

# Breaking Barriers: Partnerships to Improve Diabetic Eye Health in Alabama

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## ABSTRACT

In Alabama, diabetes is ranked 13th for prominent health indicators impacting the state. Out of an estimated state population of 4.9 million, roughly 568,000 (11.6%) Alabamians are affected by diabetes. Furthermore, 9% of the population has been notified of having prediabetes, with approximately 35,700 new diabetes cases in 2022. The medical costs associated with diabetes continue to rise with a concomitant increase in disease incidence and prevalence. Racial health disparities impact African American/Black individuals with diabetes at disproportionate rates. In Alabama, there is a higher prevalence of diabetes among African Americans. Despite current medical interventions, African Americans remain at increased risk for developing complications of diabetes, specifically vision loss and blindness. Nationally, diabetes is the leading cause of new blindness in adults. Vision loss as a complication of diabetes is a growing problem across Alabama as the incidence and prevalence of the disease continue to rise. A staggering 131,000 vision loss cases impact Alabama's health care systems, costing the state an estimated \$2.4 million annually. The impact on patients' quality of life is also alarming. In this review, we describe the burden of eye disease due to diabetes in Alabama and examine work being deployed across the state to address managed care barriers to eye health. We highlight the need to focus on health equity by linking community-based advocacy efforts with pharmaceutical industry partners to promote locally based efforts to help reduce the burden of diabetes across the state.

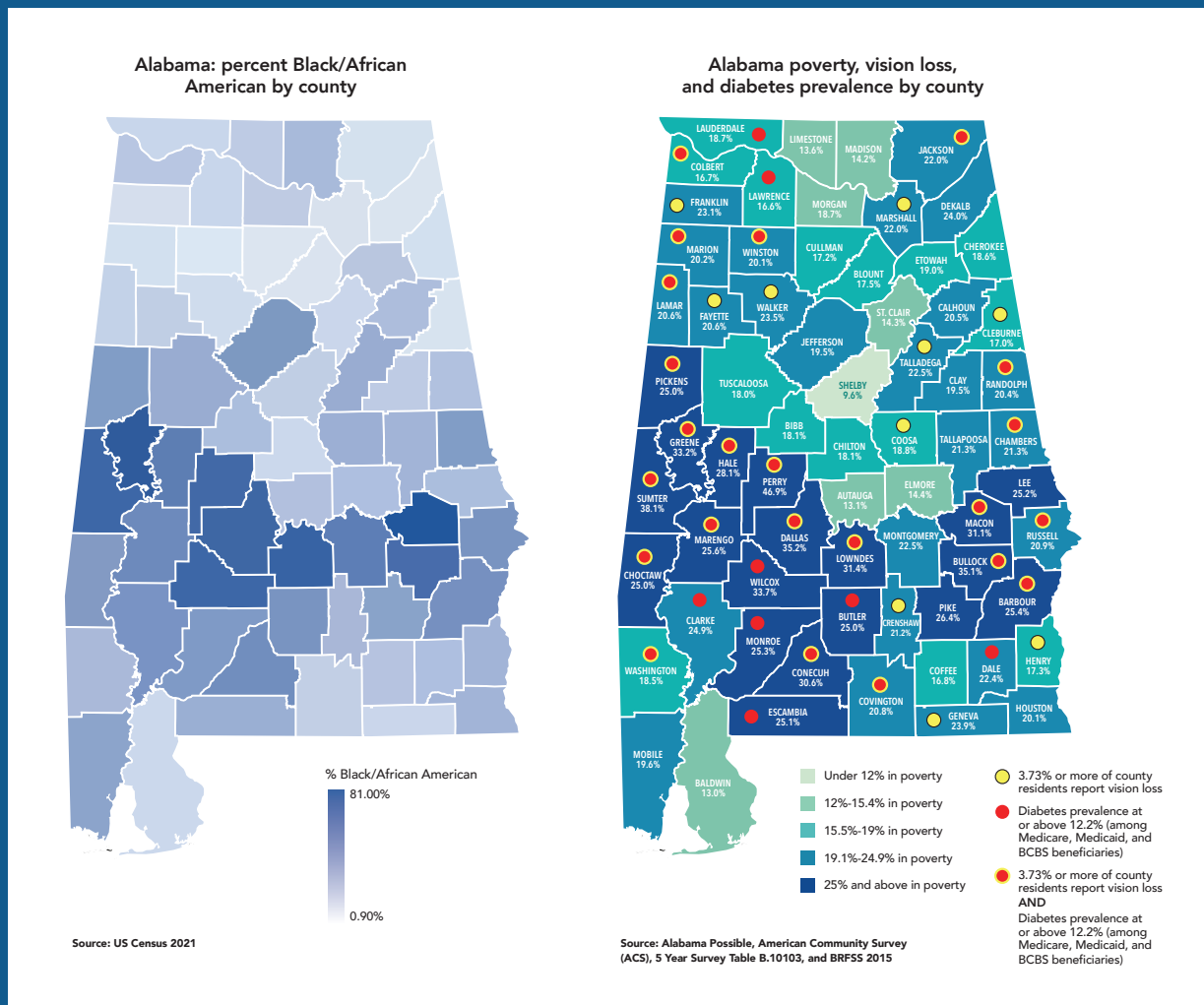
*The American Journal of Accountable Care. 2024;12(1):10-17*

Alabama is currently facing significant challenges with respect to diabetes and how it imposes considerable health burdens on communities across the state. More than 550,000 adults in Alabama have been diagnosed with diabetes.<sup>1</sup> In addition, factors such as limited access to health care, socioeconomic health disparities, and the treatment of comorbid conditions such as diabetic eye disease exacerbate poor health outcomes for those impacted.<sup>1,2</sup> Thus, articles focusing on health equity and diabetic complications are critical for enhancing awareness and urgency in highlighting a need for locally based interventions to mitigate barriers to care.

## The Burden of Vision Impairment Caused by Diabetes in Alabama

In Alabama, it is estimated that 13.9% of the population has diabetes and 9% has prediabetes.<sup>1</sup> More specifically, diabetes burdens the health of African American/Black populations and their respective communities. In Alabama, nearly one-fifth of African American/Black individuals and one-fourth of older adults have diabetes.<sup>1</sup> Diabetic eye disease is a leading cause of blindness in the US.<sup>2</sup> Specifically, African American/Black individuals and individuals living within underresourced communities are at a higher risk for developing the disease.<sup>3</sup> According to the 2012-2016 US Census Bureau American Community Survey 5-year estimates, nearly 145,000 Alabama residents reported blindness or severe difficulty seeing even with glasses.<sup>4</sup> The 2021 CDC crude prevalence of vision-threatening diabetic retinopathy in Alabama was 0.57% (95% CI, 0.42%-0.77%) of a total population of 5,039,877.<sup>5</sup>

Moreover, severe vision impairment is reported at higher rates in those with poor health (16%) vs good health (4%) and in those having less than a high school education (9%) vs those having a high school education and above (4%).<sup>5</sup> According to the 2015 CDC Behavioral Risk Factor Surveillance System data for Alabama, individuals with severe vision impairment

Figure 1. Diabetes, Vision Loss, and the Black Belt<sup>a</sup>

BCBS, Blue Cross Blue Shield.

<sup>a</sup>The left map shows Alabama divided by county, with darker blue corresponding to a higher percentage of Black/African American residents. The Black Belt is shown clearly in the southern half of the state. The right map shows Alabama poverty rates (green-blue color scale), vision loss, and diabetes prevalence by county. Comparing the 2 figures, there is a clear geographic overlap between counties that have higher percentages of Black/African American residents and reported incidence of diabetes prevalence/vision loss.

Source: Alabama state maps were obtained from the Alabama Department of Public Health and the Alabama Diabetes Program. Data encompass output from the Pharmacy, Podiatry, Optometry, and Dentistry program, which is a part of the Alabama Possible initiative. Data are extracted from the American Community Survey, 5-Year Survey, Table B.10103, and Behavioral Risk Factor Surveillance System 2015.<sup>1</sup>

were more likely to have diabetes (18% with vision impairment vs 10% without), arthritis (46% vs 27%, respectively), and mobility issues (44% vs 15%).<sup>5</sup>

Across the eastern and south-central regions of the state, there is a high concentration of counties with high poverty and

high rates of vision loss and diabetes. Ten counties (Cleburne, Coosa, Crenshaw, Fayette, Franklin, Geneva, Henry, Marshall, Talladega, and Walker) reported having 3.73% or more residents with vision loss (Figure 1).<sup>1</sup> An additional 23 counties (Barbour, Bullock, Chambers, Choctaw, Conecuh,

Covington, Dallas, Greene, Hale, Jackson, Lamar, Lowndes, Macon, Marengo, Marion, Perry, Pickens, Randolph, Russell, Sumter, Washington, and Winston) reported having 3.73% or more residents with vision loss and diabetes prevalence at or above 12% among Medicare, Medicaid, and Blue Cross Blue Shield insurance beneficiaries (Figure 1).<sup>1</sup> Twelve counties are located within the Black Belt region of Alabama (Barbour, Bullock, Choctaw, Dallas, Greene, Hale, Lowndes, Macon, Marengo, Perry, Russell, and Sumter), which comprises an agricultural ecosystem with a majority African American population of 53% compared with the US national average of 13.6%.

Strategic and local community initiatives are vital to anchoring efforts on health-promoting interventions that target populations with high unmet need. Customizing and cocreating interventions with local stakeholders is critical to building community trust and eradicating health care gaps.<sup>6</sup> Therefore, we aim to focus on health equity and link managed care advocacy efforts with pharmaceutical industry partners to promote locally based efforts to help reduce the burden of diabetes. This review highlights the breadth of work being deployed across Alabama to address barriers to eye health. Moreover, we discuss a state-based partnership between the American Diabetes Association (ADA) and Genentech to increase equitable access to eye health care.<sup>7</sup> We plan to address several barriers to eye care documented in the literature, including suboptimal screening, lack of awareness, maintenance of routine diabetic eye exams, limited access to care, and adherence to follow-up care. Through implementing community initiatives, education and awareness resources, and quality improvement research, we aim to fulfill our commitment to tackling barriers to access, screening, and treatment for eye diseases that affect the diabetes community of Alabama.

### Barrier 1: Poor Diabetes Outcomes

The burden on health due to diabetes may be reduced by preventing the onset, delaying disease progression, and effectively utilizing available therapies. According to a study that estimated the state-level burden of diabetes-attributable fractions for complications, the crude prevalence of diabetes was 13.8% for the state of Alabama.<sup>8</sup> Additionally, the age-adjusted prevalence of diabetes was 12.7% in Alabama, with the rate of diabetes-attributable hospitalizations with myocardial infarction per 10,000 population being 0.2 in the state. The rate of diabetes-attributable cases of severe visual impairment or blindness per 10,000 population was 103 in Alabama.<sup>8</sup>

This evidence signals a need for continued efforts to assist individuals with managing their diabetes and complications. Controlling risk factors in adults with diabetes requires access to quality health care and self-management resources.

Access to health care across Alabama continues to be a severe problem for many, resulting in poor quality of care and increased complications.<sup>1</sup>

### Barrier 2: Lack of Awareness and Completion of First and Maintenance of Regular Comprehensive Diabetic Eye Examinations

Disease awareness barriers could stem from the importance of eye screening after being diagnosed with diabetes not being fully understood. Furthermore, in addition to maintaining blood glucose control, individuals may need to be made aware of the importance of regular eye examinations. Several studies examining factors affecting patients' awareness and practices among individuals with diabetes have demonstrated that lower screening rates are associated with their knowledge and perceptions of eye health maintenance for preventive health.

The Rural Alabama Diabetes and Glaucoma Initiative study examined 2699 patients across 7 counties in the Black Belt region.<sup>9</sup> Of these, 39% (n=1053) exhibited a visual acuity of 20/40 or less, and 2.7% (73) were referred due to diabetic retinopathy. No subspecialists were identified within these local communities at the time of the study, and 10% (n=270) of patients had undiagnosed diabetes, as evidenced by a hemoglobin A<sub>1c</sub> level greater than 7%. An individual's perceptions of their need for regular comprehensive eye exams and the presence/severity of their disease play a key role in determining whether they utilize health care resources. These findings underscore the need to heighten awareness about the significance of regular comprehensive eye exams and empower individuals with diabetes to leverage available resources.

Elliott and colleagues assessed visual quality, eye care utilization, and the presence of eye disease among socioeconomically disadvantaged older adults residing in 19 senior subsidized housing communities across Jefferson County, Alabama.<sup>10</sup> A key objective of their study was to allow residents to self-report their vision. The individuals in the study reported a lower level of vision impairment than what was detected by the investigators using objective measures of distance and near visual acuity. Additionally, 43.3% of residents who did not see an eye care professional said they had no reason to go, which was the primary reason for failing to do so. The combination of these data suggests a discrepancy between how participants perceived their vision and what was assessed by objective visual measurements. Interestingly, the vision screenings attracted interest and participation from nearly all facilities (14 of 19; 74%) invited to participate. Residents' high level of involvement in getting screened signals that individuals are willing to undergo health assessments if given the opportunity.

An essential step toward improving patient understanding of regular eye care and screening benefits is to ensure availability and access to educational materials from their health care providers.<sup>11</sup> With poor health literacy being independently associated with higher rates of retinopathy in individuals with diabetes,<sup>12</sup> educational materials should be targeted to a population's education level, especially for those at higher risk for diabetic eye complications.<sup>13,14</sup> Health care professionals should consider using materials around a fifth-grade reading level to optimize the comprehensibility of materials for as many patients as possible. In addition to tailoring to the educational level, providers should ensure that educational materials are culturally and linguistically appropriate for individuals with diabetes.<sup>15,16</sup> Health systems should consider working with their providers on increasing research to understand the populations they serve in their communities (eg, their backgrounds, education level, language, cultural preferences, knowledge gaps) as they develop equitable educational materials.<sup>13</sup>

Online and electronic educational resources may preclude older adults and other socially disadvantaged groups from obtaining access to these materials, which may make physical brochures and pamphlets of interest for these populations.<sup>13,17,18</sup> Additionally, it is essential to consider verbally communicating health information. For example, Muñoz and colleagues found that less than 5% of their participants from a predominantly Hispanic community reported getting vision care information from written materials.<sup>15,19</sup> Individuals also stated that they seek verbal communication from their health care professionals, community, and family members,<sup>15</sup> suggesting that oral educational information may be critical for educating specific populations.

### Barrier 3: Limited Access to Eye Care

Understanding how visual rehabilitation barriers impact patients' abilities to achieve optimal visual outcomes is critical for improving diabetic eye health. In a study conducted at Cooper Green Mercy Health Services, an outpatient, county-funded facility in Birmingham, Alabama, referrals to low-vision rehabilitation services for patients with irreversible vision impairment were severely limited.<sup>20</sup> In 143 patients with irreversible vision impairment in one or both eyes, referral for low-vision rehabilitation services was low for patients with irreversible bilateral (11%) and unilateral (2%) vision impairment, as referenced in electronic health records. In the same study, more than 90% of patients indicated that their vision impairment impacted their quality of life, causing challenges in recognizing friends and colleagues and reading printed material. Of note, patients also expressed interest in learning how low-vision rehabilitation services may help their visual quality-of-life outcomes.

Keenum and colleagues reported a 29.9% engagement rate in an Alabama publicly funded county clinic for follow-up examinations referred for ophthalmology follow-up care.<sup>21</sup> Their study screened 949 individuals living with diabetes, of whom 84.5% (802 of 949) were African American, 64.5% (612 of 949) were women, and 71.7% (680 of 949) lacked health insurance. Interestingly, 112 patients had diabetic retinopathy that required immediate ophthalmic urgent care (preproliferative or proliferative disease or macular edema). However, within 7 days after receiving the results of their screening tests, a mere 17.9% (20 of 112) pursued treatment. Strikingly, 24.1% (27 of 112) had no record of an eye care visit to the ophthalmology service 2 years after their screening visit. Conversely, patients with no diabetic retinopathy or only background diabetic retinopathy with no other ocular findings adhered to recommended intervals at the rate of 35.2% (189 of 537). These results signal the existence of underlying barriers to eye health. Interestingly, within the study's protocol of interventions, some of the most commonly cited barriers to eye care were minimized (ie, transportation, the proximity of specialty care to routine health care facilities, and cost).<sup>22-24</sup> For instance, the researchers included a Jefferson County-based clinic containing onsite ophthalmology services at the location where internal medicine services were administered for diabetes care, thereby reducing patients' reliance on extended transportation.<sup>21</sup> Eye examinations were provided at low cost or free of charge. Additionally, screening coordinators assisted in getting patients scheduled for appointments. Therefore, the susceptibility of patients not getting access to care was greatly reduced because they were registered patients at the facility.

Cost and lack of insurance have been identified as barriers.<sup>25</sup> To address this, Akano's study revealed that for the state of Alabama, 41.7% of adults noted not having insurance as the main reason for not accessing eye care.<sup>25</sup> Moreover, 30.8% of patients gave cost/insurance as the reason for not seeking eye care in the previous year. However, when considered alone, insurance status does not account for the gaps in health care access and access challenges observed throughout the Alabama ecosystem. For instance, according to the 2023 County Health Rankings report, the percentage of the Alabama population younger than 65 years without health insurance was 12% compared with the US percentage of 11%.<sup>26</sup>

Factors contributing to the lack of eye care access for individuals with diabetes at the health care professional and health system levels may include limited knowledge of eye care screening and access to equipment. A retrospective study reported that primary care-based diabetic retinopathy screening may be the ideal option to reach individuals with diabetes who do not seek routine eye care, as individuals were

less likely to miss their annual primary care visits.<sup>27</sup> Although the ophthalmology training received by US family and internal medicine residents meets the baseline requirements, a 2019 cross-sectional study revealed that these residents report low confidence levels when performing ophthalmic exams and treating ocular issues.<sup>28</sup> With nearly all adults (96%) stating that they would be somewhat to very likely to participate in routine eye care screening if recommended by their primary care physician,<sup>29</sup> it may be of interest for family practice and internal medicine residents to receive additional ophthalmology training so they can comfortably perform eye screening in-house during a primary care visit, which may help providers better reach their patients with preventive eye care services.<sup>27</sup>

In addition to primary care physician knowledge and comfort level for performing eye exams, health care systems may not always have the necessary equipment to perform screening in-house. One option would be to have primary care providers refer their patients to an optometrist or ophthalmologist for screening. Unfortunately, securing referral appointments is a common barrier, especially for rural primary care physicians. This may be partially due to the lack of robust referral networks or to patients being unable to travel for screening because of lack of transportation, missing work, and the overall cost. To combat these barriers, health systems should consider generating referral networks with health care systems or advocating for expanding insurance to cover eye exams with primary care physicians for better access to screening.

#### **Barrier 4: Socioeconomic Factors and Adherence to Follow-Up Care**

Social determinant drivers of diabetic eye health inequities impose gaps in health care, access to interventions, and disease management and educational assistance. Community-based diabetic vision programs allow more citizens to participate in preventive eye care services by reducing the cost of transportation and time spent traveling for sight or health care (eg, ophthalmological examinations).<sup>9</sup> Similarly, as the burden of diabetic eye disease continues to impact patients, a concomitant increase in the number of caregivers follows. Family caregivers are increasingly tasked with assisting without formalized training or preparation and are expected to function optimally as informal extended health care team members.<sup>30</sup> In a study by Bambara and colleagues, 96 patients from a low-vision rehabilitation center in Birmingham, Alabama, and their caregivers were interviewed.<sup>30</sup> The average best-corrected visual acuity in patients' better eye was 20/110. Caregivers were 19 years or older and self-identification confirmed their status as the primary family caregiver. Of the 96 family caregivers enrolled,

35.4% were identified as at risk for depression. Additionally, dysfunctional or ineffective social problem-solving abilities were significantly associated with greater depressive symptomatology and decreased life satisfaction.

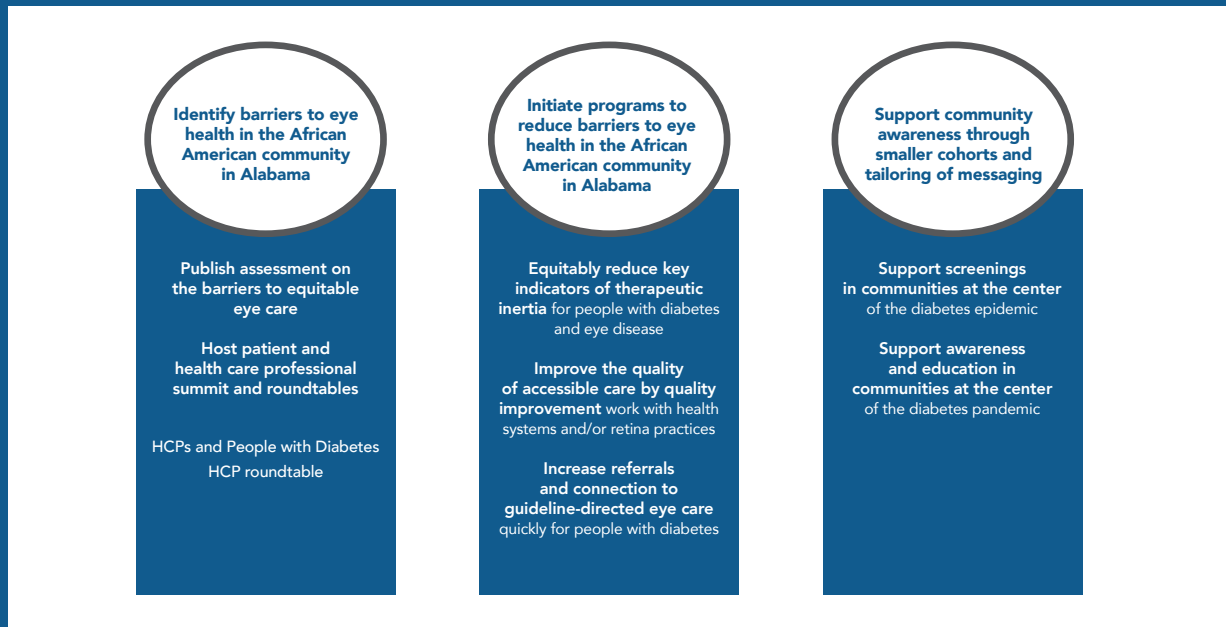
Similarly, visual impairment impacts patients' quality of life. Participation in community activities, mobility, everyday life, and visually demanding tasks are greatly diminished with reduced vision.<sup>31</sup> Moreover, the risk of hip fracture, the need for community and family support, the need for nursing home placement, and poor physical health are markedly increased due to decreased best-corrected visual acuity in a more improved eye.<sup>31,32</sup> Visual impairment is also significantly associated with increased mortality risk, fractures, and 2 or more falls in the past year.<sup>32,33</sup>

Low reimbursement to providers from major insurers (eg, Medicare and Medicaid, public insurance companies) fuels economic barriers. When this happens, the likelihood of recommending or referring patients for screening is low.<sup>2,3,11</sup> Developing a plan for those who are uninsured/underinsured for access to lower-cost vision screenings and/or eyeglasses and corrective lenses (online, other retailers, etc), especially for underserved and disadvantaged populations, would be beneficial.<sup>2,3,11</sup> In addition, providers and health care systems should also be aware and knowledgeable of low-cost screening opportunities offered by community centers, local health fairs, and worksite wellness programs and initiatives, which may mitigate some of these economic barriers for patients seeking eye care.

Several public health initiatives throughout Alabama remain dedicated to determining whether patients are adequately aware of the consequences of diabetic eye disease. Once patients are diagnosed with diabetes, they must be made aware of the consequences of diabetic eye disease and the importance of routine screening. Additionally, if evidence of diabetic eye disease is identified, referral to ophthalmic follow-up care is critical to maintaining positive visual health outcomes. The ADA recommends that patients with type 2 diabetes should have an initial dilated and comprehensive eye examination by an ophthalmologist or optometrist at the time of the diabetes diagnosis.<sup>34</sup> A further dilated retinal examination should be performed at least every year by an ophthalmologist or optometrist if any level of diabetic retinopathy is observed. Further examination will be required more often when retinopathy progresses or threatens visual acuity.

#### **The ADA and Genentech Partner to Increase Equitable Access to Eye Health Care**

In the spring of 2023, Genentech partnered with the ADA's Health Equity Now initiative, which brings together

**Figure 2.****ADA and Genentech Health Equity Now Partnership Goals to Address Barriers to Diabetic Eye Health in Alabama<sup>7</sup>**

ADA, American Diabetes Association; HCP, health care provider.

organizations focused on increasing awareness about diabetes and addressing health disparities in communities with the highest disease burden.<sup>7</sup> This partnership aims to remove barriers, reach people, and drive change in communities and health systems, working to address eye disease and diabetes awareness. Through 3 strategic key pillars (Figure 2<sup>7</sup>), this partnership is designed to obtain insights from individuals with diabetes, physicians, public health researchers, health systems, and others in the community to learn about what creates social and managed care barriers to eye care. Pillar 1 will identify barriers to eye screening, referrals, and treatment among underserved patients. Pillar 2 will initiate activities to reduce barriers to diabetic eye care. Pillar 3 will support awareness through community outreach and education with local organizations across Alabama.<sup>7</sup>

Diabetes-related health conditions such as vision loss can seriously impact individuals' quality of life. African American individuals are disproportionately affected by diabetes and are less likely than non-Hispanic White individuals to receive eye care examinations.<sup>35</sup> As such, systemic barriers to eye care for the African American/Black population must be identified—the critical focus of this partnership. To make health care more equitable and reduce health care costs, the focus is needed on

those populations with the least access and cocreated solutions with these communities to address the root barriers.

### Conclusion and Future Directions

In summary, we have described the burden of diabetic eye disease in Alabama. In this review, we have examined the depth and breadth of work being deployed across the state to address barriers to eye health. In the future, we aim to publicly share the output of this partnership via the Health Equity Now landing page.<sup>7</sup> This page will be accessible to all interested parties working in this space and will house educational resources, patient impact stories, and information about community activation initiatives. Working alongside community partners to prevent vision loss, the Eye Pledge to Fight Diabetes was launched in October 2023. This program encourages individuals with diabetes and their loved ones to get an annual eye exam, which has been shown to help reduce the risk of diabetes-related vision loss.<sup>36</sup> We plan to conduct quality improvement research studies in collaboration with large academic health systems and regional community clinics across the state. Key focus areas of our quality improvement work will be to work with health care providers to identify barriers and potential strategies to

track and improve eye screening and treatment for individuals with diabetes. Additionally, we plan to conduct focus groups to better understand the journey across local health care settings for patients with diabetes.

Together, we highlighted the need to continuously address barriers to eye health across Alabama while introducing the role strategic partnerships with industry can play in tackling this health problem. We look forward to providing insights into how this partnership model can be applied to other regions or health care settings facing similar challenges by highlighting its broader applicability as the subject of future investigations.

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**Source of Funding:** This work was funded through a partnership with the American Diabetes Association (ADA) and Genentech, a member of the Roche Group, as part of the ADA's Health Equity Now work.

**Author Disclosures:** Dr Wilson, Dr Haney, Dr Reuscher, Dr Gordon, Mr Coleman, Ms Wilson, Ms Israel, and Ms Williams are employees of and own stock in Genentech. Dr Tabano and Dr Ahmed are employees of Genentech. Dr Jinnett is an employee of Genentech and owns Roche stock. Ms Hennessy, Ms Wiggins, Dr Pekas, and Dr Bannuru report receiving corporate sponsorship from Genentech to the ADA.

**Authorship Information:** Concept and design (BAW, DH, DT, KJ, AA, AG, AC, RW, RI, JW, MPH, RRB); acquisition of data (BAW, DH, RRB); analysis and interpretation of data (BAW, AG, RRB); drafting of the manuscript (BAW, DH, DT, KJ, AA, AG, EJP, RRB); critical revision of the manuscript for important intellectual content (BAW, DT, KJ, AG, RW, EJP, RRB); statistical analysis (BAW, AG, TW); obtaining funding (RR, AC, RW, RI, JW); administrative, technical, or logistic support (BAW, DH, RR, AA, AC, RW, RI, JW, TW, EJP); supervision (BAW, RR, MPH); analytics of demographics (BAW, AG, TW); and literature search and review (BAW, AG, EJP).

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