REVIEW

Notifiable Diseases Surveillance System with a Data Architecture Approach: a Systematic Review

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ABSTRACT

Introduction: The wide range of notifiable diseases and the need for immediate reporting complicate the management of these diseases. Developing a surveillance system using precise architectural principles could ease the management of these diseases. **Aim:** The present study reviews the data architecture of notifiable diseases surveillance systems to provide a basis for developing such systems. **Methods:** A systematic review was conducted on the literature focused on data architecture of notifiable diseases surveillance systems. The searches for relevant English language articles were conducted based on the paper keywords, as well as the words Mesh and EMTREE. **Results:** The findings were categorized into five groups, including organizations involved in the generation and monitoring of notifiable diseases' data. The databases in the present study were relational and used a centralized architecture for information sharing. The minimum dataset was determined in two information categories. The data standards were categorized into three main groups. The key approaches for data quality control included checking the completeness, timeliness, accuracy, consistency, adequacy, and validity of the data. **Conclusion:** Developing a notifiable diseases surveillance based on data architecture principles could lay the foundation for better management of such diseases through eliminating the obstacles experienced during data generation, data processing, and data sharing.

Keywords: Notifiable Diseases, Data Architecture, Information System, Surveillance System.

1. INTRODUCTION

For effective disease control and management, physicians, laboratory staff, and other healthcare providers are required to immediately report notifiable diseases to relevant organizations (1). Notifiable diseases are those whose occurrence should be notified to public health authorities in a regular, frequent, and timely manner (2). The list of notifiable diseases includes infectious and contagious diseases, and it is particularly important for the disease monitoring and controlling system (3). The list of notifiable diseases varies from country to country according to specific geographical, climatic, social, cultural, and developmental features (4).

The notifiable diseases surveillance system is a subset of health information systems (5), playing an important role in collecting, organizing, processing, and retrieving data related to notifiable diseases (6). The use of notifiable diseases surveillance system may improve public health decision-making such as prevention, planning, health promotion, quality improvement, and resource allocation (7). This system is also effective in the control and prevention of the emergence and spread of infectious and non-infectious diseases (8). The importance of rapid, accurate, and timely reporting of notifiable diseases to concerned organizations has increased the need to establish a notifiable diseases surveillance system (9), considering that, in recent decades, these diseases have created many economic problems for patients, healthcare systems, and society (10, 11).

It is necessary to design a data architecture model to create an efficient surveillance system coordinated with work processes and organization (12). The expansion and

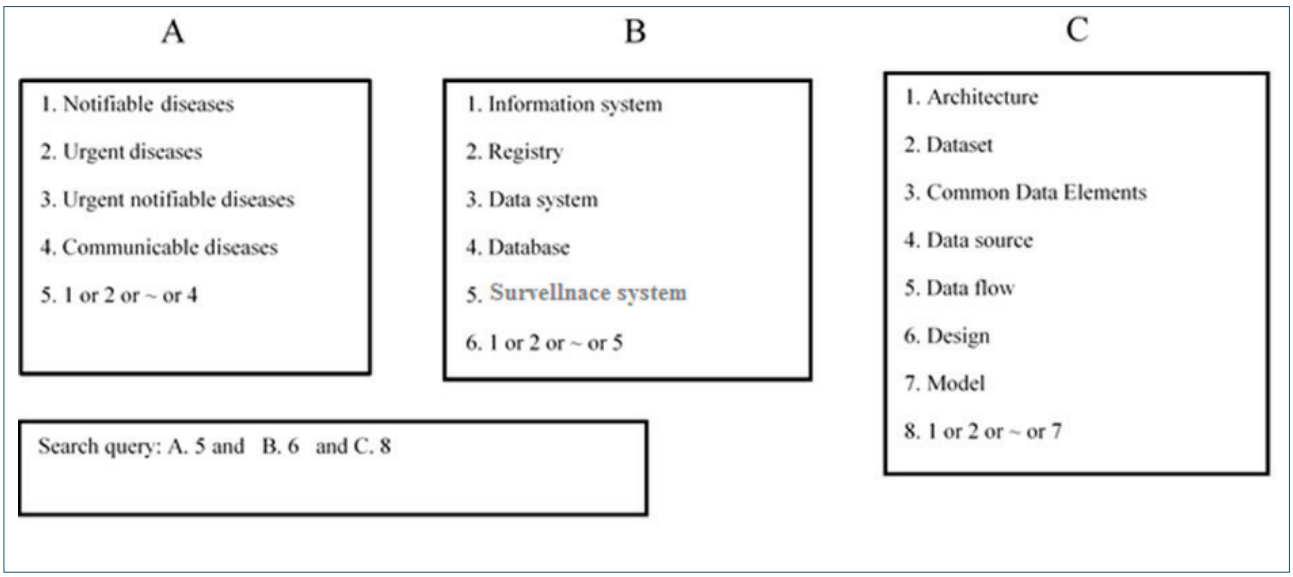

Figure 1. Search strategy

increased complexity of surveillance systems have necessitated the use of logical structure and data architecture to define and control user interfaces and integrate the components of this system (13). The data architecture depicts organizations involved in data production, processes, relationship between data elements, rules of selection, and creation and maintenance of information (14). In addition, it shows data elements, their relations, the flow of information from source to destination, and the content of information (15).

2. AIM

The present study aimed to review the studies on the data architecture of notifiable diseases information system in order to determine the requirements of data architecture, including the identification of organizations involved in data management, data minimum sets, data standards, and data quality criteria.

3. METHODS

A systematic literature search was performed according to PRISMA guidelines on December 19, 2018 to identify studies in which the data architecture of notifiable diseases surveillance systems had been discussed. For this purpose, key sources of medical data, including the Web of Science, Scopus, Science Direct, and PubMed databases were searched from 2000 to 2018 (Figure 1) and illustrates the search strategy for identifying the related articles. The first part demonstrates the notifiable diseases keywords, the second part indicates the data management keywords, and the third part presents the information system data architecture words. The results of these three parts were combined with "AND" logical operator, and the search was completed by reviewing the references of the selected articles.

Keywords, MeSH, and Emtree terms were utilized in the search strategy. Three individuals independently reviewed the titles and abstracts of the selected articles. Articles covering notifiable diseases surveillance system architecture or those addressing at least one of its aspects such as the design, implementation, and development of the system were selected. The articles on networks, databases, and registries of these diseases at local, national, and international levels were also included, whereas those which designed and evaluated data architecture software but were unrelated to notifiable diseases were excluded. The research was limited to articles and full-text reports in English (2000-2018) with valid sources. Thus, short articles, letters to the editor, articles accepted in conferences, and reports extracted from Weblogs were not included in this research. The relevance of article content to research title was the main criterion in selecting articles. Figure 2 depicts the process of selecting articles from the studied databases.

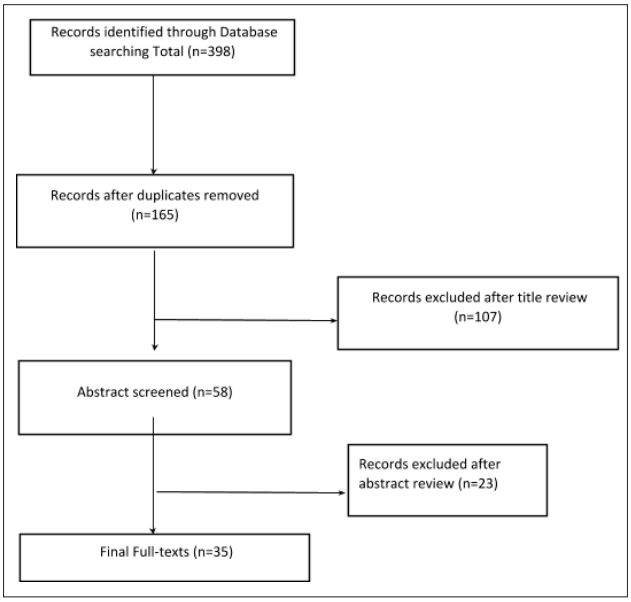

Figure 2. Search flow diagram

4. RESULTS

The database search identified 398 records, of which 165 remained after the removal of duplicates (Figure 1). Following title and abstract screening, 35 studies were included in the final analysis. The studies on notifiable

Country	Name of Organization	Frequency of Records	Reference Number
USA	Hospitals	8	(17-20, 23-25, 46)
	Physician's offices and clinics	4	(18, 20, 24, 25)
	Laboratories	8	(16-20, 23-25)
	Schools	4	(4, 16, 18, 19)
	Child care centers	4	(6, 16, 19)
	Imaging centers	1	(23)
	Blood banks	2	(4, 6)
	Blood transfusion centers	2	(4, 6)
	Prisons	1	(4)
	Dentistry clinics, day clinics, and nursing care organizations	2	(4, 6)
	Forensic medicine centers	1	(4)
	Veterinary centers	3	(6, 16, 25)
	Elderly houses	2	(16, 20)
	Hospital infection control practitioner sites (ICPs)	3	(5, 17, 28)
	Public health laboratories	3	(5, 17, 28)
Australia	Hospitals, physician's offices, and clinics	5	(4, 6, 25, 45, 49)
	Laboratories	5	(4, 6, 25, 45, 49)
	Schools and educational institutions	2	(29, 50)
	Child care centers	3	(6, 25, 49)
	Day clinics	3	(6, 25, 49)
Canada	Hospitals and health care institutions	2	(29, 50)
	Laboratories and employers	2	(29, 50)
Sweden	Hospitals, laboratories, and clinics	2	(32)
Germany	Hospitals	3	(30, 31, 50)
	Laboratories	3	(30, 31, 50)
	Physicians' offices	1	(50)
	Nursing homes	2	(31, 50)
	Clinics	2	(31, 50)
	Schools and child care centers	2	(31, 50)
	Dormitories, prisons, and refugee centers	2	(31, 50)
	Veterinary centers	2	(31, 50)
Taiwan	Health care centers and laboratories	2	(36)
China	Hospitals	4	(16, 34, 35, 37)
South Korea	Hospitals and laboratories	1	(51)
Netherlands	Clinics, physicians' offices, hospitals, and laboratories	1	(37)
England	General practitioners' (GPs) offices	2	(31, 32)
	Laboratory technicians and specialists	2	(31, 32)
	Schools and educational institutions	2	(31, 32)
	Employers' offices	2	(31, 32)
New Zealand	Physicians' offices, clinics, laboratories, and hospitals	2	(49)
South Africa	Healthcare organizations and laboratories	2	(38, 39)
	Primary care units	3	(38, 39)
	Hospitals and physicians' offices	2	(38, 39)

Table 1. Data Producers

diseases surveillance system were employed to identify the requirements of data architecture in these systems. The geographical distribution of these 35 studies was as follows: 13 studies were conducted in the USA (6, 16-27) seven in Europe(19, 28-36) eight in Asia (31, 33-37) and four in Africa (38-41), seven in Australia and Oceania (4, 19, 23, 42-45), and in four studies, there was an overlap of countries. The general areas for identifying the requirements of notifiable diseases surveillance system data architecture included: 1) organizations involved in notifiable disease surveillance system, 2) surveillance system databases, 3) minimum data sets such as non-clinical (administrative) data and clinical (medical and diagnostic) data, 3) data standards in three groups: terminology and classification standards, structure and content standards, and data exchange standards, and 5) data quality control. These items are described in the following sections.

4.1. Organizations involved in notifiable disease surveillance system

Organizations involved in this system can be categorized into three groups: a) data producers, b) data users, and c) decision-makers. Data producer organizations commence the process of reporting notifiable diseases. The number of these organizations was higher in studies related to developed countries USA (18, 20-

Country	Name of Organization	Frequency of Records	Reference Number
USA	Epidemiological organizations	6	(18-20, 22, 25, 50)
	Research and policy-making organizations	6	(18-20, 22, 25, 50)
	Agency for Health Research and Quality (AHRQ)	6	(18-20, 22, 25, 50)
	Local or regional health department	5	(18-22)
	Council of State and Territorial Epidemiologists, in collaboration with Centers for Disease Control and Prevention (CDC)	5	(5, 18, 19, 21, 50)
	Public Health Agencies (PHAs)	6	(5, 23-25, 50)
Australia	Epidemiological organizations	2	(4, 23)
	Research organizations	2	(4, 23)
	Policy-making organizations	2	(4, 23)
	National Health and Medical Research Council (NHMRC)	2	(4, 23)
	Local/Territorial and State Public Health	2	(4, 23)
	The federal government, in collaboration with the National Association for Health and Medical Research	1	(52)
	Local public health units	2	(45, 52)
Canada	Local and territorial public health offices	2	(29, 50)
	Research, policy-making, and decision-making organizations	1	(50)
	Physicians and other healthcare staff	1	(50)
	Specialized working groups	1	(50)
	Public Health Agency of Canada (PHAC)	1	(29)
	Public Health Laboratory (PHL)	1	(29)
	National Microbiology Laboratory (NML)	1	(29)
Sweden	Local and territorial public health institutions	2	(16, 32)
	Research organizations	2	(16, 32)
	Epidemiological organizations	2	(16, 32)
	County Medical Officers (CMOs)	2	(16, 32)
	Swedish Institute for Infectious Disease Control (EPI/SMI)	2	(16, 32)
Germany	Local/state/national health department	2	(52)
	Research and epidemiological institutions	1	(28)
	Local health departments and state health departments	2	(28, 29)
	County (Landkreis) Health Department and State (Land) Health Department	1	(29)
Taiwan	Local Health Department (LHD)	1	(48)
China	Local, country, and regional center for disease control (CDC)	4	(16, 34)
South Korea	Public health departments	1	(51)
Netherlands	Public health services	1	(37)
	European Centre for Disease Prevention and Control (ECDC)	1	(37)
	National Institution for Public Health and Environment	1	(37)
England	Consultant in Communicable Disease Control (CCDC)	1	(32)
	Local Health Protection Unit (LHPU)	1	(31)
	Environmental Health Officer (Local Authority)	1	(31)
	Local Council or Local Health Protection Team (HPT)	1	(34)
Sri Lanka	Public Health Inspector (PHI)	1	(31)
	Research organizations	1	(31)
	Statistical and epidemiological organizations	1	(31)
New Zealand	Public Health Service (PHS)	2	(45, 49)
	Local Public Health Office	2	(45, 49)
	Medical Officer of Health	3	(45, 49, 53)
South Africa	Local and regional public health departments	3	(38-40)
	Local and regional health information department	3	(38-40)
	Research and Epidemiological organizations	2	(38, 40)
	National Public Health Institute for South Africa (NaPHISA)	2	(38-40)

Table 2. Data Users

25, 46), Australia (19, 23, 43, 47) , Canada (6, 17), England (31, 32), and Germany (19, 28, 29). In addition to hospitals, dental centers, clinics, and long-term care organizations (nursing homes or respite care centers) were at initial levels; imaging organizations, blood transfusion organizations, blood banks, and forensic medicine centers were at secondary levels; and schools and other educational institutions, prisons, refugee centers, employers, orphan care centers, veterinary centers, and nursing homes were at tertiary levels.

Country	Name of Organization	Frequency of Records	Reference Number
USA	CDC	11	((5, 18-20, 22-25, 50)
	Council of State and Territorial Epidemiologists (CSTE)	9	(18-20, 22-25, 50)
	CDC Division of Health Informatics and Surveillance (DHIS)	9	(18-20, 22-25, 50)
	Indiana State Department of Health (ISDH)	1	(20)
	Department of Health and Human Services	2	(19, 50)
	State Health Departments (SHA)	2	(19, 50)
	Department of Public Health and Environment (CDPHE)	4	(5, 19, 25, 50)
Australia	Communicable Diseases Network Australia (CDNA)	3	(4, 19, 23)
	Department of Health and Aging (DoHA)	3	(4, 19, 23)
	Department of Health and Human Services - Center for Diseases Control and Prevention Office of Infectious Diseases	3	(4, 19, 23)
	Communicable Disease Network Australia (CDNA)	2	(4, 23)
	Public Health Laboratory Network (PHLN)	2	(4, 23)
	Case Definitions Working Group	1	(4)
	Office of Surveillance, Epidemiology, and Laboratory Services (OSELS)	1	(4)
Canada	Centre for Communicable Diseases and Infection Control (CCDIC)	1	(17)
	National Collaborating Centre for Infectious Diseases (NCCID)	1	(17)
	National Collaborating Centre for Public Health (NCCPH)	1	(17)
	Canadian Public Health Laboratory Network (CPHLN)	1	(17)
Sweden	Robert Koch Institute (RKI)	2	(30, 32)
	State health department	2	(30, 32)
	Sweden Ministry of Health and Social Affair	2	(30, 32)
	United Nation CDC	1	(32)
Germany	Robert Koch Institute (RKI)	2	(30, 31)
Taiwan	Public Health Laboratory Network (PHLN)	2	(36, 48)
	Case Definitions Working Group	2	(36, 48)
China	Health Ministry	4	(16, 34, 35, 51)
	Office of Surveillance, Epidemiology, and Laboratory Services (OSELS)	4	(16, 34, 35, 51)
South Korea	Centre for Communicable Diseases and Infection Control (CCDIC)	1	(51)
Netherlands	National Collaborating Centre for Infectious Diseases (NCCID)	1	(37)
	National Public Health and Environment Institute	1	(37)
England	Health Protection Agency (HPA)	2	(31, 32)
	Public Health England (PHE)	2	(31)
	Department of Health and Social Care	2	(31, 32)
	National Health Services (NHS)	2	(31)
	Consultant in Communicable Disease Control (CCDC)	2	(31, 32)
	European Centre for Disease Prevention and Control (ECDC)	2	(31)
Sri Lanka	Medical Office of Health (MOH)	1	(31)
New Zealand	District/National Officer of Health	2	(45, 49)
	Health Ministry	2	(45, 49)
South Africa	CDC	3	(38-40)
	National Institute of Communicable Diseases (NICD)	2	(38-41)
	Community Health Centers (CHC)	3	(39-41)
	World Health Organization - African Region (WHO-Afro)	2	(39, 41)
	National Health Insurance (NHI)	2	(39, 41)

Table 3. Decision-Making Organizations

In studies related to developing or less developed countries (Taiwan (36, 48) , Sri Lanka (31), China (16, 34, 35, 37), Korea (37), and South Africa (38-41)), the number of data producer organizations was limited and included organizations directly associated with patients and patient care. These organizations mostly provided the initial levels of care and comprised hospitals, clinics, offices, and laboratories. Table 1 lists the organizations involved in data generation.

After the identification of cases by case detector organizations, they were stored in a cumulative repository. The data user organizations utilize the results of analyzing aggregated information. In the studied countries, these organizations generally included research institutes, statistics institutes, and public health organizations at local (city), regional (province or state),

Reported Field	Frequency of Records	Reference Number
Patient data (demographics, contact, social and economic status)	12	(3-5, 10, 17, 19, 32, 34, 35, 37, 43, 53)
Notifiable diseases list	11	(3-5, 10, 17, 19, 34, 35, 37, 43, 53)
Case workflow management	1	(50)
Case finding	4	(38, 43, 50, 54)
Case definition criteria	6	(19, 28, 38, 43, 50, 54)
Certainty level (confirmed, probable, and suspected)	14	(2, 4, 5, 10, 19, 20, 23, 28, 31, 34, 36, 38, 50, 54)
Report sender and receiver identifications	8	(3, 20, 29, 49, 50, 52-54)
Timeline (immediate and non-immediate reports)	11	(2, 10, 11, 23, 30, 32, 37, 45, 48-50)
Reporting state (mandatory or voluntary)	10	(11, 16, 17, 24, 30, 32, 45, 48-50)
Search options (based on demographics and identifications)	5	(10, 28, 38, 50, 52)
Diagnosis information (disease, disease code, agent)	17	(2, 11, 16, 17, 19, 24, 30, 32, 36, 40, 41, 45, 48-51, 55)
Provider information (physician ID)	8	(10, 17, 24, 28, 38, 50-52)
Geographic information (contamination site)	11	(16, 19, 20, 24, 31, 41, 45, 49, 50, 53, 55)
Disease transmission type	13	(16, 17, 19, 20, 24, 28, 31, 41, 45, 49, 50, 53, 55)
Preventable or unpreventable status	5	(26, 38, 43, 49, 50)
Jurisdiction	14	(2, 4, 5, 10, 19, 20, 23, 28, 31, 34, 36, 38, 50, 54)

Table 4. Database Reported Fields

central (national), and international levels. These organizations are presented in Table 2.

Top level organizations monitor and manage aggregate data, using them for decision-making and policy-making. These organizations include the Ministry of Health, public health organizations, and CDCs (Table 3).

4.2. Surveillance system databases

The majority of databases used in the notifiable disease surveillance system were relational (4, 19, 23, 26, 27, 29, 30, 37-41, 43, 45, 46, 48), whereas some of them were object-oriented (27) or object-relational (17, 21). Most studies described a centralized architecture (4, 6, 15, 17-19, 21-23, 25-30, 36, 38, 39, 42, 43, 45, 46, 48) for data transmission. The names of notifiable diseases surveillance system databases in the selected countries were as follows: Australian Notifiable Infectious Disease Database (ANIDD) (4, 42, 43), Surv Net database in Germany (28, 29), National Infectious Diseases Monitoring Information System Database in China (16, 34, 35), Osiris database in Netherlands (37), NEDSS Base System (NBS) (46), Electronic Medical Record Support for Public Health (ESP) (27), Public Health Agencies Database (PHADB) (21, 25) to support local reporting requirements and Notifiable Disease Surveillance System Database (NDSSDB) or Pan American Notifiable Disease Database (PA - NDDB) (19, 21, 23, 42) to support the national reporting needs of the United States, Notifiable Disease Database in Canada (6, 17), China's central disease database (33, 34, 37), National Health Laboratory Services (NHLS) for local needs, National Notifiable Disease Surveillance System Database (NNDSSDB) for reporting requirements in South Africa (38-41) , OrgArk and EpiArk databases in Sweden (30), National Health Insurance (NHI) in Taiwan (36, 48), EpiSurv database in New Zealand (45, 49), Local Public Health Unit Database (LPHUDB), and Public Health England Database to address local and national needs in the UK (31, 32).

The databases should contain specific data for effective and efficient reporting. These data are summarized in Table 4.

3. Notifiable diseases surveillance system minimum dataset

The notifiable diseases reporting data elements included information categories, information classes, and data element instances. After the systematic review, two non-clinical and clinical information categories, 11 information classes, and 77 data elements were identified for reporting. The non-clinical (administrative and management) information category included demographic, contact, identification, socio-economic, geographic, aggregate, and legal information classes. The clinical (medical and diagnostic) information category comprised diagnostic, laboratory and evaluation, time series, and history information classes. Each clinical and non-clinical information category consisted of seven and four information classes as well as 38 and 39 data elements, respectively, as demonstrated in Tables 5 and 6.

4.4. Data standards

Data standards are essential for effective information exchange which is, in turn, one of the requirements of surveillance systems' data architecture. The traditional methods of exchanging non-electronic data (37, 44, 48), basic technologies such as telephone, fax, telecopy, telefax, and voice over Internet (VOIP)(34, 37, 38, 42, 48), electronic document interchange by Medical Information Exchange (MEDIX) and Public Health Information Exchange (PHIX) (4, 17, 18, 29, 37, 38), email (4, 17, 18, 29, 37, 38), and customized Internet pages (4, 26, 41) were used to exchange information among organizations involved in the management of notifiable diseases data in studies related to developing or less developed countries. The standards of data exchange, structure and content of terminology, and classification are summarized in Table 7.

4.5. Data quality control measures

Core Data Category	Data Element Instances	Frequency of Records	Reference Number
Demographic data	First name/surname	13	(16, 18, 23, 24, 28-35, 37)
	Age	24	(4, 5, 16, 18-20, 23-25, 28-30, 32-35, 37, 40, 41, 45, 48-50, 52, 55)
	Sex	23	(4, 16, 18-20, 23-25, 28-30, 32-35, 37, 40, 41, 45, 48-50, 52, 55)
	Marital status	10	(2, 16, 23-25, 28, 30, 32, 50)
	Nationality	14	(5, 16, 18, 20, 24, 25, 28-32, 45, 48, 50)
	Ethnicity	16	(5, 16, 18, 20, 23, 24, 28-30, 37, 40, 41, 45, 48, 52, 53)
	Local residence	2	(16, 50)
Contact information	Residence address	18	(5, 16, 18, 20, 23, 24, 28-30, 32, 37, 40, 41, 45, 48, 49, 52, 53)
	Residence phone number	12	(18, 23, 24, 29, 34, 35, 37, 39, 45, 49, 50, 55)
	Postal code	6	(5, 23, 35, 45, 50, 55)
	Fax/electronic mail address	5	(24, 29, 35, 50, 53)
Identification	Patient ID	9	(4, 20, 23, 32-34, 45, 50, 55)
	Physician ID	6	(18, 20, 32, 34, 48, 50)
	Insurance ID	6	(18, 23, 32, 35, 48, 50)
	Patient record number	10	(18, 20, 32, 34, 35, 45, 48-50, 53)
	Notifier ID	7	(18, 20, 32, 34, 45, 49, 52)
	Notification ID	7	(4, 18, 20, 40, 49, 52, 55)
	Record ID	4	(16, 45, 50, 53)
	Recipient ID	5	(18, 20, 48-50)
Social and economic status	Occupation	4	(18, 40, 48, 49)
	Education level	3	(18, 40, 49)
	Income level	2	(18, 40)
	Health status	2	(18, 40)
Cumulative data	Disease name and disease agent	4	(4, 36, 45, 52)
	Suspected, probable, and confirmed cases	4	(31, 36, 45, 52)
	Demographics	2	(31, 36)
	Geographic features	4	(31, 36, 45, 52)
	Type of disease transmission	3	(31, 36, 52)
	Time period	3	(31, 36, 45)
	Occurrence of death	3	(31, 36, 45)
	Treatment outcome	1	(36)
	Prevalence information	2	(36, 52)
Environmental data	State/city/region of exposure	13	(18, 20, 25, 29-31, 33, 40, 41, 45, 48, 51, 52)
	Country/destination	11	(16, 18, 20, 25, 29-31, 38, 41, 45, 48, 51, 52)
Statutory	Legal responsibility	2	(16, 48)
	Report confidentiality code	3	(18, 45, 52)
	Report confidentiality access level	1	(18)

Table 5. Non-Clinical Data in the Notifiable Diseases Surveillance System

Format	Proposed Standard	Frequency of Records	Reference Number
Machine-organizable data	HL7	9	(4, 5, 24, 25, 29, 32, 35, 41, 51)
Medical document exchange format	Clinical Document Architecture (CDA), Continuity of Care Document (CCD), and Continuity Care Record (CCR)	5	(17, 18, 32, 40, 50)
Markup language	XML Document Transform (XDT)	4	(2, 4, 32, 49)
Classification systems	International classification of disease (ICD, ICD9, ICD9-CM)	8	(4, 16, 17, 29, 36, 41, 51, 54)
	Other classification systems (DRG, CPT, ICECI, HCPCS,ICPM, ICF, DSM)	14	(3, 4, 11, 16, 17, 26, 32, 36-38, 41, 51, 54, 55)
Nomenclature systems	LOINC	8	(16, 18, 39, 49, 51, 52, 54)
	SNOMED	10	(18, 20, 23, 39, 49, 51, 52, 54)
	Rx NORM	4	(17, 19, 24, 25)
Standard content-maker formats	Standard address format definition, standard contact number format definition, standard ID format definition, and standard date format definition	2	(35, 50)

Table 7. *Data Standards for Notifiable Diseases Surveillance System*

Quality Control Procedure	Data Quality Criteria	Frequency of Record	Reference Number
Predefined standard information format for reporting	Completeness, consistency, and validity	5	(20, 32, 35, 41, 50)
Interoperability standard use	Timeliness, completeness, accuracy, and competencies	8	(16, 18, 32, 41, 50, 52, 55)
Basic technology avoidance	Timeliness, completeness, and accuracy	6	(4, 16, 32, 50, 52, 55)
Customized Web page design	Timeliness, completeness, and consistency	9	(4, 24, 30-32, 36, 50, 52, 55)
Revising the information fields	Completeness and validity	6	(5, 18, 34, 37, 40, 54)
Avoiding repeated data fields	Consistency and accuracy	7	(31, 32, 37, 38, 41, 48, 54)
Educating and informing	Accuracy, validity, and completeness	5	(18, 34, 38, 41, 48)

Table 8. Criteria to Control the Quality of Notifiable Diseases Reporting Data

The criteria for controlling the quality of data obtained from the identification and reporting of notifiable situations in the studied countries comprised data completeness (2, 3, 16-18, 20-26, 28, 30, 31, 34, 36, 37, 39, 41-43, 45, 46, 48, 49, 51), comprehensiveness (2, 17, 21, 30, 43, 49) , accuracy (16, 17, 20-22, 24, 25, 28-31, 33, 34, 36, 37, 39, 41-45, 48, 49), consistency (3, 4, 22, 25, 26, 29, 31, 33, 35, 39, 45, 55), adequacy (2, 3, 16, 17, 21, 28-30, 34, 36, 37, 42, 43, 49), being up to date (2-4, 16, 17, 21, 22, 27-30, 33, 34, 36, 39-43, 46, 48, 49, 51), and validity (2-4, 16, 17, 21, 27-30, 34, 36, 42, 43, 48, 49, 51). Some prerequisites necessary to ensure the quality of data in reporting notifiable diseases are listed in Table 8.

5. DISCUSSION

In the present study, organizations involved in notifiable diseases surveillance systems were data producer organizations, data user organizations, and decision-maker organizations.

More organizations are involved in developed countries. In addition to healthcare organizations, more non-health care organizations are involved in the process of identifying, using, and managing notifiable diseases data. The most important stakeholder organizations in each organizational group include hospitals, clinics, and laboratories as case detector organizations; public health, research, epidemiology, and policy-making institutions as data user organizations; and the ministry of health and national public health organizations as data-coordinating organizations.

In this study, countries customized databases according to their specific local, regional, and national needs. Due to structural independence, data independence, greater flexibility and integrity, and lower redundancy, the relational, object-oriented, and object-relational structures were frequently employed. Other types of databases such as network and hierarchy were outdated due to the lack of independence capabilities and high data redundancy. Moreover, the architectures for the transmission of health information in notifiable diseases surveillance systems included centralized architecture, decentralized architecture, and hybrid architecture. In the majority of studies, the centralized architecture was the basis of information storage and retrieval. In this architecture, the storage, retrieval, and sharing of information is based on the centralized aggregation of information in central databases. In the decentralized architecture, information-sharing is based on peer-to-peer transfer of information without using central storage capabilities. Finally, the hybrid architecture combines the capabilities of both centralized and decentralized architectures.

Given the diversity of data sources of notifiable diseases surveillance system, it is essential to determine a dataset for it. In the reviewed articles, various datasets were introduced for these diseases such as the Public Health Common Data Set (PHCDS), playing a significant role in improving the reporting of organizations involved in disease management and control. The PHCDS includes minimum, core, and standard datasets to report public health situations; it allows for reporting and comparing public health threatening diseases to meet clinical, medical, administrative, managerial, policy-making, and decision-making requirements. As a PHCDS subunit in the form of a standard minimum dataset, the identification of notifiable diseases reporting data elements plays a significant role in controlling and managing these diseases. It is recommended that a list of core data elements be provided for notifiable diseases to be used for reporting at local and national levels. In order to create an MDS for public health purposes, the special needs (specific case reporting) should be considered with patient identification information at local levels, from case detector organizations to local public health organizations. The common reporting needs were addressed for statistical purposes, epidemiology, and policy-making and decision-making analyses.

Regarding the structure and content standards, the findings revealed that the application of these standards plays an important role in the creation of organized information systems. The studies indicated that the use of structure and content standards makes it easier to manage and share data. In terms of data sharing, the findings demonstrated that HL7 standards and CDA structure may be used in data interchange as they create an integrated information platform and streamline the data flow.

In addition to ICD classification and terminology standards, the SNOMED-CT and LOINC have been introduced as key interoperability prerequisites. The information content of clinical and medical documents in case-detecting organizations is mapped to ICD-10

codes; its adoptions and laboratory and evaluation information are mapped to LOINC codes to address local needs; and eventually all content is mapped to SNOMED-CT integrated and reference codes.

Maintaining data quality to provide an optimal and efficient report is another essential requirement for the establishment of notifiable diseases information system architecture. The most important data quality criteria were completeness, accuracy, and timeliness of data. In the studied developed countries, the establishment of interoperability infrastructure for the transfer of information through special attention to standards played a significant role in improving the data quality criteria.

It is concluded that the use of correct methods for ensuring the quality of data, application of appropriate tools, continuous training of system users, and continuous data refinement may improve data quality.

6. CONCLUSION

To address the challenges of notifiable diseases and effectively manage them, it is vital to establish an integrated surveillance system to collect information from various sources, process them, and make them available at required times and places. If this system is developed based on the principles of data architecture, the management of the data on these diseases will be improved.

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