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**Barriers to Follow-Up After Teleretinal Screening for Diabetic Retinopathy in the Harris Health System**

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By

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B.S.,
University of Houston,
2016

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An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
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# Abstract

**Barriers to Follow-Up After Teleretinal Screening for Diabetic Retinopathy in the Harris Health System**

By Omar I. Ali

Introduction: The Harris Health System implemented a teleretinal screening (TS) program for diabetic retinopathy in 2013. However, rates of follow-up after screening are suboptimal with only approximately half of those referred after TS completing follow-up. This study aimed to understand the barriers patients face in successfully completing follow-up after TS.
Methods: A retrospective cohort analysis of patients screened by non-mydriatic fundus photography via the Intelligent Retinal Imaging System (IRIS) at 13 Harris Health primary care clinics in 2018 was conducted. From this initial cohort of 11,622 patients, 333 patients who were identified by TS as having sight-threatening diabetic eye disease (STDED) failed to complete a follow-up appointment with a retina specialist at Ben Taub General Hospital or Lyndon B. Johnson Hospital. This cohort was contacted, and 103 patients voluntarily completed a 13-question telephone survey assessing barriers to follow-up.
Results: The overall loss to follow-up rate (LTFU) was 37.37%. Survey results indicate that the most common barriers to follow-up are healthcare-related costs and lack of instructional clarity following TS. Our analysis found no statistically significant relationship between language preference of survey respondent, location of TS, or the age/sex/race of survey respondent and the number of barriers reported. Increased risk of LTFU was found in those patients screened at 3 primary care clinics: Baytown (RR 1.37, 95% CI 1.01-1.86), Casa De Amigos (RR 1.32, 95% CI 1.01-1.72), and Squatty Lyons (RR 1.37, 965% CI 1.01-1.87).
Discussion: Our analysis found that the suboptimal follow-up rate of 62.63% among patients with TS-identified STDED is due in large part to systemic barriers many patients face, ranging from transportation and childcare demands to cost and lack of comprehension of post-screening instructions. Future quality improvement interventions, such as a refined process in providing patient instructions, will be developed based on these findings.

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**Introduction**

Between 1980 and 2014, the age-adjusted prevalence of diabetes mellitus (DM) increased 110% in men and 58% in women worldwide (1, 2). Such an increase translates to a near-quadrupling of the number of adults with diabetes which is projected to rise to 629 million by 2045 (1, 2). Unsurprisingly, the greatest DM burden is in low-and-middle-income countries (LMICs) (1). Projections of the Centers for Disease Control and Prevention (CDC) data suggest that by 2030, 44.1 million people in the United States (US) will have diabetes (3, 4). Additionally, nearly 60% of type 2 diabetics and nearly every type 1 diabetic will develop diabetic retinopathy (DR) within 20 years of diagnosis (4, 5, 6). One study extrapolated that between 2005 and 2008, approximately 3.8% of the US population had DR and 0.6% had vision-threatening diabetic retinopathy (VTDR), which they defined as severe non-proliferative DR, proliferative DR, or clinically significant macular edema (7).

It is therefore unsurprising that DR continues to be the leading cause of new blindness among American adults (20-74 years old) (5, 8-10). Among American adults aged 40 and older, the prevalence of DR and VTDR is expected to triple from 5.5 million in 2005 to 16 million in 2050 for DR; and from 1.2 million to 3.4 million for VTDR (defined here as proliferative DR and/or macular edema) (11). Among certain age groups and subpopulations, the effects are even more pronounced; in Hispanics aged 75 and older, the proportion of people with diabetic retinopathy is expected to increase by more than

12-fold by 2050 (11). In order to address this epidemic, the American Diabetes Association (ADA) recommends that individuals with type 1 DM receive ophthalmic screening starting within 5 years of diagnosis and those with Type 2 DM be screened at the time of diagnosis (8). However, while early intervention and treatment can be instrumental to preventing DR-related vision loss, only 50-65% of diabetics in the US receive adequate screening, and this can fall as low as 25% amongst underserved populations (11-16). Meanwhile, diabetes-related blindness continues to be financially catastrophic to the individual and society, costing the US approximately $500 million annually (7, 17).

One proposed solution to the epidemic of DR and its under-screening has been the implementation of diabetic retinopathy teleretinal screening (TS) programs (4, 12, 18). Our ability to visually examine the human retina has been possible since 1851 when Hermann von Helmholtz directed the light of a candle to a handheld lens, illuminating the retina (19, 20, 21). The evolution of ophthalmic imaging, along with electricity, allowed for improved and more detailed visualization of the retina and a wider field of view. More recent advances such as optical coherence tomography (OCT) and ultra-widefield fundus photography have further improved retinal visualization capabilities (21, 22). Combining these advances in retinal imaging with cutting-edge telecommunication technology led to the feasibility of TS. TS programs facilitate retinal evaluation despite a separation in location or time, and have traditionally been used to increase healthcare access in developing countries. However, as limited access to

healthcare can occur even in developed nations, TS is increasingly utilized worldwide (21).

Studies have demonstrated that DR screening via telemedicine is effective in identifying new cases of DR (4, 18). Compliance with recommended annual dilated eye exams has historically been particularly low amongst African American (49%) and Latino American populations (32%) which often comprise a significant proportion of socioeconomically-disadvantaged urban populations with limited access to ophthalmic care; TS may be especially impactful for these cohorts (4, 23-25). TS has also been shown to be cost-effective. Medicare studies revealed cost savings of $36-$48 dollars per teleretinal-screened patient over unscreened patients, while other studies found cost savings of $31-$81 per patient (12, 26). Meanwhile rural savings are even higher at $1,206 to $1,320 per quality-adjusted life year compared to unscreened patients (4, 23, 26, 27).

Los Angeles implemented such a program in 2013 and noted a significant decrease in time to screening, increase in overall annual screening rate, reduction in specialty care visits, and reduction in wait times for screening (10, 11). The success of the national diabetic retinopathy screening program in the United Kingdom (UK) is evident (21). For the first time in over 50 years, diabetic retinopathy has been replaced by inherited retinal disease as the leading cause of blindness in working-aged adults in the UK (21, 28).

Harris County in Houston, Texas is the most populous county in Texas and the third most populous county in the US, harboring a population of 4.7 million (18, 29). Harris Health System (HHS) is a government-funded county health system which primarily serves low-income eligible residents. There are two major HHS hospitals, Ben Taub General Hospital (BTGH) and Lyndon B. Johnson Hospital (LBJ), and over a dozen outpatient primary care facilities. An estimated 15% of HHS patients have diabetes mellitus which equates to approximately 50,000 patients who need DR screening annually (18). Since 2013, a robust diabetic retinopathy TS program has operated within HHS. This program currently boasts a >90% annual screening rate for all DM patients, well above the national benchmark of 63% (30). However, despite its success in increasing the overall screening rate, a recent study demonstrated that adherence with recommended in-clinic follow-up after a positive screen was suboptimal, with only slightly over half of patients presenting as directed (18).

Adherence with post-screening follow-up is not a unique challenge to the HHS program, and several programs elsewhere have shown that follow-up rates often lag far behind screening rates. One study from the West Los Angeles VA found that of all screened patients, 37.5% were lost to follow-up (LTFU) meaning they were not seen in clinic within 2 years (31). That study also found that patients who lived further from the clinic had a higher risk of LTFU (31). A 2014 study from Atlanta revealed that 44.1% of patients referred for clinical examination after TS did not follow-up (32). The study

found that age and travel distance were not significant predictors for follow-up. Rather, the best predictor of a patient keeping their follow-up appointment was the patient's historical no-show rate (32).

There are many factors that can impact the rate of follow-up such as patient characteristics, social support, provider characteristics, practice, policies, and community/professional norms (33). One study of patients with chronic eye diseases found that legal blindness and severe glaucoma correlated with worse follow-up adherence (34). The investigators also identified difficulty receiving time off from work was associated with poor follow-up, regardless of disease type (34). Additionally, being able to answer fewer than half the questions about one's own eye disease was predictive of poor follow-up (34). While a majority of the participants in that study received education about their eye disease from ophthalmology staff, only a small proportion noted being provided with resources or a support network (34). This emphasizes that patient education alone is not always sufficient to impact patient behavior.

In order to address the policy, practice, provider, and patient level factors that can impact follow-up, the barriers that patients face in the pathway from screening to follow-up must be understood. Figure 1 illustrates the screening pathway within the Harris Health population. The aim of our study was to determine what barriers exist along the latter part of this pathway (green) that may cause discontinuity between

having sight-threatening diabetic eye disease (STDED) identified and presenting for in-clinic follow-up (Figure 1).

## Methods

This study was reviewed and approved by the institutional review boards (IRB) of Baylor College of Medicine and the Harris Health System, and is in full compliance with the tenets of the Declaration of Helsinki and the Health Insurance Portability and Accountability Act (HIPAA).

### *Teleretinal screening process*

Patients who have a diagnosis of Type 1 or Type 2 diabetes mellitus are identified in their HHS primary care clinic. If they have not received a dilated fundus examination in the past one year, the physician orders TS that is performed either that same day or in the near future; screenings are currently performed in 13 HHS primary care offices. Figure 2 illustrates the location of all 13 screening sites as well as that of the two referral centers, Ben Taub General Hospital and Lyndon B. Johnson Hospital. During the screening, undilated 45-degree single-image fundus photographs are obtained in a darkened room (DRS camera; CenterVue, Padova, Italy) by a trained technician; patients are only dilated if the images are of insufficient quality. Inter-user variability is minimized via 1-frame capture technique that uses patient autosensing, autoalignment, autofocus, and autoflash adjustment. Photographs are then uploaded to a HIPAA-compliant cloud-based platform (Intelligent Retinal Imaging Systems (IRIS), Pensacola, FL) and asynchronously interpreted by a trained ophthalmologist who grades the level of retinopathy based on the Early Treatment Diabetic Retinopathy Study classification

criteria (35). Patients who do not meet referral threshold (e.g., no DR, mild NPDR, moderate NPDR, or non-severe diabetic macular edema (DME)) were asked to return in one year for repeat TS. If patients are found to have severe non-proliferative diabetic retinopathy (NPDR), proliferative diabetic retinopathy (PDR), severe DME, evidence of other disease, or ungradeable images, they meet referral threshold for STDED as defined by the program, and they are notified by HHS staff within two weeks and asked to follow-up for an in-clinic examination with a retina specialist at one of the two referral sites.

*Telephone survey process*

A comprehensive list of all 11,622 HHS patients who received TS between January 1, 2018 and December 31, 2018 was obtained from IRIS's secure database. Medical record number (MRN), date of screening, DR grade, DME grade, and screening site were included. 891 patients had STDED, meeting the threshold for clinical referral, and were scheduled for in-clinic examination. The electronic medical records were reviewed for all 891 patients to determine if an in-clinic follow-up appointment had been completed within 1 year of the screening date or prior to the patient's next TS (whichever came first). Successful follow-up completion was verified by the presence of a note in the medical record from a retina specialist at BTGH or LBJ documenting a dilated fundus examination (DFE). 333/891 (37.4%) patients did not meet this successful follow-up criteria. Data points including age, sex, race, current residence zip code, language

preference, and contact information (up to 3 phone numbers) were also recorded for the final cohort of patients.

A survey was developed for the patients who failed to follow-up after their TS results met referral threshold. The survey intended to assess what barriers may have contributed to a patient not completing follow-up. Questions (Figure 3) were constructed with minimal medical terminology and to facilitate ease of conversation. All questions assessed important barriers as identified by prior research and based upon previous experience with this patient subset. The survey was administered by the surveyor (OA) via a secure telephone line, utilizing an official third-party Harris Health System language translator if English was not the respondent's primary language . The surveyor first introduced himself by name and role, and then inquired about the respondent's willingness to complete a 5-10-minute telephone survey regarding their experience with the HHS TS program. The patient was informed that the questions would assess what barriers they faced in completing a follow-up appointment, such as the length of their commute, clarity of instructions provided, and financial costs, among other things. In order to ensure that consent was truly voluntary, participants were informed that their willingness to participate (or not) and responses would in no way affect them negatively in any respect, and would not affect the healthcare they receive now or in the future. Participants were not charged to partake in the study nor were they compensated for their time. The first question of the survey was:

*Would you be willing to participate in this survey? Please note that none of your personal identifying information will be associated with your responses.*

If participants answered yes, then the survey was administered. Before any questions were asked, patients were given anchoring information and a brief timeline of activity in order to reduce recall bias and improve accuracy of the survey. The following script was read to patients:

*Pictures of your eye were taken at _____ (location), on _____ (date) as part of your diabetic workup, and we wanted you to come in to further discuss the findings. However, we see that you were not able to make it in for your appointment, and we were hoping to ask you why in order to better our ability to care for you and others in the future.*

The next two questions assessed if patients were able to recall this information and verified the information obtained from prior chart review.

*First, did you know that you had a follow-up appointment scheduled with the eye doctor to discuss the results of your pictures?*

*Do you confirm that you were unable to attend that appointment?*

If both of these questions were answered affirmatively then the remainder of the survey was administered. Patients who could not recall ever being told to follow-up in person or who claimed to have attended their in-clinic appointment were excluded from the

final cohort for analysis. Ten survey questions required a yes/no/NA (not applicable) response; question 3 was a numerical response; question 12 asked respondents to identify the greatest barrier that prevented follow-up; and question 13 asked patients to describe in their own words any additional barriers or expand on a previously mentioned one.

*Data acquisition and analysis*

At least two attempts, on all available phone numbers, on different days, and alternating AM or PM times were made to contact all 333 patients. No voicemail messages were left. Free response sections of the survey were transcribed verbatim during the phone conversation. Patient phone calls were completely confidential, and no identifying information was associated with responses. Patient names and MRNs were de-identified and a random numerical study ID was assigned to each participant after interviews.

Data were stored on a password-encrypted storage device. Statistical analysis was done utilizing SAS version 9.4. A p-value of $<0.05$ was interpreted as statistically significant. Tests of correlation were run between collected variables to determine whether associations between survey responses and average number of barriers were statistically significant. These included two-sample t-test, Wilcoxon-rank sum test, and one-way analysis of variance (ANOVA) test. Additionally, risk ratios were calculated to

analyze risk of LTFU based on disease severity/screening site and risk of not completing the survey based on disease severity/language preference.

**Results**

11,622 patients were screened through the HHS program in 2018. Figure 4 illustrates the breakdown of pathology as interpreted based on the TS photographs. 891/11,622 patients were referred for in-clinic follow-up by a retina specialist. Of these, 333/891 (37.37%) did not present for in-clinic examination. Of these 333 patients, all of whom for which contact was attempted, 103 (30.93%) patients completed the aforementioned telephone survey and comprised the final cohort for analysis (Figure 5). Figure 6 illustrates the breakdown of pathology amongst this final cohort.

Approximately equal numbers of males and females responded to the survey. The mean age was 56.60 years (SD 9.79). Slightly more than half preferred English as their primary language and 61.17% identified as Hispanic/Latino race (Table 1). Survey results are summarized in Figure 7. For 10 of the questions, respondents answered "yes" or "no" to whether they faced a particular barrier. "Cost" and "Unclear" were the two most commonly reported barriers, each with 48 patients responding yes, followed by "Busy" and "Transportation" with 37 and 35 affirmative responses, respectively. Respondents were also asked which barrier was the "greatest barrier" that prevented them from following-up after a positive teleretinal screen. The most common greatest barrier was "Cost" (23 patients) followed by "Unclear" (20 patients) and "Transportation" (18 patients). 18 survey respondents did not report a "greatest barrier".

Survey respondents were asked to approximate their average commute time from where they lived at the time of TS to BTGH or LBJ (whichever was nearer). Patients reported a mean commute time of 35.19 (SD 25.52) minutes. The maximum commute time reported was 180 minutes. The average number of barriers reported by each patient was 2.46 (SD 1.58) and these followed an approximately normal distribution. The maximum number of barriers reported by a single patient was 7 of 10 possible barriers.

*Association between language preference and number of barriers*

Our analysis explored a possible correlation between patient language preference and the average number of barriers. A Wilcoxon-rank sum test found no statistically significant difference in the mean number of barriers for English speakers versus Spanish speakers ($p = 0.5$). The 54 English-speaking patients experienced a mean of 2.59 barriers, and 48 Spanish-speaking patients experienced a mean of 2.33 barriers (1 Vietnamese-speaking respondent was excluded in this subgroup analysis).

Furthermore, looking specifically at the association between language preference and the "Unclear" barrier; a chi-squared analysis found no statistically significant association between language preference (English/Spanish speakers only) and the "Unclear" barrier ($\chi^2 = 2.39$, $p = 0.12$). This means that among those who replied "Yes"

to the "Unclear" barrier 44.68% spoke English and 55.32% spoke Spanish, which calculates to a relative risk of 0.72 (95% CI 0.47-1.1) of speaking English versus Spanish.

*Association between screening site and number of barriers*

Next, the relationship between the location of TS and the average number of barriers reported was analyzed. Figure 8 illustrates the number of survey respondents that were screened at each of the 13 HHS TS sites in 2018. Martin Luther King Health Center (HC) had the most survey respondents screened with 15, followed by Vallbona HC with 14, and Northwest HC with 13. A one-way analysis of variance (ANOVA) test found no significant difference in the mean number of barriers reported amongst the different testing sites ($p = 0.59$). Figure 9 is a box plot of the average number of barriers reported by screening location, which illustrates the minimal variation in the average number of barriers per patient at each site. Figure 10 maps the residence of survey respondents based on their current zip codes, which serve as a proxy of the likely zip codes the patients had in 2018 at the time of TS. The 77081 zip code had the most survey patients currently residing in at 5 (4.85%) of respondents.

*Association between demographics (age, sex, race) and number of barriers*

There was no statistically significant correlation between age at time of survey and the number of barriers ($p = 0.346$). A two-sample t-test confirmed no statistically significant difference between the number of barriers for male respondents (mean 2.29) versus female respondents (mean 2.62) (95% CI -0.30-0.94). Lastly, a one-way analysis of

variance (ANOVA) test found no statistically significant difference in the number of barriers based on race utilizing an alpha level of 0.05 ($p = 0.0879$).

*Association between DR severity and risk for loss to follow-up*

In order to analyze whether TS-based DR grade was associated with risk for loss to follow-up, data from all 891 patients (558 complied with post-TS follow-up, 333 did not) who met referral threshold was assessed. Table 2 outlines the relative risk of LTFU based on TS-graded DR severity; no statistically significant association was noted. Macular edema grade was not included in this analysis.

*Association between screening site and risk for loss to follow-up*

Table 3 summarizes the risk of LTFU based on screening location. Three locations--Baytown HC (RR 1.37, 95% CI 1.01-1.86), Casa De Amigos HC (RR 1.32, 95% CI 1.01-1.72) and Squatty Lyons HC (RR 1.37, 95% CI 1.01-1.87)--had a statistically significantly increased risk of LTFU compared to that of all locations combined.

*Association between DR severity or language preference and risk of survey non-completion*

Table 4 illustrates that patients with more severe DR (e.g., severe NPDR or PDR), as graded based on TS, had a lower likelihood (severe NPDR: RR 0.78, 95% CI 0.65-0.94; PDR: RR 0.78, 95% CI 0.62-0.97) of survey non-completion as compared to those with mild NPDR. Macular edema grade was not included in this analysis. Language

preference was not associated with survey completion (69.32% for English speakers vs 68.79% for Non-English speakers).

*Qualitative responses*

Question 13 of the survey (Figure 3) asked patients to describe in their own words any other barriers that prevented them from completing follow-up, or to expand on a previously-discussed barrier. Sixty-nine of the 103 patients surveyed (67%) responded to this question. The responses reflected a wide variety of concerns ranging from financial costs and systemic co-morbidities to not wanting "student" exams. One of the most common responses from survey respondents was related to insurance status, healthcare costs, or their financial situation in general.

*"I don't have any money right now to go to the doctors"*

*"It was very expensive, $500 dollars and I still haven't gotten it done. I use eye drops for some comfort. I am a single woman working as a security officer so it's hard to come up with that money"*

*"[I] canceled my gold card and couldn't pay for it"*

*"My gold card had expired"*

*"[was] trying to get the gold card; however the length of time between seeing the specialist" my gold card expired*

Many respondents expressed financial concerns further compounded by additional barriers.

*"I was living in a homeless shelter and was moved across town and couldn't come in. I also didn't have any money"*

*"I changed my insurance so I couldn't go. The doctors that I go to, they only prescribe me drops and tell me I am a lost cause"*

*"I don't have any money to pay for an operation. I could get there, my brother would take me. I [also] care for my mother and she is bedridden"*

*"My medical coverage finished, and when I renewed it and they told me no available appointments"*

The other predominant concern expressed by many survey respondents was difficulty scheduling an appointment with a retina specialist or a lack of instructional clarity surrounding the scheduling process post-screening.

*"Was told [I] would have to wait 9 months to get an appointment. [I] Was waiting for a confirmation"*

*"Appointments have not been available; they have not scheduled me"*

*"It's hard to get an appointment"*

*"My daughter and my husband [have been] trying to get me an appointment and haven't been able to get one"*

*"My insurance went away, and then I tried to reschedule my appointment. It had something to do with the weather. After that I never could get back. They always say you [have to] call back this day or that day. This is the first time I have ever gotten a call back to update me or tell me anything about it"*

*"No appointments and I was not told by the staff how to make an appointment or who would reach out"*

*"No appointments right now. I want to go, but no appointments"*

*"Scheduling an appointment is very very difficult. It gets very complicated scheduling an appointment or follow-up appointment. It is very complicated they always say they are going to call you back but they don't"*

*"We are not able to schedule an appointment at the eye clinic. [I] Keep being put on the waiting list, cannot get in to see the eye specialist"*

Similarly, many patients expressed confusion regarding the process itself or how the results of TS would be relayed to them which contributed to lack of understanding the importance of follow-up.

*"I thought everything is under control"*

*"Sometimes the physicians use medical terminology that goes over your head"*

*"They took pictures of my eye, but didn't tell me anything after about what I had to do"*

*"I was told I don't have to see the retina specialist because there is no inflammation. I was told everything is under control"*

One common reason that scheduling was a barrier for many was due to overlap with their existing hemodialysis schedule.

*"Every time I try to make an appointment, they make it when I have to go to dialysis: Monday, Wednesday, Friday"*

*"I am in dialysis Monday, Wednesday, Friday. In the beginning they told me the appointment was not available, then told me to call back a month later. My vision is also very blurry"*

*"I have to go to dialysis Monday, Wednesday, Friday"*

Some respondents developed another systemic co-morbidity while waiting for an appointment or experienced interval worsening of vision that precluded their in-clinic attendance.

*"[Getting] from the parking lot to the doctor is the hardest part"*

*"My vision in my eyes is very affected so I cannot drive long distances and I do not have anyone to drive me right now"*

*"[I] Was pregnant at that time"*

"[I was] *seeing a lot of doctors at that time"*

*"[I] Can't see so it would be difficult to come in. [I'm] legally blind now"*

*"I was in the hospital for a long time…and the problem is I can no longer walk"*

Many patients also expressed concerns about transportation to the follow-up appointment.

*"It's hard to get a ride, I have to take the Metro, but I have difficulty"*

*"No ride no money"*

*"Transportation is difficult because I cannot see because of the diabetes. I have a little hole in my eye now"*

Some respondents actually did present to the clinic, but expressed frustration after experiencing a long wait time, and left the clinic before completing the follow-up appointment.

*"[I] Got sick while waiting [and] had my brother take me home. [I] Had to leave that day. When I tried to reschedule they wouldn't take me. They said I was a new patient"*

*"I had a dialysis appointment that day and I had to leave early. Wait time was too long"*

*"One day I went to LBJ and I waited for 3 hours and I couldn't wait no longer, because I had to catch my Metro lift back"*

*"Sometimes people just don't care. [I] came to the clinic, was waiting a long time, and then left without being seen because it took too long"*

*"[I] Went to the clinic and was told I would have to wait 2 hours so I couldn't wait and the appointment was rescheduled"*

Respondents were also challenged by their work responsibilities or by the work responsibilities of their caretaker.

*"Scheduling was very poorly done [and] work responsibilities got in the way. Parking is very expensive. When you have to take time off work to make it into the appointment they should ask the patient's for [their] preference"*

*"[My] daughter is responsible for all appointments. With work schedule, it is difficult to get to appointments"*

*"[I] take care of special needs boy, [I was] working 2-3 jobs at a time"*

*"I was busy during the appointment, then I couldn't make it"*

Lastly, a small number of patients elaborated upon an unfavorable interaction with their provider, reservations about receiving care at a teaching facility, or fear of needing treatment.

*"The doctor I had had an attitude...I didn't like"*

*"I go to my appointments, but they never do anything, never prescribe anything. They never tell me anything. They put me in a room and give me eye drops"*

*"[A] lot of students examining me as well. [I] don't like having students examine me. Appointments take too long and [I] can lose ride back."*

*"[I am] Scared of the needles and shots"*

**Discussion**

The Harris Health System diabetic retinopathy TS program aims to increase screening for patients with diabetes and improve early detection and treatment of STDED. However, adherence with follow-up recommendations following a positive screen remains a significant issue as more than one-third of these patients did not present for their in-clinic appointment after screening in 2018. While similar rates of non-compliance have been reported in other studies, very few have explored the root cause of this behavior at the patient level. Our study attempted to identify potential barriers that may drive patients' non-compliance by speaking with these patients directly.

Our results indicate that the two most significant barriers to successful follow-up are: healthcare costs and lack of instructional clarity following TS. Many patients reported experiencing lapses in insurance coverage; even if they had insurance, the copay associated with seeing a specialist could be prohibitive. The lack of instructional clarity following TS tied as the most common barrier, with many patients reporting not being told when their appointment would be. Many patients reported confusion about who to call if they needed to reschedule their appointment or they never received an initial scheduling call. Additionally, because the TS photographs are interpreted asynchronously, results are not immediately available, leading several patients to simply forget to follow-up on their results.

Some patients were not aware of why a picture of their eye was being taken. Some reported very limited availability for appointment times or extremely long wait times as barriers to follow-up. Oftentimes, an appointment was scheduled for the patient which the patient could not make due medical, employment, or personal conflicts. Not surprisingly, transportation was a common issue as patients often did not or could not drive due to their visual impairment. The least common reason for being unable to present for in-person follow-up was availability of childcare which is likely reflective of the average age in this cohort in the mid-fifties.

Our analysis found no statistically significant association between language preference and the average number of barriers reported. This was not unexpected as Harris County is one of the most diverse populations in Texas and all Harris Health primary care clinics have qualified language interpreters. Additionally, many members of the staff are bilingual, and much of the patient instruction (e.g., phone calls, paperwork) is available in a multitude of languages, including Spanish. This finding was further bolstered by our analysis which showed there was no statistically significant association specifically between language preference and the "Unclear" barrier which assessed any confusion with the instructions patients received. The site of TS also did not impact the average number of barriers reported; this was expected as most HHS primary care clinics are located in neighborhoods with a similar mix of patients who utilize the county health system for primary care. Neither age, race, nor gender had any statistically significant effect on the average number of barriers experienced either.

We also examined the risk of LTFU based on disease severity. The initial hypothesis was that increasing disease severity might result in a greater risk of not following-up (based on patient conversations/clinical experience), and thus, the mild DR group was set as the reference category. However, there was no significant difference in the likelihood of follow-up based on TS-graded DR. Of note, our analysis did not include DME severity as an additional variable despite DME being part of the STDED criteria. Therefore, patients with mild and moderate NPDR in our analysis qualified as having STDED due to concurrent significant DME. While there was no statistically significant risk noted, there does appear to be a trend, opposite to our hypothesis, where increasing DR severity resulted in lower LTFU rates (Table 2). Similarly, we also hypothesized that increasing disease severity may result in a decreased rate of survey completion; surprisingly, the opposite was found to be true such that patients with a diagnosis of PDR or severe NPDR were more likely to complete the survey (Table 4). In this analysis we again excluded DME severity (following the analysis in Table 2).

Risk of LTFU was significantly greater at three screening locations compared to all locations combined (Table 3). This may be due to site-based differences in processes, or may be an artifact of smaller vs larger sample sizes. Two of the three locations with the greatest LTFU rate—Baytown HC and Squatty Lyons HC—are located the furthest from the referral centers (Figure 2). However, it is less likely that distance played a significant role in the LTFU rate as this trend does not hold true for Casa De Amigos HC (49.18%

LTFU rate). Additionally, El Franco Lee HC, located a similar distance from the referral centers as Baytown HC and Squatty Lyons HC, had one of the lowest LTFU rates (28.04%). Future studies should analyze site-specific barriers that may explain such drastically different follow-up rates.

One limitation of this study design was only surveying patients who failed to follow-up in retina clinic. Future studies should include a comparison group of patients who successfully completed a follow-up appointment so that differences in variables could be assessed and stronger causal relationships could be drawn. There was a 30.93% response rate to the survey; while this is higher than many survey-based studies, it also introduces the possibility of selection bias. Participating survey respondents might be those who experienced fewer barriers, are more healthy, connected socially, or had experiences significantly skewed towards either positive or negative direction. Future analysis should seek to increase the survey response rate by offering the survey via mail, email, or even text message. This would also eliminate any potential inter-call variability in survey administration. Additionally, the telephone questionnaire only included 13 questions and may have overlooked barriers that affected patient adherence to follow-up. Lastly, the authors acknowledge that a significant limitation is the possibility of recall bias. While attempts were made to help anchor patients to the events of 2018, the survey was administered more than one year later and many patients may not have been able to accurately remember the circumstances surrounding

their TS. Of note, attempts were made to control for this by eliminating respondents who could not recall the screening itself.

While many of the barriers identified in our analysis are indicative of systemic issues in healthcare—such as affordability, transportation, and access—there are ways to feasibly implement solutions to help reduce the burden of barriers patients might face. For example, the issues surrounding provision of patient instructions post-screening can be directly addressed by evaluating standard operating procedures within the HHS program. As previous studies have corroborated, patient education is a critical component in the success of a telemedicine program such as this, and should also be optimized during the TS process (36, 37, 38). Site-to-site variability in the protocols for informing the patients of their results may also have contributed to the higher LTFU rates seen at three HHS sites. While quality improvement solutions are beyond the scope of this study, further study along with standardization and refinement of TS processes may help address this challenge. In fact, the follow-up rate of 62.63% in patients with TS-identified STDED is higher than the 52.9% follow-up rate found in an earlier study, and may suggest that some of the changes that have been effected in the interval may have already had a positive impact. Figure 11 highlights points where barriers were identified and proposes possible stopgaps to be considered in future quality improvement initiatives.

Large-scale TS programs have the promise to reduce the burden of diabetic eye disease en masse. However, ensuring appropriate follow-up post-screening remains a significant barrier to their success. This study aimed to understand what barriers may preclude follow-up after DR screening in the Harris Health System program. Many of the identified barriers reflect systemic inequities manifest in all areas of healthcare: cost of healthcare, overburdened safety net systems, need for better public health education, and insufficient mass public transit. However, our analysis also revealed personal barriers that were specific to each individual: childcare needs, burden of chronic health conditions, distrust of healthcare providers, and suboptimal understanding of DR and the TS process. Future studies will focus on implementing strategies to address the barriers uncovered and optimizing the TS program for our vulnerable patient population.

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## Tables

| | |
|---|---|
| **Male sex, n (%)** | **51(49.51)** |
| **Age, years (SD)** | **56.60(9.79)** |
| **Language Preference, n (%):** | |
| *English, n (%)* | *54(52.43)* |
| *Spanish, n (%)* | *48(46.60)* |
| *Vietnamese, n (%)* | *1(0.97)* |
| **Race, n (%):** | |
| *Hispanic/Latino* | *63(61.17)* |
| *Black/African American* | *21(20.39)* |
| *White/Caucasian* | *10(9.71)* |
| *Middle Eastern* | *2(1.94)* |
| *Vietnamese* | *1(0.97)* |
| *Other* | *4(3.88)* |
| *N/A* | *2(1.94)* |

***Table 1.*** *Demographic data for survey respondents (n=103)*

| | LTFU | Total | Rate of LTFU | Relative Risk (95% CI) |
|---|---|---|---|---|
| | **Risk of loss to follow-up based on diabetic retinopathy severity** | | | |
| Proliferative | 192 | 558 | 34.41% | 0.78 (0.56, 1.08) |
| Severe | 80 | 198 | 40.4% | 0.91 (0.64, 1.30) |
| Moderate | 32 | 75 | 42.67% | 0.96 (0.65, 1.44) |
| **Mild** | **23** | **52** | **44.23%** | **1.0** |

***Table 2.*** *Risk of loss to follow-up based on DR disease severity as graded on TS*

| Location | LTFU | Total | Rate of LTFU | Relative Risk (95% CI) |
|---|---|---|---|---|
| Acres Home HC | 30 | 82 | 36.59% | 0.98 (0.72-1.32) |
| Aldine HC | 27 | 69 | 39.13% | 1.05 (0.77-1.42) |
| Baytown HC | 22 | 43 | **51.16%** | **1.37 (1.01-1.86)** |
| Casa De Amigos HC | 30 | 61 | **49.18%** | **1.32 (1.01-1.72)** |
| El Franco Lee HC | 30 | 107 | 28.04% | 0.75 (0.55-1.03) |
| Gulfgate HC | 10 | 44 | 22.72% | 0.61 (0.35-1.06) |
| Martin Luther King HC | 37 | 92 | 40.22% | 1.08 (0.83-1.40) |
| Northwest HC | 33 | 93 | 35.48% | 0.95 (0.71-1.27) |
| Settegast HC | 22 | 61 | 36.1% | 0.96 (0.68-1.36) |
| Smith HC | 11 | 26 | 42.31% | 1.13 (0.72-1.79) |
| Squatty Lyons HC | 21 | 41 | **51.22%** | **1.37 (1.01-1.87)** |
| Strawberry HC | 24 | 77 | 31.17% | 0.83 (0.59-1.18) |
| Vallbona HC | 36 | 95 | 37.89% | 1.01 (0.77-1.33) |
| **Combined** | **333** | **891** | **37.37%** | **1** |

***Table 3.*** *Risk of loss to follow-up based on screening location*

| | Non-complete survey | Total | Rate of survey non-completion | Relative Risk (95% CI) |
|---|---|---|---|---|
| | **Risk of survey non-completion based on diabetic retinopathy severity** | | | |
| Proliferative | 130 | 192 | **67.71%** | **0.78 (0.65-0.94)** |
| Severe | 54 | 80 | **67.5%** | **0.78 (0.62-0.97)** |
| Moderate | 21 | 32 | 65.63% | 0.75 (0.56-1.02) |
| **Mild** | **20** | **23** | **86.96%** | **1.0** |
| | **Risk of survey non-completion based on language preference** | | | |
| English | 122 | 176 | 69.32% | 1.0 (0.89-1.13) |
| Non-English<br>- *Spanish*<br>- *Vietnamese*<br>- *Urdu*<br>- *Mandarin* | 108<br>- *101*<br>- *3*<br>- *3*<br>- *1* | 157<br>- *149*<br>- *4*<br>- *3*<br>- *1* | 68.79% | 1.0 (0.88-1.13) |
| **Total** | **230** | **333** | **69.07%** | **1.0** |

***Table 4.*** *Risk of survey non-completion based on disease severity and language preference*

## Figures

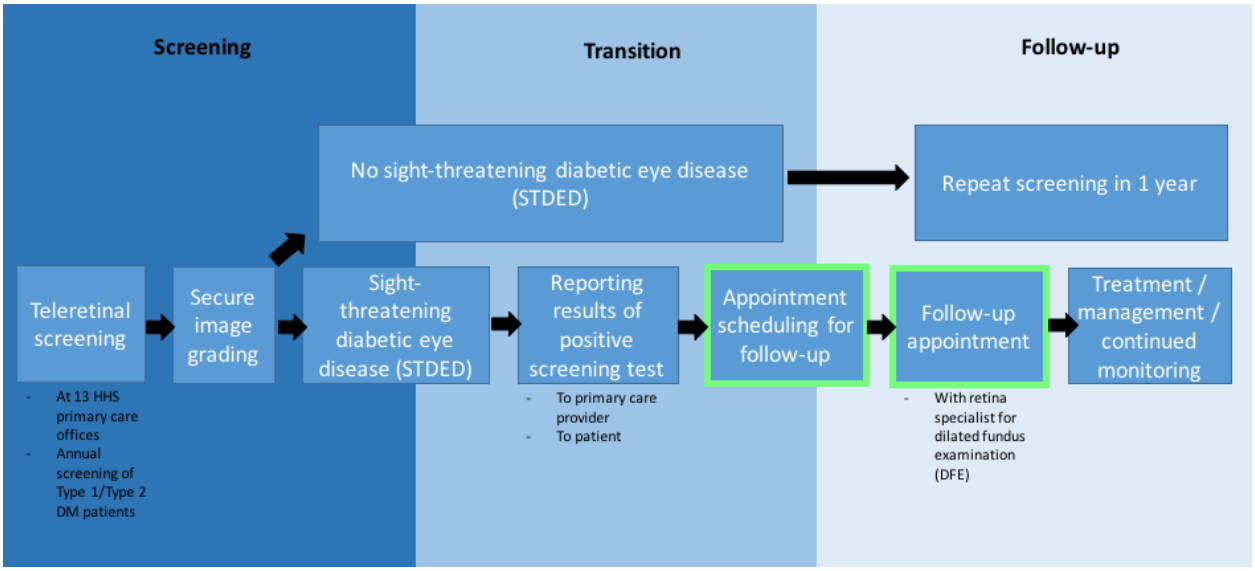


***Figure 1.*** *Pathway from teleretinal screening to follow-up appointment in the HHS DR teleretinal screening program*

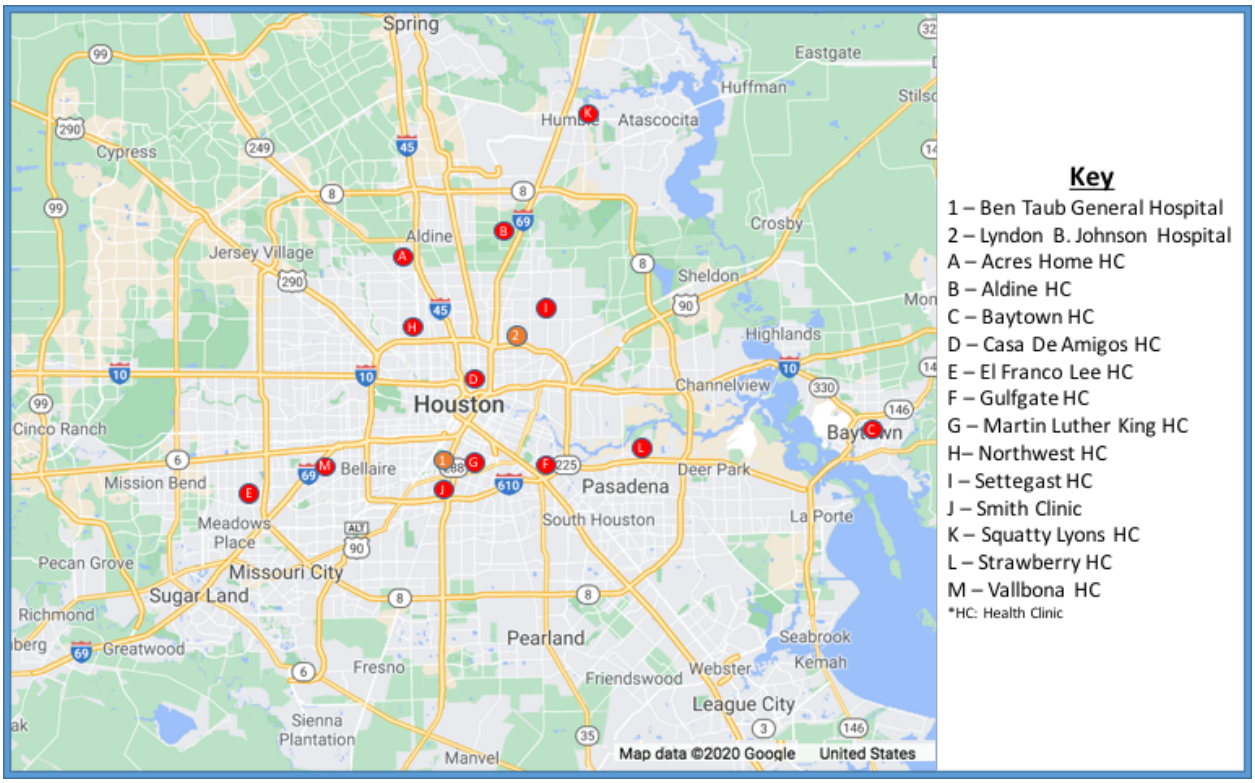


***Figure 2.*** *Map of Harris County showing the location of the 13 HHS primary care clinics with teleretinal screening cameras and 2 referral centers (BTGH/LBJ)*

1. *Was difficulty with accessing transportation a barrier to follow-up appointment?*
   **This question is abbreviated as "Transportation" for purposes of analysis*

2. *Was the length of commute to Ben Taub General Hospital or Lyndon B. Johnson Hospital a barrier to follow-up appointment?*
   **This question is abbreviated as "Commute" for purposes of analysis*

3. *In 2018, how long approximately was your commute from where you lived to Ben Taub General Hospital or Lyndon B. Johnson Hospital? (minutes)*

4. *Was there any difficulty with accessing childcare during the follow-up appointment?*
   **This question is abbreviated as "Childcare" for purposes of analysis*

5. *Was there any difficulty with the financial costs associated with healthcare or issues with insurance coverage?*
   **This question is abbreviated as "Cost" for purposes of analysis*

6. *Was there any difficulty with work responsibilities or getting time off of work for a follow-up appointment?*
   **This question is abbreviated as "Work" for purposes of analysis*

7. *Did you feel at the time that you were too busy or didn't have enough time for a follow-up appointment?*
   **This question is abbreviated as "Busy" for purposes of analysis*

8. *Did you feel the instructions you received after teleretinal screening regarding the follow-up appointment were unclear?*
   **This question is abbreviated as "Unclear" for purposes of analysis*

9. *Were you seeing a different provider (outside of the Harris Health System) for your eye care at the time?*
   **This question is abbreviated as "Other Provider" for purposes of analysis*

10. *Did you feel any fear, dislike, or distrust of doctors or your eye care providers?*
    **This question is abbreviated as "Fear/Dislike" for purposes of analysis*

11. *Did you have any concerns regarding the accuracy of the teleretinal pictures taken of your eye or did you not believe the interpretation of the results?*
    **This question is abbreviated as "Accuracy" for purposes of analysis*

12. *Which one of the above barriers would you say was the GREATEST factor in not coming for a follow-up appointment?*

13. *In your own words; was there any other barrier that prevented you from coming for a follow-up appointment to discuss the results of your eye images? Or would you like to expand on any of the above mentioned barriers?*

***Figure 3.*** *Survey questions 1-13 (*abbreviation used to represent the question)*

| | | Macular Edema Grade | | | | |
|---|---|---|---|---|---|---|
| | | N/A | Mild | Moderate | Severe | TOTAL (row %) |
| Diabetic Retinopathy Grade | N/A | 6,891 | 45 | 2 | 8 | 6,946 59.77% |
| | Mild | 2,085 | 654 | 134 | 52 | 2,925 25.17% |
| | Moderate | 615 | 219 | 86 | 75 | 995 8.56% |
| Meet Referral Threshold = 891 | Severe | 100 | 36 | 31 | 31 | 198 1.7% |
| | Proliferative | 420 | 59 | 56 | 23 | 558 4.8% |
| | TOTAL (column %) | 10,111 87% | 1,013 8.72% | 309 2.66% | 189 1.63% | 11,622 100% |

***Figure 4.*** *Breakdown of DR and DME grade amongst all HHS patients who received TS in 2018*

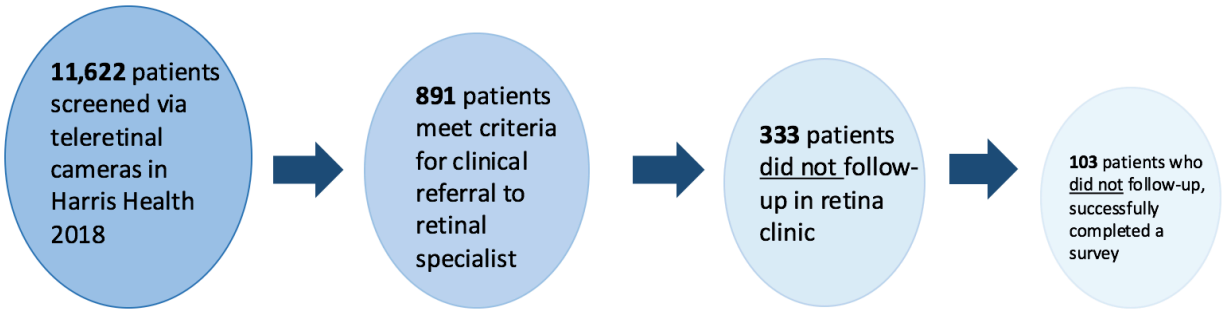


***Figure 5.*** *Selection of final cohort from initial group of all patients screened via the HHS TS program in 2018 based on photograph grade, failure to follow-up, and completion of survey*

| Diabetic Retinopathy Grade | Macular Edema Grade: N/A | Mild | Moderate | Severe | TOTAL (row %) |
|---|---|---|---|---|---|
| N/A | Did not meet referral threshold | | | 1 | 1 0.97% |
| Mild | | | | 3 | 3 2.91% |
| Moderate | | | | 11 | 11 10.68% |
| Severe | 9 | 8 | 5 | 4 | 26 25.24% |
| Proliferative | 50 | 5 | 3 | 4 | 62 60.19% |
| TOTAL (column %) | 59 57.28% | 13 12.62% | 8 7.77% | 23 22.33% | 103 100% |

***Figure 6.*** *Breakdown of DR and ME grade amongst the final cohort of patients who were detected with STDED on TS in 2018, did not follow-up in person, and completed a survey*

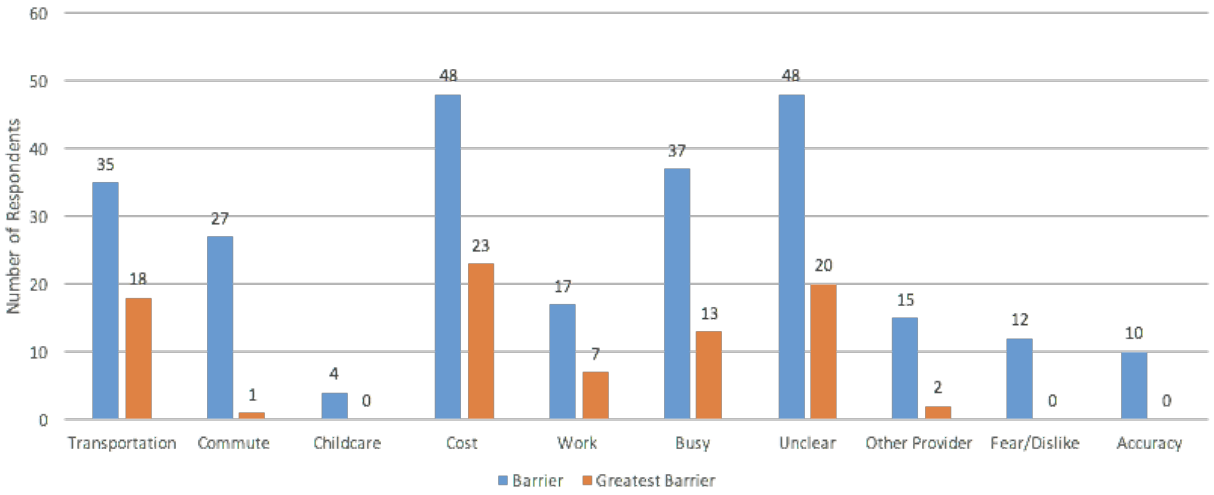


***Figure 7.*** *Reported barriers amongst survey respondents (n=103); abbreviations defined in the legend of Figure 3. Bar graph illustrates number of patients who responded "yes" to each barrier listed on the survey (blue; multiple "yes" responses were permitted) as well as those barriers selected as the "greatest barrier" (orange; only one barrier could be selected per patient)*

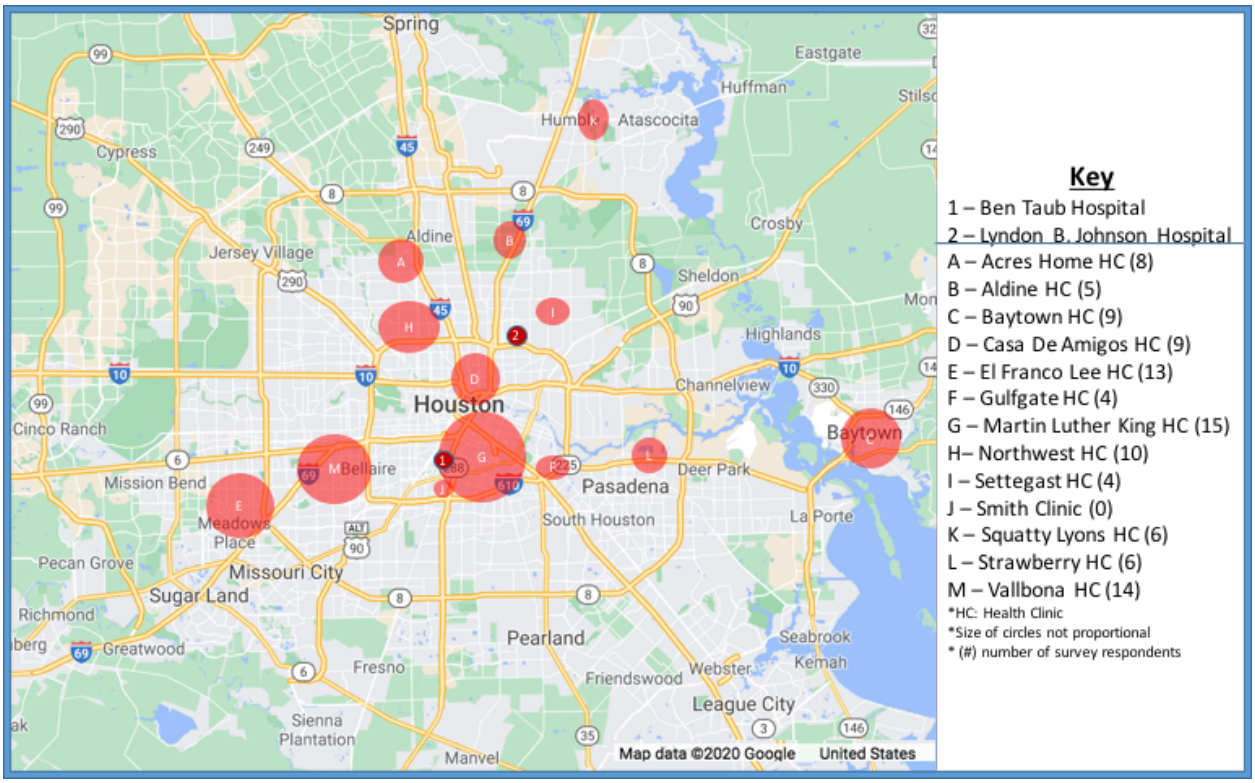


***Figure 8.*** *Harris Health System primary care clinic sites with teleretinal screening cameras and the number of survey respondents screened at each site represented by the size of circles*

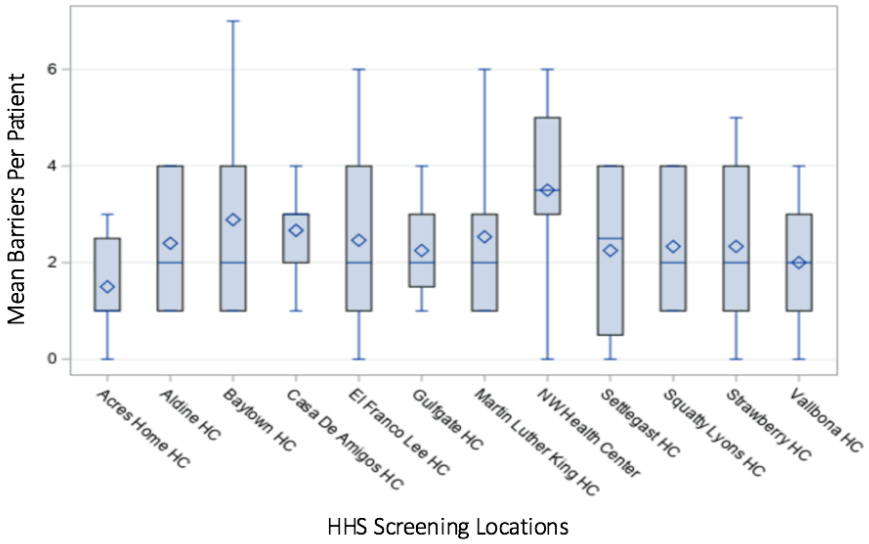


***Figure 9.*** *Distribution of average number of barriers by screening site. Diamond symbolizes the mean number of reported barriers per patient at each site, box represents the interquartile range, and whiskers represent the range.*

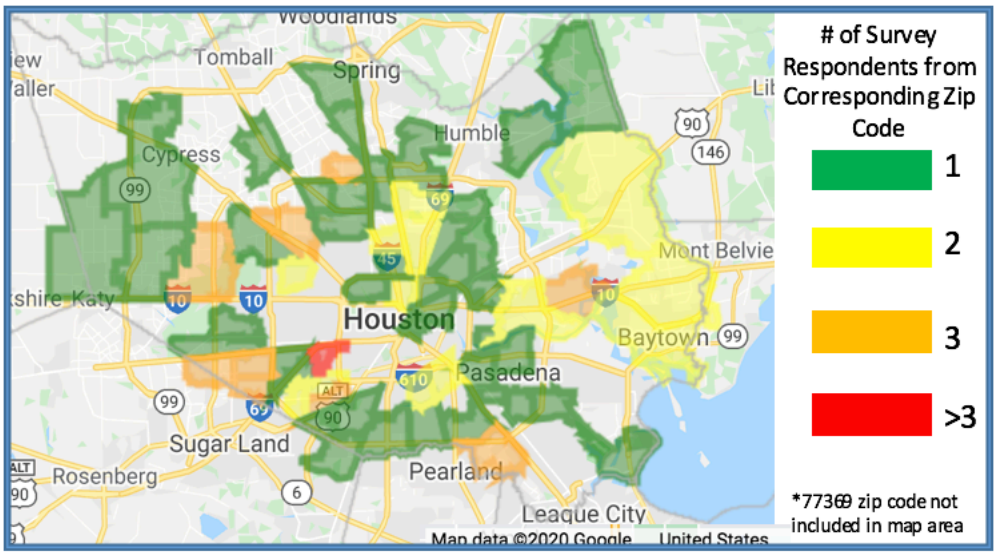


***Figure 10.*** *Map of Houston, TX divided along zip code lines. Density of survey respondents (represented by color scale) mapped to zip code of residence*

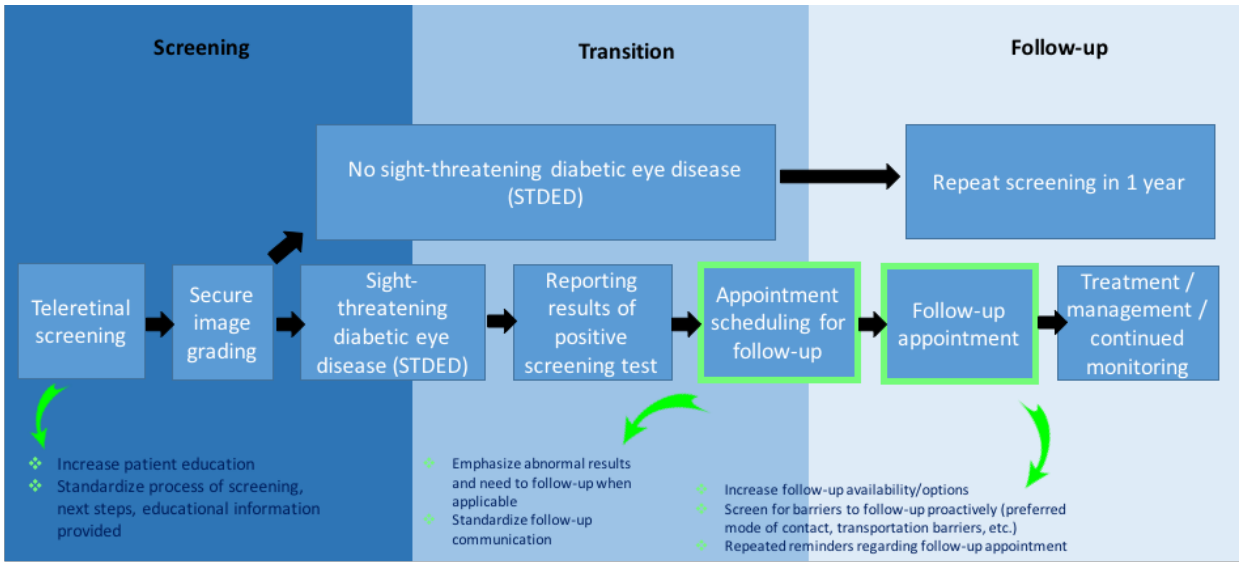


***Figure 11.*** *Teleretinal screening pathway showing where barriers were identified and proposing possible ways to lessen these barriers and improve follow-up compliance*