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Prevention of Blindness & Deafness

Opportunities in Global Eye Research



Report of a WHO Consultation

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Preamble

Under the leadership of its Director-General, Dr J.-W. Lee, the World Health Organization is committed to research that stresses the use of knowledge already gained to improve the world's health. By building capacity for improving health through the implementation and evaluation (and, thus, continual improvement) of programmes, WHO seeks to address the disparities which exist between developed and developing countries. In particular, specific emphasis will be placed on (1) means of adapting transferred technology, (2) converting knowledge to usable, concrete means by integrating research with education, (3) developing indigenous, sustainable infrastructure (human, intellectual and physical), (4) building on transnational and cross-disciplinary collaboration, and thus (5) creating a framework for a network utilizing WHO collaborating centres. By making research a bridge between knowledge and the improvement of eye health, WHO can make a significant difference in improving people's lives.

It is recognized that there is, currently, a limited capacity for conducting eye research in many developing countries. However, other programme areas such as HIV/AIDS, malaria and tuberculosis are currently strengthening national capacities for research, which it is recommended be utilized to the extent appropriate to develop eye research capacity.

INTRODUCTION

The World Health Organization (WHO) and NEI (National Eye Institute, National Institutes of Health, USA) have renewed the contract "Strengthening of the WHO Programme for the Prevention of Blindness" for three years – from 30 September 2002 to 29 September 2005.

Under this renewal, the partnership between NEI and WHO/PBD (Prevention of Blindness and Deafness) will be strengthened further in a defined consultation process, with agreement on work activities. The three tasks included in the current renewal are of mutual interest and represent priority issues for health policy and improvement in the delivery of eye care in developing countries. This is of particular significance in the context of the Global Initiative for the Elimination of Avoidable Blindness, led by WHO and IAPB (International Agency for the Prevention of Blindness), which was launched in February 1999 under the caption "VISION 2020 – The Right to Sight".

The contract deals with three broad task areas:

1. Assessment of eye care delivery services and blindness prevention programmes
2. Studies of visual impairment and refractive error in school-aged children
3. Capacity-building for implementation and evaluation of programme development

Included specifically within the third task area are the following:

- The need for a research and development agenda to foster capacity-building and eye care delivery capability in developing country settings.
- A plan of action to foster technology transfer and training relating to the treatment of eye diseases newly emerging in these countries (e.g. diabetic retinopathy, age-related macular degeneration) on the one hand, and operational research capabilities on the other.

A Consultation on Opportunities in Global Eye Research was thus held at WHO headquarters, Geneva, from 8 to 10 September 2003.

Professor Rubens Belfort was elected Chairperson, and Professor Paul Lee was appointed Rapporteur. The agenda was adopted with no modification.

The working group reports, the agenda and the list of participants are contained, respectively, in Annexes 1, 2 and 3.

SUMMARY OF DISCUSSIONS

1. Adapting transferred technology

The group confirmed the importance of key characteristics of maximizing the chances of technology being used in a sustained manner, particularly the importance of (a) an initial needs-and-capacities assessment involving key stakeholders and (b) continuing programme evaluation. The evaluation should address critical characteristics, including quality where appropriate.

Regarding the potential for cost reductions and the enhancement of services, the importance was emphasized of understanding local economic and political factors, which could act to bottleneck the capacity to address critical health needs and their solutions. It was also emphasized that there was no single solution for every country.

2. Converting knowledge to usable tools through integrating research with education

The process of the creation of guidelines and factors in their implementation was presented, with particular emphasis on the goals of guidelines being focused on improving the care provided to a population of individuals (as opposed to any specific person) and on their value in distilling, and thus integrating, state-of-the-art research into education and clinical care. The group highlighted the transnational nature of the International Council of Ophthalmology (ICO) guideline repository, which used a single uniform standard to assess the quality of local guideline development processes.

Data were presented on the actual use of guidelines in assessing the quality of care and on the importance of evaluating actual skills and demonstrated performance, as opposed to just knowledge. Ensuring access to eye care professionals (both ophthalmologists and optometrists) was insufficient to guarantee appropriate care. It was important to have a "stick" as well as a "carrot" and to include patient perspectives.

Regarding training standards, certification and education, the current lack of standards for research training in ophthalmic and other provider education, and the highly variable nature of training and assessment standards worldwide, were demonstrated. There was a shift in emphasis (started in USA) away from "credentialing" and focusing on knowledge, to one based on demonstrated competency to perform activities.

3. Building indigenous, sustainable infrastructure

An overview of research and its value, encapsulated in the motto "knowledge heals", was presented. A framework of research, as including operational research, epidemiological research and basic science research, emphasized the importance of current WHO efforts in operational research. Discussion of the international research exchanges of NEI and the creation of global research networks clearly identified the importance of a survey of the capabilities that existed in target regions to participate in research. A directory of institutions involved in work and metrics for judging the success of efforts to build infrastructure and the capacity to guide future efforts was felt to be vital. Similarly, an understanding of the local health benefits of programmes was important.

On the subjects of distance learning and of community eye health, the group emphasized the hard work involved in maintaining the value of global credibility of the resulting education. Other programmes were revealed with similar findings and the vital importance of developing "critical mass" in the graduates' subsequent work locale, as a key determinant in their success in utilizing their education. Thus, efforts to enhance the likelihood of developing "critical mass" and its

characteristics were vital to building sustainable research and care capabilities. That would involve multidisciplinary approaches, including adapting new technology in information and library science, as well as educators. In addition, ongoing evaluation of the success of these programmes would be critical to help improve their success and effectiveness.

The importance of addressing locally important needs and the continuing dynamic changes as a result of economic development or political changes meant that any research agenda or goals, as in VISION 2020 or in the ICO research agenda, would need to be a continuous dynamic process adaptable to local needs and to changes in context and environment. Thus, issues such as refractive error and low vision would be vital to WHO Member countries, even if not addressed in the ICO or current VISION 2020 goals.

Finally, the human rights and morality of the lack of basic service provision, especially refractive correction, were addressed. WHO's taking a lead position on the importance of correcting refractive error and overcoming societal barriers to such services would be helpful in overcoming local barriers.

4. Transnational and cross-disciplinary collaboration

The importance of WHO's objectives were emphasized: (1) to reduce the burden of disease; (2) to reduce risk factors for vision loss; (3) to develop better health systems; and (4) to promote a health dimension to development policy. Further, the group focused on the critical importance of catalysing partnerships as a fundamental principle of how, most effectively and efficiently, to achieve those objectives. WHO was thus reassessing its current roster of collaborating centres and other activities to ensure effective programme and activity collaboration.

The research agenda of ICO provided a framework within which to organize such transnational collaboration. In order to have effective partnerships and to maximize the leverage of transnational and multidisciplinary work, the group endorsed the whole of the research agenda of ICO, including the importance of emerging conditions such as refractive error. Further, it was demonstrated that the research agenda was arrived at through a process whereby all constituent national societies were represented in the selection of the members of the committee which drafted the research agenda, and also one in which all constituent societies had well-defined opportunities to provide input and ultimate approval in a representative fashion. As such, it was felt that the agenda as a whole was an example of how to craft a collaborative approach to this area.

5. Framework for utilizing WHO collaborating centres

Exemplar existing WHO collaborating centres for the prevention of blindness provided an appreciation of the wide array of ongoing, innovative work in blindness prevention throughout the world, particularly in developing ongoing, sustainable infrastructure (human and physical) in developing countries. Work included: research towards blindness prevention; capacity-building (especially human capital creation through training in public health and community health); development of training infrastructures in developing countries (such as Pakistan); understanding unique barriers to preventive and treatment care in each developing country; development of methods to assess disease burden and impact; operations research to assess the effectiveness of current care and programmes; specific disease-based programmes; and the need to reflect the needs of each country. The success was highlighted of a regional network of collaborating centres in South-East Asia, centred on Juntendo. The various centres echoed that theme of collaboration.

The group strongly endorsed the concept and practical importance of an advisory group to WHO and to collaborating centres that would provide a forum allowing ideas and innovations to be

presented from the field, for the mutual benefit of all collaborating centre and WHO efforts, while enabling a greater degree of prioritization of research efforts and endeavours so as to maximize efficiency and resource productivity. By combining input, consisting of the best ideas from field-level efforts, with insights into how best to achieve a "nuanced" management of the portfolio of activities, WHO would best be able to achieve its objectives.

SUMMARY RECOMMENDATIONS

1. To establish a standing, international, multidisciplinary prevention of blindness advisory group to provide advice and guidance to WHO on a regular basis, regarding: (1) research, service and training priorities; (2) identification of resources; (3) distribution of collaborative responsibilities among WHO collaborating centres, international nongovernmental organizations and other stakeholders; and (4) other recommendations regarding prevention of visual impairment and blindness.
2. To endorse all the themes of the ICO research agenda, including important or emerging conditions in developing countries, such as refractive error and diabetes-related eye disease.
3. To conduct continuing epidemiological and operations research to refine estimates of the prevalence and causes of visual impairment and blindness, along with patient-based assessment of the associated disabling consequences in both developing and developed countries. That information provided the basis for refining the global burden of disease associated with blindness and visual impairment. Further, an assessment of patient attitudes and perceptions was important in guiding the development and evaluation of infrastructure and eye care services and programmes.
4. To emphasize the demonstrated competency of eye care workers, more effectively to build sustainable human resource infrastructure. That would include assessing the applicability and usefulness of practice guidelines in improving the quality of care and subsequent eye health outcomes in target regions in developing countries. In addition, the evaluation of eye care physicians and other eye care providers would be standardized in each nation, with regular assessments and continuous improvement feedback.
5. To conduct a detailed needs assessment survey of key stakeholders within target regions, to identify critical areas for infrastructure capacity-building, with special emphasis on adapting information technology. As part of that process, to compile, characterize and maintain a directory of organizations and institutions with research capacity.

ANNEX 1

WORKING GROUP REPORTS

Working Group A **Sustainable service delivery, capacity, infrastructure, development** **and technology transfer (cost reduction) – Bridging the gap**

Principles

In addressing the charge to make recommendations for research in bridging gaps in eye care delivery and the attendant infrastructure, the working group was guided by the definition of research used by WHO. That definition characterized research as the production of, access to and utilization of knowledge.

The working group recommended that research be guided by two key principles: first, all such research should be done in a collaborative manner, with all partners as equal participants; secondly, the research should be of a high quality, with peer review publication as the benchmark for performance.

Approach

The working group adopted a staged approach to addressing issues in this area. First, the group brainstormed the major categories of "gaps" that currently existed, based on the discussions of the consultation. After identifying gaps, the group rated each for its importance to eye health and its maintenance and improvement, using an A (most important) to C (least important) rating scheme. The group then ranked the feasibility of conducting research within the WHO Prevention of Blindness and Deafness programme (PBD) to address these gaps, from 1 (feasible now) to 3 (feasible only in the long term). This grading scheme was used to prioritize the group's recommendations.

Recommendations – category A-1

1. *To review the current WHO portfolio of activities outside of PBD to take advantage of existing experience and resources to further the prevention of blindness.*
2. *To conduct onsite surveys of current service capabilities and infrastructure, especially in regions of interest in developing countries.*

This needs assessment and capacities survey was essential to understanding the current ability to provide clinical service, training and education, and research. It would also act as a guide to establishing and supporting new and ongoing efforts and thus provide a frame of reference for measurable parameters of success.

The survey would be targeted at a representative sample of countries in the regions of interest and, if possible, each country prior to the major infusion of funds. The overall organization would be a matrix of the three areas of endeavour above and infrastructure assets and needs, such as human resources, clinical facilities, research facilities, key infrastructure availabilities (e.g. broadband) and finances.

3. *To assess current capacity to access, process and utilize knowledge and information resources pertaining to the delivery of eye care in developing countries.*

In line with the recommendations of the working group on training and guidelines, it was recommended that pilot studies be conducted to assess the availability of knowledge and guidelines, the receptivity to such guidelines, and the current levels of use of guidelines. After the baseline assessment, interventions to promote the use of guidelines would be measured on the ability to enhance the process of quality of care and the status of eye health among patients.

As part of this process, WHO should assess the availability of various classes of providers and their current level of competency (demonstrated) to perform important tasks relative to accomplishing the goals of VISION 2020. To the extent feasible, WHO should also examine the relationship of these demonstrated skills to the overall success of the programme(s) in that area.

An additional rationale for this effort was that it would create a model for future efforts in this area as well as practical experience in determining methods further to streamline future efforts.

4. *To assess patient perceptions and attitudes regarding the use of eye care services.*

In addition to determining system capacities and provider abilities, pilot studies to assess recipient-/patient-centred issues would be vital to crafting an effective and sustainable programme. Existing WHO and WHO collaborating centre data and instruments (where available) should be used to provide quantitative indicators of important barriers to surmount and the success in doing so. This should include evidence of the importance of vision to patients.

This better understanding of the weights of visual impairment on functioning and preferences/utilities would allow blindness and visual impairment prevention to be more accurately placed in relation to other conditions and disease states, to guide the allocation of resources among global concerns and WHO.

Recommendations – category A-2

5. *To assess the qualification and demonstrate the ability of non-physician providers to fulfil important expanded roles.*

Through a collaborative approach, determine which roles of ophthalmologists could be filled through other providers in shortage areas and determine the minimum skill sets necessary to fulfil those roles. A pilot training programme to establish the skills necessary would form the template for additional efforts in the future, better to leverage existing manpower and to create a cost-effective work force more quickly. An example of this was to determine the skills of a refractionist and how to train and measure the continuing competency of such individuals.

6. *To conduct a survey on the availability and costs of technology in providing eye care, in order better to understand how to sustain technology in developing countries.*

Qualitative, followed by quantitative, approaches would be used to determine the barriers to using various forms of technology in patient care, with particular focus on costs, legislative restrictions (exporter and importer) and supply chain issues. Not only would political and economic leadership be asked to participate, but suppliers and others in the supply chain would need to participate to provide insights into how better to provide technology in clinical care.

The results of the surveys in Nos 1 and 6 would be helpful to create the basis for establishing a model that would be usable in later iterations to assess the likelihood of the successful establishment of sustaining programmes.

Recommendations – category A-3

7. *To assess the relative importance of human resources, physical infrastructure, social factors, economic incentives and structure, and political factors in achieving successful blindness intervention programmes in specific settings.*

Conducting research to assess the relative weighting of those factors in the current state of eye health and interventions in those factors in altering eye health would help guide the prioritization of efforts in achieving eye health and blindness prevention.

8. *To determine the characteristics associated with successfully creating and sustaining research capacity in developing countries.*

To monitor and evaluate the effectiveness of collaboration to improve research capacity in target regions, in order to determine those factors most associated with successful growth to independent status. To consider specific interventions and the targeting of new enterprises.

Recommendations – category B-1

9. *To assess the extent to which eye care interventions were sensitive to cultural diversities.*

To provide equivalent materials for patients and providers in a linguistically appropriate manner across target regions, together with training in culturally appropriate communications, to determine if that improved outcomes. Outcomes were the access to and use of literature, the use of distance learning programmes, and eye health status (potentially patient satisfaction).

Recommendations – category B-2

10. *To determine, through research, frameworks for delivering appropriate service technology within developing countries.*

Research to understand the potential variation within and between countries in absorptive capacity, focusing on provider availability and expertise (users), barriers and opportunities for indigenous industry (creation and maintenance of technology) and local economic and sociopolitical factors. To create a subsequent process of adapting technology to local conditions.

Recommendations – categories B-3, C-1 and C-2

None

Recommendations – category C-3

11. *To assess the effectiveness of patterns of care in developed countries when applied to developing country settings.*

To determine the relevance and effectiveness in the long term of Western-style approaches to care in target regions. For example, does glaucoma care with chronic medications or initial surgery work best and for how long, with cost-effectiveness and analyses of arms.

Working Group B

Effective improvements in eye care delivery

Guidelines for care

Guidelines defined a process of care provided to the patient for specific eye diseases. They were evidence-based and dynamic, and they were not intended to dictate specific care. The use of guidelines was part of the process of ensuring quality. They were intended as educational tools and to be used in areas where some minimal resources were available.

Action items

- To adopt ICO guidelines, as stated on the ICO web site.
- To undertake the following project:
 - (a) An initial assessment of absorptive capacity to use the guidelines (i.e., can they be implemented even in part?).
 - (b) A pilot programme to introduce guidelines into two selected regions. The recommended regions were the Western Pacific Region and the African Region (e.g. Nigeria).
 - (c) Once introduced, to evaluate the impact on knowledge base, delivery of care, and outcomes.

Training for ophthalmologists and additional eye care workers

Clinical training for ophthalmologists

- To incorporate ICO guidelines into the training.
- Standard national examination of the knowledge base, moving towards competency-based assessment. The group recognized the consideration of a potential role for regional and international examinations.
- Training programmes, to improve the quality of education, must have access to, and use in, training, current information.
- Association of Vision Science librarians should create an information module on how to access information data bases (e.g. HINARI).
- Organizations – such as ICO, IAPB, WHO and supranational and national societies – were charged with providing this information on how to access the data bases.
- To incorporate a community eye health module.

Research training for ophthalmologists

- Programmes should include basic skills in evaluating the literature, using for example the users' guide to medical literature available on the JAMA web site, or the distance learning modules on critical review and writing.
- To urge international societies (e.g. ARVO, ICO) and WHO collaborating centres to conduct training courses on research methods, with specific emphasis on VISION 2020 goals, at the local level.

Training of additional eye care workers

- Training programmes for additional eye care workers should be carried out in parallel to, and integrated with, the training recommendations made for ophthalmologists.
- The development of guidelines, together with training programme recommendations, was needed for these groups of eye care professionals.

Evaluation of training and eye care programmes

The goal was to improve the quality of eye care delivery by providing feedback to eye care programmes and managers. Evaluation also provided feedback on the models used for eye care delivery.

Evaluation: Training

- A survey of graduates of public health/community eye care programmes: were they meeting the objectives of VISION 2020?
- A survey of graduates as to the usefulness of education, elements needed, improvements, and other measures of satisfaction.

Evaluation: Eye care programmes – outcomes

It was recognized that other groups might develop research needs that should be integrated with these recommendations.

The group chose to focus on cataract outcomes, as that was a major component of the VISION 2020 initiative, and outcomes for cataract surgery programmes were widely used. Those were:

- (a) surgical coverage
- (b) surgical outcomes

The group recommended to WHO the further development of standardized outcome measures for refractive error, diabetic retinopathy and other conditions, for use in the evaluation of programmes.

Working Group C Transnational collaboration and exchange

Conclusions

1. There was a global agenda for blindness prevention: VISION 2020 – The Right to Sight.
2. Priority disease research areas had already been identified by ICO, described in "A research agenda for global blindness prevention", which this group accepted.
3. To undertake this research agenda, the input and expertise of a range of professionals would be required (e.g. social scientists, health economists).

4. The areas of greatest need for research and capacity-building were in Africa, particularly in Francophone and Lusophone countries.
5. The majority of the expertise was currently in industrialized countries.
6. Opportunities were being provided in resource-poor countries, where capacity was being built to address the major killing diseases.
7. There was a need for transnational collaboration and exchange to enable this research agenda to be undertaken, which should ideally entail collaboration between institutions which had, or which could have, the capacity.
8. The long-term aim was for institutions in the most needy regions to be self-sustaining and able to initiate and undertake their own research.

Recommendations

1. *Directory of partner organizations*
 - To develop a global directory of research centres which could become partner institutions to facilitate the development of a network of centres which could collaborate in, or develop, the expertise necessary to address local research needs.
 - Criteria for partner institutions: (1) relevant research experience and expertise; (2) commitment to blindness prevention.
2. *Capacity-building*
 - To undertake an evaluation of institutions in which research capacity was already under way, to identify components leading to success.
 - To identify a few partner organizations which could be strengthened to become more research- and training-active (e.g. PICO, Pakistan). That would require motivated leadership, institutional commitment and external and ongoing support.
 - Capacity-building might be required in the following areas:
 - (a) Training in research methodology
 - (b) Writing grant applications and publications
 - (c) Information technology
 - (d) Infrastructure
3. *Mechanisms for collaboration*

The establishment of a dedicated, multidisciplinary, international group, with responsibilities as follows:

 - To define and refine priorities for prevention of blindness in research, service and training.
 - To identify available resources and the distribution of responsibilities, and to facilitate collaboration.
 - To make recommendations to WHO on its programmes and to national and international agencies involved with and relevant to the prevention of blindness.
4. *Eye care professionals and society*

Visual impairment should not be held captive to narrow, parochial, professional interests. For example, in many countries, large numbers of people were disenfranchised by lack of refractive services, as those were under the control of a monopoly.

ANNEX 2

AGENDA

Opening of the Meeting
Introduction of Participants
Election of Officers

1. Review of development of technology to support affordable eye care services
2. Review of development of best practices and improvement in the quality of eye care
3. Review of capacity-building and transnational collaboration in research
4. Review of research plans (ICO, WHO, WHO collaborating centres)
5. Review of ophthalmic training standards and certification
6. Review of access to literature, practice guidelines, consultations
7. Recommendations

Closure of the Meeting

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