

A framework for monitoring maternal and infant health status

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Abstract

The Mother and Infant Network (MINET) Program was established in South Western Sydney Area Health Service (SWSAHS) in 1997. MINET developed and implemented an integrated clinical data network as a key strategy to support and inform a Continuum of Care comprising hospital and community based services. There are good data sources within the MINET program. Its scope spans care for mothers and children, which begins with the first antenatal attendance and ends at school entry.

This paper has three interrelated aims: to describe the development of the MINET program; to demonstrate the benefits of a sustainable Information Culture which can assist an Area Health Services in adopting a health outcomes based approach to service delivery; and to describe how MINET has the capacity to support Health Services Research.

Introduction

The association between maternal and childhood health is well established. Many maternal determinants, such as biological, physical, economical, social and life style have been shown to impact on childhood health. Maternal smoking is associated with a low birth weight of the baby (Li, Winsor & Perkins 1993; Hebel, Fox & Sexton 1988; Sexton & Hebel 1984), increased incidence of asthma (Gortmarker et al. 1985; Lister & Jorm 1998), otitis media (Ey, Holberg & Aldous 1995) and even Sudden Infant Death Syndrome (Klonoff-Cohen, Edelstein & Lefkowitz 1995). The links between the psychological health and the lifestyles of pregnant women with obstetric morbidity are also well documented (Zuckerman & Bearslee 1987; Keeping et al. 1996).

The literature suggests that investment in services for mothers and their young children may have a positive impact in the form of reduced rates of adolescent and adult mental illness, substance abuse, suicide and crime (Fergusson & Woodward 1999; Silver, Stein & Bauman, 1999; Preski & Walker, 1997). It is thought that the early identification of physical, psychological and social risk factors followed by early intervention for the mother and the young child may promote the health and well-being of the family and support the development of resilience in the child. The availability of a comprehensive database capturing clinical information in “real time” that incorporates information on physical, psychological and social health, and covering children within a total population perspective could be useful for service providers as well as health service researchers.

Traditionally research on maternal and child health has focussed on data collected within individual services. The capacity to monitor the complex interrelationships between the health behaviour of the woman/mother

and the physical health of her infant/child over time is only beginning to be explored (Kahn et al. 1999). The maternal and child health continuum of care comprise three distinct phases: pregnancy, infancy and early childhood. Across this continuum there is a diverse range of services available to mothers and children.

The Mother and Infant Network program (MINET) was initiated by a group of Primary Health Care Nurses (PHNs) who were operating a service without access to accurate, reliable and timely information pertinent to the care of their clients. A collaboration between a Health Outcomes Resource Team and the PHNs was established. From this collaboration a culture evolved where clinical information was not only collected but also used by the PHNs to inform the processes and outcomes of the care they provided for mothers and infants. We propose to describe the MINET program in three parts. Firstly to describe the evolutionary approach to program development within MINET, including the establishment of an information culture. Secondly to demonstrate the capacity of MINET to monitor health gain for all mothers and infants in an Area Health Service while focussing on the quality of care for the individual mother and infant. Thirdly to describe the research and evaluation framework that underpins the MINET program, and the potential this framework has for supporting Health Service Research (HSR).

Setting

The South Western Sydney Area Health Services (SWSAHS) covers an area of 6237 square kilometres and has a rapidly growing population of over 700,000. SWSAHS incorporates 6 Local Government Areas (LGAs) and the Shire of Wingecarribee. There are significant pockets of socio-economic disadvantage within South Western Sydney compared with the New South Wales (NSW) 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. There are more single parent families, and levels of unemployment are high (Table 1).

Table 1. Demographic Data Comparison between SWSAHS and New South Wales

	SWSAH(%)	State of NSW (%)
Age < 15 years	25.5	21.4
Age 65 years +	9.1	12.7
Overseas born	34.4	23.0
Non English speaking background (NESB)	28.5	15.7
Speaks a language other than English	36.5	18.1
Unemployed	10.8	8.8
Aboriginal and Torres Strait Islander	1.2	1.7
Single parent families (% of all households)	12.5	10.2
Proportion of population. Earning \$800 per week or more	7.6	11.0
Crude Birth Rate (per 1000)	17.5	14.5

In 1996-97 12,604 babies were born in SWSAHS (SWSAHS 2000). The crude birth rate for SWSAHS was 17.5 per 1000 population, higher than the rate of 14.5 per 1000 for all NSW. The rates of teenage pregnancies, premature births and low birth-weights - all associated with increased risks for the infant - are higher in SWSAHS than in all of NSW (SWSAHS 2000).

Program development

Approximately five years ago, PHNs at the Ingleburn Baby Health Clinic, one small clinic in the Macarthur Sector of the SWSAHS, began to question the impact of their services on those mothers and infants most at risk for adverse health outcomes. At the time, they did not have access to any information that could assist them in answering this question. A collaboration was established with the Health Outcomes Resource Team

(HORT) based at a Community Health Centre within the Macarthur Sector, SWSAHS. HORT consisted of a multi disciplinary team including expertise in Public Health, Data Management and Health Informatics. The overall brief of HORT was to assist clinicians in collecting structured, standardised information which could inform a Health Outcomes based approach to service delivery. Collaboratively, PHNs and the HORT developed a structured, standardised medical record based on the conventional medical record used by the PHNs in Well Baby Clinics. The structured record incorporated data items that can be used for analysis at the level of the individual client and /or the population level. The conventional medical record was modified to achieve a scannable format. Scanning these records enabled data items to be captured electronically, creating a clinical database in “real time”. SCANMARK 2500 was used for scanning the records. FLIPSOMR and SCANBOOK software were used for form design and data base design. The emphasis was on a robust, flexible and low cost information technology solution.

The information system, which evolved from this collaboration between clinicians (PHNs) and HORT was named the Ingleburn Baby Information System (IBIS). From the inception (1995) up until the present time (2000) IBIS has undergone annual revisions to ensure that the data structure reflects best practice at any given time. There is universal capture of all occasions of service for Well Baby Clinic services within three of the LGAs serviced by SWSAHS (annual birth rate for these LGAs approx. 5,000). IBIS is owned and driven by the PHNs and supported by HORT. The key achievement of PHNs using IBIS has been the capacity for targeting services at those mothers and infants most at risk for adverse health outcomes - the initial incentive that lead to the collaboration and development of IBIS had been honoured. The results from the IBIS database assisted the PHNs in monitoring clinical effectiveness as well as the health of mothers and infants at a population level. The less than optimal outcomes for key areas such as, initiation and duration of breastfeeding, a high prevalence of low birth weight of babies born to mothers who had smoked during pregnancy, and a high incidence of lower respiratory tract disease for babies whose mothers had smoked during pregnancy, highlighted the need for an integrated approach to service delivery along a Continuum of Care for mothers and infants in SWSAHS.

The MINET Information Culture

Based on the experience of IBIS similar databases were developed at other service points along the Maternal and Infant service pathway (eg. Antenatal Clinic, Birthing Unit, Post-natal Ward and Early Childhood services). MINET was conceived in 1997, based on the concept of an integrated clinical data network that would build monitoring capacity for the whole population of mothers and children in SWSAHS whilst maintaining a focus on the standards of care for individual mothers and children. The MINET scope spans the time from the first antenatal visit up until school entry.

The critical success factor has been the close collaboration between clinicians at the clinical interface and a multi disciplinary team representing skills in evaluation and research. The currency for MINET is accurate, reliable and timely information captured at the point of service delivery across the continuum, that can be accessed and used by clinicians to inform the processes and the outcomes of care. Following the Area wide launch of MINET, a collaboration was established between HORT, Macarthur Sector, and the Simpson Centre for Health Services Innovation (SC), a Centre for Health Services Research with an Area wide focus. This collaboration provided increased capacity for evaluation and research for MINET clinicians across SWSAHS. HORT is sector based (Macarthur Sector), SWSAHS is comprised of five administratively autonomous Sectors. Each sector is responsible for all the health needs of their population. A MINET Area Steering Committee, representing all the stakeholders, was established when MINET was first launched in 1997. This committee is modified on an ongoing basis to ensure that current interventions and Health Reform initiatives within SWSAHS are appropriately represented.

MINET has a range of well-developed and well-maintained databases, as well as new ones that are being developed based on clinician specifications. The task of identifying and linking the information captured on these diverse databases is one of the key challenges within MINET. These activities involve the creation of “a shadow unique identifier” for each mother and child. Data matching and linking integrate databases developed within MINET, as well as pre-existing databases capturing relevant information on mothers and babies. The result has been de-identified data sets which track process indicators and outcome indicators for mothers and

their children over time. This information is available to clinicians, managers, researchers and planners. The availability of these extensive (de-identified) data sets, capturing information on most of the children in SWSAHS, provide a rich resource of information that can inform service development and health policy review, as well as clinical and epidemiological research within South Western Sydney.

The MINET information culture is aimed at integrating the organisational structure (the service points along the Continuum of Care), Information Management and Technology (IM&T), Human Resources (HR) and the health professionals. The structured, scannable medical record is the tangible representation of the MINET information culture. The utilisation of birth weight and maternal smoking, documented in this record and captured on IBIS, will be used to demonstrate the capacity of MINET to track outcomes at the individual level and at the population level and to develop interventions targeting population sub-groups at risk. As described earlier both process and outcome indicators are embedded within the MINET clinical data network. Thus the MINET indicators are used for both monitoring maternal and child health in SWSAHS, and for describing the prevalence of adverse health phenomena within the population of mothers and infants in SWSAHS. This approach is epidemiological in nature and is based on a philosophy of *applied public health*. The criteria for timeliness in this context are defined as the availability of information to clinicians at the point of service delivery.

Results

For the purposes of this paper we will present some results from the MINET integrated clinical data network, collected during the period Jan 1995 to July 1998. The sample size for this collection period was 6,126 mothers and their infants. All of the presented results reflect information captured during the first occasion of service (baseline) for each mother and her infant.

Table 2. SWSAHS IBIS Data: Mother intra-partum history

	1995 %	1996 %	1997 %	199 %	Total %
Delivery Status					
Vaginal delivery	72.2	72.4	67.0	69.6	69.9
Assisted vaginal delivery	7.0	6.3	6.9	6.9	6.7
Induced delivery	.5	.5	16.7	19.3	10.7
Epidural during delivery	.6	3.0	4.6	2.1	
Emergency Caesarean	6.3	6.3	8.3	8.2	7.8
Elective Caesarean	6.7	6.2	7.7	8.7	7.3
Complication during pregnancy					
Pregnancy Induced Hypertension	12.0	10.3	11.3	10.4	10.9
Gestation Diabetes	6.4	6.1	7.2	9.2	7.1
Threatened miscarriage	1.5	2.1	2.1	1.8	1.9
Other complication	10.3	13.2	8.1	9.8	10.3
Labour (mother self report)					
Difficulty	15.7	26.2	36.4	39.9	31.1
Not difficulty	84.3	73.8	63.6	60.1	68.9
Gestational age in weeks					
Mean	39.26	39.18	39.1	39.07	39.14
Standard Error	0.06	0.04	0.04	0.06	0.02

Table 2 presents some intra partum characteristics of mothers registered on IBIS during the period 1995 to 1998. There were significant differences between normal vaginal delivery, induced delivery and epidural delivery ($P < 0.001$). There were no significant differences between elective and emergency caesarean delivery over this 4-year period. Overall 70% of mothers reported normal vaginal delivery, about 7% needed assistance and more than 10% reported induced delivery. In relation to complication during pregnancy, there were significant differences between mothers who reported gestational diabetes (GI), pregnancy-induced hypertension (PIH) and other complication during 1995 -1998 ($P < 0.0001$). Overall the prevalence for PIH and gestational diabetes were 11% and 7% respectively. There were no significant differences in gestational age for mothers captured on IBIS from 1995-1998.

Table 3 shows some of the characteristics of babies registered on the IBIS database from 1995 to 1998. There were no significant differences in relation to the birth weight for all of the babies registered with the IBIS system during the four-year period; average birth weight was about 3379 grams. There were no significant differences in the recorded bare weight (at time of discharge) or length of babies (at birth), with average bare weight and length being 3302 grams and 51cm respectively. However, there were significant differences in birth weight by country of birth of the mothers ($P < 0.0001$). The IBIS results reveal that babies born to mothers from an Asian country tended to have the lowest average birth weight (3290 grams) while babies of European mothers tended to have the highest birth weight (3495 grams). In addition, there were also significant differences in relation to type of antenatal care received by mothers and the birth weight of their babies ($P < 0.05$). Mothers who did not receive any antenatal care reported the lowest average birth weight (3336 grams) for their babies, while mothers whose received shared care or obstetrician care tended to have higher than average birth weight.

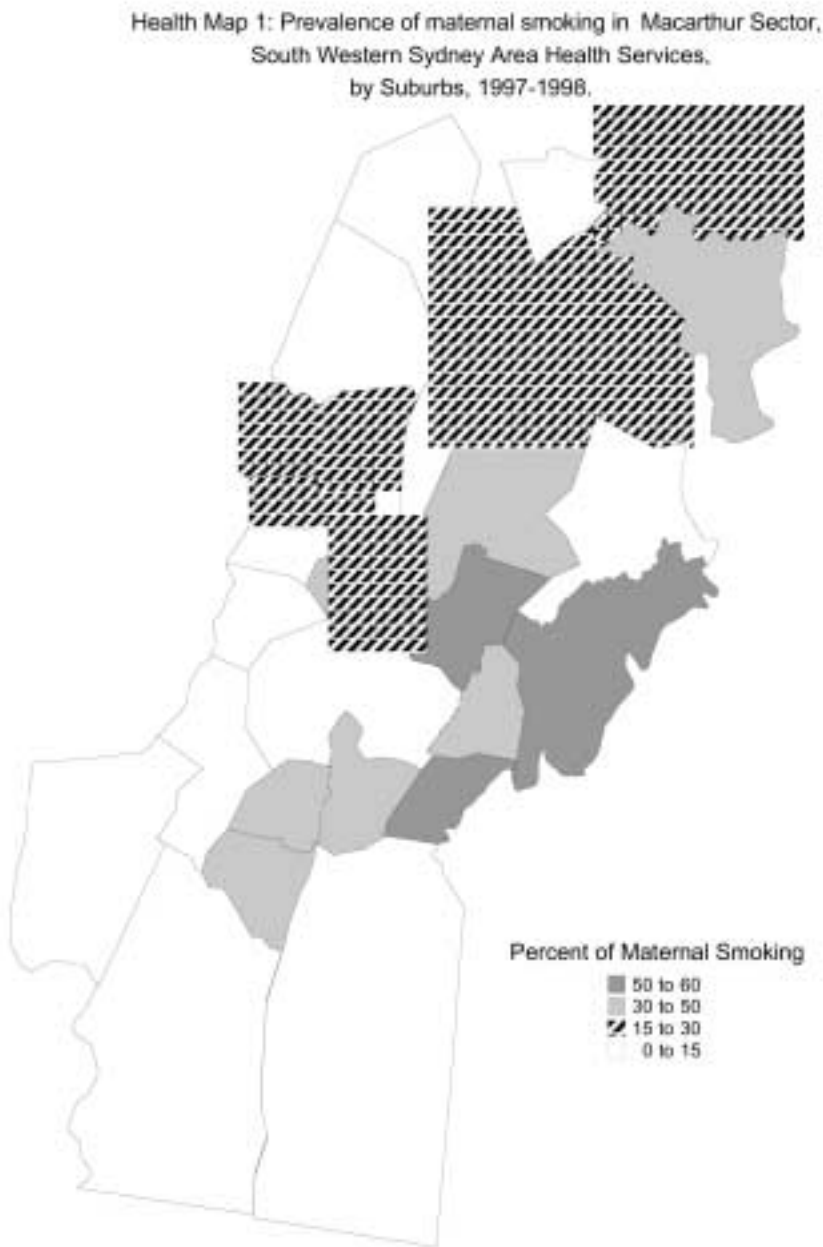
Table 3. SWSAHS IBIS Data: Baby characteristics

	1995	1996	1997	1998	Total
Birth weight (gms)					
Mean	3371.73	3392.53	3370.94	3379.87	3379.40
Standard Error	19.36	13.02	12.12	19.01	7.44
Baby Length (cms)					
Mean	50.06	49.95	51.39	52.49	50.93
Standard Error	0.32	0.2	0.11	0.62	0.14

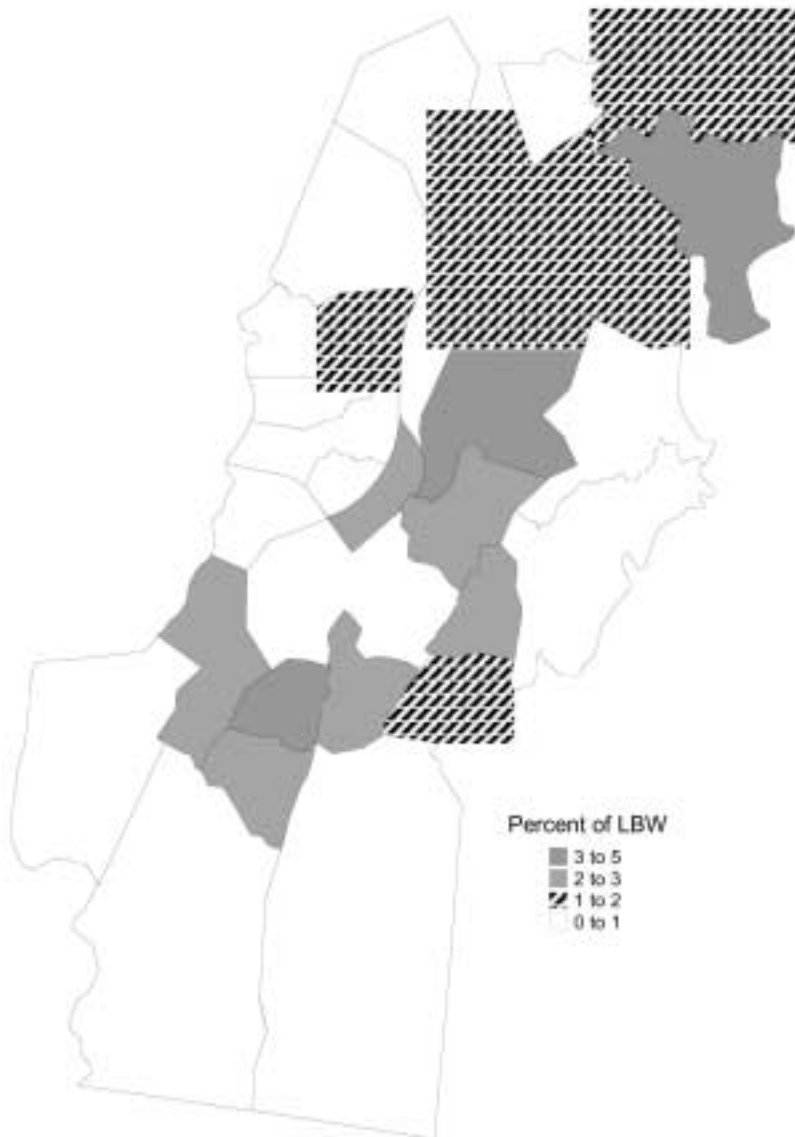
The results presented so far relate mainly to clinical effectiveness. Analysing the same data on birth weights using spatial analysis (The Geographical Information System (GIS)) the results demonstrate significant variation by small area. The birth weights of the individual infants are now indicators of infant health at a population level (the capacity for monitoring health gain for the population of infants). GIS is increasingly being used within epidemiology and Health Services Research (Moore & Carpenter 1999; Holman et al 1999; Hydman et al 1999). It is an important tool within MINET. Data on individual clients is geocoded 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 PHNs collect information on the socio-economic 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 infants physical health (birth weight) can be explored. Using geocoding to overlay this health information with other information - particularly broad socio-economic data such as 1996 Australian Census data or Socio-Economic Index for Area (SEIFA Index) (ABS, 1998) - allows the spatial distribution of this association to be geographically mapped. The MINET Health Maps (HM) are the outcomes of this process.

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 (restructuring work practices/ Health Systems Reform/ Quality Improvement). The MIMET HM which have supported clinicians and managers in the implementation of a targeted approach to

service delivery. 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 socio-economic status (SES) (HEALTH MAP 1-3). More importantly using the results, displaying 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.



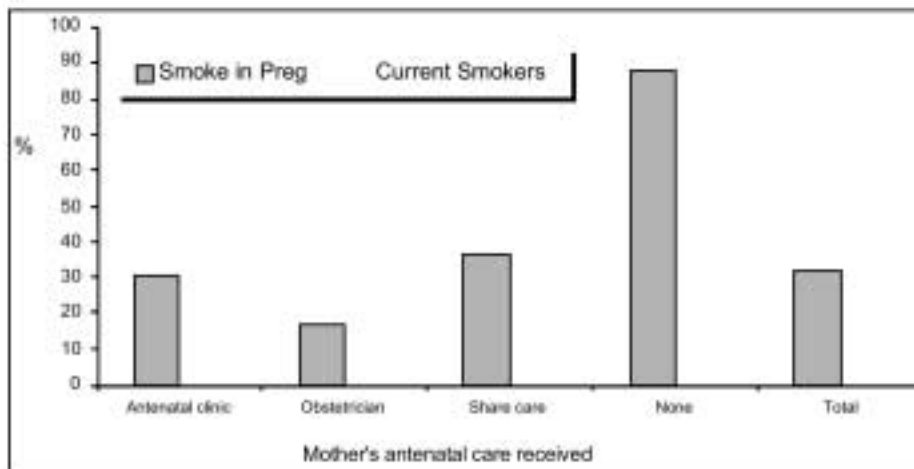
Health Map 2: Incidence of Low Birth Weight (LBW) in Macarthur Sector,
South Western Sydney Area Health Services,
by Suburbs, 1997-1998.





Results based on IBIS data for the period 1995-1998 showed significant differences between mothers who reported smoking during pregnancy ($P < 0.0001$). The IBIS results confirmed that mothers who were born in an Asian country reported the lowest percentage of smoking both during previous pregnancy and currently (less than 4%). Overall, the maternal smoking prevalence for English, European and Middle East country born mothers were 30%, 28% and 21% respectively. The availability of this information at the level of service delivery, based on local data, has been a powerful incentive to restructure service delivery. Other results on maternal smoking have also had an impact on service delivery. One example is the significant differences between the prevalence of mothers' smoking by the type of antenatal care they received ($P < 0.0001$). More than 80% of mothers who did not receive any antenatal care reported that they smoked during their pregnancy, while only 17% of mothers who received antenatal care by an obstetrician smoked during their pregnancy (Figure 1).

Figure 1. Prevalence of smoking in pregnancy by type of antenatal care received by mother.



Embedding standardised smoking questions into routine clinical information gathering, has produced results not only on clients and groupings of clients as just described, but on the whole population of mothers in SWSAHS. It is the availability of these population rates on health phenomena (eg smoking in pregnancy) that provides capacity for MINET to monitor health gain using Health Maps. The following Map on Maternal Smoking demonstrate a significant variation in maternal smoking by suburb, with some suburbs showing an unacceptably high prevalence (between 47%-57%) of smoking in pregnancy compared with 21% for NSW overall (HEALTH MAP 1). Results such as these can assist clinicians and managers in predicting negative health outcomes for the infants of these mothers in the form of a low birth weight. As a result locally targeted services which specifically address the needs of these women can be implemented.

MINET and Health Services Research

Health Services Research (HSR) is still in its infancy. The overall aim of HSR is to inform health systems reform. The key difference between HSR and other research disciplines is its multidisciplinary nature. The objects of study are health systems and service delivery - both dynamic by their very nature. Results of HSR are aimed at driving change, hence the need for the close proximity between the multi disciplinary HSR team and the clinicians (Kindig 1999; Hadley 2000). One of the keys to the achievements of MINET has been the collaboration at a local level (Macarthur) between HORT and the MINET clinicians based on "a bottom-up approach" to the development of a health outcomes based approach to service delivery. This collaboration was extended to the Simpson Centre for Health Services Innovation resulting in an increased research capacity within the areas of Clinical Effectiveness, Health Informatics, Public Health, and Change Management. The proximity between clinicians, managers and health services researchers fosters clinician ownership of the results and ensures service development is informed by these results. Developing the appropriate methodology for HSR remains a major challenge, identifying and developing the interface between qualitative and quantitative research methods is particularly challenging. One of the benefits of the HSR setting in SWSAHS for MINET has been the development of a new capacity to document and track an association between social health inequalities and the physical health status of the infant. The Health Maps on maternal smoking, low birth weight, pre term delivery and the spatial relationship between social disadvantage and these adverse phenomena identified "pockets of vulnerability" for the health services. In response to these documented needs PHNs, assisted by their managers, restructured their work practices and service delivery, aimed at engaging mothers resident within these geographical areas of "vulnerability". Piloting antenatal home visiting for these women with special needs was one important strategy in addressing the identified problem.

Presently the important task of evaluating the Information Management and Technology structure of the MINET clinical integrated data network is a high priority for HSR within MINET. Initiating and supporting research which address the information systems related risks associated with matching and linking clinical data bases is a key area of research development for MINET at the present time. The development and sustainability of a reliable and accurate monitoring system which allow the tracking of health trends both for the individual mother and her infant, as well as the whole population of mothers and children is the major aim of MINET.

Conclusion

Accurate, reliable and timely information is one of the most valuable resources within the health industry. In the last decade the ability to close the gap between policy and implementation based on evidence has become a key issue for managers. The strategic alignment between Information Management and Technology, Core Business and Human Resources has the potential for supporting information flows, which can inform management whether this gap is being closed. MINET has evolved within such a strategic framework based on the organisational support of clinician ownership of information. Another important feature of MINET has been the strong emphasis on Information Management rather than on Information Technology. Supporting clinicians in managing their information has created an information culture that has the capacity to harness technology for the benefit of clients/patients. The other important dimension of the MINET information culture is a capacity to support health services research as an integral part of routine clinical practice. Ultimately if the outcomes of an evidence based approach to medicine is to translate into “new ways of doing things” the health systems reform that is required must be based on relevant research. Finally although MINET has been developed within the context of Maternal and Child Health, the generic concepts of the MINET Information Culture are relevant to any Continuum of Care within Health.

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