

**Florida Center for Universal Research to Eradicate Disease (FL CURED)**

**Biomedical Research Advisory Council**

**Office of Minority Health, Florida Department of Health**

**HEALTH DISPARITIES RESEARCH AGENDA FOR FLORIDA:**

**Phase I**

**Prepared by**

**Health Disparities Research Advisory Committee**

**In Conjunction with**

**FL CURED Staff**

**July 20, 2011**

**EXECUTIVE SUMMARY****BACKGROUND**

Florida is increasingly one of the most diverse states in the U.S. With this diversity comes a higher incidence of disease burden from those in the ethnic/racial emerging majority and from rural, socioeconomically disadvantaged and medically underserved backgrounds. Given these trends, it is clear that Florida is at a critical juncture in determining the best strategies for improving not only the health of the ethnic/racial emerging majority and other underserved groups but also the health of *all* Floridians. To address health equity in the state, the research community joined with the Florida Department of Health—including the Biomedical Research Advisory Council, the Office of Minority Health and the Florida Center for Universal Research to Eradicate Disease (FL CURED)—to develop the Health Disparities Research (HDR) Agenda for Florida.

**HDR ADVISORY COMMITTEE**

After a statewide HDR Invitational Summit held in October 2010 in conjunction with the BioFlorida Conference, a 32-member HDR Advisory Committee was formed that identified the vision for this research initiative of *achieving health equity for all Floridians* and the mission of *developing and implementing the HDR Agenda for Florida through proactive collaborations among academic institutions, health care providers, government organizations, community-based organizations and faith-based organizations*. The Committee conducted its work in spring 2011.

**HDR AGENDA**

This research agenda includes the following major, cross-cutting research goals and research capacity goals developed by the HDR Advisory Committee.

**Research Goals**

- Advance the understanding of the relationships between multi-level health determinants (such as genomics, environment, behavior, cultural norms/beliefs/values) and health disparities using multiple levels of analysis across the life span.
- Develop cost-effective and sustainable health intervention programs that are culturally competent and linguistically sensitive to the ethnic/racial emerging majority, medically underserved, rural, and socioeconomically disadvantaged populations.
- Develop new or improved approaches for disseminating evidence-based health promotion and disease prevention information to ethnic/racial emerging majority, medically-underserved, rural, and socioeconomically disadvantaged populations.
- Improve quality of life of ethnic/racial emerging majority, medically underserved, rural and socioeconomically disadvantaged populations by implementing best practices to prevent, manage or reduce the recurrence of disease.

### Research Capacity Goals

- Develop infrastructure for research on health disparities, including, among others, collaborative bio-banks, registries, and health informatic systems (i.e., electronic medical records systems and patient health portals).
- Improve quality, accuracy and specificity of data in registries and health informatic systems (e.g., accuracy of ethnic/racial identifiers, inclusion of ancestry/country of origin and years in the United States as mandatory data).
- Promote the involvement of ethnic/racial, rural and medically underserved populations in research, seeking necessary resources to recruit and retain their participation in multiple types of health research.
- Engage, develop and sustain equitable academic-community partnerships that facilitate health disparities research.
- Engage, develop and sustain partnerships between minority serving institutions and health care centers (e.g., cancer centers) to facilitate health disparities research, education, training and community outreach.
- Facilitate statewide translational research for community stakeholders, clinicians, population scientists and basic scientists in order to provide an avenue for scientific exchange that will facilitate transfer of knowledge from trench (community) to bench to bedside and back.
- Increase access to new genomic and other emergent technologies available in the state to improve diagnostics and treatments for all cancers as well as other diseases.
- Provide a collaborative mechanism to educate current and future researchers to effectively engage in culturally and linguistically competent/sensitive research.
- Build capacity to disseminate evidenced-based best practices from health disparities research.
- Identify, train and mentor the next generation of health disparities researchers.

In addition, three substantive priority areas were identified: Health Promotion/Disease Prevention, Health Outcomes and Cancer/Genetics. For each of these priority areas, strengths and gaps, overarching research and research capacity goals, specific areas of emphases, objectives and research questions were developed.

### NEXT STEPS

The HDR Advisory Committee is providing this version of the HDR Agenda for public comment. It is noted that there are limitations in this document, including limited time and resources, priority areas that primarily reflect expertise of the Advisory Committee, and the need for broad input from diverse stakeholders. We invite this input as we finalize Phase I and begin discussions on an expanded version. We see the research agenda as a living document that will evolve and change as new knowledge is generated and translated into policies and practices to improve health.

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### ACKNOWLEDGMENTS

We would like to thank Richard Bookman, Ph.D., Chair of the Biomedical Research Advisory Council, for his vision and determination to launch this health disparities research initiative for the state of Florida. We further thank Chuck Wells, Assistant Director, Office of Public Health Research, Florida Department of Health, for his tireless efforts to develop the plans for the HDR Invitational Summit that served as a catalyst for the HDR Agenda. Finally, we thank Tad Fisher, Executive Director, Florida Academy of Family Physicians, for his efforts to facilitate the HDR Invitational Summit and to be a collaborator throughout the process.

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## VISION AND MISSION

### VISION STATEMENT

Achieve health equity for all Floridians.

### MISSION STATEMENT

Develop and implement the Health Disparities Research (HDR) Agenda for Florida through proactive collaborations among academic institutions, health care providers, government organizations, community-based organizations and faith-based organizations.

### Strategies

- Improve awareness of health disparities among researchers, policy makers and the general public.
- Increase academic-community partnerships to foster research, education, community engagement and community empowerment.
- Promote quality data gathering in health disparities research.
- Increase transdisciplinary health disparities research.
- Promote public dissemination of health disparities research to improve health policies and practices.

### DEFINITIONS

**Health disparities.** Health disparities are differences in the incidence, prevalence, mortality, and burden of disease and adverse health conditions that exist among specific population groups in the United States. These population groups may be characterized by gender, age, ethnicity, education, income, social class, disability, geographic location, or sexual orientation.<sup>1</sup>

**Emerging majority.** For the purposes of this report and our work going forward the authors chose to use the more meaningful term “emerging majority” rather than minority/minorities. Emerging majority includes all groups of minorities as established by the Office of Management and Budget (OMB) of the United States government. OMB establishes the racial and ethnic categories in the United States, which, in terms of minorities, are African Americans/Blacks (race), Hispanics (ethnicity), Asian/Pacific Islanders (race), and Native Americans and Alaska Natives (race).<sup>2</sup> The term also reflects the reality of demographic changes experienced in Florida and in other fast-growing, culturally diverse states.

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<sup>1</sup> Adapted from National Cancer Institute, National Institutes of Health. Available at: <http://dceps.nci.nih.gov/od/hd-overview.html>

<sup>2</sup> Rose, P. (2011). *Cultural competency for health administration and public health*. Boston, MA: Jones and Bartlett., p. 4.

**BACKGROUND**

Florida, one of the most diverse states in the U.S., has a total population of 18.8 million. According to the 2010 U.S. census, of that number, 22.5% are Hispanic, 16% African American/Black, 2.5% Asian/Pacific Islander, 0.4% American Indian/Alaskan, and 6.1% other races/two or more races. Florida's minority populations are now an emerging ethnic/racial majority. At the same time, there are Floridians of various ethnic/racial backgrounds who are rural, low-income and medically underserved. These Floridians—emerging ethnic/racial majority, rural, low-income and medically underserved—often carry a higher disease burden than other groups, including age adjusted higher proportions of diseases such as cancer, diabetes, heart and other cardiovascular diseases, HIV/AIDS, and infant mortality, among many others. Given these demographic and health status trends, it is clear that Florida is at a critical juncture in determining the best strategies for improving not only the health of emerging majority and underserved groups but also the health of *all* Floridians. Clearly, for the state to improve socially and economically, we need a healthy workforce and healthy citizens. We need to achieve health equity.

To address health equity in the state, the research community joined with the Florida Department of Health to develop the Health Disparities Research (HDR) Agenda for Florida. The idea for the HDR Agenda began with the Florida Department of Health, including the Biomedical Research Advisory Council (BRAC), the Office of Minority Health and the Florida Center for Universal Research to Eradicate Disease (FL CURED). BRAC, which advises the State Surgeon General on the direction and scope of the James & Esther King and the Bankhead-Coley Cancer Research Programs, held a two-day meeting in 2009 to determine strategic directions for the programs within the context of a changing funding environment and ongoing concerns about the health status of Floridians. In particular, health disparities, already a priority in the Bankhead-Coley Biomedical Research Program, became a focus of discussion in light of the growing diversity in Florida. As a result, BRAC identified health disparities as one of the five key priority areas to be addressed in its future directions. Specifically, the BRAC strategic plan stated:

*Priority: Increase investment in clinical and translational research and health disparities research.*

*Strategy: Convene a statewide work group to define a research agenda for Florida in health disparities as well as to identify infrastructure resources needed by Florida researchers for health disparities research.<sup>3</sup>*

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<sup>3</sup> State Surgeon General of Florida. (2010). *Annual Report, Bankhead Coley Research Program*. Tallahassee, Florida: Florida Department of Health.

To successfully address this priority, BRAC invited Dr. Monica Hayes, Assistant Director of the Office of Minority Health (OMH) to its January 2010 meeting to discuss possible common interests. With the vision of health equity for all Floridians, OMH's mission is to assist statewide efforts to provide more culturally and linguistically competent health initiatives designed to reach emerging majority and historically underserved populations. Dr. Hayes' discussions with BRAC led to further conversations with BRAC and FL CURED to lay the groundwork for next steps for a health disparities initiative.

In April 2010, Dr. Hayes was invited to the FL CURED Advisory Council mini-summit where health disparities research was again discussed. Dr. Erin Kobetz, assistant professor, Department of Epidemiology & Public Health, University of Miami School of Medicine, was the featured speaker, discussing her work on cervical cancer in Haitian American women and the need to use community-based approaches to improve health in this population. An action item at the meeting resulted in the following motion:

*FL CURED staff should identify and convene a working group to explore the possibility of a series of meetings of appropriate experts and community members to define a pilot project for better methods to address health disparities.*

A Planning Committee representing BRAC, FL CURED and OMH began work in May 2010 to identify health disparities research (HDR) sessions as a part of the annual BioFlorida Conference, which FL CURED was co-hosting, and to plan a post-conference HDR Invitational Summit. Purposes identified for the HDR Invitational Summit were to: 1) identify a health disparities research agenda aligned to Florida's demography, 2) identify the core resources/infrastructure needs of independent investigators necessary to advance health disparities research in Florida, 3) explore interest in ongoing engagement of the Florida health disparities research community for synergistic purposes, and 4) gain insight that can help shape potential health disparities research grant opportunities through the Bankhead-Coley Cancer Research Program and/or the James and Esther King Biomedical Research Program. In addition, the planning committee identified determinants leading to health disparities of greatest research interest.

## **HEALTH DISPARITIES INVITATIONAL SUMMIT**

As a result of the planning, approximately 50 key researchers and opinion leaders representing universities and stakeholder organizations in Florida gathered at the Marriott Harbor Beach in Fort Lauderdale on October 26, 2010 to begin identifying priorities for the HDR research agenda. Participants broke into seven groups by random assignment and completed a nominal group technique exercise to generate preliminary ideas useful in the development of a HDR research agenda based on the following three challenge questions:

- *What are the three health disparities content areas that need critical descriptive/correlative research in order to move to intervention research?*
- *What are the three primary barriers that exist today to high-quality intervention research targeting at reducing health disparities in Florida (excluding funding)?*

- *What are the five most critical outcomes related to health disparities that should be addressed by intervention research over the next five years?*

Figures 1-3 show the results of the nominal group process. In general, the HDR Invitational Summit participants indicate health literacy and health care processes/delivery and their impact on health as key content areas that need to be researched. The key barriers identified to conducting intervention research include engaging the community and building the pipeline of underrepresented minority scientists. Most critical outcomes identified related to intervention research in the next five years included enhancing prevention/increasing use of prevention services and reducing disparities in mortality, especially in children and infants, and in obesity.

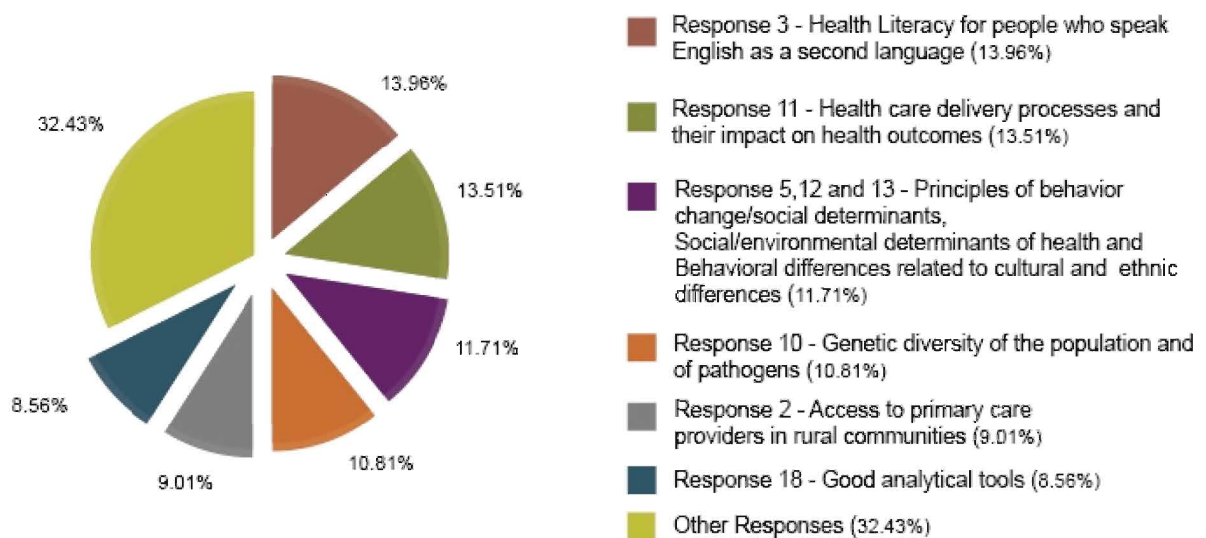
**HDR ADVISORY COMMITTEE**

Following the HDR Invitational Summit, a subset of the Planning Committee continued to meet to determine next steps. The decision was made that, in order to obtain desired goals, a HDR Advisory Committee would be formed to provide ongoing input. All HDR Summit participants, BioFlorida session speakers and other selected researchers and community stakeholders were invited to serve on the HDR Advisory Committee.

The final HDR Advisory Committee is comprised of 32 members who were invited to attend meetings on March 30 and May 19, 2011. Four members of the Advisory Committee served as a Leadership Team who worked in conjunction with FL CURED staff to plan the meetings. The HDR Advisory Committee was charged with drafting the HDR research agenda that would include research goals as well as core resources/infrastructure needs. Three Work Groups were formed, based on the expertise of the HDR Advisory Committee: Health Promotion/Prevention, Health Outcomes and Cancer/Genetics. The Work Groups developed their respective research agendas through interactive sessions at the HDR Advisory Committee meetings as well as through conference calls.

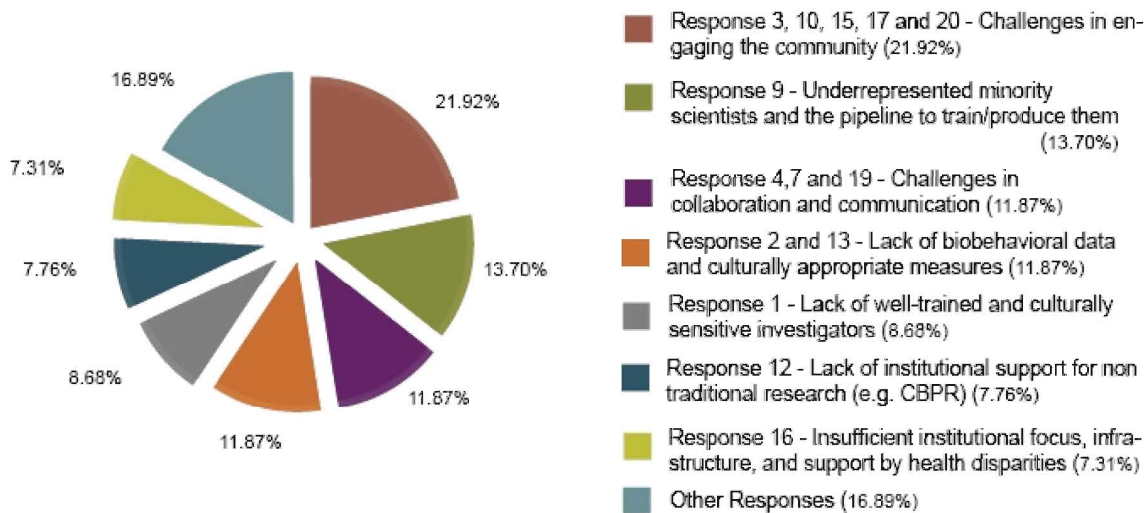
*Figure 1 - Challenge Question One Results*

**“What are the three health disparities content areas that need critical descriptive/correlative research in order to move to intervention research?”**



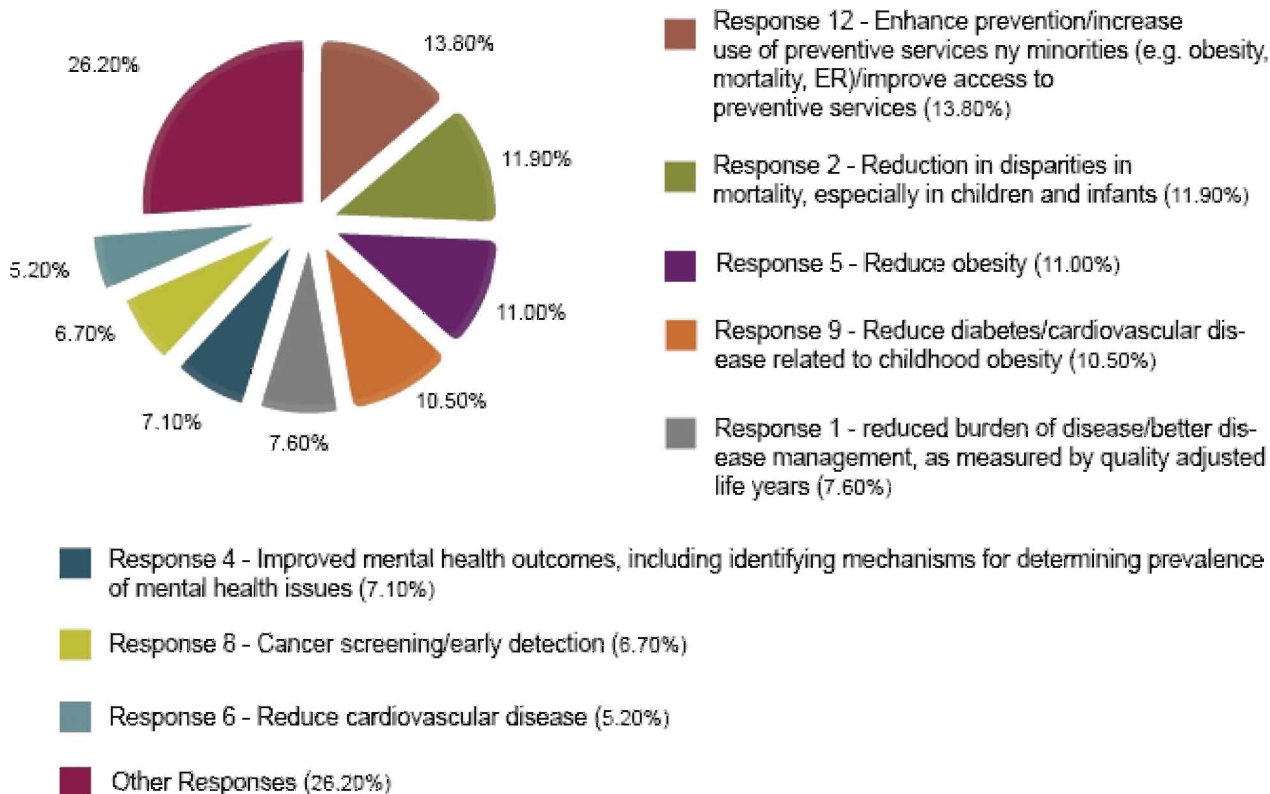
**Figure 2 - Challenge Question Three Results**

**“What are the three primary barriers that exist today to high-quality intervention research targeted at reducing health disparities in Florida (excluding funding)?”**



**Figure 3 - Challenge Question Three Results**

**“What are the five most critical outcomes related to health disparities that should be addressed by intervention research over the next five years?”**



In addition to the outcomes of the HDR Invitational Summit, the following information was presented at the HDR Advisory Committee meeting on March 30 to provide a context for the development of the research agenda.

### **Health Disparities in Florida**

Dr. Monica Hayes presented the following summary, based on Florida Department of Health CHARTS data. She cautioned that data only recently included populations other than African Americans and Whites. Further, within group data (e.g., diversity within Hispanic and Black populations) is essentially non-existent. She urged that a request for further disaggregation of data be taken into account in the development of the research agenda. Health disparities identified include the following:

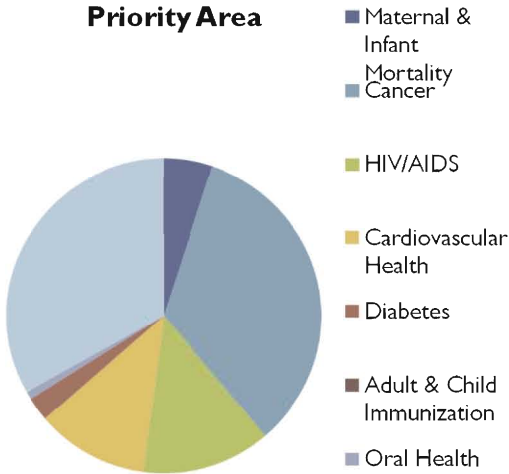
- Rates of death from coronary heart disease are about 15 percent higher among African-American/Black adults than among White adults.
- Stroke mortality rates in Florida in 2008 were about 30 percent higher among African Americans/Blacks than among Whites.
- Non-White women are more likely to be diagnosed with late-stage breast cancer and more likely to die from breast cancer than White women.
- The colorectal cancer death rate in Florida among African Americans/Blacks is approximately .5 times higher than the White population. African Americans/Blacks are more frequently diagnosed at later stages.
- The mortality rate for prostate cancer is more than 50 percent higher among non-White men than it is among White men.
- The diabetes mortality rate for non-White men and women in Florida is approximately 3 times the rate of White men and women.
- Racial and ethnic disparities continue to persist in maternal and child healthcare despite federal and state initiatives.
- A baby born to an African American/Black mother has more than twice the risk of dying the first year of life than a baby born to a White mother.
- African Americans/Blacks are more likely to receive certain less-desirable procedures, such as lower limb amputations for diabetes and other conditions. American Indians are more apt to have teeth extracted than filled.
- African Americans/Blacks represent 16% of Florida's population, but more than 50% of individuals living with HIV/AIDS.

### **Current Health Disparities Research in Florida**

FL CURED staff identified health disparities research already being conducted in Florida with funding from the National Institutes of Health (NIH) and Florida Biomedical Research Program (FBRP), using grant reporting databases from each funder. Currently-funded HDR projects from these sources were then compared to public health priority areas identified by the Florida Department of Health in its latest long-range strategic plan. This work enabled HDR Advisory Committee members to get a sense of Florida's current research capacity in each of the seven priority areas identified by DOH.

**Figure 4 – The 174 studies analyzed broke down as follows:**

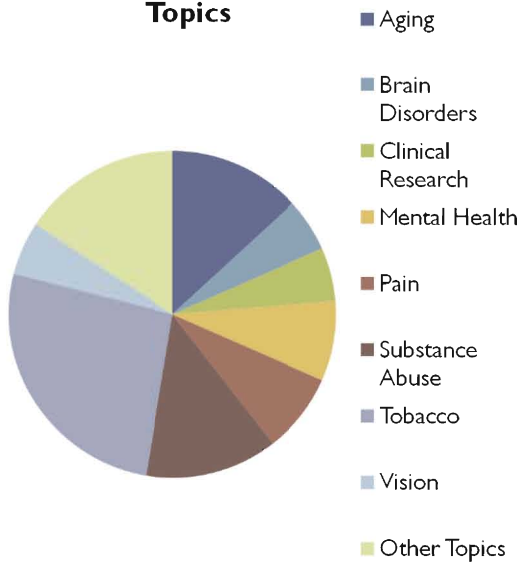
**Funded Projects by HDR Priority Area**



DOH Priority Area	Active Studies
Maternal & Infant Mortality	6
Cancer	94
HIV/AIDS	16
Cardiovascular Health	14
Diabetes	3
Adult & Child Immunization	0
Oral Health	3
Other	38

**Figure 5 – The 38 studies not included in any of the DOH priority categories covered the following topics:**

**Funded Projects on Other Topics**



Research Topic	Active Studies
Aging	6
Brain Disorders	2
Clinical Research	2
Mental Health	3
Pain	3
Substance Abuse	5
Tobacco	10
Vision	2
Other	6

Over 140 individual researchers were identified in the NIH and FBRP databases as actively conducting health disparities research in Florida. These investigators’ projects followed a relatively even distribution of basic science, clinical, and social/behavioral topics and methods. Source of funds (state versus federal) did not substantially impact the distribution of topics and methodology observed. Researchers engaging in HDR were found to have academic training primarily in biology, economics, epidemiology, health services, medicine, and/or sociology.

Despite the wealth of HDR projects identified in the NIH and FBRP databases, it was noted during the March 30 meeting that many other funders exist for HDR activities, and it may be difficult to identify and quantify all the research currently being conducted in Florida on HDR topics. HDR Advisory Committee members identified lack of infrastructure for tracking research as a key capacity issue to be addressed in creating a health disparities research agenda for the state. In fact, only a small fraction of HDR Advisory Committee members came up as “hits” in the NIH and FBRP database searches despite conducting active research funded by one or both entities, suggesting that even within major funding organizations, mechanisms for tracking and aggregating information about HDR remain far from robust.

### Research Frameworks

Three research frameworks were presented by Drs. Folakemi Odedina and Lee Green at the March 30 HDR Advisory Committee meeting to provide a context for the development of the health disparities research agenda:

- **Translation Research:** Transforms scientific discoveries arising from laboratory, clinical, or population studies into clinical applications to reduce disease incidence, morbidity and mortality. The translation continuum includes basic science discovery, early translation, late translation, dissemination and adoption.
- **Processes of Care:** Includes the continuum for health and healthcare composed of prevention and healthy lifestyles, screening and diagnostic follow-up, treatment and care delivery, and quality of life in survivorship through end of life.
- **Systems Approach:** An integrated model that includes social, behavioral and genetic interactions. The Institute of Medicine (IOM)’s report on *Genes, Behavior and the Social Environment*<sup>4</sup>, provides the following recommendations regarding this model:
  - 1) conduct transdisciplinary, collaborative research;
  - 2) measure key variables (social, behavioral and psychological, genetic, and physiological) over the life course within the context of culture;
  - 3) develop and implement new modeling strategies to build predictive models of etiologically heterogeneous disease;
  - 4) investigate biological signatures; and
  - 5) conduct research in diverse groups and settings.

Other research frameworks were discussed and used by the Work Groups.

### HEALTH DISPARITIES RESEARCH AGENDA: VISION AND PLANNING

This research initiative has the overarching vision of *achieving health equity for all Floridians*. This goal is addressed through the mission, which is *to develop and implement the Health Disparities Research (HDR) Agenda for Florida through proactive collaborations among academic institutions, healthcare providers, government organizations, community-based organizations and faith-based organizations*.

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<sup>4</sup> Institute of Medicine of the National Academies. (2006). *Genes, Behavior and the Social Environment: Moving Beyond the Nature/Nurture Debate*. Board on Health Science Policy. Available at: [http://www.nap.edu/catalog.php?record\\_id=11693](http://www.nap.edu/catalog.php?record_id=11693)

In planning the research agenda, the process was inclusive, starting with the statewide HDR Invitational Summit, followed by an open call to Summit attendees and non-attendees to join the HDR Advisory Committee, and then an interactive, collaborative process to develop the agenda itself. Those involved represented different disciplines, institutions and locations across the state. Further, community representatives from the Jacksonville area, where the HDR Advisory Committee meetings were held, were engaged in both meetings and in follow-up conference calls to provide stakeholder input and direction. Other input will be sought from stakeholders around the state as we continue to finalize the research agenda.

As the HDR Advisory Committee began its work, we examined literature on health disparities that reports major areas of concern the differences in preventive and screening services across different racial/ethnic groups as well as differences in processes of care and health outcomes in a variety of diseases, particularly cardiovascular conditions, cancer, infant mortality and HIV. Based on this evidence, three areas of priority were selected:

- **Health Promotion:** Includes all issues related to modification of health behaviors, promotion of screening services, communication between health care organizations and patients and other issues that can prevent the occurrence of disparities using a population based approach;
- **Health Outcomes:** Evaluates the extent of health disparities across a number of health conditions as well as their determinants and the impact of interventions on these disparities; and
- **Cancer/Genetics:** Generates a more in depth agenda of research for this important source of health disparities in Florida.

Strengths and gaps were identified in the three priority areas (i.e., Health Promotion/Disease Prevention, Health Outcomes and Cancer/Genetics). Strengths represented research questions that are answered and generally accepted (What we know). Gaps represented research questions that need to be answered (What we don't know). Further strengths and gaps in research capacity—the existing core resources/infrastructure needed for health disparities research—also were identified. The strengths and gaps are included in the introductory section to each priority area. As the health disparities research agenda was further developed, research directions were identified from the gaps in knowledge and research capacity in the state. Consensus was reached after numerous robust discussions at the HDR Advisory Committee meetings and on conference calls. As a result of this process, areas of emphases or broad research topics were identified followed by the development of research objectives for each emphasis area. Finally, selected research questions were generated and included with some of the research objectives. This framework provides the high priority work on health disparities that, from the view of the HDR Advisory Committee, should be undertaken.

Although this research agenda represents the work of several scholars and community representatives in Florida, it has several limitations that should be mentioned. First, this effort, undertaken with limited time and resources, necessarily reflects the expertise of the HDR Advisory Committee members and community representatives. Further work will be required to ensure that the research agenda reflects in a comprehensive way the health disparities research needs in the state. Given this limitation, this research agenda is appropriately titled Phase I and, as such, should be used as a starting point for further development. Second, there were issues

regarding target populations and language used in articulating these populations. In particular, the need to be inclusive in terms of race/ethnicity, gender, socioeconomic status, place of residence, sexual orientation, country of origin, among many others, was carefully considered. The HDR Advisory Committee itself, although representing varied groups and backgrounds, examined its own shortcomings in diversity and will be reaching out to other scholars and community stakeholders to ensure that the research agenda is truly illustrative of Florida demography.

### **NEXT STEPS**

The next steps for the research agenda are to plan for public input and feedback from community stakeholders and health disparities researchers. This will include posting the research agenda on the websites of the sponsoring organizations, including FL CURED, the Biomedical Research Advisory Council and the Office of Minority Health. Secondly, the research agenda will be presented at various meetings throughout the state, including meetings with community stakeholders. Following this review, the research agenda will be finalized and published. However, the research agenda should continue to be a “living document” that will evolve and change as new knowledge is generated and translated into policies and practices to improve health. Further, it is hoped that the health disparities research community itself will take leadership to expand the research agenda and ensure its implementation. Most importantly, this research agenda and subsequent versions are a call to action to take seriously the need for evidenced-based information to reduce and eliminate disease burden and to improve the health of all Floridians.

## **RESEARCH GOALS**

The following are the major, cross-cutting research goals identified by the HDR Advisory Committee.

- Advance the understanding of the relationships between multi-level health determinants (such as genomics, environment, behavior, cultural norms/beliefs/values) and health disparities using multiple levels of analysis across the life span.
- Develop cost-effective and sustainable health intervention programs that are culturally competent and linguistically sensitive to the ethnic/racial emerging majority, medically underserved, rural, and socioeconomically disadvantaged populations.
- Develop new or improved approaches for disseminating evidence-based health promotion and disease prevention information to ethnic/racial emerging majority, medically-underserved, rural, and socioeconomically disadvantaged populations.
- Improve quality of life of ethnic/racial emerging majority, medically underserved, rural and socioeconomically disadvantaged populations by implementing best practices to prevent, manage or reduce the recurrence of disease.

## RESEARCH CAPACITY GOALS

The following are the major, cross-cutting research capacity goals identified by the HDR Advisory Committee.

- Develop infrastructure for research on health disparities, including, among others, collaborative bio-banks, registries and health informatic systems (i.e., electronic medical records systems and patient health portals).
- Improve quality, accuracy and specificity of data in registries and health informatic systems (e.g., accuracy of ethnic/racial identifiers, inclusion of ancestry/country of origin and years in the United States as mandatory data).
- Promote the involvement of ethnic/racial, rural and medically underserved populations in research, seeking necessary resources to recruit and retain their participation in multiple types of health research.
- Engage, develop and sustain equitable academic-community partnerships that facilitate health disparities research.
- Engage, develop and sustain partnerships between minority serving institutions and health care centers (e.g., cancer centers) to facilitate health disparities research, education, training and community outreach.
- Facilitate statewide translational research for community stakeholders, clinicians, population scientists and basic scientists in order to provide an avenue for scientific exchange that will facilitate transfer of knowledge from trench (community) to bench to bedside and back.
- Increase access to new genomic and other emergent technologies available in the state to improve diagnostics and treatments for all cancers as well as other diseases.
- Provide a collaborative mechanism to educate current and future researchers to effectively engage in culturally and linguistically competent/sensitive research.
- Build capacity to disseminate evidenced-based best practices from health disparities research.
- Identify, train and mentor the next generation of health disparities researchers.

## HEALTH PROMOTION/DISEASE PREVENTION

### STRENGTHS AND GAPS

The following are the strengths and gaps in relation to health promotion/disease prevention research in the state of Florida.

#### Strengths

- Types of research fellowship/training programs within the state that are successful in producing underrepresented minority investigators, including the most successful strategies used by these programs.

- Existing university-university and university-community research partnerships to support health promotion and disease prevention research.
- Access to diverse communities in Florida, including those that will benefit from health promotion research and related interventions.
- Researchers, including minority researchers, who are willing to share their data.
- Active health seekers willing to participate in health promotion interventions.
- Participatory action is occurring with increasing numbers of community-based participatory studies.
- Support of health promotion and disease prevention research by FL CURED and similar organizations.

### **Gaps**

- Inadequate funding for health promotion and disease prevention research, particularly community-based participatory research.
- Under-representation of the following groups in health promotion and disease prevention research: epidemiologists, the aging, policy researchers, representatives from various targeted populations, physicians and non-profit organizations.
- Limited number of culturally and linguistically competent/sensitive investigators and few programs for training such researchers.
- A near absence of culture-specific/relevant theories/models for informing health promotion and disease prevention research.
- Institutional Review Boards that do not understand the challenges involved in conducting community-based participatory research.
- Lack of use of certified translators to translate research assessments and other research materials.

## **OVERARCHING GOALS**

### **Research**

- Advance our understanding of the influences on population health across the life cycle and at multiple levels of analysis, including individuals, family, community, social and physical environment, policy and health care delivery.
- Develop and evaluate culturally and linguistically competent/sensitive health promotion, disease prevention and intervention approaches at multiple levels, including individuals, communities, health care delivery and policy and legislative efforts.
- Determine best practices for disseminating health promotion, disease prevention and intervention approaches at multiple levels, including individuals, communities, health care delivery and policy and legislative efforts.

### **Research Capacity Goals**

- Allocate funding to engage, develop and sustain equitable, community-academic partnerships for health equity research.
- Educate current and future researchers and communities to effectively engage, communicate and interact as partners in conducting culturally and linguistically competent/sensitive research.

- Allocate funding/resources to recruit and retain diverse underrepresented populations in multiple types of health research.
- Build capacity to develop and implement health informatics systems (including electronic medical records systems and patient health portals) to support evaluation of health outcomes.
- Build capacity to disseminate effective intervention, health promotion and disease prevention strategies.
- Identify and enhance existing partnerships with non-profit organizations and coalitions involved in health disparities research.

## RESEARCH EMPHASES AND OBJECTIVES

### *Area of Emphasis 1: Risk Recognition (Knowledge, Health Beliefs, and Risk Perceptions)*

*Objective 1 - Identify different models of diseases (including knowledge and health beliefs) of minority and underserved individuals, as well as among different target groups (by age, gender, sexual orientation, physical ability/disability status, rural vs. urban residence and English proficiency or primary language) within these populations.*

1.1 Determine differences in the mental models or conceptualizations of disease (diabetes, CVD, obesity, among others) as expressed by different ethnic groups (e.g., as in the case of Black populations, these groups need to be differentiated by key independent variables including region of origin such as African American vs. Haitian American).

1.2 Determine differences in mental models or conceptualizations of disease as expressed by specific target groups (by age, gender, sexual orientation, physical ability/disability status, rural vs. urban residence and English proficiency or primary language) within these high-risk populations.

*Objective 2 - Identify perceptions of risk to different diseases among minority and underserved individuals, as well as among different target groups (by age, gender, sexual orientation, physical ability/disability status, rural vs. urban residence, and English proficiency or primary language) within these populations.*

2.1 Determine perceptions of risk to different diseases as expressed by different ethnic groups (and specific populations within these groups, differentiated by key independent variables including region of origin such as African American vs. Haitian American).

2.2 Determine perceptions of risk to different diseases as expressed by specific target groups (by age, gender, sexual orientation, physical ability/disability status, rural vs. urban residence and English proficiency or primary language) within these high-risk populations.

*Objective 3 - Evaluate the effectiveness of novel technologies for monitoring individual behaviors to determine and stratify risks for targeted interventions.*

### *Area of Emphasis 2: Behavior Change (Reducing Health Risk Behaviors)*

*Objective 1 - Identify motivators of and strategies to eliminate health risk behaviors among minority and underserved individuals, as well as among different target groups within these populations.*

*Objective 2 - Determine key barriers to behavior change related to different unhealthy or risky behaviors among minority and underserved individuals, as well as among different target groups within these populations.*

*Objective 3 - Test ecological/environmental and biophysiological models for understanding the occurrence of health risk behaviors among minority and underserved individuals, as well as among different target groups within these populations.*

*Objective 4 - Determine the influence of cultural values, family/social support, religious/spiritual beliefs, and fatalism on the occurrence of health risk behaviors among minority and underserved individuals, as well as among different target groups within these populations.*

4.1 Evaluate the extent to which cultural values, religion and fatalism contribute to inadequate incorporation of preventive behaviors among different population groups.

4.2 Identify effective methods for addressing barriers to preventing chronic disease related to cultural values, religious/spiritual beliefs and fatalism.

*Objective 5 - For each of the target groups, assess the relationship between psychological health indicators (e.g., levels of stress, racism related stress, mild depression, fatalism, life engagement and sense of well-being) on risk behaviors.*

*Objective 6 - Identify effective self-management techniques/mechanisms and programs for reducing health risk behaviors among minority and underserved individuals, as well as among different target groups within these populations.*

### ***Area of Emphasis 3: Delivery of Health Promotion and Disease Prevention Interventions/Programs***

*Objective 1 - Determine the efficacy of health risk reduction interventions/programs targeting minority and underserved populations including sub-groups within these populations.*

1.1 Determine the impact of health risk reduction interventions/programs implemented by Community Health Workers on health risk behaviors of minority and underserved individuals as well as different target groups within these populations.

1.2 Test the effectiveness of clinic-based, school-based, church-based and community center-based health risk reduction interventions/programs on health risk behaviors of minority and underserved individuals as well as different target groups within these populations.

*Objective 2 - Identify best practices for delivering behavior change interventions among minority and underserved populations (particularly appropriate delivery methods/modes including the use of evolving and emerging technologies).*

2.1 Determine effectiveness of population-specific efforts for different messaging/messengers and communications technologies for improving individual knowledge, empowering targeted individuals and populations, and enhancing self-efficacy for participating in healthy behaviors.

- 2.2 Explore effective methods for developing tailored/customized health promotion and disease preventions strategies using individual motivators of and perceived barriers to behavior change as well as other psychosocial determinants of health behaviors.
- 2.3 Explore the effectiveness of consumer health informatics systems/applications (i.e., patient health portals, mobile technologies, health games, among others) for health promotion and disease prevention among different target groups.
- 2.4 Determine appropriate methods for communicating the need to invest in healthy behaviors among people in low socioeconomic risk groups (e.g., taking into consideration the proximate costs of filling a prescription or buying and eating healthy foods vs. the distal individual, family and community costs from chronic disease complications; and the impact on families from one generation to another).
- 2.5 Develop and test interventions to increase health promoting/disease preventing behaviors or decrease health risk behaviors among individuals within each target group who evidence low intellectual or cognitive functioning and low daily living functioning (e.g., patients with brain injuries, chronic brain syndrome or labeled developmentally delayed).
- 2.6 Develop and test interventions to increase health promoting/disease preventing behaviors or decrease health risk behaviors among patients within each target group experiencing mental illness or severe psychological problems (e.g., clinical depression).

*Objective 3 - Evaluate different and evolving social support systems/mechanisms for motivating and promoting healthier behaviors among minority and underserved individuals, as well as among different target groups within these populations.*

- 3.1 Determine the relative value of traditional sources of social support for motivating, promoting and maintaining healthy behaviors among minority and underserved individuals, as well as among different target groups within these populations.
- 3.2 Determine how different individuals from different population groups use social networking media for health seeking/management.

#### ***Area of Emphasis 4: Healthcare Provider-Patient Relationships***

*Objective 1 - Determine the cultural/linguistic competency/sensitivity of healthcare providers in communicating health promoting and disease prevention messages to patients.*

- 1.1 Determine barriers preventing healthcare providers from being culturally and linguistically sensitive/competent.
- 1.2 Explore effective tools, strategies, technologies and health policies for overcoming the factors that prevent healthcare providers from being culturally and linguistically sensitive/competent.
- 1.3 Evaluate the effectiveness of existing cultural/linguistic competency/sensitivity training programs for healthcare providers and medical students.
- 1.4 Determine the relationship of cultural and linguistic sensitivity, competency and specificity to healthcare providers' ability to address the needs of patients.
- 1.5 Test the effectiveness of research-informed interventions/programs designed to increase healthcare providers' cultural competency in delivering health promotion/disease prevention information to patients in each target group.
- 1.6 Identify/disseminate best practices related to education on cultural/linguistic competency/sensitivity.

*Objective 2 - Assess health promotion/disease prevention and health risk reduction knowledge of healthcare providers, and determine if this differs by provider variables (e.g., race/ethnicity, age, gender, specialty, among others).*

*Objective 3 - Determine effective strategies, programs and/or technologies to empower patients to better communicate their needs to different healthcare providers and within the clinical encounter.*

3.1 Determine the specific kinds of health information patients want to receive from their healthcare providers.

3.2 Assess the perceptions of patients regarding the amount and quality of the health information they receive from their healthcare providers.

3.3 Explore different approaches for addressing disparities in health literacy and for improving competencies and skills crucial for understanding medical instructions and health information.

3.4 Evaluate methods for introducing and measuring impacts of motivational interviews in the clinical encounter on the health promoting/disease preventing behaviors of patients.

3.5 Evaluate the use of motivational interviewing in primary, secondary or tertiary approaches outside of the clinical setting (e.g., efforts related to community-based health education, smoking cessation programs and obesity programs that include nutrition and exercise interventions).

### ***Area of Emphasis 5: Health Promotion/Disease Prevention Research***

*Objective 1 - Increase participation of racial and ethnic minority populations and other underserved populations in health behavior and risk reduction research.*

1.1 Identify culturally and linguistically sensitive strategies/technologies and venues for involving different target groups in health promotion/disease prevention research.

1.2 Identify strategies for significantly reducing research dropout rates among each of the target group.

*Objective 2 - Identify and implement practical, culturally and linguistically sensitive strategies, tools, and technologies for involving members of each target group in assessing their a) motivators of and barriers to health promoting/disease preventing behaviors, b) health priorities/concerns, c) motivators for engaging in health risk behaviors, d) health promoting behaviors and e) health risk behaviors (e.g., taking into consideration the proximate costs of filling a prescription, or buying and eating healthy foods vs. the distal individual, family and community costs from chronic disease complications).*

*Objective 3 - Determine effective strategies for increasing participation and maintaining continued engagement of health disparate populations in health promotion and disease prevention interventions.*

*Objective 4 - Design and evaluate the use of novel, technology-based approaches (e.g., using patient health portals, mobile technologies, health games and social media) for monitoring, facilitating and/or evaluating outcomes of behavior change interventions targeted to health disparate populations.*

*Objective 5 - Determine the cost-effectiveness and sustainability of different approaches for delivering health promotion and disease prevention interventions targeted to health disparate populations.*

## HEALTH OUTCOMES

### STRENGTHS AND GAPS

The following are the strengths and gaps in relation to health outcomes research in the state of Florida.

#### Strengths

- Florida is a diverse state and provides an opportunity to study health outcomes with a range of vulnerable populations.
- Existing health infrastructure includes innovative models such as health insurance reform pilots, healthcare incubators, and successful demonstration projects (e.g., diabetic patients and peer mentoring, Master Diabetes Clinician program), among others.
- A history of collaboration between major institutions of higher learning on health care and health-related research.
- Florida higher education institutions are participating in a NIH-funded Clinical & Translational Science award (CTSA) project, which translates discoveries to medical practice.

#### Gaps

- Data, particularly longitudinal, pharmacy and diagnostic data, are not readily available through state sources (Agency for Health Care Administration/Medicaid/Medicare) or through data repositories in existing health organizations.
- Lack of culturally and linguistically sensitive services.
- Lack of accurate ethnic/racial identification data in existing databases.
- Lack of relationships between the academic and healthcare sectors to facilitate data availability, translation of science and improvement of care.
- Lack of information technology resources to build data infrastructure in the state.
- Lack of research capacity, especially in having a qualified and diverse workforce to prepare grants, interpret data and to design meaningful, impactful interventions.
- Lack of studies that focus on processes of care (e.g., medication adherence).
- Lack of studies that focus on children and older adult populations.

## OVERARCHING GOALS

### Research Goals

- Identify factors contributing to health disparities in disadvantaged populations across the lifespan.
- Identify strategies to improve health outcomes and reduce health disparities in disadvantaged populations across the lifespan.
- Identify community infrastructure and feasibility for health outcomes interventions.
- Use a theoretical framework to develop and/or test interventions.

### Research Capacity

- Develop infrastructure for research on health disparities and health outcomes at the state-wide level. This can include the creation of registries and/or data repositories linked to the developing electronic medical records of health systems serving vulnerable populations.
- Promote and involve minority, ethnic and vulnerable populations in research.
- Establish and identify funding sources for the support and development of infrastructure, training, inter-university collaboration and on-going research.
- Develop research capacity for community-based participatory research and meaningful partnerships.

## RESEARCH EMPHASES, OBJECTIVES AND QUESTIONS

### *Area of Emphasis 1: Research on Pediatric, Adult, and Geriatric Populations*

*Objective 1 - Identify health disparities and establish measurable health outcomes for the following groups, using comparative studies and national, state and local data to determine benchmarks for the improvement of health outcomes.*

- What are the disparities in pediatric populations related to the following health conditions?
  - Infant mortality
  - Childhood obesity
  - Asthma
  - HIV/AIDS and sexually transmitted infections
  - Severe emotional and behavior disorders
  - Transitioning youth with chronic disease
  - Violence and injury
- What are the disparities and predictors of disparities in adult populations related to the following health conditions?
  - Cardiovascular disease including diabetes, hypertension, hyperlipidemia, ischemic heart disease and congestive heart failure
  - Tobacco exposure and use
  - Respiratory diseases such as COPD and asthma
  - HIV/AIDS and sexually transmitted infections
  - Severe emotional and behavior disorders
  - Cancer

- Other measurable disease processes
- Violence and injury
- What are the disparities in geriatric populations related to the following health conditions?
  - Congestive heart failure
  - Variety of cancers
  - Alzheimer's and dementia
  - Independent functioning
  - Respiratory diseases
  - Sensory loss (vision and hearing impairments)
  - Violence and injury
  - Pain management
  - Multiple chronic condition

*Objective 1 - Identify the mediators of health disparities and health outcomes for pediatric, adult and geriatric populations.*

- What are the mediators of health disparities? Factors to consider include:
  - Patient related factors including race, socioeconomic status, geographic area of residence, country of origin, language, health literacy, health beliefs and values, trust and other factors.
  - Quality of care including access to care, patient physician communication, provider training, system barriers to diagnosis and treatment, bias/prejudice, among others.
  - Insurance such as type of insurance, Medicaid, uninsured, underinsured, co-payments.
- Specific questions that should be addressed include:
  - What is the relationship between access to and quality of care and disparities in health?
  - How does system level racism and discrimination impact access to and quality of care and produce health and health care disparities?
  - What models are most effective for monitoring access to and quality of care for minorities?
  - What is the best measure of consumer satisfaction? What is the impact of cultural and linguistic competency on measures of consumer satisfaction?
  - What is the impact of patient attitudes and preferences on access to care, quality of care and health care outcomes? Do patient preferences contribute to racial differences in medical procedure use?

### *Area of Emphasis 2: Identification of Interventions to Improve Health Outcomes*

*Objective 1 - Identify interventions, including both traditional designs as well as implementation studies, for improving health outcomes and reducing health disparities in vulnerable populations.*

- Specific questions that should be addressed include:
  - Can interventions that link academic and community efforts improve processes of care, quality of care and health outcomes? What are those interventions? What components do they have?

- What interventions (such as partnerships, personal navigators, hotlines, among others) improve quality of care and outcomes of care for at risk patients?
- What alternate models of delivering outpatient and inpatient services can reduce health disparities in the conditions of interest?
- What health system interventions can reduce health disparities and improve outcomes (e.g. mandatory use of translators, measurement of provider performance regarding disparities in process of care, use of post discharge Community Health Workers, among others)?
- Can we identify low cost strategies that can reach a large number of at-risk populations and improve quality of care (e.g., use of technology, phone based interventions and partnerships with health benefits companies or health departments)?
- What interventions are successful in modifying health behaviors such as medication adherence, appropriate diet, exercise and adherence to preventive screening or visits.
- What strategies improve patient-physician communication, trust and either improve or help overcome low health literacy?
- What interventions improve the patient centeredness and/or cultural sensitivity of providers/clinics that serve minority populations?
- What technology-based interventions help prevent systemic causes of disparities in at risk populations (e.g., tele-health to improve quality of care in rural settings, alerts to signal what is the benchmark treatment for a particular admission diagnosis such as chest pain, alerts that determine if the blood pressure measurement is above desired reference or that patient is not refilling medications)?
- Can training or continued medical education formats improve the quality of care delivered to at-risk populations in areas where disparities are known and relevant? Can these approaches reduce health disparities?

## RESEARCH CAPACITY EMPHASES AND OBJECTIVES

### *Area of Emphasis 1: Increase the infrastructure and resource funding for health disparities research*

#### *Objective 1 – Increase data infrastructure by:*

- Developing databases, which include but are not limited to registries and repositories.
- Developing statewide repositories of readily accessible datasets that could be used by investigators for relatively low cost (e.g., national datasets having Florida specific data, Veteran’s Administration data for Florida, limited claims based datasets, Medicare private insurance).

#### *Objective 2 - Increase new investigator funding for:*

- Training and fellowship opportunities
- Start up funding for pilots studies, mentored awards, minority supplements and secondary data analysis projects

#### *Objective 3 - Increase established investigator support, including:*

- Grants for pilot studies
- Mid-career non-mentored awards

- Investigator initiated research grants
- Center grants
- Grants for re-analysis and secondary data analysis of existing data

*Objective 4 - Provide support for community engaged research, including:*

- Community and academic partnerships not limited to universities, public health, health care organizations, community groups and health advocacy groups
- Training and development for community-based research

### ***Area of Emphasis 2: Education and training in health disparity-related research skills***

*Objective 1 - Provide education and training support for investigators' professional development, including the following topics:*

#### **Introductory topics**

- Cultural and linguistic competency
- Health literacy
- Advanced research design and methods
- Training on community-based participatory research

#### **Advanced topics**

- Best practices for development of academic, clinical and community partnerships
- Formulation of academic research so that it is informed and responsive to community needs and priorities
- Identification of community and infrastructure needs through using community-based participatory research approaches
- Best practices for pilot testing of interventions in target populations
- Identification of training program characteristics that can successfully train investigators for culturally sensitive and culturally informed research questions and interventions
- Types of research fellowship/training programs within the state that are most successful in producing underrepresented minority investigators, including the most successful strategies used by these programs?

## **CANCER/GENETICS**

### **STRENGTHS AND GAPS**

The following are the strengths and gaps in relation to cancer/genetics research in the state of Florida.

#### **Strengths**

- Strong programs for several major cancers (e.g., breast) exist at multiple levels (i.e., educational, community outreach and engagement, research) in individual silos across the

state. These programs need to be cohesively brought together into statewide programs than can ultimately reduce cancer disparities.

- We have tremendous technological capabilities in the state to conduct state-of-the-art genomic investigations (i.e., gene expression profiling, large-scale sequencing) to determine subtypes of cancer, with the outcome of developing better, tailored treatments to the subtypes of cancer in minority populations. Individual research programs already exist for some of these cancers, but efforts are needed to unify and strengthen this work.
- There are people interested in health disparities in many communities in the state, but few funds get beyond the researchers who have direct access to the dollars.
- We have diverse scientists who are interested in health disparities from many different disciplines, training and backgrounds. How do we capitalize on their interests and increase the breadth and depth of our workforce in health disparities?

### Gaps

- At the statewide level, public policy tends to lag behind the translation of research, which affects collective implementation of health practices that can improve health.<sup>5</sup>
- Lack of sufficient detail in ethnic and racial categories for patients in the Florida health system, which is an issue across and within various levels of health organizations in the state. Improvement is needed in order to begin to establish more accurate and helpful links between race/ethnicity and health outcomes.
- Intervention efforts stop when funds dry up, thus sustainability of cost effective interventions in the community is lacking.
- Academic-community partnerships are often threatened due to lack of true equity in the partnerships, especially in budgetary allocations in proposals.
- There is limited training in cultural and linguistic competency for health disparities researchers and a lack of coordination to develop such a mechanism in order to provide this training.
- There is no centralized data collection in the state by ethnicity subtypes which is greatly needed.
- There is a lack of research investigating psychosocial factors related to disparity in various cancers.

## OVERARCHING GOALS

### Research

- Advance the understanding of the relationships between multi-level determinants (such as genomics, environment, behavior, cultural norms/beliefs/values, among others) and cancer health disparities with the ultimate endpoint of targeted interventions.

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<sup>5</sup> See Mirvis, DM. (2009). From research to public policy: An essential extension of the translation research agenda. *Clinical and Translational Science*, 2(5), 379-381.

- Develop cost-effective, sustainable community centered interventions for cancer prevention and control.
- Understand/Improve cancer survivorship experiences of racial ethnic, medically underserved, low socioeconomic populations to reduce recurrence and improve quality of life.

### **Research Capacity**

- Develop four regional, collaborative bio-banks (cases and controls) as a shared resource for Florida using Moffitt's Total Cancer Care (TCC) as a model.
- Link bio-bank data to appropriate epidemiologic data.
- Improve the specificity of cancer registry data. Include ancestry/country of origin and years in the United States as mandatory data fields for state hospital registries.
- Develop and sustain academic-community partnerships to foster cancer disparities research and intervention.
- Create a safety-net that provides necessary and timely follow-up and treatment for persons who participate in cancer prevention and control research efforts.
- Promote cancer center-minority serving institution partnerships for health disparities research, education, training, and community outreach.
- Facilitate statewide translational research for community stakeholders, clinicians, population scientists and basic scientists in order to provide an avenue for scientific exchange that will facilitate transfer of knowledge from trench (community) to bench to bedside and back.
- Increase access to new genomic and other emergent technologies available in the state to improve diagnostics and treatments for all cancers.

## **RESEARCH EMPHASES, OBJECTIVES AND QUESTIONS**

### *Area of Emphasis I: Prostate Cancer Disparities*

#### *Objective 1 - Develop a bio-behavioral risk model for prostate cancer among Black men.*

- What is responsible for the high prostate cancer burden among Black men?
- Does the similar genetic characteristic of Black men of west and central African ancestry put them at higher risk for prostate cancer compared with other groups?
- What is the relative contribution of genetic, lifestyle and environmental factors in prostate cancer incidence and mortality among Black men?
- Are there common environmental conditions/lifestyle factors among Black men that may be responsible for the prostate cancer burden experienced by this group?

#### *Objective 2 - Identify cost-effective community-centered interventions for prostate cancer control and prevention.*

- Which intervention programs can best be sustained in the community for prostate cancer control and prevention?

#### *Objective 3 - Study the influence of US Nativity on prostate cancer morbidity and mortality.*

- Is there a prostate health advantage for foreign-born Black men compared to native-born Black men?

*Objective 4 - Understand genetics responsible for disease progression/relapse in Black and White Prostate Cancer Patients in Florida.*

- Compare gene expression profile of prostate tumors in Black men and White men in Florida.
- Compare treatment outcomes for clinically significant prostate cancer in Black and White men in Florida.
- Compare prediction of response to therapy, progress and progression of prostate cancer in Black men and White men in Florida.
- Apply circulating tumor cell technology to Black men and White men with prostate cancer.
- Is the gene expression profile of prostate tumors in U.S. born Black men and in Black men of west and central African ancestry similar and can it be used to tell us why U.S. Black men are at higher risk for prostate cancer compared with other groups?

*Area of Emphasis 2: Breast Cancer Disparities*

*Objective 1 - Develop a bio-behavioral risk model for breast cancer among Black, Hispanic and Haitian women.*

- What is responsible for the high breast cancer burden among minority/disparate populations?
- Does similar genetic characteristic(s) of Black women of west and central African ancestry put them at higher risk for breast cancer compared with other groups? How does ancestry factor into risk for Hispanic and Haitian women?
- What is the relative contribution of genetic, lifestyle and environmental factors in prostate cancer incidence and mortality among disparate populations?
- Are there common environmental conditions/lifestyle factors among ethnic groups that may be responsible for the increased breast cancer burden experienced by these groups?

*Objective 2 - Further understand the genetic contributions to disparities in breast cancer morbidity and mortality in women in minority/emerging majority populations in the state of Florida.*

- Compare the gene expression profile of breast cancer tumors in Black, Hispanic, Haitian, and White women in Florida.
- Compare treatment outcomes for clinically significant breast cancer in Black, Hispanic, Haitian, and White women in Florida.
- Compare prediction of response to therapy, progress and progression of breast cancer in Black, Hispanic, Haitian, and White women in Florida.
- Apply circulating tumor cell technology to Black, Hispanic, Haitian and White women in Florida.

*Objective 3 - Implement and evaluate community-based interventions to improve disease outcomes.*

- Are there new screening techniques that better resonate with community and cultural barriers to prevention?
- How can we best integrate Community Health Workers into education, research and intervention to close gaps in formal-informal healthcare system?

### *Area of Emphasis 3: Cervical Cancer Disparities*

*Objective 1 - Determine which population sub-groups contribute to excess disease incidence.*

- Which Black and Hispanic ethnic subgroups experience an increased risk of cervical cancer incidence and mortality?
- How is disease geographically distributed across the state of Florida? Can Surveillance, Epidemiology and End Results (SEER) registries and modeling techniques be used to identify communities that are at increased risk and therefore appropriate for intervention?

*Objective 2 - Develop academic-community partnerships (specifically in communities identified as part of Objective 1) to sustain CBPR efforts that can meaningfully address cervical cancer disparity.*

- Who are appropriate community stakeholders?
- How do we engage them in partnership?
- Where does cancer fall on their list of health and other priorities?
- What do stakeholders identify as important focus on inquiry? Gaps in knowledge?
- What is their historical experience with research?

*Objective 3 - Identify multi-level determinants of cervical cancer risk between and within diverse populations and solutions for change.*

- What are screening practices of diverse populations? Current population statistics group persons into homogenous categories of race/ethnicity, which masks meaningful variability in disease risk.
- What is HPV prevalence and type distribution between and within diverse populations across Florida?
- Do unique type distribution contribute to disease onset/progression in diverse populations (e.g., retrospectively typing tumor specimens/FFPE blocks, stratified by ancestry)?
- What biologic and behavioral factors contribute to HPV susceptibility and persistence between population sub-groups?

*Objective 4 - Implement and evaluate community-based interventions to improve disease outcomes.*

- Are there new screening techniques that better resonate with community and cultural barriers to prevention?
- How can we best integrate Community Health Workers (CHWs) into research and intervention to close gaps in formal-informal healthcare system?

### *Area of Emphasis 4: Colon Cancer Disparities*

*Objective 1 - Develop a bio-behavioral risk model for colorectal cancer among racial groups as well as between men and women.*

- What is the perception and knowledge level of African-Americans regarding colorectal cancer screening?
- What bio-behavioral factors contribute to the difference in prevalence of colorectal cancer among racial groups and between genders?

- What is the relative contribution of genetic, lifestyle and environmental factors in colorectal cancer incidence and mortality among various racial groups?
- Are there common environmental conditions/lifestyle factors among Black men and women that may be responsible for the colorectal cancer burden experienced by this group?

*Objective 2 - Identify cost-effective, community-centered interventions for colorectal cancer control and prevention.*

- What is the perception and knowledge level of African-Americans regarding colorectal cancer screening?
- Which intervention programs can best be sustained in the community for colorectal cancer screening/prevention and control?
- What resources are available to implement cost-effective community-centered interventions for colorectal cancer screening/prevention and control?

*Objective 3 - Study the influence of US Nativity on colorectal cancer morbidity and mortality.*

- Is there a difference in incidence and screening rate among different races?

*Objective 4 - Understand genetics responsible for disease progression/relapse in colorectal cancer patients in Florida.*

- Are Gene Expression Profile of colorectal cancer in Whites and Blacks in Florida similar?
- Are treatment outcomes of colorectal cancer in Blacks and Whites in Florida similar?
- Is the prediction of response to therapy, progress and progression of colorectal cancer in Blacks and Whites in Florida similar?

## **RESEARCH CAPACITY EMPHASES AND OBJECTIVES**

### *Area of Emphasis 1: Education and Training*

*Objective 1 - Develop a statewide training/certification program in cultural and linguistic competency for researchers and research staff.*

*Objective 2 - Develop a statewide training/certification program in health disparities for researchers and research staff.*

*Objective 2 - Develop a statewide collaborative research training program for minority researchers and students.*

### *Area of Emphasis 2: Infrastructure and Resources*

*Objective 1 - Facilitate statewide academic-community partnerships to eliminate cancer disparities.*

*Objective 2 - Develop a state of Florida bank of tumor samples as a shared resource.*

*Objective 3 - Facilitate statewide translational research retreat for clinicians, population scientists and basic scientists in order to provide an avenue for scientific exchange that will facilitate transfer of knowledge from bedside to laboratory and vice versa.*

*Objective 4 - Advocate for public policy as an essential extension of the translation health disparities research agenda in relation to cancer.*