Update/Le point

Childhood blindness: a new form for recording causes of visual loss in children*

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The new standardized form for recording the causes of visual loss in children is accompanied by coding instructions and by a database for statistical analysis. The aim is to record the causes of childhood visual loss, with an emphasis on preventable and treatable causes, so that appropriate control measures can be planned. With this standardized methodology, it will be possible to monitor the changing patterns of childhood blindness over a period of time in response to changes in health care services, specific interventions, and socioeconomic development.

Introduction

A standard classification for reporting the categories of visual loss was developed in 1975 and has been widely used to facilitate the comparison of data from different locations (*1*). The World Health Organization's Programme for the Prevention of Blindness (WHO/PBL) has also developed a standard protocol for reporting the causes of visual loss.[a]

In May 1990 a global meeting on the Prevention of Childhood Blindness, convened by WHO at the International Centre for Eye Health (ICEH) in London, recommended that further information was required on the prevalence, incidence and causes of visual loss in children because few data were currently available (*2*). The results from population-based studies indicate a lower prevalence of blindness in children than in adults, ranging from approximately 0.2–0.3 per 1000 children in industrialized countries to approximately 1.0–1.5 per 1000 children in very poor communities (*3*). The available information on the causes of visual loss in childhood shows marked regional variations; corneal scarring secondary to vitamin A deficiency, measles infection or ophthalmia neonatorum is the main cause of childhood blindness in Africa and Asia, while retinal disease and lesions of the central nervous system are more important causes in Europe and North America (*4*).

Difficulties in comparing the causes of visual loss in children are due to lack of a standardized reporting system which takes into account both anatomical and etiological classifications. In an effort to overcome this problem, the ICEH in London, which is a WHO Collaborating Centre for Blindness Prevention, in collaboration with WHO, has now developed a standardized protocol (the WHO/PBL Eye Examination Record for Children with Blindness and Low Vision) for reporting the causes of visual loss in children. The form is accompanied by a set of coding instructions and a database for analysis.

The new form

The object of the record is:

— to identify preventable and treatable causes of childhood visual loss so that appropriate control measures can be planned;

— to provide a mechanism for monitoring changing patterns of childhood blindness over a period of time in response to changes in health care ser-

* A French translation of this article will appear in a later issue of the *Bulletin*.

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[a] *WHO/PBL Eye Examination Record* (unpublished document WHO/PBL/EER III/1988) and *Coding Instructions for the WHO/PBL Eye Examination Record (Version III)* (unpublished WHO document PBL/88.1). Geneva, World Health Organization, 1988.

Reprint No. **5406**

vices, specific interventions, and socioeconomic development;

— to assess the requirements of individual children for medical and/or surgical treatment, optical correction and low vision services; and

— to assess the educational needs of visually disabled children so that appropriate education services can be planned.

The form is primarily designed to record the causes of blindness and low vision in children in schools for the blind and those attending hospital clinics. It can also be used to document the causes of visual disability in children identified during population-based prevalence surveys. The form is not designed for collecting information on the prevalence of eye disease in children (e.g., trachoma, xerophthalmia). The form also has sections for recording demographic data, the presence of additional disabilities, and information relating to the child's education.

Coding instructions

It is recommended that, if at all possible, a team of trained personnel should undertake the assessments, each one completing the relevant sections of the form. Ideally, the team should consist of an ophthalmologist, an optometrist or optician, a specialist with expertise in this field of education, and ancillary staff with local knowledge and experience in visual acuity and visual field assessments.

The form consists of 13 sections (Fig. 1). It is recommended that sections A1 or A2, and B, C and D should be completed by ancillary staff trained for the purpose; sections E, F, H, I, J, K, L and M by an ophthalmologist; section G by an optometrist or optician; and section K by an educationalist. All sections should be completed for every child. If this is not possible, specific sections should be used or omitted consistently throughout any one study.

The coding instructions, which accompany the form, are to be used in preparing ophthalmologists and other members of the assessment team in the use of the form prior to data collection, as well as serving as a reference. The coding instructions include methods of assessing vision, definitions of conditions, and guidelines on completing the different sections of the form.

Contents

Sections A1 and A2. Census. Section A1 is to be completed for children in schools for the blind and hospital clinics, and section A2 for children with visual loss identified during population-based prevalence surveys.

Section B. Personal details. This section records demographic data, the age of onset of visual loss, the presence of a positive family history, and whether there is a history of consanguinity.

Section C. Visual assessment. Section C is used to record visual acuity measurement (classified according to the WHO International Classification of Diseases, categories of visual loss) and a simple assessment of functional vision and visual fields.

Section D. General assessment. This section has been included for the identification of other disabilities which may assist in determining the etiology of visual loss or the educational requirements of the child. The definitions of disability given in the coding instructions are those of the International Classification of Impairments, Disability and Handicaps (*5*).

Section E. Previous eye surgery. This section is to be completed after consulting medical records, obtaining a history from adults with knowledge of the child's past medical history, and performing a clinical examination of the child.

Section F. Eye examination: site of abnormality leading to visual loss. The purpose of this section is to identify the sites of abnormality leading to visual loss (i.e., the anatomical site causing visual loss) for each eye, and then for the child. Details of definitions are given in the coding instructions.

If an eye has more than one abnormality, only *one* site should be selected as the *major* site for that eye, using the guidelines given in the coding instructions, which place emphasis on preventable and treatable conditions. Whether the major sites of abnormality are the same or different between the right eye and the left eye, only *one* is selected as the abnormality for the child, again using the criteria given in the coding instructions.

Section G. Refraction/low vision aid assessment. This section should be completed if examination of the eye suggests that refraction may improve the visual acuity. The decision to perform refraction should not be based solely on improvement in acuity with pinhole testing. The best corrected visual acuity is recorded and the corrective lenses specified.

If the child already uses low vision aids for near or distance, or is assessed for low vision aids, the visual acuity using the optical aid is recorded.

Section H. Eye examination: etiology of visual loss. The purpose of this section is to record the disease or other conditions causing visual loss, which are categorized according to the time of onset of the con-

Fig. 1. **Recto side of the new form; the verso side is on the next page.** The normal size is A4.

WHO/PBL EYE EXAMINATION RECORD FOR CHILDREN WITH BLINDNESS AND LOW VISION

A.1 CENSUS **BLIND SCHOOL / HOSPITAL STUDIES**

Country No. ☐☐☐ (1-3) School/Hospital No. ☐☐ (4-5) Child No. ☐☐☐ (6-8)

School/ Hospital _____

OR

A.2 CENSUS **POPULATION BASED SURVEYS**

Country No. ☐☐☐ (1-3) Cluster No. ☐☐☐ (4-6)

Household No. ☐☐☐ (7-9) Child No. ☐☐ (10-11)

B. PERSONAL DETAILS OF CHILD

Name: _____

Home Town\Village: _____

Ethnic Group: _____

Age: ☐☐ (12-13) In months (0-1 yr olds) Sex: ☐ Male = 1 Female = 2 (16)

☐☐ (14-15) In years (1-15 yr olds)

Age at onset of visual loss: ☐☐ (17-18)
00 Since birth
88 First Year of life
01-15 in Years
99 Unknown

Family history: Is there a family history of the same condition?
1 ☐ Yes
2 ☐ No
3 ☐ Unknown (19)
If yes, who is similarly affected? _____

Consanguinity: Is there a history of consanguinity?
1 ☐ Yes
2 ☐ No
3 ☐ Unknown (20)

C. VISUAL ASSESSMENT

1) Distance vision: With present glasses ☐1 Unaided ☐2 (21)

Test each eye separately, then together.

	Right	Left	Right & Left
6/6 - 6/18	☐ 1	☐	☐
less than 6/18 - 6/60	☐ 2	☐	☐
less than 6/60 - 3/60	☐ 3	☐	☐
less than 3/60 - PL	☐ 4	☐	☐
No light perception	☐ 5	☐	☐
Cannot be tested			
believed sighted	☐ 6	☐	
believed blind	☐ 7	☐	
	(22)	(23)	(24)

2) Functional vision: Test with both eyes together

	Yes	No	Not Tested
Can see to walk around	(25) ☐ 1	☐ 2	☐ 3
Can recognise faces	(26) ☐	☐	☐
Can see print	(27) ☐	☐	☐
Believed useful residual vision	(28) ☐	☐	

3) Visual Fields: Test each eye separately

	Right	Left
Full field	☐ 1	☐
Hemianopia	☐ 2	☐
Constricted to less than 10°	☐ 3	☐
Other field loss	☐ 4	☐
Cannot test	☐ 5	☐
Not tested	☐ 6	☐
Specify type of test	(29)	(30)

_____

D. GENERAL ASSESSMENT

Additional disability — Tick all that apply

None	(31) ☐
Hearing loss	(32) ☐
Mental retardation	(33) ☐
Physical handicap	(34) ☐
Epilepsy	(35) ☐
Other	(36) ☐

Specify _____

E. PREVIOUS EYE SURGERY

Tick all that apply

	Right	Left
None	(37) ☐	(38) ☐
Glaucoma	(39) ☐	(40) ☐
Cataract	(41) ☐	(42) ☐
Corneal Graft	(43) ☐	(44) ☐
Optical Iridectomy	(45) ☐	(46) ☐
Removed	(47) ☐	(48) ☐
Surgery, type unknown	(49) ☐	(50) ☐
Other, Specify	(51) ☐	(52) ☐

_____

Please give full details including dates, if available,

Right eye _____ Left eye _____

F. EYE EXAMINATION - Site of ABNORMALITY leading to VISUAL LOSS

For each eye mark one major abnormality and all others that contribute to visual loss

	Right Eye Major	Right Eye Others	Left Eye Major	Left Eye Others
Whole globe:	(53)		(89)	
Phthisis	☐ 1	☐ (54)	☐ 1	☐ (90)
Anophthalmos	☐ 2	☐ (55)	☐ 2	☐ (91)
Microphthalmos	☐ 3	☐ (56)	☐ 3	☐ (92)
Buphthalmos	☐ 4	☐ (57)	☐ 4	☐ (93)
Glaucoma	☐ 5	☐ (58)	☐ 5	☐ (94)
Removed	☐ 6	☐ (59)	☐ 6	☐ (95)
Disorganised	☐ 7	☐ (60)	☐ 7	☐ (96)
Other	☐ 8	☐ (61)	☐ 8	☐ (97)
Cornea:				
Staphyloma	☐ 9	☐ (62)	☐ 9	☐ (98)
Scar	☐ 10	☐ (63)	☐ 10	☐ (99)
Keratoconus	☐ 11	☐ (64)	☐ 11	☐ (100)
Dystrophy	☐ 12	☐ (65)	☐ 12	☐ (101)
Other Opacity	☐ 13	☐ (66)	☐ 13	☐ (102)
Lens:				
Cataract	☐ 14	☐ (67)	☐ 14	☐ (103)
Aphakia	☐ 15	☐ (68)	☐ 15	☐ (104)
Other	☐ 16	☐ (69)	☐ 16	☐ (105)
Uvea:				
Aniridia	☐ 17	☐ (70)	☐ 17	☐ (106)
Coloboma	☐ 18	☐ (71)	☐ 18	☐ (107)
Uveitis	☐ 19	☐ (72)	☐ 19	☐ (108)
Other	☐ 20	☐ (73)	☐ 20	☐ (109)
Retina:				
Dystrophy	☐ 21	☐ (74)	☐ 21	☐ (110)
Albinism	☐ 22	☐ (75)	☐ 22	☐ (111)
ROP	☐ 23	☐ (76)	☐ 23	☐ (112)
Retinoblastoma	☐ 24	☐ (77)	☐ 24	☐ (113)
Other	☐ 25	☐ (78)	☐ 25	☐ (114)
Optic Nerve:				
Atrophy	☐ 26	☐ (79)	☐ 26	☐ (115)
Hypoplasia	☐ 27	☐ (80)	☐ 27	☐ (116)
Other	☐ 28	☐ (81)	☐ 28	☐ (117)
Other, not listed	☐ 29	☐ (82)	☐ 29	☐ (118)

Globe appears normal (complete after refraction see Section G)

Refractive error	☐ 30	☐ (83)	☐ 30	☐ (119)
Amblyopia	☐ 31	☐ (84)	☐ 31	☐ (120)
Cortical blindness	☐ 32	☐ (85)	☐ 32	☐ (121)
Idiopathic nystagmus	☐ 33	☐ (86)	☐ 33	☐ (122)
Normal vision	☐ 34	☐ (87)	☐ 34	☐ (123)
Not examined	☐ 99	(88a)	☐ 99	(88b)

THE MAJOR SITE OF ABNORMALITY LEADING TO VISUAL LOSS FOR THE CHILD (124)

SELECT RIGHT OR LEFT EYE ☐ Right ☐ Left

G. REFRACTION /LOW VISION AID ASSESSMENT

	Yes	No	Not indicated	Not done
Vision improves with a pinhole	1 ☐ (125)	☐ 2	☐ 3	☐ 4
Refraction performed now	1 ☐ (126)	☐ 2		
Vision assessed with low vision aid	1 ☐ (127)	☐ 2	☐ 3	

1) If refraction performed, visual acuity with corrective lenses;
Distance: Test each eye separately, then together

	Right	Left	Right & Left
6/5 - 6/18	☐ 1	☐	☐
less than 6/18 - 6/60	☐ 2	☐	☐
less than 6/60 - 3/60	☐ 3	☐	☐
less than 3/60	☐ 4	☐	☐
	(128)	(129)	(130)

Specify corrective lenses and visual acuity

Right eye ---------- VA ___

Left eye ---------- VA ___

Near: Test with both eyes together

Can discern print /symbols equal to or smaller than 5mm (≤5mm) Yes (131) ☐ 1 No ☐ 2

☐ ○ △ Example of 5mm symbols

2) If assessed with low vision aid (LVA), visual acuity with LVA

Distance:

Specify type of LVA and visual acuity

Right eye ---------- VA ___

Left eye ---------- VA ___

Near:

Specify type of LVA and near acuity

Right eye ---------- VA ___

Left eye ---------- VA ___

	Right	Left
Can discern print ≤ 5mm	☐ 1	☐
Can discern print > 5mm	☐ 2	☐
Cannot discern print	☐ 3	☐
	(132)	(133)

H. EYE EXAMINATION - AETIOLOGY OF VISUAL LOSS

Select one of the categories 1-5 for each eye
Tick all that apply within the selected category.

		Right eye	Definite	Suspect	Left eye	Definite	Suspect
1) Hereditary Disease:	Chromosomal	(134)	☐ 1	☐ 2	(135)	☐ 1	☐ 2
	Mitochondrial	(136)	☐	☐	(137)	☐	☐
	Autosomal dominant	(138)	☐	☐	(139)	☐	☐
	Autosomal recessive	(140)	☐	☐	(141)	☐	☐
	X-linked	(142)	☐	☐	(143)	☐	☐
	Cannot Specify	(144)	☐		(145)	☐	
2) Intrauterine factor:	Rubella	(146)	☐ 1	☐ 2	(147)	☐ 1	☐ 2
	Toxoplasmosis	(148)	☐	☐	(149)	☐	☐
	Drugs / alcohol	(150)	☐	☐	(151)	☐	☐
	Other, Specify ----------	(152)	☐	☐	(153)	☐	☐
3) Perinatal/ Neonatal factor:	Cerebral hypoxia /injury	(154)	☐ 1	☐ 2	(155)	☐ 1	☐ 2
	R.O.P.	(156)	☐	☐	(157)	☐	☐
	Ophthalmia neonatorum	(158)	☐	☐	(159)	☐	☐
	Other Specify ----------	(160)	☐	☐	(161)	☐	☐
4) Postnatal/ Infancy/ Childhood factor:	Vitamin A deficiency	(162)	☐ 1	☐ 2	(163)	☐ 1	☐ 2
	Measles	(164)	☐	☐	(165)	☐	☐
	Neoplasm	(166)	☐	☐	(167)	☐	☐
	Trauma	(168)	☐	☐	(169)	☐	☐
	Harmful Trad. Practices	(170)	☐	☐	(171)	☐	☐
	Other Specify ----------	(172)	☐	☐	(173)	☐	☐
5) Cannot determine (unknown aetiology))	Cataract	(174)	☐		(175)	☐	
	Glaucoma / Buphthalmos	(176)	☐		(177)	☐	
	Retinoblastoma, no FH	(178)	☐		(179)	☐	
	Abnormality since birth	(180)	☐		(181)	☐	
	Specify ----------						
	Other Specify ----------	(182)	☐		(183)	☐	

THE MAIN AETIOLOGY OF VISUAL LOSS
FOR THE CHILD
SELECT ONE FROM POSITIONS 134-183 [___] (184)

I. ACTION NEEDED

1) Optical — Tick all that apply

None	(185) ☐
Refraction later	(186) ☐
Spectacles	(187) ☐
Low vision aid	(188) ☐

2) Medical / Surgical — Tick all that apply

None	(189) ☐
Medication	(190) ☐
Surgery	(191) ☐
Specify ----------	
Other	(192) ☐
Specify ----------	

J. PROGNOSIS FOR VISION — Tick one box only for each eye

	Right eye	Left eye
Could be improved	☐ 1	☐ 1
Likely to remain stable	☐ 2	☐ 2
Likely to deteriorate	☐ 3	☐ 3
	(193)	(194)

K. EDUCATION

1) Present schooling — Tick one box only

Special school for the blind	☐ 1
Special school for the multiply handicapped	☐ 2
Integrated education	☐ 3
None	☐ 4
Other	☐ 5
Specify ----------	(195)

2) Recommendations:

	YES	NO
Change in schooling recommended	(196) ☐	☐

Specify ----------

L. FULL DIAGNOSIS

Specify full anatomical and aetiological diagnosis:

Right eye:

Left eye:

M. EXAMINER:

Examined by

Date (month) (year) (197-200)

mm 0 5 10 15 20 25 30

5mm

dition. Based on the major anatomical site of visual loss (reported in section F), the etiology is recorded for each eye and then for the child. If these differ between the right eye and the left eye, the etiology of visual loss for the child should be that of the major anatomical disorder for the child (recorded at the end of section F).

The category "Cannot determine, unknown etiology" is filled in when the underlying etiology is not known. This includes conditions present since birth and those that cannot be specifically attributed to genetic or intrauterine factors.

Section I. Action needed. The examination having been completed, this section records whether optical, surgical or medical intervention is required. The type of surgery should be specified.

Section J. Prognosis for vision. This section records the likely prognosis for vision.

Section K. Education. The type of education the child is currently receiving is recorded, and whether a change in schooling or other assessment is recommended.

Section L. Full diagnosis. The full diagnosis is recorded with as many details as possible.

Section M. Examiner. This section gives the names of the examiners.

Database

A database has been created to accompany the form; it includes the facility for standardized statistical analysis of data by anatomical disorder, etiological category, age group and sex. The database has been designed so that it can be used by those with little experience of computerized data management.

A centralized data bank will be kept at ICEH in London, and in WHO in Geneva.

Pilot studies and experience

The form has been reviewed by ophthalmologists with a special interest in paediatric ophthalmology, and modified during the course of examining approximately 1600 children in schools for the blind in four different continents over an 18-month period. During the pilot studies, children were examined by local opthalmologists as well as by those involved with developing the form. The findings of some of these studies have been published (*6*, *7*). The form has so many details that an initial short period of instruction is usually required for those not familiar with paediatric ophthalmology. With a team of trained personnel, it is possible to examine and complete the form on 5–8 children/hour in schools for the blind.

Discussion

The new form, which is focused on children with blindness and low vision, is more detailed than the comparable form in general use for all age groups,[b] and reflects the more varied causes of visual loss in children. The majority of the sections in the form have to be completed by an ophthalmologist because it was not designed to be used by trained field workers or paramedical staff. The prevalence of childhood blindness is less than that of adult blindness, and the numbers in any one study are likely to be small. Additional sections have been included in the new form so that requirements for educational and optical services can also be evaluated.

The form and coding instructions have been translated into French and Spanish, and copies with the coding instructions and database are available from the International Centre for Eye Health, London, and the WHO Programme for the Prevention of Blindness, Geneva.

[b] See footnote *a* on page 485.

Acknowledgement

The valuable support provided for this work by Christoffel Blindenmission, Sight Savers, and the Oxford Ophthalmological Congress Award is gratefully acknowledged.

References

1. *Guidelines for programmes for the prevention of blindness.* Geneva, World Health Organization, 1979, p. 16.
2. *Prevention of childhood blindness.* Geneva, World Health Organization, 1992.
3. **Foster, A. & Gilbert, C.** Epidemiology of childhood blindness. *Eye*, **6**: 173–176 (1992).
4. **Foster, A.** Childhood blindness. *Eye*, **2**(suppl.): S27–S36 (1988).
5. *International classification of impairments, disabilities and handicaps. A manual of classification relating to the consequences of disease.* Geneva, World Health Organization, 1980.
6. **Gilbert, C. et al.** Causes of childhood blindness: results from West Africa, South India and Chile. *Eye*, **7**: 184–188 (1993).
7. **Gilbert, C. & Foster, A.** Causes of childhood blindness in Thailand and the Philippines. *International ophthalmology* (in press).