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Title

Increasing the uptake of cataract surgery in Madagascar

The perceptions of eye care providers on factors that contribute to success or failure

Name

JG Somerville BSc(Hons) MCOptom

Master Thesis in International Health

Credits

30 ECTS

International Maternal and Child Health (IMCH)

Department of Women's and Children's Health

Uppsala University –Sweden

Spring 2015

Word Count:

14'221

Acknowledgements

With thanks to Dr Pia Olsson, Prof. Carina Källestål and Prof. Beth Maina Ahlberg for their supervision of this thesis and field research.

Also to Filip, Jonas, Laura, Rabee and Satu who acted as critical friends throughout the course

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List of Abbreviations

CCF	Cataract case finder
IAPB	International Agency for the Prevention of Blindness
IMCH	Department of International Maternal and Child Health
MSICS	Manual small incision cataract surgery
NGO	Non-governmental organisation
WHO	World Health Organisation

Abstract

Relevance Cataract is the world's leading cause of blindness with cataract surgery being one of the strongest tools used in the Vision 2020 initiative. Uptake of cataract services in Madagascar remains poor despite some progress. In order for uptake to improve, an understanding of factors that promote or limit this uptake should be studied. **Aim** To understand what factors eye care providers in Madagascar perceive as important in the success or failure of their cataract programmes that seek to increase surgical uptake. **Methods** Focussed ethnography involving participatory observation, informal conversations and formal, semi-structured interviews were conducted during a 7 week period in Madagascar with eye care professionals and analysed using thematic analysis. **Findings** Participants described focussing their efforts in 3 main areas: finding patients, persuading patients and ensuring surgery took place. The need to find patients was often determined by their geographical distance and cultural relationship to health care. Persuading patients using cataract case finders was a common, successful strategy used to create trust and overcome fear arising from lack of knowledge surrounding disease. The influence of family was vital in decision-making. Collaborating for sustainability and quality surgery ensured surgeries could take place. **Discussion** A socioecological perspective was useful to consider factors facilitating or hindering uptake. Similar to other findings, understanding causes of an individual's self-deprioritisation, an appreciation of the influence of a patient's social network and how knowledge and trust are constructed in society are all important for success. **Conclusion** It is important to design and identify interventions that are successful at a local level through appreciation of the impact of the cultural context. Innovative solutions such as breakthrough patients, the testimony from the first patient in a community, can be a good way of spreading knowledge and gaining trust in target communities through pre-existing communication channels.

Chapter I: Introduction

Background Information

Cataract is an eye disease that can lead to visual impairment and is the world's leading cause of blindness (Pascolini & Mariotti 2011). It occurs when the naturally clear lens inside the eye becomes opaque, blocking light from entering. The World Health Organisation (WHO) estimated the number of people living with cataract to be around 20 million in 2010, accounting for 51% of the world's blindness (Pascolini & Mariotti 2011). It can be caused by many factors including measles, trauma and steroid use and can occur at any age. However by far the majority of cases occur with old age and as the global population ages, the burden of cataract is increasing (Rao *et al* 2011). Those living with cataract often have lower quality of life, lower household income (Finger *et al* 2012) and less independence (Mamidipudi *et al* 2003). Cataract is a significant burden for health systems and economies (Grimes 2013) as those with visual disability find it difficult to work and suffer from increased accidents (Meuleners *et al* 2012, Kulmala *et al* 2008). Cataract can make those who already live in poverty even more vulnerable due to the wide-ranging impact it has on their lives. Cataract can be cured with a short and straightforward surgery, usually under local anaesthetic, to replace the opacified lens with a clear implant. This is the only cure. It is a safe and cost effective procedure (Signes-Soler *et al* 2013) that is readily available in almost all countries worldwide and can be a significant factor in the alleviation of poverty, especially amongst those most at risk (Signes-Soler *et al* 2013, Kuper *et al* 2010). Rates of surgical uptake vary widely but figures reported from studies in some low and middle income countries can range around 37% in Sri Lanka to 58% in Kenya (Athanasiov *et al* 2009, Syed *et al* 2013).

Madagascar is a low income country ranked 151 out of 187 countries in the UN Human Development Index. Much of the health system suffers from the chronic political crisis and many health services rely on donation from international non-governmental organisations (NGOs) which tend to fund specific clinics or programmes rather than the health service. Formal and informal user fees are commonplace with the health budget being cut in half between 2011 and 2012 (IRIN 2012). There are also large disparities between regions within the country with an estimated only 70% of the population having access to the health system (Razafison 2008). The effects of traditional caste systems in Madagascar still

manifest in discrimination against some minority groups and affects aspects of health care (UNHRC 2013). Much of the health system is focussed on the capital city leaving remote areas devoid of services. In a recent study in one more remote region, 64% of blindness was attributed to cataract (Randrianivo *et al* 2014) of which the vast majority should be treatable. Cataract treatment in Madagascar is a private service for which patients must pay, however there are many initiatives from NGOs to help pay for some or all of the cost of treatment for those least able to pay. However, with coverage of less than 3 eye surgeons and less than 2 of any other type of eye professional per million inhabitants (IAPB 2011) and studies showing even those referred for eye surgery not attending a hospital (Razafinimpanana *et al* 2012), Madagascar's chances of reaching the Vision 2020 target of reducing avoidable blindness looks unlikely.

Madagascar and Vision 2020

The Vision 2020 project is “a global initiative that aims to eliminate avoidable blindness by the year 2020” concentrating on low income countries (WHO 2007). Cataract surgery is one of the strongest tools used in this initiative and there are many goals set concerning provision of cataract services. The target for each country is to have 4 cataract surgeons, 10 ophthalmic nurses or clinical officers and 20 refractionists per million population and to conduct 2000 cataract surgeries per year with an average of 500 per surgeon (IAPB 2011). The country factsheet produced in collaboration between various NGOs details how far Madagascar is from this target (IAPB 2011). The ophthalmologist workforce is decreasing in number and is expected to be lower in 2020 than it is today. Historically there have been no ophthalmic nurses, clinical officers or optometrists in Madagascar and none were working in the country in 2011. The country is just over half way to the 2020 target for ophthalmic surgeon workforce similar to countries such as Mali and Benin but far behind other sub-Saharan African countries such as Sudan and Senegal. It currently lies 9th out of 21 sub-Saharan African countries in terms of surgeon workforce and in last place for ophthalmic nurses and clinical officers with zero per million population compared to over 45 in Botswana. It is estimated Madagascar will need to recruit 25 surgeons, over 200 ophthalmic nurses and almost 400 refractionists if they are to successfully meet the vision 2020 target to reduce cataract blindness. It currently lies 16th out of 21 sub-Saharan countries in terms of the proportion of surgical procedures carried out and it is estimated that Madagascar will

need to perform 7 times as many surgeries each year to reach their surgery target but is projected to have a shortfall of over 46'000 surgeries by 2020. It is also visible that the distribution of professionals is biased toward cities with 62% of surgeons based in the capital where only 9% of the population live.

Uptake of cataract services remains poor (Razafinimpanana *et al* 2012) despite currently successful innovations such as cataract case finders working in some regions. Cataract case finders are a strategy used in many countries to increase the uptake of surgery. In Madagascar, where remote parts of the country are not readily accessible and where travelling would be an inefficient use of time by surgeons, lay people are trained to visit communities, give advice on ocular health and screen for those with cataract. This saves time and money and can help to increase the uptake of surgery by spending time in education.

Review of Current Literature

A literature review carried out by myself of currently available evidence shows that a number of factors limit the uptake of cataract services in low and middle income countries. The literature review was carried out before conducting this study and involved an evaluation of 11 quantitative and 4 qualitative studies. The studies were grouped into 11 that included cost as a potential barrier and 4 that had already removed primary cost as a barrier by either offering free surgery or tiered pricing. The studies covered 14 low and middle income countries and had sample sizes ranging from 24 to 3'259.

Cost was a major barrier to the uptake of cataract surgery and yet interventions to reduce cost did not significantly increase uptake (Syed *et al* 2013, Razafinimpanana *et al* 2012, Kessy *et al* 2007). Reducing cost can significantly increase uptake but does not solve the whole problem. Cost could be called the first step in the intervention for increased uptake and can be split into different types with many, such as cost of transportation, linking in with the problem that services are unavailable. Costs could be decreased using simple interventions. The cost of surgery itself could be decreased by reducing the cost of personnel and the cost of equipment. Cost of specialist personnel such as surgeons could be decreased by having mass surgical campaigns where large amounts of patients are

treated during a short time period. Mass surgical campaigns can also decrease administrative costs for clinics. The main cost involved in the surgery itself is the price of the implant. Basic intra-ocular lenses can be bought cheaply if bought in bulk and this could be a strategy to reduce direct costs to around \$20 USD per patient (Ruit *et al* 1999). One area of disagreement was in one South African study where cost was not a major barrier and the recommendation was to provide high quality care rather than high volume care (Rotchford *et al* 2002). This shows that a context-specific assessment must be made before a cost intervention is implemented. Lost revenue during recovery could be minimised by using surgical techniques that minimise the healing time. One study implemented free transportation but surgical uptake was still low (Syed *et al* 2013). It can be concluded that providing some type of transportation stipend may be a good initial step in reducing cost and increasing accessibility but will not solve the whole problem. Some studies also recommended free accommodation at hospitals. Another area of disagreement on cost is in a Tanzanian study by Kessy & Lewallen (2007) where qualitative interviews were conducted on a sample of people who had reported cost as an initial barrier (79% of the initial group of 198 patients) but then still refused after surgery was offered for free. The authors stated that cost “serves as a convenient and acceptable explanation that will not be challenged by health workers” (p1115). Other significant factors must, therefore, be looked into more deeply. The fact that 10 out of 15 studies reported a “lack of perceived need” may also show that amongst many cultures, perceptions of what is “well-being” can vary widely.

Fear was also a major barrier and can be divided into many categories: fear of a surgical procedure (blindness or death) (Chandrashekhara *et al* 2007), fear or distrust of the health system in general, fear of any kind of medical treatment or distrust or disillusionment with medical staff (Syed *et al* 2013). Fear can also generate from a lack of knowledge about the causes or treatment options available. Since it is often a disease of old age, if a patient has not accessed a great deal of formal health care in the past, especially surgical services, they may be less likely to seek an intervention they may be scared of and for which they may deem themselves too old (Yin *et al* 2009). Death is a complication so uncommon it is almost non-existent in cataract surgery that is carried out by local anaesthetic (Cortinas *et al* 2006). It has been shown by some studies that cataract surgery actually increases life expectancy (Fong *et al* 2013).

The lack of an escort is a barrier that overlies both economic and social factors. Escorts must also travel to the clinic, often taking care of the patient during the procedure, staying overnight and returning with the patient. This time away from work is lost revenue for the escort. The escort often tends to be a close family member. As the incidence of cataract is much higher amongst retired people, it is usually the family or the escort who must pay for the surgery, any informal user fees, food and accommodation and the transport costs (Gyasi *et al* 2007). Therefore the escort becomes more than someone who provides practical and emotional support but also the main funder and perhaps decision-maker.

Senile cataract is much more common in women than men at all ages and women also live longer than men. This would mean that women should be normally over-represented in surgical cases. A reasonable figure reported in one study from 2002 was that females accounted for 63% of senile cataract in a sample population (Lewallen & Courtright). However, it has been shown in many low income contexts that men are over-represented and women tragically under-represented, even by as much as 50% (Briesen *et al* 2010). Other studies have shown similar differences (Lewallen *et al* 2009). The fact that 37% of women surveyed in one Indian study reported “being female” as a self-reported barrier to surgery (Dhaliwal & Gupta 2007) suggests that it is an issue with discrimination. The study did not ask male participants about this phenomenon. A qualitative study from Tanzania amongst elderly people showed women much less likely than men to complain of vision problems for fear of being seen as a burden on their families (Geneau *et al* 2005). Two Indian studies also found women were much more likely to be afraid and report they had no one to accompany them (Chandrashekhar *et al* 2007, Vaidyanathan *et al* 1999).

Rationale

The literature review highlighted many gaps in the knowledge surrounding this subject. Most studies used quantitative methods to rank barriers to the uptake of cataract surgery. This does not allow us to really understand the thought processes behind the reasons for non-acceptance. It also allows for subjects to choose convenient labels for their decisions such as “cost” rather than allowing us to understand the wider context of the culture of health seeking and ideas on disease. All studies so far have looked at programmes from the patients’ point of view and the reasons why patients choose not to attend hospitals. In

order for cataract programmes to be successful and eliminate avoidable blindness they need to have good uptake of their services. In order for this to happen, those involved in the provision of the services need to be aware of the important factors that aid or hinder uptake and work towards improving their services. It would thus be of importance to have the perspective of those involved in work that encourages surgical uptake to share their knowledge of what factors are perceived as important in how they create successful programmes. This project aims to fill this existing knowledge gap and I have chosen a qualitative approach because understanding the deeper significance of culture on surgical uptake could be explored more deeply at a qualitative level.

I chose this topic because I am an optometrist who has worked in low income countries. I am interested in how these services can be improved and I believe that researching the perceptions of eye care providers on the important factors involved in improving uptake will add to shared knowledge to improve cataract programmes. Understanding how success or failure may be related to important, contextual factors may be useful for eye programmes considering initiating programmes in new countries to be able to begin a thorough needs assessment.

Study Aim, Objectives and Research Question

The primary aim of the study is to understand what factors eye care providers in Madagascar perceive as important in the success or failure of their cataract programmes that seek to increase surgical uptake.

The objectives are to explore:

1. The perceived reasons for success or failure of cataract programmes that aim for increased uptake
2. The cultural factors in Madagascar perceived by eye care professionals as promoting or limiting the uptake of cataract surgery

This will be done using the research question:

Which factors are perceived, by eye care providers in Madagascar, as contributing to the increase in uptake of cataract surgery?

Theoretical Framework

The Socioecological model is an important theory that recognises that there is a dynamic relationship between individuals and their physical, social and cultural environment and will be used in the discussion section of this research. It evolved from Bronfenbrenner's Ecological Systems Theory (1977) and I have used the version described by McLeroy *et al*, the Ecological Model of Health Behaviors (1988) which adapts the model for health. This model can help describe the multiple levels that need to be considered by health care professionals as they attempt to understand the health seeking behaviour of potential patients. This model states that how individuals think about health and seek care is not only influenced by the characteristics of the individual (such as their personal knowledge or genetic makeup) but by their context (family, community and society). This means that communities and society help us construct how we think about health and that barriers to care are a shared phenomenon. The socioecological model shows multiple levels of determinants of behaviour that are interdependent. These levels could be described as the individual, social network, community, institutional and society (see figure 1). This understanding of the intersectionality of the various levels of determinants shows that the most successful health programmes that tackle behaviour, consider all of these levels (Sallis *et al* 2008). In consideration of this model, I propose that increasing the uptake of cataract surgery may involve both targeting individuals but also providing an enabling environment. It will also help to consider the results of perceived important factors on a variety of interconnecting levels.

Ingrained in the socioecological model is the theory of social constructionism (Brown 1995), which examines the development of our jointly-constructed understanding of the world, including how we, as a society, attach meaning to disease. It recognises that social phenomena, such as acceptance of surgery, are corporately created and it attempts to explain how social phenomena are formed, institutionalised, known and made into tradition. It also recognises that there are both objective and subjective elements to our understanding and behaviour around disease. This theory allows us to consider disease as

having a cultural meaning and an importance determined by society. Socially constructed norms around seeking care, especially surgical care, is very relevant to elective surgeries such as that for cataract. It also emphasises the significance of language as our most important tool in creating understanding, which is a central element in ethnographic studies such as this one.

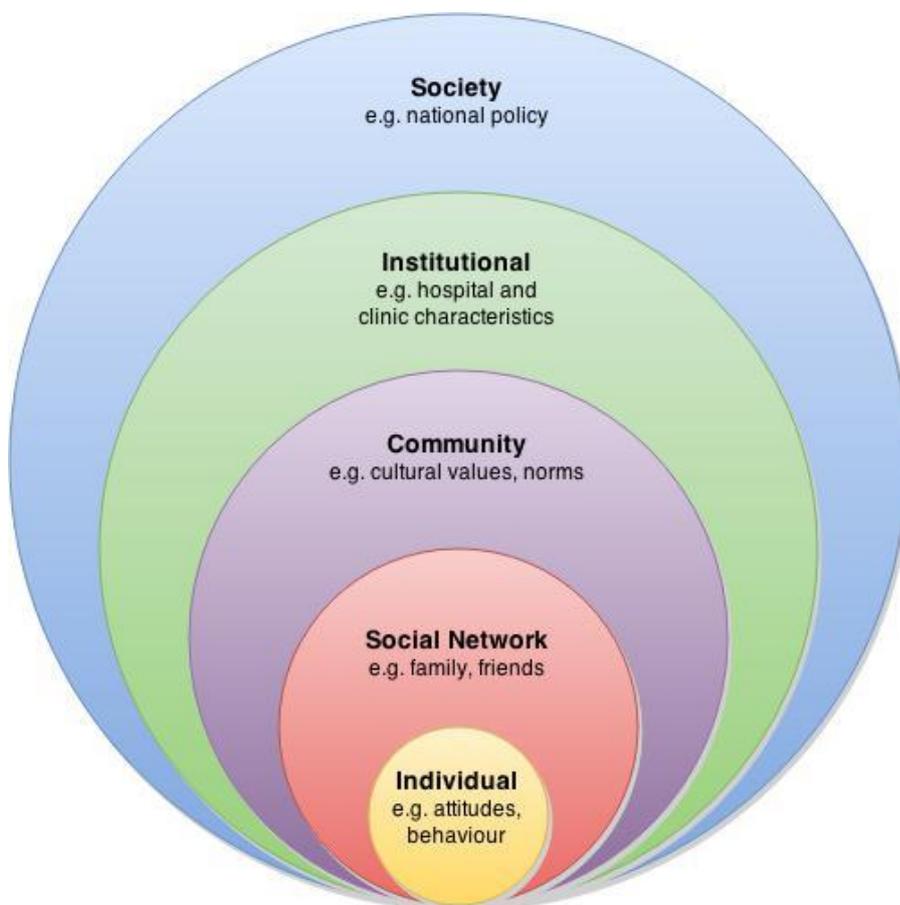


Figure 1. The Socioecological Model (adapted by McLeroy *et al* 1988)

Chapter II: Methodology

Design

A qualitative design was used to gain a richer understanding of perceptions of those attempting to increase the uptake of cataract surgery, and especially which factors they perceived as important in the potential success or failure of their programmes (Conrad 2001). Focussed ethnography was chosen because it allows for a wide variety of methods of data collection, such as observations and interviews, to enrich the understanding of the topic and collecting data from a variety of methods also helps with triangulation of data (Higginbottom *et al* 2013). Triangulation is a valuable tool that compares various methods of data collection in order to increase the confirmability and validity of the data and helps to recognise repeating patterns or inconsistencies (Karim 2013).

Data Collection

The focused ethnography took the form of participatory and non-participatory observation and formal and informal interviews. Observations and informal conversations were noted in a field notebook throughout the data collection period and formal interviews were audio recorded. Interviews were chosen alongside observations as it allowed me to question experts more deeply on issues that had been observed during the period of participatory observation (Higginbottom *et al* 2013). Semi-structured interviews were chosen as it allowed me to introduce topics of conversation based on findings from observations, informal conversations and existing findings in literature (Britten 1995). The different phases of data collection are described below. The timetable of field work is summarised in table 1:

Table 1: Timetable for Field Work

Month	Activity
October	Phase 1: Preparation
November	Phase 2: Participatory Observation
December	Phase 3: Formal Interviews

Participant Selection and Criteria

Criteria for inclusion for formal interviews were that the participant had experience in working within cataract programmes in Madagascar. This took the form of surgeons, nurses, clinical directors, health ministers and community health workers (see table 2). An additional interview was carried out with a director of an organisation working to increase the uptake of medical services in general, not just cataract services. This was deemed suitable after many interviews revealed that this expertise would provide useful general knowledge about the link between culture and uptake of health services.

Table 2: Summary of Participant Characteristics for formal interviews

Interview number	Sex	Position	Ethnicity
1	F	Optometrist, NGO	European
2	F	Programme Coordinator, NGO	N American
3	M	Eye surgeon, hospital	Malagasy
4	M	Director, hospital	Malagasy
5	M, M	CCF, hospital	Malagasy
6	M	Eye surgeon, hospital	Malagasy
7	F	Eye surgeon, hospital	Malagasy
8	F	Eye surgeon, hospital	Malagasy
9	M	Eye surgeon, clinic	Malagasy
10	M	Eye Health Coordinator, government	Malagasy
11	F	Project Coordinator, NGO	European
12	M	Eye surgeon, hospital	Malagasy
13	M	Outreach coordinator, hospital	Malagasy

Phase 1: Preparation

Preparation was begun in Sweden after conducting the literature review by searching the internet using the term “cataract surgery AND Madagascar” for potential participants. Email contact was established with the director of one eye clinic who provided the contact information for 2 surgeons. They agreed to be interviewed and assisted in networking other contacts. After arrival in Madagascar, interview dates were set with these initial contacts. An application was also made to an international NGO working in the field of health to join them working on their cataract programme. Three weeks of voluntary work was negotiated

from 2-22nd November. This organisation was chosen as I had previous experience working with this NGO in a different African country 5 years previously.

Phase 2: Participatory Observation

Participatory observation involved working with the international NGO at the very beginning of its field service in Madagascar. This NGO runs a variety of medical specialities including an eye programme concentrating on cataract surgeries. The beginning of the field service involved setting up field clinics to carry out patient selection for surgery with daily contact with patients seeking care. Problem-solving methods to improve the programme were conducted with the team along the way. During this period, daily field notes were kept focussing on observations of health-seeking culture, the patient journey, daily life, practitioners' experiences (including my own) and evaluation of the successes and failures of the programme. Many informal conversations were also noted down with patients, staff and local people as accurately as possible (Campbell *et al* 2014). Visits to local clinics during this period were also described. In total, 39 pages were written in the field notebook during this time.

Phase 3: Formal Interviews

Formal interviews were begun after the period of volunteering had ended. The main topic areas for the interviews were: challenges and opportunities in increasing uptake, strategies to increase uptake and problem-solving strategies (see interview guide, appendix 2). Two interviews were held with staff of the NGO with which I had worked and one with a local surgeon met during this time. After this, I travelled to different locations within Madagascar to interview participants and the field notebook was kept up with observations of clinics that were visited. Other participants for the formal interviews were found by snowballing from the initial contacts described in the preparation phase. Each interviewee was asked if they knew any other people that would be interested or might be interesting to include in the study. In general interviewees offered this information without being asked. The ophthalmology community in Madagascar is small so interesting contacts were easily found.

In total 10 interviews were held during this period totalling 82 pages of transcription. Ninety-one pages of informal conversations and observations were noted in the field notebook. Most of the interviews were held in locations in and around the largest city,

Antananarivo. The others included smaller towns and one small village. Most of the hospital locations were in eye departments of multidisciplinary hospitals and some in eye hospitals. Saturation was felt to have been achieved after 2 months of observation and 13 formal interviews.

Ethical Considerations

Prior to conducting research, ethical considerations were discussed by the “Field Research” class group under guidance from the Director of Studies for the Master Programme in International Health at the Department of Women and Children’s Health (IMCH) at Uppsala University. An ethical application was written and ethical approval was applied for before leaving for Madagascar via email to *La Comité Malgache de l’Ethique de les Sciences et des Technologies* but no response was received. Multiple visits and phone calls were made to their office in Madagascar and documents submitted for review but no acknowledgement or response was given. Due to the apparent dysfunction of the ethical committee, the fact that this study is not intended for publication and since the subject is not controversial; it was decided to continue with the study.

The main risk to participants of interviews was that they may have felt uncomfortable answering questions they believed had invaded their privacy. However, participants were made aware that they may refuse to answer any questions or stop the interview at any time and it could be argued that speaking to professionals about their work does not involve danger to the participant as there was no relation of dependency between myself and them.

Formal interviews were recorded using a voice recorder after asking for informed consent. This was done by reading the information sheet, available in English, to the participant and asking them for their signature (see appendix 1) after ensuring any questions they had had been answered. A copy of the information sheet was left with the participant. There was no reimbursement offered to participants for taking part. Interviews were saved securely on a password-protected USB. In order to protect participants, it was ensured that any criticisms of donors or organisations were treated in confidence and that any potentially sensitive information divulged during interviews would not be discussed with other participants. After transcription it was ensured that personal details of interviewees or patient stories were treated confidentially.

Participant observation also runs the risk of invading privacy, especially in the context of personal medical care. I tried to adhere to the principle that observations are ethically acceptable if “observed behaviour is public and observable by anyone present” (Drew *et al* 2007, p71). I considered the majority of my observations to have taken place in public settings and to minimise risk to those I observed, I tried to avoid concealment of purpose by being overt in my aims. Any informal conversations recorded in the field notebook involved myself as a participant to reduce the threat to privacy posed by revealing observed conversations. Although these participants did not sign informed consent, the topics discussed were not sensitive, were often initiated by the participant and did not involve risk of harm. Confidentiality was ensured in these cases by not using names in the transcription. The field notebook was kept in a secure place and only read by myself.

Data Analysis

The field notebook was reread and organised into 4 sections: observational data, informal conversations, personal reflection and other information. Informal conversations were typed out and printed in preparation for analysis and a log of observational locations was copied out as a reminder.

The formal interviews were transcribed verbatim by myself. To ensure reliability they were listened to a second time to correct any errors. Two interviews conducted in French were listened to multiple times and, after transcription in French by the researcher, were corrected by another French speaker known to myself and invited specifically for the task. Transcriptions were then printed in preparation for analysis.

Thematic analysis as described by Green & Thorogood (2004) was used inductively to construct the main patterns or themes analysed from the data so an in-depth understanding could be gained of the topic. Themes are described as “recurrent concepts, which can be used to summarise and organise the range of topics, views, experiences and beliefs” (p 209). Thematic analysis involves a process of familiarisation, identifying codes and themes and organising these into categories (Braun & Clarke 2006). Strategies for identifying themes were taken from Ryan & Bernard (2003) that involved looking for repetition, metaphors and differences in the data.

Analysis was approached inductively and begun by re-reading and familiarising myself with the field notes as these were the broadest form of data collection I used. Using this as a starting point allowed me to highlight which were the interesting or repetitive patterns of information regarding important factors regarding surgical uptake noted in my experience as a whole and gave pointers for what to search for within the interviews. Initial codes were then written from the field notes and rich quotes highlighted from informal conversations to help identify themes.

Formal interviews were then re-read for familiarisation and initial codes were formed from the first 3 transcriptions keeping the research question written in front of me and using paper to jot down initial ideas. At this stage any initial quotes that appeared rich were highlighted on the transcriptions to help embody the themes that were decided upon.

Codes from both field notes and transcribed interviews were then reviewed together to recognise patterns and themes developing. This was done as a process of triangulation to help discover how and why the two methods of data collection differed. These themes were then used to help code the remaining data items with any new themes taken into consideration as a sub theme or a new theme. These patterns and themes were then collated and grouped and names were given to them. These themes were then used to create a thematic map describing the relationships amongst the findings. One example of how codes, subthemes and themes were derived from the text is presented in table 3.

Table 3: Example of data analysis

Text	Codes	Subthemes	Themes	Level of SEM¹
<p>... They're afraid it will be too expensive. They are afraid they'll get referred beyond. They always go with like their whole family as well. I guess you've already noticed that. Five or six people accompanying one patient...</p> <p>(Interview 6)</p>	<p>Afraid of mounting costs</p> <p>Go with whole family</p> <p>Large family presence in hospital</p>	<p>Fear</p> <p>Family influence</p>	<p>Persuading Patients</p>	<p>Individual</p> <p>Social Network</p>

Reflexivity

The process of reflexivity acknowledges that previous understandings and experiences of the researcher can affect both how the data is collected and how it is analysed (Finlay *et al* 2008). I am a white, European male who has worked for 6 years in the field of refractive surgery in Europe and with previous experience in mass cataract surgical campaigns in West Africa. Reflexivity was conducted by writing reflections in the field notebook. This was begun in the period prior to arriving in Madagascar. This included what I expected to find, what I could be taking for granted and considering how my background and who I am could affect my findings. I concluded that being a foreign eye care professional and researcher may have biased interviewees to appear professionally adept and successful. I also considered that it was difficult for me to understand the mind set of someone who was afraid of surgery or of hospitals and purposively took a sensitive and enquiring approach to this subject.

¹ Socioecological model

Chapter III: Findings

Summary of Findings

Analysis of the experiences of eye care providers in Madagascar identified three areas that were repeatedly highlighted as important. They are summarised in this quote from an eye surgeon and represent a linear process:

“If you find 1% who needs a cataract [operation], before that you should know if these patients accept to have the surgery and when you do the surgery you need a doctor to be available to do it.” (Interview 12)

This alludes to the three themes I have identified and named as “finding patients can be challenging,” “persuading patients is often necessary,” and “the practicalities of quality surgery.” All sub-themes from the analysis of interviews, conversations and observations have been placed into one or more of these 3 main themes. The themes and how they interconnected are presented in a thematic map (figure 2). Themes are represented in the three upper boxes with sub-themes placed beneath them. The map represents a linear process where patients are found, persuaded to undergo surgery and finally the surgery takes place. The smaller arrows attempt to show how sub-themes can influence each other. For example, how people communicate has an effect on how reputation is created, which has a direct effect on reducing fear. Larger boxes that lie underneath show sub-themes which affect all aspects of the theme. For example, the distinction between urban and rural populations affects both how programmes prepare and how patients are accessed.

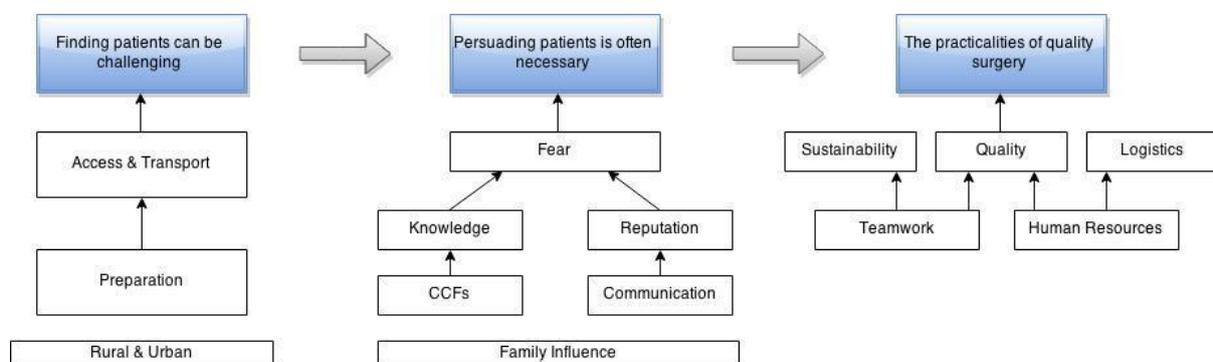


Figure 2: Thematic map of factors perceived as important to success or failure

Description of Themes

1. Finding Patients Can Be Challenging

Rather than patients solely self-presenting to the health service, in Madagascar many providers described their programmes as requiring two branches: both being available for self-presenting patients, but also needing to actively recruit patients from the field. This experience of finding patients was often described as a difficult process but without which programmes could not function.

Preparation: “I’m hoping this will work”

The preparation involved in finding patients was described as a large part of programmes. Observations confirmed it took considerable time and resources and a great deal of problem solving. A thorough needs assessment was integral to the success or failure of an outreach. Even with good planning and resources, sometimes it was still difficult to know if the outreach would be successful.

“We have to talk to people and find the places to screen and try to get out there.

It’s a challenge but I’m hoping this will work.” (Interview 2)

One NGO had to finish its programme much sooner than expected due to not finding enough patients. When asked to describe their main lessons learned from their experiences in Madagascar one interviewee cited good logistical preparation as their main need. They emphasised knowledge of existing programmes and integration with them as vital and one of the reasons their programme was not as successful as desired. The length of time required for good preparation was also emphasised.

One aspect of preparation is organising screening for patients in collaboration with various local authorities. Often screenings were carried out in poorer or less accessible places; the places patients were unlikely to self-present to clinics. Observations confirmed these communities were often structured differently with differing customs and culture. This often necessitated working with village chiefs and health officers. Collaboration was vital because local chiefs could have a great deal of influence in their villages and could be potentially difficult to work with. Success depended on their cooperation. One surgeon

recalled a story of showing up to a screening in a remote village when no people arrived. This was attributed to lack of collaboration with local authorities.

“Not even one patient! And the local place is still closed. And I checked what happened. This is the problem if you don’t work with local administrators.”
(Interview 1)

Access and Transport: “It’s almost impossible to go there!”

Often this finding of patients was described as a challenging experience due to access. Access to health in rural areas was particularly difficult due to poor roads, or no roads, connecting people to local services. Many surgeons described the difficult access to rural outreaches as challenging but necessary. One NGO project coordinator who concentrated on improving access to existing health care noted that geographical access can reduce the priority of health care in people’s lives.

“[Geography] is probably one of the key things because some of the parishes in the area are 25 or 35km from the health centre... if you have to walk 4 hours to get to a health centre you’re only going to go if you’re really sick.” (Interview 11)

Finding patients through outreach often involved the movement of personnel (in the case of some NGOs involving large teams of translators) and equipment. The delicacy and expense of much ophthalmological equipment forced some clinics to conduct their outreach using more basic equipment that did not give definitive diagnoses in the field. The lack of appropriate vehicles to access rural areas, especially in wet seasons; lack of money to conduct outreaches in distant parts of the island (sometimes this had to be by aeroplane) and spreading knowledge about screening dates were all reasons given for the difficulty in accessing patients. The reasons for patients not to come to the eye hospitals came in two categories: those that were unaware of their problem or the solution, and those that could not afford to travel to a clinic. Transportation costs were cited in all 13 interviews as one of the main barriers for people not attending a clinic.

Rural and Urban: “They’re just different worlds”

The difference between the rural and urban population was emphasised by many health workers as affecting how patients are found. Rural dwellers were less likely to present to a

clinic due to self-deprioritisation of their condition and unwillingness to travel to urban areas. Therefore the more rural the population became, the greater their “distance” from all forms of health care. One NGO pilot described it as difficult to convince patients to seek treatment in a city.

“The distance as the crow flies is not huge but you may as well tell them to go to Paris or London. They’re just different worlds and people are afraid of going to the city.” (Conversation 10)

Health seemed to be deprioritised in rural areas due to pressing material needs and lack of education in comparison to urban areas. One NGO worker described how difficult it was to prioritise health in poor areas due to other basic, pressing needs. In a place where “everybody needs everything” (interview 11) it was hard for people to sacrifice time and resources to attend a screening. This led to differences in the visual problems of those in rural areas as they often waited much longer to attend any kind of screening. They, therefore, had much denser cataracts meaning they lived much longer with visual disability.

Many rural dwellers came from the smallest of Madagascar’s 18 ethnic groups. Many groups spoke dialects of Malagasy that could be more difficult to understand and had deeply embedded variations in culture, one example being the concept of “taboo.” This tradition is extremely important in Madagascar, especially in rural minority groups, where families or whole communities have rules against “banned” behaviours passed down through generations. One example in some rural areas was a taboo against injections leading to diminished health-seeking behaviour of these communities and participants found it more challenging to integrate these minority groups into mainstream health care.

2. Persuading Patients is Often Necessary

Once a potential patient was identified, participants described their need to persuade patients to undergo surgery and strategies they employed to help with this. For those who were well informed, persuasion was often a simple procedure but observations traced hesitations back to fear, perceptions of wellness and priority of health over material needs. Programme operators needed to consider how to persuade patients as a serious element of their programme.

Fear and Distrust: “You may never come out alive”

Fear was one of the most prevalent themes in formal interviews and was the main topic of informal conversations with local people. The main fears were those of hospitals in general and of the specific rumour that the patient’s eye may be removed. Numerous interviews stated the most prominent fear was that people would never leave the hospital.

“People see the hospital like a slaughter house. You may never come out [alive].” (Conversation 1)

Fear of the unknown was also expressed as a challenge faced in persuading patients. The fear of mounting costs and an inability to pay the final bill was taken seriously by some clinics who introduced a “package price” so patients would know the final bill before they began. This initiative was seen as very successful in overcoming cost-related fears.

Just as a good reputation can boost uptake, lack of knowledge also spreads rumours limiting uptake. One rumour which was found in many formal and informal conversations amongst Malagasy people was overcoming the belief that the eye would be removed or “cut off” and sight lost for good. None of the foreign workers mentioned removal of eye as a prevalent rumour, however all foreign workers mentioned organ harvesting as a long-standing rumour detracting from their work. They described the importance of sensitisation in overcoming these fears.

However, one surgeon in a small town described that fear did not outweigh the perceived benefits by his patients. His view was that people took blindness seriously and equated blindness to being like a “dead person” (interview 12) since they needed assistance with everyday tasks. Other surgeons also held the belief that people would be easily convinced to overcome fear if they were completely blind and had less to lose.

“They are always afraid of doing surgery... but if they are blind, completely blind, they see darkness only, it is more easier to convince them that it is better for you.” (Interview 1)

Knowledge: “If they really knew it was preventable...”

Lack of knowledge around disease was seen as a reason for patients’ fear and explained why patients would not undergo surgery. It was reported that patients often supposed eye disease was an irreversible part of the natural ageing process, a result of a curse or came from some other unknown source. To many people it was as inevitable and inescapable as death. One clinic worker in a small town also reported that many people felt that nearing the end of their life meant it was not worth going through an operation. Sometimes this was because they feared they might die or that the few years of perceived benefits did not outweigh the distress. Another reason was the attitude that God had willed them to be blind and this could not be changed. It was reported by one surgeon in a small town that family can even perpetuate this idea.

Using the knowledge that patients held these deep seated fears, eye professionals designed interventions on the hypothesis that this defeatist attitude could be successfully overcome using strategies involving knowledge creation.

“If they really knew it was preventable, this blindness, they would change, you know, the priority.” (Field Notes: Conversation 5)

Cataract Case Finders: “Our intermediary with the people”

The most successful strategy to create knowledge was to use staff trained in sensitisation, often called cataract case finders (CCFs). The counselling they provide was mentioned as the single most important element in any successful campaign by many interviewees in overcoming fear.

Different words were used to describe their job- “convincing,” “persuading,” “telling,” “counselling” and “inciting.” These CCFs often travelled independently or sometimes with teams and fulfilled 2 criteria: basic screening to find those with cataract, but also, importantly, educating people about the problem of cataract and what can be done about it. The strategy was so successful that one clinic was doubling their CCF staff in the coming year. One programme director described how, after initiating a cost-free programme they still struggled with uptake. The cost of surgery could be covered by an international charity and patients were offered reimbursement of travel costs. It was recognised that

reimbursement still meant patients needed the initial cash to buy a bus ticket so an initiative was developed to send money for transport via mobile phone money transfer. Even with these initiatives uptake remained poor but it was recognised that this could be improved using the counselling and education skills of CCFs.

“We don’t know what is their problem! You ask them that we take care of the transportation and everything. They do not come. So we have to be strong in counselling... to convince these patients to come to be operated.” (Interview 4)

The main reason they were thought to be successful because of trust. Since they built a personal relationship with people they were able to create trust and use this to convince patient.

“They are very near the people and they trust them. This person is our intermediary with people.” (Field Notes: Conversation 6)

Only one interviewee expressed concern that sometimes they had limitations but on the whole they were viewed as the key to success in a good programme.

Trust and Communication: “They won’t believe unless they see”

One of the most prevalent themes discovered was that recognising modes of communication could be used to create trust and overcome fear. People, especially those in rural areas, were much more likely to trust people they knew rather than what they were told by strangers, including medical staff. This concept of *“bouche à oreille”* or “word of mouth” was relied on heavily by clinics with successful programmes. It was recognised that the particular context they worked in required that they adapt to this method of communication. It was also described that people were much more likely to trust what they saw than what they were told; especially if they saw someone they knew transformed by surgery.

“Above everything it’s patient testimonies that work... they won’t believe unless they see. It’s very difficult to convince them but when they see, it’s the easiest thing!” (Interview 8)

Fear was also overcome by speaking to, and seeing for themselves, people they trust who have already undergone surgery. Knowing that trust and fear are drivers to surgery acceptance, participants described their investment in persuading the first patient in a community. It was noted that once the first patient in a community accepted surgery, they encouraged many more through discussing their experiences.

“Before they are afraid! But if one accepts, after the surgery they see very well, and speak to one who has not come, almost always they will have surgery.”

(Interview 10)

Radio was seen as generally successful in reaching both urban and rural populations although problems with remote areas having no radio and sometimes radio giving wrong information were both highlighted.

Reputation: “That’s why the patients come here”

Obtaining and maintaining a good reputation was a vital experience for many eye care providers. A good reputation could overcome the fear of attending screening and convince the patient to undergo surgery. Some clinics were extremely proud of their reputation as it increased the amount of patients they saw.

“This... eye clinic is one of the first eye clinics here in Madagascar and [we have] a reputation. I’m sorry to say that (smiles) but that’s why they come here.”

(Interview 12)

A good reputation came mainly from carrying out good quality surgery and therefore getting good results. The experience of having “happy patients” who achieved good results after surgery was mentioned by various interviewees as one of the keys to increasing uptake as then they would be more likely to share their experiences.

Both formal and informal conversations with foreign NGOs mentioned that reputation could lead to success or failure of their programme. Affiliation with government was needed to conduct their programme but their reputation was henceforth linked to government, which was not always positive. The need to “maintain a good reputation” was seen as an important aspect of conversations with foreign NGO staff but the *formation* of a good reputation through familiarity was the key at the beginning of an outreach.

“The biggest challenge at the beginning for [us] was familiarity. They didn’t know who [we] were at the beginning so there was inherent distrust.” (Interview 3)

The role of reputation was especially important for urban dwellers. Surgeons noted that often urban dwellers could be convinced by a good reputation- either from good results or good equipment. One surgeon stated that advertising the fact that they had a laser at the clinic had a direct influence on their uptake.

Integrity and personal vocation to help others was an important part of reputation in many interviews and observations. It included diligence and thoroughness in work and expressions of compassion for the poor and needy. This made a reputation even more important as “doing good” seemed to be the motivating factor for many people. One NGO worker’s experiences working on a good programme was described in terms of how they treated the patients. Treating patients with love was seen as more important in creating a good reputation than the outcome of the surgery.

“If you treat those people with love and you know, each person is just special and unique, they will receive that love even if it is a poor outcome they’ll still go away thinking that this was a fantastic experience that, you know it didn’t work for whatever the reason but not because we didn’t care. And that to me is the biggest thing; that we can have a programme where we care and we’ll do ok.” (Interview 3)

Observations showed religion also plays a large part in society with religious elements being visible in hospitals and many actors in the health sector existing from a faith base. The vast majority came from various Christian denominations. Both professionals and patients included their personal faith as an element of their work or decision-making. One CCF worker described the link between his faith and work.

“Since we are religious, so we do something good for others. That’s good. It’s because of that that we like the work.” (Interview 5)

Family: “The patient listens to the family”

The experience of dealing with family members was also an important aspect of persuading as it acknowledged that it was not only the patient that had to be persuaded. Family were described extensively as both helping programmes increase uptake and also hindering uptake. Family can be seen as having a decision-making or advice-giving role and also in a practical role. Family members are required to accompany patients to appointments and to stay at the hospital with the patient, often to cook or clean for the patient during their stay. This naturally involved time away from work and potential loss of income for the family. Other family members can also help pay for the surgical costs or perhaps be the sole payer. If another family member is a decision maker in the house, persuasion may also need to be focussed on the wider family and not just the patient. The importance of family was described as different between those in urban and rural areas.

“People who live in town immediately accept. You say, ‘you have cataract, you need a surgery,’... he contacts only his family and the family they accept if the patient accepts. But... for the people who live in the [country], the families, sometimes they say no. It is very dangerous and the patient [listens] to the family.” (Interview 12)

This was corroborated by one surgeon who described the situation the other way round. It was described that patients themselves can convince family members they do not need surgery despite their pressure. Ultimately it did not matter what the family thought if the patient did not accept surgery for themselves. There was also a difference for elderly people who were often not decision makers.

“The aged people with cataract they have to get permission from the family because they depend on [them] financially.”(Interview 7)

However one surgeon described how family could help. If a blind patient needed to be guided and helped with everyday tasks, this required a lot of time from family members. It was described as easy to persuade a family who were burdened by a blind family member because they would have more time available to work and earn money. Conversely, busy family members can mean the patient doesn’t attend a screening. This was assumed to be

due to work commitments by most interviewees since the economy lacks much formal employment and therefore time away from work meant a loss of crucial income.

“Some old patients come to you and say you need surgery and you say where are your kids and they say oh they are working [too much] to even bring their parents here.” (Interview 6)

Only one surgeon described a scenario where the family may purposely not send patients if they wished to gain control of their oxen by maintaining them incapable of working themselves. One other situation became apparent during participant observation where a blind patient with no family spent three days walking to a screening site only to find that screening had ended. Without the help of family, this patient had many obstacles to face travelling to a clinic and accessing it during opening hours. This illustrates how a system relying on strong social networks can fail those on the outside.

3. The Practicalities of Quality Surgery

Once the patient had been persuaded to undergo surgery, the next experience described by eye care providers was working to ensure the surgery would actually happen and that the result would be good. This involved the logistical running of clinics, working with international partners to provide funds or materials, training of staff and producing good results. One surgeon summed up this dilemma in terms of equipment:

“Sometimes I receive the patients here and I have many patients to have the surgery. Is it enough the consumables? And how about the... operating room! And how about the microscope?...” (Interview 12)

Teamwork: “We cannot do everything”

Collaboration was a very prevalent experience throughout interviews, observations and conversations. Collaboration with the government and international NGOs was used to fund activities or buy equipment and to pay for individual surgeries. Some charities also assisted with programme evaluation. The importance of collaboration was noted in this interview:

“We cannot do everything... we need to work with other foreign NGO. We need to work with the health ministry and we need to work with the [national] NGOs.”
(Interview 10)

Sometimes local clinics were reluctant to collaborate with foreign NGOs due to the fact that for-profit hospitals may suffer from a lack of patients. One NGO worker described their relationship with a local surgeon as problematic as a fear of taking away his patients made the collaboration reluctant.

Many programme directors and surgeons spoke about the Vision 2020 goal and the collaboration needed to realise this goal. One governmental leader described the developments towards the goal as being attributed to good collaboration.

Human Resources: “You’re only as good as the people in the roles”

Maintaining human resources was important in ensuring surgeries took place. From my own observations, I met many highly skilled male and female eye surgeons who talked passionately about their work and were aware that the right people could make a programme a success or failure.

“You know that you’re only as good as the people in the roles implementing something and you can’t implement something well if you don’t understand it.”
(Interview 3)

Some NGOs were concerned over recruiting enough qualified surgeons from abroad, especially those trained in the correct techniques. There were also concerns over high staff turnover as this meant lessons learned were not always passed on. Local clinics highlighted the need for enough staff and especially training staff which was often difficult and sometimes had to be done abroad at great expense. Some clinics mentioned the need for trained counsellors.

“When you have many patients waiting outside you don’t have time to spend 15 minutes just to explain [the procedure to] the patient so we really need one person who will be in charge of this counselling.” (Interview 6)

Other clinics mentioned that despite the fact that there were enough eye hospitals in the capital city, it was having enough eye care professionals and material resources that determined if surgeries took place. It was important to be able to obtain materials at good prices to ensure their clinics kept running but also that the supply was regular. The training and keeping of skilled professionals was also vital to ensure clinics attracted patients. Despite the fact that these training opportunities were mainly available abroad, these experiences were always described positively and it was knowledge gained abroad that often gave the impetus to design new initiatives to increase uptake.

Logistics: “It’s hard to put it together”

The logistics of running clinics are integral in the theme of operating a successful programme. It involves successful management, implementation and evaluation of programmes. One clinic expressed the logistic difficulties working with their management:

“There is a sense that they want to the programme delivered but not a sense that it needs to be well thought out and implemented properly... I guess it’s hard to put it together because we could just go out there and do it... but that’s not a well-run programme.” (Interview 3)

Logistics also involves the upkeep of equipment and hospital buildings. From my observations hospitals vary in their size, function and structural soundness. There are a number of functioning eye care facilities including specialised clinics and eye departments of general hospitals. Many of the eye hospitals I visited were clean, organised and well equipped, although maintenance of equipment was a constant challenge as expensive equipment could be donated but difficult to maintain at a reasonable cost. Other hospitals, built by zealous governments, were crumbling and underused. Some appeared to be busy but with some staff complaining that their services are underutilised. One surgeon described his experience as an underused employee.

*“Compared to what we can do. What we must do. It is not very busy.”
(Interview 1)*

Quality: Good results ensure uptake

The quality of surgery was an important element in ensuring good programmes kept operating. Good quality surgery led to happier patients who could spread news of their experience and perpetuate the patient flow. Conversely, a bad outcome could cause major problems for a programme.

“If the first to be operated [in a village] does not have a good result, nobody will want to come.” (Interview 8)

Good quality surgery was seen as mainly depending on the skill of the surgeon and the technique used. Many surgeons were extremely conscious of improving their skills in modern surgery techniques whilst balancing costs with outcomes. It was agreed by all who mentioned this that manual small incision cataract surgery (MSICS) was the most appropriate surgery balancing good outcomes with lower costs. Training surgeons in this technique was stated as a priority by one interviewee involved in developing nation-wide blindness prevention programmes.

“Our main strategy to increase the number of cataract surgeries is first the training... We have to accelerate to emphasise the training in small incision.” (Interview 9)

The need for training in good quality surgery was mentioned by some surgeons as a difficulty in improving their programme because of the need to travel and the lack of money for evaluating their surgical outcomes.

Sustainability: “The church cannot do business”

Sustainability involved ensuring that a clinic could keep running. Some respondents weighed up the balance between humanitarian work and running a financially viable clinic:

“[Competitors] run a business but here the church cannot do business. Just help the poor people.” (Interview 4)

The link between faith or personal vocation to help the poor and running a sustainable clinic was a dilemma mentioned by some clinics who told stories of providing free surgery to

people who most needed it. This was often done using a “poor fund” or by collaborating with humanitarian organisations.

“We can give free medicine but not for every patient as I told you. We have to think about the sustainability of the hospital.” (Interview 6)

Participants described many experiences they had in achieving sustainability. These included having good patient flow, accessing supplies at low costs and using a tiered pricing system where richer patients could pay extra to subsidise poorer patients. Some interviewees mentioned working with international partners as helpful and necessary to keep programmes running.

Chapter IV: Discussion

There are many factors that are perceived as important in the success or failure of programmes that seek to increase the uptake of cataract surgery in Madagascar. The most important factors were categorised into three main processes: finding patients, persuading patients and the practicalities of quality surgery. I have found the socioecological model (McLeroy *et al* 1988) relevant for the discussion of my data. The socioecological model describes how factors that influence the uptake of cataract surgery can exist on multiple levels from the individual, the social network, through to community and society. These levels of the theoretical framework will be described in the subsequent headings.

Self-deprioritisation needs to be understood

The individual level of the socioecological model describes the component of surgery uptake that is determined by the individual patient. It appeared that is not enough to wait for patients to self-present at eye hospitals as all programmes that were visited in Madagascar had an outreach wing as part of their efforts to reach people who did not self-present. Many of these people were already blind or at high risk of blindness but had never sought care. This could be seen as originating from the concept of self-deprioritisation where individuals regard their situation as unimportant or unworthy of attention. This can develop for many reasons including lack of understanding surrounding disease, perceptions of self-worth, poverty and perhaps our own definitions of blindness and disease.

The lack of understanding around the nature of disease can be specific to cataract, or general to health care. Cataract is most often a slowly progressive and painless disease that is associated with age. This can lead to the idea of inevitability that it is part of the natural ageing process and, like old age aches and pains is natural and not possible to eliminate. Many people are not aware that cataract is a treatable disease and surgery could improve their quality of life. This was also a finding in other existing studies. A study in Nigeria by Odugbo *et al* (2012) found that 34% of participants did not know that cataract was the source of their blindness. Similarly, Rotchford *et al* (2001) found that 40% of respondents in their study in South Africa did not realise cataract was a treatable disease. It is interesting that even those who were aware that it was treatable could still have the idea that it is not

worth treating. Sometimes this can be due to deeply held spiritual beliefs that God has willed them to be blind and they should not attempt to change the status quo (Dhaliwal & Gupta 2007). If people believe that their situation cannot change, they are unlikely to seek possible treatments, especially if this involves expense in travelling to a clinic.

A patient's self-worth also determines whether they prioritise their condition or not. The status of the elderly and of women in society could be an underlying reason that helps to explain many of the self-constructed barriers. Cataract is primarily a disease of the elderly and is more common in women than in men (Klein *et al* 1998). This raises the question why treatment for a disease affecting primarily elderly women is so under-utilised. It could be that travelling to surgery centres can be inaccessible to the elderly and disabled. It is also logical that if someone is valued in society as important, then they are more likely to receive surgery as they feel they are valued by others and therefore value themselves and their own vision. This could suggest that an elderly person's or a woman's vision may not be valued. However, this still depends on the patient's perception of their own need. Elderly people in low-income settings are often people who have weathered many crises and therefore may be more resilient and less likely to complain about poor vision (Geneau *et al* 2005). It may also be the case that women are more likely to feel they can continue with routine daily activities and are less likely to perceive the need for surgery. One study from India which specifically looked at gender issues in cataract surgery suggested that the lower socio-economic and educational status of women led them to be significantly under-represented in paid-for cataract surgery (Joseph *et al* 2013). Increasing the education of women, therefore, can give them more decision-making power in the family and help decrease the burden of blindness.

Poverty may be another reason that patients de-prioritise their own situation. Poverty has been cited by many existing studies as a reason patients give for not accepting surgical services (e.g. Mehari *et al* 2013, Gyasi *et al* 2007, Rabiou 2001) but poverty is a complex phenomenon involving many associated factors. Visiting and working in different areas of Madagascar gave an important indication of the role of poverty in everyday life. In the capital Antananarivo, sprawling streets, full of congested traffic, are lined with a wide variety of housing from wooden shelters to large concrete structures. Markets bustle with trade in a wide variety of nutritious foods and yet in some places people wish for just one

meal of cassava to stave off hunger. As the mountain roads descend into unpaved tracks in thicker forest, houses are more likely to be made of wood or mud and it is very apparent that expertly cultivated terraces are the driver behind the rural economy. Poverty, especially in these rural areas is often directly linked to perceptions of social status. The perpetuation of the poverty cycle can lead people to think they are unimportant in society and even to the idea that they are not worthy of health care and that it is a luxury for the rich. In Madagascar many clinics undertook outreaches to find more patients. This could address a real need as some patients are unable to travel to a clinic due to poverty. Poverty can also lead to both actual and perceived inability to pay for surgery costs. There are many programmes that aid patients to pay for surgery costs, transport and consumables but patients may not be aware that these exist or do not trust them. Interestingly, a study carried out in Tanzania found a barrier to uptake, cited by all participants, was disbelief that the system in place to pay for surgery would function (Kessey & Lewallen 2007).

Despite this, how disease is defined or categorised affects whether it is prioritised. What does it mean to be blind? Often, it seems that the perception is that “if it does not hurt, I am not sick,” and if daily activities can continue, the individual could not be ill and therefore not need hospital intervention. I also found three existing studies that cited no perception of need as a significant deterrent to surgery (Athanasiov *et al* 2008, Rotchford *et al* 2002, Chandrashekhar *et al* 2007). This leads to the question, how is cataract disability categorised? In most cases, cataract disability is diagnosed when the patient is not able to read a certain size of character at a given distance. A preference in Western countries to operate on cataract based on symptoms, rather than arbitrary visual acuity levels, begs the question why practical disability, rather than visual acuity, is viewed as the most important factor in evaluating cataract patients in lower income countries. A study by Briesen *et al* in 2010 showed that quality of life was a much more functionally useful predictor of surgical acceptance than visual acuity. Another study suggested that a measurement of vision-dependant tasks is more useful than visual acuity (Lewallen & Courtright 2000). This is important when considering the “persuading” phase of building a successful programme as concentrating on the practical advantages surgery can have on everyday tasks may well be an important consideration for potential patients. The “medicalisation” of well-being may also be a factor in determining some people as cataract disabled when they have no self-

perceived functional impairment. Well-being in Madagascar includes not only level of vision but aspects of political and family stability, happiness, provision of material needs and work satisfaction. These are things that may or may not be improved by a surgical procedure that involves a risk. However, despite being careful that happy patients are not forced into a surgery they are unwilling to undergo, it also has to be remembered that cataract is progressive. Given the limited opportunities for some people, especially in rural areas, it could also be argued that patients should be actively sought and encouraged to undergo surgery when the opportunity exists, as the next opportunity may not present for a long time, given the lack of eye care professionals compared to the population.

The influence of social networks

As well as the individual, it is important to consider the influence of family and a patient's immediate social network on the decision-making of patients. This corresponds with the "social network" level of the socioecological model. In Madagascar, individuals are often accompanied by many family members on a hospital visit. Therefore the decision to attend a hospital can often be influenced at the family or social network level. Family and social network can affect the individual's perception of hospitals so the role of persuasion needs to be taken seriously and focussed not only on the individual but also at the family level. Patients often had many hesitations surrounding acceptance of surgery that eye care providers needed to relate to if they were to have a successful programme. These hesitations could be concerning family members or sometimes evolve from the opinions of family members. Some of the main concerns that involved family members were those of costs, escorts and fear.

Cost involves not only the cost of surgery but the cost of transportation, overnight accommodation and consumables: things often not funded by aid programmes. It was often the fear of these costs mounting uncontrollably that held people back. Informal user fees and rumours of corruption were absent from the data but by their nature may be a tacit cost taken into consideration by potential patients in some areas. One study from Ghana found budgeting for healthcare is often decided on the family level (Gyasi *et al* 2007) and my findings are concurrent with this. Therefore addressing costs involves speaking to families rather than individuals. It is very likely that the person needing the operation is not

the decision maker in the family and therefore simple package pricing that included transport helped people create a clear budget and alleviate both their own concerns and those of the wider family into prioritising cataract surgery. The structure of families in the role of decision making and paying for surgery or transport was an extremely important factor to take into account. The family system paid for 66.7% of surgeries in Ghana where 88% live below poverty line suggesting the necessity of prioritising who in a family will receive surgery (Gyasi *et al* 2007). It may also be that older family members find asking younger family members for help a difficult obstacle (Geneau *et al* 2005) or that they may not have close family.

Others may not be able to come due to lack of an escort. The escort is perceived as very important in Madagascar due to the necessity of family to cook and clean for the patient or the perception that if the patient were to die in hospital that there would be someone to take them home. When family members are unable to accompany the patient this means the patient may not attend at all. This could be if family members need to be in work and cannot take time off for fear of losing their job, potentially the only source of family income. It may be possible to persuade a patient's social network by reminding them that a blind family member needs a lot of assistance in moving and doing daily activities. Sacrificing some time to escort them to an operation, in the long term would give them the benefit of independence and ability to be a productive family member again. This is consistent with the study by Finger *et al* (2007) in India that showed many elderly people looked forward to cataract surgery as they expected to feel more useful and valued by their family afterwards. Similarly, having no family may mean a patient has no one to guide them to a clinic or carry out the tasks required of a patient, usually done by family members. Another study by Syed *et al* (2013) showed an important barrier to surgical uptake was if the patient was not married.

The main fears surrounding being unwilling to undergo a cataract operation were that hospitals were places people went to die and that the operation could involve removing eyes or stealing organs. Fear of death has been noted in studies in other countries (e.g. Athanasiov *et al* 2009, Dhaliwal *et al* 2007). However, I did not find any existing studies stating fear of having organs stolen as a factor, suggesting this may be particular to Madagascar. These fears were often perpetuated through rumours in the community.

Other fears involve deeper social and governmental issues. Distrust of the hospital system suggests a deeper failure of a national system to provide sufficient provision, quality of provision or equity in distribution. It could also be a social or political issue as some ethnic groups can be excluded from healthcare due to barriers in cultural practices or status in society. Integration of minority groups into the health system through use of community health ambassadors, education into how and when to access healthcare and increasing the status of those traditionally neglected are important strategies in reforming health systems. Fears created by rumours could be alleviated by education on cataract in general: community projects to explain how cataract develops and how it is solved; what process of pre-assessment, surgery and follow-up could be expected; healing times and information on risks. The need for education in the role of increasing uptake was also noted in many previous studies (e.g. Athanasiov *et al* 2009, Odugbo *et al* 2012, Vaidyanathan *et al* 1999). When individuals and families involved have learned more about the reasonable risks and steps involved in surgery they should be more comfortable in accepting it. This message could be useful in other contexts where fear is a hindrance to the uptake of medical services: that strategies can be successfully employed to overcome even deeply seated mistrust and myths surrounding surgical care.

Cultural sensitivity and breakthrough patients

It is important to recognise that knowledge, including that surrounding disease, is created corporately. The wider community level described on the socioecological model involves the community and culture that affects how people communicate this knowledge, who they will trust and how they will respond to knowledge. Madagascar is a diverse island nation with a large disparity in health care between those living in the city and those in the rural areas. This disparity includes how people think about health care, their opportunities to access health care and their decision to access it. Eye care is an under prioritised field leaving many people in the country blind for preventable reasons. Consequently programmes must take cultural sensitivity seriously if they are to have an effective programme.

Communication in Madagascar involves a strong element of word of mouth, especially in rural areas. Programmes that recognised and understood this tended to be more

successful. When it was recognised that time and resources needed to be spent in creating trust in a community, this was usually done by what might be called a “breakthrough patient.” This could be an important concept in developing programmes, especially in rural areas. A “breakthrough” patient could be seen as the first patient in a sceptical community who decides to undergo surgery. It is very important that this person is someone who is trusted in the community, that they have a good result and that they communicate their experience to others. This is the link in a chain from a health system or doctors that may not be seen as trustworthy from the community because of their urban location, their educational separation or class separation. Once the first person has been persuaded, they are the ambassador to the community and will help to encourage other people. This concept could be seen as in line with Bandura’s Social Cognitive Theory (1991), which states that people do not change behaviour by trial and error but rather choose whether or not to partake by observing the outcome of that behaviour in others. It is very important, therefore, that the first patient in any community has a good experience or the power of word of mouth may damage the reputation of not only the individual clinic doing the outreach, but the entire health system.

This makes us ask how much time is considered important for learning culture. It seems an obvious advantage for programmes to be run or staffed by local people who already have cultural competency although I could not find any existing research that considered the cultural competence of eye programmes. The vast majority of programmes I visited in Madagascar were entirely staffed by Malagasy people although financial aid often came from abroad. This led to important insights into culture that affected the way the programmes were run and these tended to be the more successful programmes. Many of these Malagasy staff, especially surgeons, noted the importance of continuing education and learning new surgical techniques as an important link in achieving a breakthrough patient. These skills were often taught abroad or were taught in Madagascar by foreigners. Perhaps the most useful role foreign NGOs could play in Madagascar could be to assist in training of surgeons and programme leaders and to leave patient interaction to those already with cultural competency. This may be a much better use of resources rather than spending time and money training foreign staff in cultural competency, or worse, allowing foreign NGOs to operate without adequate cultural training and perhaps break the trust of

communities through inadequately run programmes. Malagasy professionals described dealing with very different rumours to the foreign professionals. This could mean that their outreach activities might not fulfil meeting all the fears of their potential patients. Programmes, especially foreign run or staffed programmes need to take the wider community level understanding of culture, trust and communication seriously.

National policy and international funding

At the institutional and society level of the socioecological model, it is important that national policy and international cooperation are included in programmes. This is similar to some findings in other research that suggested national health strategies or collaboration with other NGOs could improve uptake (Gyasi *et al* 2007). Focussing on individuals or communities is not enough to create success. It was apparent from many visits that even after the difficult task had been undertaken of finding and persuading patients, if hospitals are not equipped or strategies not in place to provide funds for consumables, salaries and buildings, surgeries may not be performed and the build-up of trust, as mentioned earlier, may be lost. Madagascar appears to embrace the goals of the Vision 2020 project and has made good progress. However the sense that they could be doing more to prevent blindness is apparent and shows an eagerness and altruism present in the Malagasy mind set. On the other hand, rumours of corruption within the health system and distrust of government provisions can make people suspicious. It is the lack of trained personnel that is one barrier to realising this goal. On one hand increasing the number of health professionals in general can help to fill this gap but experiences in Madagascar have shown that local programmes designed by people with cultural understanding appear to be the most successful. Those with less cultural awareness did not have as successful programmes showing that the balance between providing enough trained staff whilst ensuring they have cultural competency is a delicate balance to create.

Madagascar is a country with great potential in training new eye care professionals but structural barriers exist to accessing education. Improving the access to primary and secondary education should be a priority in training native health professionals in Madagascar who will advance with both professional skills in health care and cultural competency. Access to portable and inexpensive diagnostic equipment is a worldwide

problem but would be particularly useful in Madagascar where access prevents surgeries being carried out. Mobile theatres, microscopes and slit lamps could all be useful in improving uptake. Integration of services could also be an important milestone for health in general in Madagascar. Many of the important factors identified in this research do not apply only to ocular health but many other kinds of health. This integration of health services that include eye services have also been suggested in previous research by Onwubiko *et al* (2014) as a potential for increasing uptake of services. Distrust of government, modes of communication, culture and reputation are universal themes that affect many if not all aspects of health services. By integrating other services, more work could be shared by different disciplines to achieve better results.

Strengths and Limitations

One strength of this research was the enhanced confirmability through the triangulation of data collection methods. This involved using participatory observation, informal conversations and formal interviews that could be compared and used to corroborate findings. The period of data collection began with participating in a cataract programme which allowed me to understand the context of the topic with much more depth and understanding. This participatory observation, along with informal conversations with people throughout this time, directed the topics discussed in the semi-structured interviews and allowed me to explore topics that may not have been brought up spontaneously by participants. In order to maximise the potential of the period of observation, I studied literature on how to write field notes and record informal conversations (especially Campbell *et al's* "Doing Ethnography Today" [2014]). A continuous process of reflexivity, written in the field notebook, assisted the credibility of the data.

The research was approached from my own background as an eye professional who has experience of working with cataract programmes. My thorough knowledge of the background to this subject area prior to beginning was a strength to the planning and execution. Despite this, many of the limitations of this research are due to my own inexperience in research. Many lessons were learned during the preparation, collection and analysis stage and in hindsight many aspects could have been improved. The quality of the interviews, although adequate to gain some answers to the research question could have

gleaned much richer information if I had had more experience in good interview technique. My professional experience and work within Madagascar may also have had a negative bearing on the research. This may have introduced social desirability bias where participants may have felt obligated to give answers that highlighted success for fear that future funding may rest on results of research such as this.

The selection of participants may have been suboptimal due to the snowballing technique used. This led to most of the interviewees being from urban clinics and known to each other. Sharing of ideas and information through the ophthalmology community in Madagascar led to many of the same topics and interventions being discussed. A wider variety may have existed if more remote clinics had been found. This was most likely due to constraints of time and transport but it may be true that the snowballing technique used also highlighted that more remote clinics are not only geographically distant but also professionally isolated from collaborative activities. Also there were a number of interviewees from one clinic which may have skewed the data to represent the opinions of the clinic as a whole rather than individuals. I also did not make the experience of participants part of the inclusion criteria. For those who had the least experience working within ophthalmology in Madagascar, the conversation ran the danger of discussing hypothetical situations. However, the majority of participants had a great deal of rich experiences.

The results highlight only part of a complex and multi-faceted process of undergoing surgery. The important factors highlighted here are not exhaustive and cannot be generalised to wider populations due to the time and context-specific nature of ethnography. However, they do provoke serious consideration of proper design of programmes and the fact that appreciation of culture affects the success of programmes.

Thematic analysis is a good analysis method to create broader themes in the data. It does, however, run the risk of missing nuances for example the meaning of individual words or small changes in tone in transcripts. Since it is a broad and flexible method, reliability may be questioned as various researchers may analyse data differently using thematic analysis (Braun & Clarke 2006). For this reason a strict framework of analysis was utilised.

Ethnography is a method open to a great deal of subjectivity and the results are context and time-specific to a small population (Campbell *et al* 2014). The researcher themselves must also have an appreciation for the culture to gain useful insights. As this was my first time in Madagascar, it could be questioned how culturally competent I could become in 2 months of field work.

The socioecological model allows us to theorise how society and culture affects individuals' decisions but does not consider how individuals shape their society and culture (Sallis *et al* 2008). The socioecological model could be taken much further to suggest how breakthrough patients can affect communities' perceptions on disease and treatment and how this can be used by successful programmes.

Conclusion

In order to address factors that facilitate or hinder the delivery of cataract programmes in Madagascar a socioecological perspective is helpful. It is important to design and identify interventions that are successful at a local level through understanding of the impact of the cultural context

The construction of the meaning of disease must be appreciated, which often involves a functional, subjective element. Furthermore, many patients are unaware of the causes or treatment options for cataract and some people, due to economic status, gender or age, perceive their self-worth as less deserving of surgery than others.

There also must be an appreciation of the influence of a patient's social network, which can involve family members and tightly knit communities. Decisions, including those around spending, are made within this context and not solely by individuals. These networks are important in the perpetuation of fear and rumours. Hospital visits often involve family participation and necessitate all family members to be available.

Knowledge is constructed and spread through word of mouth from trusted people and through the mechanism of "seeing is believing." Trust is created at the society level and breakthrough cases can be utilised to build trust in new communities. Competency in understanding how people view the health system and how communities might perceive potential outreach activities is key to overcoming challenges of trust.

Individuals and organisations should assess their cultural competency in this area as an important consideration in deciding how to best assist Madagascar in achieving their goal of Vision 2020. Those with less cultural competency should consider assisting in existing programmes with teaching surgical techniques or funding.

I suggest future research could study in more depth the perceptions of potential patients in both rural and urban areas and contrast these to this paper's findings.

Recommendations

Programmes operating in Madagascar should design their programmes for optimal success through consideration of the key factors- these include understanding how people and communities create priorities and trust and how they communicate this.

International NGOs should invest in their cultural competency and instigate adequate advance planning if they are to work with patients. They should consider training local staff in modern, cost-effective and context-appropriate surgical techniques as a priority.

Cooperation amongst government bodies to invest in healthcare, education and infrastructure will all contribute to the reduction of avoidable blindness in Madagascar.

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Appendix 1

Consent form

Informed Consent Form for Eye care providers in Madagascar invited to participate in research entitled “Increasing the uptake of cataract surgery in Madagascar: The perceptions of eye care providers on factors that contribute to success or failure”

Name of Principle Investigator	Joel Somerville
Name of Organisation	Dept. of Women’s and Children’s Health, Uppsala University

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction

I am Joel Somerville, working on a project at Uppsala University. I am doing research on cataract which is very common in this country. I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research.

If this consent form contains any words that you do not understand, please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or of another researcher.

Purpose of the research

Cataract is a common problem here in Madagascar. I, like you, want to find ways to help those living with cataract blindness. I believe that you can help by telling me about your experiences both about how your programme works and about what challenges and opportunities you have come across in improving uptake. I want to learn what people who work in Madagascar know about creating good cataract programmes and why some people still do not seek surgery. I want to learn about the different challenges you come across in encouraging people to have surgery, and how you design your programmes to encourage uptake and overcome problems.

Type of Research Intervention

This research will involve your participation in an interview that will take about 45 minutes

Participant Selection

You are being invited to take part in this research because I feel that your experience in providing cataract services can contribute much to our understanding and help people in Madagascar and in other countries improve the uptake of cataract services.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate there are no consequences on your job or on any work-related evaluations or reports. You may change your mind later and stop participating even if you agreed earlier.

Procedures

During the interview, I or another interviewer will sit down with you in a comfortable place you choose. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. No one else but the interviewer will be present unless you would like someone else to be there. The information recorded is confidential, and no one else will have access to the information documented during your interview. The entire interview will be tape-recorded, but no-one will be identified by name on the tape. The file will be kept on a password-protected memory stick. The information recorded is confidential, and no one else will have access to the tapes. The tapes will be destroyed after the report has been finished.

Duration

The research takes place over 2 months in total. The interview with you will be held once and will take about 45 minutes.

Risks

There is a risk that you may share some personal or confidential information by chance, or that you may feel uncomfortable talking about some of the topics. However, we do not wish for this to happen. You do not have to answer any question or take part in the interview if you feel the question(s) are too personal or if talking about them makes you uncomfortable.

Benefits

There will be no direct benefit to you, but your participation may help to find out more about how to reduce cataract blindness in your country.

Reimbursements

You will not be provided any incentive or payment to take part in the research. However, we will give you refreshments during the interview.

Confidentiality

We will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about you will have a number on it instead of your name. Only I will know what your number is and it will not be shared or given to anyone else.

Sharing the Results

The information you tell us today will not be attributed to you by name. The knowledge that I get from this research will be shared with you and your community before it is made widely available to the public. Each participant will receive a summary of the results.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so, and choosing not to participate will not affect your job or job-related evaluations in any way. You may stop participating at any time that you wish without your job being affected. I will give you an opportunity at the end of the interview to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with my notes or if I did not understand you correctly.

Whom to Contact

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact me by email: joelsomerville@hotmail.com

Part II: Certificate of Consent

I have been invited to participate in research about improving cataract uptake in Madagascar.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant _____

Signature of Participant _____

Date _____

Day/month/year

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____

Day/month/year

Appendix 2

Semi-Structured Interview guide

What are the perceived factors that contribute to the increase of uptake of cataract surgery amongst eye care providers in Madagascar?

Aim

The aim of the interview is to understand what factors eye care providers in Madagascar perceive as important in the success or failure of their cataract programmes that seek to increase surgical uptake.

Participant profile

Participants for the interviews will be recruited from snowballing contacts within the field of cataract provision in Madagascar. Factors such as age, gender and race were not considered in the selection process.

Location, time and duration

Location will be chosen by each individual participant in a location convenient for them and where privacy can be ensured. The planned duration of the interview is around 45mins to one hour.

Seating should be organised in such a manner that interviewer and interviewee can see each other and on the same level. Participants will be offered refreshments before the discussion.

Introduction (spoken to participants)

Thank you for joining me today, I really appreciate you taking your time to help with this research. As you know for this research no remuneration will be offered but I hope this time will be of some value to you as well.

My name is Joel Somerville and I am doing my master's degree in International Health in Sweden. I graduated as an optometrist 6 years ago and since then have worked for a company that provides cataract services in Scotland. I have also been involved in some cataract programmes in Africa- most recently here in Madagascar. I am interested in helping to reduce the global burden of blindness by improving the uptake of cataract services so the purpose of today's discussion is to explore your experiences in this. I am especially interested in what challenges and opportunities you have come across as part of your work.

We expect the interview to take around 45 minutes. I will ask you some questions but feel free just to talk to me about anything you feel is relevant. I'll be taking some notes as we speak.

The discussion will be tape recorded, and you have already given your consent for this. The recordings will be deleted as soon as the discussions have been transcribed and analysed. The recordings of the discussion will only be used for this project, will remain confidential and your name will remain anonymous. You may also refuse to answer any of the questions at any time or choose to end the interview at any time.

Please feel free to express your opinions. There are no set answers that I am looking for; we merely want to hear your thoughts and experiences of your involvement in cataract services in this country. I will introduce an initial question and we will then let the conversation guide the session. I may provide some additional prompts or questions further along in the conversation.

Discussion Topic: Initial Questions

Participants will be asked to consider and discuss the following questions as prompts to discussion (with follow-up questions below only if needed):

1. Tell me about your eye programme.

- How does it work
- Where do you find your patients
- Do you think it works well? Could it be better?
-

2. What challenges and opportunities do you face in persuading patients to have surgery?

- What kinds of people do you come across who refuse or are reluctant to undergo surgery?
- What reasons do people often give for not wishing to come to you for surgery?
- Where do you think these problems arise from?
- What reasons do you think make improvement in uptake more difficult in Madagascar?
- What things do you think make improving uptake easier in Madagascar?
-

3. How do you overcome the problem of people reluctant to undergo surgery?

- What kinds of strategies have you implemented to improve uptake?
- What has worked well to increase uptake?
- What lessons have you learned about trying to increase uptake?

These will be introduced by asking the participant their opinion on the context of each heading in Madagascar. After this we will discuss how this context affects uptake of surgery. An attempt will be made to create a flow of narrative discourse rather than a formulaic series of questions.

Closure

- Ask participant if there are any further comments :
- Is there anything we missed that you would like to talk about?
- What do you think were the most important points raised?

- Thank the participants
De-brief

Once the discussion has concluded do the following:

- Check recording
- Consider the notes made and make additional notes if necessary
- Consider strengths and challenges of the interview and note these for use as part of the analysis