Facilitators and barriers to glaucoma screening identified by key stakeholders in underserved communities: A community engaged research approach

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Précis:
Community-engaged research enables researchers to identify community-specific barriers and facilitators to program implementation. Broadly applicable barriers to glaucoma care, such as Cost, Transportation, and Trust, and community-specific barriers, such as Language and Convenience/Access, were identified.

Abstract

Purpose: To identify the facilitators and barriers to implementing glaucoma screening programs in two community clinics.

Methods: A concurrent mixed-methods process analysis using community-engaged research. Key stakeholders—including patients, providers, and staff members—from two community clinics were interviewed using a semi-structured interview guide. Interviews had two parts: 1) asking patients about community-based facilitators and barriers to implementing glaucoma screening and care and 2) eliciting feedback about a personalized coaching program. The transcripts were coded using Grounded Theory. Number of participants and number of representative citations were counted per theme. The qualitative analysis was coded using Dedoose 8.3.17 (Los Angeles, CA).

Results: Thematic saturation was reached after coding 12 interviews. 30 participants were interviewed, 13 from Hamilton Clinic, (Flint, Michigan), (8 patients, 5 providers and staff members) and 17 from Hope Clinic, (Ypsilanti, Michigan), (6 patients, 11 providers and staff members). The most commonly cited themes were: Priorities (98 citations, 30 participants), Knowledge (73, 26) Transportation (63, 26), Cost (60, 23), and Convenience/Access (63, 22). Broadly applicable barriers to glaucoma care, such as Cost, Transportation, and Trust were identified alongside community-specific barriers such as Language and Convenience/Access. Participants rated their likelihood to follow up with an ophthalmologist after participating in the personalized coaching program at a mean of 8.83 (on a scale of 1 to 10 with 10 being the most confident).

Conclusions: Community-engaged research enables researchers to identify community-specific

barriers and facilitators, allowing more effective program implementation.

Introduction:

Glaucoma is the leading cause of irreversible blindness globally and is expected to affect approximately 111.8 million people worldwide by 2040.[1] In the United States, of the estimated 3.1 million people affected by glaucoma, 2.4 million individuals are thought to have undiagnosed and untreated glaucoma.[2] Blacks and Hispanics also have a much greater odds of having their glaucoma go undiagnosed, illustrating a significant racial disparity.[2] Consequently African-Americans often present later in their disease course and are twice as likely to have bilateral blindness from glaucoma compared to Caucasians.[3] People with lower socio-economic status are at increased risk of developing glaucoma, even after accounting for race, education, and comorbid conditions.[4] Despite these findings, the US Preventive Services Task Force, based on the low prevalence of open-angle glaucoma in 2013 (2.1%), concluded that there is insufficient evidence to balance the benefits and risks of population screening adults for open-angle glaucoma.[5, 6] Case finding among high-risk populations with greater prevalence of glaucoma – African Americans over 50 years, Hispanics over 65 years, and anyone with a family history of glaucoma – is likely to have a more favorable cost-benefit ratio than population screening, but this benefit is greatly underutilized.[7]

Currently, glaucoma screening takes place in eye care provider clinics, which tend to be farther from uninsured and underinsured people's homes and their usual primary care provider. Telemedicine enables specialty glaucoma services to be available at local primary care community clinics by using a local health care worker to obtain basic information and clinical measures and send it to a glaucoma care provider located elsewhere.[8] This can make glaucoma screening more accessible and may offer an improved cost-benefit ratio for screening high risk

populations. The Technology-based Eye Care Services (TECS) developed in the Department of Veterans Affairs (VA) uses the principles of telemedicine to bring eye care to rural primary care clinics. In this Center for Disease Control Vision Health Initiative program, we use the VA TECS program framework to bring eye care to primary care clinics that serve the under and un-insured: a free clinic and a federally qualified health center. In addition, in our Screening and Intervention for Glaucoma and eye Health through Telemedicine (SIGHT) Program, we have created an eHealth personalized coaching tool which generates personalized educational content about a patient's test results to enable a health coach – not a physician – to offer tailored education to motivate patients to return for follow-up care if they screen positive for eye disease during their telemedicine eye health screening visit.[9, 10]

Community-engaged research (CER) provides an opportunity to bridge the gap between research and the targeted population it is intended for. By learning from key stakeholders and patients how to best implement programs to meet the community's needs, programs based on CER will have greater participation rates and decreased loss to follow-up.[11] This method has been used in prior piloted eye screening programs, and was successful in identifying high rates of individuals with undiagnosed glaucoma in two separate high-risk populations.[12, 13]

The objective of this study is to use CER to assess key stakeholder opinions about best practices, including barriers and facilitators to implementation, to devise a glaucoma screening program and eHealth coaching program to improve adherence to follow-up recommendations after screening in two community clinics.

Methods:

Study sites:

The Screening and Intervention for Glaucoma and eye Health through Telemedicine (SIGHT) Program project will be carried out through a partnership between the University of Michigan Kellogg Eye Center, the Hope Clinic, in Ypsilanti, MI, and the Hamilton Clinic in Flint, MI.

Approximately 5,000 patients access the Hope Clinic per year and 25,000 people access the Hamilton Clinic per year. The Hope Clinic is a free clinic that serves uninsured and underinsured patients. It has a general reception area, medical clinic, dental clinic, food pantry, chapel, laundromat, area for baby supplies, and meeting rooms. Details of the demographics of the Hope Clinic patient population are discussed in detail in a prior study,[14] Ypsilanti, MI where Hope Clinic is located has a per capita income was $24,562 in 2018 with over 32% of the population living in poverty.[15]

Hamilton Clinic in Flint, MI, is the main branch of the Hamilton Community Health Network, a federally qualified health center that serves the population of the greater Flint area through the main clinic and six satellite clinics throughout Genesee and Lapeer counties. It includes a general reception area, a medical clinic, a dental clinic, an eye clinic, a social work department, an obstetrics clinic, a residency training program and meeting rooms. Three-quarters of people served by the Hamilton clinic live at or below the federal poverty level and 96.9% live at or below 200% of the federal poverty level. In terms of insurance, 16.2% are uninsured, 59% have Medicaid, 8.3% have Medicare, and 4.2% are dually eligible for Medicaid and Medicare.[16] Both clinics were in Michigan, which through its Medicaid expansion program, Healthy Michigan, provides government-funded health insurance for those people who live at or below 133% of the federal poverty level ($16,000 for a single person or $33,000 for a family of four).[17] People who live above the poverty level and who are younger than 65 are expected to have

private health insurance. People over the age of 65 who have met citizenship requirements can obtain government-based health insurance coverage through Medicare, which covers roughly 80% of medical expenses, and many people opt to have secondary private insurance coverage for this gap. The Hope Clinic serves a population of people who are under-insured or uninsured, and the Hamilton Clinic serves a population of people who are mainly insured through Medicaid.

Study Population and Interview Process

A purposive sample of eyecare providers, staff members, and patients from the Hope Clinic and the Hamilton Community Health Network Clinic were interviewed. Roles of Hamilton clinic staff members interviewed included one ophthalmologist, one facility manager, one community outreach coordinator, one optician, and one health educator. Roles of Hope clinic staff members interviewed included one director of operations, one receptionist, one referral nurse, two clinic managers, two office managers, one patient support service nurse, one communications manager and one nurse practitioner.

Written informed consent was obtained from all participants. Semi-structured interviews lasted between 30-45 minutes and consisted of two parts. One interviewer completed all of the interviews. During the first part of the interview, the interviewer explored community-specific barriers to eye care and follow-up. Participants were asked how a telemedicine glaucoma screening program could be best implemented into the clinic in order to meet the community's needs. In the second part of the interview, the interviewer demonstrated the eHealth coaching program with the participant role-playing as a potential patient. The program is written at an 8th grade reading level and the coach reads the written content aloud to participants while showing them audio-visual content on a tablet, using the tablet as a teacher would use a storybook. The interviewer elicited participant's feedback on the program, including what educational

components were most salient in motivating participants to return for glaucoma follow-up care. Patients who participated were provided with a $20 cash card at the end of their interview. Interviews were audio-recorded and transcribed verbatim.

As the data gathered contained no identifiers, the study was determined to be exempt by the University of Michigan Institutional Review Board. This study adhered to all tenets of the Declaration of Helsinki.

Community-Advisory Board

Using the Socio-Ecological Model of Health, a Community Advisory Board composed of clinic patients and various executive members was formed to help guide the proposed glaucoma care program.[18] The executive members included key stakeholders from University of Michigan, Hamilton, and Hope clinic. From the University of Michigan, these members were the primary and co-investigators of the study, including a telemedicine specialist, an epidemiologist, a therapist, and three glaucoma specialists. From Hamilton clinic, these members included the Chief Executive Officer, Chief Operating Officer, and head ophthalmologist. From Hope clinic, these members included the medical director, medical clinics manager, and operations manager. The semi-structured interview guide (see Text, Supplemental Digital Content 1, http://links.lww.com/IJG/A501) was created after discussion and approval by the executive members of the community advisory board prior to recruiting participants.

Qualitative Analysis

Analysis followed a concurrent mixed-methods approach.[19] Qualitative analysis of transcribed interviews was guided by Grounded Theory (GT), an inductive process of generating theories, beginning with qualitative data.[20-22] Coders followed a stepwise approach typical of GT: 1) familiarization, 2) open coding, 3) axial coding, 4) focused coding, and 5) theory building.

Once the interviews were finished, two coders (DB, JC) read the transcripts during the familiarization stage in order to become familiar with the interview structure and general topics. Coders determined that thematic saturation, the point at which additional interviews provided no new themes, was reached after analyzing twelve of the thirty finished interviews.[23] They then used open coding to identify recurring concepts from the twelve semi-structured interviews. These recurring concepts were defined and a codebook was created. Two coders (DB, JC) then worked separately to code a portion of the transcripts using the codebook, coming together to resolve inconsistences. A third party (PANC) was included when inconsistences could not be resolved between the coders. Once >80% agreement was achieved on >95% of the codes, the two coders re-analyzed and coded the remaining transcripts.[24] The instances of these codes were identified, and their relationships were considered during the axial coding process. All coded excerpts were characterized as either facilitators or barriers, if applicable; however, some excerpts were related to a specific theme but were neither a facilitator nor a barrier, and so they were coded without this classification. The total number of times a given barrier or facilitator was expressed and the number of patients who commented on them was tabulated. The qualitative analysis was coded using Dedoose 8.3.17 (Los Angeles, CA).

Results:

Of the 30 individuals interviewed, 13 were from Hamilton Clinic (8 patients, 5 eyecare providers and staff members) and 17 from Hope Clinic (6 patients, 11 eye care providers and staff members). The kappa value for inter-rater reliability between the two coders was 0.93. Frequencies of themes as facilitators (Figure 1) and barriers (Figure 2) were recorded as well as their representative quotes as shown in Supplemental Digital Content 3, http://links.lww.com/IJG/A503 (See Table, Supplemental Digital Content 2,

http://links.lww.com/IJG/A502, which includes frequencies and additional quotes). Five main themes arose in the content analysis of the transcripts: Priorities (number of citations: 98; number of participants: 30), Knowledge (73; 26), Transportation (63;26), Convenience/Access (63; 22), and Cost (60;23).

Priorities:

Priorities was mentioned by all 30 participants for a total of 98 times: 49 times as a barrier (50%) and 49 times as a facilitator (50%). Each person prioritized their vision and health differently. Twenty-three participants mentioned how vision was low on their priority list due to many other competing concerns such as, "bad diabetes, hypertension, kidney problems, dealing with a family member who's incarcerated and unruly kids, three to four kids." Other competing priorities that were frequently mentioned included personal issues, childcare, jobs, and other health conditions. Just about as many participants (n=22) mentioned vision as a priority, discussing their vision or overall health as something they value, saying, "I've already been [to health screenings], you know, I keep a track of my health because of my age" and "my sight is very, very important to me, I value my sight."

Knowledge:

Knowledge was mentioned by 26 participants (87%) for a total of 73 times: 30 times as a barrier (41%), 41 times as a facilitator (56%), and 2 times neither as a facilitator nor a barrier (3%). Knowledge was mentioned in two contexts: knowledge of eye disease (mentioned 49 times, 67%) and knowledge of resources (mentioned 24 times, 33%).

Participants expressed how personal knowledge (or lack thereof) of different eye diseases affected their motivation to seek out care. Twelve participants shared how lack of knowledge prevented them and others from seeking out care, such as in the case of one staff member who

shared, "because [glaucoma is] painless, people who have it don't realize it." Twenty-two participants mentioned how personal experience and symptoms of other eye diseases (i.e. cataracts, low visual acuity) motivated them to seek out glaucoma care. One patient shared how a family member's recent cataract symptoms motivated him to "take a little bit more interest in [his] eyesight," and thus seek out glaucoma screening. Others expressed an interest in glaucoma follow-up after learning more about glaucoma during the eHealth program, for example sharing, "But now I listened [I know] that it's very, very important to check your vision [...and] to know if you'll have glaucoma."

Seven participants expressed barriers related to knowledge of resources. A participant commented on not getting care as they "didn't even realize that [there was an] eye center here." A staff participant remarked, "They don't really take advantage of what's here, you know, because if the information doesn't come directly to them, they don't seek it out." Eight participants cited knowledge of resources as a facilitator. A staff participant said, "Public knows about [Hope Clinic] and the word has gotten out. So, this [SIGHT] program can certainly help with that also."

Transportation:

Transportation was mentioned by 26 participants (87%) for a total of 63 times: 43 times as a barrier (68%) and 20 times as a facilitator (32%). Twenty-four participants discussed lack of access to cars or reliable public transportation as barriers, sharing that, "A lot of people don't have cars, so lot of our people rely on public transportation," and, "Public transportation [...] are out of my control." Ten participants cited availability of many transportation options to get to the clinics as facilitators to care, specifically mentioning, "Friends, family. Some people [can] use

Uber," or the fact that, "[Hope clinic is] directly on public transportation line with the bus stop being right out front."

Cost:

Cost was mentioned by 23 participants (76%) for a total of 60 times: 28 times as a barrier (47%) and 32 times as facilitator (53%). Fifteen participants cited high out of pocket cost without insurance, high co-pay, and medication expense as important barriers to care, as reflected in the quotes, "I haven't met a doctor for two years. Because I didn't have any vision insurance," and, "Am I going to have to pay for that medication? Some of them can be very expensive..." Nineteen participants mentioned how the SIGHT program being completely free will help patients seek out care. For example, "You know, if you need that help and is offered to you free, any person would go and get that help."

Convenience/Access:

Convenience or access was mentioned by 22 participants (73%) 63 total times; 31 times as a barrier (50%), 31 times as a facilitator (50%), and 1 time neither as a facilitator nor a barrier (2%). Sixteen participants mentioned how long wait times, difficulty scheduling, and inaccessible clinic locations served as barriers to care. One patient described the situation as, "You're 10 minutes behind or the bus 10 minutes behind. Bam, I have got to wait a whole another two, three months, you know, to get help." Seventeen participants mentioned close proximity of clinics and availability of specific popular time slots (usually 4pm) as facilitators. This sentiment is reflected in the quotes, "but having something that simple on site, immediate, understandable, I think that's a huge benefit," and, "if [the time slot] is convenient for me, then yeah, I will take it."

Remaining themes:

The remaining themes that were mentioned were Fear (number of citations: 49; number of participants: 25), Perceived Need/Benefit (45; 22), Social Support (41; 22), Trust (30; 18), Loss of Contact (12; 7), Policy (10; 7), and Language (7; 5). Fear was mentioned as a facilitator 24 times (49%) and as a barrier 14 times (29%). There were also 11 instances (22%) where Fear was discussed neither as a facilitator nor barrier; usually in reaction to audio-visual demonstrations of what un-treated glaucoma may look like. Thirteen participants shared fear of losing their vision motivated them to seek eyecare, "You're running scared now and you're frightened [...] So, you're going to ask what can I do? Is this reversible? How can you help me?" Seven interviewees remarked how fear of finding out what may be wrong with them prevented them from seeking care, as illustrated in the quote, "The fear, you know. A lot of times you're just afraid of what might be found."

Both Perceived Need/Benefit and Social Support were identified more frequently as facilitators (35 times, 34 times, respectively) than as barriers (9 times, 5 times, respectively). For social support, 20 participants primarily talked about availability of help from family members, friends, and community resources as facilitators. As for Perceived Need/Benefit, 20 participants quoted the benefits of participating in the research project (free glasses) as well as presence of symptoms (blurry vision) as strong facilitators of seeking out care.

Trust was mentioned as a facilitator 15 times (50%), and as a barrier 15 times (50%). Thirteen participants mentioned how prior good experiences with their community clinic encouraged them to take part in the research project, saying, "Hope [Clinic] has a history of giving quality service, and maintaining standards, and it's not about the money." The program's association with the University of Michigan was also quoted as a facilitator, for instance, "[y]ou're connected with a very identifiable hospital." Seven participants questioned the

intention of the program and whether participation is truly free. This is reflected in comments such as, "Take a day off work […] and then to find out why you don't qualify, it's not really going to be free for you," and "[p]eople are suspicious [about] what is it really for and what does it mean, and will it really help, do I really need [it]?"

Policy, Loss of Contact and Language were all mentioned almost exclusively as barriers to screening. Barriers posed by policy mainly referred to complicated insurance and hospital rules. Loss of Contact was brought up by staff members with regard to how high no-show rates and patients' frequent contact information changes made coordination of care difficult. Language was mentioned as an important barrier by Hope Clinic staff members as approximately 50% of their patients do not speak English. As we were unable to interview patients who did not speak English, we could not include the perspective of non-English speaking patients on their perception of how language functions as a barrier to obtaining medical care.

Description of experience with the coaching program:

Before taking part in the eHealth glaucoma coaching intervention, interviewees' knowledge of glaucoma ranged from "I don't know much" to "I just know that it can affect your vision" to "...some kind of pressure built up in your eye." Staff members or individuals who knew somebody with glaucoma tended to have a better understanding of the disease. After going through the eHealth coaching program, all individuals shared that they had a better and a more confident understanding of the pathophysiology and prognosis of glaucoma. The most representative quote after the coaching program was, "glaucoma is a buildup of pressure in your eye and that affects your optic nerve and can damage your optic nerve to the point where you can go blind."

When asked about their experience with the coaching program, all participants gave at least one positive comment. The comments specifically praised three aspects of the program: 1) The approachability of the interviewer; 2) The simple language, and 3) The salient visual aids. Our participants shared that the simple language and good visual aids were key to helping them understand the diagnosis of glaucoma. One of our participants who self-identified English as her second language specifically mentioned the program's easy to understand language as its key strength. The most powerful visual aids that participants commented on were depictions of what blind spots look like, sharing their opinions including, "I think the visual aids are really eye-opening and laid out what glaucoma really is about," and "the actual seeing what you're missing is the thing that really got me."

At the end of the eHealth glaucoma coaching intervention every patient was able to identify in their own words that they should follow-up and attend their appointment with an ophthalmologist if they ever were to be diagnosed as suspicious for glaucoma as they would have during the role-play. Each patient was then asked to say, on a scale of 1 to 10, what the likelihood was that they would make it to this follow-up appointment with 1 being not at all confident and 10 being the most confident. The average value given was an 8.83 (8.55 for Hamilton participants, 9.04 for Hope participants).

Program Suggestions:

Participants made suggestions ranging from cosmetic concerns to changing educational content to adding entirely new elements to the coaching program. Cosmetic concerns were infrequently mentioned and usually secondary to personal preferences regarding the visual aids or the color of the font used. There were two main suggestions made with regard to the program content. First, many participants expressed confusion about a diagram explaining what a visual

field was. Second, many participants expressed an interest in learning more about the genetic nature of glaucoma and hoped the program would tell them more about how likely their family members may have glaucoma.

Participants gave suggestions on how to reach out to the community to advertise the eye screening program. These suggestions recommended putting flyers and posters up at clinics, bus stops, and different community centers around the city. The community centers mentioned included churches, libraries, barber shops, and foodbanks. Other recommendations suggested using social media, television, and radio advertisements to reach a large number of people.

Discussion:

The goal of this study was to use the lens of CER to understand key stakeholder opinions on how to best implement a glaucoma screening program within two local community clinics. Through interviews of patients, providers, and staff members we were able to identify common barriers and facilitators to participating in a glaucoma screening program. The most frequently mentioned facilitators to glaucoma screening were Priorities, Knowledge, Perceived Need/Benefit, Social Support, and Cost (Figure 1). Similarly, the top five barriers were Priorities, Transportation, Convenience/Access, Knowledge, and Cost (Figure 2). Priorities was both the most commonly encountered facilitator and barrier for our participants. There were no differences in the themes discussed between patients and staff, although there were some thematic differences between the participants in the two different clinics.

Many of the barriers – such as Cost, Transportation, Knowledge and Trust - identified in this study are broadly applicable barriers frequently encountered in many aspects of delivering health care to people who live in poverty or come from minority backgrounds. Cost is one of the largest barriers to correcting refractive error with eyeglasses, in part due to lack of universal

vision coverage in the United States.[25, 26] In a landmark randomized controlled trial conducted by the RAND corporation, health care utilization between those randomized to plans with no cost-sharing ("free care") and those randomized to plans with high out-of-pocket payment for each medical service was analyzed. Participants with out-of-pocket payments were significantly less likely to seek out appropriate vision examinations than those on the free care plan, especially if they had limited financial resources.[27] In contrast, providing patients with free[28] or low-cost generic glaucoma medications may significantly improve follow-up and medication adherence rates.[29]

The issue of transportation has been frequently documented as a salient barrier to obtaining eye care. Nearly one-quarter (24%) of counties in the United States do not have either an optometrist or an ophthalmologist, resulting in individuals having to travel long distances to obtain eye care.[26, 30] Transportation as a barrier has specifically been cited among patients of the Hope Clinic who no-showed to their free eye appointment.[31] In a systematic review of multiple chronic illnesses, it has been shown that providing patients with bus passes, taxi vouchers, or free shuttle services improve linkage to follow-up care.[32] Trust has been cited as a barrier to seeking out care in both ophthalmologic and non-ophthalmologic settings,[25, 33, 34] and has been shown to impact both willingness to seek care and medication adherence.[35, 36] This is specifically important in minority populations, who have been shown to report lower trust in physicians and the health care system,[37] likely due to longstanding violations of trust throughout history.[38] However, in this study Trust acted as a facilitator almost as frequently as it acted as a barrier, usually in the context of prior good experiences at the community clinic. It has been shown that prior good experiences within the health-care system can increase trust.[39] This further supports

the implementation of glaucoma screening for high risk populations within community clinics that already have an existing positive relationship with their patients.

Fear as a theme arose almost twice as frequently as a facilitator than as a barrier. As a facilitator, it was mentioned usually in the context of the simulation that was shown during the coaching program that demonstrates how vision is lost over time – without people necessarily noticing - when glaucoma is not treated. A driving scene is shown, and as time progresses, different parts of the image go missing until ten years have passed, at which point the entire scene becomes blurry. Immediately after this simulation, the counselor tells the patient that this vision loss is preventable with use of and adherence to eye drops and continued follow-up care with an eye care provider. It has been shown that fear-based messaging is more effective when it is accompanied by an efficacy message that assures participants that they are capable of performing actions to avoid the fear-based negative consequences.[40, 41] This invokes self-referential thinking, a concept from the Elaboration Likelihood Model of Persuasion.[42] This model indicates that when individuals are truly cognitively engaged, they will apply what they have learned to their own situation. Self-referential thinking has been shown to lead to more sustained behavior changes,[43] which may explain why fear was cited as a facilitator more frequently than a barrier in this analysis.

The themes of Priorities and Knowledge were the most frequently mentioned facilitators in our study. These themes are also broadly applicable to other screening programs and have been studied extensively within the context of Self-Determination Theory (SDT). SDT states that in order for individuals to implement behavior change, they require intrinsic motivation to do so and motivation is influenced by three factors: 1) Autonomy, in which someone believes they are in charge of their destiny, 2) Competence, in which they have the information in order to deal

effectively with their environment, and 3) Relatedness, in which they acquire close relationships to their health care providers. The theme of "Priorities" is analogous to Motivation within SDT, and "Knowledge" is analogous to Competence. It is important to note that Priorities was a more important facilitator in our study than knowledge. SDT posits that while knowledge and feeling competent to carry out a behavior can plant the seeds of change, they cannot successfully modify behavior without intrinsic motivation. This is consistent with prior work studying glaucoma medication adherence, in which educational materials alone, even if personalized, did not improve adherence,[44-46] but programs that targeted both knowledge and motivation were successful.[47] In order to increase motivation to participate in follow-up eye care, our eHealth coaching program uses a Motivational Interviewing (MI)-based coaching technique,[48] which allows the technician to create a relationship with the patient, explore resistance to change, and build autonomous motivation.[49] MI is consistent with the framework of SDT, engaging patients by discussing priorities and obstacles to facilitate intrinsic motivation—personally compelling reasons—to change health behavior.[50] After going through the coaching program, participants rated their likelihood of going to their recommended follow-up appointment as 8.83 on a scale of 1 to 10 (8.55 for Hamilton participants, 9.04 for Hope participants).

Community based screenings often suffer from poor follow-up rates. For instance, the follow-up rate for a definitive eye exam in a community-based glaucoma screening program in Baltimore, Maryland was only 41%.[13] However, Hark et al has demonstrated that through reminder phone calls, individual counselling, reminders, and education, the follow-up rate can improve as much as up to 70%.[12] Similarly, Johnson et al[51] and Zyl et al[52] have shown that providing glaucoma patients with educational workshops and definite follow up appointment respectively were effective in improving rates of follow-up care. We have found that the follow-

up rate for comprehensive ophthalmic examinations among Hope Clinic patients is high in this context at around 76.6%.[31] We attribute the high follow-up rates as well as the high intention to attend to the positive and trusting relationship these clinics have built with their clients. We also hypothesize that the personalized education and coaching we've provided may have contributed to our participant's high desire to attend follow up appointments. The SIGHT Program has an embedded randomized controlled trial that will assess whether personalized education and coaching improves adherence to follow-up recommendations, so that data will be available in the future.

While some of the barriers and facilitators that we identified in our analysis may apply widely to other researchers or public health experts who are developing eye health screening programs for deployment in high-risk communities, there were some barriers and facilitators that were unique to our two communities. For example, language was exclusively an important barrier for patients at Hope Clinic. This is likely due to the fact that about 50% of patients at Hope Clinic do not speak English as a first language, compared to the 0.13% at Hamilton.[16] Similarly, cost was also was mentioned more frequently among Hope clinic participants than Hamilton clinic participants. This is likely due to the difference in insurance coverage of patients between the two clinics: 82.3% of Hamilton patients are insured[46] while only 24% of Hope patients are.[14] CER allows researchers to more thoughtfully tailor the program to the particular community they are trying to engage. This will contribute to the adoption, implementation, and maintenance of this program in the community clinics.[53] The differences between these two community clinics that are only 63 miles apart suggest that each community clinic has their own unique set of challenges and strengths that should be properly assessed to successfully identify the needs of each community. The hope is that using a community-engaged approach will

translate into longer term adoption and maintenance of the successful aspects of the eye health screening program within each clinic.

Results from these interviews were used to influence changes to promotional materials, the eHealth glaucoma coaching program, and the overall screening program. The issue of cost came up frequently as both a facilitator and barrier, as well as within the context of trust. Patients were unsure if they could believe a glaucoma screening program would actually be free. In response to this, promotional materials were changed to have a greater emphasis on the program being completely free to participants. Changes to the eHealth glaucoma coaching program included removing descriptions of visual field testing, which were frequently commented on as "confusing" and "intimidating." Also during the coaching session, many participants asked questions that had not been directly addressed. In response, we have added educational components to the coaching program including whether glaucoma is reversible or curable, the demographics of those most commonly diagnosed, and whether there is a genetic component. Structural changes to the glaucoma screening program were also made in response to comments. Many participants cited the proximity of screening being at their community clinic as a very important facilitator in terms of both Convenience/Access and Transportation. This reflects the findings of our prior study, in which patients had a difficult time going to ophthalmology clinics that were far from their homes. [31] In addition, many patients expressed that their complicated schedules necessitate very specific appointment times, including during lunch breaks and at the end of the day. We have addressed this by ensuring that the ophthalmic technician will be at the clinic during business hours every day that the medical clinic is open.

One significant limitation to the study was that we were not able to interview non-English speaking participants, and so we were not able to gain their perspective on the best ways to

implement eye disease screening in their community. Furthermore, we used a purposive sampling method to recruit patients who we thought were generally representative of the clientele in each clinic and did not collect their demographic data, precluding a mixed-methods analysis of these demographic factors. The strengths of this qualitative analysis include the inclusion of patients, providers, and staff from the two community clinics as key stakeholders. Using a CER lens allowed us to refine an eye disease screening program to best meet the needs of these two communities. The benefit of these methods is best described by one of the patients interviewed: "Well, I have to say that because you've taken the time to talk to me, I feel like I'm more part of the program and I'm not just, you know, outside or doing what I'm told to do and not understanding what your real job is.".

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Figure Legends:

Figure 1. Bar graph showing the number of representative citations per theme when mentioned as a facilitator

Figure 2. Bar graph showing the number of representative citations per theme when mentioned as a barrier

Supplemental Digital Content

Supplemental Digital Content 1. pdf
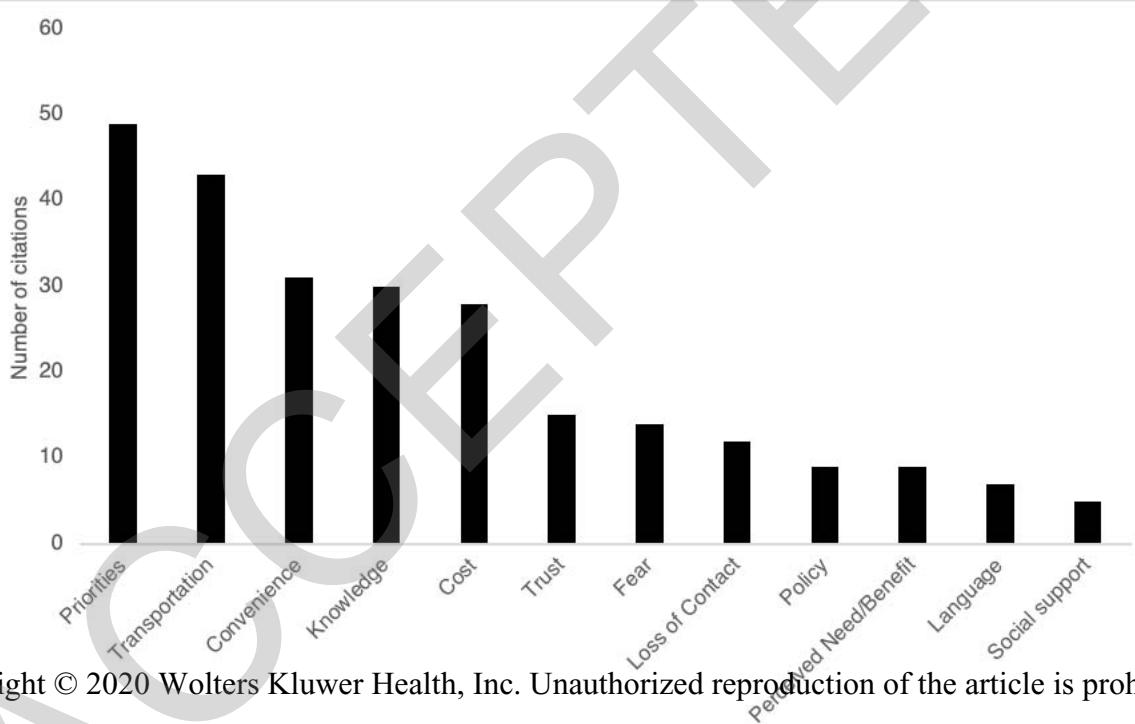

Supplemental Digital Content 2. Pdf

Supplemental Digital Content 3.

Semi Structured Interview Guide

Thank you for agreeing to talk with me about the best way to bring a vision and eye health screening program to the (Hamilton/Hope) Clinic. Our current plan is to have an ophthalmic technician, who is basically like an eye nurse, set up a screening program in your clinic. She will take a health history, check people for glasses, and take measurements and photographs of the eyes to send to the doctor. If someone needs glasses, she will help them pick out free or low-cost glasses on-line. Then, she'll send all of tests to the physician at the University of Michigan who will review the tests and give a recommendation on whether your eyes are healthy or whether it looks like they may have an eye problem that needs to be evaluated in person with an eye doctor. When they come back in 1-2 months to pick up their glasses, the technician will go over the doctor's recommendations and help them to adjust their glasses to fit their face. She will help them schedule an appointment with the eye doctor if they need one.

If participant is a health care provider, ask the following:

What is your role in the clinic?

Could you imagine participating in this eye screening program? Why/why not?

What things would encourage or support you to engage in this type of program?

Do you think people would want to participate in this eye screening program?

What might you think might be some barriers to participating in a glasses and eye health screening program at Hope/Hamilton?

(Probe: Think about and share what things get in the way for you personally to attend health screenings?)

What do you think we could do to facilitate widespread community participation in this glasses and eye health screening program?

I'm going to switch gears and ask you some questions about our glaucoma education program. I'm going to walk through the education program as if you were a patient to get your feedback on it.

After listening to this, can you describe what glaucoma is for me?

What is the program asking you to do next?

What stood out the most from this program?

Now, I'd like to get your feedback on how we might improve the program.

What, if anything, might you want to change?

How, if at all, do you think the wording needs to change to make things most clear for patients?

(Probes: Were any parts confusing? Is anything missing?)

Theme definitions, quotes, and citation count

Barrier/ Facilitator	Representative Quote	Number of pts (% of pts)	Number of citations
Convenience/ Access: Barrier- Far away clinic, inconvenient timing, not easily physically accessible, coming back for follow-up appointments Facilitator - Time, scheduling, proximity to clinic, ease of getting to clinic. (If patient asks for a certain time then we are able to accommodate for that request, so code it as a facilitator)		22 (73)	63
Barrier	*"He lives in Louisiana, in a small town. And the VA doesn't really have the resources there because they just have a clinic. And they either have to go, you know two hours either way, to the facility."* *"By the time I get off at 5:30, the doctor's offices are closed."* *"You're 10 minutes behind or the bus 10 minutes behind. Bam, I have got to wait a whole another two, three months, you know, to get help."* *"Everybody wants a 4:00 appointment because they don't want to leave work, they don't want to leave school, they don't want to take the kids early. So, I'm scheduling 4:00 appointments out until June to accommodate 4:00s"*	16 (53)	31
Facilitator	*"Especially if they can dovetail it with an appointment they're already here for, that would be awesome."* *"So, when I'm making an appointment, I make sure that the first thing in the receptionist's mouth isn't what's convenient for her to throw at me and she'll give me that. And if it is convenient for me, then yeah, I will take it."*	17 (57)	31
Cost: Barrier - Lack of insurance, high out of pocket cost, bad insurance coverage, transportation cost, anything cost related Facilitator - Alternative methods of care, donations, programs, assistance, good insurance coverage		23 (77)	60
Barrier	*"So, you're going to give me a medication, and then am I going to have to pay for that medication? Some of them can be very expensive and some of them especially those who have gone to Kellogg know this already."*	15 (50)	28

	"[Medications are] super expensive and the first generation is not you might have to take it twice a day. It might be a generic version, it might be. But that's where we have to go because we have to go, you're not getting a Cadillac, you're getting a Volkswagen." *"People don't have insurance, and I haven't met a doctor for, a doctor for two years. Because I didn't have any vision insurance. "* *"I don't trust that it's going to actually be free and I can't afford to pay for it and I don't want another bill or another bill collector."*		
Facilitator	*"I think the fact that [the research program is] free is a big plus"* *"I think a lot of our patients definitely - would definitely use this and take advantage of it because of that extra cost that you do have to spend even if your health insurance covers an eye exam"* *"So, well, because a lot of people don't have the vision coverage. And they'd want to get it, you know, they can get it free and low cost."*	19 (63)	32
Fear: Barrier - Fear of knowing progression or severity of disease (denial) Facilitator - Fear of vision loss		25 (83)	49
Barrier	*"Well, a lot of it is, you know, people fear coming to the doctor and that kind of stuff."* *"Because most people that's in, who consider themselves in good health when they find out something like this is going on, it just can be very devastating. And a lot of people don't want that. They don't want to know that. So, they'll avoid it as long as possible until they're walking into walls. That's what I found."* *"But that's another thing too. When you, when you go to, so many doctors appointments and you're like, please don't find one more thing wrong with me and then people will avoid going"*	12 (40)	14
Facilitator	*"It doesn't stop, it doesn't slow down, nothing's going to make it better, you have to get it taken care of or that will happen"* *"You're running scared now and you're frightened [...] So, you're going to ask what can I do? Is this reversible? How can you help me? Do you need to refer me to somebody else who can help me?"*	15 (50)	24

Knowledge: Barrier - Eye disease: Not knowing about glaucoma, not understanding the disease, not understanding the consequences, not understanding demographics of disease; Resources: not having knowledge of available screening/resources Facilitator - Eye disease: Knowledge of glaucoma, personal experience of self or others with eye disease; Resources: having knowledge of available resources and screening. Knowledge of glaucoma: 22 people, 49 total Knowledge of Resources: 11 people, 24 total			26 (87)	73
Barrier	**Eye disease:** *"Big barrier here is trying to educate these people. And this research thing can help us find those people and try to educate them, try to make them aware that this is a problem."* *"People tend to think of glaucoma as just being something that 60, 70, 80-year-old people have, too."* **Resources:** *"I didn't even realize that you had an eye center here."* *"They don't really take advantage of what's here, you know, because if the information doesn't come directly to them. They don't seek it out."* *"Yeah. So I think there are couple of things like that within our existing network that would just be good. We'll make sure that our partners know that this is something we're offering now. They can be referring people over here for that."*		17 (57)	30
Facilitator	**Eye disease:** *"So, we are trying to help in any way that we can. But sometimes, actually the education of our patients with the important of knowing that this is your help, you can go blind."* **Resources:** *"We certainly are much busier today than we were when we first started. Public knows about it and the word has gotten out. So, this program can certainly help with that also."* *"I hear about a lot of people that are in need of that but then when they come to Hope, we let them know, guess what, we have somewhere that you can go. And then they will take us up on anything that we can offer them."*		21 (70)	41
Language: Barrier- difficulty accessing screening due to language difficulty and trouble with translation			5 (17)	7

Barrier	*"A lot of them you'll have to have bring translators with them, someone within the family or relative or a friend. We have so many people that come to Hope that have to bring a translator with them."* *"Well, there is always a language. You know so we typically tell patients here just because we don't have a full range of interpreter services that they need to bring somebody with them"*	5 (17)	7
Facilitator	None		
Loss of contact: Loss to follow-up, loss of contact information due to changing number or etc		7 (23)	12
Barrier	*"There's a huge no show up patients broken, broken appointments."* *"But the only thing you run into them is that a lot of people's addresses change or they move on and don't have a forwarding address and things like that"* *"I don't see too many barriers except for phone numbers changing. Really, I do. People's phone numbers change frequently."* *"I would say that probably, the number of glaucoma patients that I've seen down through the years, I'm just snatching a number out of the sky because I can see the faces of different individuals. I don't see those patients anymore. What happened? What happened to them? It should be at least 75% maybe more."*	7 (23)	12
Facilitator	None		
Perceived Need/ Benefit; Barrier - Lack of symptoms Facilitator - Perception that their vision or symptoms can benefit from an intervention thus asking for help		22 (73)	45
Barrier	*"And though it's been on my mind, I hadn't done anything about it, but when I started getting blurry vision, I went and got checked out and they said, "You've now become diabetic." I said, "Oh, okay, maybe that's the reason I'm having problems."*	8 (27)	9
Facilitator	*"[Patients] love free glasses. If they know they have a vision problem and they think they might get free glasses out of it, they will be more motivated, I think."*	20 (67)	35

	"I see good at that time. And as soon and then all of a sudden, and it takes a long period of time for it to happen like three months ago, it just happened to start getting darker and darker and I'm saying to myself, I should have went to that appointment. This wouldn't happen to me"		
Priorities: Barrier - Examples of when there are competing priorities, eyesight is not a priority Facilitator - Vision and health as a priority		30 (100)	98
Barrier	*"And many of our own patients you know when you look at their medical history, you know, they you know get a bad diabetes, hypertension, kidney problems, dealing with a family member who's incarcerated and unruly kids, three to four kids, if you do that a juggle schedule to complete the day, just a number of things."* *"So, they've got their minds on a lot of different things. And eyesight as important as it is, I think is overlooked so much."* *"Only people who are conscious about their overall health. I don't see people who are 20 something even concerned about their eyes. I'm listening to people all the time and people that age don't seem to have an idea about what good health is. "*	23 (77)	49
Facilitator	*"I've already been [to health screenings], you know, I keep a track of my health because of my age."* *"Because the way I look at it, like you only go around once, so you better take care of yourself the first time around."* *"Oh yeah, but when it comes to my vision that's important so I have to use those two hours at work and I may get back of a vacation but…"* *"I'd like to, take care of my eyes. Competitive, good care and find out if I can hope, I hope, there's nothing wrong with them."* *"my sight is very very important to me, I value my sight.*	22 (73)	49
Policy: Barrier: All things to do with regulations, rules and bureaucracy that impede patients getting the appropriate screening and time. Facilitator: Policies that encourage patients to make it to screening/appointments		7 (23)	10

Barrier	*" I think the biggest fear is like medical bureaucracy and that sort of thing that scares people away that it's just too difficult and so it's not worth it. But having maybe something that simple on site, immediate, understandable, I think that's a huge benefit."* *"Because sometimes with insurance, the rides, a month are limited. And some people have to keep seeing a specialist, they've like serious appointments, and they've like real severe, illnesses and they can't miss or they, they're seeing different specialists but they ran out of the amount of rides."*	6 (20)	9
Facilitator	*"...So then they tried something else where there was some automated calling system that that they had instituted you know, through you know, admin to notifying patients. So, they've tried different things and they've also instituted policies and if you have so many no shows for your appointments that you could not make an appointment here just because I guess people were just abusive"*	1 (3)	1
Social Support: Barrier - Lack of community resources or social support Facilitator - Having good social network, good community support and resources,		22 (73)	41
Barrier	*"Because they usually depend on their adult children to bring them. And a lot of times if the adult children have to pick up somebody from school, it's like "I have to leave by 3:30"*	5 (17)	5
Facilitator	*"I have no problems with [making to my appointments]. I'm here at least one day a week because of the laundry facility, so. And sometimes, on Saturdays with the food pantry and so, I'm here an awful lot."* *"Just so I think that it's one thing to let folks like we have extensive network of churches who work with us. And a lot of how we'll frame that is people go to churches when they're in need and churches aren't equipped to handle a lot of the things that people have. So we try to be a partner with them that they feel very comfortable referring those people to who are looking for services"* *" So I think a lot of times clients will first enter for food, because it's a very low barrier program, no requirements of any kind, you can just show up for a meal or you can show up and get emergency bag of food and that sort of thing. And so we end up referring a lot of clients do there. They'll come in for something simple like food and then become aware of other services at Hope."* *"We don't have a car. Our car, our transportation, so right now, we try to just make them to where, we make all our appointments on our daughter's car. Because we know we can use her car"* *"Yes, I have a neighbor that can get my child from the bus."*	20 (67)	34

	"If I had the time and I had the right supervisor where I could call and say, hey, I got wanted to really – I needed to come to this appointment, I'll use my lunch hour, I'm going to be 30 minutes late, I've really have to do this"		
Transportation Barrier: Not having transportation to make it to screening or appointments Facilitator: Having access to adequate transportation		26 (3)	63
Barrier	*" But those aren't the people who generally have the trouble getting here so much, it's people from Detroit that there's not a bus that goes from Detroit to Ypsi, you know, there ain't anybody from outside the immediate area that lets you that's the biggest barrier for getting"* *"They might have transportation but I've had patients that have to get up and leave because the person who agreed to bring them here for their medical appointment has to leave. "* *"And transportation, lot of people don't have cars, so lot of our people rely on public transportation."* *"An eight and not a 10, because I do take public transportation and things are out of my control."*	24 (80)	43
Facilitator	*"You know, if I didn't have transportation, but I do. I'm fortunate enough to have it, but a lot of people don't."* *"Just call them up, make an appointment. Call them up, set up let them know what time you have to be there and what time, you know, you want to when you're leaving. And I think the rule is about like 20 minutes prior, 20 minutes after, something like that "* *"I've already worked it out the night before to double check that my mode of transportation is either going to come pick me up, friends, family. Some people will use Uber."*	10 (33)	20
Trust: Barrier - Lacking trust in faculty, staff, or clinic Facilitator - Trusting clinic, reputation of UM, prior good experiences with providers/ site,		18 (60)	30
Barrier	*"And you know, it's just not worth the effort it takes to get there unless truly it's free. [... not] worth it to take a day off work or to bother figuring out how to get here. And then to find out why you don't qualify, it's not really going to be free for you."*	7 (23)	15

	"When you talk to me, you better use real stats. I'm smarter than you [...] if you're going to talk to me, don't talk to me like I just come off the street and wasting my time." *"I guess they were trying to focusing on a particular segment of the diabetics that was they were falling through the cracks some way and they were not being you know, treated the way they should have been getting the treatment."*		
Facilitator	*And physically Hope has a history of giving quality service. And maintaining standards and it's not about the money.* *"And that's something that's so big with us at Hope is you know that recognizing the dignity and respect and really having each encounter be something that upholds the person, you know, because positive encounter"* *"But of course like the university has a very reputable organization"* *"You got some good people, you know, good doctors. You know, just good doctors, somebody that you can rely on."* *"You're connected with a very identifiable hospital and then just working with a few people at a time is going to get the word out."* *"No, but when you say is free, I believe it is free."* *Comfortability, you know, do they feel comfortable with how the setup is? If they can really see that the advantage for them, you know, not just being a research subject. Yeah, to really make it, you know, to uphold the dignity of the client in the ways that, you know, we're able to do that, so that they can really feel like it's a benefit to them. And yeah, just that that sense of dignity and respect not being used as an object.*	13 (43)	15

Supplemental Digital Content 3 Theme definitions and representative quotes

Theme	Definition	Representative Quote
Convenience/ Access	**Barrier:** Far away clinic, inconvenient timing, not easily physically accessible, coming back for follow-up appointments	*"[Y]ou go in the waiting room and then they do some tests and then they send you to another waiting room; it seems like a long process."*
	Facilitator: Time, scheduling, proximity to clinic, ease of getting to clinic.	*"But having maybe something that simple on site, immediate, understandable, I think that's a huge benefit."*
Cost	**Barrier:** Lack of insurance, high out of pocket cost, bad insurance coverage, transportation cost, anything cost related	*"Cost is [the] Number 1 barrier [...] the more that's free, the better."*
	Facilitator: Alternative methods of care, donations, programs, assistance, good insurance coverage	*"You know, if you need that help and is offered to you free, any person would go and get that help."*
Fear	**Barrier:** Fear of knowing progression or severity of disease (denial)	*"The fear, you know. A lot of times you're just afraid of what might be found. Being suspect is one thing, but to actually being diagnosed and anticipating what the future means in terms of treatment or if it can be treated. So, I think fear plays a big part."*
	Facilitator: Fear of vision loss	*"I mean I'm going to be 65 years old. So everything as you age, everything is another fear like, what am I going to lose tomorrow? So it's just another thing if you can prevent it prevent it, you know, and this can be happening and it could be something that doesn't have to happen, just because you're getting older. So, yeah, take care of it."*
Knowledge	**Barrier:** - Eye disease: Not knowing about glaucoma, not understanding the disease, not understanding the consequences, not understanding demographics of disease - Resources: not having knowledge of available screening/resources	*"So, people just don't know they have this. That's part of the problem [...] Because it's painless, people who have it don't -- it's -- don't realize it."* *"A lot of people don't take advantage of it. When we first started here eight years ago, people didn't know that we were here. So, they didn't know they had access to glasses."*
	Facilitator: - Eye disease: Knowledge of glaucoma, personal experience of self or others with eye disease - Resources: having knowledge of available resources and screening.	*"Well, there was a history of some of my relatives having cataracts and so I would like to take a little bit more interest in my eyesight."* *"Well, I think awareness is a big thing. You know, that just so people are clear on what we're offering because I think if that is made clear, then there's going to be a, you know, the recognition of the need, you know, will draw people, people in."*
Language	**Barrier:** - difficulty accessing screening due to language difficulty and trouble with translation	*"Many of them can't speak English on the phone so if you're not able to speak their language they're not going to talk to you on the phone or make an attempt."*
Loss of Contact	**Barrier:** Loss to follow-up, loss of contact information due to changing number or etc.	*"Because it's -- totally different population than you and I. Not a lot of follow up with medical appointments. Especially when there's something wrong."*
Perceived Need/ Benefit	**Barrier:** Lack of symptoms	*"If I was like 25 and I had nothing wrong with my eyes, I wouldn't even bother with it. But if I was like 55 and squinting to read or something like that, then I would definitely*

		participate in the program."
	Facilitator: Perception that their vision or symptoms can benefit from an intervention thus asking for help	*"Now they have blurry vision [... and] that's probably when a lot of people catch it and say, 'Hey, I got to go to the optometrist'."*
Priorities	**Barrier:** Examples of when there are competing priorities, eyesight is not a priority	*"But sometimes that person can say, oh I'll come to my appointment for the afternoon and they still don't come. And it's a lot of barrier some time with them coming, it might be transportation, it might be problems with someone keeping their children, it's a lot of things going on"*
	Facilitator: Vision and health as a priority	*"[There is] nothing to prevent me, because I want to be healthy, and other things I can prevent me is if I'm asked to pay money, and I'm not walking, but since it's free, I find health is so precious, nothing can prevent me"*
Policy	**Barrier:** Regulations, rules and bureaucracy that impede patients getting the appropriate screening and time.	*"Because sometimes with insurance, the rides, a month are limited. And some people have to keep seeing a specialist, they've like serious appointments, and they've like real severe, illnesses and they can't miss or they, they're seeing different specialists but they ran out of the amount of rides."*
	Facilitator: Policies that encourage patients to make it to screening/appointments	*"...So then they tried something else where there was some automated calling system that that they had instituted you know, through you know, admin to notifying patients. So, they've tried different things and they've also instituted policies and if you have so many no shows for your appointments that you could not make an appointment here just because I guess people were just abusive"*
Social Support	**Barrier:** Lack of community resources or social support	*"[T]hey bring the children in with them to the exam room and stuff because they don't have any way around the childcare situation. So I really just don't know. A lot of people don't have a good support system in their life."*
	Facilitator: Having good social network, good community support and resources.	*"We have other family. If I know well enough in advance that I could possibly make arrangements with them."*
Transportation	**Barrier:** Not having transportation to make it to screening or appointments	*"[H]ow do I get to the Hope Clinic to do, yeah I'd love to have my glasses fixed to taking care of and get new glasses but how do I get there, transportation is huge"*
	Facilitator: Having access to adequate transportation	*"I think being here at Hope and we're on right, directly on public transportation line with the bus stop being right out front."*
Trust	**Barrier:** Lacking trust in faculty, staff, or clinic	*"I think in the beginning there'll probably be some hesitancy [to participate in the program]. People are suspicious what is it really for and what does it mean, and will it really help, do I really need?"*
	Facilitator: Trusting clinic, reputation of UM, prior good experiences with providers/ site.	*"Well, I think that Hope as an organization has a good amount of trust with our clients like relationships. And so, when we say, okay, this thing is being offered or whatever, our clients already kind of have an existing trust that well, if you're saying this is something that's available, yeah."*