Introduction

In November 1997 the Mother and Infant Network (MINET) initiative was established in the South Western Sydney Area Health Service (SWSAHS), one of the most socioeconomically disadvantaged areas in New South Wales. This idea was initially established in response to the identified need for quality patient care for mothers and infants most at risk of adverse health outcomes (Phung et al. 2001). The continuum of care for the child has three distinct phases: foetus, infant and early childhood. Consequently, the range of services available for mothers and children in all these phases is one of the most diverse within the healthcare system. The main objective of MINET is to develop a continuum of care for all mothers and infants living in SWSAHS across in-patient services, ambulatory services, and community-based services.

In information systems and health informatics terms, MINET is a database containing health data on infants and children in the SWSAHS from the prenatal period to school age (0 - 5 years). It has been progressively evolving since the inception of its core, the Ingleburn Baby Information System (IBIS), in 1994-95. It is intended that MINET will ultimately hold all health information, together with relevant psychosocial information, about each mother and her infant and child in the Area Health Service from birth to 5 years. The information contained in the database is already being used to enable better coordination of health services and to support the identification of at-risk mothers and children, and for the provision of targeted early intervention in an area with considerable socio-economic disadvantage. The database supports evaluation of services, review and reconfiguration of services where necessary to achieve specified improvements in outcomes, or to provide better access for people with identified risk. The challenge to the MINET clinical data network is the development and the sustainability of the chronological logic when linking complex data sets dispersed in time. The main aim of this article is to describe the development and implementation of MINET with reference to the crucial role of data linkage in health outcomes/health services research.

Key words: Health information management; health care information; health informatics; data linkages; maternal and child health information systems; data management.

The setting

The SWSAHS covers an area of 6237 square kilometres and has a rapidly growing population of over 700,000. SWSAHS incorporates six Local Government Areas and the Shire of Wingecarribee. There are significant pockets of socioeconomic disadvantage within southwestern Sydney compared with the New South Wales average (SWSAHS 2000). The population of SWSAHS is younger, with a higher proportion on low incomes. The prevalence of recent migrants and people from non-English-speaking backgrounds is also higher compared with the rest of NSW.

Background and conceptual framework of MINET

Early childhood – a critical time

Early Childhood Services are a key component of Community Health Services. They target infants, toddlers and young children from the time of discharge of mothers and their new babies from hospital to the child’s entry to school at or about the age of 5 years. Early Childhood Services are based in the Well Baby Clinics. Parent Advisory Services are a particularly important service provided by the Early Childhood Nurses.

In recent years, early childhood has become the focus for attention and activity aimed at developing adolescents and adults with robust physical and psychosocial health. The prenatal period, infant and early childhood periods are seen as critical for the promotion of good health and the development of personal characteristics, which are protective against many of the intractable and insoluble problems experienced in adolescence and adulthood (Rantakallio 1983; Halldorsson et al. 1999). Adverse physical and psychosocial experiences in early childhood have been implicated in poor educational outcomes and the development of physical and mental health problems, substance abuse and other damaging social problems (Keeping et al. 1996; Zuckerman & Beardslee 1987; Morrison et al. 1989). It is believed that intervention in families with problems can improve the situation for the parents and children and improve the probability of good outcomes in adolescence and adulthood (Fried 1993). As a result, health services are increasingly focusing on...
the importance of early identification of risk and early intervention. In order to be able to do this, it is necessary to develop reliable indicators of risk from the time pregnancy is confirmed, and it is also very important to identify effective models of early intervention in a range of settings and communities. The availability of good quality, comprehensive, longitudinal information is essential for these tasks.

Coordinating health services for mothers, infants and young children

The difficulty of providing a coordinated and comprehensive healthcare service through Australia’s fragmented healthcare system is well recognised. Primary healthcare services are delivered by general practitioners, public hospital emergency departments and public community health services with little or no coordination of activity. The delivery of specialist or secondary health services is similarly disjointed, with services being provided in private medical practice and through the public hospitals. Even within the public healthcare system, there has not always been sufficient communication between antenatal healthcare, maternity services and early childhood health services. It is possible that, following delivery, mothers and babies may fail to make contact with the healthcare system at any point and that this may not be recognised by service providers. There is evidence that it is the most disadvantaged or at-risk mothers and babies who are most likely to fail to attend general practitioners or Early Childhood Services. It is important that there is good communication between different health service providers seeing the one patient so that their efforts can be coordinated and that duplication or gaps in service delivery are prevented. It is therefore important to find a cost-effective and simple way to separate systems while maintaining the operations. Better integration of all the health services being used by a mother and her infant also allows for the different service providers to identify the most appropriate person or group to supply services in response to identified need, and for coordination of the efforts of all providers in the interest of that mother and her child (Kahn et al. 1999).

Development of MINET

MINET has its origins in the Ingleburn Baby Information System (IBIS). The development of this database grew in 1995-96 from of the concerns of six primary care nurses at the Ingleburn and Campbelltown Early Childhood Centres. These nurses needed better information in order to be able to identify issues of access and health outcomes relating to their services and to evaluate those services. The information collected at that time included the patients’ postcodes. By examining the postcodes of the mothers they were seeing in the postnatal period, the nurses recognised that they were mainly seeing mothers and babies from the more socioeconomically disadvantaged parts of their sector. The data also showed that by the age of three months 60% of the infants registered with Well Baby Clinics had stopped attending. Only 20% of the original registrants had a six-month review. This finding led to consideration of the location of the Well Baby Clinics. The decision was also taken to develop a more comprehensive data collection system, which would provide more useful information for the review of services. The need for improved data collection was addressed by collaboration between the Primary Health Nurses and the Health Outcomes Resource Team. The aim was to support the Primary Health Nurses in structuring and standardising the capture of information as part of routine clinical practice in Well Baby Clinics. One aspect of this development was that technically it was a robust, flexible and low cost solution. Because it used scannable medical records based on technology using Optic Mark Recognition and did not require large numbers of data entry operators, it was likely that it could be sustained despite staffing changes and budget crises. Electronic capture of large volumes of clinical information in real time was relatively easy and reliable. Successful electronic medical record implementations share the ability to improve the quality of care by making clinical data readily available and offering decision support (Khouri 1997).

IBIS Version 1 was developed in 1995. Each record consisted of four pages of baseline data and two pages of follow-up information. Clinician involvement with and ownership of the database has meant that there has been ongoing review of the usefulness of the information being collected, and that additional information requirements have been identified from clinical experience and addressed over the years in three revisions. In 1997 IBIS underwent minor modification with the addition of a small number of descriptive items, such as the educational attainment of the mother. IBIS Version 2 records still comprised four pages of baseline data and two pages of follow-up information. The data collected continued to be purely descriptive. IBIS Version 3 was developed in 1998, at which time the database underwent a major revision and paradigm shift with the introduction, on a trial basis, of psychosocial questions.

The database is currently undergoing yet more major modification to incorporate information on social health. It will be structured differently from the first three versions, with a generic core and additional modules for mothers and babies in high-risk groups. The modules currently being developed relate to non-English-speaking women, Aboriginal women, young mothers (< 18 years) and drug-dependent women.

IBIS is now used to provide Primary Health Nurses working in Early Childhood Services with information with which to review, evaluate and, where necessary, modify the services they provide. The IBIS information architecture and underlying principle of clinician ownership have created an information culture within the community-based services for mothers and their infants and children within the SWSAHS. As a result of using IBIS to assist them to improve their everyday work, the Primary Health Nurses have begun to recognise a new dimension to their role, that of the information worker. In the clinical context an information worker is a clinician who is able to access and use information pertinent to the equality and outcome of the care he or she is providing.

The use of IBIS at a sector level allows significant differences between the sectors in relation to particular health issues, such as rates of smoking in preg-
appropriate early childhood services, such as Well Baby Clinics. This, in turn, allows programs to be developed and priorities to be set that are specific to the needs of the mothers and children in each sector. It also allows for benchmarking between the different sectors and for exploration of the reasons for the differences observed.

The IBIS database now holds baseline data on more than 10,000 babies and their mothers, and of over 50,000 visits to health services by these infants and their mothers. There are more than 4,000,000 data items on the database.

Key issues associated with the successful development of IBIS are:

- it has clinician development and ownership
- there are real-time data flows
- it contains multipurpose data of high quality which have been validated against national standards,
- it has robust, flexible information architecture with the capacity to modify and upgrade the system to reflect best practice for Well Baby Clinics.

Data linkage and health outcomes

Towards a public health approach

By 1997 the public health potential of IBIS was becoming apparent at the Area level, and work to expand its scope and utility by connecting it with related data sets within the SWSAHS was commenced. The importance of the prenatal period to the later health of mothers and babies is now well recognised, and the advantage of creating links between IBIS and other Area databases containing information on the prenatal period and the confinement could be appreciated. Such an approach would support the early identification of at-risk mothers and babies and the implementation of strategies to ensure their access to appropriate early childhood services, such as Well Baby Clinics and Parent Advisory Services. Parents may seek health care for their infants and small children from one or more of a range of public health service providers within SWSAHS. It is important that services for this group should be well coordinated, and that any health service provider seeing a young child should have access to relevant information concerning that child. Thus, it also made sense to consider linking the IBIS database with data sets held by other public health service providers, such as hospital emergency departments and public hospital inpatient and outpatient services.

The outcome of these considerations was the decision to create an Area-wide clinical data network integrating all of the services available to mothers and infants to capture all health information about the children living in SWSAHS from conception to school entry. This would be known as the Maternal and Infant Network (MINET). MINET would increase the system capacity for accessing and using information. In turn, this would inform the quality of care, with a dual emphasis on achieving improvement in population health in SWSAHS, while maintaining a focus on the individual mother and infant and the outcomes of the services provided for them.

The technical objective was to develop and implement a clinical data network, which aimed to integrate all information on healthcare over a continuous period which spans the three important developmental stages for the mother (pregnancy, confinement and parenthood) and infant (foetus, infant and toddler/pre-school child).

It was apparent that any database development would need to support the translation of theoretical epidemiological knowledge into actual clinical practice. The main strategies identified to do this were accurate data collection, sharing of those data across all points of healthcare delivery and, where the need was identified, re-engineering the system to address health problems.

It was determined that MINET will ultimately hold information on every child from conception to the age of 5 years born to the residents of SWSAHS. With about 12,000 births per annum in the Area, once it reached steady state the database would hold in excess of 60,000 active records at any time. Thus, for most of the Area’s children, MINET will eventually hold information on the prenatal period, the confinement, the period of infancy and the period of childhood up to 5 years of age.

Information will be collected, entered and analysed at a Sector level in order to support clinical practice. At the Area level it will be possible to develop policy and plan strategically for population health based on information derived from the whole database. De-identified data from the database will ultimately play a very important role in clinical and health service research. It will support better integration and coordination of health services for the target group and inform efforts to improve access to health services for infants and children across a large and disadvantaged population. It will also assist the Area to better target population health programs.

An example of the usefulness of linking databases is to be seen in the identification by Early Childhood Nurses at Ingleside of a successful solution to the problem of matching services to need. Further consideration of the problem by the Early Childhood Nurses led to a decision to introduce home visiting by Early Childhood Nurses during the antenatal period for those mothers and infants considered to be most at risk of adverse outcomes.

Another example of the usefulness of linking databases is the application of Geographic Information Systems (GIS). Analysis of birth weight data using spatial analysis (GIS) demonstrates significant variation by small area. The birth weights of the individual infants are now indicators of infant health at a population level (the capacity for monitoring health gain for the population of infants). GIS is being used increasingly within epidemiology and health services research; it is an important tool within MINET. Data on individual clients are geo-coded to the defined geographical area where the client lives. This geographical unit may be a Collector District, a Suburb or a Local Government Area (LGA). The process, as in this case, is that Primary Health Nurses collect information on the socioeconomic profile and the family characteristics of their clients (mothers and their infants) as part of routine service delivery. Combining this information and health-related data, an association between the risk behaviour of the mother (maternal smoking) and the infant’s physical health (birth weight) can be ex-
explored. Using geo-coding to overlay this health information with other information, particularly broad socioeconomic data such as 1996 Australian Census data or Socioeconomic Index for Area (SEIFA Index), allows the spatial distribution of this association to be geographically mapped.

This capacity of GIS to communicate complex outcomes of clinical care ‘at a glance’ has become a powerful means of providing feedback on outcomes of care to clinicians within MINET. GIS has the demonstrated capacity to take the final step towards ‘closing the loop’: feeding clinical information back to the clinicians, who can effect change (e.g., restructuring work practices, Health Systems Reform, Quality Improvement). Analysing the data flowing from the MINET integrated clinical data network using GIS has made it possible to identify suburbs within SWSAHS with a high prevalence of smoking in pregnancy, low birth weights and low socioeconomic status (SES). More importantly, using the results which display the geographical distribution of maternal smoking, pre-term birth and low birth weight, a preliminary hypothesis of an association between smoking in pregnancy, SES and adverse pregnancy outcomes can be generated. Linking databases also allowed the Early Childhood Nurses to work with women who were having difficulty with smoking minimisation or cessation during pregnancy.

It was decided that MINET would be developed by a collaboration between the Simpson Centre for Health Service Innovation, Liverpool; the Caroline Chisholm Centre for Women and Babies, Liverpool; the Centre for Health Equity, Training, Research and Evaluation, SWSAHS; the Epidemiology Unit, SWSAHS; and the Health Outcomes Resource Centre, Macarthur Health Sector, SWSAHS. The need for dedicated staff, together with a base for those staff, was met by locating the development team in the Simpson Centre. A multi-disciplinary research team with expertise in Health Informatics, Communication, Population Health, Psychosocial Health, Clinical Effectiveness and Epidemiology was formed to undertake the developmental work.

**Practical and technical aspects of the development of MINET**

A staged approach to the development and integration of different sites and their data sets across SWSAHS into MINET has been adopted. As a result, MINET currently contains a range of data sets of differing magnitude according to when they were commenced or incorporated into the database. Quality data elements can support clinical decision making and can improve the clinical processes. Interoperability and comparability of the health data are key factors in healthcare data processing. Better integration of data can improve the accessibility, accuracy, comprehensiveness, consistency, currency, definition, granularity, precision, relevancy and timeliness of the data. The develop-
The linking module is the crucial component of the LinkIT system. Given the data layouts for all data sets, the matching rules and the raw data from various data sets, the primary function of the linking engine is to link a patient record (using local identifier) in the data set, the primary function of the linking engine is to enable the tracking of short-, intermediate- and long-term outcomes for mothers and infants across the first five years of life (Roos et al. 1986; Wadja & Roos 1987; Gill et al. 1993). Links have been or are being developed between IBIS, the obstetrics units (antenatal, birth and postnatal information), the neonatal intensive care unit, the hospital emergency departments, and hospital inpatient and outpatient units.

There is a well-developed and validated database for the delivery of health services innovation delivery being experienced by the Simpson Centre and confidentially (National Health Information Management Advisory Council 1999).

The conceptual design of the link system can be visualised as containing several modules, including one rule governing the module (Figures 3 and 4). There are four modules in the LinkIT System: Translation Module, Rule Set Module, Linking and Matching Module and Query Module. The modules are cohesive in their design and will act as independent entities. Each module encompasses an engine, which performs the major processing task for that module, and the output from the module or engine will be stored in a file. This caters for the dynamic aspect of the link system, where, for example, the linking can be performed on any stored translation file.

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set and generate a Shadow Unique Identifier (SUI). Each record is sequentially compared to all of the other records to determine which records are for the same patient. To determine if the records match, powerful heuristic rules specified by the user are used. Once the match has been found, the linking engine saves the results with that patient's SUI, which will be used in the query module.

This system provides a very useful way to review, check and simplify the input files to the matching system, and also does a very good job of matching records in a deterministic matter; however, the probabilistic matching has some drawbacks, as the matching field comparison is binary. This means that two fields qualify if they have the same ordered sets of characters, but are not otherwise equal. A very simple matching algorithm, where one record is crossed with all other records, is used, and has a very lengthy matching process when files are larger than over 1000 records.

Clinical needs take priority over IT considerations

The MINET group has deliberately given priority to clinical needs rather than system or technological needs in all its decisions. It has set out to ensure that the system should not be driven by the Information Technology, but rather by the needs of clinicians for timely, high quality and relevant information. Much effort has been applied to ensuring that the data entered into the system are accurate and relevant. The use of scanning technology makes it easier to ensure that data entry is timely.

Every Community Health Centre in SWSAHS has a computer server with information stored according to privacy and confidentiality principles and practice. The administrative responsibility for the data lies with the nursing officers, who are assisted by Information Technology staff. Cleaning, coding and analysis of data is undertaken by the Simpson Centre. The data are aggregated at the Area level by the Simpson Centre, which is the custodian of the data at the Area level. The cleaned data file is returned to the sector by the Simpson Centre and de-identified data are archived by the Centre.

The critical success factor for the MINET integrated clinical data network is the ability to identify and embed generic cores of information for each of the health domains, such as biological health, psychological health and social health. The need for a core data set must be balanced against the clinician’s duty to provide assessment and treatment or support that is socially sensitive and culturally specific. Identifying clinicians’ needs for what information needs to be shared when has facilitated the development and implementation of critical pathways for all of the three health domains. Sector-based data items and definitions may be added to ensure that specific indicators capture the uniqueness of the needs of the population within individual sectors, as well as the kinds of services being provided. The critical pathways are subject to a clear change management control process. A trail is kept to ensure the history of the development of the data sets is available to inform the evaluation and research activities relating to MINET.

Future directions

The development of MINET has meant that an area of healthcare with important and natural connections and interactions has been organised in such a way that every intervention within the continuum of care for a particular patient can be informed by all of the relevant information already collected in any health setting about that patient. This has important implications for the coordination and comprehensiveness of care as well as for quality management. It will provide a practical framework within which health services can be accurately and sensitively targeted, patient-focused and integrated. The information available to health service providers will support proactive intervention with women and infants or children with identified risk. It will be possible to really understand the ‘continuum of care’ as it is experienced by the patient, and to do things differently where it is apparent that this would be associated with better outcomes.

Conclusion

In recent times, early childhood has become the focus for attention and activity aimed at developing adolescents and adults with robust physical and psychosocial health. It is thought that investment in services for mothers and their young children may have significant
consequences in terms of reduced adolescent and adult rates of mental illness, substance abuse, suicide and crime. It is understood that the South Western Sydney Area Health Service may so far be the only health service in Australia with an extensive community-based health database linked with databases containing hospital outpatient and inpatient information. MINET is a very valuable health information tool which assists health service providers to be better informed and to improve the appropriateness, quality, effectiveness and efficiency of the health services they provide for mothers and their babies and young children. The benefits sought from the project are mainly for the babies and young children of SWSAHS and for the adolescents and adults they will become. There are also considerable benefits for the clients of Early Childhood Services, and for health services in general, arising out of better integration of public health services, improved coordination of services and reductions in duplication and gaps in service provision.

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References


South Western Sydney Area Health Service (SWSAHS, EpiUnit) (2000). Health in South Western Sydney, An Epidemiological Profile 2000. Sydney, South Western Sydney Area Health Service Epidemiology Unit.
