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Barriers to accessing eye care services in Timor-Leste

Draft Report

Produced for Fred Hollow Foundation by SSTL



The **Fred Hollows**
Foundation



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TERMS AND ACRONYMS

Terms

Adat	Traditional customs and law (also lisan (Tetun))
Administrative Post	Governance division between municipality and suco levels
Aldeia	A Hamlet/ Sub-Village
Lisan	Traditional customs and law (also adat (Indonesian))
Matan dook	Seer/healer
Municipality	Governance division between national and administrative post
Suco	Village locality
Xefe	Leader or Chief of a suco (village) or aldeia (sub-village)

Acronyms

ADMB	Asosiasaun Deficiente Matan Bobonaro/ Blind Persons Association Bobonaro	HF	Health Facility
AHDMTL	Asosiasaun Hadomi ema ho Defisiénsia Matan Timor-Leste/Association for the Care of People with Vision Disabilities Timor-Leste	HMH	Ministry of Health
ATLASS II	Australia Timor-Leste Program of Assistance for Secondary Services - Phase II	HMIS	Health Management Information System
CEEHAT	Community Engagement in Eye Health Assessment Tool	HNGV	Hospital Nacional Guido Valadares
CHC	Community Health Centre	HP	Health Post
DFAT	Department of Foreign Affairs and Trade	HR	Human Resources
DPO	Disability People's Organisation	INO	International Non-governmental Organisation
EAVP	East Asia Vision Program	INS	National Institute of Health Timor-Leste
ECN	Eye Care Nurse - Eye Nurse With A Bachelor's Degree	LGBTQI+	Lesbian, Gay, Bi-sexual, Trans-sexual, Queer, Intersex and other non-conforming
ECSP	Eye Care Strategic Plan 2020- 2050	MoH	Ministry of Health
ECT	Eye Care Technician - Eye Nurse With A Diploma 1 Qualification And Specialist Nurse Training	MSSI	Ministry of Social Solidarity and Inclusion
ECW	Eye Care Worker	NEC	National Eye Centre (also the *DO, Department of Ophthalmology)
EHSSP	Eye Health Sector Strengthening Program	NGO	Non-Government Organisation
EHU	Eye Health Unit	NEHSP	National Eye Health Strategic Plan
EME	Ministry of Education	NHSSP	National Health Sector Strategic Plan
FHF	The Fred Hollows Foundation (Australia)	OPD	Out-patient Department
FHF	Fred Hollows Foundation	OT	Operating Theatre
FHFNZ	Fred Hollows Foundation New Zealand	PEC	Primary Eye Care
FMP	Family Medicine Program	PGDO	Post Graduate Diploma of Ophthalmology
FNTL	Fo Naroman Timor Leste	PSF	Promote Saúde Família
FPAR	Feminist Participatory Action Research	RAAB	Rapid Assessment of Avoidable Blindness
GoTL	Government of Timor-Leste	RACS	Royal Australasian College of Surgeons
HNGV	Guido Valadares National Hospital	RHTO	Ra'es Hadomi Timor-Oan/Disabled Persons' Organisation
		ROC	Regional Operations Coordinator, Australasia Regional Team, The Fred Hollows Foundation
		RPC	Regional Program Coordinator Australasia Regional Team, The Fred Hollows Foundation
		SAMES	Servicio Autónomo de Medicamentos e Equipamentos de Saúde
		SISCa	Sistema Integrado Saúde Comunitaria (Community outreach health services)
		SnF	Saúde na Família
		SSTL	Sustainable Solutions Timor-Leste
		TLNU	Timor Lorosa'e National University
		UNTL	Universidade Nacional Timor Lorosa'e (National University of Timor-Leste).
		URE	Uncorrected Refractive Error
		WGC	Washington Group Classification
		WGC-SS	Washington Group Classification Short Set Questions
		WHO	World Health Organisation

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Photo by Hugh Rutherford, 2011, supplied by FHF

EXECUTIVE SUMMARY

This study was initiated by Fred Hollows Foundation to work towards ensuring that programming related to eye health services is inclusive and does not exacerbate existing inequities. This study aimed to identify current barriers to accessing eye care services and to provide an in depth understanding of how the barriers were experienced differently by people with disability, women, girls, men, boys and those based in remote communities. It also aimed to identify opportunities to overcome the barriers to ensure that eye care services become more inclusive and accessible for all people. This report provides some practical suggestions of how to mitigate the barriers identified in the study (see Recommendations, p.10).

The target audience for this report is the Ministry of Health, Fred Hollows Foundation and Royal Australasian College of Surgeons (RAACS), and others involved in implementing, programming and decision making about eye health care in Timor-Leste. As such, the report assumes a level of awareness about the context and background to eye health care in Timor-Leste.

This study investigated knowledge, attitude and practices related to eye health and the use of glasses through an online survey and qualitative data collection tools. Stakeholder consultations and participatory exercises with identified respondents from the three target areas of Dili, Baucau and Bobonaro helped to inform the methodology in line with feminist, participatory action research principles. Data collection methods were developed using the Community Engagement in Eye Health Assessment Tool (CEEHAT) to assess community understanding, trust, motivation and opportunity to engage with eye health and care and identify areas for eye health service quality improvement. Online data collection methods were used during the study due to COVID-19 limitations.

The online survey was sent out via networks for respondents to either self-complete or complete with assistance. Despite challenges with respondents needing assistance to complete the survey and poor internet at the time (including four days of nation-wide outages), the survey reached 86 people in Dili, Baucau and Bobonaro. Within these limitations, the results give insight into the barriers people face and the gender and social factors variables that either increase or reduce those barriers. Fifteen in-depth interviews and journey maps provided the study with more detailed and nuanced information with which to understand the survey results. Interviews with health workers and local authorities helped to form a broader picture of the eye health sector, which has achieved remarkable gains over the past 20 years.

Overall, the findings show very clearly a demand and strong desire for eye health care, 80% of respondents are currently experiencing eye health issues and 95% would like to have a health worker follow-up with them. People are not following up themselves because they don't know enough about eye health and accessing services and care, and because they face multiple barriers and eye health is therefore de-prioritised. Proactively reaching out to people to meet their desire and demand for eye health care would address some of the most prominent barriers to accessing eye health care across all populations, especially more marginalised ones.

Barriers

Local health centres were a key point of people not continuing their health journeys. A lack of resources, poor treatment, unclear working hours and a lack of information and knowledge were all key factors in why health centres were a barrier to accessing eye health care; this also negatively impacted on early intervention where people were deterred from either seeking or continuing care. Difficulty with accessing services was found to be a major challenge for some people, who although they tried multiple times, have now given up in their efforts to access eye health care.

The Ministry of Health actively providing clear information about symptoms, services, treatments and the time and cost associated with these, along with easy to reach points of contact and good communication with health workers (both at the health service and through community conduits) could remove a significant number of the barriers identified in this study.

Payment for associated costs was raised as a key barrier in opportunity to access eye health care, followed closely by transport. This highlights the need for support to people in remote areas and that effective public health promotion and clinical services outreach can be critical tools in addressing preventable blindness. The journey mapping and interviews with health workers and community members highlight a number of the key challenges with outreach being able to effectively reach those in need, including not taking more than one contact phone number to follow up with patients, regular cancellations of planned trips and not providing people with sufficient notice to attend.

This study shows that **the primary barrier to people seeking eye-care is information**, which has an impact on understanding, motivation, trust and the willingness to mobilise resources. The evidence suggests that when people have enough information to make an informed decision, they will prioritise their health and the barriers to opportunity are greatly reduced. However, it is likely that as health promotion materials are increased and improved – and therefore awareness improves – other barriers evident from the study will become more prominent unless they are specifically addressed.

In particular, with improved information and access, it is likely that gender and inclusion barriers will become more prominent as women, people with disabilities and in those remote areas face more opportunity barriers. Despite the small sample size, this study indicates that gendered barriers do exist and they intersect with other socio-economic and geographical factors. People in more remote areas have high barriers to accessing eye care, as do people with disabilities. There were only two gender diverse people in the survey, whose answers were consistent with existing knowledge about LGBTQI+ people facing a lot of discrimination in the health sector. Women with disabilities in remote areas face the greatest barriers and are unlikely to be reached easily without specifically targeting both them, and importantly, their families and communities.

Table A. A summary of the key traits of people with the highest and lowest engagement with eye health scores.

MOST	LEAST
Female	Gender diverse
Married	Single
University	None
30-39	Over 60
Urban	Rural
Salaried	Work, no income
Tetun - very easy	Tetun - difficult

Factoring this expectation of the growing prominence of gender and inclusion barriers into program design now will minimise discrimination against women, people with disabilities and LGBTQI+ people, and help to directly target people in more remote areas. Working closely with community and specific groups, such as disability support groups, community mobilisers and other active networks provides a great bridge into these communities.

Barriers such as not having agency to make decisions about one’s own eye health care, needing to seek permission, not trusting health workers and services, willingness to travel, mistrust of modern medicine and stigma about glasses and their cost were found to be minimal. These findings were supported by the qualitative interviews including journey mapping. Use of traditional medicine appears to be declining for eye health and was widely avoided, with those who had used it expressing regret and a strong aversion to using it in the future.

However, **support from family** for encouragement, information, transport, money and accompaniment was very important for people, which although isn’t adequately covered in the CEEHAT modules, comes through very clearly in the journey mapping and relevant literature.

When people had access to specialist care, they were more likely to continue to treatment, but interruptions from COVID during 2020–2021 may explain why some people haven’t continued. Respondents cited not having enough information, being scared and confused as their primary reasons for not following up with treatment. A lack of follow-up and awareness of the need for regular screening, and that vision deteriorates with time, contributed to people using glasses until they became ineffective and painful – not seeking further care because they didn’t know they should.

Strengthening enablers

Some of these challenges could be easily addressed with minimal resources and through better coordination with eye health service providers, such as maintaining accurate patient lists (with more than one contact number) and having phone credit available for health workers to follow up with patients. Other challenges will require more systematic approaches to planning outreach visits in advance and conducting pre-screenings and information outreach directly or through community focal points.

The findings of the study show that there is community demand for eye health and that improving communications and access to services would likely reduce some of the key barriers. Women, people with disabilities and people in rural areas deserve targeted attention, directly or through families, groups and community activists who are highly mobile in the community. Eye health workers also need support to do their work more effectively and be encouraged to pro-actively engage with the community.

With an estimated 100,000 people suffering from preventable blindness, targeted resources, improved outreach and communications could go a long way in reducing the unnecessary suffering of people across Timor-Leste, starting with the three municipalities where this study was conducted.

“I had two operations and I can now see. I had so much support from my family and I was determined, even though I waited two years until a specialist came to Baucau. I use my experience now to encourage others to get treatment: “Don’t wait! Go to Dili, it’s worth it!”
– Joana, Baucau

RECOMMENDATIONS

The report details specific recommendations throughout to address, in practical terms, the challenges that were identified. They are presented here by strategic area in recognition of the central role of Government and the need to have systematic approaches to addressing eye health access.

The Ministry of Health has the most significant role to play in leading and ensuring allocation of resources to these recommendations, mobilising existing resources and including primary eye health care in its training and programs for community-based health workers. Other agencies, including the Fred Hollows Foundation and Royal Australasian College of Surgeons (RAACS), have key roles to play in providing technical support and additional resourcing.

Public health promotion

- Design and distribute targeted materials for radio, print and social media and ensure there are visual materials, including handouts, at health centres and posts
 - Provide information on symptoms, treatment options and contact details
 - Raise awareness of the need for early intervention through different media, including radio and in local languages
 - Be proactive in advertising when specialist services are available, including raising awareness on surgical treatment available by Timorese health workers
- Target women, people with disabilities, and people in remote areas
- Target schools, church and other public places where people regularly gather and spend time for awareness raising, mobilisation and screening
- Consider the role of a community liaison/health advocate to support outreach, health promotion, awareness raising and provide patient advocacy services

Client-centred care

- Health workers to increase client-centred care
- Health workers provide clear counselling and information to people; in particular to address the key concerns raised, including time, cost and expected outcomes
- Alternatively, this could be done by having a health advocate/community liaison who can also be responsible for outreach
- When people have to wait, provide them with estimated timelines and a way to follow-up themselves
- Provide cash grants and transport assistance for people facing multiple barriers

Human resources

- Training and ongoing support to health workers including through PEC training, key personnel to attend other available training including Disability Inclusive Health, mentoring and clinical supervision for health workers that includes addressing the challenges of providing care
- Mentoring for health workers and visiting workers to be role models
- Facilitate discussions with health workers on challenges faced & solutions

Outreach

- Scale up outreach services that are well coordinated, planned in advance and utilise accurate, well-maintained client databases
- Identify and utilise community outreach workers and focal points
- Use media and networks to raise awareness at least two weeks prior to clinical outreach and screening, ideally this would be ongoing for weeks leading up to visits and involve pre-screening and triage
- Organized in advance, follow-up with interested people, contact through community networks
- Provide assistance with transport for people with accessibility challenges

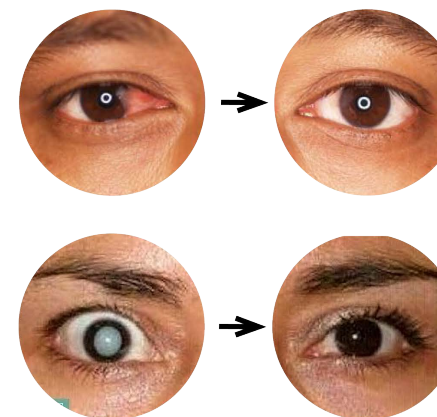
Karik iha problema ho ita nia matan? Keta tahan!

Karik ita nia matan iha sintomas ruma hanesan:

- Manas?
- Matan been sulin?
- Katar?
- Hare la mós?
- Mean?
- Mutin?
- Sente la los?

ANTES

DEPOIS



Se iha problema saúde matan, konsulta sedu!

- Moras balu bele kura ho ai-moruk hosi klínika
- Moras balu bele opera hodi hare mós
- Ema balu presiza oklu hodi hare mós, no la sente moras ona

Keta hein!



Kontatu ohin



Kontatu ba ita nia ekipa saúde sira ho gratuita!

Hakat ba HOREX ou
telefone ba:

Doutór Nuno
7749 7335



Figure 1. During the survey process the SSTL were regularly asked for information to hold onto, and to pass on to others. Based on feedback, SSTL developed simple brochures that can be easily edited and changed.

Systems

- Database with up-to-date client information
- Database to include multiple ways to contact someone
- Develop simple, easy-to-use reminder systems for follow-up, especially for those who are recommended surgery but told to wait
- Ensure regular and dependable opening hours of clinics
- Ensure health workers have adequate resources to contact people and conduct outreach (including having phone credit)

INTRODUCTION

Background

The Fred Hollows Foundation is a non-profit aid organization based in Australia and founded in 1992 by eye surgeon Fred Hollows. The Foundation focuses on treating and preventing blindness and other vision problems. It operates in 26 countries around the world across Australia, The Pacific, South and South-East Asia, the Middle East and Africa.

As an international development agency, The Foundation respects, protects and promotes human rights for all, regardless of race, religion, ethnicity, indigeneity, disability, age, displacement, caste, gender, gender identity, sexuality, sexual orientation, poverty, class, or socio-economic status.

The Foundation has been supporting the eye health sector in Timor-Leste in various capacities since 2010. In 2019, The Foundation commenced a new 'District' Eye Care Project¹, implemented in collaboration with their partners at the Royal Australasian Colleague of Surgeons (RAACS). This project focuses on strengthening systems at the Municipal level to ensure, 'All people in Timor-Leste have ongoing access to high quality, affordable and appropriate eye care services'.

Eye health

Timor-Leste still has a high prevalence of blindness and visual impairment. The 2016 Rapid Assessment of Avoidable Blindness (RAAB) found the age and gender adjusted prevalence of blindness to be 2.8% (Male 2.4%; female 3.1%) (WHO definition of blindness). Severe visual impairment was 4.5% (Male 4.0%; female 4.9%) and moderate vision impairment was 12.5%. Vision Impairment among the 50+ population was 12.5%: Male 12.0%; Female 13.1%.

Cataract is the leading cause of blindness and severe visual impairment, accounting for 84%, however cataract surgical coverage is very low compared to other Southeast Asian countries. Good visual outcome in cataract-operated eyes was 62% (presenting) and 75.2% (best corrected).

The major barriers to the uptake of available cataract surgical services in the country were 'accessibility to the services' (45.5%) and 'not having a support person to accompany individuals to services' (24.8%). A further revelation from the RAAB was the gender inequality among service recipients. The magnitude of blindness was high and cataract surgical coverage was particularly low among females in Timor-Leste.

Emerging causes of ocular impairment in Timor-Leste mirror the increasing burden of non-communicable disease and increasing age of the Timorese population and include glaucoma and diabetic retinopathy. A 2013-14 estimate of diabetic retinopathy suggested a 15% point-prevalence of diabetes mellitus in an unselected ocular outpatient population, of who 18.6% had evidence of diabetic retinopathy, an aggressive degenerative disease of the retina².

2 Dawkins, R.C.H., Oliver, G.F., Sharma, M. et al. An estimation of the prevalence of diabetes mellitus and diabetic retinopathy in adults in Timor-Leste. BMC Res Notes 8, 249 (2015). <https://doi.org/10.1186/s13104-015-1171-3>

1 Now Municipality - formerly district.

Gender

Women and men's entrenched roles are not only influenced by traditional culture, but also by the introduction of Catholicism by the Portuguese colonists; the brutally violent and militarised Indonesian occupation; and further by the progressive international norms and gender policies advocated for by the UN administration and the influx of international development and humanitarian agencies since the country's independence.

Women are still usually expected to be responsible for household and domestic jobs, while men are able to participate in decision-making roles within society and in formal employment. While there has been an increase in women's participation in the formal sector, and representation in parliament (due to introduced quotas) they are still expected to look after the household and domestic spheres³. There is also extremely low participation of women in leadership roles, particularly local village leadership (Xefe Suco) throughout rural areas of the country. Men's participation in the labour force is 50.8% compared to women at 24.6%⁴.

Gender-related barriers can be seen across the health sector in general. Equitable participation of women across the health sector, particularly in leadership and governance roles is not realised, and health information is insufficiently sex disaggregated. An important consideration is that there is a lack of suitable accommodation for midwives, single female doctors and married couple doctors making remote postings hard for women to fill.⁵

For eye health specifically, the 2016 RAAB shows that Timorese women suffer from blindness

3 TL18-01 Project Implementation Plan, 2019, p.21

4 TL18-01 Project Implementation Plan, 2019, p.22

5 TL18-01 Project Implementation Plan, 2019, p.28

and visual impairment at a slightly greater rate than men but that women were less likely to access surgery for cataract, the leading cause of blindness and visual impairment. The RAAB concluded, "magnitude of blindness was high, and cataract surgical coverage was too low among the female gender in the country." This study aimed to understand some of the reasons for this gender inequity.

Background information - People with a Disability

This study aimed to understand challenges in accessing healthcare, and specifically eye health care, for people with disabilities.

During initial scoping visits for the project the project team met with local Disabled Persons Organisations (DPOs). Only a few of the DPOs provide support services for those with permanent vision impairment but all said they were aware of the National Eye Centre (NEC) and refer people there if they are suffering from vision impairment.

Rationale

To better address eye health needs and make sure that future program designs are appropriate, it is important to explore the knowledge, attitude and behaviour of people with eye health needs. The Community Engagement in Eye Health Assessment Tool (CEEHAT) domains can help us better understand how awareness, attitudes and opportunities fit together and how they are different for different populations. The qualitative part of the study aimed to better understand the nuance and factors behind the domain scores, as well as people's actual experiences in seeking (or not) eye health care. Through the process of the study, the systems and processes around eye health care promotion and implementation were also looked at, to see where some of the institutional barriers and opportunities may exist.



Image 1. Dr Susani Barros examines a patient. Dr supplied photo, 2021

Objectives

1. To identify the barriers that prevent people from accessing and utilising eye health care services and to specify which of these are gender specific barriers and why
2. To understand the barriers faced by people with a disability in accessing eye care, and if this is also impacted by gender and/or other factors
3. To identify service provider's perspectives to the barriers to eye health care access for women and girls, people with a disability and rural populations
4. Provide specific recommendations for gender-targeted interventions to mitigate gendered barriers and thus improve access to eye health services in Timor-Leste
5. Provide specific recommendations for targeted interventions to mitigate barriers for people with a disability and improve the delivery of equitable eye health services in Timor-Leste
6. Provide specific recommendations for targeted interventions to mitigate barriers for remote populations and improve access to eye health services for all Timorese
7. To provide a broad overview of barriers to participating in the eye health workforce as this relates to gender, people with a disability and remote populations

Findings audience and utilization

- The Fred Hollows Foundation and our implementing partner, The Royal Australasian College of Surgeons (RACS), to inform GESI specific initiatives within the Timor-Leste District Eye Care Project
- Ministry of Health Timor-Leste, to inform implementation of the National Eye Health Strategic Plan (NEHSP)
- Other Eye health Stakeholders in Timor-Leste
- Gender focused organisations and stakeholders
- Disabled Persons Organisations and stakeholders

FRAMEWORK⁶

The survey and qualitative follow-up investigated knowledge, attitude and practices related to eye health and the use of glasses. It assumed that these factors have an association between each other, meaning that knowledge improvement through awareness campaigns will promote good attitude and ultimately lead to the desirable positive change in behaviour;⁷ with the assumption that although people also need the opportunity, they are often resourceful when a health issue is prioritised.

With other studies showing that negative experiences with health services are common, and negatively affect engagement, it was also assumed that trust in health services would impact on people seeking eye health care.

The Community Engagement in Eye health Assessment Tool (CEEHAT) assesses community opportunity, capacity and motivation to engage with eye health and care and identify areas for eye health service quality improvement. It was developed in 2020 by a group of public health researchers who saw the need to have more standardised approaches to the array of knowledge, attitude, practices and behaviour (KAPB) surveys that are in use, as well as define community engagement in eye health⁸.

The tool comprises ten modules, one essential, three demographic and six optional. This study used the essential and demographic modules with some modification, as well as elements of four others, excluding the trachoma and river blindness modules. To ensure a logical flow in the survey, questions were moved around but clearly mapped to each module and supplemented as required – for example, additional questions on glasses and support required.

Module 1 provides us with the “CEEHAT Scores” which are presented throughout this report, broken down by domain. These domains help to measure people's level of understanding, trust, motivation and opportunity to access eye health care, as well as using the Washington Group Short Set to assess level of difficulty. The intention of these domain or CEEHAT scores is to help guide focus on program intervention areas. The scores from Indonesia are provided as one basis of comparison.

The tables present the minimum and maximum score that was recorded by individual respondents as well as the mean and median score. The mean score is provided as at least one other CEEHAT-based study used this and it can be a useful comparison. The median score is provided in accordance with ordinal data scale Likert responses. All Likert questions had a minimum of four, and a maximum according to the number of questions multiplied by four (five questions provides a maximum possible score of 20). All domains had a maximum score which was equal to the maximum possible score.

⁶ Adapted from Fred Hollows Foundation Community Engagement in Eye health Assessment Tool (CEEHAT) Version 1
⁷ Congdon N, Li L, Zhang M, Yang A, Gao Y, Griffiths S, et al. Randomized, controlled trial of an educational intervention to promote spectacle use in rural China: The see well to learn well study. *Ophthalmology*. 2011;118(12):2343-50.
⁸ How Can We know What Helps and What Hinders People Accessing Eye Care? CEEHAT- Eye Zone Magazine – Middle East 2020

Definition of community engagement in eye health:

Community engagement in eye health care refers to behaviours people might engage in to minimise the risk of vision loss and eye disease, and/or optimise eye health and vision.

– Fred Hollows Foundation
 Community Engagement in Eye health Assessment Tool (CEEHAT)
 Version 1

THE DOMAINS



Understanding

Knowledge is created through both education and experience, this study assessed the extent to which people had knowledge, awareness and understanding about factors including:

- Positive eye care behaviours (including seeking regular eye health care)
- Where to access eye health care
- Whether people had received information and where from
- Awareness of risk for eye disorders

The survey did not look at local knowledge and beliefs around eye care but did investigate whether people used traditional medicines and the qualitative part of the study further explored this.



Motivation

The study wanted to explore further whether people think their eye health is important and then based on a previous study in Indonesia, explored people's attitudes to glasses in more depth.⁹ The survey also looked at use of traditional treatments for eye and general health care, with the assumption that because these are easier to access and understand, people may have a preference to use them.¹⁰

9 Fred hollows Foundation, 2020, Knowledge, Attitude, and Practice Related to the Use of Glasses among Students, Parents and Teachers in Nusa Tenggara Barat (NTB) Province

10 Traditional medicine, Alternative medicine, Ethno-medicine, Complementary medicine, Timor-Leste, 2020



Trust

Previous healthcare studies, anecdotal reports and experiences of health workers suggest that many people have had negative experiences with health services and that this can prevent people from seeking health care - either through their own experiences, or hearing about others.^{11,12} Other surveys have shown that 'fear' is a dominant factor in people not seeking eye care, so the study aimed to understand what people are scared about in more detail.

11 I go I die, I stay I die, better to stay and die in my house: understanding the barriers to accessing health care in Timor-Leste, 2008

12 Community Based Monitoring Evaluation, 2021, Sustainable Solutions Timor-Leste on behalf of Ministry of Health



Opportunity

Having more services does not always lead to an increase in people accessing health care¹³ and there are many neutral, gendered¹⁴ -, socio-economic- and ability-based norms and constraints which impact on different populations.¹⁵ For more vulnerable people, not having someone to support and accompany them is known to be a key barrier and this study aims to understand this in more detail, as well as ability and willingness to travel,¹⁶ take time away from work or family responsibilities and pay for associated costs.¹⁷ In particular, the high number of reports that cost is a barrier^{18,19} was looked at to try and understand better what those costs are, and whether they are real or perceived. Health care in Timor-Leste is theoretically free to all citizens, but medicines, equipment or treatment may have an additional cost associated if they cannot be provided at the health facility.

13 Eye care in Timor-Leste: a population-based study of utilization and barriers, 2008

14 Identifying national health research priorities in Timor-Leste through a scoping review of existing health data, 2003

15 Changing Barriers to Use of Eye Care Services in Timor Leste 2005 to 2010, 2013

16 Demographic and Health Survey, General Directorate of Statistics Timor-Leste 2016

17 Refractive Error and Presbyopia in Timor-Leste: The Impact of 5 Years of a National Spectacle Program, 2011

18 ibid

19 Demographic and Health Survey, General Directorate of Statistics Timor-Leste 2016

OTHER SCORES



Engagement

In this study, practice refers to actions related to eye health care, access to eye health care, health seeking behaviour related to eye complaints, etc. The survey looked at previous engagement with healthcare and this was looked at in more depth during the qualitative work.



Ability

Scored: Washington Group Short Set

Physical and mental disabilities are known to have a strong impact on people's ability to access healthcare. Using both self-identifying and Washington Group Question classifications of disability, the survey aimed to look at the differences for people with disabilities, and these were then explored in more detail as there is relatively little data available on health access for people with disabilities.

METHODOLOGY

Survey team

Team leader	Emily Morrison
Project assistant	Rosa (Lulu) Martins
Bobonaro researcher	Emerinca (Rince) Nipu
Baucau researcher	Bendita Soares
Dili researcher	Maia Tilman
KoBo Toolbox & IT support	Raul Ambrosius da Conceição Amaral
Data analysis	Johan van Duijn
Administration	Alexandria Ximenes
Graphic Design	Edy Ramos

Approach

The study followed principles of Feminist Participatory Action Research (F-PAR) which centres participants, includes collaborative design, acknowledges power relationships and always takes a do-no-harm approach. F-PAR aims to make sure results are relevant and can be used, in-line with utilization focused evaluation approaches. The study did this through:

- Engaging local co-researchers in each location who are involved in the community
- Working closely with health workers and community leaders
- Collaborative design with people experiencing vision difficulties. disability organisations and health workers informing the design
- Analysis with community workers
- Regular updates provided to and feedback sought from health workers and people affected by vision difficulties
- Providing information to people during the process, including in the survey, rather than the data collection being a one-way process

Ethics

The study design and methodology was presented to the *Instituisaun Nasionál Saúde* (National Health Institute) for ethics approval which was submitted on the 6th July, 2021; presented in person on the 17th August and approval was granted on the 28th August, 2021.

Informed consent was gained for the survey through explaining what the survey was about and how it would be used. Phone numbers were given voluntarily.

For journey mapping, verbal informed consent was gained prior to conducting the mapping and afterwards. All maps are de-identified.

To fulfil the ethics requirements, survey findings need to be presented back to respondents. This can be done via SMS and/or Whatsapp based on phone numbers provided in the survey, and with personal contact information for journey-mapping respondents.

Language

Except for interviews conducted with international representatives, all work was conducted in Tetun. The methodology design and questions were adapted into Tetun from the English CEEHAT module. All additional questions were written in Tetun and translated to English for analysis and reporting.

Setting

The study was conducted in three municipalities, selected for their current or planned eye health services: Dili, Bobonaro and Baucau. Due to COVID-19 travel restrictions and health concerns, a range of online, over the phone and, where possible, in-person methods were used for the survey and journey mapping.

Dili is considered urban, whereas Bobonaro and Baucau have areas that range from urban to remote, and an effort was made to include respondents from a range of location types.

Study Design

The study design comprised of:

1. Initial scoping and stakeholder discussions
2. Literature review

Data collection (non-linear):

1. In-depth interviews with health workers and community leaders (list available in [Annex 1](#))
1. Journey-mapping (list available in [Annex 2](#) and questions available in [Annex 3](#))
2. Survey (online via Kobo toolbox) (questions available in [Annex 4](#))

Some of the participants who completed the journey mapping also completed the survey (number not known as this was not monitored), and two people were selected from survey results to participate in journey mapping where their cases were complex or provided interesting insights. In these cases, people have not been represented twice in specific details or quotes throughout this report (using location, age and other information to cross-check and make sure there was no duplication, having been given consent to do so).

FGDs were not possible as the study was conducted at a time when there were COVID-19 related travel restrictions and health concerns.

Sample

The Terms of Reference (ToR) specified that at least 70% of respondents should be current or potential patients for the journey mapping (see full ToR [Annex 5](#)). The survey was successful in meeting this threshold with 80% of people who reported that they were currently experiencing an eye issue, and 20% who said they did not have any current issues.

Sampling Method

Journey Mapping

Sampling for the survey was also purposive and aimed to identify people with existing eye health concerns. Personal and professional networks were used, with snow-balling leading to the identification of additional respondents.

Three rounds of journey mapping were conducted, with a total of 15 maps undertaken.

1. Prior to the survey design to inform the study design, test some existing assumptions and to pilot and adjust the tool (3)
2. During the survey implementation with people who were identified with complex cases (3)
3. Following the survey results to follow up with specific people (9), with the following characteristics:
 - iv. Older women - 60 and above (3)
 - v. People who had received treatment (6), including operation (3) and glasses (6)
 - vi. People with disabilities (4)

Survey

Purposive sampling was used for the survey, using community- and health-based contacts to identify people who were experiencing eye issues. There was a sampling bias towards, women, older people and people with disabilities, as well as those experiencing vision and eye problems.

To contact people with disabilities, the team connected with local DPOs in the three municipalities.

Variables and socio-demographic characteristics

- Age (in years)
- Sex categorized as female, male, trans-woman, trans-man, non-binary, other
- Marital status
- Number of children
- Highest level of education, categorized into 1) no education, 2) primary school (or lower), 3) junior high school, 4) senior high school, 5) diploma/bachelor or higher
- Type of employment (with a range of options)
- Languages spoken, including primary language and Tetun ability
- Residential area categorized as urban, semi-urban, rural and remote (including travel time to nearest health centre)
- Disability status was asked (self-reported)
- Disability status was also measured by the Washington Group Short Set (WG-SS)

Data Collection Procedure

In-depth interviews

Semi-structured interviews were used and adapted depending on the respondent. Interviews were done one-on-one, in pairs or groups via Zoom or face-to-face (where possible).

Journey Mapping

SSTL designed a journey map based on the CEEHAT questions and other examples. It has 8 different stages that align to the CEEHAT questions:

1. First experiencing issues
2. Thinking about what to do
3. Seeking information
4. Seeking treatment (with formal health care system and traditional medicine as options)
5. Specialist eye health care
6. Getting treatment
7. Using or following the treatment
8. Follow-up

Most of the journey maps were done in person, but where we were unable to meet the person because of distance and/or restrictions, they were done over the phone. F-PAR principles were employed, treating the process as a two-way dialogue. In some cases, this also meant assisting people to access eye health care.

During journey mapping in Stage 2, Lilliana said that she had never received eye health care, despite having a long history of eye issues. She asked many general health questions, which were answered, relating to a range of concerns. The researcher explained that there is an eye health service available at the Baucau hospital and later, the researcher accompanied her to the hospital where she was able to get a consultation and is continuing to follow up with the health workers.

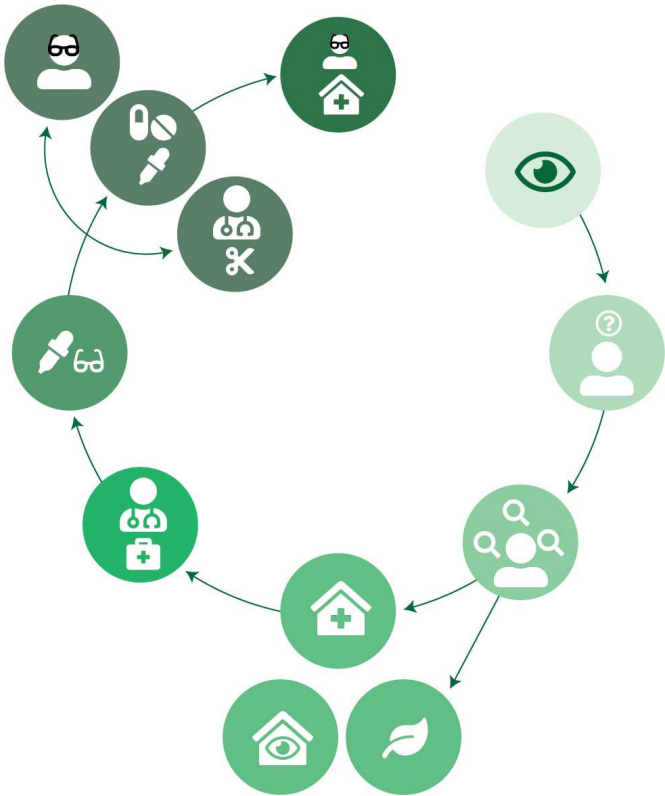


Figure 2. Journey Mapping Template

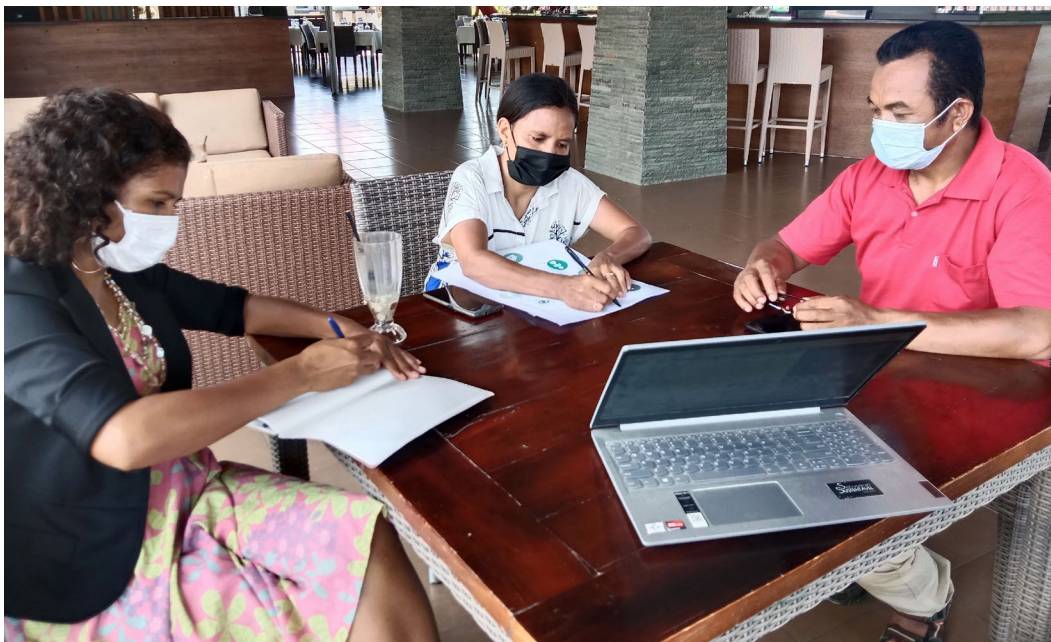


Image 2. Journey mapping in Dili. Photo by Rosa Martins, SSTL

Survey

Given the characteristics of the sample, it was assumed that some people would need assistance with completing the survey. This was done in one of three ways:

1. SSTL team member would conduct the interview either over the phone or in-person
2. SSTL identified people in the local area who would visit the person
3. The respondent asked someone from their family or neighbourhood to assist them

This information is useful for public health promotion and how to engage with people needing and/or seeking eye health information and treatment. It shows that women are more likely than men to need additional support to access information, as well as older people and those with vision impairments.

It also shows the opportunity for being able to access people through community networks. In Baucau, for example, SSTL contacted a youth network and they were able to administer the survey to the identified respondent.

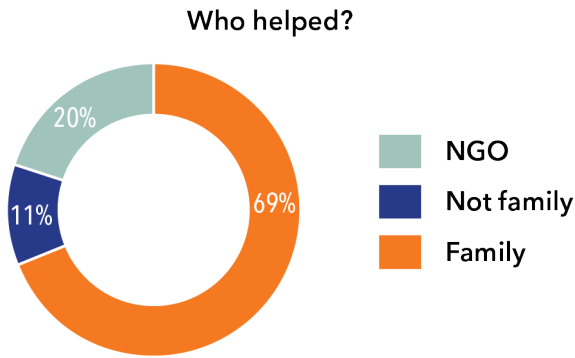


Figure 3. Who had assistance to complete the survey

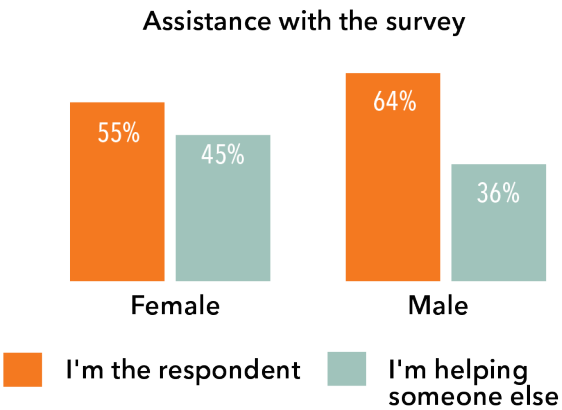


Figure 4. Who provided assistance

Joana

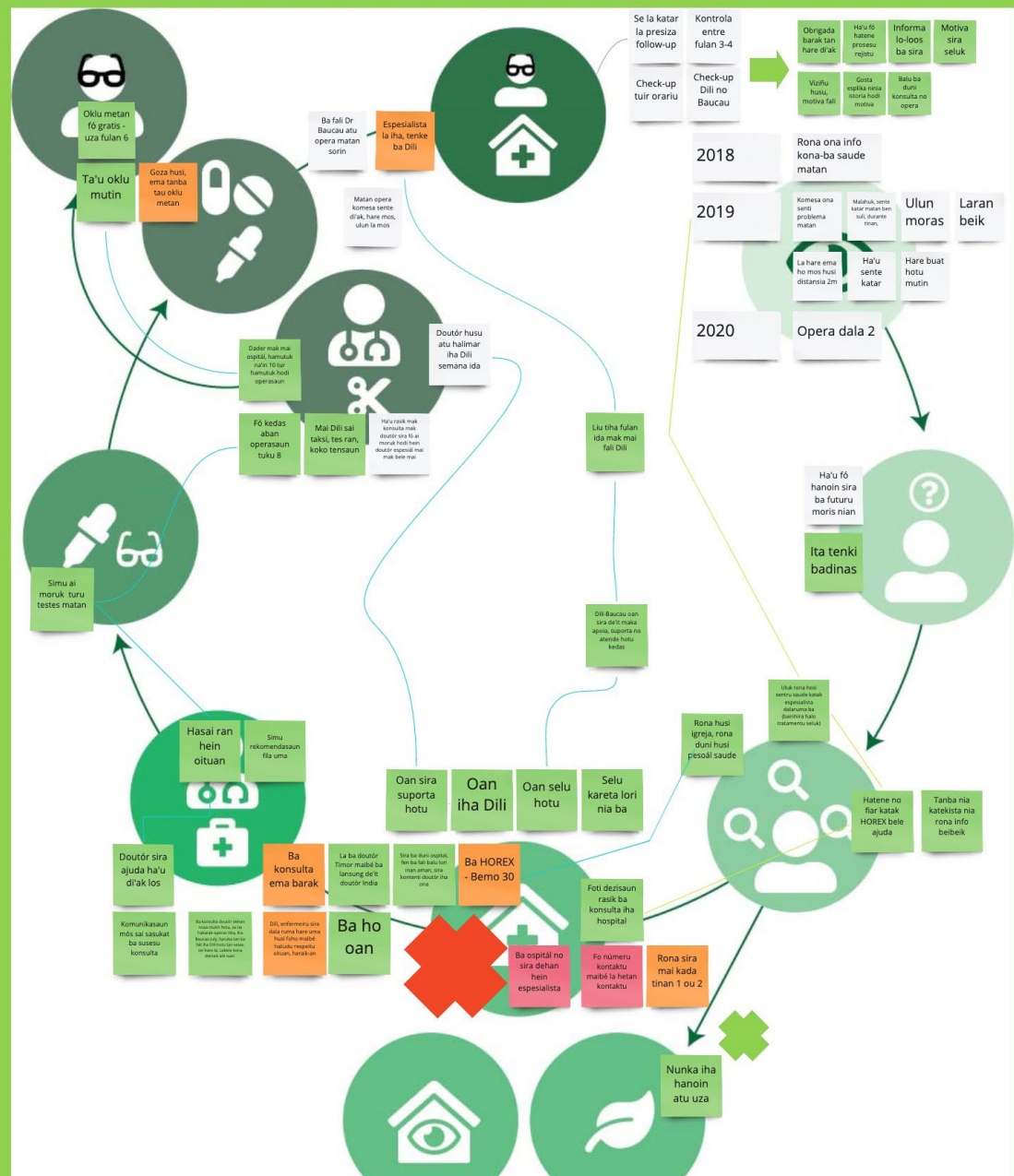
Idade	: 67
Sesku	: Feto
Hela fatin	: Baucau, Bahu
Nivel edukasaun	: SD Kuarta klas(Portu)
Nivel riku-soin	: Diak
Karakteristiku	: La defisiente
Servisu	: Agrikultura

2019 komesa sente ona problema matan.
2020 Rona espesialista iha Baucau. Opera kedas, pois ba Dili. Iha Dili, opera kedas, hamenu oklu no simu ona.

Operas ba matan rua – agora bele hare mós ona.

Nia halo adukasia ba kolega sira hodi fo info no fo korajen ba sira atu buka tratamentu.

Barriera: Info, Distansia



Data management & analysis

A summary of data management and analysis for journey mapping and the survey is provided in this report; [more information on data management is in Annex 6.](#)

Journey Mapping

Notes and symbols were used on the paper map. The SSTL team then did collaborative analysis using Miro Boards, which allowed for better visualisation and consistency (images available in Annex 7). The maps highlighted barriers, enablers and personal experiences.

A thematic analysis was then done, looking at similarities and differences looking at sex, disability, municipality and geographic distance.

Survey

The survey template was informed by the CEEHAT guide and discussions with the FHF regarding additional features of the survey that could provide valuable information for future program design.

The survey was designed to be easily understood by the participant, or by an appointed assistant. Much time went into translation and testing of the instrument to facilitate this, using plain language Tetun that was clear and incorporating multiple rounds of feedback.

The data analysis was conducted in Microsoft Excel and SPSS. Excel was used for the cleaning process, and the to establish the CEEHAT domain scores. The resulting data set was used for analysis in SPSS.

LIMITATIONS

It is important to note that the sample size of this study is small, and even smaller numbers for the different categories within the stratification. A second consideration is that the prevailing conditions did not allow for more representative sampling methods, like random selection of respondents. That is, due to the small size of the samples, the data generated may not be representative of the segments of the population that were purposely sampled.

Using the approach of people filling out the surveys themselves was effective in many ways, but also means that there is room for error through not understanding or through user error.

Covid-19

The biggest limitation for the study was the COVID-19 travel restrictions and health concerns. Health services were closed or operating on minimal staff and hours and all the research team were directly or individually affected by illness which meant absence for recovery, supporting and caring for people (from the illness and/or vaccine), and attending funerals. As with many people around the world, the emotional, physical, psychological and economic toll contributed to a lot of disruption.

Travel restrictions also presented opportunities. Although the team were not able to travel, this meant that we had to find different ways to contact people.

One area in Baucau during the study period reported over 100 deaths, which at the time of writing were still being investigated by the Ministry of Health.

Not all journey mapping was able to be done face-to-face, which limited the ability to use the tool to check and talk through the journey with the respondent.

Figure 5. Visualisation method of the journey mapping using Miro Boards



Image 3. Photo by Hugh Rutherford, 2011, supplied by FHF

Phone network

On the day that the survey went live, all three phone networks in Timor-Leste experienced outages which lasted on and off for two weeks. This was a significant disruption and meant that some people who received the survey early on never completed it as they were frustrated and gave up. Phone credit was provided to a number of individuals and groups to facilitate the survey, which helped in many cases but not all where the internet was too slow or interrupted.

Contacting people

Lists were obtained from health centres of existing patients to contact them for journey mapping based on criteria of being female, aged 60+ and in areas that hadn't been captured. However, most of the phone numbers tried were not active - this reflects a common challenge for health care workers that it can be difficult to contact people because numbers are not active when they try to contact people.

Some on the list responded that they would only do an interview in person, but this wasn't possible due to distance. This process is indicative of challenges for health workers and opportunities for improving the system of recording contact information to follow up with people and contact them for outreach services.

Table 1. Phone numbers of registered patients that were active/not active

	Bobonaro	Dili	Baucau*
Number of relevant people in lists provided from health workers	10	4	8
Number NOT active	7	3	3
Number active	3	1	5
Maps done with those with active numbers	3	0	1
Reason for not doing maps with active numbers:		Did not answer the phone	Didn't feel comfortable over the phone but too far away to travel to meet them in person

* numbers provided in a handwritten list

RESULTS

CHARACTERISTICS OF RESPONDENTS

Gender

Of the 86, one person identified as a transman, another preferred not to say. These have been grouped together as 'gender diverse' throughout the survey. Both of these people were classified as having difficulty based on WGC.

Two females identified as being LGBTQI+, neither were classified as having difficulty based on the WGC are included in the female group.

Urban/Rural

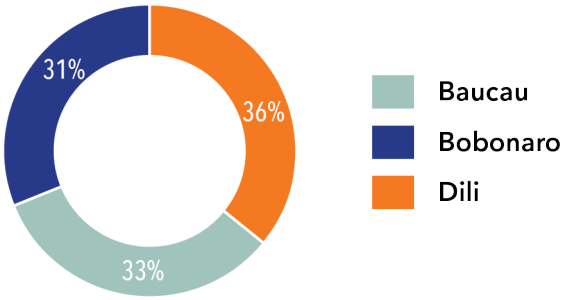


Figure 8. Municipality of respondents

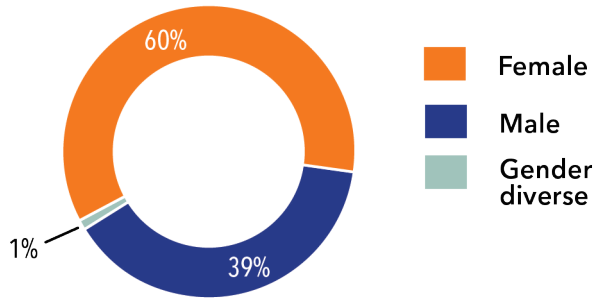


Figure 6. Sex/gender of respondents

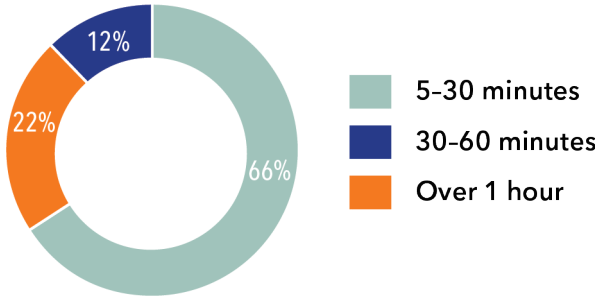


Figure 9. Time to nearest health centre for respondents Refugee or IDP

Age & sex of respondents

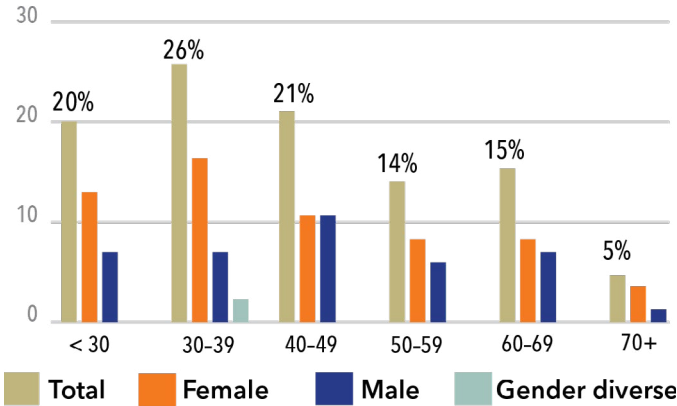


Figure 7. Age and sex of respondents

Three people (two females, one male) in total answered yes, one in each municipality. This follows on from the severe natural disasters of April 4th, 2021 where over 33,835 households were affected and over 15,000 people were displaced due to heavy rains, landslides and flooding across the country.²⁰ Of those, one female identified as having a disability.

²⁰ <https://reliefweb.int/report/timor-leste/timor-leste-floods-situation-report-no-9-21-may-2021>

Table 2. Difference between self-reported disability and WGC

Total=86	Yes		Of overall (86)	WGC		Of overall (86)	Yes to both
	#	%	%	#	%	%	#
Total	28		32.6%	25		52.0%	9
Female	18	35.3%	20.9%	13	40.0%		4
Male	10	30.3%	11.6%	10	8.0%		5
Gender diverse	0	0.0%	0.0%	2	100.0%		0
By Municipality - % per location							
Dili	6	19.4%	7.0%	7	22.6%	8.1%	3
Baucau	13	46.4%	15.1%	9	33.3%	10.5%	4
Bobonaro	9	33.3%	10.5%	9	32.1%	10.5%	2

Disability total

Overall, 33% (n=28) of survey respondents self-identified as having a disability, with a higher number of females having a disability than males due to purposive sampling.

Baucau had the highest portion of people self-identifying as having a disability, and Dili the lowest, although this evens out when looking at the WGC.

Washington Group Classification (WGC)

Only 29.1% (n=25, F=13, M=10, Other=2) had a disability based on the WGC, a slightly lower percentage than those that self-identified. There were also differences between which participants self-identified as having a disability and which participants the WGC identified.

Of people who did not self-identify as having a disability (67.3%, n=58): 29% do have a disability based on WGC, with higher percentages in Bobonaro (39%) and Baucau (33%) than Dili (16%). That is, 16 people (F=9, M=5, O=2) are classified as having a disability by the WGC, but do not self-identify. Ages range from 26 to 75, with an average of 42 years old.

This may be understandable if a number of respondents who self-report as a disability live in urban, supported environments and their

disability does not create difficulties for them. Difficulty seeing was mostly commonly reporting, followed by walking, understanding and thinking.

The results are not that surprising, but have important implications when thinking about and designing programs for people who live with multiple vulnerabilities:

- People don't identify difficulty with disability (which is the whole reason the WGC was developed in the first place)
- People with a disability don't necessarily have difficulty if they have the right support (the whole reason for universal design and supports for people with disabilities)
- The sampling was biased towards people with a disability who have some access (for example, are part of a group); and people in remote areas with eye issues who have little access to services and support.²⁸

Have an eye problem

80% reported having an eye problem, and 45% (n=39) overall responded that they had difficulty seeing - with 38.5% of those have a lot of difficulty (n=15 including 1 who can't see at all).

The difference between the high number of eye problems and reported difficulty seeing may be due to:

- Eye health related issues causing problems
- Using glasses to correct vision
- An acceptance of low vision
- **People not recognising the symptoms of eye strain as eye strain due to difficulty seeing**

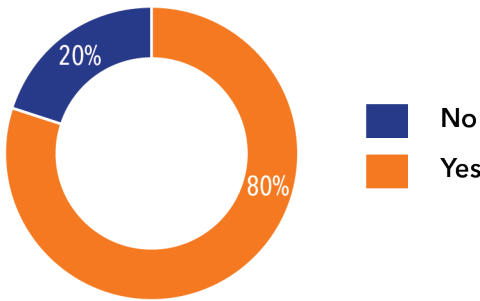


Figure 10. Currently experiencing eye problems

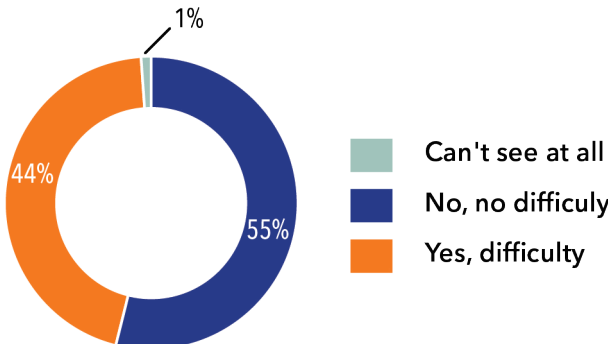


Figure 11. Difficulty seeing even with glasses

Whilst the two may not be expected to be the same, qualitative data revealed that a lot of people experienced symptoms of vision difficulties but did not recognise them as being related to vision - watery and itchy eyes in particular. This could be useful for general health workers to know - that people may not articulate that they have difficulty seeing.

Language

Out of 86 people, 5 (6%) said that they did not speak Tetun with the remaining 94% (n=80) having Tetun as a first, or other, language. Clear differences across the three municipalities has implications for public health promotion language and language support when receiving treatment.

The number of people having difficulty reading Tetun suggests that bi-lingual communications may be useful in remote areas of Bobonaro (Kemak/Bunak) and Baucau (Makasae/Waima'a), keeping Tetun as a key language for family and community members when the target may not be literate.

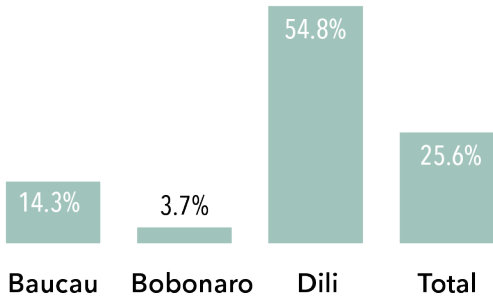


Figure 12. Tetun as the main language among respondents by municipality

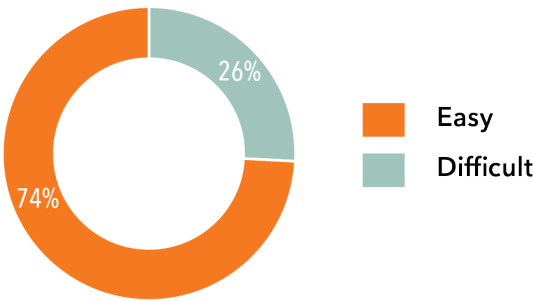


Figure 13. Easy or difficult to read Tetun

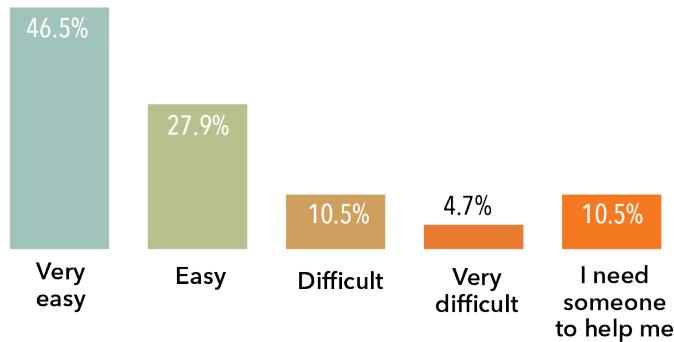


Figure 14. Level of ease/difficulty to read Tetun

FINDINGS

Information

Before looking at the CEEHAT domain scores, it makes sense to look at whether people had received information on eye health prior to this survey.

Just under half of respondents (49%, n=42) had previously had access to eye health information.

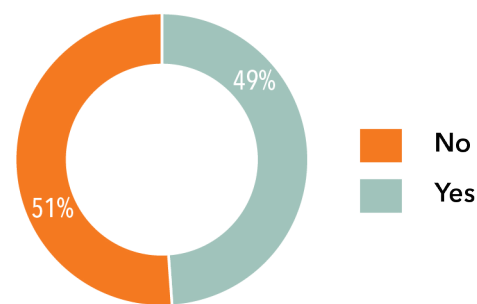


Figure 15. Have had information about eye health

Of those who said no (n=44), 34% indicated that they *had* received information that children should get eye-checks (n=15), and 36% said that they *had* received information that you should get your eyes checked regularly (n=16). This may be as a result of people not recalling that they had received eye health information when asked at the start of the survey, or not associating those two with 'eye health information'. This relates to the study finding that the vocabulary around eye health varied, and there not being a common understanding or language around 'health checks'.

The survey did not ask what information they had received, which could be a topic for future surveys to ask. The results from the journey mapping suggested that the information they had received varied, some had heard about cataracts, some about the need for and availability of testing and others about when specialist doctors were attending.

I didn't know anything about eye health, I can't remember ever hearing or seeing anything about it. But then I had problems. I couldn't deal with it anymore, I couldn't work and I was constantly sick. My eyes hurt so much, they were watering and I always had headaches. I went to Maliana hospital and saw a general doctor there who said I needed to see an eye health worker. I had to go back a few times before I got to see the eye health worker because there aren't fixed hours, but I finally managed. That was the first I heard about plus and minus, and that glasses could help. I got my glasses a few years ago and haven't been back since, I didn't know that you should get regular check-ups or that your vision can change.
– Sylvia, Bobonaro, age 50-59

Olivia started having trouble with her eyes in 2019 which was starting to impact on her ability to work and she was becoming stressed. She went to the local health centre but they didn't give her any information. She never heard anything on the radio, TV, social media or through local authorities, but one day she was complaining to a friend and they told her about being able to see someone at HOREX who prescribed her glasses. She's not sure if they told her what her prescription was, but they ordered the glasses for her.
– Olivia, Baucau, age 33

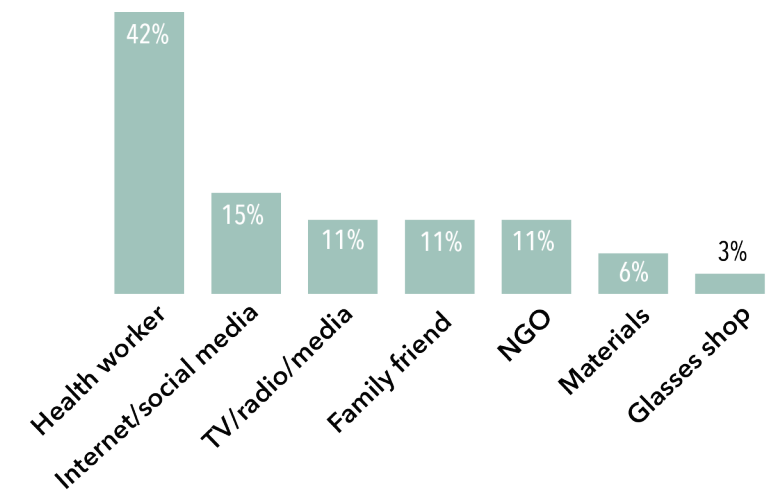


Figure 16. Sources of health information

Respondents were able to select multiple sources to indicate where they got that information from. Of those who received health information from a doctor or nurse at a health facility, most of those were from a hospital (52%, n=22) rather than a health centre (33%, n=14). Included in health workers is outreach, which had 2 respondents (5%). This may be in part attributed to the PEC training and further monitoring and evaluation of PEC graduates may help provide further insights.

TV²¹ (14%, n=6) was higher than radio (5%, n=2), with similar numbers for social media (14%, n=6) and internet (11%, n=5). In Baucau, outreach is sometimes announced via radio, but this only reaches as far as Baucau villa and none of the respondents there had heard these.

Respondents in the journey mapping mostly heard from friends, neighbours and family, with three people saying that they had heard some information from TV/radio or social media. One person heard through church.

It is not known whether people received information from health workers prior to having health issues with their eyes, or when they already had an issue however the question was partly addressed in the journey mapping which suggested that information was gained from health workers only when there was already an existing problem and people were seeking treatment. The one exception to this is in Raifun, Bobonaro where all people responded that they

had received information, and this site provides an interesting case study (see page 21).

In Baucau the health workers asked for support in this area because they have difficulty in travelling – no transport – and in contacting people. They don't have a phone allowance, they can't do outreach and so having community outreach workers would be very helpful in sharing information about services available, avoiding scams and unregulated treatment/medicines and getting people to come to the centre²².

Sources of information that no-one selected include SMS campaign²³, promotional event, loud-speaker on vehicle, matan dook (healer), community leader and school/university.

I'm a local leader and so get most information but this is the first time I've heard that we can see an eye health worker at HOREX. I'll probably go soon, but I'll wait until we don't need to do a swab test for COVID-19. Everyone here needs to know this because a lot of people have trouble with their eyes.
– Pedro, Baucau, age 48

²² Interview with health workers Baucau, 08/09/2021

²³ Not surprising since this hasn't been done since 2015 or 2016. Anecdotal evidence suggests that there may have been some positive results when this was done accurately (targeting people in upcoming outreach locations), however there were insufficient resources to follow up and evaluate these efforts (Health worker, 08/12/2021)

Information: by gender

47% (n=24) of females had received information, versus 55% (n=18) of males, suggesting that male respondents had a slightly higher access to information. The two people who identified as gender diverse had not received any information.

Information: by disability

People with a disability (self-identified) had lower access to information, with 39% (n=11) having received information compared to 49% (n=42) of people without a disability.

Of those, males with a disability had less access to information (30%, n=3 had no information) than females with a disability (44%, n=8). This is likely due to sampling bias and the small survey size.

This compares to those classified by the WGC as having a disability which suggests that women are less likely to receive information if they have a disability.

Table 3. Disability by sex: Self-identified and WGC who have received information

Have received eye health information	Self-identified disability (n=28)		% of survey total (n=86)	WGC disability (n=25)		% of survey total (n=86)
	n	%		n	%	
Total	11	38%	12.8%	9	36%	10.5%
Female	8	44%	9.3%	4	31%	4.7%
Male	3	30%	4.7%	5	50%	5.8%
Other	0	0		0	0	

Information: by geographic area

People in remote or very remote areas were less likely still to have received information, with only 36.4% (n=8) saying that they had, compared to 49% overall, representing 9.3% of the total sample. Two people in remote areas indicated that they had received information about the need for children to get eye checks, and adults to get regular checks.

Case Study: "Liliana"

Liliana²⁴ was born in a remote area with physical disabilities including with her eyes. Her vision started getting worse when she was young but to start with, she just thought it was 'normal' problems. Her family treated her with different methods, including rubbing oil in her eyes which made them hurt more. When she was older she saw something on TVTL about cataracts, the symptoms and being able to operate on them. She recognised the same symptoms in her eyes but didn't want to follow it up because she was scared that she could die if she had an operation; elder relatives had gone to hospital for operations and died, others had had their eyes operated on but still couldn't see. She's part of a disability group which shared information about nutrition, but not eye health.

She has no vision in her right eye but can see out of her left eye, with some difficulty. She had been to doctors about general health issues a number of times but was never asked about her eyes, even though her right eye has been troubling her for more than 25 years. She says the health workers seemed 'scared' of her and didn't want to get close. Liliana would really like to see a doctor about her left eye, it's painful and sometimes she can't sleep because of it. She now lives in Baucau villa, but thought that it was only possible to get a check-up in Dili or when a specialist visits; she'd heard about an Australian specialist visiting last year, but only afterwards.



Image 4. HOREX Eye Centre. Photo by Bendita Soares, SSTL

Following the journey mapping, SSTL told her about being able to see an eye doctor at HOREX and asked if she'd want to go - she wanted to very much. The next week, SSTL accompanied her to HOREX where she was able to get a consultation; she didn't feel like she needed someone to go with her but was grateful to have the extra support to make it easy. When the doctor tested her eyes and tried the optometrist glasses she noticed the difference straight away - she no longer felt dizzy, she could see clearly for the first time ever and her persistent headache started to go away. She had little concern about paying the \$35 for the glasses that have been ordered for her, and is excited to receive them when they are ready.

Summary: Information

Women, people in remote areas and people with disabilities have the lowest access to information overall, as well as men who have lower histories of engagement with health services. Language and terminology around eyecare is varied and further reveals low access to information about prevention, symptoms and treatment.

Recommendations: Information

- Put resources towards health promotion materials and activities (ensuring that services can meet demand in areas where this is done)
- Topics include:
 - Symptoms
 - Treatment options and availability
 - **Contact details**, opening hours and locations of where assistance can be sought
 - Success stories
 - The need for regular check-ups and replacement of glasses
- Ensure language is accessible, easy to understand and bi-lingual for relevant areas
- Use images that show symptoms and treatments, which will target people of low literacy and vision
- Specifically target women, people with disabilities and those in remote areas through:
 - Using imagery of target populations
 - Using existing sources of information such as health centres, church, community leaders, SISCA and social media
 - Taking advantage of community events and places where people gather such as national days and markets - people are much more likely to seek information and assistance when there has been some personal contact

²⁴ Mapping done on 17/08/2021 and follow-up on 20/10/2021, Baucau

Case study: Raifun

On follow-up, this was attributed to a health worker living in the area who regularly shared information with the community. All said they currently have eye issues, two had been for a check-up in the past two years and one person had never been for an eye check. All had been recommended to wear glasses, one got them from a glasses shop and the rest got them from the hospital/clinic.

It was revealed that four had used the glasses for a while (2 - 5 years) but their eyes had started hurting again and so they stopped using them. On asking some more questions, they said that the glasses didn't work anymore, so there was no point wearing them. Only one person knew that prescriptions can change and that they may need to get new glasses, with three saying 'we don't work in an office, we don't have to read books or look at a computer; we're in the fields so it doesn't really matter. It's better that we save money for other things like our physical health.' Two health workers at the hospital, one in dentistry and one a midwife, had the necessary knowledge about where to go but still had challenges.

The case study of Raifun suggests a few things:

- Health workers can play a really important role in health promotion
- Access to information about symptoms and where to go are very important - but not the whole story
- During consults, getting accurate and clear information about what to expect is also very important - without which, people may use glasses for a number of years and then give up
- Even people with direct access to the site of the eye clinic haven't made use of it
- Seeking healthcare feels hard for people, and is not a priority



Image 5. Fields in Raifun. Photo by SSTL

Table 4. Raifun respondents

Sex	Age	Education	Work	Know where to go for check-up	Know where to get trustworthy health info	Willing to travel/ pay for glasses	Why not using glasses	Diabetes?	Problems/ Difficulty seeing	Comments
Male	54	University	Health	Strongly agree (within past 2 years)	Agree	Yes \$5 - \$10	Eyes were hurting	Yes	Yes/Yes	I really want to get treatment for my eyes, and glasses that are right for me. Because even though I have glasses and got them after an eye exam, my eyes are always really sore and feel hot
Female (uses glasses daily)	55	Secondary	Government	Disagree (eye check: 2017)	Disagree	No \$5 - \$10	Still using	Don't know / not sure	Yes/Yes	I really want to get treatment for my eyes because my eyes are always itchy, even though I use glasses my eyes are always red. As a mother, I really need to get help. Because it's only me looking after my family and my children - I have to work hard as a teacher to get money for my children.
Male	54	University	Health	Strongly agree (within past 2 years; prior to that 2002)	Agree	Yes \$5 - \$10	Eyes were hurting	Yes	Yes/No	My eyes don't have any issues at the moment, but I need to get them checked every year; so that I can increase the strength of my glasses, because they are (... script entered as +50 - 75) I use them often when my eyes start feeling hot
Male	48	University	Unpaid work	Disagree (eye check: never. Glasses from shop)	Disagree	Yes \$20 - \$40	Eyes were hurting	Don't know / not sure	Yes/No	I really do want treatment for my eyes so that I can continue seeing clearly in the future, but it's really hard to get information about my eye health
Female	67	None	Unpaid work	Disagree (eye check: 2005) Recommended surgery in 2016	Disagree	No: Price doesn't matter	They broke	No	Yes/Yes	I want to get an operation but I get really car-sick, I don't have enough money for my family to accompany me to Dili
Male	73	None	Unpaid work	Disagree (eye check: 2016)	Disagree	No: Price doesn't matter	Eyes were hurting	No	Yes/Yes	I want to get an operation so that my eyes can see clearly, but I also have asthma and so I'm scared to get the operation

CEEHAT DOMAIN SCORE RESULTS

The CEEHAT scores are a tool designed to identify where areas could be improved and prove a way to understand better the local barriers to eye health service access uptake.²⁵ It can be used in the future to look at the effectiveness of interventions and programs and these scores can be used as a baseline for the three municipalities.

[See annex 9 for domain score correlations](#)

The minimum (min) number represents the lowest score was recorded, and the max is the highest score.

Throughout this report, the domain scores are presented as a total out of the maximum possible score for each, and with the variables listed underneath from lowest to highest. The individual questions are also presented with their Likert scale results. Only variables that were very different from the overall result are presented in these.

Table 6. Disaggregated total CEEHAT score

Disaggregated total score	n	Min	Max	Mean	Median
Total of four domains	86	42	68	55.20	55.5
Male with disability WGC	10	42	62	50.20	49
Female with disability WGC	13	42	59	50.62	50
Remote - rural	10	45	62	52.30	52
Gender diverse with disability WGC	2	53	54	53.50	53.5
Very remote - rural	12	42	59	53.58	58
Male with disability SR	10	46	66	53.70	52
Semi-urban	37	44	66	54.68	54
With disability SR	28	46	68	54.86	55
Female without disability SR	33	42	67	55.15	55
Mean Score				55.20	55
Without disability	58	42	67	55.36	55
Female with disability	18	46	68	55.50	56.5
Male without disability	23	42	63	55.83	58
Female without disability WGC	38	48	68	56.57	57.5
Male without disability WGC	23	48	66	57.35	58
Urban	27	48	68	57.70	58

Table 5. CEEHAT scores

	All				Baucau		Bobonaro		Dili		Indo
	Min	Max	Mean	Median	Mean	Median	Mean	Median	Mean	Median	Mean
Understanding	4	16	10.5	10	10.18	10	9.85	10	11.45	11	11.4
Motivation	8	20	14.4	14	14.93	15	13.44	13	14.74	15	11.5
Trust	5	16	12.7	12.5	12.64	12	12.63	12	12.87	13	14.6
Opportunity	11	20	17.6	18	16.86	17	17.22	18	18.45	19	18.1
FHF total number	42	68	55.2	55.5	54.61	54	53.15	53	57.52	59	55.6
Engagement history in Eye health	0	3	1.16	1	1.04	1	0.93	1	1.48	1	0.4
Expanded motivation domain maximum of 36	11	23	17.91	18	18.43	18	17.44	17	17.84	18	

Note: the lowest possible domain score is the maximum divided by 4. Understanding and Trust (4), Motivation and Opportunity (5); the highest possible number was achieved for all. The lowest possible FHF total number is 18 and the highest possible is 72.

25 CEEHAT Toolkit V1, Fred Hollows Foundation

UNDERSTANDING DOMAIN SCORES



Of the four domain scores, understanding came in the lowest, which is consistent with other literature that people don't have enough health information and that is a key barrier to accessing health services.^{26,27} There has also been minimal eye health promotion in recent years, which suggests an opportunity to improve awareness, particularly in schools and universities (early intervention), with community leaders and through media.

The finding of low awareness contrasts with the RAAB 2016 finding that access to information was not a barrier to seeking and receiving eye care²⁸ and suggests that it may be useful to revise the way that the question is asked and/or reporting during the next RAAB process.²⁹

The lowest possible score for understanding is 4, the highest 16.

Table 7. Understanding domain scores

		All				Baucau	Bobonaro	Dili
		Min	Max	Mean	Median	Mean	Mean	Mean
UNDERSTANDING DOMAIN VALUE		4	16	10.53	10	10.18	9.85	11.45
Variables - lowest to highest	n	Median				10	10	11
Very remote with disability WG	4	4	11	6.75	6	Although the sample size is small, the findings are consistent with other findings about health awareness, and relevant variables (being remote, female and having a disability)		
Work no income	13	4	14	8.46	8			
Female with disability WG	13	5	12	9.00	9			
Male with disability WG	10	4	12	9.10	9			
Male with disability SR	10	7	13	9.70	10			
Female	51	5	16	10.33	10			
Female with disability SR	18	8	16	10.50	10			
Male	33	4	16	10.76	10			
Female without disability WG	38	7	16	10.79	11			
Very remote without disability WG	8	7	15	10.88	10			
Male without disability WG	23	7	16	11.48	11			
Other without disability SR	2	12	12	12	12			

Table 8. Responses to understanding domain questions

Understanding - %	Strongly agree	Agree	Disagree	Strongly Disagree
I know where to go if I need an eye check-up	30.2%	34.9%	30.2%	4.7%
I know how much it will cost me to get an eye check-up*	9.3%	39.5%	45.3%	5.8%
I know where to get trust-worthy information about health problems	26.7%	43.0%	24.4%	5.8%
People with a disability (n=28)	17.9%	53.6%	21.4%	7.1%
I have received information that people should get eye checks every 2 years, or every year if they are over 40**	9.3%	18.6%	58.1%	14.0
Of those over 40 (n=47)	14.9%	10.6	57.4%	17.0%
Additional Questions				
I've received information that it's good for children to get an eye check when they are still young (like 4 years old)***	7%	20.9%	52.3%	19.8%
Those with children (n=63)	7.9%	20.6%	54%	17.5%
Those with children of school age or younger (9)	0%	0%	0	100%

*The Tetun translation reads as "I know how much I need to pay if I want to get eye health care"

**The additional part of this question was added because the surveys were being done by the respondent, and we wanted to take the opportunity to share some information as well as gather data

***As above

28 RAAB 2016

29 There were differences in the methodologies of the previous RAABs which might also account for the differences in this figure, e.g., whether the question is asked and reported on general eye health or only on getting cataract surgery

26 Disability Inclusive Health, SSTL, 2021

27 DHS, 2016

I really do want treatment for my eyes so that I can continue seeing clearly in the future, but it's really hard to get information about my eye health.
– Survey respondent, male, 48, Bobonaro

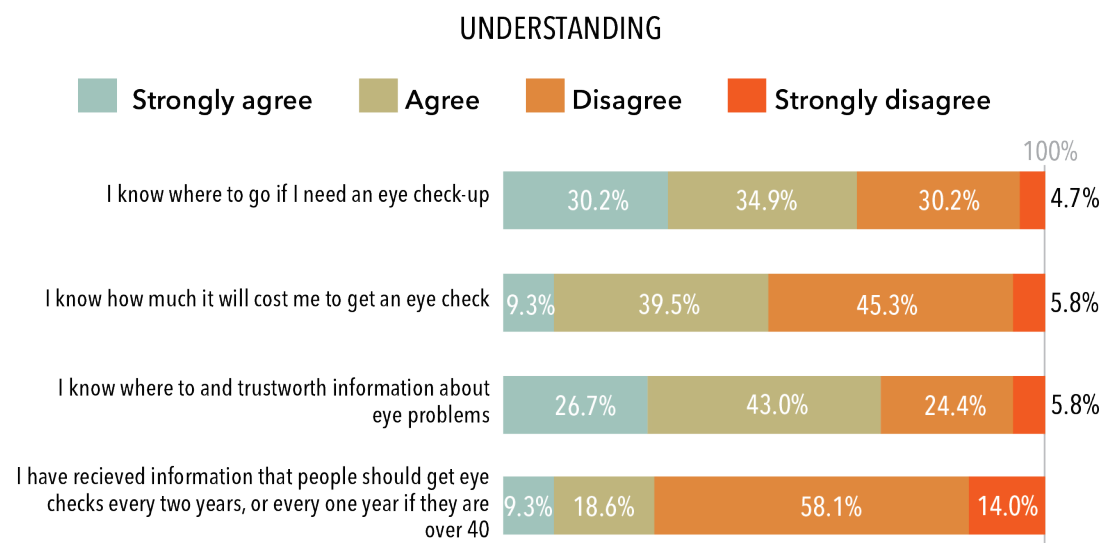


Figure 17. Responses to understanding domain questions

Follow-up after treatment

The survey found that awareness about the need for regular follow-up was low.

Table 9. When people last had an eye consultation

Consult	Yes	%	
In the past 2 years	27	31%	
Prior to 2 years ago	37	43%	
TOTAL	64	74%	
Of those prior to 2 years ago, have not been back since	20	54%	Longest time since last consult: 19 years (2002, 1 person) Shortest time: 3 years (2018, 4 people or 20%)
Number 2017 or earlier	15	75%	

The results of the journey mapping showed that only a few of the people had any information on eye health before needing to seek help, and that was gained through TV adverts and church announcements. No one had any specific information on prevention, symptoms, warning signs or treatments available and all but one had dismissed symptoms for a long time prior to seeking healthcare, if they sought it at all.

Costs can be considered in broader terms than paying for treatment, and these are discussed in more detail under the [opportunity: associated costs](#) section. The financial costs of spending time away from home, accompaniment, spending on meals, transport, accommodation, medicine, equipment and follow-up are all factors for people with gendered and ability variations.

The results show that although many people know *where* to go to get an eye check-up, they have not received information that they and their children (if they have any) *should* get their eyes checked regularly, and the number of people who don't know is still quite high (34.9%, n=30). Women had higher engagement with health services, which probably explains why their understanding was higher than men overall.

Of the 63 people who do have children, there are some slight differences as indicated above, but significantly all 8 people with children of school age strongly disagreed with the statement that they had received information that children should get their eyes checked.



Image 6. SSTL researchers with Belmerio Jeronimo at the National Eye Centre in Dili. Photo by Maia Tilman, SSTL

Awareness of symptoms

All people had experienced ongoing issues with their eyes and the most common symptoms were:

- Watery eyes
- Itchy eyes
- Headaches
- Not seeing clearly, cloudy vision
- Nausea
- Seeing yellow discolouration

No-one knew what the cause of their symptoms was or what treatment or behaviours they should follow, except for the one person who lost their sight through a mistreated injury.

Maybe the problem is from when my friend poked it when I was young. I didn't do anything about it at the time and haven't had any issues until recently. But people say that one of my eyes is all cloudy and white. I haven't had treatment because I don't anything about that.

– Filomena, Dili, age 30-35

From 2019 my eyes started to cause me problems, when it's light, when I use my phone or computer or try to read my eyes start watering and hurting and I feel nauseous. I had no idea what was happening until a friend of mine said that maybe glasses would help.

– Pedro, Baucau, age 48

Since early 2021, my eyes have been watery, itchy and I can't see clearly. It feels like there's cotton thread in my eyes. I went to the health post but I didn't talk to them about it because they just check my blood pressure. I thought about going to a matan dook but my son won't let me. I don't know anything about eye health.

– Marcelina, Baucau, age 60+

In 2002 my eyes were swollen, watering, itchy and I couldn't see. I didn't know why, I thought I'd been bitten by an ant. It got worse in 2016 an my neighbour told me that a foreign specialist was at the hospital so I walked a couple of hours. They operated straight away on the cataract and gave me glasses, I was really happy with the treatment. I went for the check-up after 3 or 4 months, but I wasn't told that I should go back.

– Adilson, Bobonaro, age 65

Awareness of treatment available

All of the 15 people had low awareness about eye health generally, and none knew about the National Eye Centre prior to being referred there (4 people), though many knew that you could get treatment in Dili. Enduring eye problems was common, with people waiting between 1-25 years after symptoms appeared to get treatment. In all cases, sufficient awareness was the primary barrier. Only one person had enough information to know that when her symptoms started, she should see an eye doctor. She didn't follow up at the time because she thought she had to wait for a specialist to visit the hospital.

Being told to wait was a common response in the RAAB results, and this also came up in the mapping. International specialists are often required for complex cases so people do need to wait for the necessary treatment or equipment and/or materials.³⁰ No one was given the option of contacting a health centre to check on when the specialist would be there, so they felt they had to just wait.

Awareness of the need for follow-up after treatment

The survey and journey mapping found that awareness of the need for regular follow-up was low and there was a common belief that once you had glasses, you only needed to replace them if they break. Two people out of the 13 who had sought treatment in the journey mapping were aware that they should go for follow-up regularly, but this was surprising for most people.

There also appears to be a general misunderstanding that this applies to all vision difficulties. Five people thought that only international doctors could attend to eye issues and three had been told to wait for specialists but had not been contacted again. They didn't say that it was because their cases were complicated, they thought that all eye problems needed an international specialist. None of those interviewed knew that there were Timorese specialists unless they had been to them.

30 Interview with NEC, 26/10/2021

They said I'd have to wait for a specialist and took my number but I never heard from them. Then one day I heard from the church that there was a specialist and I went straight away.
– Joana, Baucau, age 60+

I want to get a consult from the Australians. Because my family got treatment from Australians and their eyes are fine until now.
– Survey respondent, female, Baucau, age 77

I want to suggest to the health workers from Australia to bring their eye health program to Suku Ostiku, because a lot of the community have eye issues and want the Australian team to come and do the treatment and to facilitate equipment in the health centre.
– Survey respondent, male, Baucau, age 47

Years ago I was told to wait for the specialist, but I haven't heard anything since so I haven't had any treatment for my eyes. I need to wait for them to come from overseas.
– Lucia, Bobonaro, age under 30

I'm scared because it's foreigners doing consults. If there's a Timor doctor I'll go, but I don't speak Tetun very well.
– Survey respondent, male, Bobonaro, age 69

I only need to go back to the hospital if my glasses break.
– Sinta, Baucau, age 33

I got my glasses in 2008, I haven't been back again. I didn't know that I needed to.
– Estella, Baucau, age 68

Luckily my glasses broke and the glasses-shop told me that I should get my eyes checked again, otherwise I would have just kept wearing them and not knowing that's why I was getting headaches and not seeing clearly. I argued with them at first but then I heard that it's normal and a good thing!
– Maria, Dili, age 40-49

I really want to get treatment for my eyes, and glasses that are right for me. Because even though I have glasses and got them after an eye exam, my eyes are always really sore and feel hot.
– Survey respondent, male, Bobonaro (last eye-check 2002), age 54



Summary: Understanding

The study shows that people have low awareness across the continuum of eye care, from prevention, symptoms, finding and seeking treatment and follow-up. This has a negative impact on seeking health treatment, following treatment plans, going for follow-up and knowing what they should do long term. For those with glasses, it means that they didn't go for another consultation when they started having vision difficulties because they didn't know the cause and thought their glasses just didn't work anymore.

The cost of eye care will be addressed later under [opportunity](#), but low understanding of the time and financial cost, including direct and associated, was identified as a key barrier.

Recommendations: Understanding

- Having handouts and online information available for people would help the patient and their families to better understand what the issue is, and how to treat it
- Health workers to provide clear counselling and information to people they are attending, and answering any questions they have. In particular being clear on what the problem is and the need for follow-up
- Have clear information on what costs (financial and time) are associated with eye care
- When people have to wait, provide them with estimated timelines and a way to follow up themselves

Image 7. A health worker holding a site chart. Photo by Hugh Rutherford 2011, supplied by FHF

MOTIVATION TO ENGAGE IN EYE HEALTH CARE



The motivation question combines a number of factors, particularly how much of a priority eye health treatment is independently (Q4) in comparison to other priorities in life (Q1), how important it is (Q3) versus how much agency a person senses they have on it (Q2).

The lowest possible score is 5, and the highest possible is 20.

Table 10. Motivation domain scores

		ALL				BAUCAU	BOBONARO	DILI
		Min	Max	Mean	Median	Mean	Mean	Mean
MOTIVATION DOMAIN VALUE		8	20	14.40	14	14.93	13.44	14.74
Variables - lowest to highest	n	Median				15	13	15
Gender diverse with disability WG	2	12	13	12.5	12.5	Males with a disability appeared at opposite ends of the scale - with SR having very high motivation, and WGC having low scores. The two groups have the same average age.		
Gender diverse with disability SR	2	12	13	12.50	12.5			
Male with disability WG	10	11	16	13.40	14			
With disability WG	25	11	16	13.64	14			
Female with disability WG	13	12	16	14.00	14			
Very remote	12	8	18	14.00	14.5			
Male	33	8	20	14.09	14			
Male without disability WG	23	8	20	14.39	14.5			
Female with disability SR	18	12	16	14.61	15			
Female	51	12	18	14.67	14			
Without disability WG	61	8	20	14.70	15			
Female without disability WG	38	13	18	14.89	15			
With disability SR	28	11	20	14.75	15			
Urban	27	12	18	14.93	15			
Male with disability SR	10	11	20	15.00	14.5			

Table 11. Responses to motivation domain questions

Motivation -%	Strongly agree	Agree	Disagree	Strongly disagree
I have many more important things to do than get an eye check*	11.6%	34.9%	41.9%	11.6%
Female with a disability SR (18)	6%	22%	61%	11%
Male with a disability SR (10)	0%	40%	40%	20%
I expect to go blind when I get old	34.9%	34.9%	29.1%	1.2%
Difficulty seeing would be a big problem for me	77.9%	18.6%	2.3%	1.2%
You should do everything you can to protect your sight	74.4%	23.3%	2.3%	0.0%
I think that people wearing glasses makes someone more attractive	4.7%	43%	44.2%	8.1%

* The Tetun translation reads more like "I have many more important things that I have to do rather than go to a health facility about eye health" as the concept of regular check-ups for prevention or monitoring is not very common; people generally only go to a health facility when they have a problem that they can't tolerate

*The section on glasses use addresses the question on attitudes to glasses.

The vast majority of people responded that not seeing would be a major issue for them 96.5%, n=83) and that you should do everything you can to protect your sight (97.7%, n=84) which indicates that sight is very important for people, including females with a disability, but that doesn't necessarily translate into prioritising eye health, or believing that blindness can be prevented, with 69.8% believing that they will go blind when they are older (n=60).

A slight majority of people, 53.5% put eyecare as a priority (n=46), but only a small number would put this as a high priority (11.6%, n=10). Males were slightly more likely to agree or strongly agree that they had more important things to do (51.5%, n=17) than females (41.2%, n=21), and people with a disability were much more likely to disagree (85.7%, n=24).

This also probably reflects the priorities that people have in life, which was brought up by people in the journey mapping and the survey. The following examples from the survey all have below-average understanding scores.

I really need to get an eye check-up because my eyes feel like there's something thick in my eyes; or like something blocked. But I'm a tradesperson, and I really want to get treatment so that I can see clearly and earn an income for my children and wife at home.

– Survey respondent, male, Bobonaro, age 57

Motivation score: 13 (lower than mean for men of 14.09)

Understanding score: 9 (lower than the mean for men of 10.76)

I really want to get treatment for my eyes because my eyes are always itchy, even though I use glasses my eyes are always red. As a mother, I really need to get help. Because it's only me looking after my family and my children – I have to work hard as a teacher to get money for my children, so I can't just leave.

– Survey respondent, female, Bobonaro, age 55

Motivation score: 13 (lower than mean for women of 14.67)

Understanding score: 9 (lower than the mean for women of 10.33)

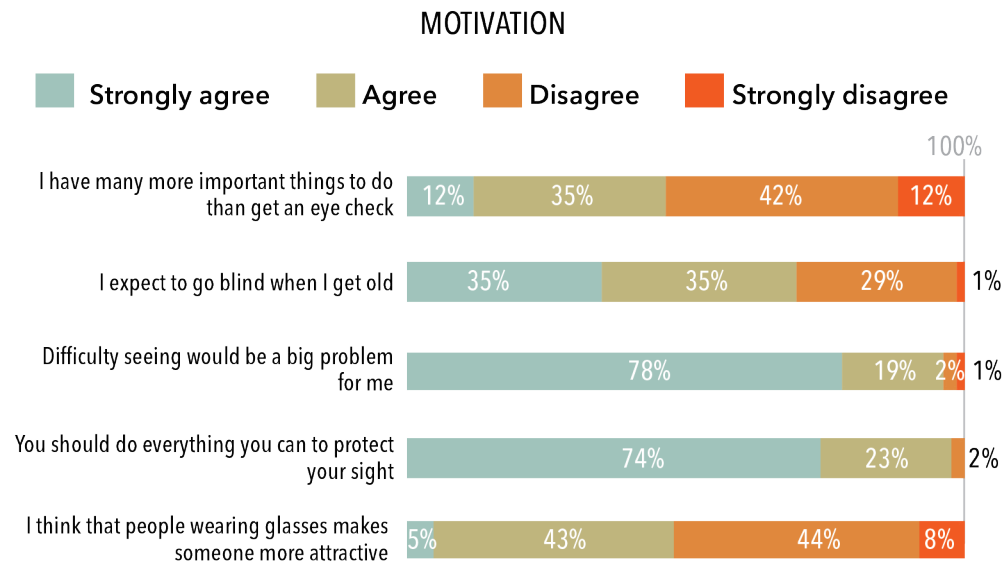


Figure 18. Responses to motivation domain questions

It may also indicate that with the number of people waiting and not receiving the eye care they need, they are becoming apathetic and don't believe that they can do anything about it. This highlights the need for health promotion that blindness is preventable, and possible – particularly though early intervention when a problem starts. Low awareness was found to have be correlated with motivation – greater understanding has a positive impact on motivation.

I went and got checked a long time ago, during Indonesian times – three times. In 2006 a doctor suggested that I get an operation overseas. But my family didn't have the resources for me to get an operation.
– Survey respondent, male, Bobonaro, age 38
Motivation score: 14 (close to the mean for men of 14.09)
Understanding score: 7 (lower than the mean for men of 10.76)

Motivation: Journey Mapping

The results from the journey mapping were mixed in regard to motivation but suggest that there are a number of reasons for people not prioritising eye health. Not having enough information came through as a dominant theme and was a primary barrier for all those interviewed, as well as not having enough resources or support to seek treatment. Needing to work was a clear positive motivator for people with office jobs, but even still that wasn't enough for some people to persist in seeking treatment when they faced multiple barriers, including having had negative experiences at health centres. At times this was also a barrier, people saying it's difficult to leave the house and farm unattended to travel and get treatment.

Four people said they were given amoxicillin and paracetamol and sent home, feeling like they were just dismissed. There have been concerns raised about the over inappropriate use of eye drops,³¹ as well as people not being given an explanation or diagnosis. Only two out of the 15 said that they got clear information on what the issue was (both cataracts) and what they could expect and needed to do in the future.

I've tried a few times over the last 6 years. At the start I really wanted to get my eyes fixed so that I could keep working and support my kids' schooling. When I went to Dili for work I went to the NEC in 2012 but there was no doctor there. I travelled the 3 hours by public bus to Maliana a couple of times but there was only a nurse there, they gave me eye drops and sent me home. My boss accused me of lying about my eyesight, it's hard speaking up as a woman in the workplace. I've been fired now because I can't see properly and I haven't tried since 2015, it's better for me to just work in the fields.
– Natercia, Bobonaro, age 40-49

After my operation and getting my glasses in 2016 I've been able to see and only went to the hospital again this year (2021) when my glasses broke. But the nurse said they would be \$100 and have to be imported. That's too expensive. This is the first time I've heard that I can get glasses in Timor, but what's the point? If someone (eye health worker) came here I'd really like that, I'd go and see them. But to travel and spend lots of money, no. I'm an old man.
– Adilson, Bobonaro, age 65

31 Interview with health associated worker, 25/11/2021

Traditional medicine use

Table 12. Responses to using traditional medicine

Traditional medicine - %	Strongly agree	Agree	Disagree	Strongly disagree
If I have a problem with my eye health I would look for a traditional healer ³²	0%	2.3%	58.1%	39.5%
If I have a problem with my eye health I would look for traditional medicine	1.2%	12.8%	60.5%	25.6%

I tried hard for years but now I'm blind and I've given up. When I was younger my parents took me for treatment at Maliana hospital but no one listened to what we were saying, there wasn't the right equipment there and they just gave me eye drops and sent me home. Then I heard from a friend that a specialist from Surabaya was visiting so I rushed there to meet them and they said they could operate on one eye, but my other eye had to get better first and they gave me eyedrops and glasses that were too big and people teased me. We waited and waited and when I went to go back, I was told the specialist had gone and got sent home. The doctor said they'd come back, but I'm still waiting for that.

When I was living in Dili years later, my friend told me that the specialist was back in Maliana. My family sold their animals and other things to raise enough money for me to travel there, but by the time we had raised the money my friend said the specialist had gone. I was devastated. I still don't know what the problem is or if it can still be cured. But now I'm blind, people call me degrading names and I'm separated from my family.

No, I haven't been to the NEC, I didn't know about it, but I couldn't be bothered even trying anymore.
– Lucia, Bobonaro, age under 30

The survey found that only 8.1% (n=7) of respondents had used traditional medicine for eye health issues; a large majority would not seek out traditional medicine for eye health and even fewer would seek a traditional healer (*matan dook*). Of the seven, three would seek traditional medicine again and the remaining four disagreed (2) or strongly disagreed (2).

This is encouraging and is consistent with findings from the journey mapping, but the 14% of people (n=12) who would seek traditional medicine is still a concern, particularly given the remedies used. Of those 12 people, 6 have had no schooling and 9 have difficulties with reading Tetun, which might mean that written materials aren't the best way to communicate the risks of traditional medicines.

They rubbed chilli in my eye and asked if I could feel it in the eye that was white. They would put coconut skins in my eyes, close them and throw stones at my eyes. That happened at least seven times. They would also put ginger in my eye. But all that happened when I was still really young so I just put up with it. But as soon as I was old enough, I refused to let them do that anymore.
– Diana, Dili, age 26

Six out of 15 journey mapping respondents had used traditional medicine which represents 40% of the sample (compared to 4.7% in the survey), but none had used any in the past 10 years and all of those had very negative experiences and are unhappy or regretful about the experience. They found it painful and unhelpful, with some attributing their blindness to using traditional medicines.

32 The Tetun used the term "*matan dook*"



Of the remaining 9 people, 8 were staunch in their refusal to use traditional methods. One person had been recommended to use morning-dew to clean her eyes, but as there was none in Dili she just used regular eye-drops. For the rest, even when family or friends suggested that they try traditional medicine, they refused.

I have zero trust in a matan dook to cure eye problems, I'd never use traditional medicines for my eyes.
– Pedro, Baucau, age 48

Some family and friends gave me suggestions but so often they just ruin people's eyes. I trust the medical doctors.
–Sinta, Bobonaro, age 30

I've never used traditional medicines for my eyes; I'm worried that I'll use it wrong and it will make things worse.
– Adilson, Bobonaro, age 65

One person had purchased and used medicines sold on door-to-door³³ which had cost her over \$100 and she believes caused blindness in both her eyes. At first she thought that it was working for one eye, but after ordering more and using it for three months in both eyes she had no vision in either eye.³⁴ Sales of similar products for eye and general health was raised by a local authority in that area as a concern.³⁵ Other unauthorised products include glasses that are advertised online through social media as protecting, curing or helping improving eye sight. There have also been concerns raised over health workers themselves buying, and even worse, selling similar unauthorised products.³⁶

Summary: Motivation

The majority of respondents answered that they expect to go blind when they are older and believe you should do everything you can to protect your sight. This suggests that people want to, but don't know how, as is supported by low levels of information and awareness. Eye checks are a high priority for only a small percentage of people, which means they are unlikely to seek treatment.

Although the use of traditional medicines appears to be in decline, the 14% of people saying that they would seek it is concerning, especially as this is higher than those who have previously used it.

Recommendations: Motivation

Understanding is connected to motivation, and so addressing the points below will likely lead to increased prioritisation of eye care.

- Public health promotion should focus on early intervention being important to increase motivation
- Efforts should be made to raise awareness that only medically directed treatments and glasses should be used to increase motivation for health services rather than alternatives
- Verbal messages though radio, that focus on positive outcomes and stories, may be more effective in reaching low literacy populations, as well as recorded messages through social media that family members can share

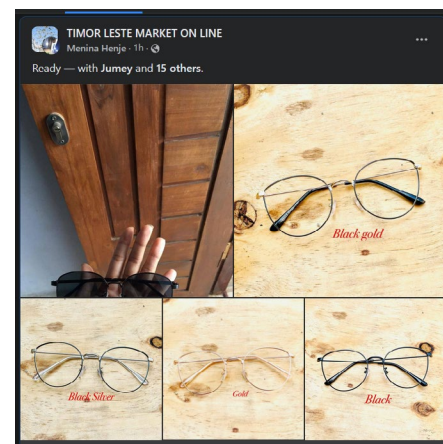


Image 8. Anti-radiation glasses advertised on Facebook in Timor. Screenshot taken by SSTL, October 27, 2021)

TRUST IN HEALTHCARE

Lowest possible score is 4, highest possible is 16.

Table 13. Trust domain scores

		ALL				BAUCAU	BOBONARO	DILI
		Min	Max	Mean	Median	Mean	Mean	Mean
TRUST DOMAIN VALUE		5	16	12.72	12.5	12.64	12.63	12.87
Variables: Lowest to highest	#	Median				12	12	13
Remote - rural	10	10	15	11.60	11.5	Females with a WGC disability have the lowest trust score, though females who SR as with a disability have a higher-than-average score. Scores may reflect the low expectations that people have of health services and or a reluctance to critique services. <i>*the minimum score of 5 was reported by only one person who is included in all these categories</i>		
Female with disability WG	13	9	16	11.70	11			
With disability WG	25	9	16	11.92	12			
Gender diverse without disability SR	2	11	13	12.00	12			
Males with a disability WG	10	10	14	12.10	12			
Female without disability SR	33	5*	16	12.48	12			
Without disability SR	58	5*	16	12.59	12			
Semi-urban	37	9	16	12.59	12			
Female	51	5*	16	12.67	12			
Urban	27	5*	16	12.70	13			
Male without disability SR	23	10	16	12.78	12			
Male	33	10	16	12.85	13			
With disability SR	28	10	16	13.00	13			
Female with disability SR	18	11	16	13.00	12.5			
Very remote - rural	12	11	16	14.08	14			

Table 14. Responses to trust domain questions

Trust -%	Strongly agree	Agree	Disagree	Strongly disagree
Eye surgery works	23.3%	57.0%	17.4%	2.3%
Female	23.5%	52.9%	21.6%	2.0%
Male	24.2%	60.6%	12.1%	3.0%
Disability WGC	16.0%	44.0%	36.0%	4.0%
I trust the health system, and medicines and treatments for eye health from clinics and hospitals	31.4%	61.6%	5.8%	1.2%
Gender diverse (2)	0.0%	0.0%	50.0%	50.0%
If I had an eye problem, I would trust my local eye service to provide high quality care	34.9%	61.6%	2.3%	1.2%
If I had an eye problem, I would trust my local eye service to treat me respectfully	27.9%	62.8%	8.1%	1.2%

33 She referred to these as *ai-moruk internet* (online medicines) but they were being sold door to door.

34 Interview with local leader 14/10/2021, Baucau and follow-up interview with the individual, 14/10/2021. This information was passed on to the health workers in Baucau, and later to the NEC who were aware of this being an issue.

35 Interview with local authority, 14/10/2021, Baucau

36 Interview with health worker, 26/10/2021, Dili

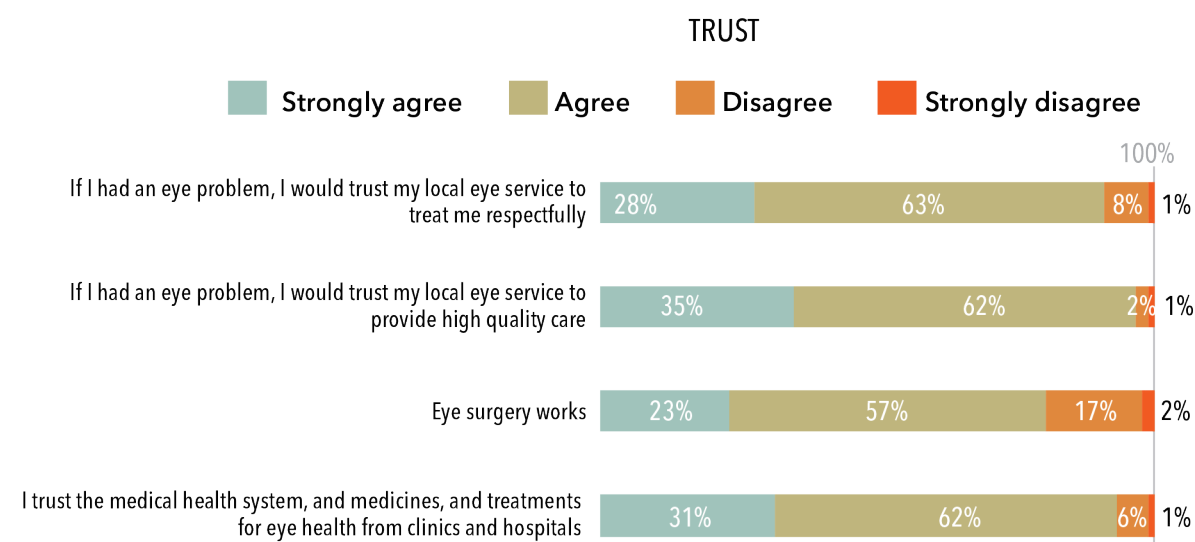


Figure 19. Responses to trust domain questions

Eye surgery

Less than 20% of people (n=17) disagreed or strongly disagreed that eye surgery works, but this was as high as 40% of those with WGC (n=10).

People with a SR disability 28.6%, (n=8) and females (23.6%, n=12) were more likely to disagree or strongly than males (15.1%, n=6) that eye surgery works, across varied education levels, types of work and geographical areas. Four people who disagreed that eye surgery works have been recommended surgery and one of those has had surgery but it was not successful.

The higher number of females not trusting that eye surgery works may account of the higher number of males receiving treatment, and this deserves further attention. There has been a long history of women being medically treated without consent, including forced sterilization under the guise of other treatments, especially during the Indonesian occupation³⁷ and this may be a lingering after-effect.

Image 9. National Eye Centre Director Belmiro Jeronimo with his uncle post-surgery. Photo by Dr. Frenky

Three had been recommended surgery (in 2016, 2020 and 2021), but none have had it so far; two had been told to wait, one was scared. In the comments section, two people explained more, and as the second one shows, the reasons are often more complex than one factor alone:



³⁷ Mason C (2005). Women, Violence and Nonviolent Resistance in East Timor. Journal of Peace Research, 42(6):737-749

I want to get an operation, but I get really car-sick, I don't have enough money for my family to accompany me to Dili
 – Survey respondent, recommended in 2016, female, Bobonaro, age 67

I want to, but I'm scared of getting the (COVID-19) swab test. I want to get an operation but there's no one to come with me and look after me (post-op), bring me food, help me out at home. My daughter got married and lives far away, so I'm all alone.
 – Survey respondent, recommended in 2021, female, Baucau, age 75

The survey sample is small, but may offer some insights into the extra counselling and/or support that some people need to be able to make an informed decision about their health. Of course, the travel restrictions in 2020-2021 will also have had an impact.

Trust of modern health

Overall, trust in modern health scored high, and the corresponding aversion to using traditional methods is supported by the journey mapping and may indicate that traditional medicines are not generally trusted for eye health, and/or that there is a shift away from using traditional medicines. This finding does suggest that eye health is considered differently to other health issues, with a strong preference for modern medicine despite difficulties accessing it.

Trust of and respect from local health services

Women were more likely to say that they disagreed or strongly disagreed that they would be treated with respect, with 15.7% of women (n= 5) and 9.7% of men (3), none of whom strongly disagreed.

The above results and those on trusting local health services are positive, though they are not supported by existing literature nor the journey mapping. One possible explanation is that even though the surveys are confidential and do not

ask people's names, people may not have felt comfortable giving criticism or negative feedback. Another is the low expectations that people have of personal treatment from health workers, as one respondent indicates:

When you go to the health centre they look at you like you are mountain-folk, but as long as you defer to them, show them a lot of respect then it's ok.
 – Joana, Baucau, age 60+

Whilst people did not directly say that they had a negative experience, they spoke of not getting what they needed. Not understanding or getting support to make a decision came up for a number of people in the journey mapping and the survey:

I didn't get any counselling or support from the health workers, they just said that I can have the operation but I'm confused and scared, what if it makes it worse? I last went in 2020 and I don't know what to do.
 – Diana, Dili, age 28

Expectations around client-centred care are low, and many people have never experienced attentive, responsive care. One person during the journey mapping spoke of her experiences with the *madres* (nuns); they were caring and nice to her, so she only ever wanted to go there. She did not critique the local health centre or health post but was very clear that she had an aversion to going there.

I always prefer to go to the nuns because they treat you better there and they usually have medicines in stock. When they told me I'd have to go to the health centre I was worried about how much it was going to cost, how long I'd have to wait. But they were able to do an eye test on the same day so it was ok. I got my glasses in 2008 and haven't been back since.
 – Estella, Baucau, age 68

People spoke of long waits, being in crowded spaces and not being sure of where to go – however, this was spoken about as a normal experience and only when prompted about what they found difficult. Others didn’t want to go back, either giving up or finding alternatives:

The health centre doesn’t have regular opening hours, you’d wait a long time after travelling distances and I just gave up and stopped going and lost faith in the system. When I heard about the private shops in Dili I decided to go there and check them out. I got a pair [of glasses] for \$15 which was great and I used them for a long time. – Maria, Dili, age 40-49

Although there are only two people who identify as gender diverse in this survey, other research into health care and the lived experiences of LGBTQI+ people suggests it is very common for them to have had negative experiences with health workers and have little trust in the health system. A report commissioned by Rede Feto found that 32% of respondents reported that they had faced discrimination in various government facilities such as schools and health centres because of their sexual orientation or gender identity.³⁸ This leads to greater mistrust of the health sector, as has been the case for many people with disabilities.

There have been some important gains in improving the way that health workers treat patients, some of which can be attributed to the jointly delivered Disability Inclusive Health training by the National Institute of Health and RHTO. One evaluation found that health workers who attended the training were more aware and sensitive, particularly of systemic rather than individual barriers,³⁹ and that this also translated into better care across all people in the

38 Rede Feto, 2017, A Research Report on the Lives of Lesbian and Bisexual Women and Transgender Men in Timor-Leste Conducted by Iram Saeed and Bella Galhos For Rede Feto, Timor-Leste

39 Disability Inclusive Health Evaluation, Sustainable Solutions Timor-Leste on behalf of the Ministry of Health, 2021

community.⁴⁰ Importantly, people with disabilities noted the difference in the way they were treated with people who had attended the training and this was an important step in gaining trust.

Summary of trust domain

Although the survey results show that there is high trust in receiving quality and respectful care, all other evidence suggests that this result is more likely due to low expectations than actual experiences, and that improvements in patient care would likely lead to better uptake in services.

Recommendations: Trust

- Healthcare workers continue to be given client-centred care, including more health-workers attending the DIH training,⁴¹ other training to include client-centred care and reinforcement from internal policies that support this approach
- Introduce feedback and complaints mechanisms that encourage clients to give confidential feedback⁴²
- The PEC training continues to provide information and awareness to health workers, and includes sections on patient centred care
- Provide mentoring and examples for health workers to follow
- Encourage regular discussions about the challenges they are facing – giving them opportunities to talk about their stresses to avoid this affecting their motivation at work
- Produce health promotion materials that showcase successful results of surgery, and designing these with specific targets in mind

40 Community Based Monitoring Evaluation, Sustainable Solutions Timor-Leste on behalf of the Ministry of Health, 2021

41 Health training for midwives is currently being developed and due to be launched in late 2021 or early 2022 that includes client-centred approaches to healthcare in a range of sectors. The training has been designed to have stand-alone modules, and may offer a great opportunity to provide in-house training, or UNTL supported training to health workers. The training has been supported by UNSW and is due to be delivered by UNTL

42 Marie Stopes Timor-Leste have implemented a system of anonymous feedback boxes with simple, diagram-based ways to provide feedback on satisfaction with services

OPPORTUNITY TO ENGAGE WITH EYE HEALTH CARE

Lowest possible score is 5, highest possible score is 20.



Table 15. Opportunity domain scores

		All				Baucau	Bobonaro	Dili
		Min	Max	Mean	Median	Mean	Mean	Mean
OPPORTUNITY DOMAIN VALUE		11	20	17.55	18	16.86	17.22	18.45
Variables: Lowest to highest	#	Median				17	18	19
Male with disability WGC	10	11	20	15.60	15.5	Males with WGC had the lowest score in opportunity, and urban populations had the highest. Disability, whether self-reported or WGC was the largest factor in opportunity, following by geographic area.		
With disability WGC	25	11	20	15.84	16			
Female with disability WGC	13	12	19	15.85	16			
Very remote - rural	12	11	20	16.00	15.5			
Male with disability SR	10	13	20	16.00	17			
With disability SR	28	12	20	16.89	17			
Remote - rural	10	14	20	16.90	16.5			
Gender diverse without disability SR	2	16	18	17.00	17			
Female with disability SR	18	12	20	17.39	18			
Semi-urban	37	11	20	17.46	18			
Female	51	12	20	17.61	18			
Female without disability SR	33	12	20	17.73	18			
Male	33	11	20	17.48	19			
Without disability SR	58	11	20	17.86	19			
Without disability WGC	61	11	20	18.25	19			
Urban	27	14	20	18.59	19			

Table 16. Responses to opportunity domain questions

Opportunity	No - no difficulty	Yes - some difficulty	Yes - a lot of difficulty	Cannot do at all
Paying for a check-up	40.7%	37.2%	18.6%	3.5%
Male with a disability WGC	10.0%	50.0%	40.0%	0%
Travelling to get an eye check-up, if you needed one?	47.7%	32.6%	18.6%	1.2%
Male with a disability WGC	20.0%	40.0%	30.0%	10.0%
Finding someone to accompany you to an eye check-up, if you needed one?	65.1%	23.3%	10.5%	1.2%
Taking time off from daily chores, employment or caregiving responsibilities to get an eye check-up, if you needed one?	74.4%	20.9%	3.5%	1.2%
Permission from your family to attend an eye check-up, if you needed one?	93.0%	7.0%	0.0%	0.0%



Image 10. Timorese family. Photo by Hugh Rutherford, 2011, supplied by FHF

The cost of treatment and transport were unsurprisingly two of the main barriers to people having the opportunity to seek treatment. It is assumed that the 'paying for a check-up' includes both direct and indirect costs. One factor in this might be knowing how much it would cost, with people who had been for an eye-check in the past two years reporting lower rates of having a lot of difficulty 7.4% and none who said they couldn't at all, compared to 23.7% of those who didn't and 5.1% who said they couldn't at all. The factors could also be the other way around, given people who have not engaged are more likely to be disabled, live far away and receive government support payments.

Associated costs

Paying for a check-up present the highest level of difficulty,⁴³ with:

Females reported higher difficulty paying than males:

- 60.8% of females would have difficulty (n=30) or cannot do at all (n=1)
- 54.5% of males would have difficulty (n=16) or cannot do at all (n=2)
- One person who is gender diverse reported that it would be difficult to pay

⁴³ Unpublished research by UNSW has recently shown that associated costs are a significant barrier to people in Timor-Leste accessing healthcare, and account for up to 1000% of monthly income of rural households.

People with a disability were even more likely still to say they would have difficulties paying:

- 71.4% saying they would (n=20) including 1 who cannot pay at all (SR)
- 85.7% of WGC saying they would have difficulty, with 1 saying they couldn't pay at all

Similar numbers were found for people living in remote (70%, n=10) or very remote (67%, n=8) at 68.2% (n=15) overall.

People with 5 children or more would have even more difficulty still, with 73.3% saying they would have difficulty (n=15), with one saying they could not at all, with 66.7% of people with 4 children experiencing some or a lot of difficulty (n=20).

Women and people with disabilities in remote areas had the most difficulty with 89% saying they would have some or a lot of difficulty paying (n=8).

They survey did not ask more questions about what those costs were but several people responded with more detail:

If you can, please help me so that I can get treatment for free
– Survey respondent #61, female, Baucau, with disability, age 20

I really want to get treatment, but I need help from the government because I am poor
–Survey respondent #32, female, Bobonaro, age 54

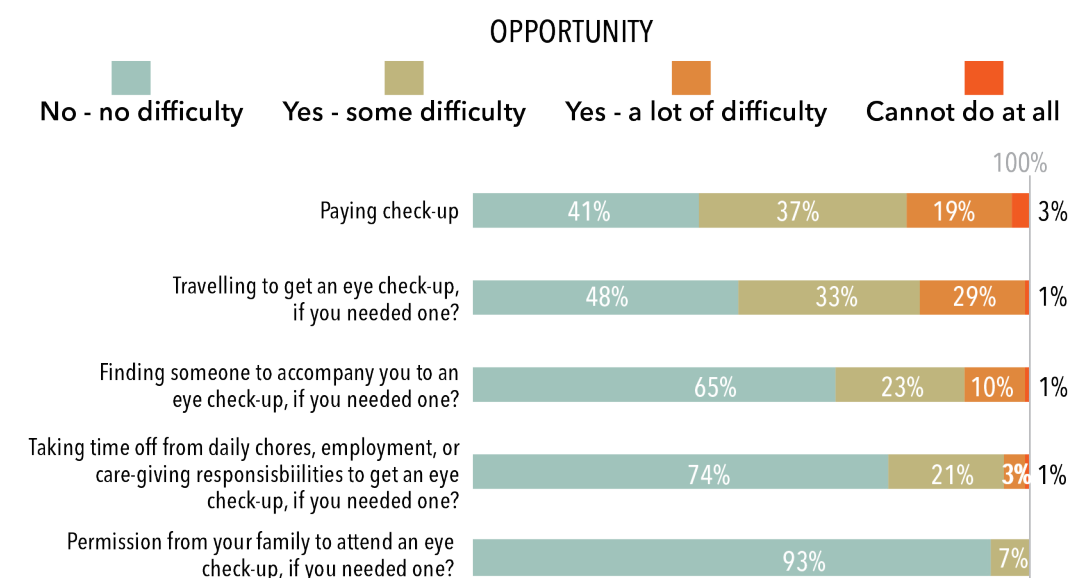


Figure 20. Responses to opportunity domain questions

I'm prepared to travel to Dili or Maliana for an eye check, but I need someone else's help. I was going to go and get an operation. But I have a disability (eyes) and have my own family, with 3 kids. My partner's mother has a lot of difficulties, and my family are poor. I really want to get help.
–Survey respondent #29, male, Bobonaro, with disability, age 64

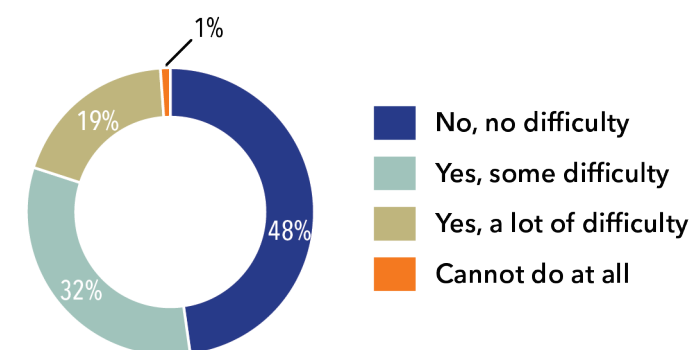


Figure 21. Difficulty travelling to get an eye check if needed

Opportunity: Journey Mapping

Costs

Associated costs were mentioned in the journey mapping as a significant barrier for some, but one that reduced when they had sufficient information and motivation. Although paying wasn't always easy, people found a way when they needed to. It makes sense that the easier and more convenient a service is, or the more urgent, the more likely someone is to prioritise it. People in more remote areas are less likely to be dependent on their eyesight for their livelihood, less likely to have information, more likely to have opportunity barriers and therefore less likely to seek help.

Transport

Transport accounted for the next majority who would have difficulty travelling, with 47.7% (n=41) saying it would be difficult for them, either some (31.4%, n=27) or a lot of difficulty (16.3%, n=14).

More women reported it being difficult for them to travel (56.9%, n=29) than males (45.5%, n=15); the largest factor in travelling difficult was unsurprisingly living in remote or very remote (68.2%, n=15).

Of women living in remote or very remote areas, 75% (n=9) would have difficulty travelling, and of women living in very remote areas, 4 out 5 would have difficulty travelling.

Table 17. Difficulty travelling disaggregated by variables

Difficulty travelling (some or a lot of difficulty)	n	%
Women in very remote areas	4	89.0%
Women WGC	10	76.9%
With disability WGC	19	76.0%
Women with disability SD	12	67.9%
Women - all	29	56.9%
Total	45	52.3%
Men - all	15	45.5%

The survey did not ask whether people regularly travelled to the nearest larger city for other purposes which may help to provide more insights, but the journey mapping and correlation scores suggest that people are much more willing to travel if they have sufficient information, which also increases their motivation. This is supported by the survey finding that of those recommended glasses, 89.1% are willing to travel to purchase them.

There are many considerations with the type of transport people have, with walking - especially long distances - being taxing and time consuming, and public transport costing direct money and being irregular at time, especially during rainy season. There are also considerations for those, mostly men, who are used to having independent transport which may cause difficulties for them if they have vision difficulties and need someone to assist them.

The most vulnerable people though are likely to have a difficulty accessing transport - they are far away, they don't have their own transport and public transport is minimal. They are not going to travel long distances without having an urgent health issue or being certain of getting the treatment that they need.

Table 18. Method of transport disaggregated by sex and disability (self-identified and WGC)

Highest scores per category are highlighted	n	Female	Male	Gender diverse	PwD	WGC
		%	%	%	%	%
Own transport &/or drive	31	23.5%	57.6%	0%	10.7%	28%
Motorbike (someone drives me)	16	21.6%	15.2%	0%	21.4%	16%
Walking	16	15.7%	18.1%	100%	32.1%	20%
Public transport	22	37.3%	9.1%	0%	35.7%	32%
Borrow a car	1	2%	0%	0%	0%	4%
	86	100%	100%	100%	100%	100%

I want help to get transport so that I can get treatment at the Baucau hospital about my eye health. Because I haven't been able to see clearly for 2 years now. And I live really far away from public transport. I don't know where to get a consult, so please help me.
– Survey respondent #64, male, Baucau, with a disability, age 60

As a health worker, we have enough equipment but we don't have the transport so that makes it hard to do outreach in rural areas and there aren't enough human resources to do consults in rural areas.
– Health worker, Bobonaro

We don't know how to contact people, so we wait for them to come to us. We don't have transport, so we need people to do that - we really hope that you can do that (to the research team).
– Health worker, Baucau

So the health workers are waiting for people to come to them, and people needing assistance are waiting for people to reach out to them and provide information.

I really need your help about my eyes not seeing well when I look at or read (letters) or anything.
– Survey respondent #72, female, Baucau, age 52

I want to suggest something to the people in charge of this program: but first let me say that I really appreciate this program. I also want to say that I can't see clearly, and my eyes are always watery when it's bright. I really need help and I'm ready to get a check-up anywhere. I hope that someone will contact me - thanks for your attention.
Survey respondent #31, female, Bobonaro with disability, age 21

To eye health workers: increase service and socialisation (awareness raising) to communities that glasses aren't about looking good (ie., using them for fashion). And give information to communities in rural areas and remote areas about eye health services.
– Survey respondent #52, male, Dili, with disability, age 30

I'd like to request that every six months or year please come and consult in our area with our elderly population, because my eyes feel all scratchy, I can't see clearly and I believe that in a year or so I won't be able to really see at all.
– Survey respondent #55, female, Baucau, age 68

One person from the journey mapping has serious eye concerns but has never had health care for their eye issues. They don't know where to go or who to see. As a rural, older woman, reaching out to health services is a huge task and without health outreach - either formally or through their families, they are unlikely to ever seek help.

Table 19. Willingness to travel by municipality

Travel to:		Dili		Baucau Villa		Maliana		Not willing	
From	Total	n	%	n	%	n	%	n	%
TOTAL	46							6	13.0
Dili	20	19	95.0	-	-			1	5.0
Baucau	9	3	33.3	8	8	-	-	1	11.1
Bobonaro	17	8	47.1	7	13	76	13	4	23.5

If I was going to go to Baucau I really need someone to go with me, to help and support me. I'm really scared that I won't be able to see at all next year but I'm on my own.
– Marcelina, Baucau, age 68

Willing to travel: Recommended glasses

Of the six who said that they are not willing to travel, the variables were mixed:

- all have trouble with their eyes at the moment
- all had previously used glasses
 - 3 continue to wear them daily (2 broke, 1 eyes were hurting)
- 5 are interested in getting surgery (4 to Dili)
- 5 are willing to travel for surgery
- 2 had been recommended surgery

These variables indicate that willingness to travel may be negatively impacted by previous engagement with eye health care and experiences.

Time opportunity is an important consideration for many people and it can be hard to leave responsibilities.

I'm a single mother and I work in an NGO; it's often really hard for me to split my time and travel far to get health care. I only want to go to Maliana.
– Survey respondent #11, female, Bobonaro, age 46

Case Study: "Anecleta"

Anecleta is a 46 year-old working mother who lives a 15-30 minute motorbike ride away from Maliana hospital, although to get there she would need someone to take her. She's married and has had 7 children, 5 of whom are still living – four are school age and one is still too young. Her life is busy. She works fulltime at an NGO and spends a lot of time looking after her family. She completed high school and knows four languages.

Although she's had some eye health information, she wasn't aware that adults and kids should get their eyes checked. She knows where to go to get an eye-check, but she has no idea how much it would cost, or where to get trustworthy information about the problems she has with her eyes at the moment. Despite that, she wouldn't seek traditional medicine and she trusts modern health. She does believe that surgery works, but also believes that she's likely to go blind when she's old and that would be a huge problem for her, she believes strongly that eye care is really important.

She makes her own decision about her eye health, although her partner makes the final decision about whether someone in the household would get healthcare if they were sick. She's never had her eyes checked formally but a nurse recommended that she wear glasses in 2016. She paid \$15 for them and got them from the hospital. She doesn't wear them now though, they're uncomfortable and she hasn't had her eyes checked since. She has some eye problems now, but not a lot of difficulty seeing.

It's likely that Anecleta would go to the hospital – if she knew what to expect, that someone would be there at a certain time and that she wouldn't have to travel to Dili for a proper consultation. With her work and responsibilities, her time is really valuable – but so is her eye-sight. She might just make the journey to Dili if it was really needed, and she could make an informed decision about that.

Agency & decision making

Most people were responsible for making their own decisions about their eye health, including women and people with disabilities both self-identified and with WGC. The people with disabilities who did not make their own decisions were mostly younger (under 30), and one identifies as a trans-man.

Decision making for who in the family decides if someone needs to see healthcare is more shared, with 46.5% making the decision in the household, and 18.6% sharing the role with their spouse. More males (18.2%, n=6) responded that their spouse makes decisions about seeking health treatment for others than females (15.7%, n=8).



Image 11. Elderly male cataract patient. Photo by Hugh Rutherford 2011, supplied by FHF

Table 20. Who makes decisions about your eye health disaggregated by sex and disability (self-identified and WGC)

	All		Female		PwD		WGC	
	%	n	%	n	%	n	%	n
Myself	86.0%	74	88.2%	45	82.1%	23	80.0%	20
My parents	8.1%	7	5.9%	3	14.3%	4	12.0%	3
Myself together with my spouse/partner	2.3%	2	2.0%	1	0.0%	0	4.0%	1
My spouse/partner	2.3%	2	2.0%	1	3.6%	1	4.0%	1
My children	1.2%	1	2.0%	1	0.0%	0		
Neighbour								
	100%	86	100%	51	100%	28	100%	25

The RAAB data showed that a number of people need to seek permission to attend eye care. The truth may be a bit more nuanced, and appears to be more about getting support, rather than seeking permission. Only 7% (n=6) said that they would need to get permission from anyone. The results of the journey mapping aligned with this, with 'permission' being referred to as support through encouragement, resources, transport and accompaniment.

Table 21. Permission needed to get eye treatment and if answered yes, by whom

Would you have difficulty getting permission from your family to attend an eye check-up, if you needed one?	
No - no difficulty	93%
Yes - some difficulty	7%
Who would it be difficult to get permission from?	
• My partner • My parents • My Children • Because my family live far away • All my children	

Summary: Opportunity

The cost, real or perceived, and transport are two of the highest barriers to people having the opportunity seek eye health care. It is likely that with enough information, motivation would increase and that would then reduce the opportunity barriers. There will still be some people who absolutely need support – whether that is through taking services to them, offering transport, accommodation, cash or accompaniment.

Agency does not appear as a significant barrier for most people, but if the question was asked ‘do you need the support of your family’ the results would likely be very different. People do need endorsement and support from their family, which is related but different.

Image 12. SSTL researcher getting her eyes checked by Fo Naroman Timor-Leste staff. Photo by Maia Tilman, SSTL.



Recommendations: Opportunity

In addition to having clear and accessible information on services available which would attract people to access services themselves, reaching out to people is important. This can be as simple as a phone call to check in on people and let them know that the eye health centre is operating and waiting to see them.

Outreach is an important service that has had successes in the past. For this to operate effectively, a number of steps can be taken:

- Maintain an accurate database of clients, with two or three contacts that they can be reached through (which might include local authorities or active community members)
- People need advanced notice of when outreach is going to visit – to mentally, physically and logistically prepare. Ideally, at least a few weeks’ notice would be given if not more, which would give time for local health and community workers to spread the word
- Outreach should be longer than a week – allowing time for word of mouth to spread and people to gain confidence in the service
- Health workers conduct advance screenings so that outreach teams can be prepared
- Checking the timing with communities is important – cultural and agricultural ceremonies will be prioritised over outreach visits
- Identify community liaison workers who can help to raise awareness, share information and act as a conduit between health services and communities.
- This role could also include, or be separate to, a health advocacy and liaison role that could spend time providing medical counselling to people, helping them to work through their decisions

For those who face significant financial hardship, have cash grants and/or transport assistance that can help them overcome economic and logistic barriers – especially for those in remote communities and who face multiple barriers such as women in remote areas, and people with disabilities.

ATTITUDE TOWARDS GLASSES



Two additional questions were asked about attitudes to using glasses, based on a similar study in Indonesia and assumption that negative attitudes towards wearing glasses may demotivate people, and could be a potential focus for social and behavioural change materials.

The results show that there is still stigma around wearing glasses, and this is supported by the journey mapping where people reported being embarrassed to wear them, being teased and only wearing them in certain situations.

I didn’t want to wear them but I had to so that I could work. I would take them off and hide them when people come in. At home, people teased me saying ‘you’re an old woman now, your body is falling apart!’ but then if I went out to any social occasions, people would say ‘look at you trying to show off and look smart’. – Sylvia, Bobonaro, age 50-59

Table 22. Responses to questions about attitudes to glasses

Attitudes to glasses - %	Strongly agree	Agree	Disagree	Strongly disagree
I think that people wearing glasses makes someone more attractive ⁴⁴	4.7%	43%	44.2%	8.1%
Female	6%	47%	43%	4%
People who wear glasses (don’t) get teased*	7.0%	46.5%	38.4%	8.1%
Female	5.9%	54.9%	35.3%	3.9%
Glasses make people look smart	4.7%	25.6%	58.1%	11.6%
Female	3.9%	35.3%	49%	5.9%

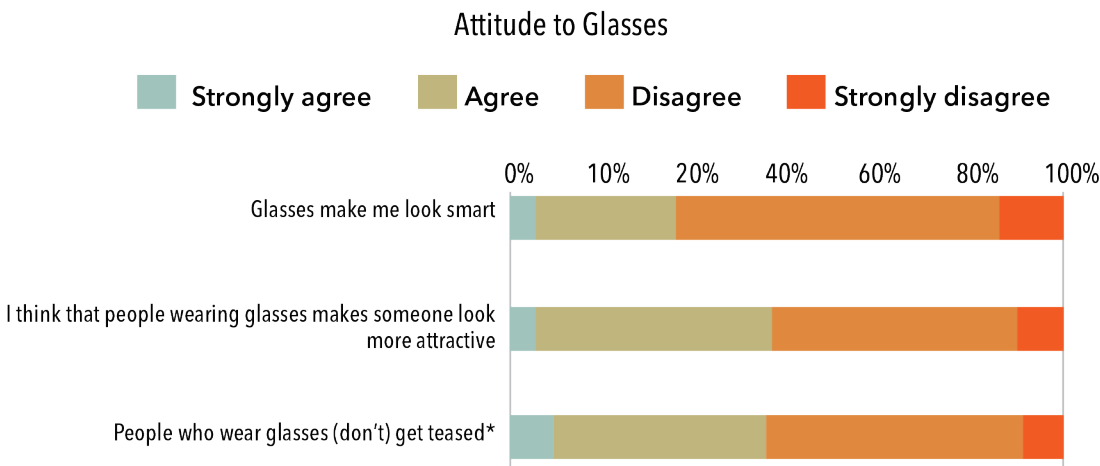


Figure 22. Responses to questions about attitudes to glasses. * Questions are reversed here for visualisation purposes

44 The question in CEEHAT was “wearing glasses is embarrassing or unattractive” this was modified to reduce the potential of repeating negative stereotypes, particularly since the survey was mostly self-administered

From the survey total, 22% (n=19) wear glasses daily, and of the people recommended glasses, 41.3% (n=19) are using them daily.

Out of the 53.5% (n=46) people who had been recommended glasses, just over half (52.2%, n=24) had been for a follow-up, 84.8% (n=39) had ever had glasses, and 48.7% (n=19) use them daily.

Table 23. Time between being recommended glasses and next consultation

Years to next consultation after being recommended glasses			Ever had glasses		Use glasses daily	
Years	n	%	n	%	n	%
Total	24	52.2%	39	84.8%	19	48.7%
0	13	54.2%				
1	5	20.8%				
2	2	8.3%				
3	1	4.2%				
9	1	4.2%				
14	1	4.2%				
17	1	4.2%				

However, most of these went in the same year, and when correlated with the information from the journey mapping, this is most likely when they went back to pick up their glasses. That leaves 23.9% who had been for a follow-up, with years ranging between 1 - 17.

We need people to know that sunglasses aren't just for men or being stylish, people really need them to protect their eyes.

– Local authority, Baucau

When I started wearing them people would tease me and call out. I would snap back at them, 'I have trouble seeing and you want to tease me?', that made them think and they'd be quiet.

– Maria, Dili, age 40-49

They gave me glasses but they were so big, people made fun of me all the time. I only used them for a short time and then stopped.

– Lilliana, Baucau, age 30-39

Negative stigma of glasses was not raised as a reason for not wearing glasses by those who had been recommended to wear them but did not wear them daily. This may then be considered something that people *think* other people think, but personal norms and need will overcome the peer pressure because of need. Three people spoke of pushing back on people who teased them for wearing glasses.

Table 24. Reasons for not using glasses for people who had been recommended but do not use daily

Reason for not using	#	%
My eyes were hurting	7	35%
Use for reading/work	7	35%
They broke	4	20%
My eyes are fine now	1	5%
They are uncomfortable	1	5%

The reasons given for not using glasses daily,⁴⁵ together with low numbers of people getting follow-up and low levels of understanding about eye health suggest that people are not getting their prescriptions updated to address changes in vision.

People mostly got their glasses from the hospital or clinic, with private glasses shop and Fo Naroman Timor-Leste following.

45 The survey did not ask if people used their glasses for specific purposes, which in hindsight might have been helpful

Table 25. Place where people got their glasses

Place where people got glasses	n	%
From the clinic/hospital	20	51.3%
Private glasses shop (Dili 5, Bobonaro 1, Baucau 1)*	7	17.9%
Fo Naroman Timor-Leste	4	10.3%
Indonesia	3	7.7%
Someone got them for me from somewhere else	1	7.7%
Local shop	1	2.6%
Someone gave them to me	1	2.6%
Total	39	

*this indicates respondents' municipality, not where they purchased them

Prices paid for glasses ranged from nothing to \$420, and 29% of the 24 people who had been recommended glasses said that the price does not matter.

[See Annex 8 for further information on glasses, including willing to pay.](#)

Image 13. Fo Naroman Timor-Leste glasses shop at the National Eye Centre. Photo by Rosa Martins, SSTL



SURGERY

Only two people in the survey had surgery, which doesn't allow us to look deeply into the data. A total of 5 people had surgery recommended but have not had it yet.

See Annex 12 for a more detailed comparison between those people who have been recommended and not had surgery and those who have had surgery.

Those who have been recommended surgery include a 54-year old (* in table below) who has vision impairment and lives 3-4 hours from Maliana by rental car. She has a low understanding domain score, and she says:

"I want to get treatment but I need help from the government because I don't have the means myself."
– Survey respondent #32, female, Bobonaro, age 54

Her domain scores are much lower than the mean and show how multiple barriers intersect to create challenges to people accessing eye health care.

Domain	U	M	T	O	Total
Mean	10.53	14.4	12.72	16.86	54.61
Her score	9	14	11	15.00	49.00

See Annex 9 for more domain score correlations

Table 26. Who has been recommended surgery

From who?	Year	Why haven't you had the operation yet?	Want surgery?	Willing to travel		
				Dili	Maliana	Baucau
Nurse - eye	2016	Doctor/health person said wait	Yes	Yes	Yes	
Doctor - eye	2008	Doctor/health person said wait	Yes	Yes	Yes	
Doctor - eye	2020	Doctor/health person said wait	Yes	No	No*	
Doctor - eye	2021	Scared - dying. Too far away I don't have transport	Yes	No		Yes
Doctor - eye	2021	Scared - eyes worse	Yes	Yes		

Surgery: journey mapping

The journey mapping included 3 people who had operations, which is not enough to draw conclusions, but rather provide insights:

- 1. Female, 60+, Baucau: Operation in both eyes: successful and happy with the results.
- 2. Male, 40 - 49, Dili: Operation in one eye as an adult after a childhood accident. Unsuccessful, with the doctors telling him that it was too late to repair and the chances of successful surgery was very low.
- 3. Male, 60+, Bobonaro: Operation was successful but still needs corrective lenses. Glasses have broken and too expensive to replace (was told \$100 by a health worker).

The first was a story of success (after the initial two years of waiting for a specialist to arrive, not knowing that she could have travelled to Dili). She was supported by her family, seen fairly quickly and able to get follow-up straight away.

The second was a complex case of a childhood trauma that was unlikely to be fixed - but the health workers wanted to give it a chance. He's disappointed but was grateful for being referred to disability services.

The third had successful surgery, but still needs corrective lenses. This was fine until the glasses broke and he was told they would be \$100 or more to replace and have to be imported (in Maliana). That took a lot of effort to try to get new ones, and he doesn't have the motivation to follow up anymore, even though he knows that in Dili glasses are available for more affordable prices.

Surgery: summary

The trust in eye surgery working is encouraging, and also suggests that there is opportunity for more positive health promotions about the possibility and benefits of surgery, especially for cataracts.

The fear that people have often relates to not knowing enough, and not having health professionals reassure them or help them weigh up the risks and benefits.

Image 14. Dr Frenky de Jesus - bilateral Cataract surgery at Outreach. Dr supplied photo, 2021



Recommendations: Surgery

In addition to raising awareness and having better health promotion, proactively following up with and providing counselling to people is likely to increase the uptake of surgery - especially for women. People need to have clear information about what to expect in order to make an informed decision.

Having health workers follow-up on people referred for surgery, but needing to wait for international visits and/or equipment and materials is a gap that could be addressed through:

- Providing people with contact details so that they can follow-up with health workers
- Recording multiple contact numbers for patients
- Make contact through community leaders and/or family and
- Health workers to be pro-active in sharing information about specialist visits well in advance of them arriving

HISTORY OF ENGAGEMENT WITH EYE HEALTH CARE

Bobonaro had the lowest rate of engagement with healthcare, followed by Baucau and Dili with the highest. Health centres are an appropriate and effective place for increasing awareness and uptake of eye health services.

Engagement with eye health has a number of variables, that despite the small sample provides some insights which come from the following four questions:

The following provides a summary of the key traits of the highest and lowest engagement scores.

MOST	LEAST
Female	Gender diverse
Married	Single
University	None
30-39	Over 60
Urban	Rural
Salaried	Work, no income
Tetun - very easy	Tetun - difficult

[See Annex 11 for further details.](#)

Table 27. History of engagement

History of engagement	Yes		Female		Male		Disability SR		Disability WGC	
	n	%	n	%	n	%	n	%	n	%
Have you had an eye check in the past 2 years?	27*	31.4%	16	31.4%	10	30.3%	8	28.6%	8	32%
Have you ever had eye surgery?	2				2		1		1	
Have you ever had glasses?	49#	57.0%	31	60.8%	17	42.4	12	42.9%	14	56%
Do you wear glasses regularly?	22	25.6%	15	29.4%	6	18.2%	5	17.9%	5	20%

*one transman included in this table
#Prefer not to say included in this table

[Further analysis can be found in Annex 10.](#)



Image 15. Timorese eye health practitioners. Photo by Hugh Rutherford, 2011, supplied by FHF

Diabetes

Of the total, 10.5% (n=9) had been told that they had diabetes. Of these, all but one had been told about the potential for vision difficulties related to their diabetes - they were also the only one of this group who has never had an eye check. Five had an eye check in the previous two years, two had their eyes checked in 2018 and the other two in 2002. All but one have problems with their eyes at the moment. Three people expressed an interest in surgery, although it has never been recommended to them.

Six have had glasses recommended and four are still using them. The other two reported that their eyes were hurting - one bought their glasses in 2002, the other in 2019.

Journey mapping: engagement with health services

People had mixed experiences with health services, but the one common point was only ever going when needed, never for prevention or regular check-ups. People shared experiences of going to local health centres but not getting satisfactory treatment and eventually giving up and this was a key point in people not continuing or waiting a long time to seek eye health care.

Summary of engagement

Overall engagement was less than a third, despite over 80% experiencing eye concerns at the time of the survey and journey mapping. There is a clear need for eye health care, as well as demand.

Recommendation: engagement

In addition to information and health promotion, the following may help increase engagement:

- Regular and dependable opening hours of clinics
- Engagement with schools as a key entry point



Image 16. SSTL researcher meets with eye health workers at Maliana Hospital. Photo by SSTL

Summary

Health promotion is an important aspect of raising awareness and encouraging people to engagement in health services, including eye health care. Whilst there are multiple barriers to seeking and getting health care, information and understanding are clearly the largest barriers that people are facing in getting eye care at the moment. People experience multiple barriers

Variable	Correlation
Education	Higher education corelates with higher understanding scores
Sex	Males had the highest scores, followed by women and then gender diverse folk
Age	People aged 30 - 39 had the highest understanding, over 60 the lowest
Marriage status	Being married correlated to higher understanding
Municipality	Dili had the highest, followed by Baucau and Bobonaro. Remote areas had the lowest scores.
Disability status	People without a disability have higher understanding scores
Source of income	People who are salaried have higher scores, work with no income the lowest
Tetun ability	Higher scores correlated with 'very easy' compared to lower scores and 'difficult'

Improved services are clearly needed, and the improvement of facilities in Maliana and Baucau are very positive steps in that direction. Taking healthcare closer to people removes some of the transport and cost barriers that prevent people from seeking treatment.

Health promotion doesn't have to be complicated or expensive but does need to be targeted and should be done by people who are knowledgeable about social and behavioural change as well as communications - rather than clinicians. Eye care, like many other areas of health, requires a public health perspective that brings in understandings about people's priorities and realities.

There are many systematic changes that will take time and will most likely improve services to eye health and general health care, including better resources in health clinics, health workers being more client focused and increased numbers and qualifications of health workers. Screenings and awareness raising in schools can help to identify issues early for children and help raise awareness among their parents and extended families. These should be worked towards, whilst also looking for some short-term solutions.

Some short-term approaches could include:

- Health promotion materials developed and shared on social media
- Having 'eye care' days which raise awareness and have on the spot consultations for people, these can take advantage of other events like the 28th November Independence Day celebrations in Baucau, and be done for minimal cost
- Using the contact list from the survey and journey mapping, contact each individual to touch base; let them know the current opening hours, ask them if they'd like to come in
- Having an 'eyecare' clinic day - where the NEC is open outside of business hours to attract people who can't usually attend
- Target government, NGO and/or private sector to do screening days for staff - raising awareness, potentially fundraising and attending to people who might not have sought out eye care
- Connect with other organisations who have done health promotion including Marie Stopes Timor-Leste, Maluk Timor, WHO

FINAL WORDS FROM SURVEY RESPONDENTS

I'm confused about eye operations. #1

Thank you for the information. #18, #20

I really want to get treatment for my eyes, because I can't see clearly and I always have watery eyes. #4

I want to get an operation so that my eyes can see clearly, but I also have asthma and so I'm scared to get the operation. #14

As a nurse that works in eye health my observations are: a lot of people don't prioritise getting their eyes checked, and those who live in rural areas don't have the resources and it's hard for them to access information or the clinic. #16

So few people have any information on eye health. #22

Thank you so much #25, #26, #56

Thank you so much for helping me to get some information about my eyes. #27

Thank you for helping me to get this information. I want to go to the hospital to get treatment. #35

Please share eye health information to the suku, because most people in rural areas don't have access to information and don't know about the eye centre. #50

I really want to get an eye check because I use glasses that I bought before, but my eyes are still constantly watering. #28

When it's bright daylight and I drive my motorbike - especially on dusty roads, my eyes get really sore and can't see the road clearly. Thank you for this survey. #49

I want to get a check-up about my cataracts so that I can see clearly, because I can't see distance clearly and at night I can't see anything at all. #51

These questions are really clear, thank you. #69

This survey is really important, I really believe that this opportunity will help to resolve my wife's problem a little bit, because she can't see distance clearly, and can't see well. With the results of this survey, I hope that my wife will be able to get better treatment for her eyes. Thank you. #80

Thank you! #82

This survey is great, sharing information and improving a bit of our awareness. #54



Journey mapping in Dili. Photo by Rosa Martins, SSTL

Annexes:

Annex 1: List of consultations and interviews

Table A 1. Health workers and community leaders consulted and interviewed

Name	Municipality	Sex	Disability	Category	Organisation
Lilia amaral	Baucau	Female	No	Health worker - eye	HOREX
Dr. Nuno da Costa	Baucau	Male	No	Health worker - eye	HOREX
Rince Nipu	Bobonaro	Female	No	NGO	FHM
Maria Soares	Bobonaro	Female	Yes	NGO	ADMB
Alito Soares De Araujo	Bobonaro	Female	No	Health worker - eye	Maliana Hospital
Rosa Martins	Dili	Female	No	NGO	SSTL
Belarmino Jeronimo	Dili	Male	No	Health worker - eye	NEC, Dili
Jenni Lillington	Dili	Female	No	Donor	RACS
Eva Mendonca	Dili	Female	No	Government	MSSI
Lucio Borges	Dili	Male	Yes	NGO	AHDMTL
Silvia Antonia Soares	Dili	Female	Yes	NGO	RHTO
Leonel Barbosa	Dili	Male	No	NGO	Fo Naroman Timor-Leste
Jerry Vincent	Overseas	Male	No	Health worker - eye	Consultant

Annex 2: Journey mapping participant list

Table A 2. Journey mapping participants (note: maps not included for two participants who were interviewed using the methodology and hand-drawn maps)

Code name	Municipality	Sex	Disability	Age	Treatment	Operation	Glasses
Lilliana	Baucau	Female	Yes	30 - 39	No	No	No
Olivia	Baucau	Female	No	30 - 39	Yes	No	Yes
Sinta	Baucau	Female	No	50 - 59	No	No	No
Joana	Baucau	Female	No	60+	Yes	Yes	Yes
Marcelina	Baucau	Female	Yes	60+	No	No	No
Estella	Baucau	Female	No	60+	Yes	No	Yes
Pedro	Baucau	Male	No	40 - 49	No	No	Yes
Damiaun	Baucau	Male	No	60+	Yes	No	Yes
Lucia	Bobonaro	Female	Yes	30 or under	Yes	No	No
Natercia	Bobonaro	Female	No	40 - 49	No	No	No
Maria	Bobonaro	Female	No	50 - 59	Yes	No	Yes
Adilson	Bobonaro	Male	No	60+	Yes	Yes	Yes
Filomena	Dili	Female	No	30 or under	No	No	No
Diana	Dili	Female	Yes	30 or under	Yes	No	Yes
Sylvia	Dili	Female	No	40 - 49	Yes	No	Yes
Mario	Dili	Male	Yes	30 - 39	Yes	Yes	Yes
Alfonso	Dili	Male	Yes	40 - 49	Yes	Yes	Yes

Annex 3: Journey mapping questions

Taken from the CEEHAT toolkit – questions were then re-written in Tetun.

Stages of Eye Health Journey



Figure A 1. The eye health journey from the CEEHAT toolkit

1. Awareness of eye issues

1.1. When did you realise you were having vision difficulties?

Probing: Probe them to share where they were, what where they doing, what they felt, what they thought was happening, what they did next.

1.2. How did you react when you began to have vision difficulties?

Probing: Probe them to share if they talked about the problem or took any actions immediately, or if they waited (and for how long). Did they speak to someone when they first noticed the vision loss? If so, who and why? What did they do next? If they didn't speak to someone, why didn't they?

1.3. What were some of the daily issues you experienced when you started to have vision difficulties?

Probing: What were the challenges? How did they handle them? Did they stop doing certain activities? Did they seek assistance from family/ friends for those activities (and if so, who assisted them)?

1.4. How did your daily challenges change over time? How much worse did things get before you sought help?

2. Seeking consultation

2.1. Tell me about how you came to make the decision to seek medical help for your eye issue (sight loss)?

Probing: What led you to the decision to be screened? Did you talk with family or friends before deciding to be screened? If so, what were the main issues/topics that you discussed with them before deciding to get medical attention for your sight loss?

2.2. Where did you go to get medical consultation?

Probing: How did you identify the location and time to get screened? Other than friends and family, where else did you (or do you) get information for where to go for your eyes?

2.3. What options did the health practitioner provide for you at the medical consultation?

Probing: What did you think about these options? What did you do after the medical consultation about the options given to you?

2.4. What was your overall experience?

3. Diagnosis

3.1. Tell me about your attendance at the referral location. Take me through the journey from leaving your house to when you went to the referral site.

Probing: Who did you go with? Where did you go? How did you get there? Was it easy to arrive there (if so, why. If not why)? What was your overall experience like? What did you expect and how did the experience compare? Would you tell a (female/ male) friend to screen their eyes at the same place? Why or why not?

3.2. What did the medical professional tell you (did you receive another referral, an appointment to return, medicine, etc)?

Probing: What questions did you have about the diagnosis/ recommendations? Did you get all your questions answered while at the eye screening facility? Why or why not?

4. Seeking Referral-based Treatment and Uptake (and/or Inaction)

4.1. Please tell me what you did about your eye issues after the medical consultation?

Probing: Did you sign up for another eye doctor's appointment? Did you go home and talk to family/ friends? If so, who and what major concerns/issues did you discuss regarding your eye diagnosis.

4.2. Would you mind telling me what decision you made?

Probing: What factors did you consider that led you to this decision?

5. Operation

5.1. Can you tell me about the day of your surgery from preparing for going to surgery site?

Probing: Who went with you? How did you prepare to go for surgery? How were you feeling before, during and after the surgery?

5.2. Can you take me through your experience with the surgery itself?

Probing: What happened? Who did you talk to? How did you feel?

5.3. What was your overall experience? How do you feel about the outcome?

Probing: What factors influenced your experience? What recommendations do you have to make it a better experience for someone like you in the future?

6. Follow-up: 24 hours and 3 months post-cataract

6.1. Can you describe what happened after your surgery and at your check-up?

Probing: Did you get a reminder? What led to your decision to return for the check-up?

6.2. Can you please take me through planning for attending the 3-month post-surgery follow-up appointment to attending the appointment (if attended, or why not?)

Annex 4: Survey questions

Table A 3. Online survey questions informed by the CEEHAT guide and discussions with the FHF and used on the KoBo collect platform in English (left) and Tetun translation (Right)

label::English (EN)	label::Tetun (TET)
Eye health Survey	Survey kona-ba saúde matan
Consent: This survey is to help us find out more information about people's access to eye health. It will help Fred Hollow Foundation and the National Eye Centre to develop better program to help people. You do not have to take part in it, but all information is useful. This survey will take about 20 - 30 minutes. We thank you for your time	Konsentimentu: Survey ida ne'e atu hetan tan informasaun kona-ba oinsa ema bele asesu ba asisténsia saúde matan. Rezultadu bele ajuda ekipa saúde matan atu fornese asisténsia di'ak liu tan. Survey ida ne'e sei han minutu 20 - 30. Obrigada barak ba ita boot nia tempu.
If there are any problems with this form, please contact with Maun Raul Amaral to help TT: 7732 6789 Telemor: 7559 3210 (WA)	Karik iha problema ruma ho formuláriu ida ne'e, bele kontaktu ba Maun Raul Amaral hodi ajuda ita ho númeru kontaktu TT: 7732 6789 Telemor: 7559 3210 (WA)
Are you the respondent or helping someone to fill this out?	Ita boot maka respondente ou ajuda ema seluk atu halo survey ida ne'e?
What's your relationship to the respondent?	Respondente sira maka ita nia saida?
Other	Seluk
Please fill out all the questions from the perspective of the respondent only	Obrigada barak ba ita nia tempu atu ajuda ho ida ne'e. Favór ida hatán ba pergunta sira ida ne'e hosi respondente nian.
Do you agree to take this survey?	Ita boot prontu atu tuir survey ida ne'e?
We really appreciate your time and effort to complete this, so that we can help improve the eye health system in Timor.	Ami apresia tebes ita boot nia tempu atu halo ida ne'e, hodi ami bele ajuda sistema saúde atu hare di'ak liu ba ema nia saúde matan.
If you're not ready to take this survey, you can close it now. You can open it at another time, but you don't have to. If you have any questions, you can contact the person who sent it to you. Thank you for your time. Please write to use if you have any questions or comments. If you don't have any, you can close the survey now.	Se ita la prontu atu tuir survey ne'e, bele taka agora. Karik iha duvidas, ita bele kontaktu ba ema ne'ebé haruka survey ida ne'e ba ita boot, ou Maun Raul (nomor iha leten). Se ita hakarak halo tempu seluk, ita bele loke fali - maibe la iha obrigasaun. Obrigada ba tempu. Favór ida hakerek ba ami se iha pergunta ou hanoin ruma. Se la iha, bele taka tiha survey ne'e agora.
How old were you at your last birthday? (Write age in years)	Ita-boot idade hira?
Personal Information	Infomasaun kona-ba ita nia aan

Are you female, male or other?	Ita feto, mane ou seluk?
Other	Seluk: favór ida hakerek
Do you identify as being gender diverse?	Ita bot LGBTQI?
Are you single, married, divorced or widowed?	Ita bot klosan, kaben, divórsiu, faluk?
Other	Seluk: favór ida hakerek
How many children do you have?	Ita iha oan nain hira?
Total number of living children	Nain hira sei moris
How many children that are too young to start school?	Nain hira seidaok tama eskola
How many children that are at school?	Nain hira ba eskola
How many children that have finished school?	Nain hira remata ona eskola
Total number of living children	Nain hira sei moris
Are you a refugee or displaced person?	Ita boot agora refujiadu ou la bele hela iha uma? IDP
Do you identify as having a disability?	Ita boot identifika aan hanesan ema ho defisiénsia?
Level of education	Nivel eskola
What is the highest level of school you attended?	Ita-boot nia nivel edukasaun ikus liu mak saida?
Please choose the one most relevant to your work and source of income, if any:	Favór ida hili ida ne'ebé relevante ba ita nia servisu no rendimentu:
Where do you work?	Ita servisu iha fatin saida?
Other - what work?	Seluk - Servisu saida?
Is your work related to health?	Ita servisu iha area saúde?
What do you do for an income?	Ita halo saida hodi buka osan?
Other - what do you do for income?	Seluk - halo saida hodi buka osan?
Is your work related to health?	Ita servisu iha area saúde?
What work or activities do you do?	Ita halo servisu ou atividade saida?
Other - what work?	Seluk - servisu saida?
Is your work related to health?	Ita servisu iha area saúde?
Where do you receive the income from?	Ita simu osan hosi ne'ebé?
Other - what is the source of your income?	Seluk - simu osan hosi ne'ebé?
Are you studying or looking for work?	Ita boot estudu ou buka servisu?
Do you receive any subsidies from the government (like veterans or parental support?)	Ita-boot simu subsidriu ruma hosi governu? (hanesan idozu, veteranus, bolsa da mae)
What is your main language?	Ita boot nia lian primeiru ida ne'ebé?
Other Language	Favór ida hakerek lian seluk
What other languages do you know?	Ita boot hatene lian saida seluk?
Other Language	Favór ida hakerek lian seluk
How easy is it for you to read things in Tetun?	Ba ita, fasil ou susar atu lee buat ruma ho Tetun?
How easy is it for you to converse in Tetun?	Ba ita, fasil ou susar atu ko'alia ho ema ho Tetun?
Thank you. The next section will ask about where you live	Obrigada barak. Sesaun tuir mai sei husu pergunta kona-ba ita nia hela fatin

Please answer based on where you normally live	Hela fatin (fatin ne'ebé ita hela bainbain)
Municipality	Munisipiu
Administrative post	Postu Administrativo
Suco	Suku
Aldeia	Aldeia
Is this area in a city, close to a city, far or very far?	Area ida ne'e iha sidade, besik sidade, dook ou dook los?
What form of transport do you usually use to travel to a health clinic?	Ita boot uza transporte saida se ita atu ba fatin saúde?
Other	Favór ida hakerek transporte saida
How long would it take you to get to the nearest place to get eye care by \${transport}?	Han minutu/oras hira atu la'o ba klínika ou fatin saúde ho \${calc1}?
Thank-you. The next questions are going to ask your opinion about eye health	Obrigada barak. Tuir mai maka pergunta sira kona-ba ita nia hanoin kona-ba saúde matan.
Information about eye health	Infomasaun kona-ba saúde matan
Health information	Informasaun kona-ba saúde
Have you ever had information about eye health?	Ita simu ona informasaun kona-ba saúde matan?
Where did you get health information from about eye health?	Ita simu informasaun kona-ba saúde matan hosi ne'ebé?
If you remember where you saw the posters, please write here	Se ita sei lembra, favór ida hakerek fatin iha ne'be maka ita hare poster/brosur
Other - please write where	Seluk - favór ida hakerek hosi ne'ebé
Where do you normally get health information from?	Ita bainbain hetan informasaun kona-ba saude en jeral hosi ne'ebé?
Other - please write where	Seluk - favór ida hakerek hosi ne'ebé
Thinking about eye health	Hanoin kona-ba saúde matan
Please indicate how strongly you agree or disagree with the following statements	Ba kada estetmentu, hateten ba ha'u se karik ita boot konkorda tebes, konkorda, la konkorda, la konkorda liu ou la hatene
I know where to go if I need an eye check-up	Ha'u hatene fatin atu ba hetan asisténsia saúde matan
I trust the health system, and medicines and treatments for eye health from clinics and hospitals	Ha'u fiar sistema saúde, ai-moruk no tratamentu ba saúde matan hosi klínika ou hospital sira
I have many more important things to do than get an eye check	Ha'u iha buat barak importante ne'ebé ha'u tenke halo duke ba fatin saúde kona-ba saúde-matan
I expect to go blind when I get old	Ha'u fiar katak ha'u sei la bele hare ona bainhira idade avansadu los
I know how much it will cost me to get an eye check-up	Ha'u hatene ha'u tenke selu hira se hakarak ba buka asisténsia saúde matan
I've received information that it's good for children to get an eye check when they are still young (like 4 years old)	Ha'u simu ona informasaun katak importante ba labarik sira atu konsulta matan bainhira sira sei ki'ik (hanesan tinan 4)

Eye surgery works	Ha'u fiar katak operasaun matan bele kura problema ho matan
If I have a problem with my eye health I look for a traditional healer.	Se ha'u iha problema ho saude matan ha'u buka matan dook.
If I have a problem with my eye health I look for a traditional medicine.	Se ha'u iha problema ho saude matan ha'u buka ai-moruk tradisional
I know where to and trust-worthy information about health problems	Ha'u hatene oinsa bele hetan informasaun ne'ebé di'ak no loloos kona-ba problema saúde
Difficulty seeing would be a big problem for me	Se ha'u la bele hare, ne'e susar boot ba ha'u
You should do everything you can to protect your sight	Ita tenke halo buat hotu hodi kuidadu ita nia saude matan no vizaun (abilidade atu hare)
If I had an eye problem, I would trust my local eye service to provide high quality care	Se ha'u iha problema ho saúde matan, ha'u fiar klínika saúde ne'ebé besik ha'u bele fornese assisténsia saúde ho qualidade di'ak
I have received information that people should get eye checks every 2 years, or every one year if they are over 40	Ha'u simu ona informasaun katak di'ak liu se ba konsulta matan kada tinan rua, ou se idade 40 ba leten, kada tinan dala ida
If I had an eye problem, I would trust my local eye service to treat me respectfully	Se ha'u iha problema saúde matan, ha'u fiar fatin saúde ne'ebé ha'u ba beibeik sei fornese assisténsia saúde ho respeita ba ha'u
If you have diabetes, you might go blind	Se ita moras ho diabetes, ita iha risku katak matan la bele hare ona/la bele hare mós
Diabetes can have a negative impact on eye health. If you, or someone you know, has diabetes, they should consult their doctor about eye health.	**Tuir lo-los, diabetes bele fo risku ba ema nia matan. Karik ita rasik iha diabetes ou ema ne'ebé ita konese ita diabetes, bele ko'alia ho doutór kona-ba saúde matan.**
I think that people wearing glasses makes someone more attractive	Ha'u hanoin ema uza oklu aumenta bonita/u
People who wear glasses get teased	Se ema ida ta'u oklu, ema seluk siempre goza nia
Glasses make people look smart	Se ema ida uza oklu, ha'u hare nia hanesan ema matenek
Thank you. The next section is about household decision making	Obrigada. Pergunta tuir mai kona-ba foti-desizaun iha uma laran
Participant Information Decision	Informasaun kona-ba partisipante foti desizaun
The questions in Demographics Module 8 are gathered by asking adults in the household (if there are two or more, only one adult is required).	Informasaun ida ne'e ita bele foti kona-ba ema boot sira iha uma-kain; se liu tiha ida, ita presiza foti hosi nain ida de'it
Who in your household makes the final decision about whether to go to a health centre if someone is sick?	Se ema ida moras iha ita nia família, se maka bele foti desizaun ikus se atu ba/lori nia ba fatin saúde?
Other: Please write who usually makes the final decision	Seluk: Favór ida hakerek sei maka bele foti desizaun ikus
Who usually makes the final decisions about eye health care for you?	Se-se maka bele foti desizaun ikus kona-ba ita nia saúde matan?

Other: Please write who usually makes the final decision	Seluk: Favór ida hakerek se maka foti desizaun ikus
Thank you. The next questions are going to ask about your eye health.	Obrigada. Tuir mai maka pergunta sira kona-ba ita nia saúde matan
Participant Information Decision	Informasaun kona-ba partisipante foti desizaun
Eye health: Please answer yes or no to the following questions.	Saúde Matan: Favór ida hatán sim ou lae ba pergunta sira tuir mai
Has a health worker ever told you that you have diabetes?	Karik pesoál saúde ida fó hatene ba ita katak Ita hetan diabetes?
Has a health worker or someone else ever told you that diabetes can make you not see well?	Pesoál saúde ou ema seluk fo hatene ona ita katak moras diabetes bele halo matan hare la di'ak?
Have you had an eye check in the past 2 years?	Ita ba konsulta saúde matan iha tinan 2019 - 2021?
Did you have an eye check before 2019?	Ita ba konsulta kona-ba saúde matan antes 2019?
What year?	Sá tinan?
Do you have any trouble with your eyes at the moment?	Ita boot iha problema ruma ho matan agora?
Have you ever had eye surgery?	Ita iha ona operasaun matan?
What year?	Sá tinan?
Where did you get it done?	Ita halo operasaun iha ne'ebé?
Where?	Outreach - favór ida hakerek fatin iha ne'ebé
Other - please write where	Seluk - favór ida hakerek iha ne'ebé
Who recommended eye surgery to you?	Se maka rekomenda ita atu halo operasaun?
Other - please write where who recommended?	Seluk - favór ida hakerek se maka rekomenda?
Have you been recommended to have surgery?	Ita boot hetan ona sujestaun atu halo opera matan?
From who?	Hosi se?
Other	Seluk - favór ida hakerek se maka fo sujestaun ba ita
What year?	Sá tinan?
Why haven't you had the operation yet?	Tanba sá seidak halo operasaun?
Who didn't give you permission?	Se maka la fó lisensa ba ita?
Other: please write who didn't give you permission	Seluk - favór ida hakerek se maka la fo lisensa ba ita
Are you interested in getting eye surgery?	Ita bot hakarak opera matan ou hakarak simu informasaun kona-ba operasaun matan?
Would you be willing to travel to Dili to get an operation?	Ita boot prontu atu la'o ba ospital Dili hodi halo operasaun?
Would you be willing to travel to Maliana hospital to get an operation?	Ita boot prontu atu la'o ba ospital Maliana hodi halo operasaun?
Would you be willing to travel to Baucau hospital to get an operation?	Ita boot prontu atu la'o ba ospital Baucau hodi halo operasaun?

Have you every been recommended to wear glasses?	Ita boot hetan ona sujestaun atu uza oklu?
From who?	Hosi se?
Other: please write who suggested to you	Seluk - favór ida hakerek se maka fo sujestaun ba ita
What year?	Sá tinan?
Have you been back to have your eyes checked since then?	Ita ba konsulta tan kona-ba ita nia matan hafoin tempu ne'eba?
What year?	Sá tinan?
How much are you willing to pay for glasses?	Ita boot prontu atu selu hira atu hola oklu?
Are you willing to travel to Dili to buy glasses?	Ita boot prontu atu la'o ba Dili (Iaran) hodi hola oklu?
Are you willing to travel to Maliana to buy glasses?	Ita boot prontu atu la'o ba Maliana hodi hola oklu?
Are you willing to travel to Baucau to buy glasses?	Ita boot prontu atu la'o ba Baucau hodi hola oklu?
Have you ever had glasses?	Uluk ou agora ita iha ona oklu (pernah iha)?
Where did you get them from? (if more than once, just the last pair that you bought)	Ita hola iha ne'ebé? Se liu tiha oklu ida, bele hakerek de'it ikus nian ne'ebé ita hola
Other: please write where you got them	Seluk: favór ida hakerek iha ne'ebé ita hola ou hetan
Why not?	Tanba sá la hola?
How much did you pay for them?	Ita hola ba presu hira? \$
other	Seluk: favór ida hakerek
Do you wear glasses daily?	Ita uza oklu lo-loron?
Why not?	Tanba sá la uza?
Other: Please write your reason	Seluk: Favór ida hakerek rezaun ne'ebé ita la uza
Have you ever seen a traditional healer for an eye problem?	Ita konsulta ona ho matan dook ou ema ne'ebé matenek kona-ba ai-moruk tradisionál kona-ba problema saúde matan?
Thank you. The next section is going to ask about difficulties that you face day to day	Obrigada barak. Tuir mai maka pergunta sira kona-ba susar ou difikuldade ne'ebé ita hasoru lo-loron
Difficulty	Difikuldade
The next questions are about difficulty that you might have when you're doing various activities. Please choose if these are difficult or easy for you.	Tuir mai ha'u sei husu pergunta kona-ba difikuldade ne'ebé karik ita-boot iha bainhira atu halo atividade ruma. Favór ida hili se buat sira ne'e halo difikuldade ba ita ou karik fasil.
Would you have difficulty paying for an eye check-up, if you needed one?	Susar ba ita atu selu hodi konsulta matan, se ita persiza konsulta?

Do you have difficulty seeing, (if you wear glasses, do you have difficulty seeing even if wearing glasses?)	Ita-boot iha difikuldade atu haree? (Se uza oklu, ita sei iha difikuldade atu haree ho momoos, maski uza ókulu?)
Would you have difficulty travelling to get an eye check-up, if you needed one?	Susar ba ita atu la'o hodi hetan asisténsia saúde se ita presiza?
Why is it difficult for you to travel?	Tanba sá susar ba ita atu la'o?
Other: please write why difficult	Seluk: Favór ida hakerek rezaun ne'ebé susar ba ita atu la'o ba buka asistensia saúde
Would you have difficulty finding someone to accompany you to an eye check-up, if you needed one?	Susar ba ita atu hetan ema atu la'o hamutuk ho ita atu hetan asisténsia saúde se ita presiza?
Why would it be difficult?	Tanba sá susar atu hetan ema?
Other	Seluk: favór ida hakerek rezaun
Do you have difficulty hearing? (If you use an aid, do you have difficulty even if using a hearing aid?)	Ita-boot iha difikuldade ruma atu rona? (Se uza ekipamentu balu, ita sei iha difikuldade maski uza ekipamentu rona nian (hearing aid)?)
Do you have difficulty walking or climbing steps?	Ita-boot iha difikuldade atu la'o ka hakat sa'e eskada?
Would you have difficulty taking time off from daily chores, employment or caregiving responsibilities to get an eye check-up, if you needed one?	Foti tempu atu sees hosi uma, servisu uma, servisu fatin ou responsabilidade hare oan no família hodi buka asisténsia saúde matan se presiza?
Do you have difficulty remembering or concentrating?	Ita-boot iha difikuldade atu hanoin hetan ka fokus?
Do you have difficulty (with self-care such as) washing all over or dressing?	Ita-boot iha difikuldade atu kuidadu ita-boot nia aan rasik hanesan hariis?
Would you have difficulty getting permission from your family to attend an eye check-up, if you needed one?	Hetan lisensa hosi família ou ema seluk hodi ba hetan asisténsia saúde matan?
Who would it be difficult to get permission from?	Susar atu hetan lisensa hosi se?
Other: please write who needs to give you permission	Seluk - favór ida hakerek se maka tenke fo lisensa ba ita
Using \${calc2}, do you have difficulty communicating, for example understanding or being understood?	Ita-boot iha difikuldade komunikasaun ruma atu kompriende ka atu halo ema seluk bele kompriende saida mak ita-boot dehan bainhira uza lian \${calc2}?
Thank you for answering these. The next questions ask about your history of eye surgery	Obrigada. Tuir mai maka pergunta sira kona-ba ita nia esperiênsia ho operasaun matan
Thank you, there are just a couple of last questions	Obrigada barak, hela de'it pergunta balu de'it
About your eye surgery	Kona-ba ita nia operasaun matan
Thinking back to when you had surgery, how easy or difficult was it for you to	Bainhira hanoin fali ba tempu ne'ebé ita hetan operasaun matan, fasil ou susar atu
Pay for the surgery	Selu ba operasaun
Travel to the eye service for surgery?	La'o ba klínika saúde matan ou fatin halo operasaun

Find someone to accompany you to the eye service for surgery?	Hetan ema atu akompañá ita ba klínika saúde matan ou fatin operasaun
Who went with you?	Se maka akompañá ita?
Other: please write who went with you	Seluk: Favór ida hakerek se maka akompañá ita?
Take time off from daily chores, employment or caregiving responsibilities to have surgery?	Foti tempu atu sees hosi uma, servisu uma, servisu fatin ou responsabilidade hare oan no família hodi hetan sirurjia
If needed, get permission from your family to have the surgery?	Hetan lisensa hosi família hodi hetan operasaun
From who?	Tenke hetan lisensa hosi se?
Other: please write who you need permission from	Seluk: Favór ida hakerek se maka tenke fo lisensa ba ita?
Talk easily with the health workers?	Dada lia no ko'alia ho ekipa saúde sira?
Find information about the surgery (such as cost, or where to go, what the process was going to be)?	Hetan informasaun kona-ba operasaun (hanesan se tenke selu ou lai, bele hetan iha ne'ebé, prosesu oinsa nst)
Would you recommend the surgery you received to a friend or family member if they needed it?	Ita sei fo rekomendasaun ba ita nia kolega ou família sira atu halo operasaun se sira persiza?
Thank you - that's the end	Obrigada: Ho ida ne'e Survey besik atu hotu ona
Do you give permission for us to contact you if there is anything to follow up?	Obrigada ba ita boot nia tempu. La iha tan pergunta seluk kona-ba saúde matan. Ita boot fó lisensa ba ami atu kontaktu fali se iha buat seluk?
What phone number can we contact you on?	Ami bele liga ho ita ho numeru saida?
What network is this?	Numeru ida ne'e uza rede saida?
Is there another number we can contact you on if \${phone} isn't active? If not, you can leave this blank	Karik iha numeru seluk se karik \${phone} la ativu? Karik la iha, bele husik mamuk
Please give the other number	Bele fo numeru ne'ebé di'ak liu atu konaktu ba ita (respondante)
What network is this?	Numeru ida ne'e uza rede saida?
Would you like someone to contact you to talk about your eye health?	Ita hakarak ema liga ho ita hodi bele ko'alia kona-ba ita nia saúde matan?
We really value your time and inputs. When we have the survey data ready, we'll send you a link. You can now save this, if it isn't finished yet and finish It another time. If errors come up, it's probably because a question or two were missed. Please go back and answer them, and then press submit. When you're ready, just press "submit" and that's it!	Ami apresia tebes ita boot nia tempu, no bainhira relatóriu ida ne'e hotu ona, ami sei haruka link ba ita boot. **Bainhira hotu ona, favór ida click 'submit'.** **Se hakarak kompleta iha tempu seluk, bele "save draft" no uza link hanesan hodi fila no kompletu iha tempu seluk**

	Karik iha error (mean) mosu favor ida hare ba pergunta sira ne'ebé seidauk kompletu karik, depois bele hili 'submit'. Depende ba jaringan, nia han minutu balu to'o haruka ona.
If you want to contact us, please call Lulu Martins (Dili) TT: 77488048 (WA) Bendita (Baucau) TT: 77285437 / WA 77285437 Rince Nipu (Bobonaro) TT: 7761 5050 Telemor: 7672 1444 (WA) If there are any problems with this form, please contact with Maun Raul Amaral on number TT: 7732 6789 Telemor: 7559 3210 (WA) If there is anything you'd like to add, you can write it here.	Karik hakarak kontaktu ami, bele liga ho Mana/Maun ba numeru kontaktu Lulu Martins (Dili) TT: 77488048 (WA) Bendita (Baucau) TT: 77285437 / WA 77285437 Rince Nipu (Bobonaro) TT: 7761 5050 Telemor: 7672 1444 (WA) Karik iha problema ruma ho formuláriu ida ne'e, bele kontaktu ba Maun Raul Amaral ho número kontaktu TT: 7732 6789 Telemor: 7559 3210 (WA) Karik iha buat ruma ita boot hakarak hatu'o ba ami, bele hakerek iha ne'e.

Annex 5: Terms of Reference



Barriers to accessing eye care services in Timor-Leste.

TERMS OF REFERENCE

January 2021

1. Research Title: Barriers to accessing eye care services in Timor-Leste.

2. Rationale for Barriers to Access research:

Whilst there is broader information about equity considerations in Timor-Leste, little refers specifically to eye care.

To ensure our programming is inclusive and does not exacerbate existing inequities The Fred Hollows Foundation (The Foundation) will undertake this research piece to identify current barriers to accessing eye care services. The research will provide an in depth understanding of the barriers experienced by people with disability, women, girls, men, boys and those based in remote communities in accessing eye care services. It will also identify opportunities to overcome the barriers to ensure that eye care services become more inclusive and accessible for all people.

The outcomes of this work will ensure any Gender, Equity and Social Inclusion initiatives we undertake are founded in evidence and will be useful and effectual.

3. Background:

The Fred Hollows Foundation

The Fred Hollows Foundation is a non-profit aid organization based in Australia and founded in 1992 by eye surgeon Fred Hollows. The Foundation focuses on treating and preventing blindness and other vision problems. It operates in 26 countries around the world across Australia, The Pacific, South and South East Asia, the Middle East and Africa.

As an international development agency, The Foundation respects, protects and promotes human rights for all, regardless of race, religion, ethnicity, indigeneity, disability, age, displacement, caste, gender, gender identity, sexuality, sexual orientation, poverty, class, or socio-economic status.

The Foundation has been supporting the eye health sector in Timor-Leste in various capacities since 2010. In 2019 The Foundation commenced a new 'District¹ Eye Care Project', which is implemented in collaboration with our partners at the Royal Australasian College of Surgeons (RACS). This project focuses on strengthening systems at the Municipal level to ensure, 'All people in Timor-Leste have ongoing access to high quality, affordable and appropriate eye care services'.

¹ Now Municipality – formerly district.

Eye Health

Timor-Leste still has a high prevalence of blindness and visual impairment. The 2016 Rapid Assessment of Avoidable Blindness (RAAB) found the age and gender adjusted prevalence of blindness to be 2.8% (Male 2.4% and female 3.1%) (WHO definition of blindness). Severe visual impairment was 4.5% (Male 4.0 and Female 4.9) and moderate visual impairment was 12.5% (Male 12.0% and Female 12.5%). Vision Impairment among the 50+ population was 12.5%: Male 12.0%, Female 13.1%.

Cataract is the leading cause of blindness and severe visual impairment, accounting for 84%, however cataract surgical coverage is very low compared to other Southeast Asian countries. Good visual outcome in the cataract-operated eyes was 62% (presenting) and 75.2% (best corrected).

The major barriers to uptake of available cataract surgical services in the country were 'accessibility to the services' (45.5%) and 'not having a support person to accompany individuals to services' (24.8%).

A further revelation from the RAAB was the gender inequality among service recipients. The magnitude of blindness was high and cataract surgical coverage particularly low among females in Timor-Leste.

Emerging causes of ocular impairment in Timor-Leste mirror the increasing burden of non-communicable disease and increasing age of the Timorese population and include glaucoma and diabetic retinopathy. A 2013-4 estimate of diabetic retinopathy suggested a 15% point-prevalence of diabetes mellitus in an unselected ocular outpatient population, of who 18.6% had evidence of diabetic retinopathy, an aggressive degenerative disease of the retina².

Gender

Women and men's entrenched roles are not only influenced by traditional culture but by the introduction of Catholicism by the Portuguese colonists; by the brutally violent and militarised Indonesian occupation and then further influenced by the progressive international norms and gender policies advocated for by the UN administration and the influx of international development and humanitarian agencies since the country's independence.

Women are still usually expected to be responsible for household and domestic jobs, while men are able to participate in decision making roles within society and in formal employment. While there has been an increase in women's participation in the formal sector, and representation in parliament (due to introduced quotas) they are still expected to look after the household and domestic spheres³. There is also extremely low participation of women in leadership roles, particularly local village leadership (Xefe Suco) throughout rural areas of the country. Men's participation in the labour force is 50.8% compared to women at 24.6%⁴.

² Dawkins, R.C.H., Oliver, G.F., Sharma, M. et al. An estimation of the prevalence of diabetes mellitus and diabetic retinopathy in adults in Timor-Leste. BMC Res Notes 8, 249 (2015). <https://doi.org/10.1186/s13104-015-1171-3>

³ TL18-01 Project Implementation Plan, 2019, p.21

⁴ TL18-01 Project Implementation Plan, 2019, p.22

Gender-based violence, especially domestic violence, is widespread in Timor-Leste. The Asia Foundation's 2016 report, *Understanding Violence against Women and Children in Timor-Leste: Findings from the Nabilan Baseline Study* described that approximately 59 percent of women who had ever been in a relationship said they had experienced physical and/or sexual violence by a male intimate partner at least. Three-quarters of ever-partnered women who had experienced physical violence from a male intimate partner had experienced severe acts of violence, compared to moderate acts, and 55% of these women said their children had been present at least once.

Gender-related barriers can be seen across the health sector in general. Equitable participation of women across the health sector, particularly in leadership and governance roles is not realised, and health information is insufficiently sex disaggregated. An important consideration is that there is a lack of suitable accommodation for midwives, single female doctors and married couple doctors making remote postings hard for women to fill.⁵

For eye health specifically, the 2016 RAAB shows that Timorese women suffer from blindness and visual impairment at a slightly greater rate than men but that women were less likely to access surgery for Cataract, the leading cause of blindness and visual impairment. The RAAB concluded, "Magnitude of blindness was high, and cataract surgical coverage was too low among the female gender in the country."

Background information –People with a Disability:

During initial scoping visits for our current project the project team met with local Disabled Persons Organisations (DPOs). Only a few of these DPOs provided support services for those with permanent vision impairment but all said they were aware of the National Eye Center and would refer people if they were suffering from vision impairment.

Through the analysis of barriers to access, we hope to further understand how strong these informal referral processes are and what services exist for those suffering from vision impairment at the municipal level.

4. Project Overview and Scope:

The research project will look at existing evidence, map patient pathways and design a research methodology to assess the access barriers for specific population groups in Timor-Leste. Specifically looking at barriers for women, people with a disability and for rural and remote populations.

It is expected that the findings and recommendations arising from this study will assist project managers in better understanding the barriers as well as the measures that can be taken to ensure equity of access to eye care services. The report will be used to inform GESI targeted activities to be implemented in the current project, project planning and where necessary amendments will be made to the existing project. As appropriate, the outcomes of the research will also help to inform implementation of activities within the Timorese Governments' National Eye Care Strategic Plan 2021-2050 (NECSP).

The research will predominantly focus on patient access, however The Foundation recognises the importance of equity in relation to the ophthalmic workforce and so the research will include a small focus on workforce. This topic undoubtedly requires more analysis but the findings from this project should provide a helpful baseline.

The target locations for the research are the districts of Maliana and Baucau, with research also necessary in Dili as this is the location of the National Eye Center. The location scope can be broader if resourcing permits.

**If the research identifies significant barriers for other populations within Timor-Leste these may be looked at in more depth during the research, The Foundation will assess this with the Research Team as appropriate. The Foundation would be interested in assessing the feasibility of including people of diverse genders and sexualities as an additional focus group.*

5. Study Objectives:

1. To identify the barriers that prevent both women/girls and men/boys from accessing and utilising eye health care services. To specify which of these are gender specific barriers and why.
2. To understand the barriers faced by people with a disability in accessing eye care, and if this is also impacted by gender.
3. To identify service provider's perspectives to the barriers to eye health care access for women and girls, people with a disability and rural populations.
4. Based on the research findings, provide specific recommendations for gender-targeted interventions to mitigate gendered barriers and thus improve access to eye health services in Timor-Leste
5. Based on the research findings, provide specific recommendations for targeted interventions to mitigate barriers for people with a disability and thus improve the delivery of equitable eye health services in Timor-Leste
6. Based on the research findings, provide specific recommendations for targeted interventions to mitigate barriers for remote populations and thus improve access to eye health services for all Timorese
7. To provide a broad overview of barriers to participating in the eye health workforce as this relates to gender, people with a disability and remote populations.

6. Findings Audience and utilization:

- The Fred Hollows Foundation and our implementing partner, The Royal Australasian College of Surgeons (RACS), to inform GESI specific initiatives within the Timor-Leste District Eye Care Project.
- Ministry of Health Timor-Leste, to inform implementation of the NECSP.
- Other Eye Health Stakeholders in Timor-Leste.
- Gender focused organisations and stakeholders
- Disabled Persons Organisations and stakeholders

7. Data Collection Methodologies:

1. **Desktop Review** – Consolidation of existing information on barriers to accessing health services.
2. **Mapping patient pathways** – Interview patients, potential patients and service providers at the community, primary, secondary and tertiary levels to understand how patients

interact with the eye sector. At least 70% of these interviews will be with patients or potential patients.

3. a) Design methodology: Information from the Desktop Review and Mapping Patient Pathways will be consolidated and researchers will identify any remaining information gaps. Research methodology is intended to meet the study objectives by addressing any gaps in information remaining after Desktop Review and Mapping Patient Pathways.

Note: *The Foundation understands the research approach will be informed by Steps 1 & 2, and so design may change during project. Changes are to be made in consultation with the Foundation.*

B) Conduct research: Research undertaken.

Potential methods for data collection include:

- Secondary compilation of statistical data where available.
- Conduct key informant interviews and focus group discussions, for example;
 - o Focus group discussion with women at community level
 - o Focus group discussion with men at community level
 - o Focus group discussion with community health agents
 - o Key information interview with ophthalmologists
 - o Key information interview with Mid-Level Ophthalmic Practitioners
 - o Focus group discussion with people who have undergone eye treatment/surgery
 - o Key informant interviews with National Eye Centre Staff
 - o Case studies of patients– potentially “walk along” methodology where researcher meets patient at home and goes on the journey with them to the eye centre/hospital and records what they see and what the patient says.

Tools for workforce data collection activities will be developed by the consultant with guidance from The Foundation.

We recommend that the core module from the validated Community Engagement in Eye Health Assessment Tool (CEEHAT) - be used to aid collection of data from beneficiaries. Additional questions will be added by the researcher to ensure all required information is collected.

Example Questions

Patients, potential patients or previous patients:

1. What makes it challenging or easy to access health services?
2. What makes it challenging or easy to access eye health services?
3. What costs are incurred when a patient accesses eye care services?
4. How do you get to the clinic or hospital?
5. Are most women able to afford the costs associated with accessing eye care services?
6. Are there any social cultural factors that prohibit women from accessing eye care services? (e.g., do women need ask for permission to travel a long distance to access services)
7. Do women prefer female surgeons or male surgeons? Why? 4. Do men prefer female surgeons or male surgeons? Why?
8. Do you feel comfortable going to the clinic or hospital?
9. How do people with a disability access services? Are there any considerations for people who require special needs e.g.: elderly, people with disabilities, women etc.?

10. Are there traditional practitioners that provide eye care services? If yes, who usually goes to these traditional medical practitioners? And for what issue
11. Has there been an impact in service provision due to COVID-19 and/or any other national events in the current year?

Service Providers:

1. What stops people from attending the eye clinic?
2. Is patient retention high? What stops patients returning for follow up appointments?
3. What are the number of women and men within the eye health workforce?
4. What are the number of people with a disability within the eye health force?
5. Are there policies that contribute to an equitable workforce?
6. Do eye health care workers conduct community awareness on eye health?
7. Looking at the discrepancy between those scheduled for cataract and those who take up surgeries. Is there a difference in the percentage of women who make it from referral to surgery vs the percentage of men that make it from referral to surgery?
8. Who attends for follow up? Are there any discrepancies between who was meant to come for follow up and who did come for follow up (looking at sex, age)
9. Are there traditional practitioners that provide eye care services? If yes, who usually goes to these traditional medical practitioners? For what issues?
10. How could the health system function more effectively to promote gender equity?
11. Where do the opportunities or entry points for change exist along the continuum of care from a supply and demand side perspective?
12. What are the most important things that need to change immediately?
13. Has there been an impact in service provision due to COVID-19 and/or any other national events in the current year?

8. Data Analysis:

The consultant will undertake data analysis.

8. Participants:

- Community members (male and female) in selected sample areas
- Community members (male and female) who have previously accessed eye health services.
- Community members (male and female) who were referred but did not end up seeking eye health services.
- Mid-Level Ophthalmic Practitioners (district based)
- Ophthalmologists and eye care practitioners based at the National Eye Center
- Ministry of Health Staff, particularly those in the NCD department (inc. Eye Officer)
- Family Medicine Practitioners at District Level

10. Timeframes, Activities and Deliverables:

Timeline (Guide only)	Activities	Deliverables
Between 3 rd -18 th March 2021	FHF accept Expressions of Interest and select research team/consultant/s.	
4 working days: Between 22 nd – 31 st March 2021	Researchers undertake Desktop Review	Consolidated report on existing information/research findings
7 working days: Between 1 st – 16 th April 2021	Researchers undertake interviews to inform accurate understanding of current patient pathways.	Clear map of pathways for patients. Patients include: Remote populations (women and men), Urban populations (women and men), People with a disability (women and men)
4 working days: Between 19 th – 30 th April 2021	Researchers develop and submit plan and methodology for the collection of additional necessary data. Plan is submitted to FHF, once approved plan is then submitted for ethics approval (if required).	Research plan with methodology, data collection tools and data collection plan
Dependent on obtaining relevant approvals 10 working days	Data collection as per Research Plan	Completed primary and secondary data sets
4 working days	Research Team prepare first draft of Barriers Analysis Report detailing key findings implications & recommendations	Draft Barriers Analysis Report
(1 week after submission)	FHF provided feedback to consultant on draft report	Feedback on draft Report
2 working days	Research team prepares and submits final report.	Final Consultant report submitted
1 working day	Research Team present findings to RACS, FHF and NEC representatives. Research Team may be asked to present to ethics committee – TBC.	Presentation

11. Budget:

Itemised budget to be provided by consultants as part of EOI. Available funding is AUD \$25,000.

The Foundation understands the budget may change as a result of the findings in Step 1 & 2 of the project. Changes will be negotiated between the consultant and The Foundation.

12. Reporting and Dissemination of Findings:

The consultant will prepare and share a draft report of key findings of the analysis and implications for future programming with The Fred Hollows Foundation.

After the report has been reviewed, the consultant will incorporate the feedback and prepare a final report to be submitted to The Fred Hollows Foundation.

Lastly the consultant will present the findings to The Foundation, our implementing partner RACS and our partners at the NEC.

13. Consultant Key Selection Criteria:

- Research team ideally Timor-Leste nationals
- Experience in equity studies
- Experience with the Timorese Health System
- Able to travel domestically in Timor-Leste.
- Available to deliver project March-June 2021

Annex 6: Data management

Data Management

Survey

The survey template was informed by the CEEHAT guide and discussions with the FHF regarding additional features of the survey that could provide valuable information for future program design. The resulting list of questions was by the team transformed in to an electronic format, an XLSfrom, for application on the KoBo collect platform. The simplicity of the survey was central in the template. In response to COVID-19 restrictions the survey was not administered by trained enumerators, but was designed to be easily understood by the participant, or by an appointed assistant. Much time went in to translation and testing of the instrument to facilitate this, using plain language Tetun that was clear.

For example, in Likert scale questions, responses were modified so they were clearly understood:

CEEHAT: **I trust modern medicine for my eye-health**

Strongly disagree

Disagree

Agree

Strongly agree

Survey: **I trust the health system, and medicines and treatments for eye-health from clinics and hospitals**

Strongly Disagree - I don't trust at all

Disagree - I don't trust

Strongly agree - I trust a lot

Agree - I trust

The completed questionnaires are uploaded to the secure KoBo platform, and submissions can be kept anonymous. The respondents were not required to provide their names, but phone numbers could be shared voluntarily by the respondents if they were open for follow-up questions and clarifications. The data was further kept confidential, with only the team members able to access the raw and analysed data.

The survey was presented in both Tetun and English, and comments made in the survey were translated into English by SSTL for the purposes of analysis.

The review and cleaning of the submitted data did not reveal major issues or discrepancies. In the case of six cases the data indicated a possible double submission. Thanks to the available phone numbers the team was able to check, resulting in the removal of two cases. As a result of this the data set consists of 86 independent cases. In two cases, missing or conflicting information was followed-up through phone calls and corrected after submitting.

A second step in the cleaning process was to reassign some of the text data. In a number of cases responses under the 'Other' choice option could be placed under existing choice options. For one of the questions, why people were not using their glasses all the time, many answered that they only need and use the glasses for reading. These were moved from the 'Other' to a new group.

Data Analysis – Survey

The data analysis was conducted in Microsoft Excel and SPSS. Excel was used for the cleaning process, and the to establish the CEEHAT domain scores. The resulting data set was used for analysis in SPSS.

SPSS allowed for to quickly establish the overall CEEHAT score, the opportunity domain, and the engagement history, for different sub-groups. Key stratification of the respondents for which these values were established include gender, age group, respondent location and main source of income.

The use of SPSS allows an exploration of possible correlations between different characteristics of the respondents and the CEEHAT scores. Among others, correlations were explored between the four domains, and the domains with age and gender. The report will only highlight any significant correlations.

Data Analysis – Journey Mapping

Notes and symbols were used on the paper map. The SSTL then did collaborative analysis using Miro Boards, which allowed for better visualisation and consistency. The maps highlighted.

- Key barriers (red)
- Key enablers (green)
- Challenges faced – but were overcome (orange)
- Symptoms, conditions and situation (white)
- Number of times that people understood their 'journey'
- Outcome of their journeys

A thematic analysis was then done, looking at similarities and differences looking at sex, disability, municipality and geographic distance.

Annex 7: Journey mapping images

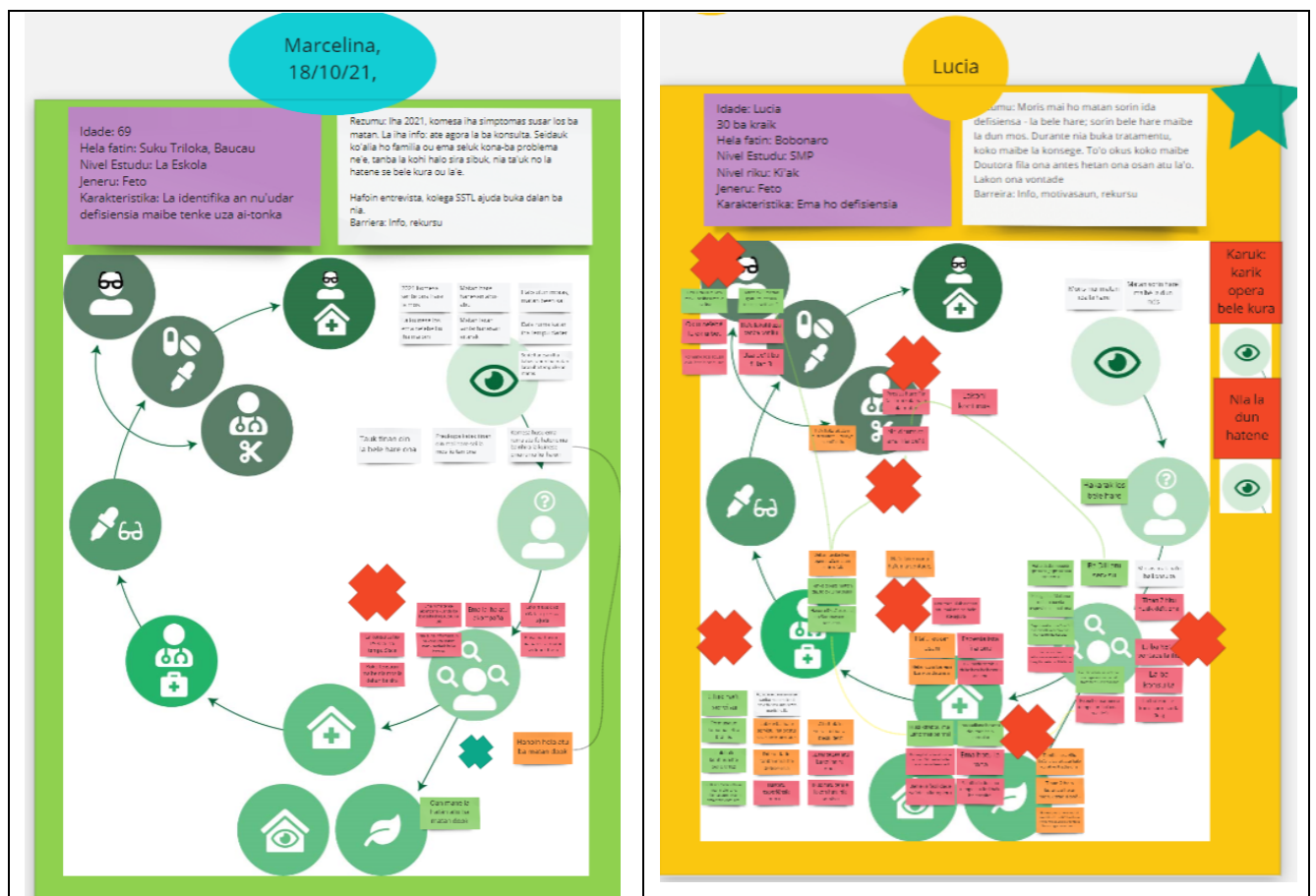
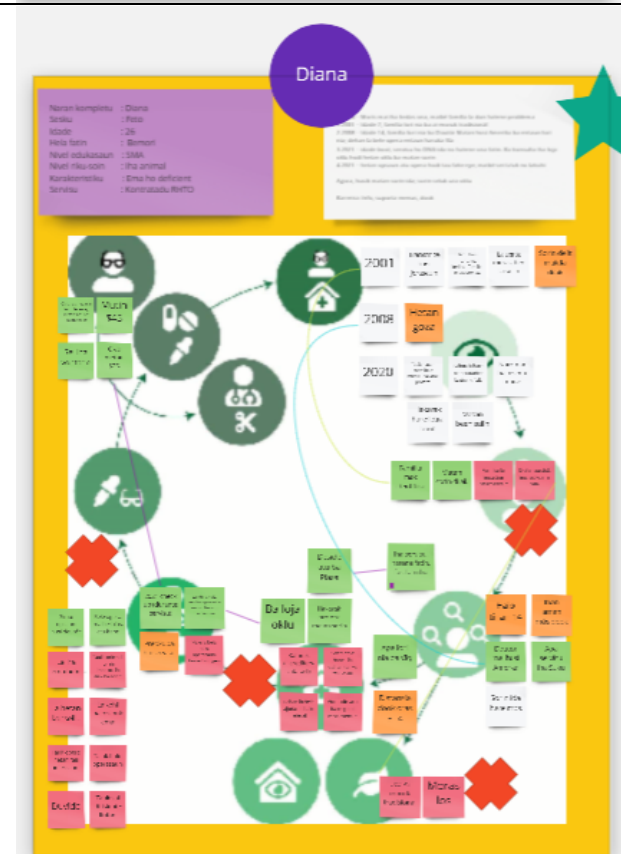
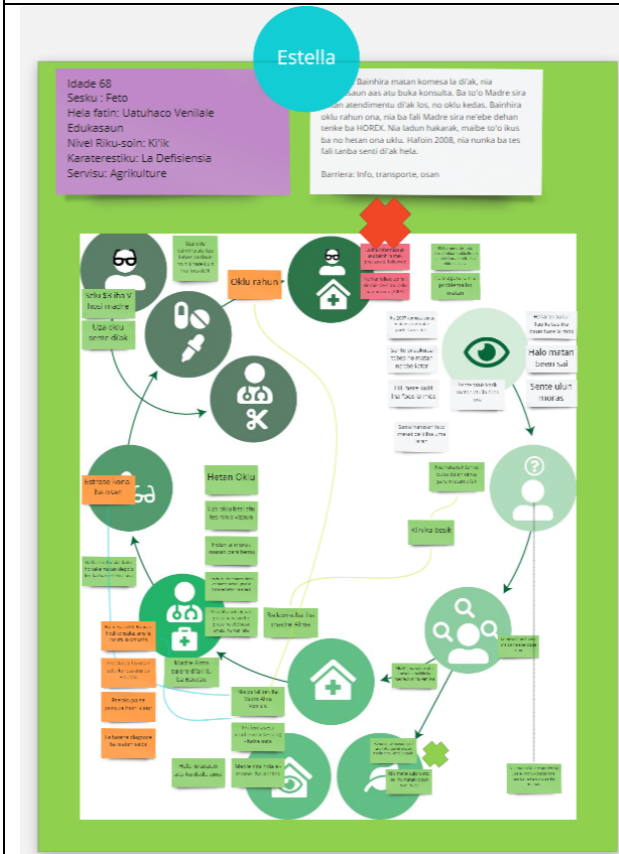
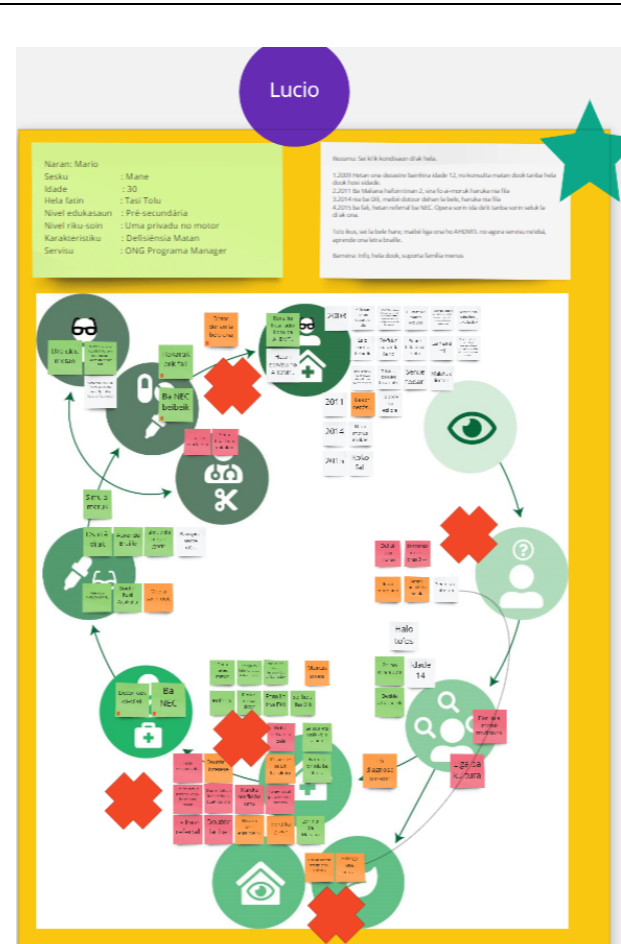
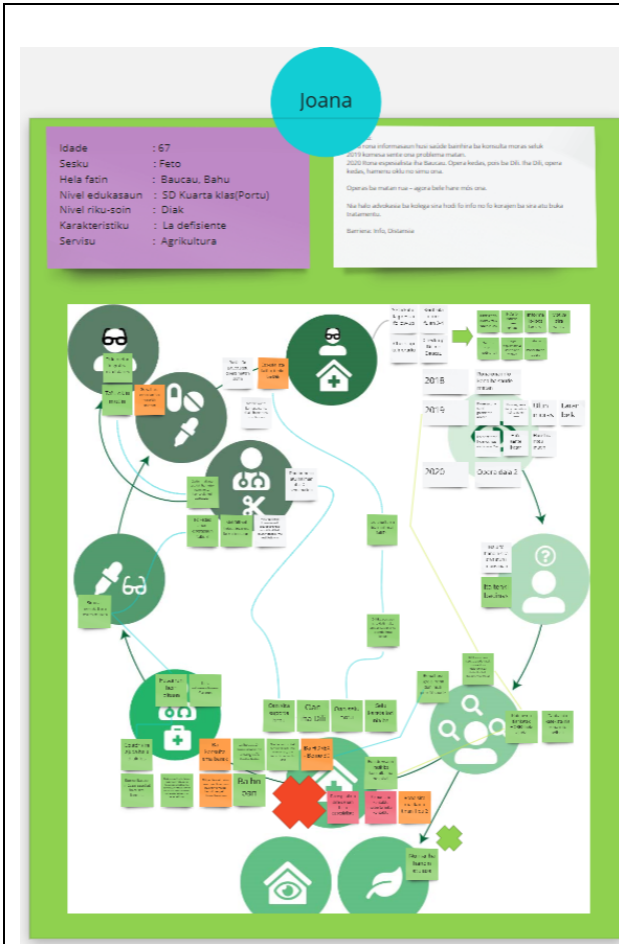
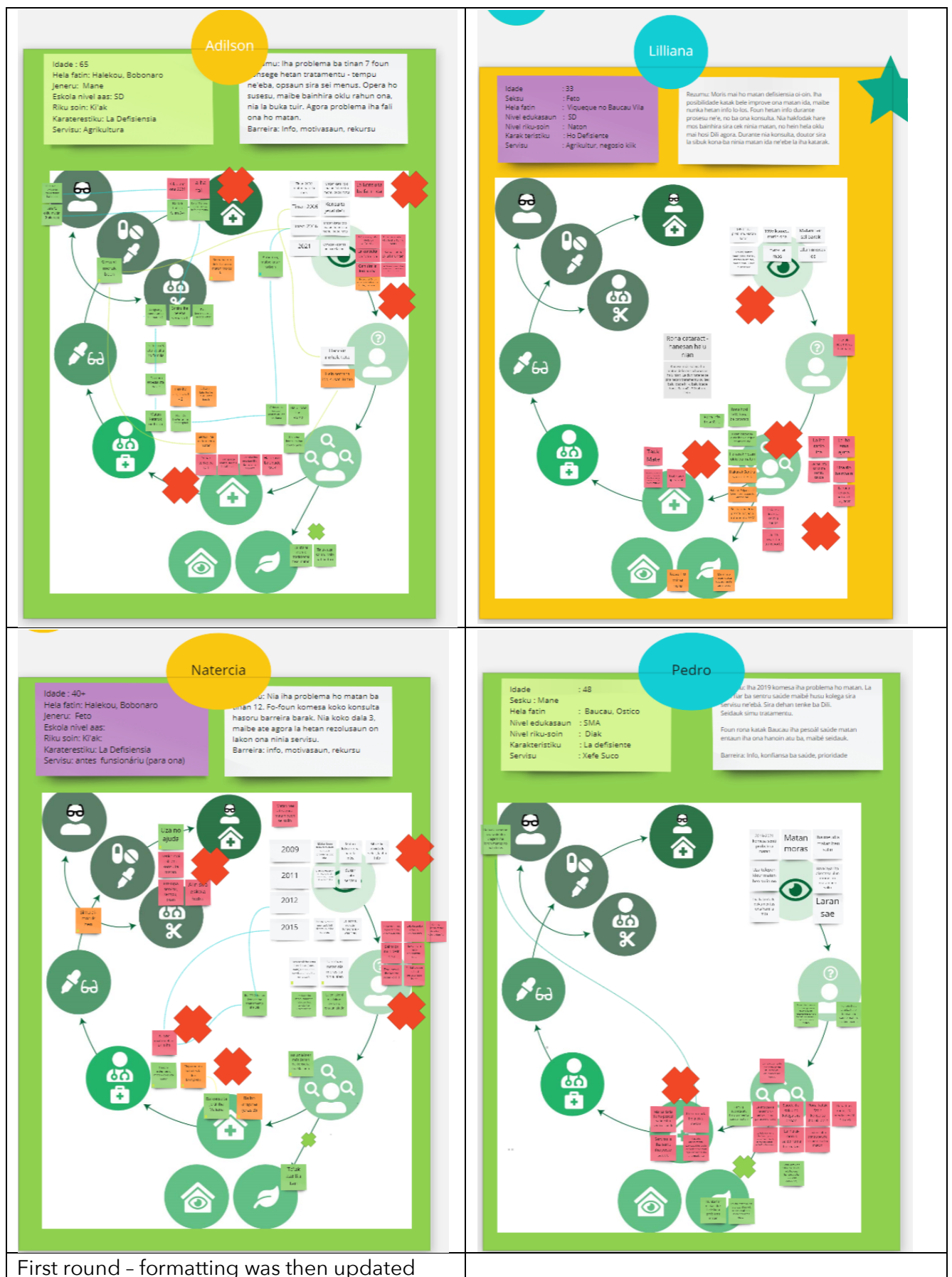


Figure A 2. Analysis of journey maps in Miro Boards





First round - formatting was then updated

Annex 8: Glasses willing to pay

How much people actually paid varied, and of the 49 people who had ever had glasses, two had not paid anything for them, with the range of the others between \$1 - \$420. This data seems to suggest that people are willing to pay for eyesight.

The figures provided for people who are willing to pay for glasses is commensurate with how much people have spent on glasses, and findings from the journey mapping. This does not suggest that the cost of glasses is not a barrier for some people. There also appears to be a low understanding that glasses often have to be changed periodically to suit changing vision, which may influence people's willingness and ability to pay once they do understand that.

Table A 5. How much people are willing to pay for glasses

Willingness to pay	n	%
Nothing	3	13%
\$1 - \$2	4	17%
\$2 - \$4	3	13%
\$5 - \$10	3	13%
\$10 - \$20	1	4%
\$20 - \$40	2	8%
\$50 and above	1	4%
The price doesn't matter	7	29%
	24	100%

Table A 4. How much people have spent on glasses

\$	-	2
\$	2.00	1
\$	3.00	6
\$	4.00	1
\$	5.00	10
\$	6.00	1
\$	9.00	1
\$	10.00	5
\$	15.00	1
\$	20.00	4
\$	25.00	4
\$	35.00	2
\$	50.00	3
\$	60.00	1
\$	65.00	1
\$	100.00	3
\$	155.00	1
\$	200.00	1
\$	420.00	1

Annex 9: Domain correlations

The level of association of variables can be analysed using a coefficient, the type depending on the kind of variables.

For the analysis using only continuous variables, the Pearson correlation coefficient (PCC) can be established. Pearson values are classified as: Small (weak correlation or association): 0.2 to 0.39; Medium: 0.4 to 0.69; or Large: 0.7 to 1. Note that these brackets vary across publications. This is a scaling that is also used for the ETA coefficient, described later. Values under 0.2 are considered a non-existing or negligible association.

The table below presents the PCCs of the different domains, plus age of the respondent (years), and the engagement history in eye-health. The table shows that an increased understanding leads to a higher trust and opportunity, as well as a higher engagement with eye-health. Age is a defining factor – age influences the understanding of eye-health.

Table A 6. PCCs of the different domains, age of the respondent (years), and engagement history in eye-health

Domains	Engagement history	Age	Trust	Motivation	Opportunity	Understanding
Understanding	.315**	-.325**	.418**	.086	.439**	1
Opportunity	.270**	-.150	.079	.218*	1	
Motivation	.119	-.151	.251**	1		
Trust	-.108	-.037	1			
Age	-.038	1				
Engagement history	1					

** . Correlation is significant at the 0.01 level (1-tailed).

* . Correlation is significant at the 0.05 level (1-tailed).

The ETA coefficient similarly describes the level of association between variables, but among which one is a categorical variable, for example Sex.

The table below presents the values of the domains and engagement history against categorical domains.

Table A 7. Values of the domains and engagement history against categorical domains

Domains	Sex	Education	Location#	Work
Understanding	.129	.450	.305	.416
Opportunity	.042	.424	.351	.376
Motivation	.220	.143	.200	.248
Trust	.075	.170	.341	.281
Total Domain score	.047	.393	.326	.382
Engagement history	.084	.246	.283	.396

** . Correlation is significant at the 0.01 level (1-tailed).

* . Correlation is significant at the 0.05 level (1-tailed).

= The location question of Urban versus Rural.

The values in the table indicate that:

- With the exception of a weak association of sex on motivation, sex does not influence them.
- Work has overall a moderate association to all the domains, with a moderate association to understanding
- Education has varying associations with the domains. It has a moderate association with Understanding and Opportunity domains, but negligible towards motivation and trust

Annex 10: Engagement correlations

Table A 8. Engagement correlations

Scores higher than the mean are highlighted in orange

Category	N	Engagement history
Overall		1.16
Gender		
Female	51	1.22
Male	33	1.06
Gender Diverse	2	1.5
Marital Status		
Married or living together	57	1.18
Never married or lived together	20	1.05
Divorced/ separated	2	1.50
Widowed	6	1.50
Education		
None	17	0.88
Primary	6	0.50
Pre-Secondary	5	1.00
Secondary	20	1.20
University	38	1.39
Age group		
< 30 years old	17	1
30 - 39 years old	22	1.05
40 - 49 years old	18	1.67
50 - 59 years old	12	1.5
60 - 69 years old	13	0.71
70 and older	4	1.25
Municipality		
Baucau	28	1.04
Bobonaro	27	0.93
Dili	31	1.48
Location - Remoteness		
Urban	27	1.37

Semi-urban	37	1.22
Remote - rural	10	1.30
Very remote- rural	12	0.42
Self- declaring living with a disability		
Yes - having a disability	28	0.93
No - not having a disability	58	1.28
WGQ - Disability indicator		
Yes - disabled	25	1.12
No - not disabled	61	1.18
Source of income		
Work for a salary	31	1.74
Non-salaried income	19	0.89
Don't work, but receive an income	5	0.80
Work, but don't receive an income	13	0.77
Don't work, and don't receive an income	17	0.88
Tetum reading		
Very easy	40	1.45
Easy	24	0.92
Difficult.	9	0.78
Very difficult	4	1.50
I need someone to help me	9	1.40
Tetum conversation		
Very easy	43	0.95
Easy	43	1.25
Difficult.	4	1.25
Very difficult	0	0.00
I need someone to help me	2	0.00

Annex 11: Lowest scores: characteristics

Lowest scores: 10 out of the 11 lowest scores were from people with disabilities (WGC). However, out of those, with only 4 self-identified as having a disability. All self-reported having problems with their eyes at the moment. This is important in understanding that people can have multiple, intersecting difficulties that prevent them from seeking health care.

There are clear differences in understanding when cross-tabulated for the below characteristics:

*Table A 9. The lowest domain scores overall
Scores equal to or higher than the median are highlighted in blue*

Age	Sex	Disability	WGC	Eye info	Tetun - first	U	M	T	O	Total	Engage
					Mean	10.53	14.4	12.72	17.55	55.20	1.16
					Median	10	14	12.5	18	55.5	1
69	Male	No	With	No		4	13	12	13	42	0
45	Female	No	With	No		5	12	11	14	42	0
66	Male	No	With	Yes		9	11	13	11	44	1
65	Female	No	With	Yes		7	12	12	14	45	1
61	Female	No	With	No		8	13	10	15	46	0
39	Male	Yes	With	No		7	14	12	13	46	1
31	Female	Yes	With	No		9	14	11	12	46	0
53	Male*	Yes	With	Yes		10	11	10	17	48	2
25	Male	No	Without	Yes		15	8	14	11	48	0
26	Female	No	With	No	1	7	14	9	18	48	3
64	Male	Yes	With	Yes		7	14	13	14	48	1

*vision impaired

Annex 12: Had surgery vs recommended by not had comparison

KEY:

Strong Positive



Positive



Negative



Strong Negative



Table A 10. Comparison of responses from people who have had surgery and those who have not had surgery but have had surgery recommended

	Recommended - but no surgery					Had Surgery	
	Dili	Bobonaro	Baucau	Bobonaro	Bobonaro	Dili	Baucau
Sex	Female	Female	Female	Male	Female	Male	Male
Age	26	67	75	64	54	30	22
Disability	Yes	No	Yes	Yes	No	Yes	No
Distance	15 - 30	15 - 30	1 - 1.5 hours	1.5 - 2 hours	2 - 3 hours	5 - 15 minutes	30 - 45 minutes
Eye health: Has a health worker ever told you that you have diabetes?	No	No	No	Don't know / not sure	No		
Information on eye health	TV/Internet	Hospital	Children (general health)	Health Centre	Hospital	Yes: Health centre, Hospital Radio	Community-based health worker/village health worker TV advert / programme Social media (Facebook / Twitter etc) no
		Car sick and not enough money	Want to - but scared of SWAB test	I'm very willing to go to Dili but I need help	I want to get treatment but I need help	Need to tell people that they shouldn't wear glasses for fashion	I have a lot of problems with my eyes in bright light
Do you have any trouble with your eyes at the moment?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Agency							
Difficulty/Would you have difficulty getting permission from your family to attend an	No	No	No	No	No	Yes - some; family are far away	No

eye check-up, if you needed one?								
Who usually makes the final decisions about eye health care for you?	Myself	Myself	Myself	Myself	Myself		Myself	My parents
Understanding of eye health care								
I know where to go if I need an eye check-up	Agree	Disagree	Agree	Disagree	Disagree		Strongly agree - I know well	Agree
I know how much it will cost me to get an eye check-up	Disagree	Disagree	Disagree	Strongly Disagree	Agree		Agree	Agree
I know where to and trust-worthy information about health problems	Agree	Disagree	Agree	Disagree	Disagree		Agree	Disagree
I have received information that people should get eye checks every 2 years, or every one year if they are over 40	Disagree	Disagree	Disagree	Disagree	Disagree		Disagree	Agree
If you have diabetes, you might go blind	I don't understand / don't know	Disagree	Strongly disagree	Disagree	Disagree		Agree	Agree
Trust								
I trust the health system	Agree	Agree	Agree	Agree	Agree		Agree	Agree
If I had an eye problem, I would trust my local eye service to provide high quality care	Strongly agree	Agree	Agree	Strongly agree	Agree		Agree	Agree
If I had an eye problem, I would trust my local eye service to treat me respectfully	Agree	Disagree	Agree	Disagree	Agree		Agree	Agree

If I have a problem with my eye health I look for a traditional healer/medicine	Disagree	Disagree	Disagree	Agree	Disagree		Disagree	Disagree
Eye surgery works	Agree	Disagree	Disagree	Strongly agree	Disagree		Disagree	Agree
Motivation								
I have many more important things to do than get an eye check	Agree	Agree	Disagree	Agree	Agree		Disagree	Disagree
I expect to go blind when I get old	Disagree	Strongly agree	Agree	Strongly agree	Agree		Agree	Disagree
Difficulty seeing would be a big problem for me	Strongly agree	Strongly agree	Strongly agree	Strongly agree	Strongly agree		Strongly agree	Agree
You should do everything you can to protect your sight	Strongly agree	Strongly agree	Strongly agree	Strongly agree	Strongly agree		Strongly agree	Agree
Attitudes to Glasses								
I think that people wearing glasses makes someone more attractive	Agree	Disagree	Agree	Agree	Disagree		Strongly disagree	Disagree
Glasses make people look smart	Strongly disagree	Disagree	Disagree	Disagree	Agree		Disagree	Disagree
People who wear glasses get teased	Agree	Disagree	Agree	Agree	Agree		Strongly disagree	Disagree
Opportunity								
Difficulty paying for an eye check-up, if you needed one?	No difficulty	No difficulty	Yes - a lot of difficulty	Yes - a lot of difficulty	Yes - a lot of difficulty		Yes - some difficulty	No difficulty
Do you have difficulty seeing, (if you wear glasses)	Yes - some difficulty	Yes - some difficulty	No difficulty	Yes - a lot of difficulty	Yes - a lot of difficulty		Can't see at all	No difficulty
Difficulty travelling to get an eye check-up, if you needed one?	Yes - some; I don't have transport &	Yes - some; I get car sick	Yes - a lot; I don't have transport	Yes - some; It's too expensive	Yes - some; I don't have transport		Cannot do at all; I don't have transport	No difficulty

	there's no-one to take me					There's no one to take me; no money	
Difficulty finding someone to accompany you to an eye check-up, if you needed one?	Yes - I don't have anyone who could	Yes - It's too expensive	No difficulty	Yes - I don't have anyone who could	Yes - Transport would be too hard	Yes - I don't have anyone who could, transport would be too hard	No difficulty
difficulty taking time off from daily chores, employment or caregiving responsibilities to get an eye check-up, if you needed one?	No difficulty	No difficulty	No difficulty	Yes - a lot of difficulty	Yes - some difficulty	Yes - some difficulty	No difficulty
Health Engagement							
Have you had an eye check in the past 2 years?	Yes	No	No	No	Yes	No	Yes
Did you have an eye check before 2019?	Yes	Yes	Yes	Yes	No	Yes	No
What year?	2009	2005	2017	2014	2020	2016	
Surgery							
Have you been recommended to have surgery?	Yes	Yes	Yes	Yes	Yes	No*	Yes
From who?	Doctor - eye	Nurse - eye	Doctor - eye	Doctor - eye	Doctor - eye	No*	Doctor - eye
What year?	2021	2016	2021	2008	2020	No*	2011
Why haven't you had the operation yet?	Scared - eyes worse	Doctor/health person said wait	Scared - dying Too far away I don't have transport	Doctor/health person said wait	Doctor/health person said wait		NEC
Are you interested in getting eye surgery?	Yes	Yes	Yes	Yes	Yes		
Would you be willing to travel to Dili to get an operation?	Yes	Yes	No	Yes	No		

Would you be willing to travel to local hospital to get an operation?	Yes	Yes	Yes	Yes	No		
Glasses use							
Have you ever been recommended to wear glasses?	Yes	Yes	Yes	Yes	Yes	Yes	No
Do you wear glasses daily?	Yes	No: They broke	Yes	No: They broke	No: My eyes were hurting	No: I don't know where to buy them Too far to get them; can't see clearly with them	No
Willingness to pay / purchase history							
Where did you get them?	Private glasses shop	From the clinic/hospital	From the clinic/hospital	Help from Europe	Local shop		
How much did you pay for them?	\$ 10.00	\$ 100.00	\$ -	\$ 100.00	\$ 9.00		
From who?	Doctor - eye	Nurse - eye	Nurse - eye	Doctor - eye	Doctor - eye		
What year?	2021	2016	2011	2009	2020		
How much are you willing to pay for glasses?	The price doesn't matter	The price doesn't matter	Can't afford or don't want to pay	\$50 and above	\$10 - \$20	The price doesn't matter	
Have you been back to have your eyes checked since then?	No	No	Yes	Yes	No		
What year?			2021	2010			

*Respondents answered 'No' but have had surgery so assumed to be a wrong answer

Annex 13: Languages by location

Table A 11: Main language of respondents by Municipality

Main language	Municipality			Total
	Baucau	Bobonaro	Dili	
Baikenu		7.4%		2.3%
Bekais		3.7%		1.2%
Bunak		11.1%		3.5%
English			3.2%	1.2%
Galolen			3.2%	1.2%
Indonesian		3.7%	3.2%	2.3%
Kemak		70.4%	3.2%	23.3%
Makalero			3.2%	1.2%
Makasae	39.3%		3.2%	14.0%
Mambae			6.5%	2.3%
Midiki	3.6%		6.5%	3.5%
Naueti	7.1%		3.2%	3.5%
Tetum	14.3%	3.7%	54.8%	25.6%
Waima'a	35.7%		9.7%	15.1%
Total	100.0%	100.0%	100.0%	100.0%

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The **Fred Hollows**
Foundation

