UNC Lineberger:
Engaging ALL Communities For Better Cancer Outcomes

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Stephanie B Wheeler, PhD MPH
Roadmap for Today's Discussion

• Community outreach and engagement at Lineberger
  • Understanding NC populations and monitoring the cancer burden in NC
  • Conducting community- and patient-responsive research
  • Disrupting barriers to cancer care access

• The Lineberger Equity Council
  • Structure and priorities
  • Planning and implementation
  • Spotlight on Gynecologic Oncology

• Actionable Opportunities
Office of UNC Lineberger Community Outreach and Engagement

**Vision:** To develop and sustain a community that actively partners with UNC Lineberger to reduce the burden of cancer and eliminate cancer disparities in the state of North Carolina.

1. **Monitor** cancer burden and identify disparities in Lineberger catchment area (North Carolina)

2. **Synergize** institutional and community efforts to engage diverse stakeholders in addressing the cancer burden and reducing cancer disparities in North Carolina

3. **Amplify** cancer outreach and supportive care efforts with diverse stakeholder audiences

4. **Facilitate** impactful and equity-focused cancer research in North Carolina and beyond
Decades of Community-based Participatory Research, Outreach & Engagement

1990’s
- 5-a-Day targeting rural NC Blacks
- Black Churches United for Better Health

2000’s
- Ne-Besp: The North Carolina Breast Cancer Screening Program
- Patient Family Advisory Council
- CARE: Caring and Reaching for Health
- JOBS & HEALTH
- Patient Advisory Research Council
- Ft. Bragg Military

2010’s
- ACCURE Study
- Health e NC
- Carolina Breast Cancer Study
- Lineberger Comprehensive Cancer Center
Our Catchment Area: All 100 Counties in North Carolina

Our **cancer research and outreach** efforts span all 100 NC counties.

We provide **cancer care** to patients from all 100 NC counties; 91% of our cancer patients are seen within central **40** counties.

Sources: UNC Lineberger Data. UNC Hospital Cancer Registry.
Our Catchment Area: All 100 Counties in North Carolina

23.1% of North Carolinians live in one of the 54 rural counties

Rural NC faces greater challenges than urban NC: higher rates of poverty, and lower rates of college degrees and access to broadband.


Sources:
2. USDA, Economic Research Service, American Community Survey, 2017
3. USDA, Economic Research Service, 2018
Monitoring Cancer Burden in NC

Black-White Mortality Disparities
- Prostate (2.3-fold)*
- Stomach (2.3-fold)
- Myeloma (2.2-fold)*
- Endometrial (2.2-fold)*
- Larynx (1.8-fold)*
- Cervix (1.7-fold)*
- Breast (1.5-fold)*
- Colorectal (1.4-fold)*
- Pancreas (1.4-fold)*
- Liver (1.3-fold)

Native American-White Mortality Disparities
- Stomach (2.3-fold)
- Prostate (1.5-fold)*
- Liver (1.2-fold)
- Endometrial (1.1-fold)*

Rural-Urban Mortality Disparities
- Larynx (1.3-fold)*
- Colorectal (1.2-fold)*
- Cervix (1.2-fold)*
- Oral/Pharynx (1.2-fold)*
- Esophagus (1.1-fold)
- Lung (1.1-fold)*
- Prostate (1.1-fold)
- Pancreas (1.1-fold)*

Hispanic/Latinx-NH White Mortality Disparity
- Stomach (1.8-fold)
- Thyroid (1.2-fold)

Cancer Deaths per 100K
- Lung (45.5)*
- Breast (21.6)*
- Prostate (19.9)*
- Colon (14.5)*
- Pancreas (11.2)*

2012-2016 NAACR CDC Compressed Mortality Data
*Asterisks and bold type indicate cancers & populations Lineberger has prioritized in research.
Monitoring Behavioral Risks in NC

UNC LCCC Catchment Area (State of North Carolina) Risk Factors

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>NH White</th>
<th>NH Black</th>
<th>NH Native American*</th>
<th>Hispanic/Latinx</th>
<th>Non-Rural</th>
<th>Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obesity</td>
<td>29</td>
<td>31</td>
<td>30</td>
<td>37</td>
<td>31</td>
<td>29</td>
</tr>
<tr>
<td>No Physical Activity</td>
<td>22</td>
<td>26</td>
<td>21</td>
<td>31</td>
<td>21</td>
<td>18</td>
</tr>
<tr>
<td>Current Smoking</td>
<td>18</td>
<td>17</td>
<td>16</td>
<td>19</td>
<td>16</td>
<td>11</td>
</tr>
<tr>
<td>Heavy Drinking</td>
<td>7</td>
<td>5</td>
<td>6</td>
<td>8</td>
<td>6</td>
<td>6</td>
</tr>
</tbody>
</table>


*NH- Native American data suppressed because did not meet statistical reliability standards.
Action Plan for Community Outreach & Engagement

Key Areas

1. Gather, assess, describe cancer burden data
2. Educate, train, provide technical assistance
3. Link researchers and community
4. Disseminate information and resources
5. Facilitate improved access to cancer prevention, treatment & support
6. Fund community-academic research teams
7. Catalyze and build capacity
Facilitating Recruitment of Under-represented Groups to Trials

Intervention trial accruals for African Americans and Hispanics/Latinx populations are well-matched to the racial/ethnic composition of incident cancer cases in NC.

- **North Carolina population**
  - 10.4 million

- **All Interventional accruals 2018-19**
  - 2,799

- **Rural Interventional accruals 2018-19**
  - 22%

**COE Office:**
- Embedded trial navigator and Spanish interpreter in clinics;
- Conducting outreach & education about trials in communities

**Accrual year:** 12/1/2018 – 11/30/2019
**2018 Tumor Registry (cancer cases); 2018-2019 All Interventional Accrual in Adults**
Confirming hotspots; LCCC seeds $ to study

Engaging community

Conducting & expanding research

Making an impact

• Developed CRC screening decision aid; adapted for Latinx and Native Americans

• 17 community partners

• ACCSIS UG3/UH3 (NCI)

• CPCRN U48 (CDC)

• CCSG rural supplement

• Engaged North Carolina CRC Roundtable and state stakeholders

• Reaching rural, uninsured

• Expanded CRCE trainee opportunities to rural NC

• Reduced access barriers through mailed programs

• Catalyzed BCBS-NC coverage policy change

>11,000 FIT kits mailed

COE Office: leveraging CCSI to expand screening outreach & research across NC; developing partnerships
Conducting Responsive Research: Developing Community-led Solutions to Disparities

Community identifies treatment disparity
Leveraging grant to explore disparity
Making an impact
Continuing to listen

ACCURE: Accountability for Cancer Care through Undoing Racism and Equity

Eliminated racial disparities in treatment of early stage lung and breast cancer

Now standard clinical care in hospital system in Greensboro

COE Office: working to embed in UNC Health; supporting research to test in rural, non-academic clinics
LCCC establishes Comprehensive Cancer Support Program

Launching statewide support network, adapting materials

Providing outreach and education for survivors and caregivers

Continuing to respond to community needs

CCSP
250,000+

NC Cancer Survivorship Professional Action Network

¿Ahora qué?

Lay Navigation

13 symposia serving 10,000+

Engaged survivorship providers trained

Patient & caregiver participants engaged

Latinx patients & caregivers reached

Patient encounters while receiving cancer care

COE Office:
• connecting to rural practices
• offering training to community providers
• Disseminating and implementing financial navigation, lay navigation, and AYA survivor support across the state
Black women experience greater financial distress than White women from breast cancer treatment…

...and higher symptom burden, lower treatment adherence, and higher discontinuation of endocrine therapies.
Currently scaling up, at 9 oncology practices in NC (5 rural, 4 non-rural), a pilot-tested financial navigation intervention, which at UNC indicated a significant improvement in financial distress scores (average improvement = 6.86, 95% CI = 4.3—9.4, p<0.0001) with excellent patient satisfaction.
Currently scaling up, nationally, a pilot-tested, multi-component, virtual behavioral intervention consisting of:

- Motivational Interviewing (5 virtual counseling sessions), and/or Text Messaging Reminders
- Introductory educational video
- Workbook
- Website and virtual resource guide containing evidence-based strategies to support ET use and linkage to other community resources
GET SET Study Video Clip
UNC Lineberger Equity Council’s Charge:

1. Make **recommendations** for how to bring DEI principles into these six areas.
2. Determine **measurables** for how to achieve them.
3. Help ensure **implementation** and **accountability**.
Education, Training & Onboarding
Goal:
Having a clear path to Educate/Train and Onboard all staff on the matter of DEI.

Culture & Climate
Goal:
Make the culture & climate at Lineberger Cancer Center more diverse, inclusive and equitable.

Patient & Clinical Care
Goal:
Having the resources & time to eliminate cancer health disparities by providing our patients with the opportunity for equitable, optimal, and culturally sensitive care that maximizes duration and quality of life.

Enhancing Research with an Equity Lens
Goal:
Ensuring equity is foundational in all aspects of research design, process, and implementation

Accrual to Clinical Trials
Goal:
To improve accrual of underrepresented individuals to clinical trials.

Workforce Diversity: Recruitment & Retention
Goal:
To recruit, develop, and retain a diverse workforce and provide equitable employment opportunities to everyone.
## Subcommittee Framework

### Identify the problem
- Where are the gaps?
  - Utilize Listening Session data
  - Conduct a SWOT analysis
- Who are the players involved?
  - Conduct a Stakeholder Analysis

### Develop Measures
- Can we measure the problem?
  - Consider practical measures before developing solutions
  - Identify steps required to address the problem and measure every part of it.
  - If you can’t measure it, you can’t fix it!

### Propose Solutions
- Develop actionable solutions.
  - Short and Long term
- How will the proposed solution make a difference?
- Identify the policies that need to be created or changed

### Develop an Action Plan
- Prioritize the proposed solutions
- Create a realistic timeline for each.
- Assign responsibility for each proposed solution.
Phase I
Assessment and Recommendations:

• Where are our gaps?
• Where can we enhance our existing programs and policies?
• How can we integrate with UNC Schools' and healthcare system’s DEI efforts?

Phase II
Implementation and Accountability:

• Develop implementation plan
• Create 5-year timeline & budget
• Establish metrics
• Integrate with UNC Schools and healthcare system
• Evaluate progress

We will engage those we employ, train, treat and serve.
We will listen.
We will act.
The Biology of Cancer
Exploring the Role of Race, Class, and Socioeconomics in the Underserved and the Underrepresented

Partnership between:

UNC Lineberger Cancer Network

Financial Toxicity/Rural Populations: Navigating Access to Care in the Community

October 23
Friday
11:00 AM – 12:30 PM

Danny Fitzgerald Ellis, MBA, PhD
Instructor, Department of Marketing and Supply Chain Management
College of Business
East Carolina University

Lecture Description
Dr. Danny Ellis will discuss existing and persistent access issues in the minority community. He will also share proven methodology of engaging Community Based Organizations in addressing access issues through research involvement.

Learning Outcomes
- Existing and persistent access issues in the minority community
- Participants will be able to describe and differentiate access issues attributed to individual circumstances (finances, transportation, knowledge, etc.) as opposed to institutionalized barriers.
- Describe the current assets within CBOs. Explain how Health Care Orgs can and should partner with CBOs. Identify current public and private partnerships with promising results.

The Courses
thetbiologyofcancer.org

The Calendar
thetbiologyofcancer.org/calendar

To Register
thetbiologyofcancer.org/20201023
Root Causes for Health Disparities
Spotlight on Gynecologic Oncology: Monitoring Determinants of Health among NC Women

- Women aged 18-64 without any health insurance: 18%
- Women without health insurance who have never had insurance: 20%
- Women who didn't take medication as prescribed due to cost: 13%
- Unemployed women aged 16+ and in the labor force: 6%
- Women who didn't see a physician due to cost: 19%
  - Non-Hispanic White: 16% / African American: 23%
- Women who currently have medical bills being paid off over time: 30%
  - Non-Hispanic White: 26% / African American: 40%

Median income, if any earned: $28,971
Women 18+ with some disability: 16.1%
Women 18+ in households receiving food stamps: 13.9%

NC Rankings: Health Insurance Coverage #42

SCHOOL OF MEDICINE Center for Women's Health Research
Spotlight on Gynecologic Oncology:
Uterine cancer is the most common gynecologic cancer in the US

<table>
<thead>
<tr>
<th>Uterine cancer incidence in the US</th>
<th>Uterine cancer prevalence in the US</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>26.0</strong> deaths per 100,000 women per year</td>
<td><strong>727,200</strong> 5% of the 15 Million cancer survivors in US</td>
</tr>
<tr>
<td><strong>63,230</strong> 2018 total new diagnoses</td>
<td></td>
</tr>
</tbody>
</table>

- **3.6%** Proportion of all new cancer diagnoses in the US

- **62 YEARS** Median age at uterine cancer diagnosis

- US population-based cancer data published by the Surveillance, Epidemiology, and End Results (SEER) program include all cancers of the uterine corpus, inclusive of endometrial cancers.

- Age-adjusted data from 2011–2015.


Spotlight on Gynecologic Oncology:
Uterine Cancer Mortality Rates by Race and Ethnicity in the United States

Long et al., Gynecol Oncol. 2013 Sep; 130(3): 652–659.
Why are there racial disparities for uterine and endometrial cancer?

- Access to equitable care
- Internal environment and response to treatment
- Higher risk of more lethal subtypes
- Higher rates of obesity and/or diabetes
- Other unknown biological factors?
1. Distribution of endometrial cancer molecular features and subtypes associated with poor prognosis

2. Variation in symptoms and receipt of guideline-concordant diagnostic procedures and treatment

3. Variation in patient experience and provider assessment of symptoms

**Advisory Groups**
- Endometrial Cancer Action Network for African Americans
- UNC LCCC Patient Advocates for Research Council
- UNC LCCC Patient Reported Outcomes Core
- UNC LCCC Office of Community Outreach & Engagement

**Investigator team**
- **Cancer & Social Epidemiology**
  - A. Olshan, PhD
  - H. Nichols, PhD
  - W. Robinson, PhD
- **Health Services Research**
  - A. Bennett, PhD
  - C. Samuel, PhD
  - L. Spees, PhD
  - S. Wheeler, PhD
- **Gynecologic Oncology**
  - V. Bae-Jump, MD, PhD
  - K. Doll, MD, MSCR
- **Pathology & Genomics**
  - R. Broaddus, MD, PhD
  - J. Merker, MD, PhD
- **Biostatistics & Bioinformatics**
  - X. Tan, PhD
  - J. Parker, PhD

**Partnership on Endometrial Cancer Research**

**UNC LCCC Patient Advocates for Research Council**
- Olshan, Nichols UG3CA260291
Andrew Olshan, PhD
Epidemiology

Hazel Nichols, PhD
Epidemiology

Victoria Bae-Jump, MD, PhD
Gynecologic Oncology

Russell Broaddus, MD, PhD
Pathology

Tope Keku, PhD
Gastroenterology

https://unclineberger.org/cecs/
Actionable Opportunities for Community Engagement, Equity and Inclusion
Communicating our Diversity Equity and Inclusion efforts

Visit our website: 
go.unc.edu/LCCC-DEI

Email us: 
LCCC_Equity_Council@unc.edu
or anonymously through our Contact Form
Engaging Community and Patient Voices in Research

(Community stakeholders are patients, caregivers, providers and community-based organizations)

**Generate Research Ideas**
- Develop research questions that are important to stakeholders by involving them early and forming valuable partnerships.

**Write Grant Proposals**
- Define relevant eligibility criteria, study benefits, and consent processes with the input of stakeholders.

**Conduct Research Studies**
- Incorporate stakeholder feedback on harms and benefits to educate and motivate study populations.

**Analyze Findings**
- Ask for stakeholder perspectives on findings and the potential impact on communities.

**Share Results**
- Include stakeholders in plan to return study findings to community, possibly asking them to co-present.

**BENEFITS**
- Builds trust and respect in communities
- Creates a renewed sense of purpose
- May lead to future sources of funding
- Enhances the relevance of your research
- May identify potential concerns and solutions
- Can increase recruitment to research studies

2020 COE
Supporting Lineberger’s Community Pilot Funding Program

**Purpose:**

- Conduct community cancer needs assessment
- Establish or expand the focus of an existing coalition to gain consensus on a local cancer issue
- Develop a plan to implement evidence-based interventions or programs to address a local cancer issue

**Total Funding to Each Organization:** $5K-30K

**Total Awards:** 3-5 community organizations
Supporting the Unmet Financial Needs of NC Patients Undergoing Cancer Care

Financial and Legal Assistance

A cancer diagnosis can affect so many parts of our lives, including finances. We all know that even without cancer finances can cause stress in our lives. Many people have unplanned expenses related to their care. Let us help you find ways to address these concerns.*

FOR MORE INFORMATION CHOOSE FROM THE OPTIONS BELOW:

- Health Insurance
- Housing Assistance
- Medication & Treatment Cost Assistance
- Organizations that can Help
- Transportation/Travel
- Work
- Legal

*This list is meant to be used as a guide and is not comprehensive. The information provided was the most current information available at the time of publication. Some material may change or become dated. The sponsors and individuals listed assume no responsibility for time.

Visit our website: https://unclineberger.org/finances/

Financial and Legal Assistance Coordinator

Cindy Rogers

Cindy Rogers, JD, is the patient assistance coordinator with the Comprehensive Cancer Support Program. She manages a charitable fund that assists patients in active treatment with non-medical financial needs, such as household bills, rent, mortgage payments and transportation costs.