Equity and Representativeness in Oncology Research - Louisiana

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No disclosures
Questions

• How can we improve the participation of underrepresented populations in oncology research? What are the major barriers that need to be overcome? What are your recommendations for advancing progress?

• What are the challenges to ensuring equity in oncology research and care, especially given the low participation rates in clinical research? What changes are needed in policy and research to overcome these challenges?

• What are the major ethical issues involved in research on the social determinants of health in oncology, especially in regard to the use of big data and analytics?

• What are the opportunities to proactively ensure that these research methods do not perpetuate structural inequities or discriminate against disadvantaged populations? How can the principle of fairness be incorporated into this research?

• Are there aspects of big datasets that make them particularly vulnerable to security and privacy concerns?

• Are there optimal data security approaches and governance models to ensure patient privacy and data security? What are the critical features of such approaches/models?

• Are there lessons learned that have been drawn from data breaches that can inform best practices for the future?
Breast cancer mortality rates for black women are 68% higher than for white women.

Incidence rates for black men are 58% higher than for white men.

Mortality rates are 40% higher for black people than for white people.

Mortality rates are 128% higher for black men than for white men.

Late stage diagnosis rate is 80% higher for black women than white women.

Data – Louisiana Tumor Registry - SEER
Cancer Health Inequalities

• **Societal / Socio-economic**
  • Lack of Access to Health Care
    • Financial – Health Care Insurance
    • Distance to clinic – rural Louisiana
  • Lack of education on health – health literacy

• **Environmental**
  • Exposure to carcinogens – River parishes
  • Characteristics of neighborhood – Nutrition, obesity, healthy living

• **Biologic**
  • Ethnic/Racial: Genetic

• **Cultural/Historical** : Tuskegee
Challenge for the Clinical Trials Program
Charity Hospital Patients

Pre-Katrina (Aug 2005)

Post-Katrina (Sept 2007)

80% MB - CCOP patients tracked by mid 2007
Traditional Cancer Center Model – Pre-Katrina

Physicians, nurses, infrastructure (regulatory, data management), grants, funding
Hybrid Cancer Center Model

Physicians, nurses, infrastructure (regulatory, data management), grants, funding
### Agreements for the Community-Academic Clinical Trials Program

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<thead>
<tr>
<th><strong>Academic Center</strong></th>
<th><strong>Community Oncologist</strong></th>
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<tbody>
<tr>
<td>• Compete for and manage the grant (CCOP - NCORP)</td>
<td>• Agree to use the SEER registry to analyze their patient population</td>
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<tr>
<td>• Provide centralized regulatory and data management support for audits and grant renewal</td>
<td>• Participate in monthly clinical trials meeting – trial selection</td>
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<td>• Provide clinical trials software</td>
<td>• Agree to use clinical trials software provided by academic center</td>
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<td>• Support participation of C. Oncologists to cooperative group meetings</td>
<td>• Agree to use C-IRB or W-IRB</td>
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<td>• Provide research nursing support and maintain records for audits</td>
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• **Determine type of disease and stage**
  • Throughout the state and each NCORP site.

• **Rapid Case Ascertainment – e-Path – 2007**
  • 95% if cancer cases reported real time
Figure 3. The Gulf South Clinical Trials Network

A. Shreveport
LSU Health Sciences Center Shreveport
Willis Knighton Medical Center
CHRISTUS Highland Medical Center

B. Monroe
UH Conway Medical Center

C. Alexandria
CHRISTUS Saint Frances Cabrini Hospital

D. Lake Charles
CHRISTUS Saint Patrick Hospital

E. Baton Rouge
The NeuroMedical Cancer-Clinic
LSU Health Baton Rouge North Clinic
Mary Bird Perkins Our Lady of the Lake Cancer Center
Louisiana Hematology Oncology Associates LLC
Medical Oncology LLC
Woman’s Hospital
Ochsner Health Center – Summa
Medical Center of Baton Rouge

F. Covington
Mary Bird Perkins Cancer Center
Northshore Oncology Associates
Lalix Karp Regional Medical Center – Independence
Ochsner Hematology Oncology North Shore Covington
Ochsner Health Center – Covington

G. Houma
Mary Bird Perkins Cancer Center at Terrebonne Oncology Center of the South Inc.
Leonard J. Chabert Medical Center

H. Metairie
East Jefferson General
Robert Well MD, LLC

I. New Orleans
University Medical Center New Orleans
LSU Healthcare Network / St. Charles
Children’s Hospital New Orleans
LSU Health Sciences Center New Orleans
Ochsner Medical Center – Kanapaz
Ochsner Medical Center – Jefferson
Ochsner Medical Center – West Bank
Ochsner Baptist Medical Center
West Jefferson Medical Center (Marrero)
Culicchia Neurological Clinic (Marrero)
Touro Infirmary

J. Slidell
St. Tammany Hospital Service District #2
Slidell Memorial Hospital
Ochsner Hematology Oncology North Shore

K. Hattiesburg (Mississippi)
Forrest General Hospital Cancer Center
Hattiesburg Clinic – Hematology/Oncology Clinic

L. Gulfport (Mississippi)
Gulfport Memorial Hospital
CANCER RESEARCH AND TREATMENTS TO OUR REGION

The latest advancements in cancer studies are available close to home through a proud partnership of the Gulf South's leading health and research entities, called the Gulf South Clinical Trials Network (Gulf South CTN).

What is a clinical trial or cancer study?

A clinical trial or research study is a way for physicians and scientists to apply the latest technology to how they care for a disease. Often, studies or trials can be an option for patients when other treatments haven't worked. Studies also collect important information that can benefit patients with similar diseases in the future. You can click here to search for available
Find a Cancer Clinical Study

Use this tool to search current cancer studies available near you in the Gulf South region. To get started, select the type of cancer and your parish or county.

I AM A PATIENT

CANCER TYPE*  
ALL

To narrow your results, you can enter your parish. You can also leave this field blank to see all relevant studies by cancer type.

PARISH OR COUNTY  
ALLEN

SEARCH
# Medicaid Expansion in Louisiana

Medicaid expansion has yielded improved access to screenings and treatment.

## Scale of Medicaid Expansion in Louisiana

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<tr>
<th>Impact</th>
<th>Description</th>
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<tr>
<td><strong>10%</strong> – Egyptian’s uninsured rate dropped between 2013 (21.7%) and 2017 (12.5%)</td>
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<tr>
<td><strong>$199 M</strong> – State’s saving as a result of Medicaid expansion</td>
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<tr>
<td><strong>433,412</strong> – Egyptian residents have signed up for Medicaid since the expansion</td>
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<td><strong>50%</strong> of new insured are African American</td>
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## Select Impacts on Cancer

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<tr>
<td>+10,000 People have been screened for colon cancer through expansion</td>
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<tr>
<td>3,169 Newly enrolled Louisiana residents had doctors remove polyps that could have caused colon cancer</td>
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<tr>
<td>+15,000 Women have received screenings through Medicaid expansion</td>
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<tr>
<td>154 Louisiana women with new Medicaid coverage were diagnosed with breast cancer since enrolling</td>
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The TMIST Team
Outcomes

• **Increased partnerships** community oncologists
  • **Balanced portfolio** selected by academic physicians, community oncologists and investigators

• **Increased awareness** in the community – asking for trials
  • Increased self referral for 2nd opinions
  • Increased interest in participation in clinical studies.

• **Increased participation of minorities:**
  • Minorities at Gulf South NCORP overall: 49%
  • Minorities in TMIST : 82%
Louisiana SEER Tumor Registry

• Determine type of disease and stage: state and each NCORP site.

• Rapid Case Ascertainment – e-Path – 2007
  • 95% if cancer cases reported real time

• Louisiana Virtual Tissue Biorepository – 2015. LTR is the “honest broker” and de-identifies all samples.
Promoting Health Equity and Representativeness

**Policy Changes**

- Community MD Partnership
- LA – Tumor Registry
  - NCORP
  - Tissue legislation
- Creation of Gulf South CTN
- Medicaid Expansion
  - Partnership with the DHH

**Societal / Socio-economic**

- Lack of Access to Health Care
  - Distance to clinic – **Gulf South Clinical Trials Network-NCORP** - Inclusion of rural FQHC’s
  - Financial – Health Care Insurance – **Medicaid Expansion**
  - Lack of education on health – **health literacy**
    - Genomics and Tissue donation

**Environmental**

- Exposure to carcinogens – River parishes
- Neighborhood – Nutrition, obesity, healthy living – **Geocoding breast, liver and colorectal**

**Biologic**

- Ethnic/Racial: Genetic – **P20 pre-SPORE Health Disparities**

**Cultural/Historical**
Issues with Multi-Institutional Clinical Trials Program

• Data management at sites with different standards
  • Different EMR’s and Clinical Trials Management software
  • Lack of Uniformity in screening and consenting

• Information security
  • Are the right security measures in place
  • How to monitor security of the data
  • How to ensure patient confidentiality

• Ethics
  • Representativeness of patients and community organizations
  • Use of research data and results