



Review

Eye injury registries – A systematic review

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ABSTRACT

Objectives: Registries are integral to monitoring, surveying, treating, preventing and prognosticating trauma. The quantity and quality of data must justify a change or intervention in treatment and/or preventive strategies and must be collected while balancing the cost and time invested in the registry. This review documents the quality, completeness and operational and funding models for ocular trauma registries worldwide.

Methods: The databases CENTRAL, MEDLINE, EMBASE and Informit Health Collection were searched using key word and mesh terms for: “Eye injury”, “Ocular trauma”, “Eye injury prevention”, “Eye protection”, “Registry”. To find relevant unpublished articles and theses, clinicaltrials.gov, Trip, MedNar and Google Scholar were searched using the key words “eye injury” OR “ocular trauma” AND “registry*”. No date or language restrictions were applied. The quality of registry data was assessed against published measures including design, operation and data quality.

Results: The electronic search retrieved 528 distinct published articles; 61 articles were assessed for eligibility. Of the 61 articles identified, 28 were eligible to be included in the review, with cross-referencing identifying a further 7 articles. The source of most articles on ocular trauma registries was the United States, followed by Germany and China. Patient follow-up was conducted in 31 studies, with 6 months being the most frequently reported period. Issues with data quality included incomplete data such as presence or absence of eye protection and initial visual acuity. Attrition bias was controlled by the United States Eye Injury Register with follow-up. Patients without follow-up data were removed for some studies and this may have introduced bias.

Conclusion: National, state and hospital-based ocular trauma registries have contributed significantly to our understanding of ocular trauma. The United States has the most frequently cited and well-resourced ocular trauma registries. It is anticipated that this review will guide the development of future registries for ocular trauma in order to inform evidence-based prevention strategies and, ultimately, improve visual outcomes. We recommend the development of a consensus guidelines for international ocular trauma registry that includes mechanism and context of injury and visual outcomes, to permit international comparison that can be implemented at low cost with secure data capture.

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Introduction

Eye Injuries and the resulting visual and economic loss continue to represent a significant burden to both developed and developing countries [1]. The incidence of primary eye trauma has been estimated at 3.0 per 100,000 population [2], with a lifetime prevalence of 13.5% for males in the United States [3]. In the past, most eye injuries occurred at work but now more occur at home or in a 'public area' [4]. Assault- and fall-related eye injuries can be particularly devastating, with half of affected individuals reported as having no perception of light [4]. The immediate cost as well as the long-term implications of vision loss are significant to the patient and the community.

A registry is defined as a dedicated data repository for trauma patients that forms the basis for monitoring and optimising 'Total Quality Improvement' (TQI) activities. Ophthalmology registries have contributed broadly to our knowledge [5] and are known to be effective drivers for evidence-based improvements in patient management [6] and prognostication of trauma [7]. High-income countries have achieved improved organization and planning of trauma care through implementing systems incorporating TQI. Guidelines published by the World Health Organization in 2004 sought to 'establish achievable and affordable standards for injury care'.

The potential for a trauma registry to improve patient outcomes, contribute to regulatory guidelines and inform advocacy relies upon the data quality (DQ). Measures of DQ include completeness, accuracy, precision, correctness, consistency, and timeliness of data [8]. When designing a registry, the time and cost of collecting data and the amount and quality of data collected must be balanced with the goal of informing cost-saving public health outcomes. Whilst many registries identify patients prospectively, data entry often occurs retrospectively, with valuable contextual information regarding the circumstances of the injury often not available. No clear guidelines currently exist for constructing a registry dedicated to ocular trauma.

The primary objective of this review is to evaluate and report on the published literature from ocular trauma registries internationally, past and present. A secondary objective is to determine the initial funding and ongoing operational models.

Methods

A systematic review of the literature was performed. Abstracts were identified by searching the following databases on the 16th of August 2018: CENTRAL (The Cochrane Library. www.thecochranelibrary.com) MEDLINE, EMBASE and Informit Health Collection.

Search terms used for identifying the articles were key word and mesh terms for: "Eye injury, "Ocular trauma", "Eye injury prevention", "Eye protection", "Registry". The exact search strings used were: MEDLINE (MESH terms "registries" OR "Trauma Severity Indices or Index" AND "Eye Injuries" with keywords "eye injur*" OR "ocular trauma" OR "eye inj*adj (penetrating or perforating)" AND "registr*" OR "Trauma severity indices"), CENTRAL ("eye injury") and EMBASE (Appendix 3), Informit ((eye injur*) OR (ocular trauma) OR (eye injur* adj3penetrating) AND (registr*)). To find relevant unpublished articles and theses, clinicaltrials.gov, Trip, MedNar and Google Scholar were searched using the key words "eye injury" OR "ocular trauma" AND "registry*".

No language or date restrictions were applied. Our review was conducted in compliance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [9]. The bibliographies of included studies were screened to identify relevant publications. Experts in the field were contacted to ask if they were aware of any other relevant registries.

Selection of studies

Studies were included if a registry was utilized to collect cases of ocular or adnexal trauma from a community or hospital-based population and data were captured either prospectively or retrospectively. We defined a registry as a 'file of data concerning all cases of a particular disease or health relevant condition in a defined population' [10]. Retrospective epidemiological studies and case reports or case series were excluded. Studies based on extractions from a general or other non-ocular trauma registry were also excluded.

Duplicates were identified and removed with EndNote software version X7.7.1 (Thomson Reuters, New York, USA). The titles, abstracts and, where appropriate, full text were screened independently through Covidence © by two authors (A.K.H., L. K.) to identify eligible studies. Each author assessed the articles according to the inclusion criteria for this review. Disagreements were resolved by discussion.

Quality analysis

Studies were assessed for methodological and data quality of the registries against published criteria previously validated for registries [11]. Operational measures of quality included the presence of a clear statement of the research objectives, patient inclusion and exclusion criteria and the choice of outcomes that are clinically relevant to the objectives. Evidence and data quality was

assessed by examining external, internal validity and analysis and reporting measures and are reported in Table 1.

Data synthesis and analysis

A.K.H. extracted data on included studies using an electronic form (See APP 1) developed and agreed by the authors and piloted on three representative studies. The form was designed to capture information on the study setting and design. Full text review of one Chinese language paper [12] was undertaken by a Chinese-speaking colleague to determine its eligibility and it was excluded by 2 authors (A.K.H. and L.K.) based on this translation.

Results

The electronic search retrieved abstracts of 528 distinct published articles; 61 articles were eligible for full-text review. Of the 61 articles, 28 were eligible to be included in the review, with cross-referencing identifying a further 7 articles (see Fig. 1 PRISMA). The studies were published between 1987 and 2014, with the largest number from the period 2001 to 2005 (See Table 2).

Features of studies

Country of origin

Registries from the United States had the largest number of publications associated with them (24, 69%) and the next largest contributor was China (6, 17%). Two of the studies were international, with data from more than one country. The United States Eye Injury Register (USEIR) and its precursors, the Eye Injury Register of Indiana and Eye Injury Register of Alabama, represented the registry with the largest number of identified publications (17).

Structure and recruitment

Registry data were collected from general or trauma-specific hospital-based ophthalmology clinics and private ophthalmology practices, or a combination of these. Patients were included based on a definition of a serious eye injury as an “injury that involved permanent and significant structural or functional changes” for 18% of the studies. A total of 58,000 patients were reported in the included articles.

Proprietary computer software was used for data collection in all of the studies, with FileMaker Pro used for EIRIN and USEIR studies and Epidata based software for EIVS. Data were transferred either on disk or via the internet for all registries.

Patients from the entire data set or a subset were reported on with specific research questions to identify either the mechanism, cause or type of injury or based on presenting vision. Data collected included age, gender, occupation, location, mechanism, presence of eye protection or spectacles, baseline visual acuity (VA), tissues damaged, comorbidities, surgical procedures as well as presence of alcohol or other substances. Longitudinal data were collected in 25 of the included articles, with periods ranging from 3 days to 1 year, with 6 months the most frequently reported follow-up time (22, 63%) (See Table 3).

Data quality and bias measures

DQ measures identified included completeness of data collection (9 at presentation, 11 at follow-up). The variables most often evaluated were age at follow-up (3), presenting VA (3), final BCVA (4) and the presence of eye protection or other spectacles (3) (See Table 1). The variables most often sighted as missing were initial VA and presence or absence of eye protection or other spectacles.

To mitigate issues of missing data, three studies only included cases with all data available [13–15] and telephone surveys were used in a further two studies [16,17]. A reminder letter was sent to the original filer of the case to request follow-up data at 6 months for the USEIR.

Precision, correctness and consistency checks were reported by the USEIR registry. The USEIR reports ‘extensive quality control’ being performed before the case is entered into the database, but the measures were not specified. A ‘cross check’ was conducted by staff entering data in the EIVS, with the data confirmed by the Chief of Staff. When stratifying by decade of data collection (1980–1989, 1990–1999, 2000–2010), no trends in DQ were observed.

The risk of bias was observed as low in 17 studies on measures of assessment, selection and classification. Where follow-up was reported, 7 studies were assessed as high risk for bias as they did not address loss to follow-up. A high risk of reporting bias or attrition bias was identified in three studies as they removed patients from the analysis if no outcome data were available [13,14,18].

Active follow-up was reported in two studies [16,17] with telephone calls made to control attrition bias. Selection and classification bias were considered low risk in all studies as they all provided clear inclusion and exclusion criteria. Included studies that collected their data prospectively and therefore minimised the data available for analysis were considered at lower risk of coverage bias.

Cost and funding models

Nineteen papers included information about funding, with full or part funding provided by government bodies (9 papers, including 3 by the Centre for Disease Control), non-government organisations (6), and national- or state-based ophthalmology organization (4). Not-for-profit foundations including Injury Prevention Centre, Merck Foundation, Hellen Keller Eye Research Foundation and Safety Research of National Institute of Occupational Safety and Health grants each provided funding for two studies. None of the articles provided information about cost to set up or run their registries. Of the registries identified, none were confirmed to be still operational.

Discussion

The major finding of this review is the need for international agreement on the data collection points with contextual, treatment and outcome data to be collected.

Clinical registries vs. Administrative databases

The use of registries in ophthalmology has grown in the last few decades [5]. In this systematic review we found publications for 9 registries in 6 countries specifically for ocular trauma. The value of utilising collected data to direct public health interventions has been established [6,7]. However the value of these data needs to be balanced against the time and the cost involved in its collection [19]. Many of the registries have relied on time-poor ophthalmologists & staff in busy emergency clinics to collect the data.

Administrative databases such as the National Hospital Discharge Survey, National Electronic Injury Surveillance System and the Consumer Product Safety Commission in the United States which rely on ICD cause codes, have also been valuable in reporting on a range of mechanisms of eye injuries and providing incidence data [20–23]. Ophthalmology-specific databases include the National American Academy of Ophthalmology’s Intelligent Research in Sight (IRIS), which captures data from an estimated 42% of US ophthalmologists [24]. Population-based and point-

Table 1
Research and Evidence Quality Assessment of included studies.

Year Pub.	Author/s	Data source	Research Question		External Validity		Internal Validity		Analysis & Reporting				Consistency of results compared with relevant research
			Clear Objectives	Clinically relevant outcomes	Completeness of data described	Participants clearly Identified	Data relating to exposure included	Data & consistency checks	Follow up period described & adequate	Methods described	Acceptable analytical techniques	Role & impact of missing data described	
1987	Morris [44]	EIRA	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
1988	Parver [15]	NETS	Y	Y	N	Y	N	Y	Y	N	Y	Y	Y
1989	White [45]	EIRA	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y
1992	Dannenberg [46]	NETS	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y
1992	Dannenberg [47]	NETS	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y
1993	Parver [18]	NETS	Y	Y	N	Y	N	Y	Y	N	Y	Y	Y
1994	Kuhn [16]	EIRA	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y
1994	Harvey [48]	EIRIN	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y
1994	Schein [49]	NETS & AEIR	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y
1996	Enger [17]	NETS & AEIR	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y
1996	Summner [50]	USEIR & HEIR	Y	Y	N	Y	N	Y	Y	N	Y	Y	Y
1998	Kuhn [51]	USEIR & HEIR	Y	Y	N	Y	N	Y	Y	N	Y	Y	Y
1999	Kitchens [52]	EIRIN	Y	Y	N	Y	N	Y	Y	N	Y	Y	Y
2000	Kuhn [53]	EIRA & HEIR	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y
2000	Lau [54]	US Mil EIR	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y
2000	May [55]	USEIR	Y	Y	N	Y	N	Y	Y	N	Y	Y	Y
2001	Viestenz [56]	FOCR	Y	Y	N	Y	N	Y	Y	N	Y	Y	Y
2002	Viestenz [57]	EOCR	Y	Y	N	Y	N	Y	Y	N	Y	Y	Y
2002	Viestenz [58]	EOCR	Y	Y	N	Y	N	Y	Y	N	Y	Y	Y
2002	Kuhn [59]	USEIR	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y
2002	Kuhn [60]	USEIR & HEIR	Y	Y	N	Y	N	Y	Y	N	Y	Y	Y
2004	Viestenz [61]	FOCR	Y	Y	N	Y	N	Y	Y	N	Y	Y	Y
2004	Kuhn [62]	USEIR	Y	Y	N	Y	N	Y	Y	N	Y	Y	Y
2004	Catalano [63]	USEIR & Bureau Labour Statistics	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y
2005	Girkin [14]	USEIR	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y
2005	Girkin [13]	USEIR	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y
2005	Alfaro [64]	USEIR	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
2006	Kuhn [65]	USEIR	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
2011	Feng [66]	EIVS	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y
2011	Feng [67]	EIVS	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y
2012	Feng [68]	EIVS	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y
2013	Garcia [32]	CEIR	Y	Y	N	Y	N	Y	Y	N	Y	Y	Y
2013	Feng [69]	EIVS	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y
2014	Feng [70]	EIVS	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y
2015	Feng [71]	EIVS	Y	Y	N	Y	N	Y	Y	N	Y	Y	Y

Key: EIRA = Eye Injury Register Alabama; CC, NETS = National Eye Trauma System, EIRIN = Eye Injury Register Indiana, HEIR = Hungarian Eye Injury Register, EOCR = Erlangen Ocular Contusion Register, AEIR = Alabama Eye Injury Register, EIVS = Eye Injury Vitrectomy Study, CEIR = Cuban Eye Injury Register, GEIR = Georgia Eye Injury Register, NR = not recorded.

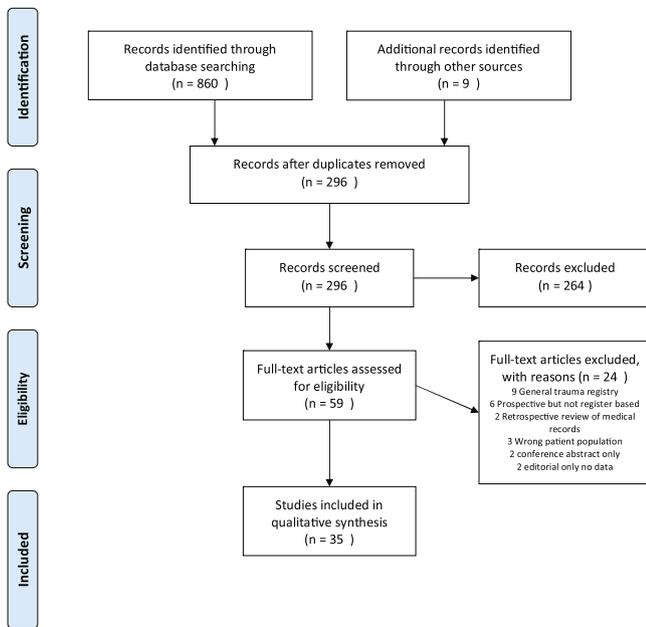


Fig. 1. PRISMA Diagram.

prevalence studies, where a snapshot of data is collected rather than continuous data collection, such as the Paediatric Ocular Trauma Study, British Ophthalmic Surveillance Unit (BOSU) in the UK, have contributed to the literature in this area [25–27]. Utilising linked data sets has also enhanced our understanding of the consequences of vision loss [28,29].

The use of large amounts of data and machine-learning algorithms offer the promise of better predictive models in research [30]. In health research these analyses often use pre-existing data with limited clinical information. General trauma registries don't provide the depth of information required both about the circumstances and the treatment and outcomes. The limited information about the circumstances of an injury, treatment and outcomes limit their value for evidence-based interventions and quality improvement for treatments outcomes. As ocular trauma is relatively low in incidence, point-incidence studies such as BOSU are valuable but may not adequately capture trends. Ocular trauma registries continue to play an important role in health management and injury prevention.

Databases like IRIS could potentially be used to mine data specifically on ocular trauma but any value to be gained is reliant

on the type and quality of data entered. Whilst these studies benefit from very large data numbers, they provide no detailed information about the nature and mechanism of eye injuries and outcome or treatment data and are limited in their interventional value [31]. More information relating to the cost to society of eye injuries would help justify the added investment in gathering and reporting ocular trauma.

Funding and sustainability

The USEIR is the largest contributor to the literature identified, covering a period of 19 years from 1987 to 2005. The USEIR has also contributed directly to the development of registries in Hungary, Cuba and Mexico and indirectly to other registries that cite use of the initial and follow-up forms from the USEIR. Despite this success, neither the USEIR nor any of the other registries are understood to be economically viable, leading to concerns about their sustainability.

Funding is key to sustain a registry. Notably only one developing country was represented in our analysis [32]. As has been demonstrated in other areas, there is a disparity between trauma registries in high and low income countries [33]. Experience and knowledge gained from high income countries well represented in the studies, would provide valuable insights for those developing countries where no registries are reported. None of the registries identified can be confirmed as still operational.

Study characteristics

Final VA is a major outcome measure for ocular trauma treatment and in the identification of risk factors. The circumstances and mechanisms of an eye injury are also crucial in determining effective interventions, including education, policies and legislation. Alternatives to specific registries for of data collection include clinical and administrative registries with the trade-offs in the data included and its quality.

A follow-up period of 6 months was considered appropriate to determine final visual outcome in almost all of the reported studies. Problems occur due to patients with diagnosis that require no further detailed follow-up, e.g. enucleation, which can make the completeness of the data appear low. Equally, for patients where lengthier follow-up is required, 6 months is not long enough to determine the final visual outcome. Other known long-term complications associated with ocular trauma, such as the increased risk of glaucoma associated with hyphema [34], should also be considered in determining follow-up period.

The role of eye protection in preventing ocular trauma has been documented in a number of environments [35–40]. The presence

Table 2
Regional, National and International Ocular Trauma Registries.

Trauma Registry	Year/s Published	Number Articles	Country/Countries
United States Eye Injury Register (USEIR) [51]	1998	2	US
Hungarian Eye Injury Register (HEIR) [59]	2002		Hungary
United States Eye Injury Register (USEIR) & Hungarian Eye Injury Register (HEIR) & Mexico [63]	2004	1	US, Hungary & Mexico
United States Eye Injury Register (USEIR) [13,14,50,55,60,62,64,65]	1996, 2000, 2002, 2004, 2005*, 2006 * 3 publications	8	US
National Eye Trauma System (NETS) [15,18,46,47]	1998, 1992*, 1993, * 2 publications	4	US
National Eye Trauma System (NETS) and Alabama Eye Injury Register (AEIR) [17,49]	1994, 1996	2	US
Erlangen Ocular Contusion Registry (EOCR) [56–58,61]	2001, 2002*, 2004	4	Erlangen, Germany
Eye Injury Vitrectomy Study (EIVS) [66–71]	2011*, 2012, 2013, 2014, 2015	6	China
Eye Injury Register Alabama (EIRA) [16,44,45,53]	1987, 1989, 1994, 2000	4	Alabama, US
Eye Injury Register Indiana (EIRIN) [48,52]	1994, 1999	2	Indiana, US
Cuban Eye Injury Register [32]	2013	1	Cuba
US Military Eye Injury Register [54]	2000	1	US Military

Table 3
Characteristics of Ocular Trauma Registries.

Year Published	Author/s	Type of study	Country	Data source	No. eyes included	Excluded	Included Eye Injuries
1987	Morris [44]	Prospective population based	US	EIRA	736	Minor injuries with good visual prognosis	Air gun-related, 15- to 19-year-old
1988	Parver [15]	retrospective	US	NETS	1400	NR	Penetrating
1989	White [45]	Prospective population based	US, Alabama	EIRA	514	No final VA. Incomplete record	Serious
1992	Dannenberg [46]	Retrospective cohort	US	NETS	648	Patients with fatal injuries	Assault-related penetrating
1992	Dannenberg [47]	Retrospective cohort	US	NETS	635	NR	Occupational penetrating
1993	Parver [18]	Retrospective cohort	US	NETS	2939	NR	Penetrating
1994	Kuhn [16]	Retrospective cohort	US, Alabama	EIRA	150	Injuries on all-terrain vehicles	Motor vehicle-related
1994	Harvey [48]	Retrospective cohort	US, Indiana	EIRIN	171	NR	Serious
1994	Schein [49]	Prospective cohort study	US	NETS & AEIR	140	NR	Severe air gun-related
1996	Enger [17]	Case control study	US	NETS & AEIR	124	NR	Air gun related 5- 19 year-olds within 5 years of injury
1996	Summerer [50]	Prospective population based	US, Georgia	USEIR & GEIR	92	Minor injuries with good visual prognosis	all
1998	Kuhn [51]	Retrospective cohort	US & Hungary	USEIR & HEIR	9600	NR	Severe
1999	Kitchens [52]	Retrospective cohort	US, Indiana	EIRIN	11	Non-Paintball	Paintball-related
2000	Kuhn [53]	Retrospective cohort	US & Hungary	EIRA & HEIR	187	NR	Firework related
2000	Lau [54]	Prospective cohort study	US Mil EIR	US Mil EIR	112	NR	Serious
2000	May [55]	Retrospective cohort	US	USEIR	8952	NR	Severe
2001	Viestenz [56]	Retrospective cohort	Germany	EOCR	417	NR	Contusion and globe rupture
2002	Viestenz [57]	Retrospective cohort	Germany	EOCR	23	NR	Elastic strap
2002	Viestenz [58]	Retrospective cohort	Germany	EOCR	7	NR	bottle cap related
2002	Kuhn [59]	Prospective population based	US	USEIR	2500	NR	Serious eye and adnexal
2002	Kuhn [60]	Retrospective cohort	US & Hungary	USEIR & HEIR	2500	NR	Serious
2004	Viestenz [61]	Retrospective cohort	Germany	EOCR	417	NR	Blunt
2004	Kuhn [62]	Retrospective cohort	US, Mexico, Hungary	USEIR	90	Intentional eye injuries	Unintentional pressurised drink bottle related
2004	Catalano [63]	Retrospective cohort	US, Alabama	USEIR & Bureau Labour Statistics	3741	Non-work or home related	Work- and home-related
2005	Girkin [14]	Prospective cohort study	US	USEIR	3627	NR	Assault-related penetrating
2005	Girkin [13]	Prospective cohort study	US	USEIR	6021	NR	Air gun-related
2005	Alfaro [64]	Retrospective cohort	US	USEIR	143	Not fishing related	Fishing-related
2006	Kuhn [65]	Retrospective cohort	US +30 countries (unspecified)	USEIR	11360	No follow up data, final VA > 20/200	Final VA < 20/200
2011	Feng [66]	Interventional case series	China	EIVS	33	Patients w/o complete records	Vitreoretinal surgery
2011	Feng [67]	Interventional case series	China	EIVS	72	Patients w/o complete records	Vitreoretinal surgery
2012	Feng [68]	Prospective cohort study	China	EIVS	14	Patients w/o complete records	Vitreoretinal surgery
2013	Garcia [32]	Prospective cohort study	Cuba	CEIR	120	NR	Severe
2013	Feng [69]	Interventional case series	China	EIVS	179	Patients w/o complete records	Vitreoretinal surgery
2014	Feng [70]	Retrospective consecutive interventional	China	EIVS	89	Patients with missing records. No 6 month follow- up.	Vitreoretinal surgery 15 & under
2015	Feng [71]	Interventional case series	China	EIVS	242	Patients w/o complete records	Vitreoretinal surgery

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or absence of safety glasses (eye protection) or spectacles is often noted but many authors reported difficulty in determining whether regular spectacles provide some role in protecting the eyes. The contribution of regular spectacles, particularly those

made from glass or CR39, to the injury and particularly when converting a blunt to penetrating eye injury has been identified previously [20,41]. Improved reporting on the presence or absence of spectacles or eye protection is therefore vital in future registries.

Data quality and bias

An important element in the established of a registry is to determine its' purpose. We found 35 publications arising from ocular trauma registries covering a range of outcomes, including measures to estimate the magnitude of a problem: determine prevalence, examine trends, assess service delivery, identify at-risk groups and describe survival. Most of the studies performed well against measures of quality relating to the research question with the objective and participants clearly identified. Quality measures for internal validity, analysis and reporting were lower, with 31% studies reporting data completeness and quality checks.

Patients referred to tertiary centres from regional areas may be more likely to be lost to follow-up as they return to their local eye health care provider. This may account for a proportion of incomplete data and introduced bias for example in tertiary care hospital-based registries, it is likely that rural patient follow-up data is lost, thereby introducing systematic bias.

Trauma registries have made important contributions across a range of areas including monitoring systems, establishing clinical guidelines, policies and injury prevention strategies [8]. The effectiveness of registries is impacted by DQ [42]. A wide range of quality dimensions have been identified [33] and models developed, which include measures for completeness, accuracy, precision, correctness, consistency and timeliness [43]. Methods for quality monitoring used in general trauma registries include checks of data accuracy to determine sequence error or identify duplicate patients and the recollection of data with deletion or imputation common solutions [33]. Staffing levels and workloads, unclear definitions and lack of training have all been identified as factors in DQ. Understanding these limitations and applying methods to mitigate them will assist in developing future ocular trauma registries.

Many of the patients identified in the included studies had a final VA of 20/200 or less and would be classified as having severe low vision according to the World Health Organization. Whilst collecting data and determining interventions across the population is paramount, registries could play a role in counselling patients with vision loss, particularly in terms of appropriate eye protection to help preserve any remaining vision. None of the registries reported on counselling provided to patients regarding the impacts of their loss of vision nor the use of eye protection, which should be a consideration in development of future registries.

Conclusions

This is the first systematic review of publications drawing on data from ocular trauma registries to identify and report on patients and their outcomes. Our systematic review was based on an extensive search of four databases with no language or time limitations so should provide a broad representation of the topic. However, many of the studies lacked detailed information about how the registries were operated or funded, which would have assisted in the analysis. Further, the registries identified (USEIR) and the related (World Eye Injury Register, WEIR) that formed the basis for the largest number of studies are no longer operational. It would be helpful to determine why they were disbanded.

We describe the characteristics and quality of data reported. Data from ocular trauma registries has helped inform interventions, including the introduction of eye protection and policies for prevention of ocular trauma. Developing countries are underrepresented in the studies identified and this information should provide a foundation for groups wishing to set-up an ocular trauma registry. An emphasis must remain on the key data required to determine appropriate interventions including the circumstances

and mechanisms of the injury, visual acuity and spectacles or eye protection worn. Another important consideration in the development of future registries is the opportunity to provide valid comparison between countries, which could be provided by an internationally agreed consensus guidelines that includes mechanism and context of injury and visual outcomes.

Presentations

This paper has not been presented at any conferences.

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Declaration of Competing Interest

All authors report no conflict of interest.

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