CPALs
CENTER FOR PATIENT ADVOCACY LEADERS
By Advocates, For Advocates

Patient Advocacy Leaders United for Obesity:
Framework for Policy Advocacy and Education

July 2023

Contents

PALs UNITED
Patient Advocacy Leaders United for Obesity

Introduction

Center for Patient Advocacy Leaders

The Center for Patient Advocacy Leaders (CPALs) is a collaborative initiative powered by The AIDS Institute (TAI). CPALs is dedicated to improving the lives of those affected by disease and chronic health conditions by educating and mobilizing health advocacy leaders to work collaboratively in developing equitable, impactful policy and advocacy solutions to timely healthcare issues. The Center facilitates engagement, collaboration, and mobilization, creating a broad-based network of health advocacy leaders utilizing a collective impact model that promotes patient-centered, quality, affordable healthcare for all people. We believe that by developing and empowering a network of patient advocates, we can more effectively improve the lives of those affected by disease and/or chronic health conditions. Our advocate-centered model, "By Advocates, For Advocates," focuses on the needs of patients and caregivers, patient advocacy leaders, their organizations, and the diverse communities they serve. Our focus is on long-term meaningful partnerships involving multiple sectors and stakeholders. To further our work in the obesity field, we have created Patient Advocacy Leaders United for Obesity to work with patients, advocates, caregivers, businesses and provider advocates impacted by obesity to help prioritize education, outreach and advocacy for policy proposals and to foster collaboration, mobilization and partnerships.

Purpose of Report

This report presents opportunities for health advocates to more effectively educate, advocate, and collaborate to make policy change. By offering a framework for action obesity health advocates and those representing other chronic diseases may gain a better understanding of the underlying issues related to the obesity epidemic and develop a collective approach to their education and advocacy work for their policy change agenda.

The framework, we believe, will be most beneficial to health advocates if it is used in conjunction with participation in convenings facilitated by CPALs. These convenings are designed to explore, in depth, the content of the framework, the framework's purposes/principles and its suggested opportunities for education, advocacy and policy. The convenings are also designed to help diverse advocates focus on finding a common policy and advocacy agenda for implementation.

After reading this report and participating in convenings we believe the health advocacy community will demonstrate:

1. Increased awareness and understanding among participants that obesity is a chronic disease with physiological, behavioral, environmental and genetic underpinnings, that it can also occur as a co-morbid condition alongside other chronic illnesses, and that it impacts individual and population health outcomes, the cost of care and quality of life of individuals and the communities in which they live;

2. Closer agreement on common themes for formulating policy and aligned advocacy strategies (either at state and/or national levels) which simultaneously address treatment access and coverage issues for obesity and other comorbid chronic conditions as well as the wrap-around services needed to address the drivers of health.

3. Increased ability to apply lessons learned from other chronic illnesses (i.e., mental health, addiction, HIV) facing stigma and discrimination to build effective programs to reduce the stigma and discrimination associated with obesity/unhealthy weight;

4. Greater motivation and willingness to mobilized with other health advocacy leaders from diverse chronic illnesses to engage in obesity education and awareness programs to use in their work, identifying opportunities for improving enhanced access to safe, comprehensive and effective obesity treatment and support interventions (in parallel with other treatments for other illnesses), and additional ways to address critical social/economic barriers that are factors to building a healthy life for both individuals living with obesity and the community as a whole;

Obesity Advocacy Through an Equity Lens

Advocacy initiatives must consider the intersectionality between obesity, other chronic illnesses and/or personal factors (age, race, gender, sexual orientation, socio-economic conditions) in order to develop the most impactful, comprehensive solutions that best address person-centered care and population health. Focusing on one condition without considering the other health condition(s) or the individual's personal and environmental factors and experiences, will lead to less likelihood of making meaningful individual or systemic change. When advocates from across different sectors, work closely together on common issues, decision makers hear the voices of many, unified around a common message, and are more likely to respond positively. Also, meaningfully including individuals with lived experience along with those from diverse and marginalized communities in all phases of the advocacy and policy work, while treating them with respect and dignity, helps create a more trusting and accepting environment to build a more effective educational and or policy campaign that may move forward with greater buy-in from all involved.

This report is primarily focused on treatment and recovery and less on prevention. We recognize, there is a continuum of advocacy work including a focus on prevention when addressing the obesity epidemic, and therefore, have included some ideas relating to education and advocacy for prevention intervention. However, given our resources and experiences, our convenings are planned to have more focus on treatment and recovery of obesity, especially in the adult and older adult populations, populations of color and other marginalized populations.

What is Obesity?

Obesity is a complex medical disease, not a lifestyle choice. Obesity is caused by the accumulation of fat cells (adiposity), which eventually leads to fat cell dysfunction and results in negative effects on the entire body due to extra fat tissue. Increased fat storage in the body results from energy imbalance due to consuming more calories (energy) than the body uses for functioning (i.e., metabolism or exercise). Additionally, there is a range of contributing factors to developing obesity. (Obesity Medicine Association, William McCarthy, MD, March 13, 2018.) which are discussed below.

According to the Centers for Disease Control and Prevention (CDC), weight that is higher than what is considered healthy for a given height is described as overweight or obesity. Obesity occurs when an individual takes in more calories than they burn through daily activities and exercise. Body mass index (BMI) is a measure of weight adjusted for height is routinely used as a screening tool for overweight and obesity.[i] (It is not a measure of the overall health of the individual and for some racial and ethnic groups, it has its limitations). Researchers are considering waist circumference measure of the central adipose tissue as a potential alternative measure, but more needs to be done in this area.

- BMI of less than 18.5 falls within the underweight range
- BMI of 18.5 to <25 falls within the healthy weight range
- BMI of 25.0 to <30 falls within the overweight range
- BMI of 30.0 or higher falls within the obesity range

Although BMI has been the standard measure for defining obesity for some time, there are some challenges associated with its use, including, it doesn't take into full account important factors including age, race, sex, body type, bone structure, and fat distribution and it does not assess concomitant presence of comorbid conditions, disease risks, or functionality. The field of health services obesity research is continuously exploring new instruments for determining unhealthy weight that do a better job at accounting for other critical factors. (See: The Science, Strengths and Limitations of the BMI as a Measure of Obesity,William H. Deitz, MD, PhD, George Washington University, School of Public Health, NASEM, Presentation, 10.25.22)

Public health researchers, physicians, patient advocates, federal and state institutions, and an increasing number of citizens recognize that obesity is a chronic illness. Like other chronic illnesses, obesity has biological, environmental, behavioral and genetic underpinnings, is influenced by social determinants, and is **not due to an individual's moral failing**. Although there is no cure, obesity is a treatable illness and, if treated effectively, living a healthy life, without discrimination, is highly possible.

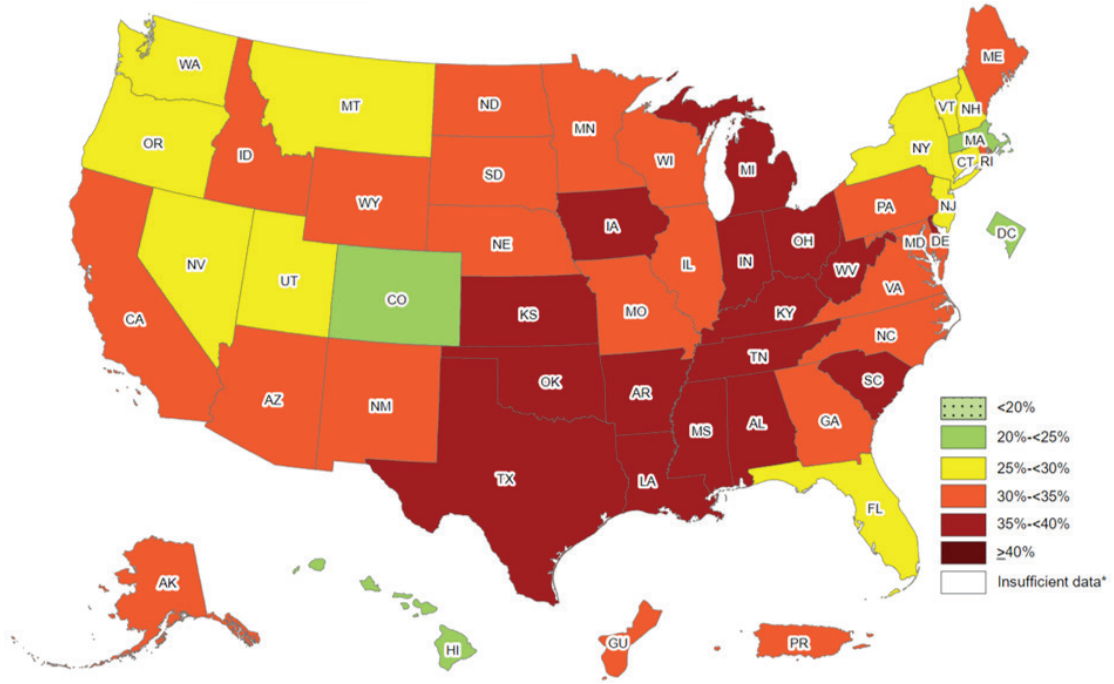
Prevalence of Obesity

National and Regional Rates of Obesity

The prevalence of obesity in the U.S. has risen dramatically over the past several decades. According to CDC, the rate of adult obesity reached 42.4 percent in 2017-2018, surpassing 40 percent for the first time. In 2020, all states had more than 20 percent of adults with obesity and 16 states had at least 35 percent of adults with obesity, up from nine states in 2018 and 12 states in 2019. States with the highest obesity rates include:[ii]

Alabama	Arkansas	Delaware	Indiana
Iowa	Kansas	Kentucky	Louisiana
Michigan	Mississippi	Ohio	Oklahoma
South Carolina	Tennessee	Texas	West Virginia

Prevalence of Self-Reported Obesity Among U.S. Adults by State and Territory, 2020



Source: Behavioral Risk Factor Surveillance System

Health Disparities

Obesity impacts some populations more than others and there are notable differences by race and ethnicity, education, age, and geographic location. The CDC reports that from 2018-2020:

- Non-Hispanic Black adults had the highest prevalence of obesity (40.7%), in the National Health and Nutrition Examination Survey (NHNES), 2020, the incidence was 49.9% followed by Hispanic adults (35.2%) in the NHNES, 45.6%, non-Hispanic white adults (30.3%) in the NHNES, 41.4%, and non-Hispanic Asian adults (11.6%) and in the NHNES,16.1%. Two studies and the latest, unfortunately, showing the trend continues upward.

- Education—Adults without a high school degree or equivalent had the highest rates of obesity (38.8%), followed by those with some college (34.1%), high school graduates (34.0%), and college graduates (25.0%).

- Age—Adults aged 45 to 54 years had the highest prevalence of obesity (38.1%) compared to adults aged 18 to 24 (19.5%).

- Geographic Location—Generally the rural parts of the country had higher rates of obesity than suburban or urban regions NHNS,2020. The Midwest (34.1%) and South (34.1%) had the highest rates of obesity, followed by the West (29.3%), and the Northeast (28.0%).

Health Impacts of Obesity

Obesity is a serious and costly chronic disease. Individuals affected by obesity

are at risk for many other serious chronic diseases, and vice-a-versa, including some of the leading causes of preventable, premature death in the U.S. For example, overweight and obesity raises risk of morbidity from the following conditions:[iii]

Hypertension-Dyslipidemia--Type 2 diabetes--Liver Disease--coronary artery disease (CAD) Stroke--Gallbladder Disease--Osteoarthritis--Sleep Apnea--Respiratory Conditions

According to the National Cancer Institute, there is also consistent evidence that higher amounts of body fat are associated with an increased risk of certain cancers including:[iv] Pancreatic—Liver—Breast—Kidney—Colorectal--Endometrial

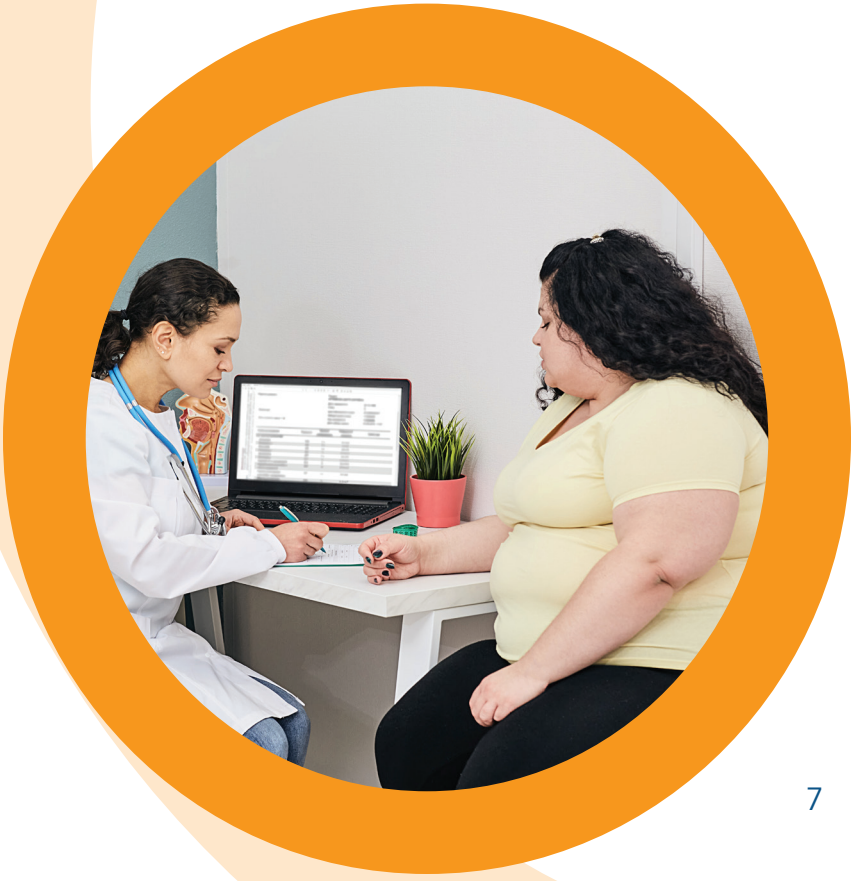
Obesity has been shown to impact the severity of COVID-19. Individuals affected by obesity may be at increased risk of severe illness, as obesity has been linked to impaired immune function and decreased lung capacity. The CDC reports that risk of hospitalization, intensive care admission, invasive mechanical ventilation, long covid and death from COVID-19 are higher with increasing

body mass index (BMI) and that having obesity may triple the risk of hospitalization due to COVID-19. In addition, COVID-19 epidemic clearly demonstrated that access to care, cost, and lack of coverage for treating obesity and the structural conditions in the healthcare system facing high-risk populations, including woman of color and older adults, exacerbates obesity and other comorbid chronic health conditions.

In addition, to the physical health impacts of obesity, adults living with obesity often struggle with mental health disorders including depression and anxiety. The National Council on Aging points to one study, which found that adults with excess weight had a 55 percent higher risk of developing depression over their lifetimes when compared to people who did not have obesity.[v] Research is underway to learn more about the link between obesity and mental health, including examination of how mental health conditions and certain medications to treat mental illness may affect a person's weight. Additionally, weight stigma and discrimination have been shown to negatively impact health (see below) and access to treatment.

Obesity results in higher medical costs. In 2016, the overall medical cost due to obesity among adults in the U.S. was $260.6 billion. Adults affected by obesity experienced $2,505 higher annual medical care costs when compared to those with normal weight, with costs increasing significantly with the severity of obesity. Medical costs were higher in every category of care: inpatient care, outpatient care, and prescription drugs. Increases in obesity-related medical costs were higher for those covered by public health insurance programs ($2,868) than for those with private health insurance ($2,058).[vi] These figures do not include indirect costs related to obesity including lost productivity, absenteeism, and higher insurance costs. Further, obesity is a leading cause of ineligibility for military service and the Department of Defense spends an estimated $1.5 billion annually in obesityrelated healthcare costs.[vii]

(The State of Obesity 2022: Better Policies for a Healthier America, Trust for America's Health noted that "Obesity is estimated to increase U.S. healthcare spending by $170 billion annually (including billions by Medicare and Medicaid)".



Weight Stigma and Discrimination - A Barrier to Diagnosis and Treatment

"Bias, stigma, and discrimination due to weight are frequent experiences for many individuals with obesity, which have serious consequences for their personal and social well-being and overall health. Given that at least half of the American population is overweight, the number of people potentially faced with discrimination and stigmatization is immense."
Rebecca Puhl, PhD, Deputy Director at the Rudd Center for Food Policy and Obesity at the University of Connecticut

Individuals affected by obesity often face stigma and discrimination. This too, is often the case for those with other chronic illness such as mental illness, or cancer. Weight stigma occurs in various settings including places of employment, academic institutions, community institutions and healthcare systems and facilities. According to the American Psychological Association, 42 percent of U.S. adults indicate they have faced some form of weight stigma, with physicians, coworkers, family members, and romantic partners listed as common sources.[viii]

Individuals affected by obesity are frequently portrayed negatively and judgmentally in the media and by society at large. In addition, information about the causes of and solutions to obesity are often framed in ways that reinforce negativity and criticism, suggesting moral failure. These stereotypes contribute to weight stigma, bias, and discrimination.[ix]

Healthcare professionals are common sources of weight stigmatization. Negative attitudes and beliefs about people living with obesity have been documented among medical students, physicians, nurses, mental health professionals, and dietitians. In one study of people living with obesity, the majority of participants pointed to doctors as the first or second most common source of weight bias.

The healthcare community can play an important role in reversing the adverse effects of weight bias and stigmatization among individuals who are experiencing obesity. Education and training are needed to raise awareness among healthcare professionals about how to avoid weight stigma, discrimination, and conscious and unconscious bias that may impact patient care.[x]

Weight stigma and bias poses significant consequences for emotional and physical health. Weight stigma in healthcare settings may lead to avoidance of seeking healthcare, reduced adherence to medical treatment, and lower trust and communication with healthcare professionals, which may in turn contribute to reduced quality of care, poorer health outcomes, and increased health disparities. In addition,

stigmatizing experiences combined with associated discrimination in multiple settings can impact mental health and lead to depression, anxiety, low self-esteem, shame, and sometimes suicidal behaviors. Weight stigma, including self-stigma, can also lead to unhealthy behaviors that exacerbate obesity, such as binge eating and avoiding exercise.[xi]

In the obesity literature and in our 2021 survey results, stigma and discrimination surfaced as a significant barrier to fully addressing obesity epidemic. Any advocacy for policy change, for any chronic illness, including obesity, we believe, must address, on multiple fronts also address, simultaneously, stigma and discrimination. The factors of self-stigma, and structural drivers of obesity, such as structural racism, biased mental and social models and behaviors, inadequate health communications within different sociocultural systems, and provider bias must be addressed as part of any policy change initiative. All these institutionalized structures are discriminatory barriers to people seeking medical and social services because of unhealthy weight.

We consider that discrimination and bias may also serve as an underlying factor for the resistance by policy makers to create and support legislation requiring policy changes in insurance coverage and payment reform for FDA approved medications. Anecdotal data shows that some providers hold implicit biases, leading to discriminatory practices, lack of a full understanding of obesity as a chronic illness, and hesitation to use approved available treatments for their patients. This bias and discrimination must be addressed through non-threatening education and advocacy work directly with policy makers and key governmental officials. *Treating people with obesity, or any chronic illness, with dignity and respect and, recognizing that obesity is NOT a moral failing, are some first steps to take while advocating for larger structural and systemic changes.*

We also believe it is critical to explore ways to change the conversation about obesity. Part of that starts with the words we use. Early findings from our research reveal that the term obese, in itself, may be stigmatizing. CPALs recommends incorporating the phrase "healthy weight" into this work, where appropriate.

Causes of Obesity

Obesity is a complex, chronic health condition with multiple causal factors. The primary causes of obesity include:

• **Genetics, Race and Physiology—** Inherited genes may affect metabolism, the amount of body fat one stores, and where in the body fat is distributed. Researchers have found that the rate of inheriting a high body mass index (BMI) is between 40% and 70%. There are 300 different genes associated with obesity and thus far researchers have noted 11 genetic abnormalities that directly cause obesity.

• **Age—**Although obesity can occur at any age, risk increases with age due to factors such as hormonal changes, changes in metabolism, and less active lifestyles.

• **Social determinants of health—** The conditions and environments in which people live, work, learn, play, and worship have a profound effect on quality of life and their health outcomes. Structural drivers and systemic issues such as limited access to healthy food, unsafe places for physical activity, public safety issues such as crime and homelessness, racism and discrimination, poor quality education, and lack of employment opportunities and transportation all contribute to higher obesity risk. Adults and children who experience food insecurity—the disruption of food intake due to lack of money—may be at increased risk for obesity.[xii] Additionally, structural racism, demonstrated as racial inequality in socioeconomic status, is associated with higher rates of obesity.[xiii] (See also Addressing Structural Racism, Bias, and Health Communication as Foundational Drivers of Obesity: Proceedings of a Workshop Series (2022) National Academy of Sciences Engineering and Medicine)

• **Lifestyles/Environment—**Often related to social determinants, poor eating habits and physical inactivity are primary causes of obesity. Contributing factors include diets that are high in calories, but low in nutrients—due to large portion sizes and consumption of processed foods, fast foods, sugary beverages, and alcohol—and sedentary lifestyles including lack of exercise and excess screen time. Contributing to this kind of diet is often food insecurity caused by lack of money and community resources, places to find healthy food at a reasonable price. Obesity may run in families, both for genetic reasons and because family members often share similar eating and activity

habits and socio-economic conditions. Often times a number of these factors may not be in the control of the individual or their family.

• **Other factors** that may contribute to obesity include certain diseases, hormone abnormalities and medications, pregnancy, quitting smoking, lack of sleep, and stress.

Obesity Prevention and Treatment

Prevention

Preventing obesity requires a multifaceted approach that includes both individual and community-based (systemic) interventions, respect and appreciation of the community's culture and conditions, and community leadership and power dynamics. At the individual level, adhering to health providers prescriptions, adopting a lifestyle that includes healthy eating and regular physical activity are key. The U.S. Department of Health and Human Services publishes nutrition and physical activity guidelines, which outline specific recommendations for various populations including adults, older adults, pregnant women, and adults with chronic health conditions. Many of these prevention activities are also applicable to those affected by other chronic conditions because they offer opportunities for healthy eating and activity which can be available to all regardless of what illness the live with.

Nutrition guidelines include:[xiv]

• Follow a healthy dietary pattern at every stage of life.

• Customize and enjoy nutrient-dense foods and beverages to reflect personal preferences, cultural traditions, and budgetary considerations.

• Meet food group needs with nutrient-dense foods and beverages within calorie limits.

• Limit foods and beverages high in added sugars, saturated fat, and sodium; limit alcoholic beverages.

Physical activity guidelines for adults include:[xv]

• Move more and sit less throughout the day.

• Engage in at least 150-300 minutes a week of moderate-intensity or 75-150 minutes a week of vigorous-intensity aerobic physical activity, or an equivalent combination of both. More physical activity beyond the minimum will result in additional health benefits.

• Engage in muscle-strengthening activities of moderate or greater intensity on two or more days a week.

At the community level, obesity prevention is focused on creating, in collaboration with the community members, social, physical, and economic activities and environments that promote health and well-being. Implementing a public health approach that addresses the social determinants of health is crucial to reducing obesity, improving physical and mental health, and reducing health disparities. Community-level efforts must focus on policies that support healthy eating and improve

opportunities for physical activity in multiple sectors including healthcare, government, business, schools, community, and childcare. Examples of community-level prevention interventions include land use and design that facilitates physical activity such as public transportation, walking and bike paths, and safe parks; eliminating food deserts by improving access to nutritional, reasonably priced foods in retail settings; establishing community and school gardens and healthy lunch programs; and improving food and physical environments in all workplace and other educational settings. If advocates are to reduce the obesity epidemic, then it is critical that a public health approach which addresses these issues across the lifespan and which incorporates recognition of the intersectionality of personal and structural factors on health outcomes is built into all prevention programs. In the long run, these upstream actions promote healthy weight, improve overall health, and can save money.

Treatment and Recovery: Continuum of Interventions

The goal of obesity treatment is to achieve and maintain a healthy weight with the aim of improving overall health and lowering the risk of obesity-related complications, including comorbid illnesses. Individuals should work with their health professional team to determine the best treatment intervention, which may include more than one intervention made simultaneously for them, depending on their overall health, severity of obesity, other co-morbid illnesses, and willingness to participate and adhere to the recommended treatment options. Steady weight loss over time is considered the safest way to lose weight and keep it off permanently. Patients must embrace the idea that, because obesity is a chronic illness like any other, it requires life-long disease management to maintain success. Obesity treatment interventions include:

- **Dietary changes—**Working with a nutritionist to help formulate a plan for healthier eating and practices to sustain such a plan over time. Efforts may include reducing calorie intake; improving nutrition by eating more plant-based foods, lean proteins, and whole grains; reducing portion sizes; and restricting calorie-dense, processed, and fast foods, as well as sugar-sweetened beverages.

- **Exercise and activity—**Help from a coach or a group of friends, or doing it alone to improve regular physical activity is an essential component of obesity treatment. Gradually increasing physical activity as fitness and endurance improve is recommended. (Before an individual starts any exercise program, they should check with their health provider). Once weight loss has occurred, moderate-intensity activities can also help to maintain healthy weight and prevent further weight gain.

- **Behavioral interventions—**Mental health professionals can provide support to those wanting to make lifestyle changes. Individual therapy can help address emotional and behavioral issues that may underly unhealthy behaviors.

• **Weight loss medications—** Weight loss medications have been available for many years, however, in the last decade newer FDA approved medications that are safe and effective have come to market helping individuals with obesity or excess weight lose 5%-10% of their weight in the first year and in some cases, with continued use weight loss can be sustained. Weight loss medications may help jump start weight loss, especially when used in conjunction with a nutrition treatment plan, behavior modifications, and/or exercise. Some medications are not recommended for those with a personal or family history of certain endocrine or thyroid tumors, specifically, medullary thyroid cancer. It is critically important that, as with any medication, individuals work with their healthcare providers to establish treatment goals and a plan of action and determine how the medication fits into the overall treatment plan.

• **Medical procedures—**Weight loss surgeries such as gastric bypass surgery, gastric banding, and gastric sleeves are intended to limit the amount of food one can comfortably eat. Other less invasive medical procedures include endoscopic sleeve gastroplasty and intragastric balloons.

• **Support groups—**In many cases, support groups are not only focused on sustaining the benefits of a surgical or medical intervention but are ongoing, and often serve a variety of individuals in their journey to address obesity and sustain their recovery. Support groups connect people with others who share similar challenges or face issues that arise due to stigma and discrimination. These groups help individuals recognize they are not alone in their desire to address their weight and each member can learn from others what might work for them. Often, individuals share their lived experiences and offer approaches they have used to overcome the feelings associated with the stigma felt or discrimination experienced in any number of social settings.

Treatment and Recovery: Team Approach

Effective treatment outcomes are more likely when there is clear communication among and between the treatment team members, including the patient, and that treatments are integrated in one plan. *(However, even if a team approach is not available a trusting patient-provider relationship is a necessary first step for addressing obesity).*

Effective obesity treatment as well as treatments for other chronic illnesses, often involves an **integrated team approach** that may include, with the patient, simultaneous coordinated, interventions including a physician to manage medication, a behavioral health specialist focused on addressing emotional and behavioral issues, a nutritionist assisting with dietary changes, an exercise coach, identified community support workers, family caregivers, (with permission). The whole team works collaboratively with the patient, as an equal partner in the person-centered care approach. *In addition, if there is another cooccurring chronic condition present in the individual's medical history, such as diabetes, hypertension or heart disease, that is being treated by another provider, such as the primary care provider, then that provider should also be part of the care team.*

It is also best if the team is well educated about the nature and course of the illness of obesity and any other illness associated with obesity. All team members need to be guided to reflect on their own implicit bias associated with persons who are obese. If both provider education about obesity as a chronic illness and provider implicit bias are not effectively addressed, data is showing that the secondary medical conditions get treated first, diabetes as an example, albeit inadequately, because the primary condition, obesity, is not fully understood, nor treated as a "real" illness in the treatment setting. As a result, cost of care may likely increase, health outcomes are not achieved and levels of trust between provider, team and patient remain weak.

Building for Obesity Education, Advocacy and Policy Change

For more than a decade there have been multiple legislative attempts at both the federal and state levels, including employee self-insured groups, including those states with high prevalence of obesity, to pass legislation that provides coverage for the prevention, treatment, and recovery from obesity. Despite these efforts, only limited insurance coverage exists which provides access to a broad range of obesity treatments

and professional therapeutic and support services, including community support workers. At the same time, research and public education has helped improve the understanding of obesity as a chronic illness, programs are in place to reduce the stigma and discrimination associated with obesity, and new treatments have become available. However, there still remains limited access to a range of treatment options, including medications, support services, and integrated healthcare approaches to address and reduce the obesity epidemic. Consideration should be given to a number of elements that are key to building an effective advocacy initiative for policy change.

Organizing for Obesity Policy Advocacy:

- **Focus on engagement and collaboration across therapeutic conditions-** Break down silos. A number of advocacy organizations across the nation are facing many of the same conditions that obesity advocates face and who are also working to address the critical issues associated with obesity such as: expanded coverage, access and reimbursement to a broader range of treatments, including medications, and comprehensive psycho-education and therapeutic support services delivered in an integrated setting. In addition, many advocacy groups are developing and implementing anti-stigma programs and activities. Our findings show that often these advocacy organizations focus directly on obesity as a chronic illness and less often on obesity as a co-morbid condition associated with a primary illness such as diabetes, liver, or heart disease. Often the comorbid conditions are left to a different advocacy organization and little engagement and collaboration exists across these health advocacy organizations and the obesity focused organization.

- **Focus on economic and cost burden of multiple stakeholders-** Policy and advocacy initiatives must not only address individual needs and direct medical and behavioral health care, but must also consider the economic and cost burdens on natural and family support networks, businesses, and educational institutions, especially those that provide education and training for healthcare providers.

Established in 2014, the Roundtable on Obesity Solutions brings together diverse sectors and voices to explore and advance effective solutions to the obesity crisis. The Roundtable examines efforts that advance progress in reducing the impact of obesity and applies equity strategies to address obesity-related disparities.

- **Recognize that policy makers may also have bias and stigma towards persons with obesity-** Identifying, gaining support, and sustaining that support from policy makers to promote legislation to fully address obesity requires considerable time and resources. Often, policy makers, like many in the public, hold biases (implicit or expressed) towards persons with obesity that may impact their behavior whether or not to promote

and support obesity legislation or changing policy to cover FDA approved medications. This discrimination and the associated implicit bias must be addressed through non-threatening education and advocacy work directly with policy makers and key governmental officials.

• **Research and data gathering is key element to an advocacy plan-**to learn more about treatment effectiveness, tools, and technologies to facilitate treatment and recovery, and address stigma and discrimination; having the right, up-to-date information for policy makers is critical to a campaign.

• **Seek out resources to help develop and support building and sustaining coalitions**; identify and support advocacy leadership, the promotion of equitable solutions especially at the community level, and create effective communications programs. Formulate clear, concise messages that all health advocates can accept and use regardless of the chronic condition of focus.

• **An advocacy campaign should identify and include a broad array of key stakeholders in addition to health advocates.** The advocacy campaign must be inclusive and demonstrate a common, supported agenda across diverse groups; consideration for inclusion in any obesity advocacy campaign for making policy change should be given to public health networks, community health centers (FQHCs), community health workers associations, and nontraditional allies including leaders from schools, churches, fitness centers, beauty and apparel entrepreneurs who may own stores in the community.

• **Natural and community caregivers** are important constituent groups to incorporate into any advocacy work.

• **Community-based services** were considered "very important" as a vehicle for improving access to care and for building trust between patient and provider; advocacy efforts must incorporate improving community based, primary care (FQHCs), and community health worker programs (**promotores de salud**), as critical vehicles for abating the epidemic.

• **Story-banking:** collect stories from individuals with lived experience as well as family members to use with policy makers as a way of demonstrating the personal impact that a person living with obesity experiences, including the lack of access to effective treatments, stigma and/or poor economic and social conditions.

Obesity Survey Results

With recognition that more efforts are needed to move policy makers, plan administrators, businesses, key stakeholders and advocates off their mark, CPALs in 2021 conducted an online survey of a diverse groups of patient advocacy leaders and advisors to help refine areas of focus for a potential future work in the obesity field. In total, 121 advocates from multiple organizations responded to the survey. Key survey findings include:

• Lack of coverage for obesity treatment was mentioned most

often as a major barrier to a comprehensive approach for treating obesity and promoting healthy weight.

- Other barriers mentioned include:
  - Stigma and weight discrimination;
  - Health disparities;
  - Limited patient/family knowledge about effective treatments; and
  - Cost of obesity care.

- When asked whether federal, state, or local policy changes are worthy of investment of time and resources, most respondents indicated all three, followed by federal level policies.

- Advocacy strategies and tactics found to be most effective include:
  - Personal stories presented to legislators;
  - Effective messaging;
  - Mobilizing patient voices, storybooks, and/or rallies;
  - Building relationships with policy and decision makers; and
  - Collaborating with other advocacy groups across therapeutic areas (e.g., building a common agenda with obesity, heart, mental health, and food advocacy groups).

- Obesity Action Coalition was mentioned as one organization that has worked effectively addressing the obesity epidemic.

Given the CPALs survey findings and because the obesity epidemic continues to grow in the U.S. impacting certain populations disproportionately, we believe, any successful policy and advocacy campaign led by volunteer non-profits must recognize and address the complexity of this public health issue and, at minimum, should include the components outlined below.

CPALs survey respondents indicated it would be helpful to collaborate and coordinate efforts across patient advocacy organizations to more effectively address obesity. They suggested building alliances with organizations that focus solely on obesity (i.e., Obesity Action Coalition)

Components for a Successful Advocacy Campaign for Policy Change; Moving Toward Collective Impact

- Policy changes takes time and **resources**; having a breadth of resources (human and financial) that are sustained over the long run must be highly considered in any initiative to make policy change.

- **Collaboration and partnerships across multiple health and human service** sectors to develop and advocate for policy that benefits multiple therapeutic areas and communities (i.e., obesity advocates should partner with other advocacy groups such as the American Heart Association, American Diabetes Association, or American Nutritionist Association, Liver Foundation); to strengthen the advocacy campaign, coalition building efforts need to bring health advocates from therapeutic areas that consider obesity as a comorbid

condition together with advocates whose primary focus is on obesity.

• **Open, honest, and regular communication** across the representatives from different sectors supported by technology and organizational structures;

• As trust and relationships among stakeholders grow, **formulation of a common agenda** is critical so that each sector does not operate in a silo, but works in concert/collectively with others for greater effectiveness;

• Identification of **competent and committed leadership** for the coordination and strategy development for the policy and advocacy work, mobilization of advocates, and which is supported by the key stakeholders. Leadership may come from an organization that has been focused on obesity issues and which can **serve as the "backbone" organization** for the campaign;

• Most importantly, **individuals with lived experience** need to be engaged and given opportunities to play meaningful roles in the campaign and are respected for their contributions by other advocates and professionals;

• Any obesity campaign must be inclusive, assure that a high priority is given to the inclusion of communities of color in all phases of the work. **All activities should be processed through an equity lens** so that health equity is promoted and disparities are fully addressed in education and policy efforts.

• **An equitable approach to program and evaluation development and design** which is truly inclusive, includes those most directly involved and impacted by program services. Those impacted by programs should be meaningfully involved in designing evaluation methods, the indicators and benchmarks to be developed and the short- and long-term goals of the education, advocacy programs and policy design for reducing the epidemic and/or improving population health. Evaluation work begins at the initial stages of the advocacy planning. It is important to seek resources both financial and human to assure an effective evaluation of the campaign.

Opportunities for Obesity Education, Advocacy and Policy Interventions - See Appendix 1

Appendix 1 lists examples of policy changes that can be promoted at the federal, state, and/or local levels, including state employee insurance networks, self-insured companies,

along with related opportunities for advocacy and education to support those proposed policy changes. Keep in mind that advocating for policy change is often a step-by-step process that takes time and perseverance. It may begin with telling a personal story-self advocacy, expand to working with others, providing education and awareness activities, eventually moving into advocacy for particular policies that are proposed to address obesity and/or comorbid obesity conditions or structural/institutional barriers in the community that are impediments to healthy outcomes. The opportunities listed in the appendix include prevention and treatment examples which are cross-cutting and may be of interest not only by those specifically in the obesity advocacy community, but all health advocates who are addressing any chronic disease in their work and, in which, obesity is likely a comorbid condition.

Next Steps

The Center for Patient Advocacy Leaders (CPALs), believes that this framework can serve as a motivating and engaging document for health advocates from across diverse therapeutic areas, including obesity, to consider implementing a common policy and advocacy agenda and collectively working to improve the health of all people affected by obesity as well as other chronic illnesses. As advocates come to understand more about the framework and consider adopting some of its overarching purposes, principles and recommendations (or develop their own), they may be more likely to coalesce around a number of policy ideas which it offers and which can lead to pathways to better health for persons affected by obesity and other chronic illnesses.

CPALs is committed to partnering with health advocates and other stakeholders to foster common agreement, collaborate, and mobilize, for the purpose of advancing optimal health and patient-centered care. Moving forward, efforts could include hosting convenings for multi-sector partners, including persons with lived experience, health advocates, and caregivers and other key stakeholders and policy makers impacted by or interested in addressing the obesity epidemic and other co-morbid chronic illnesses. Together we can develop and/or support and prioritize education, awareness, and advocacy activities for building a policy agenda that effectively addresses the obesity epidemic.

Appendix 1
Opportunities for Obesity Education, Advocacy and Policy Interventions

Obesity Policy Opportunities - Clinical/Treatment and Access	Opportunities for Policy Advocacy & Education - Clinical Treatment and Access
Expand insurance coverage through Medicaid, Medicare, Managed Care, and State Employee Health Plans to include obesity prevention, screening, and comprehensive treatment.	• Meet with federal legislators and staff members, health plan administrators and medical directors, state departments of health care services, PBMs and managed care organizations, and others who have influence and decision-making capacity on insurance plans. Coverage for obesity should be offered as a standard benefit in parity with any other chronic illness. • Advocate for increased and expanded coverage for comprehensive obesity treatment (e.g., behavioral therapy, nutrition counseling, pharmacotherapy, and/or surgery) including long- term treatment, when necessary. • Engage health advocates representing a variety of health issues and chronic diseases, as well as biomedical leaders and public health officials, to join forces and mobilize in the effort to assure full parity in the coverage and treatment of obesity. • To engage their support for advocacy and policy change, educate the public and key stakeholders about obesity as a chronic disease, resulting from a complex array of contributing factors, and the health and financial impact untreated obesity has on healthcare system costs and outcomes
Establish a new definition of medical service, especially under Medicaid rules, in order to include such interventions as nutritional food, basic equipment necessary for physical activity (e.g., sneakers, weights, bicycles), gym memberships, and/or outdoor recreation programs to covered, and assure parity.	• Educate stakeholders about disparities in access to healthy foods and opportunities for safe physical activity, as well as the relationship between food insecurity, food desserts and obesity. • Generally, link the need to address social determinants of health as a vehicle for improving health and access to obesity care. • Access and treatment of obesity should have parity with any other chronic illness.
Enact Treat and Reduce Obesity Act, which will remove barriers to and provide for the coordination of programs to prevent and treat obesity.	• Advocate with your federal legislators and their staff members to encourage support and sponsorship for this bill. Sponsors of the bill include Senators Tom Carper (D-DE) and Bill Cassidy (R-LA) and Representatives Ron Kind (D-WI), Tom Reed (R-NY), Raul Ruiz (D-CA) and Brad Wenstrup (R-OH).

Obesity Policy Opportunities - Clinical/Treatment and Access	Opportunities for Policy Advocacy & Education - Clinical Treatment and Access
Expand access to healthcare for all Americans and continue access to Medicaid for populations that were included during the "Covid Health Emergency." (As noted above, Medicaid and Medicare should cover prevention and treatment for obesity) Assure that private self-insured policies cover a full range of prevention, treatment and recovery services for obesity.	• Advocate with federal and state legislators and private insurance companies, managed care companies and PBM's to cover obesity services. • Encourage expansion of public insurance programs, especially, in those states that have not expanded Medicaid coverage and ask for coverage for obesity to be considered an "essential service". • Encourage your constituents to enrollment in ACA. Take advantage of, where available, health insurance navigators. • Support funding for state navigator programs that help educate and enroll residents, including those affected by obesity in Medicaid and in other insurance programs under the ACA.
Enact a "Health in all Policies" approach, whereby local, state, and federal governments assess all proposed policies and regulations for their impact on healthy equity and the health of all citizens (including impact on obesity)	• Advocate for state and local county policy makers to develop assessment tools to use as a guide to determine if proposed healthcare legislation and regulatory policies will address health equity principles and obesity as a chronic illness.
Enact required training programs, pre-service and in- service, on obesity prevention and treatment for physicians and other clinical providers as a requirement for licensure or for maintaining a license through continuing education.	• Inform and advocate for state medical and other clinical boards to require training on obesity prevention and treatment for licensure and require this training for reciprocal licensing and for continuing education requirements. • Advocate with American Medical Association (AMA) leaders to recommend that its members take in-service training to better understand obesity prevention and treatment and address implicit bias and discriminatory practices. • Encourage physicians to seek board certification in obesity medicine. The American Board of Obesity Medicine (ABOM) CME pathway; 30 additional hours of self-study, and then passing the board exam. • Consider local providers adopting programs that are focused on "food as medicine" and help providers offer prescriptions for food that are covered by insurance. • Training should be based on best practices and the latest evidenced based practice guidelines, either for surgeries (International Federation for the Society of Obesity (IFSO) and or other medical interventions (FDA approved medications) • Comprehensive education and training programs should help providers address: stigma and weight bias in themselves and others; incorporate concepts of culturally competent care within the context of understanding obesity as a chronic disease; utilize effective strategies for discussing obesity with patients in a trauma-informed manner; teach the shared decision-making model; focus on patient health while not judging patient character or appearance, • Use patient personal stories as vehicles, case examples, for promoting public and provider understanding and need for improved effective care.

Obesity Policy Opportunities - Clinical/Treatment and Access	Opportunities for Policy Advocacy & Education - Clinical Treatment and Access
Address the social determinants of health and build health equity	• Build awareness and educate policy makers about the impact of social determinants of health on obesity and other chronic illnesses. • Establish educational programs in schools and hospitals and public health centers that address the root causes of obesity and other chronic conditions such as racial discrimination and implicit bias, poverty, lack of affordable housing, food insecurity, lack of affordable childcare and early education- shown to be drivers of poor health. • Identify examples, through personal stories, that can be used to illustrate the impact of social determinants on individuals' health as well as the impact of stigma and discrimination on obesity/chronic illness care.
Establish and widely distribute comprehensive **clinical standards of care** for obesity treatment based on such programs as: i.e., ABOM or IFSO	• Engage healthcare champions, providers and health plan leaders to encourage development, adoption, and dissemination of clinical standards of care for obesity including screening, diagnosis, evaluation, selection of therapy, comprehensive, integrated treatment modalities (including FDA approved medications), and person-centered care. • Advocate with American Medical Association (AMA) leaders to recommend that its members take in-service training to better understand obesity prevention and treatment and address implicit bias and discriminatory practices. • Encourage physicians to seek board certification in obesity medicine. The American Board of Obesity Medicine (ABOM) CME pathway; 30 additional hours of self-study, and then passing the board exam.
Improve nutrition and food security.	• Educate federal/state legislators and staff members of the benefits of expanding food programs and strengthen federal nutrition safety net programs that address health and obesity. (Federal nutrition safety net programs such as WIC, SNAP, Child and Adult Care Food Program, and National School Lunch Program; expansion of universal school meals; local school district wellness policies; vouchers for purchase of healthy foods; and expansion of regional food systems and local food production to increase access to fresh foods) • Meet with local school board members to encourage district wellness policies that support healthy food programs. Advocacy organizations, nutritionists and dieticians, public health employees, meet with local farmers, and policy makers to support of local food systems and food production and farmers markets.
Implement policies to improve physical activity and built environments.	•Form groups of health advocates and public health networks to meet with city managers, city planners, public health and public safety representatives, building industry leaders, and transportation and health advocates in support of healthy community design and comprehensive

Obesity Policy Opportunities - Clinical/Treatment and Access	Opportunities for Policy Advocacy Education - Clinical Treatment and Access
	public transportation, safe parks, playgrounds, and walking/ biking paths. • Meet with School Boards to recommend increasing opportunities and environments promoting physical activity. • Educate and advocate for improved walkability and bicycle safety. i.e., Minnesota. State Plan for Physical Activity and Nutrition
Make improvements in community healthcare and hospital settings	• Meet with hospital and health system administrators, clinicians; local health advocates and encourage their support for healthy organizational policies and practices that address food and nutrition as part of health, such as food pantries, walking and exercise programs, and breastfeeding support for new mothers. • Advocate for nutritional food prescriptions and physical activity programs to be part of comprehensive treatment for obesity-"food as medicine" programs. • Educate clinical staff to add "food as medicine" component to its treatment repertoire for obesity.
Enact **Pricing Policies**	• Partner with your Public Health Association and meet with and inform legislators and staff members to financially support public health activities and programs to reduce obesity. • Meet with local policy makers to discuss the benefits of taxing sugar-sweetened beverages (e.g., health improvements and increased municipal revenue).
Encourage employers to incorporate information on weight bias and discrimination in mandatory trainings on equity, diversity, and inclusion.	• Meet with business leaders and chambers of commerce to educate them about the impacts of weight bias and discrimination on the obesity epidemic. • Invite chamber members to be part of any newly formed coalitions addressing the obesity epidemic. • Promote legislation to prevent discrimination of obesity in employment settings and insurance policies; assure obesity parity.
Resource investment in underserved communities by anchor institutions (hospitals, universities, corporations) which can help improve population health through better access to care and social services.	• Meet with community leaders from anchor institutions to encourage financial investment in local communities, with particular emphasis on communities of color and populations with health disparities. • Learn about ESG (environmental, social and corporate governance) initiatives in corporations in your community and work with leaders to coordinate your community initiatives to address obesity and healthcare improvements.
Increase funding for research on obesity treatment and outcomes/effectiveness of obesity prevention and/ or treatment programs.	• Share your information and experiences with leaders of public and private institutions that provide funding for medical research. • Encourage Centers for Disease Control and Prevention, National Institutes of Health, universities, biomedical companies, and private foundations to support research. • Engage, inform and empower individuals to take part in research design and delivery to assure the most effective interventions are available to address obesity. • Participatory Research Models should be considered to promote patient engagement in all phases of research.

Endnotes

i *Adult Body Mass Index.* Centers for Disease Control and Prevention. (2021). Retrieved May 2022, from https://www.cdc.gov/obesity/adult/defining.html

ii *Adult Obesity Maps.* Centers for Disease Control and Prevention. (2022). Retrieved May 2022, from https://www.cdc.gov/obesity/data/prevalence-maps.html#:~:text=35%25%20or%20more%20adults%20had,Texas%2C%20and%20West%20Virginia

iii *Clinical Guidelines on the Identification, Evaluation, and Treatment of Overweight and Obesity in Adults.* National Institutes of Health: National Heart, Lung, and Blood Institute. (1998). Retrieved June 2022, from https://www.nhlbi.nih.gov/files/docs/guidelines/ob_gdlns.pdf.

iv *Obesity and Cancer.* National Institutes of Health: National Cancer Institute. (2022). Retrieved June 2022, from https://www.cancer.gov/about-cancer/causes-prevention/risk/obesity/obesity-fact-sheet#what-is-known-about-the-relationship-between-obesity-and-cancer-

v Floriana S. Luppino, MD; Leonore M. de Wit, MS; Paul F. Bouvy, MD, PhD; et al. Overweight, Obesity, and Depression: A Systematic Review and Meta-analysis of Longitudinal Studies. Arch Gen Psychiatry. 2010;67(3):220-229.

vi Cawley J, Biener A, Meyerhoefer C, Ding Y, Zvenyach T, Smolarz BG, Ramasamy A. Direct medical costs of obesity in the United States and the most populous states. J Manag Care Spec Pharm. 2021 Mar;27(3):354-366.

vii *Unfit to Serve: Obesity is Impacting National Security.* Centers for Disease Control and Prevention. (2019). Retrieved May 2022, from https://www.cdc.gov/physicalactivity/downloads/unfit-to-serve.pdf

viii Abrams, Z. (2022, March 1). The Burden of Weight Stigma. American Psychological Association. Retrieved May 2022, from https://www.apa.org/monitor/2022/03/news-weight-stigma

ix *Guidelines for Media Portrayals of Individuals Affected by Obesity.* Rudd Center for Food Policy & Obesity. (2014). Retrieved May 2022, from https://media.ruddcenter.uconn.edu/PDFs/MediaGuidelines_PortrayalObese(1).pdf

x Puhl R, Brownell K. Confronting and coping with weight stigma: an investigation of overweight and obese adults. *Obesity (Silver Spring)*. 2006;14(10):1802-1815.

xi Ibid.

xii *Food Insecurity.* Office of Disease Prevention and Health Promotion. (2022). Retrieved May 2022, from https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/food-insecurity

xiii Bell, C, Kerr J, Young J. Associations between Obesity, Obesogenic Environments, and Structural Racism Vary by County-Level Racial Composition. Int J Environ Res Public Health. 2019 Mar; 16(5): 861.

xiv *Dietary Guidelines for Americans, 2020-2025.* U.S. Department of Agriculture. (2020). Retrieved May 2022, from https://www.dietaryguidelines.gov/sites/default/files/2021-03/Dietary_Guidelines_for_Americans-2020-2025.pdf

xv *Physical Activity Guidelines for Americans, 2nd Edition.* U.S. Department of Health and Human Services. (2018). Retrieved May 2022, from https://health.gov/sites/default/files/2019-09/Physical_Activity_Guidelines_2nd_edition.pdf