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# The Design and Development of a National Registry of Pediatric Neurological Diseases in the Philippines - A Preliminary Report

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## ABSTRACT

One of the important prerequisites in developing health programs and policies for pediatric neurologic diseases is accurate information about the status of these diseases in the country. At present, there is no existing registry of pediatric neurological diseases in the country. The Child Neurology Society Philippines (CNSP) sought to develop and implement a national registry for pediatric neurologic diseases. Specifically, it aimed to 1.) determine a consensus for the purposes of the registry, 2.) develop an implementation system from data collection until information dissemination, 3.) install a system for evaluating data reliability, and 4.) establish a feedback system for improvement. Results showed that the CNSP members wanted a census of diseases, to use the data for research, to identify participants for a research study, and for epidemiological surveillance. Data collection is by filling up forms at the clinic level and its submission to the centralized encoder. Monthly and annual census of diseases are generated and e-mailed to each member who has subscribed to these reports. Custom reports may be produced when requested. Early challenges in the implementation of the database include negative personal preconceived ideas about the database, collecting data, possible ethical concerns, and logistical limitations.

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## INTRODUCTION

The Child Neurology Society of the Philippines (CNSP) is an organization that exists to promote pediatric neurological health by capacity building through its accredited training programs, health education among the population, and advisory roles in various policy-making activities of the Department of Health and the Philippine Pediatric Society. One of the important prerequisites in developing health programs and policies is accurate information about the status of pediatric neurological diseases in the country. A registry is an official list or record of data that can be used for various activities that need basic information such as census, budget

allotment, and personnel assignment for health care. At present, there is no existing registry of pediatric neurological diseases in the country that is available for reference.

The development of a national register of diseases poses many challenges. The kind of information that needs to be included in the register should be established by reviewing the organization's needs and requirements. In the previous attempt at the development of a database for the CNSP, the information gathered was very specific and extensive such that collecting data became a very tedious task that garnered a lot of resistance among end-users. Data collection is a major issue in different national register projects and have been addressed through various methods<sup>1,2</sup>.

In general, data that has been obtained from various sources provide a more comprehensive and accurate register. Another issue in national registries is the process of banking and using the data. Barriers to its use include financial reasons,

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For the Database Project Group of the Child Neurology Society Philippines Inc.

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technical, and time factors<sup>3</sup>.

A registry can be used in different ways such as identifying patients for participation into a research study<sup>4,5,6</sup>, gathering data for a research study<sup>7</sup>, social and professional networking among specialists<sup>8</sup>, assisting a clinician with diagnosis<sup>9,10</sup>, decision-making in health administration<sup>11</sup>, and public health surveillance<sup>12</sup>. Its design should be tailored to the organization's main objectives for the registry and should consider confidentiality and security issues<sup>2,13</sup>. The development of a registry entails a multidisciplinary collaboration from primary stakeholders such as clinicians, researchers, and patients as well as information and communication technology specialists. After the development of the registry, implementation poses a new challenge in data collection and information dissemination thus requiring close supervision by a registry administrator<sup>2,13,14</sup>. Major barriers in the development and implementation of a registry include issues about registry objectives, manner of data collection, personalities or institutions given access to enter and to obtain information from the registry, complexity of the system, privacy and security, and reliability of the system.

While the task of establishing a registry requires much effort from the project coordinators, the advantages of having the information outweigh the challenges. This project sought to develop and implement a national registry system for pediatric neurologic diseases in the Philippines. Specifically, it aimed to 1.) determine a consensus for the purposes of the registry, 2.) develop an implementation system from data collection until information dissemination to end users with minimal computing skills, 3.) install a system for evaluating data reliability, and 4.) establishing a feedback system for improvement of the registry.

## METHODS

The entire project consisted of four phases: 1.) Needs assessment, 2.) Designing and constructing the Data Collection Process,

Database Program, and the Database Information Dissemination System, 3.) Launching and Implementing the Database Project, and 4.) Evaluation and Feedback of the Database Program. The project proposal was submitted to and subsequently approved by the Zamboanga City Medical Center Institutional Ethics Review Board since the project base was in Zamboanga City. However, separate proposals with regards to data collection from individual institutions were submitted to each institution for approval prior to collection of data. With regards to the recruitment of respondents, for Phase 1 (Needs Assessment), 50 fellows of the Child Neurology Society of the Philippines practicing in the country were identified to receive the survey. For Phase 2 (Design and Development), 8 past presidents and the current president were given copies of the database and its implementing rules and guidelines for their comments. As of December 2017, this project has completed three phases. Phase 4 is scheduled to be completed by the end of 2018. Phase 1 utilized a survey questionnaire to determine the needs of the members. The questionnaire consisted of a 2-page, 5-question survey to obtain opinion on the primary objectives for a database, its accessibility, and its implementation. Various possible answers were provided with check boxes and a blank line was provided to allow respondents to give answers not among the choices presented. More than one choice was allowed. A "consensus" was achieved when 75% of the respondents agreed on one item. After the collection and summation of the survey results, Phase 2 proceeded with the design of the registry. The database project group designed a database system that included the entire procedure of data collection to reporting. This was then presented in the form of printed manuscripts of the database and implementing guidelines to the past presidents of the society for comments. The

comments were then consolidated and the appropriate revisions were adapted. Face validity was performed through continuous feedback from end-users regarding the ease of filling up, clarity of instructions, and ease of returning and receiving forms. Issues such as font size, definition of terms, and indicators for required fields to fill up were raised with regards to the hard copy forms. Issues regarding accessibility to the online site, report generation, and lost passwords were frequently raised with regards to the online database. Comments and suggestions were taken into consideration and the appropriate changes were applied. Thereafter, a test run of the entire system simulating the actual implementation of the program was done in several sites all over the country from October 2013 to March 2015. Phase 3 consisted of the launching of the program last June 2015.

**RESULTS**

Out of the 50 members invited for the survey, 27 (54%) completed the survey. Among the 9 CNSP presidents, 7 (78%) provided feedback. Three (33%) returned the paper form with written comments while two (22%) provided verbal comments to the primary investigator and two (22%) sent e-mail comments.

**Table 1.** Frequency of Responses for the Objectives of the Database of Childhood Neurologic Diseases

Purpose of the Database	Number of Responders N=27 n (%)
For census purposes	26 (96.3)
To identify participants to enroll in a research study	20 (74.1)
To gather data for an existing research study	21 (77.8)
For social networking	4 (14.8)
To assist you in diagnosing a patient	7 (25.9)
To assist you in decision-making with regards to health administration	15 (55.6)
For public health surveillance	24 (88.9)
For maintaining patient medical records	8 (29.6)

**Table 2.** Frequency of Responses for the Information Needed in the Database of Childhood Neurologic Diseases

Information in the Database	Number of Responders N=27 n (%)
Name	25 (92.6)
Contact numbers	24 (88.9)
Address	25 (92.6)
Age at diagnosis	27 (100)
Date of birth	26 (96.3)
ICD 10 classification	25 (92.6)
Diagnosis	27 (100)
Attending physician	16 (59.2)
CNSP member only	14 (51.9)
Outcome	25 (92.6)
Ethnicity	24 (88.9)
Sex	26 (96.3)
Religion	17 (63.0)
Treatment received	22 (81.5)
Mother's name	6 (22.2)
Father's name	5 (18.5)
Hospital/Clinic	12 (44.4)
Date of Diagnosis	16 (59.2)
Family tree	2 (7.4)
Education	2 (7.4)
Number of Family Members	1 (3.7)
Chief complaint	2 (7.4)
Duration of Treatment	1 (3.7)

**Phase 1: Needs Assessment Survey Results**

Items with at least 20 respondents who concurred were taken into consideration for the design of the database. For the purpose of the

database, 4 objectives were identified: to provide census of diseases, to use the data in the database for research, to identify participants for a research study, and for public health or epidemiological surveillance (Table 1). For information that is needed to be in the database, the respondents required basic demographic data such as name, address, age, contact information, ethnicity, gender, religion, age at diagnosis, ICD 10 classification, diagnosis, outcomes, and treatment received (Table 2). Other additional information that were volunteered but not among the choices were: family tree, level of education of parents and patient, number of family members, chief complaint, and duration of treatment.

In terms of method of data collection, there was no consensus achieved however, the most number of respondents (17 or 63%) indicated that they preferred either hiring a database clerk or having the attending neurologist herself/himself collect the data. In terms of encoding the data, the respondents preferred having a CNSP member (23 or 85%) or hire a data encoder (20 or 74.1%) to enter the data.

On the aspect of accessing the database, two questions were presented to the respondents. The first considered privacy issues and dealt with who has access to the database and the second consideration was how the database can be accessed. Most respondents (19 or 70.4%) agreed to allow any member of the CNSP to gain access into the database. In terms of how to access the database, the consensus (22 or 81.5%) was to access it via the internet (Table 3).

When surveyed on what kind of information a member would like to get from the database, the consensus was an annual census (25 or 92.6%) and disease-specific epidemiologic data (26 or 96.3%) (Table 4).

## Phase 2: Design of the Database of Neurologic Diseases in Childhood

In the design of the database, the study group considered various factors such as the survey results, appropriateness of the survey result with the objectives of the database, and ethical

**Table 3.** Frequency of Responses for the Access of Data for the Database of Childhood Neurologic Diseases

Person who can access	Number of Responders N=27 n (%)
Registry clerk	17 (63.0)
Board members of CNSP only	7 (25.9)
Fellow of CNSP only	13 (48.1)
Any member of CNSP	19 (70.4)
Parent or patient registered in the database	2 (7.4)
Public	1 (3.7)
Any researcher	9 (33.3)
<b>How the data can be accessed</b>	
Web-based access	22 (81.5)
Written request addressed to BOT	7 (25.9)

**Table 4.** Frequency of Responses for the Kind of Information to be Received from the Database of Childhood Neurologic Diseases

Information to receive from the database	Number of Responders N=27 n (%)
Annual census/epidemiologic data	25 (92.6)
Disease-specific census/epidemiologic data	26 (96.3)
Identities of patients	2 (7.4)
Contact information of patients	1 (3.7)

considerations in terms of confidentiality and ownership of the data. While a consensus was reached for the items on contact numbers of patients (24 or 88.9%) as well as treatment received (22 or 81.9%), the contact numbers were excluded in respect to the ownership of the primary attending neurologist of the data of his or her patients and privacy issues. The study group decided to identify the attending neurologist so that in the event that the particular patient is needed to be contacted, the attending neurologist will be assigned to contact the said patient. With regards to the "treatment received", the study group decided not to include this item because it does not achieve any of the objectives

identified for the database. The main features of the database include basic epidemiologic data, ICD 10 classification of diseases, the International League Against Epilepsy (ILAE) 2010 classification of seizures and epilepsy, and different levels of access to all data, even among CNSP members. English and Tagalog versions of the form are available.

The main features in terms of the implementation of the registry include strict confidentiality, informed consent, and ownership of data. Confidentiality is ensured by the application of different levels of access. For research purposes using the data from the database, approval from the board of directors should be obtained. Each patient's data shall only be encoded once the parent or guardian signs a consent form and the child 7 years old or above gives his or her assent to provide information to the database. To ensure accuracy of data, double-entries are flagged and entry cannot be done unless revised by the individual with full-access.

The group also allowed each member of the CNSP to subscribe to regular monthly and annual census reports. Each CNSP member can also request for census reports of his or her own patients.

### ***Basic Infrastructure***

One of the main requirements of the registry is that data can be input into and accessed from the registry globally thus the registry is web-based. For the client-side implementation of the website, HyperText Markup Language (HTML) and JavaScript programming languages were used. PHP and MySQL were used server-side, with SQL as the language employed in creating the database.

### ***Design Specifications***

The basic website design has been tailored to match the main, official website of the Child Neurology Society of the Philippines. It highlights the logo of the society at the top-left portion of the website, and uses the same shades of green and blue.

It is noted that the online registry needs to be user-friendly, to assist users who might not be technology-savvy or who might have a psychological barrier from fear of trying new technology. The website has been designed to take advantage of intuitive and easy-to-reach buttons for links to functions of the website. Examples of these features include the name of the user highlighted on top of the page that when clicked, leads the user to the user account profile page; and clickable names of patients in the form page, which lists the names of patients, that leads the user to the patient information page.

The architectural design of the database was conceptualized using Object-Oriented Design principles. The requirements of the database were gathered iteratively over the entire duration of the project, with milestone deliveries submitted periodically. Blue-skying for features and personal interviews with the database administrator and data encoder were conducted. To capture user requirements, Use Cases were employed. Class Diagrams were designed to show the relationship between design objects. To specify and describe the classes and the data used, a Class Dictionary was also developed.

### ***Security and Access***

CNSP members, an encoder, and a few selected institutions are given accounts to use to log on to the online registry. The accounts allow users to enter, view and edit data, perform patient information searches and generate reports. The website is protected by Secure Sockets Layer (SSL), which was deemed adequate at the time of design, provided by its website host page.

There are three types of accounts, namely, Neurologist, Institution and Encoder. As suggested by the names, the Neurologist accounts are given to members of the society. The Encoder account is given to the hired clerk who inputs the data, while the Institution accounts are given to selected institutions. Aside from account types, there are also two access levels: a Full-Access level

account and a Limited-Access level account.

A Full-Access user essentially has access to all the features of the registry, which includes the creation, deletion and editing of users' account and patients' information, viewing of list of all patients entered by any user, viewing of incidence, prevalence and monthly reports of any year and month and generating custom reports. It is important to note that Full-Access users can change the access level of any account. Moreover, to satisfy the requirement of ensuring respect for ownership of patient information, Full-Access users may, at the express agreement of the (Limited-Access) users concerned, transfer ownership of patient information from one user to another.

Limited-Access users, on the other hand, may only edit their account information, view and edit patient information entered under their account, and generate current year and month reports that show only data of the patients under their account. Limited-Access users may not generate custom reports.

Generally, only the website administrator and the society board members have Full-Access levels. Other users with Neurologist and/or Institution account types may be given Full Access for any length of time by a Full Access user. Encoder account types have Limited Access, but have the special feature of being able to assign the patient classification type and ownership of patient data. This is because encoders handle patient information from many neurologists and institutions, and so must be able to assign patient information to the appropriate neurologist or institution. However, the security of personal computing systems of each of the encoders and neurologists is beyond the control of the database team.

### ***Patient Information***

The Form page shows the list of patients under the user account. Limited access users only see the list of patients under them; Full-Access users see the list of all patients in the registry. Clicking the "Add New Patient" button leads the user to the patient information entry page.

A new patient information entry is automatically assigned a patient ID, based on the month, date, year and time the patient entry was created. Once the user sets the birth date, date of clinical presentation and date of diagnosis, the system automatically computes the age of the patient, the age at clinical presentation, and age at diagnosis, respectively. In the event of a double entry, the second entry of the same patient is flagged with a pop up notice. This is identified through identical full names and date of birth. In such situations, additional entries for other attending neurologists and additional diagnoses can be added.

New diagnoses may be added by clicking the "+Diagnosis" button. To enter the ICD10 codes, the user needs only to set the ICD letter, number, sub-classification, and the decimal values of the ICD code. The disease and the group code is automatically set by the system. The patient classification may only be set/edited by a Full-Access user, or a user with encoder account type. Other users may no longer do so as the system sets the patient classification based on the user's account type and name.

### ***Reports***

The online registry has the feature of generating reports based on input patient information. There are four kinds of reports, namely, Incidence, Monthly, Prevalence and Custom reports. Full-Access users can access all reports and search for results of any year and/or month. Limited-Access users do not have access to the Custom report, and may only generate Incidence, Monthly and Prevalence reports of the current year and/or month.

Custom report allows a Full-Access user to search using ICD, Age, Culture and Diagnosis filters. Each filter has many options; for instance, under Diagnosis, the user may ask the system to generate a report for patients under a certain neurologist and/or the outcome of their diagnosis. All report types initially display in table form the list of

patients that match the report type, and in the case of custom report, based on the filters set by a Full-Access user. Users may ask the system to display a pie/bar chart simply by clicking buttons at the bottom of the table.

The generated reports are automatically sent annually (for annual incidence reports) and monthly (for monthly reports) to the e-mail addresses of users who asked to subscribe to the reports. Generated reports may also be extracted and saved to the hard disk of a user.

### **Phase 3: Launch and Implementation of the Database**

The database program was launched in May 2014 in Davao City amongst the CNSP members from the Mindanao area, June 2014 among members in the Visayas region, and March 2015 among Luzon-based members. Over a 4-hour workshop, the database administrator and software developer explained the implementing rules and guidelines from data collection to data encoding to report generation. Comments generated from the workshops and subsequent implementation in their respective areas garnered comments that produced subsequent revisions in the forms and implementation guidelines for the project.

### **DISCUSSION**

The development and implementation of a national registry or database for any kind of disease or disease group has always posed a major challenge among different institutors<sup>1,2,13,14,16</sup>. This particular project faced mostly similar challenges as well. The design and development of the software represented only one aspect of the entire project. Its design depended heavily on the needs of the group. For the CNSP, some members were confused between having a database or registry in contrast to having an electronic medical record (EMR). An EMR is basically a digital version of a patient's medical record. It consists of a patient's medical details from demographics to information given about every disease state that he ever had, a

comprehensive developmental, immunization, prenatal, maternal, and perinatal history, and laboratory results and treatments received. In contrast, a database or registry is in essence a list of individuals with specific characteristics. In the presentation of the implementing rules and guidelines for this project, many members had expectations that did not coincide with the objectives of the database based on the previous needs assessment. This ambiguity may be due to the fact that only 54% of the members returned the survey for needs assessment. Another reason for this may also be the length of time from the conduct of the survey to the presentation of the database (approximately 20 months). Therefore, it is essential in any implementation of a project to orient and re-orient end-users regarding the objectives, capabilities and limitations of the endeavor periodically.

One of the major challenges that the team faced was in the collection of the data forms. In Haberman's report regarding the North West Thames registry<sup>1</sup>, data collection was done using data mining through ICD 10 codes. They used a program that identified hospital admission discharge code for Guillain Barre Syndrome and detected the file for the registry. This entails a comprehensive network that would connect all the hospitals and out-patient clinics so that the database would be able to run through and filter the data from all of these different records. This is not possible at this time in the Philippines. Another way to collect the data would be to ask each neurologist to encode directly into the database himself/herself. Direct encoding into the database by each neurologist however, has its own share of challenges. Previous reports indicated that various levels of computing skills by end-users can affect the rate and accuracy of data encoding<sup>3</sup>. Moreover, familiarity or its lack of the software can produce various levels of frustration and eventual discouragement in the encoding of data. Busy neurologists also may not have the time to sit and encode the data of all of their patients and thus prefer to fill up the hard copy

forms and submit these to the encoder instead.

Issues on data accuracy will always be a limitation of any form of registry or database. Since the distribution of child neurologists in the Philippines is skewed towards Luzon where about 80% of the CNSP members are based, data from other parts of the country may not be included in the registry due to the inability of patients to seek consult in areas where there is a lack of child neurologists. In these areas, adult neurologists also see neurologic cases among the pediatric population. Since adult neurologists are not included in the data collection phase of the project as of this time, it is expected that the incidence and prevalence of diseases may be underestimated especially in Mindanao where only 8% of the child neurologists are based. A solution to this problem is to include the entire population of neurologists in data collection. The accuracy of each diagnosis is also a limitation of this project. It is assumed that each fellow of the CNSP has attained the minimum level of competency as required by the society and thus it is implied that he or she is capable to diagnose accurately. To obviate the problem of conflict in diagnoses between 2 or more neurologists who have seen one individual case, the implementing rules and guidelines dictate that the data shall be withheld from being encoded and an objective mediator will discuss the issue between and among the neurologists involved. This action also considers the ethical issues regarding clinical practice in medicine. This respects the opinions of all neurologists involved and encourages constructive discussion among the CNSP members. As a corollary, the database also respects the rules of ownership of the data, where each primary attending and the CNSP are co-owners of the data of the primary attending alone. One neurologist is limited to access only the data of his or her own patients, whether managed alone or co-managed with another

neurologist.

Finally, logistical concerns offer a major barrier to the implementation of the project. Most of the costs pertain to courier services, salaries and honoraria for the staff of the project. Other hidden costs include travel expenses, communication expenses, and other operating expenses such as printing and photocopying costs. Maintenance of the program may take up to 25% of the annual income of the society. This is a major issue that the society will need to consider in the future.

### CONCLUSION

The CNSP commissioned a database project team to develop a registry system for childhood neurologic diseases in the Philippines. The database was developed to determine a consensus for the purposes of the registry, develop an implementation system from data collection until information dissemination to end users with minimal computing skills, install a system for evaluating data reliability, and establish a feedback system for improvement of the registry. After 2 years since the team started with needs assessment, a database has been installed and can be accessed online. Early challenges in the implementation of the database include negative personal preconceived ideas about the database, collecting data, possible ethical concerns, and logistical limitations.

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