

CURRENT TOPIC

Computerised neonatal information systems

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Since its inception the British Paediatric Association (BPA) computer group has provided a forum for the demonstration of neonatal information systems. Of the 10 reported at BPA meetings from 1984-90 eight are currently still in use.^{A-J} One of the first systems to be presented was developed primarily to assist with neonatal audit.¹ Now that participation in audit is a requirement for all doctors the interest in computerised information systems has increased and is no longer confined to a small group of enthusiastic pioneers. Detailed information about workload and outcome will soon be required for the purpose of negotiating contracts between purchasers and providers and it is difficult to see how this can be achieved without access to database technology. Many of the systems demonstrated have been highly successful and a number have been implemented in more than one unit. The guidance given below has been formulated after discussion with those involved in developing these systems.

The dataset

The key to any information system is to formulate an appropriate dataset. This should include the categories shown in table 1. With the power of modern database technology there is a tendency to collect a great deal more data than one could ever possibly use. This leads to a very cumbersome system and much frustration on the part of those who collect or input data but never see it used. Therefore it is most important to base the dataset on planned outputs of the

Table 2 Type and purpose of output

Type of output	Purpose of output
Front sheet summary of mothers	For easy reference to important information at the front of the child's neonatal record
Comprehensive discharge summary	Communicate with general practitioner Permanent record
ICD9 coded diagnoses	Körner requirements
Regular cumulative reports on: Perinatal mortality Admissions and survival Mortality review Outcome for transfers Intracranial scan results Ventilation review Procedure review Infection and antibiotics Workload	Comprehensive annual report Audit Resource management Quality assurance Research

type illustrated in table 2. In this way the dataset will be precise and relevant and those using the computer will be able to appreciate the value of the data they collect. This will greatly enhance the quality of data collection.

The pioneer systems are very individualistic with respect to the dataset. Even when similar information is collected there may be variations in the coding classifications used. For example, in one system all attempted umbilical artery catheterisations may be recorded, another may record only successful catheterisations. A third may not distinguish between umbilical and radial artery catheterisation. Such differences mean that it will be difficult to compare data collected on different databases. For this reason it would be helpful if an interested group formulated an agreed core dataset which should not be large but should be carefully defined. Each unit could then add its own embellishments to cater for local information requirements which vary greatly from one unit to another.

Diagnostic coding

There is a need for diagnostic coding both for Körner requirements and so that patients with like conditions can easily be compared. Unfortunately the *International Classification of Diseases, 9th revision (ICD9)* codes are inadequate for neonatal use for a number of reasons. First, there is often inadequate detail. The ICD9 code for Menkes's syndrome and Zellweger's syndrome is not different. Second, the diagnostic label attached to the code may vary from local

Table 1 Guide to neonatal dataset

Categories	Examples of information collected
Demographic	Name Address Hospital number
Mother	Medical history Family history Past obstetric history Antenatal history
Admission details	Delivery Date and time Origin Reason
Progress	Diagnoses Procedures Medication Feeding
Discharge details	Date and time Destination Outcome Follow up arrangements
Recommendations	Discharge medication Immunisation

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usage. Few of our senior house officers refer to umbilical cord sepsis as omphalitis. Third, certain important conditions require coding in two parts. *Listeria pneumonia* is coded as 'pneumonia bacteria (NOS)' and 'listeriosis infection'. Fourth, when coding for a unilateral lesion it is not possible to code for the side of the lesion. Finally, only a small subset of the ICD9 coding system is relevant to neonatology. In the North Staffordshire Maternity Hospital over a one year period 460 babies were given 1322 coded diagnoses. Only 145 different codes were used, although 370 were available in the computer dictionary.

In order to overcome these difficulties a number of neonatal databases use their own dictionary of codes.² Most of these are cross referenced for ICD9 codes. With ICD9 an additional digit can be added to the existing codes to create more subgroups. As such dictionaries are not exhaustive a facility to add additional codes is required. It is also helpful if the user can enter diagnoses in free text when an appropriate coded diagnosis is not available. These can be coded later when the dictionary has been amended.

A comprehensive dictionary of codes specific for neonatal diagnoses that could be utilised by all would be a great asset. Documentation should include definitions of some of the more controversial diagnostic categories so as to ensure uniformity in the coding of conditions such as bronchopulmonary dysplasia, transient tachypnoea, birth asphyxia, and necrotising enterocolitis. Such a dictionary of codes is under development and may be available shortly (the BPA Diagnostic Codes Project).

Obtaining an accurate and complete list of diagnostic codes for each patient is not a trivial problem. This can be achieved only by involving medical staff in the coding process. It is helpful if guidance is provided by senior doctors on a regular basis, either on ward rounds or at regular coding meetings.^C Diagnoses appropriate to each patient can be selected from the dictionary that may be available on line, although it can be easier to refer to a printed copy.

Powerful diagnostic support software based on the Read system is now available to assist with the task of coding. When a unique diagnosis such as 'Down's syndrome' is entered this is immediately accepted and automatically coded. A partial diagnosis such as 'pneumonia' will give rise to a comprehensive list of diagnoses that include pneumonia. These are normally presented in a window on the screen. The coder is thereby encouraged to consider making a more precise diagnosis, although the option of making a non-specific diagnosis will remain. This type of coding support encourages diagnostic accuracy, saves time, and is fun to use.

In neonatology it is common for a number of codable diagnoses such as pneumothorax or intraventricular haemorrhage to be included in the dataset. It is easy for these to be forgotten unless they are automatically coded and included in any list of diagnoses generated for the patient.

Data input

The simplest method of data input is to provide a worksheet that is completed during the patient's stay.³ There may be different sections of the work sheet for clerical, nursing, and medical staff. When the worksheet is complete clerical staff may enter the data into the computer or an optical reader can be used to avoid transcription errors.^F The main disadvantage of this method is that there is no interaction between the computer and user. Such interaction can be used to improve the quality of data collected as exemplified by the coding support software described above. Furthermore if a large amount of data is collected then a questionnaire based system becomes cumbersome.

When doctors and nurses are required to enter data as part of their daily routine it is most important that the database is easy and quick to use. One source of frustration for busy staff is a slow response time. A requirement to answer numerous irrelevant questions is another. The latter may be avoided by using key items to determine which parts of the dataset are relevant to the individual patient and selecting only these for completion.^J⁴

Data may be collected in real time or retrospectively. In a clinic with a terminal on the desk there is no doubt that real time data collection is the ideal method. This is not necessarily true of neonatal data collection. To collect all of this data in real time would require access to a terminal from each cotside. Furthermore preterm infants change condition rapidly and this can lead to the collection of superfluous data. For example, a child may have a number of different cranial ultrasound scan appearances before developing right periventricular leukomalacia. Clearly those with a special interest in cranial ultrasonography will wish to record all the changes observed, but in most situations a final summary diagnosis will be more useful and easier to analyse later.

Information collection should be tailored to fit in with the working practices of the unit. It is often very helpful to record details of admissions and discharges in real time so that the computer can be used to keep track of the patients. Some information may usefully be recorded on a daily basis. This might include blood culture results, the use of intermittent positive pressure ventilation, and nursing dependency levels. In this way a running total of ventilation days and other similar parameters can be made available. Finally at the point of discharge or shortly afterwards other information including diagnosis codes may be added retrospectively.

Demographic data may be entered by clerks. Nurses are often in the best position to review progress on a daily basis and enter this type of data. For the reasons outlined above diagnostic information is probably best entered by medical staff. This task is made considerably easier if a problem list is kept at the front of the notes.

Data audit

It is very difficult to assess the quality of information stored in hospital notes and the fact that

vital information is missing may not come to light until it is required at some time in the future. In contrast computerised data fields can and should be checked on a regular basis. Programs can be written to search data fields and produce an analysis indicating which data items are missing in which patients. In this way data collection can be audited. When the users are required to input the missing data the quality of initial data collection rapidly improves.

When admissions and discharges are recorded in real time it is possible to use the computer to highlight patients who have not had the dataset completed and diagnostic codes added. In this way it is possible to get quality information on 100% of patients for later analysis.

Output requirements

It is imperative that those who have the task of entering data are rewarded with a useful output.⁵ For example at the North Staffordshire Maternity Hospital it had been a nursing task to copy details from the maternity notes onto a form that was then filed in the front of the neonatal notes. This task was replaced by the task of entering similar information into the database. On completion a front sheet summary was printed, checked for errors, and filed in the front of the notes. The summary proved to be of value to the medical team when reviewing the case. A similar principle applies to the production of a computerised discharge summary that may obviate the need for a dictated summary.

Computerised discharge summaries are often criticised for being impersonal and less informative than dictated summaries. On the other hand they are less likely to have important items of information missing and they tend to be available earlier and in a higher proportion of patients.^{6,7} In our experience an enormous amount of secretarial time can also be saved. The personal touch can be added by including comments in free text, although there is a tendency for junior doctors to concentrate on the dataset and ignore this facility. The format of the letter will make a lot of difference to its readability and usefulness and therefore it is well worth investing time and effort to get this right.

The prime objective in setting up a neonatal database is to be able to use the data collected. Certain information will be required on a regular basis (table 2) and it is well worth generating such information as a standard report that can be produced for any time period at the touch of a button. As an example the quality parameters required by the West Midlands Regional Health Authority for monitoring regionally funded neonatal intensive care are shown in table 3. It seems likely that similar information will be required by other purchasers of neonatal services.

Standard reports will not cater for unforeseen or one off information requirements and so it is very useful to be able to conduct an ad hoc inquiry. This normally consists of a list of patients with characteristics that have been specified from the dataset by the inquirer. Once the selection has been made it is normally possible to stipulate which information is to be

Table 3 Quality parameters for neonatal intensive care

Quality parameter	Stratification
Admissions	Birth weight, gestation, inborn/outborn/in utero transfer
Mortality	Birth weight, gestation, early/late deaths
Ventilation:	
Duration	Birth weight, gestation
Outcome	Birth weight, gestation
Air leaks	Birth weight, gestation
Bronchopulmonary dysplasia	
Necrotising enterocolitis	Birth weight, gestation
Retinopathy >grade 3	Birth weight, gestation
Cranial ultrasound scan	Birth weight, gestation
Postmortem examination	Birth weight, gestation

printed out in the selected patients. Facilities to sort patients may also be available. Databases vary in the complexity and ease of use of their inquiry language but ideally it should be possible for someone with little or no programming experience to obtain information in this way.⁸

Interface with other systems

Demographic information must be available for effective data analysis. This is recorded in many hospitals on a patient administration system. Clearly it is useful if the neonatal database can be linked for electronic transfer of such details. Neonatal and maternity records have much data in common and therefore when both are to be computerised, communication or complete integration is desirable.^{E, J} This will obviate the need for laborious transcription of antenatal records. Ideally the delivery record and neonatal record should form the basis of the paediatric record. A link with the community child health computer is also desirable. Although laboratory links are useful for obtaining clearly tabulated results, this is less essential for acute neonatal management than for the long term management of children in outpatient clinics.

Many district health authorities are making plans for the development of hospital wide integrated information systems and therefore it is important to consider how any proposed neonatal database will interface into such a system. Almost certainly the district information system will require coded diagnoses and other Körner data. Consideration also needs to be given to the possibility of transferring data electronically into other software packages. These may be used for word processing, statistical analysis, or graphical presentation.

Software considerations

Some of the earlier neonatal databases were written from scratch usually by an enthusiastic doctor and a programming expert.^A Although this approach has been successful, it is much easier to start with a database program which can be configured to meet ones own requirements.^H Several of the aforementioned systems have been developed in this way. At first sight it may seem easy to develop a new neonatal application using such a database program, but the considerable time and effort required to get a system operational should not be underestimated. Therefore it is better to adopt and adapt a system that has already been

developed rather than starting again. Probably the only good reason for writing a new neonatal application is in cases where the district adopts a database package that does not have a neonatal module and there is commercial support for the development of such.

System support

In choosing or writing a database application, consideration must be given to the support of the system. There is considerable variation in database size and complexity. A system resident on a single microcomputer with a relatively small dataset and no interface with other systems will require much less support than a large multiuser system interfacing with other hospital information systems and keeping data on line for many years. Although single user systems have proved very valuable the large multiuser systems are much more likely to be able to adapt and grow to meet new challenges as district information systems continue to develop. Support for such systems will need to be provided in a number of ways. Technical support will be required for both hardware and software. It is a disaster if a system goes down for days or weeks once it has been integrated into a department. It is almost impossible to catch up with the data backlog in such an eventuality.

Continued software development is essential. Once a system is operational deficiencies inevitably become apparent. Furthermore working practices and information needs change with time. Modification of the dataset or data analysis program may be a problem if system support is dependent on one individual who may leave the project after implementation. Some applications are commercially supported, which can be very useful provided the cost of modification is not prohibitive. Systems that cannot be modified are likely to atrophy and eventually die.

Training support is a requirement that is often forgotten. It is essential that all grades and types of users are taught how to use the system.

Many junior doctors still have no computing training and therefore may require a lot of support when first introduced to a system. With rapid staff turnover this is an ongoing requirement. Finally a comprehensive manual is an asset.

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