To Whom It May Concern, Dear Friends,

I am a co-chair of the Topic Advisory Group (TAG) for ophthalmology, organized by the International Council of Ophthalmology (ICO), to advise the WHO on the 11th revision of the International Classification of Diseases (ICD-11).

This revision is planned as a major one, serving not only the WHO’s need for public health statistics, but also the terminology needs for Electronic Medical Records (EMR) and other Health Information Technology (HIT) applications.

I am requesting your help, expertise and input on one aspect of this endeavor as explained below. I hope that you can help on this important topic.

Sincerely,

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The Burden of Vision Loss

The framework

The WHO has a special interest in defining the Global Burden of Disease (GBD) as a means to compare the impact of various diseases and to set health policy priorities. For vision, this translates to the Burden of Vision Loss. This burden can be viewed at different levels, such as the individual burden, the burden to the health care system, the burden on the family or the burden to society. Within eye care there is an increasing awareness of these various burdens and health care payers need them to justify the cost of vision rehabilitation.

Until its 8th revision, the ICD knew only the distinction between vision (no code) and blindness. In the 1970’s, as we prepared ICD-9, the category Low Vision was added, mainly defined in terms of visual acuity loss. It is time to go further and to define categories that can capture the broader concept of the Burden of Vision Loss. Since today we are still mainly using the categories defined 35 years ago, it is reasonable to assume that the broad categories defined today will still be used 25 years from now, although they undoubtedly will be filled in with additional data. However, if we fail to provide some broad categories now, there will be no place for the details later.

The final format for ICD-11 has not yet been defined. I expect that it will be a hybrid between the one-dimensional hierarchy of the present ICD, used for summary health statistics, and the multi-dimensional web of relationships, needed for more advanced HIT applications. This means that our initial proposals should be driven more by a list of desirable aspects and items, than by a precise determination of the coding hierarchy.

Aspects of Vision Loss

To discuss both the causes and the consequences of vision loss, I find it useful to consider four aspects. Of these, two relate to the organ of vision and two relate to the person.

First we may consider how various external causes may result in structural changes. Here the focus is on the tissue and on changes such as scarring, degeneration, atrophy or loss.
However, the structural changes do not tell us how well the eyes actually function. We need to widen our view to the organ as a whole, measuring organ functions, such as visual acuity, visual field and contrast sensitivity.

Yet, even knowing how the eyes function, does not yet tell us how the person functions. So we need to widen our perspective again, this time to the person level, considering tasks, such as reading, mobility, face recognition and activities of daily living (ADL).

Beyond that, we need to look at the person in a societal context. Do these changes impact on the person’s participation in society, on the ability to perform necessary tasks and on general satisfaction with one’s quality of life?

### ASPECTS of VISUAL FUNCTIONING

<table>
<thead>
<tr>
<th>THE ORGAN</th>
<th>THE PERSON</th>
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<tbody>
<tr>
<td><strong>Focus on:</strong></td>
<td><strong>Focus on:</strong></td>
</tr>
<tr>
<td>Structure</td>
<td>Function</td>
</tr>
<tr>
<td>Tissue</td>
<td>Organ</td>
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<tr>
<td><strong>Examples:</strong></td>
<td><strong>Examples:</strong></td>
</tr>
<tr>
<td>Scar, Loss, Atrophy, Degeneration</td>
<td>Vis. Acuity, Vis. Field, Contrast</td>
</tr>
<tr>
<td>Eye Health</td>
<td>Visual Functions</td>
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</table>

How the eyes function How the person functions

These different aspects have been discussed under various headings. The International Classification of Diseases (ICD) and its revisions have been mainly concerned with the structural and organ-related aspects. In 1980 the WHO published the International Classification of Impairments, Disabilities and Handicaps (ICIDH) to expand coverage to the other aspects. As an extension of ICD, the ICIDH emphasized the medical origin of handicaps and the loss of functioning. In 2001 its successor, the International Classification of Functioning, Disability and Health (ICF), extended attention to societal and environmental factors and promoted the use of neutral terms, emphasizing participation, rather than handicap.

### DIFFERENT CLASSIFICATIONS

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</tbody>
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ICD: **Diseases**

ICIDH: **Impairments** **Disabilities** **Handicaps**

ICF: **Structure** **Function** **Activities and Participation** **Environment**

These aspects can be read from right to left or from left to right. Patients, who seek medical help, will start on the right. They will complain about difficulty reading (functional vision); the
doctor will translate this to a statement about visual function ("visual acuity has dropped by two lines") and will then examine the structure of the eye to discover the cause.

THE DIAGNOSTIC PROCESS

<table>
<thead>
<tr>
<th>Etiology</th>
<th>THE ORGAN</th>
<th>THE PERSON</th>
</tr>
</thead>
<tbody>
<tr>
<td>Injury</td>
<td>Cataract</td>
<td>Acuity loss Can’t read Dissatisfaction</td>
</tr>
</tbody>
</table>

Most medical textbooks will start on the left and discuss cause and effect.

CAUSE and EFFECT (Medical Model of Disability)

<table>
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<tr>
<th>Environment</th>
<th>THE ORGAN</th>
<th>THE PERSON</th>
</tr>
</thead>
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<tr>
<td>Etiology</td>
<td>Cataract</td>
<td>Acuity loss Can’t read Loses job</td>
</tr>
</tbody>
</table>

Since each aspect is flanked by two other aspects, it can be approached from two sides. We may measure visual acuity to detect possible deviations from optimal eye health. We may also test visual acuity to predict functional problems.

Various activities may cover more than one aspect. When reading, the minimum print size falls under the aspect of organ function (retinal resolution); reading speed (words/minute) and reading endurance (hours/day) define abilities of the person. Reading enjoyment, finally, falls under the aspect of quality of life.

Each Aspect Relates to Adjacent Aspects

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<tbody>
<tr>
<td>Structure</td>
<td>Function</td>
<td>Abilities</td>
</tr>
<tr>
<td>Tissue</td>
<td>Organ</td>
<td>Participant</td>
</tr>
<tr>
<td>Eye Health</td>
<td>Visual Functions</td>
<td>Functional Vision</td>
</tr>
<tr>
<td>Eye Health</td>
<td>Visual Functions</td>
<td>Quality of Life</td>
</tr>
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</table>

Indicates Eye Health Predicts Abilities

Resources Tasks, Goals

Personal Abilities Societal Demands

In the context of vision rehabilitation, we need to consider the visual resources (acuity, field, contrast, etc.) that determine visual abilities; we also need to consider which activities are needed to perform tasks and to achieve goals for optimal participation. Both abilities (stressed in ICIDH) and activities (stressed in ICF) are important; they are two sides of the same coin.

Similarly, under participation and quality of life, we need to consider societal demands as well as personal abilities and attitudes.
Questions for the Development of ICD-11

The needs for ICD-11 can be discussed in terms of the various aspects discussed above. Questions have been added in italics.

How the eyes function – Visual acuity

Visual acuity remains the most used measure of visual performance. Presently, most classifications are based on “best corrected acuity” for each eye or for the better eye. This is appropriate when the goal is the detection of eye disease. It is also appropriate for the determination of benefits.

However, when the goal is to determine how people function, the definition “presenting acuity with both eyes open” (as recommended by the 2003 WHO consultation) is more appropriate, since this describes how people go through life.

Should there be two classifications or a code with a modifier to identify the two conditions?

Having separate codes would avoid possible confusion between data based on best-corrected and data based on presenting acuity. This is significant since it is estimated that the most frequent cause of visual impairment is the difference between best-corrected and presenting acuity, due to uncorrected or under-corrected refractive error.

Presently, the classification is based on distance acuity. However, most activities of daily living require near or intermediate acuity.

Should there be an additional scale for near or for intermediate acuity?

If so, should the classification be based on visual angle (letter size relative to viewing distance) or on reading ability (print size, at whatever is the preferred distance)?

If so, should the classification be based on best corrected reading vision, on available reading glasses, or even allow for available low vision aids?

Especially for the older population where visual impairment is most frequent, ignoring these differences can result in vastly different statistics.

For illiterate subjects and in developing countries, should it be based on other near tasks? If so, which?

Other organ functions

Should there be scales or categories for other visual functions?

If so, which? Contrast, glare, color vision, etc.?

How the person functions in vision-related activities of daily living

The reading questions already cross over to visual abilities.

Should there be additional scales or categories for travel vision and Orientation and Mobility?

Should there be scales or categories for other Activities of Daily Living?

If so, which?

Even if detailed scales are not available today, it is likely that Rasch analysis of visual function questionnaires and similar techniques will be able to provide more detailed scales in the future.
The fact that such scales or categories would be available would not mean that their use would always be mandatory. It would mean, however, that for those who want to use them, a standardized set would be available, which would make comparisons between different studies much easier.

**Vision-related Participation and Quality of Life**

This is the most difficult area, but also the most important one, since any ophthalmic or social interventions should ultimately be judged by their effect on participation and quality of life.

Scales or categories in this domain are no longer strictly visual but reflect the interaction of the subject’s abilities with the demands of both the social and the physical environment.

Measurement techniques in this domain are more complex than those for parameters such as visual acuity, since this domain includes more subjective elements. It is likely that the next decades will see improvements in assessment methodologies. When such improvements occur, a broad classification should be available to allow more uniform reporting.

*What broad categories would you suggest for this domain?*

*Should there be separate categories for the personal burden (quality of life) and for the societal burden (socio-economic)?*

There is a need for broad categories that could possibly be used by primary care practitioners and for more detailed sub-categories for use in specialized studies.

**Current Classifications**

While ICD classifies *diseases* and other *health conditions*, on the left side of the diagram, the main emphasis in ICF is on *activities* needed for *participation*, on the right side of the diagram. For instance, the ICF category “Applying Knowledge” covers reading and writing together with other activities such as thinking and problem solving. In this context, no distinction is made between the activity of reading print and the activity of reading Braille (talking books are not mentioned). In the context of rehabilitation, however, reading print and reading Braille require very different *abilities*. Similarly, ICF categorizes products and technologies according to the purpose that is served, not according to the resources (vision, hearing, touch) that are required.

ICF has some codes for “seeing functions”, but these are rather rudimentary.

**Vision related Codes for Organ Function in ICF**

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
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<tbody>
<tr>
<td>b210</td>
<td>Seeing Functions</td>
</tr>
<tr>
<td>b2100</td>
<td>Visual Acuity functions</td>
</tr>
<tr>
<td>b21000</td>
<td>Binocular Acuity – distance</td>
</tr>
<tr>
<td>b21001</td>
<td>Monocular Acuity – distance</td>
</tr>
<tr>
<td>b21002</td>
<td>Binocular Acuity – near</td>
</tr>
<tr>
<td>b21003</td>
<td>Monocular Acuity – near</td>
</tr>
<tr>
<td>b2101</td>
<td>Visual Field Functions</td>
</tr>
<tr>
<td>b2102</td>
<td>Quality of Vision</td>
</tr>
<tr>
<td>b21020</td>
<td>Light Sensitivity</td>
</tr>
<tr>
<td>b21021</td>
<td>Color Vision</td>
</tr>
<tr>
<td>b21022</td>
<td>Contrast Sensitivity</td>
</tr>
<tr>
<td>b21023</td>
<td>Visual Picture Quality (floaters, distortion, flashes)</td>
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</tbody>
</table>
The ICD category for Low Vision and Blindness has sub-categories based on visual acuity, but does not cover the normal range, since normal vision is not a disease. In ICD-9-CM (the US clinical modification), which is based on the 5-digit extensions developed by the ICO, the normal range is covered. In ICD the extent of concentric visual field loss is rated by equating it with ranges of visual acuity loss. For other defects, such as hemianopia and scotomata, there are descriptors, but no scales.

Should there be scales for the degree of non-concentric field losses?
If so, how should these be constructed?

Classification structure

Since the final structure of ICD-11 has still to be decided, it is presently more important to develop a listing of items that should be included, than to develop a detailed structure.

If your thoughts go in this direction anyway, it may be useful to consider the structure used for ICD-9.

3-digit codes diagnoses that can be made with a flashlight
4-digit codes diagnoses that require a slitlamp or ophthalmoscope
5-digit codes diagnoses that require more specialized equipment or expertise.

Example: 3-digit – retinal disorder, 4-digit – macular degeneration, 5-digit – wet AMD.

This structure allows an initial diagnosis to be recorded with limited precision, with additional refinements to be added as they become available.

Final thoughts

It is possible that not all proposals resulting from the ICO effort will make it into the ICD. In this case, a separate publication for vision may be considered.

At this point we want to collect as much information as we can. Therefore, if you have thoughts about even one of the points raised here, please do not hesitate to share them as soon as possible, since initial proposals are due to be presented to WHO before the summer.

If you know of others who are interested in any part of this topic, please share this document with them and pass their name and email along to me. We need all the input we can get.

We plan to have a work group meeting for a more detailed discussion of the suggestions that will have been received on September 9, 2009, preceding the “Envision 09” Low Vision conference in San Antonio, Texas.

Thank you for your help.
Sincerely,

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