Journal of Medical Systems, Vol. 12, No. 2, 1988

Computerized Newborn Screening in Texas—A Multiple Microcomputer Approach*

Bradford L. Therrell, Ph.D., and Lois O. Brown, R.N.

The Texas Department of Health expanded its newborn screening program to include four disorders in February of 1980. Because of the large volume of specimens being processed (approximately 2500 daily), it was essential that laboratory aspects of this program be computerized. Currently, both laboratory and follow-up activities are linked by computer. The modular, microcomputer approach employed has provided the necessary capabilities to ensure accurate and efficient tracking of newborns from specimen submission through diagnosis and treatment. Continual program evaluations are also possible through statistical tabulations of various types of data collected and maintained in the system.

BACKGROUND

Newborn screening for inherited disorders such as phenylketonuria (PKU) has been a vital public health program throughout the United States since the early 1960s. As laboratory methodologies became more sophisticated, expanded testing was made possible. Thus by the late 1970s most states were screening for (or considering screening for) at least two disorders. Of necessity, larger states such as New York, California, and Texas became deeply involved in computerization.

In February of 1980, Texas began to screen all newborns for hypothyroidism along with PKU, galactosemia, and homocystinuria. The latter three disorders were of extremely low incidence and appropriate case management by manual methods had previously presented little difficulty. Inclusion of hypothyroid testing created a more complex management problem since the incidence was much greater (approximately 1 in 3500 newborns). Likewise, varied laboratory statistical and data manipulation needs (analytical curve calculations, specimen value determinations, quality control evaluating, etc.) were impossible to accomplish manually with the limited staffing resources available. Priority was therefore given to procurement of a computerized laboratory manage-

From the Bureau of Laboratories and Bureau of Maternal and Child Health, Texas Department of Health, 1100 West 49th Street, Austin, Texas 78756.

* This paper first appeared in the Proceedings of the Twenty-First Annual Hawaii International Conference on System Sciences, Volume IV: Applications. Washington, DC, Computer Society Press, January 1988. Reprinted here (in a slightly revised and modified version) by permission of the copyright holder, IEEE.

ment system. It was intended that this system be capable of providing the necessary case management support needed and that it would also be expandable as necessary.

The initial computer system (Neometrics, Inc., E. Northport, N.Y. 11731) consisted of three 64K, 8-bit microcomputers utilizing Z-80 technology operating under CPM and programmed in MBASIC. With improved software technology, expanded database management was soon possible utilizing dBASE II. This dBASE II software continues to be central to the system. The hardware configuration, however, now consists of several 6MHZ, Z-80 TurboDOS microprocessors networked for ease of data transfer. While dBASE II is no longer the state-of-the-art standard for systems of this complexity, its shortfalls are manageable and it allows user flexibility not easily provided for with more sophisticated relational and post relational software systems.

METHODS

Initially all patient demographic information is completed by the specimen submitter on a laboratory request form (see Fig. 1). Specimens arriving at the laboratory are grouped for analysis and assigned a 9-digit accession number[1] which is embossed on both the specimen filter paper and the demographic information sheet. The specimen and data sheets are then separated for processing. Ten key entry operators, each responsible for 268 specimens daily, enter demographic information into the system. Each operator maintains responsibility for his "batch" of specimens throughout all interactive laboratory manipulations including appending of laboratory results.[2]

Three principal databases are maintained on-line along with identical copies of each for inquiry work and emergency back-up. The "archival" database contains records of all completed specimens including demographic information, laboratory results, date of receipt, and date of result mailing. A copy of any record exhibiting one or more abnormal findings(s) is placed into a "presumptive positive" database where additional information may be appended to trailing databases by those responsible for patient tracking and follow-up care (i.e., Bureau of Maternal and Child Health (BMCH)). Upon confirmation of diagnosis, a copy of the "presumptive positive" record with trailer information is transferred to a "diagnosed" database where additional data may also be appended in order to maintain a more comprehensive patient record.

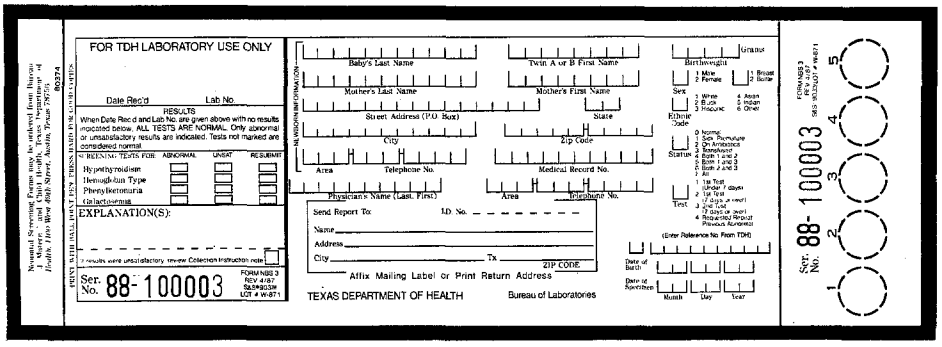

Figure 1. Texas neonatal screening submission form.

Table 1 lists the data elements captured for inclusion in the "archival" database. Input is currently by key entry from laboratory submittal forms. A "pilot" system for data entry at point of submission is, however, under evaluation in Ohio and may prove to be useful for most high volume submitters in Texas. This system allows phone transmission of demographic and result information thus limiting paper flow within the system. If patient information can be input accurately and efficiently by an outside mechanism, significant time benefits will be realized by the health department program.

As finalized patient records are placed into the archival database, a "presumptive positive" database is created containing records exhibiting abnormal laboratory results. Table 2 lists the data elements captured. These records are fully accessible to follow-up personnel through remote terminals and are linked to trailing databases containing pertinent information concerning the patient's current physician, additional laboratory test results, and actions taken by personnel relative to follow-up contacts. As follow-up contacts are made, coded information[3] is added to the patient's record for documentation of action(s) taken. Follow-up dates may be entered which allow creation of daily computerized listings of patient records requiring specialized handling. These listings provide bookkeeping assistance essential in ensuring that no patient is overlooked in efforts to provide adequated follow-up care.

As final dispositions of follow-up actions are made, the database is manually updated. Patient records classified as "normal" or "lost to follow-up" are listed on a printout and purged from the database. Those diagnosed with a specific disorder are copied to a "diagnosed case" database. In addition to the information transferred from the presumptive positive database and its trailers, a new trailer database is created (Table 3) which includes some of the information already captured (this information is redefined for programmer convenience) along with certain additional information needed for various management reports. Thus, detailed patient files are maintained and expanded as

Table 1. Data Items Contained in Archival Database

Item Description	Length (Characters)	Item Description	Length (Characters)
Accession number	9	Sex (code)	1
Baby's last name	11	Birthweight (gms)[a]	4
Baby's first name	8	Date of birth	6
Mother's last name[b]	11	Date of specimen	6
Mother's first name	8	Submitter I.D. no.	8
Patient's address	15	Test (code—initial repeat, etc.)	1
City	11	Previous accession no.[d]	10
State[c]	2	Infant status (code)	1
Zip code	9	Thyroid result (code)	1
Patient's phone	10	Sickle result (code)	1
Medical record no.	10	PKU result (code)	1
Physician's name	10	Galactosemia result (code)	1
Physician's phone	10	Date report out	6
Race (code)	1		

[a] Automatically converts from pounds upon keystroke instruction.
[b] Defaults to baby's last name unless overwritten.
[c] Defaults to TX unless overwritten.
[d] If previously screened—preceded by code letter for abnormal test(s).

Table 2. Data Elements Contained in Presumptive Positive Database

Primary Record—Contains all data elements routinely captured for all records

Trailing Data #1—Multiple records (if needed) to document varying follow-up actions including telephone calls, letters, etc. All records include the following elements.

Item description	Length (characters)
Accession number	9
Action (code)	2
Action date	6
Contact code[a]	4
Date for further action	6
Comments	30

Trailing Data #2—Multiple records (if needed) to maintain information on additional laboratory testing. All records including the following elements:

Item description	Length (characters)
Accession number	9
Test performed (abbrev.)	4
Test result	5
Test date	6
Comments	15

Trailing Data #3—Multiple records (if needed) to document changes in primary care physician. All records include the following events:

Item description	Length (characters)	Item description	Length (characters)
Accession number	9	State	2
Physician's name	10	Zip code	9
Physician's address (line 1)	15	Public health region	2
Physician's address (line 2)	15	County (code)	3
City	11	Physician's phone	10

[a] Used to specify which particular letter sent, etc.

necessary in order to ensure efficient case management and to capture meaningful statistical information for program needs.

As demographic information is recorded on newly submitted specimens, a coded entry specifies those which have been requested as a part of the reevaluation and follow-up protocol used in the neonatal screening program. Overnight the computer checks all "second test" specimens (Texas recommends or, in certain instances, requires second tests on newborns at 1 to 4 weeks of age) by name and date of birth against the "presumptive positive" database. Each morning a listing of all specimens marked as "requested repeat" specimens, as well as those matching outstanding specimens in the "presumptive positive" database but not identified as repeat specimens, is generated for use by follow-up personnel for updating the "presumptive positive" files. Additionally, listings grouped by disorder are created showing any specimens with an abnormal finding released in the last 24 hr. These listings allow BMCH personnel to begin on these patients record keeping in order to ensure appropriate follow-up. As final abnormal reports are

Table 3. Additional Date Elements Included in Diagnosed Case Database[a]

Item Description	Length (Characters)	Item Description	Length (Characters)
Accession number	9	County code	3
Case number	5	Age at screen	3
Screen T4	5	Age at diagnosis	3
Screen T4 cutoff	4	Birth certificate information	
Repeat (1) T4	5	verification	1
Repeat (1) T4 cutoff	4	Case disposition	1
Repeat (2) T4	5	Disposition date	6
Repeat (2) T4 cutoff	4	Action date	6
Repeat (1) TSH	4	Follow-up date	6
Repeat (1) TSH cutoff	2	Physician's phone number	10
Repeat (2) TSH	4	Physician's address	15
Repeat (2) TSH cutoff	2	Physician's city	11
Consultant code number	2	Physician's state	2
Breast or bottle fed code	1	Physician's zip code	9
Public health region	2	Baby's last name	11

[a] All data elements previously captured for the presumptive positive database are maintained. Certain additional elements are carried in a trailer database for easier access. The elements included in this database are shown in table.

mailed from the system, copies are forwarded to the follow-up staff as a means of confirming the reporting process and triggering additional follow-up actions.

CONCLUSION

The current modular microcomputer local area network system in the Texas Newborn Screening Program offers a unique approach to the problems of laboratory data management and follow-up case management in the public health environment. From a meager beginning of a few small memory computers, the current system of multiple networked microprocessors, hard disks, and output devices provides both a powerful and comprehensive system. The ability to quickly access patient information, to generate accurate listings of specimens received for repeat analysis, and to obtain daily reports of specimens requiring individualized follow-up has greatly enhanced the quality of service offered in support of improved health outcome for patients at risk for disorders associated with newborn screening. The numbers of patients whose records have been closed with a registered letter notifying parents of potential abnormal thyroid findings (the final step before ceasing follow-up efforts) has decreased from 15% in 1985 (prior to computerization) to 8% in the last half of 1986 while the relative numbers of abnormal results remained constant over this time period. This decrease is attributed to computerized assistance which has resulted in faster and more accurate tracking of follow-up specimens on patients with initial abnormal screening results. Tabulation of more detailed program statistics accumulated as needed have not only allowed self-improvement assessments to be made with subsequent program refinements but have also contributed to considerations relative to public health needs such as program expansions and redundancy (i.e., second specimen collection).

In order to facilitate computerized reporting, an adjunct database of submitter information is also maintained. This database allows maintenance of supply ordering profiles as well as updated listings of contact persons and correct phone numbers. The latter information enhances the ability of follow-up personnel to deliver pertinent information to primary care providers in a timely manner.

The data summation reports possible from all areas of the system are varied and depend primarily on the knowledge of the computer operator with respect to dBASE II. The more common and highly useful reports are included as menu options. Despite the limitations of dBASE II in a multiuser environment, we have found it to be adaptable to virtually any need for which we have attempted its usage. The massiveness of data accumulated by our program sometimes causes difficulties in summations and searches; however, these are problems more appropriately assigned to limitations of microcomputers and not necessarily the program language. Thoughtful planning and careful implementation of computer software have proven most beneficial in making ours a comprehensive and efficient newborn screening program.

ACKNOWLEDGMENT

The authors acknowledge the assistance of Ms. Virginia Enriquez in the preparation of this manuscript.

REFERENCES

1. Therrell, B.L., Use of commercially available computerization—Texas, New York, Louisiana programs. *Proceedings of the National Symposium* of Lab Aspects of Newborn Screen (B.L. Therrell, ed.), Austin, 1981, pp. 163–174.
2. Therrell, B.L., Modular computerization applied to newborn screening. *Advances in Neonatal Screening* (B.L. Therrell, ed.), Elsevier, Amsterdam, 1987, pp. 517–520.
3. Brown, L.O., and Therrell, B.L., Computerized follow-up system in the Texas newborn screening program. *Advances in Neonatal Screening* (B.L. Therrell, ed.), Elsevier, Amsterdam, 1987, pp. 559–562.