Optimizing Reproductive Health and Preconception Wellness for Women with Chronic Conditions

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Acknowledgments

Tribal Partners
The Land
Our History
Our Institutions
Our Charge to Be Better
Our Funder

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Maternal Morbidity and Mortality

- Pregnancy related deaths are rising in the US (17 per 100,000 live births)
- Black and Native American women have rates 2-3 fold higher
- Many more complications that significantly impact, patients, families and communities
- 40-60% preventable

*Figure 1. Continuum of maternal morbidity, by severity. (Adapted from NYC Department of Health & Mental Hygiene. 2016. Severe Maternal Morbidity in NYC, 2008–12. New York, NY.)*
Chronic Conditions and Morbidity/Mortality

• Chronic Conditions → Higher Morbidity and Mortality
  – 43% US women of reproductive age have chronic disease
• Black and Native American → more chronic conditions
• Need to move upstream
  – Control conditions prior to pregnancy
  – Provide accurate information about pregnancy risk so patients can make informed choice
But it’s Not Just About Pregnancy

• Whether or not an individual with chronic conditions desires to conceive, managing their chronic condition and promoting their health and well being is a good in and of itself (Reproductive Justice Framework)
  – This will result in decreased maternal morbidity and mortality

**Health Justice** is when all people have the opportunity to attain their full health potential and no one is disadvantaged from achieving this potential because of their social position or other socially determined circumstance.

“When we talk about disparities we shouldn’t talk about people, but about policies. Black isn’t a risk factor, racism is.”

—DR. JOIA CREAR-PERRY OF NATIONAL BIRTH EQUITY COLLABORATIVE
Black and Native American women with chronic conditions are not receiving the care they need.

- Only 18-45% of women with chronic conditions receive preconception care
- Only 15% of ambulatory visits for women of reproductive age include preconception care

1 Steel, Lucke, & Adams, 2015.
Study Aims

**Increase understanding** about how Black and Native American women with chronic conditions think about their reproductive health decision-making and ways to optimize their health.

Identify patient-centered, patient-designed strategies to identify **testable and sustainable** preconception and reproductive health practices.

Set building blocks in place to **support future collaborative action** to drive the research roadmap forward.
34 “patient” participants who identified as female, Black and/or Native American and having one or more chronic conditions.

Women came from 18 counties in NC and one county in Ohio.

Chronic conditions included obesity, hypertension, diabetes, kidney disease, cancer history, sickle cell disease, fibroids, endometriosis, and PCOS.

13 researcher/clinician stakeholders with expertise in improving maternal health, chronic disease and/or health equity outcomes. All from North Carolina. Held varying identities and perspectives.
Methods

• Two-Session Focus Groups with Women
  • Session 1 focused on preconception health, reproductive health, and chronic condition care
  • Session 2 focused on strategies for improved care and ideas for research

• Two-Session Discussion groups with researchers, clinicians and public health leaders
  • Session 1 focused on care challenges and opportunities
  • Session 2 focused on strategies

• Final Convening – Women and Researchers/Clinicians came together to review findings and work together on adding detail to strategies.
Approach

• All focus groups and gatherings held virtually

• “Rolling focus groups” for patient participants to attend when available

• Smaller discussions and “walking to the parking lot” time

• Recorded research webinar

• Graphic notetaking

• Continuous feedback loops with community partners
Building Community

PCORI Study: Improving Care for Women

November is Native American Heritage Month
We hope you enjoy some of the resources we’ve shared below. Please let us know if you’d like to share anything in our next newsletter!

Research Update
We have finished our focus groups for this project. Thank you all for trusting us with your experiences and ideas! We are looking forward to coming together for one last time via zoom on November 9 from 5:30-8:30pm and November 13 from 10am-1pm (choose one date) to review what we have learned and work together to develop several new projects to improve health care for women with chronic conditions. The meeting will be interactive and patient stakeholders will be paid $50 an hour for their time. Marinda will be sending more information about the meeting by email this week including a detailed agenda so everyone knows what to expect.

Before our November meeting, please watch the video summarizing what we have learned. It’s about an hour long. If you are a patient stakeholder, after you’ve watched it, please let Marinda know (mpoore@live.unc.edu) as we can send you a $50 gift card as a thank you for your time.

Check out the image of Rio Holiday, a graphic recorder, created during the video! Click here for the video! Yen Azzaro, another graphic recorder, will join us for our November meetings.

Building Community + Facebook!

Community Connections
After the focus group session on “walk to the parking lot”, one group held a great conversation about creativity and art. That was when we discovered the work of some of the beautiful artists participating in our study. Click here to visit Hands and Love Artistry and Native and Elisa Designs. We also learned about an exciting new mentoring program, click here to learn more. If you have links to your work or art that you’d like to share, please email Marinda and we will put them in our next issue!

Meet the Team!
Melissa Silver Richardson is a citizen of the Haliwa-Saponi Tribe and lives in Macon, NC with her husband Marcy and daughter Michelle. She graduated from East Carolina University and works for UNC Health Care as an Applications System Analyst in the Information Services Division. She enjoys volunteering in her church, tribe, community, and society. She also enjoys sharing her culture through song at Powwows with the Stony Creek Singers, an internationally known Pow Wow singing group. Melissa is a community partner on our research team.

American Indian Heritage Celebration
The NC Museum of History is having their 26th annual American Indian Heritage Celebration online on Nov. 20. Please join! Other events listed here.

Resources for American Indian Heritage
Melissa shared this website from the NC Commission on Indian Affairs - they have some great resources.

Qua shared this Health Guide for American Indian Women created by the North Carolina American Indian Health Board. Please read and share!

Correlation of Indian Affairs
The UNC American Indian Center
Consider clicking on this page for events hosted by the UNC American Indian Center in November.
CHALLENGES & OPPORTUNITIES
YOUR JOURNEY

**Self Reliance**
- Changing and finding doctors
- Self advocacy

**Racism and Provider Bias**
- Ageism
- Weight discrimination
- Blame
- Shame

**Don't Feel Seen or Heard**
- Pain and suffering is discredited
- Don't feel that health problems are taken seriously

**Trust**
- Primary care
- Specialty care
- Trust

**Stressful**
- Have to work hard to get what they need
- Hard to take care of self when stressed

**Care Is Caring**
- Importance of provider listening

**Lack of Emphasis on Prevention**
- Preventing stress, mental health

**Physiological Connections**
- Between stress and health

**History of Miscarriage, Loss, Infertility**
- Preventing stress, mental health

**Culturally Competent**
- Need knowledgeable person and centralized navigation

**Contextual Factors that Impact Weight**
- Eating
- Hormonal changes
- How manage medical conditions

**Contextual Factors**
- Accessible
- Balanced
- Levels

**Data**
- Providers did not respect that they knew their own bodies
- Have to broker own care

**Whole Person Perspective, But Aren't Getting It**
- Don't have one

**Strength**
- Sister circles
- Learning network

**Alone**
- Relationships
REPRODUCTIVE WELLNESS STRATEGIES
Focus Group Findings

- Need for Self-Reliance
- Not Feeling Seen or Heard
- Negative Mental Effects

“In terms of mental health...the anxiety I feel like I have developed as a result of chasing down diagnoses and having to advocate for myself. In fear. Absolute fear of going to hospital because I’m worried there’s a conspiracy against women of color to even have babies. It doesn’t even seem like people want us to have babies with the way we are treated.”
Focus Group Findings

- Provider Biases
  - Racism
  - Ageism
  - Weight discrimination

- Care is Caring

“Here, nobody took me seriously...I don’t know if it was because I was black, or because I was young, or because I was a woman...they weren’t listening, they weren’t taking me seriously.”
Focus Group Findings

• Needs from Primary Care Doctor

• Information Should Be Provided in Multiple Ways

• Need Centralized Care and navigation through care

“I felt like nobody [was] looking at me from the holistic point of view. Not looking at the bigger picture. Until I got to an OB that truly listened to me and looked at everything from the holistic perspective, felt like missing something.”
Getting information about health

Balanced Info: Pros & Cons

- Birth Control & Hormones
- More General Information
- Fibroids
- Endometriosis

Do you have PCOS?

Database with Survey

Access as an App

Make it EASILY understandable

Saves

Namesake brings trust & community engagement

Would add more

Push notifications to prompt healthy habits

My Name is UNC

Consultation on Health Plan

- Coordinated Health
- True Care
- Full Support

I can give you all of the information

A Health Review Board - Know latest studies

Health plan with choice

Expansive access

Telehealth and permanent considerations

Offer screenings

Consider language & messaging

Advocate

Dignity in Design

Don't trust you

A 'quarter-back' looking out for me
Strategies for Change

• Comprehensive Care Clinics / Build on other Models of Quality Care

• Care Coordination / Care “Quarterbacks”

• Improved educational materials for patients

• Improved training for clinicians to increase capacity to build trust and provide quality, equitable care

• Design scripts and phrases to improve clinician ability to talk with women about infertility, miscarriage and infant loss – the whole spectrum of reproductive health

• Design and implementation of patient-centered measures for change
Lessons Learned

• Address miscarriage, infertility and loss
• Be inclusive around condition type
• Community and peer-to-peer support is important
• Research can be a healing space
• Informal yet personal engagement works well
• Graphic notetakers can portray complex themes
Systems Mapping Strategies for Change

• Increase research funding for diseases/conditions that affect women (people with uteruses).

• Women’s health care and care around reproductive health must be made part of basic training and board standards for all clinicians, especially internal medicine.

• Providers, policy folks, and payors agree that there is a need to continue to explore innovative models of providing care and reimbursement for care.
  • Proven models of care, including group counseling, physician extenders, and community health educators/navigators, need increased support to move from demonstration stage to standard of care.

• Need for incentives to support systematic reproductive intention screening.
National Survey Findings

• 56% of people surveyed had 1 or more chronic conditions.
  • The majority did not receive any counseling about their reproductive health

• 79% thought it was important (61%) / somewhat important (18%) to talk with a provider about reproductive goals. 11% felt this was important only if planning a pregnancy. Only 7.8% didn’t think this mattered.

• 1:4 women did NOT know that health prior to pregnancy was important.

• People want health education directly from their health care provider during a visit. They want information from the HCP via follow up contact/texts with their provider.
Health Resources for People of Reproductive Age

- Information about healthy lifestyles
- Information about Annual Check Ups
- New Health Education Sheets
- Connection with Others

ShowYourLoveToday.com
Resources for Health Care & Public Health Professionals

• Women’s Health Practice Bulletin
• Free Online Training Modules
• Policy Information
• Webinars
• Screening Tools
• And more at www.BeforeandBeyond.org
E-News

NEW! Women’s Health Practice Bulletin 2020
Health care providers and community workers are busy. The time that they have with patients/clients is valuable and important. The intent of this practice bulletin is to provide key information and tips to make the most of those important encounters. Additional resources and information for professionals are available at BeforeandBeyond.org.

Click to download the Bulletin

Pilot Testing in a Pandemic
Have you been wondering how your team is to keep up with the pandemic. More info!

Women’s Health Week
National Women’s Health Week is May 10-16. While this has been an uncertain and hard time in our country, we have unique opportunities to support women in new ways. This pandemic has shown a spotlight on the faults in our systems. Organizations are being pushed to make changes and find innovative ways to support women’s wellness. The use of telehealth has surged in the past few weeks, which has opened doors for many women to seek virtual help and connect with providers in different ways. What still rings true is the need for real connection, timely and trustworthy information, and uplifting messages and support.

Join Us!

CDC Bi-Weekly Research Listerv
Subscribe by emailing: List@cdc.gov with the email subject line: ‘SUBSCRIBE CDCL-PRECONCEPTION-LITERATURE’
Participant Hopes and Wishes for each other

- Resources
- Keep moving
- Solidarity
- Answers & support
- Manifest love
- Community
- Kindness to self
- Care
- Always be your own advocate
- Incredible support
- Hope
- Keep twine
- Centering mind body spirit
- Remain in community
- And she does too

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