POND4Kids: A Global Web-based Database for Pediatric Hematology and Oncology Outcome Evaluation and Collaboration

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Abstract. The Pediatric Oncology Network Database, (www.pond4kids.org, POND), is a secure, web-based, multilingual pediatric hematology/oncology database created for use in countries with limited resources to meet various clinical data management needs including cancer registration, delivery of protocol-based care, outcome evaluation, and assessment of psychosocial support programs. Established as a part of the International Outreach Program at St. Jude Children’s Research Hospital in Memphis, Tennessee, POND serves as a tool for oncology units to store patient data for easy retrieval and analysis and to achieve uniform data collection to facilitate meaningful comparison of information among centers. Launched in 2003, POND now has 233 sites registered with over 1,000 users in 66 countries. However, adoption and usage of POND varies widely among sites. This paper reviews some of the challenges to developing a global collaborative clinical platform based on the experiences of developing POND. The paper also presents a case study of POND use in Guatemala, where the Guatemalan National Oncology Unit (UNOP) has developed extensive internal and external global collaborations using POND.

Keywords. Cancer registry, pediatric oncology, international, collaboration, clinical improvement, clinical informatics, e-health, data management programs

1.0 Introduction

Developed by International Outreach Program at St. Jude Children’s Research Hospital, the St. Jude Pediatric Oncology Networked Database (POND, www.POND4Kids.org) is a secure, online, multilingual database for pediatric hematology/oncology patients. Its purpose is to improve the care of pediatric oncology patients in countries with limited resources by the exchange of information and experience between oncologists in diverse geographic regions who practice in a similar medical environment [1,2,3,4]. The major objectives of POND are to:

1. Allow oncologists to store, share, and control access to patient data.
2. Provide uniform data collection to facilitate meaningful comparisons
3. Provide educational support for data collection, quality control, and analysis.
4. Provide a multi-lingual system that supports data sharing and comparison in a universal format while allowing data entry and reporting in the user’s native language.
This paper presents a technical overview of the system, reviews global usage of POND, and identifies some of the barriers and facilitators for adoption and usage of POND, and provide an example of successful POND use at the National Pediatric Oncology Unit of Guatemala, and highlight on-going challenges.

2. POND4Kids Systems Design

POND4Kids allows uniform data collection so that clinical data can be shared and meaningfully compared between centers. POND4Kids uses a centralized web server (Linux, MySQL, and PHP) that can host multiple virtual sites. Each site has an administrator that can add users and control the level of access of each user. Data can be shared with individuals at another POND site, and sharing can be deactivated at any time. By design, personal information such as names cannot be shared between sites, such that shared data always complies with HIPAA privacy rules in the US, which are similar to privacy rules in many other countries. The intent is to allow data about a particular disease to be shared with a disease expert to assist with analysis and development of strategies to improve outcomes. Users can create Quick Data Entry forms that can be used within a POND site or shared with other sites via a common library. Protocols templates can also be created and used locally, or shared with other sites via a common library. Using the online meeting capabilities of the Cure4Kids website (www.Cure4Kids.org), training is provided on best practices for clinical data collection and clinical quality improvement programs. Additional details of the POND system can be found in [4,5,6]

3. Outcomes

Since its launch in 2003, POND use has increased steadily, with use spreading only by word of mouth in the pediatric hematology/oncology community. As of September 12, 2012, POND has 1,222 users from 233 sites in 66 countries. There are over 50,000 records and 800 collaborative data shares and 4,000 logins each month (Figure 1).

Figure 1 - Total Number of Logins (all sites)  Figure 2 - Records in POND Guatemala

In Guatemala, a pediatric oncology clinic called Unidad Nacional de Oncología Pediátrica (UNOP) was established with a focus on pediatric cancer. Given the limited government resources, a non-profit foundation called Fundación Ayúdate a Vivir was founded in May 1997 to provide the necessary resources for the proper maintenance,
operation, and growth of UNOP as a center of excellence for treating pediatric cancer in Guatemala. Each year, about 400 children newly diagnosed with cancer are treated at UNOP. Survival rates for some types of cancer have increased from 28 percent in 1996 to 70 percent in 2012. Fundación Ayúdame a Vivir subsidizes the treatment for patients who cannot pay. The rate of abandonment of treatment has decreased mostly due to psychosocial intervention, and the provision of housing and transportation. The use of POND by UNOP was initiated in 2004 and has grown consistently with the support of five dedicated data managers. The UNOP clinic has entered data for both current and past patients. As of September 12, 2012 UNOP POND Site had 4748 records of patients (Figure 2). The UNOP site is currently the most active of all POND sites. UNOP accounts for almost half the logins to POND each month. Over the years the number of active data shares has increased as UNOP expands its collaborations with experts in specific diseases at other pediatric cancer centers. UNOP accounts for more than half of the 800 data shares among all POND sites, and UNOP participates in collaborative clinical protocols with many other Latin American countries. Over 1000 reports are generated each month (Figure 3) by all POND sites and UNOP accounts for over 700 of them (Figure 4). These reports are used widely by a multi-disciplinary team of doctors, nurses and allied health professionals at the clinic for patient care, administration, and outcome evaluation. The increased usage and analysis of clinical data is a contributing factor to the increase in survival rates at the UNOP clinic.

![Figure 3- Total Number of POND reports.](image1)

![Figure 4 – Number of Guatemala Reports.](image2)

4. Discussion

POND provides clinical tools that fill an unmet need at many pediatric oncology hospitals, particularly those that have common protocols and wish to share information. There are several reasons for the success of POND at some sites, and lack of use at other sites. Challenges include training, adequate data manager staffing, and quality management. Availability of online training and support is one of the factors that has helped the deployment of POND but at times it can be difficult due to limited bandwidth and lack of Internet reliability. POND is sufficiently easy to use with minimal training for most users. Online help and training are available in English and Spanish. However, data managers need to have computer experience, and some may need additional supervision and guidance. A regional network of POND data managers was formed in Central America that allows for continued training and mutual support.
and encouragement. The UNOP site in Guatemala has provided regional training support for other Latin American centers both online and by hosting data managers from other Spanish-speaking sites when they are starting their data management programs.

The availability of appropriately trained data managers and funding for salaries is a major challenge for many sites. Lack of consistent funding for data managers at some sites has led to inconsistent data entry. Since 2004 a grant from the Pediatric Oncology Group of Ontario (Canada) and financial support from St. Jude Children’s Research Hospital (Memphis, TN) have funded full-time data managers in several Central America countries, and these tend to be the sites with most active use. Other sites do not have sufficient funding to hire data managers, and the clinical staff does not have the time to enter records. The UNOP site now has 5 data managers that facilitated the widespread use of POND by doctors, nurses, nutritionists, and psychosocial support staff.

High-quality data is the cornerstone on which quality improvement rests, so POND has specific quality reports that identify the most common data entry errors, including unlikely and impossible values [4]. However, these reports need to be regularly run and acted upon to improve areas of missing or incomplete data. There may also be a lack of standard operating procedures, inconsistent data collection methods, or missing paper records. More training and on-site audits could facilitate additional improvement in data quality and efficiency. Recent additions to POND include error-checking tools that show missing or possible out of range data. UNOP also has implemented a daily review all data entered in POND in the previous day that has greatly improved data quality.

Security is an important part of any medical records system. The POND software resides in a dedicated server with a security firewall. Users with administrator credentials manage access to data by users of the site and control sharing with external collaborators. Although the data are encrypted and password protected, some administrators are reluctant to store data outside their institution. The location of the POND server in the United States has provided some concern to some sites. Future development of a local POND system would facilitate use by those sites that do not wish their data to reside on foreign servers.

To obtain benefit from the data-sharing capabilities of POND, access to clinical experts is essential. Common treatment protocols used by pediatric oncology units in Central America were created in POND. Principal investigators of shared protocols have regular virtual meetings to review individual patients with complicated medical problems, protocol data, and administrative issues, and to develop strategies to improve clinical outcomes. These clinical meetings are held online on www.Cure4Kids.org, a web-based education and conferencing platform [5]. UNOP regularly participated in multiple online meetings per week to discuss clinical cases that are in POND.

POND is upgraded regularly in response to feature-specific requests from users. Developing features that meet the priorities of each site remains a challenge not only because of the volume of requests, but also because countries have different data standards, different systems of units for common laboratory values, and other national/regional particularities that must be stored both in the original value and converted to other values when comparing data. Some sites also suffer from slow or unreliable Internet connections, and POND currently lacks offline functionality.
5. Conclusions

POND4Kids provides pediatric hematology/oncology units with platform for data collection and outcome evaluation that facilitates local evaluation and multicenter collaboration. Despite many of the challenges that developing countries [1,2,3,7] face in health care, many sites in developing countries have been able to use POND to collect data for clinical improvement. The UNOP site is one of the most active POND sites, and its staff has been able to overcome many of the challenges related to funding, training and data management. Further efforts are still needed in the areas of standard operating procedures for data collection, data entry, data quality monitoring, and data analysis. The increasing usage of data shares shows that global collaborations can occur between low income countries as well as between low and high income countries. Protocol template forms have allowed consistent data collection and enabled comparison of data across multiple countries. Future development plans include improvements in usability, more flexible reports with additional customization options, support for additional languages, enhanced statistical analysis, the ability to enter and access data while offline, and synchronization across a network of online and offline POND4Kids servers. Future challenges include the prioritization of requests for new features and the need for common data standards for comparisons among centers.

References

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