NEONATOLOGY TODAY

News and Information for BC/BE Neonatologists and Perinatologists

Volume 2 / Issue 12
December 2007

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NEONATOLOGY TODAY

Editorial and Subscription Offices
16 Cove Rd, Ste. 200
Westerly, RI 02891 USA

www.NeonatologyToday.net

Neonatology Today (NT) is a monthly newsletter for BC/BE neonatologists and perinatologists that provides timely news and information regarding the care of newborns and the diagnosis and treatment of premature and/or sick infants.

Managing NICU Patient Information with Computers Requires Re-Conceptualizing NICU Care - Part 1

By Joseph Schulman, MD, MS

This is a two-part series adapted from: Schulman J., Managing Your Patients' Data in the Neonatal and Pediatric ICU: An Introduction to Databases and Statistical Analysis. Oxford, UK: Blackwell, 2006; with permission). Part 2 will be published in the January 2008 issue.

Introduction

Good patient care, at all levels, depends upon competently managing and analyzing patient data*. Good patient care depends on understanding the determinants of desirable outcomes and on applying dependable criteria for evaluating care. To identify these determinants and criteria we must explicitly connect the data about our patients and what we do to them with the data about how things turn out. For this, we need special tools.

We commonly believe that because we work hard and care deeply about what we do, we must be doing a good job.[1] Rarely do outcomes data support this relationship. Though you may have years of experience in these areas, experience does not reliably enhance competence.[2-5] For experience to inform future action, we must reflect on all that has happened, not just what was most memorable; we must give proper weight to each observation – each patient; and we must discern just how some observations relate to others.

We may manage and analyze patient data at multiple levels. At the individual level, we work with the data to formulate a patient's problems and plan of care. At the group level, we work with the data to determine how well our system of care serves our patients. Together, the data from these two levels can largely describe our work. However, in actuality, we seldom achieve such comprehensive description of our work and we have few

*Data management: Meaning depends on context
- As a clinical process, it refers to the overarching process that begins with planning which data to collect, collecting them, manipulating the data, interpreting them, and reporting both data and interpretation in a specified way.
- As a database software process, it refers to the software features that control and manipulate the data that reside in the database.

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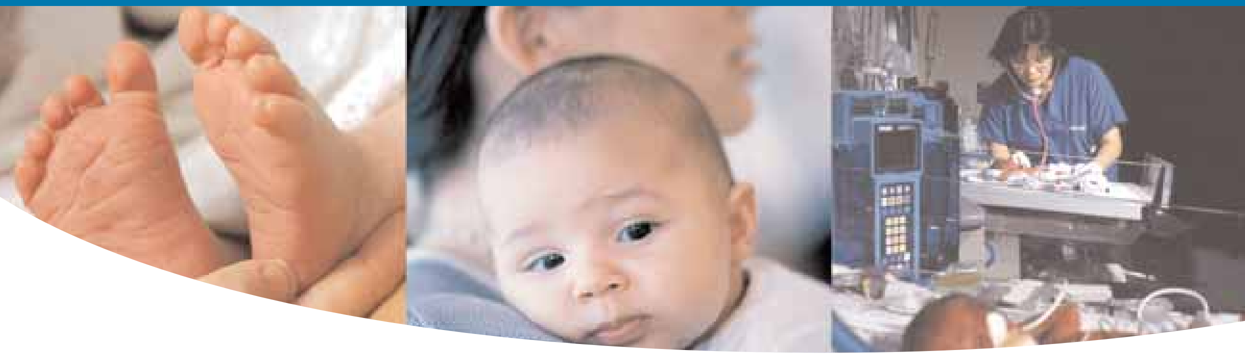

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dependable criteria by which to evaluate it.

School-age children ask the riddle: *"Why do you always find things in the last place you'd think to look for them?"* The answer, of course, is: *"Because that's when you stop looking."* Our daily work is too complicated and demanding to accept having to rummage through a patient chart, with little idea of exactly where to find the information we seek. A central aim of patient information management is to ensure that you get the information you need in the first place you look. But this may require profound advances in: how an organization's members collect, manage, and interpret data; how they learn from their experience; and how they share the learning among all whom can benefit.

This article introduces readers to core concepts and tools for managing patient data. Why should clinicians understand this? "When the only tool you have is a hammer, everything looks like a nail." (Abraham Maslow)

We clinicians often succumb to the vast amount of complex information in our daily work by changing our perception of reality or by not letting it all in. We formulate simplified versions of complicated situations, confident that we have included the essence of the problem (see Eddy,[6] Chapter 30; also Weick,[7] Chapter 4, especially page 87); but rarely, if ever, testing that we have done so. In making a complex medical decision we may need to process in our heads more information than we can handle.[8] Perhaps for this reason, we apply to this vast amount of information decision making methods that are often tacit (Weinstein and Fineberg[9], especially p 28). Of course, the resulting knowledge is tacit too.[9] Applying such imprecise methods as we do, is it any wonder that our care and documentation vary widely?[10,11] Some claim this variation is integral to the "art of medicine," a notion traditionally thought to embody the wisdom of experience. I think Eddy counters best: "When different physicians are recommending different things for essentially the same patients, it is impossible to claim that they are all doing the right thing."[8]

Here's the point. Neither traditional nor newer information processing methods enable us to account for all important determinants of the outcomes we observe. Nor do we have a sound basis to determine exactly which outcomes we ought to observe. We poorly understand the quantitative dimension of our work. The ever-growing demands of processing information in our heads are overwhelming. We are in trouble.

We recognized this information overload to some extent long ago, when we set up paper-based information systems. But a paper-based system is inadequate.[12,13] To recall a lab value or remember to check on an X-ray, we may jot the information down on an index card, or the back of an envelope. Even better, so we don't lose it, we might write it on the leg of our scrub pants. A computer-based information system is potentially far better.

A computer is a wonderful tool to keep track of more things than we can in our heads. But most computers and the programs they run are not designed to handle tacit knowledge and implicit processes. If we are to benefit from the things computers can do enormously better than humans can, we must think explicitly about clinical data elements. This entails articulating precise methods for collecting, managing, analyzing, interpreting, and acting on this data – in excruciatingly fine-grained detail. Such methods differ radically from traditional, tacit approaches. Unfortunately, institutional decision makers may replicate the long-standing tacit and implicit methods in new computer technology – if they prioritize clinicians' accepting the new technology above optimizing its potential. This may be an innocent misjudgment; few clinicians are solidly trained in data modeling, database design, and implementation.[14]

Often when clinicians imagine a computer managing their patient information, they imagine the computer doing it the same way the clinicians have always done it; just faster, and with less direct clinician involvement. But to genuinely "computerize" patient information management, to represent and conduct our daily work with the aid of a computer, we must change the way we typically think and work. We can't consider the computer a "black box" that will "do" our work if only we enter the kind of unspecified free-text as we did in the days of paper-based charting. A computer is unintelligent; it only does what it is told to do. If you had to tell a layperson exactly what to do with some data so that it was properly processed, could you? For example, consider a serum creatinine value: is it normal or abnormal; does it influence other decisions – such as drug doses, and which drugs; what question(s) does it answer; should particular follow-up or interventional cascades be triggered; and so on.

To conduct our work with a computer we must precisely specify as many essential details about our work as possible. We must represent our work on a computer: carefully map conceptual elements to specific software elements, and specifically structure it. Often more than one representation option is possible, yielding varying degrees of success for the performance of the resulting tool. That tool, in one form or another, is database** software.

Computerized patient information management systems and their potential to optimize clinical work have engaged the serious attention of national governments.[15,16] Increasingly, governments appreciate that it matters greatly how we think about representing, storing, and manipulating patient information; to guide formulating problems and solutions, produce reports, and to answer research and performance evaluation questions.

Free-Text Data

Chances are, the computer-based system you may have experience with uses so-called free-text fields. These are fields that allow you to write anything you'd like in them (within some size limit). People reluctant to abandon the way they've been writing patient notes over many years tend to like free-text fields. Free-text fields make them feel good about "getting all the data into the computer." And in truth, until we can comprehensively represent our work in an explicit data structure, free-texting may be the best way to represent

**Database: A collection of data. Surprisingly simple? The term does not necessarily imply computers or software program applications. The card catalog that today is disappearing from libraries is an example of a useful, low-tech database. Computerized, high-tech databases aren't just faster versions of low-tech databases. Computerized databases usually reflect more sophisticated design principles than traditional, low-tech databases. Computerized databases also can be connected to each other to achieve search results undreamed of with older technology.

the important elements of each patient's individual experience. On the other hand, free-text fields impede the potential of computer manipulation of data and enable workers to continue thinking tacitly and implicitly. Powsner, Wyatt, and Wright attribute most present benefits of computer-based records to data fields that contain structured, coded data.[17] Optimal ways to structure data are still being developed, so searching free-text fields remains an active area of investigation.

Discriminating Symptom from Diagnosis

"Alice came to a fork in the road. 'Which road do I take?' she asked.

'Where do you want to go?' responded the Cheshire cat.

'I don't know,' Alice answered.
'Then,' said the cat, 'it doesn't matter.'"

~Lewis Carroll, Alice in Wonderland

So many hospitals now use computer-based information systems that it is natural for readers to think the solution to health care's problems with managing patient information is computer-based patient records. Before accepting this implicit problem formulation and solution, consider the difference between a symptom and a diagnosis. A symptom is a manifestation of a problem. An ideal diagnosis identifies the root cause of the problem. The increasing use of electronic records reflects the increasing recognition of symptoms – problems – stemming from the traditional way we have worked with patient information. I argue that current (computerized) problem-solving approaches often represent merely symptomatic relief. It may be more productive to think of a computer not as a solution, but as a powerful tool – with great potential to facilitate implementing the real solution. Real solutions reflect clarity of thought about details of the problem, and about exactly what one wishes to achieve via the solution.

Exactly what should our information systems enable us regularly to achieve? Most patient settings I've observed have few explicit aims that guide their information management processes – with the notable exception of those relating to regulatory compliance. That is, we tend to think of information management systems the way many people think of art: we know it's good when we see it; no matter that we can't articulate the specific criteria by which we make the determination. Laboratory and imaging systems, though explicitly implemented, often appear to have developed independently of a broader vision for the overarching institutional mission. Their aims reflect local imperatives – the laboratory or imaging department – more than they do the needs of data consumers.

Toward Explicit Thinking About Aims

The Institute of Medicine (IOM) proposed explicit aims for patient records:[13]

- support patient care and improve its quality
- enhance the productivity of health care professionals and reduce the administrative costs associated with health care delivery and financing…
- support clinical and health services research…
- be able to accommodate future developments in health care technology, policy, management, and finance…
- have mechanisms in place to ensure patient data confidentiality at all times…

These are explicit, but broadly articulated. To achieve them, we require aims for the individual components of patient records, described at a fine-grained level of detail. Many clinicians haven't thought pointedly about exactly what an admission note, or a "progress" note, or a "discharge" summary, should achieve. Further, how many readers can operationally define what they mean by quality of care?

Too often, our healthcare system hasn't forced us to tackle these problems. As Donald Berwick observes, "…performance is embedded into the design of the system…all systems are perfectly designed to achieve the results they get." (http://www.ihi.org/IHI/Topics/Improvement/ImprovementMethods/Literature/WantaNewLevelofPerformanceGetaNewSystem.htm; accessed 5 August 2004). This observation articulates such profound wisdom that it merits special reflection.

What proportion of complaints about new information technology might actually be about this technology's requirement for explicit thinking – about being forced to recognize exactly what it takes to achieve the results we want to get?

Ontology

Even if we share a common idea of information and how to explicitly represent it, we may still have problems communicating. The term ontology describes a special kind of framework to represent our shared knowledge. Ontology in our context is how we specify our idea of our work. It includes precisely defining the vocabulary we use in our discourse, and in our databases. On their own, workers in different settings come up with different terms and structures for representing essentially similar information. For example, consider the variety of definitions of chronic lung disease, an entity often represented in a database as a simple "yes" or "no."

The lack of a common ontology has been called the "Tower of Babel" problem.[18] Within different databases, data with the same label may have different meaning. Other times, we may mean the same thing but use different labels. The potential for learning from our aggregate experience is awesome, but it requires that we resolve the inconsistencies among our data tools. Uniform terminology, representation, and data structure are central to achieving the potential of the new information technology.[19] Calibrating all our data models and database applications to one common ontology could produce unimaginable opportunity to do our work better.

To learn more about uniform terminology for health care records, visit the web sites of the standards-development organizations called Health Level 7 (HL7), at: http://hl7.org/about/hl7about.htm (accessed 08 February 2005); and Systematized Nomenclature of Medicine – Clinical Terms (SNOMED-CT), at: http://www.snomed.org/snomedct/ (accessed 08 February 2005).

Data Modeling: Overview

Explicitly structuring the data that constitute our work entails a data model. A data model is an abstraction aimed at broadly representing the ideas and things that constitute an organization's work. It is the framework that specifies what kind of data to keep and how to store them.

A data modeler works with information system users much as an architect works with a building's future dwellers.[20] Both architects and data modelers are designers, people who work with problems that have more than one correct solution.[20] One models – maps – the important objects and events of the reality, so they may be "saved" and subsequently "manipulated." Why provide technical detail on this subject? Well, if you retain an architect to

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design and oversee construction of your home would you not want to understand and approve the blueprints; would you just move in without repeatedly confirming that the design and the product represents your residential needs? We shall concentrate on a particular type of data model called the relational data model; so named because it is based on the notion of mathematical relations – for our purpose, tables. Though tables[***] often are related to each other, that is not why the model is called relational.

The relational model specifies a variety of table features. Each of the relations, or tables, must have a unique name, as must each of the columns, or attributes. The values each attribute may have are specified by a domain. This notion of domain introduces meaning to the data contained in an attribute and helps to avoid incorrect relational operations. For example, a domain might dictate that telephone numbers contain only digits and may not be subjected to arithmetical operations. Each row (observation, record) in a table must be unique. Each cell, that is, each intersection of a row and column should contain only one value (jargon: field values should be atomic). In other words, a single cell holds a single answer. Informed database application users know that trying to query cells containing multiple answers or free-text may be problematic.

Relationship[+] Diagram

Some appreciation of what data modeling is about may be gained by looking at a diagram of a relatively simple data model. Figure 1 shows the data model for eNICU, a software tool for managing patient information in the NICU.[21,22] The figure is very complicated, but it makes the point that someone ultimately must decide which data elements to include and how to connect them. Accepting a data modeler's design without careful reflection on how well it has mapped the daily work, i.e. the users' (not the modeler's) reality, can result in a disappointing product. This point underlies Dr. Muenzer's lament in the November, 2007 issue of Neonatology Today: that software available to physicians is "…clumsy, klutzy, slow and expensive…"

In the relationship diagram, I use the convention of naming a table with the prefix "tbl" and "camel caps" instead of a space between words that constitute a name. Relationships between tables are indicated by lines drawn from the primary key field[++], in bold font, of one table to the foreign key[+++] field of the other table. When the relationship is one-to-one, the number 1 appears at each end of the connecting line. When the relationship is one-to-many, the many side of the relationship is represented by the symbol ∞.

The eNICU data model describes, but does not explain. Exactly how did I decide I needed a separate table for Infants, Patient Problems, Loose Ends, etc? Truth be told, the scheme did not emerge from one exhilarating epiphany. It is the result of a reiterative process. That process reflected guidelines ranging from simple rules as: "Provide a separate table for each class of 'real world' object about which you are trying to store information in the database," to complex ones: those that concern normalization[++++] (described in Part 2 of this article, appearing in the next issue of Neonatology Today). Ultimately, the data model must also resonate with the database aims: what you want to be able to do with the data.

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[***]Table: A container for holding data that share common attributes. Tables have rows (horizontal divisions) and columns (vertical divisions). Each column describes one attribute of whatever the table is intended to describe. Each row contains one instance of the table's attribute set, one observation of the thing the table describes. Each row is also called a record. Each column is also called a field. If you had a table for storing several attributes of your patients, each row would contain the information for one patient (one record), with each column recording the information for each attribute (field). In database jargon, a table is also called a relation.

- Even though you think of a table as a rectangular structure that's neatly subdivided and has data in each of those subdivisions, your computer doesn't. The table appears that way on the screen only because your computer is trying to relate to people. Your computer actually stores the data as magnetic charges distributed not so uniformly on the computer disc. This gives the computer and database software lots of flexibility to manipulate and represent the data in tables.

[+]Relationship: The logical connection between information in one table (relation) with the information in another table (relation). When one record in table A can relate to only one record in table B, a one-to-one relationship exists. Thus, each patient can have only one set of admission vital signs because a second set would no longer describe the condition at admission. When one record in table A can relate to many records in table B, a one-to-many relationship exists. One mother, for example, can have more than one infant.

[++]Primary key: One or more fields uniquely identifying each record in a table. That is, for each record, the value entered in the primary key field(s) is unique among all records in the table. Without a primary key, records in a database may become confused and database content degraded.

[+++]Foreign key: A good way to link a record in one table with a record in another table is for each record to share some common attribute value. Thus, if we wish to connect a particular record in a table of infant data with a particular record in another table of maternal data, we would ensure the infant data table includes a field containing the mother's unique identifier – primary key value. Such a linking field is called a foreign key. The linked records together describe one instance of a higher entity, the mother/infant dyad in our example, constituted by the various tables in aggregate.

[++++]Normalization: A set of design rules specifying what each of the multiple tables in a database is about, and the attributes that belong with each table. These rules generally optimize data storage and retrieval by anticipating the things you'll want to do with the data, and ensuring you'll be able to carry them out. Normalization thus enables reliable queries.

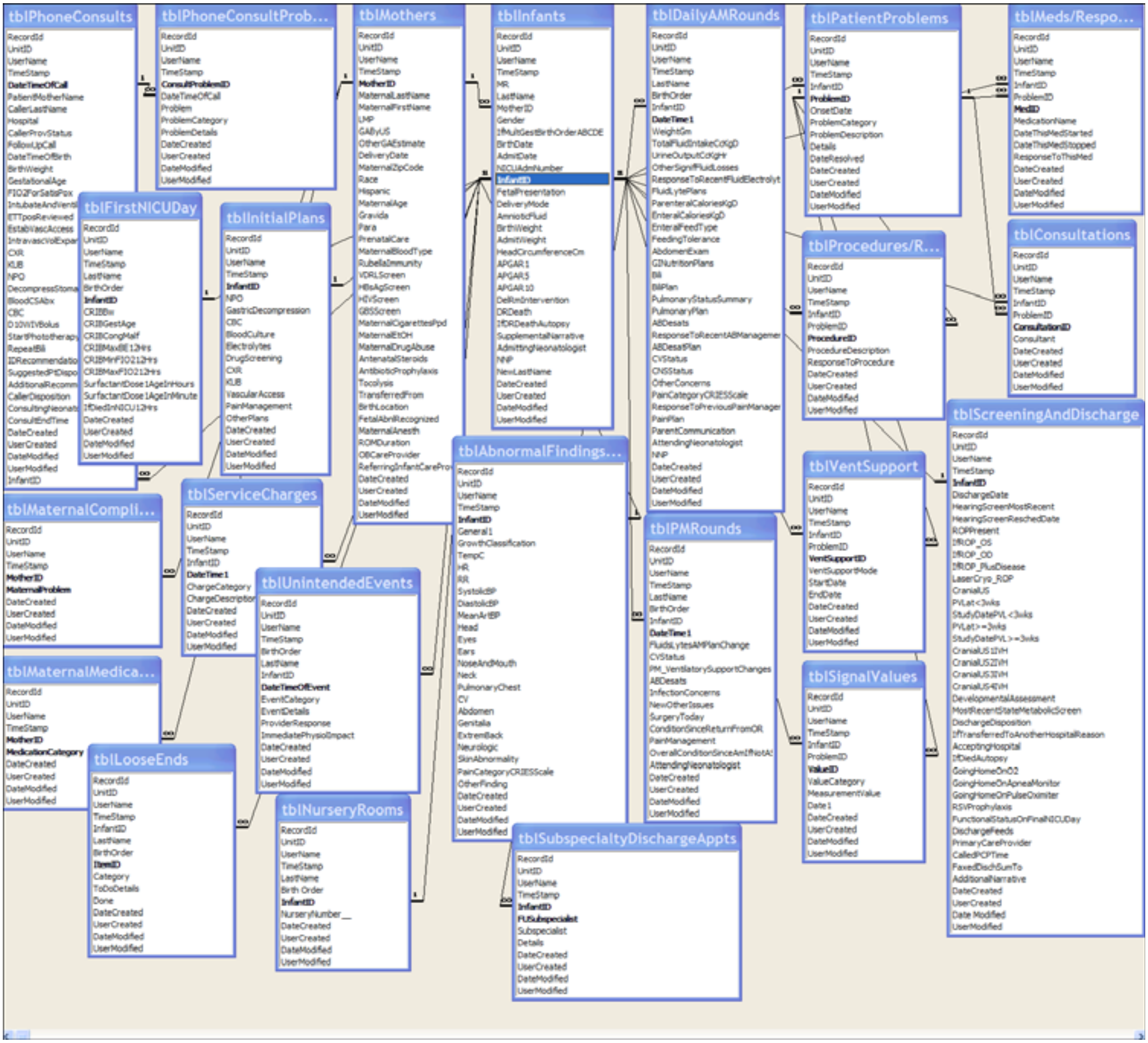

Figure 1. The eNICU data model (From Schulman J. Managing Your Patients' Data in the Neonatal and Pediatric ICU: an Introduction to Databases and Statistical Analysis. Oxford, UK: Blackwell, 2006; with permission).

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Appendix

The following images on pages 9-14 (Figures 2-8), illustrate eNICU data model capability. The data entry interface is a handheld device such as a Palm OS® or Windows Mobile® computer and the data management interface – for notes, queries, etc. – is on a PC. If desired, both data entry and management may be performed on a PC. Complete operational details are available.[22]

NT

Next month, Part 2 of this article shall:
1. *Outline the reiterative process of database design. Understanding this process enables one to reflect on model adequacy.*
2. *Discuss how to think about the impact of a change in information technology.*
3. *Explore a view of the ultimate aim of information technology, i.e. creating tools that make us smarter.*

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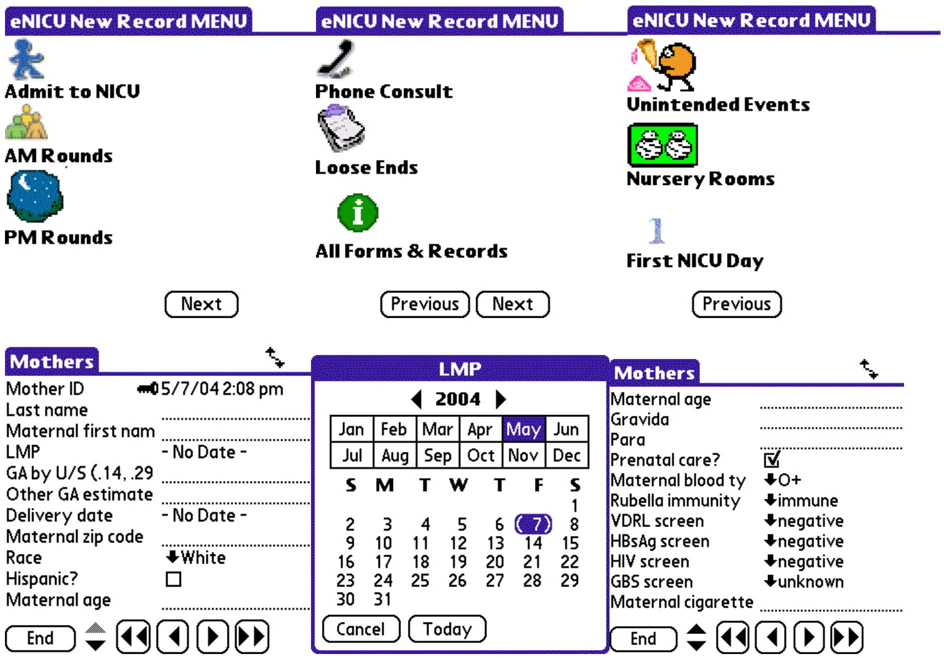

Figure 2.

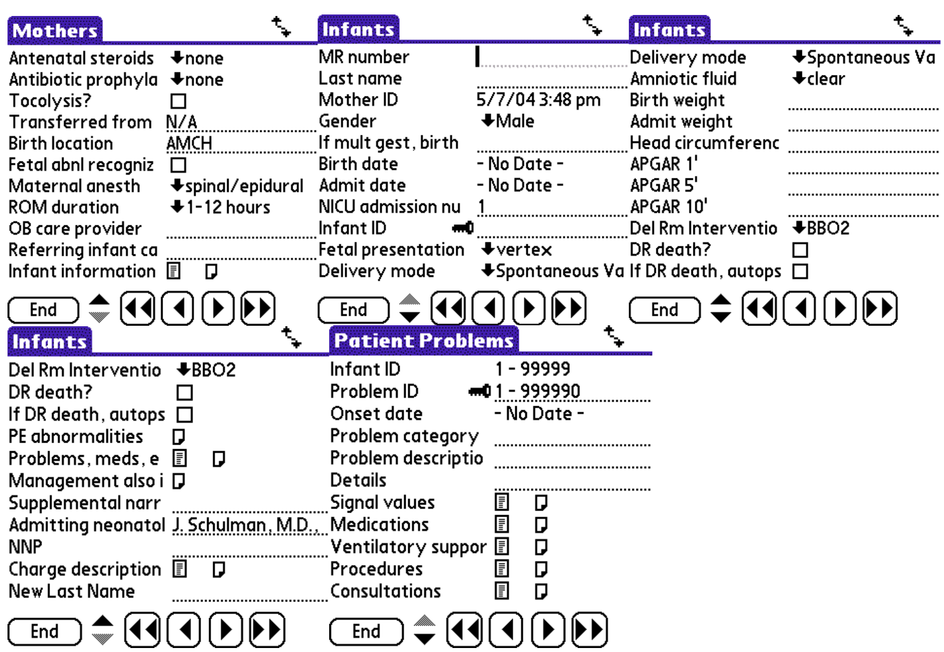

Figure 3.

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Conference description
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The purpose of this course is to provide an objective examination of many of the most critical and exciting areas in modern neonatal-perinatal medicine.

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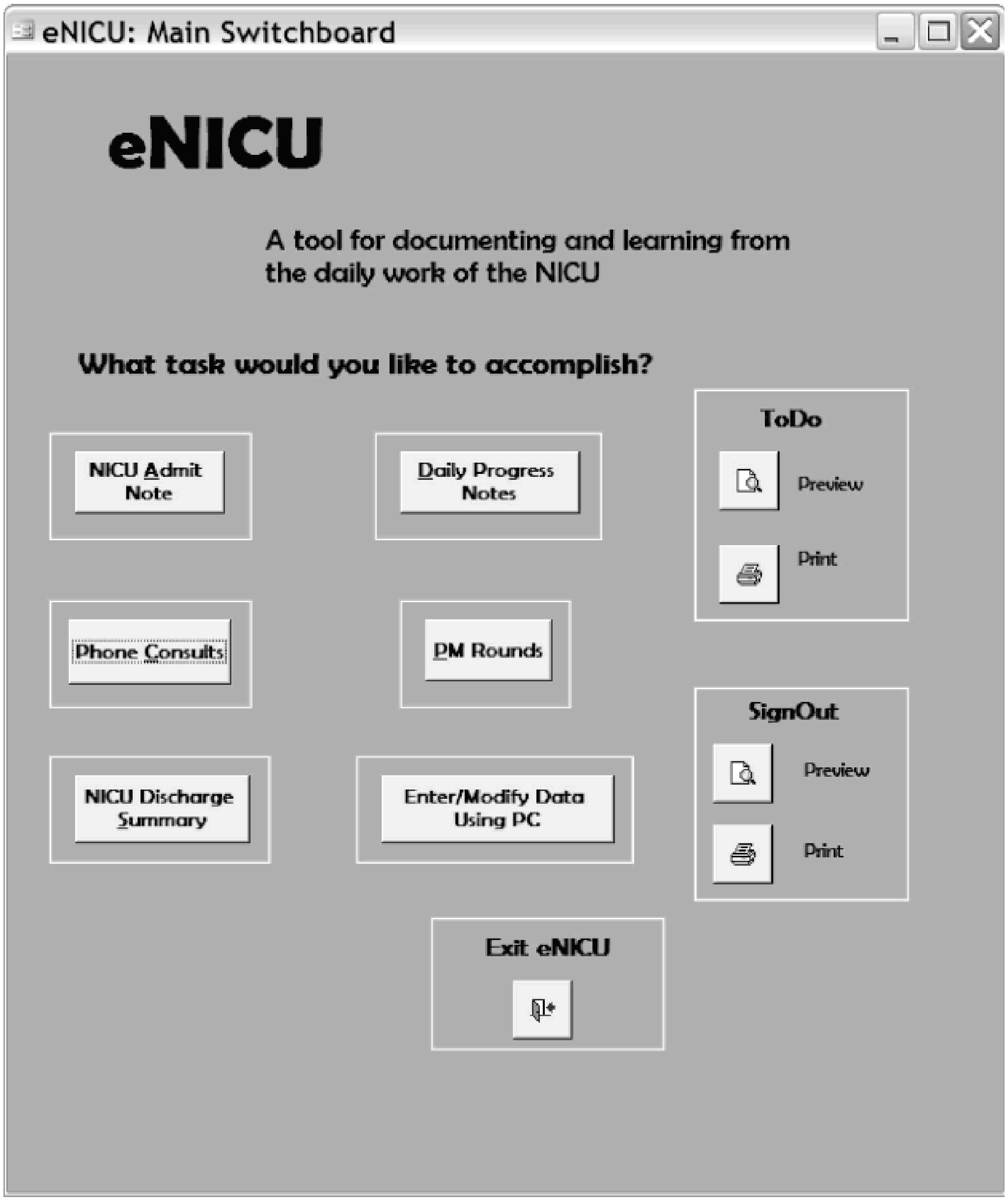

Figure 4.

"Accepting a data modeler's design without careful reflection on how well it has mapped the daily work, i.e. the users' (not the modeler's) reality, can result in a disappointing product. This point underlies Dr. Muenzer's lament in the November, 2007 issue of Neonatology Today: that software available to physicians is '…clumsy, klutzy, slow and expensive…'"

eNICU:DailyProgressNote

Attending Neonatologist: [redacted]

InfantID 1 - 2 [redacted] *LastName* [redacted] *Gender* Male *Birth Order (if mult gest)*

MR 2 [redacted] *Date* [redacted]

This note reflects interim chart review, appropriate PE, and review with housestaff.

WeightGm 3560

ParenteralCaloriesKgD:

EnteralCaloriesKgD: 118

TotalCaloricIntakeKgD:

Feeding Tolerance: po feeding

AbdomenExam: benign

GINutritionPlans: continue present plans

TotalFluidIntakeCcKgD 147

UrineOutputCcKgHr

OtherSignifFluidLosses none

Response to recent fluid/lyte mngmt:

FluidLytePlans: continue present plans

Bili: N/A *BiliPlan:* N/A

CNSStatus: no concerns

CVStatus: stable

PulmonaryStatusSummary: FIO2 decreasing *PulmonaryPlan:* Room air trial this am

ABDesats: resolved *Response to recent mngmt:* N/A *ABDesatPlan:* N/A

CRIES categ: low: 0-2 *Response to previous mngmt:* remains comfortable *PainPlan:* continue present pl

Problems/Interventions

1. *Category*: CNS — *Description*: **neuromuscular tone: low** — *Details*: — *Onset*: 5/30/2005 — *Resolved*: 6/1/2005

2. *Category*: CONTROL RESP — *Description*: **apnea** — *Details*: Possible magnesium sulphate depression — *Onset*: 5/30/2005 — *Resolved*: 6/6/2005

Vent support assoc with this problem	*Start Date*	*End Date*
conventional mech ventilation	5/30/2005	6/1/2005

3. *Category*: CV — *Description*: **blood pressure: low** — *Details*: — *Onset*: 5/30/2005 — *Resolved*: 6/1/2005

Meds associated with this problem	*Started*	*Response*	*Stopped*
dopamine	5/30/2005	improved	6/3/2005
NaCl	5/30/2005	improved	6/1/2005

Daily Progress Note [redacted] [redacted] [redacted] *Page 1*

Figure 5.

4.

Category	Description	Details	Onset	Resolved
PULMONARY	RDS		5/30/2005	6/10/2005

Meds associated with this problem	Started	Response	Stopped
surfactant	5/30/2005	Improved	5/31/2005
racemic epi	6/28/2005	Improved	6/29/2005

Vent support assoc with this problem	Start Date	End Date
conventional mech ventilation	5/30/2005	6/1/2005
NCPAP	5/30/2005	5/30/2005
HFOV	6/1/2005	6/9/2005
HFJV	6/9/2005	6/28/2005
NCPAP	6/28/2005	6/28/2005

5.

Category	Description	Details	Onset	Resolved
PULMONARY	diaphragmatic eventration	8/4 US right diaphragm-no paradoxical movement of hemi-diaphram. Limited excursion of left when compared to right.	5/30/2005	

Vent support assoc with this problem	Start Date	End Date
HFJV	6/9/2005	6/28/2005

6.

Category	Description	Details	Onset	Resolved
INFECTION	MRSA colonized	8/5 nasal swab positive. Continue contact precautions.	6/3/2005	

Meds associated with this problem	Started	Response	Stopped
bactroban to nares	8/8/2005		

7.

Category	Description	Details	Onset	Resolved
CV	PDA: significant		6/4/2005	6/5/2005

Meds associated with this problem	Started	Response	Stopped
indomethacin	6/4/2005	Improved	6/5/2005

Consultants for this problem: cardiology

8.

Category	Description	Details	Onset	Resolved
INFECTION	sepsis > 72 HRS: culture-positive	MRSA	6/4/2005	6/20/2005

Meds associated with this problem	Started	Response	Stopped
vancomycin	6/5/2005	Improved	6/20/2005

9.

Category	Description	Details	Onset	Resolved
INFECTION	pneumonia	? small effusion	6/4/2005	6/21/2005

Meds associated with this problem	Started	Response	Stopped
vancomycin	6/4/2005	Improved	6/20/2005

Consultants for this problem: ID

Vent support assoc with this problem	Start Date	End Date
HFJV	6/4/2005	6/28/2005
NCPAP	6/28/2005	6/28/2005

10.

Category	Description	Details	Onset	Resolved
PULMONARY	PIE		6/7/2005	6/21/2005

Vent support assoc with this problem	Start Date	End Date
HFOV	6/1/2005	6/9/2005
HFJV	6/9/2005	6/21/2005

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Figure 6.

11.

Category	*Description*	*Details*	*Onset*	*Resolved*
HEMATOLOGIC	**thrombocytopenia**	?etiology	6/8/2005	6/21/2005

Signal values related to this problem

platelets 53 6/13/2005

12.

Category	*Description*	*Details*	*Onset*	*Resolved*
HEMATOLOGIC	**anemia**		6/22/2005	6/27/2005

Meds associated with this problem	*Started*	*Response*	*Stopped*
Ferinsol	6/22/2005		

13.

Category	*Description*	*Details*	*Onset*	*Resolved*
PULMONARY	**atelectasis**		6/24/2005	6/26/2005

Vent support assoc with this problem	*Start Date*	*End Date*
HFJV	6/9/2005	6/26/2005

14.

Category	*Description*	*Details*	*Onset*	*Resolved*
PULMONARY	**BPD**		6/29/2005	

Meds associated with this problem	*Started*	*Response*	*Stopped*
aldactone	6/29/2005		8/10/2005
chlorothiazide	6/29/2005		8/10/2005
NaCl	7/4/2005	complete problem resolution	8/5/2005
albuterol	7/8/2005	questionable	

Consultants for this problem

pulmonary

Vent support assoc with this problem	*Start Date*	*End Date*
Vapotherm	6/28/2005	8/8/2005
nasal cannula O2	8/8/2005	8/9/2005

Other concerns:

Parent communication: MD available for update

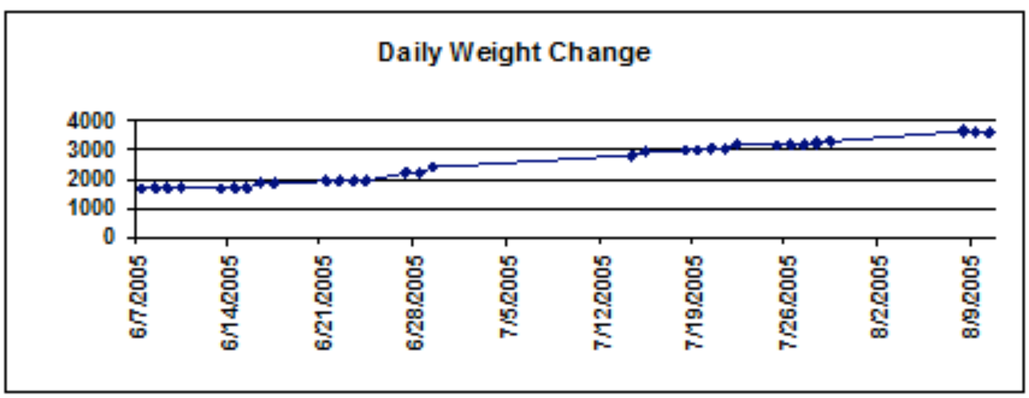

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Figure 7.

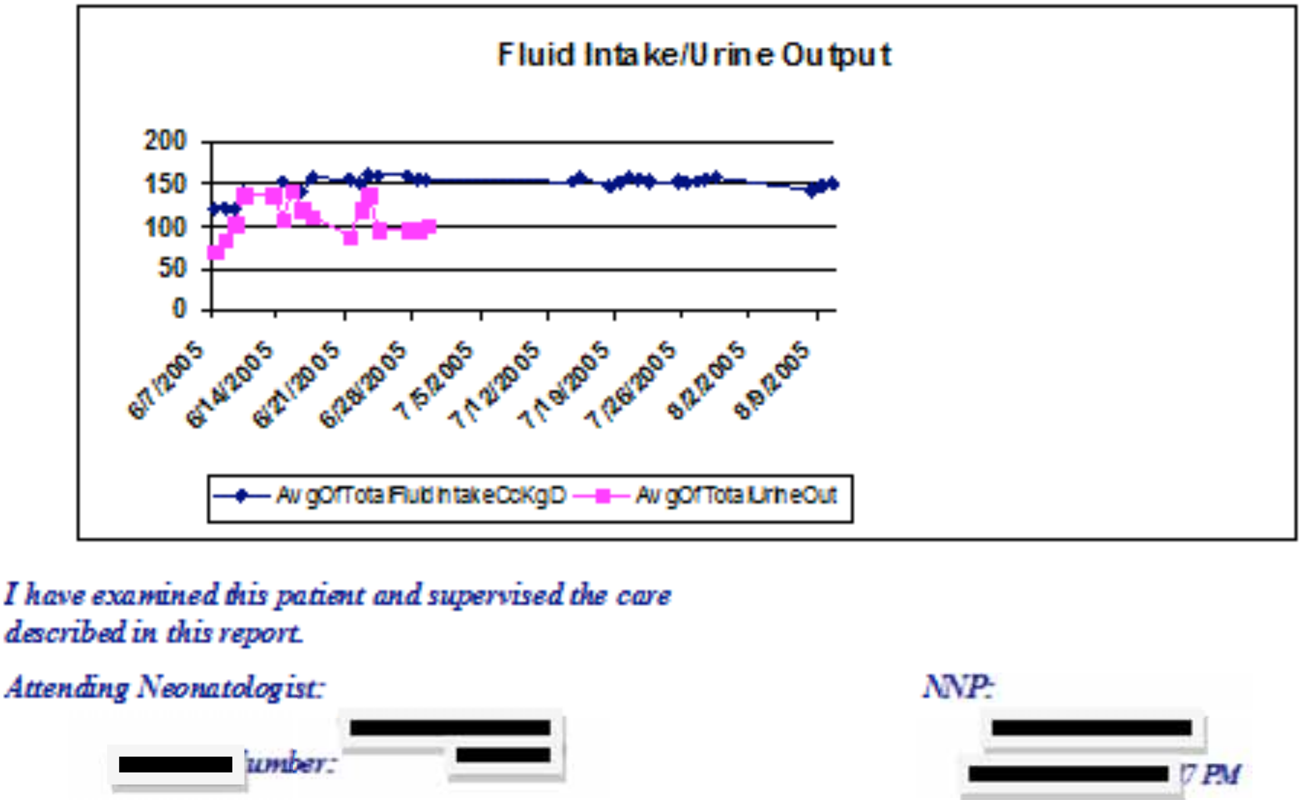

Figure 8.

Neonatology Today

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