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Computerized Tracking for Newborn Screening and Follow-up: A Review*

F. John Meaney

In the third decade of newborn screening for phenylketonuria (PKU) and other disorders computers are being used increasingly for both the laboratory and the follow-up aspects of screening programs. In 1984 slightly less than 40% of the state programs had automated follow-up. Lack of funding is probably the major inhibitor of more widespread use of computers in tracking newborns through the newborn screening process. It is suggested that federal funds be made available to ensure wider distribution of currently used tracking systems and development of methods for tracking newborns from birth through follow-up.

INTRODUCTION

More than 20 years have elapsed since the advent of newborn screening for phenylketonuria (PKU) to prevent the mental retardation seen in the untreated individual with this disorder. Recently Guthrie, the physician-scientist who developed the dried blood spot filter paper test for PKU and continues to be a major force behind newborn screening, nationally and internationally, has provided a stimulating review of the development of newborn screening.[1] In the United States, all 50 states currently screen for both PKU and hypothyroidism, with the majority of states testing for one or more additional disorders in their newborn screening programs.

As newborn screening programs developed and testing became more widespread and sophisticated, it was inevitable that computers would play an important role in various aspects of the screening process. The late Arthur Veale, a pioneer in the use of automated procedures and computers in newborn screening, has summarized the role of the computer as follows:

From the Genetic Diseases Section, Division of Maternal and Child Health, Indiana State Board of Health, Indianapolis, Indiana 46206-1964; and Department of Medical Genetics, Indiana University School of Medicine, Indianapolis, Indiana 46223.

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> Any repetitive procedure where it is necessary to maintain the identity of individual items or processes lends itself in some way to the assistance of high technology by way of computers or robots or both. It is hard to imagine that any sizeable laboratory engaged in neonatal screening has been able to resist this process.[29]

Veale and his New Zealand colleagues began screening newborns for PKU in 1969. The New Zealand program currently,[2] as in 1969,[3] tests specimens from all New Zealand neonates as well as from newborns in many other island nations scattered across the South Pacific. Interestingly, Veale admitted in the reading of his recent paper[2] that computers were used first to keep track of newborns by the country of origin of the specimen.

The session on automation and computerization at the Sixth International Neonatal Screening Symposium in November 1986, including papers by Veale and others, provided a comprehensive update on applications of these methodologies in newborn screening. Computers have been used in both the laboratory and follow-up aspects of newborn screening as exemplified by the session papers. Therrell[4] presented a summary of current trends in computer usage in the laboratory, including the future use of computer image enhancement to support optical tray scanning of bacterial inhibition assays such as the Guthrie test for PKU. Automated optical techniques with computerization of results have been used routinely in both New Zealand[5] and Texas,[6] but currently only Texas continues to use the procedure in documenting results for both PKU and galactosemia.[7] Another application of the computer in the screening laboratory has been the use of a microprocessor to control the preparation of the blood spot filter paper samples by the punching device commonly used in large newborn screening laboratories.[8] Doubtlessly the newborn screening laboratory will continue to be the target of many exciting new automated procedures and computer applications.

The remainder of this paper will focus on the application of computers in newborn screening follow-up. Most newborn screening laboratories have increasingly used computers to track specimens and results of tests through the laboratory process to the transfer of results to physicians, public health officials, and others in the follow-up system responsible for ensuring appropriate diagnosis, treatment, management, and counseling of newborns positively identified in the screening process. A number of computerized systems have been developed in the United States and elsewhere[9,10] to track newborns through all or parts of the newborn screening and follow-up processes. In the next section the status of current computerized tracking systems will be presented with an evaluation of the advantages and problems encountered with tracking systems and their application in newborn screening follow-up.

CURRENT STATUS AND PROBLEMS

Computerized tracking systems have been developed and reported by several groups in recent years. Dayhoff and Ledley[11,12] have developed a Newborn Screening Information System (NBSIS) that tracks newborns from the screening laboratory through the final follow-up testing. In 1984, Paichel[13] reported a system for processing newborn screening that tracked newborns from birth at two Chicago hospitals. In Australia, Bowling and his colleagues[9] have developed a mini-computer-based system that has completely automated the screening services from the capture of laboratory results through follow-up requests.

Table 1. States Reporting Automated Follow-up in 1984[a]

State's Report	Number	Percentage
No	30	60
Yes	14	28
Partial	5	10
Pending funds	1	2
Total	50	

[a] Source: Newborn Screening: An Overview of Newborn Screening Programs in the United States, Illinois Department of Public Health, January 1985.

Several states have reported implementation of computerized tracking systems, including California,[14] Illinois,[15] Oregon,[16,27] and Texas.[17,25,26] Each of these systems emphasizes a different aspect of screening and follow-up, but all are designed to track newborns from the screening laboratory or specimen entry stage. To date, the only region-wide system reported to track newborns from birth through follow-up is one developed in Birmingham, U.K.,[10] although a system that uses data entry by several hospitals to track newborns from birth is being piloted in Ohio.[18]

In 1984, Sydney Kling and her co-workers in the Illinois Department of Public Health surveyed all 50 states to determine the status of newborn screening programs nationwide.[19] Another survey will be conducted in early 1988 to obtain updated information on each state program.[28] One of the questions to which programs were asked to respond in 1984 concerned automation of newborn screening follow-up. Table 1 presents the responses by states regarding automated follow-up. Almost 40% of states reported that automation of follow-up had been implemented for all or some of the disorders in their respective newborn screening programs. The states reporting complete or partial implementation of automated follow-up are shown in Table 2.

Table 2. Names of States with Automated Follow-up in 1984[a]

Alaska	Mississippi[b]
Arizona	North Carolina
Arkansas	Ohio
California	Pennsylvania[b]
Colorado	Texas
Connecticut	Utah
Georgia[b]	Virginia
Illinois	Washington[b]
Iowa	Wyoming
Massachusetts[b]	

[a] Source: Newborn Screening: An Overview of Newborn Screening Programs in the United States, Illinois Department of Public Health, January 1985.

[b] Automated follow-up for some disorders for which state screens newborns.

The tracking systems reported to date for newborn screening have unique advantages and shortcomings. Some of the reported advantages are presented in Table 3. It is apparent that the usual advantages of computerization apply to newborn screening tracking, but computerized tracking in newborn screening is also perceived as assisting in program evaluation from the public health perspective. The chances for legal action cannot be reduced to zero by any computerized tracking system, but certainly are minimized when rapid, accurate record-keeping is done by a computerized system that maximizes the opportunities to capture data at all stages of the newborn screening process.

As with many programs in the genetic services arena, costs and funding are the major problems for those considering the development and implementation of computerized tracking in newborn screening. Some states still do not have a central laboratory for newborn screening nor a coordinated program for follow-up. With multiple laboratory systems valuable resources may be spent to ensure comparability of laboratory results between laboratories when these resources could be better allocated for state-of-the-art automated equipment in a central laboratory and computerized tracking of all newborns. For example, California has spent funds on equipment for an eight-laboratory system and a computer configuration to monitor both laboratory quality assurance and follow-up,[20] yet a cost savings of millions of dollars may have been realized if the originally proposed three-laboratory scheme had been adopted. Even a single, central laboratory may have worked adequately given the experiences of New York and Texas with similar annual numbers of newborns.

Another consideration relative to computerized tracking for newborn screening follow-up is the problem of how far to go in designing a system. The ideal tracking system would obviously be one that tracked newborns from birth through all aspects of follow-up for those infants who are diagnosed with a disorder and require tracking through management and treatment and genetic and dietary counseling. The limiting factor for most public health utilization of such tracking systems is doubtlessly funding. This will continue to be the major hinderance to progress as decision-making in newborn screening is often based on considerations other than a commitment to assuring that all newborns are screened and followed in the most efficient, cost-effective manner.

RECOMMENDATIONS

Computers will continue to impact dramatically on medical information flow and communication, and the public health arena cannot afford to lag behind during this revolution. Harley and Wolfson[21] have forecasted accelerated usage of microcomputers, elec-

Table 3. Some Advantages of Computerized Tracking for Newborn Screening

Improved data storage, retrieval, and transfer
Rapid communication
Increased accuracy, reduced errors
Ease of follow-up
Ease of program monitoring and evaluation
Minimizing chance of legal action

tronic mail, and other advances that should rapidly impact on developments in tracking of newborns through the newborn screening and follow-up processes. As increasingly more hospitals, local health agencies, and other health facilities participate in the computerization of health information, the tracking of newborns from birth rather than receipt of the specimen in the screening laboratory should become feasible on a broader basis than realized so far in this country. Tracking from birth should significantly decrease the probability of missing a newborn altogether, as attested by the report of Green,[10] who found that 1–2% of Birmingham babies were being missed before the implementation of on-line linkage of recorded births with the newborn screening system.

One strategy that states might use to improve the chances of obtaining support and funding for computerized tracking is to stress the importance of follow-up through intensive educational programs and the often dreaded promulgation of rules and regulations. Of interest in this regard is the fact that Andrews[22] found the majority of states had no mention of follow-up in their laws and regulations about newborn screening. Recently Indiana's newborn screening law was amended to recognize the follow-up aspects of screening and provide a mechanism for funding a coordinated program of follow-up, including a system for tracking and follow-up of all newborns. The current rules for newborn screening in Indiana specifically mention that the state department of health is to maintain a tracking system for follow-up of the results of newborn screening and a confidential registry for infants with confirmed diagnoses.

The importance of follow-up in newborn screening programs has been demonstrated in the recent reports of Holtzman *et al.*[23] and Tuerck *et al.*[16] These data and legal liability issues should stimulate renewed interest by states to obtain funding to improve current methods of record-keeping and tracking in newborn screening. Computerized tracking systems have proven valuable in several state programs, but information on the advantages, pitfalls, costs, and other factors in decision-making about these systems needs to be disseminated to all state programs. Given the demonstrated importance of follow-up, federal funds should be made available for the development of improved tracking systems or the sharing of existing systems and models between state programs. The federally supported regional networks for genetic services should provide leadership in the sharing of information as they have been expected to do with data collection and reporting for genetic services.[24] It is hoped that such federal initiatives and state and regional collaborative efforts would then lead us into a new era of newborn screening in which assurances are truly maximized concerning appropriate screening and follow-up of all newborns in the United States.

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