

Equity and Representativeness in Oncology Research - Louisiana

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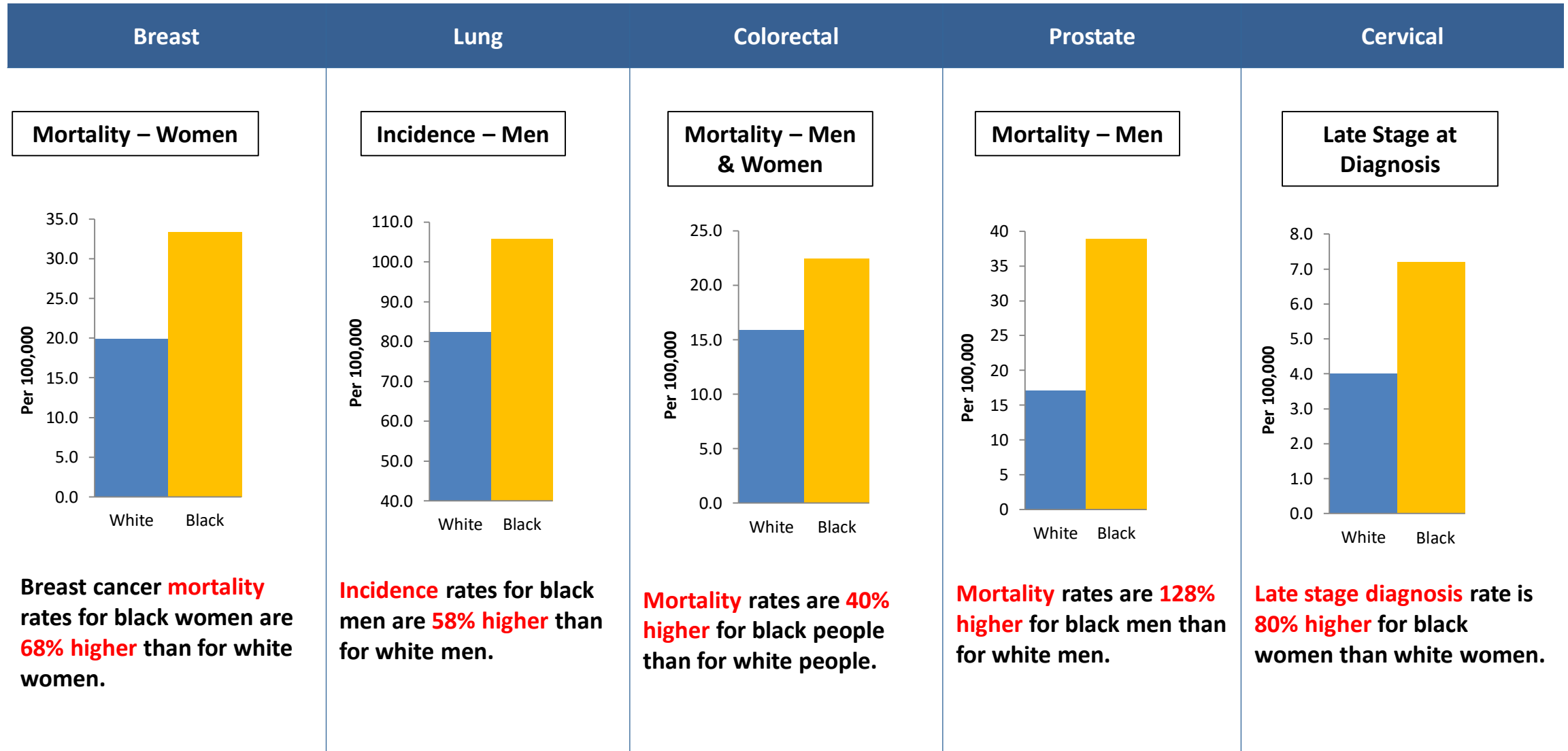


No disclosures

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?

Cancer Health Disparities in Louisiana



White 65%; African Americans 32%; Other 3%

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

Hurricane Katrina 8/29/2005



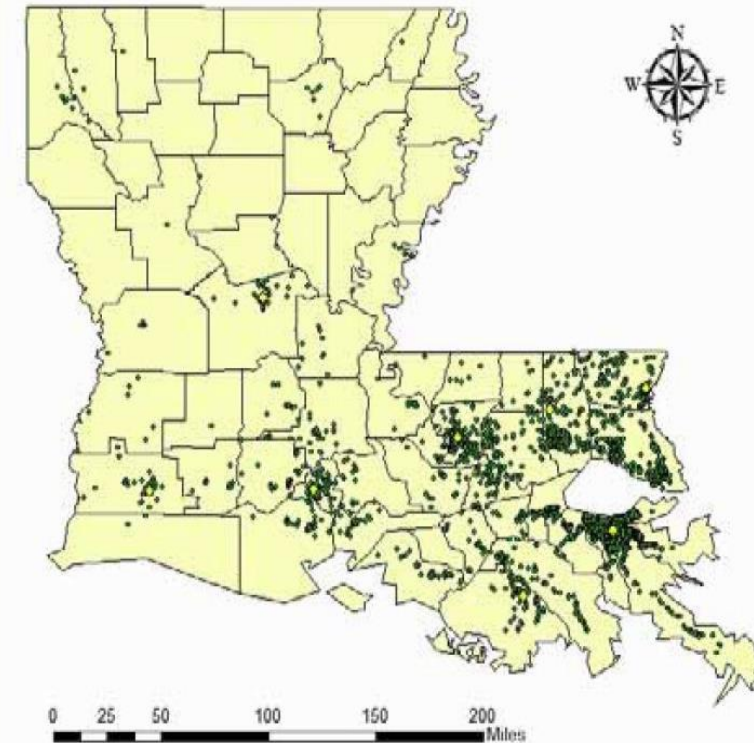
Challenge for the Clinical Trials Program

Charity Hospital Patients

Pre-Katrina (Aug 2005)

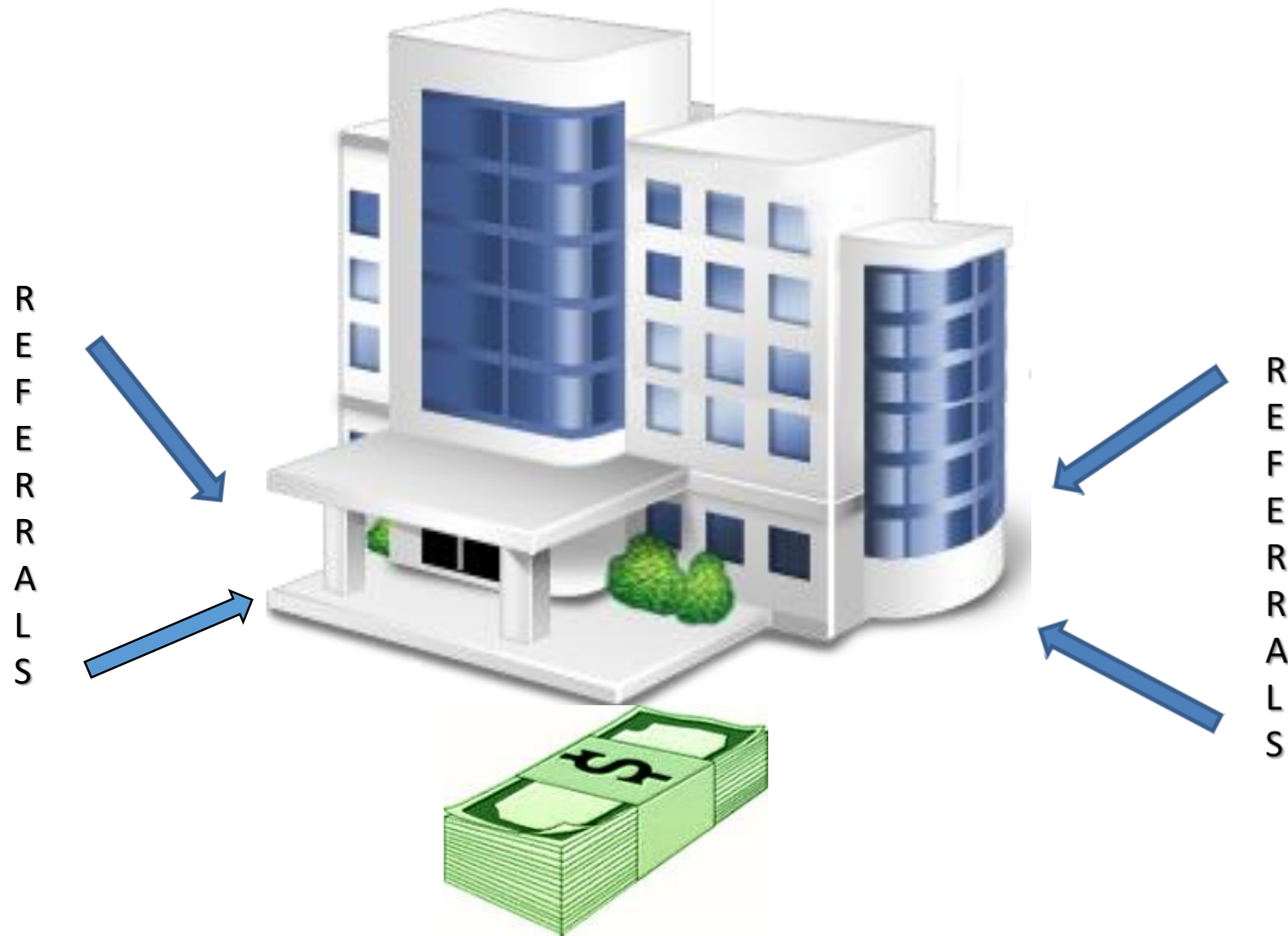


Post-Katrina (Sept 2007)



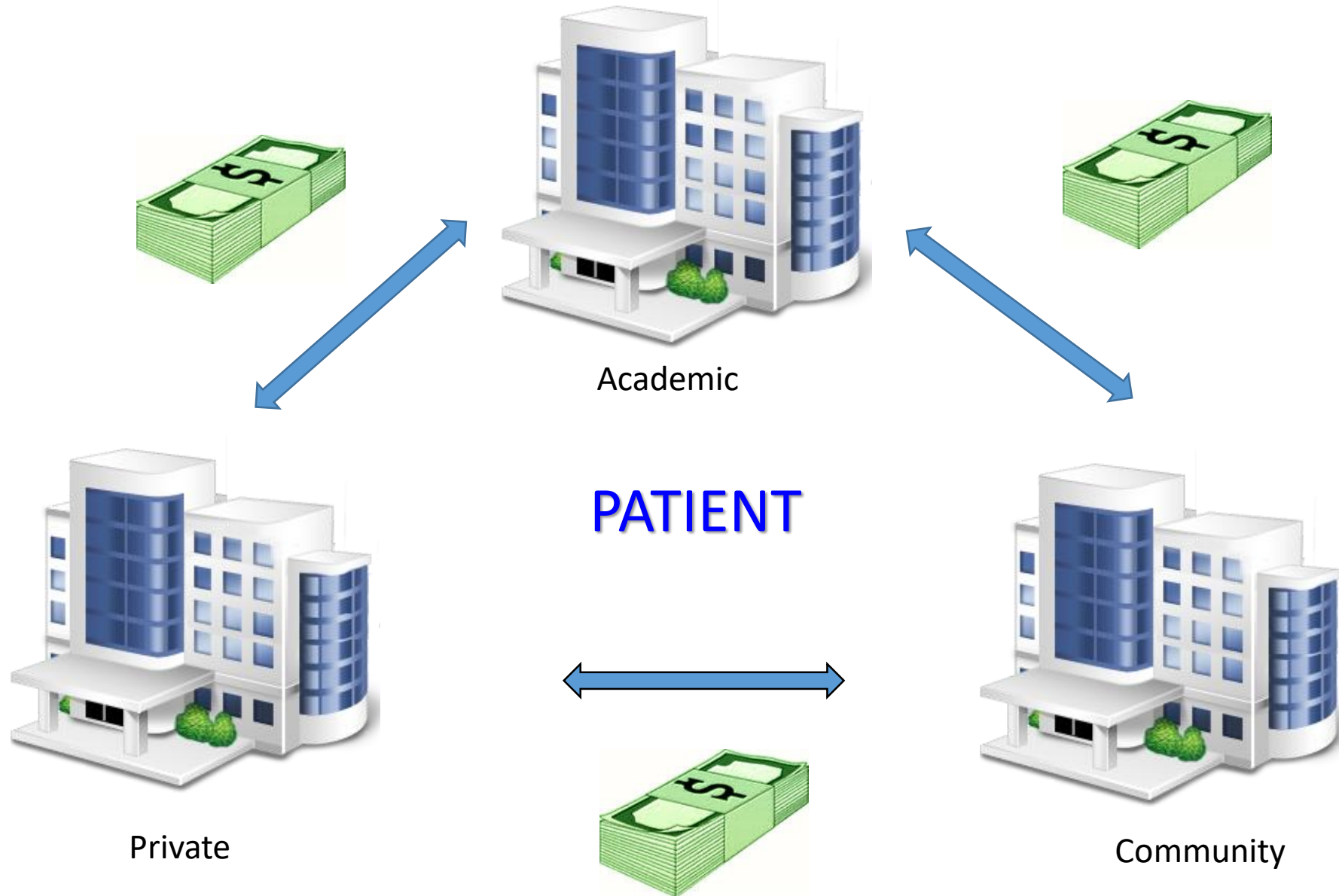
80% MB - CCOP patients tracked by mid 2007

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

Academic Center

- Compete for and manage the grant (CCOP - NCORP)
- Provide centralized regulatory and data management support for audits and grant renewal
- Provide clinical trials software
- Support participation of C. Oncologists to cooperative group meetings

Community Oncologist

- Agree to use the SEER registry to analyze their patient population
- Participate in monthly clinical trials meeting – trial selection
- Agree to use clinical trials software provided by academic center
- Agree to use C-IRB or W-IRB
- Provide research nursing support and maintain records for audits

Louisiana SEER Tumor Registry



- Determine type of disease and stage
 - Throughout the state and each NCORP site.
- Rapid Case Ascertainment – e-Path – 2007
 - 95% of cancer cases reported real time

Cancer Community Oncology Programs (CCOP) in Louisiana -2009

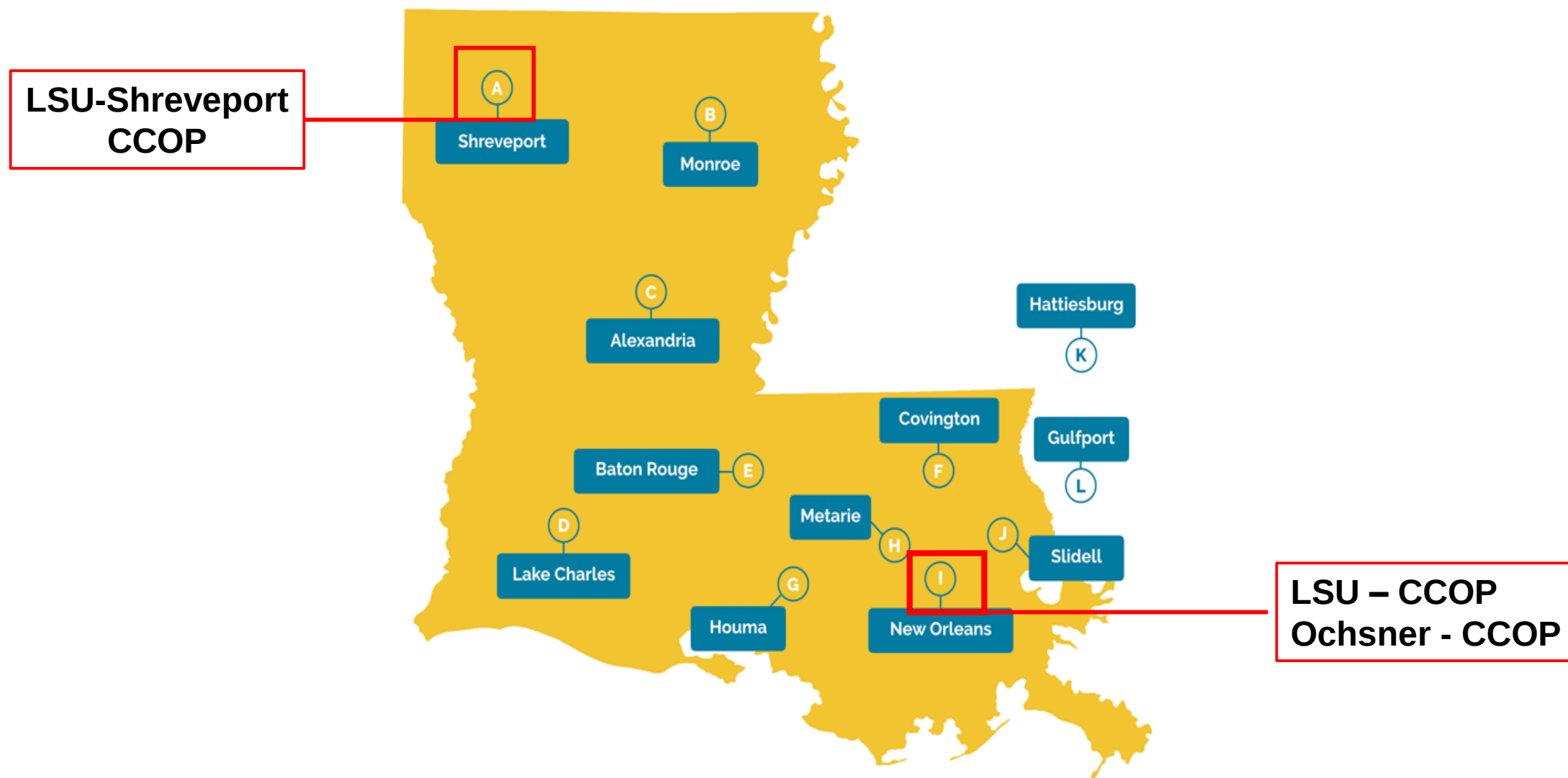
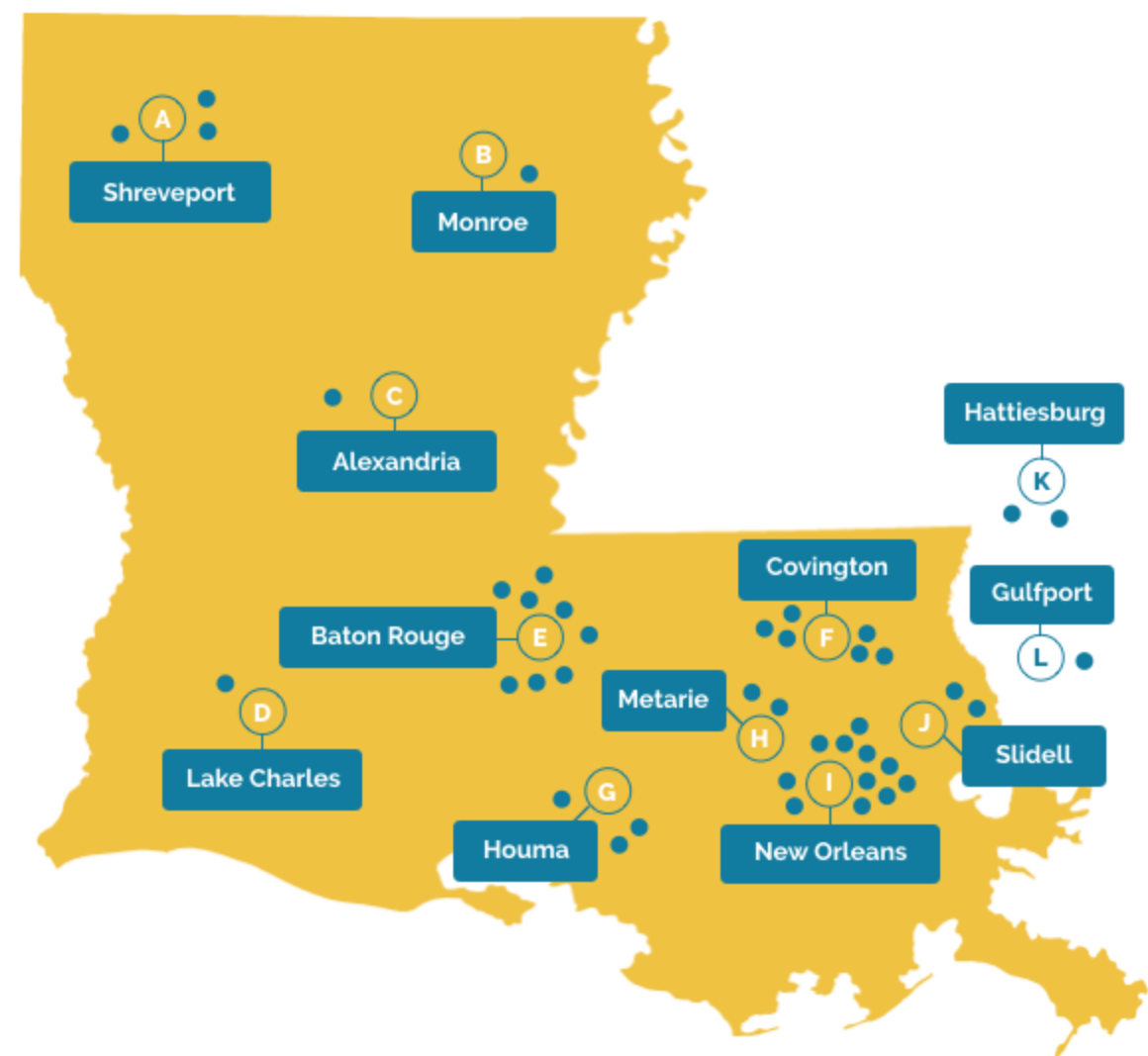


Figure 3. The Gulf South Clinical Trials Network



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
Women's Hospital
Ochsner Health Center – Summa
Medical Center of Baton Rouge

F. Covington

Mary Bird Perkins Cancer Center
Northshore Oncology Associates
Lallie Kemp 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 Veith MDLLC

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 – Kenner
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



GULF SOUTH

CLINICAL TRIALS NETWORK

[ABOUT](#) [FOR PHYSICIANS](#) [FOR PATIENTS](#) [RESOURCES](#) [CONTACT](#)

[CLINICAL STUDY SEARCH](#)



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).

LSU HEALTH

MARY BIRD PERKINS CANCER CENTER

OCHSNER HEALTH SYSTEM

OCHSNER LSU HEALTH



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



www://gulfsouthclinicaltrials.org



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	Select Impacts on Cancer
➤ 10% – Louisiana 's uninsured rate dropped between 2013 (21.7%) and 2017 (12.5%) ➤ \$199 M– State's saving as a result of Medicaid expansion ➤ 433,412 – Louisiana residents have signed up for Medicaid since the expansion ➤ 50% of new insured are African American	➤ +10,000 People have been screened for colon cancer through expansion ▪ 3,169 Newly enrolled Louisiana residents had doctors remove polyps that could have caused colon cancer ➤ +15,000 Women have received screenings through Medicaid expansion ▪ 154 Louisiana women with new Medicaid coverage were diagnosed with breast cancer since enrolling

The TMIST Team



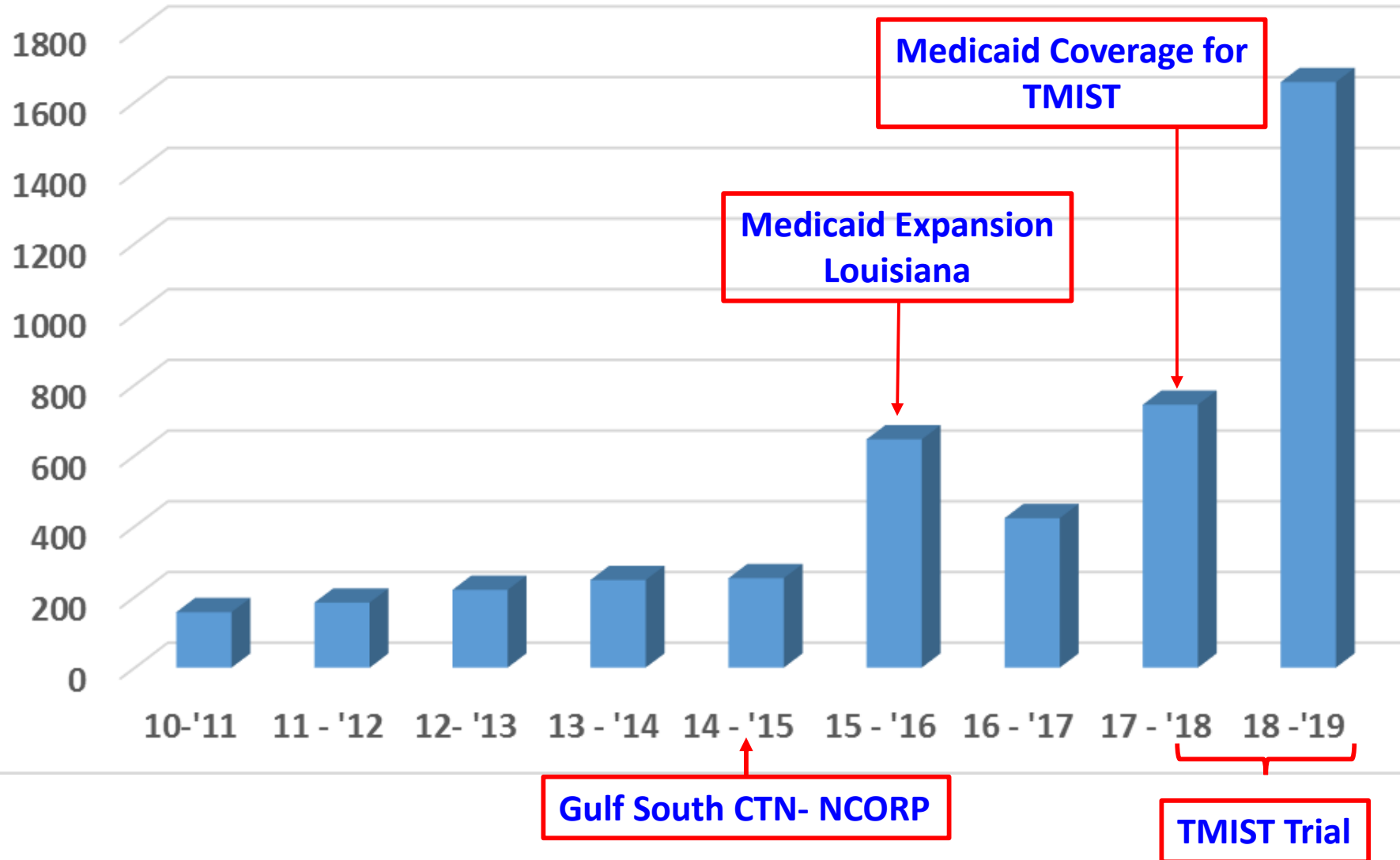
NCI

Community Oncology
Research Program

A program of the National Cancer Institute
of the National Institutes of Health

GULF SOUTH
CLINICAL TRIALS NETWORK

Patient Accruals to Clinical Trials in Louisiana 2010-2019 - CCOP and NCORP



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.

—GENERAL

hospitals, pathology laboratories, radiation centers, physicians, nursing homes, hospices, and other licensed health care facilities and providers.

4. Diagnosis-related material, such as cancer biospecimens and pathology slides, as well as biological materials such as saliva samples, shall be sent to the Louisiana Tumor Registry if requested.

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

