

Fall 2020 SWOG RECRUITMENT & RETENTION CMTE (RRC) Meeting – Virtual

SUMMARY

Date: September 23, 2020

Time: 10 am – 12 pm CT

Attending: 128 attendees

Agenda:

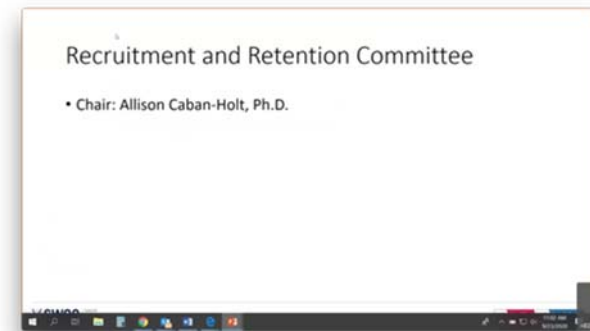
1. [Welcome and Introductions](#) (10 min.) – Allison Caban-Holt, PhD, Committee Chair
2. [Recruitment and Retention Committee](#) (15 min.) – Allison Caban-Holt, PhD
 - Year in review and future plans
3. [Minority Recruitment for NCORP Studies](#) (30 min.) – Colmar Figueroa-Moseley, PhD
4. [Reports](#) (5 min.) –
 - [Education](#) (5 min.) – Kamara Mertz-Rivera
 - [SWOG Accrual Update](#) – Allison Caban-Holt, PhD/Jennifer Maeser
 - Accrual during COVID (NCTN/NCORP)
 - Report of Studies available online: <https://www.swog.org/member-resources/report-studies>
5. [Committee Updates](#) (20 min.) –
 - a. [Digital Engagement](#) – Wendy Lawton
 - b. [Patient Advocates](#) – Desiree Walker
 - c. [NCTN Accrual Core Team](#) – Jennifer Maeser
6. [Cancer Briefs, Episode 2 – Diversity](#) (15 min.) – Jonathan Sommers/Erik Stone
 - Background
 - Preview of rough cut
7. [Adjourn and Next Meeting](#) (5 min.)

Next Monthly Meeting: October 22, 2020

Welcome and Introductions

0:01:20

Alison Caban-Holt introduced herself as chair of the RRC since the beginning of the year (all of COVID), having taken over the role when Elise Cook retired.



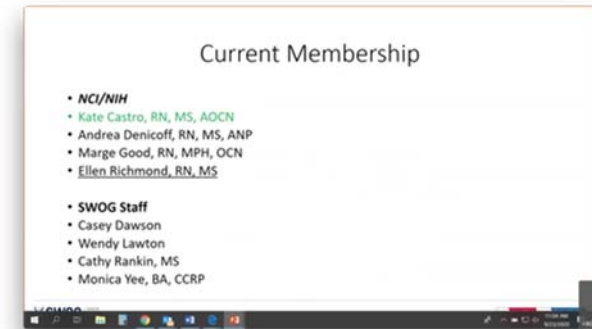
0:01:25

Caban-Holt thanked the cmte membership for being an excellent resource as group looks at recruitment and diversity in clinical trials.

- Highlighted new RRC members
-

0:02:45

Caban-Holt also welcomed colleagues from NCI and NIH and SWOG staff members who contribute to the committee.

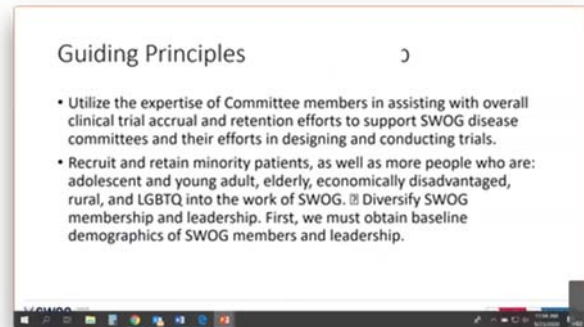


Recruitment and Retention Committee

0:03:00

Caban-Holt emphasized the need to keep coming back to guiding principles to remember group's purpose.

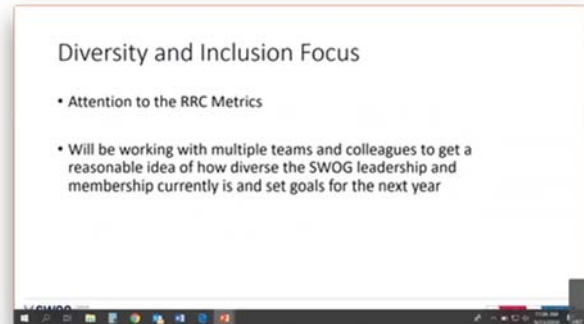
- Use expertise of cmte members to aid in trial recruitment and retention
- Also to recruit and retain minority patients and patients from other underrepresented groups
- Want to ensure pool of patients is as diverse as possible to do best science possible
- Related goal is to diversify SWOG membership and leadership
 - If SWOG is not diverse, less likely we can share perspectives and ideas to solve problems limiting recruitment and retention
- A primary goal now is to get better idea of baseline demographics:
 - Will let us understand where we are and where we need to go



0:04:41

Caban-Holt spoke of particular focus this year on diversity and inclusion in RRC.

- Want to return to recruitment and retention metrics RRC had assembled several years ago and assess progress
- Will collaborate with other teams to assess diversity of SWOG membership and leadership
- Probably have not been asking the questions we need to to provide idea of what our membership is
 - Will work with leadership in coming months to set goals for next year



0:05:57

Noted collaboration with other committees.

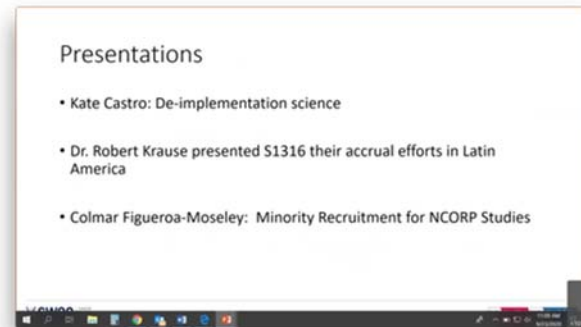
- Working with Digital Engagement Committee and Patient Advocate Committee on proposal to Hope Foundation on diversity and inclusion in SWOG
 - Want funding to train young investigators on inclusion and diversity
 - Values are invoked by leaders delivering messages to teams
- Also collaborating with patient advocates to contribute to Team Science Module 6 training guide
 - Advocate for diversity in patients we serve



0:07:47

Caban-Holt reviewed excellent presentations committee has seen this year.

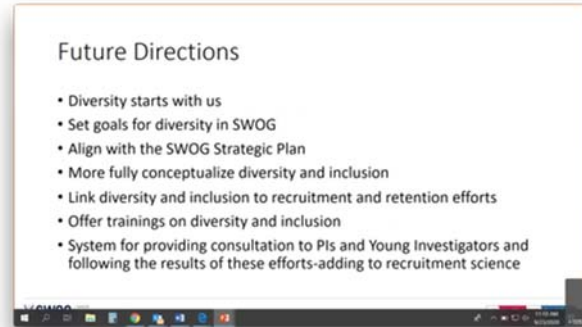
- Encouraged members to propose others for fall and spring meetings and for team meetings last Thursday of every month
- Kate Castro at April meeting did great presentation on -implementation science
- Robert Krouse at last meeting presented on S1316's accrual efforts in Latin America
 - Implementation efforts had to be changed to accommodate various Latin American countries and languages
- Presentation today from Colmar Figueroa-Moseley on minority recruitment in NCORP studies



0:09:19

Future directions: Caban-Holt noted diversity starts with members.

- We are leaders in these areas
- In coming months want to set goals for diversity within SWOG in line with SWOG Strategic Plan
- Wants team to more fully conceptualize what diversity and inclusion look like
 - Not only racial and ethnic diversity but extending it to other concepts
- Should be linking importance of diversity and inclusion to recruitment and retention efforts
- Training planned for next year on diversity and inclusion
- A major goal is to establish system for this team to provide consultation to PIs and young investigators
 - Do this informally now but do not have a system to evaluate impact
 - Important for publishing findings to contribute to science
 - Need feedback loop to understand what methods and strategies are working



Minority Recruitment for NCORP Studies

0:13:09

Caban-Holt introduced Figueroa-Moseley to present on minority recruitment for NCORP studies.

Figueroa-Moseley opened with request to learn more about meeting participants. Asked two questions in poll of members:

- 1) Who is participating in this workshop?
 - a. CR Nurses
 - b. Researchers
 - c. Patient Advocates
 - d. Site Managers/Administrators
 - e. Other

Figueroa-Moseley read out questions members had posted to Chat:

- Way to participate in poll via Chat?
- What group should CRAs select?
 - Probably choice D (or E)

Results of voting showed most participants selected “Other,” followed by “site managers” and “CR nurses.”

- 2) What SWOG sites are participants from?
 - a. Urban
 - b. Suburban
 - c. Rural

Casey Dawson noted a Chat question asking for clarification on SWOG sites.

- Figueroa-Moseley suggested primarily NCORP sites; asked Caban-Holt for input
- Caban-Holt suggested it should be all sites
- Also noted some members had checked several choices and others were not aligned with a particular site

**SWOG Group Meeting
Recruitment & Retention Committee (RRC)**
September 23, 2020
8-10 am PT, 10-12 pm CT, 11 – 1 pm ET

Agenda

- | | |
|---|--|
| 1. Welcome and Introductions (10 min.) | Allison Caban-Holt, PhD, Committee Chair |
| 2. Recruitment and Retention Committee (15 min.) <ul style="list-style-type: none">• Year in review and future plans | Allison Caban-Holt, PhD |
| 3. Minority Recruitment for NCORP Studies (30 min) | Colmar Figueroa-Moseley, PhD |
| 4. Reports (10 min.) <ul style="list-style-type: none">• Education (5 minutes)• SWOG Accrual Update<ul style="list-style-type: none">○ Accrual during COVID (NCTN/NCORP)○ Report of Studies available online:
https://www.swog.org/member-resources/report-studies | Kamara Mertz-Rivera
Allison Caban-Holt, PhD/Jennifer Maeser |
| 5. Committee Updates (20 min.) <ul style="list-style-type: none">○ Patient Enrollment○ Metrics & Studies | |

Voting results: most members were from urban areas, followed by rural and suburban areas.

- 30% did not answer, perhaps because they cover multiple site locations

0:23:00

Figueroa-Moseley introduced NIH-funded qualitative study on minority participation in CCOP research studies (NCORP studies were formerly CCOP).

MINORITY PARTICIPATION IN CCOP RESEARCH STUDIES

Colmar Figueroa-Moseley, Ph.D., M.P.H.
Cambridge Measurement Group

Supported by NCI grants U10CA037420 and U10CA037420-S1

0:24:30

Figueroa-Moseley reported study grew out of census research showing US undergoing demographic change.

- By 2045, US will be minority white



0:24:54

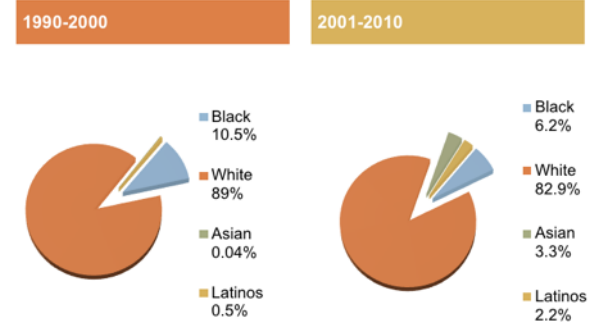
- These changes will affect how we do clinical research
- How will we acknowledge and implement plans to ensure research is relevant to all populations?
- Covid-19 has exposed many institutional vulnerabilities
 - Also opened up room for growth



0:25:20

- Graphs show minority participation in NIH phase 3 trials 1990–2000 and 2000–2010

National Cancer Institute
Phase 3 Cancer Clinical Trials
Enrollment by Race and Ethnicity



0:25:38

- Takeaway: participation of people of color in clinical trials remains low
- Noticeable decrease in 2000–2010 period compared to 1990–2000
- Although Black participation has decreased in phase 3 clinical trials, it increased noticeably in clinical prevention trials

Background

- Participation of minorities in clinical research and cancer clinical trials remains small
- Notable decrease in Blacks entering into clinical trials from 10.5% to 6.2% during the same period (Kwiatkowski et al., 2013)
- Black participation in clinical prevention trials increased (1990-2000: 5.5%; 2001-2010:11.6%)
- Although the Tuskegee Syphilis Study may be on the minds of many minorities, it does not fully explain minorities participation

0:26:08

Figueroa-Moseley studied barriers to participation and components that support greater recruitment and retention.

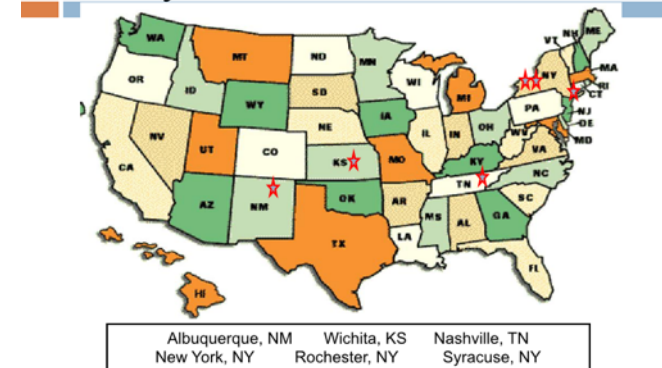
SPECIFIC AIMS

- Determine major environmental, cultural, and economic barriers to participation in clinical research trials for minority patients with cancer to Clinical Community Oncology Practice (CCOP) studies
 - Determine the components of an environment that supports greater recruitment and retention of minorities with cancer to Clinical Community Oncology Practice (CCOP) studies
-

0:26:26

- Study sites across the US
- CCOP sites chosen based on openness to being introspective and willingness to participate in pilot
- Sites included
 - Wichita NCORP
 - New Mexico MU-NCORP
 - Montefiore MU-NCORP
 - Baptist Memorial Health Mid-South MU-NCORP
 - U Rochester NCORP Research Base
 - Hematology Oncology Associates of CUNY

Study Sites



0:27:10

Demographics:

- Focus group participants mostly female
 - Mostly Black
 - Ages 29–78
- 18 providers participated
 - 5 doctors
 - 13 nurses

Demographics

Focus Group Participants	
Gender	88% Female
Ethnicity	43 Black Females 5 Black Males 16 Latino Females 2 Latino Males
Non-English Speakers	4 (Language: Spanish)
Age (range)	29-78
Providers	
Number of Providers	18 (5 doctors, 13 Nurses)

0:27:29

Eligibility

- Adults
- Minority status
- No current substance abuse
- Current or past cancer

Methods

□ Eligibility Criteria

- Adult (age > 17)
- Stage 1 or Stage 2 Cancer
- Minority Status
- No current substance abuse

0:27:54

Interviews

- 20-minute in-depth interviews of providers
 - Site recruitment
 - Retention practices
- Focus groups 90–120 minutes
 - Separated by ethnicity
 - Focused on beliefs re cancer and perceptions of medical research
 - Interpreters for Spanish-speaking participants

Methods

□ In-depth interviews (staff, providers)

- 20 minutes in length
- Questions pertinent to the site recruitment and retention practices

□ Focus Groups (cancer patients)

- 1.5-2 hours in length
- Current or former patients at stage 1 or 2
- \$25- 40 remuneration depending on area
- Focused on beliefs concerning their cancer and their perceptions of medical research
- Separated by ethnicity
- Interpreters were provided for Spanish speaking participants

0:28:24

Focus groups had 3 components:

- Introduction and warm-up
- Introductory questions
 - Health?
 - How long coming to particular hospital?
- Perceptions of medical research

Examples of Focus Group Topic Areas & Questions

Introductions and Warm-up

- Name, Birthplace, Favorite Food, and Cancer Story

Introductory Questions

- Tell me a little about your health. How long you have been coming to ____ (hospital)?

Perceptions of Medical Research Questions

- What comes to mind when I say medical research?
- What concerns do you have about participating in a study?
- How familiar are you with the Tuskegee Syphilis Study? Can you tell me what you know about it?
- If the researcher were the same ethnicity as you would you be more likely to participate in a study?
- What recommendations do you have for researchers to improve minority participation in research?

0:28:52

Questions for providers focused on

- Barriers to recommending trials
- Reasons for underrepresentation of people of color
- Site efforts to increase participation
- Lessons learned that would be useful to other groups

Questions for CCOP Providers

1. In your CCOP, What are the barriers that make you less likely to recommend a clinical trial to your minority cancer patients?
2. In your opinion, What are the reasons why minority patients are underrepresented in clinical trials?
3. What has your CCOP done to increase participation of minorities in clinical trials? Have your efforts increased minority accrual rates?
4. What are some "lessons learned" from your CCOP in regards to minority recruitment and retention to CCOP trials that would be helpful to other CCOPs?

0:29:16

Analysis

- Six focus groups analyzed from recordings of nearly 18 hours of audio
 - Used program Atlas.ti to guide coded analysis
 - Grounded theory used to guide analysis and link work to other studies
- Analyzed providers' verbal and written responses

Method of Analysis

- In-depth provider interviews
 - ▣ Verbal and written responses analyzed
- 6 focus groups
 - ▣ audio recorded
 - ▣ verbatim transcription
- Atlas.ti was used in all focus group analyses in guiding theme analyses
- Grounded Theory
- Triangulation with other qualitative and quantitative studies

0:29:50

Results

Results

0:29:52

Top themes among Black participants:



Top Themes Among Blacks

0:29:58

Issues surrounding Tuskegee:

- Highlighted beliefs summed up in quote in slide
- Tuskegee was one of top issues

TUSKEGEE (12 Quotes)



- A participant comment reflects a general belief among the Black community:

"I don't remember what group it was, this group of men that they did this research job ..., Tuskegee. ..., and see, when it comes to Black people that's where we go, you know."

0:30:27

Trust:

- Another issue topping the list for Black participants
- Compelling that one participant said what they look for in a doctor is not ethnicity but humanity:
 - “When I listen to him do I trust what he is saying to me?”
 - If no confidence in doctor, never comfortable

Trust (11 quotes)

“The reason I don’t like doing research is mostly because me personally, this is my personal opinion. I think they experiment on the poor and uninsured.”

“What I look at in a doctor is not his ethnicity. It’s humanity. When I listen to him, do I trust what he is saying to me? Do I have confidence in him? Because if I don’t, I am never comfortable.”

0:31:06

Medication concerns also major issues among Black participants:

- Mentioned Vioxx trial, which was later shown to increase risk of cardiovascular events such as stroke and heart attacks
- One participant leery of joining; after learning of Vioxx trial, happy they did not participate

Medication Concerns (8 Quotes)

“Because there is a certain amount of uncertainty..... You don’t know... they are doing research on you and you don’t know how it is going to affect you...My medical doctor he wanted me to participate in a trial I think it was for vioxin *sic* [vioxx], and I was reluctant to do it, and I am glad I didn’t because shortly after this whole thing came outvioxin *sic* [vioxx] causes all these problems. I said I am glad I didn’t do that. But you just never know.”

0:31:54

Concern over being seen as a guinea pig:

- Whether researcher was concerned about next research break or they truly had good intentions for people
- Many of these beliefs come from deep-seated knowledge of experimentation with Blacks that go beyond Tuskegee experiment

Guinea Pig (7 quotes)

"Are they doing the research to... for better of mankind or just doing it to be doing it to do a paper that is required while they are in school. Or are they doing it for negative reason. My concerns are for research ... These are the concerns I have...I am being used as a guinea pig."

0:32:29

Top themes among Hispanic/Latinos ...

Top Themes Among Hispanics/Latinos

0:32:38

... were language barriers:

- Problem with willingness of researchers to adapt and provide interpreters
- One participant identified need to adapt to language barrier and participant culture to get proper research and let them participate

Language Barriers (3 Quotes)

"Because sometimes we need to adapt to ... I'll say Spanish Latinos because that is what I am. That's where I came from. But you need to adapt to their language barriers and their culture in order to get proper research and to let them participate in places like this."

0:33:16

Insurance status another concern:

- Patients reported receiving bills from research studies
 - Not returning to study because of this
- One participant referred to poor people living in small towns; don't get medical care and when they get to sites they are beyond helping.
 - Could be financial barriers too
 - Patients not returning for tests

Insurance Status (2 Quotes)

"And I wonder also if it's economic in a sense that a lot of our poor people live in small towns and they don't get in to medical care and this is really bad. And then by the time they get there, they are beyond the point where they could be help. But they also... maybe there is financial barriers too you know they would say come back for test and they never come back for the test."

0:34:04

What do participants want most from research?

What Do All Participants Want Most From Researchers?

0:34:09

- More information and education about clinical trials process
- Arm themselves with knowledge they need to make appropriate decisions
- Everyone must be educated as much as possible
- Want to know what is going on before entering the hospital and after getting out

More Information & Education About Clinical Trials Process (10 Quotes)

"...and even though they do have insurance sometimes they don't pay for everything they still don't get educated very well. Everybody needs to be educated as much as they possibly can to know about the circumstances or anything they are going through...To give them information that would help. That would be most appreciative to not just us, you know, for everybody. So we can know what is going on before we go in to the hospital after we get out..."

0:35:06

Providers on barriers to recommending trials:

- History of no-shows
- Insurance status
- Cost of trials
- Patient fluency in English
- Comorbidities
- Current treatment regimens
- Issues around physician reimbursement
- Issues around physician-patient interpersonal process
 - How they got along with their patients

Provider Perspectives

18 providers interviewed

- Barriers to recommendations for clinical trials
 - History of 'no-shows' for clinic visits
 - Insurance status
 - Cost of conducting trials
 - English fluency (translational services expensive)
 - Co-morbidities
 - Current treatment regimen
 - Physician reimbursement
 - physician-patient Interpersonal Process.

0:37:17

Provider perspectives on reasons for minority underrepresentation: issues related to

- Trust
- Access to care
- Eligibility criteria too strict
- Type of insurance
 - Particularly if patient had Medicaid
- Participant's cultural and personal beliefs

Provider Perspectives

- Reasons for minority under-representation in clinical trials
 - Trust
 - Access
 - Eligibility too strict
 - Type of insurance (Medicaid)
 - Cultural and personal beliefs

0:37:43

Provider perspectives on efforts to increase minority participation:

- Most people don't ask
- Great need to get involved in communities in which they are providing care
- Necessary to build relationships
 - More than just presenting a research study
 - Must know what some of the major issues of concern in community are
 - Being able to connect them to services

Provider Perspectives

- Efforts to increase minority participation
 - "Ask"
 - Get involved in the community
 - Relationship Building

0:38:23

Issues affecting participation in research:

- Black participation
 - Tuskegee
 - Trust
 - Medication concerns
 - Being seen as guinea pig
- Hispanic/Latino participation
 - Language barriers
 - Insurance
- Majority of Latinos in focus groups unaware of Tuskegee syphilis study
 - But cited other studies targeting Latinos
 - Particularly Texas study involving Latino military personnel

Participation in Research

- Top concerns influencing Black participation in CCOP research studies:
 - Tuskegee
 - Trust
 - Medication Concerns
 - Guinea Pig
 - Issue affecting Hispanic/Latino participation:
 - Language Barriers
 - Insurance Status
 - Majority of Latinos that participated were unaware of Tuskegee Syphilis Study
-

0:39:24

Conclusions

- Black and Latino participation may be influenced by cultural, medical, and economic concerns
- Both groups wanted more information about the research
- Most Latino participants not aware of Tuskegee study
- Many provider's concerns about barriers echoed in focus groups
- Efforts to increase participation among providers were linked to infrastructure and relationship building

Conclusions

- Black and Latino participation in clinical research and trials may be influenced by cultural, medical, and economic concerns
- Both groups wanted more information concerning the research being conducted
- Majority of Latino participants were unaware of Tuskegee syphilis Study
- Many of the providers barrier concerns were echoed in focus group
- Efforts to increase participation among providers linked to infrastructure and relationship building

0:40:00

Limitations of pilot study

- A preliminary analysis to gather data
- Sites participating were self-selected; no randomization

Limitations

- Preliminary analysis to gather data about the problem of recruiting minorities
 - Self-selection bias of both providers and patients to study
-

0:40:30

Future directions:

- Consider examination of SWOG and NCORP system-related infrastructure issues that may affect recruitment and retention of participants of color
- Possible implementation of health communication and marketing pilots in NCORP studies
- SWOG RRC has begun to collaborate with SWOG patient advocates to include diverse populations

Future Directions

- Examination of SWOG and NCORP system-related infrastructure issues that affect recruitment and retention of minorities
- Implementation of Health Communication and Health Marketing pilot into NCORPs
- Collaborations with SWOG Patient Advocacy Committee that are inclusive of diverse communities

0:41:13

Acknowledgements

- Not possible without cancer patients
- Or team of NCORP sites as listed in slide
- Also thanked SWOG team behind the scenes
 - Jennifer Maeser
 - Whitney Leslie
 - Casey Dawson

Acknowledgements

- **Cancer Patients**
 - **Wichita NCORP** (formerly Wichita CCOP)
 - **New Mexico Minority Underserved NCORP** (formerly University of New Mexico MBCCOP)
 - **Montefiore Minority Underserved NCORP** (formerly Our Lady of Mercy-Former MBCCOP)
 - **Baptist Memorial Health Care/Mid South Minority Underserved NCORP** (formerly Meharry MBCCOP)
 - **University of Rochester NCORP Research Base** (formerly URCC CCOP Research Base)
 - **Hematology-Oncology Associates of CNY** (former CCOP)
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0:41:59

Questions and comments

Bernard Parker from NIH/NCI:

- Commended Figueroa-Moseley on very informative pilot study presentation
- Asked if pilot study included questions about champions among physicians involved with studies
 - 1) One element encouraged is to have physician champions in service area
 - 2) Having physician champions who look like patients encourages trust
- Figueroa-Moseley noted that in this 6-site study:
 - In the past, Marge Good was at Wichita NCORP; had community member participants who were champions
 - Wichita had high recruitment of minority participants to NCORP studies
 - Particularly Hispanics/Latinos
 - In pilot study all physicians were white
 - Nurses were of various ethnic backgrounds
 - Wished there had been physician champions who looked like participants but ...
 - Ethnicity of physician did not matter, but whether they could be trusted did matter and whether they could connect with participants did matter

Craig Nichols, SWOG executive officer, asked about type of research participants had been exposed to: local institution, pharma-sponsored, or federally sponsored?

- Figueroa-Moseley answered it was mostly NCORP/CCOP studies at the time
- But some had comorbidities, and primary care physicians may have referred them out to other studies too
- But did learn from certain pharma studies that sending patients from one state to another there may be limitations to how we can connect individuals to issues re participation or nonparticipation

Questions and Comments?



Thank You!

Caban-Holt referred to several questions posted in Chat:

- Will slides be available?
 - Yes
- Lucy Gansauer complimented presentation and endorsed having NCORP sites conduct focus groups to better understand views in their catchment areas
- Question from Ron Brand: Was socioeconomic status considered?
 - Was considered, but they wanted to capture everyone able to come, and stratification by socioeconomic status may have missed people
 - Reimbursement: Provided travel costs to and from study site for focus group
 - For some sites, went to community areas—e.g., to Gilda's Club—to conduct research there

Ron Brand followed up: Used to work in Henry Ford system in Detroit in public health science department:

- Socioeconomic status (SES) was bigger issue
- Would send low-income participants cabs to bring them to study site
 - Participants responded well to this
- Also paid participants
- Figueroa-Moseley replied that many factors could be looked at: SES, race, other factors
 - SES may have been major issue in Brand's area, but not necessarily the case in other areas
 - When people are treated well and know what study is for and what they stand to benefit, they will participate
 - In looking at these issues, need to be more open that beyond finances, patients getting better care will participate, helping improve care for all patients

Caban-Holt noted question from Wendy from Chat:

- Is takeaway that Black patients don't trust cancer system and Latinx patients can't access system because of language issues?
-

- Figueroa-Moseley agreed and cited two issues when approaching these communities: both trust and access
 - Noted African-Americans may have access issues in other parts of the country
 - These locations were willing to have them come and willing to be introspective
 - Survey of 30 CCOPs at NIH headquarters resulted in only 6 sites participating
 - NCORP/CCOPs must be introspective, do focus groups, identify their populations' needs and issues re participation or lack thereof

Caban-Holt spoke of work she is doing on trustworthiness.

- Are we trustworthy?
- What as researchers and professionals can we do to make ourselves as trustworthy as possible?

Commenter noted that we're asking people why *they* did not participate.

- Said we have not looked at our *own* internal barriers
- Meta-study found that >50% of time patients had not been offered a study
- If we do not have the right trials for them, we exclude many people
- Structural barriers as well put up by institutions that make it not possible for people to participate before we even ask them

Caban-Holt thanked this commenter

Craig Nichols asked whether problems of paternalism or lack of shared decision-making was an issue they found.

- Figueroa-Moseley said this did not come up
 - Institutional support and funding were issues among these providers. CCOPs may not have provided enough funding to do outreach
 - Important that instead of saying NCORP studies need to increase focus on minority populations, we as institutions must think about how to approach patients from different groups and be more inclusive
-

- Mayo Clinic issued \$500 million initiative to address disparities; more than just window dressing
- Excluding people may ultimately affect our bottom line
- Including more groups means we may do better medicine

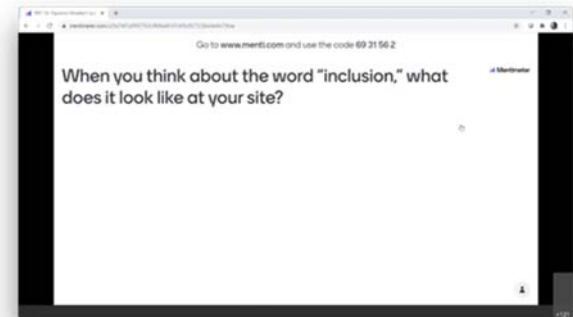
Caban-Holt thanked Figueroa-Moseley for presentation. Noted additional comments and questions in the Chat.

1:00:10

Figueroa-Moseley presented two final poll questions for participants.

1:00:33

Asked participants to respond to poll with at least three words they associate with word "inclusion."



(Word cloud of initial results in slide.)

When you think about the word "inclusion," what does it look like at your site?

(Word cloud of initial results in slide.)

When you think about the word "inclusion," what does it look like at your site?

Figueroa-Moseley noted that results indicated “inclusion” meant *(audio interruption)* followed by diversity ... all races included.

When you think about the word "inclusion," what does it look like at your site?

1:03:04

Go to www.menti.com and use the code 69 31 56 2

When you think about the word "inclusion," what does it look like at your site?



1:03:48

Figueroa-Moseley posted final poll question for participant responses, asking about future topics for RRC agenda.

Go to www.menti.com and use the code 69 31 56 2

What future topics would you like to see on the Recruitment and Retention meeting agenda?

 Mandiant

1:05:06

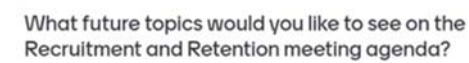
(Word cloud of initial results in slide.)

Go to www.menti.com and use the code 69 31 56 2

What future topics would you like to see on the Recruitment and Retention meeting agenda?

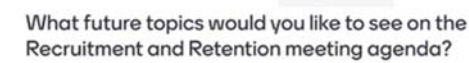


Figuerroa-Moseley thanked participants for their responses and returned the floor to Caban-Holt.

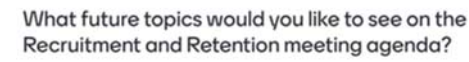


1:05:41

1:05:50
Caban-Holt thanked Figueroa-Moseley and participants.



Caban-Holt thanked Figueroa-Moseley and participants.



Reports

1:06:00

Caban-Holt introduced Kamara Mertz-Rivera for update on Education.

Education

1:06:15

Mertz-Rivera said she had no major updates, but ...

- Had in the past proposed providing rural education on how to best piggyback on telehealth to accelerate possibilities of reaching rural patients and consenting them remotely
 - Silver lining of COVID has been increased participation via telehealth and remote monitoring
 - Do have interest from those who can provide presentations on this
- At her site because of telehealth they were able to increase accrual of rural participants who otherwise wouldn't have been able to make it in to the site

1:08:00

Caban-Holt reminded participants of discussion of details of doing remote consent.

Mertz-Rivera agreed this would be great, as barriers have been noted.

- Perhaps shared practice and roundtabling on how we can use this to continue participation

Caban-Holt noted COVID has probably moved the thinking and problem-solving on this.

Accrual Update

1:08:53

Caban-Holt updated group on accrual.

- Attached to agenda is report on accrual.
 - Cathy Rankin could not be on call, but provided information and insights.
-

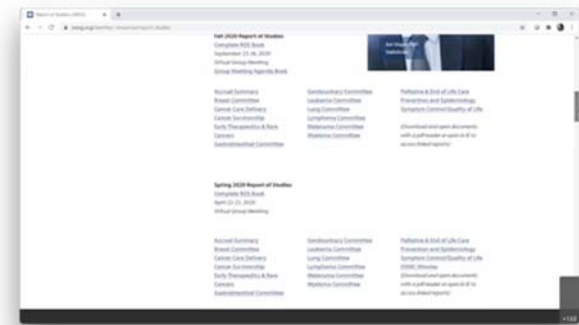
Caban-Holt asked Jennifer Maeser to share Cathy's update.

Maeser noted that Report of Studies was out and a PDF version of accrual chapter attached.

- End of August weekly accrual of ~62 per week.
- At about 75% of pre-COVID accrual, between NCTN and NCORP studies

1:10:25

- Most accrual is NCTN studies
- One theory for this is that high-accruing S1415CD closed in April
- S1417CD closed last year but was high-accruing



1:10:45

- NCTN close to pre-COVID accrual numbers
- NCORP is about 41% of pre-COVID numbers

Maeser encouraged participants to review accrual report.

1:11:05

Caban-Holt noted that in Report of Studies recruitment of diverse populations was lower in phase 1 and 2 trials than in phase 3 and 4 trials.

Committee Updates

1:11:50

Caban-Holt moved to committee updates.

- Introduced Wendy Lawton to provide update on Digital Engagement Committee

Digital Engagement Committee

1:12:00

Lawton introduced herself as staff liaison to Digital Engagement Committee (DEC).

- Later in session group will see update on one DEC project with Hope Foundation funding: Cancer Briefs
 - Using infotainment to raise awareness of interesting clinical trials
 - Creating 3 videos
 - DEC also last year took on task of reviewing all surveys conducted at SWOG; several reviewed this year
 - Big news is that chair Don Dizon has received Hope funding to engage digital health companies to create partnerships to test some of their tools in SWOG trials
 - One company is Doximity
 - Huge physician communication platform
 - Enrolls large number of physicians, particularly oncologists
 - Creating proposal to work with them
 - Work is farther along with company Oura
 - Oura Ring is wearable device to track sleep, body temperature, and activity levels
 - Created proposal to test ring in trial at SWOG
 - DEC will meet later today with Blue Note Therapeutics
 - Blue Note is testing digital behavioral health program with COVID patients
 - Interested in working with SWOG on mental health interventions with cancer patients and survivors
 - Today's session will also discuss mission of DEC
 - Committee has existed for around 4 years
-

- Has evolved in mission and goal
- Will revisit and ask what should relationship be?
 - Is vetting companies and making introductions to investigators in protocol-producing committees a good way the DEC can serve SWOG?
 - Potential for DEC to run its own studies?
- Big picture discussions for DEC kicking off today, continuing in coming months
- Many research support committee missions will be looked at under SWOG Strategic Plan, as they have evolved
 - E.g., Alison Caban-Holt will be working on this as well
- Craig Nichols (on this call) is SWOG's executive officer for research support committees
 - Ensuring these committees are empowered as much as possible to do best good for our trials as part of Strategic Plan
- Lots of fun, big-picture discussions in DEC right now

1:16:12

Caban-Holt introduced Desiree Walker to give patient advocate update.

Patient Advocates

1:16:20

- Walker acknowledged she was new to RRC and to Patient Advisory Committee
 - Spoke to two issues discussed recently at meetings
 - In preparation for group meeting, Dana Sparks talked to advocates to focus on post-COVID innovation task force
 - What lessons can be learned from COVID?
 - Patient Advocate Committee (PAC) will discuss today how to ensure changes are implemented so SWOG operates efficiently and effectively and is patient friendly
-

- Task force of 11 members chaired by Dr. Blanke
- Patient advocate Barbara Segarra-Vazquez is member of task force
- Also emphasized that Patient Advocate Committee addresses diversity and inclusion at SWOG
 - Important issues at SWOG regardless of committee
- PAC chair and vice chair Rick Bangs and Hildy Dillon have worked to have PAC think outside the box in terms of how advocates can help committees they serve on
- Many community advocates added to PAC before Walker's arrival, but more have been added since
 - Excited about this as these advocates address groups traditionally underrepresented, including military, young adults, older patients, Asian-Pacific Islanders, African-American voices

Lawton noted she had added to the Chat box a link to the agenda book:

https://www.swog.org/sites/default/files/docs/2020-09/AgendaBook_Fall2020_0.pdf

Book includes photos of all seven new advocates brought on to SWOG in 2020.

NCTN Accrual Core Team

1:21:25

Caban-Holt introduced Jennifer Maeser with the NCTN Accrual Core Team update.

Maeser noted team was also known as the ACT.

- ACT is group of people from cooperative groups and NCI members
- Have monthly calls for groups to present studies for input on accrual
- Recently had 2 SWOG studies reviewed: S1914 and S1823, latter Dr. Nichols' study

1:22:55

Maeser said in October SWOG would have opportunity to lead a 30-minute discussion session.

1:23:26

Nichols noted that he found participating as a PI in ACT calls very useful.

- Got tips about communicating trial broadly
- ACT also includes Canadian clinical trials group
- Highly recommended participating in this: should improve and accelerate trial accrual

1:24:25

Susan Rogers asked what study Nichols was discussing.

- S1823

1:24:57

Maeser returned with better audio.

- ACT call is opportunity to present trial and get input on accrual strategies
- Each group has time to present topic of choice
 - SWOG's slot is in October
 - Hope to discuss some of the post-COVID strategies Walker just discussed

1:26:10

Dawson passed control of software to Jonathan Sommers for his presentation.

Cancer Briefs: Episode 2 – Diversity

1:26:20

Sommers introduced himself.

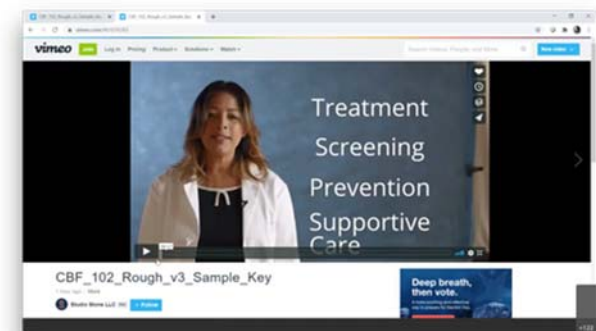
- Serves on SWOG's Digital Engagement, Patient Advocate, and AYA committees
- Noted Maeser has helped him with project called Cancer Briefs
 - Hope-funded project:
 - Can we use media and technology—or infotainment—to increase awareness of clinical trials?
- Sommers is writer and producer of digital entertainment and a cancer survivor
- Tries to use his experience with cancer to help others

Cancer Briefs

- Funded to make 3 episodes
- Each episode has different thematic element
- Episode 1: News show about creating awareness of NCTN clinical trials
- Episode 2: Cancer disparities: Can we increase awareness among these groups?
 - Will show rough cut to RRC
- Episode 3: Can we increase awareness of one particular trial: S1501?
 - Faux pharma commercial

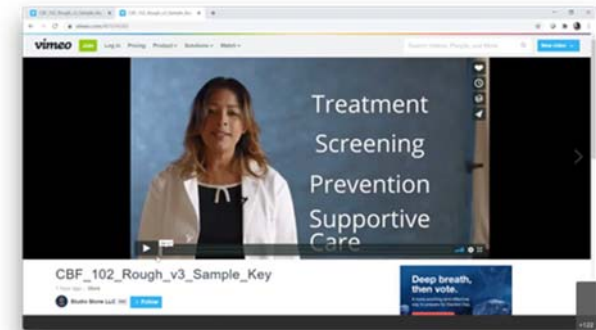
1:29:13

- Sommers noted his partner, Erik, had developed 103.7 fever on previous day and could not complete edit
- Instead will screen rough cut



1:29:33

Video display started but without audio.



1:30:08

Sommers apologized and shared Vimeo URL instead:

<https://vimeo.com/461016383>

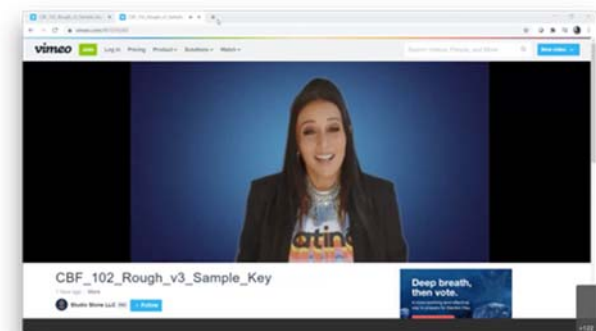
1:30:25

Sommers noted they are using various metrics to gauge their success.

- After video he will also discuss marketing of videos

1:32:25

- Campaign is targeting 50 million in US interested in cancer care and research
- Reached through Facebook, Instagram, and in-feed paid ads
- Will include multiple formats: mobile, desktop, video, static images, image carousels, stories
- Launching Thrive Cancer Network at TV4 Entertainment
- Videos also posted there
- Promoted through channels that already have large followings
- Looking for organic social campaign elements
 - E.g., SWOG or Hope Foundation tweets
- 3 episodes to be launched altogether

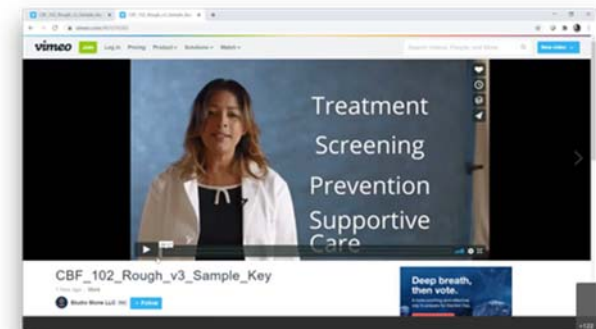


- Now is not the best time given COVID and the election
- Spending \$750 to \$1,000 for marketing on each episode
- Looking for audience of 3–5 million impressions
- Some KPIs:
 - Video views on Facebook and Instagram
 - Ad engagement: likes, shares, comments
 - Clicks from teaser videos in ads link to full videos
- Secondary KPIs:
 - Increased website traffic to Hope Foundation and SWOG site
 - Email signups through SWOG or Hope
 - All videos end with “For more info, go to swog.org,...” etc.
 - Donations to Hope Foundation
- Questions? Email Sommers: jonathan.sommers@gmail.com

1:35:48

Episode 2 video ran successfully with audio (~4 min, 20 sec):

- What do you think about cancer?
 - What’s the first thing that comes to mind?
 - Being bald and sick
 - Taking my grandmother to the hospital
 - Chemo
 - It’s why I became a doctor
 - Chemo hits you like a sledgehammer
 - [Doctor] Dad was cancer survivor until he wasn’t. Treating patient is opportunity to help someone like my Dad
-



1:36:33

- Cancer doesn't discriminate by age, race, ethnicity
- Affects people of color at alarming rate compared to white population
- Black men and women have highest rate of getting and dying from cancer
- Disparities not just in Black community
- Hispanics have highest rate of new diagnosis of cervical cancer
- Asian and Pacific Islanders have highest rates of stomach and liver cancer
- Black men twice as likely to die from prostate cancer as men from other races



1:37:10

- We can do something about it
- You can
- Cancer clinical trials
- NCI is publicly funded agency of NIH that conducts many types of cancer clinical trials
- Trials are how medical community improves treatment
- Lead to new medications
- Every major treatment for cancer was tested in a trial



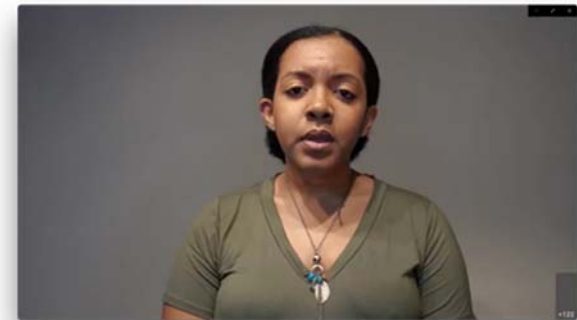
1:37:52

- NCI trials include trials for treatment, prevention, screening, and supportive care
- Close supervision and rigorous oversight to be as safe as possible
- Done with respect for patient
- Certain cancers affecting minority groups differently
- Need trials to research this
- People to take part in them
- Very few minority cancer patients take part in clinical trials
- Not being in trials means not being reflected in findings
- Need research and results that represent everybody
- Need trial enrollment as diverse as US population
- Find answers that speak to all of us



1:38:40

- In Black community, long-standing mistrust of medical system
- From 1932 to 1972, Public Health Service wrongfully conducted Tuskegee experiment
- Black men thought they were being treated for syphilis but received no treatment
- People were not respected and were seriously harmed
- From this awful experiment came many of the laws and regulations that now protect people in clinical trials
- Trials today follow strict protocols and ethical guidelines
- With protections to keep patients as safe as possible



1:39:20

- Especially trials by National Clinical Trials Network (NCTN) and run through government
- Need you
- If you or someone you know has cancer, ask doctor if there's an NCTN trial
- Go to cancer.gov to learn about all NCTN trials
- So you can help improve future cancer outcomes
- In Black, Hispanic, and Asian and Pacific Islander communities
- More info on how you can be part of the change at swog.org

End of video



1:40:07

Sommers said video included some celebrities, some average people.

- Aimed for diverse group
- All made remotely because of COVID
 - Starting filming with doctors before COVID
 - Now editing in same blue background for all clips
- Many on the RRC helped with this video

1:41:55

Marge Good, NCI DCP, liked video but noted NCTN focus was problematic because NCTN is primarily treatment, but video also refers to prevention, survivorship, and symptom management study, which are done primarily through NCORP.

- Recommended adding NCORP or switching to NCI instead of limiting to NCTN
- Sommers acknowledged

Sommers invited questions to be sent to his email address:

jonathan.sommers@gmail.com

1:43:55

Chat question from Peggy Zuckerman:

- Will there be way for individual patient watching to seek trial? How to capture this person and guide them properly?
- Sommers noted primary goal was to increase awareness of trials among underserved groups
 - Not in a position to direct to individual trials
 - Episode 3 focused on awareness of one trial: S1501

Caban-Holt suggested Zuckerman contact her or Maeser to discuss question.

Marge Good noted S1501 is an NCORP-funded trial.

Sommers said Episode 3 on S1501 is a “medicinema” episode making light of pharma commercials.

- Sommers said he would send script if someone wanted it
- Again thanked RRC members who helped
- Caban-Holt thanked Sommers.

Adjourn and Next Meeting

1:45:45

Caban-Holt said group had reached end of agenda for today.

- Next RRC meeting is October 22nd, Thursday

1:47:25

Caban-Holt adjourned meeting.
