



Timor Leste Eye Health Survey 2005



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Abbreviations

CHC	Community Health Centre
CSC	Cataract Surgical Coverage
DHS	District Health Service
IAPB	International Agency for the Prevention of Blindness
MOH	Ministry of Health
NCD	Non-Communicable Diseases
NECS	National Eye Care Strategy
RACSS	Rapid Assessment of Cataract Surgical Services
WHO	World Health Organisation

Executive Summary

In order to better understand the eye care needs of the people of Timor Leste, we surveyed and examined 1414 people over the age of 40 years: the age group that would have the most vision needs. This survey sought to obtain information about the prevalence of vision impairment in those older than 40 years in a rural (Bobonaro) and urban (Dili) district, and also to understand what people thought about present eye care services, or what stopped them using these services. Information about the coverage and visual outcomes of cataract surgery and spectacles were also obtained.

The following recommendations are made to inform the Ministry of Health (MOH) in the process of developing a National Eye Care Strategy (NECS) that addresses the quality, equity, efficiency and acceptability of eye care services making the best use of limited resources. These recommendations are made being mindful that this survey investigated only the population above 40 years (since this is the group that has the highest level of vision impairment), and that childhood blindness also needs to be considered when developing the NECS. Implementation of these recommendations for high quality, equitable and accessible eye care services within a comprehensive eye care programme - especially by developing universal primary eye care services, integrated into the primary health care package – will be of benefit to the whole Timorese population.

Prevalence and Causes of Vision Impairment

Extrapolating the survey results to the national population, approximately 47,000 people in Timor Leste over the age of 40 are vision impaired (worse than 6/18 better eye). Cataract and refractive error, conditions treatable by surgery or spectacles, caused approximately 90% of vision impairment. Those most likely to be vision impaired are older, illiterate, not in paid employment, living in a rural area and unmarried.

Recommendations for NECS

1. Eye care services should initially be focused on cataract and refractive error, as these conditions are treatable by surgery and spectacles, and are the cause of more than 90% of all vision impairment (and more than 80% of all blindness) in the population over 40 years.
2. In order to be equitable, eye care services need to be planned with particular attention paid to those with the highest burden of vision impairment, including those who are older, not in paid employment and / or living in rural areas.

Eye Care Services: Utilisation and Barriers

Although most (91%) of the sample reported a previous or current eye or vision problem, only 34% of these had ever used eye care or vision services. The most common reasons for not using services were lack of awareness of service availability (34%), being unable to afford transport (12%), feeling that having a vision problem is part of aging (9%) and that the service is too far away (9%). Illiterate people, those living in a rural area, and subsistence farmers were less likely to report a history of an eye or vision problem, or to utilise services.

Of those utilising services, 75% utilised MOH facilities, while 14% utilised external teams (Australian, Indonesian, US etc) and 7% utilised private optical shops.

Satisfaction with services utilised was associated with the service provider. People were most satisfied with private optical shops (94% satisfied or very satisfied), with government services (Hospital and Community Health Centre: CHC both 68%) faring better than the visiting Australian teams (62%).

Recommendations for NECS

3. In order to increase utilisation of eye care services awareness of eye and vision problems and the availability of services needs to be raised in the community, as well as creating services which are more accessible, affordable and acceptable (including quality of outcomes), especially to those in disadvantaged groups.
4. In order to improve satisfaction with eye care services, the factors contributing to patient satisfaction need to be identified, and services adapted accordingly wherever possible.
5. In order to obtain overall improvement in utilisation, all eye care providers (including those external to government services) should be included in regulations, plans and procedures in order to improve quality, equity, efficiency and acceptability of eye care services.

Cataract and Cataract surgery

Cataract is the second most prevalent cause of vision impairment and most frequent cause of blindness in people over the age of 40 years. Its treatment, by surgery, had occurred in 28 survey participants, for a total of 42 eyes. Fifty percent of those who had received surgery were female. The surgical coverage was higher in the urban compared to the rural district, though this was not statistically significant.

The cataract surgical coverage, being the proportion of operable cataract cases that have undergone operation, was 27.8% at the 3/60 levelⁱ.

Overall, 76% of people remained vision impaired after surgeryⁱⁱ, which is far worse than the WHO standard of <20%. Thirty-five percent of these remained blind, compared to the WHO standard of <5%. There was a difference in surgical outcome associated with different surgeons, and a corresponding difference with patient satisfaction with surgery. The Visiting Indonesian and Australian teams produced results far below WHO standards (47.3% and 29.5% remaining blind out of 84.2% and 76.5% remaining vision impaired respectively), while the services provided by the resident Chinese ophthalmologist produced outcomes very close to, or meeting, WHO standards (0% blind and 25% vision impaired).

The main causes of vision impairment following surgery were surgery related complication (52%), uncorrected aphakia (24%) and uncorrected refractive error (21%). Surgery related complications are most likely due to poor selection of patients, or poor surgical technique. Given the costs associated with providing cataract surgery, both monetary and in terms of patient inconvenience, discomfort and time, it is of great concern that such a high proportion of patients remain blind after the intervention. Standard treatment guidelines need to be set and adhered to in order to ensure better selection of patients and surgical techniques. Refraction services are required following surgery (and on an ongoing basis) to maximise the visual outcome.

The information gathered in this audit indicates that the quality of surgical outcomes needs to improve, especially by certain providers. A system monitoring surgical outcomes would provide more accurate information about areas of cataract surgical services requiring improvement, and may also serve to act as a catalyst for improving the results of surgery.

Participants who had previously received surgery, or were vision impaired due to cataract, were questioned regarding their willingness to pay for cataract surgery. Of these, 93% were unwilling and/or unable to pay \$10 for surgery, indicating that cost-sharing for cataract surgery may present further barriers to utilisation of services. Literacy was the only socio-economic factor associated with a willingness to pay for cataract surgery ($p=0.003$). Each of the six participants willing and able to pay \$30 for cataract surgery had previously undergone surgery on at least one of their eyes.

Recommendations for NECS

6. In order to improve the cost effectiveness, quality of outcomes and patient satisfaction with surgical services, all providers need to provide service according to Timor Leste's Standard Treatment Guidelinesⁱⁱⁱ, and all outcomes monitored by the MOH. Continued poor outcomes should be investigated and their cause rectified.
7. In order to achieve best outcomes, after-care services that include refraction and spectacle provision need to be available, accessible and affordable for all undergoing surgery.
8. In order to increase cataract surgical coverage, more surgery needs to be undertaken. However, if services are to be more equitable and efficient, not only does surgery need to be available at Referral Hospitals, but reliable screening programs and referral pathways have to be established from the surrounding districts.

Refractive Error and Spectacles

Despite the fact that most people older than 40 would benefit from wearing spectacles to see clearly at near, only 15% of the sample were currently wearing spectacles. A further 8% had previously worn spectacles but were no longer wearing these. Most (96%) said they would be prepared to wear spectacles in the future to correct their vision. This reinforces that good quality refraction services should be easily accessible, as well as ensuring the availability of an ongoing supply of good quality spectacles.

ⁱ'Operable cataract' can be defined as cataract where both the patient and the eye surgeon agree that cataract surgery is indicated. The visual acuity in the operated eye or in the better eye at the time of surgery is not known. It is assumed that people with the worst vision are operated upon first, but that does not always happen in practice. Therefore the CSC for visual acuity <3/60 may be overestimated when patients with a preoperative visual acuity better than 3/60 have also been operated upon.

ⁱⁱ Presenting Vision

ⁱⁱⁱ Minimum standards of care for cataract surgery and refraction services are currently being developed by MOH, with technical assistance from Fred Hollows Foundation (NZ), to be incorporated into the next edition of the Standard Treatment Guidelines, due for release in 2006.

Those more likely to be currently using spectacles were males, those who are literate, those in paid employment and those living in an urban area. The main reasons people were no longer wearing spectacles were that they did not see well with them (44%), and that they broke (24%).

The range of prices paid for spectacles in the past was between \$0 and \$260. Almost half (48.8%) of those having current or previous spectacles had received them at no cost. The median price paid for spectacles (excluding those receiving them at no charge) was \$3.00. Optical shops had not dispensed any spectacles at no charge, had the highest median price (\$7.13) and the highest level of satisfaction (94% very satisfied or satisfied), while the visiting Australian eye teams dispensed 63% of spectacles at no charge, had the lowest median price (\$2.00) and the lowest satisfaction (63%). Government services fell between these two: CHC dispensed 61% at no charge, median price was \$7 and satisfaction 85%, while Hospitals were 52%, \$3 and 75% respectively. This suggests that satisfaction is linked to the provider and may be due to factors such as convenience and product range. It also suggests that higher price is not necessarily a deterrent to satisfaction.

Overall 43.3% of people said they would be unwilling and / or unable to afford to pay \$1 for spectacles. 89.5% of these people had not worn spectacles previously. Other factors associated with this were increasing age, being female, being illiterate, living in a rural area, not being in paid employment, being unmarried, and being vision impaired.

Recommendations for NECS

9. In order to improve satisfaction with refractive error and spectacle services and increase the use of spectacles, accessibility, acceptability and quality of the refraction service, and the quality of the spectacles dispensed needs to be improved and maintained. This could be done by further exploring the factors influencing satisfaction with services and spectacles.
10. In order to improve equity for refractive error correction, an information education and communication program needs to be undertaken to increase awareness of the benefits of spectacle wear. In addition, a subsidization protocol is required that will deliver equitable, sustainable refractive error services, including dispensing of spectacles. When developing a subsidization protocol, particular attention is required for those who are most likely to be unable to pay for spectacles, being those who are: women, illiterate, rural, vision impaired, unemployed and those who have never worn spectacles before.

1. Context

The Global Situation

It is estimated that there are currently 161 million people with vision impairment worldwide, of whom 37 million are blind (1). Approximately 80% of blind people live in the developing countries of Asia and Africa, typically in rural areas with few or underutilized eye care facilities (2,3,4). People belonging to lower socioeconomic groups have been shown to be ten times more likely to be blind compared to people in the upper socioeconomic groups (5).

Blindness causes a decrease in quality of life to the individual, as well as an economic burden on the individual, family and society in general. Although the bulk of visual disability occurs in older adults, childhood blindness contributes significantly to the current and future burden of unnecessary visual disability. It is second only to cataract in blind-person-years (6). In addition, there are developmental, educational, economic and quality of life implications for the life of a blind child. It is estimated that 50% to 75% of blindness is either preventable or curable, and blindness prevention and treatment interventions are among the most cost-effective of all known medical interventions (2,7).

Significant progress in the prevention of avoidable blindness has already been made through individual efforts of the international community, including the WHO, governmental departments, non-governmental organisations and the private sector. Given the scenario outlined above, it has been realized that a major focused and concerted international effort to combat avoidable blindness is required (4). *Vision 2020: The Right to Sight* was initiated as a partnership between WHO and the non-governmental organizations (who are represented by the International Agency for the Prevention of Blindness: IAPB) that share the objective of eliminating avoidable blindness as a public health problem by the year 2020.

Vision 2020 was officially launched in 1999 and in May 2003 the World Health Assembly adopted the Resolution on the Elimination of Avoidable Blindness. This resolution calls on member nations to develop and implement Vision 2020 national eye care plans (8). The current global priorities for eliminating avoidable blindness are cataract, eye infections, vision loss in children, and the correction of refractive error and low vision.

The number of blind people is increasing and it is estimated that at least 7 million people become blind each year: even with all interventions combined, blindness is increasing by 1-2 million cases per year (9). Without additional interventions the global number of blind individuals is projected to increase to 76 million by the year 2020 due to population growth and aging (10). It has been estimated that with the implementation of a successful Vision 2020 initiative the projection is of those blind in 2020 will be less than 25 million, rather than 76 million. This would save over 400 million years of blindness between now and 2020 with a conservative estimate of the economic gain being US\$102 billion (10).

Cataract as a leading cause of vision impairment

Cataract is a condition where the normally clear crystalline lens inside the eye becomes increasingly opaque, reducing the light entering the eye until clear vision is no longer possible. It is curable by removing the cataractous lens. Extracapsular extraction of the lens (ECCE) and correcting for its loss by using some form of artificial posterior chamber/endocapsular intraocular lens (IOL) is increasingly undertaken in developing countries.

Approximately 50% of the world's blind suffer from cataract (1) and it has been recognized that the provision of good-quality, affordable cataract surgery to all in need is the main challenge for prevention of blindness activities (4).

While cataract surgical output is inhibited by the number of available surgeons in some countries, it may also be inhibited for a variety of other reasons, including inadequate consumables, too few trained support staff, inadequately trained ophthalmic surgeons and inequitable distribution of eye care services (11). A major barrier to the uptake of cataract services in many countries is the perceived poor visual outcome after surgery, and there has been a growing realization that too much emphasis is placed on the quantity of cataract surgeries performed, often at the expense of quality outcomes (12). This concern is supported by recent information from population-based studies which report that 40-75% of post-operative eyes remain visually impaired (have vision of worse than 6/18) (13,14,15,16,17,18). The impairment was mainly due to surgical complications or lack of post-operative refractive correction.

WHO has established standards regarding acceptable post-operative outcomes(19), and tools and protocols have been developed (20) to monitor surgical outcomes. According to WHO, 80% of operated eyes should have vision of 6/18 or better (more than 90% best-corrected), and less than 5% should have a 'poor' outcome (worse than 6/60).

Prospective monitoring of outcomes has been shown to influence cataract surgical outcomes, with improvement in appropriate case selection, management of surgical complications, and the proportion of patients obtaining a good visual outcome (21). The WHO recommends that all surgeons should monitor their performance and identify reasons for poor outcome (selection, surgery, spectacles, sequelae) (19). Information obtained from monitoring will facilitate understanding of reasons for poor outcomes, so that these can be addressed and improved (22).

Refractive Error as a leading cause of vision impairment

Uncorrected refractive error (or the need for spectacles) has only recently been recognised as a leading cause of global visual disability. Uncorrected refractive errors and presbyopia (the need for near vision spectacles) pose an enormous unmet need in many parts of the world. People's access to the necessary correction is limited in many countries by a lack of trained eyecare personnel and access to affordable spectacles of good quality.

Refractive error data collected in multi-centre population-based studies in children between the ages of five and fifteen years has shown that prevalence of refractive error varies significantly from one country to the next. The most dramatic need was in China where 41% of children aged 15 had significant refractive error, of whom 85% had no spectacles. The amount of uncorrected refractive error was: 46% in Chile, 92% in Nepal, and 86% in rural India. (23,24,25,26,27).

Similarly uncorrected refractive error is a leading cause of low vision in adults in many parts of the world (28). In addition to blindness due to naturally occurring high refractive error, inadequate refractive correction of aphakia after cataract surgery (occurring when an artificial intraocular lens is not inserted during surgery) is also a significant cause of blindness in developing countries.

There are a number of barriers which have been associated with uncorrected refractive error, including socioeconomic factors and limited access to services (29), as well as reluctance to wear spectacles within some age groups (30) or cultures (31). Even in developed countries, people are not always able to access or afford spectacles (32). This suggests that education programs and interventions to improve access to affordable eye care could significantly decrease the burden of visual loss.

The WHO Refractive Error Working Group has recommended that affordable 'readymade' spectacles that can be dispensed on the spot are presently the most feasible correction option for refractive error correction (33), and it has been shown that the distance vision of 72 - 74% of adults can be satisfactorily corrected with readymade spectacles (34, 35). Readymade spectacles are available from various Asian countries for as little as US\$1-2, and can therefore be provided at relatively low cost to ensure affordable spectacles are available for the majority of those in need. It is important, however, that readymade spectacles be of appropriate optical and structural quality and acceptable appearance (36).

Another recommendation is that refractive error programs should develop supply chains for providers and access to regional optical workshops that can provide affordable custom-made spectacles for those with more complex refraction needs.. The use of recycled or 'second-hand' spectacles should be avoided (33).

This working group also recommends training nurses as the mid-level providers of basic refraction care to introduce refractive services into existing eye and health care facilities. In some countries refraction services have addressed community needs, improved the reputation of the service, and in some cases, generated income.

Since the treatment of refractive error is perhaps the simplest and potentially the most cost-efficient form of eye care, it has been proposed that a population with blindness due to refractive error is indicative of inadequate eye care services in that population. (28).

Eye care services

In order to achieve the aim of *Vision 2020: The Right to Sight* and eliminate avoidable blindness by the year 2020, the 56th World Health Assembly called upon Member States to:

"...commit themselves to supporting the Global Initiative for the Elimination of Avoidable Blindness by setting up, not later than 2005, a national Vision 2020 plan...." (8).

Countries need to establish comprehensive eye care services to deal with the problems existing in their local context, and these should be integrated with primary health care services as much as possible. These need to be

carefully planned to ensure quality and equity, as studies have shown that there are many barriers to people accessing eyecare, such as poverty, living in rural areas, female gender and increasing age (37,38,39,40,41).

The Timor Leste Situation

The Ministry of Health (MOH) is committed to planning services based on sound information, in order to set priorities for the allocation of scarce resources. While some eye care services are currently available in Timor Leste and monitoring information is available from some of these services, this is the first population based Eye Health Survey to be undertaken in Timor Leste.

Therefore the purpose of the *Timor Leste Eye Health Survey* was to gather information to assist the MOH with the development of National Eye Care Strategy (NECS), and the first five year strategic National Eye Care Plan (NECP) 2005-10, in order to provide appropriate, high quality eye care services to the people of Timor Leste. The survey's principle aims were to determine the prevalence of vision impairment in Timor Leste, to gather information about the coverage and visual outcomes of services such as cataract surgery and spectacles, and to understand current perceptions of eye care services, including barriers to care.

2. Research design

2.1. Logistics

The survey was conducted by the MOH in two districts in early 2005, with technical assistance from the International Centre for Eyecare Education (ICEE).

Ethics

Ethics approval was sought and obtained from the Minister of Health prior to commencement of the survey. In addition, written informed consent was obtained from both the Suco and Aldeia chiefs of the selected clusters, as well as all survey participants, prior to commencement of any form of examination or activity related to the survey.

Schedule

The survey was conducted during the following periods:

- Pilot: Dili November 17-25, 2004
- Survey: Dili March 7 - April 11, 2005
Bobonaro April 26 - May 26, 2005

Survey work within each cluster was completed within one day.

Dissemination

This survey report will be distributed by the MOH to relevant departments and eye care personnel within the MOH, as well as to other stakeholders in the National Eye Care Program: local and international non-government organisations, and organisations such as WHO, the International Agency for the Prevention of Blindness and aid agencies.

2.2. Preparation

Questionnaire Design

The questionnaire was adapted from the standard Rapid Assessment of Cataract Surgical Services Protocol (RACCS) (42) by adding specific components to investigate issues of importance in the context of the Timor Leste National Eye Care Program. These components included assessment of vision-related quality of life and willingness to pay for cataract surgery and spectacles.

The questionnaire was developed in English and translated into Tetum. The translated version was field tested and final adjustments were made to ensure clarity of questionnaire content.

Pilot

In November 2004, a pilot study was conducted in a selected cluster in Dili to validate and refine the questionnaire, and to undertake concordance testing of the interviewers. This cluster was not included in the final survey activities or analysis.

Survey Team and Training

Separate survey teams were formed for the Dili and Bobonaro districts, each comprising one optometrist in the role of team leader, responsible for visual assessment and eye health examination, and three local field workers, trained in questionnaire administration and completion of survey data forms. The team was complemented by the addition of the local eyecare nurse during survey activities in the Bobonaro district. All survey personnel underwent three days of training in survey techniques to ensure standardization of data collection prior to the commencement of the survey in each district. Optometric team leaders underwent concordance testing to confirm uniformity in assessment of vision, lens status, and cause of vision impairment. The kappa statistic for agreement between diagnosis and measurement by the ophthalmic team leaders was within acceptable limits.

Community Liaison

District health services (Chief DHS and CHC) were advised of survey activities, including proposed schedules, through information distributed by the NCD department of the MOH approximately one month prior to survey commencement in each of the districts. Suco chiefs from those clusters selected for survey participation were also informed of survey activities through a letter distributed by NCD. In most cases, this letter was sent to the CHC in closest vicinity to the involved Suco, with CHC staff bearing responsibility for ensuring this information was passed on to village leaders.

2.3. Study Design

Participants

Participants in this survey were those older than 40 years of age. This is due to the largest burden of blindness falling in adults of increasing age. The inclusion of younger age groups would have required a much larger sample size.

Sampling

The sampling for the survey was based on the WHO RACCS Protocol (42).

The sample frame for this study included Dili district (an urban population of 167,777) and Bobonaro district (a rural population of 82,385, two to six hours by road from Dili). Using an anticipated prevalence of vision impairment (presenting visual acuity worse than 6/18 in both eyes) of 11% in the target population, precision of $\pm 20\%$, with 95% confidence, and a design effect of 1.3 (for a cluster size of 30 persons), the required sample size was estimated as 1500 persons. A systematic random sampling strategy identified 50 clusters, being 25 across all 6 subdistricts of both Dili and Bobonaro, with probability proportionate to subdistrict population size (Table 1). Final schedules for participating survey clusters within each of the districts are included in Appendix 2.

Table 1: Cluster distribution based on sub-district population

Bobonaro District			Dili District		
Sub district	Population	Clusters	Sub district	Population	Clusters
Atabae	9,553	3	Vera Cruz	33,463	5
Balibo	13,602	4	Nain Feto	22,800	3
Bobonaro	22,021	7	Metinaro	3,757	1
Cailaco	8,405	3	Atauro	7,857	1
Lolotoe	7,021	2	Dom Aleixo	58,459	9
Maliana	21,783	7	Cristo Rei	41,441	6
Total	82,385	25		167,777	25

Participant Recruitment

The survey was undertaken on a door-to-door basis within each nominated cluster. The survey team leader selected the households to be targeted in each cluster, using a random process. Eligible participants aged 40 years and older were then enumerated by the Timorese fieldworkers. This continued until 30 participants were enrolled in each cluster. If potential participants declined the offer to participate, their demographic information was noted, if this was made available.

Assessment

Survey participants underwent vision and eye health assessment as well as the verbal administration of a questionnaire in Tetum or the local dialect.

A standardized survey record form was completed for each participant (Appendix 1). Demographic details of age, gender, wealth indicators, marital status and literacy were collected. For those who had previously utilised eye care services, the fieldworker also enquired about that service, including location, by whom, and at what cost. Satisfaction with the vision outcome, and willingness to pay for future services (ie. cataract surgery, spectacles) were also assessed. In addition, barriers to utilising services and vision-related quality of life were investigated.

Presenting distance visual acuity (with spectacle correction if the participant was using any) was determined for each eye separately, using a simplified 3 m chart with tumbling 'E' equal to sizes 120, 60 and 18 in the standard Snellen chart. Individuals with vision of worse than 6/18 (either eye) underwent further vision assessment with pinhole. Presenting near visual acuity for each participant was also measured. Anterior eye examination and lens observation was undertaken without dilation on all participants using a pen torch under semi-dark conditions. The lens status on examination was classified as normal, obvious lens opacity, pseudo aphakia or aphakia. Participants with presenting vision impairment in either eye underwent retinal examination of that eye through an undilated pupil using a direct ophthalmoscope.

A cause of vision loss was determined for each eye with a presenting visual acuity worse than 6/18. Refractive error was considered to be the cause of vision loss where acuity improved to 6/18 with pinhole. When refractive error and lens opacity coexisted, refractive error was nominated as the cause. Where no refractive error existed, and obvious lens opacity was observed, cataract was noted as the cause. Glaucoma was implicated if the vertical cup-to-disc ratio was greater than 0.8, or there was significant asymmetry with the other eye. Other causes of vision impairment, including corneal opacity, required clinical findings of sufficient magnitude to explain the level of vision loss. The principal cause of vision impairment, defined as that most readily treatable where two causes of vision impairment co-existed, was then recorded by the team leader.

Data Entry and Analysis

Data was entered by the principal investigators into a specifically designed database on a regular basis throughout the duration of the survey. Prevalence estimates were age and gender adjusted for the population of Timor Leste (based on the 2004 Census), and 95% confidence intervals were derived around the point estimates using SPSS 12.0.1. Fisher's exact test and the chi square test for bivariate analysis and a multiple logistic regression model for multivariate analysis were used. Odds ratios (OR) and 95% confidence intervals (95%CI) were estimated. A p value of <0.05 was taken as significant for this analysis.

2.4. Service for participants

All participants were advised of the availability of permanent eyecare services within their district hospitals (National Hospital and Maliana Referral Hospital).

While it was not part of the survey, participants found to have significant bilateral vision impairment resulting from cataract were offered transport for a more extensive eye examination and assessment of eligibility for cataract surgery by an ophthalmologist at the National Hospital, Dili.

From the Dili clusters, 37 people were referred during the survey, 16 people utilised the transport to the hospital, and available records indicate that four of these people ultimately underwent cataract surgery. People in need of refraction were referred to the National Hospital.

All willing participants within the Bobonaro district requiring spectacles underwent refractive assessment and spectacle provision where available by the local eyecare nurse on the day of the survey. Participants identified with vision impairment, blindness, or eye problems requiring other treatment were referred to Dili National Hospital, and transport and accommodation were provided. Overall 26 people were referred during the survey in Bobonaro. Nine people utilised the transport and accommodation, and all of these ultimately underwent cataract surgery. Given the more difficult circumstances faced by the rural population in accessing services, more stringent referral criteria were applied for the Bobonaro participants. It is of note that even after agreeing to travel to Dili to undergo further assessment, and with transport and accommodation provided, only 35% of the patients referred from Bobonaro presented. The further barriers experienced by the remaining 17 people would be very informative for understanding service utilisation and its barriers in the future.

3. Results

Participants

A total of 1414 people > 40 years of age participated in the survey, a participation rate of 96.2%. 671 (47%) were from Dili District, and 693 (49%) were female.

3.1. Prevalence and Causes of Vision Impairment

The gender adjusted^{iv} prevalence of blindness (vision worse than 3/60 in both eyes) in those 40 years and over was found to be **4.7 ± 1.1%**, while the prevalence of low vision (vision worse than 6/18 but better than 3/60 in both eyes) was **18.5 ± 2.0%**. The socio-economic associations with blindness and low vision are shown in Table 2. The table shows that those most likely to have vision impairment are those who are: older, illiterate, not in paid employment, living in a rural area and unmarried.

Table 2: Prevalence and associations of Blindness and Low Vision (40+ years) in Timor Leste

	Not Vision Impaired	Low Vision		Blind		Total
			OR (95%CI)		OR (95%CI)	
Total						
Sample	76.8 % (1086)	18.5 % (262)	-	4.7% (66)	-	100% (1414)
Population		37,648 (33,578 to 41,718)		9,565 (7,326 to 11,803)		203,500
Age						
40 - 49	94.0 (566)	5.3 (32)	1.0	0.7 (4)	1.0	100 (602)
50 - 59	81.9 (281)	17.2 (59)	1.3 (0.3-5.9)+	0.9 (3)	3.7 (2.4-5.8)	100 (343)
60 - 69	59.1 (150)	32.3 (82)	14.2 (4.8-41.6)	8.7 (22)	9.7 (6.2-15.1)	100 (254)
>=70	41.4 (89)	41.4 (89)	31.1 (10.9-88.4)	17.2 (37)	17.7 (11.1-28.1)	100 (215)
Gender						
Male	77.1 (556)	17.9 (129)	1.0	5.0 (36)	1.0	100 (721)
Female	76.5 (530)	19.2 (133)	0.9 (0.5-1.4)+	4.3 (30)	1.1 (0.8-1.4)+	100 (693)
Literacy						
Literate	90.5 (419)	8.2 (38)	1.0	1.3 (6)	1.0	100 (463)
Illiterate	70.1 (667)	23.6 (224)	3.7 (2.6-5.3)	6.3 (60)	5.1 (2.2-12.0)	100 (951)
Employment						
Govt. / Self employed / Pvt	92.0 (184)	7.5 (15)	0.3 (0.2-0.5)	0.5 (1)	0.1 (0.0-0.4)	100 (200)
Farming	77.1 (378)	21.2 (104)	1.0 (0.8-1.3)+	1.6 (8)	0.2 (0.1-0.4)	100 (490)
Unemployed	72.4 (524)	19.8 (143)	1.0	7.9 (57)	1.0	100 (724)
Area						
Urban (Dili)	83.5 (560)	12.5 (84)	1.0	4.0 (27)	1.0	100 (671)
Rural	70.8 (526)	24.0 (178)	2.3 (1.7-3.0)	5.2 (39)	1.3 (0.8-2.2)+	100 (743)

* Factors not associated with blindness or low vision were gender and size of household
+ not significant

Extrapolating to the population of Timor Leste, it is estimated that there are 9,565 blind and 37,648 people with low vision over 40 years of age (based on population estimate of 203,500 >40 years).

Table 3 shows the main causes of vision impairment for those over 40 years in Timor Leste are cataract and refractive error, being responsible for more than 90% of all vision impairment.

^{iv} This data has been gender-standardised, and will be age standardized when the 2004 Timor Leste Census results become available. Therefore these figures may vary slightly in future MOH documents.

Table 3: Causes of Blindness and Low Vision in Adults (40+ years) in Timor Leste

Cause	Blindness		Low vision		Total %
	%	No. people	%	No. people	
Cataract	78.8 ± 9.9	6,590 to 8,484	32.8 ± 5.7	10,202 to 14,494	42.1 ± 5.3
Refractive Error	1.5 ± 1.0	29 to 823	63.0 ± 5.9	21,497 to 25,901	50.6 ± 5.4
Other	19.7 ± 5.4*		7.2 ± 5.1		7.3 ± 5.4
Total	100%	7,326 to 11,803	100%	33,578 to 41,718	100%

* Other causes of blindness included posterior segment disorder (7.6%) and corneal opacity (6.1%).

3.2. Utilisation, Satisfaction and Barriers to Eye Care Services

History of eye or vision problem

Previous or current eye or vision problems were reported by 91.4% of the sample. Blurry vision (distance or near) was the most frequent problem experienced (Table 4). Females, those who are illiterate, those who live in rural areas and those who are subsistence farmers were less likely to report a history of an eye or vision problem (Table 5).

Table 4: History of eye or vision problems (>40 years)

History of Eye Problem	% (number)	Type of Problem	% (number)
Yes	91.4 (1293)	Blurry Vision	81.0 (1145)
		Red/ Itchy/ Painful Eyes	9.2 (130)
		Eye Injury	1.2 (18)
No	8.6 (121)		
Total	100 (1414)		

Table 5: Factors associated with reporting history of eye or vision problems (>40 years)

Factor		Odds Ratio	95% Confidence Interval
Gender	Male	1.0	
	Female	0.6	0.4-0.9
Literacy	Literate	1.0	
	Illiterate	0.5	0.3-0.7
Location	Urban	1.0	
	Rural	0.2	0.2-0.4
Employment	Unemployed	1.0	
	Farming	0.4	0.3-0.6
	Paid employ	1.2+	0.6-2.5

+ Not significant

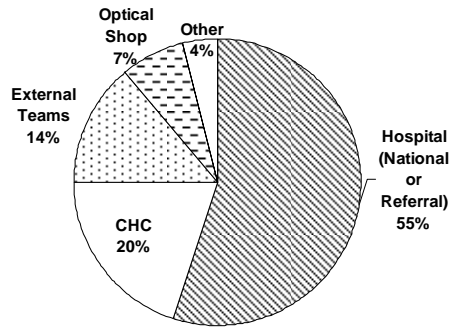
Utilisation of eye care services

Of those people reporting a vision problem, only 33.6% had ever utilized any form of eye care or vision services (Table 6). Figure 1 shows that MOH facilities were utilised by 75% of the sample, while external teams (Australian, Indonesian, US etc) provided service to 14% and private optical shops to 7%.

Table 6: Utilisation of eye care services by those over 40 years with a history of an eye or vision problem

Type of Problem History of Eye Problem	% Seeking Treatment (number)	% NOT Seeking Treatment (number)	% (number)
Blurry Vision	31.4 (360)	68.6 (785)	100 (1145)
Red/ Itchy/ Painful Eyes	50.8 (66)	49.2 (64)	100 (130)
Eye Injury	50.0 (9)	50.0 (9)	100 (18)
Total	33.6 (435)	64.4 (858)	100 (1293)

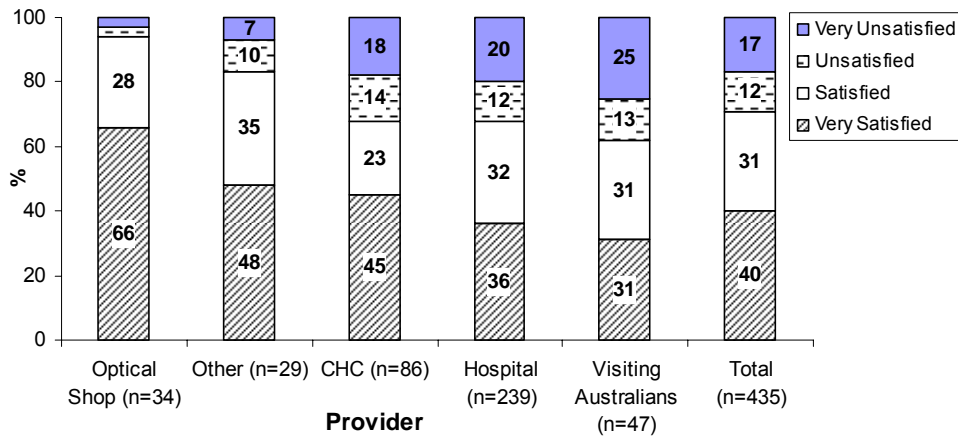
Figure 1: Services utilised by those over 40 years with an eye or vision problem (n=435)



Satisfaction with eye care services

Private optical shops had the highest proportion of patients very satisfied or satisfied with their service (94%) while visiting Australian eye teams had the lowest (62%), and government services fell in between (Figure 2). Similarly, optical shops had the least proportion of patients very unsatisfied (3%), while visiting Australian eye teams had the highest (25%), and government services were in between.

Figure 2: Satisfaction with eye care services by those over 40 years with a history of an eye or vision problem who utilised services, by provider (n=435)



Barriers to eye care service utilisation

The most common reasons given for people not utilising services were lack of awareness (34%), unable to afford transport (12%), and that the service is too far away (9%) (Figure 3). A further 31% of people did not use services because they said ‘vision problem is part of aging’ (9%), ‘fear’ (8%), ‘feel there is no need’ (7%) and ‘accept the problem’ (7%). Health promotion and education could increase use of services by these people in the future. People living rurally, those who are illiterate, those not in paid employment or those who are subsistence farmers are least likely to utilise services (Table 7). Females were 1.1 times more likely to NOT utilise service, although this was not statistically significant.

Figure 3: Reasons for not utilising eye care services (n=858)

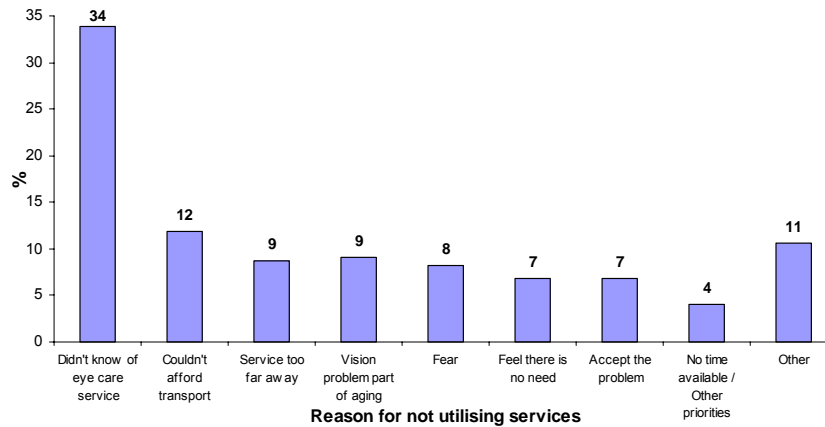


Table 7: Factors associated with NOT utilising eye care services amongst those reporting history of an eye or vision problem

Factor		Odds Ratio	95% Confidence Interval
Gender	Male	1.0	
	Female	1.1+	0.9-1.4
Literacy	Literate	1.0	
	Illiterate	3.7	2.9-4.8
Location	Urban	1.0	
	Rural	3.8	3.0-4.9
Employment	Unemployed	1.0	
	Farming	3.3	2.4-4.5
	Paid employ	0.6	0.5-0.9

+ Not significant

3.3. Cataract and cataract surgery

Cataract surgical coverage

For those 40 years and older, cataract is the second most prevalent cause of low vision, and most frequent cause of blindness in Timor Leste (Table 3). Its treatment, by surgery, had occurred in 28 survey participants (2.0%), for a total of 42 eyes. Fifty percent of those who had undergone surgery were female. The surgical coverage was higher in the urban than the rural district, though this was not statistically significant.

There were a further 55 people in the sample bilaterally blind at the 3/60 level, with cataract as the cause. This gives a cataract surgical coverage (proportion of people receiving surgery who are blind due to cataract) of 26.7% at the 3/60 level (Table 8).

Table 8: Cataract surgical coverage in Timor Leste

Cataract Surgical Coverage		%
Level	Category	
6/60	Eyes	15.3
	Persons	20.2
3/60	Eyes	22.3
	Persons	26.7

CSC (Eyes) at 6/60= $(100a/(a+b))$, where a = pseudophakic+aphakic eyes, and b = eyes with worse than 6/60 (or 3/60) vision caused by cataract.

CSC (Persons) = $(100(x+y)/x+y+z)$, in which x = persons with unilateral pseudophakia or aphakia in one eye and worse than 6/60 (or 3/60) vision caused by cataract in the other eye, y = persons with bilateral previously operated cataract, and z = persons with bilateral cataract causing vision worse than 6/60 (or 3/60) in each.

Cataract surgical outcome

The overall cataract surgical outcome (proportion of people not vision impaired after surgery) was 24%, far below the WHO standard of 80%. There was a difference in surgical outcome between providers (Fig 4), and a corresponding difference with post-surgery patient satisfaction (Fig 5), with the visiting Indonesian and Australian teams producing results far below WHO standards, while the services provided by the resident Chinese ophthalmologist produced outcomes very close to, or meeting, WHO standards.

The main causes of vision impairment following surgery were surgery related complication (52%), uncorrected aphakia (24%) and uncorrected refractive error (21%) (Figure 6). Surgery related complications are most likely due to poor selection of patients or poor surgical technique. Given the costs associated with providing cataract surgery, both monetary and in terms of the patient’s inconvenience, discomfort and time, it is of great concern that such a high proportion of patients remain blind after the intervention.

Refraction services are required following surgery (and on an ongoing basis) to maximise the visual outcome.

Figure 4: Post-surgical a) presenting and b) best corrected vision by surgeon (n=40 eyes, 27 people)

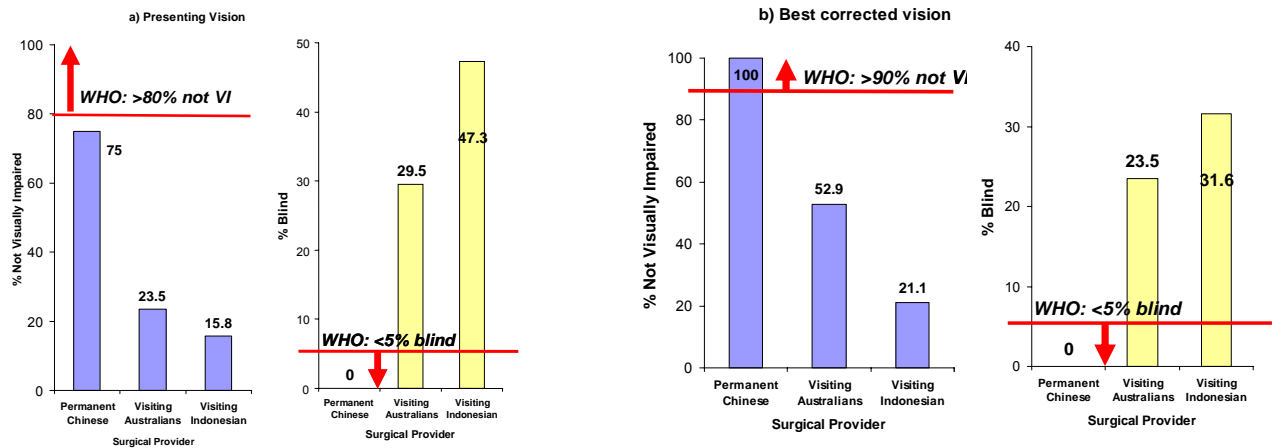


Fig 5: Satisfaction with surgical outcome (n=26)

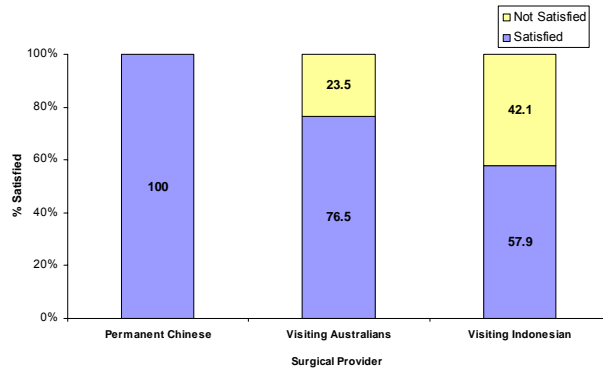
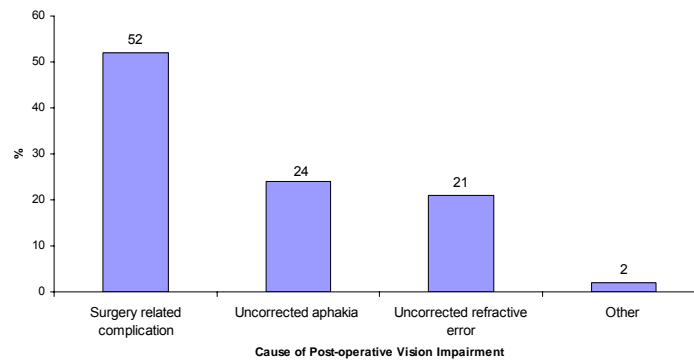


Figure 6: Causes of vision impairment following cataract surgery (n=33)



Willingness to pay for cataract surgery

The cost of the surgical consumables for one cataract surgery is estimated at USD\$20. Participants who had previously received surgery, or were vision impaired due to cataract, were questioned regarding their willingness to pay for cataract surgery. A bidding process was used to elicit the price points of \$20, \$10 and \$30.

Ninety-three percent (93%) of participants were unwilling and/or unable to pay \$10 for surgery, indicating that if a cost-sharing system were to be implemented with patients for cataract surgery this could present further barriers for utilisation of services (Table 9). Patient education may improve the uptake of services and willingness to pay, in addition to improvement in surgical outcomes. Literacy was the only socio-economic factor associated with a willingness to pay for cataract surgery ($p=0.003$). Each of the six participants willing and able to pay \$30 for cataract surgery had previously undergone surgery on at least one of their eyes.

Table 9: Maximum price those having had cataract surgery, and those vision impaired with cataract, are willing and able to pay for cataract surgery (n=101)

Maximum price willing and able to pay (USD)	VI from cataract % (#)	Previous cataract surgery % (#)	Total % (number)
30	0	18.5 (6)	5 (6)
20	0	0	0
10	1.4 (1)	0	1 (1)
<10	98.6 (73)	81.5 (21)	93 (94)
Total	100 (74)	100 (27)	100 (101)

3.4. Refractive error and spectacles

Utilisation of spectacles

Almost all people over 40 years of age could benefit from presbyopic correction (near vision spectacles) to provide them with clear near vision for tasks such as reading, sewing, cleaning rice and carpentry. However, in this sample, only 15.1% (213) were currently wearing spectacles (for distance or near tasks), while a further 8.3% (117) had previously worn spectacles. When asked whether they would be prepared to wear spectacles in the future to improve their vision, 96% of participants said yes.

Those more likely to be currently using spectacles were males, literate, in paid employment and living in an urban area (Table 10).

The main reasons people were no longer wearing spectacles were that they did not see well with them (44%), and that they broke (24%) (Figure 6).

The range of prices paid for spectacles in the past was between \$0 and \$260 (Figure 7). Almost half (48.8%) of those having current or previous spectacles had received them at no cost (n=140). When spectacles were dispensed at a cost, the mean price was \$12 ± \$25 while the median was \$3.00 (Table 11). The median price for spectacles was highest for the optical shops (\$7.13), and lowest for the visiting Australians (\$2.00). Data for 43 participants was missing so was not included in this analysis.

Table 10: Factors associated with current spectacles use (n=213)

Factor		Odds Ratio	95% Confidence Interval
Gender	Male	1.0	
	Female	0.6	0.4-0.8
Literacy	Literate	1.0	
	Illiterate	0.1	0.1-0.2
Location	Urban	1.0	
	Rural	0.3	0.2-0.4
Employment	Unemployed	1.0	
	Farming	0.3	0.2-0.4
	Paid employ	2.4	1.7-3.4

Figure 6: Reasons people were no longer wearing spectacles (n=117)

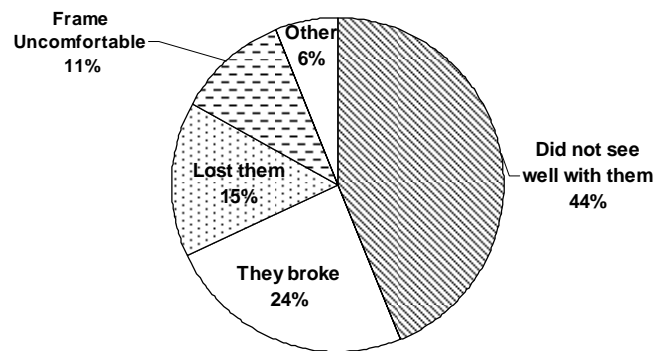


Figure 7: Price paid for spectacles by current or previous spectacles wearers (n=287)

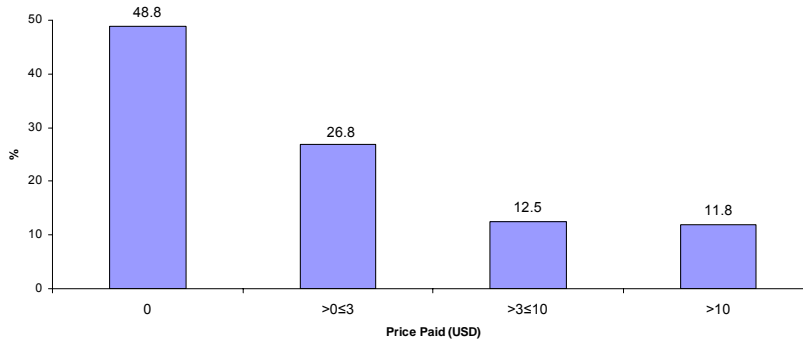


Table 11: Price paid for spectacles by provider (n=287)

Provider	n	Number dispensed at no charge (%)	Mean* ± SD USD	Median* USD	Range* USD
Optical Shop	32	0	12 ± 12	7.13	0.50 – 50
CHC	41	25 (61.0)	18 ± 20	7.00	2 - 60
Hospital	150	78 (52.0)	9 ± 14	3.00	0.20 - 60
Visiting Australians	40	25 (62.5)	3 ± 1	2.00	1 - 7
Other	24	12 (50.0)	34 ± 74	2.63	0.50 – 260
Total	287	140 (48.8)	12 ± 25	3.00	0-260

*Of those paying some amount

Spectacle coverage (Distance)

Of all subjects examined, 31 (2.2%) wore distance spectacles that corrected their distance vision to 6/18 or better in the better eye on presentation: 19 men (2.6% of all men examined) and 12 women (1.7% of all women examined). This is referred to as the ‘Met Need’, while 166 were habitually uncorrected but would have achieved 6/18 or better in the better eye with correction: the ‘Unmet Need’. This gives a Spectacle Coverage of 15.7% (Table 12). For women coverage was 12.8%, and for men it was significantly higher at 18.4% ($\chi^2 = 0.039$). Spectacle coverage among those living in the rural areas was 5.2%, which was significantly lower than coverage of 38.7% for those living in urban areas ($\chi^2 = 0.01$).

Factors associated with wearing distance spectacles were identified, by comparing the Met Need with the Unmet Need. There was no significant difference between males and females wearing spectacles to correct vision impairment. Those who were illiterate were significantly less likely to be wearing spectacles compared to those who are literate (OR 0.07), as were those living rurally compared to urban inhabitants (OR 0.26). Those who were illiterate were significantly more likely to have uncorrected refractive error than those who were literate (OR 2.9), as were those living in rural areas compared to urban inhabitants (OR 3.47), those who were not married compared to those who were (OR 1.9) and those who were subsistence farmers compared to those in paid employment (OR 2.85) (Table 13). Older subjects were significantly more likely to have uncorrected refractive error than younger subjects. This was significant ($P < 0.001$) in all older age groups compared to the 40-49 year age group: 50-59 years OR 2.6; 60-69 years OR 4.9; 70+ years OR 7.43.

Table 12: Spectacle coverage according to gender and location

Factor		Total	Wears distance specs and achieves $\geq 6/18$ in better eye	Needs distance specs to achieve $\geq 6/18$ better eye	Coverage
Gender	Male	721	19	84	18.4
	Female	693	12	82	12.8
Location	Urban	671	24	38	38.7
	Rural	743	7	128	5.2
Total		1414	31	166	15.7

$$\text{Spectacle Coverage} = \text{Met Need} / (\text{Met Need} + \text{Unmet Need}) \times 100\%$$

Table 13: Factors associated with the wearing of spectacles, the met need (n=31) and the unmet need (n=166)

Factor		Total	Wears distance specs and achieves $\geq 6/18$ in better eye	Needs distance specs to achieve $\geq 6/18$ better eye	Odds Ratio of Need for Spectacle Correction	95% CI	P
Gender	Male	721	19	84	1.00		
	Female	693	12	82	1.02+	0.74-1.41	0.915
Literacy	Literate	463	27	26	1.00		
	Illiterate	951	4	140	2.90	1.88-4.48	<0.001
Location	Urban	671	24	38	1.00		
	Rural	743	7	128	3.47	2.37-5.06	<0.001
Age	40 - 49	602	7	26	1.00		
	50 - 59	343	9	40	2.58	1.55-4.31	<0.001
	60 - 69	254	8	46	4.90	2.95-8.13	<0.001
	≥ 70	215	7	54	7.43	4.51-12.24	<0.001
Married	Married	1033	20	101	1.00		
	Not Married	381	11	65	1.90	1.36-2.66	0.000
Employment	Unemployed	724	24	72	1.59+	0.86-2.93	0.139
	Farming	490	2	81	2.85	1.55-5.25	0.001
	Paid employ	200	5	13	1.00		
Total		1414	31	166			

+ Not significant

Satisfaction with refractive error service / spectacles

Satisfaction with refractive error services and spectacles at government facilities (CHC 83% very satisfied or satisfied and hospital 75%), was not as good as at private optical shops (94%), but better than visiting Australian eye teams (63%) (Figure 8). ($\chi^2=0.05$). There was an association with cost and level of satisfaction ($\chi^2=0.007$), with those paying more for spectacles more likely to be satisfied than those receiving spectacles at no charge (Table 14). There could, however, be a number of explanations for this, including the following associations with the provider:

- a difference in the perceived quality of care, based on the examination delivered and the language of delivery.
- private optical shops perhaps have a greater range and freedom of choice for spectacles;
- private optical shops may be more convenient and involve less waiting time than other services;
- acceptance of free products regardless of quality
- less long term satisfaction with those providers dispensing cheaper spectacles of a poorer quality.

Figure 8: Satisfaction with current or previous spectacles by provider (n=286)

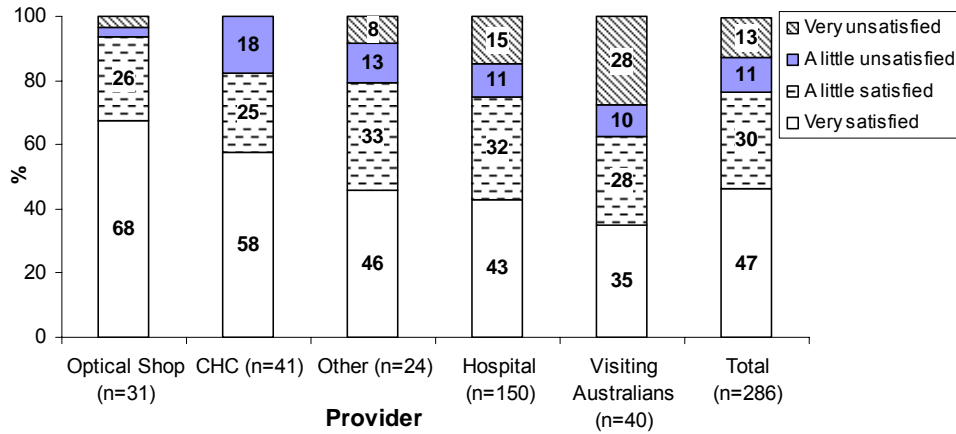


Table 14: Satisfaction with current or previous spectacles by price paid (n=287)

Level of satisfaction	Price Paid (USD)%				Total % (n)
	0 (n=140)	>0≤3 (n=75)	>3≤10 (n=36)	>10 (n=34)	
Very satisfied	42.9	40.8	58.3	60.0	46.3 (133)
A little satisfied	25.7	40.8	22.2	31.4	30.0 (86)
A little unsatisfied	15.7	3.9	16.7	2.9	11.1 (32)
Very unsatisfied	15.7	14.5	2.9	5.7	12.5 (36)
Total	100%	100%	100%	100%	100 (287)

Willingness to pay for spectacles

Two different types of ready-made spectacles are currently available from the National Spectacle Program at a price of \$1 and \$3. Willingness to pay these prices for spectacles was investigated. Overall 43.3% of people said they were unwilling and / or unable to pay \$1 for spectacles. Factors associated with this were increasing age, being female, being illiterate, living in a rural area, not being in paid employment, being unmarried, not having previously worn spectacles, and being vision impaired (Table 15).

Table 15: Factors associated with being willing and able to pay \$3, \$1 or <\$1 for spectacles (n=1358)

Factor		\$3			\$1			<\$1		
		%	Odds Ratio	95% CI	%	Odds Ratio	95% CI	%	Odds Ratio	95% CI
Age	40 - 49	37.8	1.0		27.9	1.0		34.2	1.0	
	50 - 59	28.4	0.7	0.5-0.9	29.6	0.9+	0.6-1.2	42.1	1.4	1.1-1.8
	60 - 69	26.7	0.6	0.4-0.8	23.5	0.6	0.4-0.8	49.8	1.9	1.4-2.6
	≥70	14.3	0.3	0.2-0.4	22.2	0.4	0.3-0.6	63.5	3.3	2.4-4.7
Gender	Male	32.1	1.0		27.9	1.0		40.0	1.0	
	Female	27.9	0.8	0.6-1.0	25.3	0.8	0.6-1.0	46.8	1.3	1.1-1.6
Literacy	Literate	60.3	1.0		22.7	1.0		17.0	1.0	
	Illiterate	14.9	0.1	0.1-0.2	28.6	0.4	0.3-0.5	56.5	6.3	4.8-8.4
Location	Urban	48.5	1.0		22.9	1.0		28.6	1.0	
	Rural	13.0	0.2	0.1-0.2	30.1	0.7	0.5-0.9	56.9	3.3	2.6-4.1
Employment	Unemployed	34.2	1.0		24.0	1.0		41.8	1.0	
	Farming	8.6	0.2	0.1-0.3	32.3	1.0+	0.7-1.3	59.1	2.0	1.6-2.6
	Paid employ	65.5	3.7	2.6-5.1	23.0	3.5	2.0-6.0	11.5	0.2	0.1-0.3
Marital status	Married	33.9	1.0		27.5	1.0		38.6	1.0	
	Single / Widow / Divorce	19.4	0.5	0.4-0.6	24.4	0.6	0.5-0.8	56.2	2.0	1.6-2.6
Current or Previous Spectacle wear	No	19.9	1.0		29.1	1.0		50.9	1.0	
	Yes	62.2	6.6	5.0-8.6	18.8	1.7	1.2-2.5	19.1	0.2	0.2-0.3
Vision status	Not Vision impaired	34.9	1.0		27.6	1.0		37.5	1.0	
	Vision impaired	13.5	0.3	0.2-0.4	23.5	0.5	0.4-0.7	62.9	2.8	2.2-3.7
Total		30.0			26.7			43.3		

+ Not significant

4. Additional Resources

CD roms (available from Vision 2020):

Vision 2020 Tool Kit

Monitoring Cataract Surgical Outcomes

Websites:

<i>IAPB</i>	http://www.iapb.org/
<i>WHO PBL</i>	http://www.who.int/pbd/blindness/en/
<i>Vision 2020</i>	http://www.v2020.org/main_page.asp
<i>Iceh / journal ceh</i>	http://www.lshtm.ac.uk/iceh/
<i>Journal of Community Eye Health</i>	http://www.jceh.co.uk/
<i>Aravind Resources</i>	http://www.laico.org/v2020resource/

Documents:

A framework and indicators for monitoring Vision 2020 – The Right to Sight: The Global Initiative to Eliminate Avoidable Blindness.WHO/PBL/03.92.

5. Further Research

- **Prevalence and causes of vision impairment**

Prior to the development of the next phase of the National Eye Care Program (2010-15), another Eye Health Survey should be undertaken, in order to measure the impact of services in Phase I, and to provide information on which to base Phase II.

- **Utilisation, satisfaction and barriers to eye care services**

The influences on patient satisfaction need to be better understood in order to improve services. Research should aim to identify the factors influencing satisfaction, and to monitor the impact of any interventions undertaken (eg. Improving efficiency, increasing information provided to patients, providing services closer to the community).

Research should be undertaken to inform the development of community education and health promotion strategies, and the impact of these strategies should be measured.

Interventions should be undertaken to address some of the barriers to utilisation identified in this survey, and the impact of these interventions should be measured.

- **Cataract and cataract surgery**

The impact of the introduction of minimum standards of care and a comprehensive monitoring system on surgical outcomes can be explored.

- **Refractive error and spectacles**

The development of an equitable, sustainable subsidisation protocol should be a result of comprehensive research. The impact of this protocol should be researched.

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