

Formative Behavioural Analysis in the Glaucoma Project: Insights Report from Ganjam, Odisha



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Foreword

Glaucoma affects around 65 million people worldwide, with 7.5 million experiencing blindness due to the disease, making it the second most common cause of blindness globally. In India, studies have shown that between 2.7% and 4.3% of adults aged 40 and above have glaucoma. This condition is responsible for causing blindness in 1.2 million individuals, accounting for 5.5% of total blindness cases in India, (*source: <https://www.ncbi.nlm.nih.gov/>*) primarily because many cases go undiagnosed or are detected at advanced stages. The main challenges in managing glaucoma in India include low awareness, undiagnosed cases, limited access to diagnosis and treatment, and issues with treatment compliance. Addressing these challenges at various levels, including public awareness, healthcare providers, and the eye healthcare system, has become a pressing public health concern.

To combat this issue, Sightsavers India and Allergan launched a community-based glaucoma screening program called "Keep Sight India" in Ganjam District, Odisha. The aim is to integrate and improve glaucoma management within existing eye care services to prevent blindness caused by untreated glaucoma. In September 2022, a formative analysis was conducted in Ganjam district among the target audience to gather evidence and develop activities and messages crucial for changing behaviours related to glaucoma within the community. This study was carried out by the ETI Consulting Pvt Ltd.

This report offers valuable insights into the barriers to diagnosis and treatment adherence, aiding focused program planning. The findings will help identify effective communication channels within the community, bridge gaps in advocacy and communication regarding glaucoma, and understand the local norms and practices, enabling positive behavioural changes. I commend the efforts of Sightsavers India, Sankara Eye Hospital, Ganjam, and ETI for identifying these gaps, which will enhance project implementation. My heartfelt congratulations go to the team members involved in producing this report.

RN Mohanty,
CEO, Sightsavers India

Abbreviations

AWWs	Anganwadi Worker
ANM	Auxiliary Nursing Midwifery
ASHAs	Accredited Social Health Activist
CDR	Cup-Disc Ratio
CoC	Cost of Care
COVID-19	Coronavirus Disease of 2019.
COM-B	Capability, Opportunity, and Motivation -Behaviour
CSO	Civil Society Organization
DALY	Disability Adjusted Life Years
FGD	Focused Group Discussion
GOA	Glaucomatous Optic Atrophy
GDI	Glaucoma Drainage Implants
HIV	Human immunodeficiency Virus
H1N1	“H” (Hemagglutinin) and the “N” (Neuraminidases)
JOAG	Juvenile open-angle glaucoma
LGBTQIA	Lesbian, Gay, Bisexual, Transgender, Queer, Intersects and Asexual
IDIs	In-depth Interviews
IOP	Intra-Ocular Pressure
POAG	Primary Open-Angle glaucoma
PACG	Juvenile Close-Angle glaucoma
PWG	People diagnosed with Glaucoma
QoL	Quality of Life
SBCC	Social & Behavioural Change Communication
WHO	World Health Organization
NGO	Non-Government Organization
PRIs	Panchayati Raj Institutions
PVA	Presenting Visual Acuity
SHGs	Self-Help Groups
TB	Tuberculosis
VF	Visual Field
PI	Peripheral Iridotomy

Executive Summary

Glaucoma is the commonest cause of irreversible blindness. In 2020, 4.13 million people aged 50 years and older suffered moderate and severe visual impairment, and 3.6 million were blind as a result. This presents that glaucoma is attributed to 11 percent of all global blindness in adults aged 50 years and older (Rawal, 2021). Also known as the ‘silent thief of sight’, the disease erodes the optic nerve, depleting peripheral vision at first, making it difficult to notice the vision loss at an earlier stage. The disease is characterised by optic nerve damage and visual field loss which, if left untreated, progresses to blindness.

This report ‘Formative Behavioural Analysis’ identifies the knowledge management tools for glaucoma care for the Keep Sight project. It collates data from the formative analysis carried out in the Ganjam district of Odisha in India. The project aims to integrate and enhance glaucoma management into the existing eye care structures to reduce the number of people going blind due to untreated glaucoma and presents suggestions for dealing with the young, apparently healthy populations for early intervention. It also aims to understand the methods of behavioural change communication employed by Sankara Eye Hospital in Ganjam to identify key stakeholders and influencers in eye health services and communities to carry out specific behavioural change interventions, and to observe how the general population received and perceived these messages.

The behavioural analysis undertakes a literature review to understand glaucoma as a public health issue and its clinical classification. It also aimed to look at the economic, social, and mental health burden incurred as a result of living with glaucoma and understand the state response and the health-seeking behaviour. Based on the literature review and the existing target audience groups, 3 sets of stakeholders were identified. These included:

- Population above 40 years of age at risk of glaucoma
- People diagnosed with glaucoma (PWG)
- Eye care service providers

The analysis utilises a mixed-method study for the data collection to ensure a holistic view is undertaken. It was designed using focus group discussions (FGDs) and in-depth interviews (IDIs) which were cross triangulated with the quantitative data from a pool of 1029 individuals who had been part of the initial diagnosis under the Keep Sight project. The data collection process was conducted with the participants in and around Aska where the Sankara Eye Hospital is also located.

The behavioural analysis found that nearly half of those who had been diagnosed with glaucoma dropped out of the adherence cycle immediately after they were advised treatment, and by the end of the series of four follow-ups only 3 percent had judiciously followed the suggested pathway. The barriers to diagnosis and treatment adherence ranged between distance, time, and the financial costs incurred. Acute observation also shows how one's socio-political identity is significant in charting the course of their health journey. While there is still scope to understand the communication channels active in the community, to bridge the gap in advocacy and communication with respect to glaucoma, it is imperative to invest in audio-visual media along with active dialogue to build awareness.

1. Introduction

Sightsavers India's 'Keep Sight India' initiative focuses on a community-based glaucoma screening program to prevent loss of vision in Ganjam, Odisha – which is one of the first multi-year initiatives to treat and prevent the disease.

To tackle glaucoma in India, Sightsavers India is working with pharmaceutical company Allergan. The project, starting in 2019, aims to help protect the sight of as many people as possible by raising awareness, conducting out eye screenings, training health workers, and providing treatment. A counsellor has been appointed for deeper engagement with identified cases and their families to ensure higher compliance with the advised treatment regimen. Although glaucoma is incurable, it can be controlled. This research adopts aims to understand stakeholders in eye health and communities to carry out behavioural change interventions.

Around 80 km surrounding the Sankara Eye Hospital, Sightsavers India organizes weekly camps for glaucoma screening. To reach the audience – especially young, apparently healthy people, announcements are made over megaphones via vans and pamphlets. A walk-in screening is available in the community for the convenience of the local population. The community-based screening tests to detect the IOP and the fundus photo were taken to assess the cup-to-disc ratio (CDR) and these are non-invasive and hassle-free. After the persons are screened, counselling is given to emphasize the immediate need for a confirmed diagnosis of the at-risk cases, and they are referred to the Sankara Eye Hospital. These are called 'glaucoma suspects'. Even for those who have not been suspected, general information is provided on glaucoma, especially regarding the need for annual screenings and to mobilize their fellow community members to come for these camps.

Once the suspects arrive at the hospital, either via referral from the camps or on their own, they are given a hospital registration number and assessed by the trained staff. They are checked for visual acuity, pupillary reaction, IOP, anterior chamber depth, and the optic disc assessment. Those who do not have glaucoma are filtered out. Those finally enrolled in the project are given a unique project identifier, with a sticker on their folder, and are checked for other vital signs like blood pressure and co-morbidities. The next stage is a specialist evaluation through gonioscopy, disc assessment, and visual field assessment. After a glaucoma diagnosis is completed, a management plan is developed to provide counselling. If surgery is planned, normal protocol is observed, and clinical protocols are applied for post-operative patients. For either course of treatment, a long-term follow-up strategy is pursued; patients are counselled and adherence to treatment and progression is monitored. For those who are not enrolled in the Keep Sight project, the vital signs are checked as well including blood pressure. Further, counselling is provided, and a full-eye examination is conducted. Since glaucoma was suspected of this sub-group as well, the next stage is to assess any risk factors for glaucoma that they may have, and they are advised to come back for routine eye exams and glaucoma assessment.

2. Literature Review

Glaucoma erodes the optic nerve, depleting peripheral vision, and making it difficult to identify the disease at an early stage. Increased intra-ocular pressure and a family history

of glaucoma are important risk factors. It often is asymptomatic till there is severe damage to the eye, thus identification is delayed. Evidence suggests that nearly 40 million individuals in India have glaucoma or are at risk of having it, and at least 1.1 million have gone blind because of having glaucoma (Indian Express, 2022).

The disease presents itself with only a few symptoms in the initial stages and later the visual field threatens central vision loss (Gogate, Deshpande, Chelekar, Deshpande & Deshpande, 2011). As these nerve fibres die, blind spots are developed in the vision that might not be noticeable until most of the optic nerve fibres die. It is at this point that there is a complete loss of vision, which is irreversible. While glaucoma is not a curable disease, it can be controlled. However, if detected and treated early in its progression, it can be slowed, and serious vision loss delayed or prevented. It is the second leading cause of blindness, and the most common irreversible cause of blindness (Parihar, 2016). Routine eye examinations are a rarity in developing countries which translates to people being at high risk of recognising their symptoms at a later stage and higher chances of irreversible blindness.

There are two common types of glaucoma – Primary Open Angle Glaucoma and Primary Angle Closure Glaucoma. The former is a ‘chronic, progressive, and irreversible multifactorial optic neuropathy that is characterized by the open angle of the anterior chamber, typical optic nerve head changes, progressive loss of peripheral vision followed by central vision field loss for which intraocular pressure is an important risk factor’. The disease is usually bilateral- in both eyes but depends upon the aetiology [1]. The latter is a ‘chronic optic neuropathy associated with a loss of retinal ganglion cells and their axons which typically affects the elderly, which can be caused by pupil block, where aqueous is impeded on its passage between the lens and posterior surface of the iris, as well as non-pupil block (Amerasinghe & Aung, 2018). A glaucoma is considered advanced if the "evidence of glaucomatous optic disc and visual field (VF) loss in both upper and lower hemifield and/or a defect encroaching within 5° of fixation" (Kastner A. & King A., 2020). Glaucoma’s can also be secondary. These are glaucoma’s caused due to an underlying medical condition or trauma.

Primary open-angle glaucoma is estimated to affect 6.48 million persons and the estimated number with primary angle-closure glaucoma is 2.54 million (George, Ve, & Vijaya, 2010). Another kind of glaucoma considered for this report is Juvenile Open Angle Glaucoma (JOAG). This is a subset of POAG defined by early onset (above 3 years and below 40 years of age), high IOP, and autosomal dominant inheritance (Kwun, Lee, Han & Kee, 2016). Two more types of glaucoma have been studied as part of this study.

There are multiple challenges both from the demand and supply side affecting glaucoma care – social, economic, and cultural barriers that must be understood to improve health-seeking behaviours toward addressing the challenge. The projected global disability-adjusted life years (DALY) numbers present that refractive error alone stands at the 8th rank in 2030, however, if all causes of vision impairment group into one outcome (vision loss), then vision loss may probably lie within the top five causes of DALY loss (Senjam, 2020). It is estimated that the number of people with glaucoma worldwide will increase to 111.8 million in 2040, disproportionately affecting the Asian and African regions (Tham et al, 2014).

The management for glaucoma is focused on lowering the IOP, which is a modifiable risk factor. The treatment is provided as a prescription eye drop(s) or surgery. The former requires regular application throughout the course of the treatment and the latter is often a one-time procedure that might require the continued application of eye drops to not further the deterioration of vision.

There are different kinds of surgeries to address the challenge of glaucoma. Trabeculectomy creates a new pathway for fluid inside the eye to be drained (Johnson, n.d.). Visco canalostomy is a non-penetrating procedure to increase the outflow facility and lowers the IOP (Carassa, 2011); and Glaucoma Drainage Implants (GDI) which is largely for refractory glaucoma where a silicone tube is introduced into the anterior chamber (Agarwal & Bhardwaj, 2020).

Other challenges include poor awareness among individuals and communities about the disease, its risk factors, and understanding of when to get tested. The disease receives lower attention than others, and the lack of perceived severity leads to affects regular testing. Given that glaucoma is not curable, the lack of immediate benefit hinders people from continuing long-term treatment.

However, despite the identification of the burden and challenges, there remain multiple lacunae in research – which are also scattered. There is little to no understanding of factors affecting treatment adherence, ensuring last-mile delivery, and impact on mental health. The research, even the one available in the public domain exists mostly for researchers and academicians and is hardly broken down into data easily understood by the general population.

2. (a) COM B Model

This study utilized a COM-B model to understand the capabilities, opportunities, and motivations of individuals that impact the behaviour of the individuals who seek treatment, and those who do not, making it comprehensive in scope for planning intervention. The model is used to cover aspects of service delivery, and health-seeking ideologies, in addition to the clinical and social forms of the illness itself.

The Capability, Opportunity, Motivation, and Behaviours (COM-B) model developed by Dr. Susan Michie, Maartje van Stralen, and Robert West in 2011 aims to understand human behaviour in its sensitivity to one or more components (capability, opportunity, and motivation) as they alter in response to a targeted intervention. The differential impact on how the three factors interact is dependent upon the design of these interventions and the mode of delivery. The intersection is almost always unique at both the community and the individual level, but regularities may be found with qualitative investigations. [i]

The COM-B model applied for this study was selected because it provides a comprehensive base for understanding the complex processes involved in social organization. The model gives a descriptive overview of the multiple factors involved and allows one to understand the behaviour of an individual. Using this model allows us to design solutions that keep the key factors influencing behaviour in mind.

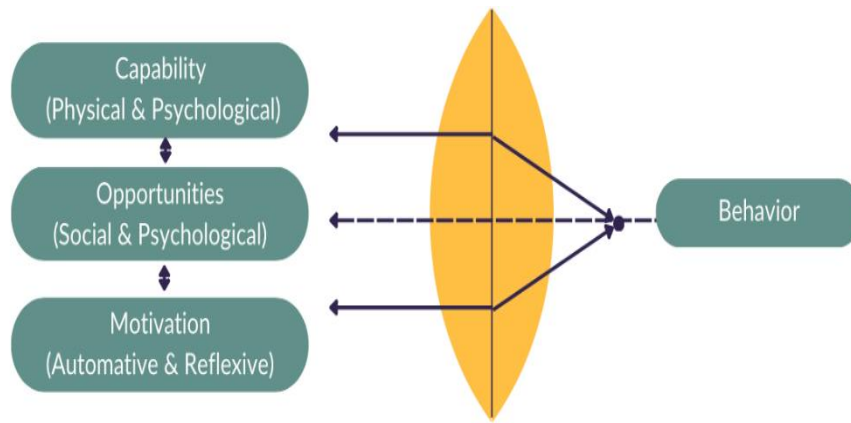


Figure 1: COM-B Model

Economic Burden

Glaucoma – from its diagnosis to care has a heavy out-of-pocket expenditure, which makes it particularly difficult for individuals from vulnerable socio-economic backgrounds to seek proper care. Expenditure can be calculated in two different ways – the cost of care (CoC) (direct expenditure) including medication, travel, and hospital expenses; and the consequential loss (indirect expenditure) incurred due to the burden of having the disease like loss of job and daily work.

Persons with glaucoma, especially those with advanced glaucoma, faced reduced mobility, and are at a higher risk of road collisions. These possible risk factors pose another challenge at the physical level which would require additional financial expenditure.

To track the journey of a patient from screening to treatment – expenditure is calculated at various junctures. Multiple sources from across the country identify that the general cost of screening for the disease using a visual field test which ranges from Rs. 1,500 – 1,700 for both eyes. The cost of a single eye drop (the most common form of treatment) which typically lasts a month or two, is estimated at Rs. 500 and these require continuous purchases. The cost of surgery is also considerably high – at around INR 35 to 40,000 for single-time use. Given that lifelong control of the IOP is a necessity, the expenditure, unlike in most other diseases, is continued for a lifetime for most patients.

Most developed countries have schemes or insurance for glaucoma care, however the same does not stand true for developing countries. (Nayak et al., 2015). A recent study indicates that in 2015 the annual cost of treatment for glaucoma varied from as low as Rs. 193.3 and up to Rs. 6616.72, which is quite similar to the cost of treatment in 2005 (Bhatt & Golwala, 2022).

These estimated costs do not account for other factors like travel to access care and doctor consultations at health centres. The cost-effectiveness of the medication depends also on the frequency of consumption which in turn depends on the intensity of glaucoma.

Social Burden

There remains inadequate age and gender disaggregated data around health conditions. However, a reading of social role, behaviours, and traditions finds how identities come to play a central role in accessing care services as well as response of care service providers.

Individuals have multiple social identities, like caste, class, gender, that are imbricated over each other in social spaces, thereby creating a unique set of roles (expectations) and challenges for each of them. These severely impact health-seeking behaviour. Intersectionality within the vulnerabilities further hinder populations from accessing healthcare but this area is hardly explored in research available in the public domain.

The vulnerable groups like women, aged populations, members of Lesbian, Gay, Bisexual, Transgender, Queer, Intersects and Asexual (LGBTQIA++) community, migrant workers, among others often find it difficult to navigate healthcare through formal settings. What is to be considered here is how the additional counts of vulnerability increase the burden of the challenges and limit access to required care.

The National Family Health Survey- 5 (NFHS-5) data found that as many as 60 percent women face trouble while accessing healthcare in India. The women cited at least one of the following problems while trying to access healthcare: money (21 percent), distance to a health facility (23 percent), transport (22 percent), no female healthcare provider is available (31 percent), no healthcare provider is available (39 percent), no drugs are available (40 percent). This situation is further exacerbated by the fact that only 30 percent of women between the ages of 15-49 years are covered by any health insurance or financing scheme, creating a major barrier in accessing care from private service providers.

Mental Health Burden

Mental health continues to remain an ignored and deeply stigmatised issue. India finds heavy rates of common mental health conditions, like depression and anxiety. These are also commonly associated with pressures of debilitating life conditions. It would not be a difficult leap to make to consider the diagnosis and living with glaucoma is likely to cause stress and possibly, mental health challenges among individuals. However, it is pertinent to make the careful distinction that those with glaucoma are not predisposed to any mental health challenges.

There remains a lacuna in research on glaucoma that identifies the subsequent challenges to mental health, which can also lead to a significant impact on health-seeking behaviour. The consequential impact of having glaucoma is evidently felt on the mental health of individuals, given that it severely impacts the Quality of Life (QOL). Treatment often limits itself to preserving vision and does not account for mental health. Glaucoma also has psychosocial implications, where research suggests that anxiety starts building up from the early stages of visual field loss itself and worsens one's perception of the "self-image" with the accretive loss of visual acuity (W. Chan et al., 2014). Research showcases that individuals with glaucoma tend to develop negative emotions such as anxiety or depression, which are detrimental to their daily functioning and well-being (Dayal, 2021). The worsened mental health leads to decreased participation in social activities due to impaired visual function, and increased economic burden, and may also lead to discontinuation of treatment, leading to the challenge being accentuated.

Odisha Health Seeking Behaviour

In a study done across four districts of Odisha - Jajpur, Nayagarh, Puri and Cuttack, in people aged 40 years and above, it is found that 76.69 percent people had little or no awareness about glaucoma while about 88.07 percent of them did not know that the blurry vision caused by glaucoma is irreversible. However, half of the population had a fair idea about cataract surgery. (B. Rath et al., 2018). One of the reasons for increased awareness of cataract is attributed to the priority given to the disease by the central and state government.

Eye-health care is a key priority in Odisha and availability of infrastructure to reach vulnerable populations is well developed and with state-of-the-art facilities. However, the challenges continue.

A study conducted by Harvard T.H. Chan School of Public Health found that the out-of-pocket expenditure for residents in Odisha on medicines was around 69 percent, and existing government health insurance programs hardly provided for outpatient care or medicine expense. Due to poor availability of drugs, distance and timings at public facilities, people rarely access care from private sector.

Evidence generation alone is not enough to build health-seeking behaviours. Over years, there have been multiple projects across India aiming to build health-seeking behaviours among the most vulnerable and marginalized populations.

India has successfully eradicated major public health challenges like polio receiving its Polio-Free Certification from the WHO in 2014. Other challenges like Human Immunodeficiency Virus (HIV) and Tuberculosis (TB) have been brought into the national framework and are under control using multiple initiatives run by the government, International non-governmental organisations (INGOs), non-government organisations (NGOs), civil society organisations (CSOs), and other stakeholders. These have been made possible by continuous research, the development of communications material to reach the people and other stakeholders, and advocacy with different groups.

Looking at the success of these projects provides a framework for understanding/learning what motivates and influences people in the area. While all solutions may not necessarily be applicable, it is critical to learn from the successes and failures of others.

- **TB-Mitra App:** To spread awareness of TB and make Odisha TB-free, the Health Department of Odisha Government released communication materials on TB survivors and also launched the 'TB Mitra' mobile application for easy assistance of patients. It allows people an opportunity to enrol themselves, enquire about diagnostic centres and the availability of drugs, lodge grievances, and get assistance from the government.
- **Accessible Communication Material:** In a project led by the Department of Women & Child Development, Government of Odisha, multiple Information, Education and Communication (IEC) materials like leaflets, flyers, and posters in local languages were developed with specific content designed for different target audiences. For example – some general posters focused on anaemia, iodine supplementation in children, and how to protect against swine flu & H1N1, among others. The communications assessment also suggests involving Balika mandals, and school health.
- **Portable Communication Devices:** UNICEF provided Odisha with multiple communication devices to be used by Accredited Social Health Activists (ASHA),

Anganwadi Workers, and Auxiliary Nurse Mid-Wives (ANMs) to build community engagement. The use of megaphones, jingles, jukeboxes for playing recorded messages, and projectors with short key messages on COVID-19-related behaviour change. These were also used at tribal markets to reach vulnerable populations.

Rationale for the Study

Glaucoma testing and diagnosis do not naturally form a priority list for people across various backgrounds. People also are largely not aware about the disease, its clinical classifications, and consequential impacts. Given the limited information regarding the disease, it is often mistaken as losing eyesight with age, and since peripheral vision is lost first, people tend to care less as long as they can see the objects in front of them. This elongates the gap between the advent of the illness and getting diagnosed for it, which leaves a very small window for treatment to be taken up.

It is presumed that the fact that glaucoma is irreversible disincentivizes individuals from going to the hospital and taking up treatment at all. What is observed here is the problem of human behaviour, and the only way to address it, and make people more accepting of the treatment requires Social and Behavioural Change Communication (SBCC) tools which this project intends to create, post data collection and analysis.

Objectives

The overall objective for the 'Formative Behavioural Analysis' research is to generate evidence and produce activities and messages that are critical to glaucoma behavioural changes in the community in Odisha.

The specific objectives of the study include:

- To understand the norms and practices of the people in the project area in order to create a change that will have a positive impact on the behaviour of the people.
- To generate evidence to produce activities and messages that are critical to glaucoma behavioural changes.
- To build communication strategies towards improving awareness and building an environment for testing and treatment adherence.
- To understand behaviours around patients attending an initial eye screening, and patients with glaucoma adhering to the treatment plan prescribed by their doctors.

The priority from the target group included:

- The general population at risk to understand what informs their health-seeking behaviours and what motivates them to visit screening sites.
- PWGs to understand their awareness about the need for continued care, and associated risks.

- Counsellors and other eye health service providers engaged in additional procedures to understand their willingness to screen regularly those coming to their centres.

Study Area

The study 'Formative Behavioural Analysis' was conducted in the Ganjam district of Odisha in India. This is the prime location for the implementation of the Keep Sight project in the state.

The district covers an area of 8070.60 sq. km and is divided into two zones – coastal plain area in the east and hills in the west. Agriculture is a traditional occupation and the way of living of the inhabitants of the Ganjam district. The district is well known for its fertile soil and agricultural productivity (Odisha, n.d.). According to the 2011 census data, there are a total of 3,529,031 people and out of these, around 63 percent of the population is literate (District Census 2011, n.d.).

India has been running the National Program for Control of Blindness since 1976 when it became the first country in the world to recognise blindness and visual impairment as a critical public health policy (Verma, Khanna, Prinja, Rajput, & Arora, 2011).

The program aims to build eye health clinics across all districts, improve the quality-of-service delivery, enhance community awareness. Odisha launched universal eye health coverage in October 2017 and became the first Indian state to officially respond to the World Health Organization's Global Action Plan 2014-2019. The government pledged INR 6,820 million over 5 years for eye health care in the state. The budget is focused on the direct benefit, building infrastructure & human resources, and the creation of a digital eye health platform for uniform documentation and policy planning (Das & Pattanayak, 2018). The Department of Health and Family Welfare in the state also built a committee that will be working to design and oversee the implementation of a universal health care system.



Figure 2: Ganjam district, Odisha

Conceptual Framework

The research utilised literature review from multiple sources including government data, peer-reviewed journals, and grey literature, along with the Phase 1 trial data. This secondary analysis was followed by primary data collection with the key stakeholders to identify key themes and the way forward. The key stakeholders identified included – eye health service providers, adults over the age of 40 years, and persons with glaucoma. The research (quantitative and qualitative) was analysed and discussed with the Sightsavers India team in a participatory meeting. The data has been utilised to build insights report along with a creative brief which determines the key next steps and focus areas to enhance the outcomes of the Keep Sight project.



Figure 3: Research Framework

Data analysis

Phase-I of the Keep Sight project entailed the standardised diagnosis of Glaucoma at the various project sites in the Ganjam district for the period of October 2019 to March 2021. The dataset of 1029 individuals obtained for the final analysis is composed of the individuals who after being screened at either the hospital or community (and being identified as “suspects” of Glaucoma), reported at the hospital for their final evaluation. The data was cleaned and organized for meaningful interpretation as per the research requirement. The data analysis exercise was done with the help of the statistical software, STATA 15.1. This includes the descriptive and comparative analysis of the key parameters of the people diagnosed with Glaucoma. The analysis is done at the individual-level, as well as at the eye-level.

For data analysis, a few operational definitions were taken, which may be considered as caveats to the research proposed below–

- To classify a person as having Glaucoma or not, the criterion was employed for the worse eye i.e., if either eye has Glaucoma, the person was labelled as a “person diagnosed with Glaucoma” (PWG).
- For accounting the visual impairment, visual acuity is judged based on the vision in the better eye. The International Classification of Disease 11th revision (ICD-11) defines blindness as presenting visual acuity (PVA), i.e., with available refractive error correction, less than 3/60 in the better eye. The categories of

severe, moderate, and mild vision impairment are defined according to the visual acuity (VA) thresholds.

Mild: Presenting Visual Acuity (PVA) <6/12-6/18 in the better eye, Moderate: PVA <6/18 to 6/60 in the better eye, Severe: <6/60 - 3/60 in the better eye and Blindness: PVA <3/60 in the better eye.

To classify the type of Glaucoma an individual has:

1. if both eyes have the same type of Glaucoma or only one eye is identified with a certain type of Glaucoma, it is simply used as the category (of Glaucoma) under which the individual would be classified (for the purpose of analysis).
2. in case both eyes were detected with different types of Glaucoma, the following definition is considered: if either eye has GOA, we have classified the eye under "Open angle" or "Closed angle" Glaucoma, as per the diagnosis of the other eye. Similarly, in case either eye has Secondary Glaucoma, we have classified the eye as "Open angle", "Closed angle", or "GOA" as per the diagnosis of the other eye.

Basic demographic analysis

A total of 1029 persons reported to the hospital for further evaluation and diagnosis of Glaucoma. Out of which, 45 percent were female (467) and 55 percent were male (562). Among them, 61 percent were in the age group of '41-60 years and 36 percent were in the age group 'greater than 60 years. The remaining (3 percent) belonged to the age group 'less than 40' years. Among females, 64 percent belonged to the age group '41-60 years', while among males this ratio was 58 percent.

SEX	AGE GROUP			TOTAL
	<40 years	41-60 years	>60 years	
FEMALE	19	300	148	467
MALE	12	328	222	562
TOTAL	31	628	370	1029

Table 1: Age & Sex Bifurcation of Respondents

Descriptive Analysis for Glaucoma

Out of all community level screenings conducted persons reported to the Sankara Eye Hospital for further evaluation and diagnosis of Glaucoma. From those who reported to the hospital, 752 persons (73 percent) were “diagnosed with Glaucoma”.

Among those who were identified with Glaucoma, 55 percent were males and 45 percent were females (sex distinction). Coming to the distinction based on the age categories, 59 percent were in the age group ‘41-60 years’, 38 percent were in age group ‘>60 years’, and the remaining were in the age group of ‘<40 years’. This also is true to the understanding that glaucoma is particularly common among individuals over the age of 40 years.

AGE GROUP	FREQUENCY	PERCENTAGE
<40 years	20	2.66
41-60 years	446	59.31
> 60 years	286	38.03
TOTAL	752	100

Table 2: Age Bifurcation of People Diagnosed with Glaucoma (PWG)

The next table looks at the visual impairment levels among those who have been diagnosed with glaucoma. The Phase-1 data showcases that out of the population diagnosed, 69 percent had mild distance visual impairment; 19 percent had moderate distance visual impairment, and 11 percent had severe distance visual impairment. The visual impairment level is based on the vision in the better eye and has been considered as per the WHO standard classification. “People diagnosed with Glaucoma” had at least a mild visual impairment in both eyes, categorisation is based on the better eye's visual acuity¹. acuity². “People diagnosed Glaucoma” had at least a mild visual impairment in both eyes, considering that the categorisation is based on the better eye's visual acuity³.

¹ measure of the ability of the eye to distinguish shapes and the details of objects at a given distance (Community Eye Health Journal)

VISUAL IMPAIRMENT LEVELS	FREQUENCY	PERCENTAGE
Severe (<3/60)	86	11.44
Moderate (<6/18 – 6/60)	144	19.15
Mild (>6/18)	522	69.41
TOTAL	752	100

Table 3: Visual Impairment among PWGs

Comparative Analysis for Glaucoma

Among those in the age group above 60 years who were suspected of having glaucoma, 77 percent were found to be having Glaucoma. Of those in the age group between 41 to 60 years, 71 percent were found to be having Glaucoma, and in the age group more than 40 years', it was the lowest at 65 percent.

While for those who reported for examination, there was a higher proportion of people in the age group '>60 yrs.' of having diagnosed with glaucoma, this pattern was not statistically significant. $p = 0.053$

AGE GROUP	GLAUCOMA		TOTAL
	NO	YES	
<40 years	11	20	31 (3.01%)
41-60 years	182	446	628 (61.03%)
>60 years	84	286	370 (25.96%)
TOTAL	277	752	1029

Table 4: Age Bifurcation of PWG

Among Females, 72 percent were found to have Glaucoma, while among Males, 74 percent were found with Glaucoma.

Similar to the relationship with age, while there was a seemingly higher prevalence of glaucoma among the male population than the female, this pattern was also not found to be statistically significant ($p= 0.545$)

SEX	GLAUCOMA		TOTAL
	NO	YES	
FEMALE	130	337	467
MALE	147	415	562
TOTAL	277	752	1029

Table 5: Sex Bifurcation of PWG

Note: The statistical significance was tested using Chi-Square tests.

Table number 6 presents the data for prevalence of glaucoma divided across levels of visual impairment.

Among those who had 'blind' distance visual impairment, 82 percent were found to be having Glaucoma. Of those who were having 'moderate to severe' distance visual impairment, 71 percent were found to be having Glaucoma, while for those with 'mild' distance visual impairment, it was 72 percent.

VISUAL IMPAIRMENT LEVEL	GLAUCOMA		TOTAL
	NO	YES	
Blind (<3/60)	19	86	105
Moderate to Severe (<6/18 - 6/60)	59	144	203
Mild (>6/18)	199	522	721

Table 6: Prevalence of Glaucoma divided across levels of visual impairment.

The visual impairment levels were found to be the highest in the blind category, and lowest among those who were in the mild category, however there was no statistically significant relationship. ($p = 0.091$).

Among those who had IOP (intraocular pressure) >30 mm Hg, 83 percent were found to be having Glaucoma. Of those who were had the IOP in the range of 22-30 mm Hg, 73 percent were found with Glaucoma, and finally, for those with the IOP in the range of 16-21 mm Hg, it was 72 percent. For analysis, the IOP in the eye that has (the depicted type of) Glaucoma has been utilised. Please note that there was one individual whose IOP was not recorded for either eye during the screening process, hence the total is 1028 (in the table given below). It was found that there is a statistically significant relationship between glaucoma diagnosis and IOP ($p = 0.048$).

IOP	GLAUCOMA		TOTAL
	NO	YES	
16-21 mm Hg	202	513	715
22-30 mm Hg	55	147	202
>30 mm Hg	19	92	111
TOTAL	276	752	1028

Table 7: Prevalence of Glaucoma divided across levels of IOP

Table 8 looks at division across levels of CDR (cup-disc ratio). Among those with the CDR > 0.7, 88 percent were identified with Glaucoma. Of those whose CDR is in the range of 0.6-0.7, 75 percent were found to be having Glaucoma, and for the last category, CDR <0.6, 61 percent were found with Glaucoma. (For analysis of the Glaucoma patients, we have taken the CDR of the eye that has Glaucoma.) Results from tests indicate that there is a statistically significant relationship between the 'Glaucoma detection' and 'CDR' (chi-square with two degrees of freedom = 79.5505, $p = 0.000$).

CDR	GLAUCOMA		TOTAL
	NO	YES	
>0.7	47	347	394
06.-0.7	30	92	122
<0.6	161	247	408
TOTAL	238	752	924

Table 8: Prevalence of Glaucoma divided across range of CDR

Descriptive Analysis based on the eye.

When classified based on both eyes, 67 percent of people were found to be having glaucoma. Of those who had glaucoma, 56 percent were identified with Open Angle Glaucoma, 35 percent with Closed Angle Glaucoma, 6 percent with GOA, 3 percent were found to be having Secondary Glaucoma, and the remaining 0.2 percent had Known Glaucoma. Thus, we notice a significantly higher prevalence of Open Angle Glaucoma closely followed by Closed Angle among the population, in Ganjam.

TYPE OF GLAUCOMA	FREQUENCY	PERCENTAGE
Closed Angle	481	34.86percent
GOA	82	5.94percent
Known Glaucoma	3	0.22percent
Open Angle	773	56.01percent
Secondary Glaucoma	41	2.97 percent

Table 9: Description of Types of Glaucoma (eye)

When the visual impairment levels were mapped over the type of glaucoma, it was found that more than half of the individuals who had open angle glaucoma had a mild defect, followed by 24 percent with moderate distance visual impairment and 128 persons with severe visual impairment. With Closed Angle Glaucoma, 63 percent were found in the range of mild distance visual impairment, 19 percent fell in the category of severe distance visual impairment and the remaining 18 percent were found to have moderate distance visual impairment.

The significant numbers for GOA and secondary glaucoma, with respect to severe visual impairment, remained at 89 percent and 51 percent, respectively.

TYPE OF GLAUCOMA	VISUAL IMPAIRMENT LEVELS			TOTAL
	SEVERE	MODERATE	MILD	
Closed Angle	91	89	301	481
GOA	73	1	8	82
Known Glaucoma	2	1	0	3
Open Angle	128	186	459	773
Secondary Glaucoma	21	12	8	41
TOTAL	315	289	776	1380

Table 10: Types of Glaucoma with visual impairment level

The descriptive analysis was also done for the intraocular eye pressure in PWG. 68 percent eyes were found with the IOP in the range of 16-21 mm Hg, 21 percent with the IOP in the range of 22-30 mm Hg, and 11 percent with IOP greater than 30 mm Hg. Among eyes detected with Open Angle Glaucoma, 70 percent have an IOP in the range of 16-21 mm Hg, followed by 20 percent with IOP in the range of 22-30 mm Hg. The remaining 10 percent of the eyes that had open angle Glaucoma had the IOP more than 30 mm Hg.

For the eyes detected with Closed Angle Glaucoma, 66 percent have an IOP in the range of 16-21 mm Hg, followed by 23 percent with IOP in the range of 22-30 mm Hg, and 11 percent with an IOP of more than 30 mm Hg.

For GOA, 57 percent individuals have an IOP in the range of 16-21 mm Hg, followed by 26 percent with an IOP of more than 30 mm Hg.

Among eyes detected with Secondary Glaucoma, 76 percent have an IOP in the range of 16-21 mm Hg, followed by 17 percent with IOP in the range of 22-30 mm Hg.

TYPE OF GLAUCOMA	INTRAOCULAR PRESSURE TEST			TOTAL
	16-21 mm Hg	22-30 mm Hg	>30 mm Hg	
Closed Angle	315	110	55	481
GOA	47	14	21	82
Known Glaucoma	3	0	0	3
Open Angle	546	153	74	773
Secondary Glaucoma	31	7	3	41
TOTAL	942	284	153	1380

Table 11: Types of Glaucoma with IOP

The cup-disc ratio (CDR) for the glaucoma eyes was also divided to understand the distribution among the respondents.

Among eyes detected with Glaucoma, 49 percent were found with a CDR more than 0.7, 37 percent with CDR less than 0.6, and 13 percent with CDR in the range of 0.6 – 0.7.

Among eyes detected with Open Angle Glaucoma, 55 percent were found to be having a CDR more than 0.7, followed by 28 percent with a CDR less than 0.6, and 17 percent of eyes had a CDR in the range of 0.6 – 0.7.

For the eyes detected with Closed Angle Glaucoma, 54 percent were found to be having CDR less than 0.6, followed by 36 percent with CDR more than 0.7. 10 percent of eyes were having CDR in the range of 0.6 – 0.7. Among eyes detected with GOA Glaucoma, 84 percent were found to be having CDR more than 0.7.

Among the eyes detected with Secondary Glaucoma, 82 percent have CDR less than 0.6, and 18 percent have a CDR greater than 0.7.

TYPE OF GLAUCOMA	CUP-DISC RATIO			TOTAL
	>0.7	0.6-0.7	<0.6	
Closed Angle	142	39	211	392
GOA	53	0	10	63
Known Glaucoma	3	0	0	3
Open Angle	402	126	206	734
Secondary Glaucoma	7	0	31	38
TOTAL	607	165	458	1230

Table 12: Types of Glaucoma with CDR

Descriptive Analysis based on the individual.

The respondents were also analysed with the individual diagnosed with Glaucoma as a unit, and for this, the diagnosis of the worse eye (if either eye has glaucoma) was considered. Out of the total of 1029 persons who reported to the hospital for further evaluation and diagnosis of glaucoma, 73 percent of individuals were identified with glaucoma.

Of this population, further classification was done into Open Angle Glaucoma, Closed Angle Glaucoma, GOA, Secondary Glaucoma, and Known Glaucoma. For analysis, in case either eye has GOA, it has been classified as Open angle or Closed Angle as per the diagnosis of the other eye. Similarly, in case either eye has secondary glaucoma, it has been classified as Open/Closed/GOA as per the diagnosis in the other eye.

TYPE OF GLAUCOMA	FREQUENCY	PERCENT
Closed Angle	254	33.78
GOA	42	5.59
Known Glaucoma	2	0.27
Open Angle	432	57.45
Secondary Glaucoma	22	2.93
TOTAL	752	100

Table 13: Distribution of Types of Glaucoma (Persons)

Table 14 identifies different types of glaucoma and scatters it across the 3 sets of age groups that have been selected for the project.

Among people detected with Open Angle Glaucoma, 59 percent were from the age group '41-60 years', 39 percent were 'greater than 60 years', and 2 percent were '<40 years'.

For Closed Angle Glaucoma, 67 percent of people were '41-60 years', 30 percent were older than 60 years, and only 3 percent were younger than 40 years.

Of those with GOA, 60 percent were '>60 years' while the remaining 40 percent were between the ages of 41 and 60 years. 82 percent of people from the category of secondary glaucoma were from the age group '>60 years', and 18 percent were from '41-60 years'.

TYPE OF GLAUCOMA	AGE (YEARS)			TOTAL
	<40 years	41-60 years	>60 years	
Closed Angle	8	171	75	254
GOA	0	17	25	42
Known Glaucoma	1	1	0	2
Open Angle	11	253	168	432
Secondary Glaucoma	0	4	18	22
TOTAL	20	446	286	752

Table 14: Types of Glaucoma across age groups

The people with glaucoma were also divided based on their sex to understand whether glaucoma has any predisposition based on physical characteristics. It is showcased that men (63 percent) were more likely to get open-angle glaucoma (the commonest form). Among women, the chances of having open-angle glaucoma were exactly half the overall probability of having glaucoma at all. Also, they were found to be more susceptible (40 percent) to developing closed-angle glaucoma than men (28 percent). On the other hand, men were found to be more susceptible to open angle glaucoma than the women.

TYPE OF GLAUCOMA	SEX		TOTAL
	Female	Male	
Closed Angle	136	118	254
GOA	24	18	42
Known Glaucoma	0	2	2
Open Angle	169	263	432
Secondary Glaucoma	8	14	22
TOTAL	337	415	752

Table 15: Types of Glaucoma across sex

The next division was done based on visual impairment. For analysis, if a person was diagnosed with mild impairment in one eye and moderate/severe impairment in another eye, the final categorisation was mild impairment, and if a person was diagnosed with moderate impairment in one eye and severe impairment in another eye, it is classified as moderate impairment.

While severe impairment only surpassed mild impairment in the case of GOA, the number of moderate visual impairments remained more than half of the "mild" cases in both GOA and Secondary Glaucoma. Mild visual impairment is found to be particularly high among individuals with open angle glaucoma.

TYPE OF GLAUCOMA	VISUAL IMPAIRMENT LEVELS			TOTAL
	Severe	Moderate	Mild	
Closed Angle	22	42	190	254
GOA	26	6	11	42
Known Glaucoma	1	1	0	2
Open Angle	33	88	311	432
Secondary Glaucoma	5	7	10	22
TOTAL	86	144	522	752

Table 16: Glaucoma with different levels of visual impairment

The group of people were also understood based on their intraocular pressure test. Low IOP (16-21 MM Hg) was common with more than half the number of individuals under any kind of Glaucoma. This is considered to be normal IOP, and thus the damage to vision is minimal in the majority of the population. Only those affected with GOA were more likely to have severe IOP levels (>30 mm Hg) than moderate (22-30 mm Hg). 92 persons were found to have >30 mm HG which is higher than normal, with open angle glaucoma having a higher record.

TYPE OF GLAUCOMA	INTRAOCULAR PRESSURE TEST			TOTAL
	16-21 mm Hg	22-30 mm Hg	>30 mm Hg	
Closed Angle	162	56	36	254
GOA	24	6	12	42
Known Glaucoma	2	0	0	2
Open Angle	309	81	42	432
Secondary Glaucoma	16	4	2	22
TOTAL	513	147	92	752

Table 17: Glaucoma with different levels of IOP (people)

The next table presents the division of the glaucoma on the basis of cup-disc-ratio. While the CDR is found to more likely to be less than 0.6 in the cases of closed angle and secondary Glaucoma. In GOA individuals were (more than) thrice as likely to have their CDR more than 0.7.

TYPE OF GLAUCOMA	CUP-DISC RATIO (CDR)			TOTAL
	>0.7	0.6-0.7	<0.6	
Closed Angle	79	24	111	214
GOA	25	0	7	32
Known Glaucoma	2	0	0	2
Open Angle	237	68	112	417
Secondary Glaucoma	4	0	17	21
TOTAL	347	92	247	686

Table 18: Types of Glaucoma with CDR (person)

Treatment Advised (based on the eye)

Among eyes detected with Glaucoma, all were advised some kind of treatment. These included glaucoma surgery, Laser Peripheral Iridotomy (LPI), medical management and others.

A majority (55 percent) were advised medical management (eye drops), followed by Laser PI (23 percent), others (15 percent), and glaucoma surgery (including combined surgery) (7 percent). This was then further divided to understand the medication style between the different types of glaucoma - Open Angle, Closed Angle, GOA, Known, and Secondary glaucoma.

Type of Glaucoma	TREATMENT ADVISED				Total
	Glaucoma surgery	Laser PI	Medical management	Others	
Closed Angle	12	314	94	61	481
GOA	2	1	58	21	82
Known Glaucoma	0	0	0	3	3
Open Angle	83	6	595	89	773
Secondary Glaucoma	2	1	7	31	41
Total	99	322	754	205	1380

Table 19: Treatment Advised for different types of Glaucoma.

While all kinds of Glaucoma, except closed angle, relied on medical management as the prominent course of treatment advised, treatment adherence was not common, and most people did not follow the treatment that was suggested to them. This factor of treatment adherence has been analysed throughout the series of four follow-ups that happened during different phases of the Keep Sight project.

It was found that almost half (45percent) of the population did not follow the treatment that was advised by the medical professional. The heavy cost of not taking the treatment involves blindness and vision loss, which makes this a severe category to be prioritised for further intervention. The adherence also seems to depend on the type of treatment advised.

In the case of treatment advised as others or medical management (eye drops), the follow-up was relatively higher (89 percent for others and 70 percent for medical management).

While in the case of treatment advised as Glaucoma surgery or Laser PI, the adherence was very low (5 percent for Glaucoma surgery and 15 percent for Laser PI).

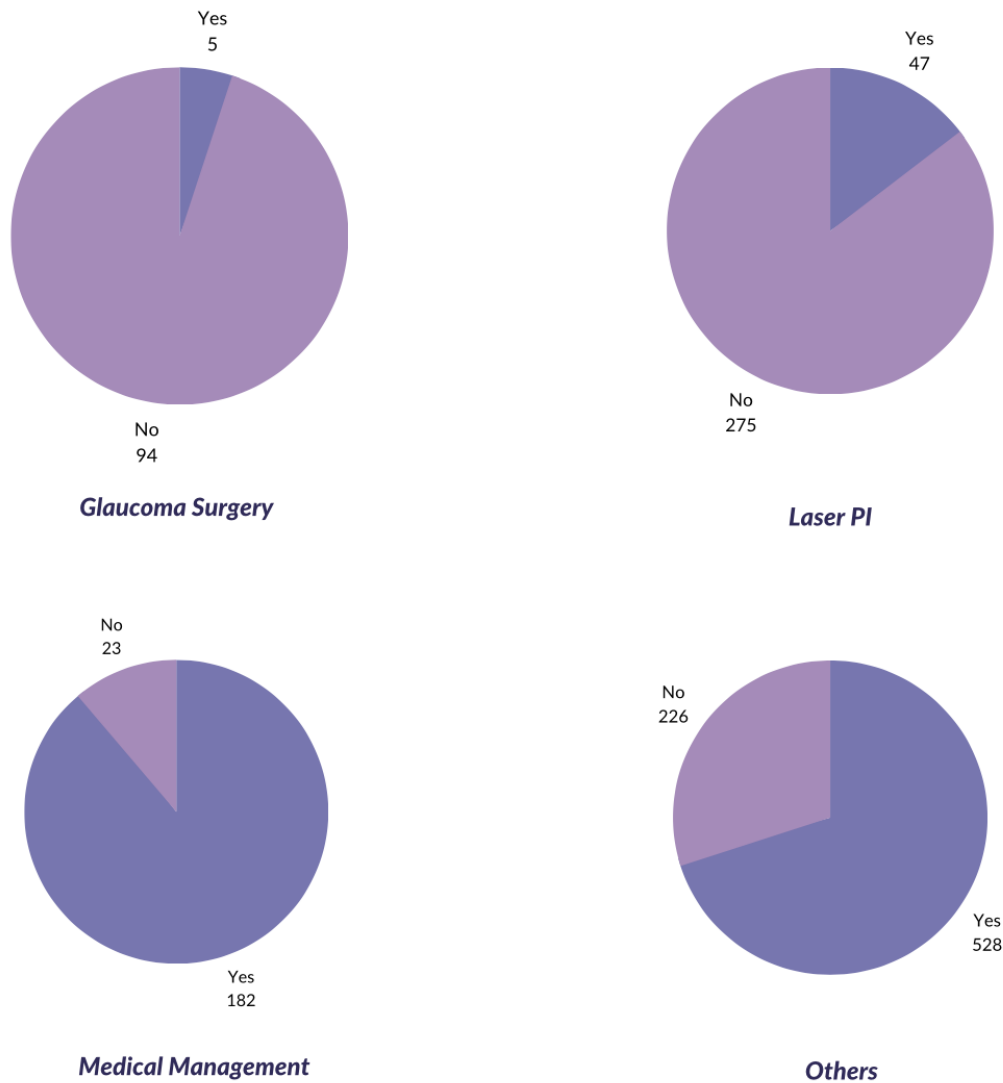


Figure 4: Treatment taken, as advised by the hospital (clockwise, from the top left): Glaucoma surgery, Laser PI, Medical management, and others on the basis of eye

Among eyes detected with Glaucoma with severe distance visual impairment level, 37 percent were not taking treatment as per advised treatment. For Glaucoma eyes detected with moderate distance visual impairment level or mild distance visual impairment level, 47 percent were not adhering to the advised treatment.

Treatment Advised (based on the individual)

The data was looked at from PWG as the unit of analysis. Of those who were detected with glaucoma, all were advised some kind of treatment to ensure visual preservation. 54 percent were prescribed medical management (eye drops), followed by Laser PI (22 percent), others (15 percent), and Glaucoma surgery (8 percent). This was then divided

into different categories of glaucoma to see the uptake of treatment as per the kind of glaucoma.

Most of the prescription for medical management was given to those diagnosed with open angle glaucoma, followed closely by those with GOA. Those with Closed Angle Glaucoma were majorly advised the Laser PI surgery, & those with secondary glaucoma, a majority were advised for 'other'.

Among persons detected with Glaucoma, a huge proportion (44 percent) did not take the advised treatment. In the case of treatment advised as others or medical management, the treatment taken proportion was relatively higher (90 percent & 72 percent respectively). While in the case of treatment advised as Glaucoma surgery or Laser PI, the proportion of those who had taken treatment was very low (3 percent & 14 percent, respectively). This analysis corresponds to the descriptive analysis of treatment adherence done on the basis of eyes. This indicates that the number of eyes affected with Glaucoma had little to do with altering the individual behaviour, i.e., if a person was diagnosed with Glaucoma in one eye, it is likely that they would adhere (or not) to the treatment with similar attitudes, as they would in case both eyes were affected.

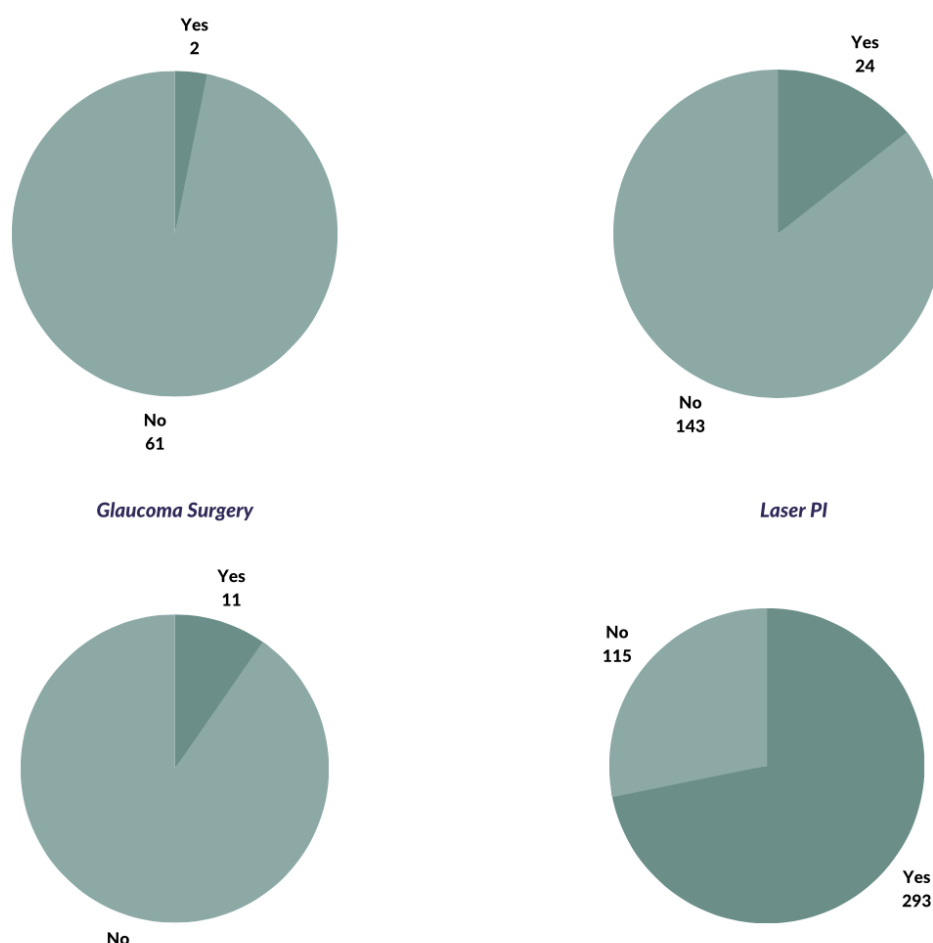


Figure 5: Treatment taken, as advised by the hospital (clockwise, from the top left): Glaucoma surgery, Laser PI, Medical management, and others at the individual level

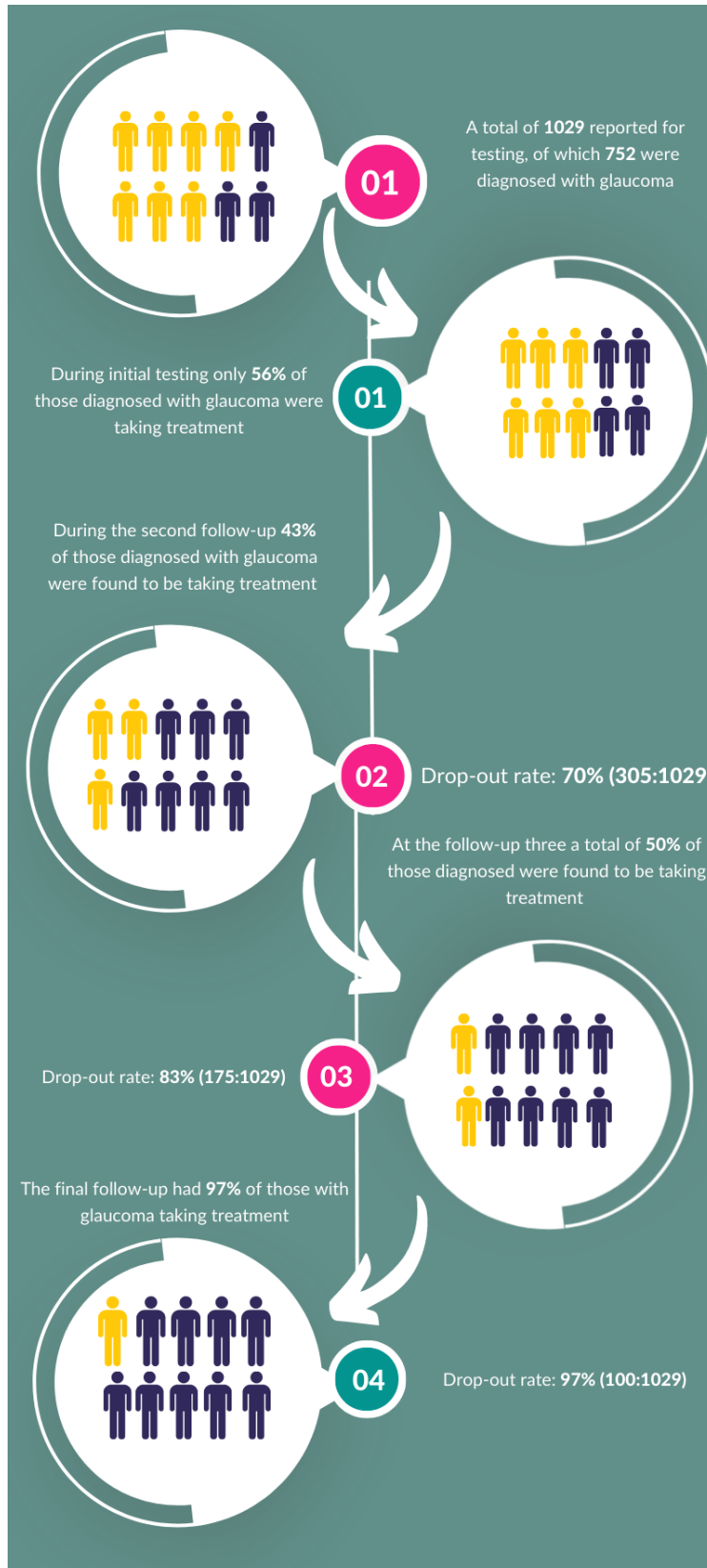


Figure 6: Trajectory of PWG

The total number of people who reported to the hospital for diagnosis was 1029. Out of this, 752 were diagnosed with glaucoma but only 422 were taking the medicine.

This number consistently dropped at every follow-up visit with the total number showing up for the fourth and final follow-up being only 100, a drop of about 97 percent - which is a concerning factor considering the seriousness of the disease.

While the number of people reporting consistently dropped, those diagnosed with glaucoma found to be taking treatment increased at every follow up visit, with only 56 percent of those initially reporting to the hospital taking treatment.

This number grew to about 97 percent during the final follow-up with 81 of the 83 diagnosed with glaucoma taking treatment.

Design of the Research

The next step was to do a preliminary analysis of Phase I's data of the Keep Sight project, obtained from 4 successive screenings in different blocks of the Ganjam district done by Sightsavers India.

The fieldwork entailed the collection of data for three different groups of stakeholders:

- Ophthalmologists, Vision Technicians, and Counsellors - Psychologist and Camp
- The general population that has not been tested yet for glaucoma.
- The people who have been diagnosed with glaucoma.

The data helped us in recognizing the multiple perceptions of Glaucoma in society—awareness, stigma(s), the economic and psycho-social burden on the patients, and the existing state of infrastructure for diagnostics, care, and treatment.

The methods used for data collection were primarily FGDs and IDIs.

- **IDIs (Annexure 1)** were conducted in the form of face-to-face discussions to provide a detailed picture of the willingness of the counsellors and hospital staff to screen people for glaucoma. IDIs conducted with the PWGs focused on understanding their experiences, attitudes, what compelled them to get tested, and treatment adherence. It aimed to understand the motivations and factors (economic, social, cultural) that might affect access to healthcare.
- **FGDs (Annexure 2)** worked to identify the beliefs and opinions of a selected group of 'at-risk' participants on specific areas related to the project. The focus was to understand the participants' views, motivators, and barriers related to healthcare. The FGD was an open discussion with regulated questions to provide a pace and theme for the group.

3 separate sets of questions were developed for the select targeted groups and finalized in close consultation with the Sightsavers India team. These tools were left open-ended

to ensure maximum understanding from the target audiences and to develop insights towards understanding behaviour change communication. Before administering the qualitative assessment, a consent form was distributed and explained to the participants to ensure that an informed discussion takes place. Given that the target population preferred Oriya (the local language), the consent forms and the testing tools were translated for ease of communication.

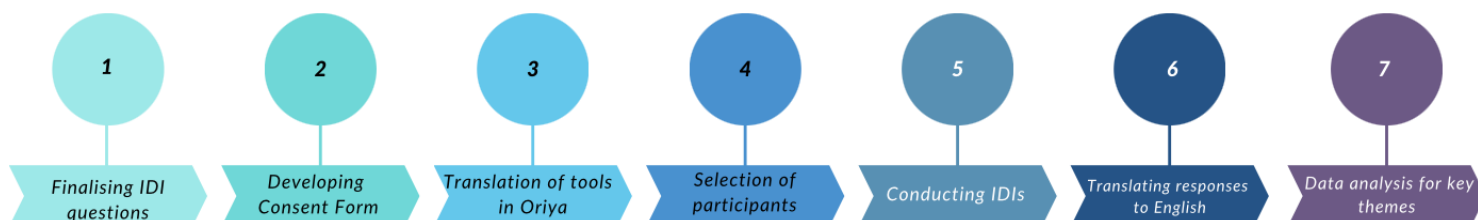


Figure 7: IDI Methodology

The data collection was conducted with the support of a language expert and utilising a voice recording device that was referred to later for transcription and analysis. The translations were done by a professional translator and transcribed for storage purposes. All data collection tools were reviewed by the Sightsavers India team in New Delhi.

The FGDs were conducted in two settings - the hospital with populations visiting for issues like headache, redness in the eye and in a village nearby. The participants were selected on the basis of availability. Post consent form discussion, the FGD was conducted and analysed in a manner similar to the IDIs.

Field Study Sample and Distribution

The formative data collection exercise was conducted with three stakeholders - eye care service providers, people diagnosed with glaucoma, and general population at risk of glaucoma.

To select the sample of each group, a different methodology was adopted.

- The list of interviewees from the first group (counsellors, doctors, and hospital staff) was provided by Sightsavers India through the network of eye care centres and hospitals run on the field.
- The sample for the general population--at risk--was the group of people visiting the eye centre. The research was conducted before the OPD to ensure that the data does not get diluted. One FGD was conducted in a village setting, away from any healthcare centre, to understand the differences in perceptions between those visiting the hospital and those who do not.
- The PWG list was identified through the method of purposive, stratified sampling. For this, the data on people above 40 who were diagnosed with Glaucoma (by Sightsavers India) was bifurcated based on sex—male and female,

to ensure representation and understanding of the gendered perspective of the illness. The two sub-groups were then divided further based on geography.

The identified group was random to select a sample of nearly 20 respondents who were then interviewed in person. Accounting for the logistical barriers, a buffer of 30percent will be used for the sample, generating an initial roll of 26 prospective participants.

To ensure a targeted population is utilised for the purpose of the research, an inclusion and exclusion criteria was designed in close consultation with Sightsavers India team.

For Inclusion

- **Doctors and hospital staff** - Only those who were familiar with the glaucoma screening and treatment practices for more than 6 months were considered for the interviews; and those part of the Keep Sight project.
- **People diagnosed with glaucoma** – Since the incidence of Glaucoma is higher in people above the age of 40 years, the interviews for this group were done only with those who match the age criterion.
- **General population at risk of glaucoma** – The same principle as in the case of “those identified with Glaucoma” was followed here.

For Exclusion

- **Doctors and hospital staff** – Those not acquainted with glaucoma care and management for more than 6 months were kept out of the study. Those who were not involved with the Keep Sight project were also not made a part of the study.
- **People diagnosed with glaucoma**– In cases where the patients have both Glaucoma and cataract(s), they were categorized as cataract patients and not glaucoma patients. This is because cataract has progressive vision loss and improved treatment adherence.
- **General population at risk of glaucoma** – The exclusion of the general population was done based on their location -- due to the time constraints in conducting the study on the field making geographical proximity a desirable factor -- apart from the age criterion mentioned above (40 years).

Based on the above criterion, there were 10 IDIs conducted with eye care service providers within the Sankara Eye Hospital, and 18 with persons diagnosed with glaucoma.

There were 3 FGDs conducted with the general population at risk. One was conducted within the population visiting Sankara Eye Hospital for various kinds of eye examinations, and the other two were conducted in local spaces around the Aska village.

VENUE	RESPONDENT PROFILE	TOOL UTILISED	NO. OF RESPONDENTS
SANKARA EYE HOSPITAL	Eye Care Service Providers	In-depth Interviews	10
	Adults over 40 (at-risk population)	Focus-Group Discussion	2 groups (8-10 participants each)
VARIOUS LOCATIONS (ASKA VILLAGE)	Persons diagnosed with glaucoma	In-depth Interviews	9
SANKARA VISION CARE CENTRE	Persons diagnosed with glaucoma	In-depth Interviews	9
ASKA VILLAGE	Adults over 40 (at-risk population)	Focus-Group Discussion	1 group (10-12 participants)

Table 20: Primary Research Respondents

Target Group

There were three target groups selected for the project:

(i) Adults at risk of Glaucoma aged 40 years and above: The data collected from this group aims to reveal the on-ground realities of the awareness of glaucoma, what informs their health-seeking behaviour. This enabled knowing the behaviours, current level of knowledge, beliefs, and attitudes, the channels through which they receive and act on information, and the barriers to adopting new health behaviours related to eye care. It also guided in understanding the structural obstacles and catalysts for the general population to visit a screening site, even when any symptoms are absent.

(ii) Adults diagnosed with Glaucoma: The sample of this group comes directly from the data collected by Sightsavers India, it was used to observe how these individuals recognise their illness and the risks related to it. In addition, their response to the treatment and what they perceive as the benefits of it were also recorded through the interviews. One of the key challenges with Glaucoma is the non-compliance with the recommended treatment course, insights on this element were derived from the data.

(iii) Eye care service providers: Ophthalmologists, Optometrists, and Counsellors: This group provided information on how important the experts think the outreach activities and camps related to Glaucoma are, and also on how the diagnosis of Glaucoma is processed by the patient while highlighting their role in it. These interviews were also contextualized to answer questions related to treatment and compliance effectively and the factors affecting the same.

Research Ethics

The data collection process prioritized ethics in all forms of research and had strict compliance policies laid out for the same.

For this project, the teams visiting the field obtained written informed consent forms from all participants, which contained exhaustive information on the objectives of the study, the confidentiality clauses, the post-research benefits, and the agreement of voluntary participation. Each of these consent forms was also co-signed by the corresponding researcher. In cases where the participant could not read, the consent form was explained to them in detail by the language expert accompanying the researcher. The consent forms were made in English and were also translated into Oriya (the local language) to ensure there were no linguistic barriers hindering understanding of the research.

The data collected during the exercise is protected from any misuse by all parties that will have access to it thereafter. All personal information related to the project will be deleted by post 1 year of the closing date of the report release.

The researchers also ensured that a brief is given to the participants post the interaction and a guide towards how they will be benefitted from the project to ensure post-research benefits. The post-research benefit of this research for the at-risk population process included providing information regarding glaucoma and discussions on the need for getting diagnosed and tested for glaucoma, along with contact details for referrals to visit the Sankara Eye Hospital.

The ethics of confidentiality were also adhered to, and in case any individual felt uncomfortable sharing their name or any other identity markers, these were left from the research. The final document does not name any research participant to avoid detection.

Considering glaucoma is a visibility hindering condition, a few interviews - especially ones with individuals with poor visibility - were conducted at their/in the vicinity of their homes to avoid any physical difficulties one might face in visiting a location only for an interview as well as to avoid any unnecessary financial costs the travel would incur.

Findings

Profile of the Respondents

Among the 10 medical staff members who were interviewed, there were two ophthalmologists, one counsellor, one data entry operator, two camp coordinators, and four vision technicians/optometrists, all working at/with Sankara for more than 6 months.

Out of the 18 PWGs interviewed, the responses were bifurcated based on age and sex. The categories were divided into age groups of 40-49 years, 50-59 years, and 60+ individuals between the men and the women.

While conducting the formative analysis, there were 3 cases where the participants had both cataract and glaucoma (which was realised during the process of the interview), considering the exclusion criteria, these responses were removed from the final analysis. This is considering that cataract, unlike glaucoma, is a disease that people are more aware of and spreads quickly disrupting vision and it has thus been associated with improved health-seeking behaviour among populations across various economic and social backgrounds.

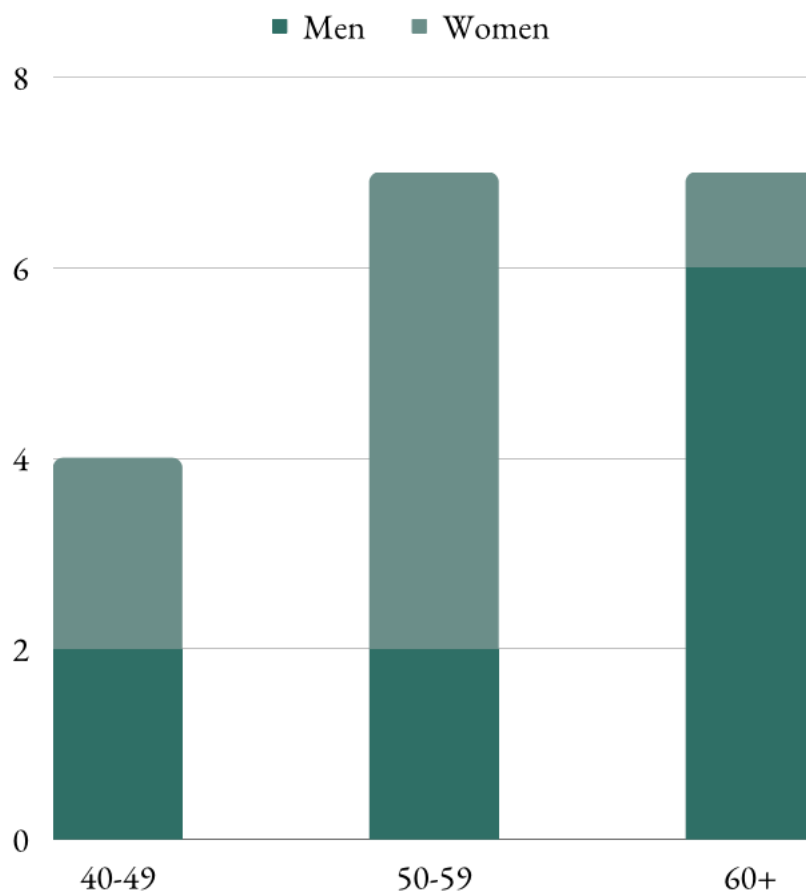


Figure 8: Age & Sex Bifurcation of PWGs

The next division of the respondents was done based on their educational qualifications from a range of never been to school to post-school education. Many of the respondents found it difficult to write beyond their names.

Out of the 18 PWGs, there was a majority that had never attended school. There were 2 respondents who had studied beyond school and also went on to become teachers at the local government school.

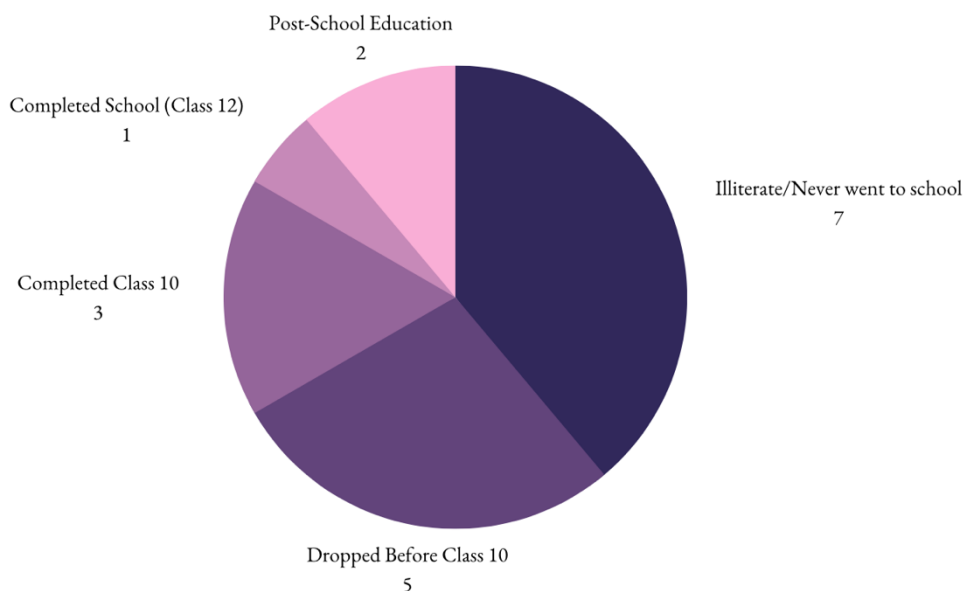


Figure 9: Educational Qualification of all respondents

The third bifurcation was done on the basis of the occupation of the respondents. Most women respondents were homemakers, and some respondents engaged in a series of blue-collar jobs (farming, working out of stores). 2 respondents were aged and unemployed – and while one of them was accessing government schemes for affordable healthcare services, the other had little to no knowledge about the same.

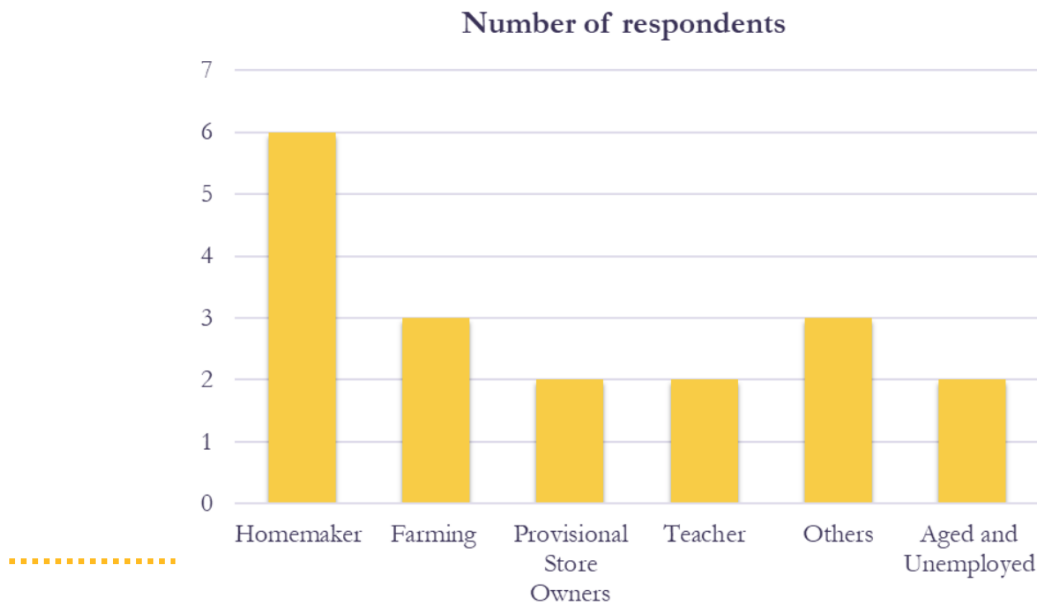


Figure 10: Occupational Profile of all respondents

The Proposed Interventions: Addressing the Objectives

To suggest the actual capabilities, opportunities and motivations alongside the identified barriers, the research found a few critical themes that address the objectives suggested at the outset. While these barriers and enablers are reproduced generically, they may not apply to all participants equally.

Objective 1: To understand the norms and practices of the people in the project area in order to create a change that will have a positive impact on the behaviours of the people.

To understand the norms and practices of the people in Ganjam district, the research aimed to understand the enablers and barriers towards glaucoma services uptake and, in general, the health-seeking behaviour. For this purpose, the COM-B model was utilised to understand the gaps and potential bridges in the current structure of Glaucoma care in Ganjam.

When a doctor prescribes medication, the placebo effect induces compliance but also a torpid outlook toward the illness, especially in the case of glaucoma where, conversely, the loss of sight is not very prominent. This may cause glaucoma patients to drop medication after the first (few) sets of drops are used. This exhibits that the patients would largely follow the course of treatment when physical discomfort is felt. The patients who followed through on the medications reiterated constantly that these should suffice, and they did not feel the immediacy to comply till their vision was affected drastically. This could also be because the patients have an irrevocable trust in the medical expertise that the ophthalmologists personified. Even when other eye service providers, placed below the ophthalmologist in the hierarchy, suggested anything, they were not as convinced to follow the advice.

Since all the PWGs were aware of the chronicity of glaucoma, they accepted that there was not much that they could do about it. At least 5 PWGs interviewed for the study expressed that the disease was a result of their “buri kismet” (bad luck) and that it must be some misdeed they did in this or another life that God punished them for. This follows the concept of the Karmic cycle where pain and illness are begotten when one causes harm to a fellow living being. This also re-affirms the truism that people often try to navigate the plains of knowledge -- even in the so-called rational spheres of science and medicine – through more relatable beliefs and idiosyncrasies. What this means is that where they lack scientific explanation, they often look towards religion and spirituality, which are far more pronounced in their everyday lives.



"..Yes, there is mental distress but I have no one to blame but my own *huri kismet* (misfortune) for being diagnosed with this illness."

"I have become completely dependent on others for even the most basic things. I cannot leave the house without assistance. I am helpless and even need my family members for the most basic things...I think my bad luck caught on"

Figure 11: Excerpt from IDI on blaming luck for illness

Enablers and Barriers for uptake of services

Enablers for uptake of screening

Opportunities for conversation via outreach effort-:

- Sankara Eye Hospital with Sightsavers India conducts outreach activities in the nearby villages which helps people get a basic understanding of the availability of facilities. These activities included conducting weekly camps for free glaucoma screening referrals, making announcements in the panchayat, using promotional vehicles for awareness, and distributing pamphlets. These helped encourage people to test themselves at the Sankara Eye Hospital.
- Most of the respondents were encouraged to attend camps and hospital from their friends, neighbours, and family members to get their eyes tested when they discussed their challenges with them.
- The at-risk population was aware of the camps that were organized in the village settings, however, not all were inclined to get their eyes tested regularly and did not understand what glaucoma is, while they were aware of cataracts.

Positive experience and relatively affordable care at the camps and hospital-

The respondents viewed Sankara Eye Hospital as the primary site for accessing care related to eye health, as it was affordable (than private care) and had state-of-the-art facilities. The PWGs appreciated the hospital staff and felt it was a welcoming space. If they could not visit the hospital, they felt they had access to the vision centres, located much closer to them, which were well-equipped for preliminary testing. Since getting

tested and consulting the doctor is free upon being enrolled in the Keep Sight project, it acted as the most permanent, long-lasting catalyst for accessing healthcare at Sankara.

Barriers to uptake of screening

Low awareness – Almost all, except 2, participants interviewed were unaware of what 'glaucoma' means, including those who had glaucoma for more than a year. In fact, for many, the data collection process was the first time they heard about the term. Most of the patients mistook glaucoma to be cataracts ('motiyabindu') and believed their defect to follow the same trajectory. This is probably due to the prominence of cataracts in the world of ocular illnesses, and hence its predominance in the colloquial understanding of eye-related challenges.

The uptake of Glaucoma-related services based on the outreach activities undertaken by the Sankara is disproportionately small. While suspect cases are referred from the vision centres and the weekly camps, logistical gaps need to be bridged for the confirmed diagnosis and treatment to begin at the tertiary centres. The Glaucoma patients seldom approached the camps, even when they were offering free services: this was a consequence of either the lack of awareness borne by them as a function of their socio-political identity or their lackadaisical attitudes towards the illness, which is partly owed to its inherent stagnant pace of advancement.

The identification of Glaucoma in an individual is largely accidental and often happens when they report an allied symptom in the eye, like headache or redness of the eye.



"Yes.. know what cataract is. Never heard about glaucoma.

"..never visited an ophthalmologist as a part of routine healthcare.."

"...Often do not go to eye health camps because never felt the need to. Don't understand it (glaucoma) and there is no concern with something that is unknown"

Figure 12: Excerpt from FGD on low awareness

The service providers mentioned that the outpatients, most people who knew what glaucoma is or had even heard of the disease, were mostly either from a service background or had completed graduation. The others had never heard of the disease.

Lack of somatic consciousness about the disease- The awareness of glaucoma was rarely explained by its effect and symptoms, where most patients could not identify their peripheral vision depleting until their tunnel vision was impacted. This characteristic of glaucoma makes it a 'silent thief of sight'. The PWGs only understood that they were required to take the medicine daily, the reasons and impact for the same were not thoroughly explained to them. Since the auxiliary symptoms of glaucoma are associated commonly with refractive errors, most the individuals did not take it seriously. The lack



"My children don't have glaucoma and I have not done their eye tests yet. They can see just fine and they have not complained about anything. Now if they do not have an issue, why would I take them to a doctor to get them tested."

"My children have not gotten their eyes tested for glaucoma. Why would they need to? they have never complained about any issue related to their eye - be it headache, or redness. I won't take them to the doctor unnecessarily. Their eyes are fine right now and they will be fine without medicines or a doctor "

Figure 13: Excerpt from IDIs on lack of somatic consciousness

of proper information from the hospital staff contributed to the patients not understanding the gravity of the illness.

The formative analysis identified that the respondents did not know that glaucoma is hereditary and could follow the line of descent to affect their children. Out of the 18 PWGs, only 2 had gotten their children tested for glaucoma, post-diagnosis, and ensured they were also provided with proper treatment and care.

Enablers for compliance to treatment/ Advice for

Supportive community-based care- Ensuring support for accessing treatment of glaucoma often requires the support of another person, especially if the disease has progressed to a significant level, be it from the family or the community. While conducting the field analysis, an interesting case was witnessed. Two elderly women (PWGs) from the neighbouring village in Aska were accompanied by a man who did not have familial relations with them but only lived near them. When asked, they mentioned that the man sometimes supported them with travel to the hospital and vision centre given that the women could not commute by themselves, and nobody in their family would travel along

with them. At least 5 respondents stated that they got to know about Sankara or the need for eye testing from a fellow member of the community.



"I have had a difficult time travelling without assistance due to my eyesight. I came to the interview with a few people from my village. I often travel with a young man from my neighborhood who accompanies me and my neighbor (who also has glaucoma) when we go out to visit the doctor, vision center or the hospital. He also accompanies us when we have to go to get medicine that we need. Due to the condition of my eyes I am dependent for most routine activities on others. I believe this has been a helpful assistance as my children do not live with me."

Figure 14: Excerpt from IDIs on community-based care model

Free surgery & consultation under Keep Sight Project- The provision of free surgeries and consultation at the Sankara Eye Hospital under the Keep Sight Project has enabled 3 PWGs to continue taking the treatment. Even if they had not had their surgeries yet, they were comforted by the fact that if surgery was required in the future, it would be free and that kept them motivated enough to continue glaucoma care.

Supportive and organised behaviour by hospital staff- The PWGs expressed their difficulties while trying to navigate the private health providers where they faced challenges like long wait periods and dissatisfactory treatment. On the other hand, the hospital staff at Sankara was viewed as polite and supportive, especially to those with visual challenges, and organised with the documentation thus the process was eased for those coming to the hospital for accessing care.

Barriers for compliance/ Advice for PWG

High cost of care- While the respondents were not averse to the idea of surgery, they had reservations regarding the same. One of the major challenges faced, mostly by individuals from poor socio-economic backgrounds was the heavy cost of surgery. Respondents also displayed hesitation on continuing treatment (use of eye drops or follow-ups), post-surgery as it was a financial cost they would have to take for the rest of their lives.

One of the respondents expressed their concern over having to pay for further glaucoma treatment even after having spent a considerable amount on the surgery, and whether government provisions could be made for the care.

While concerned about the heavy out-of-pocket expenditure, other than 3 individuals, everyone continued to take the medications to preserve their eyes. When the data from the first phase is corroborated, it was found that there was a heavy dropout rate in cases of surgery which amounted to more than 80 - 90 percent. There was also a high drop out between the 4 sets of follow-ups conducted by the Sankara Eye Hospital where the 'missing patients' either started care at another facility or stopped taking their

“

The cost of medication is very high, and I have to travel to buy the medicine which is something I cannot afford. I don't have the finances to do this for the rest of my life. And I also have to think about my own young kids who also have glaucoma. How are they going to be able to afford this expensive treatment for the rest of their lives? I am helpless. How will I tell my children that they will end up like me, unable to do the most basic of things. Everything is so expensive now.

Figure 15: Excerpt from IDIs on high cost of care

“

..A lot of people visiting the hospital are farmers - and from relatively poor economic backgrounds. When I tell them that you have glaucoma or pain in the eye - they always tell me what will we do - we don't have money to eat food many times, how will I keep buying this medicine..."

medication.

Figure 16: Excerpt from IDIs by vision technician on patient experiences of cost

No visual improvement – Despite following prolonged courses of medication and/or surgery, 5 respondents felt that there was no apparent improvement in their vision, which led to them discounting the treatment altogether. 2 respondents of the 18 continued the medication but not on a regular basis. The highest treatment adherence (70 percent individuals from Phase-1) was seen in the case of medical management which suggests that people are still willing to take up treatment that is cost effective and hassle free. For invasive treatment like glaucoma surgery (including combined surgery) and YAG PI, the drop-outs rates were as high as 95 and 85 percent respectively.

Poor family support – Family support forms a core of glaucoma care. The distance to accessing care, the financial burden, the medical dependency, and emotional instability among other debilitating factors, necessitate the family to consistently provide comfort and companionship. While 12 participants expressed that their family members (children or grandchildren), the rest mentioned difficulty in reaching the vision centre, or hospital or putting the drops and had to request the medical staff or neighbours to ask for help.

Financial difficulties in accessing surgery- While the provision of free surgeries enabled respondents to continue with their treatment, none of the participants in our field study had accessed the same. All the respondents who had undergone surgery (5-6) had paid for them out of their pockets. A few respondents (4) opted out of having their surgeries done due to a heavy out-of-pocket expenditure involved.

Distance to the hospital- The respondents also felt that the Sankara Eye Hospital is geographically inaccessible. This is especially true for the aged and women, all of whom depended on another companion, and expressed the inconvenience of regular visits for check-ups and procuring the prescribed drugs. 2 respondents highlighted that the closest they could get their medicine was the hospital itself, and since going there was not convenient, they had no option but to irregularly skip out on their doses or drop treatment altogether.

The barriers result in poor treatment adherence among the patients and also disincentivize testing for the at-risk and young-apparently healthy populations.

When noting the norms and practices, one of the hypotheses for the project was annulled. *The longevity of the treatment—a lifetime in some cases--was considered to be a barrier to continued health-seeking behaviour towards glaucoma.* However, the data collection process revealed this to be incorrect. The respondents generally accepted the treatment, especially eye drops, and felt that vision is a priority and that if they need to, they will continue investing in it for however long it takes - to protect their vision from further deterioration.

All respondents interviewed, contrary to prior understanding, considered vision and visual preservation as health priorities. They mentioned that carrying out any routine activity necessary for survival - eating, walking, or working, could not be done without a proper vision. However, an interesting thing to note was that while vision was considered to be a priority, it was only when there was physical, 'visible' discomfort that people were inclined to get screened.

None of the respondents from the at-risk population had either attended the camps or did regular eye check-ups as they mentioned that they felt fine and could continue to do their work without any hindrance. When the PWGs were asked about their motivation to get tested, almost all mentioned that they had constant headaches and difficulty continuing their daily tasks. At this point they reached out to either a member of the family, a friend or a fellow community member who suggested an eye test.



"How will I function without my eyes. Everything depends on them. I thought the surgery would solve everything, but now I have to continue medication. Still, I have to be able to see because I have to earn and feed my family. How will they survive if I don't continue to work.."

Figure 17: Excerpt from IDIs on importance of eyes

Looking at the service provider angle, the analysis identified that only 4 out of 10 providers (both the ophthalmologists, an optometrist, and a camp coordinator) were aware of the Standard Operating Procedure (SOP) under the Project, which makes the standardization of Glaucoma care more difficult, especially when the project is being implemented at such a large scale.

This angle presents the common perceptions of challenges that the persons visiting the hospital share. Respondents noted how those coming from lower socio-economic backgrounds were more worried about their rozi roti (daily bread) than their health challenges that do not necessarily have a significant physical manifestation at the outset. When the service providers suggested taking medicine - the people would often respond with things like "I don't have food to eat at home. How is wearing glasses or taking medicine important?" or expressed concerns over how they will be able to function being 'providers' of the family if the illness hinders their visual ability.

This presents the importance of looking at the individual challenges that those coming to the hospital face and finding opportunities to build solutions that can encourage health seeking behaviour.

The Gender Aspect

The research looked at gender and the challenges one's social identity brings to understand health-seeking behaviour. The National Family Health Survey (NFHS) has estimated that about 60 percent of women in India face trouble when accessing healthcare, with at least 13 percent stating that they were refused permission to seek healthcare. This juxtaposed with the usual attention on women's health being limited to sexual and reproductive care (as if it is their destiny), also results in the low prioritisation of issues like eye health.

Another glaring challenge for health seeking behaviour comes from the lack of education which hinders access to information. The formative data collection in the rural villages of Ganjam district in Odisha saw only 3 individuals who completed high school. Of the 7 respondents who never attended school, 4 were women, and of those who dropped out before class 10, 3 were women. An outcome of this was that many of these women did not have access to information related to glaucoma. The opportunities to understand eye health that they did have often came from family members and friends and were mostly focused on getting their eyes tested but not being explained the importance or consequences for the same. This limited access to information is hardly ideal to support health seeking behaviour, especially for issues like glaucoma, where the physical manifestation often is presented at a later stage.

The formative research was encountered with issues where women did not find the opportunities to speak freely. Most of the women were accompanied by a male member (mostly family – their partner or children) who were often adamant on answering questions on their behalf. The research and Sankara team had to intervene to ensure that the woman could present her case. This behaviour showcases the general trend where men of the household assume they understand the challenges faced by their wives and try to answer on their behalf. One such case was when a woman identified for the interview was contacted. The phone was answered by her husband, who refused to let her participate in the research process. When asked if permission for participation could be sought from the woman herself, he refused to let her talk on the phone.

Objectives 2 – To generate evidence to produce activities and messages that are critical to glaucoma behavioural changes.

Objective- 3 To build communication strategies towards improving awareness and building an environment for testing and treatment adherence.

The project aimed to use the data to build evidence-based strategies that would improve glaucoma care management at the community level and support in the reduction of blindness due to glaucoma. This section focuses on facilitating health-seeking behaviours and providing opportunities for building an environment where these are encouraged while addressing the barriers. To ensure this, it is suggested to use a mix of activities and messaging. These must keep the local languages, and cultures in

mind. This section identifies the existing gaps and suggests changes to the status quo for improved provision of glaucoma care. These are based on the behaviours that should be encouraged.

Existing Gaps and Suggestions

When solutions and treatment mechanisms are developed, the social identities must be kept in mind along with one's economic standing. This will ensure continued adherence and little difficulty for the patient.

To encourage a larger audience to get tested regularly:

- **Hereditariness must be prioritized-** Glaucoma is a hereditary disease, the implication of which can be used as an effective tool for improving health-seeking behaviour. Many respondents, when informed about it, were concerned with the consequential impact of the disease on their children. The experiences of PWGs were so severe that it made them concerned about their family's health and the challenges that their children might have to go through if they have to live with the disease as well.
- **Improving the outreach program activities-** The current outreach activities conducted by Sankara Eye Hospital were a somewhat effective source of awareness creation among the served communities. However, most respondents, particularly those who were at risk of glaucoma, did not attend these camps or awareness programs despite being aware of these. These prompts improved and targeted outreach to the at-risk populations. The suggestions made ranged from word of mouth to visual mediums of communication.

Word of mouth: The respondents' main source of information, especially regarding healthcare, came from community healthcare workers (Accredited Social Health Activists [ASHA], Aangwadi Workers [AAWs] and Auxiliary Nurse Midwives [ANMs]) and the members of their local area. Holding focused outreach activities that are participatory in nature would be a helpful means of building awareness of glaucoma.

Visual medium of communications: The visual media was unanimously preferred by the PWGs, the at-risk groups, and the service providers who were included in the interview for communication. They believed that advocacy made through videos and graphic messages created a greater sense of consciousness and was also more feasible and useful for the population of Ganjam characterised by medium to low levels of literacy. The suggested tools, in this case, were television ads (video messaging like the ones used in TB, polio, and dengue), newspaper snippets, radio messaging, and use of social media applications (especially WhatsApp for updates regarding eye health camps & Facebook which are used commonly by those interviewed).

- **Mental health must be prioritized -** Given the negative impact, the mental health of the PWGs must be accounted for when developing care models. The current service delivery by Sankara Eye Hospital only has one counsellor and other untrained mental

health professionals providing support to a large group of people, which does not necessarily yield effective results.

- **Community-based care model-** A community structure model must be developed to ensure that hard-to-reach populations are covered in the care delivery mechanism. Earlier interventions with community models have yielded effective results when it comes to public health challenges – be it issues like tuberculosis or mental health, which have a heavy stigma attached to them. The community structure allows for preventive care and encourages those with the disease to access continued treatment. This would require working with self-help groups (SHGs), civil society organisations (CSOs), Panchayati Raj Institutions (PRIs) and non-governmental organisations (NGOs) to build community resource persons who can coordinate within the community.
- **Baseline Study:** A large-scale baseline understanding of the critical challenges of how aspects like social identities impact health seeking behaviour, and access to healthcare in general must be conducted.



Figure 18: Common mediums of communication

Behavior to influence	Proposed Intervention
<p>Improving eye testing rates among young, apparently healthy populations at risk of glaucoma</p>	<p><i>Engaging local healthcare networks</i> - like ASHA workers, AAWs, SHGs, PRIs, district collector among others to build awareness about the issue and encouraging testing</p> <p><i>Sensitisation camps in villages</i> - keeping key target populations as focus, conducting camps to discuss what glaucoma is, risk factors and why should people get tested</p> <p><i>Tie ups with doctors and hospitals focused on co-morbidities</i> - like diabetes, hypertension to ensure these patients also come for glaucoma testing</p> <p><i>Improving somatic consciousness</i> - Encouraging people diagnosed with glaucoma to get their children tested</p>
<p>Ensuring treatment adherence among persons diagnosed with glaucoma</p>	<p><i>Improved follow-ups:</i> Once a person is diagnosed with glaucoma, there should be sessions organised to train them on basic glaucoma management. Four categories - <i>Medical, Surgical, Post Surgical Care & Post Surgery No Further Care</i> should be developed to understand challenges in the category and developing solutions accordingly. The follow-ups should be done at a regular interval designed to suit the needs of the group</p> <p><i>Automated Messaging:</i> Using common communication mediums like WhatsApp and Text Messages as creative reminders for follow-ups on appointments, buying medicines among other common information needed for glaucoma care</p> <p><i>Central Monitoring & Evaluation System:</i> There should be a centralised system for recording data of those taking treatment from the hospital and understand the current status of PWGs enrolled under the program.</p>

	<p><i>Mental Health Support:</i> The counselors should prioritize mental health of the PWGs, and look out for signs of anxiety, depression to identify whether these act as barriers in treatment deliverance.</p>
	<p><i>Subsidised care:</i> Providing the medicines and surgeries through subsidised care is essential. This can be possible only when working with the state government.</p>
<p>Increased Awareness on glaucoma and other eye health challenges</p>	<p><i>Community Based Interventions especially using audio-visual mediums:</i> Using activities like nukkad natakas, wall paintings, radio shows, tv ads related to the themes around glaucoma which would involve not only those aged above 40 and at risk but also young populations to ensure that information on the issue is provided at the earliest and positive behavior towards the same can start at an early age.</p>

Conclusion

The study aimed to establish a connection between the triad of expectations of the people (from the program), dispositions of the individuals (as a unit of the community) to care-seeking, and the observed outcomes of the Keep Sight project (that intends to eliminate Glaucoma) at large in the district. While a lot of what the program offers concerns itself with outreach through an end-to-end service delivery process, from diagnosis to treatment, it was found that the enrolled patients weren't aware of the exact nature of the illness, or the benefit accrued to them under the initiative. There seems to be a greater felt need, unanimously, to shift to the traditional channels of mass media with visual tools. This will also help in establishing the difference between "Glaucoma" and "Cataract", where the high prevalence of the latter almost always fogs the understanding of the former.

The characteristic of Glaucoma being the "silent" thief of sight delays the demand, till the tunnel vision is entirely lost, which often overlaps with the age-sensitive onset of cataract. The strategy thus requires a greater push not only in favour of those who are enrolled for the treatment at Sankara, owing to the high attrition rates over successive meetings at the hospital but also towards reimagining the strategy of approaching the population at risk. In both scenarios, it was obvious that logistical barriers to accessing care—the distance, the time, and the money—are predominant in the momentary or stable decision-making for accessing the service, apart from the intersection of identities (gender and age) aggravating the experience. Community-based models for communication work well in the peri-urban and rural areas that surround the hospital; the fact that Sankara is considered a major secondary and tertiary health centre, and

that its service facilities in local settings are quite popular among the residents implies that the supply side variables are sufficient in infrastructure, and projects a lot of hope for the program to be an exemplary model for even a larger geography, only if the gaps of demand generation are revisited.

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Annexures

Annexure 1: Camp Form

Name		Block		Contact no.					
SCREENING									
History		Tests		RE	LE	Examination		RE	LE
Age (Yrs)	<40	Distance VA	>6/18			Lens	Clear		
	40-60		<6/18 [^]				Cataract [^]		
	>60		<3/60				Operated		
Family H/o Glaucoma or blindness due to unknown cause	No	Near VA	>N8			Anterior Chamber	Deep		
	Yes		<N8'				Shallow		
	Not Sure						Not sure		
High BP	No	IOP (mm Hg)	16-21			C:D ratio	<0.6		
	Yes		22-30*				0.6-0.7		
	Not Sure		>30				>0.7		
Steroid use or long term use of unknown eye drops	No	Pupil	Normal			Assymetry	<0.2		
	Yes		Abnormal				>0.2		
	Not Sure		Not sure				N/A		
Others		Any other findings				Referral	No		
							Yes		

This form is utilised by the camp coordinators when the weekly camps are set near the village settings for the initial screening of persons with glaucoma. This understands the IOP, CDR, Anterior Chamber Depth, distance and near visual acuity and whether the person has a family history of glaucoma or co-morbidities. This is the initial stage of the project.

Annexure 2: Hospital Sheet

Presented below is the hospital front sheet which is used under this project to record the data for persons who were initially screened at the camps and turned up at the hospital. This is stage where a person is diagnosed with glaucoma or not.

Name		Block		Contact no.	
SCREENING					
History		Tests		RE	IE
Age (Yrs)	<40 40-60 > 60	Distance VA	>6/ 18 <6/ 18^ <3/ 60		
Family H/o Glaucoma or blindness due to unknown cause	No Yes Not Sure	Near VA	>N8 <N8'		
High BP	No Yes Not Sure	IOP (mm Hg)	16-21 22-30* >30		
Steroid use or long term use of unknown eye drops	No Yes Not Sure	Pupil	Normal Abnormal Not sure		
Others		Any other findings			
DIAGNOSIS					
Referral	Self reported Camp PEC Family CHW Others	Reminder calls	None One call 1-3 calls CHW Others	Comments by Counsellor	
Tests Advised		Results		RE	IE
1 GAT		Normal Borderline Abnormal Not Done			
2 Gonioscopy		Normal Borderline Abnormal Not Done			
3 VFA		Normal Borderline Abnormal Not Done			
4 Others		Normal Borderline Abnormal Not Done			
Diagnosis					
1 No Glaucoma 2 POAG (Early) 3 POAG (Moderate) 4 POAG (Advanced) 5 Angle closure 6 Angle closure Glaucoma 7 Others.					
Treatment Advised					
1 No Treatment 2 Follow up 3-6 months 3 Medical treatment (1 drug) 4 Medical treatment (>1 drug) 5 LASER PI 6 Glaucoma Surgery 7 Others.					
Next Follow up date				Counsellor	

Beyond the diagnosis, it understands the type of glaucoma - POAG - early, moderate, or advanced or angle closure glaucoma. It also records the type of treatment advised and the follow-up procedure

Annexure 3: Standard Operating Procedure

The Standard Operating Procedure (SOP) is relevant for the service providers in the space of glaucoma care as it highlights the risk factors, suggested care at the different types and stages of glaucoma that an individual might have.

Standard Operating Procedure for Glaucoma at Sankara Eye Hospital, Samarajhola.

SOPs for glaucoma screening @ Doctor's level

- All patients above 40 yrs of age will arrive at the consultation room after a glaucoma screening workup from the refraction area.
- Suspect closed angle on Van Herrick 2 or less, follow SOPs for closed angle glaucoma care.
- **Open angle glaucoma sops:**
- Van Herrick 3 \geq Suspect POAS:
- A diagnosis for primary open-angle glaucoma (POAG) suspect is established by the presence of one of the following conditions:
 - -a consistently elevated intraocular pressure (IOP) >21 mmHg,
 - -a suspicious-appearing optic nerve CD ratio > 0.5

Risk Factors for OAG Suspect

- Family history of glaucoma in 1st degree relative
- Thin central corneal thickness (< 555 nm)
- High IOP (>21 mmHg)
- Pseudo exfoliation or pigment dispersion syndrome Wherever

≥ 3 risk factors are positive = high risk

≤ 2 risk factors are positive = low risk

Procedures to be followed-

1. Applanation Tonometry (mention time)
2. Undiluted Gonioscopy.
3. Anterior segment examination
4. Undiluted fundus examination with 90 D lens.
5. Dilated fundus examination.
6. if Primary Open Angle Suspect criteria meets: Advise Glaucoma Package. (Automated visual field + OCT + Applanation Tonometry adjusted for CCT)
7. Start the first line Anti Glaucoma Medicines (beta blockers / prostaglandins) if clinical suspicion is high (IOP > 24 mmHg {cct adjusted}, O.N. findings: SR/ IR thinning / notch; CDR ≥ 0.8)
8. Avoid beta blockers, if patient is known case of ASTHMA and CARDIAC Disease.

9. Go for Pg. Analogue or 2nd line of AGM (individual or combination): BRIMONIDINE; BRINZOLAMIDE

10. IOP >30 mmHg, prefer combined therapy / 2 drugs: (beta + brimonidine; brimonidine + brinzolamide) with oral carbonic anhydrase inhibitors (Tab acetazolamide 250 mg TID X 5 DAYS)

11. rule out h/o kidney disease before starting acetazolamide

12. Assess response of AGM within 1 month of starting AGM; But if patient has IOP more than / equal to 30 mmHg and / or cd ratio ≥ 0.8 , review patient within first two weeks.

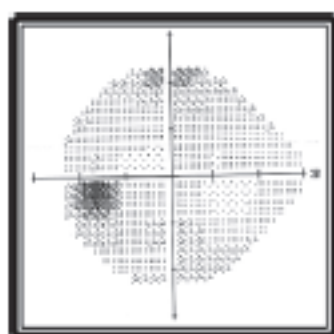
Table 3 - Initiating Open Angle Glaucoma Care - International Recommendations

Glaucoma Severity	Findings	Suggested IOP Reduction	Treatment Considerations
Early	Optic Nerve Damage ± Visual Field Loss	Lower IOP ≥25%	Medication <i>or</i> Laser trabeculoplasty
Moderate/ Advanced	Optic Nerve Damage + Visual Field Loss	Lower IOP ≥25 – 50%	Medication <i>or</i> Laser trabeculoplasty <i>or</i> Trabeculectomy ± Mitomycin C <i>or</i> Tube (± cataract removal and intraocular lens [IOL]) <i>and/or</i> Cyclophotocoagulation (<i>or</i> cryotherapy)
End-stage (Refractory glaucoma)	Blind Eye ± Pain	Lower IOP ≥25 – 50% (If painful)	Medication <i>and/or</i> Cyclophotocoagulation (<i>or</i> cryotherapy) <i>and</i> Rehabilitation Services

Mild or Early Stage Glaucoma

ICD-10 7th digit "1"

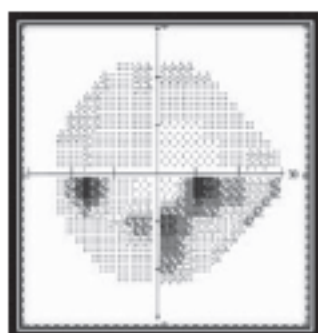
- Optic nerve abnormalities consistent with glaucoma
- but NO visual field abnormalities on any visual field test
- OR abnormalities present only on short-wavelength automated perimetry or frequency doubling perimetry



Moderate Stage Glaucoma

ICD-10 7th digit "2"

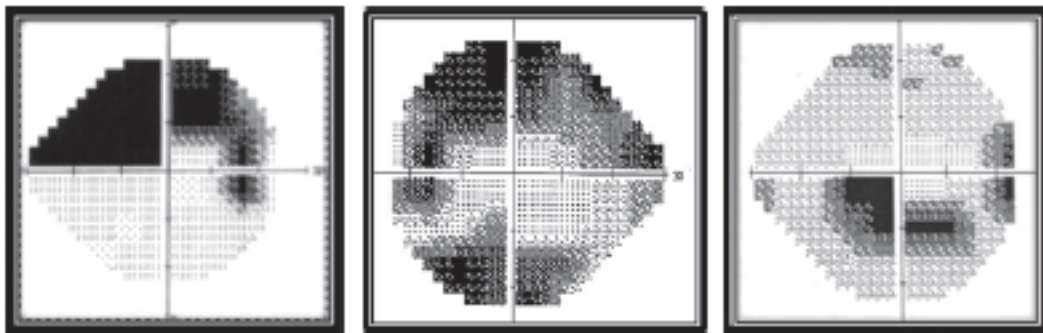
- Optic nerve abnormalities consistent with glaucoma
- AND glaucomatous visual field abnormalities in ONE hemifield and
- NOT within 5 degrees of fixation (note: 5 degrees = involvement of spots nearest fixation)



Advanced, Late, Severe Stage

ICD-10 7th digit "3"

- Optic nerve abnormalities consistent with glaucoma
- AND glaucomatous visual field abnormalities in BOTH hemifields
- AND/OR loss within 5 degrees of fixation in at least one hemifield



Approach to Closed Angle Glaucoma Care

- Suspect closed angle on VH2 or less.
- Check for pupillary reactions
- Perform Applanation Tonometer
- Perform Undiluted Gonio
- Do an Undiluted fundus examination with 90 D lens.
- Advise YAG PI if angles are concludable.
- CLASSIFY Primary Angle Closure Disease as per International Society for Geographical and Epidemiological Ophthalmology.
- Start AGM if clinical suspicion of angle closure glaucoma (follow SOP similar to POAS).
- Current classification of primary angle closure disease (PACD) is based on the definition. Geographical and Epidemiological Ophthalmology (ISGEO).

Classification of PACD

(1) Primary angle closure suspect (PACS)

An eye in which there is irido-trabecular contact for at least 270° on gonioscopy with the eye in the primary position, without compression, using

appropriate illumination, with normal intraocular pressure (IOP), optic disc and visual fields.

(2) Primary angle closure (PAC)

The presence of irido-trabecular contact for at least 270°, with either raised IOP and/or peripheral anterior synechiae (PAS), but with normal optic disc and visual fields

(3) Primary angle closure glaucoma (PACG)

PAC with evidence of glaucoma (optic disc/field Changes)

(4) Acute angle closure crisis

Symptoms of pain, either ocular or periocular, often accompanied by headache, nausea or vomiting, presenting with an IOP of >21 mmHg, with

signs such as circumcorneal congestion, corneal edema, mid-dilated non-reactive pupil, and a shallow anterior chamber

Table 8 - Initiating Closed Angle Care - International Recommendations

Diagnosis	Clinical Findings	Essential Treatment	Surgical Options
Acute or Chronic Closed Angle (Pupil Block)	Iris-trabecular contact Iris bowing	Constrict pupil and lower IOP Laser iridotomy (desirable) or Surgical iridectomy (laser to fellow eye)	Lens extraction/IOL ± Trabeculectomy ± Mitomycin C
Closed Angle (Plateau Iris)	Iris-trabecular contact Flat Iris	Constrict pupil and lower IOP Laser iridotomy (desirable) or Surgical iridectomy (laser to fellow eye) and Laser iridoplasty	Lens extraction/IOL ± Trabeculectomy ± Mitomycin C

Management of acute angle closure crisis (AcACC)

After diagnosis: check for B.P.; rule out h/o kidney disease, cardiac disease: GIVE STAT 100 ml I.V. Maznitol, timolol BD; Brimonidine TID, Oral acetazolamide 250 mg TID, prednisolone QID.

Refer to Glaucoma Clinic.

Table 10 - Ongoing Closed Angle Glaucoma Care - International Recommendations

Classification	Exam Findings	Treatment	Follow-up
Stable Glaucoma	No Change to Angle, IOP, Optic Nerve, and Visual Field	Continue	~ 6 months – 1 year (depending on disease severity, risk factors, and resources)
Unstable Glaucoma	Persistent Angle Closure and Increased IOP ± Increased Optic Nerve Damage ± Increased Visual Field Damage	Additional IOP lowering needed by ≥ 25% (Refer to Table 11)	1 – 4 months (depending on disease severity, risk factors, and resources)

Annexure 4: Consent Form (English and Oriya)

Table 11 - Unstable Closed Angle Glaucoma - International Recommendations

Glaucoma Severity	Findings	Suggested IOP Reduction	Treatment Considerations
Early	Persistent Angle Closure + Optic Nerve Damage ± Visual Field Loss	Lower IOP ≥25%	Medication Lens extraction/IOL
Moderate / Advanced	Persistent Angle Closure + Optic Nerve Damage + Visual Field Loss	Lower IOP ≥25 – 50%	Medication <i>and/or</i> Trabeculectomy or tube (with or without goniosynechiolysis, cataract removal, and IOL) <i>and/or</i> Cyclophotocoagulation (or cryotherapy) Rehabilitation Services
End-stage (Refractory glaucoma)	Blind Eye ± Pain	Lower IOP ≥25 – 50% (If painful)	Medication <i>and/or</i> Cyclophotocoagulation (or cryotherapy) Rehabilitation Services

Informed Consent Form

For In-Depth Interview

(To be read to participants prior to the survey)

Study title: Formative behavioural analysis of Glaucoma project

Introduction and Purpose of the study: Hello. My name is _____. I work for Sightsavers India, and we are providing eye care services in your area. A project on eye care is being implemented in Ganjam district by Sightsavers India in partnership with Sankara eye hospital. We are conducting a study to understand the norms, behaviour, and practices of the people who have been screened for Glaucoma and the general population of project area to create a change that will have a positive impact on the behaviours of the people and will improve their eye health status.

Procedure: I request your permission to be a part of the study, and you may deny it if you decide not to participate. The interview will be conducted in a private place and will take approximately 15-30 minutes. The entire interview shall be recorded on a voice-recording instrument, for the notes to be prepared later and verified, apart from being archived.

Privacy and confidentiality: The information you provide during this survey will be kept confidential and used only for the specific purpose of this study. Your name or the location of your house and other information that could reveal your identity will be removed before the results of the study are made public or shared between people other than the main researchers working on the project. Your data will be transferred to computers protected by passwords. For analysis, the data from your previous consultations with Sankara Eye Hospital will also be used for the purpose of cross-triangulation.

Risks and benefits of participation: If you choose to answer the questions, there will not be any direct or monetary benefit to you but you will help us to understand how to improve the eye care services in your locality. The findings of this survey will be disseminated to relevant policymakers and health partners so they can be used to inform the planning of services to reduce the number of people going blind due to untreated glaucoma and are also expected to bring changes in the communities and in the hospitals where glaucoma care and follow-ups take place.

Withdrawal: Participation in this study is completely voluntary. Choosing not to take part will not disadvantage you in any way. It is up to you to decide whether to take part or not. If you decide to take part, you are free to withdraw at any time and without giving a reason.

Would you like to participate? Yes No

If YES, then the signature of the respondent

Participant Name

Participant signature/Thumb

Date

Study staff Name

Study staff signature

Date

Consent form in Odiya

ସୂଚନାଯୋଗ୍ୟ ସମ୍ମତି ଫର୍ମ |

ଗଢ଼ାଉତା ସାକ୍ଷାତକାର ପାଇଁ |

(ସର୍ବୋତ୍ତମ ଅଂଶଗ୍ରହଣକାରୀମାନଙ୍କୁ ପଢ଼ି ଶୁଣାଇବା କୁ ହେବ)

ଅଧ୍ୟୟନର ଶିରୋନାମା : ଗ୍ଲୁକୋମା (Glaucoma) ପ୍ରକଳ୍ପର ଗଠନମୂଳକ ଆଚରଣ ବିଶ୍ଳେଷଣ |

ଅଧ୍ୟୟନର ପରିଚୟ ଏବଂ ଉଦ୍ଦେଶ୍ୟ: ନମସ୍କାର ମୋର ନାମ ହେଉଛି _____ । ମୁଁ ସାଇଟସେଭର୍ସ ଇଣ୍ଡିଆ (Sightsavers India) ପାଇଁ କାମ କରେ, ଏବଂ ଆମେ ଆପଣଙ୍କ ଅଞ୍ଚଳରେ ଚକ୍ଷୁ ସେବା ଯୋଗାଉଛୁ । ସଙ୍କର ଚକ୍ଷୁ ଡାକ୍ତରଖାନା ସହଭାଗିତାରେ ସାଇଟସେଭର୍ସ ଇଣ୍ଡିଆ ଦ୍ୱାରା ଗଞ୍ଜାମ ଜିଲ୍ଲାରେ ଚକ୍ଷୁ ଚିକିତ୍ସା ଉପରେ ଏକ ପ୍ରକଳ୍ପ କାର୍ଯ୍ୟକାରୀ ହେଉଛି । ଗ୍ଲୁକୋମା ଏବଂ ପ୍ରକଳ୍ପ କ୍ଷେତ୍ରର ସାଧାରଣ ଜନତାଙ୍କ ପାଇଁ ସ୍ତ୍ରୀମାନଙ୍କୁ ହୋଇଥିବା ଲୋକଙ୍କ ଆଦର୍ଶ, ଆଚରଣ, ଏବଂ ଅଭ୍ୟାସକୁ ବୁଝିବା ପାଇଁ ଆମେ ଏକ ଅଧ୍ୟୟନ କରୁଛୁ, ଯାହା ଲୋକଙ୍କ ଆଚରଣ ଉପରେ ସକରାତ୍ମକ ପ୍ରଭାବ ପକାଇବ ଏବଂ ସେମାନଙ୍କର ଆଖି ସ୍ୱାସ୍ଥ୍ୟ ଅବସ୍ଥାରେ ଉନ୍ନତି କରିବ ।

ପ୍ରଣାଳୀ: ଅଧ୍ୟୟନର ଏକ ଅଂଶ ହେବାକୁ ମୁଁ ଆପଣଙ୍କର ଅନୁମତି ଅନୁରୋଧ କରେ, ଏବଂ ଯଦି ଆପଣ ଅଂଶଗ୍ରହଣ ନକରିବାକୁ ନିଷ୍ପତ୍ତି ନିଅନ୍ତି ତେବେ ଆପଣ ଏହାକୁ ଅସ୍ୱୀକାର କରିପାରିବେ । ସାକ୍ଷାତକାର ଏକ ବ୍ୟକ୍ତିଗତ ସ୍ଥାନରେ କରାଯିବ ଏବଂ ପ୍ରାୟ 15-30 ମିନିଟ୍ ସମୟ ଲାଗିବ । ସମଗ୍ର ସାକ୍ଷାତକାର ଏକ ସ୍ୱର-ରେକର୍ଡ଼ ଉପକରଣରେ ରେକର୍ଡ଼ ହେବ, ନୋଟ୍ ଗୁଡ଼ିକ ପରେ ପ୍ରସ୍ତୁତ ହୋଇ ଯାଏ ହେବ ।

ଗୋପନତା ଏବଂ ଗୋପନୀୟତା: ଏହି ସର୍ବେକ୍ଷଣ ସମୟରେ ଆପଣ ପ୍ରଦାନ କରୁଥିବା ସୂଚନା ଗୋପନୀୟ ରଖାଯିବ ଏବଂ କେବଳ ଏହି ଅଧ୍ୟୟନର ନିର୍ଦ୍ଦିଷ୍ଟ ଉଦ୍ଦେଶ୍ୟ ପାଇଁ ବ୍ୟବହୃତ ହେବ । ଆପଣଙ୍କ ନାମ କିମ୍ବା ଆପଣଙ୍କ ଘରର ଅବସ୍ଥାନ ଏବଂ ଅନ୍ୟାନ୍ୟ ସୂଚନା ଯାହା ଆପଣଙ୍କର ପରିଚୟ ପ୍ରକାଶ କରିପାରିବ ତାହା ଅଧ୍ୟୟନର ଫଳାଫଳ ସାର୍ବଜନୀନ ହେବା ପୂର୍ବରୁ କିମ୍ବା ଏହି ପ୍ରକଳ୍ପରେ କାର୍ଯ୍ୟ କରୁଥିବା ମୁଖ୍ୟ ଅନୁସନ୍ଧାନକାରୀଙ୍କ ବ୍ୟତୀତ ଅନ୍ୟମାନଙ୍କ ମଧ୍ୟରେ ଅଂଶୀଦାର ହେବା ପୂର୍ବରୁ ଅପସାରିତ ହେବ । ଆପଣଙ୍କ ତଥ୍ୟ ପାସପୋର୍ଟ ଦ୍ୱାରା ସୁରକ୍ଷିତ କମ୍ପ୍ୟୁଟରକୁ ସ୍ଥାନାନ୍ତରିତ ହେବ । ବିଶ୍ଳେଷଣ ପାଇଁ, ସଙ୍କର ଚକ୍ଷୁ ଚିକିତ୍ସାଳୟ ସହିତ ଆପଣଙ୍କର ପୂର୍ବ ପରାମର୍ଶରୁ ତଥ୍ୟ ମଧ୍ୟ ବ୍ୟବହୃତ ହେବ ।

ଅଂଶଗ୍ରହଣର ବିପଦ ଏବଂ ଲାଭ: ଯଦି ଆପଣ ପ୍ରଶ୍ନର ଉତ୍ତର ଦେବାକୁ ବାଞ୍ଛିଛନ୍ତି, ତେବେ ଆପଣଙ୍କ ପାଇଁ କୌଣସି ପ୍ରତ୍ୟକ୍ଷ କିମ୍ବା ଆର୍ଥିକ ଲାଭ ହେବ ନାହିଁ କିନ୍ତୁ ଆପଣ ନିଜ ଅଞ୍ଚଳରେ ଚକ୍ଷୁ ସେବାରେ କିପରି ଉନ୍ନତି କରିବେ ତାହା ବୁଝିବାରେ ଆପଣ ଆମକୁ ସାହାଯ୍ୟ କରିବେ । ଏହି ସର୍ବେକ୍ଷଣର ଫଳାଫଳଗୁଡ଼ିକ ସମ୍ପୂର୍ଣ୍ଣ ନୀତି ନିର୍ଣ୍ଣୟକାରୀ ଏବଂ ସ୍ୱାସ୍ଥ୍ୟ ସହଭାଗୀମାନଙ୍କ ନିକଟରେ ବିସ୍ତାର କରାଯିବ ଯାହା ଦ୍ୱାରା ଚିକିତ୍ସା ହୋଇନଥିବା ଗ୍ଲୁକୋମା କାରଣରୁ ଅନ୍ଧ ହୋଇଯାଉଥିବା ଲୋକଙ୍କ ସଂଖ୍ୟା ହ୍ରାସ କରିବାକୁ ସେବା ଯୋଜନା ବିଷୟରେ ସୂଚନା ଦିଆଯାଇପାରିବ ଏବଂ ସମ୍ପ୍ରଦାୟରେ ଓ ଯେଉଁ ଡାକ୍ତରଖାନାଗୁଡ଼ିକରେ ଗ୍ଲୁକୋମା ଯତ୍ନ ଏବଂ ଅନୁସରଣ କରାଯାଏ, ଏହା ମଧ୍ୟ ପରିବର୍ତ୍ତନ ଆଣିବ ବୋଲି ଆଶା କରାଯାଉଛି ।

ପ୍ରତ୍ୟାହାର: ଏହି ଅଧ୍ୟୟନରେ ଅଂଶଗ୍ରହଣ ସମ୍ପୂର୍ଣ୍ଣ ସ୍ୱେଚ୍ଛାକୃତ ଅଟେ । ଏଥିରେ ଅଂଶଗ୍ରହଣ ନକରିବା ଆପଣଙ୍କୁ କୌଣସି ପ୍ରକାରେ ଅସୁବିଧା କରିବ ନାହିଁ । ଏଥିରେ ଅଂଶଗ୍ରହଣ କରିବେ କି ନାହିଁ ତାହା ଆପଣଙ୍କ ଉପରେ ନିର୍ଭର କରେ । ଯଦି ଆପଣ ଭାଗ ନେବାକୁ ଛାଡ଼ି କରନ୍ତି, ଆପଣ ଯେକୌଣସି ସମୟରେ ଏବଂ ବିନା କାରଣରେ ସାକ୍ଷାତକାର ପ୍ରତ୍ୟାହାର କରି ପାରିବେ ।



ଆପଣ ଅଂଶଗ୍ରହଣ କରିବାକୁ ଚାହୁଁଛନ୍ତି କି? ହଁ ନା

ଯଦି ହଁ, ତେବେ ଉତ୍ତରଦାତାଙ୍କର ଦସ୍ତଖତ |

ଅଂଶଗ୍ରହଣକାରୀଙ୍କ ନାମ
ତାରିଖ

ଅଂଶଗ୍ରହଣକାରୀଙ୍କ ଦସ୍ତଖତ / ଚିପ

ଅଧ୍ୟକ୍ଷ କର୍ମଚାରୀଙ୍କ ନାମ
ତାରିଖ

ଅଧ୍ୟକ୍ଷ କର୍ମଚାରୀଙ୍କ ଦସ୍ତଖତ

Annexure 5: In-Depth Interviews with Service Providers (English and Oriya)

This is the In-Depth Interview conducted with the service providers at the Sankara Eye Hospital to understand their perceptions, knowledge, and willingness to screen people for glaucoma.

FORMATIVE ANALYSIS FOR THE GLAUCOMA PROJECT

Target Group 1: Eye Health Care Providers

Tool Used: In-Depth Interview

Target Population: 10 interviews with hospital staff, optometrists, ophthalmologists, doctors, and 1 with the Counsellor.

Basic Profile

Name:

Age:

Gender:

Designation:

Understanding the patient and awareness

1. What type of patients generally come to you? Please define in terms of age, gender, education, occupation, and financial bracket.
2. How aware are they regarding eye health – what kind of questions do they generally ask?
3. In your understanding, do they understand what glaucoma is? What do you think are the sources of their information?
4. Are the people aware of the symptoms, consequences, and treatment related to glaucoma?
5. On average, how many screenings do you conduct in a month?
6. What is the first reaction of people when they are told they have been detected with glaucoma?
7. In your experience, do the patients accept treatment?
8. On average, how many diagnosed patients accept treatment?
9. Those accepting treatment, do they continue it regularly?
10. Have you ever recommended surgery for glaucoma to any patient?
 - 10.1 Did they take it? Yes/No

- 10.2 How was it to convince someone to do the surgery?
- 10.3 What feedback did you receive post the surgery?
11. There are also those who discontinue treatment. What do you understand are the most common reasons for this?
1. Where does eye health stand in people's health priority?
 2. Why is eye care/health low among people's health priorities? (if they say its low)
 3. How much does the incurability of glaucoma impact the treatment decision?
12. Has any glaucoma patient talked to you about any issues/barriers? (*Related to high cost, poor mental health, etc.*)
13. How do you support the cases diagnosed with Glaucoma to take the necessary decisions regarding their treatment?

Camps and Keenness to screen

14. Does your hospital conduct any outreach campaigns to screen potential glaucoma patients? YES / NO
- 14.1 If yes, how frequently are these campaigns conducted?
- Monthly | Bi-monthly | Every 6 months | Once a year | Once 2-3 years | 5 years or more**
- 14.2 If yes, on average, how many people visit?
- 14.3 If yes, how do you encourage people to attend?
15. Do patients come to vision centres for screening?
- 15.1 If not, then what are the reasons according to you?
16. What do you think motivates people to visit screening sites, even if they don't have symptoms?

Recommendations and the Way Forward

17. Are you aware of the technical SOP on Glaucoma?
18. What do you suggest should be done for glaucoma treatment and services?
19. How do you suggest we enhance awareness regarding glaucoma in the region?

Questionnaire in Odiya

ଗ୍ଲାଉକୋମା ପ୍ରକଳ୍ପ (GLAUCOMA PROJECT) ପାଇଁ ଗଠନମୂଳକ ବିଶ୍ଳେଷଣ

ଟାର୍ଗେଟ୍ ଗ୍ରୁପ୍ ୧ : ଚକ୍ଷୁ ସ୍ଵାସ୍ଥ୍ୟ ସେବା ପ୍ରଦାନକାରୀ ।

ବ୍ୟବହୃତ ସାଧନ: ଗଭୀରତା ସାକ୍ଷାତକାର ।

ଲକ୍ଷ୍ୟ ଜନସଂଖ୍ୟା (Target Population): ୧୦ ଜଣ ଡାକ୍ତରଖାନା କର୍ମଚାରୀଙ୍କ ସହିତ, optometrists, ଚକ୍ଷୁ ବିଶେଷଜ୍ଞ, ଡାକ୍ତର, ପରାମର୍ଶଦାତା ସହିତ ୧ ।

ମୌଳିକ ପ୍ରୋଫାଇଲ୍

ନାମ :

ବୟସ :

ଲିଙ୍ଗ :

ପଦବୀ :

ରୋଗୀ ଓ ସଚେତନତା କୁ ବୁଝିବା

୧. ସାଧାରଣତ କେଉଁ ପ୍ରକାରର ରୋଗୀ ଆପଣଙ୍କ ନିକଟକୁ ଆସନ୍ତି? ବୟସ, ଲିଙ୍ଗ, ଶିକ୍ଷା, ବୃତ୍ତି ଏବଂ ଆର୍ଥିକ ସ୍ଥିତି ଅନୁଯାୟୀ ବୟାକରି ବ୍ୟାଖ୍ୟା କରନ୍ତୁ ।

୨. ଆଖି ସ୍ଵାସ୍ଥ୍ୟ ସମ୍ବନ୍ଧରେ ସେମାନେ କେତେ ସଚେତନ - ସେମାନେ ସାଧାରଣତ କେଉଁ ପ୍ରକାର ପ୍ରଶ୍ନ ପଚାରନ୍ତି?

୩. ଆପଣଙ୍କ ବୁଝିବାରେ, Glaucoma କଣ ସେମାନେ ଜାଣନ୍ତି କି ? ସେମାନଙ୍କ ସୂଚନାର ଉତ୍ତର କଣ ବୋଲି ଆପଣ ଭାବୁଛନ୍ତି?

୪. Glaucoma ସହିତ ଜଡ଼ିତ ଲକ୍ଷଣ, ପରିଣାମ ଏବଂ ଚିକିତ୍ସା ବିଷୟରେ ଲୋକମାନେ ଅବଗତ କି?

୫. ହାରାହାରି, ଆପଣ ଗୋଟିଏ ମାସରେ କେତେ ସ୍ତ୍ରୀ କରନ୍ତି?

୬. ଲୋକମାନଙ୍କର ପ୍ରଥମ ପ୍ରତିକ୍ରିୟା କ'ଣ ଯେତେବେଳେ ସେମାନଙ୍କୁ କୁହାଯାଏ ଯେ ସେମାନଙ୍କୁ Glaucoma ସହିତ ଚିହ୍ନଟ କରାଯାଇଛି?

୭. ଆପଣଙ୍କ ଅଭିଜ୍ଞତାରେ, ରୋଗୀମାନେ ଚିକିତ୍ସା ଗ୍ରହଣ କରନ୍ତି କି?

୮. ହାରାହାରି, କେତେ ରୋଗୀ ଚିକିତ୍ସା ଗ୍ରହଣ କରନ୍ତି?

୯. ଯେଉଁମାନେ ଚିକିତ୍ସା ଗ୍ରହଣ କରୁଛନ୍ତି, ସେମାନେ ଏହାକୁ ନିୟମିତ ଜାରି ରଖୁଛନ୍ତି କି?

୧୦. ଆପଣ କୌଣସି ରୋଗୀଙ୍କୁ Glaucoma ପାଇଁ ଅସ୍ତ୍ରୋପଚାର ପାଇଁ ପରାମର୍ଶ ଦେଇଛନ୍ତି କି?

୧୦.୧ ସେମାନେ ଏହାକୁ ନେଇଛନ୍ତି କି? ହଁ / ନା

୧୦.୨ କାହାକୁ ଅସ୍ତ୍ରୋପଚାର କରିବାକୁ ମନାଇବା କିପରି ହେଲା?

୧୦.୩ ଅସ୍ତ୍ରୋପଚାର ପରେ ଆପଣ କେଉଁ ମତାମତ ଗ୍ରହଣ କରିଛନ୍ତି?

୧୧. କିଛି ଲୋକ ମଧ୍ୟ ଅଛନ୍ତି ଯେଉଁମାନେ ଚିକିତ୍ସା ବନ୍ଦ କରନ୍ତି | ଆପଣଙ୍କ ଜାଣିବାରେ ଏହାର ସବୁଠାରୁ ସାଧାରଣ କାରଣ କ'ଣ?

୧. ଲୋକଙ୍କ ସ୍ଵାସ୍ଥ୍ୟ ପ୍ରାଥମିକତା ମଧ୍ୟରେ ଆଖି ସ୍ଵାସ୍ଥ୍ୟ କେଉଁଠାରେ ଅଛି / ସ୍ଥିତି କଣ ?

୨. ଲୋକଙ୍କ ସ୍ୱାସ୍ଥ୍ୟ ପ୍ରାଥମିକତା ମଧ୍ୟରେ କାହିଁକି ଚକ୍ଷୁ ଯତ୍ନ / ସ୍ୱାସ୍ଥ୍ୟ କର୍ମ? (ଯଦି ସେମାନେ କୁହନ୍ତି ଏହା କମ)

୩. Glaucoma ର ଅସ୍ପଷ୍ଟତା ଚିକିତ୍ସା ନିଷ୍ପତ୍ତି ଉପରେ କେତେ ପ୍ରଭାବ ପକାଇଥାଏ?

୧୨. କୌଣସି Glaucoma ରୋଗୀ ଆପଣଙ୍କ ସହ କୌଣସି ସମସ୍ୟା / ପ୍ରତିବନ୍ଧକ ବିଷୟରେ କଥା ହୋଇଛନ୍ତି କି? (ଉଚ୍ଚ ମୂଲ୍ୟ, ଖରାପ ମାନସିକ ସ୍ୱାସ୍ଥ୍ୟ ଇତ୍ୟାଦି ସହିତ ଜଡ଼ିତ)

୧୩. ସେମାନଙ୍କ ଚିକିତ୍ସା ସମ୍ବନ୍ଧରେ ଆବଶ୍ୟକ ନିଷ୍ପତ୍ତି ନେବାକୁ Glaucoma ରୋଗରେ ଚିହ୍ନଟ ହୋଇଥିବା ମାମଲାଗୁଡ଼ିକୁ ଆପଣ କିପରି ସମର୍ଥନ କରିବେ?

ଶିବିର ଓ ପରୀକ୍ଷଣ ପ୍ରତି ଆଗ୍ରହ

୧୪. ସମ୍ଭାବ୍ୟ Glaucoma ରୋଗୀଙ୍କୁ ସ୍ତ୍ରୀନିର୍ଦ୍ଧାରଣ କରିବା ପାଇଁ ଆପଣଙ୍କ ଡାକ୍ତରଖାନା କୌଣସି ପ୍ରଚାର ଅଭିଯାନ କରେ କି? ହଁ / ନା

୧୪.୧ ଯଦି ହଁ, ଏହି ଅଭିଯାନଗୁଡ଼ିକ କେତେ ବ୍ୟବଧାନରେ କରାଯାଏ?

ମାସିକ | ଦ୍ୱି-ମାସିକ | ପ୍ରତି ୬ ମାସରେ | ବର୍ଷକୁ ଥରେ | ଥରେ ୨-୩ ବର୍ଷ ରେ | ୫ ବର୍ଷ କିମ୍ବା ଅଧିକ

୧୪.୨ ଯଦି ହଁ, ହାରାହାରି, କେତେ ଲୋକ ପରିଦର୍ଶନ କରନ୍ତି?

୧୪.୩ ଯଦି ହଁ, ଆପଣ କିପରି ଉପସ୍ଥିତ ହେବାକୁ ଲୋକଙ୍କୁ ଉତ୍ସାହିତ କରନ୍ତି ?

୧୫. ରୋଗୀମାନେ ସ୍ତ୍ରୀନିର୍ଦ୍ଧାରଣ ପାଇଁ ଭିଜନ ସେଣ୍ଟରକୁ ଆସନ୍ତି କି?

୧୫.୧ ଯଦି ନୁହେଁ, ତେବେ ଆପଣଙ୍କ ଅନୁଯାୟୀ କାରଣଗୁଡ଼ିକ କ'ଣ?

୧୬. ଆପଣ ଭାବୁଥିବେ କି ସ୍ତ୍ରୀନିର୍ଦ୍ଧାରଣ ସାଇଟ୍ ପରିଦର୍ଶନ କରିବାକୁ ଲୋକଙ୍କୁ କ'ଣ ପ୍ରେରଣା ଦିଏ, ଯଦିଓ ସେମାନଙ୍କର ଲକ୍ଷଣ ନଥାଏ?

ସୁପାରିଶ ଏବଂ ଅଗ୍ରଗାମୀ ପଥ

୧୭. Glaucoma ର ଯାନ୍ତ୍ରିକ SOP ବିଷୟରେ ଆପଣ ଅବଗତ କି?

୧୮. Glaucoma ଚିକିତ୍ସା ଏବଂ ସେବା ପାଇଁ କ'ଣ କରିବା ଉଚିତ ବୋଲି ଆପଣ ପରାମର୍ଶ ଦିଅନ୍ତି?

୧୯. ଆପଣ କିପରି ଏହି ଅଞ୍ଚଳରେ Glaucoma ବିଷୟରେ ସଚେତନତା ବୃଦ୍ଧି କରିବାକୁ ପରାମର୍ଶ ଦେବେ ?

Annexure 6: Focus Group Discussions with at-risk populations (English and Oriya)

Target Group 2: General Population at risk – Above 40 years

Tool Used: Focus-Group Discussion

Target Population: 3 groups with 8-10 members each

The FGD starts with an activity – ‘What would you not be able to do if you could not see? And songs with the importance of eyesight’ // Blindfolding

Basic Profile

Name:

Age:

Gender:

Educational Qualification:

Occupation:

Understanding the patient and the area

1. What are the common eye health problems you face?
2. Have you ever been to an eye doctor/ophthalmologist? If yes, then what was the reason?
3. How often do you get your eyes checked?
4. Do you visit an ophthalmologist as a part of routine healthcare?
5. Who do you talk to about eyecare issues?
6. Have you ever heard about glaucoma?
7. If yes, what do you know about it?
8. What are your common sources for receiving information on eye health?
9. Have you actively visited an eye health camp?
10. If yes, what drew you to it?
11. Apart from camps, do you ever voluntarily visit screening sites like Vision centres or Hospitals for Glaucoma screening?
12. How far do you have to go to seek eye care in the area of your residence?
 - 12.1 How do you travel to it?
13. Do you visit any eye care centre other than Sankara Hospital? Are these government or private?
14. Are you aware of any eye health schemes of the government? Please elaborate.
15. How has your experience at eye care facilities been like?
16. What are the barriers to accessing eye care?

Recommendations

17. What do you think can be done to improve the quality of screening and/or treatment for Glaucoma?
18. In your opinion, how can the awareness of Glaucoma be enhanced in your region?

Questionnaire in Odiya

ଟାର୍ଗେଟ୍ ଗ୍ରୁପ୍ 2 : ବିପଦରେ ଥିବା ସାଧାରଣ ଜନସଂଖ୍ୟା - 40 ବର୍ଷରୁ ଅଧିକ

ବ୍ୟବହୃତ ଉପକରଣ : କେନ୍ଦ୍ରିତ - ଗୋଷ୍ଠୀ ଆଲୋଚନା

ଲକ୍ଷ୍ୟ ଜନସଂଖ୍ୟା (Target Population): ଶା ଗୋଷ୍ଠୀରେ, ପ୍ରତ୍ୟେକ 8-10 ସଦସ୍ୟଙ୍କ ସହିତ

FGD ଏକ କାର୍ଯ୍ୟକଳାପରୁ ଆରମ୍ଭ ହୁଏ - 'ଯଦି ଆପଣ ଦେଖି ନ ପାରନ୍ତି ତେବେ ଆପଣ କ'ଣ କରିପାରିବେ ନାହିଁ? ଏବଂ ଆଖି ଦୃଷ୍ଟିର ଗୁରୁତ୍ୱ / ଦୃଷ୍ଟିହୀନ ସହିତ ଗୀତରେ '

ମୌଳିକ ପ୍ରୋଫାଇଲ୍

ନାମ :

ବୟସ :

ଲିଙ୍ଗ :

ଶିକ୍ଷାଗତ ଯୋଗ୍ୟତା :

ବୃତ୍ତି :

ରୋଗୀ ଏବଂ ଅଞ୍ଚଳକୁ ଦୁର୍ଦ୍ଦିବା

୧. ଆପଣ ସାମ୍ନା କରୁଥିବା ସାଧାରଣ ଚକ୍ଷୁ ସ୍ୱାସ୍ଥ୍ୟ ସମସ୍ୟାଗୁଡ଼ିକ କ'ଣ?
୨. ଆପଣ କେବେ ଚକ୍ଷୁ ଡାକ୍ତର / ଚକ୍ଷୁ ବିଶେଷଜ୍ଞଙ୍କ ନିକଟକୁ ଯାଇଛନ୍ତି କି? ଯଦି ହଁ, ତେବେ ଏହାର କାରଣ କ'ଣ ଥିଲା?
୩. ଆପଣ କେତେଥର ଆଖି ଯାଞ୍ଚ କରନ୍ତି?
୪. ଆପଣ ନିୟମିତ ସ୍ୱାସ୍ଥ୍ୟସେବାର ଏକ ଅଂଶ ଭାବରେ ଚକ୍ଷୁ ବିଶେଷଜ୍ଞଙ୍କ ନିକଟକୁ ପରିଦର୍ଶନ କରନ୍ତି କି?
୫. ଚକ୍ଷୁ ସମସ୍ୟା ବିଷୟରେ ଆପଣ କାହା ସହିତ କଥାବାର୍ତ୍ତା କରନ୍ତି?
୬. ଆପଣ କେବେ Glaucoma ବିଷୟରେ ଶୁଣିଛନ୍ତି କି?
୭. ଯଦି ହଁ, ଆପଣ ଏହା ବିଷୟରେ କ'ଣ ଜାଣନ୍ତି?
୮. ଆଖି ସ୍ୱାସ୍ଥ୍ୟ ବିଷୟରେ ସୁଚନା ପାଇବା ପାଇଁ ଆପଣଙ୍କର ସାଧାରଣ ଉତ୍ସରୁଡ଼ିକ କ'ଣ?
୯. ଆପଣ ସକ୍ରିୟ ଭାବରେ ଏକ ଚକ୍ଷୁ ସ୍ୱାସ୍ଥ୍ୟ ଶିବିର ପରିଦର୍ଶନ କରିଛନ୍ତି କି?
୧୦. ଯଦି ହଁ, ଆପଣଙ୍କୁ ଏହା ଆଡ଼କୁ କ'ଣ ଆକର୍ଷିତ କଲା?
୧୧. କ୍ୟାମ୍ପ ବ୍ୟତୀତ, ଆପଣ କେବେ ସ୍ୱେଚ୍ଛାକୃତ ଭାବେ Glaucoma ସ୍ତ୍ରୀମାନଙ୍କ ପାଇଁ ଭିଜନ ସେଣ୍ଟର କିମ୍ବା ହସ୍ପିଟାଲ୍ ପରି ସ୍ତ୍ରୀମାନଙ୍କୁ ସାଇଟ୍ ପରିଦର୍ଶନ କରନ୍ତି କି?
୧୨. ତୁମ ବାସସ୍ଥାନ ପରିସରରେ ଚକ୍ଷୁ ଯତ୍ନ ନେବାକୁ କେତେ ଦୂର ଯିବାକୁ ପଡ଼ିବ?
୧୨.୧ ଆପଣ କିପରି ଯାତ୍ରା କରିବେ / ଯିବେ ?
୧୩. ଆପଣ ଶଙ୍କର ହସ୍ପିଟାଲ୍ ବ୍ୟତୀତ ଅନ୍ୟ କୌଣସି ଚକ୍ଷୁ ଚିକିତ୍ସା କେନ୍ଦ୍ର ପରିଦର୍ଶନ କରନ୍ତି କି?
ଏହି ସରକାରୀ ନା ବେସରକାରୀ?
୧୪. ସରକାରଙ୍କ କୌଣସି ଆଖି ସ୍ୱାସ୍ଥ୍ୟ ଯୋଜନା ବିଷୟରେ ଆପଣ ଅବଗତ କି? ଦୟାକରି ବିସ୍ତାର କରନ୍ତୁ ।
୧୫. ଚକ୍ଷୁ ଚିକିତ୍ସା କେନ୍ଦ୍ର ଗୁଡ଼ିକରେ ଆପଣଙ୍କର ଅଭିଜ୍ଞତା କିପରି ହୋଇଛି?
୧୬. ଚକ୍ଷୁ ଯତ୍ନ ନେବାରେ କ'ଣ ପ୍ରତିବନ୍ଧକ ଅଛି?

ସୁପାରିଶ

୧୭. Glaucoma ସ୍ତ୍ରୀମାନଙ୍କ ପାଇଁ ଏବଂ / କିମ୍ବା ଚିକିତ୍ସାର ଗୁଣରେ ଉନ୍ନତ ଆଣିବା ପାଇଁ କ'ଣ କରାଯାଇପାରିବ ବୋଲି ଆପଣ ଭାବୁଛନ୍ତି?

୧୮. ଆପଣଙ୍କ ମନରେ, ଆପଣଙ୍କ ଅଞ୍ଚଳରେ Glaucoma ବିଷୟରେ

Annexure 7: In-Depth Interviews with PWG (English and Oriya)

Target Group 3: Population identified with glaucoma.

Tools Used: In-Depth Interviews

Target Population: 15-20

Basic Profile

Name:

Age:

Gender:

Educational Qualification:

Occupation:

Understanding the patient and the area

1. What is your understanding of glaucoma?
2. Has any other member of your family previously been diagnosed with Glaucoma?
If yes, where and how did they seek treatment for it?
3. Where did you first receive information about glaucoma?
4. What are your common sources for receiving information on eye health?
*Radio | News/TV Mobile Phone/WhatsApp | Newspaper| Announcements in health facility/panchayat/community | Word of mouth (Neighbour/Friend) | Community Health worker
Hospital Staff | Any other (please specify)*
5. Who do you talk to about eyecare issues?
6. Did you take decisions for your treatment independently or any other family member helped you in this regard?
7. When did you get screened and diagnosed with glaucoma?
8. What encouraged you to get screened? Where was it done?
*What: someone I know got diagnosed | I was attending a health camp| Self-motivation
Where: vision centre | Sankara Eye Hospital | any other place (please specify)*
9. What was your first reaction when you were diagnosed with glaucoma?
9.1 What were some of your worries when you learned you had glaucoma? (probe if there is no response: cost of treatment, infecting others, change in lifestyle, future of your eyesight)
10. How has having glaucoma impacted your daily functioning?
11. How has your family supported your post-diagnosis?

12. What has been the doctor's recommendation for your treatment?
13. Do you take these medications regularly?
 - 13.1 Have you been advised of surgery? If yes, did you take it? If not, why?
14. On average, what is your monthly out-of-pocket expenditure towards glaucoma care?
15. Have you ever faced difficulties in accessing the services? If yes, what are they?
16. Are you aware of any govt. schemes related to eye health? If yes, please elaborate.

Recommendations

17. What do you think can be done to improve the quality of screening and/or treatment for Glaucoma?
18. In your opinion, how can the awareness on Glaucoma be enhanced in your region?

Questionnaire in Odiya

ଟାଗ୍‌ଲାଇନ୍ ଗୁପ୍ତ ନାମ : Glaucoma ଚିକିତ୍ସା ଜନସଂଖ୍ୟା

ବ୍ୟବହୃତ ଉପକରଣଗୁଡ଼ିକ : ଗଢ଼ାରିତା ସାକ୍ଷାତକାର

ଲକ୍ଷ୍ୟ ଜନସଂଖ୍ୟା (Target Population): ୧୫ – ୨୦

ମୌଳିକ ପ୍ରୋଫାଇଲ୍

ନାମ :

ବୟସ :

ଲିଙ୍ଗ :

ଶିକ୍ଷାଗତ ଯୋଗ୍ୟତା :

ବୃତ୍ତି :

ରୋଗୀ ଏବଂ ଅଞ୍ଚଳକୁ ବୁଝିବା

୧. Glaucoma ବିଷୟରେ ତୁମର ବୁଝାମଣା କ'ଣ / ତୁମେ କଣ ଜାଣିଛ?

୨. ଆପଣଙ୍କ ପରିବାରର ଅନ୍ୟ କୌଣସି ସଦସ୍ୟ ପୂର୍ବରୁ Glaucoma ରୋଗରେ ଆକ୍ରାନ୍ତ ହୋଇଥିଲେ କି? ଯଦି ହଁ, ସେମାନେ କେଉଁଠାରେ ଏବଂ କିପରି ଏହାର ଚିକିତ୍ସା ପାଇଁ ଖୋଜିଲେ?

୩. Glaucoma ବିଷୟରେ ପ୍ରଥମେ ଆପଣ କେଉଁଠାରୁ ସୂଚନା ପାଇଲେ?

୪. ଆଖି ସ୍ୱାସ୍ଥ୍ୟ ବିଷୟରେ ସୂଚନା ଗ୍ରହଣ କରିବା ପାଇଁ ଆପଣଙ୍କର ସାଧାରଣ ଉତ୍ସାହଗୁଡ଼ିକ କ'ଣ?

ରେଡିଓ | ସମ୍ବାଦ / ଟିଭି | ମୋବାଇଲ୍ ଫୋନ୍ / Whats App | ଖବରକାଗଜ | ସ୍ୱାସ୍ଥ୍ୟ ସୁବିଧା / ପଞ୍ଚାୟତ / ସମ୍ପ୍ରଦାୟରେ ଘୋଷଣା || ମୁଖର ଶବ୍ଦ (ପତ୍ରେକା / ବନ୍ଧୁ) || ସମ୍ପ୍ରଦାୟ ସ୍ୱାସ୍ଥ୍ୟ କର୍ମୀ | ହସ୍ପିଟାଲ କର୍ମଚାରୀ | ଅନ୍ୟ କୌଣସି (ଦୟାକରି ନିର୍ଦ୍ଦିଷ୍ଟ କରନ୍ତୁ)

୫. ଚକ୍ଷୁ ସମସ୍ୟା ବିଷୟରେ ଆପଣ କାହା ସହିତ କଥାବାର୍ତ୍ତା କରନ୍ତି?
୬. ଆପଣ ସ୍ୱାଧୀନ ଭାବରେ ଆପଣଙ୍କର ଚିକିତ୍ସା ପାଇଁ ନିଷ୍ପତ୍ତି ନେଇଛନ୍ତି ନା ପରିବାରର ଅନ୍ୟ କୌଣସି ସଦସ୍ୟ ଆପଣଙ୍କୁ ଏହି କ୍ଷେତ୍ରରେ ସାହାଯ୍ୟ କରିଛନ୍ତି?
୭. ଆପଣ କେବେ ସ୍ତ୍ରୀ ହୋଇ Glaucoma ରୋଗ ନିର୍ଣ୍ଣୟ କଲେ?
୮. ସ୍ତ୍ରୀ କରୁଥିବା ଆପଣଙ୍କୁ କ'ଣ ଉତ୍ସାହିତ କଲା? ଏହା କେଉଁଠାରେ କରାଯାଇଥିଲା?
*କ'ଣ: ମୁଁ ଜାଣେ କେହି ରୋଗ ନିର୍ଣ୍ଣୟ କଲେ | ମୁଁ ଏକ ସ୍ୱାସ୍ଥ୍ୟ ଶିବିରରେ ଯୋଗ ଦେଇଥିଲି | ଆତ୍ମ-ପ୍ରୋଗ୍ରାମ |
 କେଉଁଠାରେ: ଦର୍ଶନ କେନ୍ଦ୍ର | ସଙ୍କରା ଚକ୍ଷୁ ଚିକିତ୍ସାଳୟ | ଅନ୍ୟ କୌଣସି ସ୍ଥାନ (ଦୟାକରି ନିର୍ଦ୍ଦିଷ୍ଟ କରନ୍ତୁ)*
୯. ଯେତେବେଳେ ତୁମେ Glaucoma ରୋଗରେ ଆକ୍ରାନ୍ତ ହେଲ ତୁମର ପ୍ରଥମ ପ୍ରତିକ୍ରିୟା କ'ଣ ଥିଲା?
 ୯.୧ ଯେତେବେଳେ ତୁମର Glaucoma ଅଛି ବୋଲି ଜାଣିବା ପରେ ତୁମର ଚିନ୍ତା କ'ଣ ଥିଲା?
 (ଯଦି କୌଣସି ପ୍ରତିକ୍ରିୟା ନାହିଁ ଯାଞ୍ଚ କରନ୍ତୁ: ଚିକିତ୍ସାର ମୂଲ୍ୟ, ଅନ୍ୟମାନଙ୍କୁ ସଂକ୍ରମିତ କରିବା, ଜୀବନଶୈଳୀରେ ପରିବର୍ତ୍ତନ, ଆପଣଙ୍କ ଦୃଷ୍ଟି ଶକ୍ତିର ଭବିଷ୍ୟତ)
୧୦. Glaucoma ରହିବା ଆପଣଙ୍କ ଦୈନନ୍ଦିନ କାର୍ଯ୍ୟକୁ କିପରି ପ୍ରଭାବିତ କରିଛି?
୧୧. ପରବର୍ତ୍ତୀ ନିରାକରଣ ପାଇଁ ଆପଣଙ୍କ ପରିବାର ଆପଣଙ୍କୁ କିପରି ସମର୍ଥନ କରିଛନ୍ତି?
୧୨. ଆପଣଙ୍କ ଚିକିତ୍ସା ପାଇଁ ଡାକ୍ତରଙ୍କ ସୁପାରିଶ କ'ଣ ଅଛି ?
୧୩. ଆପଣ ଏହି ଔଷଧ ଗୁଡ଼ିକୁ ନିୟମିତ ଗ୍ରହଣ କରନ୍ତି କି?
 ୧୩.୧ ଆପଣଙ୍କୁ ଅସ୍ତ୍ରୋପଚାର ପାଇଁ ପରାମର୍ଶ ଦିଆଯାଇଛି କି? ଯଦି ହଁ, ଆପଣ ଏହାକୁ ନେଇଛନ୍ତି କି? ଯଦି ନୁହେଁ, କାହିଁକି?
୧୪. ହାରାହାରି, Glaucoma ଯତ୍ନ/ ଚିକିତ୍ସା ପାଇଁ ଆପଣଙ୍କର ମାସିକ ଖର୍ଚ୍ଚ କ'ଣ?
୧୫. ଆପଣ ସେବାଗୁଡ଼ିକୁ ପାଇବା ପାଇଁ କେବେ ଅସୁବିଧାର ସମ୍ମୁଖୀନ ହୋଇଛନ୍ତି କି? ଯଦି ହଁ, କ'ଣ?
୧୬. ଆପଣ କୌଣସି ସରକାରୀ ଆଖି ସ୍ୱାସ୍ଥ୍ୟ ସମ୍ପନ୍ନାୟ ଯୋଜନାଗୁଡ଼ିକ ବିଷୟରେ ଅବଗତ କି? ଯଦି ହଁ, ଦୟାକରି ବିସ୍ତାର କରନ୍ତୁ |

ସୁପାରିଶ

୧୭. Glaucoma ସ୍ତ୍ରୀ ପାଇଁ ଏବଂ / କିମ୍ବା ଚିକିତ୍ସାର ଗୁଣରେ ଉନ୍ନତ ଆଣିବା ପାଇଁ କ'ଣ କରାଯାଇପାରିବ ବୋଲି ଆପଣ ଭାବୁଛନ୍ତି?
୧୮. ଆପଣଙ୍କ ମତରେ, ଆପଣଙ୍କ ଅଞ୍ଚଳରେ Glaucoma ବିଷୟରେ ସଚେତନତା କିପରି ବୃଦ୍ଧି କରାଯାଇପାରିବ?

Annexure 8: List of Tables

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- Table 2: Age Bifurcation of People diagnosed with Glaucoma (PWG)
- Table 3: Visual impairment in PWG
- Table 4: Age Bifurcation of PWG
- Table 5: Sex Bifurcation of PWG

- Table 6: Prevalence of Glaucoma divided across levels of visual impairment.
- Table 7: Prevalence of Glaucoma divided across levels of IOP
- Table 8: Prevalence of Glaucoma divide across the range of CDR
- Table 9: Distribution of types of Glaucoma (eye)
- Table 10: Types of Glaucoma with visual impairment levels (Eye)
- Table 11: Types of Glaucoma with Intraocular Pressure Test (Eye)
- Table 12: Types of Glaucoma with Cup-Disk Ratio (Eye)
- Table 13: Distribution of types of glaucoma (persons)
- Table 14: Distribution of glaucoma across age groups (Eye)
- Table 15: Distribution of glaucoma across sex (Eye)
- Table 16: Glaucoma with different levels of visual impairment (Person)
- Table 17: Types of Glaucoma with Cup-Disc Ratio (Person)
- Table 18: Glaucoma suspect with age criteria
- Table 19: Treatment Advised for different types of Glaucoma
- Table 20: Primary Research Respondents

Annexure 9: List of Figures

- Figure 1: COM-B Model
- Figure 2: Ganjam district, Odisha
- Figure 3: Research Framework
- Figure 4: Treatment taken, as advised by the hospital (clockwise, from the top left): Glaucoma surgery, Laser PI, Medical management, and others on the basis of eye
- Figure 5: Treatment taken, as advised by the hospital (clockwise, from the top left): Glaucoma surgery, Laser PI, Medical management, and others on the basis of individual
- Figure 6: Trajectory of PWG
- Figure 7: IDI Methodology
- Figure 8: Age & Sex Bifurcation of Glaucoma Patients
- Figure 9: Educational Qualification of respondents
- Figure 10: Occupational Profile of the respondents
- Figure 11: Excerpt from IDI on blaming luck for illness
- Figure 12: Excerpt from FGD on low awareness
- Figure 13: Excerpt from IDIs on lack of somatic consciousness
- Figure 14: Excerpt from IDIs on community-based care model
- Figure 15: Excerpt from IDIs on the high cost of care
- Figure 16: Excerpt from IDIs by vision technician on patient experiences of cost
- Figure 17: Excerpt from IDIs on the importance of eyes
- Figure 18: Common mediums of communication



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