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***Combined Physician
-Parent Decision
Support Tool***

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Abstract:

Within the context of a newborn intensive care unit (NICU), we explore the design compromises that must be made while developing a PPADS (Physician and Parent Decision Support) tool. This work develops earlier exploration by fostering a clinical information storehouse and a clinical decision support system (CDSS) to enhance mortality and complication prediction in the newborn intensive care unit (NICU). Using a cooperative methodology known as shared direction, our group is blending doctor and parent assets to foster a framework that will help guardians in pursuing essential treatment choices for their newborn children in the NICU. We have framed the construction and engineering plan for making the mixture clinical expert patient device. We determined the applicable criteria for this kind of decision system's design, its mode of operation, and its standards. We also investigated current open-source tools that are well suited to this architecture. The nurse decision support expert and our physician colleague both gave us input on the prototype we developed. A preliminary usability study will be conducted in a tertiary NICU in the near future.

Keywords:

Measurement of risk level estimations, clinical outcomes, clinical decision support, neonatal intensive care unit, health and e-health, physicians and parents.

1. Introduction:

Infants as little as 400 grams and as young as 23 weeks of gestation may be kept alive with the use of neonatal technology and practices [1]. While preterm birth survival rates have increased over the last two decades, moderate to severe impairments are still common among extremely preterm children who make it to adulthood. While still relatively uncommon, these births are on the increase. The ethical, social, and financial burdens placed on families and healthcare providers by the lengthy and extensive care many of these newborns need are substantial. Many of the babies who do make it will need expensive, multidisciplinary care for the rest of their lives [3]. Decisions about patient care are often made based on probabilistic risks [4], and Aggressive or invasive therapies are being questioned more and more when a patient's guess is poor and palliative or solace care may be better [5, 6]. Physicians and parents may struggle to decide whether to continue aggressive critical care or palliative care when a baby's prognosis is poor. When making decisions about whether or not to begin invasive intensive care, the parents or guardians of a baby who is extremely premature bear the emotional and financial costs, so they should be included in these discussions. It has been demonstrated that adopting a computational approach to clinical dynamic in the NICU is helpful [6, 7, 8]. Both families and staff in the NICU would benefit from tools that guarantee parents obtain vital information before making any tough choices about their infant's care. This is why the authors of this publication decided to conduct their exploratory study. The objective of this venture is to assist guardians with settling on informed conclusions about their debilitated baby's consideration in the neonatal emergency unit giving them data about their kid in an agreeable, intuitive arrangement. This advice will only be given to parents of critically sick infants, so it has to be helpful and detailed without being too prescriptive. A couple of choice instruments have been created for the NICU setting, in spite of the way that information the board for moral choice help has gotten little consideration [8, 9, 10]. A choice help device for clinicians working in neonatal escalated care units is the objective of the Child drive. Because doctors and nurses have distinct areas of competence, the NEONATE system is designed to make data collection easier for both of them [11]. Clinician concerns are addressed, but parental choice support is left out [10]. In the United States, "Clinician Support Technology" has brought its research project Baby CareLink to market as a commercial solution for parents to use [12, 13]. The's device will likely give a quiet climate where guardians can effectively take part in their newborn child's consideration in the neonatal emergency unit, whether they are present in the room or not. Our proposed apparatus varies from both the Youngster and Child CareLink frameworks in that they don't give choice help to support the common dynamic cycle between

individuals from the interprofessional group and guardians, and they don't use information mining or example acknowledgment ways to deal with result risk level assessments. Our group has recently dealt with a doctor clinical decision support system (CDSS) that gives evaluations to various clinical results utilizing information from the Canadian Newborn Network (CNN), an enormous vault of infant results from NICUs across Canada [8, 9]. As auxiliary results, we chose bronchopulmonary dysplasia (BPD), necrotizing enterocolitis (NEC), intraventricular hemorrhage (IVH), and passing. Following this, a clinical information vault framework was created to store ongoing information from the neonatal emergency unit at the Children's Hospital of Eastern Ontario (CHEO) in Ottawa. This data includes measurements like the infant's weight, discharge diagnoses, laboratory and imaging test results, and vital signs taken by monitoring devices. Critical choices in the NICU are based on evidence, and this tool is anticipated to improve that evidence for doctors, other carers, and parents.

2. Methodology:

2.1. Improvement of a Parent:

Specialist Asset for the Neonatal Emergency unit calculated design and engineering of our parent doctor instrument (PPADS) were created in the beginning phases of its turn of events. We did broad writing surveys and had useful conversations with our clinical neonatal consideration trained professionals, like Dr. Bariciak, a neonatologist at CHEO, Sandra Dunn, a choice help expert at the Champlain Maternal Infant Territorial Program, and our understudies and specialists, to achieve this. We fostered a model of the PPADS framework and the UI as per two arrangements of plan rules in the wake of choosing a system and engineering: 1) basic principles for sending achievement; and (2) explicit plan rules to urge NICU guardians to partake in shared decision-production for testing care choices. The hidden round of plan examinations included wide guidelines for additional creating clinical decision sincerely strong organization rollout. In the event that the framework meets these prerequisites, it will have a superior possibility working in a clinical setting [16]. We then integrated design features aimed at encouraging parents of NICU newborns to take part in the shared decision-making process while making emotionally charged healthcare choices for their children. The parents' requirements for autonomy in making decisions in the NICU setting may best be served by adhering to these guidelines. Our clinical newborn care specialists were consulted and literature reviews conducted to develop the design requirements. Experts in newborn care offered comments at two distinct phases. The information to be transmitted to users was first

examined by analysing prototype system screenshots for content and organisation. In the second phase, specialists in newborn care used the tool and offered further input, which was included in the revised design. The second audit looked at how well the PPADS interface communicated with users.

2.2. The Architectural Plan:

Our prior database architecture served as inspiration for the new PPADS system, which depends on the persistent assortment and capacity of information on a server inside the emergency clinic's inner organization's Clinical Data Repository (CDR). This CDR information base server accumulates information from the Admissions/Discharge/Transfer (ADT) framework, research facility results, and clinical readings from patient screens at an inspecting pace of once each moment [14]. Crude clinical information is consequently kept separate in the CDR, and confidential patient data is safeguarded from general visibility [15]. The CDR data set is counseled when a specialist looks for a patient in the CDSS interface, and just the specialist's approved information is shown. Figure 1 shows the framework chart for the CDR and CDSS when utilized together.

2.3. Interior design:

The essential UI has two segments: a tool for parents and a tool for doctors. A specific Uniform Resource Locator (URL) can be used to access both resources through a desktop, laptop, or mobile web browser. Because user data is saved on a safe web server, no further programme installations or configurations are required. With this method, even a brand-new user may quickly and simply access their account at the specified URL and get acquainted with the many features available to them.

2.4. Content Management System (CMS):

Drupal, an open-source CMS, has been selected for this project. The content management system is modular, allowing for the addition of features such as user authentication and the presentation of calculated risks. Drupal was selected because of its lively online support and development community, which is responsible for the creation and maintenance of several modules. Because of the solidity of its core code, Drupal's modular architecture enables for changes to be made with no impact on the CMS's functionality. Since many modules merely need tweaking based on what users choose to show, designing new modules (such a graph of the temperature trend of a baby) is easy.

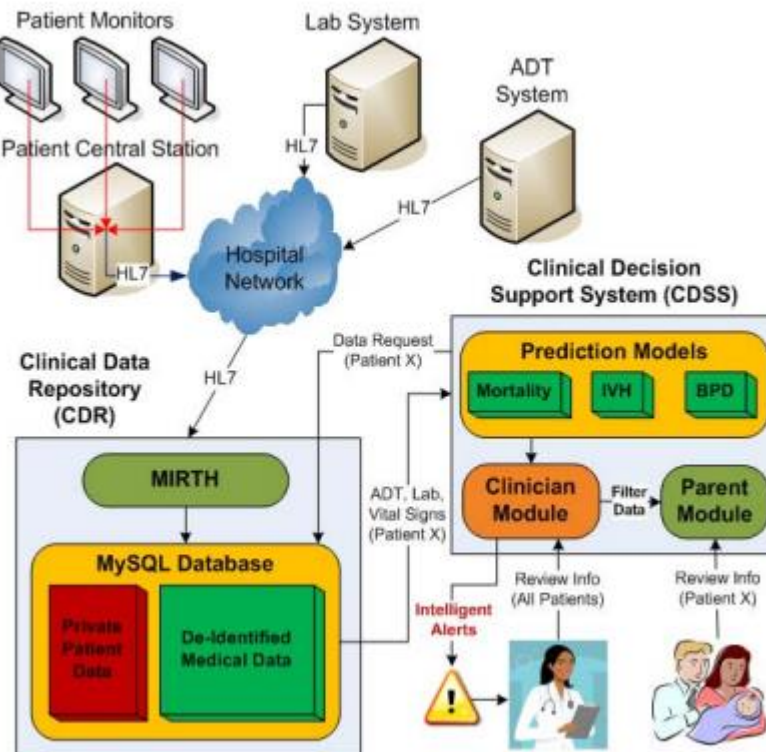


Figure 1. CDR and CDSS System Diagram

Figure.1. CDR and CDSS System Diagram

2.5. User Interface for Clinical Tools Risk Assessment:

Patient lookup, user administration, and lexicon tweaking are just some of the features available in the Clinician's Tool. The clinician's landing page summarises key patient data for quick review and provides access to the system's additional functionalities. On the homepage, you can see the latest admonitions as well as a rundown of patients whose alarm levels have changed essentially or whose result risk gauges are in the high or medium gamble classification. In Fig. 2, you may see an example of the PPADS prototype clinician site. Death, necrotizing enterocolitis (NEC), intraventricular hemorrhage (IVH), and bronchopulmonary dysplasia (BPD) are all now estimated in the "risk measurement" module. The CDSS is able to generate smart alerts and warnings that may be shown on the screen and emailed to a mobile device. The latest prediction results will be available to physicians. In addition to measuring historical patterns, they will be given insight into how patients' risk profiles have changed in light of the care they've received. Doctors may use the system's "patient search" module to look up their patients' past records by name, hospital ID number, or search by date range. Clinicians with the proper permissions will be able to update the existing data as well as add new diagnoses, treatments, and notes.

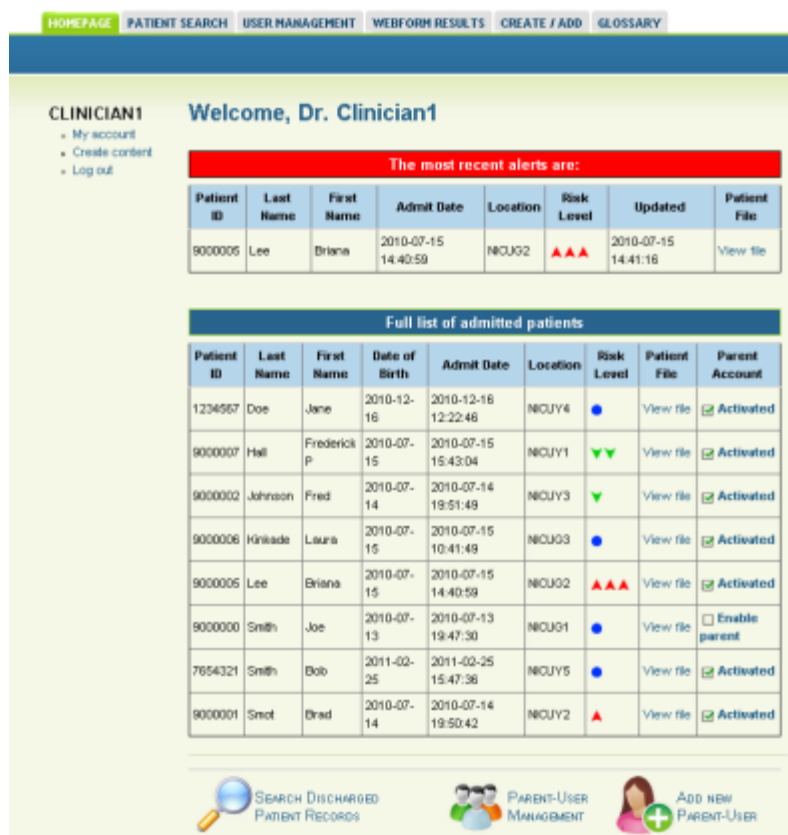


Figure.2: Clinician Homepage

2.6. UI for a Nurturing Instrument

Among the Parent Device's numerous modules are current circumstances, current treatments, result in risk level expectations, choice help, and a word reference of clinical terms. The parent apparatus has restricted admittance that should be conceded by the specialist. Before parents may see their children's medical records, a doctor must first activate the Parent Tool connected with that file using the Clinician Tool. During this activation stage, the modules to which the parents will have access are selected. By default, just the medical terminology definitions and explanations module is shown to parents. Each parent will be assigned a username and password that will allow them to see just the records of their children. Parents may access information about their child's present health status, available therapies, the likelihood of various outcomes, decision support resources, and medical terminology through links on the site. In Fig. 3, we see a screen capture of the prototype parent site for PPADS.

In the "current condition" section, doctors may record the specific illnesses their patients have been diagnosed with and leave a note for the parents. The physician may detail the numerous treatments being utilised to treat each neonate in the "current treatment" section. Predicted mortality and risk levels for the aforementioned medical illnesses may be found in the "outcome risk level estimations" module. The "decision support" module educates parents on

their range of caregiving options for their newborn and facilitates the expression of their values in relation to those possibilities. The target of the module is to work with parent cooperation in the NICU's common dynamic cycle in regards to desperate consideration choices for newborn children. Decisions may include whether to discontinue aggressive life support in favour of palliative care, whether to restrict further intensification of treatment, whether to issue a Do Not Resuscitate (DNR) order, and whether to keep providing full and active care. The module asks a series of questions designed to get parents thinking about their own beliefs and priorities in light of the potential advantages and drawbacks of certain treatments and alternatives. A parent's session may be stored as they navigate the tool's features and picked up where they left off at a later time. You may print off a summary sheet to peruse before your appointment or after your appointment with the doctor. The web-based module's questions and layout are consistent with the IPDAS (International Patient Decision Aid Standards).

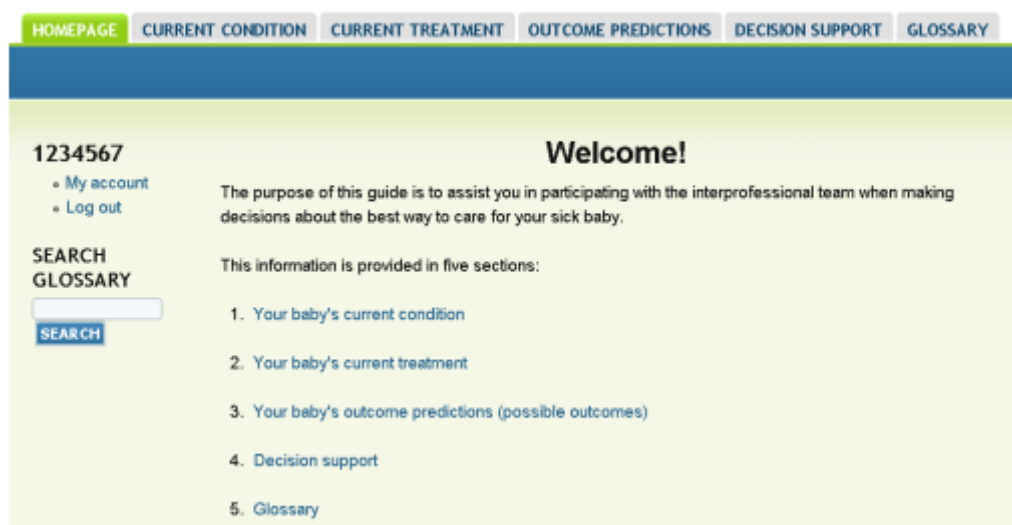


Figure.3: Parent Homepage

The patient decision-aids included in IPDAS have been evaluated against a set of criteria designed to guarantee high quality. The goal of the IPDAS recommendations is to make sure that patients are not pressured into making a choice they aren't ready for and that practitioners aren't being substituted for patient decision aids. The objective of patient decision support is to help patients make educated, value-based choices in collaboration with their healthcare providers [17]. Parents will not have access to their children's medical records. To make the tool accessible to parents of varying educational levels, the information is written at the eighth-grade reading level.

3. Results: The Tool's Preliminary Evaluation

3.1. Prototype feedback:

Our clinical neonatal specialists provided extremely favourable comments on the PPADS prototype, incorporating a variety of suggestions for modifying the tool's design, wording, and displayed data to improve its user interface.



Figure.4: Pictorial representation of risk of mortality

Suggestions included providing a visual representation and a verbal explanation with a numerical number when displaying expected hazards (such as risk categories for mortality; low, medium, and high). Fig. 4 shows the updated implementation. Here, an illustration of a high risk and a textual explanation are utilised instead of presenting the risk level like 85% for neonatal death. It was also suggested that each module be broken out into its own set of pages. A user may access any of the five sub-sections (current condition, current therapy, risk forecasts, decision assistance, and the glossary) from the main page. In addition, users may navigate between different sections by clicking the tabs at the top of each page. Figure 5 depicts the active therapy module.

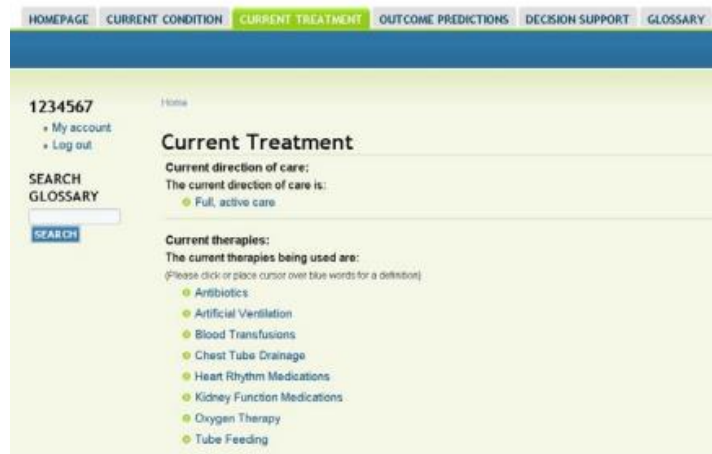


Figure.5: Parent module current treatment page

Our two clinical neonatal specialists are enthusiastic about the PPADS tool's potential and look forward to seeing it evolve. In the forthcoming pilot usability research, they will continue to participate.

5. Conclusion and future work:

The first stages of the PPADS system's development are now complete. The main phase of this study was deciding how successfully to coordinate parental and clinical choice help with the neonatal emergency unit. We teamed up with CHEO's doctors and attendants to decide the rules and method of activity, explored the pertinent principles for this kind of plan, and examined the accessible open-source advances to figure out which were the best counterpart for our plan objectives. Predictions of death and other clinical consequences are made using data collected in real time. When weighing treatment alternatives, these metrics are useful for both the doctor and the parents. The prototype assessment, which should be finished within the next several months, will allow us to build on our previous work in this area [10] by making adjustments to the design and user interface. The ethical approval has been granted for the next stage of the system's development, a pilot usability study with parents whose children have previously been admitted to the NICU at CHEO.

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