

# **Avoidable waste in ophthalmic epidemiology: a review of blindness prevalence surveys in low and middle income countries 2000–2014**

Jacqueline **Ramke**<sup>1</sup>  
Hannah **Kuper**<sup>2</sup>  
Hans **Limburg**<sup>3</sup>  
Jennifer **Kinloch**<sup>4</sup>  
Wenhui **Zhu**<sup>5</sup>  
Van C **Lansingh**<sup>6</sup>  
Allen **Foster**<sup>2</sup>  
Nathan **Congdon**<sup>7 8 9</sup>  
Clare E **Gilbert**<sup>2</sup>

1. University of Auckland, School of Population Health, Faculty of Medicine and Health Sciences, Auckland, New Zealand
2. London School of Hygiene and Tropical Medicine, International Centre for Eye Health, Clinical Research Unit, Department of Infectious & Tropical Diseases, London, UK
3. Health Information Services, Nijenburg 32, 1613LC Grootebroek, Netherlands
4. Bath Spa University, School of Science, Enterprise, and Environment, Bath, UK
5. The First Affiliated Hospital of Sun Yat-sen University, Department of Ophthalmology, Guangzhou, Guangdong, China
6. Help Me See Latin America, Instituto Mexicano de Oftalmología, Queretaro, Mexico
7. Queen's University Belfast, TREE, Centre for Public Health, Belfast UK
8. Sun Yat-sen University, Preventive Ophthalmology Department, Zhongshan Ophthalmic Center, Guangzhou, China
9. Orbis International, NY, USA

**Corresponding Author:** Jacqueline Ramke    [jramke@gmail.com](mailto:jramke@gmail.com)

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## **Abstract**

### **Purpose**

To assess avoidable waste in ophthalmic epidemiology by examining the availability of information from blindness prevalence surveys undertaken in low and middle income countries (LMICs) between 2000 and 2014.

### **Methods**

On December 1 2016 we searched MEDLINE, EMBASE and Web of Science databases for cross-sectional blindness prevalence surveys undertaken in LMICs between 2000–2014. All surveys listed on the RAAB Repository website were also considered. For each survey we assessed i) availability of scientific publication, survey report, summary results tables and/or datasets; ii) time to publication and journal attributes; iii) variability in blindness definitions; and iv) rigour when information was available from more than one source.

### **Results**

Of the 279 included surveys (from 68 countries) 186 (67%) used RAAB methodology; 146 (52%) were published in a scientific journal, 57 (20%) were published in a journal and on the RAAB repository, and 76 (27%) were on the Repository only (8% had tables; 19% had no information available beyond registration). Datasets were available for 50 RAABs (18% of included surveys). Time to publication ranged from <1–11 years (mean, standard deviation 2.8±1.8 years). The extent of blindness definitions reported within studies varied; those with both a published report and RAAB Repository tables were most complete. Discrepancies were found in participant numbers (14%) and blindness prevalence (15%) reported in publications and RAAB tables of the same survey.

### **Conclusion**

Strategies are needed to improve the availability, consistency and quality of information reported from blindness prevalence surveys, and hence reduce avoidable waste.

## Introduction

Good quality evidence is required to achieve the ambitious goal of universal eye health set by the World Health Assembly in 2013.<sup>1</sup> This evidence includes data from prevalence surveys on the magnitude and causes of visual impairment and blindness. Over the past two decades an increasing number of prevalence surveys have been undertaken, especially in low and middle income countries (LMICs). The current global eye health action plan of the World Health Organization (WHO) calls for more prevalence surveys to be undertaken to provide up-to-date local evidence for planning.<sup>2</sup>

An important factor in the recent increase in blindness prevalence surveys is the development of a protocol and software that can be downloaded freely from the internet<sup>3</sup>—the *Rapid Assessment of Avoidable Blindness* (RAAB) and its predecessor the *Rapid Assessment of Cataract Surgical Services* (RACSS, hereafter collectively referred to as RAAB). RAAB is a population based survey of visual impairment in people aged 50 years and above that correlated well with data from total population surveys.<sup>4</sup> Because RAAB surveys are restricted to those aged 50 years and above, where blindness prevalence is highest,<sup>4</sup> the sample size is smaller, and the survey is shorter and less expensive than traditional surveys.<sup>5</sup> RAAB uses simple examination methods, and the software includes a data entry and automated analysis package.

A consequence of the increasing number of blindness prevalence surveys is a reluctance by editors of scientific journals to publish them, as they offer little novelty in terms of purpose or methodology.<sup>6</sup> In this publishing environment the online RAAB Repository<sup>7</sup> has played an important role in dissemination of survey findings. The Repository was launched in May 2014 and by December 1 2016 the webmaster (HL) had registered 266 RAABs on the Repository.

In 2009 Chalmers and Glasziou highlighted the issue of “avoidable waste” in the production and reporting of health research.<sup>8</sup> In the context of ophthalmic epidemiology, sources of avoidable waste include duplication of effort (i.e. numerous surveys in the same area); and survey reports remaining unpublished, gaining publication after a long delay, or being incomplete or of poor quality. The aim of this review was to assess avoidable waste in ophthalmic epidemiology by examining the availability of information from blindness prevalence surveys undertaken in LMICs between 2000 and 2014.

## Methods

### Search strategy

We sought to identify cross-sectional surveys of visual impairment and/or blindness undertaken in LMICs between the years 2000 and 2014. On December 1 2016 MEDLINE, EMBASE and Web of Science (2000 to November 2016) were searched without language restrictions using the algorithm '*blindness or vis\* impairment or low vision*' and '*prevalence or rapid assessment or population-based*'. To identify additional surveys to include, we examined reference lists of all articles selected for screening, as well as review articles of blindness prevalence.<sup>9-16</sup> All surveys listed on the RAAB Repository website<sup>7</sup> on December 1 2016 were reviewed.

### Study selection

The titles of all citations identified during the initial search were systematically screened by two authors (JR and JK) to exclude publications that clearly did not meet the inclusion criteria. The full-text article was retrieved for review if the citation was potentially relevant. All surveys listed on the RAAB Repository website<sup>7</sup> on December 1 2016 were reviewed and for each eligible survey all available reports, tables and datasets were downloaded.

Surveys were included that:

- (i) took place from January 2000 to December 2014;
- (ii) were conducted in countries classified by The World Bank as LMIC in 2014;<sup>17</sup>
- (iii) presented population-based data; and
- (iv) provided information on bilateral blindness prevalence.

We excluded surveys that:

- (i) focused on specific populations (e.g. in hospitals, 'institutionalised', 'diabetics');
- (ii) only included children;
- (iii) presented self-reported blindness; or
- (iv) only presented the prevalence of disease-specific blindness without providing overall blindness prevalence data.

If a survey report was published in two languages, the English version was assessed.

## Data extraction and analysis

For each survey included in the review the following items were extracted by one author (JR or WZ): the location, the year the survey concluded, the year it was published, and whether the RAAB protocol was used. We also recorded whether it was published in a scientific journal, and whether the journal was open-access on 1 December 2016. For RAABs, we recorded whether it was registered on the RAAB Repository, and whether a survey report, summary tables of results and the survey dataset had been uploaded to the Repository.

Surveys were categorised as those

- i) only published in a scientific journal;
- ii) only with RAAB results tables on the Repository;
- iii) published and with RAAB results tables on the Repository; and
- iv) only registered on the Repository.

Descriptive analysis included the proportion of studies that used the RAAB protocol; the proportion that were published and the lag-time to publishing from the time of the survey; the proportion making tables and datasets available; and the proportion published in an open-access journal.

To assess variability of information available within surveys we extracted information on whether surveys reported blindness prevalence by one or both of:

- i) best-corrected and presenting visual acuity;
- ii) a cut-off of  $<3/60$  and  $<6/60$ , the World Health Organization categories of blindness and severe visual impairment;
- iii) unilateral and bilateral;
- iv) the sample prevalence and the prevalence adjusted to the age and sex profile of the survey area;
- v) overall as well as disaggregated by sex.

Finally, as a test of rigour, for the surveys that had two sources of information available (i.e. publication or survey report and RAAB tables) any discrepancy between the data reported in the two sources in relation to i) the number of participants, and ii) the sample blindness prevalence and confidence interval were noted.

Ethics exemption was granted for this literature review by from the London School of Hygiene & Tropical Medicine (Reference 10779).

## **RESULTS**

### **Study selection**

A summary of study selection is presented in Figure 1. From the literature search a total of 4,818 publications were identified for screening, including 24 identified from citation lists of screened publications. Following screening of titles and abstracts, 253 publications were identified for full review; the majority were in English, with 44 in Chinese, 9 in Spanish and none identified in other languages. After the initial assessment against the inclusion and exclusion criteria, 109 records were excluded for reasons provided in Figure 1. This left 144 publications—including 15 in Chinese and three in Spanish—reporting 156 separate studies for inclusion in this analysis.

In addition to the literature search, the 266 RAAB surveys listed on the RAAB Repository on December 1 2016 were assessed against the inclusion and exclusion criteria. Of these, 76 were excluded for reasons provided in Figure 1, leaving 190 studies for inclusion in this analysis. Once duplicates appearing in both searches were removed, 279 separate studies were included in this analysis (listed in Supplemental Tables 1 and 2).

### **Description of included studies**

The 279 studies were undertaken in 68 countries (Table 1) and two-thirds used either RAAB or RACSS protocol (n=186; 67%). Countries with the most studies were China (45), Vietnam (28), India (21), Bangladesh (14), Nepal (14) and Nigeria (14). One-quarter of LMICs with a population  $\geq 20$  million (11/43) and 62% of LMICs with a population  $< 20$  million (58/93) had no study undertaken between 2000 and 2014 (Table 1).

### *Published studies*

We identified 203 published studies: 165 in a scientific journal (in 153 manuscripts, including 72 RAABs reported in 60 manuscripts) and 38 in a report of study methods and results available on the RAAB Repository. Seventeen of these studies (8%) sampled the whole country, while the remainder were limited to regions within countries (Table 2).

Information on when a study was completed was available for 188 of the published studies (93%). The time to publication ranged from <1 year (for study reports) to 11 years, with a mean and standard deviation of  $2.8 \pm 1.8$  years. Approximately half of the studies were published within two years ( $n=99$ ; 49%) of study completion, and 85% of all studies were published within five years of study completion (172/203). The number of studies published increased over time, as did the proportion published in open-access journals (from 40% in 2000-4 to 57% in 2010-14; Table 2).

### *RAABs*

Of the 186 RAABs, more than half ( $n=110$ ; 59%) had published results (72 in scientific journals and 38 in online reports). The remaining 76 studies (41%) only had information available on the Repository; twenty-three of these had RAAB summary tables and/or datasets available and 53 (28% of all identified RAABs) had no information available beyond registration on the Repository.

Of the 53 RAABs where no information was available, 16 (30%) were conducted in the last 3 years, 11 (21%) 4-5 years ago, and 26 (49%) more than 5 years ago. Studies without results available were most often conducted in Malaysia ( $n=5$ ), Indonesia ( $n=5$ ) and Vietnam ( $n=4$ ) (Supplemental Table 2). Fifty RAABs (27%) had datasets available on the Repository.

### **Available information within studies**

Table 3 shows reporting from the 226 surveys that were published and/or had RAAB tables available. Surveys with both RAAB tables and a study report available provided results for all five combinations of blindness definitions, while reporting was more variable for surveys that were published only (i.e. without summary results tables). Blindness prevalence was most commonly reported disaggregated by sex as well as overall (91%). Reporting both <3/60 and <6/60 cut-offs was also frequent (69%), followed by reporting both bilateral and unilateral blindness (67%), the sample and adjusted prevalence (60%) and finally, reporting best-corrected as well as presenting visual acuity (55%). The assessment for rigour showed discrepancies between the tables and publication for both outcomes—the number of participants and blindness prevalence differed 14% and 15% of the time respectively.

## DISCUSSION

To avoid waste, data from surveys should be summarised in a report which is made publicly available in a timely fashion, so that the results can be used by stakeholders for prioritising and planning future services. This review of blindness prevalence surveys undertaken between 2000 and 2014 identified some good practices in relation to availability of information. For studies that were published, the majority achieved this within a reasonable time frame, and the proportion of studies available from open-access journals has increased (Table 2). The Repository provided an accessible infrastructure to track publication of registered surveys, as well as housing survey results, reports and datasets. The Repository also increased availability of study information and improved completeness of reporting through the provision of RAAB results tables (Table 3).

This review also highlights where improvements can be made. First, survey reports remained unavailable for 1 in 5 of all identified RAABs [n=37] four or more years after study completion. These studies may yet be published in a scientific journal, but summary reports (and datasets) could be made available regardless, as demonstrated by the 23 unpublished studies with results tables available on the Repository. Failing to make a study report available is a waste of resources, and researchers must be accountable for the investment made by funding agencies, often using public resources. Unpublished research also has opportunity costs, including other research projects that could have been supported, and the services that members of the survey team—often eye health workers—could have delivered during time spent undertaking the survey.

Second, we identified discrepancies in the range of blindness definitions reported (Table 3). The utility of survey findings would increase if comparable definitions were more consistently reported. Our findings reinforce the call for specific reporting guidelines to be developed for blindness prevalence surveys to ensure comparable information is collected and reported.<sup>18</sup>

Third, the global coverage of surveys is unequal, with some countries having a high number of surveys relative to their population, while other countries have no information available from surveys (Table 1). A better distribution could be achieved if guidance is developed on how often a population based survey of eye health / visual impairment is required for what population size.



Fourth, only 1 in 6 studies (16%) provided full datasets. Whether researchers want to share data or not, the era of data sharing in epidemiology has arrived<sup>19</sup> and is increasingly expected. Ophthalmic epidemiology has already seen the benefits of data sharing in syntheses to estimate global blindness<sup>9,12</sup> and the incidence of vision-impairing cataract.<sup>20,21</sup> Another benefit of data sharing is the improvement in data quality that occurs when it is known it will ultimately be shared.<sup>22</sup> The discrepancies we identified between the datasets and published reports (Table 3) indicate the need for quality improvement in reporting of information. Beyond ensuring appropriate consent processes are in place, questions remain for implementation of data sharing, such as how to assure the quality of analyses arising from data sharing, and how to manage derived variables.<sup>19</sup> The societal advantages of data sharing require stakeholders to address these questions rather than use them as an excuse for inaction, and fortunately guidance is emerging.<sup>22,23</sup>

Our analysis must be interpreted in the context of its limitations. We were unable to assess non-RAAB studies that have been completed yet remain unpublished, as there is currently no registration process or repository for these studies. Further, registration on the Repository is currently not compulsory for RAABs, so it is likely that there are completed RAABs which we did not identify. The registration role of the Repository can be further enhanced by promoting compulsory prospective registration (for instance, by it being a requirement for use of the RAAB survey tools, or before receiving funding).

We were also unable to assess whether studies had been published locally and used for local planning, as no mechanism currently exists to measure this. It is possible some of the studies we categorised as unpublished have been summarised in reports not identified by our search. **This information gap could be overcome in future if principal investigators reported to the Repository regarding how survey results were disseminated locally.** While we performed our search without language restriction, it is likely that the databases we searched fail to index every study published in a language other than English.<sup>22,24</sup> Finally, we did not contact researchers listed on the Repository to request the tables and datasets from their study or to find whether reports were available elsewhere. Doing so may have increased the proportion of studies for which information was available, but our results represent what is readily available and accessible.

Beyond increasing the availability of information, strategies are also required to increase the translation of research to policy and planning. Failing to analyse the results of prevalence surveys within the local context to inform planning and action is possibly the biggest (if currently unquantified) source of waste in ophthalmic epidemiology. Together with spending on prevalence surveys it is important that resources are also made available to translate the evidence into meaningful activities based on the results of the survey, and to do more intervention research to identify effective strategies to reduce blindness.<sup>25</sup>

Investment in prevalence surveys in LMICs is set to continue in the pursuit of universal eye health.<sup>2</sup> Availability and quality of information from blindness prevalence surveys would improve if prospective registration of studies and availability of study reports and datasets becomes the expectation rather than the exception.<sup>26</sup> The RAAB Repository facilitates study registration, full and consistent reporting of results and universal data access and in so doing provides a rare and valuable infrastructure<sup>27,28</sup> to disseminate study information. We hope that this analysis promotes discussion amongst the ophthalmic community, increases the availability of study information, reduces avoidable waste from surveys and ultimately improves eye health.

**Table 1: Blindness prevalence surveys undertaken in low and middle income countries 2000-2014**

Country	World bank estimated 2010 population (millions)*	Time period			Total
		2000-4	2005-9	2010-14	
<b>Countries &lt;20 million</b>					
Bhutan†	0.7	-	1	-	1
Bolivia	9.9	-	-	1	1
Burkina Fasso	15.6	-	-	1	1
Burundi	9.5	-	-	1	1
Cambodia	14.4	3	1	1	5
Cuba	11.3	-	1	1	2
Dominican Republic†	9.9	-	1	-	1
Ecuador†	14.9	-	1	-	1
El Salvador†	6.0	-	-	1	1
Eritrea†	4.7	-	1	-	1
Fiji	0.9	-	1	-	1
Guatemala	14.7	1	-	-	1
Guinea Bissau	1.6	-	-	1	1
Honduras†	7.5	-	-	1	1
Jordan	6.0	-	-	1	1
Laos	6.3	-	1	-	1
Liberia	4.0	-	-	1	1
Libya†	6.3	-	-	1	1
Malawi	14.8	-	1	1	2
Mali	15.2	-	1	1	2
Moldova†	3.6	-	-	1	1
Mongolia	2.7	-	-	4	4
OPT	3.8	-	1	-	1
Panama†	3.6	-	-	1	1
Paraguay†	6.2	-	1	1	2
PNG	6.8	-	1	-	1
Rwanda	10.3	-	1	-	1
Senegal	13.0	-	-	2	2
Sierra Leone	5.8	-	-	1	1
South Sudan	10.1	-	1	-	1
Suriname	0.5	-	-	1	1
The Gambia	1.7	-	1	-	1
Timor-Leste†	1.1	-	1	1	2
Turkmenistan†	5.0	1	-	-	1
Zambia	13.9	-	-	1	1
<b>Countries ≥20 million<sup>^</sup></b>					
Afghanistan	28.0	-	-	3	3
Bangladesh††	151.6	1	4	9	14
Brazil	198.6	2	1	-	3
Burma	51.7	7	1	1	9
China	1337.7	7	22	14	43
Columbia	45.9	-	1	-	1
Egypt	82.0	-	2	-	2
Ethiopia††	87.6	1	3	1	5
Ghana	24.3	1	2	-	3
India	1231.0	4	5	7	16
Indonesia	241.6	3	1	3	7
Iran	74.3	1	4	3	8
Kenya	40.3	1	3	1	5
Madagascar	21.1	-	-	1	1
Malaysia	28.1	1	-	6	7
Mexico	118.6	-	1	2	3
Mozambique	24.3	-	-	2	2
Nepal	26.9	1	11	2	14
Nigeria††	159.4	5	6	1	12
North Korea	24.5	-	-	1	1
Pakistan††	170.0	2	-	-	2
Peru	29.4	1	-	1	2
Philippines	93.0	-	2	1	3
South Africa	50.8	-	2	2	4
Sri Lanka	20.7	-	1	-	2
Sudan	36.1	-	-	7	7
Tanzania	45.6	-	2	-	2
Thailand†	66.7	-	-	1	1
Uganda	33.1	-	1	3	3
Vietnam	86.9	8	16	4	28
Yemen	23.6	1	1	1	3
<b>Total</b>		<b>52</b>	<b>109</b>	<b>103</b>	<b>264<sup>^^</sup></b>

\*downloaded from <http://data.worldbank.org/indicator/SP.POP.TOTL> [last updated 14/10/2015];

<sup>^</sup>32/43 (74%) LMICs with a population ≥20 million in 2010 had at least one survey undertaken between 2000 and 2014; the 11 countries ≥20 million population without at least one survey were Algeria, Angola, Congo, Cote d'Ivoire, Iraq, Morocco, Romania, Syrian Arab Republic, Turkey, Ukraine, Uzbekistan;

<sup>^^</sup>15 studies did not report the date of the survey and were not included in this table (India=5; Cameroon, China, Nigeria=2; Botswana, Kenya, Pakistan, Tanzania=1). (Botswana study sampled from the national population);

† Includes at least one RAAB study that used a national sampling frame;

†† Includes at least one non-RAAB study that used a national sampling frame.

**Table 2:** Summary of included studies (blindness prevalence surveys in low and middle income countries 2000—2014)

Description	RAAB studies*	Non- RAAB studies	All studies
<b>Included Studies</b>	<b>n=186</b>	<b>n=93</b>	<b>n=279</b>
<b>Number of countries</b>	63	25	68
<b>Publication</b>			
Scientific journal	72 (39%) (in 60 manuscripts)	93 (100%)	165 (59%)
Online report	38 (20%)	—	38 (14%)
Not published	76 (41%)	Unknown	76 (27%)
<b>Results Dissemination</b>			
Published only	53 (28%)	93 (100%)	146 (52%)
On Repository			
Published, datasets and results tables	34 (18%)	—	34 (12%)
Published and results tables	23 (12%)	—	23 (8%)
Datasets and results tables	16 (9%)	—	16 (6%)
Results tables	7 (4%)	—	7 (3%)
Registered only	53 (28%)	—	53 (19%)
<b>Published studies</b>	<b>n=110</b>	<b>n=93</b>	<b>n=203</b>
<b>National studies</b>	12 (11%)	5 (5%)	17 (8%)
<b>Time to publication</b>			
Unknown**	6 (5%)	9 (10%)	15 (7%)
≤2 years	61 (55%)	38 (41%)	99 (49%)
>2 years≤5 years	33 (30%)	40 (43%)	73 (36%)
>5 years	10 (9%)	6 (6%)	16 (8%)
<b>Scientific Journals</b>	<b>n=60</b>	<b>n=93</b>	<b>n=153</b>
<b>Language</b>			
English	54 (90%)	78 (84%)	132 (86%)
Chinese	—	15 (16%)	15 (10%)
Spanish	6 (10%)	—	6 (4%)
<b>Open-access (year published)†</b>			
2000-4	0/2 (0%)	4/8 (50%)	4/10 (40%)
2005-9	9/21 (43%)	19/35 (54%)	28/56 (50%)
2010-14	20/33 (61%)	20/37 (54%)	40/70 (57%)

\* includes RACSS studies;

\*\*study completion date not given;

†28 studies published after 2014 not included.

**Table 3:** Availability of information within included studies\* (blindness prevalence surveys in low and middle income countries 2000—2014)

	Availability of study information			Total <i>n</i> =226 <sup>^</sup>
	Published Only		RAAB Tables ± Published ± Datasets**	
	RAAB <i>n</i> =53	Not RAAB <i>n</i> =93		
	%	%	%	%
<b>Blindness definition</b>				
<b><i>Proportion of studies that report blindness in terms of both:</i></b>				
Best-corrected and presenting visual acuity <3/60 and <6/60 cut-off	26	33	100	55
Unilateral and bilateral visual acuity	47	51	100	67
Sample and adjusted	60	26	100	60
Overall and disaggregated by sex	83	87	100	91
<b>Rigour</b>			% (n)	
<b><i>Proportion of studies with consistent results reported in RAAB tables and published report</i></b>				
Number of participants	-	-	86 (49/57)	-
Blindness prevalence †	-	-	85 (47/55)	-

\*53 studies registered on the RAAB Repository with no further information were not included in this table;

\*\* includes 57 studies that were published;

† 2 studies did not report sample prevalence in the publication so this item could not be assessed.

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