THE GLOBAL MAPPING OF LOW VISION SERVICES

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Abstract

Low vision impacts on Quality of Life (QoL). Thus, low vision services are essential to enhance the QoL of people with functional low vision. However, of the estimated 70 out of the 124 million people with low vision who require services, approximately 5-10% has access to services. The demands for low vision services will continue to grow due to the emerging global trends in ageing populations and changes in the epidemiology of vision impairment. While critical data and information are available for other forms of vision impairment, there is a paucity of information on the distribution, needs, and priorities for improving low vision service delivery at the national, regional, and global levels.

This thesis addressed the problem by first developing and distributing a survey to Vision 2020 contacts, government, and non-government organizations in 195 countries during 2006-2008 to assess the current situation of low vision services globally. The survey was first pilot tested leading to improvements in the length, layout, and content of its form. Specifically, the survey topics included: epidemiology, policies, human resources, service provision, barriers, equipment, and monitoring and evaluation.

The Classification Analysis and Regression Tree (CART), logistic regression methodology and grounded theory analysis were used to present the findings and identify the critical success factors of low vision service coverage. The qualitative component consisted of case studies in three countries (India, Ghana, and Cameroon) during November 2007 and 2008. A total of 101 interviews were carried out. The case studies provided an overview and historical perspective of services, effectiveness, cost, efficiency, acceptability, access, equity, sustainability, and ideal situations as recommended by interviewees. Qualitative findings from the case studies were produced with the assistance of the NVivo software.

The primary results are that the majority (80%) of countries have poor (≤10%) coverage. Key issues pertinent to the current situation of service coverage are: human resources (number and combination of disciplines), funding (sustainability and arrangements), type of services provided (comprehensive and multidisciplinary) and its
Abstract

locations (NGOs or government facilities), and the sociodemographic and economic barriers (costs, awareness, and rural areas) to accessing services.

The critical success factors found in this research are represented by the ‘FRAME’: Funding (sustainable source, public and private mix), Rehabilitation workers (e.g., adequate numbers of multidisciplinary personnel), Access to low vision devices, Multidisciplinary services; and External contextual influences in which low vision services operate in. The case studies identified seven major themes that further build on the FRAME: sustainability, governance, advocacy, human resources, access, awareness, and service delivery.

The conclusion of the thesis is that a global picture of the current situation of low vision services was acquired and it is now known which countries have poor (≤10%) and better (>10%) coverage. It also found the critical success factors that will assist the WHO Low Vision Working Group and Vision 2020 to improve the current models of service delivery, future planning, training curriculum development, and priorities setting. Specifically, these need to be achieved through three areas of action: human resources development, sustainability, and advocacy.
Declaration

This is to certify that

This thesis comprises only my original work towards the PhD,

Due acknowledgement has been made in the text to all other material used,

The thesis is less than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices.

--------------------------------------------------------------

Peggy Pei-Chia Chiang, BN, MIPH (Hons)
Declaration
Preface

The following publication has been included as part of Chapter Two-Literature Review:

Publications and Presentations

Publications


Work in progress:

1. Chiang, P.P.C., O’Connor, P., Le Mesurier R.T., Keeffe, J.E. “Global mapping of low vision services”

2. Chiang, P.P.C., Xie, J., Le Mesurier R.T., Keeffe, J.E. “Predicating critical success factors in low vision service delivery using the Classification Analysis and Regression Tree methodology”

Presentations


2. International Agency for the Prevention of Blindness (IAPB) 8th General Assembly, Buenos Aires Argentina, August 2008: ‘The global mapping of low vision services’


4. LV Prasad Eye Institute Workshop, Hyderabad India, February 2007: ‘An introduction to my research- the global low vision services mapping project’


6. IAPB Pacific Islands Sub-Regional Meeting, Sydney, November 2006: ‘low vision – introduction to challenges; low vision training, resources, and networks’
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4. University of Melbourne Academic Activity Grant, School of Graduate Studies, 2006-2007 (for the CERA student journal club activities $750)

Coursework Undertaken During PhD

- Epidemiology & Analytic Methods I
- Epidemiology & Analytic Methods II
- Study Design in Epidemiology
- Survival Analysis and Regression for Rates
- Linear and Logistic Regression
- Database Management

Other Activities

- Coordinator of CERA student and staff journal club 2007-2008
- CERA Student Representative 2007
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Definitions of Terms

Key terms used throughout this thesis are defined below.

**Best Corrected Visual Acuity**
The best acuity one can achieve with glasses, contact lenses, or surgery.

**Critical Success Factors (CSFs)**
CSFs is a term for an element which is necessary for an organisation or project to achieve its mission.¹ CSFs are elements that are vital for a strategy to be successful. In this research, CSFs are factors that could facilitate the success of a service and good coverage of low vision services.

**Coverage**
Coverage is the total number of people who received low vision services divided by the total number of people with low vision.

**Developed countries**
Developed country is a term used to describe countries that have a high level of development according to specific criteria. There is contention and debate about which criteria, and which countries are classified as being developed. For the purpose of this thesis, developed countries are classified by the Human Poverty Index (HPI). HPI-1 refers to developing countries while HPI-2 refers to developed countries and all Organisation for Economic Co-operation and Development (OECD) countries.²

**Developing countries**
The list of developing countries is approved by the United Nation General Assembly and reviewed every three years.³ This classification is based on quality of life and economic measures that include life expectancy at birth, combined primary and secondary school enrolment, adult literacy, instability of agricultural production, instability of exports of goods and services, diversity of exports, percentage of Gross Domestic Product (GDP) that is generated by manufacturing and service industries, and population size.³
Definitions of Terms

Human Poverty Index (HPI)
The HPI is an indication of the standard of living in a country, which was developed by the United Nations (UN).\(^2\) It is a measure of the extent to which people in a country are not benefitting from development. HPI is a measure of deprivation and it assesses three components:\(^2\)

1. longevity - measured by the proportion of the population not expected to survive to the age of 40 years
2. knowledge - measured by the adult illiteracy rate
3. standard of living - a composite value measured by the proportion of the population without access to clean water, health services, and the proportion of children under the age of five years who are underweight.

For developed countries, there is an extra component: social exclusion (that is long term unemployment rates).\(^2\) The HPI was used as a tool to present and categorise the descriptive analyses of this study.

Low vision
Low vision is defined by the World Health Organisation (WHO) in two ways:

1. Epidemiology (the Tenth Revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10))\(^4\)
   “visual acuity of less than 6/18 (20/60) but equal to or better than 3/60, or corresponding visual field loss, to less than 20 degrees, in the better eye with best possible correction.”\(^4\)

In 2009 the term ‘low vision’ was removed from the ICD-10, leaving the terms ‘moderate vision impairment (presenting visual acuity of < 6/18 to 6/60)’ and ‘severe vision impairment (< 6/60 to 3/60)’, from all causes.\(^5\) However, the term ‘low vision’ will be used throughout this thesis.

2. Provision of services (Bangkok functional definition)\(^6\)
   “vision impairment even after treatment and/or standard refractive correction, and a visual acuity of less than 6/18 to the perception of light in the better eye or a visual field of less than 10 degrees from the point of fixation, but with the potential to use vision for the planning and/or execution of a task.”\(^6\)
To avoid confusion in this thesis, when the term ‘low vision’ is used it will be meant as functional low vision (definition ‘b’) unless otherwise stated.

**Low vision services**

Low vision services include clinical, rehabilitation services and the use of adaptive technologies.  

Clinical low vision care involves a comprehensive examination of the eyes and vision by an ophthalmologist and/or an optometrist, including an assessment of visual function.

Rehabilitation services refer to assistance with activities of daily living, counselling, orientation and mobility training, peer support groups, community and social services, advocacy (support groups and organisations) and education and employment and training.

The term ‘forms of rehabilitation’ in the thesis refers to orientation and mobility, sports and recreation, vocational training and technology training.

Adaptive technologies can be optical—magnifiers and telescopes, and non-optical—glare control devices, bold lines pen and paper, writing guides, needle threaders, high contrast watches, talking calculators, enlarged print and computers with audio output or enlarged display. Adaptive technologies help low-vision patients maximise their visual potential or maximally use their residual vision. Low vision care also includes environmental modifications such as lighting, tactile markers, and colour contrast.

**Monodisciplinary care**

Only one type of service is provided and it is usually clinical care i.e. clinical assessments, prescription of low vision devices and suggestions for non-optical devices.

**Multidisciplinary care**

The service delivers clinical care plus a range of other services such as rehabilitation, counselling, education, and social welfare.
Definitions of Terms

Member states
Member states are countries that are members of the United Nations General Assembly.\(^{11}\) There are currently 192 UN member states.\(^{11}\) All countries which are members of the UN may become members of World Health Organisation (WHO) by accepting its Constitution.\(^{12}\) Other countries may be admitted as members when their application has been approved by a simple majority vote of the World Health Assembly (WHA). Members of WHO are grouped according to regional distribution (see ‘WHO regions’).\(^{12}\)

Quality of Life (QoL)
The World Health Organisation Quality of Life (WHOQoL) Group defined QoL as “an individual’s perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person’s physical health, psychological state, level of independence, social relationships, and (his/her) relationship to salient features of their environment”.\(^{13}\)

The key dimensions of QoL in low vision are vision, social, functional, economic, psychological and emotional.\(^{14}\)

Vision impairment
Vision impairment (also referred in some texts as visual impairment) is “vision loss (of an individual) having reduced vision as to constitute a handicap that constitutes a significant limitation of visual capability resulting from disease, trauma, or a congenital or degenerative condition that can or cannot be corrected by conventional means, including refractive correction, medication, or surgery”.\(^{15}\)

Vision impairment is not the eye disorder itself but the consequence of a functional loss of vision caused by the eye disorder.\(^{15}\) The eye disorders which can lead to vision impairments can include both treatable and untreatable ones—retinal degeneration, albinism, cataracts, glaucoma, muscular problems that result in visual disturbances, corneal disorders, diabetic retinopathy, congenital disorders and infection.\(^{16}\)

Vision impairment incorporates both refractive and non-refractive vision loss.\(^{16}\)
WHO regions

WHO Member States are grouped into six regions—Africa, the Americas, Eastern Mediterranean, Europe, South East Asia, and Western Pacific. Each region has a regional office.
Definitions of Terms
## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
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<td>AMD</td>
<td>Age Related Macular Degeneration</td>
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<tr>
<td>BCVA</td>
<td>Best Corrected Visual Acuity</td>
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<tr>
<td>CART</td>
<td>Classification Analysis and Regression Tree</td>
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<tr>
<td>CBM</td>
<td>Christian Blind Mission</td>
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<td>CBMI</td>
<td>Christian Blind Mission International</td>
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<tr>
<td>CERA</td>
<td>Centre for Eye Research Australia</td>
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<td>CNIB</td>
<td>Canadian National Institute for the Blind</td>
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<tr>
<td>CSFs</td>
<td>Critical Success Factors</td>
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<tr>
<td>DALY</td>
<td>Disability Adjusted Life Years</td>
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<tr>
<td>GDP</td>
<td>Gross Domestic Product</td>
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<tr>
<td>HPI</td>
<td>Human Poverty Index</td>
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<tr>
<td>IAPB</td>
<td>International Agency for the Prevention of Blindness</td>
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<tr>
<td>ICD-10</td>
<td>Tenth Revision of the International Statistical Classification of Diseases and Related Health Problems</td>
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<td>INGOs</td>
<td>International Non Government Organisations</td>
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<td>LNGOs</td>
<td>Local Non Government Organisations</td>
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<td>LVDs</td>
<td>Low Vision Devices</td>
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<td>LVPEI</td>
<td>L V Prasad Eye Institute</td>
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<tr>
<td>MLOP</td>
<td>Mid Level Ophthalmic Personnel</td>
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<tr>
<td>NCBI</td>
<td>National Council for the Blind</td>
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<td>NFP</td>
<td>National Focal Person</td>
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<td>NGOs</td>
<td>Non Government Organisations</td>
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<td>Abbreviation</td>
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<tr>
<td>O&amp;M</td>
<td>Orientation and Mobility</td>
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<td>PBL</td>
<td>Prevention of Blindness Committee</td>
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<td>PHC</td>
<td>Primary Health Care</td>
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<td>QALY</td>
<td>Quality Adjusted Life Years</td>
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<td>QoL</td>
<td>Quality of Life</td>
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<tr>
<td>RNZFB</td>
<td>Royal New Zealand Foundation for the Blind</td>
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<tr>
<td>SSI</td>
<td>Sight Savers International</td>
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<td>UK</td>
<td>United Kingdom</td>
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<td>UN</td>
<td>United Nations</td>
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<td>USA</td>
<td>United States of America</td>
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<td>WHA</td>
<td>World Health Assembly</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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<td>WHO LVWG</td>
<td>World Health Organisation Low Vision Working Group</td>
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Chapter One – Introduction
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1.1 Background of Study

In 1999, the World Health Organisation (WHO) in partnership with the International Agency for the Prevention of Blindness (IAPB) launched Vision 2020 – the Right to Sight global initiative (hereafter referred to as Vision 2020). In this, low vision became one of Vision 2020’s priority areas.\textsuperscript{6}

Low vision is permanent vision impairment that is not correctable to normal vision with spectacles, contact lenses, or surgical intervention.\textsuperscript{18} The functional definition used in the provision of low vision services states that low vision is vision impairment even after treatment and/or standard refractive correction.\textsuperscript{6} It is visual acuity $<6/18$ to the perception of light in the better eye or visual fields $\leq 10^\circ$ from the point of fixation but with the potential to use vision for the planning and/or execution of a task.\textsuperscript{6}

In the last 10 years, research studies\textsuperscript{14,19-28} have demonstrated the impact of vision impairment on an individual’s quality of life (QoL). For instance, loss of social independence,\textsuperscript{19,20} social relationships\textsuperscript{14} and functional impairments, such as reduced mobility\textsuperscript{14}, which in turn lead to an increased risk of falls\textsuperscript{19,20} and hip fractures.\textsuperscript{21,22} There are also psychological and emotional consequences such as depression\textsuperscript{21,22}, as well as economic impacts.\textsuperscript{23-25} When compared with other chronic conditions, vision loss has been found to affect the health-related QoL more than type two diabetes, coronary heart disease, and hearing impairment.\textsuperscript{26}

Thus, low vision services are undoubtedly important, and exist to “enhance vision-related QoL for people with functional low vision” (Vision 2020).\textsuperscript{27} Services should be comprehensive, integrated, sustainable, equitable, and include the principles and practices of primary health care.\textsuperscript{27} However, of the estimated 70 of the 124 million people with low vision who are likely to need special services, only 5-10\% (of the 70 million) can access such services. This estimate was based on 22 countries.\textsuperscript{28} Crucially, low vision services are either not available in many countries, particularly developing countries, or are located only in urban regions.

Furthermore, emerging global trends are exacerbating the situation of low vision services. Advances in medical technology, changes in lifestyle, and development, have
seen an increase in the ageing population. This growth combined with the positive impact of Vision 2020 activities in the last 10 years, also have caused a shift in the epidemiology of eye diseases. Recent evidence suggests that the overall prevalence of vision impairment has remained the same, stabilised, and/or even declined in some parts of the world. However, the problem now is that untreated causes of low vision from chronic and non-communicable vision disorders, such as glaucoma, age-related macular degeneration and diabetic retinopathy, have increased. This means that the demand for low vision services will increase significantly in the coming years.

1.2 Significance of Study

To be able to address the current and future low vision service needs, information is critical to inform the WHO and Vision 2020 in terms of planning, setting priorities, mobilising resources in areas such as human resources, infrastructure, and advocacy. Data and information are available for other forms of vision impairment, for instance cataract surgical rates, but there is none for low vision services. This paucity of information on the distribution, need(s) and priorities for low vision service delivery at the national, regional, and global levels need to be addressed.

In addition, the Vision 2020 2006-2011 strategic plan underlines important limitations facing low vision services:

- Low vision services are not financially profitable thus many eye care professionals are not interested in providing low vision care.
- Epidemiological data such as the prevalence and causes of functional low vision is lacking hence the need for low vision services is not acknowledged.
- Persons with low vision often think that nothing more can be done for their vision and are therefore not aware of the ways low vision services can help.
- There is poor integration, communication, and referral between low vision services and other key sectors such as eye care, special education, and rehabilitation.
- Planning for low vision services is insufficient in many of the national Vision 2020 plans. Despite many countries being committed to providing support for
Vision 2020—only 32% of the Member states had drafted a national Vision 2020 plan by 2005. In two World Health Assembly Resolutions by the WHO, there was an urge to countries without national Vision 2020 plans to commit fully to vision impairment, which includes low vision.\textsuperscript{38,39}

Other compelling considerations also supporting the significance of this study include:

1. The relative neglect of low vision services by governments. While it is understandable that HIV/AIDS, tuberculosis (TB), and malaria receive such a high level of attention because they kill and they affect millions of people around the world, it is less clear why, in this evidence-based age, conditions like low vision receive so little attention, when the distribution and numbers are comparable. Low vision affects 124 million people\textsuperscript{29}, compared to 42 million affected with HIV/AIDS.\textsuperscript{40} Despite the significant socioeconomic implications associated with low vision, services are either not available or governments do not provide adequate resources for the prevention and treatment of eye conditions that lead to low vision.

2. Research in the field of low vision service delivery: the majority of research to date has focused mainly on individual aspects of service delivery rather than the overall provision. Prior areas of research include: low vision health professionals,\textsuperscript{41-43} the effectiveness of low vision devices and interventions,\textsuperscript{44-48} client satisfaction\textsuperscript{49}, the types of services\textsuperscript{22,50} and service delivery at the organisation level.\textsuperscript{51-53}

An overview of the effectiveness of international low vision models of service delivery led to the conclusion that "research now needs to focus on improving coverage of, and access to, low vision services...more research is needed to identify what, where and how services are delivered worldwide for effective models of care".\textsuperscript{8}

Culham \textit{et al}\textsuperscript{54} concur. Their study found that when compared to the probable number of people with vision impairment in the UK, there are inadequacies in service provision in terms of distribution, magnitude, and coordination. These findings are relevant to service provision in general. The researchers argue that “…the current inadequacies in the system ... require further research in order to
provide the essential information on which future low vision service provision should be planned” 54.

3. Practical and wider application of the research findings: in addition to providing the WHO and Vision 2020 with the essential evidence for the planning and development of low vision services, an arrangement has been made between the researcher, supervisors, and the WHO in October 2008 for the survey data on each country to be entered into the WHO InfoBase later this year (2009). Future implications of this include updating the database on a regular basis. The database can then become an important advocacy, monitoring and evaluation tool for services. Governments, service providers, policy makers, other researchers, and anyone with an interest in low vision—especially those living in developing countries—will be able to have access to such information for the planning and development of their services.

1.3 Research Aims and Methods

The dearth of information on service provision, number of people with low vision requiring low vision care, impact of low vision, changing epidemiology of eye diseases, increasing ageing population, the poor low vision service coverage, and the other key limitations listed above thus provide the fundamental basis for conducting this research. Consequently, this research has three aims:

1. To map the current global situation of low vision services provided in each country
2. To identify the critical success factors in the coverage of low vision services
3. To identify the issues behind the critical success factors in the coverage of low vision services

Headline results from this research show that the majority (80%) of countries have poor (≤10%) coverage. This poor coverage can be explained by the current situation of human resources, funding sources and management, aspects of service provision, and the sociodemographic and economic barriers to service access. Through researching these three aims, areas of action will be proposed to establish strategies to improve
Chapter One - Introduction

the current situation of low vision services and provide information that will be useful for policy makers, project managers, and service providers.

For this research, the methods were to: 1. develop and distribute a survey to 195 countries to obtain data on systems and types of low vision services provided; and 2. conduct three country case studies (India, Ghana, and Cameroon) to identify the critical success factors associated with poor and better coverage of low vision services.

Ultimately, it is envisaged that the results from the research will contribute to and complement strategies outlined by Vision 2020 for low vision. In addition to this, this research will further expand on and/or build on strategies to those already formulated by Vision 2020.

The key Vision 2020 strategies for low vision 2006-2011 that are most relevant to this research are:

- advocate for the inclusion of low vision care as part of eye care, education and rehabilitation services, and for awareness about low vision and low vision services in the community and among health, education and rehabilitation professionals
- include low vision in the curriculum of ophthalmologists and other eye-care personnel
- establish or promote low vision services in tertiary- and secondary-level eye-care centres
- summarise existing evidence and conduct research on the best practice for the provision of low vision services, their impact on life and limitations to their provision and uptake.

1.4 Overview of the Research

Chapter 2 of this thesis explores existing literature to further build on the significance of this research introduced in this Chapter and provides the proof that there is no better time to conduct this assessment of the current situation of low vision services globally. Although recommended and optimal approaches to improving and delivering
low vision services were found, to date no services meet the ideal. Sustainability of services remains elusive. Many of the barriers faced by service providers and people with low vision historically are still relevant today. Last, the Chapter explores the pros and cons of using the survey and case study methodologies to investigate the three aims of this thesis.

Based on Chapter 2, Chapter 3 describes the development and distribution of the survey and the procedures carried out to conduct this global mapping exercise of low vision services. It also emphasises the importance of survey data verification and describes the different stages and types of data verification practices. In addition, the Chapter demonstrates the application of a novel statistical technique (Classification Analysis and Regression Tree) to identify the critical success factors in the coverage of services. Lastly, the Chapter outlines the case study design and rationale behind the selection of the three countries – India, Ghana and Cameroon, that will be used to explore the issues behind the critical success factors.

Chapter 4 displays the overview of the global situation of low vision services e.g. presence and coverage of services, human resources, type and location of services, and barriers to access. The aspects of the current situation provide valuable insight into countries with poor (≤10%) and better (>10%) coverage. Furthermore, the CSFs found to impact on the coverage of services lead to the development of FRAME. FRAME is a framework that was developed by the researcher to summarise the key critical success factors. The FRAME is subsequently explored through the three case study experiences. Most importantly, these case studies uncovered examples of approaches to establish, implement, and improve services. The Chapter concludes with the notion that the data from both the survey and case studies combined, provide the basis on what can be done to improve current and future services.

A comprehensive discussion of results is presented in Chapter 5. This brings together strategies/approaches to improve the current situation and the development of low vision services for policy makers, project managers, and service providers. Numerous examples of service delivery/models are taken from examples from both the survey and the case studies.
Chapter One - Introduction

Finally, conclusions of Chapter 5 are provided in Chapter 6. This Chapter will concisely indicate how the three aims have been fulfilled. The major contributions of this research are the identification of the areas for action to improve low vision services. However, the limitations, strengths, findings and implications exposed a number of areas that warrant further investigation. Thus, ideas of future research are outlined before concluding the thesis with a memorable final note emphasising the importance of this research and the impact that can be made on individual’s lives.
2.1 Introduction

Chapter 1 presented the significance and rationale for conducting this study. One of the more important observations of Chapter 1 was that there is a lack of information on the distribution, needs and priorities for low vision service delivery at the national, regional, and global levels. Before the mapping of current services and identification of CSFs can commence it is essential to find out what is currently known about service provision and delivery. A detailed background of low vision is provided (Section 2.2) which will then lead to highlighting the increasing importance of low vision services in Section 2.3. Section 2.4 presents a discussion on the situation of low vision services by providing a critical appraisal of past and current models of service delivery, and the Chapter ends with a review of the research methodologies (Section 2.5).

2.2 Background

2.2.1 Definition of Low Vision

Low vision is permanent vision impairment that is not correctable with spectacles, contact lenses, or surgical intervention.\textsuperscript{18}

The World Health Organization (WHO) defines low vision in two ways. The first is used in epidemiology (ICD-10)\textsuperscript{4} In this context, low vision is “visual acuity of less than 6/18 (20/60) but equal to or better than 3/60, or corresponding visual field loss, to less than 20 degrees, in the better eye with best possible correction.”\textsuperscript{4}

The second is a functional definition for use in the provision of services.\textsuperscript{6} In this context, low vision is “vision impairment even after treatment and/or standard refractive correction, and a visual acuity of less than 6/18 to the perception of light in the better eye or a visual field of less than 10 degrees from the point of fixation, but with the potential to use vision for the planning and/or execution of a task.”\textsuperscript{6}
Chapter Two – Literature Review

2.2.2 Causes of Low Vision

The major causes of vision impairment globally are: cataract (39%), uncorrected refractive errors (18%), glaucoma (10%), age-related macular degeneration (7%), diabetic retinopathy (4%), corneal opacities (4%), childhood blindness (3%), trachoma (3%), onchocerciasis (0.7%), and others (11%). Low vision results from conditions that cannot be treated or corrected to restore normal vision, these causes include macular disorders, diabetic retinopathy, glaucoma, and other retinal conditions such as retinitis pigmentosa. As many surveys have not included low vision, quantification of low vision is difficult due to the scarcity of data but it is estimated that for every person who is blind, there are three with low vision. The main causes of low vision are increasingly becoming age-related. Where data are available, past studies have indicated that the causes of low vision are similar across developed countries with some differences in developing countries, particularly in children.

2.2.3 Epidemiology of Low Vision

Of the 161 million people with vision impairment, 37 million people are blind and 124 million people have low vision. The actual number of people with low vision could be substantially higher as low vision has only recently been addressed in large epidemiological studies. Ninety percent of the people with vision impairment live in developing countries; and women constitute two-thirds of the world’s vision impairment.

2.2.4 Vision 2020 and Low Vision

Vision 2020 was launched in Geneva on February 18th 1999 by the WHO. It was established to eliminate avoidable blindness particularly in developing countries by the year 2020. The initiative is a collaboration of the WHO and the International Agency for the Prevention of Blindness (IAPB). IAPB represents non-governmental organisations, international agencies, eye care providers, and civil societies.

Low vision is one of the nine priority eye conditions in Vision 2020. The other priorities are cataract, refractive errors, childhood blindness, trachoma,
onchocerciasis, age-related macular degeneration, diabetic retinopathy, and glaucoma. The Vision 2020 goal for low vision is to ‘enhance vision-related quality of life for people with functional low vision’.  

Vision 2020 has brought about an increased public awareness of vision impairment through improved professional and political commitments, as well as creating partnerships amongst non-government organisations (NGOs), United Nations (UN) agencies, industry, and governments. On May 27th 2006, the 59th World Health Assembly endorsed the resolution on “Prevention of Blindness and Visual Impairment”. This called for member states to provide the necessary additional support in order for countries to take more intensive action to halt and reverse the rise of preventable blindness.

Positive impacts of Vision 2020 have since emerged: firstly, despite increases in the world’s population between 1990 and 2002, the number of blind people has remained at approximately 38 million. Without Vision 2020, this number would likely increase.

Secondly, in its first three years of operation (compared with data from 1995) there were seven million fewer cases of blindness from ocular infections such as onchocerciasis, and trachoma, and corneal scarring from vitamin A deficiency.

Finally, there has been stabilisation in the number of people blind from cataracts. Morocco, Nepal, Sri Lanka, India, Philippines, and Thailand have all demonstrated significant decreases in the prevalence of blindness. In The Gambia, the impact of a national eye care program had shown a 40% reduction in the prevalence of blindness between 1986 and 1996.

2.2.5 Impact of Low Vision

Low vision has consequences on an individual’s Quality of Life (QoL). Vision, social - social contact and interpersonal relationships, psychological and emotional – cognitive function, emotional status and well being, functional – self care, mobility, activity level, activities of daily living, and economic – direct and indirect financial costs.
Chapter Two – Literature Review

Since the launch of Vision 2020 in 1999, many studies have assessed the impact of vision impairment. It is now accepted that vision impairment is associated with decrease life expectancy and QoL. Although the majority of these studies measured vision impairment which included both blindness and low vision, the impacts discussed in the next few paragraphs are in keeping with the consequences of low vision on QoL.

According to Langelaan et al, vision impairment has been found to affect QoL more than type two diabetes, coronary heart disease, and hearing impairment.

Vision impairment also leads to: a loss of social independence and impeded social relationships, functional ability such as reduced mobility and the ability to care for oneself, increased risk of falls, and hip fractures. There are also psychological implications such as depression. One study found that elderly people with vision impairment are more likely to be admitted to nursing homes earlier.

Vision impairment also has a significant economic impact. Australia was found to have the most comprehensive national assessment of the economic cost of vision impairment. Direct and indirect costs of vision impairment in Australia are provided below.

Direct costs relate to all expenditures incurred from seeking eye health care. For example: inpatients, outpatients, optometry, pharmaceutics and other health professionals. The direct cost of treating eye conditions that leads to vision impairment in Australia in 2004 was AUD$1.8 billion.

In terms of indirect costs, there is first the financial cost resulting from the disabling nature of vision impairment. This includes premature mortality, additional age care, loss of earnings (the loss of production or earnings associated with illness and premature death), costs of caregivers and of low vision devices, environmental modifications, social welfare, and taxes.

Then there are non-financial costs from the loss of healthy life. The total indirect cost was estimated to be AUD$3.2 billion, while, loss of wellbeing contributed AUD$4.8
billion. Combining all costs, vision impairment cost the country an estimated AUD$9.85 billion in 2004. This places eye conditions seventh, ahead of coronary heart disease, diabetes, depression, and stroke.  

In the United States, recent research showed that vision impairment was associated with significant medical care expenditure, a large number of informal care days, and a decrease in health utility. The economic impact included USD$5.5 billion spent on medical and informal care as well as a loss of more than 209,000 quality-adjusted life years (QALY). QALY is an indicator of disease burden that measures the equivalent of healthy years lived.

Evidence of the economic benefits of addressing vision impairment rehabilitation, and/or prevention is not yet available from a global perspective. However, one study estimated that the annual global economic impact of vision impairment in 2000 was US$ 42 billion. If the prevalence of vision impairment did not decrease by the year 2020, this figure was projected to rise to US$ 110 billion per year. If the implementation of Vision 2020 for low vision is successful, the annual loss of productivity of individuals with vision impairment was projected to rise to only US$ 58 billion in 2020, equivalent to an overall global saving of US$223 billion over 20 years.

Furthermore, recent empirical data have shown a link between vision loss and poverty. The poverty cycle leads to a loss of access to education, poor living conditions and personal circumstances. The Millennium Development Goals (MDGs) are committed to the eradication of extreme poverty and provision of health care to poor people. Thus, addressing vision impairment means that progress towards a broader global development agenda, such as the MDGs, can be further promoted and accelerated.

### 2.3 Low Vision Services

Low vision services are important because they exist to lessen the impact of vision impairment by helping people improve their QoL and maintain independence. These services need to address not only vision but also the
Chapter Two – Literature Review

social, psychological, emotional, functional and economic consequences of low vision.\textsuperscript{10}

It has been estimated that 90% of individuals with vision impairment have a degree of useful vision, which could benefit from low vision care.\textsuperscript{81,101} The aim of low vision care is to improve functional abilities of the client with the vision available. This involves the provision of devices or training techniques for the enhancement of vision, performing activities of daily living (ADL) and orientation and mobility.\textsuperscript{83,102} The components of a comprehensive low vision service encompass clinical care, rehabilitation, and the use of adaptive technologies, for instance: handheld magnifiers; electronic vision enhancement systems; and mobility related devices, such as long canes and night-vision systems.\textsuperscript{18}

However, of the 70 million people (out of the 124 million with low vision) who require or are likely to benefit from low vision services, approximately 5% of the low vision population have access to services, a figure that was based on data from 22 countries at a 2001 WHO workshop in Hong Kong.\textsuperscript{27,103}

2.3.1 A Lack of Information

As part of the National Programmes for the Prevention of Blindness\textsuperscript{104}, data and information are available for other forms of vision services such as cataract surgical rates\textsuperscript{37} and the distribution of Trichiasis.\textsuperscript{105} This information is essential for determining priorities, mobilising and allocating resources, providing support at all levels of eye care, organising training and health education, and evaluating program activities. However, for low vision there has been a paucity of information on the distribution, needs and priorities for low vision service delivery at the national, regional, and global level. Such information is critical for the planning of current and future low vision service needs and if the Vision 2020 goal to enhance vision-related quality of life for people with functional low vision is to be achieved.
2.3.2 Emerging Global Trends

Advances in medical technology, changes in lifestyle, and country development have resulted in an increase in ageing populations. Evidence suggests that disability due to chronic disease is a public health problem from age 45 years onwards.\textsuperscript{106} By the year 2025, it has been estimated that there will be 1.2 billion people over the age of 65 years\textsuperscript{107} and three-quarters of these people will reside in developing countries.\textsuperscript{108} For developed countries, the fastest growing age cohort is not only those over 65 years but also people over 80 years.\textsuperscript{23,109} Population over 65 years has a higher rate of vision loss than any other age group\textsuperscript{110,111}; the number of people over this age with low vision is expected to steadily rise.\textsuperscript{29}

There is also a shift in the epidemiology of vision impairment. Recent evidence suggests that the overall prevalence for vision impairment has remained the same, stabilised, and/or declined in different parts of the world.\textsuperscript{29-34} However, untreatable causes of low vision from chronic and non-communicable vision disorders have increased relative to the treatable causes.\textsuperscript{35,36} This can be explained by the success of prevention of blindness programs in combating the most common causes of blindness (cataract, infectious diseases and malnutrition) which generally affect the young; secondly, by the positive impact of Vision 2020; and thirdly, as described above, the demographic shifts, resulting in age-related, chronic, non-communicable eye conditions becoming increasingly prevalent.\textsuperscript{112}

2.3.3 Precedence for This Research

In response to the emerging global trends, poor service coverage as well as the lack of information for planning and setting priorities, the WHO formed a Low Vision Working Group (LVWG) following the 2001 Hong Kong workshop.\textsuperscript{28} The LVWG developed a plan in the areas of human resource development, low vision resources and equipment, advocacy, and the global mapping of programs. The latter (global mapping) suggested and supported the need for this PhD research.

The aims of this research are both important and timely because not only will it assist the LVWG with the essential information for the planning, mobilising of resources, and
Chapter Two – Literature Review

ensuring comprehensive coverage, it will also establish priorities for the next VISION 2020 five-year plan.113

2.4 Appraisal of Low Vision Service delivery

Fundamental to contextualising the methodology and findings of this research, the following sections cover a brief history on the evolution of low vision services; appraisal of past models of low vision care, proposed Vision 2020 approaches to low vision service delivery. The context of current delivery models and the barriers faced by service providers and clients are also presented.

2.4.1 Historical Background

Low vision service provision has a long and fragmented history. Low vision rehabilitation in the form of aids and devices can be traced back to as early as the 13th century. In 1270 Marco Polo discovered elderly people in China using magnifying glasses for reading.114 However, it was not until 1637 that the first magnifying aid for the correction of visual defects was formally claimed by Renè Descarte.114 In 1862, Herman Snellen developed the first visual acuity chart.114 Significant advances in the development of low vision aids and devices were made by William Feinbloom who subsequently went on to found the company ‘Designs for Vision Inc’ in 1961.115 The LogMAR chart (logarithm of the minimum angle of resolution) was developed by Bailey and Lovie in 1976.116 This chart’s significance is discussed below.

Until sixty years ago the term ‘low vision’ did not exist. Instead, ‘partial blindness’, ‘sub-normal vision’, or ‘partially sighted’ dominated vision terminology. For example, in 1893 the British government considered blindness as being “too blind to read the ordinary school books used by children”117; while in the 1930s having insufficient vision “for the ordinary activities of life for which sight is required”, was used by the American government to define people with blindness.117

Throughout the 19th and 20th centuries, resources were primarily directed at people who were blind.117 The inclusion of low vision under the banner of blindness meant that the rehabilitation of people with low vision was directed by a ‘blindness’
paradigm. Two widespread misconceptions evolved: first, that less than normal vision was not usable, and second, that to prevent further eyesight damage, those with low vision had to avoid using their existing vision.\textsuperscript{117} This latter misconception was reinforced by the coining of the term ‘sight-saving’ by the National Society for the Prevention of Blindness’ in 1915.\textsuperscript{117} It was not until 1930 that ophthalmologists published a report to refute this commonly held belief that using vision was harmful.\textsuperscript{117}

The American Medical Association in 1934 stipulated that legal blindness should be defined by Snellen chart measures.\textsuperscript{117} While this chart proved useful in measuring normal or near-normal vision, research would later indicate that this tool was ineffective in measuring low vision.\textsuperscript{118} The LogMAR system was adopted instead to assess both near and distance vision.\textsuperscript{119} The key features of this system are the arrangement of symbols in rows of decreasing size that are equally legible and follow a geometric progression of sizes. There are equal numbers of symbols per line (usually five) and spacing between the symbols and lines is related to the size of the symbols. The geometric progression allows consistent results to assess changes in distance and also provides a basis for prescription of magnification.\textsuperscript{118}

With the formal inauguration of the term ‘low vision’ by Gerald Fonda and Eleanor Faye\textsuperscript{117} in the early 1950s, came a recognition that new programs and materials needed to be designed and developed. This not only applied in the rehabilitation context but a clinical component also became a necessity.

Care for people with low vision originated with philanthropists and charity organisations whose original intent was to provide education for the blind.\textsuperscript{120} In Australia, for example, the Victorian Asylum and School for the Blind (later known as the Royal Victorian Institute for the Blind) was established by Reverend James Miriam in 1866. In England, the first centre was the Norwich Asylum and School for the Blind, founded in 1805 by a merchant with low vision.\textsuperscript{117} The first school for partially sighted children was set up in London in 1908\textsuperscript{117} and a series of sight-saving schools were established between 1910 and 1920 in Britain.\textsuperscript{117} In the United States, these classes were started in 1913.\textsuperscript{114}
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World War II saw service provision move away from its largely educational and child focus to physical rehabilitation, vocational guidance and training of veterans with vision loss and working-age adults. After the war, the Veterans Administration (now the Department of Veterans Affairs) (VA) continued to provide rehabilitation services to veterans, while state governments extended services to civilians, mainly children and working-age adults.

The first low vision clinic opened under the direction of Gerald Fonda and George Hellinger at the Industrial Home for the Blind (now Helen Keller Services for the Blind) in New York in 1953. Denmark established its first clinic in 1958. Australia’s first low vision clinic was established in Melbourne in 1972 by the Association for the Blind in collaboration with Melbourne University Department of Ophthalmology and Department of Optometry. This Foundation has since merged with other organisations to become Vision Australia, a non-profit rehabilitation agency providing low vision care.

Although limited, there were some key pieces of literature on low vision throughout the 20th century. ‘Outlook for the Blind’ established in 1907 (later ‘New Outlook for the Blind’ and now ‘Journal of Visual Impairment and Blindness’) became the first journal on low vision. In 1910, M Von Rodgin was the first to publish a paper on telescopic and microscopic spectacles and in 1935, Feinbloom wrote the “Introduction to the Principles and Practice of Sub-normal Vision Correction”. Three years later, he reported on 500 cases of low vision in the American Journal of Optometry and Archives of the American Academy of Optometry. The first textbook on children with low vision came out in 1943 and a paper on prescribing low vision aids was published by Habel and Sloan in 1956.

Retinopathy of prematurity (ROP), a vaso-proliferative disorder of the eye affecting premature babies, was an important cause of childhood vision impairment during the mid 20th century. Campbell’s work in 1951 suggested that uncontrolled supplementary oxygen was responsible for ROP reaching epidemic proportions during the 1940s. A second epidemic of ROP occurred in the late 1970s and 1980s.
was attributed to advances in intensive care facilities and technologies which had enabled high survival rates of neonates born at less than 27 weeks.  

ROP resulted in many children with low vision and the educational opportunities for these children at the time were limited to the blind schools. This was to change with Natalie Barraga’s work on developing a new approach on the assessment of visual function, structured learning, and sequential development during the 1960s. Her work which included the ‘Teacher’s Guide for the Development of Visual Learning Abilities’ and ‘Utilization of Low Vision’, as well as the ‘Visual Efficiency Scale’ in 1970, revolutionised approaches to teaching children with low vision. These works emerged after studying the visual behaviour of children.

Between the years 1903 and 1950 only 162 publications on low vision were produced. Since then the pace has increased to an average of 400 articles a year. While 10,000 articles have been produced in the last 50 years, the majority (80%) have been published in the last 20 years and half of these in the last 10 years. Two thousand articles were generated between 1999 and 2003 alone. Journals in optometry, ophthalmology, special education and rehabilitation house the majority of the low vision literature. Until recently, literature on ageing and the elderly constituted only a small percentage and was found to be four times less likely to be covered by journal citations than those on children.

### 2.4.2 Models of Low Vision Care

#### 2.4.2.1 Monodisciplinary Model of Low Vision Service Delivery

Prior to the 1970s, the original models of low vision care were predominantly clinically oriented. They focused on prescribing aids and devices in a single visit to an outpatient clinic which was often attached to a hospital with little or no follow up. Although multiple disciplines were involved in providing low vision care across a spectrum of public and private organisations, this type of approach was often criticised for being too ‘monodisciplinary’.
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Individual disciplines built up their knowledge and skills with minimal cross-disciplinary communication. Often disciplines worked independently with discordant relations. Ophthalmologists and optometrists focused on the clinical aspects such as refraction, dispensing aids and devices. Educators focused on alternative methods of learning and saving the sight of children and occupational therapists worked on improving activities of daily living and function. Ophthalmologists and optometrists were usually the first point of contact for people seeking low vision care. However, many clients went into rehabilitation and/or education without ever seeing an ophthalmologist or optometrist.

In most developing countries, services were generally limited or non-existent. Rehabilitation for people with low vision often operated on the same principles as services for people who were blind. Care was mostly provided by national and international non-government organisations such as the associations of the blind. Often less than five percent of the population was served. In most developing nations there were no community-based rehabilitation programs in rural areas. Lack of networking and coordination between organisations resulted in the replication of services. With very few local training resources available, organisations sent professionals abroad to undertake training in vision rehabilitation. However, their capacity to do so was limited by funding. Furthermore, availability of equipment also depended heavily on donations from abroad.

2.4.2.2 Multidisciplinary Model of Low Vision Service Delivery

A new approach to the delivery of low vision care started to emerge in the early 1970s, partly related to the work of Barraga. One of the first countries to lead the way for a multidisciplinary model was Sweden. The model was introduced by Linstedt-Gertzand. It consisted of a systematic team approach involving a low vision teacher, ophthalmologist, optometrist, psychologist, low vision counsellor, rehabilitation officer and secretary, working together with the individual in a low vision centre. This model concentrated on a ‘shared’ approach to care. Examples of this model can be found in Australia, New Zealand, Belgium, Denmark, France, Germany, United States...
and Spain also. Services concentrated also on the availability, provision, and distribution of low vision aids and devices.\textsuperscript{139}

In Australia and New Zealand, services were networked into regional areas during the 1980s and 1990s. Provision of care was made available in smaller satellite clinics and centres around the country. Referrals were made if needed to the main multidisciplinary clinics, which were based in the main cities.\textsuperscript{142}

In the United States, the important providers of multidisciplinary care were Veterans Affairs, who specifically dealt with veterans and their dependants, and Lighthouse International (previously known as ‘The Lighthouse’)\textsuperscript{121} a non-profit organisation whose aim is to preserve vision and provide vision health care services to people of all ages with vision loss. During the early 1980s, Lighthouse established the ‘National Centre for Vision and Aging’. This centre included research and education in addition to services and community outreach.\textsuperscript{121} It is important to note that both organisations do not offer services nationwide. Veterans Affairs has established services in six residential facilities around the United States and these services are mainly targeted at legally blind veterans, i.e. those with visual acuity of 20/200 or less or visual field of 20 degrees of less. Lighthouse International provides direct services in the United States and internationally.

While services in the UK were also provided by a team of eye health professionals located in both government and non-profit based organisations, care was mainly provided in hospitals.\textsuperscript{54} However, unlike the ‘one-stop-shop’ styled-services provided under the United States or Australian models, services in the UK were not co-located. Another distinguishing feature of the UK system is that access to services was, and still is today, largely dependent on a registration system. Under this centralised national database once a person with vision impairment is registered,\textsuperscript{143} multiple service providers were alerted and the person could receive low vision care.\textsuperscript{144} However, while this registry system works well once the person is registered, recent research has found that only a minority of those with low vision are registered.\textsuperscript{144} In 2005 it was estimated that as many as half a million people with low vision who are eligible are unregistered in the UK.\textsuperscript{145}
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The range of low vision cadres available in many of the developed countries may not be readily available in most of developing countries. For instance, there is often a shortage of ophthalmologists and optometrists. Training these cadres and other more highly skilled eye care personnel is a long term investment that is also expensive. Thus, in many developing nations a range of care can be provided by a team-driven system consisting of mid level ophthalmic personnel (MLOP). These MLOP take over many of the functions of the more traditional health professionals with specialist qualifications. MLOP have a lower entry educational qualifications and a shorter period of training than more highly skilled eye care personnel.

2.4.3 Vision 2020 Approaches to Optimal Service Delivery

To achieve the goal ‘to enhance vision-related quality of life for people with functional low vision for low vision’, Vision 2020 stipulates that low vision services must be comprehensive and integrated into existing health care systems sustainably, and equitably. Also, it must be based on the principles and practice of primary health care. These five components imply that there are direct links between the eye care activities of Vision 2020, health equity, and social justice. Each of the five components is described in more detail below.

2.4.3.1 Comprehensive and Integrated Model of Low Vision Service Delivery

The ‘comprehensive’ service delivery model has three multidisciplinary components spanning primary, secondary, and tertiary tiers of care (Table 1). This model also includes human resource and infrastructure development strategies of the Vision 2020 initiative through advocacy and mobilisation of resources.

Table 1 Comprehensive delivery of low vision services

<table>
<thead>
<tr>
<th>Level/tier</th>
<th>Activities</th>
<th>Human resources</th>
<th>Function/role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community based</td>
<td>Awareness</td>
<td>Primary health care</td>
<td>Detect vision</td>
</tr>
<tr>
<td></td>
<td>Detection</td>
<td>Primary eye care</td>
<td>impairment and refer</td>
</tr>
<tr>
<td></td>
<td>Referral</td>
<td>Community-based</td>
<td>Promote eye health</td>
</tr>
<tr>
<td></td>
<td>Basic</td>
<td>rehabilitation</td>
<td>Supply simple low vision devices</td>
</tr>
<tr>
<td></td>
<td>rehabilitation</td>
<td>Teachers</td>
<td></td>
</tr>
<tr>
<td>Level/tier</td>
<td>Activities</td>
<td>Human resources</td>
<td>Function/role</td>
</tr>
<tr>
<td>-----------</td>
<td>------------</td>
<td>-----------------</td>
<td>---------------</td>
</tr>
<tr>
<td><strong>Secondary</strong></td>
<td></td>
<td></td>
<td>Basic rehabilitation</td>
</tr>
<tr>
<td><strong>District eye unit</strong></td>
<td>Diagnosis and treatment</td>
<td>Ophthalmologist/ophthalmic clinical officer</td>
<td>Perform a good refraction</td>
</tr>
<tr>
<td></td>
<td>Refraction</td>
<td>Refractionist</td>
<td>Diagnose and assess low vision</td>
</tr>
<tr>
<td></td>
<td>Low vision assessment</td>
<td>Multiskilled worker</td>
<td>Prescribe and dispense low vision devices</td>
</tr>
<tr>
<td></td>
<td>Prescription of devices and training in usage</td>
<td>Ophthalmic technician</td>
<td>Provide rehabilitation and adaptive techniques</td>
</tr>
<tr>
<td><strong>Tertiary</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Low vision clinic</strong></td>
<td>Diagnosis and treatment</td>
<td>Ophthalmologist</td>
<td>Perform a good refraction</td>
</tr>
<tr>
<td></td>
<td>Refraction</td>
<td>Optometrist</td>
<td>Diagnose and assess complex low vision</td>
</tr>
<tr>
<td></td>
<td>Low vision assessment</td>
<td>Orthoptist/ophthalmic Technician Teacher</td>
<td>Prescribe and dispense complex devices Provide rehabilitation and adaptive techniques</td>
</tr>
<tr>
<td></td>
<td>Prescription of high-power and complex devices</td>
<td>Rehabilitation specialist</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Referral and consultation</td>
<td>Orientation &amp; mobility</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rehabilitation</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Quaternary</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>National programs, training centres</strong></td>
<td>Guide and provide leadership for national program including training</td>
<td>National focal person</td>
<td>National planning, monitor and coordinate low vision activities</td>
</tr>
</tbody>
</table>

There are two features of this comprehensive model that are fundamental to ensuring successful service delivery outcomes: integration within each level into existing eye care, education and rehabilitation services as well as networking between the levels. Most important in this proposed framework is ‘what’ is delivered rather than ‘who’ is delivering the care or ‘where’ the services take place. Accordingly, it is the effectiveness and coverage of low vision care that are the key issues.
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Provision also exists for a quaternary tier in this model, one that focuses on the training of eye health professionals in low vision care. Not every professional or country will need this level. For example, in many developed countries low vision training has already been incorporated into the curriculum of rehabilitation, education, optometry, and ophthalmology. In developing countries such as the Pacific Islands, there is one facility i.e. the Pacific Eye Institute which provides training to professionals from all Pacific islands from their base in Fiji. 148

2.4.3.2 Sustainability

The sustainability of services depends on a variety of factors, such as coordination and cooperation from government and NGOs 149, training of local health care workers 150, and community engagement 151. But one of the main forms of sustainability is long term levels of adequate funding. 27 It is the capacity of the service to overcome its current financing problems as well as the challenges of future maintenance and service development. 152 Insurance schemes, whether public or private, government subsidies, and cost recovery, where for instance the sale of glasses and ophthalmic drugs can help cover the cost of low vision devices, reduce the cost for clients who cannot afford it through cost recovery.

2.4.3.3 Equitable Services

Equitable services imply that ideally anyone with low vision should have a fair opportunity to access low vision services. 153 Promoting social justice is critical in ensuring inequity is addressed. 154 Consequently, the WHO has called for health inequities to be addressed through action on the social determinants of health. 154 The three overarching principles of action from WHO to achieve equity are as discussed in the context of low vision services.

1. Improving daily living conditions – the circumstances in which people are born, work, grow, live and age. Creating social protection policies for people with low vision such as access to employment and disability concessions is required to address inequalities for those with low vision. Early intervention for children can improve the chances of coping with integrated education programs in
regular schools, minimising the likelihood of dropping out. To address gender inequalities, ensuring girls and women have access to low vision services on par with the male population; can improve well-being and opportunities to acquire an education and employment.

2. **Tackling the inequitable distribution of power, money, and resources**—locally, nationally, and globally. Tackling low vision requires commitment, good governance and collective action from all stakeholders: government, civil societies, private sector, and the community.

3. **Measure and understand the problem and assess the impact of action.** Acknowledging that low vision is a problem and ensuring that the social determinants of health leading to inequalities in access to low vision care are measured – within countries and globally.

### 2.4.3.4 Primary Health Care

Primary health care is defined as “the first level contact for individuals, the family, and community with the national health system. It brings health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process”.\(^{155}\)

The primary level of the low vision service delivery model (Table 1) is an integral part of primary health care. Many of the principles and practices of primary health care are in keeping with low vision prevention, rehabilitation, community based activities, and management strategies as well as the three overarching principles of action towards health equity.

In 1978, representatives from 134 countries gathered in Almaty in Kazakhstan, a city formerly called Alma-Ata and declared that primary health care was the key to delivering health for all by the year 2000.\(^{155}\) The content of the Alma-Ata Declaration consisted of a philosophy for development. It saw health not merely as a result of biomedical interventions but also as an outcome of social determinants.\(^{156}\) The principles raised by the declaration included ones already covered in this review—
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equity, social justice, and health for all; community participation, health promotion, appropriate use of resources and intersectoral action.\textsuperscript{156}

The declaration caused a shift in attitude from a focus on ill health and hospitals, to a focus on communities and families controlling their own health. Many countries made efforts to improve service coverage and focused on making contact with the groups most difficult to reach. Precepts of social justice became an integral part of health planning.\textsuperscript{156}

As part of the goal to accomplish health for all by the year 2000, the WHO introduced the community based rehabilitation (CBR) strategy.\textsuperscript{157} For low vision, this innovative approach relies on delivering low vision care by community workers, with an emphasis on prevention (e.g. social support, early intervention, practical information) and the underlying determinants of health such as the environment, agriculture, education, and livelihoods.\textsuperscript{156} The WHO defines CBR as “a strategy for rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of people with disabilities”.\textsuperscript{158} CBR promotes collaboration among key stakeholders—mainly community leaders, people with disabilities, and their families.\textsuperscript{158}

The health challenges faced in 1978 still remain a challenge today, but now there are new challenges, such as demands of an ageing population and increasing chronic diseases. The tenets of Alma-Ata remain as relevant today as they did back in 1978.

Since 1978, an increase in the amount of evidence-based research exists which proves primary health care to be effective and efficient. At the macro level, countries that provide a broader range of services allocate resources according to health needs of the population, and eliminate co-payments—in medical insurance terms—a contribution made by the insured patients towards medical treatment— have better health outcomes with lower costs.\textsuperscript{159} The benefits of a health care system led by the primary health care sector is that it is more accessible (with minimal out-of-pocket payments), has a focus on the client rather than on the disease, provides universal coverage, better coordination among providers, and can provide a wider range of services.\textsuperscript{156}
Improved primary health care also results in less use of secondary care, which includes advanced technology such as medical imaging and lab testing. Primary health care focuses on more cost effective prescribing and prevention.\textsuperscript{160}

Of the five components, tackling health service inequity through action on the social determinants of health and primary health care through community development may be the most difficult to achieve, but will provide the greatest impact in the long term.\textsuperscript{161} This has already been witnessed by the disappearance of blinding infections and malnutrition in many parts of the world.\textsuperscript{161}

To achieve each of the five components in low vision service delivery, Vision 2020 presents three approaches: disease control, human resource development, and infrastructure and technology.\textsuperscript{27}

\subsection*{2.4.3.5 Disease Control and Eye Care}

The aim of this approach is to enhance vision-related QoL for people with functional low vision.\textsuperscript{27} This comprises advocating for the inclusion of low vision at the level of services, the community, and health care professionals, including low vision into the training curriculum of ophthalmic personnel, and establishing networks.\textsuperscript{27} The success of this depends on the two approaches below.

\subsection*{2.4.3.6 Human Resources Development}

The second strategy is an appropriately trained workforce. This requires establishing a multidisciplinary team (optimal human resources mix) to provide care, lobbying the government to encourage and facilitate development for ophthalmic personnel, and create settings to encourage commitment, staff retention, and productivity. Additionally, supporting training programs including refresher training and establishing training centres will ensure continued service delivery.\textsuperscript{27}

\subsection*{2.4.3.7 Infrastructure and Technology}

\textbf{Infrastructure} refers to securing resources especially for development in poorly served areas. For instance, buildings providing basic low vision care, low vision rehabilitation
centres, and optical shops that sell low vision devices. Along with providing this infrastructure, is increasing awareness in the population to increase use of the infrastructure via means such as public transport.²⁷

**Technology** aims at ensuring an optimal supply of appropriate, high quality affordable equipment, instruments, and consumables for the delivery of low vision services.²⁷ This can be achieved through:

- encouraging local manufacturers to produce both optical and non-optical low vision devices
- providing training on medical equipment maintenance to ophthalmic workers and support staff
- increasing the number of material resource centres to ensure a local supply of low vision devices and examination equipment
- supporting access to information on the latest technology (i.e. latest research and devices)
- the provision of supplies (e.g. basic low vision clinic equipment) needed for effective delivery of care.²⁷

To examine the status of each Vision 2020 recommendation, it is important to assess the performance of current models of low vision service delivery.

### 2.4.4 Emergence of a New Approach to Low Vision Service Delivery

There are positive signs that low vision service delivery is moving towards a comprehensive model. Epidemiologic data derived from several large population studies such as the Melbourne Visual Impairment Project (VIP) ⁵⁷, the Blue Mountains Eye Study ¹⁶², the Beaver Dam Eye Study ¹⁶³, the Baltimore Eye Study ¹⁶³, the Rotterdam study ¹⁶³, the Andhra Pradesh Eye Diseases Study (APEDS) ¹⁶⁴, and research into the consequences of low vision have prompted the evolution of such a model.

While current examples have been found to represent optimum models of comprehensive care in theory, in reality current practices globally do not fully match the ideal. Evidence from a literature search indicates that to date no country has fully
adopted this comprehensive model for delivering low vision care. However, several proposals have been presented to implement this approach.

The SmartSight model in the United States (developed countries) and the L V Prasad ICARE model in India (developing countries) are two such examples. Both models can be globally adapted and modified to reflect specific national or regional needs under the Vision 2020 initiative.

The SmartSight model is a relatively new concept that has been developed for implementation and integration in several communities in the United States and Canada. The L V Prasad ICARE model is a working model that has been applied to general eye care services which could also be adapted for low vision services. While both models differ in appearance and originate from different regions of the world, they share the similar concepts and functions of a comprehensive template. Therefore, either could be applied in developed or developing nation context.

2.4.4.1 The SmartSight Model

The ‘SmartSight’ low vision rehabilitation model was developed by the Low Vision Rehabilitation Committee of the American Academy of Ophthalmology (AAO). The model was developed specifically for ophthalmologists, for three main roles:

- to decrease the barriers to accessing existing eye care services for adults with vision impairment. This can be achieved through increasing ophthalmologists’ awareness of patients’ need for services, increasing ophthalmologists’ awareness of their new role as gatekeepers to rehabilitation services for patients and providing ophthalmologists with printed information about rehabilitation and resources that they can then pass on to patients.

- to encourage general ophthalmologists to add a few additional steps to their routine eye examinations to hopefully become standard practice, thereby helping patients with early vision loss. This involves advice on the use of stronger reading devices, lighting and sunglasses. This stage does not involve low vision assessment, prescribing and dispensing devices, nor does it provide rehabilitation techniques.
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- to encourage the establishment of comprehensive vision rehabilitation services within the medical system. This is particularly applicable to systems like or similar to the United States where, with most state programs, being designated as legally blind is a prerequisite for receiving services. As a result, adults with progressive vision loss cannot receive services in the public sector when they need them. Another issue is that most state programs are designed for children and young adults. Finally, state programs are underfunded, particularly in terms of services for seniors. Thus services in the private sector are important.

The model, which was first designed in 2003 and formally launched in 2005, has recently been reviewed and updated. Originally a four-level concept, the SmartSight Model now suggests a three-level program with levels three (basic and comprehensive low vision evaluation) and four (vision rehabilitation training) incorporated as one.

The strategy for its adoption involved educating ophthalmologists about this model. A website and a telephone directory were set up and copies of SmartSight patient handouts were distributed to the profession through the American Academy of Ophthalmology.

The rationale behind this model was to encourage all ophthalmologists to adopt a role or function of providing services at one of these levels. The comprehensive model also advocates that other eye health professionals, particularly optometrists, adopt this approach. By doing so, access and coverage could be improved for all people with low vision. It was therefore designed to integrate low vision into existing eye or health care services rather than operate in isolation.

Level One of this model calls for action from all ophthalmologists. Their role is to ‘recognise and respond’ to people with low vision and supply patients with SmartSight information pamphlets designed by the AAO. At Level Two, patients with moderate vision loss receive basic low vision care in the form of refraction and prescription of aids in private practices or hospital clinics. Patients at this level do not yet require all the services offered at the multidisciplinary level (Level Three). Specifically, as previously mentioned Level Two involves advice on the use of stronger reading devices, lighting and sunglasses – a minimal add-on to an ophthalmic examination.
Communication between the patient’s general practitioner/primary health care physician and the ophthalmologist about the potential impact of vision loss are encouraged at this level. Levels one and two are similar in role to the primary and secondary tiers of Table 1 respectively. Integration here takes place in the form of low vision care being carried out as part of the general or standard level of eye care consultation. Ophthalmologists who adopt Level One as their preferred mode of practice can refer their patients to general ophthalmologists or other health professions who have elected to provide basic low vision care at Level Two or higher.

Level Three of the SmartSight model is similar to that of the multidisciplinary model illustrated in the secondary and tertiary tiers of Table 1. Ophthalmologists at these levels provide low vision services as part of their practice.\textsuperscript{166} Level Three includes both basic and comprehensive levels of low vision care. More complex aids and devices are also made available. In addition, there is also a vision rehabilitation training component that involves the use of complex aids and activities of daily living.

Comprehensive care is delivered by a range of low vision health care workers. These include ophthalmologists or optometrists, occupational therapists, ophthalmic technicians, low vision therapists, rehabilitation teachers, vocational counsellors and orientation and mobility specialists.\textsuperscript{166}

\subsection*{2.4.4.2 L V Prasad ICARE Service Delivery Model}

Set in a developing nation, the L V Prasad ICARE service delivery model (Figure 1)\textsuperscript{167} in India was developed by the L V Prasad Eye Institute (LVPEI), a world-class eye hospital providing eye care research, training and rehabilitation.\textsuperscript{167} It is a five-tiered pyramidal approach to the delivery of comprehensive eye care at all levels.
Figure 1 The L V Prasad ICARE service delivery model

In this model, a total of 50 million people are serviced within the pyramid. The LVPEI Centre for Excellence occupies the top of the pyramid and supports all tiers below it. Only one Centre of Excellence is needed per 50 million population. This Centre of Excellence represents a quaternary level of service, providing training and fellowships in the latest low vision rehabilitation techniques. Research is encouraged among professionals working at this level. Complex cases needing specialist ophthalmologists and/or low vision specialists are referred to the tertiary eye care level in this model.

The next layer of the pyramid consists of secondary eye care, i.e. rural district hospitals and is similar to that of Level Two of the SmartSight model. For instance, comprehensive care, outpatient care, and preventative care are performed at this level.

Community-based eye care services comprise the primary level of the L V Prasad ICARE model. Vision centres are similar to Level One of the SmartSight model. Each centre is staffed by a ‘Vision Technician’ who is usually recruited from the local community and trained for one year at the tertiary level or the Centre of Excellence. The technician screens, refers and provides both basic clinical and rehabilitation services to the local
community. Each vision centre is integrated into community organisations and networked with a secondary level service centre to where referrals are made.168

The bottom layer of the pyramid comprises the ‘Vision Guardians’. These volunteers support and work with vision technicians in the same local community providing community eye care. They are also integrated with local self-help or peer support groups within the community.

While the SmartSight and the L V Prasad ICARE models arguably represent optimum models of comprehensive care, in reality current practices globally do not fully match the ideal. The majority of countries, particularly developed nations, provide low vision care at the tertiary and maybe secondary tiers of the comprehensive template. There are few services provided at the primary level—i.e. community-based generic services. For example, in Australia122, Canada166, and the United States137, community-based low vision care is generally limited. Only a limited number of optometrists in private practice provide some form of basic rehabilitation in Australia. Ophthalmologists and optometrists do, however, refer patients on to other services42,43 such as non-government voluntary organisations like Vision Australia, Canadian National Institute for the Blind (CNIB), or government organisations such as the Veterans Affairs. Normally, clinical and support services, and information are provided at no cost to the client. However, the cost of devices generally has to be met by the clients themselves.122

Likewise, no developing country is currently implementing all the components of comprehensive low vision care. At LVPEI for example, low vision care is not available at the three lower layers of the pyramid i.e. community eye care, primary eye care, and secondary eye care. Instead, more complex low vision care and rehabilitation occurs at the tertiary level.

Primary health care provision is also an issue in many developed countries. Vision 2020 states that comprehensive services must be based on the principles and practices of primary health care. However, so far primary health care either constitutes a very small part of health care system or is lacking in the majority of countries.
Nonetheless, in countries where there are attempts to include primary care into the existing health care system, the outcome appears to be moving towards a positive one. One of the key examples of initiatives to address this deficit is Wales. Wales recently revamped its low vision service provision in order to improve access and coverage\textsuperscript{169}. This represented a national response to improving many of the previously fragmented services that varied in terms of availability and accessibility; it also addressed poor communication between health care professionals involved in eye care. The changes in services resulted in an increased focus at the primary level i.e. Level One of the SmartSight model. Access to the new service has been optimised by ensuring that services are geographically spread throughout Wales. Multidisciplinary services continue to be provided at the major hospitals and centres; low vision care is also being integrated into existing optometry services at the community level and/or at the secondary level. The Welsh initiative is comparable to levels one, two and three of the SmartSight approach.

2.4.5 Barriers to Coverage and Access

The barriers to coverage and access fall into three main categories: service related issues, people-related issues and health professional issues (Table 2)

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## Summary of barriers to coverage of and access to services

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### 2.4.5.1 Underserved and Marginalised Groups

Research has indicated that particular groups in society have been less able to gain access to eye care services and, by default, low vision services. These groups include, people from different ethnic, racial and religious backgrounds, older people, men or
women (dependent on region), people living in rural or remote areas, culturally and linguistically diverse people and socio-economically disadvantaged populations.

The study in India showed that Hindus were less likely to seek treatment than Muslims. Spiritual reasons have also been cited as a barrier in the Owsley study. A study in Tehran found that men, younger people, and those less educated with vision problems have never utilised any eye care services.

Likewise, Keeffe et al found that utilisation of services were poor among older people, males, those who were unable to communicate in English, and people living in rural regions. Specific barriers experienced by people from culturally and linguistically diverse backgrounds and those who are socio-economically disadvantaged have been identified in a recent study by Lim. Being unable to communicate in English, shortage of interpreters, lack of information of services, long waiting lists and waiting times were issues perceived to affect utilisation of eye care services.

Given that access to low vision services is normally, though not necessarily, through eye care services, an understanding of the barriers to eye care services is important to understand barriers to low vision referral and access.

Current low vision service delivery does not match the ideal proposed by Vision 2020. As can be seen in Table 2, there are many barriers facing the delivery of low vision services. To understand why this is the case, the effectiveness of past and current low vision services needs to be examined closely.

2.4.6 Effectiveness of Low Vision Services

Methodologies to evaluate the effectiveness of low vision service delivery have, like the models of service delivery themselves, been evolving over time. One of the key difficulties in this regard is the issue of from whose perspective effectiveness is evaluated. Three possible perspectives exist: service providers/clinicians, individual clients, and policy makers. While effectiveness can be defined as “the degree to which a desired or planned improvement is accomplished in the subject’s usual
environment\textsuperscript{102}, the adoption of this definition is not unanimous from all perspectives.

### 2.4.6.1 Effectiveness from Service Providers’ Perspectives

Traditionally, the outcomes of vision rehabilitation were assessed only by clinicians rather than patients. Indications of success were based on the individual’s ability to perform specific tasks within a clinical setting, for example, the ability to read a newspaper using aids, reading speeds, and mastering technologies such as eccentric viewing\textsuperscript{36,188,189}. Patients were often left to practise using the prescribed devices and devices on their own, resulting in incorrect usage, irregular use, and non-compliance\textsuperscript{136}. Leat and colleagues\textsuperscript{190} found that a lack of follow up and training was one of the main reasons why 75% of clients could use the prescribed aid or device effectively in the clinic, yet only around 35% could do so at home. Moreover, Shuttleworth \textit{et al}\textsuperscript{51} demonstrated that better patient satisfaction and higher aids usage rates could be obtained with guiding the person in learning new sensorimotor coordination not only in the eye and head movement but also hand and body movements as well\textsuperscript{136}.

This emphasis on performance-based outcomes in a clinical setting was later shown to be too ‘simplistic’\textsuperscript{136}, particularly as effectiveness evaluations were largely based on anecdotal observations\textsuperscript{21,174,191}. While evidence-based research outcomes have become more common, this is still limited in the area of low vision. Only two reviews pertaining to interventions in low vision rehabilitation have achieved Cochrane collaboration status to date – one on the effect of orientation and mobility training\textsuperscript{192} and the other on assessing the effect of reading aids for adults with low vision\textsuperscript{44}. The Cochrane collaboration represents the gold standard of evidenced-based medicine that explores the evidence for and against the effectiveness and appropriateness of treatments (medications, surgery, education, etc). Even so, the two reviews only look at specific aspects of low vision rehabilitation rather than the overall effectiveness of service delivery. This highlights the shortage of evidenced-based information that currently exists in terms of effectiveness, assessment and evaluation in the delivery of low vision services.
Furthermore, there have been only a few studies that use longitudinal methodologies that go beyond simple comparisons of the psychosocial impact of services, and a limited number of randomised controlled trials and prospective controlled studies.

2.4.6.2 Effectiveness from an Individual Client’s Perspective

The shift to multidisciplinary care prompted a change in practice and subsequently led to rehabilitation outcomes being agreed to by clients rather than the service providers. More recently, there has been an increased emphasis on evaluating patient satisfaction and impact of low vision interventions on the psychosocial aspects such as the quality of life. Other research has indicated that age-related low vision impedes mobility and restricts vision-dependent recreational activities, and that social support can provide an effective buffer against the negative effects on age-related low vision. The fact that only modest QoL improvements have been shown following vision rehabilitation may reflect the small number of questions that are vision-related in some studies. A study in the UK found that although vision rehabilitation appeared to have had a positive impact on the QoL of people with low vision, feelings of loneliness or isolation could not be reduced and many participants in the study were still unable to perform activities of daily living in their own environments.

Two studies in particular have shed an interesting perspective on the effectiveness of services. First, the study by Lamoureux et al showed that not everyone with low vision uses all services available in a multidisciplinary service. Usual care for many is a clinical assessment, prescription of low vision devices and advice on lighting and use of contrast, suggestions for non-optical devices, and welfare entitlements. However, changes did occur when services were provided: the domain of reading and accessing information showed modest gains; and all people had been to a low vision clinic. Reeves et al conducted a Randomised Controlled Trial, in which one intervention arm consisted of a supplementary home-based component (ELVR) and the other was the conventional low vision rehabilitation provided in a hospital clinic (CLVR). The CLVR consisted of standard hospital care and follow-ups were arranged at the hospital.
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at a later time. The ELVR model included all components of the CLVR but provided follow-up home visits from a specially trained low vision rehabilitation officer. The outcomes assessed in this study were visual-related QoL, general health-related QoL, psychological adjustment, task performance at 12 months and self-rated restriction in everyday activities. Interestingly, the evidence concluded that ELVR was not more effective than the basic service i.e. CLVR arm. This could be due to there being no difference or that the tools used to measure change were not able to do so.

2.4.6.3 Effectiveness from a Policy Perspective

For many policy makers, coverage and access serve as key indicators of service success. In Australia less than 20% of the low vision population access low vision care while figures from the United States indicated that access ranged between 4% to 9% of all people with low vision. Survey in the UK have shown that up to 80% of those not currently using services could benefit with aids and devices. From a policy perspective therefore, this raises the issue of why such a mismatch exists between need and uptake. To address this, the barriers to coverage and access need to be identified and overcome.

2.4.7 Monitoring and Evaluation

Barriers to coverage of and access to services (Table 2) impeded the effectiveness of low vision services. It is therefore vital that monitoring and evaluation are incorporated into the planning of services.

A review of the literature has indicated a lack of evaluation and monitoring in the delivery of low vision services. One of the few tools identified in this review is the vision-specific QoL questionnaire, called the ‘Impact of Visual Impairment’ (IVI). This questionnaire was developed by the Centre for Eye Research Australia (CERA) and is a valid tool for assessing outcomes of low vision services. Another tool—the 25-item National Eye Institute Visual Functioning Questionnaire (NEI-VFQ), was designed to measure vision-specific health-related quality of life. The questionnaire is useful to evaluate the functional status and QoL of people with low vision and the impact of low vision services. Likewise, the Veterans Affairs Low Vision Functioning Questionnaire
(VA VFQ) is a tool developed to measure visual difficulties in people who receive low vision rehabilitation and can be used in the assessment of rehabilitative outcomes and planning of services.\textsuperscript{205} Few such tools have yet been validated for use with children.\textsuperscript{206}

As the history of low vision demonstrates, low vision is an evolving field. The last two decades have seen significant advances in the delivery of low vision care and also in the evaluation of services. This is mainly due to changing needs of the low vision population, which has been influenced by changing demographics, significant events in history such as WWII, and better understanding of low vision through research and dedicated practitioners. Nonetheless, despite new developments in the delivery of low vision care, there are still huge disparities between need and usage. The two main issues in this regard are first, barriers that impede service delivery and uptake and second, limitations with current models of service delivery. Both of these ultimately serve as impediments to the effectiveness of low vision services and most importantly, to fulfilling the goal and components of Vision 2020 for low vision.

### 2.5 Study Methodology

To answer the three research questions, two research methodologies were adopted (Chapter 3). First, the survey — a quantitative approach that will capture the current situation of low vision services in countries, as well as identify the critical success factors in the coverage of services. Second, case studies in three selected countries—a qualitative technique that will allow the researcher to gain an understanding of the reasons and issues behind countries with good and poor coverage. The following sections will provide discussion on the advantages and disadvantages of using such methodologies—specifically the common pitfalls to avoid when designing a survey, features to be built into the case study design, reasons underlying the selection of the outcome variable and the rationale for the application of certain tools to analyse the data.
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2.5.1 Survey

Surveys are defined as “information collection methods used to describe, compare, or explain individual and societal knowledge, feelings, values, preferences, and behaviour”.\(^{207}\) Surveys can be conducted as an interview in person, via the telephone, or self-administered.

Surveys are cost effective, allow people time to think, relatively convenient to complete, the risk of interviewer bias is minimised, and it can be easily mass-distributed to cover a wide geographical area.\(^{208}\) If there are few open-ended questions and they are pre-coded, surveys can be relatively quick and easy to analyse.\(^{209}\)

However, there are common drawbacks to these surveys. The quality of the answers may be affected and response rates may be poor, especially self-administered surveys.\(^{210}\) Often the characteristics of people who do not respond to a survey are different to the people that do, so there is likely to be a level of bias in the results.\(^{208}\) A proportion of the survey will often be part completed, some respondents may ‘misuse’ or misunderstand the categories and some may under- or over-estimate in their responses.\(^{209}\) Participants are more likely not to answer questions that are not salient to them.\(^{208}\) Often, participants may read the whole survey before answering the first question. This leads to question order effect. Then there is also the issue of not knowing whether the right person has answered the survey. In addition, self-administered surveys do not allow additional data to be collected and there is a limitation on the number of questions that can be asked without affecting the response rates.\(^{208}\) The risk of missing data is greater in self-administered surveys. Furthermore, there will be participants who will answer questions regardless of whether they are well-informed or offer responses on topics with little thought.\(^{211}\) The accuracy of responses will depend on participant’s memory and responses may be exaggerated, understated or misleading, particularly for questions which require sensitive answers. Lastly, the quality of responses may be dependent on the attitudes of the participants.\(^{208}\)
There are several strategies to minimise these issues. According to Sudman and Bradburn\textsuperscript{212} questions should follow the guidelines below:

- be specific as possible
- all reasonable multiple choices should be offered
- recruit respondents currently working in the field so that memory does not affect the quality of the answers
- permission given to participants to consult documentary sources
- including a ‘do not know’ response category to reduce any perceived threat. There has been evidence found in the literature concurring with the use of the ‘do not know’. Hawkins and Coney\textsuperscript{213} found that the rate of uninformed responses were reduced with the inclusion of the ‘do not know’ option and another study by Bishop and colleagues\textsuperscript{214}, suggested giving people a ‘no opinion’ option
- asking several questions on the same theme to reduce the likelihood of successful guessing, particularly when yes/no questions are required
- avoiding double barrelled questions
- limiting the number of open-ended questions. Leaving an ‘other, please state/specify’ option is also further suggested by Schuman and colleagues\textsuperscript{215}
- numeric scales used where appropriate.

McColl and colleagues\textsuperscript{210} highlighted the likelihood of social desirability bias among participants, which can be related to potential culture factors. For instance, the issue of ‘losing face’ could affect the way participants provide responses. Strategies to overcome this include:\textsuperscript{207,211,216}

- use simple language
- avoid abbreviation e.g. referring to the term ‘visual acuity’ instead of ‘VA’
- keep question sentences short (i.e. less than 20 words)
- avoid ambiguity in questions
- avoid the use of double negatives
- avoid leading questions
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- ensure every question asked will be worth each participant’s time, i.e. not recalling detailed information that is not directly relevant or the information is already available for example: prevalence of low vision.

There is also the tendency for postal surveys to generate lower response rates than comparable structured interview surveys, thus the following steps have been frequently suggested by past research to improve response rates:

- writing a good covering letter.\textsuperscript{208} The letter should state the importance of the study, why the participant has been selected; mention any sponsorship and guarantees of anonymity and confidentiality. Some authors advocate the need to personalise covering letters\textsuperscript{217,218}
- keep surveys short, less bulky, question topic salient, and begin with questions that are more likely to be of interest to the participant
- ensure clear instruction and an attractive layout\textsuperscript{218}
- follow-up with multiple reminders. It has been suggested to send the first reminder two weeks after the initial mailing, reasserting the nature and aims of the survey and suggesting that the person should contact the research person responsible if he or she requires the survey to be resent
- providing a stamped addressed envelope or return postage. Monetary incentives may work if the survey is to be conducted within the country of the researchers; however, it is not possible in this study as the survey is covering different countries.

Once the survey has been designed, a pilot study and pre-testing of the survey is warranted. The purpose of conducting a pilot study is to ensure that the questions and the survey as a whole function well.\textsuperscript{208} A pilot test will identify any confusion and generate fixed multiple choice answers so that open-ended questions can be minimised. A pilot study can eliminate questions where participants’ replies have been the same time each time and identify questions that are frequently not answered. Adequacy of instructions and question flow can also be determined. Past research advises against using participants from the pilot test in the actual study as this can affect the representativeness of any subsequent sample.\textsuperscript{208}
This survey will be translated into six different languages (Chapter 3). However, there are issues to be considered when surveys are translated.\textsuperscript{219} First, ensuring semantic equivalence across languages is important. This means making sure that appropriate words and phrases in the target language have the exact meanings to the original language. Second, there is the matter of differing conceptual equivalence across cultures, meaning the concepts being studied may be interpreted differently in another context.

The degree of impediment by any of the above concerns depends on the type of information sourced. One of the advantages of the survey instrument used in this research is that it requires an objective rather than a subjective level of knowledge. It is not a test or exam to gauge the participants’ awareness about low vision services.

In addressing the first issue (semantics), selecting words that come from the same topic may not be difficult in this research; for instance, the term ‘definitions of low vision services’ are similar across countries. The second issue (conceptual equivalence) – the information sought does not involve abstract concepts and constructs. Chapter 3 will demonstrate the steps taken to minimise these issues.

\textbf{2.5.2 Coverage as an Outcome Measure}

Coverage in some situations implies adequate, quality services reaching and being utilised by all those who need them.\textsuperscript{354} Tanahashi defined coverage of services (used in the context of low vision) as ‘the ability of a low vision service to interact with the people who should benefit from it (the low vision population), i.e., the ability to transform the intention to serve people with low vision into a successful low vision intervention for their health.’\textsuperscript{220} In this research coverage is referred to as the proportion of people with low vision having access to low vision services. The reason for the use of coverage as an outcome measure in both methodologies is provided below.

The development of low vision services requires the effective use of available resources and technologies. This implies that service delivery should:

1. be allocated and organised to serve as many people as possible
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2. reach the people in need
3. be effective in meeting those needs.

Knowledge of service coverage and the critical success factors related to coverage is essential if these three areas are to be addressed. Evaluating coverage in this research is therefore vital because it not only enables challenges to be identified in the operation of low vision services, but also to analyse the issues responsible for barriers in service delivery, and assist in selecting effective measures for service development.²²⁰

The question that now arises is how feasible is it to ask survey respondents to provide a good estimate of coverage? To be able to provide an estimate, good epidemiological information is required as well as a record of the number of people using services. Since 1994 the amount of data available on vision impairment (which included low vision)²²¹ has increased considerably.²⁹ Many countries now have sound epidemiological data on vision impairment. Thus it can be argued that it is feasible to ask such a question to the survey participants.

Coverage can be evaluated in different ways. Tanahashi²²⁰ identified five levels that individuals, groups, or populations in need must pass through to obtain effective services or intervention. The first one is availability coverage. This is the ratio between the capacity to provide enough resources (human resources and low vision devices) and the size of the target population. The second is accessibility coverage. Even if all necessary resources are available, services must be easily reached and used. Once this is accomplished, services need to be accepted by the target population. This stage is termed acceptability coverage. The fourth is contact coverage, the contact between the low vision health professional and the client. This measures the number of people who have contacted the service. The final level is effectiveness coverage. Even though contact has been made, the success of the intervention depends on client satisfaction.²²⁰

As it has been demonstrated in earlier sections of the Chapter, traditional low vision services and research have focused mainly on effective and contact coverage at the expense of availability, accessibility and acceptability coverage. This is a concern
because as each coverage level progresses, i.e. from availability to effective coverage, the proportion of people able to access care diminishes. This research will focus on identifying the critical success factors associated with the availability, accessibility and acceptability coverage.

In this research poor coverage has been defined as ≤10% and better coverage is >10%. The 10% cut-off point was used as the criterion for service coverage because as earlier mentioned in this Chapter, previous estimates indicated that very few countries had >10% low vision service coverage (2001 WHO workshop). Furthermore, the findings from the survey in this research will later show that only a small proportion of countries have >10% low vision service coverage (Chapter 4).

2.5.3 Case Studies

The case study methodology was chosen to complement the findings of the survey. According to Yin case studies are “empirical inquiries that investigate a contemporary phenomenon within its real-life context, when the boundaries between phenomenon and context are not clearly evident, and in which multiple sources of evidence are used”.

While surveys make attempts to deal with the phenomenon and context, its ability to deal with the context are limited. On the other hand, case studies act as a function in evaluating research and in its ability to explain the causal links in real-life interventions that are too complicated for the survey to elicit. Case study designs seek to achieve more complex and fuller explanations of the phenomena. The focus is on understanding the dynamics i.e. the reasons, rationalisations, and arguments behind the critical success factors identified from the survey.

The use of case studies is appropriate in this research because ‘how’ and ‘why’ questions are being asked. There is little control over events (aspects of service delivery), and the phenomenon (low vision services) being studied within a real life context (India, Ghana, Cameroon). De Vaus argues that including the context in the investigation is vital as the behaviour takes place within a context and its meaning develops mainly from the context. Also, as this literature review has cemented-low
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vision is an evolving discipline so case studies are particularly useful when fields being researched are still in formative stages.\(^\text{225}\)

The context is hypothesised to contain important explanatory information about the phenomenon. The context is all-important for understanding how low vision services operate and interact with external influences. Chapter 3 will show how this is accomplished.

Furthermore, case studies entail the detailed and intensive analysis of a single case. The term ‘case’ associates the case study with a location, such as a community or organisation. It is defined as an ‘object’ of study or a unit of analysis about which information is collected.\(^\text{222}\) The unit of analysis can be an ophthalmologist, project manager, or client whom the researcher tries to build up an understanding about and is informed by the context in which the case exists. However, the unit of analysis is not restricted to an individual level. Other types of cases include family members of the client, the local community, and organisations such as a business, school, government departments, and unions which are all units of analysis.\(^\text{222}\) Therefore, an understanding of the whole case and viewing of the case from within the broader context in which it operates is important.\(^\text{222}\)

There are three elements that can be built into the design of a case study that are relevant to this study:\(^\text{224}\)

a) theory testing or theory building

b) parallel or sequential case studies

c) retrospective or prospective.

2.5.3.1 Theory Testing or Theory Building

Often case study research has a theoretical dimension. There are three ways in which theory is used to design the case studies: theory testing, theory building, and clinical case studies.

The one that is the most relevant to this research is theory building. This is where the case studies approach is used to help develop and refine existing theories. In this
research, the case studies will provide more insight and understanding behind the factors that either facilitate or act as a barrier in service delivery. No previous theories pertaining to this currently exist. However, parallels can be drawn from other health service and vision fields. For instance, goals and approaches of Vision 2020, principles of primary health care, and the social determinants of health impacting on health equity have all been incorporated into the case studies design (Chapter 3).

2.5.3.2 Parallel or Sequential

The conduct of the case studies will be sequential (one after the other) rather than parallel (at the same time). The advantage of this is that the selection of each case and some of the issues examined can be informed by issues identified in earlier cases. One case in one country can conjure up ideas or new questions that will influence the selection and approach of subsequent cases in the next two countries. Issues can then be followed up in subsequent cases. This type of approach is particularly beneficial when the theory building approach has been adopted in this research.\(^{224}\)

2.5.3.3 Retrospective or Prospective

A retrospective design involves collecting, on the one occasion, information relating to an extended period \(^{224}\); while a prospective design involves tracking changes over time. This study attempts to capture the situation in the present time and also retrospectively. The ultimate goal is to build up a clear and detailed picture of the sequence in which events took place and of the context in which they occurred in order to capture the delivery process of low vision services.

It is not enough merely to design the case study and implement it. The case studies should be designed in a way to enhance its ability to meet certain criteria. The criteria are measurement validity, internal validity, external validity, ecological validity, reliability, and replicability. Not all criteria apply to this research.\(^{208}\) The researcher found that internal validity and external validity warranted further investigation.

Internal validity refers to the extent to which the structure of a research design enables the researcher to draw unambiguous conclusions from the results.\(^{224}\) Threats
to internal validity stem from the danger that factors other than the variable are producing any changes observed. To maximise internal validity, de Vaus proposes that case studies should be full and well-rounded accounts.

Take the hypothetical example of a client who is not satisfied with the level of care received. By seeing the client dissatisfaction with other possible causal factors such as the intervention itself, interaction with the health professional, or difficulty faced trying to access the service, the researcher can assess both the relative importance of particular causes in the way in which various causes interrelate, thus producing a balanced account of the process and avoiding mistaking cause with correlation.

Case studies can attain internal validity by building up a picture of the sequence of events that led to the client dissatisfaction, the context in which they occur (e.g. in the hospital clinic, background of the client), and the meaning of actions and events as interpreted by participants and their meaning as given by a context. By examining the wider context (the service system) and exploring the extent to which these events contribute to observed outcomes (for instance, the services were hard to reach, cost of devices), understanding of the cases can be further enhanced and threats to internal validity minimised. Improvement to the quality of the case studies can be achieved if the researcher identifies possible historical/contextual factors (poor public transport, client’s expectations and awareness about low vision) and includes them in the discussion.

For these reasons, case studies in this research will attempt to investigate any historical and present external factors that influence or impinge on the delivery of services in the country studied.

One of the standard criticisms of the case studies methodology is its external validity or generalisability. Practitioners of this methodology would rebuff this by acknowledging that the evidence they present is limited because it has restricted external validity and that the purpose of this design is not to generalise. On the other hand, quantitative researchers would disagree as the aim of survey research is to generalise their findings to the larger population through random sampling.
Although it is not possible to produce the findings from the proposed case studies and apply it to other cases in other countries, the researcher’s hypothesis is that there will be common issues that would be similar across countries. In addition, the inclusion of the survey in this research already minimises this issue; the combined impact of both methodologies will provide the holistic overview and the detailed insight into the delivery of low vision services.

2.5.4 Data Analysis Tools

Statistical and development tools have been applied to find the answers to the research questions (Chapter 4). Two of the tools are novel for this type of research. Therefore, to facilitate better understanding of the application of these tools in Chapter 4, further critical review of its applications are discussed below.

2.5.4.1 Human Poverty Index (HPI)

There are eight Millennium Development Goals developed by the UN, aimed at galvanising the international effort to halve levels of extreme poverty by 2015. Many of the goals are relevant to low vision prevention, rehabilitation, and management strategies. Ultimately the Millennium Development Goals are committed to the eradication of extreme poverty and provision of health care to poor people. Recent empirical data have shown a link between vision impairment and poverty. The poverty cycle leads to a loss of access to education, poor living and personal conditions. One of the many possible scenarios could include a child required to be a carer for an elderly vision impaired relative, thus denying the opportunity for an education and subsequent potential to escape poverty. Loss of employment due to low vision is a significant burden as well. For example, a child with low vision may be unable to get access to low vision care such as basic magnifiers and/or the proper training in how to use it. Consequently, it may be rare for children with vision impairment living in developing countries to receive adequate schooling. Because of the link between the Millennium Development Goals and poverty with low vision, the Human Poverty Index (HPI) was thought to be an appropriate tool to present and categorise the descriptive analyses of this study (Chapter 4).
Chapter Two – Literature Review

The HPI is an indication of the standard of living in a country, developed by the United Nations (UN).\(^2\) It is a measure of the extent to which people in a country are not benefitting from development. HPI is a measure of deprivation and it assesses three components: longevity—measured by the proportion of the population not expected to survive to the age of 40 years; knowledge—measured by the adult illiteracy rate; standard of living—a composite value measured by the proportion of the population without access to clean water, health services, and the proportion of children under the age of five years who are underweight. For developed countries, there is an extra component: social exclusion (that is long term unemployment rates).\(^2\)

There is a myriad of criticism levelled against the use of measures of development and poverty like the HPI.\(^{226}\) It has been labelled as an incomplete measure of deprivation and concerns for data quality in developing countries.\(^{227}\) While others have argued that such an index on poverty and social exclusion would summarise too much, for example, if there is a worsening of one dimension of well-being, it may not show up in the overall value of the index.\(^{228}\) Nonetheless, many have noted that measures of income growth such as the headcount ratio, which measures the proportion of the population considered to earn an income less than the standard required for basic needs\(^{226}\), do not necessarily reflect the deprivation in human development. On the other hand, indicators like the HPI can provide a reasonable picture of how well countries are performing beyond mere income growth.

2.5.4.2 Classification Analyses and Regression Tree (CART)

The Classification Analysis and Regression Tree (CART) method has been applied in this study to identify the most significant critical success factors in delivery of low vision services using the survey data (Chapter 4).

The CART, also called recursive partitioning, is a nonparametric statistical procedure that identifies mutually exclusive and exhaustive subgroups of a population whose members share common characteristics that influence the dependent variables of interest.\(^{229}\) Since its development by Brieman and colleagues in 1984\(^{229}\), CART analysis has been applied to numerous research studies mainly in the field of clinical health
Recent examples of such studies include epidemiologic studies assessing risk factors for mortality and morbidity from specific diseases\textsuperscript{233}, predicting the probability of adverse events for patients hospitalised for medical or surgical treatment\textsuperscript{232}, identifying mental illness in the community\textsuperscript{234}, utilising characteristics of health to predict health outcomes\textsuperscript{235}, identifying the risk of acquiring a certain disease in a group of people with a particular characteristic\textsuperscript{236}, and developing a tool for detecting undiagnosed diseases.\textsuperscript{237}

The CART has also been applied in the arena of public health but to a lesser extent. The only study found to investigate a health problem from a global perspective using the CART was a study that looked at the determinants of diarrheal illness from a 192 country data set of country-level attributes.\textsuperscript{238} In recent years, research groups have started the studies on the application of the clinical classification techniques in community situations.\textsuperscript{233,234,238-240} The results of these studies suggest that the classification techniques can identify the most significant differences in all respects of the target variables. This proves that the CART will gradually show its significance in topics such as reducing inequalities in health and public health interventions.

However, so far, studies on the application of the CART in the area of public health ophthalmology and eye care service delivery are still lacking, particularly those that use classification trees as targeted interventions. The literature search revealed that only two studies\textsuperscript{241,242} in the area of clinical ophthalmology have been published but none in the area of delivery of eye care services. Possible reasons for the infrequent use of CART may be because traditionally health service outcomes are often dichotomous, thus traditional regression modelling methods such as logistic regression have been sufficient to determine the average effect of an independent variable on a dependent variable.\textsuperscript{243}

There are several reasons to why the CART was applied in this research. As the review of the literature on the survey methodology has alluded to, there are common problems associated with the type of data collected, most notably poor response rates and missing data on some questions. This leads to problems later when analysing the
data using traditional regression modelling methods such as logistic and linear regression.

The CART avoids the limitations associated with logistic regression and other standard methods. For instance, the CART uses a set of predictors to create subgroups of individuals that vary in risk for the main outcome of interest, ultimately producing a user-friendly classification tree that can be employed to guide care, treatment and prevention efforts in clinical settings.\textsuperscript{236} In other studies, the CART has been found to create subgroups that had better predictive ability, equivalent sensitivity and better specificity, compared with traditional logistic regression models with common demographic and risk predictors.\textsuperscript{236}

The CART is less restrictive than with parametric assumptions in logistic regression.\textsuperscript{244} In other words, no assumptions are made regarding the underlying distribution of values of the predictor variables. Thus, CART can handle numerical data that are highly skewed or multi-modal, as well as categorical predictors with either ordinal or non-ordinal structure.\textsuperscript{245} This is an important feature, as it eliminates analysis time which would otherwise be spent determining whether variables are normally distributed, and making transformations.\textsuperscript{245} It is doubtful that in real-world settings, variables have straightforward linear relationships with important health outcomes; nonparametric techniques like the CART are better able to identify these complex relationships.\textsuperscript{236}

The CART can perform well with many missing variables.\textsuperscript{245,246} Generally there is a dearth of information from low-income and middle-income countries\textsuperscript{28,247}, so the research expected that there would be missing data from these countries. The CART can still produce outputs even when important predictor variables are not known for all countries. Countries with missing predictor variables are not dropped from the analysis but, instead, “surrogate” variables containing information similar to that contained in the primary splitter are used. Predictions for countries with missing predictor variables are based on the values of surrogate variables as well.
Chapter Two – Literature Review

The CART is also able to detect interactions and is not easily affected by multicollinearity between variables compared to other regression modelling techniques.\textsuperscript{246}

Finally, relatively little input is required from the researcher to generate the CART output e.g. after exporting the data into the statistical software it is then a few simple clicks to generate the tree, making the CART easy to use.\textsuperscript{245} The CART outputs are also simple and practical for non-statisticians to understand.\textsuperscript{245}

With any tool there are always disadvantages. These were also considered when the decision was made to use this tool. As the CART is easy to run in the statistical software package, there is the risk of including too many possible independent variables into the model, resulting in data dredging.\textsuperscript{248} This can be solved by choosing only the necessary and key independent variables to be included in the analysis.\textsuperscript{249,250} Another disadvantage is that the structure of a classification tree can grow into multiple levels or splits, which can result in an extremely complicated and unexplainable tree structure rendering it practically insignificant.\textsuperscript{245,248} To avoid this, the literature suggests restricting the growth of the tree by setting priority stopping rules (the most appropriate tree size) and applying the cross-validation procedure to randomly divide the sample data into a prediction sample group and a validation sample group.\textsuperscript{248-251}

The disadvantages are not difficult to overcome and the CART represents a novel approach to analysing a complex global issue such as low vision services.

\section*{2.6 Conclusions}

This Chapter has demonstrated that this research is both important and timely. First, the literature has shown that since low vision became a Vision 2020 priority 10 years ago, a multitude of studies have attested the severe impact of low vision on an individual’s QoL as well as the economic consequences at the national level. Low vision services are therefore vital in minimising the impact of low vision. Second, emerging global trends such as an increasing ageing population and a shift in the epidemiology of eye disorders signified that the demand for low vision services will increase by 2020
Chapter Two – Literature Review

and beyond. This is further compounded by the fact that service coverage is poor; however, this was previously only based on data from 22 countries. Thirdly, unlike other forms of vision impairment, it has been substantiated that not only is there almost no data on the coverage of services, there is little or no information existing to guide the WHO, Vision 2020, policy makers, and service providers about the priorities essential in the improvement of current and planning of future services.

Although, the literature found recommended approaches to achieving the ideal service delivery (i.e. comprehensive services based on the principles and practices of primary health care and tackling the social determinants of health), and gave examples of places where there have been attempts to deliver a comprehensive service, no services to date meet the ideal. The literature also provides an insight into how services evolved into the current state and why service coverage may be poor by providing a historical overview of low vision services, and discussing the various barriers to coverage and access. The literature established that research regarding the effectiveness of services has emerged only recently and very little is carried out to monitor and evaluate current services.

Consequently, there is not at present clear guidance or a solution to the problem of providing comprehensive low vision services with adequate coverage. There is no information on what is the current situation of low vision services in the majority of countries and the factors associated with countries that have good and poor coverage.

This research attempts to address this problem by ascertaining the current situation of low vision services in each country, determining the factors contributing to poor coverage, and identifying the key factors as well as approaches to improve and develop services. It will provide a much-needed needs/gap analysis on the situation of low vision service delivery and build on existing models of low vision care. The significance of this research is that it will provide the WHO LVWG and Vision 2020 with the data to set priorities for better curriculum and training, policy and program development, and advocacy.
3 Chapter Three – Methodology
Chapter 3 Methodology
3.1 Introduction

The literature review revealed an array of problems associated with improving the delivery and coverage of low vision services. One obvious problem is that at present, there lacks a clear solution to the issue of providing comprehensive low vision services with adequate coverage. This is partly because there is limited information on what the current situation of low vision service provision is throughout the world, and the factors associated with good and poor coverage.

The purpose of this Chapter is to outline methodologies used to address this lack of information on low vision service provision. This Chapter starts with topics covered and investigated by the survey and the case studies. This is followed by a description of how the survey was developed, pilot tested, and distributed to 195 countries to map the current situation of low vision services and identify the CSFs in low vision service coverage. Finally the Chapter will show how the case studies were designed and facilitated in the three selected countries (India, Cameroon, Ghana) in order provide insight and understanding into the CSFs of service coverage.

3.2 Topics

A range of topics were investigated in this research for both the survey and the case studies. While the survey covered seven themes, the case studies allowed the researcher to examine these seven themes in greater detail and depth, as well as seven additional topics (Appendix B and D provide the actual survey and the questions used in the case studies respectively).

The topics were sourced from resources and literature identified in Chapter 2 viz. Vision 2020, Alma-Ata (primary health care), the social determinants of health, appraisal of past and current models of low vision service delivery and barriers facing service provision.

The seven themes of the survey are: epidemiology of low vision, policies, human resources, service provision, barriers, equipment, monitoring and evaluation. Each of these is discussed below in context of both the survey and the case studies.
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Current situation and history of services

The case study interviews started with the researcher enquiring about the past and current situation of services in the country. This is important because historical information on the triggers for service establishment, in addition to positive and negative experiences of service delivery can yield valuable insight into how services are being provided. Furthermore, an overview of the current situation of low vision services provides an understanding of how services relate to the overall health care system.

Description of services

Description of the services were sought to find out where, what, and how services were delivered. Service provision relates to the location, type, funding of services, and typical waiting times. Also included were questions on whether a national health insurance scheme exists for low vision services and whether the insurance policies provide universal access to low vision services.

Epidemiology of low vision

The questions covered in this section of the survey addressed the way the country defined low vision, the level of vision impairment required before being eligible to receive low vision services, causes of low vision, and the coverage of services i.e. the proportion of people with low vision using low vision services.

Policies

This section assessed the inclusion of low vision in national policies. The questions relate to whether or not low vision is included in the national eye care plan, referral guidelines and standards of low vision practice policies.

Referral and follow-up systems

This topic is another important aspect of service provision, for the reason that delays in referrals often result in more vision loss and late intervention, while poor compliance in the uptake of low vision devices are associated with a lack of follow-up training (Chapter 2.4.5;
The ‘policies’ section explored the presence of national referral guidelines, this section explored the presence of, and barriers to, a functioning referral system.

Networking and integration

The presence of networks with other organisations is an integral part of referral pathways. Integration is a part of Vision 2020’s approach to deliver comprehensive low vision services. Therefore, the questions in the case study focussed on the presence of networks and the kinds of networks established with other organisations, whether or not there was a continuum of care between eye care, refraction, low vision services and the rest of the health care system, and whether or not the services are integrated with other systems and/or organisations.

Human resources

Human resource development is one of the Vision 2020 strategies towards achieving comprehensive low vision services. The capacity of the service to provide care is dependent on the availability of human resources. Human resources, the number, type, percentage of low vision professionals holding low vision qualifications, and percentage undertaking follow-up or refresher training were explored. Training i.e. forms of follow-up training—where, who, and what training was provided, the type and the location (local or international) of training courses undertaken by professionals were also covered.

The categories of low vision health professionals who provide eye care at the primary, secondary, and tertiary levels vary in each country. A multidisciplinary team of personnel is required for optimal low vision service delivery. The survey therefore examined the following low vision personnel—ophthalmologists, optometrists, and mid level ophthalmic personnel (MLOP). ‘Ophthalmic personnel’ is a broad term encompassing the following—orthoptists, ophthalmic nurses, ophthalmic assistants, optical assistants, rehabilitation officers, teachers, and community based rehabilitation workers.

Questions relating to professional development were covered by the case studies, e.g. whether or not low vision professionals have access to the latest low vision research and technology, and if and how people access activities of professional development.
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Barriers

The barriers section of the survey includes questions on the groups of people less likely to access low vision services and the most common reasons for those groups not accessing them. Additionally, respondents were asked to specify the most common reasons for the lack of low vision resources or services.

Equipment

This section ascertained the availability of, and barriers to, obtaining low vision equipment e.g. whether or not low vision devices are available as part of the low vision service, the kinds of low vision equipment available through low vision services (e.g. optical and non-optical low vision devices), and the proportion of children and adults obtaining low vision devices when prescribed. Additional areas probed within the case study interviews include how these devices were sourced and the cost of devices.

Monitoring and evaluation

The questions on monitoring and evaluation investigated the current procedures in place to monitor services, and evaluate outcomes of low vision services and programs.

Providing quality care is an important aspect of low vision services, and without ongoing monitoring and evaluation, there is no means to identify the effectiveness and efficiency of services being provided.\textsuperscript{252} Quality low vision service consists of doing the right things for the right people at the right time, and doing things right first time.\textsuperscript{252} According to Maxwell\textsuperscript{253} there are six core dimensions of quality—effectiveness, efficiency, acceptability, access, equity, and relevance. All these dimensions have a critical impact on the coverage of delivery and services.\textsuperscript{220}

While the survey determined the presence of monitoring and evaluation and examined what was being done, exploring the various aspects of monitoring and evaluation in much greater detail was possible in the case studies. The next six topics identify the areas explored in the case studies (Appendix D).
Service effectiveness

Some of the questions asked in the case studies to gauge effectiveness were:

1. How many people have accessed these services since its establishment (or this year)?
2. What is the total number of people requiring these services?
3. How have the services helped you? (question directed to the client)
4. What more can be done to further improve client outcomes?

Service efficiency

The questions on service efficiency related to more or other efficient ways to deliver low vision services.

Service access

1. What proportion of people with low vision can or do access services?
2. Can people get service when they need it?
3. What barriers did you face when accessing these services or before you accessed these services?
4. How do you deal with barriers when accessing low vision services?
5. Who cannot use services?

Service acceptability

The case study questions used to determine service acceptability included:

1. Are services relevant?
2. Are services fair?
3. Are services flexible?
4. Are services responsive to the demand of peoples’ need for low vision services?

Service equity

Service equity is also a part of Vision 2020’s goal in working towards establishing comprehensive low vision services. Equity through action on the social determinants of
Chapter 3 Methodology

health has also become one of the WHO’s latest approaches to development (Chapter 2.4.3.3; p.26).

Some of the case study questions further exploring the topic of equity were:

1. What is being done so far to include people most likely not to access services?
2. What are the challenges in ensuring everyone can access services?

Relevance

Relevance refers to the balance and overall pattern of services while taking into account the needs and wants of the low vision population. To measure relevance the following case study interview questions were asked:

1. If you had a magic wand, what would you like to see happen in the delivery of low vision services? I.e. what would be your ideal low vision service system?
2. What do you think are the steps/strategies to take to achieve this ideal situation?

Sustainability

Sustainability of services is essential if current services are to serve the needs of the low vision population and keep up with changing global trends. Service sustainability is also a component of Vision 2020’s goal to have in place a sustainable, equitable, comprehensive eye-care system (Chapter 2.4.3.2; p.26). Questions included in the case study interviews were:

1. What aspects of low vision services are most/not sustainable?
2. What strategies could be used towards achieving sustainability?

Participant information

This included the name and the type of organisation the person worked for and any affiliations their organisation had. This was to determine whether the person was associated with an official organisation(s) such as Vision 2020, national prevention of blindness committees and/or the government or non-official organisations such as local or international NGOs. The other questions covered current job position and profession e.g. ophthalmologists or optometrists etc., and details about any formal qualifications and training completed.
3.3 The Survey

Once the range of topics was determined and questions generated, a survey form (Appendix B) was developed, pilot tested and then distributed to 195 countries. Ethics approval was applied for and obtained at the Royal Victorian Eye and Ear Hospital (RVEEH) in 2006 (Appendix G). A review of the literature revealed that there were no previous types of surveys available to conduct this research and source the kinds of information required. Thus the development of a new survey was necessary to address the following research questions:

1. What is the current global situation of low vision services provided in each country?
2. What are the critical success factors in the coverage of low vision services?

3.3.1 Survey Development

A self-administered survey was developed between March and June 2006 (Appendix A). The survey sought information from a national perspective. During the development stage, common pitfalls associated with survey design as identified in the literature review were taken into consideration (Chapter 2.5.1; p.44). For example:

- To improve poor response rates - provide unambiguous questions that are clear, short, and specific; limit the number of questions asked; and include only the most important questions.
- To reduce missing data - increase the number of multiple choice questions and have more close-ended question rather than open-ended questions.

From July to October 2006, a pilot study was conducted to examine the overall format of the survey (Appendix A) and the questions. A reference group consisting of 18 persons was given two months (July to August 2006) to provide feedback. The reference group was chosen to represent the target population who would eventually complete the survey, and was asked to complete the survey from a national perspective in their respective countries. The group consisted of people from the WHO, Sight Savers International (SSI), Christian Blind Mission International (CBMI), Christian Blind Mission Australia, Vision 2020 Australia, National Focal Persons, Vision Australia and eye health professionals from the Victorian Low
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Vision Working Group. As part of the pilot study, a pre-test was carried out with members of CERA staff to detect any structural issues in the survey (Appendix A).

The survey (Appendix A), an evaluation form, and covering letter were e-mailed to the reference group. The evaluation form (Table 3) consisted of 13 questions requiring a ‘yes’, ‘no’, or ‘not applicable’ response. Spaces were also provided for participants to provide further comments and identify the question(s) requiring further review. The evaluation form assessed three main areas pertaining to the survey:

1. format of the questions
2. content of topics
3. layout of the questions

Table 3 Pilot study evaluation form

<table>
<thead>
<tr>
<th>Area</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Format of the questions</td>
<td>Are the directions in the survey easy to follow?</td>
</tr>
<tr>
<td></td>
<td>Are all the questions appropriately worded?</td>
</tr>
<tr>
<td></td>
<td>Are any of the questions asked in a biased manner?</td>
</tr>
<tr>
<td></td>
<td>Are all possible alternatives for all questions provided?</td>
</tr>
<tr>
<td></td>
<td>Are the choices in multiple choice questions mutually exclusive?</td>
</tr>
<tr>
<td></td>
<td>Are all the questions asked necessary?</td>
</tr>
<tr>
<td>2. Content of topics</td>
<td>Do you feel all topics covered are relevant?</td>
</tr>
<tr>
<td></td>
<td>Are there any important topics missed?</td>
</tr>
<tr>
<td>3. Layout of questions</td>
<td>Are the questions logically ordered and sequenced?</td>
</tr>
<tr>
<td></td>
<td>Is there enough space provided to fill out responses?</td>
</tr>
<tr>
<td></td>
<td>Are branching or skipping questions easy and logical to follow?</td>
</tr>
<tr>
<td></td>
<td>Is the overall layout of the survey appropriately designed and set out?</td>
</tr>
<tr>
<td></td>
<td>Is the survey too long?</td>
</tr>
</tbody>
</table>

In October 2006 feedback from the respondents in the pilot study was analysed and the survey (Appendix A) was modified accordingly. The list of issues addressed by the pilot study and pre-testing included the length of the survey, repetition of questions, order and sequencing of questions and themes, suitability of open and closed-ended questions,
logistics of the survey, aesthetics of the form, general readability and the content and presentation of the cover letter. The pilot study resulted in numerous changes to the survey form (Appendix A) and supported the rationale behind the format of the final survey (Appendix B). The key changes are detailed below.

Feedback from the pilot study identified that the survey (Appendix A) needed to account for countries either without good or reliable data or data that may not be known. To maximise response rates and maintain consistency in responses the reference group suggested that where possible, questions should be closed and multiple choice. Thus, 26 out of the 33 questions (Appendix B) were either closed (e.g. a yes/no response required only) or multiple-choice. Additionally, the option ‘other’ with space to accommodate additional responses was provided (Appendix B).

The reference group also drew attention to the three tables in the human resources section (Appendix A). Members of the group felt that the multiple tables deterred them from filling out the survey form as a lot of information was being sought by the researcher and it was time-consuming to complete. Hence, the tables were condensed into one table (Appendix B) by limiting the questions to only two open ended questions (the number and location of low vision training) and for the remaining questions, multiple choice responses were provided from which the participants could choose.

For multiple choice questions that required a numerical response—e.g. questions that asked about the coverage of services or the percentage of people having access to low vision devices—a range of possible answers was provided (Appendix B). Coverage categories were presented as multiple choices (increasing in 10% increments leading up to 100%) in the coverage question of the survey (Appendix B question 17). Although this reduced data precision, it was designed to increase the response rates in reporting coverage as many countries did not have good prevalence data.\textsuperscript{68} The final version of the survey (Appendix B) was shown to visiting WHO delegate Dr. Serge Resnikoff, who, at the time, was the Coordinator of Chronic Diseases Prevention and Management.

The survey was designed in Microsoft Word and setup so that respondents could complete the survey in the Word document and email their responses (Appendix B). The survey was
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sent as an attachment via e-mail with the covering letter (Appendix C). Where there were no e-mail addresses available, the survey form was either posted or faxed. Alternative options were considered prior to deciding on the Word format. This included designing a web survey using free online websites (such as http://www.surveymonkey.com/) or designing the form in a writable PDF format. However those options were deemed unsuitable because it could not be readily assumed that all participants would have access to the Adobe software or regular Internet access. The survey was in English and translated into six other major languages – French, Portuguese, Spanish, Chinese (simplified), Chinese (traditional) and Russian.

The letter (Appendix C) provided a brief background to the research, rationale for the study, and asked the survey participants where possible to provide responses that reflected the national situation of services in their country. If this was not feasible the participants were asked to indicate beside the question concerned what perspective the response(s) were answered from (e.g. organisation, regional, and provincial). This would enable the researcher to judge whether to source a different contact or additional contacts to piece together one national perspective.

Other instructions given were to provide responses in English where possible, the date, and how to return the surveys i.e. via e-mail, fax, or post. The contact number and e-mail of the researcher was also provided before thanking the person and concluding the letter (Appendix C).

3.3.2 Recruitment of Participants

Two months prior to survey distribution, the researcher started to build up a list of potential contacts. A ready-list of potential contacts to complete the survey was not available initially, thus, the researcher adopted the snowballing technique to generate a list of contacts (Figure 2). The initial contact was made with a small group of people who were supervisors and experts in the field. The contacts obtained, in turn, provided more contacts in more countries and the process was repeated until contacts were obtained for the majority of the countries throughout the world.
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The types of participants sourced and contacted were service providers, program managers, and directors of eye care organisations working or affiliated with official organisations. For example: Vision 2020 Committees and National Prevention of Blindness Committees (PBL). If no contacts were elicited, persons from the International Agency for the Prevention of Blindness (IAPB), the WHO, government departments (Ministry of Health or the Ministry of Education) were contacted. If still no contacts could be found, then both international and local NGOs were approached for potential contacts (Figure 2). For countries where no contacts could be obtained, the researcher continued efforts through consulting supervisors again and re-contacting official organisations, NGOs, WHO, IAPB, and governments to establish whether anyone from these organisations were aware of possible contacts for certain countries (Figure 2).

![Figure 2 Snowballing technique to source survey participants](image)

3.3.3 Data Collection

Once the list of potential contacts was compiled, the survey was distributed in November 2006 to 192 WHO member states\(^{254}\) and three additional countries—Hong Kong, Taiwan, and Wales. Wales was not included with the United Kingdom as it has a separate low vision
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service system. The member states were divided into six WHO regions— the Americas, Africa, Europe, Middle East, South East Asia, and the Western Pacific. Survey participants were asked to complete the survey from a national perspective of low vision services.

The researcher acknowledged that providing an overall view of services in some countries would be difficult. Diversity within countries was acknowledged. For example, an absence of a functioning coordinating body for low vision in China meant that the survey was only completed on a limited number of provinces and required substantiation from other sources. Similarly, fragmented information from the United States meant that more than one participant was necessary and multiple responses had to be collated to obtain a national perspective.

Several countries had more than one potential contact; hence more than one copy of the survey was sent to those countries. This was done to ensure a better chance of eliciting a response. Contacts were not found for all countries in the first mail-out. Efforts to source contacts continued till May 2008. Follow-up and distribution times varied between countries, depending on when viable contacts were found. For example, eight different sources were contacted in Norway before an eligible and/or willing group of respondents was found.

In countries where a response was received either from official or non-official contacts, an average of four to five follow-ups on a monthly basis were made between December 2006 and May 2008, unless data were received (Figure 3). Copies of the survey were distributed throughout November and December 2006, in some cases more than one copy was sent to one country.

3.3.4 Data Cleaning

Once data were received, data cleaning commenced (Figure 3). The data were checked for any inconsistencies, contradictions, and outliers. Data cleaning took approximately three months. Open-ended questions and ‘other, please state’ items in multiple choice questions were answered differently across the respondents. For example, some people filled in one word answers while others communicated in two to three paragraphs and others attached extra information such as reports and published papers with the survey.
Contradictory or incomplete data were reported by 44 countries and these were returned for clarification to the survey participants concerned. Survey data from a further 12 countries that were not completed by official contacts were sent to experts in Vision 2020 such as regional offices and the WHO for verification (Figure 3).

Survey responses in languages other than English were also received such as Spanish, French, Russian, and Chinese. There were no responses in Portuguese. Data cleaning of translations consisted of translating the English translation back to the original language by an independent translator (back translation). The objective of back translation is to ensure that the meanings of the responses were interpreted correctly.
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Figure 3 Flow chart showing survey distribution pathways
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Once the data cleaning process was complete, the responses were entered into a Microsoft Access database by the researcher. A master list of all respondents was retained by the researcher in a Microsoft Excel spreadsheet. Time taken for data entry totalled approximately one and a half months. The data were randomly checked to ensure there were no data entry errors. If more than 20% of errors were detected, all data received would be double checked.

3.3.5 Results Verification

For contacts that failed to respond to the invitation to complete the survey and countries that failed to report any data after multiple follow-ups, verification by secondary sources was conducted.

Sources such as the World Wide Web, grey literature, and unpublished resources (conference proceedings or reports) were used. This process consisted of searching secondary resources using databases (MEDLINE, Web of Science, PubMED, Scopus), Library catalogues, Google, Google Scholar, websites of major International and national NGOs, and government websites of individual countries. Miscellaneous websites pertaining to the vision field were also covered. Two examples were http://www.tiresias.org/index.htm\(^{255}\) which is an information resource for people working in the field of visual disabilities, and http://allafrica.com/.\(^{256}\)

In some instances e-mail addresses of staff in organisations working in the field of vision were found, and attempts were made to contact these organisations for any information about services in the country. Unfortunately, no information on services could be found using this strategy as no one replied or the e-mails had bounced. The main keywords used were low vision, low vision services, vision/visual impairment, vision agencies, blind, vision rehabilitation, and country name. Subsequent to secondary data verification, the researcher contacted the relevant experts in the field (again sourced from WHO, IAPB, and/or Vision 2020 regional offices) for confirmation of the presence of services and/or further information.
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For the countries where no contacts could be found or no further information could be sourced after secondary data searching and consultation with experts, the service status of these countries was entered as ‘no information available’ in the Access database.

After data entry on all countries was complete, the countries were classified into four categories (Figure 3):

1. Data and presence of low vision services confirmed through survey
2. Some evidence of services confirmed though secondary sources
3. Confirmation of no low vision services confirmed through survey and experts in the field of the respective regions
4. No information - no evidence of services could be found from survey, secondary sources or experts in the regions concerned

Following this, one final attempt was made for verification. Data on all countries, organised in their respective regional tables and classified into the four categories, were sent out to WHO experts, IAPB, and regional coordinators to confirm the presence or non-presence of services.

The original timeline given to follow-up on survey responses was six months. By the end of five months, the response rate was 35% (68/195). Lack of responses was mainly from countries in Europe, Eastern Mediterranean and African regions. The follow-up period was extended by another eight months in order to maximise the response rates so that the researcher could confidently generate meaningful results, and continue to search for alternative contacts through the snowballing effect. By March 2008, 62% (120/195) of countries had responded. Over the last two months of follow-up, only seven more responses were received.

3.3.6 Importance of Results Verification

For data to be entered into the WHO Infobase (in late 2009), the data must be verified by official persons i.e. WHO, Vision 2020, and IAPB. Thus, data verification was a crucial component because in addition to clarifying inconsistencies and contradictory pieces of information, it enabled official verification of data in countries where the survey did not come from official contacts (Figure 3).
3.3.7 Data Analyses – Part I

The sources of data consisted of information from the survey, interviews, secondary sources, and experts. Qualitative techniques were used to summarise the findings from the pilot study, while quantitative techniques were used to conduct the survey data analyses. Queries were conducted within the Access database to draw out the data required. The data were then exported into Microsoft Excel 2007 to generate the descriptive statistics and graphs. In addition, individual country data were exported to Microsoft Word and entered into a table template to generate the tables for preparation of entry into the WHO InfoBase (Appendix F).

3.3.7.1 Pilot Study

Findings from the pilot study were summarised into the following areas:

- response rates from the reference group
- content of the survey
- presentation and format of the survey (including specific questions pointed out by the reference group)
- other recommendations made by reference group i.e. changes to the cover letter.

3.3.7.2 Survey Distribution

The following survey distribution outcomes were summarised:

- response rates (percentages and counts)- overall and regional rates
- response rates compared with other data i.e. presence of a national vision 2020 committee and national eye care plan (bar graph).

3.3.7.3 Results Verification

Data verification was carried out prior to addressing the three research aims. Descriptive statistics i.e. frequencies and tables were used to describe this section. It included processes adopted to manage:

- inconsistencies identified in the survey data
- countries requiring data clarification
- countries requiring secondary source verification
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- countries with more than one survey received
- service status presence/absence of services for each region.

3.3.7.4 Survey Respondents

Descriptive statistics i.e. percentages and table were used to sum up the characteristics of respondents.

3.3.8 Data Analysis – Part II (Research Questions)

Data for the first two research questions (current global situation of services and identification of CSFs) were taken from the survey. Data were exported from the Access database into the statistical software package STATA 10 (StataCorp, College Station, Tex., USA) and SPSS 17.0. For the third research question (the issues behind the CSFs in the coverage of low vision services to gain an understanding of the reasons for good/poor coverage) data were analysed from the case studies.

3.3.9 Question 1: Current Global Situation of Low Vision Services

Question 1 identified the current situation i.e. what, where, who, and how services are delivered in each country. Frequencies, relative frequencies (proportions and percentages), and graphs were generated for this question. The data were presented using the HPI. Comparisons were made between developed and developing countries and illustrated by a bar graph. Further to this, chi-squared tests were carried out to test for significant associations with HPI.

The aspects of service provision examined in this research question were based on the following survey themes:

- **Epidemiology of low vision**: Percentages and counts were used to show the main definitions reported by countries to define low vision as well as the level of vision impairment required for people to be eligible to receive services and main causes of low vision.
• **Policies:** Percentages and counts were used to present the data on the existence of national eye care plans, eye care plans that included low vision, national referral guidelines for low vision, and guidelines for standards of low vision practice.

• **Human resources:** The regional number and mix of human resources were presented using a bar graph. Univariate analyses using the chi-square tests were carried out to determine any association between the different mix of human resource cadres and the dependent variable coverage. Under the human resources training section, for both developed and developing nations, three bar graphs displaying frequencies were generated to display: the number of low vision personnel holding low vision qualifications (0%, ≤50%, >50%), training type (formal and informal), and training locations (local, international, and both).

To assist with interpreting results for human resources, the following terms are clarified:

- Formal training—refers to certificates, diplomas, masters, and training that is part of a recognised degree.
- Informal training—denotes on-the-job and/or national focal person training.

Throughout the results Chapter, the ratio of health professionals per 10 million population is used. This ratio was chosen to be consistent with the Vision 2020 target.5

• **Service provision:** data showing the location and type of services were again presented using the HPI and illustrated by a bar graph.

• **Funding:** a table was used to present the percentages and counts on the different sources of funding used to provide low vision services in countries. These were: being fully funded by government, fee-based and subsidised by government only, fee-based and/or subsidised by government as well as non government support, and finally local and international non government support only.

• **Low vision devices:** percentage and counts were used to describe the inclusion of devices in low vision care and its affordability.

• **Barriers:** Several features of barriers pertaining to service provision i.e. reasons for people not obtaining devices, groups of people most likely to miss out on services, barriers to accessing services, and reasons for the lack of services or resources were compared between developed and developing countries using the HPI. All features asides from reasons for lack of service or resources were illustrated using bar graphs.
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- **Monitoring and evaluation:** Percentages and counts were also used to present the number of countries that carried out monitoring and evaluation of low vision services. Comparisons between developed and developing countries were made on the most frequent procedures, indicators, and outcome measures used.

**Global presence and coverage of services**

This section identifies which countries have services and which do not, as well as ascertains the coverage of low vision services in countries that do have services. First, descriptive statistics were used to determine the number of countries and regions with a presence/absence of services. This was presented in a table. The table also included the number of countries with low vision prevalence data sourced from the Pascolini et al. study.

Second, a bar graph was generated to compare the regional presence of services with regional Cataract Surgical Rates (CSR) per million. The data on CSR per million were sourced from Vision 2020, imported into the Access database and then grouped into three categories: <1000, 1000-2499, and >2500 per million. However, it was found that including all three rates cluttered the bar graph and obscured this result. Thus, only the presence and CSR <1000 per million were displayed in the final graph.

Third, in countries with a presence of low vision services, the coverage of these services was outlined according to the following categories: ≤10%, 11-50%, and >50%. The regional presence of services is subsequently presented as one bar graph in order to make comparisons. The global presence and categories of coverage of services are presented in a global map generated using the Global Mapper v9.03 software.

Finally, a count revealed that only eight countries had coverage >50%. A table displaying these countries was generated.

**3.3.10 Question 2: CSFs in the Coverage of Low Vision Services**

Question 2 relates to the identification of the factors that contribute to poor (≤10%) or better (>10%) coverage. To do so, univariate analysis, logistic regression, and the Classification Analysis and Regression Tree (CART) methodology were used. While STATA 10 was used to perform univariate associations and multivariate logistic regression analysis,
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CART was analysed using SPSS 17.0. The dependent variable (coverage) and selected independent variables were investigated in the analyses.

3.3.10.1 Dependent Variable

Coverage of services was the dependent variable in this question. A country with better coverage is one that has >10% of those requiring services accessing low vision services while poor coverage is defined as those countries with ≤10% of those requiring services who access low vision services. Other cut-off points such as 20%, 30%, and 50% were also tested with the CART methodology. However, these produced insignificant outputs as only a very small number of countries had >10% coverage.

3.3.10.2 Independent Variables (Critical Factors)

The independent variables were factors judged to be critical in the delivery of low vision care, hence the term ‘critical factors’.

The factors were categorised into two groups:

1. Service-related (Table 4), are from the items of the survey that had been sourced from Vision 2020, Alma-Ata (primary health care), the social determinants of health, appraisal of past and current models of low vision service delivery and barriers facing service provision; and examined under research question 1.

2. Socioeconomic and demographic variables (Table 5), which were secondary data drawn from the WHO\textsuperscript{29,257,258}, Vision 2020\textsuperscript{74}, United Nations (UN)\textsuperscript{2}, and the World Bank\textsuperscript{259}. These variables were included to represent the broader health care system in which low vision services operate and assessed whether they influence the coverage of low vision services.

Service-related critical factors

**Table 4** Services-related critical factors

<table>
<thead>
<tr>
<th>Service-related</th>
<th>National policies on low vision</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Presence of a national eye care plan that includes low vision</td>
</tr>
<tr>
<td></td>
<td>National referral guidelines for low vision services</td>
</tr>
</tbody>
</table>
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### Service-related
- Standards of practice guidelines for low vision services

### Type of low vision care—monodisciplinary care compared with the different types of multidisciplinary care:
- Type 1: Clinical, education, rehabilitation and social welfare services
- Type 2: Clinical and education and social welfare and any one of form of rehabilitation service*

### Funding type
- Fully funded by government
  - National health insurance
  - National health insurance (with universal access)
- Subsidised by government
- Out-of-pocket
- Private insurance
- Supported by NGO
- Supported by INGO

### Barriers to access
- Lack of integration between low vision services with other eye care services, education, and rehabilitation
- Waiting times between urban and rural areas
- Lack of funding
- Lack of human resources
- Lack of referral networks
- Lack of awareness on low vision
- Lack of infrastructure
- Lack of a national policy on low vision

### Low vision human resources per 10 million of population
- Ophthalmologists
- Optometrists
- MLOP
- Specialist teachers
- Community based workers
- Rehabilitation officers
### Service-related

**Human resources skills mix e.g. within HR mix 1 and HR mix 2**

**HR mix 1:**
1. MLOP $\alpha$ and (Education and rehabilitation)$\beta$ vs.
2. Ophthalmologist and MLOP and (Education and Rehabilitation)$\beta$

**HR mix 2:**
1. MLOP and (Education and Rehabilitation)$\beta$ vs.
2. Ophthalmologist and MLOP

**Clients – adults and children**
- Proportion of children and adults obtaining devices when prescribed
- Proportion of children and adults receiving services

**Location of low vision services**

**Location type 1:**
1. Only hospitals vs.
2. Hospitals and have one of these rehabilitation locations**

**Location type 2:**
1. Public hospitals and NGO rehabilitation agencies or community based services vs.
2. Public hospitals and government rehabilitation agencies vs.
3. Private hospitals and clinics and NGO rehabilitation

*Forms of rehabilitation- orientation and mobility, sports and recreation, vocational training and technology training*

$\alpha$ MLOP = consists of MLOP and Optometrists

$\beta$ Education and rehabilitation = consists of CBR and Rehabilitation workers and teachers

**Rehabilitation locations- government rehabilitation agency, NGO rehabilitation agency, and community based services**

The following independent variables—type, location of low vision services, and types of groups of human resources (i.e. HR mix) — were included to understand service provision in the real world (Table 4). For example, services in some countries are provided predominantly by ophthalmologists and optometrists, while in other countries, services are provided mainly by MLOP and community health workers. Therefore, it was important to investigate whether the different combinations and mix were associated with coverage of low vision services. Many different combinations were explored provided that they were realistic with the situation in the field and had enough data. Not all of these are shown in Table 4 as either they did not have enough data or no country had such combinations.
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Socioeconomic and demographic critical factors

Table 5 Socioeconomic and demographic-related factors

<table>
<thead>
<tr>
<th>Socioeconomic and demographic-related</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health expenditure</strong></td>
<td></td>
</tr>
<tr>
<td>- Per capita total government expenditure on health</td>
<td></td>
</tr>
<tr>
<td>- Private expenditure on health as percentage of total expenditure on health</td>
<td></td>
</tr>
<tr>
<td>- Out-of-pocket spending on health as percentage of private expenditure on health</td>
<td></td>
</tr>
<tr>
<td>- External resources on health as percentage of total expenditure on health</td>
<td></td>
</tr>
<tr>
<td>- Social security expenditure on health as percentage of general government expenditure on health</td>
<td></td>
</tr>
<tr>
<td><strong>Population statistics</strong></td>
<td></td>
</tr>
<tr>
<td>- Population over 60 years (%)</td>
<td></td>
</tr>
<tr>
<td>- Population under 15 years (%)</td>
<td></td>
</tr>
<tr>
<td>- Population living in urban areas (%)</td>
<td></td>
</tr>
<tr>
<td>- Population living on &lt;$1 a day (%)</td>
<td></td>
</tr>
<tr>
<td><strong>Human resources in general</strong></td>
<td></td>
</tr>
<tr>
<td>- Physicians per 10,000 population</td>
<td></td>
</tr>
<tr>
<td>- Nursing and midwifery personnel per 10,000 population</td>
<td></td>
</tr>
<tr>
<td>- Community health workers per 10,000 population</td>
<td></td>
</tr>
<tr>
<td>- Other health care workers density per 10,000 population</td>
<td></td>
</tr>
<tr>
<td><strong>Development status</strong></td>
<td></td>
</tr>
<tr>
<td>- Annual economic growth (GDP)</td>
<td></td>
</tr>
<tr>
<td>- Country income level (low, middle, high)</td>
<td></td>
</tr>
<tr>
<td>- Information and communication technologies access per 1000 population</td>
<td></td>
</tr>
<tr>
<td>- Human poverty Index (HPI)</td>
<td></td>
</tr>
</tbody>
</table>

The socioeconomic and demographic-related variables are listed in Table 5. One of the issues with using the CART is that there is the risk of including too many critical success factors into the model, resulting in data dredging (Chapter 2.5.4.2; p.54). After consultation with supervisors and reviewing the literature, the researcher was able to reduce this risk by including only the most relevant socioeconomic and demographic-related variables into the CART model. This was achieved using the following: in cases where two variables related to the same topic, only one would be included in the model, e.g. information and communication technologies policy and Information and communication technologies access. The latter was selected, as ‘access’ was an integral part of service coverage. The rationales for selecting other critical factors are provided below.
Health financing: this is a critical component of health systems. The survey identified whether services are funded by government or by the private sector. Past studies have shown that relying on one source of funding is often unsuccessful in terms of achieving universal coverage.\(^{260-262}\) Instead, establishing a system in which services are funded by both public and private sources is more likely to lead to sustainable financing of health services.\(^{263}\) Hence, the following health expenditure factors assessed whether the different types of funding could be associated with the coverage of low vision services.

- Per capita total government expenditure on health
- Private expenditure on health as a percentage of total expenditure on health
- Out-of-pocket spending on health as percentage of private expenditure on health (measured as direct expenses households made to health care professionals and suppliers of pharmaceuticals, therapeutic appliances and other goods and services)
- External resources on health as percentage of total expenditure on health (all grants and loans whether passing through governments or private entities for health goods and services, in cash or in kind)
- Social security expenditure on health as percentage of general government expenditure on health

Population statistics: these are factors that could impact on the proportion of services delivered to adults and children as well as on the distribution of services and human resources between urban and rural areas.

- Population over 60 years (%): this indicator may influence what services may be available as many causes of low vision are age-related. For instance, in developed countries, there may be a greater need for adult rehabilitation as there are greater numbers of people over 60 years.
- Population under 15 years (%): this indicator could also shape what services may be available. For instance, in developing countries the population is younger and so there may be more services for children.
- Population living in urban areas (%): this can give a good indication of the percentage of people living in areas and be related to the location of low vision services.
- Population living on <$1 a day (%): poverty may also affect people accessing low vision care and services.
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Health care workers: indicators that assess the availability of health workers are critical to understand the health resources in a country. While there are no gold standards to assess the sufficiency of the health workforce to address the health care needs of a given population, low numbers of health personnel usually suggest inadequate capacity to meet essential services. Low numbers may also reflect the human resource situation in low vision service provision, e.g. if there was a shortage of nurses in the country then there may also be a shortage of ophthalmic nurses.

- Physicians per 10000 population
- Nursing and midwifery personnel per 10000 population

The World Health Report in 2006 estimated that countries with fewer than 23 physicians, nurses and midwives per 10000 population generally fail to achieve adequate coverage rates for selected primary health care interventions.

- Community health workers per 10000 population: many countries, especially ones with shortages and maldistribution of highly skilled medical and nursing professionals, rely on community health workers i.e. community health aides, trained and working in the communities from which they come from, to render basic health services.
- Other health care worker density per 10000 population: The number of other health service providers (except physicians, nursing and midwifery personnel, dentistry personnel and community health workers) per 10000 population. This indicator was used because it included: general ophthalmic personnel, i.e. optometrists and opticians.

Development status of the countries: the development level and wealth of the country may have an impact on the resource distribution on low vision service provision as well as the country’s ability to support low vision care.

- Annual economic growth: annual economic growth is measured by the Gross Domestic Product (GDP)
- Country annual income level: low income ≤$765; middle income $766-$9385; high income >$9386 as at 2006
- Information and communication technologies access per 1000 population: Access to digital technologies, such as networked computers, video games, the Internet, mobile phones and DVD per 1000 of population
- Human poverty Index
3.3.10.3 Univariate Analysis

Univariate analysis was carried out to detect significant associations between the outcome coverage and each of the service-related (Table 4) and socioeconomic-demographic (Table 5) independent variables respectively. Specifically, chi-square, Fisher Exact, and the Wilcoxon-Mann-Whitney tests were applied. The chi-square test detects if there is a relationship between the outcome and categorical independent variables. The test assumes that each cell has an expected frequency of five or more, while the Fisher’s Exact test has no such assumption and can be used regardless of how small the expected frequency is. Thus, the Fisher Exact test was used when one or more of the cells had an expected frequency of five or less.

The Wilcoxon-Mann-Whitney is a non-parametric test and was used when it could not be assumed that the continuous (ordinal or interval) independent variable was normally distributed. Normality was determined by conducting the Skewness-Kurtosis test in STATA.

For socioeconomic-demographic critical success factors, coverage had three groups—countries with zero, ≤10% (poor) or >10% (better) coverage. Service-related variables used two coverage groups; ≤10% (poor) or >10% (better). This was because countries with zero coverage do not have any service-related variables to contribute to the analyses.

Data were presented in tables and described as medians (25th percentile, 75th percentile) for continuous variables, and as counts (percentage) for categorical variables. For socioeconomic-demographic independent variables, the differences in continuous variables and the three groups of coverage (i.e. countries with zero, ≤10% or >10% coverage) were compared using Kruskal-Wallis rank test. This was followed by a post hoc Wilcoxon-Mann-Whitney test with Bonferroni correction if significant effects were revealed.

For logistic regression analysis, collinearity, number of missing values, and missing patterns were checked among all independent variables. Missing pattern checks were conducted to determine whether the variables were missing randomly or not. Variables with ≤20 missing values were included in the analyses. In addition, the STATA command ‘tetrachoric’ enabled all the variables entered into the model(s) to be checked for high correlations i.e. r > 0.8, at the same time. If two variables displayed high correlations with one another, one of the
variables was excluded from the analyses. For instance, national low vision health insurance and national low vision health insurance with universal access displayed an $r$ value of 0.9. Since both variables relate to the same topic, the latter was excluded from the analysis as the frequencies were smaller. $P$-values of $<0.05$ denote statistical significance.

### 3.3.10.4 Comparison of the CART with Logistic Regression

Once the independent variables with significant, univariate associations with coverage were identified, the service-related variables were grouped into the following themes—type of care provided, funding, barriers to accessing services, and human resources. Following this, the information is applied in stepwise logistic regression modelling to demonstrate the advantages of the CART over more traditional methods and to strengthen the argument for the application of the CART in this research.

For the socio-economic and demographic variables, as there were three outcomes (zero, ≤10%, >10% coverage), a logistic regression multinominal model was carried out to check for associations between these external contextual factors and coverage. However, to adjust for both service-related and socioeconomic and demographic factors, multivariate logistic regression modelling was conducted. Thus, countries with zero coverage were excluded in order to achieve this. Odds ratios (OR) are used instead of regression coefficients as it facilitated simpler interpretation. Confidence intervals are set at 95% and $P$-values of $<0.05$ denote statistical significance. Multivariate analyses are then conducted for each item and variables found significant are entered into the final multivariate logistic regression model if significant.

Finally, in order to be able to make statistical inference from the final model, a check was performed to ensure that the model fits sufficiently well. To assess the model fit, a classification table was produced using the ‘estat’ command in STATA to measure the overall predictive performance of the model as well as its sensitivity and specificity. The outcomes were compared with the model performance of the final CART model.
3.3.10.5 Identification of Critical Success Factors Using the CART

CART analysis is used to identify the critical success factors in the coverage of low vision services. The outcome variable in the CART is coverage and has either a value of 0 or 1—0 for ≤10% (poor coverage) or 1 for >10% (better coverage). CART constructs a tree that separates the data in the most appropriate or ‘best’ way by finding binary splits on variables and the best splitting point at each stage. The decision rule is determined by the Gini criterion, a measure of variability within the new subgroups. The Chi-squared Automatic Interaction Detection (CHAID) ‘growing’ method is applied to identify the independent variables that exhibit the strongest interaction with the outcome, coverage.

Other ‘growing’ methods were also tested to identify which produced the best model fit, e.g. Exhaustive CHAID—a modification of CHAID that examines all possible splits for each predictor, QUEST (Quick, Unbiased, Efficient Statistical Tree)—a method that is fast and avoids other methods’ bias in favour of predictors with many categories, and CRT—Classification and Regression Trees, which split the data into segments that are as homogeneous as possible with respect to the dependent variable coverage. Homogeneous, also known as a ‘pure’ node, is a terminal node in which all cases have the same value for the dependent variable. However, none of the other methods were able to achieve a higher predictive model performance percentage than CHAID. Cut-off points other than 10% were also considered; however, as previously discussed, there are too few countries with coverage >10% to be able to produce valid results.

The criteria set in the CHAID growing method to produce the CART models is listed below.

- The significance level for splitting nodes and merging categories is set at 0.05, which is consistent with the P-values of <0.05 applied in the univariate and multivariate analyses.
- The chi-square statistic for determining node splitting and category merging is calculated using the likelihood ratio. This method is the most appropriate method, given the small sample size in this research.
- The tree-growing criterion is set to control the number of levels in the tree and control the minimum number of cases for parent (the root) and child nodes (branches). This is
because the structure of a classification tree can grow into multiple levels or splits which can be practically insignificant and result in extremely complicated and an unexplainable tree structure. Therefore, it is important to restrict the growth of the tree and set priority stopping rules (the most appropriate tree size). Thus, the maximum tree depth was limited to three levels to control the maximum number of levels of growth beneath the parent node. The minimum number of cases, which controls the minimum numbers of cases for nodes, was ten cases for parent nodes and five cases for child nodes. Other cut-off points were also trialled for the ‘minimum number of cases’ e.g. 100 and 50 or 50 and 25: however the results were not meaningful. For instance, in one scenario only one parent node showing ‘proportion of children obtaining devices when prescribed’ was produced, while in another scenario only one parent (same as above) and one child node (percentage of population urbanised) were created.

- In terms of handling missing values, unlike logistic regression modelling, missing independent variable values are included in the analysis as a single, combined category. The CHAID ‘growing’ method first generates categories using valid values, and then decides whether to merge the missing category with its most similar (valid) category or keep it as a separate category.

- For each CART output, a classification table is displayed. This table indicates the overall predictive performance of the model (i.e. percentage of countries correctly classified with respect to each category of the dependent variable coverage) as well as the sensitivity and the specificity.

A CART model comprising of all relevant service-related and socioeconomic and demographic-related variables was generated with the CHAID growing method. Furthermore, validation was carried out on the CART output to assess the generalisability (how well the findings of the CART can be applied to real world settings) of the CART structure. Two validation methods were available—cross-validation and split-sample validation. The cross-validation method, with a 10 sample fold, was chosen. This was due to the small sample size (only 131 countries were included by the CART) hence, there were insufficient data for a separate test sample. The split-sample validation requires a training
sample. If the training sample is small there may not be enough cases in some categories to adequately grow the tree.  

The cross-validation procedure works by dividing the sample into a number of sub-samples, or folds. Tree models are then generated, excluding the data from each sub-sample in turn. The first tree is based on all of the cases except those in the first sample fold. The second tree is based on all of the cases except those in the second sample fold, and so on. For each tree, misclassification risk is estimated by applying the tree to the sub-sample excluded in generating it.

Applications of the CART technique on health service-related topics, especially in the arena of eye health services are limited. Possible reasons for the infrequent use of CART may be because traditionally, health service outcomes are often dichotomous; thus regression modelling such as logistic regression have been sufficient to determine the average effect of an independent variable on a dependent variable. Indeed if the CART had not been applied in this research, the results generated from the logistic regression modelling would be presented instead.

3.4 Case Studies

The survey was able to identify the current situation of low vision services (question 1), and establish the presence and coverage of low vision services, and identify the CSFs associated with coverage of services (question 2) using the CART methodology described above.

3.4.1 Question 3: Issues behind the Critical Success Factors

However, in order to gain an in-depth understanding into the CSFs associated with better (>10%) and poor (≤10%) coverage (question 2), the findings of the survey needed to be further corroborated with those of the case studies. Case studies allow further exploration into the factors identified by the survey and provide deeper insight into how to specifically achieve better coverage of low vision services.

This case study methodology is organised into the following sections:

a) Quality of the case study design
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b) Case study site selection
c) Data collection
d) Data analysis

3.4.2 Quality of the Case Study Design

Chapter 2 identified that case studies are to be designed in a way to enhance the ability to meet certain criteria. Furthermore, internal and external (generalisability of the study) validity may be an issue. While designing the case studies (e.g. how to conduct the case studies and the procedures required for data collection) the researcher took into consideration these potential issues (Table 6).

Consequently, internal and external validity, plus two additional criteria—construct validity and reliability, were incorporated into the stages of the case study methodology in order to achieve an appropriate level of quality.222

1. **Construct validity**—identifying the correct operational measures for the concepts being studied.
2. **Internal validity**—seeking to establish a causal relationship, whereby certain conditions are believed to lead to other conditions.
3. **External validity**—defining the domain to which a study’s findings can be generalised.
4. **Reliability**—the extent to which what is recorded as data is what actually occurred in the setting that was studied.

Several tactics have been employed to overcome the study’s shortcomings within the four tests (Table 6).

Table 6 Tactics deployed for four design tests

<table>
<thead>
<tr>
<th>Tests</th>
<th>Case study tactic used</th>
<th>Phase of research in which tactic occurred</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Construct validity</strong></td>
<td>Use of multiple sources of evidence</td>
<td>Research design, data collection</td>
</tr>
<tr>
<td><strong>Internal validity</strong></td>
<td>Not applicable for descriptive or explorative studies</td>
<td>Not applicable</td>
</tr>
<tr>
<td><strong>External validity</strong></td>
<td>Hypothesis made by researcher that there will be common issues among the three countries</td>
<td>Research design</td>
</tr>
</tbody>
</table>
Three of these criteria (construct validity, reliability, and internal validity) warrant further explanation:

- **Construct validity & reliability**

The researcher utilised multiple sources i.e. interviews, detailed recording of data, direct observations, archival records (e.g. past project reports), and where available, published or grey literature. Thus, the risks of generating subjective judgments were minimised and the researcher felt that this research is reliable as defined by these actions.

- **Internal validity**

Internal validity is a concern among explanatory case studies, when a researcher attempts to explain how and why event x led to event y. As the case studies in this research are descriptive and explorative in nature, internal validity is not a major concern.

### 3.4.3 Case Study Site Selection

Having determined themes and questions to use in the case study interviews, three countries were selected. They were India, Ghana, and Cameroon. These countries were chosen through recommendations from the WHO Low Vision Working Group, this is especially important given that the findings from this research are to be used by the group. Additional consultation with supervisors also guided the decision to focus on India, Ghana and Cameroon. These countries exhibit a cross section of the various features of delivery features and characteristics (Table 7).

<table>
<thead>
<tr>
<th>Features of optimal service</th>
<th>Source</th>
<th>Country and comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease control and eye care: inclusion of low vision at the</td>
<td>Vision 2020</td>
<td>India</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ghana</td>
</tr>
</tbody>
</table>

Source: Adapted from Yin 2009
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### Features of optimal service delivery

<table>
<thead>
<tr>
<th>Feature</th>
<th>Source</th>
<th>Country and comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service level and presence of services</td>
<td>Cameroon</td>
<td></td>
</tr>
<tr>
<td>Multidisciplinary services:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>Chiang et al$^6$</td>
<td>India</td>
</tr>
<tr>
<td>Education</td>
<td>Vision 2020$^{27}$</td>
<td>Cameroon (plans to start rehabilitation)</td>
</tr>
<tr>
<td>Rehabilitation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comprehensive services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary level</td>
<td>Vision 2020$^{27}$</td>
<td>India (successful)</td>
</tr>
<tr>
<td>Secondary level</td>
<td>Chiang et al$^8$</td>
<td>Ghana (unsuccessful)</td>
</tr>
<tr>
<td>Tertiary level</td>
<td></td>
<td>Cameroon (starting)</td>
</tr>
<tr>
<td>Quaternary level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Integration:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Levels of comprehensive services integrated into existing services and sectors i.e. medical, education, rehabilitation</td>
<td>Vision 2020$^{27}$</td>
<td>India</td>
</tr>
<tr>
<td></td>
<td>Chiang et al$^8$</td>
<td>Ghana (re-establishing)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cameroon (starting)</td>
</tr>
<tr>
<td>Sustainability</td>
<td>Vision 2020$^{27}$</td>
<td>An issue for all three countries but more so for Ghana and the medical and rehabilitation sectors in India. Services in Cameroon only starting.</td>
</tr>
<tr>
<td>Equitable services</td>
<td>WHO$^{154}$</td>
<td>Examples found in each of the three countries</td>
</tr>
<tr>
<td></td>
<td>Vision 2020$^{27}$</td>
<td></td>
</tr>
<tr>
<td>Primary health care:</td>
<td>Alma-Ata (WHO)$^{155}$</td>
<td>India (existing)</td>
</tr>
<tr>
<td>Community based rehabilitation (CBR)</td>
<td>Vision 2020$^{27}$</td>
<td>Ghana (unsuccessful)</td>
</tr>
<tr>
<td></td>
<td>Chiang et al$^8$</td>
<td>Cameroon (plans to implement)</td>
</tr>
<tr>
<td>Human resources:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low vision cadres-ophthalmologists, optometrists, MLOP, rehabilitation officers, community based workers, specialist teachers</td>
<td>Vision 2020$^{27}$</td>
<td>India</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ghana</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cameroon</td>
</tr>
</tbody>
</table>
Chapter 3 - Methodology

<table>
<thead>
<tr>
<th>Features of optimal service delivery</th>
<th>Source</th>
<th>Country and comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infrastructure and technology:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low vision infrastructure and low vision equipment e.g. devices</td>
<td>Vision 2020</td>
<td>India</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ghana</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cameroon</td>
</tr>
</tbody>
</table>

3.4.3.1 Background of Each Country

India

India is a country of 1,166,079,217 people. European traders, beginning in the late 15\textsuperscript{th} century, began arriving in India and by the 19\textsuperscript{th} century the British had colonised the country and assumed political control. India achieved independence in 1947.

India’s economy encompasses traditional village farming, modern agriculture, handicrafts, a wide range of modern industries, and a multitude of services. These services are the major source of economic growth, accounting for more than half of India’s output, with less than one third of its labour force. Slightly more than half of the workforce is in agriculture.

India consists of twenty-eight states and seven union territories. Each state or union territory is further divided into 604 districts for basic governance and administration. The districts in turn are further divided into tehsils and eventually into villages.

Table 7 shows that low vision services in India were able to provide both positive and negative insights into the various features of service provision. According to the WHO LVWG and literature, clinical low vision services in India have been operating for more than 10 years—particularly in the southern part of the country. Thus, the majority of case study interviews were conducted in Tamil Nadu. Consultations with experts from the WHO LVWG revealed that services are delivered as part of an extensive eye care network of private, public and voluntary organisations and providers.

In the eye care and rehabilitation sector for low vision, large eye care organisations exist such as the Aravind Eye Hospital Group in Madurai and Joseph Eye Hospital in Tiruchirappalli. There is also a presence of international non-government organisations such
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as SSI\textsuperscript{275}, Christian Blind Mission (CBM)\textsuperscript{276} and the Fred Hollows Foundation (FHF).\textsuperscript{277} Finally, there are a number of small private hospitals and clinics in Tamil Nadu.

As for access to education for those with low vision, in 1994 the Indian Government launched the Education For All (EFA) program. The program offers free and compulsory education to all children up to the age fourteen.\textsuperscript{278} As part of the EFA program, children with low vision are able to attend regular schools through the Integrated Education Program (IEP). Specialised teachers, educational texts, selected aids and appliances (e.g. large print books, reading stands) all support children with low vision to cope in regular classrooms.\textsuperscript{279}

The case studies in India were conducted in November to December 2007 in four districts of Tamil Nadu (Figure 2): first Chennai, then Tiruchirappalli District (also known as Trichy District), followed by Madurai District, and finally Coimbatore. One participant was located outside Tamil Nadu, so the interview was conducted in the capital city Bangalore in the state of Karnataka (Figure 4, Table 8). The researcher spent one week in each of the four districts except for Bangalore where only one day was required.

Table 8 Places, organisations, and features visited in India, November 2007

<table>
<thead>
<tr>
<th>Places visited</th>
<th>Type of organisation</th>
<th>Feature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chennai (Madras)</td>
<td>• SSI supported district private eye hospital</td>
<td>• Clinical low vision care</td>
</tr>
<tr>
<td></td>
<td>• Corporate private eye hospitals</td>
<td>• Rehabilitation for children with low vision and other disabilities</td>
</tr>
<tr>
<td></td>
<td>• Societies for disabled children</td>
<td>• Education for children with vision impairment</td>
</tr>
<tr>
<td></td>
<td>• School for the Blind</td>
<td>• Low vision human resources training</td>
</tr>
<tr>
<td></td>
<td>• Tertiary optometry training institute</td>
<td>• Government services</td>
</tr>
<tr>
<td></td>
<td>• Government</td>
<td></td>
</tr>
<tr>
<td>Madurai</td>
<td>• Aravind eye hospital (clinical low vision care, training institute, district hospitals, vision centres)</td>
<td>• All levels of comprehensive care</td>
</tr>
<tr>
<td></td>
<td>• IEP</td>
<td>• Primary level of care – community based rehabilitation and Integrated education for children with low vision</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Government EFA national program</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Low vision specialists</td>
</tr>
<tr>
<td>Tiruchirappalli (Trichy)</td>
<td>• Joseph eye hospital (clinical low vision care, low vision eye camp and</td>
<td>• CBM supported low vision programme</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• All level of comprehensive care</td>
</tr>
<tr>
<td>Places visited</td>
<td>Type of organisation</td>
<td>Feature</td>
</tr>
<tr>
<td>----------------</td>
<td>----------------------</td>
<td>---------</td>
</tr>
<tr>
<td></td>
<td>outreach, and training)</td>
<td>Community based services</td>
</tr>
<tr>
<td></td>
<td>• University training social workers and teachers</td>
<td>Training for social workers, specialist teachers and rehabilitation officers</td>
</tr>
<tr>
<td></td>
<td>• Rehabilitation training college</td>
<td>Government services</td>
</tr>
<tr>
<td></td>
<td>• Government – district disability officer</td>
<td>Low vision specialists</td>
</tr>
<tr>
<td>Coimbatore</td>
<td>• IEP in government and private schools</td>
<td>Government EFA national program</td>
</tr>
<tr>
<td></td>
<td>• LNGOs (community based programmes, training, services for disabled persons)</td>
<td>Training for specialist teachers</td>
</tr>
<tr>
<td></td>
<td>• Teacher training universities</td>
<td>Clinical low vision care</td>
</tr>
<tr>
<td></td>
<td>• Private eye hospital</td>
<td></td>
</tr>
<tr>
<td>Bangalore</td>
<td>• CBM</td>
<td>INGO</td>
</tr>
</tbody>
</table>
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Figure 4 Route travelled by researcher in India

Source: Travel made easy
West Africa – Ghana and Cameroon

Low vision services in Ghana and Cameroon (Table 7) provide critical insight into priorities and barriers of service provision. Services in these two countries have both been set up by the same INGO – Sight Saver International.

Ghana

The Republic of Ghana is located in West Africa. It borders Côte d’Ivoire (Ivory Coast) to the west, Burkina Faso to the north, Togo to the east, and the Gulf of Guinea to the south.\(^{281}\) Ghana was colonised by the British in 1874. However in 1957, it became the first sub-Saharan country in colonial Africa to gain its independence.\(^{282}\)

Ghana is divided into 10 regions and subdivided into a total of 138 districts.\(^{281}\) The population of Ghana is 23,832,495 and the percentage of population urbanised is 50%.\(^{282}\) The country has an abundance of natural resources and the per capita output is twice of the poorest countries in West Africa. Nonetheless, Ghana remains heavily dependent on international financial and technical assistance. The domestic economy continues to revolve around agriculture, which accounts for about 35% of GDP and employs about 55% of the workforce, mainly small landholders.\(^{282}\)

The researcher spent three weeks in Ghana during November 2008 and visited organisations and people in the greater Accra (one week) and Volta (two weeks) regions (Table 9). The greater Accra region has a population of 2,905,726.\(^{283}\) The population of the Volta region is 1,635,421.\(^{284}\) It is located east of Lake Volta and the districts visited by the researcher in this region were: Hohoe, Krachi, and the Krachi-East district.\(^{284}\) The latter is one of the newest districts of Ghana being a recent division from the Krachi District. The damming of the Volta river at Akosombo has resulted in the isolation, from the mainland, of small pockets of populations.\(^{285}\) Consequently, the people living on these islands encounter challenges in gaining access to health care (Figure 5).
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Table 9 Places, organisations, and features visited in Ghana, November 2008

<table>
<thead>
<tr>
<th>Places visited</th>
<th>Type of organisation</th>
<th>Feature</th>
</tr>
</thead>
<tbody>
<tr>
<td>The greater Accra region</td>
<td>• SSI</td>
<td>• INGO</td>
</tr>
<tr>
<td></td>
<td>• School for the blind</td>
<td>• Education</td>
</tr>
<tr>
<td></td>
<td>• Society for the blind</td>
<td>• Government services</td>
</tr>
<tr>
<td></td>
<td>• Association for the Blind</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Ministry of Education</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Ministry of Health (low vision unit)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Government tertiary hospital</td>
<td></td>
</tr>
<tr>
<td>Volta region</td>
<td>• Government district hospitals</td>
<td>• Clinical low vision services</td>
</tr>
<tr>
<td></td>
<td>• SSI supported eye care clinic</td>
<td>• Community based services</td>
</tr>
<tr>
<td></td>
<td>• SSI supported community based rehabilitation services</td>
<td>• IEP (SSI supported)</td>
</tr>
<tr>
<td></td>
<td>• District education office</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(government)</td>
<td></td>
</tr>
</tbody>
</table>
Figure 5 Route travelled by researcher in Ghana

Source: Nations online project
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Ghana, like India, had low vision services more than 10 years ago that were set up by INGOs; however, services operated intermittently over the years and eventually low vision programs were not successful before being re-established by SSI two years ago. Thus, through the Ghana experience, the researcher was able to investigate in detail the factors that led to Ghana’s poor service provision and development.

Cameroon

A contrasting case study to Ghana’s experience is found in Cameroon. Low vision services were established for the first time in 2006 in the Southwest region of Cameroon as part of the government’s comprehensive eye care services program. According to the WHO LVWG, experts in Cameroon, and SSI, services were being delivered to the low vision population from the outset. Thus, the Cameroon experience provided the opportunity to investigate factors that contributed the successful establishment of low vision services.

One part of Cameroon was colonised by the French (Francophone) while the other part by the British (Anglophone). In 1961, both sides merged to become the country it is today. It is bordered by Nigeria to the west, Chad to the northeast, the Central African Republic to the east, and Equatorial Guinea, Gabon, and the Republic of the Congo to the south. The population of the country is 18,879,301.

Red tape, high taxes, and endemic corruption have impeded growth of the private sector. Unemployment was estimated at 30% in 2001, and about 48% of the population was living below the poverty threshold in 2000. The main source of domestic income is from agriculture. An estimated 70% of the population farms, and agriculture comprised an estimated 45.2% of GDP in 2006. Most agriculture is done at the subsistence level by local farmers using simple tools. They sell their surplus produce, and some maintain separate fields for commercial use.

The researcher travelled to the Southwest region. This region of Cameroon is one of two English speaking provinces, much of which is situated in the equatorial rainforest. Most of the estimated 1.2 million inhabitants live in rural areas. Like the majority of the country the main occupation is agriculture for subsistence and employment in agro-industrial estates.
Four towns were visited to conduct interviews—Buea (capital of the region), Limbe, Kumba, and Mamfe (Figure 6, Table 10). A total of one week was spent in Cameroon.

Table 10 Places, organisations, and features visited in Cameroon, November 2008

<table>
<thead>
<tr>
<th>Places visited</th>
<th>Type of organisation</th>
<th>Feature</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Buea</strong></td>
<td>• Government eye health program</td>
<td>• Overview of program</td>
</tr>
<tr>
<td></td>
<td>• School for the Blind</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• SSI</td>
<td></td>
</tr>
<tr>
<td><strong>Limbe</strong></td>
<td>• Government district hospital</td>
<td>• Clinical low vision services and outreach</td>
</tr>
<tr>
<td></td>
<td>• Government schools</td>
<td></td>
</tr>
<tr>
<td><strong>Kumba</strong></td>
<td>• Government district hospital</td>
<td>• Clinical low vision services and outreach</td>
</tr>
<tr>
<td></td>
<td>• Government school</td>
<td></td>
</tr>
<tr>
<td><strong>Mamfe</strong></td>
<td>• Government district hospital</td>
<td>• Mamfe was the most remote and difficult to reach due to roads impassable during the rainy season</td>
</tr>
<tr>
<td></td>
<td>• Department of Social Welfare</td>
<td>• Clinical low vision services and outreach</td>
</tr>
<tr>
<td></td>
<td>• Association for the Blind</td>
<td>• Government involvement</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Rehabilitation services about to start</td>
</tr>
</tbody>
</table>
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Figure 6 Route travelled by researcher in Cameroon

Source: Nations online project\textsuperscript{291}
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Three case studies produced stronger arguments than one because they together further substantiated the findings, and reduced criticism regarding the uniqueness and artificial conditions frequently associated with conducting just the one case study. Though each country is unique in its provision of services all three countries shared characteristics of other low vision systems in other parts of the world and therefore provide insight into the factors impacting on the coverage of low vision services.

3.4.4 Data Collection

The main source of data collection was interviews. The other sources included field observations and secondary information, e.g. background information about the program or services collected in reports and pamphlets.

The purpose of interviews was to find out from people things that cannot be observed to extract feelings, thoughts, intentions and behaviours that took place at some previous point in time. The interview style was semi-structured which is defined as a mix between a structured and an open-ended interview. This style of interviewing was used because it was predicted that the interviewee may not necessarily cooperate to the line of questions. The researcher had to be flexible and adapt to the circumstances where appropriate.

A prelude to commencing the interviews was to develop a case study protocol (Appendix E) and a list of questions (Appendix D) constructed and categorised into different topics.

The protocol (Appendix E) was sent to people and organisations the researcher intended to interview two months prior to travel, for feedback and feasibility. Feedback was obtained from these key persons about the appropriateness of the proposed interviews, questions, and the case study protocol (Appendix E). Each organisation was contacted, permission obtained, a copy of the protocol and questions provided (so that people were aware of what was going to be asked of them), and exact date and time confirmed before the researcher left Australia.

The contents of the case study protocol (Appendix E) included the following:

1. An overview of the case study project
2. Field procedures
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3.4.4.1 Overview

The overview covered the following—background information of the research, context and perspective of the research, statement of purpose, details of the researcher, project sponsors, and research questions being examined.

3.4.4.2 Field Procedures

Efforts were made to cater to the interviewee’s schedule and availability. Preparatory steps were taken prior to travel included organising and seeking permission to access key organisations and interviewees, gifts and souvenirs purchased as dictated by cultural norms; funds to cover fees and expenses; identifying mentors for assistance and guidance; establishing a clear schedule of data collection activities and the expected travel and interview time.

The topics formed the focus for the interviews but the tone of the interview was conversational and the interviewee was encouraged to provide additional information that may have not been addressed in the questions. The topics of the case studies were turned into a list of questions and categorised into 14 topics (Appendix D).

For each topic, the exact question wording depended on three interviewee types—program managers, service providers, and clients. For example, the question “what do you think is an ideal service?” was asked to all three groups of people. In another example one subject required two different question styles—“what are the levels of client satisfaction?” (to the service provider) and “how have the services helped you?” (to the client).

The researcher communicated in English with all interviewees. The organisations were generally willing to provide a member of staff to translate if necessary. This person was usually the project manager or field worker who was familiar or acquainted with the clients. The interviews began with introductory statements to give interviewees an appreciation of the research objectives and the importance of their input and time. Interviews were expected to take 30 minutes to one hour. However, the researcher allowed additional time in case there were opportunities for direct observation of the services being delivered. Direct observation provided insights into interpersonal behaviour and provided a contextual perspective.
After each interview, the researcher summarised what had been said and discussed the content with the interviewee to verify that the researcher had accurately recorded their opinions or responses. Thereafter, the researcher did a prompt transcription of the interviews into MS Word and exported into it NVivo (computer software for managing qualitative data) for coding. None of the interviews were tape recorded. This was due to ethical and cultural issues as well as known issues of tape recorders acting as a deterrent to obtaining information or views from the interviewees.

### 3.4.5 Case Selection

Selecting people and organisations to be interviewed involved the following considerations:

1. type of group i.e. program managers, service providers (ophthalmologists, optometrists, field workers, low vision specialists), clients (adults and children)
2. type of organisation i.e. government, private sector, international and local NGOs
3. sufficient access to the potential interviewees and organisations
4. contribution to the research question.

The process of identifying potential interviewees and places to visit began with the researcher sourcing local contacts in each of the countries from supervisors and the WHO LVWG. Key persons or networks of the targeted organisations were then contacted two months prior to travel. In each country there was usually one key person or group who were able to provide advice and support about the travel. These people also placed the researcher in contact with other organisations. For instance, in India, CBM and SSI offices arranged permission with other organisations for the researcher to visit. In Ghana and Cameroon, the administrator in each of the SSI offices made the appropriate arrangements.

### 3.4.6 Data Analysis

The program NVivo (version 8) was used to code and categorise large collections of interview data. However, NVivo’s role was not to analyse the data for the researcher but rather serve as a tool to generate the outputs for the researcher to determine meaningful patterns from the interviews.
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Two strategies of analysis—analytic induction and grounded theory—were considered. Analytic induction is ‘an approach to the analysis of data in which the researcher seeks universal explanations of phenomena by pursuing the collection of data until no cases are inconsistent with a hypothetical explanation...of a phenomenon are found’. On the other hand, grounded theory is defined as ‘theory that was derived from data, systematically gathered and analysed through the research process...data collection, analysis and eventual theory stand in close relationship to one another’. In other words, grounded theory argues that theory can be built up through careful observation of the social world.

Grounded theory was the strategy chosen to analyse the qualitative data in this research. This was because grounded theory studies investigate questions about “what is going on here?” and this research attempts to identify the situation of low vision services. Moreover, the intention of the researcher is to learn from the organisations and people in each of the three countries in order to understand details surrounding low vision service provision making the grounded theory well suited to this study. Although grounded theory is an approach to the generation of theory it can also, generate concepts rather than theory.

Grounded theory required the researcher to ‘seek issues...work with data records and records of idea to tease them from the concepts and the linkages that might generate insight’. Once the issues had been identified, the researcher explored the relationships between these issues in order to develop concepts. Analysis was done in two steps—open and axial coding.

3.4.6.1 Open Coding

Open coding refers to reading through the data, then fracturing the data to identify an issue or idea. To do this, the researcher began with coding (indexing) each of the interviews into free nodes using NVivo. Free nodes allowed the researcher to capture ideas without imposing any structure on the ideas and there with no assumed relationships with any concepts. The coding technique used is called microanalysis. This involves a slow, reflective exploration of texts i.e. segmenting the data, doing line-by-line coding, identifying the issues/ideas, categorising the data, seeking patterns and coherences, and thinking about
the concepts discussed. The whole process was repeated until all interviews had been coded.

### 3.4.6.2 Axial Coding

Axial coding involves grouping similar issues/ideas identified from open coding into concepts and ultimately into overarching themes. The researcher began this by sorting the free nodes into tree nodes in NVivo. Tree nodes are the equivalent of folders on the computer to help people organise their files. They are nodes that allow the researcher to connect the ideas of the free nodes together and create a catalogue or taxonomy of concepts/topics.

Having classified free nodes (issues/ideas) into tree nodes (concept/topics), the next step was to establish theoretical connections between the nodes to develop overarching themes. Each theme would contain concepts/topics which have the theme present throughout the data. This was performed using several other tools offered by the NVivo software viz. sets (grouped the tree nodes into different themes) and models which illustrated the themes and assisted the researcher to visually identify patterns and connections between themes and make sure that the tree nodes were categorised appropriately. Once all the themes were identified, each theme was summarised. Under each theme, the concepts were presented, each with a brief description in individual tables. Finally, the themes and concepts were reapplied to the CSFs identified in question 2 to provide in-depth understanding of the factors impacting on poor and better coverage.

### 3.5 Conclusion

This Chapter has demonstrated how the procedures and processes of the two methodologies—the survey and the case studies—addressed the dearth of information on the current situation of low vision services throughout the world, and the factors associated with countries that have better (>10%) and poor (≤10%) coverage.

Both methodologies have covered and investigated a wealth of topics pertaining to low vision service provision. These topics were guided by the resources and literature identified
in the previous Chapter viz. Vision 2020, primary health, WHO social determinants of health, past and present models of care, and the various barriers challenging service provision.

The survey methodology sought to identify and map the current situation of services while the case study methodology uses detailed semi-structured interviews, observations and review of documents to gain an understanding and the factors impacting on services. Efforts were made by the researcher to ensure the validity of the data through data verification using multiple sources. The same methodology was applied to the case studies, in which careful planning took place. Careful consideration was given to the four criteria (construct, internal, external validity and reliability) pertaining to case study design, as well as the use of multiple sources for validity. All this demonstrated the reliability and trustworthiness of the two methodologies.
4 Chapter Four - Results
4.1 Introduction

The structure of this Chapter is as follows. First, the findings from the pilot study that led to the final format of the survey are discussed. This is followed by the outcomes from the survey distribution and the survey data verification process. Outcomes of the data cleaning process are also included. The Chapter is then organised into two main sections: survey and case studies. The results of the first two research questions will be addressed under the survey section as the data were generated solely from the survey. This section outlines the current situation for low vision services and coverage of services, followed by the identification of critical success factors to improve service coverage. The case study section then explores these factors in more detail to understand why these factors exist from those who are vested in the provision of low vision services (both care givers and recipients alike).

4.2 Survey Findings

4.2.1 Pilot Study

Several changes to the first draft (Appendix A) of the survey were made as a result of the pilot study. The overall response rate from the reference group was 67% (12/18). Responses were received from the following groups: WHO (n=4), Vision 2020 (n=3), national focal persons (n=2), and International Non-government Organisations (INGOs) (n=3). All feedback from the reference group was addressed with appropriate changes being made before distributing the survey to the wider audience.

Comments from the reference group concluded that the content of the survey adequately covered the required areas of low vision service delivery. The majority of the feedback related to the presentation and format of the survey.

The survey instrument was deemed to be too long (Appendix A). The pilot version of the survey consisted of 54 questions over eight pages. In particular, respondents stated that the three tables under the ‘human resources’ section required much time and effort to complete and would “put off” respondents from providing further information.
Chapter 4 - Results

The following questions were found to be repetitive: question 9-“where is low vision care provided in your country?” was similar to question 21- “what low vision facilities are available or provided in your country?” (Appendix A)

Question 28 –“what are the criteria for prescribing low vision aids and devices in your country?”, question 14-“what level of impairment do people have to have to be eligible to receive services and care?”, and question 1-“how is low vision defined in your country?” were identified as questions which overlapped.

Additional questions identified as repetitious were 47– “what outcomes are used to evaluate low vision services and programs?” and question 48 –“how are client outcomes assessed in determining improved function among people with low vision in your country?”

For all the examples, either one question was selected or the questions were merged and reworded as one.

Suggestions were also made by the pilot study group that led to rearranging the ordering of themes to ensure that questions most familiar to the respondents were asked first. For example, the section seeking details of respondents was placed at the beginning of the survey.

Questions were also reordered to better group related questions together. For example: questions 37a –“what essential resources does your country need most that it does not currently have?” and 37b-“what are the reasons for the lack of resources or services?” These two questions were reworded and moved to the section on coverage and barriers.

Numerous open-ended questions were changed to multiple-choice questions. This reduced the length of the survey and minimised issues associated with translating responses. For example, under the monitoring and evaluation section, the questions were changed to multiple-choice format and reduced from five to four questions. A useful technique to limit the number of open-ended questions was to provide an ‘other, please state/specify’ option.\textsuperscript{215}

Instructions given to respondents to move between sections (i.e. skipping questions) were found by the reference group to be unclear.
An additional question (12b) was recommended for inclusion by Dr. Serge Resnikoff. He suggested including a question about the source of information for question 12-“What are the main causes of low vision in your country?” (Appendix B question 12b). This then provided a reference check on where the survey information was sourced.

Question 18 was removed from the survey (Appendix A). The question was: “How do you feel about the level of importance in the provision of low vision care and services in relation to other eye health services?” The respondents filling in the survey would already have an interest in low vision to be willing to participate in the survey, thus the question would not have provided an overview of the perceived importance of low vision services.

The reference group also recommended the use of ‘do not know’ as a valid response. Past researchers concur that the rates of uninformed responses are reduced by the inclusion of the ‘do not know’ option. A ‘do not know’ response category was subsequently provided in almost all multiple choice questions in the final survey.

Other minor issues identified in the pilot study included: using simple language; avoiding abbreviations i.e. using visual acuity instead of VA; keeping questions short (i.e. less than 20 words); avoiding ambiguity in questions, for example: question 22 – “what types of services are most commonly used?” (Appendix A) was deemed to be too ambiguous and subsequently reworded in the final version (Appendix B) as “what types of low vision services are most commonly used in your country?”; avoiding the use of double negatives; avoiding leading questions, e.g. rather than writing “do you think there are particular groups of people less likely to access services?”, in the final version (Appendix B) – this question was reworded as “are there any groups of people less likely to access low vision services?” (Question 23); and ensuring every question asked would be worth each respondent’s time i.e. not recalling detailed information that was neither directly relevant, nor the information was already available.

All members of the reference group were able to access the survey instrument in Word format via an e-mail attachment. The majority returned comments via e-mail. One participant returned the survey through fax and two people posted the surveys.
Chapter 4 - Results

The advantage of using the e-mail for this study was that it not only enabled rapid surveying i.e. allowing the survey to be sent to many parts of the world in an instant, it is also inexpensive since it eliminates postage, printing, and/or telephone costs.

Finally, the feedback on the cover letter was that it lacked clarity on what was required from the respondents and why they should complete it. Based on this, the researcher rewrote the cover letter including clearer benefits to the respondent for completing the survey.

4.2.2 Survey Distribution

After refinements were made to the survey based on the pilot study, the survey (Appendix B) was distributed to respondents. In total, 14 months was spent following up the survey contacts and respondents. Over 1000 e-mail reminders were sent – all survey forms were sent or returned electronically except for Laos and Papua New Guinea which were both e-mailed and faxed. All respondents returned survey responses as an e-mail attachment with the exception of respondents from five countries who rather than that either posted or faxed their responses.

The overall response rate was 65% (127/195). No contacts were found for the remaining 35% countries. Including secondary sources - data were obtained from 91% (178/195) of countries. Response rates differed by regions, ranging from 100% in the Americas to 38% in Europe (Figure 7).

Regional rates were compared with the presence of the Vision 2020 national committee (Figure 7). For instance very few countries in Europe have a Vision 2020 national committee (Figure 7). Similarly, the researcher encountered the most difficulties when obtaining responses (or trying to elicit a response) from potential contacts in Europe. The researcher contacted the World Blind Union and the regional Vision 2020 committee for Europe. Both were helpful and passed on useful contacts however, not all countries had contacts and many of the e-mail addresses provided by the World Blind Union were old e-mail addresses and thus could not be delivered.
Figure 7 Regional survey response rates compared with the presence of a national Vision 2020 committee and eye care plan

*Data from survey
Consequently, European countries reported the lowest survey response rate (Figure 7). Nonetheless, it is worth noting that through secondary sources (Table 12) and verification by experts, it was found that 72% of countries in this region have low vision services. For example a report by AMD Alliance International documented that the organisation ONCE (Organización Nacional de Ciegos de España) in Spain provides comprehensive low vision services (Table 12)²⁹⁷ but attempts to gain a response were not successful.

### 4.2.3 Results Verification

Data verification is used to identify inconsistencies or contradictions in responses. Examples of inconsistencies include:

- **Question 22** – “Of all people receiving low vision services what proportion are children and adults?” In this question, some responses did not add up to 100%.
- **Question 25** – “Are low vision aids and devices available as part of the low vision service?”; **Question 26** – “Is there a supply source of affordable low vision aids and devices”; and **Question 27** – “What kinds of low vision related equipment are available through low vision services in your country?” Many respondents had answered ‘no’ to both Question 25 and Question 26 but had gone on to answer Question 27. And some had answered ‘no’ to Question 25 but then went on to answer ‘yes’ to Question 26 and also completed Question 27.

Less frequent issues identified were:

- The lack of information provided to generate an understanding of services in the country.
- There was unclear information pertaining to services for the blind or low vision.
- There were missing data on coverage rates (Question 17) in countries known anecdotally to have some services.
- There were queries on the number of human resources actually involved in low vision (excluding general eye care). For example, in Iceland the coverage of low vision services was reported to be between 91-100% but there is only one ophthalmologist, one optometrist, two rehabilitation officers and two special teachers providing low vision services in the country.
- There was conflicting anecdotal information concerning the presence of services.
The number of countries requiring data clarification to follow up on inconsistencies and/or contradictory data is shown in Table 11.

**Table 11 Countries with surveys that required data clarification**

<table>
<thead>
<tr>
<th>Region</th>
<th>Countries</th>
<th>Number of countries (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td>Algeria</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Gabon</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Liberia</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mauritania</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Namibia</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rwanda</td>
<td></td>
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<tr>
<td></td>
<td>Seychelles</td>
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<tr>
<td></td>
<td>Sierra Leone</td>
<td></td>
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<tr>
<td></td>
<td>South Africa</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tanzania</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Zambia</td>
<td></td>
</tr>
<tr>
<td>Americas</td>
<td>Brazil</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Canada</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Costa Rica</td>
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<tr>
<td></td>
<td>Cuba</td>
<td></td>
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<tr>
<td></td>
<td>Ecuador</td>
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<tr>
<td></td>
<td>Guatemala</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Guyana</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Paraguay</td>
<td></td>
</tr>
<tr>
<td></td>
<td>United States</td>
<td></td>
</tr>
<tr>
<td>Eastern Mediterranean</td>
<td>Afghanistan</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Bahrain</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Iran</td>
<td></td>
</tr>
<tr>
<td>Europe</td>
<td>Armenia</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Croatia</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Denmark</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Kazakhstan</td>
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<tr>
<td></td>
<td>Lithuania</td>
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</tr>
<tr>
<td></td>
<td>Netherlands</td>
<td></td>
</tr>
<tr>
<td>South East Asia</td>
<td>India</td>
<td>2</td>
</tr>
</tbody>
</table>
Chapter 4 - Results

<table>
<thead>
<tr>
<th>Region</th>
<th>Countries</th>
<th>Number of countries (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thailand</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Western Pacific</td>
<td>Cambodia</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>China</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fiji</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hong Kong</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Japan</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Malaysia</td>
<td></td>
</tr>
<tr>
<td></td>
<td>New Zealand</td>
<td></td>
</tr>
<tr>
<td></td>
<td>PNG</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Solomon Islands</td>
<td></td>
</tr>
<tr>
<td></td>
<td>South Korea</td>
<td></td>
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<tr>
<td></td>
<td>Taiwan</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tuvalu</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Vanuatu</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Vietnam</td>
<td></td>
</tr>
<tr>
<td><strong>Total (n)</strong></td>
<td><strong>45</strong></td>
<td></td>
</tr>
</tbody>
</table>

Some countries had more than one response as a result of the snowball sampling technique employed. In some countries it was difficult to obtain a national picture of the entire country from one person and/or organisation especially in countries with diverse regional/provincial differences. These countries required multiple sources and/or persons to complete the survey. Such countries were Tanzania, the United States, New Zealand, Afghanistan, and Taiwan.

All responses received for each of these countries was double checked with the respondents, compared, and contrasted with any grey literature available and feedback from experts in the field. In cases where there were two different responses on one question - the researcher consulted supervisors and thereafter, the data were sent for verification (Table 11).

In the case of the United States, the researcher included data and checked the survey data against a recent publication by Owsley et al in May 2009 who described the characteristics
of services, providers, and patients in low vision rehabilitation organisations serving adults. 298

Table 12 lists the countries in which secondary source searches were conducted to confirm the presence of low vision services. These were for countries where there were no data received or no contacts found.

**Table 12 Countries with surveys requiring secondary sources verification**

<table>
<thead>
<tr>
<th>Region</th>
<th>Country</th>
<th>Secondary sources found to confirm some presence of services (references)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td>Angola</td>
<td>Website299</td>
</tr>
<tr>
<td></td>
<td>Central African Republic (CAR)</td>
<td>None found</td>
</tr>
<tr>
<td></td>
<td>Cote d’Ivoire</td>
<td>None found</td>
</tr>
<tr>
<td></td>
<td>Chad</td>
<td>None found</td>
</tr>
<tr>
<td></td>
<td>Cape Verde</td>
<td>None found</td>
</tr>
<tr>
<td></td>
<td>Equatorial Guinea</td>
<td>None found</td>
</tr>
<tr>
<td></td>
<td>Guinea-Bissau</td>
<td>None found</td>
</tr>
<tr>
<td></td>
<td>Ethiopia</td>
<td>None found</td>
</tr>
<tr>
<td></td>
<td>Lesotho</td>
<td>Website300</td>
</tr>
<tr>
<td></td>
<td>Somalia</td>
<td>None found</td>
</tr>
<tr>
<td></td>
<td>Sub-Saharan Africa</td>
<td>None found</td>
</tr>
<tr>
<td></td>
<td>Zimbabwe</td>
<td>Website301</td>
</tr>
<tr>
<td>Eastern Mediterranean</td>
<td>Jordan</td>
<td>Journal article302</td>
</tr>
<tr>
<td></td>
<td>Lebanon</td>
<td>Website303 and journal article304</td>
</tr>
<tr>
<td></td>
<td>United Arab Emirates</td>
<td>Website305</td>
</tr>
<tr>
<td>Europe</td>
<td>Austria</td>
<td>Websites306, 307, 308</td>
</tr>
<tr>
<td></td>
<td>Albania</td>
<td>Website309</td>
</tr>
<tr>
<td></td>
<td>Belgium</td>
<td>Website310</td>
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<tr>
<td></td>
<td>Bulgaria</td>
<td>Website311</td>
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<tr>
<td></td>
<td>Czech Republic</td>
<td>Websites312, 313</td>
</tr>
<tr>
<td></td>
<td>France</td>
<td>Electronic report314</td>
</tr>
<tr>
<td></td>
<td>Germany</td>
<td>Electronic report315</td>
</tr>
<tr>
<td></td>
<td>Hungary</td>
<td>Websites316, 317</td>
</tr>
<tr>
<td></td>
<td>Luxembourg</td>
<td>Websites318, 319</td>
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<tr>
<td></td>
<td>Macedonia</td>
<td>Website320</td>
</tr>
<tr>
<td></td>
<td>Malta</td>
<td>Websites321, 322</td>
</tr>
<tr>
<td></td>
<td>Portugal</td>
<td>Websites323, 324</td>
</tr>
<tr>
<td></td>
<td>Republic of Ireland</td>
<td>Electronic report325</td>
</tr>
<tr>
<td></td>
<td>Spain</td>
<td>Electronic report297</td>
</tr>
</tbody>
</table>
Chapter 4 - Results

<table>
<thead>
<tr>
<th>Region</th>
<th>Country</th>
<th>Secondary sources found to confirm some presence of services (references)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Slovakia</td>
<td></td>
<td>Website&lt;sup&gt;326&lt;/sup&gt;</td>
</tr>
<tr>
<td>Switzerland</td>
<td></td>
<td>Electronic report&lt;sup&gt;327&lt;/sup&gt;</td>
</tr>
<tr>
<td>Turkey</td>
<td></td>
<td>Website&lt;sup&gt;328&lt;/sup&gt;</td>
</tr>
<tr>
<td>Turkmenistan</td>
<td></td>
<td>None found</td>
</tr>
<tr>
<td>Ukraine</td>
<td></td>
<td>Websites&lt;sup&gt;329,330&lt;/sup&gt;</td>
</tr>
<tr>
<td>South East Asia</td>
<td>Myanmar</td>
<td>None found</td>
</tr>
<tr>
<td><strong>Total (n)</strong></td>
<td><strong>35</strong></td>
<td></td>
</tr>
</tbody>
</table>

Once data entry was complete, the countries were classified into four categories (Table 13 to Table 18). These tables present a summary of the low vision service status of each country according to the WHO regions. These tables were sent to experts in the field with knowledge of the countries in each region. For instance, the Vision 2020 Committee responsible for Latin America provided verification for all Latin America and Caribbean countries. Specifically, the regional committee passed on the individual country survey data to the respective Vision 2020 national coordinators in each country to check the responses.

The office of the WHO and IAPB for the Eastern Mediterranean Region (EMR) also carried out the same processes and assisted in the verification for the whole region including countries that did not have data.

The International Agency for the Prevention of Blindness (IAPB) Western Pacific Chair (the researcher’s supervisor) and the director of the Pacific Eye Institute in Fiji provided verification for countries in South East Asia and Pacific Island nations.

Some experts, particularly those from the Africa and Europe region were difficult to reach via e-mail or a response was not able to be elicited. Fortunately, the researcher attended the IAPB Eighth General Assembly in August 2008 in Argentina, where many of the key persons with a regional perspective and others working in the prevention of blindness attended. The conference also provided a useful networking opportunity to meet survey respondents in person.

The researcher followed up appropriate contacts from countries still requiring information and verification. For example, the African region results were verified by the coordinator for VISION 2020 in Africa. Individual countries in Europe and South East Asia were verified by
new contacts sourced during the conference, for example, persons working in INGOs and newly elected IAPB committee members. Data from China were verified in person with the director from the Hong Kong Society for the Blind and members of the national prevention of blindness committee in China.

In summary - the global mapping data presented here are a compilation of three types of information: survey (65%; 127/195); experts in the field (14%; 28/195), and secondary sources (12%; 23/195). No information could be obtained for 17/195 (9%) countries using any of these three sources.

Table 13 Presence of services in Africa, August 2008

<table>
<thead>
<tr>
<th>1. Have data and presence of low vision services</th>
<th>2. Some evidence of a service(s)</th>
<th>3. Have confirmation of no low vision services</th>
<th>4. No data available and no confirmation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Algeria</td>
<td>Ethiopia</td>
<td>Angola</td>
<td>Equatorial Guinea</td>
</tr>
<tr>
<td>Cameroon</td>
<td>Zimbabwe</td>
<td>Benin</td>
<td>Mozambique</td>
</tr>
<tr>
<td>Congo (DR)</td>
<td>Botswana</td>
<td>Sao Tome &amp; Principe</td>
<td></td>
</tr>
<tr>
<td>Gambia, The</td>
<td>Bukina Faso</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ghana</td>
<td>Burundi</td>
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</tr>
<tr>
<td>Kenya</td>
<td>Cape Verde</td>
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<td></td>
</tr>
<tr>
<td>Liberia</td>
<td>Central African Republic</td>
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<td>Malawi</td>
<td>Chad</td>
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<td>Mauritania</td>
<td>Comoros</td>
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<tr>
<td>Namibia</td>
<td>Congo (Brazzaville)</td>
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<tr>
<td>Nigeria</td>
<td>Cote d'ivoire</td>
<td></td>
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<tr>
<td>Rwanda</td>
<td>Eritrea</td>
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<td>Seychelles</td>
<td>Gabon</td>
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<td></td>
</tr>
<tr>
<td>Sierra Leone</td>
<td>Guinea (Conakry)</td>
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<tr>
<td>South Africa</td>
<td>Guinea-Bissau</td>
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<td>Swaziland</td>
<td>Lesotho</td>
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<td>Tanzania</td>
<td>Madagascar</td>
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<tr>
<td>Uganda</td>
<td>Mali</td>
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<td>Zambia</td>
<td>Mauritius</td>
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<td>Niger</td>
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<tr>
<td></td>
<td>Togo</td>
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</tr>
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</table>
### Table 14 Presence of services in Americas, August 2008

<table>
<thead>
<tr>
<th>Country</th>
<th>1. Have data and presence of low vision services</th>
<th>2. Some evidence of a service(s) (2° sources)</th>
<th>3. Have confirmation of no low vision services</th>
<th>4. No data available and no confirmation</th>
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</thead>
<tbody>
<tr>
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<tr>
<td>Antigua &amp; Barbuda</td>
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<tr>
<td>Belize</td>
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<tr>
<td>Bahamas</td>
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<tr>
<td>Bolivia</td>
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<td>Barbados</td>
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<tr>
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<td>St Kitts &amp; Nevis</td>
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<td>Trinidad &amp; Tobago</td>
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<td>Venezuela</td>
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### Table 15 Presence of services in Eastern Mediterranean, August 2008

<table>
<thead>
<tr>
<th>Country</th>
<th>1. Have data and presence of low vision services</th>
<th>2. Some evidence of a service(s) (2° sources)</th>
<th>3. Have confirmation of no low vision services</th>
<th>4. No data available and no confirmation</th>
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<tbody>
<tr>
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<td>Djibouti</td>
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<td>Iraq</td>
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<td>Bahrain</td>
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<td>Unites Arab Emirates</td>
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<td>Libyan Arab Jamahiriya</td>
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<td>Jordan</td>
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<td>Tunisia</td>
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### Table 16 Presence of services in Europe, August 2008

<table>
<thead>
<tr>
<th>Presence of services in Europe, August 2008</th>
<th>1. Have data and presence of low vision services</th>
<th>2. Some evidence of a service(s) (2° sources)</th>
<th>3. Have confirmation of no low vision services</th>
<th>4. No data available and no confirmation</th>
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<tr>
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<td>Serbia (Yugoslavia) &amp; Montenegro</td>
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<tr>
<td>Ukraine</td>
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### Table 17 Presence of services in South East Asia, August 2008

<table>
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<tr>
<th>Presence of services in South East Asia, August 2008</th>
<th>1. Have data and presence of low vision services</th>
<th>2. Some evidence of a service(s) (2° sources)</th>
<th>3. Have confirmation of no low vision services</th>
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<td>Thailand</td>
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</table>
Chapter 4 - Results

Table 18 Presence of services in Western Pacific, August 2008

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<th>2. Some evidence of a service(s) (2° sources)</th>
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<td>China</td>
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<td>Laos</td>
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<td>Tuvalu</td>
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<td>Taiwan</td>
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<tr>
<td>Vietnam</td>
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4.2.4 Survey Respondents

Eighty percent (91/103) of respondents were associated with one of the official organisations: government, national prevention of blindness committee (PBL) or Vision 2020. Of the 95 respondents who stated their professional occupations, 53% were ophthalmologists and 15% were optometrists.

Table 19 Professions of survey respondents

<table>
<thead>
<tr>
<th>Profession</th>
<th>Total number</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Ophthalmologist</td>
<td>50</td>
<td>53%</td>
</tr>
<tr>
<td>Optometrist</td>
<td>14</td>
<td>15%</td>
</tr>
<tr>
<td>MLOP (nurse, orthoptist)</td>
<td>9</td>
<td>10%</td>
</tr>
<tr>
<td>Academic/researcher</td>
<td>4</td>
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<tr>
<td>Administrator/manager</td>
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<td>5%</td>
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<tr>
<td>Low vision specialist</td>
<td>6</td>
<td>6%</td>
</tr>
<tr>
<td>Social worker/psychologist</td>
<td>7</td>
<td>7%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>95</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>
Chapter 4 - Results

Of the 85 respondents who answered question 4a (do you have qualifications in low vision?): 62% (53/85) stated that they had.

The remainder of this Chapter addresses each of the three research questions (current situation of low vision services, identification of CSFs, and exploration of question 3-the issues behind the CSFs). The results are derived from the countries with survey and secondary data (n=103) rather than the total number of countries confirmed to have low vision services (n=115). This is because while 12 countries have some level of service, no additional information could be found about these services. Additionally, not every question was answered in all surveys, thus, the total number of countries providing data on each question is often less than 103.

4.3 Question 1: Current Global Situation of Low Vision Services

Epidemiology of low vision

The survey found that 69% (62/90) of respondents defined low vision as a person having best corrected visual acuity <6/18 (20/60) to 3/60 (20/400). Furthermore, in terms of the level of impairment required before people with low vision are eligible to receive low vision services - 33% (31/94) of all respondents reported that their countries used the definition of best corrected visual acuity <6/18 (20/60). In addition 20% (19/94) of countries used this definition and also visual field <10°.

While cataracts remain one of the most common causes of vision impairment in developing countries, diabetic retinopathy, age-related macular degeneration, glaucoma, and childhood causes were found to be the most commonly reported causes of low vision across all countries (Figure 8). Statistical differences were detected in two causes between developed and developing nations: childhood onset (χ²=7.30; p=0.007) and eye infections (χ²=13.31; p<0.000). No countries in developed nations had stated eye infections as a cause of low vision.
Figure 8 Main causes of low vision reported in developed and developing countries

Furthermore, respondents reported that the main source of information used to complete the survey for Q12 – what are main causes of low vision in your country? - were a combination of personal records 67% (60/89), published reports 56% (50/89), and hospital records 49% (44/89).

Policies

Low vision has been included in 80% (47/59) of developing countries that had national eye care plans (Table 20). However, developed countries had a slightly higher percentage of countries with national referral guidelines 45% (13/29) and 48% with standards of practice guidelines (14/29) when compared to developing countries (Table 20).

Table 20 Policies on low vision in developed and developing countries

<table>
<thead>
<tr>
<th>Aspects</th>
<th>Developed countries</th>
<th>Developing countries</th>
<th>Total (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Existence of national eye care plan</td>
<td>41% (12/29)</td>
<td>80% (59/74)</td>
<td>103</td>
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<tr>
<td>National eye care plan includes low vision</td>
<td>75% (9/12)</td>
<td>80% (47/59)</td>
<td>71</td>
</tr>
<tr>
<td>National referral guidelines</td>
<td>45% (13/29)</td>
<td>32% (24/74)</td>
<td>103</td>
</tr>
<tr>
<td>Guidelines for standards of low vision practice</td>
<td>48% (14/29)</td>
<td>36% (27/74)</td>
<td>103</td>
</tr>
</tbody>
</table>

Human resources

The numbers of low vision health professionals providing low vision care was relatively low across all regions, with fewer than 10 per 10 million for almost all low vision professional groups. Despite this, the mix and range of low vision health professionals is different across
the regions (Figure 9). Interestingly, univariate analysis showed that having >3 optometrists ($\chi^2=6.03; p=0.014$) and rehabilitation officers ($\chi^2=7.01; p=0.008$) per 10 million of population were found to be significantly associated with coverage of low vision services.

In the Americas region, the number of community based rehabilitation workers and optometrists was higher than the number of rehabilitation officers, specialist teachers, MLOP, and ophthalmologists (Figure 9). On the other hand, in the Latin Americas region the mix and range of low vision health professionals was evenly distributed but low across all groups.

There were very few rehabilitation officers and community based rehabilitation workers in the African (with the exception of The Gambia and Algeria), and Eastern Mediterranean (Figure 9).

In Europe, three countries - Norway, the Netherlands, and Sweden contributed to the higher numbers of low vision health care workers, for example ophthalmologists, optometrist, and MLOP. Thailand in the South East Asia region and Japan in the Western Pacific region both had higher numbers of specialist teachers and MLOP (Figure 9).
Figure 9 Global skills mix of low vision professionals
Training of human resources

Developing countries

In developing countries, few low vision health professionals held formal low vision qualifications (Figure 10), for example only 17/55 countries reported ophthalmologists holding qualifications.

Figure 10 The number of low vision personnel holding low vision qualification(s) in developing countries

Ophthalmologists (19/36), optometrists (16/29) and community workers that refreshed their skills/knowledge tended to do so through more formal training. However, MLOP such as ophthalmic nurses (20/27) and teachers (16/26) undertook informal training (Figure 11).
Chapter 4 - Results

Figure 11 The type of training received by low vision personnel in developing countries

Training was obtained both in-country and overseas (Figure 12). Few ophthalmologists and optometrists were trained locally (Figure 12).

Figure 12 Location of low vision training received by low vision personnel in developing countries
Developed countries

In contrast, more ophthalmologists, optometrists, and teachers in developed countries tended to hold formal qualifications in low vision care (Figure 13).

Figure 13 The number of low vision personnel holding low vision qualification(s) in developed countries

With regard to training type, more ophthalmologists (13/17) and teachers (9/13) received formal training. On the other hand, more optometrists (9/14) and ophthalmic nurses (5/7) received informal training than other cadres (Figure 14).
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The majority of training in developed countries took place in-country (Figure 15).

**Figure 14** The type of training received by low vision personnel in developed countries

**Figure 15** Location of low vision training received by low vision personnel in developed countries

**Service provision**

In developing countries, services were provided predominantly by non government rehabilitation agencies (26/41 countries) rather than public hospitals and government
rehabilitation agencies (15/41 countries). No significant differences were found between developed and developing countries (Figure 16).

![Figure 16 Common locations for low vision services in developed and developing countries](image)

Low vision care in most developing nations was clinical (39/41). In some instances, other types of services were also provided (Figure 17). In contrast, in more than half of the developed nations that responded to this question (21/40) not only clinical care was provided, but also education, social welfare, and at least one of the following forms of rehabilitation: orientation and mobility, sports and recreation, vocational and technology training (Figure 17). Significant differences were found between developed and developing countries in the different forms of rehabilitation: social welfare services ($\chi^2=26.78; p<0.000$); Information on low vision ($\chi^2=11.49; p=0.001$); orientation and mobility ($\chi^2=4.60; p=0.032$); sports ($\chi^2=13.54; p<0.000$); vocational training ($\chi^2=11.70; p=0.001$); and technology training ($\chi^2=14.34; p<0.000$).
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![Graph showing percentage of countries providing different types of low vision services in developed and developing countries.]

**Figure 17** Common types of low vision services provided in developed and developing countries

For client waiting times, urban waiting times averaged less than one month in many countries (46/95) while rural regions had waiting times ranging from greater than six months to over one year (37/86).

Finally, of the 43/94 countries who responded to the question on integration, 46% stated that there was effective integration between low vision services and other eye care, education, and rehabilitation services.

**Funding**

A little over half (51%) of the low vision services in developing countries were solely funded by non government organisations. This finding is in contrast with the developed countries where the funding is mainly by government either fully (32%) or subsidised (50%) (Table 21). Not surprisingly, significant differences were found between developed and developing countries in being fully funded by government ($\chi^2=4.10; p=0.04$) and those supported by international non government organisations ($\chi^2=30.21; p<0.000$).
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Table 21 Funding sources and mix of low vision services in developed and developing countries

<table>
<thead>
<tr>
<th>Aspects</th>
<th>Developed countries</th>
<th>Developing countries</th>
<th>Total (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fully funded by government only</td>
<td>32% (7/22)</td>
<td>12% (6/49)</td>
<td>71</td>
</tr>
<tr>
<td>Fee-based and subsidised by government only</td>
<td>14% (3/22)</td>
<td>0%</td>
<td>22</td>
</tr>
<tr>
<td>Fee-based and/or subsidised by government and non government support</td>
<td>50% (11/22)</td>
<td>37% (18/49)</td>
<td>71</td>
</tr>
<tr>
<td>Local and international non government support only</td>
<td>5% (1/22)</td>
<td>51% (25/49)</td>
<td>71</td>
</tr>
</tbody>
</table>

Of the countries that responded to the question on insurance, 18% (19/103) had a national insurance scheme that included low vision care; however, universal access for all to services was only present in 68% (13/19) of these countries.

Low vision devices

Devices were a common feature of low vision care in 96% (24/25) developed countries and 87% (60/69) developing countries. Out of this, 68% (17/25) in developed nations and developing nations 58% (40/69) who provided devices reported them as being affordable, that is clients were able to purchase them.

Barriers to low vision devices and services

The most frequent reasons for people not obtaining devices when prescribed were similar in developed and developing countries. These included: cost, fear of stigma (e.g. classmates making fun of person using devices) and devices being too difficult to use (Figure 18). Cost ($\chi^2=6.65; p=0.010$) was the only significant difference between developed and developing countries.
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**Figure 18** Reasons that individuals do not obtain low vision devices in developed and developing countries

**Figure 19** Disadvantaged groups less likely to access services in developed and developing countries

Specific groups of people were identified as being most likely not to access low vision services. In developing countries, these comprised of those with low income (61%; 45/74), living in rural areas (73%; 54/74), women (20%; 15/74), children (19%; 14/74), and people with disabilities (38%; 28/74). In developed countries, ethnic minorities (24%; 7/29), refugees (21%; 6/29) and elderly people (21%; 6/29) were less likely to access services (Figure 19). However, significance differences were found only between people with low income ($\chi^2=11.21; p=0.001$), people living in rural areas ($\chi^2=17.91; p<0.000$), and women ($\chi^2=4.49; p=0.034$) between developed and developing countries.
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Cost and distance to the nearest service were the most commonly reported barriers to accessing services in developing countries: 62% (46/74) and 72% (53/74) respectively (Figure 20). Lack of awareness, lack of referral networks, and poor communication between clients and health professionals were among the frequently cited reasons for not accessing services in developed countries. The perception that “nothing more can be done” was a common barrier across all countries. (Figure 20) Significant differences between developed and developing countries were found in culture ($\chi^2$=4.12; $p=0.04$); costs ($\chi^2$=15.83; $p=0.000$); and distance ($\chi^2$=11.14; $p=0.001$).

In terms of the reasons for the lack of services or resources - both developed (17/29) and developing (51/74) countries reported a lack of funding as the biggest factor. With respect to other reasons, Statistical differences were found in trained workforce ($\chi^2$=11.21; $p=0.001$); infrastructure ($\chi^2$=9.97; $p=0.002$); and awareness about low vision ($\chi^2$=10.05; $p=0.002$) between developed and developing regions.

**Monitoring & Evaluation**

Monitoring and evaluating the impact and quality of low vision services is limited throughout the world. Where it did occur, the most frequent method to monitor services in developed nations was surveys, (38%; 11/29) while a review of reports was the most common method used in developing nations (58%; 43/74). Developed and developing
Chapter 4 - Results

nations used similar indicators to monitor services, namely the number of people using services and obtaining low vision devices. Globally, the two most common outcome measures were improved visual function and use of low vision devices.

Global presence and coverage of services

Figure 22 (p.142) illustrates the coverage of services globally. The presence or absence of services was established for 178/195 (91%) countries (Table 13 to Table 18; p.123-126). Low vision services were present in 103/178 (58%) countries. A further 12/178 (7%) countries had some level of service but no additional information could be found about these services. Thirty-five percent of countries (62/178) had no low vision services, therefore zero coverage.

Of the 115 countries with low vision services (Table 22), 39 countries (34%) had ≤ 10% coverage (Figure 22). Furthermore, 22 (19%) countries had coverage between 11-50% (Figure 22), and only eight countries had coverage >50%. Coverage was not reported in 41% of countries (47/115) (Figure 22).

Table 22 Regional presence of low vision services and availability of prevalence data

<table>
<thead>
<tr>
<th>Region</th>
<th>Countries (n)</th>
<th>Presence of services (%),n</th>
<th>Number of countries with low vision prevalence data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td>46</td>
<td>46% (21)</td>
<td>52% (24)</td>
</tr>
<tr>
<td>Americas</td>
<td>35</td>
<td>57% (20)</td>
<td>20% (7)</td>
</tr>
<tr>
<td>Eastern Mediterranean</td>
<td>20</td>
<td>65% (13)</td>
<td>35% (7)</td>
</tr>
<tr>
<td>Europe</td>
<td>53</td>
<td>72% (38)</td>
<td>28% (15)</td>
</tr>
<tr>
<td>South East Asia</td>
<td>11</td>
<td>70% (7)</td>
<td>64% (7)</td>
</tr>
<tr>
<td>Western Pacific</td>
<td>30</td>
<td>52% (16)</td>
<td>32% (10)</td>
</tr>
<tr>
<td>Total (n)</td>
<td>195</td>
<td>115</td>
<td>70</td>
</tr>
</tbody>
</table>

Of the 70 countries with prevalence data on low vision, one third had ≤10% coverage (Table 22). With 10% being such a poor coverage rate and the large number of countries with less than this coverage, 10% was deemed an appropriate cut-off point to identify poor coverage.
Figure 21 Regional presence of low vision services compared with cataract surgical rates (CSR) <1000 per million\textsuperscript{27}
Figure 22 Global geographic distribution and coverage of low vision services
The presence and coverage of low vision services also reflects the Cataract Surgical Rates (CSR) (Figure 21; p.141). For instance, 46% of countries in Africa were reported to have services and 83% of countries had a CSR <1000 compared to 57% of countries with a presence of services in the Americas region and a lower percentage of countries with CSR <1000 (Figure 21).

Figure 22 and Table 22 show that most of the African region had either no services, very poor coverage or no information could be obtained. Moreover, though 100% response rate was achieved in the Americas region, the overall coverage rate appears to be mostly in red (i.e. ≤10%), with just over half of the countries (57%) having a presence of low vision services. Just a little over half (52%) of the countries in the Western Pacific had services. This was because there were no low vision services in all the Pacific Island countries except for Fiji.

In Europe, some of the countries specified as having no coverage data still deliver low vision services, however, no reliable source of information was identified (Figure 22). For these countries, prevalence data were not possible to obtain (Table 22). One example is Norway where services are known to exist however; no reliable source of information could be obtained.

Table 23 lists the eight countries with coverage >50%.

Table 23 Countries with >50% low vision service coverage

<table>
<thead>
<tr>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>Algeria</td>
</tr>
<tr>
<td>Canada</td>
</tr>
<tr>
<td>Iceland</td>
</tr>
<tr>
<td>Kazakhstan</td>
</tr>
<tr>
<td>New Zealand</td>
</tr>
<tr>
<td>Sweden</td>
</tr>
<tr>
<td>The Netherlands</td>
</tr>
<tr>
<td>United Kingdom (Wales)</td>
</tr>
</tbody>
</table>
4.4 Question 2: CSFs in the Coverage of Low Vision Services

4.4.1 Dependent Variable

Low vision service coverage is the dependent variable. It is defined as the proportion of people with low vision having access to low vision services. The number of countries with poor (≤10%) coverage is 101, which is composed of the 62 countries with zero coverage plus the 39 countries with ≤10% coverage. The total number of countries with better (>10%) coverage is 30 (22 countries with coverage between 11-50% plus 8 countries with coverage >50%).

4.4.2 Independent Variables

Independent variables – service-related critical factors

The statistically significant service-related critical factors associated with coverage are presented in Table 24. Obviously, countries that reported an absence of low vision services are not included. As not all questions were answered by respondents, there were variations in the total number of variables investigated against poor (≤10%) and better (>10%) coverage. Note that the term ‘critical factors’ are used here because at this stage of the Chapter these factors have yet to be identified as ‘critical success factors’ (CSFs).

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>Coverage ≤10%</th>
<th>Coverage &gt;10%</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presence of national policies on low vision</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>National referral guidelines for low vision services</td>
<td>39</td>
<td>28 (71.8)</td>
<td>11 (28.2)</td>
<td>0.005</td>
</tr>
<tr>
<td>Standards of practice guidelines for low vision services</td>
<td>33</td>
<td>24 (72.7)</td>
<td>9 (27.3)</td>
<td>0.009</td>
</tr>
<tr>
<td>Presence of a national eye care plan that includes low vision</td>
<td>10</td>
<td>5 (50.0)</td>
<td>5 (50.0)</td>
<td>0.436</td>
</tr>
<tr>
<td>Type of low vision care provided</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type 1- Clinical and education and rehabilitation and social welfare services</td>
<td>16</td>
<td>5 (31.3)</td>
<td>11 (68.8)</td>
<td>0.024</td>
</tr>
<tr>
<td>Type 2 (comprehensive)- clinical and education and social welfare and any one form of rehabilitation*</td>
<td>28</td>
<td>11 (39.3)</td>
<td>17 (60.7)</td>
<td>0.019</td>
</tr>
</tbody>
</table>
## Chapter 4 - Results

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>Coverage ≤10%</th>
<th>Coverage &gt;10%</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td></td>
</tr>
<tr>
<td>Funding</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fully funded by government</td>
<td>16</td>
<td>5 (31.3)</td>
<td>11 (68.8)</td>
<td>0.016</td>
</tr>
<tr>
<td>- National low vision health insurance</td>
<td>51</td>
<td>33 (64.7)</td>
<td>18 (35.3)</td>
<td>0.027</td>
</tr>
<tr>
<td>- National low vision health insurance (universal</td>
<td>16</td>
<td>13 (81.3)</td>
<td>3 (18.8)</td>
<td>0.009</td>
</tr>
<tr>
<td>Subsidised by government</td>
<td>27</td>
<td>16 (59.3)</td>
<td>11 (40.7)</td>
<td>0.796</td>
</tr>
<tr>
<td>Out-of-pocket</td>
<td>25</td>
<td>15 (60.0)</td>
<td>10 (40.0)</td>
<td>0.736</td>
</tr>
<tr>
<td>Private insurance</td>
<td>5</td>
<td>2 (40.0)</td>
<td>3 (60.0)</td>
<td>0.415</td>
</tr>
<tr>
<td>Supported by LNGO</td>
<td>35</td>
<td>19 (54.3)</td>
<td>16 (45.7)</td>
<td>0.598</td>
</tr>
<tr>
<td>Supported by International Non Government (INGOs)</td>
<td>36</td>
<td>25 (69.4)</td>
<td>11 (30.6)</td>
<td>0.032</td>
</tr>
<tr>
<td>Barriers to access</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of Integration between low vision services with other eye care</td>
<td>31</td>
<td>18 (58.1)</td>
<td>13 (41.9)</td>
<td>0.796</td>
</tr>
<tr>
<td>services, education, and rehabilitation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban waiting times</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- ≤ one month</td>
<td>37</td>
<td>18 (48.7)</td>
<td>15 (53.6)</td>
<td>0.544</td>
</tr>
<tr>
<td>- &gt;1 year</td>
<td>28</td>
<td>13 (35.1)</td>
<td>11 (39.3)</td>
<td></td>
</tr>
<tr>
<td>Rural waiting times</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- ≤ one month</td>
<td>31</td>
<td>9 (29.0)</td>
<td>8 (34.8)</td>
<td>0.546</td>
</tr>
<tr>
<td>- &gt;1 year</td>
<td>23</td>
<td>16 (51.6)</td>
<td>13 (56.5)</td>
<td></td>
</tr>
<tr>
<td>Lack of national policy on low vision</td>
<td>36</td>
<td>23 (63.9)</td>
<td>13 (36.1)</td>
<td>0.248</td>
</tr>
<tr>
<td>Lack of trained workforce</td>
<td>42</td>
<td>30 (71.4)</td>
<td>12 (28.6)</td>
<td>0.003</td>
</tr>
<tr>
<td>Lack of awareness</td>
<td>52</td>
<td>35 (67.3)</td>
<td>17 (32.7)</td>
<td>0.003</td>
</tr>
<tr>
<td>Lack of funding (any not type)</td>
<td>50</td>
<td>33 (66)</td>
<td>17 (34)</td>
<td>0.016</td>
</tr>
<tr>
<td>Lack of infrastructure</td>
<td>32</td>
<td>23 (71.9)</td>
<td>9 (28.1)</td>
<td>0.022</td>
</tr>
<tr>
<td>Lack of referral systems</td>
<td>32</td>
<td>23 (71.9)</td>
<td>9 (28.1)</td>
<td>0.022</td>
</tr>
<tr>
<td>Human resources</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤3 Ophthalmologists per 10 million population</td>
<td>28</td>
<td>19 (67.9)</td>
<td>9 (32.1)</td>
<td>0.215</td>
</tr>
<tr>
<td>≤3 Optometrists per 10 million population</td>
<td>35</td>
<td>25 (71.4)</td>
<td>10 (28.6)</td>
<td>0.014</td>
</tr>
<tr>
<td>≤50 MLOP per 10 million population</td>
<td>45</td>
<td>28 (62.2)</td>
<td>17 (37.8)</td>
<td>0.198</td>
</tr>
<tr>
<td>≤50 Community based workers per 10 million of</td>
<td>50</td>
<td>31 (62.0)</td>
<td>19 (38.0)</td>
<td>0.069</td>
</tr>
<tr>
<td>education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤3 trained teachers per 10 million population</td>
<td>24</td>
<td>15 (62.5)</td>
<td>9 (37.5)</td>
<td>0.568</td>
</tr>
<tr>
<td>≤3 Rehabilitation workers per 10 million of</td>
<td>39</td>
<td>27 (69.2)</td>
<td>12 (30.8)</td>
<td>0.008</td>
</tr>
</tbody>
</table>
### Chapter 4 - Results

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>Coverage ≤10%</th>
<th>Coverage &gt;10%</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td></td>
</tr>
<tr>
<td><strong>HR mix 1:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. MLOP (MLOP &amp; Optometrists) &amp; (Education and rehabilitation - CBR &amp; Rehabilitation workers &amp; teachers)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>N/A</td>
</tr>
<tr>
<td>2. Ophthalmologist and MLOP and (Education and Rehabilitation)</td>
<td>9</td>
<td>2 (28.6)</td>
<td>7 (71.4)</td>
<td></td>
</tr>
<tr>
<td><strong>HR mix 2:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. MLOP and (Education and Rehabilitation)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>N/A</td>
</tr>
<tr>
<td>2. Ophthalmologist and MLOP</td>
<td>18</td>
<td>9 (50.0)</td>
<td>9 (50.0)</td>
<td></td>
</tr>
<tr>
<td><strong>Clients - adults and children</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤50% adults obtaining devices when prescribed</td>
<td>29</td>
<td>19 (65.5)</td>
<td>10 (34.5)</td>
<td>0.174</td>
</tr>
<tr>
<td>≤50% children obtaining devices when prescribed</td>
<td>20</td>
<td>15 (75.0)</td>
<td>5 (25.0)</td>
<td>0.041</td>
</tr>
<tr>
<td>≤50% adults receiving services</td>
<td>29</td>
<td>22 (75.9)</td>
<td>7 (24.1)</td>
<td>0.035</td>
</tr>
<tr>
<td>≤50% children receiving services</td>
<td>45</td>
<td>25 (55.6)</td>
<td>20 (44.4)</td>
<td>0.101</td>
</tr>
<tr>
<td><strong>Location of services</strong></td>
<td></td>
<td>N=9</td>
<td>N=6</td>
<td>0.292</td>
</tr>
<tr>
<td>Location type 1:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Only hospitals</td>
<td>1</td>
<td>1 (11.1)</td>
<td>2 (33.3)</td>
<td></td>
</tr>
<tr>
<td>2. Hospitals and have one of these rehabilitation locations**</td>
<td>8</td>
<td>8 (88.9)</td>
<td>4 (66.7)</td>
<td></td>
</tr>
<tr>
<td>Location type 2:</td>
<td></td>
<td>N=18</td>
<td>N=20</td>
<td>0.429</td>
</tr>
<tr>
<td>1. Public hospitals and NGO rehabilitation agencies or community based services</td>
<td>8</td>
<td>8 (44.4)</td>
<td>11 (55.0)</td>
<td></td>
</tr>
<tr>
<td>2. Public hospitals and government rehabilitation agencies</td>
<td>3</td>
<td>3 (16.7)</td>
<td>5 (25.0)</td>
<td></td>
</tr>
<tr>
<td>3. Private hospitals and clinics and NGO rehabilitation</td>
<td>7</td>
<td>7 (38.9)</td>
<td>4 (20.0)</td>
<td></td>
</tr>
</tbody>
</table>

*Forms of rehabilitation - orientation and mobility, sports and recreation, vocational training and technology training*

**Rehabilitation locations - government rehabilitation agency, NGO rehabilitation agency, and community based services*
Countries with ≤10% coverage encountered barriers such as lack of awareness (67.3%) and infrastructure (71.9%) (Table 24). A high percentage (69.4%) of services in these countries was funded by international INGOs. Conversely, countries with >10% coverage have more funding from the government (68.8%), a wider variety of low vision care, and greater than three low vision health professionals per 10 million people (Table 24).

**Independent variables – socioeconomic and demographic-related critical factors**
The following are the socioeconomic and demographic-related critical factors associated with coverage showing statistically significant differences. Here, countries with zero coverage could be included since socioeconomic and demographic information was available. Countries with >10% coverage have a higher percentage of older people and a more urbanised population. There is also less dependence on external resources for health expenditure. Countries with ≤10% coverage were low income countries, have less people with access to information and communication technology, fewer numbers of health care workers per 1000 of population (density), a lower GDP, and a higher private expenditure on health (Table 25).
### Table 25 Socioeconomic and demographic-related critical factors

<table>
<thead>
<tr>
<th>Variables</th>
<th>Zero coverage</th>
<th>Coverage ≤10%</th>
<th>Coverage &gt;10%</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median (p25,p75)* n=62</td>
<td>Median (p25,p75) n=39</td>
<td>Median (p25,p75) n=30</td>
<td></td>
</tr>
<tr>
<td><strong>Health expenditure</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Per capita of total government expenditure on health</td>
<td>32.0 (16.0, 135.0)</td>
<td>72.0 (20.0, 258.0)</td>
<td>439.0 (64.0, 1613.0)</td>
<td>0.016</td>
</tr>
<tr>
<td>• Private expenditure on health as % of total expenditure on health</td>
<td>37.3 (22.5, 51.2)</td>
<td>54.0 (34.6, 62.1)</td>
<td>36.1 (24.7, 54.9)</td>
<td>0.027</td>
</tr>
<tr>
<td>• Out of pocket on health as % of private expenditure on health</td>
<td>90.2 (79.0, 99.9)</td>
<td>83.6 (64.4, 93.6)</td>
<td>80.1 (48.7, 93.8)</td>
<td>0.01</td>
</tr>
<tr>
<td>• External resources for health as % of total expenditure on health</td>
<td>12.7 (1.8, 27.7)</td>
<td>0.9 (0.1, 13.3)</td>
<td>0.0 (0.0, 1.2)</td>
<td>0.0001</td>
</tr>
<tr>
<td>• Social security expenditure on health as % of general government expenditure on health</td>
<td>0.0 (0.0, 14.4)</td>
<td>4.4 (0.0, 51.4)</td>
<td>14.6 (0.5, 45.6)</td>
<td>0.027</td>
</tr>
<tr>
<td><strong>Population statistics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• % of population over 60+</td>
<td>3.6 (3.0, 6.3)</td>
<td>4.9 (3.4, 5.8)</td>
<td>8.2 (4.0, 13.1)</td>
<td>0.001</td>
</tr>
<tr>
<td>• % of population under 15</td>
<td>40.6 (35.3, 46.1)</td>
<td>37.3 (34.0, 44.5)</td>
<td>32.9 (31.0, 36.3)</td>
<td>0.0003</td>
</tr>
<tr>
<td>• % of population urbanised</td>
<td>42.0 (33.0, 59.0)</td>
<td>55.8 (36.9, 64.6)</td>
<td>74.8 (48.7, 84.7)</td>
<td>0.013</td>
</tr>
<tr>
<td>• % of population living &lt;$1/day</td>
<td>25.3 (17.4, 49.5)</td>
<td>10.7 (2.2, 25.9)</td>
<td>7.0 (2.0, 25.5)</td>
<td>0.028</td>
</tr>
</tbody>
</table>
### Chapter 4 - Results

<table>
<thead>
<tr>
<th>Variables</th>
<th>Zero coverage</th>
<th>Coverage ≤10%</th>
<th>Coverage &gt;10%</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Median (p25,p75)</strong></td>
<td>n=62</td>
<td>n=39</td>
<td>n=30</td>
<td></td>
</tr>
<tr>
<td><strong>Human resources</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physician density per 10000 population</td>
<td>0.4 (0.1, 0.9)</td>
<td>0.8 (0.2, 1.9)</td>
<td>1.6 (1.1, 3.2)</td>
<td>0.0001</td>
</tr>
<tr>
<td>Nurses density per 10000 population</td>
<td>1.6 (0.6, 3.2)</td>
<td>1.7 (0.8, 3.8)</td>
<td>3.7 (1.1, 9.7)</td>
<td>0.02</td>
</tr>
<tr>
<td>Community health workers per 1000 population</td>
<td>0.09 (0.03, 0.29)</td>
<td>0.36 (0.05, 0.91)</td>
<td>0.08 (0.03, 0.20)</td>
<td>0.36</td>
</tr>
<tr>
<td>Other health care workers density per 10000 population</td>
<td>0.1 (0.0, 0.2)</td>
<td>0.4 (0.1, 1.0)</td>
<td>1 (0.2, 3.7)</td>
<td>0.0002</td>
</tr>
<tr>
<td><strong>Development status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Annual economic growth (GDP)</td>
<td>3.7 (2.5, 5.5)</td>
<td>5.2 (4.2, 5.7)</td>
<td>6.1 (2.9, 7.6)</td>
<td>0.11</td>
</tr>
<tr>
<td>Level of country income (n (%))</td>
<td></td>
<td></td>
<td></td>
<td>0.0009</td>
</tr>
<tr>
<td>High</td>
<td>3.0 (5.4)</td>
<td>4.0 (10.5)</td>
<td>11.0 (40.7)</td>
<td></td>
</tr>
<tr>
<td>Medium</td>
<td>0.0 (0.0)</td>
<td>6.0 (15.8)</td>
<td>4.0 (14.8)</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>53.0 (94.6)</td>
<td>28.0 (73.7)</td>
<td>12.0 (44.4)</td>
<td></td>
</tr>
<tr>
<td>Human poverty index (HPI) (n (%))</td>
<td></td>
<td></td>
<td></td>
<td>0.024</td>
</tr>
<tr>
<td>Developed countries</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developing countries</td>
<td>1.0 (6.7)</td>
<td>3.0 (20)</td>
<td>11.0 (73.3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>58.0 (51.8)</td>
<td>35.0 (31.3)</td>
<td>19.0 (17.0)</td>
<td></td>
</tr>
</tbody>
</table>
## Chapter 4 - Results

<table>
<thead>
<tr>
<th>Variables</th>
<th>Zero coverage</th>
<th>Coverage ≤10%</th>
<th>Coverage &gt;10%</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information and communication technology access</td>
<td>0.4 (0.3,0.5)</td>
<td>0.5 (0.4,0.5)</td>
<td>0.5 (0.5,0.8)</td>
<td>0.0001</td>
</tr>
</tbody>
</table>

* n=62, Median (p25,p75)*

* p25= 25th percentile; p75= 75th percentile

# Includes a large number of occupations such as dieticians and nutritionists, medical assistants, occupational therapists, operators of medical and dentistry equipment, optometrists and opticians, physiotherapists, podiatrists, prosthetic/orthotic engineers, psychologists, respiratory therapists, speech pathologists, medical trainees and interns.
Post hoc analyses revealed that statistically significant differences were detected in countries with zero and better (>10%) coverage in the majority of variables. An exception to this was private expenditure on health as % of total expenditure on health and out of pocket on health, which showed an association between countries with zero and poor (≤10%) coverage.

Per capita of total government expenditure on health was the only variable that did not show any significant difference between any of the coverage categories; while physician density per 10,000, external resources for health, information and technology access, and income level of country revealed differences between all three coverage categories. Furthermore, nurse density per 10,000, other health care workers per 10,000, population over 60 years, population under 15 years, population living on < $1/day, percentage of population urbanised, and human poverty index also exhibited significant differences between countries with poor (≤10%) and better (>10%) coverage.

4.4.3 Logistic Regression Modelling

Logistic regression modelling was compared with the CART methodology. To do so, a multivariate model was created to identify the critical factors of service coverage by adjusting all variables.

For the service-related component of the multivariate model, the variables were sourced from Table 24. Under each of the six topics, the variables were adjusted with other variables belonging to the same topic. After checking for collinearity and the number of missing values, there were six variables found to be significant and thus entered into the multivariate model (Table 26).

Interestingly, the variable ‘national referral guidelines for low vision services’ was found to have a negative association with coverage. It was speculated that there might be other factors that might not have been included in the survey to explain the relationship between these factors and coverage. For example, while referral guidelines may be important in service provision, without a good referral network or systems to implement these guidelines, coverage of services may still be poor.
Chapter 4 - Results

Table 26 Multivariate model showing the associations of service-related critical factors and coverage

<table>
<thead>
<tr>
<th>Variables</th>
<th>OR</th>
<th>P value</th>
<th>95% confidence interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>National policies on low vision</td>
<td>0.20</td>
<td>0.006</td>
<td>0.08-0.66</td>
</tr>
<tr>
<td>National referral guidelines for low vision services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of low vision care provided</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type 2 (comprehensive)- clinical AND education AND social welfare AND any one form of rehabilitation</td>
<td>3.60</td>
<td>0.02</td>
<td>1.21-10.71</td>
</tr>
<tr>
<td>Funding</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fully funded by government</td>
<td>5.72</td>
<td>0.015</td>
<td>1.40-23.38</td>
</tr>
<tr>
<td>Supported by International Non Government Organisations (INGOs)</td>
<td>0.21</td>
<td>0.008</td>
<td>0.07-0.66</td>
</tr>
<tr>
<td>Barriers to access</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of trained workforce</td>
<td>0.27</td>
<td>0.02</td>
<td>0.09-0.81</td>
</tr>
<tr>
<td>Human resources</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤3 Optometrists per 10 million of population</td>
<td>4.43</td>
<td>0.02</td>
<td>1.21-16.18</td>
</tr>
<tr>
<td>Clients- adults and children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤50% children obtaining devices when prescribed</td>
<td>6.47</td>
<td>0.116</td>
<td>0.63-66.38</td>
</tr>
</tbody>
</table>

The socioeconomic and demographic-related variables were sourced from Table 25. A logistic regression multinomial model was first carried out to examine the association between the coverage of low vision services and socio-economic and demographic characteristics of countries (Table 27).

Like the multivariate model, collinearity and the number of missing values were checked. Six variables were included in the final multinomial model: population over 60+ years, out of pocket spending, private expenditure on health, external resources on health, social security expenditure on health, and human poverty index.

Private expenditure on health and social security on health had an association with coverage (Table 27). Being a developing country was inversely associated with better (>10%) coverage. Countries with more private and social security expenditure on health were more likely to have some level of coverage rather than zero coverage (Table 27).
Table 27 Multinomial model showing the association between socioeconomic and demographic related critical factors and coverage

<table>
<thead>
<tr>
<th>Variables</th>
<th>Coverage 10%</th>
<th>P value</th>
<th>Coverage &gt;10%</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>RRR (95% CI)</td>
<td></td>
<td>RRR (95% CI)</td>
<td></td>
</tr>
<tr>
<td>Private expenditure on health</td>
<td>1.05 (1.02-1.08)</td>
<td>0.001</td>
<td>1.03 (0.99-1.07)</td>
<td>0.115</td>
</tr>
<tr>
<td>Social security expenditure on health</td>
<td>1.03 (1.00-1.05)</td>
<td>0.035</td>
<td>1.01 (0.99-1.04)</td>
<td>0.270</td>
</tr>
<tr>
<td>HPI_1 (developing countries)</td>
<td>0.05 (0.00-1.66)</td>
<td>0.10</td>
<td>0.04 (0.01-0.90)</td>
<td>0.043</td>
</tr>
</tbody>
</table>

Note: Reference group – countries with no services (zero coverage)
Pseudo $R^2$ =0.19, p<0.0001.

However, to adjust for socioeconomic and demographic variables in the multivariate logistic regression model- 62 countries with zero coverage had to be excluded in order to detect both service-related AND external factors impacting on service coverage.

After recalculating the univariate associations excluding the 62 countries - a total of eight variables were found to be significantly associated with coverage. These eight were: percentage of population urbanised, population over 60 years, population under 15 years, per capita of total government expenditure on health, external resources for health as a percentage of total expenditure on health, Human Poverty Index, and level of country income. None of these variables were retained after adjusting for each other in the model.

To generate the final model, all six variables were checked for collinearity and the number of missing values. Only four could be included as the variables (referral guidelines, funding by government, funding by INGO, and lack of trained human resources). It was found that ≤ 3 Optometrists per 10 million of population and type 2 (comprehensive care) of low vision care provided both had >20 missing values. Table 28 shows the results of the final multivariate logistic regression modelling:

Table 28 Final multivariate model of the CSFs associated with coverage of low vision services

<table>
<thead>
<tr>
<th>Variable</th>
<th>OR</th>
<th>p value</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>INGOs</td>
<td>0.22</td>
<td>0.019</td>
<td>0.06-0.78</td>
</tr>
<tr>
<td>Fully funded by government</td>
<td>4.00</td>
<td>0.071</td>
<td>0.89-18.09</td>
</tr>
</tbody>
</table>

Note: Pseudo $R^2$ =0.15, p=0.0077.
A test for model fit revealed that this model predicted only 38% of countries correctly, with a sensitivity of 100% and specificity of 0%, meaning that the predictive performance of this model is poor (Table 28).

Only two critical success factors were detected. But only one variable was significant (Table 28). In light of this, the researcher concluded that logistic regression modelling did not give enough ‘justice’ to the data and sought an alternative method to explore the relationships between the critical factors with the outcome coverage. Hence the CART methodology was adopted.

### 4.4.4 Identification of Critical Success Factors using the CART

The CART methodology enabled the researcher to reconsider all 36 service-related and 17 socioeconomic and demographic critical factors from Table 24 and Table 25.

At first, all 53 critical factors were included in the CART. However, conflicting information was again found in the following service-related critical factors: *national referral guidelines for low vision services* and *standards of practice guidelines for low vision service*. This relationship was also seen for referral guidelines in Table 26 of the logistic regression results above. These two variables were found to have a negative impact on coverage of low vision services where the researcher had expected the reverse to be true. There may be other factors affecting these two variables and coverage that were not measured.

Hence, it was determined that these two factors may not be directly linked to the outcome coverage and were thus removed from the CART analysis, leaving 51 critical factors to be included in the CART model. These two variables are a good example of data dredging.

The critical success factors (adjusted for both service-related and socioeconomic and demographic variables) are exemplified in the form of a decision tree by the CART in Figure 23: The green box at the top of the CART tree displays the outcome, coverage. To avoid repetition, the results of one side of the outcome are shown i.e. no or poor (≤ 10%) coverage. The boxes in yellow are the important predictors to the outcome. Level 1 is the most important predictor followed by levels 2 and 3. The first predictor at level 1 splits the tree roots (parent node) into three branches (child nodes) and so on. Each of these branches
then becomes a parent node and splits into further branches until the CART tree stops growing and the node terminates (e.g. node 13). Each node displays: the node number, the total number of countries, and the percentage of countries with poor (≤10%) coverage.

Six critical success factors were found by the CART to be significant predictors of coverage. The most important factor identified was: the proportion of children obtaining devices when prescribed ($\chi^2=44.0; p<0.0001$), followed by level 2 predictors: percentage of population urbanised ($\chi^2=14.5; p=0.002$), monodisciplinary vs. multidisciplinary care ($\chi^2=4.7; p=0.03$), and the number of rehabilitation workers per 10 million of population ($\chi^2=4.5; p=0.034$). The third level predictors include: private expenditure on health as percentage of total expenditure on health ($\chi^2=14.6; p=0.015$) and fully funded by government ($\chi^2=6.0; p=0.014$).

Interestingly, when the CART diagram is viewed horizontally a theme/topic can be identified from each level: level 1 is an indication of service completeness; level 2 is about service provision i.e. geographic distribution of services, type of care, and human resources; and level three is about funding i.e. public and private sources (Figure 23).

Figure 23 Critical success factors in the coverage of low vision services
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In the first branch where there is a higher percentage of children obtaining devices but less urbanisation (most people in many countries live in rural areas) - the proportion of countries with poor coverage is 78.9%. Furthermore, on top of these two characteristics - if countries have either lower (≤35.5%) or higher (>43.6%) private expenditure on health then the proportion of countries with poor coverage is both 100%. Examples of countries in these nodes included: Guyana, the Gambia, Croatia, India, Guatemala and the Dominican Republic.

On the other hand, in more urbanised countries, if services were fully funded by government then the likelihood of that country having poor coverage is reduced to 0%. Countries classified under this node were: United Kingdom (Wales), The Netherlands, Taiwan, Sweden, and Norway.

Where there is a lower proportion of children with access to low vision devices and only monodisciplinary care, the proportion of countries with poor coverage is 68.8%. Sri Lanka, Laos, South Africa, Bahrain, and Argentina are examples of countries in this category.

Nodes 7, 3, and 9 have been displayed by the CART as missing nodes. Unlike logistic regression where variables with missing data are excluded from the analysis, the CART model groups missing data with the predictor or category it is most similar or highly related to and displays them as surrogate nodes. Therefore, in this instance: the CART tree indicates that countries in node 7 all have poor coverage and these countries are related to the proportion of children obtaining devices when prescribed and the predictor monodisciplinary vs. multidisciplinary care. Examples of countries under node 7 are Tunisia, Namibia, Liberia, Gabon, and East Timor.

Node 8 shows that the proportion of countries with poor coverage is related to countries having ≤ 3 rehabilitation workers per 10 million and the proportion of children obtaining devices when prescribed. Benin, Armenia, Cambodia, Ghana, and Cameroon were some of the countries here. While Czech Republic, Germany, Cook Islands, and Haiti were a few examples of countries under node 9. Node 9 indicates that the proportion of countries with poor coverage is related to an unknown number of rehabilitation workers.
Finally, cross validation analysis indicated that the predictive performance of this CART model was 90.1% with a sensitivity of 93.1% and specificity of 80.0%. This implies that very few countries have been incorrectly classified in their respective categories of coverage.

### 4.4.5 FRAME

As a result of the findings from the CART, the ‘FRAME’ framework was developed. The framework can be used as a concise summary of the CSFs for low vision service coverage:

<table>
<thead>
<tr>
<th>FRAME</th>
<th>Critical success factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding</td>
<td>providing a sustainable funding mix i.e. between government and private</td>
</tr>
<tr>
<td>Rehabilitation workers</td>
<td>human resources type and mix</td>
</tr>
<tr>
<td>Access</td>
<td>devices and care</td>
</tr>
<tr>
<td>Multidisciplinary services</td>
<td>clinical care, rehabilitation, education</td>
</tr>
<tr>
<td>External contextual influences</td>
<td>population needs, existing health care system</td>
</tr>
</tbody>
</table>
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In the majority of cases, the researcher was able to obtain the relevant information from contacts arranged prior to travel. However, in some cases, other eligible or alternative candidates were discovered after arriving in the country. For instance in Ghana, an interview had been arranged initially with the project manager of the community based eye care rehabilitation program, who could not answer all the questions. Instead, another interview was arranged with the community-based field worker the next day, allowing the researcher to gather more informative data.

A total of 101 semi-structured interviews were conducted. The types of government ministries interviewed were: Ministries of Health, Ministries of Education, and Ministries of Social Welfare (Figure 24).

![Figure 24 Types of organisations visited by the researcher](image)
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4.6 Qualitative Analysis

The issues behind the CSFs were either identified as specific to countries or relevant across countries Figure 26.

Figure 25 Type of respondents interviewed by researcher

Figure 26 Identification of issues between countries or within a country
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Using the grounded theory approach, a total of 1229 free nodes were identified in NVivo from the 101 interviews. The free nodes were then coded into concepts/topics and represented by 53 tree nodes. The seven themes and their sub-topics are summarised in Figure 27.

4.6.1 Summary of Themes

Figure 27 Issues behind the critical success factors of low vision service coverage

4.6.1.1 Theme One – Advocacy

Advocacy is defined as ‘the act of arguing on behalf of a particular group of people, so that voices are heard and their interests are taken into account’.\(^{331}\) The aim of advocacy is to lobby those in authority (i.e. the government) or those with influence (e.g. policy makers) to use their authority to promote actions that are desirable and beneficial for low vision persons.\(^{331}\)

Advocating for low vision includes lobbying the government for recognition, appropriate inclusion of low vision into national policies, providing resources, funding, and social welfare. Advocacy also involves increasing employment opportunities of and acceptance
from the community. Tools such as research data and utilising NGOs as facilitators of advocacy are essential in lobbying the government.

Government policies can have an immense effect on low vision. For instance, in India the Disability Act defined low vision as blind. Consequently, government benefits apply only to those who come under this definition. Poor parents would thus rather have their child classified as blind so they can access free education at the Schools for the Blind and receive other government benefits.

In other parts of South India, children with low vision who are able to access the Education For All (EFA) program are able to receive free low vision devices from the government. An additional side bonus in providing these devices is that there has also been improved awareness among teachers and students in regular schools about people with low vision.

Another positive example of lobbying for government involvement and commitment can be found in Cameroon. Prior to low vision services existing as part of the comprehensive eye care program in the Southwest province, a planning phase of establishing low vision services was enacted. Large meetings were organised and facilitated by Sight Savers International involving key stakeholders (government, private sector). The Ministry of Public Health took the lead role in coordinating these meetings. Today there are low vision clinics in three government district hospitals (Limbe, Kumba, and Mamfe).

On the other hand, in Ghana, although the Sir John Wilson Optical centre (located in Hohoe, Volta region) was established in 1999, not until 2008 that the centre was integrated with the eye department at the nearby government district hospital. It took Sight Savers International two years of lobbying to achieve this.

**Table 30 Theme One Advocacy**

<table>
<thead>
<tr>
<th>Theme One – Advocacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advocacy</td>
</tr>
<tr>
<td>- Lobby at the government level – program managers in India and country director in Cameroon talked about the use of the global initiatives such as Vision 2020 and international events e.g. International Day for Disabled Persons (IDDP) as useful tools for lobbying at the government level.</td>
</tr>
</tbody>
</table>
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Theme One – Advocacy

- **Lobby for recognition of low vision** – The manager in charge of the low vision unit at the Ministry of Health in Ghana said it was difficult to convince upper levels of government to fund his unit because the country is dealing with basic health issues such as access to clean water as well as more acute health problems such as HIV, Tuberculosis, and Malaria. So although low vision is on the agenda of Vision 2020 and the country has signed the Vision 2020 declaration it is difficult for them to fully fund low vision services.

- **NGOs are an effective advocacy facilitator** – for example in 1992, the Ghana Society for the Blind carried out a survey that examined 12,000 children. It was found there were many children with low vision studying at the Blind schools and these schools were not coping with the number of students. In response to this, Sight Savers International and the education department held meetings and in 1994, the integrated education program (IEP) was initiated in the Akropong district north of Accra. This meant that instead of going to the School for the Blind and ‘reading’ Braille some children with low vision was able to attend regular schools.

- **NGOs used research findings e.g. surveys to lobby the establishment of services; setting up self-help groups; distributed papers and pamphlets.**

- **Presence of services** – some clients stated they became aware of services and the need for eye care when community based rehabilitation (CBR) workers provided services in their village. Another example was found in Ghana: just the presence of the Sir John Wilson optical centre in Hohoe brought awareness among the local community. According to the optometrist working at the centre- people seemed satisfied with the quality of services since clients were returning for follow ups. On top of this, the centre was receiving clients living from as far as Accra (three hour bus drive) to access low vision care. Some came because they heard others had good experiences with the centre and that devices were cheap for adults and free for children; and some because they were referred by a health professional.

- **Government support** – service providers working in the medical and rehabilitation sectors in India stated that when government was supportive there was less red tape, and thus better service delivery.

- "**Training is the key to improving coverage**" – program managers reported that if the government increased the number of training places for low vision health professionals, then coverage could also increase.

Employment

- **Employment opportunities in the community** – clients in community based rehabilitation programs consistently voiced the need for better employment pathways after a person with
### Theme One – Advocacy

low vision completes schooling. Program managers said there was a need for more interest from local organisations to employ people with low vision.

- **Job security for low vision personnel** – MLOP (e.g. refractionists and community field workers) in both Ghana and Cameroon expressed insecurities about their jobs in the long term as their salaries were being paid by Sight Savers International (SSI) rather than the government. Even though these low vision health professionals work in the government hospitals and system. Both governments do not formally recognise these ophthalmic professions since the training was provided by SSI.

- **Persons with low vision unemployed in the community** – children with low vision who had the opportunity to receive training and education, but upon graduation are unable to find employment. As one father of a low vision teenager in Cameroon summed up: “...puts other people off in the community in accessing low vision services because people think- what is the point of going through the training and then finding themselves unemployed afterwards?”

- **Sustainable employment** – MLOP in the African countries voiced the need for governments to create and provide employment for low vision health professionals. This would also motivate people to stay working in the field.

### Finance

- **Access to national funding** – In Ghana, the national health insurance covers eye examination and low vision assessment costs but not the low vision devices.

- **Government support leads to better access** – Children with low vision in The Education For All (EFA) initiative in India, are able to attend regular schools. The EFA Initiative (Sarva Shiksha Abhiyan (SSA)) is a national elementary education program that aims to enrol all 6-14 year-olds in school by 2010, and have all of them complete grade 8 with appropriate learning levels.\(^{278,332}\)

- **Affordable devices**- children attending schools in India through the IEP were able to access free or low cost devices and special teachers.

### Social welfare services

- **Importance of social welfare/Ministry of Social Welfare** – the social welfare district officer in Cameroon revealed that her department was not recognised by the community and within higher levels of government. Hence she reported that her unit lacked the essential resources, i.e. funds and social workers, to be able to provide adequate support needed by its clients.

- **Social welfare support unbalanced** – Service providers said while it was good that
### Theme One – Advocacy

Government support was provided to children with vision impairment e.g. exemption from school fees; there was a lack of support provided to adults and family members caring for the low vision person.

### National policies – advocating for low vision national policies

- **Definitions of low vision** – the government personnel at the National Institute for the Visually Handicapped (NIVH) said that a national definition of low vision that is distinct from the definition of blindness is needed. This will ensure that the right types of clients are identified by low vision service providers.

- **Guidelines and structure** – service providers voiced the need for clear and structured national policies and detailed guidelines.

- **Consequences of policies** – service providers said consideration needs to be given on the implication of policies in practice when making them. For example, only social welfare concessions were provided to people who are blind. To access these social benefits many low vision children were classified as blind. This resulted in children with low vision reading Braille at the school for the blind in India. These children were prevented from accessing regular schools with integrated educational programs (IEP).

- **Inclusion of low vision into national policy** – program managers believe that this will lead to the recognition of low vision as a priority in the country. An example of this is to include low vision in the national health insurance scheme.

- **Target the policy makers not the policy implementers** – program managers believe that this will make the most difference.

### Acceptance – advocacy at the service delivery level leads to acceptance of low vision and low vision services

- **Community acceptance** – Community field workers reported that involving the local community in low vision service delivery early will lead to better acceptance of services. Also, using international events to advocate is effective – for example IDDPI to advocate in the community.

- **Desensitisation** – community field workers emphasised the importance of education through the CBR program and breaking down stigma held by some of the clients such as: “I don’t want to be labelled as a disabled person because of my vision...or because I am wearing glasses”. In some villages there was still the belief that if the first person you saw in the morning was a blind person then you would also become blind yourself.

- **Acceptance by regular schools** – special teachers reported that since IEP was established in
Chapter Four - Results

<table>
<thead>
<tr>
<th>Theme One – Advocacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>India there were more understanding of low vision among regular teachers and students in the classroom of the schools where IEP was present.</td>
</tr>
<tr>
<td>- <strong>Attitudes towards adults with low vision</strong> – many service providers commented that “adults are set in their own ways so they are difficult to train”; “adults are only worth investing if they are of a productive age and are educated to read”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Poverty – advocating for the poor population who face the most difficulty in accessing services</th>
</tr>
</thead>
<tbody>
<tr>
<td>- An ophthalmologist in India commented: <em>low vision services are not sustainable because it is more of a poor person’s condition than the wealthy</em> – service providers also expressed that low vision can affect anyone; however, compared to the rich, poor people are less able to access care and devices.</td>
</tr>
<tr>
<td>- Service providers reported that poverty was one of the main barriers to accessing services.</td>
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</tbody>
</table>

4.6.1.2  **Theme Two – Service Delivery**

Service delivery explores how low services are delivered. Positive aspects of service delivery include integration of services into existing systems, services for children with multiple disabilities, and outreach services which lead to improved service coverage. Despite this, services for adults were limited in the three case study countries. There is a need for more rehabilitation services, and issues such as poor referral networks and loss to follow up were challenges in the provision of care.

Both India and Ghana demonstrated examples of innovative approaches to service delivery. In Ghana, integration of the Sir John Wilson Optical Centre into the local government hospital provided a one-stop-shop for clients, making it easier for them to access all optical services at once as well as obtain affordable low vision devices. Prior to this, clients usually had to pay twice to access both the optical centre and eye care clinic at the hospital. With integration, clients now only have to pay a one off fee to access all services.

The Sir John Wilson Centre was already sustainable prior to integration because the sale of glasses, consultation fees, and drugs covered the costs of running the low vision clinic. This ‘cross-subsidy’ is another advantage of integration into an existing eye care system. This is where the profits from one activity cover losses from another thereby making low vision services more sustainable in the long term.
Chapter 4 - Results

In India—both Aravind and Joseph Eye hospitals used the concept of ‘cost recovery’. For instance, patients who can pay, cover the cost of those who cannot. The low vision team at the Joseph Eye Hospital in Trichy adopted a flexible approach and was aware of the constant changing needs of the low vision population. For instance, the team were increasingly treating children with multiple disabilities; however, the low vision team lacked proper training in working with such clients. Thus, an external expert was invited to the hospital to provide training on working with low vision children with multiple disabilities. Since the training, the team has established collaborations with local organisations working with disabled children to conduct regular clinical outreach.

Table 31 Theme Two Service-delivery

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<tr>
<th>Theme Two – Service-Delivery</th>
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<tbody>
<tr>
<td><strong>Service delivery</strong></td>
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<tr>
<td>• <em>Service type</em></td>
</tr>
<tr>
<td>- Multidisciplinary services i.e. combinations of clinical care, educational, outreach and/or centre based services.</td>
</tr>
<tr>
<td>- Monodisciplinary (for example: limited to clinical low vision care in the medical sector and education for children in the education sector).</td>
</tr>
<tr>
<td>• <em>Ideal</em> – service providers voiced the need to provide holistic care not just eye care. For instance, having functional assessments available in all low vision clinics.</td>
</tr>
<tr>
<td>• <em>No government support</em> – clinical low vision services and education are mainly supported by NGOs in the case study countries.</td>
</tr>
<tr>
<td>• <em>No social concessions</em> – LVDs are not free for adults.</td>
</tr>
<tr>
<td>• Service providers working in the low vision clinics suggested the availability of multidisciplinary services such as rehabilitation and counselling in addition to low vision care.</td>
</tr>
</tbody>
</table>

**Integration**

• *Low vision is not a stand-alone discipline* – program managers said that in order for low vision to be prioritised – it should not be viewed as a separate discipline to other forms of disabilities.

• *Low vision can be integrated with other disabilities* – In Coimbatore- the Cheran Region Christian Society for Disabled Children (CRCS), is an organisation that provides rehabilitation services to hearing impaired, multiple handicapped children and those with learning difficulties. They also run a low vision clinic and implement the Integrated Education for Disabled program in the region. In addition, CRCS also implements the community based
Theme Two – Service-Delivery

rehabilitation program which covers all disabilities such as intellectual and physical. Low vision is a part of this program. The revenue generated from other activities administered covers some of the costs incurred by the delivery of low vision services. The organisation is supported by the government and received additional funding and technical support for its various programs from different NGOs such as CBM (for low vision and rehabilitation) and Sense International (DeafBlind children).

- Low vision should be integrated with other services but still maintain its own separate identity and speciality by having its own space and human resources within the existing service system – low vision specialists talked about how it was important to have the space and equipment to carry out functional assessments in the low vision clinic located within the eye hospital.

Services for children

- Services were mainly targeted at children
- Service concessions available for children only – for example, free access to LVDs in India.
- Government initiatives – ‘Education for All’ (EFA) ensures that children with low vision have access to the IEP program.

Services for low vision children with multiple disabilities

- Encountering clients with more than one health issue – take into consideration other co morbidities facing clients. For example, the low vision team at Joseph Eye Hospital started caring for low vision children with multiple disabilities.
- Low vision is also present in other types of disabilities – the staff at Joseph Eye Hospital found that low vision could also be incorporated into the screening procedures for other conditions (provided that proper training is given to staff).
- Specialised rehabilitation and CBR required for low vision children with multiple disabilities.

Services for adults

- Limited services available for adults – this was an issue in all three countries. Services were mainly targeted at children. Services for adults were mainly provided in the form of vocational training such as basket weaving and farming skills as part of the community based rehabilitation program.

Rehabilitation services

- A great need for low vision rehabilitation, especially community based – clients voiced the need for more rehabilitation to cope in their own home environment, be able to use low vision devices, and have enough skills to attend university, and have employment opportunities.
### Chapter 4 - Results

#### Theme Two – Service-Delivery

- **Specialised** – low vision specialists suggested there needs to be recognition that low vision rehabilitation is a specialised area requiring adequate physical space, equipment, and human resources to be able to provide adequate rehabilitation care.

- **Lack of continuity of care between education and rehabilitation** – for example, special teachers voiced concerns that after the children complete their schooling and become adults, there is no rehabilitation services to follow up, providing skills to enable them to find employment.

- **Low vision rehabilitation is not the same as blind rehabilitation** – low vision specialists emphasised this point, as other eye care providers and educators often classified low vision rehabilitation as the same as blind rehabilitation.

#### Outreach – “Go to the client rather than waiting for the client to come to you” (quote by an ophthalmologist working at a low vision clinic in India)

- **Outreach to community essential** – according to service providers, people benefit from outreach from low vision teams with visits to regular/special schools, and villages.

- **Improve coverage** – service providers stated that one of the advantages of outreach was that it overcame transport issues for clients. In India, staff can reach clients living up to 300km away from nearest eye hospital in Trichy.

- **Improve follow up** – outreach was most effective in the African countries as the population is smaller, more mobile, and less dense.

- **Tertiary hospitals conduct outreach** – large tertiary hospitals (e.g. Aravind, Joseph Eye Hospitals in India) can be a valuable resource to conduct outreach to nearby communities.

#### Educational services

- **Well-established for children** – especially in India - high numbers of children with low vision attend the IEP in regular schools, with teachers providing support and training, and given free materials e.g. large print, reading stands and magnifiers.

- **100% government support** – EFA initiative in India.

#### Availability of services

- **Resources** – physical infrastructure is required e.g. a room (6 by 6 meters) to carry out functional assessment, equipment, and materials.

- **Supply vs. demand** – service readily available when needed. For example, the father of a client in a small village in Ghana said that people would hear about low vision care and try to access such care in their local health clinic and find that low vision services do not exist.

- **Availability of a low vision clinic in tertiary eye hospital**
## Theme Two – Service-Delivery

- **Services being made available** – essential services suggested by service providers in order to provide quality low vision care: rehabilitation, counselling, services for adults, and social welfare.

## Counselling – to improve compliance

- **Poor compliance in the use of LVDs** – quotes from child clients: “LVDs are ugly and I get a sore arm from holding the telescope”, “I don’t like using my telescope because other children laugh at me”.
- **Poor compliance** – quote from adult client: “low vision is something I have to live with”, “why should I use this [magnifier] to read? My children can read to me”.
- **Ongoing counselling and education can improve compliance** – suggestion made by service provider.

## Follow up

- **Loss to follow up** – common reasons reported by service providers on clients not returning for follow up: transport issues, costs, seeking cure, and poor or no follow up system.
- **Not enough follow up** – many service providers talked about the lack of time given to clients for training in the use of LVDs. This was because there were many clients to see and they also had other roles.

## Referral networks

- **Point of referrals** – internal referrals within hospitals, referrals from cataract eye camps, referrals made by regular school teachers, referrals made by NGOs.
- **Poor referral networks** – in India a few service providers working in two of the major tertiary eye hospitals described a lack of communication between the place where the referral was made to and the place that made the referral. No referrals are made for adults to receive rehabilitation or social welfare care. Also, only internal hospital referrals were made. Special teachers talked about the fact that not many regular teachers are aware of vision problems among students and so some do not refer students to the hospital or the IEP program for further care.

## Low vision delivery approaches

- ‘**Amoeba structure with strong skeleton**’ – suggestion of an approach to delivering low vision service made by a low vision ophthalmologist in India. This approach included adapting to changing population trends, and the needs of the low vision population. For example, training in dealing with low vision children with multiple disabilities. However, at the same time, having a strong internal structure with the facilities, committed human resources, and
Chapter 4 - Results

<table>
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<tr>
<th>Theme Two – Service-Delivery</th>
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<tbody>
<tr>
<td>equipment to deliver services.</td>
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<tr>
<td>• ‘Organic vs. mechanistic’ – “putting the client at the top of the hierarchy and bypassing red tape, hospital bureaucracy, and politics” – an approach suggested by a low vision optometrist.</td>
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</table>

4.6.1.3 Theme Three – Access

The third theme derived from the case studies is access to services. The issues that define access include low vision resources, geographical coverage of services, the timing of the low vision person receiving low vision care and family support.

An interesting feature identified in India was the timing of the intervention. This depends on referral systems and networks, but also relates to having access to early intervention programs. One centre visited was in Coimbatore city. The staff at the centre provided vision rehabilitation and stimulation to children as young as two years old before these children started the integrated education program (IEP) in regular schools. According to the low vision specialist working at the centre, these children were then able to cope better in school having received this training. However, only a small number of children were using these services (i.e. 20 at the time of interview) as the capacity of the centre was limited in terms of physical space (only one room) and human resources (only two special teachers). On average, these children require three years of care.

<table>
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<tr>
<th>Table 32</th>
<th>Theme Three Access</th>
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<tr>
<td><strong>Theme Three – Access</strong></td>
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</table>

#### Access

- *Physical inaccessibility* – a few of the barriers cited by service providers on clients accessing services: services located too far for client to travel to, clinic times not matched to the schedule of the client, long waiting times.
- *When service access improve* – increase awareness in the use of LVDs.

#### Equipment

- *Access to high powered LVDs and non-optical materials* – This was a suggestion made by resource teachers in the IEP in India e.g. teachers making large print books by copying materials by hand.
- *Access to multipurpose and practical devices* – service providers talked about reasons why
### Theme Three – Access

Clients rejected LVDs. These included: the devices are bulky, difficult to use, have to change between a magnifier to telescope when looking at the board making it slow for the student to copy from the board, and devices not being fashionable.

### Equipment maintenance

- **Access to latest technology** – service providers working in the government sector suggested that it would be good to be able to access to the latest low vision devices and other equipment in the low vision field.

- **Have the means to carry out equipment maintenance** – so providers can continue to provide services. For example, the manager at a government assessment centre in Ghana, which screens for hearing, intellectual, and vision disabilities in newborns and children, said there were limited funds to send their equipment for regular maintenance. Once the equipment broke down it would either sit and gather dust or the staff had to wait for months before it could be fixed.

### Groups of people less likely to access services

- **Groups marginalised due to political history** – for example, the Anglophone community in Cameroon is becoming increasingly marginalised from the francophone community and government. For instance, issues with finding employment (Anecdotal evidence from clients and health care workers and website[289](#)).

- **Terrains** - difficult to follow up people living in rural and remote areas – people living in these areas have less access to public transport. In Ghana, people living in the Kete-Krachi district located in the Volta region are isolated in pockets of small islands from the mainland due to the damming of the Volta River. The only mode of transport is small boats and canoes. Boat transportation is the equivalent to the daily wage (USD$1).

- **Poor people** – according to service providers, people were often unable to afford services and devices if they had managed to reach the service centre.

- **People with a lack of social support** – for example, if no one was able to take the client to the low vision clinic, then clients are lost to follow up.

- **Elderly clients** – especially those living in remote areas (according to community field workers).

### Coverage

- **Geographical coverage** – some clients interviewed by the researcher had travelled up to 4 hours to reach the low vision clinic in Madurai district India.

- **Coverage of services is not known** – some of the managers and service providers in all three
### Theme Three – Access

- Countries were not sure of the local low vision population total and what percentage of the low vision population their services cover.

- *Training health care workers to have low vision skills*—suggestion made by a service provider/manager in Ghana: increase the number of low vision specialists conducting outreach. Additionally, have nurses in general eye clinics to be able to assess and refer low vision cases.

- *Better distribution of low vision health professionals*—for instance urban vs. rural.

- *Satellite eye care units*—located outside major cities and rural areas can improve coverage.

- *NGO service coverage is only limited*—focuses on specific areas of a country to work in. For example: SSI only works in the Southwest region of Cameroon. In India, only Tamil Nadu has the extensive network (predominately private NGOs) of low vision services.

### Intervention timing (Suggestions made by service providers)

- *Access to early intervention important*—rehabilitation, vision stimulation, establishes foundation to cope with IEP.

- *Access to right timing of intervention*—for example, between time of referral and next appointment or detection and intervention.

- *More early intervention centres needed*

### Integration

- *Low vision training integrated into the current mainstream tertiary training*—for example medical professions and optometry. This was a suggestion made by an optometrist working in Cameroon. He received his training in Nigeria as there were no schools of optometry in his native country.

- *Low vision services integrated into government health care system*—low vision services in Ghana and Cameroon have yet to be integrated into existing government systems.

- *Example of integration IEP in India*—children with hearing and vision disabilities are able to be a part of the regular school system giving them the opportunity to interact with other, non vision impaired children.

### Family support

- *Supportive family*—Many service providers working with children voiced that gaining the support of the family was the gateway for clients to access services. For example, unsupportive parents refusing to bring the child to receive low vision care.

- *Parental acceptance of child having low vision*—service providers said counselling was important in convincing some parents that having a child with low vision is not shameful and
Theme Three – Access

also minimising ‘doctor shopping’ (seeing many different doctors at the same time to obtain several opinions about the diagnoses).

4.6.1.4 Theme Four – Awareness

The fourth theme identified in the case studies is Awareness. Awareness among service providers, schools, the local community, and clients are important in facilitating better coverage of low vision services. For example in India, the low vision agenda was driven by an ophthalmologist interested in the field at the Aravind eye hospital. The culture at this hospital and many others that the researcher visited were based on a hierarchical system, thus the influence of an ophthalmologist had a strong impact.

Table 33 Theme Four Awareness

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<tr>
<th>Theme Four – Awareness</th>
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<table>
<thead>
<tr>
<th>Awareness among health professionals</th>
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</thead>
<tbody>
<tr>
<td>• Ophthalmologist support – ophthalmologists working in low vision encouraged peers to commit time to work in a low vision clinic.</td>
</tr>
<tr>
<td>• Include low vision into ophthalmology training curriculum - suggestion made by an ophthalmologist to overcome staff shortages.</td>
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<tr>
<th>Awareness in schools (recommendations made by special teachers, regular teachers, child clients, and school principles)</th>
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<tbody>
<tr>
<td>• Awareness among teachers – increase sensitivity among special teachers to detect children showing signs of having difficulties in reading or seeing the blackboard in classrooms.</td>
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<tr>
<td>• Awareness in classrooms – classmates should be made aware of students who use low vision devices, to have an understanding of what vision loss means, and not make fun of the person using an assistive device. One child client with Albinism said every time she used her magnifier or telescope many students would become curious and crowd around her.</td>
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<tr>
<th>Awareness by doing (suggestions made by health service providers)</th>
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<tbody>
<tr>
<td>• Conduct screening in the community.</td>
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<tr>
<td>• Student placements in the community.</td>
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<tr>
<td>• Presence of services – increases awareness in the community.</td>
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<thead>
<tr>
<th>Awareness of accessing services early (suggestions made by health service providers)</th>
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<tbody>
<tr>
<td>• Early intervention – preschool children and children with multiple disabilities</td>
</tr>
<tr>
<td>• Rehabilitation – particularly at the primary level</td>
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</table>
Chapter 4 - Results

### Theme Four – Awareness

- **Referrals** – timely referrals to low vision rehabilitation upon diagnosis

### Low vision services are different to the services for the blind

- **Low vision rehabilitation needs are different to rehabilitation needs for the blind** – comments made by low vision specialists.
- **Lack of services for low vision persons – many of whom attend Schools for the Blind instead.**
  This was according to the principal at the Akropong School for the Blind in Ghana.

### Client awareness of low vision

- Client acceptance that low vision has no cure, accepting the use of low vision devices (LVDs), rehabilitation, and minimising ‘doctor shopping’.

#### 4.6.1.5 Theme Five - Human Resources

The human resources theme examines in detail the roles and issues affecting the various low vision cadres. India has shown strategies in dealing with the shortage of rehabilitation workers. For example, in Tamil Nadu there is a college that trains low vision rehabilitation officers, approximately 25 graduates each year. However, as the college accepts only females, the number of rehabilitation officers available decreases over the years after the girls get married and usually stop working and/or locate to where their husbands are residing (e.g. outside Tamil Nadu).

To ensure a more adequate supply of rehabilitation officers, the ophthalmologist coordinating the low vision services at Joseph Eye Hospital has tapped into another source of graduates studying the Master of Social Work at the local University and at the time of the interview, had started arranging for these students to do placements in the community through the hospital.
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Table 34 Theme Five: Human Resources

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<tr>
<td><strong>Low vision human resources</strong></td>
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- *Lack of low vision human resources* – was present in almost all places visited. Managers talked about the risk of staff burnout and capacity being stretched. For example, in Ghana, although there are currently 52 ophthalmologists in the country\(^{334}\), only one is providing low vision care. This ophthalmologist is only based at the tertiary general hospital in the capital city Accra and runs low vision clinics three times a week in the mornings. At other times, the ophthalmologist allocates her time to teaching, doing surgery, and runs the paediatric clinics. There are no optometrists practising low vision at this tertiary hospital. The two optometrists at the hospital are shared by other departments so when low vision clients are referred for clinical assessments to see one of these two optometrists, they often have to wait for many hours or go home without being seen and told to come back next time. In addition, only one full time optometrist currently practices low vision in Ghana. This person is based at the Sir John Wilson optical centre in Hohoe and also manages other projects.

- *Eye care staff to commit time to work in a low vision clinic* – common comments were that ophthalmologists, nurses, and optometrists should provide low vision care during certain times of the day or certain days of the week. Also time given by social workers.

- *Competing priorities* – low vision health professionals have other commitments, for example: glaucoma clinics. Therefore health professionals do not have enough time to implement low vision care. Additionally, low vision care can be time consuming i.e. at least one hour required for each patient.

- *Perception of some eye health care professionals in general* – according to some service providers, some people see providing low vision care as an extra workload and not part of their primary roles.

- *Poor remuneration* – especially when working with government. In Ghana, some service providers talked about having to pay out of own pocket to cover transport costs when following up a client. In another example: because the Cameroon government has yet to recognise key ophthalmic professional groups such as optometrists, refractionists, and opticians; the government does not pay for their salary even though these personnel already work in the government system. The low vision personnel interviewed by the researcher voiced concern about their job security in the long term as their salary was being paid for by SSI. On the other hand, low vision personnel in India preferred to work in the NGO and private sector as the remuneration is better than that offered by the government.

- *Poor working conditions* – ophthalmic nurses at the district hospital in the Volta region in
Chapter 4 - Results

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<th>Theme Five – Human Resources</th>
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<tbody>
<tr>
<td><strong>Ghana</strong> described poor working conditions for example: working in 40°C heat with no air conditioning, retention issues, lack of professional development (e.g. access to journals or latest devices) and lack of job security (e.g. delays in getting paid). The nurses had also remarked that they lacked opportunities for refresher training. This is important because there were no ophthalmologist working at the clinic. The nurses said that they had to take on many roles of the ophthalmologist.</td>
</tr>
<tr>
<td><strong>Low vision expertise lacking</strong> – specialist rehabilitation officers and teachers (more commonly reported by service providers in the two African countries)</td>
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<tr>
<td><strong>Sustainable source of human resources</strong> – having more than one source to acquire staff (refer to the Trichy example above).</td>
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<thead>
<tr>
<th>Ophthalmologists</th>
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<tbody>
<tr>
<td><strong>Lack of interest in low vision</strong> – service providers outlined reasons why it is difficult to recruit or retain people to work in low vision: time consuming, not profitable, cannot provide a cure for the client.</td>
</tr>
<tr>
<td><strong>No time to spare to work in a low vision clinic</strong> – service providers said that low vision clients require a lot of time.</td>
</tr>
<tr>
<td><strong>When ophthalmologists supportive and take an interest in low vision (e.g. the ophthalmologist at Aravind Eye Hospital)</strong> – it is to advocate for services and support establishment of low vision services within the hospital system.</td>
</tr>
<tr>
<td><strong>Strategies</strong> suggested by low vision ophthalmologists – include low vision in ophthalmology training curriculum, increase awareness in professional associations and unions.</td>
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<tr>
<th>Teachers</th>
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<tr>
<td><strong>View low vision children as extra workload and not part of their job</strong> – views held by special teachers on regular teachers.</td>
</tr>
<tr>
<td><strong>Clients and families suggest more teacher support and being able to detect vision problems in their child early.</strong></td>
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<tr>
<td><strong>Retention of specialist teachers</strong> – source local personnel from the community (suggestion by program manager)</td>
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<tr>
<th>Community rehabilitation workers</th>
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<tbody>
<tr>
<td><strong>Field workers in India and Cameroon improve coverage and are able to reach the most vulnerable and marginalised populations</strong> (advantages of CBR workers according to a program manager).</td>
</tr>
<tr>
<td><strong>Able to provide rehabilitation to adults and children</strong> (observed by researcher visiting village in</td>
</tr>
</tbody>
</table>
### Theme Five – Human Resources

**India**

- *More community rehabilitation workers needed* (according to community field workers in all three countries)

### Training (recommendations made by service providers unless otherwise stated)

- *Increase training places for better coverage of services.*
- *More training opportunities and locations within the country.*
- *Low vision training curriculum* – needs to be more practical and promote more critical thinking (former graduates of rehabilitation training college).
- *Training provided to clients and families* – more rehabilitation training required e.g. use of LVDs, activities of daily living, counselling, and training families with how to help cope with family members with low vision.
- *Informal training* – good to have workshops, short training courses, seminars provided by NGOs or within hospitals.
- *Training to deal with staff shortages* – training provided to mid level ophthalmic personnel, nurses to take over some of the roles not filled by optometrists or ophthalmologists (approach taken by NGO providing low vision services).
- *Sources of training* – NGOs provide technical assistance and expertise, private tertiary hospital, government universities provide training for special teachers, low vision training often based externally, for example: optometrist in Cameroon travelled to Nigeria to receive optometric training.

### Task shifting

- *Training* - delegating tasks to less specialised eye health workers to address staffing shortages.
- *Less specialised health workers can take on multiple roles or specialised roles (given the right training)*
- *Example:* in Ghana Volta region - the ophthalmic nurses and vision technicians based at the district hospital were the main providers of low vision care. These cadres managed minor eye conditions, did home visits, and local school screening.
- *Example:* in Cameroon, the store manager in the eye care unit at the Mamfe government district hospital not only managed the stock but also carried out low vision assessments, prescribed low vision devices, and did refraction. The store manager was trained on the job by the refractionist, who in turn received the training from the optometrist. When the refractionist does outreach or is away on holidays the store manager takes over his
## Theme Five – Human Resources

responsible for the time he is away.

**Professional development (suggestions made by service providers)**

This involves low vision personnel having access to:

- *Latest research, journals, technology in low vision: in Mamfe Cameroon,* there was no Internet at the hospital and Internet could be only accessed during certain times of the day at the Internet cafe in town. Power cuts are also common. Subsequently, staff had very limited access to the latest research and journals.

- *Regular refresher training seminars or workshops:* the ophthalmologist working in Mamfe district, Cameroon said it has been five years since he had the opportunity to receive any follow up training.

- *Attend local and/or international conferences:* the low vision optometrist working in Hohoe remarked that one of the things that would entice staff to work in the field longer if they had opportunities to attend conferences, share experience, knowledge, and meet other people working in the same area.

- *Opportunities to conduct research:* in India, services providers did not have time to access the latest research, technology, or attend conferences because they either had too many clients to see and/or had no funding. On average, service providers worked 6 days a week, Monday to Saturday. Outreach can take longer due to travelling time. Only in places with NGO support received follow up or in-service training from visiting consultants. For example, CBM funded a local consultant to train the team in dealing with low vision children with multiple disabilities at Joseph Eye Hospital. In addition, some of the service providers the researcher met had an interest in conducting research to improve the services they were providing. For example, exploring the reasons people do not return for follow up; however, again due to lack of time and funds, this was not possible.

### 4.6.1.6  Theme Six - Governance

Governance relates to the management of low vision services. This refers to the type of governance (i.e. government vs. NGOs), monitoring and evaluation of services and establishing networks and collaborations with the different stakeholders involved in service provision.
Chapter Four - Results

Table 35 Theme Six Governance

| Governance |
|-----------------|--------------------------------------------------|
| One government department to coordinate low vision care – low vision care involves more than one discipline for example, health, education, and social welfare. This often results in no ministry taking responsibility for low vision services. It is also unclear which ministry should take the leading role in coordinating services. Services became fragmented. For instance, low vision services are well provided for in the education sector in India but poorly funded and under-resourced in the rehabilitation sector. Therefore, suggestions were made to designate one government ministry to coordinate low vision services whilst working with other government departments (suggestions made by program managers) |
| Corruption – for example service providers in India talked about how at the grassroots level doctors are charging clients to have their disability cards verified even though government states it is free of charge. This creates mistrust among the local population. People become less willing to access other types of western medicine. |
| Low vision services are not a priority among private for profit hospitals – as low vision services are not profitable (service providers working for hospitals affiliated with NGOs referring to reasons why private for profit hospitals do not provide low vision services). |
| Coordination among stakeholders – program managers remarked about the poor cooperation between private and government sectors in India. |
| Government and private sector partnership – with government taking the lead (recommendation made by program managers). |
| Need to focus at the right level of government and right government ministry: recommendations made by program managers |
| Leadership – according to the low vision ophthalmologist working at Joseph Eye Hospital who had been able to set up outreach services: “good leadership results in expansion and development of services”. |
| Management style – According to the same ophthalmologist when there is less hierarchy, more promotion of the team environment, and accountability – better productivity and motivation of staff. |
| Organisation – taking the time to plan, assess, and establishing a structured system (Country Director of Cameroon). |

Capacity building

| Government – focus on building up the capacity of government so that governments can take over the coordination of low vision services (sustainability), build up capacity to work |
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**Theme Six - Governance**

with all stakeholders (suggestions made by one program manager in Ghana)

- *Existing local resources* – rather than creating new services, find out what local resources are in the community that will play a major role in service delivery and build up the capacity of these existing local resources (suggestions made by a program manager of NGO).

- *Low vision managers* – provide management training. For example, the optometrist/manager working at the Sir John Wilson Optical Centre was at the time of the interview studying for a degree in Masters in Business Administration.

- *Training* – capacity building through human resources training (suggestions made by a program manager of NGO).

**Monitoring and evaluation (M&E)**

- *General lack of M&E* – in looking at service delivery, service output, and population reached. No monitoring systems in place in many places visited across the three countries, mainly reports submitted to NGOs as part of donor requirements. For example, the community based program manager submits quarterly reports to SSI but when asked about the coverage of services, he was not sure what the coverage was.

- *Epidemiology and statistics lacking* – for example: population coverage, prevalence of low vision in the area (many service providers said they had referred to the WHO estimate of 1%), what the population needs are e.g. whether or not children or adults needs more services and what type of services are needed most. For example service providers did not know the exact number of clients accessing services compared to the total number of people needing services.

- *Mainly carried out by NGO* – but in accordance to the specification of the NGO project only. For example, NGOs needed to report to the donors.

- *Client satisfaction* – for example; one of the adult clients in Ghana had suggested that it would be useful for the clinic to gather feedback about the levels of client satisfaction.

- *Lack of reporting or system in place for low vision health professionals to report back to* - the manager at the low vision unit in the department of health in Ghana talked about how no systems had been in place (or motivation) for government optometrists in Ghana who had received low vision training by an INGO a few years earlier. Subsequently, after the training was completed, no one reported back to the low vision unit at the Department of Health on what they did with their training, how many low vision patients they were seeing, what they were doing at present.
**Theme Six: Governance**

**Collaboration** (suggestions made by NGO country directors, program managers, and service providers)

- All stakeholders coming together – government, schools, NGOs and working together for one agreed goal.
- Contribution – clear guidelines and agreement on who (the stakeholder) is contributing what and how much.
- Roles – clear understanding among all stakeholders on the role of each.
- Inter-government working together - one government ministry taking charge to coordinate the management of low vision services, while the other ministries have an understanding and agree to work together with each contributing to different aspects of low vision care.
- Inter-NGOs – collaboration among all NGOs involved in eye care delivery.
- NGO are good facilitators – for example, can facilitate collaboration efforts among government departments and private not for profit stakeholders.
- Communication among all stakeholders.
- Syncing all disciplines of low vision care – Education in sync with rehabilitation and clinical low vision care.
- Not working in parallel with each other but working together in an integrated manner.

**Networking** (suggestions made by NGO country directors, program managers, and service providers)

- Within an existing system.
- With government.
- With industries - to create more attractive and affordable devices.
- With universities and training institutes.
- To sharing of resources among all stakeholders
- With disability organisations.

**NGOs**

- Majority of low vision services started by NGOs (observations made by researcher)– NGO still play a major role in providing low vision services. In Tamil Nadu the extensive network of general eye care and low vision services are mainly run by NGOs and private organisations.
- Often the only source of care received by clients is from NGOs.
- NGOs are a major source of low vision funding, training, and providers of free materials.
- Donor fatigue – program managers and service providers talked about NGOs gradually reducing funds over time and making it difficult for them to provide all the care. For
Chapter 4 - Results

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example, a community field worker in Ghana said that he had to limit the number of clients admitted to the CBR program for the year due a reduced amount of funding from SSI.

- **Type of care** – NGOs works at the grassroots level and targets marginalised and vulnerable groups. NGOs also conduct eye camps in collaboration with a local hospital.

- **Good management characteristics** – accountability and transparency.

- **Issues of sustainability** – NGOs set up short term projects of three to five years raising issues of sustainability (refer to the Ghana experience in the next theme).

- **External resource** – e.g. many service providers affiliated with or working NGOs raised concerns about the long term future of their services because the main sources of funding came from NGOs.

### 4.6.1.7 Theme Seven - Sustainability

The seventh and final theme emerging from the case studies was sustainability. Issues contained within this theme include: funding schemes, government ownership, NGOs’ roles and contribution, and taking into consideration the external contextual influences low vision services are established and developed in.

The case studies in India demonstrated both positive and negative aspects of sustainability. A positive example of public and private partnership is found in the educational aspect of low vision. In schools (government and/or private) taking part in the IEP program, each have a resource room staffed by one teacher. This teacher usually holds a Master in Special Education and his/her salaries are paid for by the government. NGOs such as CBM work in collaboration with these organisations and government to provide technical support and training where appropriate.

Children with low vision are able to attend mainstream schools with the support of the resource teacher and materials (uniforms, books, and stationery) which are supplied free by the government. Moreover, through the government branch – the National Institute for the Visually Handicapped (NIVH), the children in the program also receive free basic low vision devices such as hand-held magnifiers and reading stands. CBM also provides technical support and resources.
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The resource teacher also makes home-visits to find out about the children’s family situation, background and their parents’ involvement. They then give advice to parents on ways to guide and help their children’s activities at school and their studies. These teachers come from formal training institutes such as Ramakrishna Mission Vidyalaya and the Avinashilingam University for Women. The courses are recognised by the National Council for Teacher Education and the Rehabilitation Council of India (RCI).

Ramakrishna Mission Vidyalaya also has a low vision clinic on campus which was established 10 years ago. Students are able to do their placements through this clinic and staff and students conduct vision screening at all public schools and government run eye camps. Approximately, 40 students are screened at each school visit. The centre also has its own integrated education school within which students can do their placements. Ramakrishna Mission Vidyalaya receives a free supply of low vision devices to distribute as well as technical support from CBM. Furthermore, the school has previously established a joint training program with CRCS and is at present working with NIVH to implement a new training program in low vision.

The Avinashilingam University for Women established the teacher training program with CBM in 1985. The university founded the program for training teachers to work in inclusive education in 1994. Since 1985, 800 teachers have been trained. Sixty percent of this figure was comprised of special teachers. Originally, the courses started with vision impairment but it was soon realised that other forms of disabilities needed to be addressed as there were many children with multiple disabilities, hence low vision training was integrated with training for other forms of disabilities. The University also has its own school on campus in collaboration with the RCI. Currently 33 students attend this school and use the RCI curriculum. RCI in turn provides computer training courses for teachers. The school is again supported by CBM and the salaries of teachers are provided by the government. Lastly, the University also networks with the District Disability Rehabilitation Office (DDRO). The two parties share research information and statistics e.g. survey on low vision children. The DDRO is responsible for handing out disability cards which entitles people to government benefits. The office also collects information on organisations working in the area, coordinates primary health care for people with disabilities in rural regions, and works with hospitals and training institutes to conduct vision assessments.
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According to the teachers, project managers, government personnel, and students interviewed, the benefits of the Integrated education program were evident by an increase in the number of primary schools taking up the program over the years, an increase in the number of low vision children enrolled each year, reduction in the number of low vision children in Blind schools or staying at home, and better transition experiences from primary to secondary school. Students were also better able to interact better with other fellow children without disabilities.

By contrast, the eye care and rehabilitation sectors experience a different situation to that of the education sector. These two sectors are predominantly privately run. The services are not integrated with the government system. The government feels that eye care (including low vision) and rehabilitation services belong to the realms of the private sectors as historically these services were established by philanthropic organisations. As a result, several issues have arisen.

First, according to the people interviewed, the government views the private and volunteer sector as competitors encroaching on government territory. This has led to duplication of some services; for instance, eye camps being run around the same time by both the government and the private tertiary hospitals. Another example was the presence of low vision clinics at CRCS and community based rehabilitation programs running parallel to similar services being provided at the Aravind (Coimbatore and Madurai branches). As the services are free, many clients go to two eye camps on the same day leading to a waste of resources.

Second, the low vision clinics at Aravind and Joseph Eye Hospitals could not easily obtain access to the low vision devices at NIVH. The researcher was told by the ophthalmologist at Aravind that to apply for a supply of devices from the government, he had to go through a lot of paper work and spend time waiting and following up for a reply from the government. These hospitals instead purchase low vision devices from local manufacturing companies and sell them at a subsidised price to the clients. Often the clients who are from a poor background end up not purchasing these devices because they cannot afford it, even at the subsidised rate. This results in stocks of low vision devices sitting in store rooms of both the government and private sectors.
Third, because eye care and rehabilitation sectors of low vision are viewed differently by the government; clients and service providers have faced challenges in accessing government benefits. For example, depending on the person processing the application, the DDRO will not recognise medical certificates provided to clients by private or volunteer organisations. These medical certificates state that the client has low vision and entitles the person to free public transport and social welfare benefits. Consequently, this leaves some clients feeling frustrated about the system. Others go to government doctors to have the medical certificates reissued.

In an attempt to overcome this issue, the ophthalmologist at Joseph Eye hospital regularly made social visits to the DDRO in person to improve rapport with the officer processing the application. He also invited the officer to events at the hospital. Unfortunately, the officers are on rotations and every few months a new officer would take over the role and again the ophthalmologist had to re-establish rapport with the officer.

The researcher tried to make an appointment to visit the DDRO officer both in Madurai and Trichy. Both appointments were made by the ophthalmologists at both hospitals. In Madurai, the relationship between the hospital and DDRO was poor so the request was denied immediately. In Trichy, initially the officer agreed; however, when the researcher arrived, she was told to wait outside and told that someone will call her to come in. After one hour of waiting, the researcher eventually left as other interviews were arranged at other organisations. Interestingly, earlier in her travels the researcher was able to interview the government official at NIVH in Chennai. It was one of the rare interviews the researcher was able to access to obtain a government perspective. The interview was arranged by a person working in the education sector.

In Ghana, one of the main reasons why earlier low vision services collapsed was because services were driven by the NGO. CBM had trained a few government eye health personnel in low vision care and it was overseen by an expatriate optometrist. As soon as the expatriate left, no one from the government took over its management.

A similar event occurred with the community based rehabilitation services in Hohoe (run by the Sight Savers International): a few years ago Sight Savers International had established its
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first community based rehabilitation project in the Kete-Krachi region in conjunction with a local church organisation. The program ran for five years and eventually Sight Savers International withdrew from the project. Within a year the program collapsed. The main reasons for this collapse, according to SSI and former managers of the program, were poor management and funding issues. Two years ago Sight Savers International re-established another community based rehabilitation project in the same area but this time, it formed collaboration with the local government instead.

Table 36 Theme Seven-Sustainability

<table>
<thead>
<tr>
<th>Government (recommendations made by project managers, service providers, NGO country directors)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 100% commitment – when there is commitment from government there is acceptance, awareness, and involvement.</td>
</tr>
<tr>
<td>• Involvement– governments should be the main leading player.</td>
</tr>
<tr>
<td>• Program or service in agreement with government agenda – services must be wanted and initiated by government and not by the NGO. For example, low vision may be on the agenda of Vision 2020 and therefore becoming a priority for eye NGOs, but governments must also be convinced that low vision is a part of their national agenda (also observed by researcher).</td>
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<table>
<thead>
<tr>
<th>Ownership (recommendations made by project managers, service providers, NGO country directors)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Government ownership– contribution by funding. Not merely to accept and allow the NGOs to do the work but also commit by providing funding to services, and employ low vision human resources.</td>
</tr>
<tr>
<td>• Government to implement services– NGO can provide assistance but not become the main implementer; government can establish training institutes and NGO can provide the technical expertise to build up the manpower initially.</td>
</tr>
<tr>
<td>• Governments feel that low vision services belong to the realms of the private sector – historically services were established by charities.</td>
</tr>
<tr>
<td>• Low vision seen as standalone discipline by government (comment made by service provider in India) – one of the reasons behind the lack of government ownership.</td>
</tr>
<tr>
<td>• Community ownership - community field workers emphasised the importance of the local community taking responsibility, involvement and support in determining the success of the community based rehabilitation program.</td>
</tr>
</tbody>
</table>
Theme Seven - Sustainability

- **Example of government ownership** – The EFA initiative in India resulted in a number of IEP established within regular schools, providing free materials and devices with minimal red-tape.

NGO

- **Coverage of services in certain regions of the country rather than the whole country:** The eye care program in Cameroon set up by SSI in collaboration with the government is only present in the Southwest Region. In India, eye care services are concentrated in south India (primarily Tamil Nadu), and in Ghana, only the Greater Accra and Volta regions have a presence of low vision services.

- **Government see that NGOs are delivering services and bring in funding so do not feel that it needs to do anything** - comment made by program managers working for NGOs when probed by the researcher about reasons as to why difficult it was difficult to obtain government ownership.

Relationship with government

- **Cited as important by NGOs**

- **Reluctance from government towards the private and voluntary sector** – service providers remarked that government may see the private and voluntary sector as competitors encroaching on government territory. This may help explain the challenges faced by the private sector (refer to Theme one – advocacy and the Indian experience).

- **Relationship** – the private and voluntary sector encounters red tape, making it challenging for clients to obtain government benefits. For example, in India, in the rehabilitation and clinical fields, clients who have been referred by private or voluntary hospitals have found it difficult to access disability cards, which entitle them to government benefits. The government does not recognise the diagnosis provided by the private sector and requires clients to see a government doctor before being eligible to receive a disability card. No such difficulties are encountered by clients accessing government educational services as it is 100% supported by the government through the EFA initiative (refer to Theme one – advocacy and the Indian experience. Hence, this is one of the reasons for the lack of rehabilitation services compared with educational ones.

Duplication of services (observations by the researcher)

- **Poor relationship with government** – leads to duplication of services. For example: In the Trichy district both the government and private sector run the same eye camps at the same time.
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<table>
<thead>
<tr>
<th>Theme Seven-Sustainability</th>
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</thead>
<tbody>
<tr>
<td><strong>Unused resources</strong> – for example, in Chennai district India the government has an abundance of cheap, locally manufactured low vision devices but they are not being used or distributed. The private sector has no access to this stock.</td>
</tr>
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<table>
<thead>
<tr>
<th>Local resources</th>
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<tbody>
<tr>
<td>Local population mentality – many clients expressed that any services provided by foreigners and NGOs are better than local services. This has led to services provided in government hospitals not being used.</td>
</tr>
<tr>
<td>Local access to materials – in Ghana there is a local materials centre where low vision health professionals can purchase low vision devices without having to source them from overseas. In India, there are companies that now manufacture basic low vision devices, which have reduced the price significantly.</td>
</tr>
<tr>
<td>Local training locations – service providers talked about the fact that it would more feasible if people can attend training courses in the country rather than having to travel overseas. An effective means would be to invite trainers from overseas.</td>
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<table>
<thead>
<tr>
<th>Funding schemes</th>
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</thead>
<tbody>
<tr>
<td>Cost recovery – “rich patients pay for the poor” – a system adopted by Aravind and Joseph Eye Hospitals.</td>
</tr>
<tr>
<td>Cross subsidy – as low vision services are not profitable, using the profits made from sale of glasses and drugs to cover the cost of low vision services (method used by the Sir John Wilson Optical centre in Hohoe Ghana – hence the centre is now self-sustaining)</td>
</tr>
<tr>
<td>Incorporation of low vision into the national budget (suggestion made by program managers).</td>
</tr>
<tr>
<td>Including low vision into national health insurance (if the country has one) - (suggestion made by program managers).</td>
</tr>
<tr>
<td>Funding mix – rather than relying 100% on NGOs or 100% on government- services are funded by a mix between the public and private sector including out of pocket payments, and contributions made by companies (e.g. the Aravind and Joseph Eye hospitals system)</td>
</tr>
<tr>
<td>Involvement of credit unions and banks to provide Micro-financing schemes. Many of the clients in Ghana and India stated that micro-financing has given them self-employment (selling bread, farming, making incense), which represents independence and empowerment. It has given them the opportunity to become breadwinners again and not resort to begging or relying on their families. For instance: “I use to feel hopeless but now I feel I am useful again” – quote from a woman who received a loan from the bank through</td>
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</table>
Chapter Four - Results

<table>
<thead>
<tr>
<th>Theme Seven-Sustainability</th>
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<tbody>
<tr>
<td>the community based rehabilitation program in Ghana. She now runs her own grocery shop.</td>
</tr>
</tbody>
</table>

External contextual influences

- *Understanding the country history and politics* – country directors of NGOs.
- *Adapting to emerging trends in population* – for instance longer life expectancy, need for adult rehabilitation (observations of researcher)
- *Appropriateness of intervention* – for example: eye camps were suited to the Indian context but were not appropriate to the environment, population, and situation found in Ghana and Cameroon (comments from service providers)
- *Taking into consideration the broader health care system in the country* (suggestion of government personnel working in low vision unit in the Department of health in Ghana)
- *Understanding national agenda and policy* – for example, in Cameroon there was a lack of policy on disability in general. The concept of disability was still quite new, so it was difficult to implement low vision into the national agenda in the beginning.
- *Understanding the needs of the poor* (suggestion from program managers)
- *Being aware of market influences* – if low vision is not in demand, create it by making its products competitive and appealing alongside other products (suggestion by low vision ophthalmologist).
- *Adapting to environmental changes* – for example, conduct outreach during dry season where roads are still passable (low vision team in Mamfe Cameroon).

### 4.6.2 Application of Case Studies Findings to the FRAME

The ‘FRAME’ framework developed in research question 3 and used to summarise the findings of the CART can now be expanded on using the findings of the case studies. The entire framework now provides detailed insight and understanding into the issues behind these CSFs (Table 37).

<table>
<thead>
<tr>
<th>FRAME</th>
<th>Themes of the case studies</th>
<th>Critical success factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding</td>
<td>Sustainability, governance, advocacy</td>
<td>Achieve a funding mix between government and private sector, lobbying the government for ownership, commitment, funding;</td>
</tr>
</tbody>
</table>
### Chapter 4 - Results

<table>
<thead>
<tr>
<th>FRAME</th>
<th>Themes of the case studies</th>
<th>Critical success factors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>NGOs can provide support; national budget to include low vision, leadership and efficient management, monitoring and evaluation.</td>
</tr>
<tr>
<td>Rehabilitation workers</td>
<td>Human resources, awareness, advocacy</td>
<td>Task shifting, local training places and opportunities, professional development, strengthen primary level care i.e. outreach and community based rehabilitation services by mid level ophthalmic personnel, awareness among service providers, achieve a range and mix of human resources i.e. ophthalmologists, optometrists, MLOP, community based workers, specialist teachers.</td>
</tr>
<tr>
<td>Access</td>
<td>Access, awareness</td>
<td>Employment, monitoring and evaluation of service output and client needs, social welfare, services for adults and children, government support, geographical coverage, and innovative approaches to service delivery.</td>
</tr>
<tr>
<td>Multidisciplinary services</td>
<td>Service delivery, advocacy</td>
<td>Tertiary, secondary, primary level services integrated with government and other existing services, integration of low vision curriculum into ophthalmic personnel training, networking and collaboration between stakeholders.</td>
</tr>
<tr>
<td>External contextual influences</td>
<td>Sustainability</td>
<td>History of country and current service situation, understanding the environment, local community needs, understanding national agenda, and</td>
</tr>
</tbody>
</table>
4.7 Conclusion

The purpose of this Chapter was to answer the research questions identified in Chapter 1. The initial section identified the present situation of low vision services while the latter section demonstrates in detail, what could be done to improve current and future services.

This Chapter has not only confirmed that the majority of countries have poor coverage, but obtained coverage rates in most countries where data were not previously available. The Chapter identified each country with poor (≤10%) and better coverage (>10%).

The issues surrounding human resources show that not only is there a lack of low vision cadres, the mix and range of personnel are not balanced. Further to this, the situation is further exacerbated by the lack of formal training as well as limited professional development opportunities available to current personnel working in the field.

Historically the majority of low vision services have been supported and managed by the private sector. The findings in this Chapter confirm that this is still the case today. This raises considerable concerns about the long term sustainability of services. It was found that cases and situations where services have a mix of both government and private funding, the services were more sustainable. Moreover, it was observed that services governed, owned, and driven by government with a level of technical support from NGOs had better geographical coverage.

The human resources situation and the funding of services appeared to contribute to the underlying reasons for monodisciplinary services and the lack of services at the primary level (i.e. community based rehabilitation care and outreach).

This leads to the identification of barriers for service access and coverage. In developed countries it is the social components such as people with disabilities, the elderly, refugees, and ethnic minorities as well as the lack of awareness among service providers and clients that generated commonly reported issues. All these issues reflect the social inequity that manifests across various intersecting social categories and pose threats to achieving an
Chapter 4 - Results

equitable low vision service. In addition to the factors stated above- other important barriers were poverty and the unequal geographic distribution of services for developing countries. Women and children were also more likely to miss out on services in these nations.

The CART methodology revealed the key ingredients that could either impede or improve services. In addition, the CART methodology proved to be an innovative technique over traditional methods to explore non-linear and complex relationships in the field of eye care service delivery and to maximise the use of the dataset allowing the researcher to identify the critical success factors for low vision service coverage.

The case studies provided new insights and deeper understanding into these critical success factors. Examples of approaches to establish, implement, and improve services were provided. These include (but are not limited to) integration of services, human resources training, task shifting, funding mechanisms and arrangements, better governance, and advocacy. Finally, the FRAME framework provided a clear and concise summary of the critical success factors.
5 Chapter Five - Discussion
Chapter 5 - Discussion

5.1 Introduction

An excellent survey response rate was achieved for this project, allowing a global picture of the current situation of low vision services to be developed, and helped identify which countries have poor (≤10%) and better (>10%) coverage.

In the preceding Chapter, an understanding of the current situation and presence of low vision services was provided. Additionally, the critical success factors associated with poor (≤10%) and better (>10%) coverage of services were provided.

This Chapter consolidates the three research aims, and establishes the implications and areas of action that need to be taken to assist the WHO and Vision 2020 in planning, priority setting, and mobilisation of resources.

The Chapter is organised into two sections:

1. a critique on the reliability and validity of the results with comments on the strengths and limitations of the research
2. the significance of the findings, and where possible, strategies discussed.

In the second section, numerous examples will be drawn from country survey results, case studies and secondary sources of information. Formal conclusions are reserved for the next and final Chapter of this thesis.

5.2 Validity and Reliability of Data

5.2.1 Survey Distribution Outcomes

Survey response rates

Assessment of response rates is important in the critical appraisal of health research. The survey achieved a response rate of 65%, a major strength of this study. When compared with other mail-administered health service related surveys, this response rate is considered very good. For instance, a global survey of 191 WHO Member States was conducted in 2002 to gather a better understanding of the worldwide epidemiology of salmonellosis and the national surveillance programs used for salmonella infections in humans, achieved a
response rate of 54.5%. The Owsey et al study in 2009 on the national characteristics of low vision rehabilitation in the United States had a response rate of 49.5%. Finally, the Canadian National Physician Survey in 2008 attained a response rate of 34.1.

This high response rate is attributable to:

1. the extended data collection period of 14 months, and regular/persistent follow-ups by the researcher
2. efforts taken to acquire appropriate contacts using the snowballing technique i.e. Vision 2020 regional offices
3. pilot testing the survey
4. action to avoid common pitfalls of mail-administered surveys, such as unclear questions and instructions, and survey length
5. limiting the number of open-ended questions.

Figure 7 (p.117) showed that all regions with >50% of responses had at least over 50% of countries in that region with a national Vision 2020 committee. For instance, the highest response rate was found in the Americas region where 57% of countries had set up a Vision 2020 national committee. When the researcher contacted the Vision 2020 Latin America regional office, the coordinator distributed the survey to all countries in the region on behalf of the researcher. Follow-up e-mails also were passed on by the regional office, thereby improving response rates.

The same positive experience was encountered in the Eastern Mediterranean region. In first few months, the response rate was slow. The researcher then elicited the help of the region’s WHO/Vision 2020 regional office to pass on the survey and response rates subsequently improved. For Europe, only 30% had a national Vision 2020 committee. Not surprisingly, Europe had the lowest survey response rates (38%) (Figure 7; p.117).

Interestingly, many of the countries across the six regions where a response could not be elicited and/or no secondary data could be sourced, were also the same countries that either did not respond or report to the WHO about Vision 2020. For example, no information is available on whether a Vision 2020 national committee existed in Spain, Portugal, or Switzerland. Another example is Equatorial Guinea in Africa where the
Chapter 5 - Discussion

researcher could not find any information about low vision services. Incidentally, the country was reported by the WHO that no Vision 2020 national committee exists.\(^\text{27}\)

5.2.2 Characteristics of Respondents and Participants

Despite not all surveys being completed by official organisations i.e. Vision 2020, national prevention of blindness committees, WHO, IAPB and government, there was still a high number of respondents associated with an official organisation. In addition, 83\% of survey respondents were ophthalmic personnel (Table 19) and a high percentage had qualifications in low vision (p.126). All this suggests that people completing the survey had good knowledge of low vision and its services within their respective countries.

Interestingly, the characteristics of the organisations represented in the case studies were consistent with how services were established historically. For instance, many of the services were founded and run by philanthropic organisations. Moreover, the services were mainly aimed at children, which is still the case for many countries today. One of the strengths of the case studies was that the researcher covered a variety of organisations as well as a wide range of participants—service providers, clients, and managers. However, a high percentage of these organisations were either NGO (mostly international) and/or affiliated with the voluntary sector. This meant that the researcher was only able to gather limited views from the government. In addition, as reported in Chapter 4, the researcher also encountered reluctance from some government officials (especially in India) to meet with the researcher, limiting the insight derived from the government sector.

5.2.3 Presence of Low Vision Services

Some countries focus on eliminating avoidable blindness before being concerned with low vision. For instance, The Gambia first focused on the elimination of trachoma and cataract.\(^\text{30}\) The purpose of examining the regional Cataract Surgical Rates (CSR) was because it presented a possible association into the presence and absence of low vision services. Furthermore, many countries still identify cataract as one of the main causes of vision impairment.\(^\text{27,29,68}\) Accordingly, if CSR is low in a country then it can be speculated that it would be unlikely that the country will have low vision services. This is due to the backlog of cataract cases to treat. For instance, in the Africa region, the presence of services is 46\%. A
possible explanation for this is because there is a high percentage of countries that have a CSR of <1000 per million (Figure 21; p.141). The target set by the WHO is a CSR of 2000 per million. On the other hand, in the Eastern Mediterranean region, 65% of countries have low vision services and only 30% of countries had a CSR <1000 per million (Figure 21; p.141). The same association can be applied to Europe (Figure 21; p.141).

Further understanding into the presence of low vision services is demonstrated in both Cameroon\textsuperscript{287} and Pakistan.\textsuperscript{338} Services in Pakistan are relatively new (services started around 2001) and originally evolved from a focus on infectious and nutritional related diseases and cataracts. Similarly in Cameroon, emphasis was previously on onchocerciasis and once this disease was under control, this led to the establishment of comprehensive eye care services in the Southwest region, before low vision services were eventually founded in 2006. Both examples support the theory that once the backlog of treatable causes of vision impairment such as cataract had been addressed, this would in turn alter the epidemiology of eye diseases and population demographics; eventually creating the demand for low vision services.

According to Kocur and Resnikoff\textsuperscript{339}, low vision services are a frequently neglected component of the eye care system in many European countries. The authors identified that the presence (or absence) of services in countries in Europe were dependant on the current socioeconomic status of the countries.\textsuperscript{339} For instance, Western and Central Europe is comprised of highly industrialised countries such as Austria, Luxembourg, Portugal, Greece, Demark, Finland, Germany, Iceland, Italy, Switzerland, and the United Kingdom.\textsuperscript{339} Coincidentally, all these countries have a presence of low vision services. On the other hand, the Eastern European region is still going through economic difficulties and transforming their healthcare systems under the new economic conditions from the former socialist system.\textsuperscript{339} Countries in this region include: Estonia, Russia, Belarus, and Ukraine. All these countries either have no low vision services or no information could be found.

5.2.4 Coverage of low Vision Services

Coverage of low vision services was the outcome measure used to investigate the various aspects of service provision e.g. human resources, funding, and sustainability. In most
countries, coverage of low vision services was found to be ≤10% (poor). Examples include Nepal, Namibia, Slovenia, Argentina, Brazil, Hungary, Poland, Morocco and St. Lucia. What is striking is that 53% (61/115) of the countries with low vision services have ≤50% coverage. This includes developed countries such as Singapore, Finland, and Taiwan. Only approximate estimates of coverage were obtained in this research. This was because in calculating coverage, two figures are required:

1. people using services and
2. prevalence of people with low vision.

As shown in Table 22 (p.140), approximately 70 countries have some prevalence data. Thus, the question on coverage (question 17) in the survey was structured as a multiple choice question. This resulted in reduced precision and ranges within the categories of coverage, with the objective being to increase the number of countries responding to this question. In addition to this, presence of prevalence data was used to verify coverage data. For instance, Algeria and Kazakhstan were reported to have >50% coverage (Table 23; p.143); however, no low vision prevalence data were available on these two countries. There was also no anecdotal evidence to support the coverage reported. Data on Algeria were verified by an official source from the WHO; while the researcher was unable to get a response from sources in Europe verify the data supplied by Kazakhstan. In countries where data were sent for verification and the coverage rate was confirmed to be true the researcher included the data into the analysis. On the other hand, in countries where the reported coverage rate could not be confirmed, the researcher excluded the data from analysis.

5.2.5 Research Methodology

5.2.5.1 Survey

In countries where secondary sources were available, for example France, Germany, and the Republic of Ireland, the vast majority of materials found were ‘grey’ literature i.e. reports, conference proceedings, and websites.

For many countries, particularly larger nations, only limited or fragmented information could be obtained through the survey, e.g. China, and the United States. Data had to be
sourced and pieced together using multiple strategies. For example, in the United States the study by Owsley et al\textsuperscript{298} which examined services, providers, and patients in low vision rehabilitation entities servicing adults in the United States, was a valuable source of information for this research. However, the United States is one of the very few countries to have this type of data. For instance, similar studies did not exist for China. It was also found to be difficult to obtain data in countries where there were no functional national Vision 2020 committees, for instance Tanzania and Papua New Guinea.

Unfortunately, the survey data could not be compared with other low vision surveys in countries for which data had been collected, with the exception of the United States where a study like Owsley et al\textsuperscript{298} had been published. This would have increased the validity of the current approach; however the review of the literature and secondary sources search confirmed that no such data were available for the majority of countries.

With regards to the statistical methods used to analyse the survey findings, the researcher found several problems whilst applying logistic regression modelling to the data. One of these reasons was the amount of missing data, a common issue with self-administered postal surveys.\textsuperscript{210} For instance, many of the respondents gave ‘do not know’ answers. Another example was the lack of, or poor information available from many countries on the estimated numbers of human resources per 10 million population, hence the variable optometrist could not be included. The various combination of the human resources skills mix could not be fully or properly explored. Less than 60 countries provided information on human resource numbers. In some categories such as community-based workers, only 29 countries provided information. This was either due to the survey respondent not having access to these data or the country not having any such workers. Due to the dearth of survey data on the human resources section, the researcher was not able to determine whether there was any statistical difference between the different mix and range of low vision cadres.

Other statistical methods such as multiple computations were considered but there were concerns that predicting the survey response would further dilute the data. Furthermore, this method could not be applied because the missing data in this study is not random. This was shown by carrying out a missing pattern test demonstrating that the majority of missing
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data came from countries in regions where the survey response rates were the poorest, for example in Europe.

The WHO delegate, Dr. Resnikoff shed further insight into countries in Eastern Europe (e.g. Turkmenistan, Kyrgyzstan, and Tajikistan) suggesting that the WHO often faced difficulties in obtaining information from these countries for other health topics. This was found to be the case for this research.

Also, some countries in Europe were anecdotally known or have been reported to provide good comprehensive low vision services i.e. Scandinavian countries like Norway and Denmark. However, as the coverage rate was not known (after following up with the survey respondents), their survey response was excluded. As a consequence, many countries were not included in the logistic regression analysis resulting in a small sample size and very few variables to be included in the analysis.

Multicollinearity, i.e. $r > 0.8$, especially among variables related to the same topic, was another problem. For example, the Human Poverty Index was highly correlated with income level of the country. There were no formal guidelines on choosing the ‘correct’ variable. Thus, the variable chosen was at the discretion of the researcher and/or consultation with supervisors and the literature based on which variable had the closest relevance to low vision services. For instance, national referral guidelines were highly correlated with the national guidelines for standards of low vision practice. Referral guidelines were chosen because referral networks and systems were an integral part of low vision services and Vision 2020 approaches.

Finally, translating findings into practice and policy was also questioned. The researcher deduced that there was too little information to draw implications from the results of logistic regression modelling; i.e. only one critical success factor was detected (Table 28; p.153). Given that many variables could not be included using this analysis, it was decided that this method was not going to give justice to the data obtained, especially in countries that did not provide information on the outcome variable coverage.

The application of the CART proved to be advantageous for this research. This method is also a novel way to explain complex non-linear relationships, maximise the use of the data.
available, and overcome many of the issues associated with survey methodology. Furthermore, past studies\textsuperscript{235,236,248} have reported overall predictive performances ranging from 51\% to 77\%, making the predictive performance score of 90.1\% in this research an excellent value supporting this technique.

\textbf{5.2.5.2 Case studies}

One of the major inherent limitations of using the case study methodology is that the findings cannot be generalised to all situations. Furthermore, one may dispute that findings cannot be generalised to developed countries because all three countries were developing countries. Nonetheless, it is important to re-emphasise that these three countries were chosen because they represented the various features of optimal service delivery as dictated by the literature and Vision 2020, as well as being recommended by the WHO LVWG. Most importantly, the researcher also identified from the survey, numerous examples of services/models delivered in developed countries (e.g. Australia, United States, the Netherlands, Spain, and Republic of Ireland) with positive (as well as negative) features of service provision. Moreover, valuable secondary data were able to be found for some countries, for example: Wales and Canada. The survey data further strengthened the external validity of the case studies.

It is important to recognise that the case studies reported on low vision services in Ghana and Cameroon represent the whole country, however, services in India correspond to the situation in Tamil Nadu (this was due to budget and time constraints). Other limitations include not being able to tape the interviews owing to ethical and cultural reasons. However, this was minimised by the researcher taking extensive notes and writing them up shortly after completing the interviews. Another limitation, which is more difficult to control, is ‘reactive effects’, which is peoples’ knowledge of the fact that they are being observed making them behave less natural in front of the researcher.

As the researcher was a stranger in these countries, the issue of reflexivity (i.e. interviewee gives what the interviewer wants to hear) was a concern. This was the case when interviewing clients, especially children. Another issue was the language: frequently, the clients did not speak English and a interpreter was required, often the community field
worker or manager. For example in one case, the client provided a long response to a question asked; however, the translated response by another person was significantly shorter. This left the researcher wondering if everything the client said was translated. Also, there may be other cultural issues e.g. losing face and/or talking in front of someone with authority. So the presence of the service provider i.e. the community field worker could affect the validity of the responses given as the clients may not have wanted to share all their opinions in front of the service provider.

The researcher was always accompanied by local staff member from the organisation (usually a person familiar with the client she was interviewing on the day) when visiting clients. Efforts were made to ensure privacy was being provided to the clients interviewed without too much disruption to the surrounding environment. Nonetheless, some clients, particularly many of the children interviewed were shy in the presence of a stranger. In remote rural villages, foreigners (with fair skin) were not a common sight and this caused a lot of curiosity. The researcher would have a group of people following her to the house of the client.

At other times, people from the surrounding buildings or neighbourhood would crowd around the person being interviewed or the room where the interview was taking place. For example, the researcher visited a low vision child during school time in a small village – the best place to do the interview was outside and away from the classroom so as not to disrupt the class. Unfortunately, the entire class became curious and tried to come out to see what was happening. These circumstances could have an effect in shaping the type of responses given.

Despite these limitations, several strengths can also be acknowledged: first the use of semi-structured interviews to collect data meant that there was more flexibility, less intrusion into peoples’ lives, and the process allowed access to a wider variety of people and situations. In addition the use of observation strengthened the data collected from the interviews. However, the use of the grounded theory warrants recognition of two biases:

1. The effects of the researcher on events.
2. The behaviour of participants.
Additionally, the researcher’s own beliefs, values and prior assumptions can prevent adequate investigation and consideration of possible contradictory data and unduly influence in the analysis of the case study evidence. To counter this, the researcher used multiple sources of evidence such as observation and secondary sources such as annual reports and Internet resources.

It is worth acknowledging that these two biases could also be minimised with longer term observations, i.e. participants becoming familiar with the researcher and thus acting more naturally. However, as mentioned earlier, due to time constraints and budget, the researcher could not stay for long periods to observe the practices and services being delivered.

5.3 Low Vision Service Provision

5.3.1 Definitions and Causes of Low Vision

The Bangkok functional definition of low vision (VA <6/18 to the perception of light in the better eye or a visual field of less than 10° from the point of fixation) is the appropriate definition to adopt in service provision. However, only 33% of countries used this definition to specify the level of impairment required for people to be eligible to use services. Additionally, 69% of countries reported to use the ICD-10 definition (VA <6/18 to 3/60) for low vision.

The results from this research were consistent with the literature review. For instance the main causes of low vision are increasingly age-related. However, cataract was reported in the survey to be one of the common causes of low vision. This was mostly in developing countries such as Afghanistan and Sudan but also developed countries like Japan and Malaysia. As a treatable/correctable eye condition, cataract is not included as a cause of low vision. This could shape the type of services available e.g. mainly clinical care. Respondents completing the survey could also be referring to other eye care services in addition to low vision.
5.3.2 Human Resources

Prior to this research there was no global information on who provided low vision services. This research has shown that ophthalmologists, optometrists, community-based workers, rehabilitation officers, specialist teachers, and MLOP (Mid Level Ophthalmic Personnel) which included opticians, orthoptists, ophthalmic assistants, make up the majority of low vision cadres.

Vision 2020 recommended that for eye care personnel in general, there should be a ratio of at least one ophthalmologist per 250,000 population. However, almost across all low vision cadres there were less than 10 per 10 million population. This further highlights the dire situation of low vision human resources. Interestingly, when general health care professionals were tested for significant association with coverage it was found that higher number of specialised cadres such as doctors, nurses, and other health care workers were associated with countries that had better coverage (Table 25; p.148). The World Health Report had estimated that countries with fewer than 23 doctors, nurses and midwives per 10,000 population generally fail to achieve adequate coverage rates for selected primary health care interventions. Unfortunately, even though countries with >10% coverage have a slightly higher number of doctors and nurses, the number of these health care professionals displayed by countries across the three coverage levels (0%, ≤10%, >10%) were all well below 23, which indicates a critical shortage of general health care workers (Table 25; p.148). Recent literature also adds further support to this, i.e. across the world but especially in developing nations, human resources have been in decline and there is a global shortage of health care personnel in general. Surprisingly community health workers per 10,000 population were not found to be statistically significant. This could imply that these personnel are not related to coverage or that they have less impact on coverage because they are less specialised and thus limited in the range of care they can provide. It may also mean that numbers are too few to be detected statistically.

5.3.2.1 Regional Situation

In the Americas region the number and mix of low vision cadres are low except for community based rehabilitation workers. This is due to Canada, which has a nationwide organisation- CNIB (formerly known as the Canadian National Institute for the Blind) acting
as the main provider of low vision services at the specialist and community level. Incidentally, Canada was also one of few countries with >50% coverage. When only Latin America was considered, the range and mix of low vision human resources is well spread but remained low. Not surprisingly, the majority of the countries in Latin America aside from Peru, Colombia, Uruguay, and Belize, were coloured in red on the world map.

5.3.2.2 Outliers

In Africa the higher numbers of community based rehabilitation workers were largely from Algeria and The Gambia. For Algeria, the numbers of low vision human resources are not well supported anecdotally; however, as the data came from an official source (WHO personnel) and was also verified by another WHO employee familiar with the Africa region, these numbers were subsequently accepted. However, the second WHO employee mentioned that while these numbers could be accurate, there is the possibility that the respondent could have also included eye care personnel not involved in providing low vision care. Subsequent attempts by the researcher to contact the survey respondent to reconfirm this were unsuccessful.

As for The Gambia, the survey was also completed by an official source and verified by the same WHO employee. Again, the WHO employee raised the possibility that numbers could also include eye care personnel involved in services targeting conditions resulting from correctable low vision causes. However, unlike Algeria there is evidence to support these numbers. In 1986 a national eye care programme (NECP) was founded to provide an integrated approach to reducing the national burden of blindness and low vision.\(^{30}\) The NECP was briefly mentioned in the literature review as one of the successes of Vision 2020. Between 1986 and 1996 the crude prevalence of blindness fell from 0.70% to 0.42% despite a 51% population increase during this time.\(^{30}\) The program also achieved a CSR of 2000 and a fall in blinding trachoma from surgical correction of cases of trichiasis.\(^{30}\) Integrated eye care services were established from the community to the tertiary level and over 1000 village health workers were trained in primary eye care.\(^{30}\)

Nonetheless the coverage of low vision services was reported to be ≤10% in the survey. One possible explanation for this is that the focus was mainly on acute and treatable eye
diseases such as cataract, trachoma and correctable causes of low vision. For instance, Faal\textsuperscript{30} had reported that there were an estimated 8800 people with low vision due to cataract in 1996, that represented over half of the national burden of “low vision”. This suggests that the impact of the growing ageing population and chronic eye conditions have yet to make an effect which would move the focus onto low vision rehabilitation. Indeed, Faal\textsuperscript{30} remarked that the country was still in the process of consolidating the activities of the NECP with reducing blindness and blinding cataract and only after that, will the program be able to fully concentrate on the problem of low vision.

In the European region, although low, the number of optometrists, MLOP, and ophthalmologists was higher than rehabilitation officers, specialist teachers and community-based workers. These numbers were predominantly from the Netherlands, Sweden, and Norway. Both the Netherlands and Sweden had >50% coverage. Data were completed by official contacts and in Norway a group of low vision experts representing key organisations around the country provided the information.

There is grey literature further supporting the fact that other countries in Scandinavia i.e. Iceland, Finland, and Sweden have well established service delivery systems.\textsuperscript{343} For example, the main low vision centre in Stockholm has 82 staff members and five regional multidisciplinary units of excellence.\textsuperscript{343} In addition, the survey found that Iceland and Finland also had coverage >50%. The number of low vision cadres in these two countries, in comparison to other European countries is low; however, these numbers must be viewed in respect to the population size which is relatively small (Finland - 5,244,749 and Iceland - 304,367). For Iceland, this further supports the coverage reported, which was stated to be between 91-100% in the survey. In the Netherlands, services are provided by low vision clinics in hospitals, two national specialised centres and regional rehabilitation centres.\textsuperscript{344} These services are provided by a team that can consist of ophthalmologists, optometrists, psychologists, low vision rehabilitation specialists, and MLOP such as opticians.\textsuperscript{344}

As for the rest of the countries in Europe, several factors identified from the case studies could explain the low numbers and lack of skills mix in low vision human resources:

1. other competing eye priorities such as glaucoma faced by eye health professionals
2. not enough time to provide care as at least 30 minutes to one hour is required for each low vision client
3. eye health professionals not viewing low vision care as part of their duties but as an extra workload
4. clinical professionals such as ophthalmologists and optometrists, receive limited satisfaction from providing low vision care because low vision is not financially profitable and a cure cannot be provided
5. there is simply a lack of low vision expertise to provide services.

In South East Asia, the higher numbers of low vision personnel can be attributed to Thailand; however, the coverage of low vision services was still reported in the survey to be ≤10%. The literature illustrates that the government of Thailand introduced universal coverage of health insurance in 2001\textsuperscript{345} and has also implemented comprehensive primary health care.\textsuperscript{346} This generates two possible reasons for the poor coverage: first, an imbalanced distribution of human resources in terms of both geographical areas and specialisation.\textsuperscript{345} For instance, in 2001, the doctor density in the capital, Bangkok, was 10 times the density of the poorest Northeastern region. In terms of specialty, more than 72.5% of medical doctors were classified within one of the 45 medical specialities.\textsuperscript{347} This could indicate that many of the low vision professionals are concentrated in urban regions or work in urban specialised centres. The second reason could be because the focus is on other areas of health rather than low vision. For instance, the focus of the comprehensive primary health care is prioritised to maternal, newborn, and child health and community workers’ focus is on increasing coverage for immunisation, family planning interventions, and nutrition promotion.\textsuperscript{346}

\subsection*{5.3.2.3 Human Resources and Training}

Training institutions were more likely to be located within the country in developed countries e.g. France, Spain, and Croatia rather than developing ones such as Zambia and Swaziland. In developing nations, there are less formal facilities in-country to train low vision professions such as the case in Ghana and Cameroon. The health professionals, especially those that are more highly specialised that do receive training are frequently sponsored and provided by NGOs. For example, the ophthalmologists and optometrist in
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Cameroon went to Nigeria to receive their training while less specialised personnel i.e. MLOP received on the job training provided by Sight Savers International (SSI) in the country.

The lack of formal training opportunities and limited professional development opportunities within many countries further exacerbates the shortage of low vision personnel to meet the growing demands of the low vision population and expectations of services.

5.3.2.4 Strategies to Strengthen Human Resources

Hitherto the discussion focused on the issues and challenges surrounding the human resources component of low vision service provision. The significance of having adequate numbers of low vision personnel, as well as the range and mix, are essential in providing accessible and timely comprehensive care as well as attaining the Vision 2020 goal of enhancing vision-related quality of life for people with functional low vision. In addition, at the primary level the success of low vision interventions is dependent on the interpersonal interactions between the low vision personnel and the families and communities. Thus human resources are critical not just in skill, but in their relationships with the clients and the people surrounding the client. An optimal functioning workforce is dependent on skilled, supported, and motivated health care personnel. Awareness among service providers is essential to improve referral networks and client access to services. Therefore, strategies are needed to achieve all this. Insight from both the survey and case studies allowed the researcher to put forward four pivotal strategies to be considered to strengthen low vision human resources. These are training, task shifting, capacity building, and maintaining productivity.

Training

Increasing training opportunities for extra people as well as existing ones is an effective method to build up low vision cadre numbers and mix, particularly in regions such as Latin America (Figure 9). Recommendations for training include increasing the number of places providing training for low vision cadres, ensuring training places are located within the
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country, integrating low vision into existing curriculum and making certain the curriculum is not too theoretical but practical.

The example from India described in Chapter 4 where the ophthalmologist tapped into more than one source to ensure a supply of low vision rehabilitation officers, is one way to increase numbers of low vision personnel. This approach could also work in other countries.

Another example is Wales, which proves that it is possible to accomplish a sustainable supply of low vision personnel. This country is one of the few countries reported in the survey to have coverage between 91-100% (Table 23; p.143). A few years ago reforms were made to low vision services and new services were launched in 2004. Accredited practitioners, namely optometrists and dispensing opticians, have been providing low vision care since then. Formal accreditation for optometrists is offered by the Welsh Assembly Government and opticians are accredited by the School of Optometry and Vision Sciences, Cardiff University.\textsuperscript{169,349} The content of the training includes both theoretical modules as well as practical training and accreditation.\textsuperscript{349} Since 2004, just over 400 primary eye care professionals in Wales qualified to undertake the low vision training and accreditation.\textsuperscript{349} Currently 125 practitioners are accredited and are providing the service in 141 optometry practices.\textsuperscript{349}

Wales is also a prime example of how the low vision curriculum can be integrated into an existing ophthalmic curriculum. Another example is found in Germany- ophthalmic-optical rehabilitation including the provision of low vision devices is a compulsory part of the current training curriculum of ophthalmologists.\textsuperscript{315} Additionally, training courses are provided during the annual congress of the ‘German Academy of Ophthalmologists (ADD)’. This is a major congress people attend. These training arrangements ensure that ophthalmologists have a minimum standard in the knowledge of low vision rehabilitation in the country. Integration of low vision curriculum into existing systems represents how low vision can be incorporated at the quaternary level (i.e. national programs and training centres) of the comprehensive model (Chapter 2.4.3.1; p.24).

Other examples of training were found in the Netherlands and Switzerland where the low vision personnel receive both formal and informal training to provide care. In the
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Netherlands, the providers of low vision care have a degree in optometry. The degree is a four year course and includes 80 hours of compulsory low vision rehabilitation training. Note that this is another example of integration of low vision into the existing optometric curriculum. In addition, there is a college that provides a two-month training course and about 40-60 optometrists undertake this course to become low vision specialists. Most importantly, the training is funded by the government.

In Switzerland, services are provided by opticians and low vision trainers (occupational therapists and social workers). The opticians hold formal qualifications (termed ‘Master diploma’). Training of both groups is provided by the Swiss Council for the Blind (SZB). Similar to Wales, the training is recognised by the government e.g. a SZB training certificate is required for both low vision opticians and low vision trainers to be recognised by the National Insurance Scheme.

Another example of integration can be through the education curriculum. In India, the Ramakrishna Mission Vidyalaya College and the Avinashilingam University for Women provide low vision training as part of their Master of Special Education programs.

The strategies described above concentrate on formal training. However, in some countries formal training systems may not be readily available or are limited. So informal training may be the viable alternative in the shorter term. For example, in Cameroon, eye care is relatively new. Before the Southwest Provincial Eye Care Programme started in July 2001, there was no resident ophthalmologist, optometrist, or other specialist eye care worker in government hospitals. Only last year (2008) after much lobbying from NGOs, government institutions started training ophthalmic nurses. Prior to 2001, eye care services were delivered by travelling eye care teams based in Mission Hospitals (Mbingo Baptist Hospital and Acha Tugi Presbyterian Hospital) in the neighbouring North Province. The teams referred all their surgical cases to their base hospitals over 300 km away (about seven hours drive).

By the time low vision services started in 2006, the following milestones were established. A full time optometrist was contracted by the Provincial Delegation of Health to develop the refraction services. A contract refractionist, trained at a Train-The-Trainers Course run by
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the International Centre for Eye Care Education (ICEE) in South Africa, assisted him. A two-month refractionist training course was started in the program in April 2005 to meet the need for refraction personnel in all eye units. Eleven people have been trained as ophthalmic nurses and were working in the government eye units. They were trained in West Africa as there is no in-country training for specialised eye workers in Cameroon.\textsuperscript{287} With the support of SSI, the optometrist in turn trained all refractionists and ophthalmic nurses at each of the three eye units in Limbe, Kumba, and Mamfe. He is based at the regional hospital in Limbe but travels frequently to other districts to provide refresher training on the job.

SSI continues to lobby the government to integrate training of refractionists and opticians into the existing national training system. At the time of the researcher’s visit, talks with the government related to the issue of length of training. Currently, it takes two months to train a refractionist however; the government was not accepting any courses that are less than two years, so the country director of SSI was contemplating an alternative strategy to overcome this issue.

Other examples of how informal training could be established are through private organisations. For example in the Netherlands, organisations that sell low vision devices provide low vision rehabilitation training to optometrists. Although the length of the training varies, it is paid for by the companies.

In Spain, low vision rehabilitation is not part of the basic curriculum for ophthalmologists and optometrists. Instead ophthalmologists can undergo a one-month training course and optometrists a two-month training course provided by ONCE (Organización Nacional de Ciegos Españoles- National Organization of the Spanish Blind) to become low vision ophthalmologists and optometrists respectively. Rehabilitation specialists have to undergo nine months of training (six theoretical and three practical) to practise low vision care. This training is also provided by ONCE. However, the rehabilitation personnel must hold a formal diploma qualification.
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Task shifting

Boosting training infrastructure is optimal but in many countries, this is the longer-term objective. In the shorter-term, the strategy of task shifting is one possible way to overcome low vision cadre shortages. Task shifting is the process of delegating tasks to less specialised health workers. In many countries there are not enough ophthalmologists and optometrists. The case studies identified that ophthalmologists often do not have time or lack interest in providing low vision services.

Training for ophthalmologists and other more highly skilled eye care personnel takes a long time and is expensive. Furthermore, these professionals mostly tend to work in urban regions, as the Ghana example demonstrates. Task shifting is in keeping with the two features of the comprehensive model described in the literature review. The model emphasises ‘what’ is being delivered rather than ‘who’ is delivering the care or ‘where’ the services take place. The training and deployment of low vision cadres then becomes orientated to community need.

Thus, MLOP such as ophthalmic nurses, vision technicians as well as ‘hybrid’ professionals, who can perform a variety of functions, become essential if the low vision human resource needs are to be met. MLOP can, and do, perform some of the functions of the more traditional health professionals with specialist qualifications, with the advantages of lower entry educational qualifications and a shorter period of training than ophthalmologists or optometrists. Some of the vital tasks within the remit of community based rehabilitation workers include conducting outreach services such as eye screening and eye health promotion. This cadre also can be more easily deployed to work in rural regions to provide accessible and much needed care. An example of this is the low vision staff in Mamfe Cameroon. One of the shifting focus of comprehensive primary health care also substantiate the expanded use of mid-level and community health workers.

Task-shifting can overcome the barrier of reaching people living in rural or remote areas, help lower the costs of care, provide more continued client-centred care, and district based low vision care for the local community. This strategy could be highly effective in regions such as Africa, Eastern Mediterranean, and South East Asia where a higher number of MLOP
and Community-Based Rehabilitation workers exist than ophthalmologists and optometrists. Unfortunately, in areas such as Latin America where all groups of low vision health cadres are low, task shifting opportunities may be limited.

**Capacity building**

‘Capacity building’ is another strategy. A distinction of this concept can be made from ‘task-shifting’: with the latter about delegating tasks to other workers, ‘capacity building’ makes more of an assumption that the more highly specialised personnel are available to take on other roles. However, there are situations where there is a lack of or limited supply of specialised personnel in the system to provide the relevant care and delegate the tasks. This is where ‘capacity building’ can build up the appropriate mixture of skills and jobs that low vision services need within the existing system.

‘Capacity building’ can also be interpreted as altering the 'skills mix' by lowering the fences between the traditional health professions. This is an example of what has been called ‘workforce flexibility’. An example of this is the Ghanaian ophthalmic nurses working in the Volta region where there are no ophthalmologists. In Cameroon, SSI was building up a group of sub-professionals i.e. refractionists and opticians to fill in the low vision human resources gaps needed by the eye care system in the Southwest region. This is a form of upgrading certain professional groups. In Australia, the scope of clinical practice of registered nurses has been expanded to enable nurses to practise as independent nurse practitioners in rural and remote areas and care for mainly indigenous communities who reside in these areas. There are also ‘practice nurses’ who perform health assessments of persons over 75 years and wound management. ‘Capacity building’ through training 'sub-professionals' such as ophthalmic nurses, MLOP and community workers can be both a relevant and affordable way of supporting low vision service priorities. Once this recognition is attained, the next step is to provide formal and informal training of the actual professionals.

**Productivity**

Even where the numbers and mix of low vision personnel are adequate and training has been strengthened, maintaining the enthusiasm and motivation of staff is another
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challenge. There is also the risk of overburdening personnel especially MLOP through task shifting and capacity building. The case studies found that poor remuneration, no strong sense of job security, the community not being aware of low vision services, client non-acceptance of no cure, isolation from professional and academic bodies, difficulties in dealing with technology and equipment, and working in harsh environments are often responsible for poor staff retention issues and motivation. For example, nurses were working in 40 degree heat with no air conditioning in one hospital based in Ghana and service providers did not have the time to access the latest research, technology, or attend conferences because they have too many patients to see.

If the motivation among low vision cadres is to be maintained and valuable staff retained, features of effective services should include a mix of delegation and skills, better planning, investment in supervision, and adoption of standard staff management protocols. The protocol can include more opportunities for professional development e.g. on the job training and appropriate remuneration in keeping with the national context. Low vision personnel should be equipped with the skills and the technology to carry out their roles, and given the technical wherewithal to manage and maintain equipment, as well as the advocacy and communication tools to establish networks and collaboration.

5.3.3 Location of Services

This research has shown that low vision services are commonly located in NGOs and/or hospitals. However, as the case studies demonstrate frequently these hospitals are affiliated with or supported by NGOs to provide low vision services e.g. SSI supported secondary private hospitals to provide clinical low vision care in Chennai, India.

This situation of where services are located impacts three areas:

1. coverage of services
2. long term sustainability of services
3. types of services offered.

An example of number three above is services being mainly clinical (being in a hospital) or just providing one main form of services such as education.
Coverage and sustainability is a concern because non profit organisations often have a specific area of focus and target a geographical location in keeping with the goals and strategies of the organisation. For instance, people with low vision living outside the Southwest region in Cameroon or the greater Accra and Volta regions in Ghana do not have easy access to care due to being outside the area of involvement of the NGO.

Therefore, service coverage is limited and in terms of types of care provided, as it may be difficult for these organisations to provide care at all levels (primary, secondary, tertiary) and in all sectors (clinical, education, rehabilitation) of low vision services. Fascinatingly, a connection to data can be made with level 2 of the CART i.e. the percentage of population urbanised, which implies the importance of balanced distribution of services in both urban and rural areas. In less urbanised countries, the likelihood of having poor coverage is high. This is in congruence with the current situation of low vision services in many countries like France\textsuperscript{314}, Germany\textsuperscript{315}, and Republic of Ireland\textsuperscript{325}, in which services are mainly monodisciplinary (usually clinical care or rehabilitation) and located mainly at the secondary and tertiary levels. Not surprisingly, rural dwellers were one of the groups of people less likely to access low vision services as reported by the survey.

### 5.3.4 Type of Services

Survey results showed that low vision care in most developing nations was mostly clinical i.e. low vision care provided in a low vision clinic. By contrast, it was found that in addition to clinical care, developed countries were more likely to provide other forms of low vision services i.e. rehabilitation. Developing nations have limited resources and funds and hence are more likely to be funded and supported by NGOs. These nations also have to deal with more urgent health issues such as HIV and malaria. Moreover, developing nations have younger populations so there may not be the demand for certain types of low vision services such as rehabilitation. This finding relates to another predictor identified in level 2 of the CART – monodisciplinary vs. multidisciplinary care. Countries with multidisciplinary care had a lower percentage of nations with poor (≤10%) coverage.

Multidisciplinary care is also a key ingredient of comprehensive care which is an ideal model of service delivery\textsuperscript{27} (Chapter 2). Part of comprehensive care is multidisciplinary care
delivered by a range of health disciplines (e.g. optometrists, opticians, rehabilitation officers, or community based workers) as it promotes the integration of services and incorporates all three levels of low vision care—primary (community-based), secondary (district eye unit), and tertiary. Recent studies have proven multidisciplinary low vision care to be effective. For example, Stelmack et al conducted a multicentre randomised clinical trial that found a combination of the following interventions—clinical low vision care, provision and education in the use of low vision devices, and rehabilitation in the activities of daily living—showed significant improvements in all aspects of visual function for clients with macular diseases. These findings concur with that of Lamoureux et al who also found that a multidisciplinary low vision rehabilitation program resulted in significant improvements in the overall quality of life of the individual.

Furthermore, the >50% coverage rates demonstrated by the Scandinavian countries, the Netherlands and New Zealand further substantiated this. The European countries provided multidisciplinary care that included visual assessment and instruction, the use of optical and non-optical devices and electronic devices, together with a wealth of social service funds, that have allowed the Scandinavians to provide comprehensive services to people with low vision. In New Zealand, a similar range of services are also provided. These include clinical low vision care delivered by optometrists and ophthalmologists based at clinics from hospitals, universities and private practices, as well as, low vision rehabilitation (functional low vision interventions and provision of devices) delivered by field staff at the Royal New Zealand Foundation of the Blind (RNZFB). New Zealand recently adopted the comprehensive approach to delivering these interdisciplinary services. However, this approach is not yet widely adopted throughout the entire country and the existing services are neither evenly distributed nor is it cohesively coordinated among providers. This could possibly explain the fact that although coverage was reported to be >50% it was not as high as Canada or Wales, i.e. the survey respondent reported coverage to be between 51-60%.

The low number of low vision health professionals has direct implications for the service capacity to provide the multidisciplinary care because the limited range and mix of low
vision health professionals raises concern in the services’ ability to provide care at the different types of comprehensive low vision care.

At the primary level of care, the case study examples showed characteristics of services that were able to reach rural dwellers, people with multiple disabilities, and poor people. These were the services that had community field workers going into the local villages and testing visual acuity, eye care education, rehabilitation training, and making referrals to district eye hospitals where necessary. Another instance was where tertiary eye hospitals in India were able to reach clients as far as 300km from the hospital through the establishment of vision centres and outreach activities. The literature review also emphasised the importance of primary health care in which community based rehabilitation is part of Vision 2020’s strategy. The lack of rehabilitation services at the community level can severely impact on service coverage and accessibility.\textsuperscript{348}

However, this research has shown that the majority of services were found to be monodisciplinary and concentrated at the secondary and tertiary levels. For instance, the United States provides a wide range of different types of low vision services, but these services were predominantly clinical and rehabilitation services were limited.\textsuperscript{298} In many countries, this is most likely due to the low numbers or lack of rehabilitation officers, specialist teachers and community-based workers. The findings from the case studies concur. For instance, low vision clients interviewed voiced the need for more rehabilitation to cope in their environment and provide skills for employment. Employment has been identified as one of the important social determinants of health because of what it provides: financial security, social status, personal development, social relations, self-esteem, and protection from physical and psychosocial hazards.\textsuperscript{358} Moreover, the researcher found that rehabilitation services were limited and lacking in the areas visited. This was consistent in all three countries. In India, some of the vision health professionals did not always have time for counselling, which led to poor compliance in the uptake of low vision devices. Service providers stated that loss to follow up was an issue.

The importance of comprehensive care is further highlighted by the fact that the most important predictor identified from the CART (level 1) was the ‘proportion of children obtaining devices when prescribed’ which suggests ‘completeness’ or ‘service efficiency’. 
For instance, if services are only available for children, then adults may not have access to appropriate and available services.

Historically, services in many countries were established by charities and philanthropists intended for children and Schools for the Blind.\textsuperscript{117} The focus in many countries today is still on children and education.\textsuperscript{8} The case studies also identified that services were mainly targeted at children. For example, in India, only children had access to free low vision devices. Through the Education For All (EFA) initiative, children with low vision are able to attend regular schools through the support of the integrated education program (IEP). Despite this, the researcher found that there were a limited amount of services such as economic rehabilitation available for adults.

\textbf{5.3.4.1 Strategies to Achieve Comprehensive Low Vision Care}

Two key strategies to work towards achieving comprehensive care are proposed in this thesis—primary low vision care and integration of service.

\textbf{Primary low vision care}

The principles and practices of primary low vision care (e.g. community based rehabilitation) are in keeping with many aspects of Primary Health Care (PHC) from the Alma Ata declaration (Chapter 2).\textsuperscript{155} Primary low vision care is about establishing first level contact of low vision clients, the family, and community with services bringing care as close as possible to where people live and work.\textsuperscript{155}

This strategy is also in accordance with the growing global support for PHC as the solution to achieve ‘health for all’.\textsuperscript{156,247,346,359-361} Evidence suggests that health systems orientated towards PHC are more likely to deliver better health outcomes and greater community satisfaction at low costs.\textsuperscript{362} PHC is the key interface linking community programs with secondary, and tertiary low vision care.\textsuperscript{360} Low vision personnel involved at the community level (i.e. community health workers) act as a bridge between the community and the health services.\textsuperscript{363} The links formed between community and primary health indicate when the services of one or the other is required, and when clients should be referred to secondary or tertiary levels of low vision care.\textsuperscript{156}
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Tackling the social determinants of health is also a key feature of Alma Ata PHC. Primary low vision services are better equipped to be able to reach the most disadvantaged or those who have most difficulty in accessing services, i.e. as one of the ophthalmologists interviewed commented: “Our service motto is to go to the client rather than wait for the client to come to us”. Primary care also raises awareness of the benefits of low vision care among the community. This is not to say that other levels of the comprehensive model are not necessary; all levels are required for optimal service delivery. What this research is suggesting is to formulate a system like the L V Prasad ICARE model where primary level care is the larger piece of the pyramid. Several examples from the case studies as well as countries with better (>10%) coverage identified from the survey are provided below. Experiences from these countries could be used by other countries to formulate better services and policies.

The first example is Canada, which was one of few countries with coverage between 91-100% (Figure 22; p.142). CNIB is a community based volunteer and charitable organisation with a mission to assist and enhance independence for people who are blind or have low vision. It is based in Toronto but has offices in eight provincial and territorial divisions. The organisation has approximately 1,100 full-time employees and 10,000 volunteers. CNIB provides a variety of services including, registration and referral, assistive technology services, career and employment services, child and family services, counselling, and independent living. CNIB is the primary source of support for people with low vision and is often their first point of contact.

With the exception of the province of Quebec, in which vision rehabilitation services are provided by provincial government funded rehabilitation centres (with CNIB still as the first point of contact) CNIB delivers vision rehabilitation using a multi-disciplinary approach across the entire country. Last financial year (2007-2008) 40% of funds were used to provide rehabilitation services. CNIB multidisciplinary teams include social workers, rehabilitation teachers, vision rehabilitation workers, orientation and mobility instructors, consumer products and assistive device specialists, employment counsellors, and occupational therapists. These teams work closely with community service agencies and health care providers to ensure complete services for each person who comes to CNIB. The
organisation also works with the families of people experiencing low vision, providing support and practical assistance.\textsuperscript{364}

One point of concern with this setup where one organisation is the main provider of low vision care, is that people (for whatever reason) might not be able to access services provided by the CNIB or who are outside its system. No evidence has been found to support this notion for CNIB; however, experiences from countries like the Republic of Ireland and Spain justify this concern. In the Republic of Ireland, beyond the services offered by the National Council for the Blind (NCBI), no data exists on the overall levels and location of other low vision services and the people who uses these services.\textsuperscript{325} In Spain, while people with severe low vision are offered highly specialised low vision rehabilitation services, people who do not meet the criteria for ONCE membership are faced with services provided by private clinics that are more expensive and offer a different standard of quality.\textsuperscript{297}

Emphasis on providing low vision care at the primary level will also have implications in terms of shaping the skills mix in low vision human resource development. For instance, it might create a demand for community based workers. In France, services are mainly provided by three professions i.e. ophthalmologists, orthoptists, and opticians mainly at the secondary and tertiary levels. These professionals are located in hospitals, rehabilitation centres or special schools for vision impaired children in urban centres.\textsuperscript{314} Not surprisingly, one of the challenges facing the low vision population in France is access to services in rural areas. Even if barriers such as lack of transportation and costs are overcome, it can sometimes be too strenuous for an elderly person to travel long distances from his/her home to the nearest service and back.\textsuperscript{314} This highlights the importance of primary level care and the need for low vision personnel who practice at this level such as community based workers. Primary low vision care could also address another challenge facing the low vision population which is waiting times. Currently, waiting times can vary between several weeks to several months for a low vision person to get an appointment to be assessed for low vision rehabilitation including the provision of low vision devices.\textsuperscript{314}

A similar situation was also found in the Republic of Ireland where there are long waiting times to see an ophthalmologist for a referral to low vision services. Given that the majority of services are located in larger hospitals, this suggests that people with low vision in
remote areas may face greater difficulties in accessing services.\textsuperscript{325} By contrast, the situation in Switzerland may offer a solution towards overcoming the challenges faced in both France and the Republic of Ireland. In Switzerland, there are mobile units that have been successful in providing low vision rehabilitation as well as general advice on vision problems.\textsuperscript{327}

Nonetheless, Switzerland is a relatively small country so most people may not have problems in accessing services. A country that has shown that it is possible to reach populations living in rural and remote areas hundreds of kilometres away from the urban centre is India. The researcher found that the majority of service providers visited incorporated a primary level component consisting of community based rehabilitation and outreach. This was necessary because the majority of the Indian population live in rural and remote areas. For instance, at the Aravind Eye Hospital in Madurai, the low vision team conducted regular low vision screening in both normal and blind schools. Moreover, vision centres of the Aravind eye care system, were purposely located in rural and remote regions to provide basic eye care and referrals to the nearest Aravind District Eye Hospital. When nothing more can be done for the client-treatment and surgery-wise, clients are referred to the low vision clinic at the tertiary level. Furthermore, community field workers were progressively being trained to carry out basic low vision assessments such as vision stimulation. Services at Aravind covered a 250km radius from the main tertiary hospital. Similar activities were also identified at Joseph Eye Hospital in Trichy.

The Cheran Region Christian Society for Disabled Children (CRCS) in India is another example. The kinds of service offered in the CRCS community based rehabilitation program consisted of:

- assisting people in accessing government benefits, such as medical certificates, identity cards, transport passes, educational scholarships, and the physically handicapped pension (for low vision children with multiple disabilities)
- vocational training
- activities with daily living
- orientation and mobility
- micro-financing
- help with obtaining employment


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- establishing awareness programs in the local community
- self-help groups.

Cameroon and Ghana also have examples of community based rehabilitation services but not as extensive as in India. Due to differences in population demographics, eye camps were not considered suitable; there was more prominence placed on outreach. For example, satellite eye care units based outside Buea in Cameroon conducted day trips to surrounding villages.

The final example proving the importance of primary level care is Wales. A survey in 2001 revealed that access to services had been restricted by the poor geographical distribution of services. For instance, people with vision impairment, many of whom are elderly and with multiple disabilities, were frequently required to make a round trip of 100 miles or more, often on routes not served by public transport, to reach the nearest service provider. Low vision services were revamped to ensure that it was located in community based optometric practices and exists alongside established services in secondary care.

Since 2004, the new system works closely with ophthalmologists, social services, education, and the voluntary sector. Access has been optimised, ensuring that services are geographically spread throughout Wales, referrals into the service are accepted from a range of professionals and from individuals themselves, and waiting times for most people have been reported to be less than 2 weeks (rather than the previously recorded 18 months).

What is fascinating is that while services are provided by community-based field workers in developing countries like India, in developed countries such as Wales, it is the optometrists and opticians who provide similar services at this level. This not only further reinforces the fact of ‘where’ and ‘what’ is being delivered rather than ‘who’, but also the importance of ‘task shifting’ when there is a shortage of low vision personnel and ‘capacity building’ to upgrade certain groups of professionals to take on some of the roles of the professionals traditionally providing these services.
Integration of services

This research confirms that low vision services are being delivered by a broad range of disciplines (medical, education, social welfare, and rehabilitation). Thus, rather than create new systems to provide low vision care and rehabilitation, it is better to focus instead on developing services that can be integrated into existing eye care systems. Integration of services is important because it can potentially lead to a reduction in the differences in access and use of low vision services between geographical and socioeconomic groups thus improving coverage. Integration of services, rather than top-down, single issue programs, is further supported by Alma-Ata. There has been a recent shift in approaches to other areas such as maternal, newborn, and child health towards integration. Horizontal integration of health programs are integral to the attainment of the Millennium Development Goals. Integration involves collaboration across the different sectors involved in low vision and is also one of the essential components of primary health care. In fact, recognising the inter-relationship between components of a health system has in the past resulted in better efficiency.

The following provide examples of ways to integrate low vision services within the different levels of the comprehensive model into existing eye care, education, and rehabilitation services, as well as collaboration and networking between the levels.

One of the most commonly reported issues from the case studies is that eye care professionals do not want to practise low vision care because it is unprofitable, time consuming, and unsatisfying because there is no cure. A way to overcome these barriers is to integrate low vision clinics into major tertiary or district level eye hospitals. An example of this is the Sir John Wilson Optical Centre in Ghana. Moreover, in India, both the Aravind and Joseph Eye Hospitals have used the concept of ‘cost recovery’ i.e. patients who can pay to cover the cost of those who cannot.

Integration also breaks down the barriers to getting access to low vision care in both developing and developed countries. For example in Australia, low vision rehabilitation is not usually provided within the Australian public hospital system or in private practice. Consequently, many clients who could benefit from such services are not receiving them as
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part of a continuum of care. Instead, under the current system, clients attend a hospital for medical care and some are then referred to NGOs such as Vision Australia and Guide Dogs for low-vision services. Services provided by these NGOs include low vision clinical care, orientation and mobility training, counselling, assistance with activities of daily living, equipment demonstration and sale, information provision and advocacy. Because services referred to by the hospital are not co-located in the same building, issues such as proximity, transport, and costs arise. For example, to get to Vision Australia, assuming the client does not have a car or cannot drive because of poor vision and/or transport cost. From the Eye and Ear hospital, the person has to take two modes of transport (tram and train) and then walk a small distance from the train station to arrive. On top of this, if there is no one there to guide the person then it becomes increasingly difficult. Subsequently, many clients do follow up on the referral leading to delayed intervention. This provides some understanding of into the coverage of low vision services reported for Australia in the survey, which was between 11-20%.

Another issue is awareness among eye care professionals. To make the referral, eye care professionals need to be aware of the benefits of low vision care. Past research has found that there are often delays to referral to services by ophthalmologists, especially to rehabilitation services or peer support groups. Moreover, inadequate provision of information by the eye health professional about the service appears to have a negative effect in ensuring client compliance. To overcome these issues, a low vision clinic was established towards the end of last year (2008) within the Eye and Ear Hospital in Melbourne, Victoria. Unpublished research data collected so far reveal that clients from non-English speaking backgrounds have been able access the low vision clinic because of the availability of onsite translators in the hospital. This is one example of overcoming a sociodemographic barrier. For example, the non-English speaking clients were often from ethnic minorities which was identified as one of the groups most likely to miss out on low vision services in the survey.

When there is successful integration there will be a flexible and well-defined referral mechanism between the different levels of the care. The mere physical presence of such a clinic not only makes it easier for clients to access low vision care and be followed up more regularly, but also raises awareness among the community and eye health professionals.
within the hospital. The case studies have shown that the mere presence of services increased awareness among the local community in Ghana.

Finally, integration of services also helps address the low vision human resource shortages where integration of low vision curriculum into existing ophthalmic training at the quaternary level is possible. For example, in Quebec province, Canada, there are at present five hospital-based low vision clinics. Some of these are affiliated with McGill University and the University of Montreal.3 These hospitals in turn provide education and training for residents in ophthalmology and run half-day clinics once per week or once every two weeks, thereby creating a sustainable source of low vision cadres providing services. Access to other low vision personnel becomes accessible as they are all within the same location. For instance, the ophthalmologists and residents are assisted by a nurse, an orthoptist, a technician or other staff, depending on their setup.3 A nearby optician or a specialised store usually fills prescriptions for optical or non-optical devices.3 It also makes it easier for low vision cadres with an interest in research to carry out studies. For example, some of the ophthalmologists are involved in low vision research projects with PhD researchers.3

5.3.5 Funding of Services

Services in over half of the world’s countries are funded by NGOs, raising the issue of the long term sustainability of low vision services. Historically, services in low vision were established by charities and philanthropic organisations.8 This is still the case in many countries today.8

The survey findings demonstrate that funding by government is limited, particularly among developing countries. This could be because low vision may not fall within stated national priorities of the country even though low vision is a priority within Vision 2020 (thus also becoming a priority in the policies of many NGOs).370 For countries where low vision is not a priority, significant human resources and facility maintenance is required even if all physical infrastructure and equipment are provided by non-profit organisations.370 Once donor fatigue sets in or the project finishes, it can often become challenging for governments to continue to support these resources, as the Ghana experience demonstrates. As a result of services being supported by the NGO the government lacks involvement due to feeling that
the provision of low vision service is not their responsibility and should be treated as a standalone discipline. This mentality was found in all three countries in the case studies.

The role of government is vital because in theory, services operated by government cover the whole country so there is better service coverage. A form of government funding is national health insurance. In the survey only 18% of the countries reported having a national insurance scheme that included low vision. There is compelling evidence favouring publicly funded health-care system and that out-of-pocket expenses should be kept at a minimum.\textsuperscript{371} User-fees, particularly in developing countries has led to reductions in the use and worsening of health outcomes.\textsuperscript{371} An interesting example to refer to is the United States: the study by Owsley et al\textsuperscript{298} had displayed that the country provides an impressive array of low vision services across the country, yet the coverage of services was reported to be between 11-20% in this research. This could be because nearly 47 million people are without health insurance coverage.\textsuperscript{372} Past studies have shown that those who are uninsured were more likely to postpone necessary health care, use preventative services, and have poorer health outcomes.\textsuperscript{373-375} On the other hand, in the Netherlands (which had better coverage) higher income earners are insured privately whereas people on lower incomes are members of statutory health insurance schemes and pay a certain percentage of their salaries into the health insurance.\textsuperscript{344} Clients who are referred by an ophthalmologists to low vision rehabilitation services are covered by their health insurance.\textsuperscript{344}

Funding can also affect other aspects of service provision. Since 2004, insurers in Germany only cover people with no more than 30% (best corrected) vision.\textsuperscript{315} There are also talks in place to gradually reduce the amount paid for by the insurance companies.\textsuperscript{315} The impact of this has subsequently created the situation where some ophthalmologists are reluctant to accept new patients.\textsuperscript{315}

External contextual factors identified by the CART also provide insight into funding related issues. Although external contextual factors were not the key determining factor of coverage, the percentage of population urbanised and percentage of private expenditure on health, were closely related to low vision service coverage.
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The percentage of private expenditure on health includes NGO funding. Note that this factor was shown by the CART to be on the same level as being fully funded by government, which signifies that private funding is as equally important as being funded by government. The CART output indicated that countries with higher private funding (compared to government expenditure) can lead to poor coverage. This was observed in Ghana and Cameroon where low vision services are only available in one or two regions of the two countries due to being highly dependent on private funding.

By contrast, in Switzerland, care is funded mainly by government and low vision services are present in each of the 26 Cantons. Low vision devices are covered by two types of national insurance while consultations are provided free of charge. The costs incurred of providing low vision services at the advisory centres (which provide a range of low vision care) in each Canton and the SZB (Swiss Council for the Blind) are subsidised by private donations as well as significant contributions from the government (the Federal Ministry of Social Insurance).

Alternatively, having little private funding can also lead to poor coverage. One such example is in Chennai city, India. While visiting an organisation for disabled children, the researcher met up with a low vision specialist with two MLOP from a small private eye hospital conducting clinical low vision screening. The low vision rehabilitation specialist invited the researcher to visit her hospital later in the week. The researcher met the ophthalmologist who owned a small private hospital. He had a keen interest in providing low vision care for philanthropic reasons; however, the hospital was limited by a lack of funds as well as human resources. The hospital is a for-profit organisation and the majority of its income is fee-based. The hospital is not supported by any NGO or the government. Consequently, despite having a keen interest in providing low vision care, services were limited to running a low vision clinic twice a week for half a day, as well as conducting clinical low vision screening once every few months in the surrounding schools and in organisations that cared for disabled children.

Finally, these examples emphasise the fact that public and private sectors are highly interdependent. Both are required for the funding of services.
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5.3.5.1 Strategies to Improve Financial Sustainability

The issues above emphasise the importance of achieving financial sustainability in the provision of low vision services. Practical and realistic strategies are required. Although there is high importance given to government funding by the preceding arguments, the feasibility of this is often dependent on the socioeconomic status of the country. Also, governments are increasingly faced with demands from other competing health priorities and usually have limited resources. In theory, public policies offer health care coverage to the whole population; in reality health priorities may be politically influenced and many governments can find it difficult to ration health care so that public expenditure is tailored to the needs of the low vision population.

For instance, although Ghana is slightly more prosperous than many of its neighbours, it is still a developing country. The manager in charge of the low vision unit at the Ministry of Health said that it was difficult to convince the upper levels of government to fund his unit because the country is dealing with basic health issues such as access to clean water, as well as more acute health problems such as HIV, Tuberculosis, and Malaria. Even though low vision is on the agenda of Vision 2020 and the country has signed the Vision 2020 declaration, it is still difficult for some countries to fully fund low vision services.

Studies on other areas of health have suggested that relying on complete government interventions to achieve universal health coverage has often proved unsuccessful. Consequently, NGO support is still essential. For instance, to provide some of its activities, the low vision unit in Ghana receives a level of support from CBM to carry outreach in other government health centres as well as low vision screening in schools of neighbouring countries—Togo, Benin, Burkina Faso, and the Ivory Coast. This approach is supported by the CART findings i.e. having a certain level of private funding can lead to better coverage of services.

It is clear that both public and private funding sources are required. The key is to formulate a balanced funding arrangement between private and public sectors to address the social determinants surrounding the low vision population. Strengthening public sector finance requires fair allocation between geographical regions and disadvantaged groups; while in the private sector- focusing on better coordination among donors and stronger alignment
with NGO and national development plans will produce better cross-sectoral financing.\textsuperscript{371} Suggestions to achieve this are provided below.

Establishing a relationship and promoting linkages between the public and private sector/stakeholders, rather than each party acting parallel to one another, are better ways towards the sustainable financing of low vision services. However, government should be the dominant partner and take the ownership and lead in managing the linkages in the partnership. This is because if government rise to set the priorities themselves (rather than the commodity-driven) and act, there will be more sustained progress even though it may be slow.\textsuperscript{348} Furthermore, community participation is a central principle of Alma-Ata as well as being a crucial tenet of comprehensive care.\textsuperscript{348} In this principle health prioritisation and action are to be owned and driven by the communities themselves and linked to other sectors other than health.\textsuperscript{348} This is in direct keeping with Alma-Ata as the government is also a part of the community and low vision also relates to education, rehabilitation, and social welfare.

The importance of government ownership is substantiated by the issues and challenges encountered in Ghana and India. In Cameroon on the other hand, the government and SSI signed a memorandum of understanding (MOU) prior to establishing low vision services. Low vision clinics are integrated within the existing government health care system and are part of the eye care units in three district government hospitals in the Southwest region. However, the government has yet to expand this model to the other regions of Cameroon.

For well developed countries, a nationwide low vision service is not impossible to achieve and Wales can certainly attest to this. The National Assembly Government has funded the implementation of the ‘Wales Low Vision Service’ as part of the Welsh Eye Care Initiative. The service is administered centrally by Carmarthenshire Local Health Board (LHB).\textsuperscript{349} Wales is an excellent example of how clients can access services within their local community. A client needing to have a low vision assessment can refer themselves to an accredited practitioner or be referred by any of the following to their local low vision service provider listed below:\textsuperscript{349}

- a GP or family doctor
- an optometrist
• social services
• community services
• an ophthalmologist in the hospital eye service.

In Wales, along with the presence of national policies on low vision, there are other factors that enable the policies to be applied, for example: funding from the government, as well as commitment and ownership to delivering services, training of personnel to ensure a supply of low vision cadres to provide the services, and integration of services into existing systems. National policies combined with these factors, facilitate better collaboration between different sectors and personnel. This can then trickle down to the local level to facilitate linkages or networks.\textsuperscript{348}

This above is also supported in the univariate and CART analysis, which revealed that having the presence of national referral guidelines for low vision services and standards of practice guidelines for low vision services, were found to have a negative impact on coverage. This implies that it may not be enough to only have guidelines and policies in place. Similarly, signing the Vision 2020 declaration alone may not result in action without a functioning Vision 2020 national committee to implement the strategies. China is one such example. Other ingredients are required to follow through with the policy.

The Wales example is also evidence that it is possible to overcome the financial barriers in accessing devices, as the appointment with the low vision practitioner is provided at no cost by the National Health Service (NHS) and all the low vision aids are available on loan and free of charge.\textsuperscript{349} How this works is that an electronic order is generated and sent to the low vision aid supplier who sends the devices to the practice for collection. The low vision aids are provided on a loan basis so there is less waste of resources. A ‘Vision Passport’ is issued to people at the end of the assessment and like the ‘Personal Child Health Record’, promotes individual empowerment, provides information and facilitates interagency communication.\textsuperscript{349}

Less duplication of services and harmonious collaboration between the public and private sector can be achieved by both sectors having a clear understanding of who, where, and how services are to be delivered. For instance, in Canada, with the exception of the province of Quebec, CNIB provides the services while the Government provides a level of funding to
the organisation. In its last financial year (2007-2008), CNIB raised $82 million. Of this amount, 23% came from the government.

In Quebec, the majority of services are provided by government sponsored rehabilitation centres such as l’Institut Nazareth et Louis-Braille (INLB) and the Montreal Association for the Blind in Montreal and through their counterparts throughout the province, the Centres Régionaux de Réadaptation en Déficience Physique.\(^53\) CNIB’s role in this province is to refer rather than provide the same rehabilitation services as they are already being provided by the government. Services for low vision rehabilitation are covered by Medicare and include providing the client with low vision aids at no cost.\(^53\)

Countries like Wales and Canada highlight the importance of government and its leadership to take ownership in the provision of low vision services. Nonetheless, it is also crucial to point out that a nationwide low vision service has been possible in countries like Wales because it is a small country and an existing eye care system was already well-established. This made it easier for low vision services to be incorporated. By contrast setting up similar services may be very difficult for countries like Indonesia.

Government support may be more possible in developed countries than developing. However, Pakistan has shown that government ownership is certainly possible. In Pakistan, low vision has been included into the national eye care plan and budget and is implemented in each of the four provinces.\(^338\) An EFA plan for vision impairment is also available. Though coverage of services were reported to be \(\leq 10\%\) in the survey because of the large population size of the country, this coverage will eventually improve as services are expanding continually.\(^338\) There is also integration of services into existing eye care services at the hospital-based levels.

**5.3.6 Low Vision Devices**

Only 94 countries had stated that low vision devices were available as part of the services provided however out of this number just over half of developing countries and 68% of developed countries had stated that low vision devices were affordable. This result point to the ability of people being able to obtain low vision devices when needed and can also be linked to the predictor—‘proportion of children obtaining devices’. Affordability remains a
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universal challenge.\textsuperscript{360} However, affordability alone may not be linked to obtaining devices. As the survey and case study findings show there could be other factors such as acceptance, awareness, and stigma. The CART findings substantiate this and show that getting access to equipment is dependent on a number of factors—the physical location of the service (e.g. availability of transport, distance of nearest service), whether the low vision client is receiving proper training in the use of the technological aids\textsuperscript{379} and availability of proper health personnel to provide this training, ongoing education and follow up.\textsuperscript{47,380} Furthermore, the main predictor ‘proportion of children obtaining devices’ was also found to be related to— human resources, location and type of services and funding (CART findings). The implications of this is that proper training in the use of low vision devices for children, as well as attaining a level of care for the increasing number of adults with low vision is attained only when comprehensive services and sufficient numbers of appropriately trained health personnel are available.

5.3.7 Barriers

Finance-related barriers were the most frequently reported. Issues surrounding accessing equipment such as cost of devices and services are one of the numerous barriers faced by both service providers and clients with respect to low vision services. In Ghana, the national health insurance scheme only covers eye examinations and cataract-related care services. So while people are able to have their eyes assessed, the majority were unable to purchase the devices when prescribed. The fact that many people do have access to health insurance in the United States also affects peoples’ ability to access services. On the other hand, with the Indian government’s EFA initiative in the areas of research, most children attending schools with IEP were able to access free or low cost devices.

The issue of devices being too difficult to use relates to the number, range and types of low vision human resources or the services provided. For instance, regular training and counselling is often required to achieve better compliance in the use of devices. However, due to possible underlying reasons such as cost, lack of transport, or lack of awareness, many people do not return for follow up. One such example relating to the lack of awareness and training was identified in Cameroon: the researcher interviewed a client at her home who recounted how she had stopped using her telescope because it was too
difficult to use. When probed further, she disclosed that she had attended the low vision clinic once where she had received training in the use of the device. However, since she attended the clinic, she did not feel the need to go back for follow-up.

Poor coverage of services in many countries can also be attributed to geographical barriers such as distance. For example, some clients interviewed in India had travelled up to four hours to reach the low vision clinic at Aravind Eye Hospital. In Ghana, due to the damming of the Volta River, communities surrounding the river have been isolated from the mainland and live on small pockets of land. A mother whose daughter has low vision told the researcher that the cost of using the boat to reach the service on the mainland costs US$1, the equivalent of what the mother earns farming in two days. Even the community based field worker stated he has difficulty in reaching all the people living on these islands. Water transport is expensive and in some places only small two-man canoes can pass through the narrow canals. The field worker also reported that they have yet to cover the whole community to determine potential clients with vision problems and who would benefit from services.

Both cost and geographical coverage pose issues for health equity. Vision 2020’s goal towards achieving comprehensive low vision care includes action to ensure anyone with low vision has a fair opportunity to access low vision services. Unfortunately, people living in rural areas, those with low income, women, children, the elderly, the disabled, ethnic minorities, and refugees are not accessing services as required. The first two groups are more of an issue for developing countries while the last two groups are more frequently reported in developed countries.

These groups represent the social inequity that manifests itself across various intersecting social categories and pose threats to achieving an equitable low vision service. For example, in the United States, people who are uninsured are usually the working poor\textsuperscript{381}, the elderly\textsuperscript{382}, minority groups such as Asians\textsuperscript{383} and Latinos.\textsuperscript{384} This is also consistent with the findings of the survey.

The current situation of low vision services and barriers are further confounded by the lack of awareness among the clients themselves, family members, local community, service
providers, and the government. For instance, in Ghana, a low vision student said to the researcher that whenever she used her telescope in the classroom, the other students would become curious and crowd around her, while others would make fun of her for using a magnifier to read. Indeed, 45% of countries had reported the barrier ‘fear of stigma’ as one of the reasons that people do not obtain low vision devices when prescribed.

The barrier “nothing more can be done” was commonly reported in the survey. For example, the low vision specialist at the Joseph Eye Hospital reported that adults often refused to use low vision devices because they felt that low vision is something they have to live with while some even believed that it was ‘karma’ to have low vision. ‘Karma’ may also explain one of the issues behind the barrier ‘culture’ which was more commonly reported by developing countries in the survey.

5.3.8 Monitoring and Evaluation

Coverage was discussed in the literature review as a measure of service efficiency and effectiveness. Thus monitoring and evaluation was included as one of the topics investigated by both the survey and case studies in Chapter 3 due to its importance in measuring coverage and effectiveness.

The survey and case studies identified that very little is carried out to evaluate the outcome of services and impact of services on the quality of life. Most of the monitoring and evaluation was usually due to the field workers reporting back to the NGO as part of donor requirements. In these cases, the reporting was only related to the specifications of the project. As illustrated by the world map, numerous countries had no information on the national coverage of low vision services. Additionally, many countries did not have available or good prevalence data so only estimates of coverage could be obtained.

This situation can be improved as had been demonstrated by Wales. Practitioners use a standard record card and once an assessment has been completed key information is entered into a computer database in Carmarthenshire to allow the monitoring and evaluation of services. Obviously a system like this requires commitment of resources such as policy and financial support.
5.3.9 Advocacy

Vision 2020 recognises the need for low vision care to be delivered through national programs that are tailored to individual countries. Up to this point, this Chapter has provided strategies and numerous examples to improve the current situation of low vision services and the future development of services at the national level. Various techniques have been discussed under two main areas of action: human resources and sustainability.

However, the overwhelming message is that none of this is possible without national support and funding. While NGOs and donor agencies provide some level for ongoing funding, as well as flexible start-up funds for new low vision services, the long term sustainability of these services must eventually come from governments and their insurance programs and training of low vision cadres, despite the reality that clients will continue to pay for some of the costs e.g. low vision devices. Government policies can have an immense effect on low vision. For instance the national policies in India had major implications for the low vision population. This example of India also alludes to the importance of social protection systems that have been found to have better population health and government policies can make a significant difference. For example: in Sweden and Norway social welfare benefits to disadvantaged families have been associated with low rates of child poverty. Therefore, to enable strategies for the various components of low vision services to be implemented successfully, the largest impact must be made through advocacy and lobbying the government.

The case study findings show that lobbying the government should also specifically focus on lobbying one Ministry instead of the whole of the government. This is because low vision care involves more than one discipline i.e. health, education, and social welfare, which means that it is vital that one ministry take responsibility for coordinating low vision services and other Ministries relevant to low vision. Otherwise, as seen in India, Ghana, and Cameroon, this may lead to uncoordinated fragmentation of services and lack of government ownership. This situation was also reflected in Lithuania. Correspondence with the survey respondent from Lithuania found that services were/are traditionally under the realms social services rather than medical. Subsequently, ophthalmic personnel such as ophthalmologists were not involved in providing clinical low vision care and prescribing low
vision devices. Services are mainly provided by the associations for the blind and the vision impaired (adults) and special teaching institutions (children). Consequently, low vision persons outside these organisations cannot easily access low vision devices. The Lithuanian experience adds further support to the fact that all sectors, i.e. medical, social welfare, rehabilitation and education, are required for low vision services to be delivered holistically.

There were suggestions made by a few of the case study participants on which Ministry would be most appropriate and effective in leading other departments. One person referred to the example of Hong Kong where the Department of Disability were the main coordinator and delegated tasks to other departments. Two other persons suggested the Ministry of Health because of the clinical care component. In Cameroon, it was the Ministry of Public Health that coordinated the planning meetings prior to establishing low vision services.

5.3.9.1 Advocacy Tools

Research

Specific tools can be used to lobby the government. Good data is one of those tools. To be effective, advocacy must be supported by high quality information and this is acquired through research.

For example, in Wales it was a series of research findings\textsuperscript{367,386} that prompted the Welsh National Assembly to take the revolutionary step of introducing a nationwide low vision service. The findings alluded to the fragmented nature of the service with differences in availability and accessibility, the lack of communication between healthcare and social care professionals, barriers to access, long waiting times and the poor geographical distribution of services in the country. In another example, a survey carried out in Ghana led to the establishment of the integrated education program in 1994.

One of the positive impacts of Vision 2020 is the amount of evidence-based data that can now be used to lobby governments. In the past 10 years numerous research studies have proven the impact of low vision on an individual’s quality of life\textsuperscript{14,19,20,89-92} as well as its economic impact.\textsuperscript{23,24} Moreover, research has also proven that low vision intervention is effective in improving the QoL of the person with low vision.\textsuperscript{81,83,354,387-390} This information,
and the findings from this research, can be used to alert governments to the importance of low vision services, the costs of not doing more, and the benefits of funding and supporting low vision services.

**NGOs-advocacy tool and partnership with government**

An effective method for communicating with the government is to come together as one voice. In terms of who, the researcher believes that it is the eye NGOs themselves who should be uniting as one voice. Advocacy is more effective if it is undertaken by a group of organisations. Historically, eye NGOs have supported, and continue to support, low vision and its services. This research has seen organisations like CNIB, NCBI, RNZFB, SSI, and CBM successfully introduce and guide the implementation of various low vision programs in countries.

As low vision is one of the priority areas of Vision 2020 and with the changing patterns of disease, these organisations and others like them (e.g. the UK Royal National Institute for the Blind, and Helen Keller International) are now focusing their efforts more on the field of low vision and thus are powerful advocacy tools themselves to lobby governments. For example, one of the reasons why the low vision population in Quebec, Canada are able to access free low vision devices and receive free services today, is because many groups and associations of people with vision impairment came together in the 1970s and lobbied the government for support for their cause.\(^{53}\)

In Cameroon, SSI organised several meetings and workshops over the course of two years with all stakeholders (i.e. government departments in public health, health, education, and social welfare and other NGOs) to plan for the establishment and implementation of low vision services in the Southwest region.

Coming together as one voice to lobby the government requires one organisation to coordinate the group. This is where the important role of Vision 2020 is emphasised. National governments are expected to be the ones responsible for working towards national Vision 2020 plans. The reality is that in many countries, governments are the ones needing advocacy. Several countries have established national Vision 2020 programs, however, in
countries that do not have a national Vision 2020 committee or a functioning one – services can become fragmented or uncoordinated.

Examples of this lack of national coordination were found in larger countries like China, Russia, and the United States. China does not have a functioning Vision 2020 committee. In the United States, the researcher was able to gather a national perspective from the US Department of Veterans Affairs as well as two other perspectives from the field of optometry and ophthalmology which gave a fragmented representation of services in the country. Fortunately, the recent study by Owsley et al provided the first national picture of the characteristics of low vision services outside the Veterans Affairs system\(^{298}\) and enabled the researcher to use the data from this study to update the data in the survey. The researcher has also been informed by her principal supervisor and there are also reports that plans are in process towards establishing a national Vision 2020 USA in 2009.\(^{391}\) The aim of this organisation will be to bring together all blindness prevention stakeholders which include NGOs, academics in ophthalmology and optometry, government at all levels, and any other entities with an interest in blindness prevention. The function of Vision 2020 USA will be to enhance advocacy and raise funds for prevention of blindness activities.\(^{391}\)

Australia is one example where a national Vision 2020 program has been successful in leveraging the combined efforts of many organisations under one umbrella to raise awareness and funds for other priority areas of Vision 2020. Examples of past successes include but are not limited to the launch of the National Eye Framework in 2004, funding from the government, and public eye health campaigns in 2009.\(^{392}\)

The achievements of Vision 2020 Australia in eye care are an example of how the same efforts could also be directed specifically at low vision. Compared to many other countries, Australia is in a better position to lobby the government. This is because there is already good access to quality research evidence. For example, in addition to the existing research already carried out on QoL\(^{83,393,394}\), service-related studies\(^{175,395}\) and barriers\(^{43,173}\), the country has the most comprehensive national assessment of the economic cost of vision impairment.\(^{24,25,109}\) Studies such as the Melbourne Vision Impairment Project (VIP)\(^{57}\) and the Blue Mountains study\(^{162}\) further add to the wealth of information. Additionally, organisations such as Vision Australia provide good quality low vision care and Vision 2020
Australia is now well established. Australia is also a high income country with existing infrastructure and affordable access to health care through the Medicare system (national health insurance scheme).

When the National Eye Framework was launched, there was barely a mention of low vision. However, through the continuing advocacy by Vision 2020 Australia and its partners, recognition of low vision is growing. In September 2009, Vision 2020 Australia and the government will come together to create the country’s first national framework on low vision rehabilitation. The researcher will also be attending this workshop to share with others the findings from this research.

5.4 Summary

From this research, the critical success factors in the coverage of low vision services were identified and this was conceptualised by the FRAME. The FRAME led to the proposal of strategies under three areas of action: human resources development, sustainability, and advocacy. However, it has been shown that these three areas exhibit interdependence with one another. There are interactions and interlinks which combined together, contribute to better coverage. This is not only supported by the findings in the CART (Figure 23; p.155) but also illustrated by the various working examples in countries such as Wales\textsuperscript{169}, Canada\textsuperscript{364,396}, the Scandinavian nations\textsuperscript{340,341}, and Pakistan\textsuperscript{338}. In these countries, the inclusion of low vision into national policies and budget is further followed up by training of human resources, monitoring and evaluation of services and integration of services into existing systems which together have helped in broadening the distribution of services across the country. On the other hand, in places where one or two areas are lacking, problems have surfaced. For example, in Ghana, the lack of government ownership led to the collapse of community based services. In Germany\textsuperscript{315} and the Republic of Ireland\textsuperscript{325} in spite of having training systems incorporated into existing ophthalmic curriculum, the absence of a sustainable funding system i.e. insurance to obtain affordable low vision devices, and national policies like referral guidelines, have resulted in barriers such as delays in referring people to low vision rehabilitation.
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What is fascinating is that Vision 2020 recommendations to optimal approaches to service delivery were consistent with findings from this research. For instance, comprehensive delivery of low vision services (put forward by the WHO), SmartSight, and the L V Prasad ICARE service delivery models, are consistent with the elements, strategies, and numerous examples of models in countries identified in this research. These included: integration between levels of care, providing multidisciplinary care, developing human resources through training opportunities and institutes at the quaternary level, and focusing on “what” is being provided rather than “who” is providing the services (capacity building and task shifting). Furthermore, although all levels of care (i.e. primary, secondary, tertiary, and quaternary) are required to achieve a better coverage of low vision services, the models described in the literature review and the findings from this research support promoting emphasis on primary and community based care, of which an analogy can be drawn with the two largest pieces of the pyramid in the ICARE model of L V Prasad.
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The survey and three country case studies provided comprehensive insight into the current situation of low vision services globally.

Prior to this research, the coverage of low vision services was estimated to be poor. The information was based on only 22 countries in 2002.\textsuperscript{27} Moreover, this research identified which countries have poor (≤10%) and better coverage (>10%). Poor coverage was not restricted to developing countries; it was found also in more developed countries such as Malaysia and Poland. In numerous European countries, where there had been anecdotal evidence of high quality comprehensive low vision services, the coverage rates could not be ascertained or no information and/or response could be elicited.

The main factors behind countries with varied low vision service coverage are now known. These are outlined in the ‘FRAME’ i.e. F-funding sources, R-rehabilitation workers (human resources), A-access i.e. low vision devices and services, and overcoming socio-demographic and economic barriers, M-multidisciplinary services, and E-external contextual factors. FRAME summarises the critical success factors that will assist the WHO LVWG and Vision 2020 to improve the current models of service delivery, future planning, low vision training and curriculum development, and priorities setting. This should be achieved through three areas of action—human resources development, sustainability, and advocacy. Focusing on these will help guide countries to move from being red (≤10% coverage) on the global map (p.142) to green (>50% coverage) and for countries which have yet to establish services and/or are in the process of planning to set up services to move from being grey (zero coverage) to red.

For human resource development, the critical messages are that more training facilities are required to provide specialised training in order to achieve a sustainable number of low vision personnel, and more critically, provide a good mix of skills. This involves integration of low vision into current existing ophthalmic curricula as well as conducting informal training workshops and courses where formal training opportunities are lacking. The second strategy is task shifting. A unique feature of ‘task-shifting’ is that it focuses on ‘what’ is being delivered rather than ‘who’. Maintaining the enthusiasm and motivation of staff through better remuneration and professional development activities is another important aspect of developing low vision human resources.
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Under sustainability, key approaches include strengthening primary level low vision care through community-based rehabilitation and outreach. By doing so, people disadvantaged in accessing services simply because they are poor, live in rural areas, are disabled or are elderly have access to care. Through outreach, clients can be followed up thereby minimising the loss to follow-up and non-compliance with using low vision devices. Moreover, children with poor vision can be detected early.

Integration of low vision into existing education, rehabilitation and eye care systems is another strategy. Moreover, establishing appropriate and healthy collaborations between the government and private sector promotes sustainability. It is unrealistic to expect government to fully fund and support low vision services given the resources and competing health priorities. Thus, both sectors are crucial to ensure the financial sustainability of services. However, for this to work, government needs to be the leading player in the partnership, and take ownership of the programs and services. The role of NGOs is to provide support to governments where necessary—for example technical support and human resources to establish training opportunities. A successful relationship between the public and private sector means that both parties work in a complementary manner rather than parallel to one another, which can ultimately avoid duplication of services and unnecessary competition.

The third and final area of action is advocacy. This is where the biggest impact can be made. The long term success of the above two (Human Resources and Sustainability) is dependent on the success of advocacy. Advocacy for low vision requires three essential tools: first, using strong research evidence to formulate an effective message to deliver to the government. Second, this research has shown that NGOs are in the best position to facilitate and influence government. The third tool is the act of forming a partnership. This is where all stakeholders with an interest in low vision come together under one umbrella organisation, i.e. a national Vision 2020 office to lead the group, and deliver the message with one clear voice. By forming a partnership, the power of this voice is increased as they all support and share the same objectives.
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6.1 Recommendations for Future Research

This research, both through its inherent limitations, strengths, findings and implications, exposed a number of areas in which further research is warranted.

Results will be made available on the WHO InfoBase. With the first global baseline data on low vision services established, there can now be regular updates, e.g. every 5 years and mapping of low vision services either at the national, regional, and/or global level to follow up the progress of low vision services and assess areas of need, trends, the impact of Vision 2020, and other interventions. This research could be coordinated by Vision 2020 regional offices as well as national offices, in collaboration with research institutes located within the country or regions.

A way to achieve that is to include questions pertaining to low vision and its services into national surveys or other existing surveys such as the RAAB (Rapid Assessment of Avoidable Blindness). The RAAB assesses the burden of sampling and major causes of (avoidable) blindness. It comprises a random cluster survey of people aged >50 years which is useful for developing countries as 80% of vision impairment occurs in this group.\(^{397}\) The RAAB includes more detailed data on causes of low vision and blindness besides cataract and has an updated data entry and analysis package with extra reports and consistency checks.\(^{33}\) The global mapping survey could be modified and integrated into such surveys which can in turn, minimise and overcome some of the limitations of the survey. Additional or revised questions can include also those that addressed the various topics in more detail, and more multiple choices made available. More specific information also could be sourced about the location of services. One example would be the number of kilometres they were from the city centre.

Assessing services at the national level will provide a deeper and more comprehensive characterisation of what services are available throughout the country. The information can then be used to conduct clinical trials to measure the effectiveness of low vision models specific to the country, and the data used to guide decisions about how to enhance the likelihood of positive outcomes.\(^{298,389}\)
Another potential area of research is the application of the CART methodology. In this research, this statistical technique has shown several advantages over more traditional methods for analysis of survey-related research methodology. There can be wide-ranging implications for its application in the monitoring and evaluation of low vision service efficiency in various settings. For instance, the CART methodology can be applied to identify the critical success factors specific to the country and the information used to develop national low vision frameworks that will guide referral systems and standards of practice. The CART may also be used to identify groups of people most at risk of not accessing low vision services and/or to investigate predictors of barriers that deter people from accessing services.

Research is also warranted to further develop the three areas of action. This research has outlined what should be done to achieve better service coverage and provision. Logically, the next step is to look at developing effective national guidelines and frameworks to make each of the strategies under each area of action become more concrete. For instance in developing models to integrate low vision cadres, specifying, what roles could be ‘task-shifted’ or ‘capacity built’ without overburdening the low vision personnel, could be one avenue for further research. Moreover, research can further look into the minimum mix and range of low vision cadres required to deliver an adequate level of services in low resource and rural settings. For strategies to lobby the government – in this study, the specific government department best suited to take the lead in coordinating and delegating other departments to delivering services at the national level has not been identified. Therefore, additional research could help identify which department is best suited.

In addition, further research into investigating appropriate funding mechanisms or arrangements between the public and private sectors and/or formulating more innovative ways to integrate low vision services into current and future policies is required. Devising methods to actively encourage governments to prioritise low vision care is another potential area of research. Lastly, further exploration is necessary on refining and validating the ‘FRAME’ for its application to assess and measure the effectiveness of low vision services at the organisation level.
6.2 A Final Note

“I used to feel hopeless but now I feel I am useful again” – quote from a 33 year old woman with low vision. She had received a loan from the bank through the help of the community based rehabilitation program in Ghana. Through the program she learnt skills that helped her adapt to the environment. She now runs her own grocery shop and is the breadwinner of the family. Before she was able to access these services she relied on family members to walk to town and sat at home most of the time not able to do anything. (One of the interviews from the Ghana case study)

Perhaps what was most amusing was that when the researcher asked her about the impact of services on her family she replied that because she is now the breadwinner of the family her husband had to do as she says!

It is success stories like these that make the implications of this research all the more important and conducting such work worthwhile. To be able to access low vision services, this person overcame many of the barriers identified in this research. She is one of the lucky ones. But it should not have to be this way. Access to low vision services should not be fraught with challenges and obstacles. With the increasing ageing population and changes in the pattern of eye conditions, the situation for low vision services will only get worse. This thesis has addressed an important gap in the field of low vision. It has provided the crucial information to inform the WHO and Vision 2020 to address the current and future low vision service needs in terms of planning, and setting priorities which can be achieved through tackling three areas of action outlined above. Low vision is no longer a blank map. The challenge now is to ensure that the significance of this research becomes a reality and not be confined within the pages of this thesis. Thank you.
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7 List of References
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8 Appendices
Appendices
## 8.1 Appendix A – Pilot Survey

### Mapping Low Vision Models of Care Questionnaire – Reference Group Pilot Test

#### SECTION ONE: NATIONAL BASELINE INFORMATION ON LOW VISION

1. **How is low vision defined in your country?**
   - Visual Acuity < 6/18 or ≥ 3/60
   - Visual Acuity < 6/80
   - Any impairment of visual functioning
   - Other, please state: ____________________________  

2. **Has your country signed the ‘Vision 2020 Global Declaration of Support’?**
   - Yes
   - No
   - Do Not Know

3. **Is there a Vision 2020 National Committee/Prevention of Blindness Committee in your country?**
   - Yes
   - No
   - Do Not Know

4. **Is there a national eye health care plan in-country?**
   - Yes, please go on to question 5
   - No, please explain why: ____________________________  (please go to question 6)

5. **Does the current plan include low vision?**
   - Yes
   - No

6. **Are there national guidelines for referring clients to low vision services?**
   - Yes, please go to question 7
   - Do not know, please go to question 8
   - No, please explain why: ____________________________  (Please go to question 6)

7. **What are your national guidelines for referring clients to low vision services?**
   __________________________________________________________

8. **Are there uniform guidelines for standards of practice in low vision care? Please explain your response:**
   __________________________________________________________

9. **Where is low vision care provided in your country? Tick all that apply**
   - Public Hospitals
   - Community-based services
   - Government rehabilitation agencies
   - District Hospitals
   - Private hospitals
   - Private clinics
   - NGO-based rehabilitation agencies
   - Other, please state: ____________________________

10. **What low vision services are available in your country? Tick all that apply**
   - Clinical low vision care
   - Rehabilitation and training
   - Low vision awareness and health promotion
   - Social welfare services
   - Other, please state: ____________________________
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11) Are there collaborations between low vision services for equipment and infrastructure within organizations and services?
   ☐ Yes ☐ No ☐ Not sure

12) Are there collaborations between low vision services for human resources within organization and services?
   ☐ Yes ☐ No ☐ Not sure

13) Please describe the low vision services in your country:


14) What level of impairment do people have to have to be eligible to receive services and care?
   ☐ Visual Acuity <6/12 ☐ Visual Acuity <6/18 ☐ Visual Acuity <6/60
   ☐ Visual Field <10° ☐ Other, please state: ______________________________

15) What are the main causes of low vision in your country? Tick all that apply:
   ☐ Cataracts ☐ Age-related Macular Degeneration ☐ Glaucoma
   ☐ Diabetic Retinopathy ☐ Eye infections ☐ Childhood onset
   ☐ Other, please state: ____________________________________________

16) How are low vision services funded? Tick all that apply:
   ☐ Fully funded by government ☐ Subsidies from government ☐ Fee for service
   ☐ Support from international NGOs ☐ Support from local NGOs ☐ Private insurance
   ☐ Other, please state: ____________________________________________

17) Approximately how many people access low vision services in each month? ____________________________

18) How do you feel about the level of importance in the provision of low vision care and services in relation to other eye health services? Please circle one number that most applies to you:


19) Do you think low vision services are provided adequately to support your answer in question 17?
   ☐ Yes ☐ Do not know ☐ No

   If you have answered 'no' to the above question, please give reason(s) for your answer:


20) Are there any changes or additions you would like to make to the current provision of low vision services?
   ☐ Yes ☐ Do not know ☐ No

   Please give reason(s) for your answer:


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Appendix A

SECTION TWO: PROVISION OF SERVICES

21) What low vision facilities are available or provided in your country? Tick all that apply

☐ Clinics in hospitals      ☐ Clinics in other centres    ☐ Clinics in schools
☐ Residential training centre ☐ Day Centres for activities    ☐ Libraries of alternative format materials
☐ Sports and Recreation    ☐ Vocational training centres    ☐ Special education support centres
☐ Other, please state: ___________________________

22) What types of services are most commonly used? Tick all that apply

☐ Assessment of low vision    ☐ Activities of daily living    ☐ Skills training – specify example: ___________________________
☐ Counselling                 ☐ Day care programs             ☐ Educational training and support
☐ Use of adaptive technology ☐ Orientation and mobility      ☐ Vocational training and support
☐ In-home training/support    ☐ Other, please state: ___________________________

23) What are typical waiting times to access services in your country? Tick one only

☐ < One week       ☐ 1-4 weeks       ☐ > One month       ☐ > One year       ☐ Other, please state: ___________________________

24) On a day to day basis, are appointments on average usually? Tick one only

☐ Always booked out     ☐ Half booked out    ☐ Sometimes booked out
☐ Hardly ever booked out ☐ Other, please state: ___________________________

25) Are Low Vision Aids and Devices available as part of the low vision care?

☐ Yes, please go on to question 26      ☐ No, please give reason(s) to your answer below:

__________________________

(Please go to the next section)

26) What kind of Low Vision Aids and Devices and other low vision related equipment are available through services in your country? Tick all that applies

☐ Near magnifiers/glasses    ☐ Distance telescopes    ☐ Glare control devices
☐ Closed circuit television ☐ Electronic magnification systems ☐ Examination equipment
☐ Other, please state: ___________________________

27) What influences prescriptions of Low Vision Aids and Devices in your country?

☐ Needs of client      ☐ Clients’ ability to pay    ☐ If clients express interest    ☐ Other, please specify: ___________________________

28) What are the criteria for prescribing Low Vision Aids and Devices in your country?

☐ Mild visual impairment (<6/12)    ☐ Moderate visual impairment (<6/18)
☐ Severe visual impairment (<6/60)   ☐ Impaired vision >N8
☐ Clients with specific diseases, please specify: ___________________________    ☐ Other, please state: ___________________________

29) When Low Vision Aids and Devices are prescribed, approximately how many people purchase these? (please tick only one option)

☐ 0-20%       ☐ 21-40%       ☐ 41-60%       ☐ 61-80%       ☐ >80%
36) What are the reasons that clients do not purchase Low Vision Aids and Devices? Tick all that apply

- Cost
- Not interested
- Too difficult to use
- Disagreement with clinical diagnoses
- Vanity
- Fear of stigma
- Fear of stereotyping
- Other, please state: __________________________

SECTION THREE: HUMAN RESOURCES

31) Is there a communication network set up between low vision professionals or organizations?

- Yes
- Not sure
- No

32) Please answer questions for all health professionals involved in low vision care:

<table>
<thead>
<tr>
<th>Type of group</th>
<th>The number of health professionals involved in low vision care?</th>
<th>Ratio between urban and rural based health professionals?</th>
<th>What are the tasks and responsibilities of these health professionals in low vision?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ophthalmologists</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ophthalmic Clinical Officer (OCO) or Ophthalmic Medical Assistant (OCM)</td>
<td></td>
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</tr>
<tr>
<td>Optometrists</td>
<td></td>
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<tr>
<td>Refractionists</td>
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<tr>
<td>Orthoptists/ Ophthalmic Technicians</td>
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<tr>
<td>Opticians</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ophthalmic Nurses</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Based Rehabilitation Workers</td>
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<tr>
<td>Community Based Eye Care Workers</td>
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</tr>
<tr>
<td>Trained Teachers/Worker (working with low vision students)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rehabilitation Officers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other, please state:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### 33) What low vision qualifications or training in low vision do professionals in your country have? Please answer questions for all health professionals involved in low vision care:

<table>
<thead>
<tr>
<th>Type of group</th>
<th>Holds Low Vision Qualification</th>
<th>Other low vision training - Please specify</th>
<th>Length of Course</th>
<th>Main content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ophthalmologists</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ophthalmic Clinical Officer (OCO) or Ophthalmic Medical Assistant (OCM)</td>
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<td>Refractionists</td>
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<tr>
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<tr>
<td>Rehabilitation Officers</td>
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<tr>
<td>Other, please specify</td>
<td></td>
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</tr>
</tbody>
</table>

### 34) Is regular low vision training provided to current staff within services?

- [ ] Yes, please go to question 35
- [ ] Do not know, please go to the next section (question 38a)
- [ ] No, please state reasons: _____________________________________________________________

Please go to the next section (Q08a)
### Appendix A

#### 35) Please give details where appropriate:

<table>
<thead>
<tr>
<th>Type of group</th>
<th>Who conducts training</th>
<th>Frequency of training</th>
<th>Length of training</th>
<th>Content</th>
<th>Location: In-country or elsewhere (state country)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ophthalmologists</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ophthalmic Clinical Officer (OCO) or Ophthalmic Medical Assistant (OCMA)</td>
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<td></td>
</tr>
<tr>
<td>Optometrists</td>
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<tr>
<td>Orthoptists/Ophthalmic Technicians</td>
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<tr>
<td>Opticians</td>
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<td>Ophthalmic Nurses</td>
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<tr>
<td>Community-Based Rehabilitation Workers</td>
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<tr>
<td>Other, please state:</td>
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</tr>
</tbody>
</table>

### SECTION FOUR: EQUIPMENT AND INFRASTRUCTURE

36) a) What do you think are the most important equipment and infrastructure for providing low vision care in your country? Please list:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

b) Are these resources currently available?

☐ Yes  ☐ No
37) a) What essential resources does your country need most that it does not currently have? Please list:


5) What are the reasons for the lack of resources or services? Please rate in order of priority from 1 (highest priority) to 5 (lowest priority) or up to 6 (if ‘other’ reason(s) apply). You may assign items with the same level of priority if required.

<table>
<thead>
<tr>
<th>Reasons</th>
<th>Priority Rankings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding</td>
<td></td>
</tr>
<tr>
<td>Lack of infrastructure</td>
<td></td>
</tr>
<tr>
<td>Awareness about low vision</td>
<td></td>
</tr>
<tr>
<td>Trained workforce</td>
<td></td>
</tr>
<tr>
<td>Referral systems</td>
<td></td>
</tr>
<tr>
<td>Other, please specify:</td>
<td></td>
</tr>
</tbody>
</table>

SECTION FIVE: COVERAGE AND BARRIERS

38) What is the prevalence of low vision in your country? Specify %: ______________________

39) What are the proportions of clients using national services in your country?

- Children - state %:
- Adults - state %:

40) Are there any groups of people less likely to access low vision services?

- Low income group
- People living in rural areas
- Woman
- Other; please state: ______________________

41) What are the most common reasons for not accessing low vision services?

- Culture
- Language
- People believe nothing can be done to improve vision
- Costs
- Client refusal to attend
- Clients/patients too busy
- Location - nearest service too far
- Logistics - e.g. lack of transport
- Other, please specify: ______________________

42) Are clients referred to or use services outside your country?

- Yes
- Do not know
- No

43) When are clients referred to foreign professionals or services in your country?

- Preference from client
- Lack of appropriate local personnel to deal with client needs
- Inadequate resources
- Certain diseases - please specify: ______________________
- Other, please state: ______________________
SECTION SIX: MONITORING AND EVALUATION

44) What are the current procedures in place to monitor low vision services and care?

________________________________________________________________________

45) What are the current policies in place to monitor low vision services and care?

________________________________________________________________________

46) What indicators are used to monitor low vision services and programs? Please state below:

________________________________________________________________________

47) What outcomes are used to evaluate low vision services and programs? Please state below:

________________________________________________________________________

48) How are client outcomes assessed in determining improved function among people with low vision in your country?

☐ Use of surveys & questionnaires  ☐ Interviews

☐ Data from national statistics  ☐ Other, please state: __________________________

SECTION SEVEN: DETAILS OF PERSON FILLING IN THIS QUESTIONNAIRE

49) What type of Organization do you work in?

☐ Public/government  ☐ Private  ☐ Non-profit  ☐ Corporate

☐ National PDL committee  ☐ Vision 2020  ☐ Other, please state: __________________________

50) What is your name? (Optional) __________________________

51) What is your job position? (Optional)

__________________________

52) Summarise your roles and responsibilities in your position?

__________________________

53) What is your profession?

__________________________

54) We would like to give you feedback on the outcomes of our research, what is the best contact to reach you?

__________________________

Thank you!

Please place your completed questionnaire in the envelope provided. Alternatively you can send the completed questionnaire in PDF format as an attachment and e-mail it to this address: p.chiang@perad.unimelb.edu.au

Or you can fax it to this number:

+61 3 9062 3559
### Appendix B – Survey

**Global Mapping Survey of Low Vision Services**

**Section one: details of person completing the survey**

1) What type of organization(s) do you work in? Tick all that apply.
- Public/government
- National (prevention of blindness) PBL committee
- International Non-Government Organization
- Vision 2020
- Local Non-Government Organization
- Non-profit
- Private
- Other, please state:

2) What is your name?

3) What is your job position?

4) a) Do you have qualification(s) in low vision? Please Select One
- Yes
- No

   4b) What was the name of your training course?

   4c) Where did you receive your training?

5) What is your profession?

**Section two: general information on low vision**

6) Is there a Vision 2020 National Coordinating body or Prevention of Blindness Committee (PBL) in your country? Please Select One
- Yes
- No

7) a) Is there a national vision or eye care plan in your country? Please Select One
- Yes
- No
   7b) Does the current plan include low vision? Please Select One
- Yes
- No

8) Are there guidelines for standards of low vision practice? Please Select One
- Yes
- No

9) Are there national guidelines for referring children and adults to low vision services? Please Select One
- Yes
- No

10) How is low vision defined in your country? Tick one only
- Best corrected visual acuity < 6/18 (20/60 or 0.3) or ≥3/60 (20/400 or 0.05)
- Best corrected visual acuity < 6/60 (20/200 or 0.1)
- Any impairment of visual functioning
- Other, please state:

11) What level of impairment is required before children and adults are eligible to receive low vision services and care? Tick one only.
- Best corrected visual acuity < 6/12 (20/40 or 0.50)
- Best corrected visual acuity < 6/18 (20/60 or 0.30)
- Best corrected visual acuity < 6/60 (20/200 or 0.1)
- Visual Field < 10°
- Other, please state:

12) a) What are the main causes of low vision in your country? Tick all that apply
- Cataracts
- Age-related Macular Degeneration
- Glaucoma
- Diabetic Retinopathy
- Childhood onset
- Eye infections
- Other, please state:
Appendix B

Global Mapping Survey of Low Vision Services

12 b) Please state the source(s) you used. Tick all that apply

<table>
<thead>
<tr>
<th>Source</th>
<th>Ticked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Knowledge</td>
<td>☐</td>
</tr>
<tr>
<td>Published Reports</td>
<td>☐</td>
</tr>
<tr>
<td>Internet</td>
<td>☐</td>
</tr>
<tr>
<td>Hospital Records</td>
<td>☐</td>
</tr>
<tr>
<td>Non-Published Reports</td>
<td>☐</td>
</tr>
<tr>
<td>National Plan</td>
<td>☐</td>
</tr>
<tr>
<td>Other, please state:</td>
<td>☐</td>
</tr>
</tbody>
</table>

Section three: Provision of Low Vision services

13) Where is low vision care provided? Tick all that apply AND write the number in the box e.g. Public Hospitals 8

<table>
<thead>
<tr>
<th>Service</th>
<th>Ticked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public Hospitals</td>
<td>☐</td>
</tr>
<tr>
<td>Community-based services</td>
<td>☐</td>
</tr>
<tr>
<td>Private clinics</td>
<td>☐</td>
</tr>
<tr>
<td>Government rehabilitation agencies</td>
<td>☐</td>
</tr>
<tr>
<td>Private hospitals</td>
<td>☐</td>
</tr>
<tr>
<td>NGO-based rehabilitation agencies</td>
<td>☐</td>
</tr>
<tr>
<td>Other, please state:</td>
<td>☐</td>
</tr>
</tbody>
</table>

14) What low vision services are available? Tick all that apply

<table>
<thead>
<tr>
<th>Service</th>
<th>Ticked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical low vision care</td>
<td>☐</td>
</tr>
<tr>
<td>Information on low vision</td>
<td>☐</td>
</tr>
<tr>
<td>Vocational training</td>
<td>☐</td>
</tr>
<tr>
<td>Rehabilitation and training</td>
<td>☐</td>
</tr>
<tr>
<td>Orientation &amp; mobility</td>
<td>☐</td>
</tr>
<tr>
<td>Technology training</td>
<td>☐</td>
</tr>
<tr>
<td>Social welfare services</td>
<td>☐</td>
</tr>
<tr>
<td>Sports and recreation</td>
<td>☐</td>
</tr>
<tr>
<td>Education</td>
<td>☐</td>
</tr>
<tr>
<td>Other, please state:</td>
<td>☐</td>
</tr>
</tbody>
</table>

15) Is there effective integration between low vision services and other eye care education, and rehabilitation services? Please Select One

<table>
<thead>
<tr>
<th>Integration</th>
<th>Ticked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fully funded by government</td>
<td>☐</td>
</tr>
<tr>
<td>Fee-based</td>
<td>☐</td>
</tr>
<tr>
<td>Support from local NGOs</td>
<td>☐</td>
</tr>
<tr>
<td>Subsidies from government</td>
<td>☐</td>
</tr>
<tr>
<td>Private insurance</td>
<td>☐</td>
</tr>
<tr>
<td>Support from international NGOs</td>
<td>☐</td>
</tr>
<tr>
<td>Other, please state:</td>
<td>☐</td>
</tr>
</tbody>
</table>

17) What proportion of people with low vision use low vision services? Please Select One

18) a) Is there a national health insurance scheme for low vision services? Please Select One

b) Does it provide universal access for all to low vision services? Please Select One

19) List in order of importance the priorities for developing or improving low vision care in your country?

<table>
<thead>
<tr>
<th>Priority</th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>6.</th>
</tr>
</thead>
</table>

20) What are typical waiting times to access low vision services in your country?

<table>
<thead>
<tr>
<th>Type</th>
<th>&lt; 1 week</th>
<th>1-4 weeks</th>
<th>&gt; 1 month</th>
<th>1-6 months</th>
<th>&gt; 1 year</th>
<th>Other, please state:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Rural</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Please return your completed survey by reply E-mail: p.chiang@pgrad.unimelb.edu.au or Fax: +61 3 9662 3859 – mark: ‘Attention of Peggy Chiang’

- Page 2 of 4 -
Appendix B

Global Mapping Survey of Low Vision Services

Section four: human resources

21) Please answer questions for all health professionals involved in low vision care:

<table>
<thead>
<tr>
<th>Type of group</th>
<th>The number of health professionals involved in low vision care</th>
<th>% of these professionals holding low vision qualification</th>
<th>% of these professionals undertaking follow-up/refresher training?</th>
<th>What type of training courses do these professionals undertake?</th>
<th>Location of the low vision training - if overseas provider please name the country</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ophthalmologists</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td></td>
</tr>
<tr>
<td>Ophthalmic Assistants: Mid Level Ophthalmic Personnel (MLOP) including Ophthalmic Nurses</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td></td>
</tr>
<tr>
<td>Optometrists</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td></td>
</tr>
<tr>
<td>Opticians, Optical Assistants and Refractionists</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td></td>
</tr>
<tr>
<td>Orthoptists</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td></td>
</tr>
<tr>
<td>Community Based Rehabilitation/Eye Care Workers</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td></td>
</tr>
<tr>
<td>Trained Teachers/Worker (working with low vision students)</td>
<td>Please Select One</td>
<td>Please Select One</td>
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<td>Please Select One</td>
<td></td>
</tr>
<tr>
<td>Rehabilitation Officers</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td></td>
</tr>
<tr>
<td>Other, please state:</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td>Please Select One</td>
<td></td>
</tr>
</tbody>
</table>

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- Page 3 of 4 -
## Global Mapping Survey of Low Vision Services

### Section five: Coverage and barriers

22) Of all people receiving low vision services what proportion are children and adults?

<table>
<thead>
<tr>
<th>Children</th>
<th>Please Select One</th>
<th>Adults</th>
<th>Please Select One</th>
</tr>
</thead>
</table>

23) Are there any groups of people less likely to access low vision services? Tick all that apply

- ☐ Low income group
- ☐ Women
- ☐ Children
- ☐ Disabled adults and children
- ☐ People living in rural areas
- ☐ Ethnic minority
- ☐ Refugees
- ☐ Other, please state:

24) What are the most common reasons for people not accessing low vision services? Tick all that apply

- ☐ Culture
- ☐ Belief that nothing more can be done
- ☐ Location – nearest service too far
- ☐ Costs
- ☐ Individual refuse to attend
- ☐ Language
- ☐ Other, please specify:

---

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Global Mapping Survey of Low Vision Services

Section six: low vision equipment, Instruments, and infrastructure

25) Are low vision aids and devices available as part of the low vision service?  Please Select One
26) Is there a supply source of affordable low vision aids and devices?  Please Select One

27) What kinds of low vision related equipment are available through low vision services in your country?  Tick all that apply
- Near magnifiers/glasses
- Distance telescopes
- Glare control devices
- Closed circuit television
- Electronic magnification systems
- Non-optical devices
- Examination equipment
- Other, please state:

28) Approximately what proportion of children and adults obtain low vision aids and devices when prescribed?
- Children
- Please Select One
- Adults
- Please Select One

29) What are the reasons that individuals do not obtain low vision aids and devices?  Tick all that apply
- Cost
- Too difficult to use
- Not suitable
- Vanity
- Not interested
- Fear of stigma
- Other, please state:

30) a) What essential low vision equipment and resources does your country need most that it does not currently have?  Please list in order of importance:
1. 
2. 
3. 
4. 
5. 
6. 

30) b) What are the reasons for the lack of low vision resources or services?  Tick all that apply
- Funding
- Infrastructure
- Awareness about low vision
- Trained workforce
- Referral systems
- National policy on low vision
- Other, please state:

Section seven: Monitoring and evaluation

31) What current procedures are in place to monitor low vision services and care?  Tick all that apply
- Surveys
- Interviews
- Review of reports
- Other, please state:

32) What indicators are used to monitor low vision services and programs?  Tick all that apply
- Number of people using low vision services
- Number of people obtaining low vision aids and devices
- Coverage (spread) of low vision services
- Number of people providing services
- Number of people trained to provide low vision care
- Other, please state:

33) What outcomes are used to evaluate low vision services and programs?  Tick all that apply
- Quality of Life (QoL)
- Improved visual function
- Visual acuity
- Use of low vision aids and devices
- Number of services providing low vision care
- Other, please state:

Please return your completed survey by reply E-mail: p.chiang@pgrd.unimelb.edu.au or Fax: +61 3 9662 3859 – mark: ‘Attention of Peggy Chiang’
8.3 Appendix C – Cover Letter

Centre for Eye Research Australia

Global Survey of Low Vision Services

Low vision affects 124 million people worldwide; half of whom will need low vision services, yet at present less than 6% can access them.

While the scale of the problem and the range of service delivery options differ between countries, providing effective low vision services and addressing the barriers that prevent those in need from using available services are issues common to health, education and rehabilitation services globally.

Such questions can only be answered by understanding low vision settings worldwide. As a key person in this field your knowledge and skills will provide information critical to a successful global low vision situation analysis. This will go a long way to provide WHO and all working in this field with the evidence needed for better access to services, setting priorities for curricula, training, program development and low vision advocacy.

I am a researcher at the University of Melbourne under the supervision of Professor Jill Kreege and the IAPB VISION 2020 Regional Coordinator, Associate Professor Richard Le Mesurier, and we would like to invite you to share your expertise in this area by completing the attached survey.

The purpose of my research and survey is to identify the priorities and critical success factors for delivery of low vision services. I will of course let you know the results and analysis of the survey. Confidentiality and anonymity are assured.

Suggestions for completing the survey:
- Most of the survey is multiple choice (just tick your options)
- Where possible, your answers should reflect the *national situation* in your country. Otherwise please answer from your own local perspective but indicate that beside the question concerned.
- Please answer in *English* if possible

Kindly return the completed survey by Month Date Year either by E-mail: p.chiang@unimelb.edu.au or Fax: +613 9340 3859, marked “For attention of Peggy Chiang”.

Should you have any queries please feel free to contact me at the above e-mail or telephone number: +613 9340 8766. Thank you very much.

Yours sincerely,

Peggy Chiang
CERA, University of Melbourne

---

Centre for Eye Research Australia

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East Melbourne, Vic 3002

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Tel. +61 3 9929 8360
Fax. +61 3 9962 3859

cera-info@unimelb.edu.au

www.cera.org.au

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The University of Melbourne

WHO Collaborating Centre for the Prevention of Blindness
## 8.4 Appendix D – Case Study Questions

Each of the coloured squares pertains to which group(s) the subsequent question will be asked

<table>
<thead>
<tr>
<th>Program managers</th>
<th>Providers</th>
<th>Clients</th>
<th>Themes of questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Descriptive</strong></td>
<td></td>
<td></td>
<td>A. Overall situation &amp; historical perspective</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>1. What is the low vision situation in Ghana and Cameroon?</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>2. How does the health care system work in the country?</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>3. What is the situation of low vision services in relation to all the other health care services in the country?</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>4. What is the need for low vision services?</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>5. How do you determine the need for low vision services?</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>6. When were the first services established?</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>7. What triggered its establishment?</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>8. What have been the positive aspects of services?</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>9. What have been the negative aspects of services?</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>10. What is the role played by the private/voluntary sector?</td>
</tr>
<tr>
<td><strong>B. Description of services</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>1. How is low vision defined in your country?</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>2. What is the eligibility to use services in the country?</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>3. What services are currently available or running today? (What type of care do you provide to clients?)</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>4. Give examples of the type of support provided to adults with low vision?</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>5. Give examples of the type of support provided to children with low vision?</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>6. Where are the services located? (geographic coverage)</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>7. Who set up the services?</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>8. Who is running these services?</td>
</tr>
<tr>
<td>Program managers</td>
<td>Providers</td>
<td>Clients</td>
<td>9. Who are the services targeting?</td>
</tr>
</tbody>
</table>
### Each of the coloured squares pertains to which group(s) the subsequent question will be asked

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<thead>
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<tbody>
<tr>
<td></td>
<td>10. How are services funded?</td>
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<td></td>
<td>11. Who is funding the services? (e.g. Governments, NGOs, patients)</td>
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<td></td>
<td>12. What % is funded by each of the groups you mentioned above?</td>
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<td></td>
<td>13. Who are the people that make use of low vision services? (e.g. characteristics of clients i.e. SES, Age)</td>
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<td></td>
<td>14. Where do the clients come from?</td>
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</table>

### C. Monitoring & Evaluation – service effectiveness

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<table>
<thead>
<tr>
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<tbody>
<tr>
<td></td>
<td>1. Have there been monitoring &amp; evaluation of services in the past and currently?</td>
<td></td>
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<tr>
<td></td>
<td>2. What are the indicators of success in a low vision service?</td>
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<td></td>
<td>3. What are the outcome(s) these services intend to achieve?</td>
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<td></td>
<td>4. Do services produce the desired outcome(s)?</td>
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<td></td>
<td>5. How do you create the demand for low vision services?</td>
<td></td>
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<td></td>
<td>6. How do you determine what services or care the low vision population need?</td>
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<td></td>
<td>7. What assessments have been used to measure the level of need for low vision services?</td>
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<td></td>
<td>8. Does the service currently provide what the low vision population want?</td>
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<td></td>
<td>9. Do you assess client satisfaction of services received?</td>
<td></td>
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<tr>
<td></td>
<td>10. How do you do so?</td>
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<td></td>
<td>11. What are the levels of client satisfaction?</td>
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<td></td>
<td>12. How have the services helped you? Give examples of in what way?</td>
<td></td>
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<td></td>
<td>13. For example: how have the benefits of care outweighed the negatives consequences of low vision?</td>
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<tr>
<td></td>
<td>14. What are the immediate effects that can be observed?</td>
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<tr>
<td></td>
<td>15. How do you record these immediate effects?</td>
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<tr>
<td></td>
<td>16. Do you know of the longer effects of care? (e.g. employment, integration into mainstream schools)</td>
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<tr>
<td></td>
<td>17. What will you do now or plan to do in the long term, now that you have received services to help your vision?</td>
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<td></td>
<td>18. (For people with co-morbidities and who receive other forms of health care or services)</td>
<td></td>
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<tr>
<td></td>
<td>19. What other care do you currently receive or require in addition to low vision care?</td>
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<tr>
<td>Each of the coloured squares pertains to which group(s) the subsequent question will be asked</td>
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<td>--------------------------------------------------</td>
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<tr>
<td>20. For people with co-morbidities and who receives other forms of health care or services)</td>
<td></td>
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<tr>
<td>21. How can low vision services be further integrated/modified into existing health care services to make it easier for you to receive low vision care?</td>
<td></td>
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</tr>
<tr>
<td>22. Do you think more can be done to address the needs of clients?</td>
<td></td>
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<tr>
<td>23. What more can be done to further improve client needs?</td>
<td></td>
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</tr>
<tr>
<td><strong>D. Monitoring &amp; Evaluation – service cost/efficiency</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Are there more efficient ways to deliver these services?</td>
<td></td>
<td></td>
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<tr>
<td>2. Are there other forms of low vision service that would be a better use of resources?</td>
<td></td>
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</tr>
<tr>
<td>3. What are the strategies that could work towards achieving sustainability in low vision services?</td>
<td></td>
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</tr>
<tr>
<td><strong>E. Monitoring &amp; Evaluation – service acceptability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Are services relevant?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Are services fair?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Are services flexible?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Are services responsive to the demand of people’s need for low vision services?</td>
<td></td>
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</tr>
<tr>
<td><strong>F. Monitoring &amp; Evaluation – service access</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. What proportion of people with low vision can access services?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Can people get service when they need it?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Were there any barriers or difficulties faced by clients using services?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. What were the barriers?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. What barriers did you face when accessing this service? Before accessing service?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Who cannot use services?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Are there barriers in the delivery of services?</td>
<td></td>
<td></td>
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<tr>
<td>8. How are these barriers/challenges addressed?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. How do you deal with barriers when accessing low vision services?</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>G. Monitoring &amp; Evaluation – service equity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Are there particular groups most likely to miss out on services?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Why are these particular groups missing out on services?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix D

### Each of the coloured squares pertains to which group(s) the subsequent question will be asked

<table>
<thead>
<tr>
<th></th>
<th>3.</th>
<th>What is being done so far to include them (promoting equity)?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4.</td>
<td>What are the challenges in ensuring everyone can access services?</td>
</tr>
<tr>
<td></td>
<td>5.</td>
<td>What have been the barriers to access services?</td>
</tr>
<tr>
<td></td>
<td>6.</td>
<td>What do you do or have done in the past to deal with these barriers and challenges?</td>
</tr>
</tbody>
</table>

**H. Monitoring & Evaluation – sustainability**

<table>
<thead>
<tr>
<th></th>
<th>1.</th>
<th>Do you think low vision services are sustainable?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2.</td>
<td>What aspects of low vision services are most/not sustainable?</td>
</tr>
<tr>
<td></td>
<td>3.</td>
<td>Why? Can you expand on that further?</td>
</tr>
<tr>
<td></td>
<td>4.</td>
<td>What factors can contribute towards services becoming more sustainable than are now?</td>
</tr>
<tr>
<td></td>
<td>5.</td>
<td>What strategies could be used towards achieving sustainability?</td>
</tr>
</tbody>
</table>

**I. Service delivery**

<table>
<thead>
<tr>
<th></th>
<th>1.</th>
<th>What is the referral system in the country/between services?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2.</td>
<td>What made you interested to become involved in providing low vision care?</td>
</tr>
<tr>
<td></td>
<td>3.</td>
<td>For people with early signs of disease, what are the interventions? Or what is generally done for them? (duration – whether right patients are receiving care and interventions at the right time)</td>
</tr>
<tr>
<td></td>
<td>4.</td>
<td>Who is getting referred? (E.g. VA, age, status)</td>
</tr>
<tr>
<td></td>
<td>5.</td>
<td>What proportion of people with low vision is getting referred?</td>
</tr>
<tr>
<td></td>
<td>6.</td>
<td>Who is making the referrals to low vision services?</td>
</tr>
<tr>
<td></td>
<td>7.</td>
<td>How do you determine who gets referred or not?</td>
</tr>
<tr>
<td></td>
<td>8.</td>
<td>What mode of transport is used by clients to arrive at a service location?</td>
</tr>
<tr>
<td></td>
<td>9.</td>
<td>Is there a waiting list?</td>
</tr>
<tr>
<td></td>
<td>10.</td>
<td>If so, how long are the waiting times? &amp; list?</td>
</tr>
<tr>
<td></td>
<td>11.</td>
<td>How long are the waiting times between referrals?</td>
</tr>
<tr>
<td></td>
<td>12.</td>
<td>How long are the waiting times between the different interventions i.e. from clinical to rehabilitation?</td>
</tr>
<tr>
<td></td>
<td>13.</td>
<td>Are clients followed up?</td>
</tr>
</tbody>
</table>
### Each of the coloured squares pertains to which group(s) the subsequent question will be asked

<table>
<thead>
<tr>
<th>Group</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>14.</td>
<td>How are people followed up?</td>
</tr>
<tr>
<td>15.</td>
<td>When are people followed up?</td>
</tr>
<tr>
<td>16.</td>
<td>Who is being followed up?</td>
</tr>
<tr>
<td>17.</td>
<td>What are the reasons for the follow up?</td>
</tr>
<tr>
<td>18.</td>
<td>What are challenges you face in delivering low vision care?</td>
</tr>
</tbody>
</table>

### J. Equipment & resources

<table>
<thead>
<tr>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
</tr>
<tr>
<td>2.</td>
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<tr>
<td>3.</td>
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<tr>
<td>4.</td>
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<tr>
<td>5.</td>
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<tr>
<td>6.</td>
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<tr>
<td>7.</td>
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<tr>
<td>8.</td>
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<tr>
<td>9.</td>
</tr>
<tr>
<td>10.</td>
</tr>
<tr>
<td>11.</td>
</tr>
</tbody>
</table>

### K. Professional development

<table>
<thead>
<tr>
<th>Questions</th>
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<tbody>
<tr>
<td>1.</td>
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<tr>
<td>2.</td>
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<tr>
<td>3.</td>
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<tr>
<td>4.</td>
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<tr>
<td>5.</td>
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### L. Human resources

<table>
<thead>
<tr>
<th>Questions</th>
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<tbody>
<tr>
<td>1.</td>
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<tr>
<td>2.</td>
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<td>3.</td>
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### Appendix D

Each of the coloured squares pertains to which group(s) the subsequent question will be asked

<table>
<thead>
<tr>
<th>Question</th>
<th>Group(s)</th>
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</thead>
<tbody>
<tr>
<td>4. Is there a particular health professional group that act as main coordinators of low vision care?</td>
<td>Red</td>
</tr>
<tr>
<td><strong>M. Human resources training</strong></td>
<td></td>
</tr>
<tr>
<td>1. Where did you receive your training for low vision?</td>
<td>Yellow</td>
</tr>
<tr>
<td>2. In hindsight, what did you find most useful out of your training?</td>
<td></td>
</tr>
<tr>
<td>3. What would you suggest to improve in the current training programs for low vision care?</td>
<td></td>
</tr>
<tr>
<td>4. Do you receive any form of follow up training?</td>
<td></td>
</tr>
<tr>
<td>5. If so, where, who, and what do you receive?</td>
<td></td>
</tr>
<tr>
<td><strong>N. Networking &amp; Integration</strong></td>
<td></td>
</tr>
<tr>
<td>1. Is there a continuum of care between eye care, refraction and low vision services and the rest of the health care systems? If so, could you give examples?</td>
<td>Red</td>
</tr>
<tr>
<td>2. Do you currently have networks with other organisations?</td>
<td>Yellow</td>
</tr>
<tr>
<td>3. Who are they?</td>
<td></td>
</tr>
<tr>
<td>4. What kind of interaction do you have with them?</td>
<td></td>
</tr>
<tr>
<td>5. Is your service integrated with any other systems or organizations?</td>
<td></td>
</tr>
<tr>
<td>6. If so, can you give example?</td>
<td></td>
</tr>
<tr>
<td><strong>O. Relevance – the ideal situation (magic wand)</strong></td>
<td></td>
</tr>
<tr>
<td>1. If you had a magic wand, what would you like to see happen in the delivery of low vision services? I.e. what would be your ideal low vision service system?</td>
<td>Red</td>
</tr>
<tr>
<td>2. What do you think is an ideal service?</td>
<td>Yellow</td>
</tr>
<tr>
<td>3. What would you change now if you had all the resources you need?</td>
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</tr>
<tr>
<td>4. What do you think are further needed to provide a better service?</td>
<td></td>
</tr>
<tr>
<td>5. What do you think are the steps/strategies to take to achieve this ideal situation as much as possible?</td>
<td>Red</td>
</tr>
<tr>
<td>6. Given the current situation of low vision services, how do you envisage services to be in 5, 10, 20 years time?</td>
<td>Yellow</td>
</tr>
</tbody>
</table>
8.5 Appendix E – Case Study Protocols

Statement of purpose for case study research in Tamil Nadu India

Goal of research:

To identify critical success factors and barriers associated with effective low vision models of care and delivery of services in Tamil Nadu, India

In order to contribute to the:

- **Overall research aim** -
  To identify appropriate and effective model(s) of comprehensive low vision care in both developed and developing countries

And achieve the following outcomes:

- **Overall research outcome** -
  1. Assist the WHO Low Vision Working Group in setting priorities for curriculum development training, program development and advocacy
  2. Contribute to the goals of Vision 2020, *the Right to Sight* program specifically in the areas of low vision and comprehensive eye care delivery

What do I hope to achieve at the end of the research:

- How low vision services are delivered in the Indian context of Tamil Nadu
- Gain a picture of who/what cadres is providing low vision care
- Gain an understanding of how services are structured and delivered
- Meet all relevant stakeholders involved in low vision care and service including patients and providers

Proposed time: 12th November 2007 to 10th December 2007

Proposed places to travel:

- Chennai
- Madurai
- Tiruchirappalli
- Coimbatore
- Vellore

Organizations to interview and visit:
Appendix E

- Public hospitals (tertiary, secondary)
- Private hospitals (tertiary, secondary)
- Private clinics
- Community based services
- Training institutions
- Non-Government Organizations (local and international)
- Schools (primary and secondary)
- Schools for the Blind

People to meet and interview at these organizations:

- Managers
- Low vision specialists
- Other eye health professionals involved in providing low vision care
- Teachers
- People who make the referrals to low vision services
- Patients, their families, parents and children

Methods of conducting the case studies:

- Semi-structured interviews
- Non-participatory observation of meetings and clinics
- Reading through annual reports and statistical data

Feedback to participants:

- Summary report of findings
- Acknowledgement when outcomes are published
Appendix E

Statement of purpose for case study research in Ghana and Cameroon

Description of the project

The Centre for Eye Research Australia (CERA) at the University of Melbourne, has undertaken a study to identify and understand low vision settings worldwide.

This research aims to identify critical success factors associated with effective low vision models of care and delivery of services and factors causing barriers that weakens such delivery. The data will identify coverage, access, and equity issues in low vision services globally. This study will contribute to existing models of low vision care and provide the World Health Organization with the essential evidence for priorities setting, training, program development, and low vision advocacy.

The research project comprises two stages. The first stage is designing, validating, and distributing a survey to produce a global map of low vision services. The second stage is conducting in-depth interviews (case studies) in three developing countries – Ghana, Cameroon, and India.

The global mapping survey of low vision services has provided a snapshot of what, who, where, and how services are currently being delivered. This mapping is now complete and the Indian case study was completed in November 2007.

Ghana and Cameroon are the final case studies to be conducted in order to achieve this project’s goal.

Goal of research

To identify critical success factors and barriers associated with effective low vision models of care and delivery of services

Outcome

Identify information to:

- Set priorities for training, program development and advocacy
- Understand factors that promote services
- Understand barriers that impede services
- Contribute to the goals of Vision 2020
- Inform the WHO LVWG (World Health Organization Low Vision Working Group) evidence to priorities setting, training, program development and low vision advocacy.
Appendix E

Proposed time

- Ghana (2 weeks): November 10th to 21st
- Cameroon (1 week): November 24th to 28th

People to see

- Program managers
- Funders
- Service providers
- Clients – adults and children

What do I hope to achieve at the end of this field research

- How low vision services are delivered in the Ghana and Cameroon
- Understand the critical success factors
- Gain a picture of who/what cadres are providing low vision care
- Gain an understanding of how services are structured and delivered
- Meet all relevant stakeholders involved in low vision care and service including patients and providers

Methods of conducting the case studies

- Semi-structured interviews (please see attached topics)
- Non-participatory observation of meetings and clinics
- Reading through annual reports and statistical data

Feedback to participants

- Progress report – CERA website
- Acknowledgement in future publications

Please suggest and recommend

- **Proposed places to travel**
- **Low vision organizations to interview and visit**
  - Public hospitals (tertiary, secondary) with low vision clinics
  - Private hospitals (tertiary, secondary) with low vision clinics
  - Private clinics providing low vision care
  - Community based services with low vision care
  - Low vision training institutions
  - Non-Government Organizations (local and international) providing low vision services
  - Schools (primary and secondary) with integrated education for children with vision impairment
  - Schools for the Blind with low vision services
- **People to meet and interview at these organizations**
  - Managers
  - Low vision specialists
  - Other eye health professionals involved in providing low vision care
- Teachers
- People who make the referrals to low vision services
- Patients, their families, parents and children

**Logistics needed**

- Suggestions for accommodation and transport
### 8.6 Appendix F – Sample Table for WHO Info Database

<table>
<thead>
<tr>
<th>Region:</th>
<th>Country:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participant details</strong></td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td></td>
</tr>
<tr>
<td>Position title</td>
<td></td>
</tr>
<tr>
<td>Low vision qualification</td>
<td></td>
</tr>
<tr>
<td>Profession</td>
<td></td>
</tr>
<tr>
<td><strong>Baseline low vision information</strong></td>
<td></td>
</tr>
<tr>
<td>Presence of low vision services</td>
<td></td>
</tr>
<tr>
<td>Vision 2020 or Prevention of Blindness Committee</td>
<td></td>
</tr>
<tr>
<td>National vision or eye care plan</td>
<td></td>
</tr>
<tr>
<td>Current national vision or eye care plan includes low vision</td>
<td></td>
</tr>
<tr>
<td>Guidelines for of low vision practice</td>
<td></td>
</tr>
<tr>
<td>Guidelines for referrals to low vision service</td>
<td></td>
</tr>
<tr>
<td>Definition of low vision</td>
<td></td>
</tr>
<tr>
<td>Level of impairment for eligibility to receive service</td>
<td></td>
</tr>
<tr>
<td>Main causes of low vision</td>
<td></td>
</tr>
</tbody>
</table>
### Provision of low vision Services

<table>
<thead>
<tr>
<th>Location of low vision services</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Low vision services provided</td>
<td></td>
</tr>
<tr>
<td>Funding of services</td>
<td></td>
</tr>
<tr>
<td>Proportion receiving services population</td>
<td></td>
</tr>
<tr>
<td>Waiting times</td>
<td>Urban</td>
</tr>
<tr>
<td>National insurance scheme for low vision</td>
<td></td>
</tr>
<tr>
<td>National insurance scheme for low vision with universal access</td>
<td></td>
</tr>
<tr>
<td>Priorities for low vision services development</td>
<td></td>
</tr>
<tr>
<td>Equipment, instruments, and infrastructure</td>
<td></td>
</tr>
<tr>
<td>Aids and devices available as part of services</td>
<td></td>
</tr>
<tr>
<td>Affordable supply source of devices</td>
<td></td>
</tr>
<tr>
<td>Equipment available in country</td>
<td></td>
</tr>
<tr>
<td>Proportion of people obtaining devices when prescribed</td>
<td>Children</td>
</tr>
<tr>
<td>Barriers to obtaining devices</td>
<td></td>
</tr>
<tr>
<td>Reasons for lack of low vision resources or services</td>
<td></td>
</tr>
<tr>
<td>Essential equipment and resources needed</td>
<td></td>
</tr>
<tr>
<td>Coverage and barriers</td>
<td></td>
</tr>
<tr>
<td>Proportion receiving services</td>
<td>Children</td>
</tr>
</tbody>
</table>
## Groups of people less likely to access services

## Barriers to accessing services

## Monitoring and evaluation

### Monitoring of services

### Indicators for monitoring

### Outcomes evaluated

### Low vision human resources

<table>
<thead>
<tr>
<th>Profession</th>
<th>No.</th>
<th>Ratio/10 million</th>
<th>Low vision qualification</th>
<th>Refresher training</th>
<th>Type of training</th>
<th>Location of training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ophthalmologists</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MLOP - Mid-Level Ophthalmic Personnel</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MLOP – Opticians, Optical Assistants and Refractionists</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>MLOP - Orthoptists</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Optometrists</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CBR - Community-Based Rehabilitation workers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CBR – Trained Teachers/Workers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rehabilitation officers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
8.7 Appendix G – Ethics

May 18, 2006

Miss Peggy Chiang
Dept of Ophthalmology
The University of Melbourne
Box No. 2 Vio

Dear Miss Chiang

Re: Human Research & Ethics Committee – NEW PROJECT
Research Project - Mapping Low Vision Models and Programmes in Developed
and Developing Countries

The Human Research & Ethics Committee considered the above project at its 11 May 2006
meeting. I am pleased to inform you that ethical approval was granted in principle. The
questionnaire should be refined and resubmitted to the Committee for further consideration.
It was noted that no consent was required for this project.

Yours sincerely

Kerryn Baker
Secretary
Human Research & Ethics Committee
kerryn.baker@eyeandeare.org.au
Telephone +61 3 9929 8525
July 3, 2006

Miss Peggy Chiang
Dept of Ophthalmology
The University of Melbourne
Box No. 2 Vic

Dear Miss Chiang

Re: Human Research & Ethics Committee – NEW PROJECT
Research Project - Mapping Low Vision Models and Programmes in Developed and Developing Countries

I acknowledge receipt of the revised questionnaire for the above project. The Executive Committee of the Human Research & Ethics Committee considered the above project. I am pleased to inform you that ethical approval has now been granted.

This decision will be ratified at the 20 July 2006 meeting.

The project number 06/688H was allocated, and this number should be used in all future correspondence. The Committee requires an annual progress report, and must approve any proposed amendments to the protocol. All serious or unexpected adverse effects on participants or any unforeseen events that might affect continued ethical acceptability of the trial must be reported to the Committee.

The Committee requires you to preserve the confidentiality of information about research subjects, and to ensure the confidentiality of records. Information obtained for your research that is confidential or personal must not be used for purposes other than those specified in the approved protocol.

Ethical approval is valid from the date of this letter until 11 May, 2011. At the end of this period, or at the conclusion of the research, a final report is required along with a copy of any publications.

On behalf of the Committee, I wish you every success with your project.

Yours sincerely,

Kerryn Baker
Secretary
Human Research & Ethics Committee
kerryn.baker@eyeandear.org.au
Telephone +61 3 9929 8525
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Author/s:
Chiang, Peggy Pei-Chia

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2009

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File Description:
The global mapping of low vision services

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