

# Understanding the Knowledge Gap Experienced by U.S. Safety Net Patients in Teleretinal Screening

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## Abstract

*Safety-net patients' socioeconomic barriers interact with limited digital and health literacies to produce a "knowledge gap" that impacts the delivery of healthcare via telehealth technologies. Six focus groups (2 African-American and 4 Latino) were conducted with patients who received teleretinal screening in a U.S. urban safety-net setting. Focus groups were analyzed using a modified grounded theory methodology. Findings indicate that patients' knowledge gap is primarily produced at three points during the delivery of care: (1) exacerbation of patients' pre-existing personal barriers in the clinical setting; (2) encounters with technology during screening; and (3) lack of follow up after the visit. This knowledge gap produces confusion, potentially limiting patients' perceptions of care and their ability to manage their own care. It may be ameliorated through delivery of patient education focused on both disease pathology and specific role of telehealth technologies in disease management.*

## Introduction

Diabetes is estimated to affect 21.3 million adults in the United States, with 1.7 million new cases of diabetes diagnosed every year.<sup>1</sup> Compared with non-Hispanic whites, racial and ethnic minorities are more likely to be diagnosed with diabetes, including 9.0% of Asian Americans, 12.8% of Hispanics, and 13.2% of non-Hispanic blacks.<sup>1</sup> California has one of the highest rates of diabetes in the country, with 9.9% of the population diagnosed with the chronic disease.<sup>2</sup> One complication of diabetes mellitus is diabetic retinopathy, which causes damage to the blood vessels of the retina.<sup>3</sup> Diabetic retinopathy is the leading cause of blindness in the United States with more than 100,000 new cases identified each year.<sup>4</sup>

Safety net clinics in the United States offer primary health care services to over 16 million patients nationwide and 2.3 million patients in California, whether or not these patients have the ability to pay for health care services.<sup>5</sup> Patients in South Los Angeles experience limited access to care, and many are African American and Latino. Limited access to appropriate eye care and delays in diagnosis and treatment can result in advanced disease, such as diabetic retinopathy and vision loss among such populations.<sup>3,6</sup> In a study of Los Angeles inner city minority residents, patients were 3.5 times more likely to present with advanced diabetic retinopathy and more than 5 times more likely to require immediate intervention, referral or follow-up than newly presenting patients in a predominately white non-urban setting<sup>7,8</sup>. The American Diabetes Association (ADA) guidelines for best practices necessitate annual retinal screening examinations, timely disease diagnosis, and on-going treatment to prevent the loss of eyesight due diabetic retinopathy. At-risk patients can benefit from laser photocoagulation surgery if retinopathy is detected early (in an annual examination).<sup>9</sup>

There is a growing body of research evaluating the efficacy of telehealth programs<sup>10,11</sup> and the use of telemedicine to screen for diabetic retinopathy has shown promise as a way to provide screenings to patients in areas where there is a lack appropriate access to these services.<sup>12-14</sup> Given the shortage of specialty eye care in medically underserved areas, such as South Los Angeles, the larger study of which this paper is a part, examined the use of teleretinal screening as an innovative way to address this gap in care. In the clinical use of teleretinal screening, technology is conceptualized as facilitating communication between a primary care provider and specialists (though other health care team members may be involved); the patient's retinal images are instrumental to that communication but no direct engagement of the patient by clinicians occurs beyond the generation of retinal image data. Studies of the clinical use of teleretinal screening have focused primarily on providers' use and perceptions of technology. In this paper, we shift the focus from provider to patient to explore one aspect of the qualitative findings of the larger study: patients' reported feelings of fear and confusion about teleretinal screening at critical points during the delivery of care. This is especially important to understand given that even with the introduction of teleretinal screening, safety

net screening rates lag behind national screening rates.<sup>15</sup> In order to understand this outcome, it is necessary to explore patient perceptions of telemedicine and the quality of care they received. As the primary setting in which many of the most disenfranchised healthcare users encounter health technologies, safety-net clinics present a particularly important site to understand how structural inequalities preconfigure patients' interactions with such technologies in the healthcare setting, and how these technological encounters may shape patients' beliefs and behaviors around the self-management of their chronic disease. Specifically, our findings indicate that these patients' limited health literacy compounds with pre-existing socioeconomic barriers and low technological literacies to produce a "knowledge gap" that limits patients' understanding of what is happening with the screening and their ability to comply with prevention goals and treatment plans.

**Materials and Methods**

*Study Setting*

The study took place from August 2010 to September 2011 and involved six safety-net primary care clinics in South Los Angeles<sup>15</sup>. During the study period, a total of 2,732 unique patients were screened for diabetic retinopathy by three ophthalmologist readers, with 1,035 receiving a recommendation for referral to specialty care. The study focused on both the technical challenges of implementing and screening patients, as well as the patient and staff perceptions of telemedicine. Each clinic used digital retinal cameras to conduct retinal screenings of Type 2 diabetes mellitus patients. The six clinics primarily serve immigrant Latino and African-American patients in communities that have 28% of the population living below the federal poverty level.

The gold standard for detecting and diagnosing diabetic retinopathy is seven-field 35-mm stereoscopic color fundus photographs and grading protocols, as defined by the Early Treatment Diabetic Retinopathy Study (ETDRS).<sup>16</sup> However, ETDRS photography is impractical for use in clinical settings so the more common method of diabetic retinopathy screening is via an in-person examination with a licensed eye care provider (Optometrist or Ophthalmologist). Diabetic patients in Los Angeles who visit safety net primary care clinics were traditionally referred to the Los Angeles Department of Health Services outpatient eye clinics for yearly retinal screening examinations and treatment of diabetic eye complications, resulting in long wait times for appointments. Prior to the introduction of teleretinal screening, primary care clinic staff report that patients could wait up to eight months to receive an initial retinal examination, diagnosis, and treatment. Complications such as proliferative diabetic retinopathy may result in permanent vision loss when screening and treatment are delayed.

Teleretinal screening for diabetic retinopathy, however, allows for routine screening via retinal images taken with a fundus camera by ancillary staff in primary care settings, with subsequent analysis by trained readers to determine presence and extent of disease. To conduct a teleretinal screening, clinic staff took six retinal images and two external images of a patient's eyes. The patient's case, consisting of images and basic biometric data, were then uploaded into EyePACS<sup>13</sup>, teleretinal screening software platform developed at UC Berkley and already in use in over 360 California safety net clinics. Three board-certified ophthalmologists contracted as image readers, assessed patients' cases, recommended referrals for further care, and rated quality of the retinal images provided.

*Approach and Procedures*

Focus group techniques<sup>17</sup> were used to assess the acceptability of teleretinal screening among Latino and African American patients who had received screening at one of the participating clinics. Six focus groups were conducted with two groups in English with patients who self-identified as African American and four groups in Spanish with

Latinos, most of whom spoke Spanish as a primary language. The subjects were 18 years or older, diagnosed with diabetes, both male and female, separated by gender. Each focus group included 6-9 patients, with the total sample size for the focus groups equaling 42 participants (29 Latinos, 12 African American, 1 unreported).

**Table 1: Racial/ethnic breakdown of patients in a) Six Study clinics, b) Teleretinal Screening Study sample and c) Focus groups sample**

	Six Study clinics	T.S. Study Sample	Focus Groups Sample
African American	14.4%	16.3%	29%
Latino	76.5%	75.4%	71%
Asian	.02%	7.9%	

Our study sample is representative of the Los Angeles county health services planning area 6 in which the clinics are located as well as the study clinics' overall populations. First, 9.5% of LA County population was diagnosed with diabetes in 2011,<sup>18</sup> perfectly mirroring the diabetes rates in the six clinics from which our retrospective study sample

was selected in the same time period. Our sample for the study represented 20% of the diabetes population in the six study clinics and for the most part, reflects the overall clinics' patient populations. For example, Table 1 shows that the racial ethnic breakdown of the patient populations at the six study clinics and our study samples were very similar. Because recruitment of participants for the qualitative study was opened up to screened African American and Latino patients from all participating clinics, we believe that both our larger study sample and focus group study sample are reflective of the clinics' overall patient pool.<sup>15</sup>

A script guided interviews, with questions arranged by category, focusing on patient perceptions about accessibility, acceptability, and satisfaction with the teleretinal screening that they received, as well as barriers to compliance with ophthalmologic referrals. Each focus group lasted approximately 90-120 minutes and the monolingual Latino groups

<b>Characteristics</b>	<b>African American</b> N(%)12 (29)	<b>Latino</b> N(%) 30 (71)
<b>Age (mean)</b>	56	48
<b>Gender</b>		
Male	6 (50)	15 (50)
Female	6 (50)	15 (50)
<b>Education</b>		
College grad	2 (17)	3 (10)
Some college	6 (50)	3 (10)
Secondary grad	1 (8)	1 (3)
Some secondary	2 (17)	18 (60)
Missing	1 (8)	5 (17)
<b>Income</b>		
0-500	4 (33)	11 (37)
501-999	3 (25)	11 (37)
1000+	5 (42)	8 (26)
<b>Own computer</b>	6 (50)	9 (30)
Male	4 (67)	4 (44)
Female	2 (33)	5 (56)
<b>Internet access</b>	5 (42)	5 (17)
Male	3 (60)	2 (40)
Female	2 (40)	3 (60)

were conducted in Spanish. All groups were audio taped and transcribed by a professional transcription company (to which participants consented). Upon each subject's completion of participation in the focus group session, the subject was provided with remuneration of \$50

#### *Data Analysis*

Using Atlas ti software to help manage and analyze the data, focus group transcripts were coded and indexed by team members to develop analytical categories based on qualitatively informed and modified grounded theory techniques of analysis<sup>17, 19</sup> Team members performed open coding independently to identify themes and to generate codes. Then transcripts were recoded with the team-developed codes. Constant comparison within and across categories allowed researchers to check codes against the rest of the data to establish categories that reflect the nuances of the data, key themes and theoretical insights. Scientific rigor is strengthened through use of common procedural guidelines for qualitative studies.<sup>20</sup> Credibility of the results is supported through use of data from 6 focus groups with carefully chosen participants, and a team with diverse research expertise and backgrounds. An iterative mode of data analysis by multiple team members increased dependability of the findings. Transferability of findings is made possible through published description of the methods and findings.

#### **Results**

##### *Demographic Data*

Table 2 shows participant characteristics. 29% of focus group participants were African American and 71% of participants were Latinos. 50% of all

participants were female, with both African American and Latino focus groups being split evenly between males and females. 60% of Latinos had not completed high school, while on average African Americans had attained a higher education status with 50% having attended some college. 62% of participants earned less than the 2012 poverty level of \$ 11,170 per year. Computer ownership was greater among African Americans (50%) than among Hispanic participants (30%). Latinas (56%) reported a slightly higher rate of computer ownership than Latinos (44%), while only 33% of African American females reported owning a computer compared to (67%) of African American males. Among Latinos, internet use was low, with only 17% of participants reporting access.

##### *Focus Group Results*

Findings indicate that in teleretinal screening, the patients' knowledge gap becomes consequential at three critical points: (1) when patients' pre-existing personal (structural) barriers to care became exacerbated in the clinical setting; (2) during the encounter with technology during the screening; and (3) during the doctor-patient follow-up after the screening. Summary of results are presented in Table 3 below.

1) Patients' Personal Barriers (Structural barriers)

Patients in this study group expressed concerns about their a) personal barriers to care, including the ability to access care, the quality of care that they receive, the costs of care, and the ability to follow treatment plans as prescribed. Patients also expressed b) confusion regarding the pathology of their disease.

1.a) *Nature of personal barriers to care:* Participants generally report a variety of barriers to accessing healthcare including, obtaining appointments, long wait-times, need for multiple appointments, loss of patient information by clinic, lack of clarity regarding the cost-of-care to patient, and the receipt of unexpected bills after care. These barriers were compounded by the fact that many participants indicated time pressures due to work and family obligations, transportation issues, as well as, financial pressures. For example, many patients spoke of the difficulty of complying with treatment plans due to daily schedules. Work regularly intervened in participants' ability to take

<b>Table 3: Three primary points at which the “knowledge gap” is produced in teleretinal screening</b>		
<b>1) Patients' Personal Barriers (Structural Barriers)</b>	<b>2) Encounter with Technology During Screening</b>	<b>3) Impact of Lack of Clinician Follow-up</b>
<p><i>1.a) Nature of personal barriers to care</i></p> <ul style="list-style-type: none"> <li>▪ Lack of resources (time, money)</li> <li>▪ Lack of information</li> <li>▪ Limited ability to negotiate clinical interactions</li> <li>▪ Inability to follow treatment plan</li> </ul>	<p><i>2.a) Role of the retinal screening</i></p> <ul style="list-style-type: none"> <li>▪ Confusion about role of teleretinal screening in disease management</li> <li>▪ Misunderstanding the teleretinal screening as a visual acuity test</li> </ul>	<p><i>3.a) Confusion over lack of follow up</i></p> <p>Patients were confused about:</p> <ul style="list-style-type: none"> <li>▪ What to do after screening</li> <li>▪ How to get results (most patients never received results)</li> </ul>
<p><i>1.b) Confusion regarding disease pathology</i></p> <ul style="list-style-type: none"> <li>▪ Confusion about pathology of diabetes</li> <li>▪ Difficulty communicating concerns with providers</li> </ul>	<p><i>2.b) Concerns about the technology during screening</i></p> <ul style="list-style-type: none"> <li>▪ Lack of confidence in operators abilities</li> <li>▪ Confusion about how photos are shared between clinic and specialist</li> <li>▪ Fear of technology</li> </ul>	<p><i>3.b) Quality of patient-provider interactions</i></p> <p>Some patients felt that the providers:</p> <ul style="list-style-type: none"> <li>▪ Were rushed</li> <li>▪ Didn't take time to answer questions</li> <li>▪ Were not thorough enough</li> </ul>

prescribed medications at the proper time, to eat healthily and consistently throughout the day, and to find the time to exercise. One Latino respondent put it this way, “I sell food in the morning and I practically don't eat. I eat at around 3:00 pm and that's not good, so they say...That's bad, I have to be eating a little every now and then, and eat only once a day.” Compliance with treatment plans was especially difficult for African American men, who spoke of this difficulty at twice the rate of other respondents across ethnicity and sex. One respondent reported that his experience of incarceration made complying with prescribed diet extremely difficult. He said, “I was incarcerated, I cheated (on my diet plan) because we have common food. So when I eat ice cream, I've got to work a little harder to burn it off... the doctor told me, mine comes from bad diet. Okay? It's not hereditary, it's bad diet.”

1.b) *Confusion regarding disease pathology:* Further complicating this situation, patients expressed confusion about pathology of their disease. Patients uniformly expressed concerns related to unresolved symptoms they attributed to their diabetic status. Such concerns included, dizziness, exhaustion, circulation-related foot pains, and, most significantly for this study, vision problems. One female Latina participant expressed confusion about her disease pathology in this way: “I had a question - I'm hearing terms like diabetic retinopathy...And then I've heard macular regeneration [sic]...And then [the doctor] talked about cataracts...Are those three different ailments of diabetic...symptoms?” Like this patient, the majority of participants expressed uncertainty about the cause of these health conditions. Patients indicated difficulty communicating these concerns to their providers, particularly due to the medical language and communication styles of the clinical setting. Significantly, patients felt that they were not given adequate education before, during, or after their appointments to address their concerns about their health.

Despite this limitation, patients generally expressed a desire to know more about their disease and learn how to manage it better, but were uncertain how to obtain this knowledge easily.

## 2) Encounter with Technology during Screening

With regards to diabetic retinopathy screening, patients demonstrated a similar lack of clarity as to the technical aspects of the teleretinal screening process specifically, and retinal screening generally. Despite having received teleretinal screening in-clinic, patients were uncertain about 1) the role of the retinal screening in their disease management and 2) what was happening during their encounter with technology in the screening.

*2.a) Role of the retinal screening:* Patients across all the focus groups misunderstood the purpose of the retinal diabetic retinopathy screen. Most patients did not understand that retinal screening is used to detect signs of diabetic retinopathy, with some patients confusing it with visual acuity testing. For example, one Latina female expressed her confusion about the role of teleretinal screening in preventing her diabetes-related retinopathy as follows: “I’ve been wanting to ask you, the test that we had done for our eyes. Well, they already told me that I had liquid and it was leaking...does that have anything to do with, if I need to increase my [glasses] lenses? The doctor didn’t say exactly the name of the problem. He only said you have this problem, your eyes are starting to leak from inside and that’s it. [I don’t] understand the word.” One African American woman put the confusion this way: “I’ve been a diabetic for, like, 24 years, and I just started feeling like sometimes I can’t read street signs...When I left from the clinic [after the teleretinal screening], they referred me over to Martin Luther King...got me a new set of glasses and everything...now I’m good, you know. Just I’ve got a large nerve in the back of my eye, and that’s about it.” Some patients who were screened shared that they continued to experience poor vision or undefined eye pain, symptoms although their screening had been negative for diabetic retinopathy. These patients were concerned and felt that the screening received might have been inadequate since they continued to exhibit impaired visual acuity. The examples above demonstrate that the patients did not understand their pathology and the purpose of screening.

*2.b) Concerns about the technology during screening:* A majority of patients were nervous about their encounter with teleretinal diabetic retinopathy screening technologies. Patients expressed concerns about potential human error in handling of private health information over the Internet, mishandling of the technology by clinic staff, or the feeling that something could go wrong during the screening that might result in damage to the eyes (due to the drops, flash, or camera hitting the eye.). One Latina woman put her fears this way, “[I felt] afraid because I have a sister who lives in Honduras and she had an eye operation and instead of improving her vision they damaged her... And that’s why I got scared... because [my sister] couldn’t see but they made it worse...”

Patients expressed a variety of emotions about the absence of a specialist in the room during the exam, from indifference to resignation to confusion. African Americans in particular seemed to feel resigned to the lack of a specialist in the room. For those who understood the role of the specialist, not seeing a specialist directly seemed to be consistent with their experiences of other types of healthcare in safety net clinics. While the responses were not wholly negative, African American women respondents reported preferring to have the specialist in the room but understanding that this was not always possible due to lack of resources in the clinic. For example, one African American woman said, “...I like personal attention and personal care, so of course, I want the best hands possible. I would want to be in the hands of an ophthalmologist or an optometrist, but in this case, I was going to get a screening. It’s kind of like how you have the PA’s versus a doctor who do the vital signs or whatever, I just thought this was a routine sort of thing. I didn’t know it was like new age.... Well, had I been told that an online person would be evaluating the screening; it may have made me feel like it was less personal. But, to be honest with you, knowing that [the specialist is remote] doesn’t make me feel that different then.” In other words, this patient population is accustomed to being seen by lower level staff than the specialist, or even the primary care doctor.

Having retinal images taken by a technician (medical assistant) rather than a specialist, however, led some individuals, particularly African American and Latino men, to feel a sense of insecurity in the ability of the technicians,. These patients felt that medical assistant photographers lacked the necessary medical/technical knowledge to handle the equipment and could not answer health-related questions. One African American patient described the medical assistants as ‘fresh out of school’ while another said, “[T]he people that they have in there [operating the screening equipment], they’re kids. They don’t know anything. You know? They’re looking at you – they’re no specialists and they look like they just come out of a training school.” A Latino male elaborated, “...I don’t know if they were well trained or they needed more training to learn how to work with the machine because the person that was taking the photos...wasn’t sure on how to work the machine and I think what that person was supposed to do was something simple and yet it took longer due to the lack of experience.”

### 3) Impact of Lack of Clinician Follow-up

The large majority of patients in these focus groups expressed concern and confusion about the follow up procedures and the regular lack of follow up, post-screening. In addition, although many patients were pleased with their providers, some patients felt concern about the quality of the interactions they had with the clinician.

*3.a) Confusion over lack of follow up:* The majority of patients expressed confusion about what to do following the teleretinal diabetic retinopathy screening and about how to get their results, how suggested diagnoses would be returned, and what procedures typically follow the test. Most patients reported never receiving the results, post-screening. One Latino male participant said, “I, at least, expect to know my results because knowing that I have diabetes, you tend to have a little fear...[so] they should tell [me] how I’m doing inside.” While standard protocol is that patients should be informed of a negative screening result, patients were not informed that it may happen at the next follow up visit with the primary care provider and not via special outreach.. Another African American male put his concerns over the lack of results this way. “[T]he first time I was diagnosed was with another doctor, and she sent me to the [screening] and I had it. That was over a year ago. I remember [her] just getting back to me with having the tests done again, but I’ve never had anyone respond to me from the clinic about the results of the tests that I had there.” Since patients did not understand the standard procedure for a negative result,, they felt they lacked quality care. Part of their confusion stemmed from the challenges of sharing results and information internally among the clinics and between clinics and specialists, which occasionally resulted in patient screening results being lost or misplaced. One Latino respondent described being asked to locate his own results and bring them in to his doctor himself. He said, “They mailed me mine because when I went to see the doctor, the doctor asked me for them and they told me they were going to fax it here but the doctor said he didn’t have them and he told me I had to bring them in. So I had to lose a day from work to pick them up and bring them over to the clinic.” Other patients did not understand why they had not heard back from their doctor after the teleretinal screening

*3.b) Quality of patient-provider interactions:* Some of the patients felt that their doctors and medical assistants were rushed and did not take enough time to answer all their questions, and as a result were not being thorough. One Latino male put his concern this way, “...I asked what [the screening] was for and the [medical assistant] didn’t know how to answer and then I asked the doctor and he said, ‘No, everything came out fine.’ But that was the only thing they said.” Similarly, an African American male felt that the doctors were rushed and didn’t take the time to educate him. He said, “...your doctor doesn’t say anything, he just tells you, ‘I’m going to give you some drops’, you know, and send you on your way. But he doesn’t sit down plainly [and tell you what to do].” Consequently, patients such as these were concerned that the care providers’ inability to explain the teleretinal screening was indicative of an inability to provide patients with on-going, quality care.

### **Discussion**

Telemedicine has been lauded in the health information technology (HIT) literature as a means of increasing access to specialty care in low resource settings, such as rural or inner city community clinics. The Chronic Care Model (CCM) includes the use of HIT as one avenue for addressing the challenges of chronic disease care management through use of clinical information systems and clinical decision support<sup>21</sup>. Health communications studies have also demonstrated the ways in which HITs can be used to a) support individual health information seeking<sup>22</sup>, b) facilitate doctor-patient communication<sup>23</sup>, and c) promote consumer understanding about prevention and treatment opportunities<sup>24</sup>. Overall, patients who participated in this study, too, shared the general perspective that telemedicine advances the delivery of care by improving communication between providers. While this is likely the case in terms of the general adoption of telemedicine at sites where no specialty services existed before, this research team has reported elsewhere the challenges of implementing effective workflow communication pathways in the delivery of telemedicine workflows<sup>25</sup>. Challenges include missing or misreported patient information, primary care providers’ difficulty interpreting diagnostic results to patients, and the inability to track patients across multiple information management systems. Although unknown to patients directly, these clinical workflow difficulties are experienced by patients in ways not obviously related to the communication challenges in the clinic as reported in the results above.

Patients in the populations studied here face a number of challenges in accessing healthcare. In addition to challenges reported in the literature, participants in this study describe several others, which we conceptualize as a knowledge gap in the clinical setting, which appears to be produced at three points during the delivery of care: (1) through exacerbation of patients’ *pre-existing* personal barriers in the clinical setting; (2) through encounters with technology *during* screening; and (3) and through lack of follow up *after* the visit. In the following discussion, we elaborate on the patients’ experiences of the knowledge gap at the three points and consider the types of knowledge/information that patients are lacking and potential approaches to fill these gaps in the teleretinal screening process.

### *Addressing patients' pre-existing barriers: The role of health literacy*

Participants in this study lacked adequate understanding regarding the purpose, processes and goals of preventative tests such as the retinopathy screening. This finding reflects larger trends in the literature that indicate low levels of health literacy around diabetes pathology among medically underserved minority populations<sup>26</sup>. Retinopathy screening is complicated by the fact that for the most part, the disease is asymptomatic until it gets to the advanced stages, so patients without symptoms may be baffled by the need for screening while patients with non-diabetic symptoms are frustrated by the screenings not addressing their existing symptoms. When told that they needed retinal screening, they were not educated sufficiently about the need for screening in the context of diabetes. From the patients' perspectives, as demonstrated by focus group data, they often believed they were receiving a visual acuity test, rather than a retinal screen related to their diabetes. While these patients had access to diabetes management classes in some of the clinics, it was clear from their comments that they had not been provided any consistent, structured education about the role of retinal screening in diabetes. Based on our interviews, clinic providers were aware of patient concerns and many actually attempted to provide information to patients but these efforts were neither comprehensive nor systematic and thus obviously not effective. It is important to acknowledge the difficulty that these providers faced in describing disease progression to patients with limited literacy in their native languages. Nevertheless, a comprehensive educational approach that systematically addresses differing levels of patient health literacy with sensitivity to their preexisting barriers is one key factor necessary in addressing the knowledge gap among safety net patients going through teleretinal diabetic retinopathy screening.

Patients also faced significant preexisting socioeconomic barriers that shaped their access to care and their understanding about the importance of care. For example, 25% of the African Americans and 63% of the Latinos had received only a secondary education with, 60% of the Latinos having only some secondary education. Furthermore, 58% of the African American participants and 74% of the Latino participants made less than \$1000 per month. Lack of resources such as time, money and information and limited ability to negotiate clinical related interactions resulted in great challenges for these patients to follow recommended treatment plans to manage their health conditions, such as diabetes. It is in the context of such severe preexisting barriers that their knowledge gap becomes consequential for follow through on teleretinal screening. These patients were challenged by limited health literacy when receiving health care in general, and in this instance, resulting in misunderstandings about their diabetic disease pathology and progression. This was most especially observable when patients misconstrued generalized symptoms of discomfort related to the eye (including symptoms unrelated to diabetes or diabetic retinopathy), to have been caused by their disease.

### *Addressing patients' fears during screening: The role of technological literacy*

A second point at which the knowledge gap is consequential is during the visit is when the patient encounters the technology associated with teleretinal screening. Patient engagement can be difficult to attain in the safety net because the typical patient may not understand the health technologies or the implications of their use. Whereas patients from a wide range of backgrounds are increasingly using computers and accessing the internet for health-related reasons, a gap continues to exist between those who can more effectively access and use information technology compared to those who do so less effectively<sup>27</sup>. Healthcare scholarship has linked this gap to a pre-existing "digital divide" among certain groups of HIT users. The low rate at which patients owned computers and had access to the Internet among participants in our study highlights the digital divide experienced by these populations. Only 30% of the Latino participants owned a computer and 17% had access to Internet compared to 50% of the African Americans who owned a computer and 42% had access to the Internet. Whereas the digital divide has conventionally been conceptualized in terms of individual and population-level lack of access to technology (computers, internet)<sup>28</sup>, health communications scholarship has noted that 'access', particularly in the context of healthcare delivery, also includes meaningful use of technologies and exploring the social context in which people's interactions with HIT take place<sup>29</sup>. Extending the conceptual reach of the 'digital divide' beyond the scope of patients' individual abilities or technology savvy to include technological literacy in the clinical setting sheds light on the role that limited literacy plays in individual experiences of access in *other* contexts, especially in the safety-net setting.

Patients who lack familiarity with medical technologies are more fearful of the equipment and are anxious that the machine may damage their eyes during the exam. This perception may discourage patients from complying with screening appointments. Furthermore, patients were concerned that photographers were medically and technically under-skilled. This may have been caused, in part, by high turnover among medical assistants, as well as minimal on-going training and interaction with the technology to maintain photographer technical skills. Also, in one clinic

out of the six involved, clinic protocols prevented medical assistants from offering any medical or technical education during the screening. For some patients, photographer lack of confidence or unwillingness/inability to answer questions about care coupled with the absence of a specialist evoked concerns about the quality of care and the adequacy of the screening.

Patients' lack of familiarity with process of teleretinal screening and with medical technologies could be addressed by informing patients about how teleretinal screening works. The first step may be to assess patients' past experiences with retinal screening since this is the starting point for educating them about teleretinal screening. For example, it was not clear from our focus group data as to how many of our participants had ever received retinal screening for diabetic disease management. Patients may differ on their prior experiences and thus may need different types of information about teleretinal screening. Participants reported being put at ease with the technology and the screening process when there were interactions with their providers, particularly when information and education was provided during the exam. Thus, a systematic approach to educating patients about teleretinal screening should include a focus on a) how technology is used in the screening process, b) how training is provided to photographers/medical assistants and other clinic personnel in the appropriate use of the technology, c) how security of confidential electronic health data is managed during data transfer and d) the role of telehealth technologies in disease management. Such a systematic educational approach would improve patient technological literacy, allay some of their fears and begin to address the knowledge gap in teleretinal screening.

#### *Addressing patients' confusion after the visit: The role of Improved Provider-Patient communication*

Following the exam, most patients appear to have little understanding of the significance of their diagnosis. Typically, patients were not contacted regarding a negative teleretinal screening result, whereas during an in-person retinal screen, a patient is given negative results immediately. Patients do not know how to interpret the lack of follow up by clinics; rather than an indication of a negative screen, lack of communication is perceived as no result at all. As a consequence, patients do not understand their own health-status and are unable to make effective use of the teleretinal screening results to direct and manage their own care.

Since patients do not adequately understand the pathology of diabetes and diabetic retinopathy, they have difficulty interpreting the results that may be delivered by the primary care provider (i.e. one patient reported that the provider only said "You're fine"). Providers, who must concern themselves with all aspects of a patient's pathology, may not take adequate time to explain the significance of a negative retinal screening resulting from diabetic retinopathy to a patient or try to work around patients' perceived limitations. From the patient perspective, the lack of patient education about the role of teleretinal screening in their disease management plan seems to reinforce patient perception that, despite having received the screening, they are receiving subpar or incomplete care. For patients who already face a number of challenges to accessing care, this perception may hinder their ability or desire to comply with preventative screening in the future.

The confusion experienced by these patients with regards to post-screening results seems aligned with the lack of standardized education or consistent communication from providers. Low health literacy patients should be given clear information about posttest protocols - what it means to get no call, that negative results are good and that they have the right to call and find out screening results. Providers and other clinic staff may need to consider how to best communicate information about screening results with adequate detail and depth, nuanced to address the knowledge gaps of patients with differing levels of health and technological literacies and socioeconomic barriers.

#### **Conclusion**

In summary, patients' pre-existing socioeconomic barriers along with their level of understanding regarding their disease and teleretinal screening technologies, combine to produce a knowledge gap in the clinical setting. Confusion about their disease, compounded by fear and lack of knowledge about disease management technology, may cause patients to feel powerless to understand or address their health concerns, their personal health/disease status, and result in unsatisfactory encounters with providers. Each of these outcomes has the potential to discourage patient compliance with treatment plans and to diminish patients' ability to manage their own health care.

These findings support other studies regarding the challenges of health care access and health literacy in this population, which has been well documented over the last ten years<sup>3,6,7,26-29</sup> Our research builds on these findings by presenting new information about how patients understand and perceive the digitization of clinical communication and the use of new technologies as an aspect of their chronic diabetes management. Despite their specific confusions related to teleretinal screening, most participants were generally pleased with the quality of care they receive at these community clinics. Patients also reported a strongly positive perception of the incorporation of new technologies



into the primary care visit, particularly in the context of eye health. They associated such new technologies with progress in science and improved quality of care. While patients were generally satisfied with the overall care they received from their primary care providers, patients were concerned about specific aspects of teleretinal screening that arise as a result of the technology and the clinic protocols.

These findings suggest that patients in this clinical population, who exhibit both limited health literacy and limited technological literacy, need to be educated before, during, and after their telemedical appointments. Patient education regarding both the health and technological aspects of the screening is essential in encounters with medical staff of all levels. Such education helps to ensure that patients understand the role of technology in their disease management, the procedures of the test, what to expect after the test, and how to interpret the results of their test. This is likely to have an impact upon patient understanding of teleretinal screening and, ultimately, upon patient compliance with diabetic retinal screening protocols. Our findings call for going beyond a definition of the “digital divide” that focuses on the patient’s personal access to and use of technology to consider how their level of technological literacy, health literacy and socioeconomic barriers together affect their experience of the increasing use of HIT in health care institutions. This will be particularly important, as patients are required to engage more actively in self-management of chronic diseases such as diabetes. Patient education will be important to ensure that telemedicine in the clinical setting does not become an additional barrier that contributes to the knowledge gap that exists among these populations.

There are some limitations to our study and findings. We have a relatively small convenience sample and our participants are not statistically representative of the wider population in inner-city settings and this limits the generalizability of our study’s conclusions. However, as is common to qualitative methods, they represent information-rich cases, homogeneously stratified across race and ethnicity, to allow in-depth understanding of their perceptions and experiences of teleretinal screening among these groups. While five years have elapsed between data collection and presentation of these findings, the results presented here are applicable to other resource-poor clinics implementing teleretinal screening programs to serve similar socio-economic populations.

This paper explored the way in which African American and Latino diabetic patients’ with less access to healthcare experienced teleretinal screening as an encounter with HIT in U.S. urban community clinic settings. This study’s significance lies in its identification of how patient disparities in health literacy, technological literacy and access to healthcare interact to produce a knowledge gap in their experience of teleretinal screening, potentially compounding their confusion and fear about the progression and management of their disease. Consequently, in the safety net clinic setting with a low health literate population, without adequate patient education, teleretinal screening may represent a new challenge to effective disease management. Patient education regarding the function and purpose of telehealth technologies, particularly in the specific contexts of their use in the health care setting, and improved provider awareness and communication of this information to the patient is critical to ensuring effective teleretinal screening, improving patient engagement in the self-management of chronic illnesses and addressing the knowledge gap experienced by most such patients in the clinical setting.

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