Review Article

Eye Health Information Systems in Selected Countries

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Abstract

One of the important factors for achieving "Vision 2020" targets is the availability and accessibility of eye health information systems. This study aimed to describe eye health information systems in selected countries. The status of eye health information systems in Australia, the United States, and England was reviewed. Data were gathered from the PubMed, Scopus, and ScienceDirect databases. The main key terms used included, but were not limited to "National Action plan", "Eye Health Information System", "Database", and "Registery". Also, the websites of the World Health Organization, the International Agency for the Prevention of Blindness, and Departments of Health in the selected countries were accessed. Fifty documents and articles of 170 retrieved references related to the research goals were used in this study. In all three countries, the issue of eye health is considered to be a national health priority. Concerning data gathering, the most common point in these countries was data gathered directly (health information systems, eye registries) and indirectly (studies, projects, and surveillance systems) by the organizations that participated in eye health programs. Producing accessible, timely, and highly quality information about eye health is one of the most important goals in the formation of eye health information systems in the selected countries, which facilitates achievement of the goals of the "Vision 2020: The Right to Sight" initiative.

Keywords: Eye Health Information System; Vision 2020; World Health Organization

INTRODUCTION

Visual impairment and blindness are two significant problems associated with public health[1-3] because they

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can affect the lives of individuals, families, and societies.[4] The most important effects of visual impairment and blindness are negative health consequences (increase in mortality rate and reduction in quality of life)[2,5-8] and negative social-economic implications (loss of employment, economic power, and productivity).[2,6] According to the visual status report of the World Health Organization (WHO) in 2010, 4.25% of the global population experienced some form of visual impairment (low vision and/or blindness),[9] while 80% of these impairments are avoidable or curable.[9-11] In this

regard, the WHO and the International Agency for the Prevention of Blindness (IAPB) introduced the "Vision 2020: The Right to Sight" initiative in 1999. The goal of this initiative is to control visual impairments and blindness. Providing efficient and available holistic eye health care and integration with health systems are the most significant objectives of this vision.[11] From the perspective of the WHO, eye health services are considered to be a part of any complex and large health system. In this system, health information is the basic foundation because it creates awareness of the status of public eye health. Accordingly, it will be possible to identify eye health priorities, plan and implement programs, monitor existing programs, and promote eye health. The presence of accurate, up to date, high-quality, and accessible information in the field of eye health depends on eye health information systems to achieve their stated goals. If the components of these information systems are defined and designed appropriately, they represent a powerful tool to manage relevant data at national and regional levels.[12] Therefore, development of eye health information systems makes it possible to actualize the goals of "Vision 2020" to prevent blindness and promote eye health. Accordingly, the purpose of this study was to review eye health information systems in selected countries. In this regard, components of eye health information systems, including datasets, and data gathering, processing and reporting were compared with one another.

METHODS

In this research, the status of eye health information systems in Australia, the United States, and England was reviewed. These countries were selected based on their progressive developments in relation to the delivery of eye health services considering Vision 2020,[13-15] and the availability and accessibility of published eye health data in these countries,[14,16,17] as well as considering that the prevalence of blindness and low-vision is much less in high-income countries.[9] Therefore, these countries were specifically selected because of their advanced eye health systems that manage eye health information.

Information systems generally consist of data gathering, processing, and reporting. The search in the present study was conducted using the PubMed, Scopus, and Science Direct databases using keywords that included, but were not limited to, "National Action plan", "Eye Health Information System", "Database", "Registry", "Surveillance system", "Australia", "United States of America" and "England". Furthermore, the websites of the WHO, IAPB, and the Department of Health (DOH) of Australia, the United States, and England were searched for relevant information. Being governmental reports, and the latest editions were taken into consideration as the main criterion in the process of searching the

countries' documents. Retrieved references were reviewed regardless of time limitation and study type (research or review). Of 170 retrieved references, 50 documents and articles related to the research goals were used.

RESULTS

Datasets, data processing, and the resulting reports are the main parts of an information system.[18] These components are explained in relation to eye health information systems of Australia, the United States, and England.

Datasets and Data Gathering Approaches

Organizations that participate in eye health programs generate eye health data based on their activities. In fact, each organization has its own database. Therefore, there is diversity in eye health data generation, as data sources differ. Accordingly, eye health data are obtained from the delivery of eye health care services through clinical information systems housed at national health statistics centers,[19-21] conducting of surveys, studies, projects, and relevant projects to eye health. In Australia, each organization manages data according to the type of services provided.[13] These organizations include the DOH, Departments of Human Services, Department of Social Services, and state-based registries, centers, associations, research centers, foundations, organizations, institutions, and colleges. Data are gathered based on an agreement for exchanging data related to health and welfare by the Australian Institute of Health and Welfare (AIHW).[22] In the United States, eye health data are defined for each survey[23] and surveillance[24] so that eye health data are gathered based on these definitions by the National Center for Health Statistics (NCHS) from the United States Department of Health and Human Services (USHHS), Department of Labor, The Consumer Product Safety Commission, and vital national registration centers.[19] In England, eye health data are gathered as Public Health Outcomes Frameworks (PHOF) by Public Health England.[25]

In Australia and the United States, there are no defined datasets reflecting clinical eye health data,[14,15] while in England, General Ophthalmic Services Activities Statistics (GOS),[15] National Health Service (NHS) Outcomes Frameworks (NHSOF) are defined.[26] In addition, data relevant to eye diseases are gathered by eye disease registries in the three countries. There are two national registries in the field of corneal graft and advanced glaucoma in Australia. Relevant data to identify cases at the national level are submitted to management centers of these two registries in the Department of Ophthalmology at Flinders University (Adelaide, South Australia). The collected data are processed based on the registry goals.[27,28] The Intelligent Research in Sight

Registry (IRIS) belongs to the American Academy of Ophthalmology (AAO), and the Measures and Outcomes Registry for Eye care (MORE), belongs to the American Optometric Association (AOA) in the United States.

The main purpose of the IRIS Registry is to automatically collect data related to eye diseases using electronic health systems across the United States. These data will be used to estimate the prevalence of various eye diseases, to survey the outcomes of health care, and to improve the quality of eye care services. The MORE registry is also designed to measure outpatient outcomes of eye care services provided by registered optometrists. The two registries, based on a memorandum of understanding with the United States Department of Health, electronically collect eye-related data from the electronic health records in outpatient and inpatient clinics. These two registries electronically gather data related to visual and eye status from the electronic health records of individuals in outpatient and inpatient treatment centers based on the agreement with the DHHS.[29-31] The United States Eye Injury Registry (USEIR) is another national registry in the United States. Information relevant to eye injuries in all states submit to the management center of this registry located in the Ophthalmology Unit of the University of Alabama (Tuscaloosa, Alabama, USA) based on a national memorandum of understanding.[32] A visual impairment registry exists in England, in which relevant information to identify cases of blindness and visual impairment around the country are submitted to the management center of visual impairment and blindness database located in Moorefields Hospital (London, England) based on legal obligation. A copy of information regarding identified cases is also sent to the local public health authority England. If the eligible individual is willing to receive support, training, and rehabilitative services, his/her information will be recorded in the Visual Impairment and Blindness Registry.[33] The National Ophthalmology Database (NOD) is another source of eye health data in England. This database receives information related to disease status, and eye and visual treatment based on an agreement between the NHS and the Royal College of Ophthalmologists through clinical information systems.[34]

In this database, data related to cataract, glaucoma, macular, cornea, retinal detachment, and diabetic retinopathy are collected through a defined dataset. Data from this database are used to conduct clinical audits of the services provided.

Data Processing

There are no defined mechanisms for health and administrative data processing in the countries investigated. The processing of these data can be seen in Australia and, to some extent, in the United States. In Australia, these data are processed based on reports sent in certain formats of national eye health data by the Australian Institute of Health and Welfare.[16] Results of surveys and surveillance systems are processes in the United States that consider national eye health goals.[23,24] In Australia, the United States, and England, data related to eye care services are processed by National Health Statistics Centers.[19-21] These centers process data based on national eye health indicators. These indicators in Australia consist of the prevalence of visual impairments (based on age groups and different populations, native and foreign), eye care providers (based on job status), cataract surgery, and hospital indicators associated with clinical eye procedures.[35] These indicators in the United States consist of a coverage level of screening programs for children, the proportion of eye injuries, visual impairments and blindness, use of rehabilitative services and eye protective tools.[36] In England, data associated with eye health are processed in two parts. Part one consists of national eye health indicators of the NHS, including statistics related to eye care providers, hospital events, the number of registered individuals with low vision and blindness, and the costs of eye care services.[17] Part two consists of national indicators of eye health outcomes that are obtained based on indicators of Public Health Outcomes Frameworks (PHOF),[25] NHSOF,[26] and Adult Social Care Outcomes Frameworks (ASCOF).[37] Processing of data obtained from corneal grafts and advanced glaucoma in Australia consists of calculation of indicators for corneal graft and advanced glaucoma, causes, treatment results, and outcomes.[38,39] In the United States, the IRIS and MORE registries ascertain the prevalence of different types of eye diseases, and the success rate of clinical methods and clinical outcomes.[29,30] In addition to these registries, the United States Eye Injury Registry provides information related to injury causes and outcomes.[32] In England, the NOD uses indicators such as prevalence of different types of eye diseases, success rates of clinical methods, and treatment outcomes.[34]

Reports

The gathered data are processed to generate high-quality, accessible, and timely information in the context of eye health. In this regard, the AIHW prepares statistical reports related to eye and visual health status based on indicators introduced by the WHO annually.[40-45] In the United States, the National Center for Health Statistics prepares annual reports related to visual indicators in the Health People 2020 strategy.[46] In England, reports of national eye health indicators are provided online by NHS Digital,[20] and reports of national indicators of eye health outcomes are provided by VISION 2020 UK annually.[47] Reports related to indicators of every registry are prepared by registry management centers in the studied areas.

A comparison of findings from eye health information system in the selected countries is presented in Table 1.

DISCUSSION

Being aware of eye health status is the first step in identifying health events, prevention of disease, and improving health behaviors. Obtaining knowledge about eye health status is a complicated process given that data are gathered from multiple sources. These sources consist of data from public health surveillance, public health research, clinical surveys, environmental monitoring, reports and information of disease registries, and clinical information systems.[48-50] These data can reflect the effect of various factors on public eye health.[49] Hence, attempts were made to establish eye health information systems to raise awareness of public health status in the studied countries. Although the eye health information systems of the selected countries have similarities and differences, eye health is, nevertheless, considered to be a national health priority.

Table 1. Description of eye health information system components in selected countries based on published information in the selected databases

Selected countries Eye health information system component	Australia	United States	England
Datasets	Eye datasets obtained from study results Eye datasets obtained from national survey results Eye datasets obtained from results of national projects and plans Eye datasets retrieved from national surveillance systems Clinical datasets obtained from clinical information systems Datasets of corneal graft and advanced glaucoma registries	Eye datasets obtained from results of national surveys Eye datasets obtained from national surveillance systems Clinical datasets obtained from clinical information system Datasets of IRIS, MORE, and USEIR registries	Eye datasets obtained from national surveillance systems Clinical datasets obtained from clinical information system Datasets of visual impairments registry and NOD
Data processing	Eye national data processing based on national eye health indicators (prevalence of visual impairments, eye care providers, cataract surgery, hospital indicators related to clinical eye procedures) Processing of registry data based on its establishment goals and indicators (corneal graft indexes, advanced glaucoma indexes, causes, treatment results, and treatment outcomes)	Eye national data processing based on national eye health indicators (coverage of screening programs for children, proportion of eye injuries, visual impairments and blindness, use of rehabilitation services, and use of eye protective tools) Registry data processing based on establishment of goals and indicators (prevalence of different types of eye diseases, successful clinical methods, treatment outcomes, causes for injuries, injury causes)	Eye national data processing based on national eye health indicators (A: NHS Digital indicators including relevant statistics to eye care providers, relevant statistics to hospital events, number of registered individuals with low vision and blindness, costs of eye care services. B: National indicators of eye health outcomes including public health outcomes frameworks, and ASCOF) Registry data processing based on establishment of goals and indicators (prevalence of different types of eye diseases, successful clinical methods, treatment outcomes)
Reports	Reports from national eye health indicators Reports from corneal graft and advanced glaucoma registries	Reports from national eye health indicators Reports from the IRIS, MORE and USEIR registries	Reports of national eye health indicators Reports of visual impairments registry and NOD

IRIS, Intelligent Research in Sight Registry; MORE, Measures and Outcomes Registry for Eye care; USEIR, US Eye Injury Registry; NOD, National Ophthalmology Database; ASCOF, Adult Social Care Outcomes Frameworks; NHS, National Health Service

To have a comprehensive view of eye health, devoting attention to a wide range of eye health data generated from different sources is essential. Some of these data are produced by the organizations responsible for implementing eye health programs when providing eye care services. Others are generated by organizations that are not directly responsible for implementing eye health programs and eye care services, but create eye related data during the provision of other services.

On the other hand, a holistic view on gathering eye health data through surveys, studies, surveillance and clinical information systems, and registries in the selected countries is another similarity. Defined national eye health datasets in England distinguish this country from Australia and the United States in terms of eye health information systems. There are different registries in these countries based on needs and priorities in the context of eye health data gathering. In this regard, Australia has corneal graft and advanced glaucoma registries, the United States has USEIR, and England has the Visual Impairment Registry. However, there is a second mechanism to gather eye health data in the United States and England. This process is similar to clinical information systems and electronic health records that exchange clinical data to build an accurate information registration process in clinical information systems. The IRIS and MORE registries in the United States, and the NOD in England, are examples. This process is managed electronically using data from clinical information systems, leading to the generation of statistics, eye health indicators, and eye health reports. The number and diversity of eye health indicators in England distinguishes this country from Australia and the United States. The centralized approach for eye health data processing in Australia is a distinguishing feature of this country in terms of its eye health information system.

SUMMARY

Activities that are undertaken in the field of achieving the goals of the "Vision 2020: The Right to Sight" initiative in the selected countries reflect the special attention devoted to the issue of eye health information management. In fact, they define and extend the processes of gathering and processing data from different data sources, as well as analyzing relevant information and producing reports needed to access timely, high-quality information about eye health.

The present study had some limitations. The countries were purposively selected; therefore, published data in the selected databases were taken into consideration. Thus, some informationmay have been missed, or some systems may have undergone changes or were discontinued. In addition, some relevant information may not have been published yet.

Conflicts of Interest

There are no conflicts of interest.

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