



# **The NCAB Handbook**

**A reference Guide for NCAB Members**

**How the NCAB works!**

**Version 2**

**March 18, 2024**

## Table of Contents

Handbook Summary .....	4
1 - Welcome to MWCCS & the NCAB .....	5
2 - National Community Advisory Board (NCAB) .....	5
NCAB Merger .....	5
NCAB Representatives.....	5
NCAB Member Selection.....	5
NCAB Member Expectations .....	6
NCAB Governance.....	6
NCAB Bylaws .....	6
Code of Civility .....	6
Confidentiality.....	7
NCAB Leadership.....	7
NCAB Chair & Co-Chair Selection & Term .....	7
Chair Role .....	7
Co-Chair Role.....	9
Secretary Role .....	9
Proposed Leadership Activities & Schedule.....	10
MWCCS NCAB Leadership History .....	11
NCAB Meetings .....	11
Regular Meetings .....	11
Semi Annual EC Meetings .....	11
NCAB Leadership Election Meeting .....	12
NCAB Meeting Attendance .....	12
NCAB Meeting Minutes.....	12
NCAB Standing Committees.....	12
NCAB Science & Research Committee (Concept Sheet Review).....	12
NCAB Communications Committee .....	13
NCAB Initiatives.....	13
The NCAB Handbook.....	13
External Conference Sponsorship for NCAB Members .....	14
NCAB Advocacy .....	15
MWCCS Autopsy Program.....	15

NCAB Member Compensation .....	16
Additional Support for the NCAB .....	16
Stigma Study Feedback .....	17
Climate Crisis and Possible Anxiety .....	17
Social Connections Study .....	17
3 - MWCCS Study .....	18
Overview .....	18
Studies History .....	18
MACS History .....	18
WIHS History .....	19
MWCCS Leadership Committees & Groups .....	19
MWCCS Steering Committee (SC) .....	19
MWCCS Executive Committee (EC) .....	19
Project Directors Working Group (PDWG) Meetings .....	20
Data Analysis and Coordination Center (DACC) .....	20
Clinical Research Sites (CRS).....	20
Principal Investigators (PI).....	20
MWCCS Working Groups .....	20
For More Information - MWCCS .....	21
MWCCS Acronyms.....	21
4 - Other Information.....	21
NCAB Email .....	21
NCAB Zoom Account .....	21
Georgetown BOX.....	21
Access & Passwords .....	21
DACC Support Requests .....	22

## Handbook Summary

You've been asked to join the MWCCS National Community Advisory Board (NCAB), but you likely don't really know what you are getting into or what is expected of you? How do you catch up, learn, and understand how things work? This handbook was created to serve as a resource tool for NCAB members, explaining much of what NCAB members should know about the board. It may not be bedtime reading but can be used as a resource tool and accessed when a question comes up.

This handbook is organized into three main sections:

- 1 - NCAB Organization, governance, leadership, meetings protocols and NCAB advocacy initiatives
- 2 - MWCCS Study overview, leadership, and committee structures
- 3 - Logistical information about NCAB email, Zoom, etc.

What can you learn from this handbook?

What's the NCAB?	Group of volunteers and MWCCS study participants representing each of the study sites
Why does the NCAB exist?	To represent the interests of the participants in the study and serve in an advisory role to study leadership. A lot is asked of study participants with the blood draws, various diagnostic test, questionnaires, etc. The NCAB can provide feedback if we feel something is too burdensome or think some change may be needed
Study Sites	You represent your study site, where you go for study appointments. You may be on a local site Community Advisory Board (CAB) or perhaps a study participant. Check with your site Project Director (PD) to understand your opportunities to share information you've learned on the NCAB with your site's participants
What is expected of NCAB members?	Attend and actively participate in NCAB meetings which are generally held every other month, represent your site's interests, participate in an NCAB Committee (Communications or Science & Research) and an MWCCS Working Group
What are the NCAB leader roles and what is expected?	The NCAB is run by a leadership team consisting of a Chair, Co-Chair, and Secretary. The roles and responsibilities are explained in this handbook. Having a good understanding of the workings, policies, history, and organization of the NCAB and MWCCS is helpful. Especially if you are looking to serve in a leadership role
What else should I know about how the NCAB is governed?	Besides understanding the overview of the NCAB and MWCCS provided in this handbook, the NCAB has an official Bylaws document that provides higher level governance information. This guidebook is complementary with the Bylaws and provides more practical, process and procedure types of information than what is in the official Bylaws
MWCCS is a mouthful, what does it mean?	The official name of the study is the MACS-WIHS Combined Cohort Study (MWCCS). The name signifies the merger of two earlier independent studies of HIV, one for men (MACS) and one for Women (WIHS)
How does the Study work?	There is an established committee structure to provide oversight and ongoing direction for the study. You can read more about it in this handbook

Remember, this handbook was written by volunteers who serve on the NCAB, just like you. If you think something is not clear, or there is something you think would be helpful to include, raise it at an NCAB meeting. All feedback is welcome.

## 1- Welcome to MWCCS & the NCAB

This handbook is intended to be a reference document for the members of the MACS/WIHS Combined Cohort Study (MWCCS) NCAB. The handbook provides background information, NCAB member expectations, an overview of NCAB processes and procedures, and a summary of how the overall study is governed. We hope this document helps maintain the institutional knowledge of the organization that should be helpful for all current and future NCAB members and leadership.

As a participant in MWCCS, you play an important role in the longest standing HIV/AIDS research projects, initially founded in 1984 with the MACS Study and in 1993 with the WIHS Study. The current MWCCS study is a result of a 2001 merger of the former MACS and WIHS studies which brought together two previously independent HIV-related studies for men (MACS) and women (WIHS).

## 2- National Community Advisory Board (NCAB)

The National Community Advisory Board (NCAB) is a group of volunteer study participants representing each of the study sites who serve on the NCAB in an advisory role. Our NCAB goals are to encourage participant involvement, to provide feedback and suggestions to MWCCS Study leadership and staff regarding directions, processes, burdens, and decisions for the study. In addition, NCAB carries out various initiatives to provide relevant news, information, updates back to study participants.

### NCAB Merger

Since the 2020 announcement of the eventual merger of the MACS and WIHS studies into the MACS-WIHS Combined Cohort Study (MWCCS), the two independent NCABs began discussion of how they should be merged.

During the merger planning period a joint NCAB leadership team of Marta Santiago, Marc Wagner, Queen Hatfield and Dan Fitzgerald was set up. One of the first activities was to create a Bylaws document which would govern the merged MWCCS NCAB—the Bylaws were formerly approved by both the WIHS NCAB and the MACS NCAB. The task force met regularly through October 2021. The NCABs announced their merger would be on September 20, 2021, and the first official meeting of the new NCAB would be November 11, 2021 where the first MWCCS NCAB leadership team would be elected following the process in the bylaws.

### NCAB Representatives

NCAB representative must be active participants of the MWCCS study and are elected or appointed by each individual MWCCS study site to represent them.

### NCAB Member Selection

Each local MWCCS site selects up to two study participants to represent the site and serve on the NCAB. Both HIV positive and negative status individuals, and representation of all age groups are included in the study.

Generally, participants selected are members of the local site's CAB, but this is up to each individual site. There are a total of 13 sites (with some additional subsites).

There is no defined term for NCAB members—this is managed by the local CAB or Site Project Director (PD).

### NCAB Member Expectations

The general expectations for NCAB members are summarized below.

- Attend NCAB meetings. Try to be on time for all meetings and be able to focus on the meeting
- Practice good meeting attendance.
- Represent your local site's interests, reporting on site news and bringing back to the site CAB any important updates or messaging from the NCAB
- Actively participate in meeting discussions and votes
- Participate in NCAB committees as needed: Science & Research, and Communications
- Join and participate in an MWCCS Working Group. For descriptions of the working groups: <https://statepi.jhsph.edu/mwccs/working-groups/>
- Be kind, patient and courteous to your fellow NCAB members
- Refrain from using profanity
- Use the Raise Hand icon to indicate your wish to speak. Mute your microphone if you not speaking

The time commitment for an NCAB member can vary, depending on your level of participation and involvement. Generally, you can expect 1 to 2 hours a month of activity for a regular member.

### NCAB Governance

The NCAB primarily governs itself. A formal bylaws document was approved in 2021 which documented governance and policy. In addition to the Bylaws, the NCAB has indirect oversight from the MWCCS Executive and Steering Committees. These committees are discussed later in this document.

### NCAB Bylaws

Following the formal merger of the MACS & WIHS studies in 2021 the NCAB Bylaws were ratified by the NCABs of both the MACS and WIHS projects at a joint meeting of the NCABs on February 10, 2021. The Bylaws were originally drafted by a MACS NCAB Subcommittee with input from both studies. The purpose of the bylaws is to document the general governance model and procedures associated with the organization.

There is a documented bylaws amendment process at the end of the Bylaws which stipulates the proper way the document can be changed. This includes a notification to members process that must be carried out in advance of the actual meeting. Bylaws changes require 2/3 of the members present at the meeting. This is a higher threshold of amendment approval than typical NCAB business approvals due to the significance of making a change to this governing document. Changes should be well thought out and ensure the members of the NCAB are aware of any proposed changes vote.

The NCAB Bylaws can be accessed on the NCAB website.

### Code of Civility

In September 2021, the NCAB adopted a Code of Civility. It contains ten items that should guide us in our formal and informal interactions amongst the NCAB members. They are:

- 1) We are all here working towards a common goal.
- 2) We greet and acknowledge each other.
- 3) We treat each other equally and with respect.
- 4) We acknowledge the impact of our behavior on others.
- 5) We welcome feedback from each other.
- 6) We are approachable.
- 7) We are direct, sensitive, and honest.
- 8) We acknowledge the contributions of others by praising them publicly and coaching privately.
- 9) We respect each other's time commitment.
- 10) We address incivility – at the moment it occurs.

### Confidentiality

Serving on the NCAB, all members should be aware of confidentiality concerns with the names of individuals and other sensitive information.

### NCAB Leadership

The NCAB Bylaws define three leadership roles for the organization: Chair, Co-Chair and Secretary. This sheet defines and provides elaboration of the roles.

#### NCAB Chair & Co-Chair Selection & Term

Per the Bylaws, the Chair and Co-Chair are selected annually for a two-year term by a majority vote of the members. To achieve gender equity, the NCAB Bylaws dictate a woman, and a man should alternately hold the roles of Chair and Co-Chair and be from two different sites.

To achieve this equity, every year, the Co-Chair will automatically be promoted to the Chair position. The replacement Co-Chair will be newly elected, following the Bylaws provision to ensure there is a woman and a man holding these two positions. While technically each position is for a one-year term, the member elected to the Co-Chair role accepts a two-year leadership commitment—Co-Chair for a year and then elevation to the Chair term for a second year.

#### Chair Role

The Chair is the chief managing position for the organization and is responsible for providing leadership and oversight to the NCAB. The expectations for the Chair role extend beyond simply NCAB meeting administration and management but also include several important liaison roles.

As Chair, he or she is serves as a liaison with MWCCS Study Leadership and the MWCCS Steering Committee (SC). The SC expects the Chair to maintain regular contact with the SC by attending SC meetings which are held bi-weekly on Fridays at 9:30 am Eastern.

The purpose of the MWCCS Steering Committee (SC) is to discuss operational and scientific issues to be brought to the Executive Committee (EC) for consideration and to set the agenda for the CCS meetings. The group serves as an intermediary between the NIH representatives and CCS EC.

It is recognized that attendance at every SC meeting may not be possible, but the NCAB Bylaws dictate the chair attend at least 75% of the meetings and when not able to attend, assign a consistent designate to attend in her/his place. It is important we do not have a revolving door of NCAB representation on the SC so effective relationships can be established and maintained.

The Chair also may attend, in addition to the Co-Chair, the MWCC Executive Committee (EC). The Executive Committee (EC) governs the MWCCS leadership. The committee includes investigators from the MWCCS clinical sites and the MWCCS Data Analysis and Coordination Center (DACC), representatives from each of the NIH sponsoring agencies, and the NCAB. EC meetings are scheduled on the 1<sup>st</sup> and 3<sup>rd</sup> Tuesdays of the month at 9:30 am Eastern.

The chair also should maintain regular communications with SC Leadership and be comfortable raising specific concerns of the NCAB when necessary.

The Chair is expected to lead all meetings of the NCAB:

- Setting the regular meeting schedule for the NCAB
- Serve as primary author of the NCAB meeting agenda, with the assistance from the Co-Chair and Secretary. The joint meeting agenda creation process is intended to share the burden of this activity among all three leaders and serve as a cross-training opportunity for the Co-Chair and Secretary.
- Actively chair all NCAB meetings following the spirit of Roberts Rules of Order to achieve an orderly, civil, and productive meetings for all representatives.
- The Chair should drive meeting topics to keep discussions relevant to the topic, and so they do not get out of hand and begin to be redundant.
- Ensuring of the properly recording of any official NCAB vote is also expected to be the responsibility of the Chair
- The Chair is also expected to break any tie for official votes of the NCAB
- Address any member's attendance issue by raising it to the member and if necessary, to the member's Project Director
- Understand the NCAB organization structures and descriptions as described in the NCAB Bylaws. Be prepared to address Bylaws issues and what it takes to amend the Bylaws

The Chair should resist the urge to fill in for other members who are assigned tasks.

Helpful skillsets for the Chair include:

- Meeting leadership and management experience
- Good communications and listening skills
- Organization skills
- Understanding of the NCAB Bylaws
- Familiarity with Roberts Rules of Order

The time commitment for the NCAB Chair can vary, depending on your level of participation in meetings and other activities. Generally, you can expect 6 to 10 hours a month of activity.

### Co-Chair Role

The Co-Chair serves as the backup for the Chair and performs the Chair duties in the absence of the Chair.

The Co-Chair has another very important expectation; to learn what it takes to be Chair so after the Co-Chair term ends, the Co-Chair knows the Chair role and should feel comfortable ascending to the Chair.

It can't be overstated the importance of the Co-Chair's one year term of learning and preparation. There are a lot of expectations and knowledge required for the Chair role and the Co-Chair should proactively utilize his term to assist the Chair and become comfortable with the Chair duties.

One way to accomplish this preparation is for the Co-Chair to actively participate with the other NCAB Leaders to prepare meeting agendas. While this may seem to be a simple task, this is an opportunity to participate, ask questions and make substantive contributions.

Another way to assist the Chair could be sharing actual NCAB meeting management. Perhaps working with the Chair to take over management of the motions made in the meeting to ensure discussion is focused, redundant discussion is controlled, and proper votes are taken and recorded. This will allow the Chair to focus on the merits of the discussions and mentally prepare for the next agenda item.

The Co-Chair typically represents the NCAB at the MWCCS Executive Committee (EC) meetings. EC meetings are scheduled on the 1<sup>st</sup> and 3<sup>rd</sup> Tuesdays of the month at 9:30 am Eastern.

There are no other formal responsibilities for the Co-Chair. The Co-chair should use her/his term to learn the Chair roles.

The time commitment for the NCAB Co-Chair can vary, but you should be prepared to spend 5 to 8 hours a month of activity

### Secretary Role

The Secretary role is like typical secretary roles in other organizations, but for the NCAB, the Bylaws split the duties in two different groups: General Secretary and Recording Secretary. In the NCAB today these are all performed by the single Secretary role but have been organized into groups to facilitate a potentially split into two roles, if desired.

The General Secretary duties

- Work with Leadership to confirm meeting schedules and develop meeting agendas
- Advise leadership of potential or proposed changes to the Bylaws

The Recording Secretary duties are more administrative in nature and include:

- Support the chair with Zoom meeting scheduling and management
- Support the chair with meeting agenda package creation and distribution
- Taking and distributing meeting minutes
- Support Chair in maintaining the roster and maintain meeting attendance records
- Notify NCAB Leadership if member attendance concerns arise (e.g., excessive absences)

- As roster changes are made, use the DACC’s NCAB Support Request Process to keep the DACC up to date on who is on the NCAB; they may also maintain a distribution list
- Load (or confirm with Chair) appropriate documentation is loaded to Georgetown Box folder “NCAB Documents” or the appropriate subfolder
  - Meeting Agendas, Minutes, Meeting Attachments
  - Bylaws Revisions
  - Roster
  - NCAB Opinions
  - Presentations
  - Any significant correspondence received or sent

The Secretary typically represents the NCAB at the MWCCS Project Directors Working Group (PDWG) meetings. PDWG meetings are scheduled on the 2<sup>nd</sup> Wednesdays of the month at 1:30 pm Eastern.

Like the other two leadership roles, the selection of the Secretary is made annually by majority vote of the members and the term is one year.

Helpful skillsets for the Secretary include:

- Meeting minutes documentation
- Good listening skills
- Organization skills
- Understanding of the NCAB Bylaws

Annually, the NCAB elects its own leadership: Chair, Co-Chair and Secretary from the body of the NCAB. There is a separate NCAB Quick Reference Cards that describes these roles’ responsibilities and expectations.

#### Proposed Leadership Activities & Schedule

Event / Milestone	When expected	Initiated by
Bi-monthly NCAB Meeting Zoom Invites sent out for rest of the regular meetings	By Feb 1 of each year	Chair
Leadership Zoom Call <ul style="list-style-type: none"> <li>• Review and approve upcoming NCAB meeting agenda as proposed by Chair</li> <li>• Discuss what handouts should be sent out with the meeting agenda</li> <li>• Review and update previous meeting minutes and confirm ready for distribution</li> <li>• Discuss any NCAB issues or problems and responsibility or actions needed</li> <li>• Review any significant interactions with SC, EC or PDWG</li> </ul>	3 weeks prior to NCAB Meeting	Chair
NCAB Meeting Agenda & handouts distributed	1 week before NCAB Meeting	Chair
Regular NCAB Meeting	3 <sup>rd</sup> Monday of Month (of meeting)	Chair
NCAB Meeting Minutes Drafted and sent to Leadership	3 weeks after an NCAB Meeting	Secretary

## MWCCS NCAB Leadership History

Year	Role	Leader
2022	Chair	Marc Wagner (Pitt)
	Co-Chair	Alicia Diggs (UNC)
	Secretary	Dan Fitzgerald (Chicago NU)
2023	Chair	Alicia Diggs (UNC)
	Co-Chair	Tony Billups (UAB)
	Secretary	Marta Santiago (Chicago Cook County)
2024	Chair	Dan Fitzgerald (Chicago NU)
	Co-Chair	Queen Hatfield (UAB-Jackson)
	Secretary	Lanell White-Brown (Atlanta)

## NCAB Meetings

In this section the various types of meetings conducted by the NCAB are presented.

### Regular Meetings

The NCAB generally conducts regular Zoom meetings bimonthly on a weekday evening (currently, the third Monday at 7 pm eastern time). We understand due to time differences, this can be early for West Coast representatives. Considering Semi Annual EC meetings and holidays, the meeting dates may need to be adjusted annually. Typically, the NCAB meets in the following months:

January  
March  
May – EC Semi Annual Meeting  
July  
September  
October – EC Semi Annual Meeting  
November – Elections Meeting

Meetings are normally 60 to 90 minutes long and are generally conducted following the spirit of Roberts Rules of Order.

### Semi Annual EC Meetings

Twice a year, the NCAB holds an in-person meeting in conjunction with the MWCCS Study Executive Committee (EC) Science meetings. The NCAB generally meets on the first day of the three-day gathering and conducts a regular business meeting in the morning of that first day. The NCAB organizes scientific or specialty topic presentations for the afternoon session. The NCAB polls its members of topics of interest and someone on the NCAB uses the MWCCS network of individuals to identify and schedule appropriate speakers on the topics.

The second and third days of the EC meeting contain Study Reports, update sessions of MWCCS Working Group science progress, committee reports, etc. The NCAB members are encouraged to attend.

Travel expenses to the in-person meetings twice a year are usually paid by the local site. Members should verify this with their individual PD before incurring any expense.

### NCAB Leadership Election Meeting

Annually NCAB Leadership elections should take place. Recently, they have been at the November meeting with the terms beginning in January. The election should be done by secret ballot and Zoom Polls have been used for this purpose.

### NCAB Meeting Attendance

Attendance at NCAB meetings is recorded and maintained. From time to time, site Project Directors have requested their representatives' attendance record to monitor their commitment serving on the NCAB.

### NCAB Meeting Minutes

Meeting minutes are important to document the business conducted at the meeting. They are helpful for those missing the meeting to learn what happened in their absence.

Meeting attendance should also be properly recorded in the minutes.

Most meetings are also recorded (using Zoom recording features) and used to help create the meeting minutes. These recordings are also stored on the Georgetown Box.

### NCAB Standing Committees

There are two standing Committees of the NCAB.

#### NCAB Science & Research Committee (Concept Sheet Review)

This committee is focused on supporting the relevant science & research related objectives stated in the NCAB mission. This committee is often referred to as the Concept Sheet Review Committee, as that is the main activity of the group.

Concept sheets are drafted by potential researchers who are requesting study support (material, new procedure, new study component, etc.). These concept sheets are standardized and managed by the DACC using AirTable. Some concept sheets are proposing some action that may have an impact to participants—this is referred to as participant burden. If a new concept sheet has the “Participant Burdon” box checked, it is automatically forwarded to the NCAB. The workings of the committee are summarized below.

- Currently, NCAB EC liaison Andres Vasquez Ortiz (Miami) receives email notification of a new Concept Sheet available for NCAB review
- Andres emails committee members with the new concept sheet attached and requests they download the sheet, document their comments in the excel spreadsheet provided, save comments and reattach it to the email and resend it to Andres.
- Once the committee's comments are collected, Andres completes a form on the AirTable system to formally submit the NCAB opinion and comments.

## NCAB Communications Committee

This committee is focused on the identification, design, development, and distribution of NCAB messaging to participants, including but not limited to, creation of a national newsletter and a NCAB participant website.

### *Newsletter*

It was the intention of this committee to create a national NCAB newsletter that could be sent to all MWCCS participants highlighting news and updates on a regular basis (perhaps annually). We learned that there is no easy distribution at the national level; participant names and contact information is maintained at each independent site. As a result, any NCAB newsletter would need to be mailed (or emailed) from each individual project site at their expense and timing. For most sites they need to agree to do this and likely would require their site's IRB review and approval which made it difficult to publish a newsletter with dated information.

A couple of newsletters were created, but the distribution challenges noted above, as well as the lack of individuals to write the newsletter, the national NCAB newsletter was abandoned. The newsletters that were created (2021-2022) are located on the NCAB Website.

In 2023, we started using the NCAB website to also collect and provide access to individual site newsletters. Many individual project sites create their own newsletters, but only one site has contributed their newsletter. The NCAB members could be used to advocate for the submission of their site newsletters to the NCAB website.

### *The NCAB Website*

The NCAB website serves as a reference site for both the NCAB and the public. It is maintained by the DACC and is a subpage of the overall MWCCS website. As a repository, it holds:

- NCAB Announcements
- Newsletters
- Study Visit Updates
- NCAB Organizational Documents (including the Bylaws)
- NCAB Scientific Presentations created for sponsored by the NCAB
- Member Perspectives – documents about our participants and participation

The website was created by Dan Fitzgerald in 2021 and is still being updated by him. Specific changes to the website are submitted to the DACC for update using the DACC Support Requests process which is explained later in this handbook.

## NCAB Initiatives

The NCAB has undertaken several initiatives in support of overall study goals. These include the maintenance of the NCAB Handbook, and some policy decisions affecting the NCAB.

### *The NCAB Handbook*

The NCAB Handbook (this document) contains explanations of what the NCAB does, how it works, as well as our interactions and involvement with the MWCCS study leadership.

It had become apparent that over the years the institutional knowledge of NCAB organization, operations, past decisions, and leadership was not being well-passed on to new NCAB members. As a result, many members felt they did not understand the NCAB, or some felt unprepared to accept leadership roles in the organization.

The NCAB Handbook (this document) was created by Dan Fitzgerald in 2023 to serve as a reference guide for current and future NCAB members and share NCAB history and accomplishments.

#### External Conference Sponsorship for NCAB Members

While there is great appreciation for MWCCS project site support for sponsoring NCAB members to attend the semi-annual EC meetings, there has been increasing interest by the NCAB to extend this support to relevant external conferences and meetings. Some feel that the cohort is siloed amongst the HIV/AIDS health care community and having NCAB members representing MWCCS at external meetings may be a way to raise visibility of the study and potentially support new participant recruitment.

On June 2, 2023, NCAB Chair Alicia Diggs raised the request at the MWCCS SC meeting. She reported that the request was viewed favorably, but the ultimate decision maker for each specific request is the NCAB member's own site Project Director (PD). Some sites may already sponsor such meetings.

On June 20, Alica documented in a letter to the SC outlining the general proposal in more detail. An NCAB ad hoc committee convened and developed suggestions on how the program would work. These include:

- Active NCAB members should be able to attend 2 external conferences/meetings per fiscal year. Only 2 NCAB members should attend the same conference/meeting
- A travel cap per NCAB attendee be set between \$3,500 and \$5,000 per event which would include conference registration, travel, lodging, meals and local transportation
- Federal per diem rates based on the location of the conference would be in effect and paid in advance at the time of travel
- The NCAB member can present an abstract at a conference allowable by MWCCS. This would allow us to showcase that the MWCCS is all about at a glance.

To show transparency of how attending a conference benefits our attendees and the MWCCS, some responsibilities of the NCAB representative who attends an external conference/meeting upon their return have been suggested:

- Submit a summary of the conference in writing to their site, including workshops attended, speakers, content and takeaways from each session attended
- Share a summary of the external conference/meeting at an NCAB and local CAB meeting

The goal is not to limit the specific conferences/meetings a member could attend, but some suggested options could include:

- International AIDS Conference (when it is in the United States)
- Positive Living
- US Conference on HIV/AIDS
- Biomedical HIV Prevention Summit

The ultimate decision maker for approving NCAB members' external conference/meeting sponsorship requests is with each member's study site. Any NCAB members interested should contact her/his Project Director (PD) with a request and proposal.

## NCAB Advocacy

The NCAB has undertaken several issues/topics and has supported/performed advocacy on topics important to study participants. These include:

### MWCCS Autopsy Program

#### *Background*

In 2023, the NCAB became aware that an MWCCS Autopsy research program did not seem to be supported any longer, despite no formal announcement. Both the MACS and WIHS studies had autopsy research programs at some point in the past.

In November 2023, Marc Wagner (Pittsburgh) commented that the MWCCS Autopsy program was no longer being funded. Many members of the NCAB are interested in this program. The last mens autopsy was about six years ago. Samples are stored for all sites at the Pittsburgh site, and they would like to get these transferred to a national site. Pittsburgh holds paraffin embedded tissues as well as the frozen tissues.

The original PI Dr. Charles Renaldo at the Pitt site was the person responsible for the MACS autopsy program. Pittsburgh is maintaining the liquid nitrogen in the repository container. Changing responsibilities have resulted in Dr. Renaldo no longer wanting responsibility for the current samples. There is no funding for the expensive maintenance of them. Per Marc, in summary the challenges of the program include the funding, resources support and the collection of samples timely after a participant's death (before sample degradation occurs) and an organized procedure for dissemination of samples if requested for an approved research effort.

Today, any researcher could request samples via an approved concept sheet, but this is a challenge with today's lack of funding.

Marc was unsure of the status of the women's program.

#### *Current Status*

The NCAB did communicate our support of reinstating the program to the EC/SC. NCAB Chair Alicia Diggs shared a letter with the SC/EC dated November 1, 2023, explaining the NCAB's interest in the autopsy program. It is unclear their level of support or next steps.

Funding and the responsibility for the program is in question. It was suggested we bring NIH persons on a call to express the importance to us of this program and our interest to reinstate the autopsy program.

Alicia was fine with an NCAB subcommittee writing another letter to the SC to get this back on the table with a formal written request. Marc, Bob, Jeannette, and Michelle expressed interest in working on this effort.

### NCAB Member Compensation

Unlike other members of the MWCCS study team, most NCAB members contribute their time and talents without any formal or consistent compensation.

A 2023 poll of the NCAB members indicated some sites (a minority of sites) compensate their NCAB representatives for attending NCAB meetings, as much as \$60 per meeting. The consensus of the NCAB was that the inequities of compensation from sites is unfair and there should be a study-wide and approved program of such compensation.

In addition, some NCAB leaders have expressed frustration with the amount of work required to perform leadership duties and attend many study conference calls and meetings. The NCAB has experienced push-back from its members and some reluctance to serve in leadership roles due to the amount of time required. For this reason, the NCAB suggests some type of compensation be considered for those members taking on specific leadership roles.

This topic has no resolution. It has been raised yet to study leadership. The NCAB is currently working on a compensation recommendation to the EC.

### Additional Support for the NCAB

Alicia reported to the EC on October 10, 2023 the responsibilities to manage the NCAB meetings and other administrative tasks, require a lot of time and effort for volunteers. She reported the findings of an NCAB ad hoc committee that looked at the topic of NCAB membership being overburdened and requested the consideration of additional support from MWCCS, including:

- NCAB Meeting Support
  - Zoom Administration - scheduling zoom Calls for NCAB regular and ad hoc meetings, and send out invites to members; note- zoom access was previously provided by EC to enable NCAB to do this without requesting
  - Attend NCAB meetings and take NCAB meeting minutes which can even be done via AI recording option and then publish the minutes to the NCAB in a time
- Financial Support
  - Consider providing stipends for the NCAB Leaders and representatives attending EC and PD meeting, and potentially other time-consuming roles
- Orientation Support
  - Help create orientation sheet explaining SC,EC,PD and how study hierarchy and roles work
- Communication Initiatives Support
  - Provide support to create a national NCAB Newsletter
  - Support with collection of newsletter content and to ensure site newsletters are uploaded to NCAB website
  - Spanish Language translation is also needed for website / newsletter articles

This topic has no resolution. It has not had any follow up to study leadership. The NCAB needs to decide how to proceed, if at all.

### Stigma Study Feedback

In April 2023, the NCAB was asked to provide feedback on the questionnaire associated with an approved study component on stigma. The stigma research component was to be performed at selected sites to male-identified participants.

One of the effort's Principal Investigators Mackey Friedman came to the NCAB for our opinions and suggestions on the questions being proposed as part of a participant survey on stigma. The NCAB was happy to participate and enthusiastic to provide their feedback. While the NCAB acknowledged the importance of researching stigma, it did find some of the survey questions unacceptable, awkward, confusing, or inappropriate.

In the feedback letter provided back to the Principal Investigator NCAB Chair Alicia Diggs commented:

After convening on Monday, April 17, 2023, we the NCAB members agree that the wording in the current stigma survey is entirely unacceptable. We feel the questions could do more harm than good. The questions listed are not only stigmatizing but generate trauma for many. There were responses from our NCAB members stating that the questions hurt their feelings, and some almost cried. It was even said by one of our members that the questions made them feel bad, not just about themselves but the fact that the questions were even being asked in this way and at all. Some were so taken aback that they said they could not even answer the questions. None of these questions applies to how we as an NCAB currently feel or see ourselves.

There should be questions that relate to us thriving instead of internalized or external stigma. These questions do not represent who we are as people thriving with HIV, and at this time, we cannot support the survey questions. We do suggest that your team work with members of the NCAB to recreate the current Stigma Survey so that the wording is not so stigmatizing, triggering, or harmful. Another suggestion would be to allow the participants to state how we are feeling. If this request is not acceptable, then we will have to decline completing this survey during our visits and would prefer the survey to be completely removed.

No additional actions were asked of the NCAB for this research.

### Climate Crisis and Possible Anxiety

Alica Diggs reported at the 10/18/23 EC meeting that the NCAB will do future collaboration with Marge Cohen on an upcoming project about climate crisis and possible anxiety because of climate crisis.

### Social Connections Study

Alica Diggs reported at the 10/18/23 EC meeting that there are several NCAB members who are participating on the Social Connections Study with Tracy Wilson as a Community Advisory Group who are providing input on the questions that will be asked once the project is complete.

## 3- MWCCS Study

### Overview

The MWCCS is a collaborative research effort that aims to understand and reduce the impact of chronic health conditions—including heart, lung, blood, and sleep (HLBS) disorders—that affect people living with HIV.

The study is designed to investigate a spectrum of questions relating to the basic science, clinical science, and epidemiology of HIV infection in the U.S., with a focus on comorbidities among men and women living with HIV.

Major areas of investigation include:

- Cardiovascular and pulmonary
- Neuropsychological
- Aging
- Cancer
- Psychosocial
- Health disparities

For decades, the National Institute of Allergy and Infectious Diseases (NIAID), part of the National Institutes of Health (NIH), has supported the separate MACS and WIHS cohort studies. MACS was a study of gay and bisexual men, while WIHS was a study of women who had risk factors for HIV.

In 2019, the National Heart Lung and Blood Institute (NHLBI) became the primary steward of the new MACS/WIHS Combined Cohort Study (MWCCS).

### Studies History

Since 1999 MACS and WIHS studies were merged into the MWCCS study. The study is carried out at 13 principal MACS/WIHS clinical research sites (CRS).

### MACS History

MACS stands for the Multicenter AIDS Cohort Study which began in 1983 as a research study of HIV in gay and bisexual men in the United States. At its highpoint, more than 7,300 study participants were enrolled and were evaluated twice a year in study visits. It's hard to think back to 1984, a time where gay men were becoming sick and dying from a mysterious illness nicknamed the "gay plague" or "gay cancer". We just didn't have the answers of what was happening so this historic study was started, and now over 35 years later, has provided a tremendous amount of research that has helped countless researchers and scientists get to the point where HIV was discovered, antiretroviral therapies were developed, and HIV is now treatable disease.

## WIHS History

The Women's Interagency HIV Study (WIHS) was organized in 1993 to study the progression of HIV disease but focused on women. Over 2,600 women were initially enrolled in WIHS and participated in research topics focusing on the impact of HIV on women's reproductive health, clinical outcomes (for example, cardiovascular disease, diabetes, and others), and the effectiveness of antiretroviral therapy. The WIHS research has made important contributions to medical knowledge and has led to a greater understanding of how HIV impacts the health of women.

## MWCCS Leadership Committees & Groups

The MWCCS study is managed by several leadership committees and other groups.

### MWCCS Steering Committee (SC)

The purpose of the MWCCS Steering Committee (SC) is to discuss operational and scientific issues to be brought to the Executive Committee (EC) for consideration and to set the agenda for the MWCCS meetings. The group serves as an intermediary between the NIH representatives and MWCCS EC.

This is a smaller group than the Executive Committee with currently 17 members. The NCAB Chair is a member of the SC and represents the NCAB.

2024 SC Co-Chairs: Mirjam-Collette Kempf (PI, UAB), Brad Aouizerat (PI, NYU)

The Co-Chairs have two-year terms, and the terms expire in alternate years.

The complete list of SC members can be found at this Airtable.

<https://airtable.com/appRssVqTxNurdU2E/shrLb5JNGLWCbcjNH/tblSWyzGgDq7nzRnY>

### MWCCS Executive Committee (EC)

The Executive Committee (EC) governs the MWCCS leadership. The committee includes investigators from the MWCCS clinical sites and the MWCCS Data Analysis and Coordination Center (DACC), representatives from each of the NIH sponsoring agencies, and the NCAB. The EC:

- Determines the overall MWCCS research agenda
- Guides Working Group research plans
- Prioritizes Concept Sheet proposals
- Evaluates and recommends the distribution of resources among the different components of the MWCCS
- Oversees the core protocol and quality assurance initiatives

The EC has the same Co-Chairs as the SC. It currently has 42 members.

The complete list of EC members can be found at this Airtable.

<https://airtable.com/appRssVqTxNurdU2E/shrH1Y9iRrUWN3HT2/tblSWyzGgDq7nzRnY>

### Project Directors Working Group (PDWG) Meetings

The Project Directors Working Group (PDWG) working meeting of Project Directors from all the study sites. The Project Director is responsible for the management of the study operations at her/his site and generally under the guidance of a site-specific Institutional Review Board (IRB). Study operational issues are discussed and scientific challenges facing the study site researchers and coordinators.

The Project Directors (PD) meetings are scheduled once a month (2<sup>nd</sup> Tuesday).

### Data Analysis and Coordination Center (DACC)

The DACC is responsible for all aspects of data collection, reporting, and statistical analysis for the MWCCS. The DACC also designs and maintains the study databases, and provides centralized data management, as well as data management training.

### Clinical Research Sites (CRS)

Study participants enrolled in the MWCCS complete the study interview, laboratory testing, and exams at Clinical Research Sites (CRS) located throughout the United States. There are currently 13 official sites, but with subsites, the NCAB recognizes 14 sites.

### Principal Investigators (PI)

The MWCCS Principal Investigators are the backbone of the scientific research being approved and carried out as part of the study. They are committed to rigorous research that is based on principles of scientific integrity conducted in an environment of mutual respect.

The investigators use a “Concept Sheet” as a primary vehicle to review and approve research efforts that may become part of the study. It serves as a detailed overview research proposal.

The NCAB Science and Research Committee is included in the concept sheet approval process. The committee reviews new concept sheets and potentially meets with investigators to understand the proposed effort and analyze the participant experience and burden associated with the proposal and provides feedback to the appropriate investigator or Working Group.

### MWCCS Working Groups

The study has several working groups to provide oversight and directional guidance for scientific and research categories.

The complete list and descriptions of the working Groups can be found at:

<https://statepi.jhsph.edu/mwccs/working-groups/>

NCAB members are encouraged to participate in at least one working group. Meeting schedules vary by group.

## For More Information- MWCCS

Much of the information provided in this sheet comes from the MWCCS website located at:

<https://statepi.jhsph.edu/mwccs/>

### MWCCS Acronyms

The MWCCS Guidelines for Investigators document is available on the [Work With Us page](#) on the public website and has a list of MWCCS acronyms.

Here is the direct link to the document: [https://statepi.jhsph.edu/mwccs/wp-content/uploads/2022/10/MWCCS\\_Guidelines-for-Investigators\\_Oct2122.pdf](https://statepi.jhsph.edu/mwccs/wp-content/uploads/2022/10/MWCCS_Guidelines-for-Investigators_Oct2122.pdf)

MWCCS also maintains a Google spreadsheet with a more extensive list of acronyms that can be found here: [https://docs.google.com/spreadsheets/d/1jonjAvjNahmN7xUa-JIAAko726wainnQeJaXEuLT\\_rU/edit?usp=sharing](https://docs.google.com/spreadsheets/d/1jonjAvjNahmN7xUa-JIAAko726wainnQeJaXEuLT_rU/edit?usp=sharing)

## 4- Other Information

### NCAB Email

Gmail is used for the official email account of the NCAB. The account was initially set up with the help of Todd Brown (and the DACC).

[mwccsncab19812021@gmail.com](mailto:mwccsncab19812021@gmail.com)

The current recovery phone and password on the account is set to the Chair.

### NCAB Zoom Account

The NCAB uses Zoom to set up and manage conference calls and meetings.

[mwccsncab19812021@gmail.com](mailto:mwccsncab19812021@gmail.com)

### Georgetown BOX

The Georgetown Box is the main repository for NCAB documents. It was established by Michael Plankey (NCAB EC Liaison) and he manages BOX access. The NCAB Leadership should have accounts for the BOX to upload and access appropriate documentation, including agendas, meeting minutes, zoom recordings, etc. The main BOX folder for accessing and uploading documents is “MWCCS NCAB Documents.

The subfolder “Agenda & Minutes” contains the location for documents pertinent to NCAB meetings. For easy retrieval, folders are organized by calendar year and each meeting has a dated sub folder that identifies the meeting using a consistent and standard file folder naming format: “YYYY-MM-DD – NCAB Meeting”. By keeping meeting documents named consistently, it is easy to find minutes for a specific meeting date.

### Access & Passwords

To maintain control and confidentiality, a separate list of NCAB accounts, including login credentials and passwords is maintained. This is maintained by the NCAB Chair and passed on to new NCAB leaders.

## DACC Support Requests

From time to time, the NCAB needs to request information or support from the MWCCS DACC. To facilitate the request process and ensure requests are not lost in someone's email, the DACC has created a standardized form for making requests to the DACC.

Submit a support request using the NCAB Support Request Form including the following information:

- Name
- Email address
- Description of the request
- Any necessary attachments (documents for the website, roster for Zoom call, etc.)

The request form can be accessed at:

<https://form.jotform.com/211244673548155>

## Document Approval & Updates

3/18/2024 – Handbook approved by the NCAB