

National Eye Database – A Web Based Surveillance System

P P Goh, H Elias, N NorFariza, I Mariam, on behalf of the National Eye Database Steering Committee

Ophthalmology Department, Hospital Selayang, 61800 Batu Caves, Selayang, Selangor, Malaysia

SUMMARY

National Eye Database (www.acrm.org.my/ned) is a web based surveillance system which collects data on eye diseases and clinical performance in ophthalmology service. It is a prospective study with online data collection, concurrent descriptive data analysis and real time report. It includes cataract surgery registry, diabetic eye registry, glaucoma registry, contact lens related corneal ulcer surveillance and monthly ophthalmology service census. This article presents the methodology and some registries reports. The web based surveillance system has made dissemination of report prompt, easy and without barrier.

KEY WORDS:

Database, Surveillance, Census, Web based, Cataract surgery registry, Diabetic eye registry, Glaucoma registry, Contact lens related corneal ulcer surveillance

INTRODUCTION

Systematic, prospective collection of data on disease distributions, natural history and treatment outcomes in the form of register is valuable in disease surveillance, monitoring clinical performance and healthcare planning. With the advancement in information technology, this effort can be optimized through web application.

The Swedish National Cataract Register (NCR) has been collecting data on cataract extractions since 1992 and has good coverage of all cataract operations performed in Sweden¹. It has evolved into a web-based European Cataract Outcome Study Group with participation from 15 countries (www.eurocat.org)². Data from these cataract surgery registers have been instrumental in setting the basis for quality assurance and enabling further clinical studies. The European Cataract Outcome Study Group has evaluated the database and published articles on cataract surgery outcome³, Cost effectiveness⁴, and quality of life^{5,6}. Due to the large number of cataract surgery registered, the data enable study on rare events such as post-operative infectious endophthalmitis⁷. In the United States of America, the annual National Health and Nutrition Examination Survey (hosted at (<http://www.cdc.gov/nchc/nhanes.htm>)) utilizes web site to disseminate results to public and allows data download for those interested. In United Kingdom, the British Ophthalmological Surveillance (<http://www.inopsu.com>) reports rare but important eye diseases which led to a better understanding and improvement in management^{8,9}.

In 2002, the Ophthalmology service of Ministry of Health (MOH) established the National Cataract Surgery Registry (NCSR). It is a paper-based registry participated by 33 Ophthalmology departments. It contains data on 60,077 patients who have had cataract surgery from 2002 to 2004.

Annual reports^{10,11,12}, and data on various aspects of NCSR has been published^{13,14,15,16,17,18,19,20,21}. As a paper-based registry is effort intensive, it was withheld in 2005 while effort was put into developing a web based registry.

National Eye Database (NED) was established on 1st January 2007. It is a web-based patient registry consisting of Cataract Surgery Registry (CSR), Diabetic Eye Registry, Glaucoma Registry, Contact Lens Related Corneal Ulcer Surveillance, and Monthly Ophthalmology Service Census, MOH. It is supported by the MOH and hosted by the Association of Clinical Research Malaysia (ACRM) at www.acrm.org.my/ned.

The main objectives of NED are to determine the magnitude and trend of eye diseases, to facilitate quality initiatives at individual ophthalmology departments through monitoring of key performance indicators (KPIs), and to stimulate research. The long term goals are to promote quality improvement and provide a benchmarking for comparing and demonstrating good practice. We present the method and some reports of NED in this article.

MATERIALS AND METHODS

NED is a prospective, multi-center cohort study designed to have on-line data entry at study site. Participating centers or source data producers (SDP) are any clinical sites, both public and private, that provide eye care services in Malaysia. Eligible study populations are those fulfilling the criteria for each specific registry. Currently all 35 MOH ophthalmology departments participate in it.

NED is sponsored by the Ophthalmology Service and Clinical Research Centre, MOH. It has a steering committee which establishes policy, directs its activities and is governed by an advisory board. It is managed by a clinical registry manager who coordinates with site coordinators at each SDP.

NED has high level security in protecting its data. Data protection is being ensured at all time through strict compliance with regulatory requirements such as authentication of users and web application owners, access control, encryption, audit trail, control of external

Table I: Data from National Cataract Surgery Registry 2002 to 2004 and NED 2007

	2002	2003	2004	2007 (January to September)
Number of participating centre	25	32	33	30
Total number of surgeries reported	12,798	16,815	18,392	12,072
Number of cases with post-operative vision (%)	12512 (97.7%)	14,683 (87.3%)	6228 (33.9%)	5273 (43.7%)
Patients' Demographic				
Mean age (years)	64.0	63.7	63.5	64.0
% Women	51.0%	50.0%	51.0%	51.5%
% Second eye surgery	30.0%	29.5%	29.8%	29.8%
% Ocular co-morbidity in operated eye	28.8%	36.0%	38.0%	41.3%
Cataract Surgery Practice				
% Performed by specialists	69.0%	71.8%	71.6%	77.2%
% Phacoemulsification (phaco)	39.7%	45.6%	50.7%	65.8%
% Extracapsular cataract extraction (ECCE)	54.0%	47.6%	42.5%	29.2%
% Phaco convert to ECCE	2.4%	2.9%	2.5%	1.7%
% Local anaesthesia	93.6%	93.2%	92.5%	93.6%
% IOL implanted	97.3%	97.5%	97.6%	98.2%
% Implanted with foldable IOL	26.5%	37.8%	45.6%	68.5%
Surgical Outcome				
Rate of posterior capsular rupture (KPI standard- 5%)	6.0%	4.6%	4.1%	4.4%
% of patients with post-operative refracted vision of 6/12 or better for :				
All Patients (KPI standard- 85%)	80.7%	88.6%	89.5%	84.4%
Phacoemulsification	86.9%	93.2%	93.8%	87.6%
ECCE	77.5%	84.5%	85.0%	79.9%
Annual incidence of post-operative infectious endophthalmitis	0.20%	0.24%	0.16%	0.26%

Table II: Characteristics of diabetic patients registered to Diabetic Eye Registry, NED, January to September 2007

	All pts reported N=7797	Pt without DR N=4335	Pt with DR N=2838
Age Mean (SD) years	57.0 (11.4)	56.9 (12.3)	56.6 (9.8)
% Female	54.2	55.0	46.4
Type of diabetes mellitus (DM)			
- % NIDDM	91.5	92.6	90.9
- % IDDM	5.8	4.8	6.7
Mean Duration of DM, years (SD)	7.7 (7.0)	6.3 (6.1)	9.9 (7.4)
% with systemic co-morbidity	77.8	75.9	80.0
% with hypertension	64.5	63.2	67.0
% with hypercholesterolemia	17.7	17.5	18.3
% with ischaemic heart disease	11.7	12.0	11.9
% with renal impairment	6.2	3.5	10.3
% Smoking	9.68	8.54	10.99
No. of patient without DR (%)	4335 (55.6%)		

Table III: Status of diabetic retinopathy on diabetic patients registered to Diabetic Eye Registry, NED, January-September 2007

	Right eye	Left eye
With diabetic retinopathy (DR) only	2559 (32.8%)	2580 (33.1%)
With maculopathy	703 (9.0%)	663 (8.5%)
Types of DR		
% Mild non proliferative DR	44.4%	44.8%
% Moderate non proliferative DR	25.9%	25.7%
% Severe non proliferative DR	9.3%	8.6%
% Proliferative DR	14.8%	14.9%
% Advance diabetic eye disease	7.2%	6.3%



Fig. 1: National Eye Database home page at www.acrm.org.my/ned

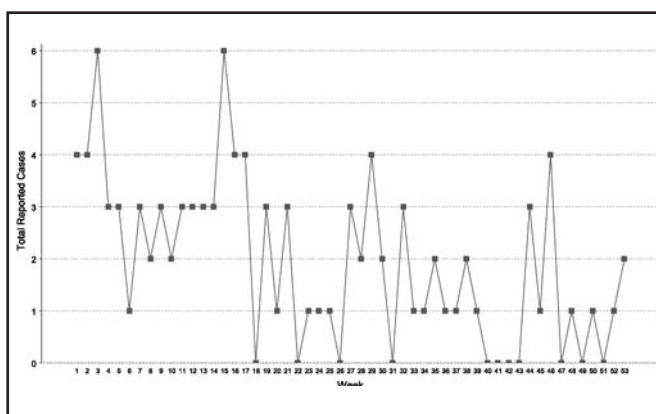


Fig. 2: Epidemiologic curve of contact lens related corneal ulcer, by week, 2007

communication links and access, as well as system backup and disaster recovery.

Head of departments and site sub-investigators, usually ophthalmologists at each SDP, are given the right to manage data entered by their own centres, including data edit, data download and view centre reports. They ensure complete data ascertainment and up to date data entry. Site coordinators, usually optometrists or paramedical staffs are responsible to enter data and supervise other staff to enter data.

Descriptive analysis is performed concurrently as the data are being received and are displayed as tables and graphs in reports. Reports are of two types, SDP report based on data entered by individual SDP, and overall report based on aggregated data entered by all SDPs. Individual patients' identification is never displayed in the report. Reports are accessible in real time on the website. Annual reports are

published, both on the web and hard copy. By having reports on the web, timely dissemination is especially effective.

RESULTS

NED home page is shown in Figure 1. The icon 'eNED web application' will bring registered users to the protected web page for data entry and to view reports.

Table I displays CSR data entered from 1st January to 30th September 2007 and for comparison, data from the NCSR for the year 2002, 2003, and 2004 were shown. Over the years, patients who have had cataract surgery had similar mean age at surgery, i.e. 64 years, had equal gender distributions and about one third of them had second eye cataract surgery. The proportion of cataract surgery performed using phacoemulsification technique has increased from 54.0% in 2002 to 65.8% in 2007. This trend is reflected in the increasing proportion of foldable intraocular lens (IOL) being implanted, from 26.5% in 2002 to 68.5% in 2007. Results for KPI based on cataract surgery shown reduction in the rate of posterior capsular rupture, from 6.0% in 2002 to 4.4% in 2007, with the standard sets at 5%. While percentage of patients with post-operative refracted vision of 6/12 or better over the years was above target set, i.e. 85%.

From January to September 2007, 7797 diabetic patients, who were seen for the first time at Ophthalmology clinics, were registered at Diabetic Eye Registry (Table II). More than half (55.6%) did not have diabetic retinopathy. Among those who have diabetic retinopathy, 70% of the eyes have mild or moderate non-proliferative diabetic retinopathy, while 30% has severe non-proliferative diabetic retinopathy, proliferative diabetic retinopathy or advanced diabetic eye disease. The later group of patients will need laser photocoagulation or vitrectomy. (Table III)

Figure 2 shows the epidemiologic curve of the incidence of contact lens related contact lens ulcer reported to NED in 2007. A total of 103 cases were reported. Most of them related to monthly disposable lens and caused by bacteria.

DISCUSSION

The findings from cataract surgery and diabetic eye registry demonstrate their usefulness in evaluating patients' characteristics and status of diseases, in monitoring the trend of cataract surgery practice and surgery outcomes. The database has made tracking of KPI and clinical practice trend easy and efficient.

NED provides useful information in epidemiology of eye diseases with data on visually threatening eye diseases such as cataract, diabetic retinopathy, glaucoma and contact lens related corneal ulcer. The clinical outcome data in NED is useful in assisting MOH, Non-Governmental Organizations, private healthcare providers and industry in program planning and service evaluation. This effort will lead to better management of eye disease, thus continuous improvement of ophthalmic service.

There is a plan to incorporate audit tools such as cumulative sum (CUSUM) 22 into NED web application to effectively monitor doctors' clinical competency. This will be implemented once the pilot study on CUSUM in monitoring surgeons' cataract surgery complication, i.e. posterior capsular rupture and post-operative visual outcome has been completed. NED will actively promote participation by university hospitals and private eye care providers so that its' database will truly be national.

The main challenge faced by NED is incomplete caseascertainment, especially when the registry collects outcome data in a prospective manner. For example, in cataract surgery registry, only 43.7% of patients operated in 2007 have records on post-operative refracted vision. Measures to increase active case ascertainment include awareness through road shows, newsletters, NED specific scientific meetings, journal publications and presentation at national and international scientific meetings, as well as active reminders by NED clinical registry manager. The other challenge is to ensure continuous funding to support NED web application.

CONCLUSION

The attempt in applying information technology in clinical performance monitoring is timely, especially with the government's effort to improve public service accountability and MOH's commitment in ensuring high standards of healthcare. The NED web application will overcome conventional constraints in paper-based surveillance, i.e. short of human resources, delay in timely dissemination and storage place for data collection forms. With electronic-NED, ophthalmologists will have access to individual centre and

national aggregated data on important eye diseases and eye services by a click of the mouse.

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REFERENCES

1. Lundström M, Stenevi U, Thorburn W. The Swedish National Cataract Register: A 9-year review. *Acta Ophthalmol Scand.* 2002; 80: 248-57.
2. Lundström M, Barry P, Leite E, Seward H, Stenevi U. 1998 European Cataract Outcome Study. Report from the European Cataract Outcome Study Group. *J Cataract Refract Surg* 2001; 27: 1176-84.
3. Lundström M. Measuring surgical outcomes. Ed. *J Cataract Refract Surg.* 2004; 10: 2025-26.
4. Kobelt G, Lundström M, Stenevi U. Cost-effectiveness of cataract surgery: Method to assess cost-effectiveness using registry data. *J Cataract & Refract Surg* 2002; 28: 1742-49.
5. Lundström M, Stenevi U, Thorburn W. Quality of life after first- and second-eye cataract surgery. Five-year data collected by the Swedish National Cataract Register. *J Cataract & Refract Surg.* 2001; 27: 1553-59.
6. Lundström M, Brege KG, Florén I, Lundh B, Stenevi U, Thorburn W. Cataract surgery and quality of life in patients with age-related macular degeneration (AMD). *Brit J Ophthalmol* 2002; 86: 1330-35.
7. Lundström M, Wejde G, Stenevi U, Thorburn W, Montan P. Endophthalmitis following cataract surgery. A nation-wide prospective study evaluating incidence in relation to incision type and location. *Ophthalmology.* 2007; 114: 866-70.
8. Stanford MR. A British ophthalmological surveillance unit. *Br J Ophthalmol* 1997; 81: 932-33.
9. MR Stanford on behalf of the British Ophthalmological Surveillance Unit Steering Committee. Five years of surveillance. The British ophthalmological surveillance unit. *Br J Ophthalmol* 2002; 86: 838-39.
10. Goh PP, R Sharmala, G Rajalakshmi, Ronald AD. The First Report of National Cataract Surgery Registry 2002.
11. Goh PP, R Sharmala, G Rajalakshmi, Ronald AD. The Second Report of National Cataract Surgery Registry 2003.
12. Goh PP, R Sharmala, G Rajalakshmi, Ronald AD. The Third Report of National Cataract Surgery Registry 2004.
13. Rajalakshmi G, Goh PP, Mariam I. National Cataract Surgery Registry 2002-2003- Profile of Patients Presenting for Cataract Surgery. *Am J Ophthalmol* 2005; 139: S1 (supplement).
14. Yen SS, Goh PP, Mariam I. National Cataract Surgery Registry 2002-2003 - A Report of Clinical Outcome. *Am J Ophthalmol* 2005; 139: S2 (supplement).
15. Tara MG, Rampal SL, Choong YF, Goh PP. National Cataract Surgery Registry: Cataract Surgery in Diabetes Mellitus. *Am J Ophthalmol* 2005; 139: S2 (supplement).
16. Li Chang, Choong YF, Goh PP. National Cataract Surgery Registry (NCSR) - Types of Anaesthesia And Intra-Operative Complications. *Am J Ophthalmol.* 2005; 139: S3 (supplement).
17. Goh PP, Rampal SL, Choong YF. National Cataract Surgery Registry 2002-2003 - The Risk of Acute Endophthalmitis Following Cataract Surgery. *Am J Ophthalmol* 2005; 139: S4 (supplement).
18. Goh PP, Rampal SL, Choong YF. National Cataract Surgery Registry 2002-2003 - Predictors for Poor Visual Outcome. *Am J Ophthalmol* 2005; 139: S4 (supplement).
19. Shamala R, Goh PP, Mariam I. National Cataract Surgery Registry-Cataract Surgery Practice Pattern and Its Trend in Malaysia. *Am J Ophthalmol* 2005; 139: S4 (supplement).
20. Poh EP, Choong YF, Goh PP. National Cataract Surgery Registry: Postoperative Clinically Significant Cystoid Macular Oedema. *Am J Ophthalmol* 2005; 139: S8 (supplement).
21. Lee PP, Goh PP, Lim TO. National Cataract Surgery Registry- Methods *Am J Ophthalmol* 2005; 139: S67 (supplement).
22. Aziz S, Choong YF, Goh P, Ismail M, Lim TO. Cusum - A Statistical Process Control Charting to Monitor Surgeon Performance in Cataract Surgery. *Am J Ophthalmol* 2005; 139: S1 (supplement).