPANT COUNTS

Membership in the new MWCCS NCAB will include representatives from current MACS & WIHS study sites' CABs. At present, this includes 10 women's sites CABs and 5 men's sites CABs.

Women's CABs are from: Atlanta, Bronx, Brooklyn, Chapel Hill, Chicago Cook County, Miami, Mississippi, San Francisco, University of Alabama, and Washington, D.C.

Men's CABs are from: Baltimore/DC, Chicago Core Site, Chicago Northwestern University, Pittsburgh, and Los Angeles.

As of July, 2020, according to the Study DACC, the total number of participants in the WIHS study was 2,132 women and in the MACS study there were 1,902 men. The study does have plans to enroll additional participants at sites, and in the future, some former WIHS sites are expected to begin enrolling men.

NCABs MERGER TIMELINE ANNOUNCED

The existing joint NCABs voted and approved a May 11, 2021 merger of the existing Women's and Men's NCABs into the new MWCCS NCAB. To support the merger, they are working on defining critical activities to take place following the merger.

Until finalization of the MWCCS NCAB members nomination process, the current members of the existing Women's and Men's NCABs are expected to continue to serve on the new NCAB.

In addition, the current Merger Task Force leadership team will continue to provide direction and oversight of the new MWCCS NCAB.

The MWCCS NCAB will begin defining the formal notification process to CABs of the new MWCCS NCAB membership nomination process and deadlines

To learn more about the CAB and NCAB responsibilities you can contact your site's current NCAB member. You can learn who they are by contacting your site Project Director.

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MWCCS NCAB MEMBERSHIP NOMINATION PROCESS COMING

We're getting close to seeking/confirming the membership of the new MWCCS NCAB. We have a few refinements to our Bylaws to finalize before we formally start the process, but it's clear that participant representation from Study CABs is key and critical. If you think you might be interested in becoming a member of the NCAB, you may wish to contact your current CAB or Site Project Director for more information.

The new MWCCS Bylaws directs NCAB representatives should be approved by the various site CABs. This is nothing new for some current sites, but at some sites, representatives were previously identified by site Project Directors (PDs).

Interested CAB members that wish to serve on the NCAB should notify their local site CAB of their desire to serve on the NCAB. Each CAB will determine its own process to identify their NCAB representative(s). If you are unsure how to contact your site CAB, reach out to your site's Project Director to learn who to contact.

NEW NCAB WILL ESTABLISH TWO KEY STANDING COMMITTEES TO CARRYOUT MISSION

The recently approved MWCCS NCAB bylaws document includes two standing committees to carry out the NCAB mission:

<u>Science & Research Committee</u> - focused on supporting the relevant science & research related objectives stated in the NCAB mission

<u>Communications Committee</u> - focused on identification, design, development and distribution of NCAB messaging to participants, including but not limited to, creation of a national newsletter or participant website

More information will be available at a later date after the September NCAB startup, when the committees are organized and accepting members. Stay tuned for more information on how you may contribute.

NCAB WEBSITE UP & RUNNING

The Merger Task Force received approvals and established a website that will feature topics, articles and news relevant to study participants. The site is still in its infancy stage, but we have plans to provide content that we think will be of interest to study participants.

You can reach the website at:

https://statepi.jhsph.edu/
mwccs/ncab/

Or you can access the website directly by hovering your smart phone's camera over the QR code displayed here.



NCAB MERGER TASK FORCE

A small group of dedicated volunteer participants have been working since May 2020 to help plan and carryout the merger of the existing WIHS and MACS NCABs. The women and men that have worked to accomplish to merger include:

From WIHS: Queen Hatfield from Mississippi, Marta Santiago from Chicago Core, and Lynn Murchison as Study Liaison

From MACS: Chris Camp from Baltimore/DC, Dan Fitzgerald from Chicago NWU, and Marc Wagner from Pittsburgh, and Dr. Michael Plankey as Study Liaison

These individuals have spent countless hours to develop the NCABs merger plan, draft the new MWCCS Bylaws document, create the merger timeline and facilitate the merger communications and prepare for the new MWCCS NCAB's transition.

HOW TO CONTACT THE NCAB TASK FORCE

If you have a question or wish to learn more how you may be able to volunteer to support the NCAB's mission, send an email to the NCAB at:

mwccsncab@gmail.com

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