




Keep Sight Nigeria pilot project: formative behavioural analysis.

Summary
June 2021

Glaucoma is the most common cause of irreversible blindness around the world. It is also the second leading cause of avoidable blindness. Glaucoma is also called ‘the silent thief of sight’ because vision loss occurs slowly and does not produce symptoms until very late in its progression. It is not a single disease, but a group of diseases characterised by optic nerve damage and visual field loss which leads to blindness if left untreated. It gradually reduces peripheral vision, which makes it difficult to notice at an early stage. Since many glaucoma patients do not notice the sight loss early, they often come to the hospital when they already have profound sight loss. So, because the goal of treatment is visual preservation, there is not much that can be done for them. However, if glaucoma is detected and treated early in its progression, it can be slowed, and serious vision loss can be delayed or prevented. Some of the risk factors identified for glaucoma and its resulting blindness include: advancing age (over 40), ethnicity (African, Caribbean or Asian origin), increased intraocular pressure (sometimes fluid in the eye is unable to drain properly, leading to a build-up of pressure) and a family history of glaucoma.

The Sightsavers’ Keep Sight project seeks to integrate and enhance glaucoma management into existing eye care services to reduce the number of people going blind due to untreated glaucoma. The project in Nigeria has been piloted in Abuja, starting in October 2019. This involved community screening for people at risk of glaucoma, and clinical assessment of those referred from the communities or adults self-reporting at the hospital. The Keep Sight project was funded by Allergan Pharmaceuticals (AbbVie).

The project adopted a social behaviour change (SBC) approach, which aims to encourage people to make positive changes to their behaviour by making interventions within their community. The project does this by identifying key influencers within eye health and in the communities, who can provide insights into specific behaviours. These insights then shape how we carry out specific behavioural change interventions. We conducted a formative behavioural analysis to help inform this work.



Social behavior change (SBC) influences healthy behaviours and actions that people carry out and creates a supportive environment for these to flourish.

Why is this issue important?

In Sub-Saharan Africa, it is well known that early diagnosis of glaucoma is not very common. A significant proportion of patients arrive at clinics already blind from glaucoma. Most patients will require life-long medical treatment, and some may benefit from surgical treatment in order to preserve sight and reduce the rate of further damage, so adherence to medical treatment at any stage of glaucoma is critical.

Although we already understand, based on a literature review, some of the reasons why people do not seek care for glaucoma, we chose to conduct formative analysis to determine the drivers of these behaviours in the specific communities where we work. Findings from this formative evaluation are intended to support the development of localised solutions, and to design appropriate SBC materials and interventions to align with the aspirations and contexts of the those at risk.

What did we do?

The Keep Sight project sought to prioritise the following behaviours of interest:

1. Men and women over 40 who are at risk of glaucoma attend a screening centre (screening uptake).
2. Men and women over 40 who are at risk of glaucoma attend a hospital testing facility (testing uptake).
3. People with a glaucoma diagnosis attend regular follow up appointments (hospital attendance).
4. People with a glaucoma diagnosis adhere to medical treatment with eye drops or accept surgery as a means of vision preservation (treatment uptake).

The aim of our formative analysis was to (a) identify the factors (**barriers** and **enablers**) that influence the adoption of the stated behaviours of interest, and (b) determine significant knowledge gaps which will receive more priority in this formative analysis.

We conducted the study among 52 respondents in two locations: the University of Abuja Teaching Hospital and the Primary Healthcare Center in Dobi community, Gwagwalada Area Council of the Federal Capital Territory. A questionnaire on demographics was administered to all respondents. Checklists called the Key Informant Interview and Focus Group Discussion were used to gain further insights from clinicians/ophthalmologists, community-based volunteers, individuals diagnosed with glaucoma, and individuals at risk of glaucoma.

What do the findings tell us?

Key messages

- Health workers' behaviours have a tremendous impact on patients' acceptance of and adherence to treatment. The quality of counselling received by patients enables or deters them from keeping up with treatment.
- Social elements of a patient's environment (advice/help from family/friends, traditional and religious authorities) play a significant role in their acceptance of screening or treatment for glaucoma.
- The belief that patients are powerless to do anything to protect their sight, or the acceptance that vision loss is a normal part of ageing, are key barriers that can be modified.

Summary

Key insights from the formative analysis were categorised into broad groups of critical enablers of and barriers to treatment uptake and adherence.

For the **enablers**, the following six factors were identified as crucial facilitators of the expected behaviour changes:

1. **Desire to prevent blindness.** This includes reasons of personal wellbeing and security, social acceptance, ability to engage in economic activities, etc.
2. **Appearance, intensity and severity of symptoms.** While this factor is an enabler in this context, it is important to note that early detection is critical for vision preservation, especially for glaucoma patients. This factor is more challenging given the necessity of early presentation for vision preservation.
3. **Quality of counselling and advice received from doctors.** Patients with good counselling were encouraged to get tested at a testing facility, and to adhere to their medical appointments.
4. **Social elements.** Advice and help from family/friends, community volunteers and traditional and religious authorities were a factor in treatment adherence and follow-up. For example, when patients received help from family members in applying eye drops, it led to much less wastage of the medicine. Family members also provided support for respondents to go for testing and follow-on appointments.
5. **Fear of surgery, with associated misconceptions.** For patients who were referred to the hospital, fear of surgery influenced their decisions to choose eye drops and medications as their preferred treatment option.
6. **Preference for one-off treatment.** For patients who are already attending hospital appointments, some respondents were inspired to go for surgery rather than apply eye drops for life.

Seven **barriers** were identified as the critical influencers that need addressing in order to influence behaviour change, as follows:

- 1. The belief that people are powerless and incapable of protecting their eyesight.** This belief is further entrenched by the fact that most of the respondents do not know what glaucoma is, many neither know when nor where to go for eye health screening, some believe that blindness naturally comes with age, and some are aware that that treatment does not restore vision.
- 2. Cost of care and treatment.** A comprehensive eye test costs about 15,700 naira (about £30) for an initial medical consultation and 40,000 naira (£76) for surgery. Eye drops cost between 2,500 and 7,000 naira (£5 - £13) for a month's supply. Sixty-five percent of respondents who had not yet gone for hospital screening earn below £50 a month and 40 per cent of those already attending the hospital and receiving treatment earn above £200 a month.
- 3. Fear of surgery.** Although fear of surgery is an enabler for the uptake of eye drops as a preferred treatment option, conversely, it is a direct barrier for people opting for surgery.
- 4. The poor attitude of some health care workers.** Instances of unwelcoming attitudes and utterances by health staff, as well as misplaced documentation (case files) were reported by many respondents. It appears that some health care workers are unaware of the impact their behaviour can have on their work and patients.
- 5. Limited personnel, services, drugs at the hospital.** Most respondents complained that they spend the whole day waiting to see a doctor. In terms of services, at times, patients are asked to go for some tests which are not available at the hospital at other locations outside, and often prescribed medication is not available in the hospital.
- 6. Length of treatment.** Patients can be put off by the idea that when treated with medication, they will have to attend follow-on appointments and apply eye drops for life. This comes with its own challenges including forgetfulness in applying the drops every day, pain and discomfort felt with the eye drops, and cost.
- 7. Lack of visible improvements from treatment.** Most patients get discouraged with time when they do not see marked improvements in their vision.

The following interventions were proposed:

- **To improve attendance at eye health screening centres (behaviour 1) and hospital testing facilities (behaviour 2).**
 - **Goal/aim:** Enhance individuals' belief in the existence of diseases that can cause blindness without them knowing, and in their ability to protect their eyesight. **Intervention:** Sensitisation and enlightenment activities, and communication materials to enhance knowledge on how to protect their eyesight.
 - **Goal/aim:** Promote a culture of going for regular eye checks (even without symptoms) for at-risk individuals. **Intervention:** Awareness-creation sessions on the dangers of late detection of eye diseases, re-training of community volunteers on negotiation and persuasion skills and identification and sharing of testimonials and success stories on early detection.

- **Goal/aim:** Improving access to eye screening and clinical services and making the cost of care more affordable. **Intervention:** Funding to introduce subsidies and to organise free medical outreaches should be explored.
- **To further improve uptake of patients seeking eye tests (behaviour 2) and increase attendance to regular follow-on appointments (behaviour 3).**
 - **Goal/aim:** encourage greater empathy and support for patients by healthcare workers. **Intervention:** Interactive sessions to discuss the effect of health care workers' actions on patients and how to overcome challenges and be more supportive. Health care workers should be re-trained in professional ethics and interpersonal skills including communication.
- **To influence attendance at regular follow-on appointments (behaviour 3) and adherence to treatment (behaviour 4)**
 - **Goal/aim:** Make the cost of care and treatment more affordable. Increasing the availability of eye medications, increasing acceptance and adherence to medication treatment (despite lack of visible improvements). **Intervention:** Enrolling more patients on the National Health Insurance Scheme (NHIS), advocate with the government to include more glaucoma drugs in NHIS.
 - **Goal/aim:** Strengthening patients' ability to cope with longevity of treatment and associated discomforts. **Interventions:** (a) Enlightenment events to enhance knowledge on glaucoma and treatment purpose/outcomes. (b) Sensitisation sessions to educate patients on proven ways to cope with their treatment plans. Communication materials on coping strategies for a long-term treatment regimen should be designed and distributed; peer forums/support groups should be created and supported to ensure that patients continue to encourage and motivate each other.
- **To improve uptake of surgery (behaviour 4)**
 - **Goal/aim:** Improve uptake of surgery and patients' acceptance of surgery as a means of vision preservation. **Intervention:** Awareness-creation events on pros and cons of surgery as a treatment option should be organised, individual and/or group counselling opportunities should be made available, SBC materials to stimulate acceptance of surgery should be designed and distributed, and surgery-related testimonials and success stories should be shared.

Limitations and suggestions for future research

Some limitations of this analysis include:

- **The location of the study.** This analysis was conducted in a community situated 15 minutes away from a tertiary centre. The responses and opportunities for screening and treatment would be more varied for communities located miles away from a treatment centre.
- **Doctors' willingness to conduct surgery.** Doctors' views on their capability and confidence in dealing with complications following glaucoma surgery and how this

impacts their willingness to offer surgery as a treatment option could be a potential suggestion for future research.

- **Sample size too small.** Few patients who have had surgery participated in the interviews, this not being a completely representative sample.

Learn more about

- Summary author: Selben Penzin.
- **[Read the full report here](#)**
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