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EXECUTIVE SUMMARY

Setting priorities for health and investment in health interventions is increasingly being based on the economic burden of disabilities to a country or community, and on the cost-effectiveness of the interventions. Little work on these issues has been done in relation sensory disabilities, especially in developing countries, but it is believed that they lead to substantial economic costs.

In order to address these issues in relation to visual and hearing disabilities, WHO convened a consultation with a small group of experts from developing and developed countries. The participants first reviewed available epidemiological data on these disabilities from developed and developing countries and assessed its usefulness for economic analysis. Some examples of recent experiences of economic analyses in developed and developing countries were presented.

Types of economic analysis were considered and the methods and data that would be needed were reviewed, including in relation to WHO’s initiative on cost-effectiveness of interventions for developing countries.

The participants concluded that sensory disabilities, mainly blindness and deafness, lead to substantial social and economic costs but that there is a widespread lack of economic analyses to assess these costs, particularly in developing countries, and that this severely limits raising awareness, advocacy, prioritization and resource mobilization.

The consultation recommended that WHO’s role in the economic analysis of sensory disabilities should focus on assessing their burdens (costs and health status) and interventions that reduce them, giving a high priority to contributing to the WHO generalised initiative on cost-effectiveness analysis. Particular visual and hearing disabilities were identified for evaluation by this initiative.

Further refinement of available evidence on these burdens and interventions against them should be undertaken; standard WHO survey instruments for blindness/visual impairment and deafness/hearing impairment should collect additional data for economic analyses, especially through costing modules on productivity loss, medical and informal support, non-medical adaptations, and prior intervention. Information on outcomes of intervention, and disability specific and generic quality of life measures should also be collected.

To further these activities, it was also recommended that the available evidence should be reviewed, and instruments and protocols for data collection should be developed and field tested and data collection piloted in developing countries and developed countries. The completed instruments and protocols should be made available to interested parties (Governments, Non-Governmental Organizations etc) to facilitate local health care priority setting, particularly in developing countries.
1 PURPOSE AND OUTPUTS OF THE CONSULTATION

The effects of sensory disabilities, particularly blindness and deafness, produce substantial social and economic costs, but there has been almost no economic analysis to assess them. This lack, particularly in developing countries, makes it much more difficult to raise awareness and facilitate advocacy, for example through the media, and even within WHO. Increasingly, priority setting on the health agenda and investment in health interventions is being based on the economic costs of a disease or disability to the country and community, and on the cost-effectiveness aspects of these interventions. Reliable economic impact data is equally important to convince major donors that these disabilities are significant problems for which donor investment would yield substantial returns in improving human health and society.

Governments, particularly in developing countries, could use economic tools for prioritization. At present, since they have little or no knowledge of the economic costs of the burden of these disabilities and the costs of their prevention, control of sensory disabilities remains low on most national health agenda.

This meeting convened a small group of experts in WHO Headquarters in Geneva from 28 to 29 November 2000. The meeting was opened by Dr Derek Yach, Executive Director, Cluster for Non-Communicable Diseases and Mental Health. In welcoming the participants, he outlined the likely substantial economic and social costs of sensory disabilities but emphasised the lack of credible data available to quantify this accurately, especially in developing countries. He mentioned the work of the team for Prevention of Blindness and Deafness in developing initiatives, such as Vision 2020, to raise awareness and assist countries but how credible economic data is urgently needed to support them. He also highlighted the bringing together of experts from the developed and developing world, and the cross-cluster collaboration with the cluster for Evidence and Information for Policy.

Dr Thulasiraj and Professor Davis were appointed chairman and co-chairman respectively and Dr Frick was appointed rapporteur.

During the meeting, the participants appraised the available data on the epidemiology of sensory disabilities, focusing on blindness and visual impairment, and deafness and hearing impairment. They assessed the appropriateness of this data for economic analysis and what further data is required. They then determined and made recommendations on what further steps would be necessary to develop tools for the economic analysis of sensory disabilities, especially in developing countries.

- Determination of the appropriateness of available data on economic analysis of sensory disabilities
- Identification of further data required
- Proposed steps for the development of tools for economic analysis of sensory disabilities
- Recommendations for further actions

Outputs of the consultation
1 THE CURRENT SITUATION.

2.1 Available data on blindness and visual impairment.

2.1.1 Epidemiology and burden of blindness and visual impairment

Definitions of blindness and low vision, taken from ICD-10\(^1\), are shown in figure 1. Methods of assessment of blindness are based on cross-sectional surveys with a large sample size, and a randomly selected sample so that it is representative of the district, region, or country being assessed. For countries without data, the results of such surveys could be extrapolated provided the demographic, social and environmental situations are similar.

The global estimate for 1990 for numbers of persons with blindness was 37.9 millions, with low vision was 109.91, total 149.61 million. Estimates for these categories and for prevalence, distributed according to World Bank regions, have been made (see figure 2). For each of these regions the number of blind persons according to the major causes, has been estimated. The example of sub-Saharan Africa, which has the highest regional prevalence, is shown in figure 3.

Cataract remains the single greatest cause of blindness (42% of all cases of blindness) with a backlog that increased 3 million to 16 million between 1990 and 1995. The increase is due to better data collection and ageing of the population, enabling more people to survive to develop cataract. Trachoma (15%) is still an important cause in some countries, especially in remote, underserved populations, but is gradually coming under control. Glaucoma (14%) is a greater problem than previously thought and is also likely to increase because of ageing of the population and lack of eye care resources. Onchocerciasis is an important cause in Africa and Latin America. Vitamin A deficiency (xerophthalmia) is the leading cause of childhood blindness and has a high mortality. Other causes of blindness include diabetic retinopathy, macular degeneration, ocular trauma and leprosy. The prevalence of blindness increases markedly with age (see figure 4).

\(^1\) International Classification of Disease, 10\(^{th}\) Revision, 1994, WHO, Geneva. Figure source: Prevention of Blindness and Deafness, WHO, Geneva, 1994
2.1.2 Review of the literature on economic analysis

The estimated social cost of blindness in India in 1989 was US$4.6 billion\(^2\); in the USA in 1991 it was US$4.1 billion\(^3\). Substantial budgetary savings could be made if these causes are prevented. For example US$ 639 million could be saved per year with appropriate eye care (screening and prevention) for diabetic retinopathy\(^4\) (all type I and type II diabetes).

For the year 2000, more data has become available from population-based studies in districts and regions, and more surveys have used the ICD10 definitions of blindness. Data is now available from 69 countries in 189 studies (see figure 5). There have been 77 population based surveys (20 national, 57 regional or district), and 112 estimates at national or regional/district level.

Some key questions relating to collection of epidemiological data and economic analysis include:

- What gaps are there in the available data for economic analysis?
- What should be the methodology for data collection for economic analysis in epidemiological surveys?
- How often should this data be updated?
- Are country-specific economic data available for modelling?

Economic recession and greater demands on services have forced the need to look for new ways of financing, improved cost-effectiveness and for evidence of cost benefit value of activities for prevention of blindness.

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\(^3\) As above

\(^4\) As above
In order to help to better allocate available resources from governments, foundations and Non-Governmental Development Organizations and to develop new tools for advocacy and funding of activities, a review of current information was prepared by the International Centre for Eye Health, London\(^5\). For this work, 234 publications on less and more developed countries were accessed and the abstracts annotated and included in the review in order to assess what is known about the cost and effectiveness of interventions targeting the prevention, treatment or control of blindness. The review consists of a methodological guide to economic analysis, followed by an annotated bibliography of studies of blinding conditions and of economic analysis in this field.

The review concluded that "In less developed countries, economic analysis has had very limited usage, and appraisals and evaluations are few. This is a serious situation in view of the limited funding available for health investments. WHO, collaborating with Ministries of Health, needs to promote experiments and initiatives that can act as demonstration studies".

2.2 Available Data On Deafness And Hearing Impairment

2.2.1 Epidemiology and burden of deafness and hearing impairment in developing countries

One of the commonest causes of sensory disability is deafness and hearing impairment. However, the issues of prevention and management of deafness and hearing impairment are still of low priority in most developing countries. Because in all developing countries the younger generation makes up the largest part of the population, it is also very important to analyse the situation in this group.

In many countries, there is a lack of accurate and reliable data on the magnitude and pattern of hearing impairment. Literature review shows a large variability of the prevalence of congenital deafness, prevalence of hearing impairment and middle ear infection in many developing countries such as in Sub-Saharan countries\(^6\), Saudi Arabia, China, India, Philippines, Cambodia, Thailand\(^8\) and other countries. Sporadic data currently available are mostly incomplete and use different criteria, which cause difficulties in comparison and estimation of the problem.

It is estimated that 50 percent of hearing impairment is primarily preventable, while the remaining can be taken care of by secondary and tertiary prevention, including rehabilitative measures. Therefore it is very important to obtain reliable data for objective and successful implementation of prevention of deafness and hearing impairment and promotion of ear care.

To obtain population-based data with emphasis and analysis of the prevalence and etiology of hearing impairment, a multicentre epidemiological study on the magnitude and etiology of deafness and hearing impairment, using a WHO Protocol, was conducted in several developing countries: Oman, India, Sri Lanka, Myanmar and Indonesia. The prevalence of disabling hearing impairment (see presentation 3.2.1 for definition) in the overall study population of these countries was Oman 2.1%; Indonesia 4.1%; India 5.9%.

The Indonesian study, conducted in Bandung, West Java. It was a multistage stratified cluster sample of 5604 subjects performed in Bandung Municipality and the surrounding District to determine the magnitude and etiology of hearing impairment. Direct questioning regarding ear pain, ear discharge, hearing impairment was conducted followed by ear otoscopy and audiometric tests using the WHO Ear & Hearing Disorders Survey Protocol.

The results showed that the prevalence of hearing impairment of either ear in children under 4 years old was 12%; the prevalence of hearing impairment in the whole population was

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\(^7\) Hearing International Series, Vol.2 No.2 (June 1993) until Vol.8 No.2 (June 1999)
\(^8\) Prasansuk S. From Primary Health Care to Primary Ear Care: An Essential Ear and Hearing Care Challenge. Otological Center, Bangkok Unit, Faculty of Medicine Siriraj Hospital Mahidol Univ. Thailand, 1990.
4.5%. Middle ear infections (chronic suppurative otitis media, acute otitis media and otitis media with effusion) occurred in 7.9% of all subjects. This is higher than reported by the Indonesian Eye and Ear Health Survey (not using the WHO protocol) in other provinces, which was 2.6 to 5.7%\(^9\). Other main causes of ear disease in the Bandung study were dry perforations of the tympanic membrane and non-infectious conditions, mostly presbyacusis.

The study showed a high prevalence of preventable hearing loss and ear pathology in Bandung area. Priority should be effective treatment of otitis media and upper respiratory infections in the scope of effective "primary ear care " programs in Indonesia as well as other developing countries\(^10\).

2.2.2 Epidemiology and burden of deafness and hearing impairment in developed countries

The epidemiology of hearing impairment is an essential component to both service planning and research strategy and priority. Without good information, both at a global and also at a local level decisions are often made using prejudice, out of date notions or inapplicable data.

The descriptive epidemiology of hearing impairment in Europe and USA is slowly evolving. We know a fair amount about the prevalence of adult acquired hearing impairment and the extent to which services meet the needs of the hearing impaired in certain countries e.g. UK, Italy, Netherlands. However, considerably less is known about the incidence of hearing impairment and deafness, and the natural history of these conditions is fairly notional.

We assume that there are only a few people who have sudden onset hearing impairment in their 40s and 50s and that most people’s hearing deteriorates slowly over a decades. There are not many clues as to the exogenous factors associated with change over time, and whilst some dominant genes have been associated with late-onset deafness there is as yet no idea of how extensive their impact might be in the general population.

Factors associated with hearing impairment per se rather than rate of change do not account for much variability once age and noise immission have been controlled. Thus it may make some sense to ask whether the variability within these factors may be attributable to a genetic ageing or noise susceptibility factor. The genetic epidemiology is evolving, but population studies in this area have a long gestation period.

More work has been done on the descriptive epidemiology of childhood hearing impairment, especially the permanent types of deafness as opposed to glue ear. The work that has been done in the UK, Denmark, Estonia, and other countries in Europe suggests that there are indeed substantial differences between the prevalences of hearing impairment and deafness in the different countries. Also the risk factors are different in the different countries.

The Medical Research Council (MRC) Institute of Hearing Research has been looking at the specific aetiologies of the children who have been ascertained in UK studies. There seems to be a difference between the cases reported from clinic series and the population samples that this work has ascertained in terms of the specific genetic background to the population.

The MRC Institute of Hearing Research has four ongoing studies that may help further our understanding of the burden of hearing impairment. The first is a national study of ENT symptoms in the UK. This household questionnaire asks about common ENT symptoms e.g. hearing problems, tinnitus, dizziness, nasal problems, throat problem, the extent to which they are a burden to the individual, and the services that they have sought for the problem.

The second study is a health economic study comparing the provision of services for hearing impairment and deafness in the UK and in Nordic countries.

The third study that is underway is an attempt to implement and evaluate a 'modemised' hearing healthcare service. This study will provide a lot of detail concerning the quality of life of hearing impaired people in England and the cost-effectiveness of interventions for hearing impaired people.

The fourth study is a complete ascertainment of hearing impaired children in the UK. This unique study which has used a capture-recapture model provides the best estimate for the number of hearing-impaired children in the UK.

The pattern of late-onset permanent deafness and acquired hearing impairment is detailed for the first time. The extent to which permanent childhood hearing impairment represents an enormous educational burden for children with a moderate or severe hearing impairment is really quite considerable with the average attainment in terms of IQ being 15-20 points below that for normal hearing children. The impact of cochlear implants for profoundly deaf children is being studied in detail.

2.2.3 Global overview of epidemiology and burden of deafness and hearing impairment

When measuring hearing impairment it is essential to define the threshold(s) of measurement and the age range, since prevalence varies markedly with these parameters. The grades of hearing impairment as currently used by WHO are shown in the table. The definition of disabling hearing impairment which is the main current WHO measure of disability caused by hearing impairment is moderate or worse hearing impairment in the better ear (see below for full definition11).

WHO estimated in 1995 that there were 120 million persons in the world with disabling hearing impairment12, which was approximately 2.1% of the global population then. This estimate has been increased in 2001 to 250 million (4.2%)13. The increase is most likely due to better ascertainment and population ageing, capturing more subjects with presbyacausis. Two thirds are in the

<table>
<thead>
<tr>
<th>Grade of impairment</th>
<th>Corresponding audiometric ISO value (Average of 500, 1000, 2000, 4000 Hz)</th>
<th>Performance</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 No impairment</td>
<td>25 dB or better (better ear)</td>
<td>No or very slight hearing problems. Able to hear whispers.</td>
<td>Counselling. Hearing aids may be needed.</td>
</tr>
<tr>
<td>1 Slight impairment</td>
<td>26 - 40 dB (better ear)</td>
<td>Able to hear and repeat words spoken in normal voice at 1 metre.</td>
<td>Hearing aids usually recommended.</td>
</tr>
<tr>
<td>2 Moderate impairment</td>
<td>41 - 60 dB (better ear)</td>
<td>Able to hear and repeat words using raised voice at 1 metre.</td>
<td>Hearing aids needed. If no hearing aids available, lip-reading and signing should be taught.</td>
</tr>
<tr>
<td>3 Severe impairment</td>
<td>61 - 80 dB (better ear)</td>
<td>Able to hear some words when shouted into better ear.</td>
<td>Hearing aids may help understanding words. Additional rehabilitation needed. Lip-reading and sometimes signing essential.</td>
</tr>
<tr>
<td>4 Profound impairment including deafness</td>
<td>81 dB or greater (better ear)</td>
<td>Unable to hear and understand even a shouted voice.</td>
<td></td>
</tr>
</tbody>
</table>

Grades of Hearing Impairment

11 WHO DEFINITIONS OF DISABLING HEARING IMPAIRMENT:

Disabling hearing impairment in adults should be defined as a permanent unaided hearing threshold level for the better ear of 41 dB or greater; for this purpose the "hearing threshold level" is to be taken as the better ear average hearing threshold level for the four frequencies 0.5, 1, 2, and 4 kHz."

Disabling hearing impairment in children under the age of 15 years should be defined as a permanent unaided hearing threshold level for the better ear of 31 dB or greater; for this purpose the "hearing threshold level" is to be taken as the better ear average hearing threshold level for the four frequencies 0.5, 1, 2, and 4 kHz."


developing world. Adult onset hearing loss is just over 222 million and in the WHO regions this latter estimate comprises approximately 17 million in the African Region, 37 million in the Americas Region, 62 million in the South-East Asian Region, 51 million in the European Region, 16 million in the Eastern Mediterranean region and 39 million in the Western Pacific Region. However, these figures are provisional and more accurate figures are urgently needed especially for developing countries.

WHO has produced an Ear and Hearing Disorders Survey: Protocol and Software Package to enable a country, especially a developing country, to conduct a population-based, random-sample survey of the prevalence and causes of, and actions needed for, deafness and hearing impairment. The survey can be conducted at the national or district level.

The protocol comprises guidelines on survey methods and an ear and hearing examination form with coding instructions. It has been developed over several years with the advice of experts, and coordinated by WHO. By using the standardized format of the protocol, results can be compared between surveys conducted in different places and in the same place at different times (see chart Figure 6.). The software enables data entry and basic analysis and can be linked to other programmes, such as EPI-INFO, for more detailed statistical analysis.

The main uses of the protocol are shown in the box. The package is available at no cost to countries and organizations that are planning to conduct a population-based survey of deafness and hearing impairment.

The protocol has been or is being used in 8 countries and others are planning surveys (see map Figure 7). The major causes of deafness and hearing impairment and those that can be fully or partly prevented are shown in the diagram. Field survey methods at present can identify prevalences of important ear diseases and indicates infectious, non-

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infectious and undetermined causes of hearing impairment in the population studied. Further refinements of the methodology are needed to indicate the specific causes.

2.2.4 Review of the literature on economic analysis of deafness and hearing impairment.

There is almost no information or studies of economic analysis of deafness and hearing impairment in developing countries and all published material on this subject concerns developed countries. Examples found cover subjects such as the costs of communication disorders, audiological services, screening, interventions against otitis media, hearing aids and cochlear implants. For example a recent study\textsuperscript{16} estimated that the cost of communication disorders in the USA - due to habilitation, special education and loss of employment - was about 2.5% of the gross national product in 1999. There have also been a number of studies comparing cost-effectiveness of audiological services and screening programmes, especially on universal versus targeted neonatal hearing screening, interventions against otitis media, and studies on hearing aids and cochlear implants.

However even in developed countries, economic analysis of deafness and hearing impairment has only started to be addressed in any depth. Because of its massive global burden, it is apparent that a substantial initiative is needed to address this issue throughout the world, but particularly in developing countries where the burden and needs are greatest.

\textsuperscript{16} Redefining survival of the fittest: communication disorders in the 21\textsuperscript{st} century. Ruben RJ, The Laryngoscope 2000;110:241-245
3 EXPERIENCE IN ECONOMIC ANALYSIS OF SENSORY DISABILITIES

3.1 Economic Analysis of Blindness in India

In 1976 and 1986 two National Surveys were done to estimate the prevalence and cause of Blindness. A third survey is currently under progress. All the surveys indicate a high prevalence level of blindness (defined in India as vision in the better eye <6/60.) The blindness estimates from the earlier surveys were 1.4% and 1.49% respectively. While the current survey is likely to show a slightly lower prevalence rate, it will still be well above the 1% level. For a country of 1 billion population, this would mean that 10 – 13 million people are blind. About 80 % of blindness is treatable and vast majority of the remaining could have been prevented through early diagnosis and appropriate intervention.

**Economic Burden of Blindness.**

Majority of the blind are in the older age group with the mean age between 55 – 60 years. Some of them are physically healthy otherwise and if they had normal vision can continue to be very productive and the others would be able to provide significant support to the family and thus release those assisting them to become more productive. However today this entire population is not only unproductive but also consumes the time and resource of those who are productive to support and help them in day-to-day living activities. In the cultural setting of joint families, it is not uncommon to see the elderly blind left in the care of children of school going age thus depriving the children of their normal academic development. In an article published in 1998 by Dr. B.R. Shamanna and others, they have attempted to quantify the economic burden based on per capita income and life expectancy estimates. They have estimated the total annual economic loss at US$ 4.4 billion and cumulative loss over lifetime at US$ 77.4 billion. This roughly works out to a loss of productivity of $1 per day for each blind person and the annual loss works out to about US $370.

**Economics of Cataract Intervention.**

As mentioned earlier, about 80% of the blindness is treatable and Cataract surgery currently accounts for 70% of blindness. The cost of Cataract Surgery varies in different settings depending on the clinical protocol, overheads and the operating efficiency of individual programmes. The cost varies from US $17 to US $45. The average can be estimated around US $22. While this is the cost of intervention from the provider’s side, the patients often have to spend by way of transport and other related costs, another $7 – $10 to get the Cataract Surgery. Thus for a one time investment of US $30, one can potentially restore an annual productivity of US $370 and this would recur every year. This return on investment of 1200% is what encouraged the World Bank to support a cataract intervention programme in India. The World Bank support for the Cataract programme is nearing completion and has helped in more than doubling the number of Cataract Surgeries in India and promoting surgeries with IOL implant.

**Intervention Strategies for cataract Blindness**

A few years back a clinical trial was conducted at Aravind Eye Hospital Madurai to compare the traditional intra-capsular cataract extraction with aphakic glasses against extra-capsular cataract extraction with posterior-chamber intra-ocular lens implant. In addition to looking at clinical outcome, the study also documented the impact on work status. Almost all the individuals (99.6%) in the study were involved in some activity prior to the onset of vision impairment or blindness. At the time of enrolment to the study only a small proportion of 29.5% was still productive. A year after the Cataract Surgery these persons were interviewed once again to determine the work status. A significant proportion of 75.0% was able to return to some form of economically productive activity. Further analysis done on the data showed that a greater proportion of those who were unproductive for less than a year prior to surgery returned to work when compared to those who were not working for a longer period due to blindness. The analysis also showed that a greater proportion of those who received IOL implant returned to work when
compared to those receiving aphakic glasses. This clearly indicates that Cataract surgery done well, regardless of the technique restores significant productivity. Earlier intervention and IOL implant surgery further increases the level of productivity.

**Economic Rehabilitation for the Blind**

Among the blind, roughly 10% are incurably blind. This works out to roughly 1 per thousand or 0.1% of the population. In India this would amount to 1 million people. Some of them are educated and are economically productive while the vast majority is dependent on the family or the society for their day-to-day living. Structured Community Based Rehabilitation (CBR) programmes can address the situation effectively. The programme is designed to provide customized rehabilitation package for each client (blind person).

- The elderly are essentially trained in mobility and to carry out activities of daily living, so that they can become independent in taking care for themselves and for social interaction.
- These in the working age group (20–50 years) are trained in a vocation in addition to mobility and activities of daily living. The women are also trained to cook and do other household chores. The vocation can vary from rearing goats/chicken to running a small shop.
- The children are integrated in to regular schools and an itinerant teacher assists their learning. For the adults the rehabilitation is a one-time effort. As an outcome of this effort the elderly become independent and release those assisting them to focus on work. Those in the working age group not only become independent but are also able earn a livelihood of at least $1 or 2 a day. CBM International and Sight Savers International are actively promoting this rehabilitation model in India.

The cost of rehabilitating a blind adult person in the project done by Aravind works out to approximately $75. This is a one-time expense. For children who are admitted in regular schools, the cost of rehabilitation is higher and it also extends for a longer period of time. However these children have the potential to study further and get better jobs. The additional cost supporting the learning of a blind child with the support of itinerant teachers works out to approximately US$ 175 per year and the average duration for such support is five years. Though not worked out, the CBR intervention for the incurably blind would compare favourably with the cataract intervention in terms of cost-benefit.

**Other Causes of Blindness**

The other causes of blindness vary from simple refractive errors to more difficult conditions like Glaucoma, Retinal disorders, Corneal infection, etc. For conditions like refractive errors cost-effective solutions are available while for other conditions the solution lies in early diagnosis and appropriate clinical intervention. In this regard, for Glaucoma and Diabetic Retinopathy cost-effective models for early diagnosis and intervention are still in the process of development.

### 3.2 Trachoma: Summary of Experiences Measuring Cost-Effectiveness or Net Benefit of Components of the SAFE\(^{17}\) Strategy

Projects involving the economic valuation of trachoma or trichiasis control have been conducted in three settings in the last three years. At present, additional studies are planned or ongoing in four areas; some of the geographic areas overlap with studies that have already been completed. These studies are summarized briefly:

1. In Tanzania, a cost-effectiveness study compared methods of recruitment for mass treatment with azithromycin. One method involved village government representatives leading recruitment. Community volunteers led recruitment in the other method. Foresight in planning for and resources made available for economic analysis allowed for collection of data on foregone activities and the value of the activities that villagers typically perform.

\(^{17}\) SAFE = Surgery, Antibiotic treatment, Facial cleanliness, Environmental improvement
The values of activities were elicited in focus group discussions in which market prices were elicited. The study presented results from the villagers’ perspective, the government’s perspective, and society’s perspective. Sensitivity analyses varied the value of time imputed to individuals for whom foregone activities were unavailable. The costs of donated pharmaceuticals were not included in the analyses.

(2) In Nepal, a cost-effectiveness study compared mass and targeted household treatment with azithromycin. The mass treatment strategy involved children ages one to ten; the targeted strategy screened children ages one to ten and treated households of those with an infection. Fewer resources were available for this economic analysis. The value of time was imputed from international productivity figures—the average value added per agricultural worker. A key difference between this study and the Tanzanian study was the lack of a focus group to collect data on the market prices of local activities. This study included the cost of the pharmaceutical in some analyses, even though the pharmaceutical was donated.

(3) In The Gambia, a randomized trial was conducted in which clusters were randomized to two levels of trichiasis surgery availability: availability at the regional level (the norm) or availability within the cluster. The original study reporting on these data indicated that surgical uptake rates were higher when surgery was available locally. The economic study used a price implied by the combination of public transportation costs and the value of time. The value of time was again imputed from international productivity figures. Patients obtaining surgery were not required to pay the fee for each eye undergoing surgery that is usually required at the regional health center. In addition to inferring individual patients’ levels of willingness to pay, this study also calculated the costs of providing surgery locally and projected economic productivity gains. The costs were stated as average costs of providing surgery locally, the additional costs of transportation, and the total costs of moving all surgeries to a local site. Assumptions were made to bias productivity gains downward, but the productivity gains were estimated to be over 50 times the average willingness to pay. Further exploration is needed for willingness to pay in one period for treatments with lifetime benefits.

Two additional Tanzanian studies are ongoing. The first links trachomatous visual impairment to the inability to perform particular tasks. This will help to characterize better the economic productivity loss associated with this condition. Information about economic productivity loss is important for studies like the one in The Gambia and long-term projections of the net benefit of reducing the prevalence of trachomatous infection at present. The other study in Tanzania is a cost-effectiveness study comparing community-volunteer recruitment for mass treatment with azithromycin with community-volunteer screening for trachomatous infection followed by targeted treatment.

A study is being planned in a different location in Nepal that will further examine the task difficulties associated with trachomatous visual impairment and the costs associated with obtaining trichiasis surgery.

In Vietnam, a cost-effectiveness analysis of the full implementation of the SAFE strategy is planned.
Issues that must be addressed as this line of research continues to move forward include the following:

- Whose perspectives should be addressed? Economic theory suggests that the societal perspective should be used for decision-making. However, the villagers’ perspective is very important for predicting compliance and for considering the burden of the costs of an intervention to control trachoma.
- What is the value of rural villagers’ time in the countries in which trachoma remains endemic? Can data be elicited on the local market values of activities?
- How should donated drugs be treated? What is the opportunity cost of using donated drugs for trachoma control?
- How can health economists, epidemiologists, and clinicians work together more productively to plan for high quality data gathering in order to assure the best possible economic evaluations?
- How can health economists transmit information to policy makers and planners in a way that the data will be put to their best use?

3.3 Hearing Screening Services, Hearing Aids

The UK National Health Service (NHS) research and development effort has been driven by the need to obtain data on effectiveness and cost-effectiveness of interventions. The UK National Institute for Clinical Excellence (NICE) Organization has been set up, in part, to appraise new (and sometimes existing) interventions to examine whether there is value for money in different health interventions. This drive to examine effectiveness and clinical cost-effectiveness means that there is openness to finding the evidence for different treatments and interventions. One of the recent priorities has been new developments in hearing aids. The conclusion of the review was that there was not sufficient evidence to invest in new digital technology at this time. There were few studies that showed effectiveness, none that showed cost-effectiveness and few studies that made valid comparisons between conditions. However, involvement in the process has shown that there is a need to ask three questions (a) were the right questions asked in the first place (b) are the data capable of answering the question and (c) how may any findings be implemented in a real-life non-trial situation? Probably the most important of these is the first.

The same three questions need consideration in any economic modeling of the consequences of sensory pathology. It is very important that the perspectives of the professionals, patients, families are used to construct a societal perspective concerning the questions that are asked and how the different scenarios that emerge as candidates for implementation might be valued. The wisdom of those who have worked with patients and of the patients should not be under-valued as they can often understand when there are complex interactions in implementation that might negate predicted gains from simple economic models. The extent to which these qualitative perspectives value different aims, processes and outcomes should be used to compare models. However, be prepared (a) to recognize that a different perspective may often suggest a different key question in the first place (b) that data that are valid to answer a question from one perspective may not do so from another and (c) that implementation, audit, reduction in burden will only occur if there is leadership, consensus as well as evidence.

The Medical Research Council Institute of Hearing Research has recently assessed (1) the effectiveness and cost-effectiveness of universal neonatal hearing screening for permanent childhood hearing impairment, (2) the effectiveness of screening for otitis media with effusion (OME), (3) the effectiveness and cost-effectiveness of paediatric and adult cochlear implantation, (4) the effectiveness of different screening methods for identifying adults over 55 who might benefit from amplification, (5) the component and lifetime costs of services for the hearing impaired in England and (6) the comparative costs of hearing aid provision in the Nordic countries and the UK.

It is clear that different economic indicators are important within different political and pragmatic contexts. For example the ‘cost-effectiveness’ of a new programme may figure highly in whether it is adopted as a high priority and wins consensus for action where there are many competing claims for resources. This enables some comparisons to be made between often highly
different health choices. Once a decision has been made then the total programme resource dominates. When the prevalence is low (e.g. 1 in 4000) and the costs high (e.g. $40,000), then different societal weights may have to be considered compared to when the prevalence is very high (e.g. 1 in 2) and costs low (e.g. $150). Where decisions have to be made between ‘X’ treatments / interventions / screens that may make a difference to the same underlying conditions then it may be that costs per outcome need to be considered – if there is a sensitive measure of outcome.

One of the main problems we have had in making an outcome based, societal perspective economic model of hearing impairment in adults has been that those who come forward in the UK, USA and Europe are generally aged 75 years, have had a hearing problem for 15-20 years and have expectations of 5-10 years. Hearing screening at 55 may alter that position. However, to collect the evidence may take some time. A second major issue concerns universal neonatal hearing screening. We know the costs. The benefits are in terms of potential. It will take a long time to show the overall benefits to education and employment.

In brief, the burden is difficult to categorize. Natural history of hearing impairment for adults tends towards small changes year on year – the effects on the individual and ‘wider family’ are chronic and insidious. For children, the burden of sensory deprivation is high – the effects of intervention can appear to be huge. Sensitive measurement of these effects is difficult because very few good relevant scales of outcome exist. A good economic model should take these elements into account e.g. having multiple measures of outcome, conducting appropriate quantitative work to validate constructs and appraising the model that different key stakeholders have of the process of ‘appraisal to implementation’.

3.4 Cochlear Implants in Children: Quality Of Life And Cost-Effectiveness

A cochlear implant enables a deaf child to get a significant degree of sound perception. Being aware of sound improves the speech perception and production skills. The ability to perceive sound affects the total lifestyle of these children. There are not only positive effects. The aim of this study was to determine the quality of life in children with cochlear implant compared to deaf children not treated with cochlear implant and to determine the cost-effectiveness.

Twenty children aged 4 to 14 received a 22 channel cochlear implant without complications, and entered the rehabilitation programme. By the time of this study they had had 1 to 2 years experience with a cochlear implant. They were matched with non-implanted children on hearing loss, pure tone average of the best ear, cause of deafness, age, school and sex. Eighteen pairs of children could be found. The parents completed a questionnaire using the Meaningful Auditory Integration Scale (MAIS) for the audiological assessment; and the Quality of Life for School going Deaf Children (QoL-SDC) for measuring physical and emotional well-being, social relations, autonomy and school performance. Health status was judged on a Visual Analogue Scale (VAS).

Costs of cochlear implants were assumed to be additional to costs normally involved in treating deaf children and real costs of medical care were based on a life expectancy time horizon. Costs of selection, implantation and rehabilitation were empirically measured and future costs were modelled. A cost effectiveness analysis was performed based on the VAS results resulting in costs per quality-adjusted life year (QALY) gained for cochlear implant in children.

The Results showed that children with cochlear implant had a significantly better audiological outcome (MAIS). Except for school performance the difference in quality of life did not differ significantly. The mean utility scores for the cochlear implant children was 0.87, (standard deviation 0.13). The difference in VAS score was 0.05 (not significant). Based on the utility difference and the life time costs, both discounted at 5%, the cost per QALY was $127,648.
Costs of Cochlear Implants in Children (in US$)

<table>
<thead>
<tr>
<th></th>
<th>Total costs</th>
<th>Costs/cochlear implant child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selection [106 children]</td>
<td>156,811</td>
<td>7,841</td>
</tr>
<tr>
<td>Implantation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hardware</td>
<td>25,518</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>5,290</td>
<td></td>
</tr>
<tr>
<td>Rehabilitation [First year after cochlear implant]</td>
<td>13,589</td>
<td></td>
</tr>
<tr>
<td>Total costs first year</td>
<td></td>
<td>52,238</td>
</tr>
<tr>
<td>Life time costs [discount rate 5%]</td>
<td>71,216</td>
<td></td>
</tr>
<tr>
<td>Total costs life time</td>
<td></td>
<td>123,454</td>
</tr>
</tbody>
</table>

**Conclusion**

- Cochlear implant in children seems to be beneficial regarding audiological outcome and school performance.
- The absolute utility scores were high for the children which indicates that valuation of the health status of the child was hardly affected by their deafness. The utility difference is not as high as was assumed in other studies.
- The costs of cochlear implant are considerable, especially during the first year. Costs per QALY gained seem to be considerable.
- Longer term follow up is necessary, because hardly anything is known about the long term effects on quality of life and costs.

4 TYPES OF ECONOMIC MODELS AND FEASIBILITY OF CONSTRUCTING AN ECONOMIC MODEL OF SENSORY DISABILITIES.

An economic model of the value of avoiding or rehabilitating a sensory disability would pose the following question: “Consider the satisfaction (utility) that an individual would achieve in two states of the world:

1. Satisfaction enjoyed by a person with a sensory disability when resources gained from activities with a sensory disability are used to purchase a preferred combination of goods and medical care services
2. Satisfaction enjoyed by a person without a sensory disability when resources gained from efforts made without a sensory disability are used to purchase a preferred combination of goods and medical care services

How much more satisfaction would a person have in the second state than in the first state? What resources would a person be willing to give up to move from the first description to the second description?”

There are a number of ways that this might be measured. The most theoretically sound would be a cost-benefit study.

**Cost-benefit studies** compare the opportunity costs of a treatment or intervention with the willingness-to-pay for the benefits of the treatment or intervention. This values the resources used for a treatment, program, or intervention and the benefits of the same in monetary units so that a simple calculation can be done to determine whether the effects are positive or negative or net.
Opportunity cost is the value of the best alternative use of a resource. In general, theory suggests that this should be represented by the price of the good or service, although this is not always the case.

Willingness-to-pay measures the maximum amount of resources a person would forego so that she would be just as well off with an intervention and with less resources as she was without the intervention and with her original quantity of resources. The full value that a person would be willing to pay is made up of several components. First, medical conditions generally and sensory disabilities specifically often affect one’s earning potential. The gain in earnings potential is one component of the willingness to pay. This increase is a result of both the fact that less time is spent on obtaining medical care and individuals are often sometimes more productive without a sensory disability. Second, medical conditions generally and sensory disabilities in some cases require resources for treatment or rehabilitation. The averted expenditures are a component of the willingness to pay. Finally, an individual with the exact same resources (including time) to be consumed on things other than medical care may simply be happier when she has no sensory disabilities than when she has sensory disabilities. This last component of the willingness to pay is the most difficult to measure.

Cost-of-illness studies can contribute to the measurement of the willingness to pay. The cost-of-illness is often defined as the combination of the medical care costs and the foregone earnings associated with a condition. While this seems like a relatively straightforward measure, a review of the literature by Kenkel has shown that the cost-of-illness remains difficult to calculate. The cost-of-illness studies do not help to measure the most difficult to measure aspect of the willingness to pay.

The costs associated with a condition are not simply the costs of treating and rehabilitation but also the cost of prevention. The costs of prevention could be the most substantial costs with respect to sensory disability.

The measurement of the cost-of-illness for sensory disability is further complicated by the fact that individuals with sensory disabilities can be accommodated quite well in some economies. Particularly in the existing market economies, policies can be developed and technologies are sometimes available for increasing the productivity of individuals with sensory disabilities. In developing economies the degree of accommodation, the availability of technologies, and the helpfulness of policies may all be quite limited. Even in economies in which there are technological accommodations and policies aimed at helping those with sensory disabilities, the accommodations may be quite costly and are not necessarily available to everyone who needs them. These costs should also be considered as part of the cost-of-illness.

While the cost-of-illness studies have the potential to inform a cost-benefit analysis, in isolation, cost-of-illness studies are not useful for decision-making. Cost-of-illness studies measure the only impact of a disease. Only by complete cure or prevention will society be able to gain back the entire cost-of-illness. As indicated above, cost-benefit studies are the most theoretically sounds and compare the cost of an intervention or treatment with the change in the impact of a disease or condition that might not be completely eliminated. Specifically, a cost-benefit study compares the total costs and total benefits associated with a program or intervention. If a program does not lead to anyone having negative net benefits and has positive net benefits for at least one person, this is referred to as a Pareto Improvement and would be adopted. If a program leads to a net gain but does not benefit everyone, it is referred to as a Potential Pareto Improvement; such programs could be adopted, although a fair distribution of benefits is not guaranteed.

Some issues that arise in using cost-benefit studies to inform policy are:

- Can we measure costs and benefits for everyone?
- If we ask only those with a condition, will these individuals value the gains to those around them?
- How should we weight the results?
While the patients or those at risk of a sensory disability will benefit most directly from any related intervention, others may benefit as well, e.g. a parent or spouse who does not need to provide as much informal care to their relative who does not have a sensory disability. In general, it is not expected that the patient will incorporate the full value of the effect on others into their own valuation of the treatment. Thus, the value of an intervention to those who are not affected directly by an intervention or condition needs to be assessed.

Theory suggests that we should count everyone’s net benefits equally, i.e. everyone has the same standing. The issue of weighting the willingness to pay or net benefit has received a great deal of attention over time. A social decision rule that gives a higher weight to those with disability (sensory or otherwise) could be adopted and then would likely lead to additional resources being devoted to the treatment and prevention of sensory disabilities. However, this might not be an efficient use of resources when everyone’s benefits are valued similarly and individuals might find it inefficient in the long run. Another weighting scheme would try to make the worst outcome in society as good as it can be.

Cost-utility analysis. The issue of weighting is not confined to cost-benefit. A cost-utility analysis values each person’s quality adjusted life year similarly rather than valuing each person’s willingness to pay equally. This is substantially different as the willingness to pay can vary by wealth while the health related quality of life would not. Other measures in more general cost-effectiveness studies include clinical outcomes in which each person’s clinical outcome is valued similarly. Also, disability adjusted life years could be used and each person’s disabilities would be valued similarly. Not everyone agrees that quality adjusted life years that accrue to all individuals should be counted equally, and intellectual effort has been devoted to attempting to develop alternative relative valuations.

Cost-utility analyses have other difficulties. The utility (or disability in the case of disability adjusted life years) associated with sensory disabilities may vary substantially internationally. This is likely to depend on the degree of accommodation. Further, the methods available for valuing health states do not always yield similar values.

Sensory disabilities can have an important impact on individuals and societies. Sensory disabilities may receive special policy attention if individuals without sensory disabilities weight their prevention and rehabilitation highly, using a theory of making those who are worst off on a particular characteristic as well off as they can be. Alternatively, if little gain is expected from rehabilitation (either because individuals are well accommodated or few tasks can be performed by those with sensory disabilities), the resources devoted to treatment may be limited. In either case, policy can be informed by—but not made by—economic models that contribute to understanding the costs and benefits of a program. Economic concepts underlie the description of the costs in a summary measure called the cost-of-illness. Cost-benefit studies are just one option, although they are tied most directly to the underlying economic theory. Cost-effectiveness and cost-utility studies are another alternative for assessing interventions. Regardless of the techniques that are used, assessing the value of the benefits of sensory disability rehabilitation and prevention is an important task and requires substantial data about the economic opportunities available to and policies that affect those with disabilities in area where the studies are being performed.
5 ECONOMIC ANALYSIS OF SENSORY DISABILITIES: METHODS AND DATA.

It is first necessary to define the questions we want to ask. Types of economic analysis comprise economic impact analysis and efficiency analysis. The latter includes cost-effectiveness (including cost-utility) and cost-benefit.

Economic impact is used sometimes to complement epidemiological impact such as burden of disease analysis. It is mainly done for advocacy - but priorities cannot be set with this information. There are also major problems with methods, especially in countries with less than full employment.

Cost-effectiveness analysis can be comparing different ways of doing the same thing (e.g. delivering drugs to rural areas). This is largely concerned with technical efficiency. It can also be comparing different ways of improving health, which is allocative efficiency. The rationale for cost-effectiveness analysis is that there will never be enough resources to provide everyone with all the interventions that might reduce risks of death and poor health or reduce disability associated with poor health, so that some form of rationing or priority-setting is necessary. cost-effectiveness analysis requires the comparison of alternatives. One cannot look just at the cost-effectiveness of blindness or deafness prevention by themselves, but must obtain information on cost and effectiveness of all possible interventions to compare and select the mix that maximizes health for a given set of resource constraints. The cost-effectiveness mix depends on the availability of resources.

The types of cost-effectiveness analysis include traditional or incremental analysis, which compares new with current practice, in order to decide if a new method is more efficient than the old. However it does not show if the old is worth doing but only evidence of the large potential improvements in health brought about by switching resources from cost-ineffectiveness to cost-effectiveness.

The goal of generalised cost-effectiveness analysis is to provide information on efficiency of existing interventions as well as potential changes to them. It requires a counter-factual approach by asking what would happen if current interventions stopped, and then each possible intervention is introduced in turn.

WHO is looking at generalised cost-effectiveness analysis, which will include consideration of interventions in up to 17 sub-regions, and will produce regional league tables to show interventions that are highly cost-effective in that setting, highly cost-ineffective, and something in between. This information will be used to enter the policy debate and the impact of different mixes on population health can be weighed against their impact on other goals of the health system such as reducing health inequalities, improving responsiveness, and reducing inequalities in responsiveness.

The box shows the data that will be required to take part in this initiative. Data from assessment of interventions against sensory disabilities could be included in the initiative. Help could be given to determine what data is required or missing.

- Background demography - population age and sex structure
- Background epidemiology - prevalence, incidence, duration, severity, disability weights, remission, case fatality by age and sex
- Effectiveness and coverage of interventions against the above
- Costs of interventions

Data Requirements
6 CONCLUSIONS AND RECOMMENDATIONS

The effects of sensory disabilities, particularly blindness and deafness, produce substantial social and economic costs, but there are very few useful economic analyses to assess them. This lack, particularly in developing countries, makes it much more difficult to raise awareness and facilitate advocacy.

Increasingly, priority setting on the health agenda and investment in health-related interventions is being based on the economic burden of disabilities to the country and community, and on the cost-effectiveness of these interventions. Reliable economic data is equally important to convince major donors that these disabilities are significant problems for which donor investment would yield substantial returns in improving human health and society.

The informal consultation recommends that:

1. Economic analysis of sensory disabilities focuses on measuring the burden of those disabilities (costs and health status) and the evaluation of interventions that reduce that burden.

2. A high priority should be given to contributing to the WHO Generalised cost-effectiveness analysis initiative led by the team for Effectiveness, Quality, Costs, Gender and Ethics (EQC), in the Department of Evidence for Health Policy (GPE). Evidence-based effective interventions for the following conditions should be included for evaluation by this initiative: visual disabilities due to conditions such as cataract, diabetic retinopathy, trachoma, onchocerciasis, and refractive errors, and hearing disabilities resulting from conditions such as chronic otitis media, permanent childhood hearing impairment and adult hearing impairment.

3. Further refinement of the evidence concerning burden and evaluation of interventions should be undertaken. The validated standard survey instruments currently in use for assessment of blindness/visual impairment and deafness/hearing impairment should be supplemented to include additional data required for the recommended economic analyses.

4. The additional data for the recommended economic analyses should include the following costing modules:
   - productivity loss
   - medical support
   - informal support
   - non-medical adaptations
   - prior intervention

Minimum and comprehensive versions of these modules should be developed for use according to requirements and resources available.

Information on outcomes of intervention, disability specific and generic quality of life measures should also be collected.
5. The following steps should be undertaken to further the above recommendations –

   Review of available evidence (using procedures such as those adopted by the Cochrane Collaboration)

   Development and field testing of instruments and protocols for data collection

   Pilot of data collection in developing countries and developed countries

   Refinement of instruments and protocols

6. These instruments and protocols, when finalized, should be made available to interested parties (Governments, Non-Governmental Organizations etc) to facilitate local health care priority setting, particularly in developing countries.
2 ANNEX 1: WORKING SCHEDULE

1. Scope, Purpose and expected outcome of the consultation
   Presentation by: Dr A. W. Smith, WHO

2. The Current situation:-
   (i) Available data on the epidemiology and burden of blindness and visual impairment, and review of the literature on economic analysis.
       Presentation by: Dr S Mariotti, WHO
   (ii) Available data on the epidemiology and burden of deafness and hearing impairment
       Presentations by:-
       a. Dr B Djeantik : Developing Countries
       b. Prof A Davis : Developed Countries
       c. Dr A. Smith : Global overview and review of literature on economic analysis

3. Experience in economic analysis of sensory disabilities
   Presentations by:-
   (1) Dr Thulasiraj : Blindness in India
   (2) Dr Frick : Trachoma
   (3) Prof Davis : Hearing screening services, hearing aids
   (4) Dr Severens : Cochlear implants

4. Types of economic models and feasibility of constructing an economic model of sensory disabilities.
   Presentation by: Dr K Frick

5. Possible methods for economic analysis of sensory disability, appropriateness of available data, and further data required.
   Presentations by: Dr D Evans & Dr M Sylla, WHO

6. General discussion on the appropriateness of available data, and further data and action required.

7. Discussion of draft conclusions and recommendations.
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