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DEAN OF THE FACULTY OF GRADUATE AND POSTDOCTORAL STUDIES

AN EVALUATION OF A PERINATAL SURVEILLANCE SYSTEM IN EASTERN AND SOUTHEASTERN ONTARIO

Amira H. Ali

Thesis submitted to the
Faculty of Graduate and Postdoctoral Studies
in partial fulfillment of the requirements
for the degree of Master of Science in Epidemiology

Department of Epidemiology and community medicine
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ABSTRACT

This thesis evaluated the perinatal surveillance system of the Perinatal Partnership Program of Eastern and Southeastern Ontario, using the CDC's guidelines for evaluating surveillance systems, with respect to its content, data collection, data analysis and reports, and its uses. The evaluation consisted of a re-abstraction of a sample of 1542 case-room logbook and charts records, a survey of stakeholders, direct observation, review of files and reports, examination of the data entry screen and linkage to aggregate census data.

The system was found to be useful, timely, flexible and representative of hospital births. Its content was more hospital-based than population-based, and its on-line reporting feature was not entirely acceptable to the participating hospitals.

Recommendations include marketing the system to potential funding agencies, standardizing the sources of data entered, modifying some of the variables in the entry screen and improving the on-line report generation.

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CHAPTER 1. INTRODUCTION

The provision of effective and efficient clinical and preventive services and the development of sound health policy depend on comprehensive and reliable public health information systems. Surveillance forms the heart of these information systems, by providing the potential for early warning of changes in health problems and evidence for policy and program development, risk assessment, trend analysis and the evaluation of prevention and control strategies.[1]

Adverse reproductive outcomes pose a health concern for public health and health care professionals. Improving the health of women, infants, and children has been a goal of public health efforts for more than a century. Perinatal surveillance information is a fundamental tool to enhance these efforts permitting timely identification of "red flags" and tracking of temporal trends and geographic and other disparities. Moreover, it permits the assessment of the effect of changes in clinical practice and public health policy. In this respect, perinatal health surveillance provides both a measurement tool and a stimulus to action.[2]

Several perinatal surveillance systems and programs exist in Canada. At the national level, there is the Canadian Perinatal Surveillance System (CPSS), which was developed in 1995 with a mission to contribute to improved health for pregnant women, mothers and infants in Canada. It is coordinated through the Bureau of Reproductive and Child Health at the former Laboratory Center for Disease Control (LCDC), now part of the Population and Public Health Branch at Health Canada.[3] Sources of data include vital statistics, hospitalization data and the National Longitudinal Survey of Children and Youth. At the provincial level, perinatal programs include: The British Columbia Reproductive Care Program (which maintains a Perinatal Database Registry as its surveillance system)[4], the Reproductive Care Program of Nova Scotia[5], and the Northern and Central Alberta Perinatal

Outreach Program (which uses the Perinatal Audit database for the collation of data collected from health care facilities providing perinatal care).[6]

This thesis studied the Perinatal Surveillance System in the eastern region of Ontario, which is coordinated by the Perinatal Partnership Program of Eastern and Southeastern Ontario (PPPESO). This surveillance system uses the Perinatal Database* as its source of data to assess perinatal outcomes, risk factors and interventions. The PPPESO Perinatal Surveillance System and database have never been formally evaluated before.

The literature on surveillance systems emphasizes the need for their evolution and improvement with time, especially with respect to data quality and accuracy, and their periodic evaluation.[1,7-11] The timing was ideal to conduct the evaluation because the Perinatal Database underwent major evolution and enhancement in 2000. The evaluation will assist the system managers to improve its quality and usefulness to its partners.

A surveillance system identifies health problems that need to be investigated further. Therefore, the thesis will also assess the potential of the Database to be used for research purposes through linkage with other population-based datasets.

1.1 Study Objectives

The thesis had two objectives:

1. To evaluate the perinatal surveillance system of the Perinatal Partnership Program of Eastern and Southeastern Ontario.
2. To evaluate the feasibility of linking the Perinatal Database to census data.

* Renamed the Niday Perinatal Database, after Patricia Niday, PPPESO's first executive director.

1.2 Format of the thesis

To achieve the above objectives, a two-phase research plan was designed:

Phase 1: To address objective one, a formal evaluation of the surveillance system was undertaken according to the *"Updated Guidelines for evaluating surveillance systems"*[9] published by the Centers for Disease Control and Prevention, Atlanta. The following attributes of the Perinatal Surveillance System were assessed: simplicity, timeliness, flexibility, representativeness, acceptability, data quality, stability and overall usefulness. Seven data collection methods were used:

1. Assessment of data quality through data re-abstraction: A random sample of delivery records from each participating hospital was reviewed to assess the concordance between the data in the Database, the case room logbook and the mother's chart.
2. Survey of stakeholders (hospitals, public health units and PPPESO staff): all members of each stakeholder group completed a questionnaire to assess the content, data collection, data analysis and reports and the overall usefulness of the system.
3. Direct observations of hospital procedures.
4. Review of PPPESO files, reports and administrative records.
5. Examination of the Database on the CritiCall system.
6. Comparison of the number of births with data from the Canadian Institute for Health Information (CIHI).
7. Linkage of the Database to the census files (objective two).

Phase 2: Linkage to Census data: In order to address objective two, the Database was geocoded using the 2002 Postal Code Conversion File Plus (PCCF+, version 3J) to enable linkage to census data. Successful linkage would allow the study of relationships

between aggregated census variables and reproductive outcomes, controlling for other variables imported from the Perinatal Database.

The findings of this project served as the basis for proposing recommendations for improving the perinatal surveillance system in Eastern and Southeastern Ontario.

Throughout this thesis, the use of the terms "Perinatal Database" and "Database" refers to the *Niday Perinatal Database*.

CHAPTER 2. BACKGROUND LITERATURE

This chapter describes surveillance, its history, objectives and uses, different approaches and basic elements. An explanation of perinatal surveillance is also provided, followed by a description of the evaluation of surveillance systems and health programs.

2.1 Surveillance

In his Dictionary of Epidemiology, Last[12] quotes several sources that have defined the term surveillance, among which he quotes the Centers for Disease Control and Prevention in their definition of surveillance as "The ongoing systematic collection, analysis, and interpretation of health data, essential to the planning, implementation, and evaluation of public health practices, closely integrated with the timely dissemination of these data to those who need to know. The final link in the surveillance chain is the application of these data to prevention and control. A surveillance system includes a functional capacity for data collection, analysis, and dissemination linked to public health programs." All of the quoted sources used the terms "continuous", "systematic", "timely" and "dissemination and feedback" in their definitions of surveillance, making these descriptors fundamental to any surveillance system.

2.1.1 Brief History

The process of observing, recording and collecting facts and the analysis of the direct courses of medical intervention dates back to the time of Hippocrates.[13] The history of public health surveillance and the first real public health action related to surveillance can be traced back to efforts to control the bubonic plague in the 14th century, when public health authorities boarded ships in the port near the Republic of Venice to prevent persons suffering from a plague-like sickness from disembarking.[13-15]

The establishment of a health council and the application of numerical analysis in mortality statistics were first called for by von Leibnitz in the 1680s. About the same time, John Graunt published the *Natural and Political Observations Made Upon the Bills of Mortality* which defined disease-specific death counts and rates, and the concept of disease patterns, some of the fundamental principles of public health surveillance.[13,16]

In 1850 Lemuel Shattuck produced a landmark publication relating death, infant and maternal mortality, and communicable diseases to living conditions. He was also credited with proposing a standardization of nomenclature for the causes of disease and death, and the collection of health data by age, sex, occupation, socioeconomic status and locality.[13,15,16]

William Farr (1807 – 1883) was renowned for formulating the concepts of surveillance we know today. In his capacity as superintendent of the statistical department of the Registrar General's Office of England and Wales, Farr collected, analyzed, interpreted and evaluated vital statistics. He disseminated his results to the responsible authorities and to the general public.[13,15-17]

Until 1950, surveillance was restricted to watching contacts of communicable diseases such as small-pox, in order to detect early signs and symptoms so that these contacts could be isolated to prevent spread of the disease.

Langmuir further formulated modern concepts of public health surveillance by emphasizing the role of surveillance in describing the health of populations. In 1963, he defined the term as "*the continued watchfulness over the distribution and trends of incidence through the systematic collection, consolidation and evaluation of morbidity and mortality reports and other relevant data and the regular dissemination to all who need to know*". Although he recognized the relationship between epidemiologic studies, surveillance and control activities, Langmuir distinguished surveillance both from direct responsibility for control activities and from epidemiologic research.[13,15]

In the 1968 twenty-first World Health Assembly, which focused on the national and global surveillance of communicable diseases, Langmuir's 1963 description of surveillance was endorsed and three main features of surveillance were described: a) the systematic collection of relevant data; b) the consolidation and evaluation of these data; and c) the timely dissemination of the results to those who need to know, principally those in a position to take action. At that assembly, the World Health Organization broadened its concept of surveillance to include a full range of public health problems (beyond communicable disease) such as childhood poisoning, leukemia, congenital malformation, abortions, injuries and behavioral risk factors.[13,16]

In the 1980s, the introduction of microcomputers began to transform surveillance systems, allowing decentralized data analysis and electronic linkages of participants in surveillance networks.

The central role of surveillance was emphasized when the Institute of Medicine defined three fundamental functions of public health in 1988: "1) assessment of the health of communities, which depends largely on surveillance; 2) policy development based on the "community diagnosis" and prognosis established through surveillance; and 3) assurance that necessary services are provided, using surveillance as one measure of the impact of programs".[16]

2.1.2 Objectives and Uses of Surveillance

The most common purposes of surveillance include[16]:

- *Descriptive epidemiology of health problems:* by monitoring the trends in incidence or prevalence of specific health problems, documenting their impact in defined populations and characterizing affected persons and those at greatest risk.

- *Links to services:* at the community level, surveillance information can direct health departments in providing services to individuals. Surveillance data can also be used to guide and evaluate health programs.
- *Links to research:* although surveillance data are useful in describing the basic epidemiology of health problems, they infrequently provide sufficient detail for examining more in-depth epidemiologic hypotheses. While surveillance data provide detailed information about individuals with a specific health problem, they often do not provide a comparison group of individuals without the health problem in question. However, surveillance can provide an important conduit to researchers by providing clues for further investigation of health problems and by identifying individuals who may be subjects in specific research projects. Surveillance activities have frequently led to epidemiologic investigations of etiology. An example is the cessation of the National Influenza Immunization Program in 1976, when cases of Guillain-Barré syndrome were reported to the CDC through a nationwide surveillance system monitoring illnesses associated with influenza vaccination. Ensuing epidemiologic studies established a relationship between the syndrome and the swine influenza vaccine that was used.[13]
- *Evaluation of interventions:* by charting trends in the numbers or rates of events, or characteristics of affected individuals, surveillance may help in the assessment of the impact of intervention programs. This is particularly helpful when full-scale evaluations for the effectiveness of interventions are too costly or not feasible.

- *Projections:* since public health planners often need to predict future demands for health services, surveillance data can be used to estimate future trends through a combination of the observed trends in disease incidence coupled with other information about populations at risk.

- *Education and policy:* after information is obtained by the collecting organization and returned to those who need it, the cycle of surveillance becomes complete when that information is applied. Surveillance information educates those directly responsible for providing health care and those who influence the distribution of health resources.

The uses of surveillance information can be organized on the basis of three categories of timeliness: immediate, annual or biannual, and archival.[14,18]

- *Immediate use* – detecting epidemics, newly emerging health problems and changes in health practices.
- *Annual or biannual use* – estimating the magnitude of health problems, assessing control activities, setting research priorities, testing hypotheses, monitoring risk factors and changes in health practices and documenting distribution and spread of health problems.
- *Archival use* – storing readily accessible data that can be used to conduct research into the predictors of adverse health events and to document the evolving health status of populations.

2.1.3 Approaches to Surveillance

Depending on information needs and resources, a broad range of methods can be employed in conducting surveillance activities. Some of the approaches used include:

Active and passive surveillance. An "active" approach means that the organization conducting surveillance initiates procedures to obtain reports. Such procedures include regular telephone calls or visits to physicians or hospitals. A "passive" approach means that the organization conducting surveillance does not regularly contact potential reporters but rather leaves the initiative for reporting to them.[16] While the terms "active" and "passive" surveillance are conceptually useful, "they are insufficient for describing a surveillance method"[16] since surveillance systems may not be either totally active or totally passive. Rather than describing whether a system is active or passive, it is more important to describe how surveillance was conducted, who was contacted and how often, and what if any, back-up procedures were in place to identify cases.

Notifiable disease reporting. Based on legally mandated reporting of certain diseases, this approach has mainly been used (although not exclusively) for infectious diseases. Depending on the nature of the disease, regulating mandatory reporting have varying time requirements (some as short as within 24 hours), and varying levels of responsibility for reporting (individual physicians, laboratories, clinics and/or hospitals). Since ethical issues such as confidentiality arise when personal identification information is collected, laws that mandate disease reporting generally provide concomitant protections and sanctions to prevent inappropriate release of identifying information.

Laboratory-based surveillance. The use of diagnostic laboratories as the basis for surveillance can be highly effective, with the ability to identify patients seen by different

physicians, specifically when the laboratory testing and services are centralized. Using this approach however has the disadvantage of not providing information on epidemiologically or clinically important patient characteristics.

Volunteer providers. When information needs exceed the capabilities of routine approaches such as notifiable disease reporting, special networks are sometimes developed to meet such needs. Such situations may arise when more timely or detailed information is required, when there is a need to obtain information on a health event that is not legally deemed to be reportable, or when there is a reason to focus surveillance efforts on practitioners of a certain medical specialty.

Registries. These include listings of all occurrences of a disease, or classes of diseases within a distinct area (e.g. cancer, birth defects). Because they collect relatively detailed information, registries may identify patients for long-term follow up or for specific laboratory or epidemiologic investigation.

Sentinel surveillance. This approach involves a limited number of selected reporting sites, from which reports may be generalizable to the whole population, making this type of surveillance useful for common conditions where complete case counting is neither important nor feasible, and where public health action is not determined by individual reported cases. Aggregate data from sentinel surveillance are provided at a relatively lower cost than case-based reporting systems, and are usually collected on a weekly basis by telephone, fax, or electronic mail. Because the data are crude and often aggregated, detailed analysis may be limited. An example of a sentinel surveillance is monitoring the annual incidence of influenza.[7]

Surveys. Periodic or regular/ongoing surveys can be an important approach to collecting surveillance data by providing a method for monitoring an array of factors influencing health and disease such as behaviours associated with disease, knowledge/attitudes that influence health behaviours, personal attributes that affect disease risk, self-reported disease occurrence and use of health services.

Record linkages: By linking records from different sources, their usefulness for surveillance may be enhanced. As an example, linkage of birth certificates (which list birth weight) and infant death certificates (which do not list weight) may be used to determine trends in birth weight-specific neonatal death rates. Moreover, linkage of surveillance records to an independent data source can be used to identify previously undetected cases and thus measure and improve the completeness of surveillance[16].The ease of performing such linkages depends on the accuracy and specificity of identifying information.

Information Systems. These are large databases collected for general, rather than disease specific purposes. They can be applied to the surveillance of specific conditions, and more often, the use of these systems for monitoring health may be secondary to other objectives. Since these systems serve multiple objectives, their use for surveillance (or epidemiologic research) requires caution as the data collected may not encompass stringent data quality procedures. Examples of such systems include: vital records, where information on the characteristics of newborns or the causes of death can be used to monitor the health of the population; hospital discharge records, where data on discharge diagnosis may provide a convenient source of information about morbidity; and insurance billing records, which can provide information on inpatient and outpatient diagnosis and treatment.

2.1.4 Key Elements of a Surveillance System

Several key elements make up a surveillance system[8,16,19]

1. Framework describing the population, health and illness events included in the surveillance system. The needs of the decision makers who will use the data should be reflected in the health events included in a surveillance system. Populations included may range from individuals at specific institutions, to residents of a community or residents of a nation. Previously defined health goals should ideally determine the health events to be included in a surveillance system, and the data collected should point to policy decisions that are necessary to improve these goals.

2. Data collection. Data collection must produce valid and reliable data. Factors to be considered in the data collection component of a surveillance system include: amount of time needed for data collection, data sources, data collectors and methods of data transmittal. If existing sources of data such as administrative databases are used, caution must be sought since these sources often present limitations in terms of timeliness and comprehensiveness, because their original intent was not for surveillance.

3. Data analysis. A determination of the appropriate analytic approach should be an integral part of the planning of any surveillance system. Development of a data analysis plan confirms what will be done, how often and by whom. In addition, the plan must consider whether the data analysis will be centralized or performed by the organizations that collect the data. Generally, routine analyses are conducted in response to pre-designed requirements of the system, while special

analyses are done to explore various findings that emerge from the routine analyses or to probe into specific research questions.

4. Interpretation and reports. Data must be analyzed and presented in a convincing and forceful manner so that decision makers at all levels can readily see and understand the implications of the information. Routine reports are produced in response to the timing requirements of decision and policy makers.

5. Information dissemination. A comprehensive dissemination plan should be integral to the planning of any surveillance system. Depending on the type of surveillance system, the audience for the information include: health planners and decision makers, non-governmental organizations, the private sector and the general public. Privacy and confidentiality issues should be considered in the dissemination plan. Knowledge of the characteristics of the audience for the information and how they might use it may dictate any of a variety of communication systems. The Internet provides a great medium for readily available information to a large portion of the population.

6. Use of surveillance information. This turns surveillance information into intelligence, where the information is both understood and used by the receivers. Ideally those who will use the information (e.g. health planners and managers) should be involved in the development and modification of the system to ensure that it will meet their needs.

7. Evaluation and revision. Evaluation of a surveillance system should be an integral part of its operations. The evaluation should address the structure, processes or activities and outcomes of the system.

Periodic evaluation, coupled with a formal process for reviewing it and recommending changes, assures that the system remains vibrant in meeting its goals and objectives.

2.1.5 Perinatal Surveillance

With the broadening of the concepts of surveillance outside communicable diseases, a wide spectrum of surveillance activities including perinatal health surveillance were initiated.

The WHO defines the Perinatal Period as *"the period commencing at 22 completed weeks (154 days) of gestation (when birth weight is normally 500 g) and ends seven completed days after birth"* [20] Other sources have also used the term to include up to 28 completed days of life after birth.[2,4] In this respect perinatal surveillance gathers information pertaining to both the mother and the baby during pregnancy and after delivery.

In 1987, the Pregnancy Risk Assessment Monitoring System (PRAMS) was initiated in the United States in response to the slow decline of both infant mortality rates and the prevalence of low birth weight.[21] Various maternal behaviours and experience before, during and after pregnancy (e.g. unintended pregnancy, late entry into prenatal care, smoking) are associated with adverse health outcomes for both the mother and the infant.[22] PRAMS was launched with the goal of improving the health of mothers and infants by reducing adverse outcomes such as low birth weight, infant mortality and morbidity, and maternal morbidity. It is an on-going state-and-population-based surveillance system designed to monitor selected self-reported maternal behaviours and experiences that occur before, during, and after pregnancy among women who deliver a live-born infant.[22]

In Canada, the Canadian Perinatal Surveillance System (CPSS)[2], developed in 1995, is part of Health Canada's initiative to strengthen national health surveillance capacity. Based on the concepts of health surveillance, the CPSS collects and analyzes data on all recognized pregnancies, regardless of their outcome (abortion, ectopic pregnancy, stillbirth, live birth), and on health during the first year of life. The CPSS is guided by a multisectoral and multidimensional steering committee with members from national health professional associations, the provincial and territorial governments, consumer and advocacy groups and federal government departments as well as Canadian and International experts in perinatal health and epidemiology.[3] The system uses data from multiple existing sources (mainly administrative) such as national statistics and hospitalization data. The data are analyzed collaboratively with perinatal health surveillance partners. Based on its target audience which includes policy makers, health care providers, researches, and the general public, the CPSS uses various vehicles for information dissemination such as fact sheets, peer-reviewed publications and the World Wide Web.

The CPSS has established short, medium and long term goals. The short and medium goals are: 1) to continue to analyze and report on existing national perinatal health data; 2) to work collaboratively with partners to standardize definitions of perinatal health variables across the country, and promote the addition of key variables to existing databases; 3) to strengthen and expand surveillance in priority areas (e.g. congenital anomalies, and women's knowledge, perspectives, practices and experiences in pregnancy, birth and parenthood). The long term goal is to establish a comprehensive national perinatal database through electronic transfer of data from vital event registration, hospital services and community-based services.[3]

The Canadian Perinatal Surveillance Report – 2000, identified several areas where surveillance information is inadequate for the purpose of quantifying and fully

understanding the state of perinatal health in the country. The inadequacies are a result of areas where little or no information is available for Canada as a whole (e.g. use of assisted delivery), areas where routine information is not collected (e.g. parity in relation to cesarean section rates and behaviours and experiences in pregnancy), areas where the quality of routine information is insufficient (e.g. the province of Ontario in previous years), and areas where information on routine surveillance information is lacking (e.g. in the case of Aboriginal Canadians).[2] The CPSS has launched several initiatives aimed at addressing the shortfalls presented above. As an example, efforts are being made, in collaboration with Statistics Canada and the Canadian Institute for Health Information, to increase the content of national vital statistics and hospital discharge databases to better serve perinatal health surveillance. Another example involves conducting regular surveys in order to document important behaviours and practices during pregnancy.

The current gaps in the system of perinatal health in Canada indicates a strong need for regional perinatal health programs and surveillance systems to improve their data quality and increase the amount of detailed information collected, so that they can identify local issues more quickly, explore areas of regional concern and better respond to disparities identified by national level surveillance.

2.2 Evaluation of Surveillance Systems

Evaluation is the systematic investigation of the merit, worth, or significance of an object.[23] The overall purpose of evaluating public health surveillance is to obtain feedback about the operation of the system to promote the most optimal use of health resources. The evaluation of surveillance systems should assess whether a system is serving a useful public health function and is meeting its stated objectives.[11,23,24]

The Centers for Disease Control and Prevention (CDC) recommend that all public health surveillance systems "be evaluated periodically, and that the evaluation should include recommendations for improving quality, efficiency and usefulness".[9]

2.2.1 Evaluation Guidelines

Often textbooks of surveillance describe ways to conduct evaluations of surveillance systems as well as the attributes to be assessed in the evaluation,[16,23,24]by citing the CDC's guidelines (by far the most widely accepted approach), as the source of the guidelines and methods that they had described.

In 1988, the CDC published "*Guidelines for Evaluating Surveillance Systems*" to promote the best use of public health resources through the development of efficient and effective public health surveillance systems. These guidelines were based on the CDC's "*Framework for Program Evaluation in Public Health*". In 2000, the guidelines were updated to incorporate the need for the integration of surveillance and health information systems, the establishment of data standards, the electronic exchange of health data, and changes in the objectives of public health surveillance to facilitate the response of public health to emerging health threats.[9] The new document *"Updated Guidelines for Evaluating Surveillance Systems"* published in 2001, described six tasks involved in evaluating a public health surveillance system, with the understanding that not all the tasks may be appropriate for evaluating all surveillance systems. These tasks are summarized in Table 2.1.

The attributes of surveillance described in the table are interdependent, and the improvement of one may improve or compromise the other. For example, increasing the sensitivity of a system to detect a greater proportion of a given health event in a population may also improve representativeness and usefulness yet lead to greater cost, lower specificity and more false-positive events.[9,11] Similarly, depending on the type of

surveillance system under evaluation, some attributes might be more important than others, hence evaluations should be tailored to include the relevant attributes for the surveillance system, which stem from its objectives and purposes.

Table 2.1 CDC's Recommended Tasks for Evaluating a Public Health Surveillance System

Task	Summary Description
Task A Engage the Stakeholders in the Evaluation	The stakeholders who may be interested in defining questions to be addressed by the evaluation and subsequently use its findings should be engaged early on in the process. These stakeholders include: public and private health practitioners, all levels of governments, health care providers, data providers and users and representatives of affected communities.
Task B Describe the Surveillance System to be Evaluated	Describe the public health importance of the health-related events under surveillance. Describe the purpose and operation of the system, and the resources used to operate it.
Task C Focus the Evaluation Design	Determine the specific purpose of the evaluation, identify "intended users" and "intended uses" of the evaluation, specify the evaluation questions and determine the standards for assessing the performance of the system.
Task D Gather Credible Evidence Regarding the Performance of the Surveillance System	Describe the level of usefulness of the surveillance system: does it detect diseases, injuries, adverse or protective exposures of public importance in a timely manner? Does it provide estimates of the magnitude of morbidity and mortality related to health-related events, including risk factor identification? Does it detect trends? Does it lead to improved clinical, behavioural, social, policy or environmental practices? Does it stimulate research leading to prevention or control? Describe the system attributes: simplicity, flexibility, data quality, acceptability, sensitivity, predictive value positive, representativeness, timeliness and stability. Decide which attributes are most important for the system under evaluation.
Task E Justify and State Conclusions, and Make Recommendations	Justify conclusions through appropriate analysis, synthesis, interpretation and judgement of the gathered evidence regarding the performance of the surveillance system (Task D). State conclusions about whether the surveillance system is meeting its objectives and addressing an important public health problem (Task B). Make recommendations addressing the modification and/or continuation of the surveillance system.
Task F Ensure the Use of Evaluation Findings and Share Lessons Learned	Make deliberate efforts to ensure that the findings from the evaluation are used and disseminated appropriately. Customize strategies for communicating the findings from the evaluation to relevant audiences including persons who provided the data used for the evaluation.

Source: Updated Guidelines for Evaluating Surveillance Systems, CDC 2000.

With the widening scope of surveillance activities to include health events other than communicable diseases, published evaluation studies have included other surveillance activities e.g. injury surveillance,[25-27] perinatal surveillance[28], although the majority still concentrate on communicable diseases or infections.[29-34] It is important to note that not all these studies focused on merely evaluating the surveillance system itself, some compared one approach of surveillance to another,[26,34] others evaluated accuracy of reporting.[30,32] Only those studies that focused primarily on evaluating the surveillance system in terms of some or all of the attributes suggested by the CDC are described below.

In 1995 Lenaway et al[31] evaluated a school-based influenza surveillance system for sensitivity by comparing the epidemic curves from the school-based system with those of a pre-existing communicable disease sentinel surveillance system. Additional attributes evaluated included acceptability, simplicity, timeliness and overall usefulness. Their study concluded that the surveillance system closely followed the general rise, peak and fall of epidemic influenza-like illness as measured by the pre-existing sentinel system. The school-based system was found to be acceptable to both school officials and nursing staff, was simple, timely and useful, being an ideal setting for detecting epidemic influenza since children play an important role in the acquisition and spread of influenza within a community.

Macarthur and Pless[25] evaluated the national injury surveillance system employed by the Canadian Hospital Injury Reporting and Prevention Program (CHIRPP) by assessing the system's sensitivity, positive predictive value, and representativeness. The surveillance population of interest was acutely injured children attending children's hospitals and the study was conducted in four centres, two in Quebec and two in Ontario. The authors found the system to have an almost perfect positive predictive value in one site, and its sensitivity ranged from 30% – 91% at the four centres. In terms of the system's representativeness, one site was found to systematically miss admitted injuries, poisoning and those presenting overnight.

The National Non-Natural Mortality Surveillance System in South Africa (a pilot project commencing in 1998 to draw forensic-medical services and state mortuaries into a nationwide fatal injury surveillance system), was evaluated in terms of its simplicity, flexibility, acceptability, sensitivity, positive predictive value, representativeness, timeliness and usefulness.[27] The sensitivity of the system was internally assessed and ranged from 65 – 95% for manner of death. Positive predictive value was also internally measured and ranged from 74 – 80% for manner of death and from 71 – 82% for mechanism of death. The system was found to be timely; with basic reports covering most items being available 6 weeks after a case had been examined. While staff found it to be simple, its level of acceptability was dependent on the individuals involved at the different mortuaries and was compromised by bureaucratic barriers. End users found it useful in describing and reporting the epidemiology of fatal injuries.

Robotin[29] evaluated the Australian Creutzfeldt-Jacob Disease (CJD) surveillance system in terms of its timeliness, flexibility, acceptability, positive predictive value and representativeness. The system was found to be deficient in its timeliness, but satisfactory in the other attributes.

In the state of Mississippi, the state health department used the CDC evaluation guidelines to evaluate maternal death surveillance.[28] The maternal mortality rate in Mississippi ranks among the highest in the United States. While the authors were conducting the evaluation, and even before completion of all the tasks described by the CDC, they found major weaknesses and flaws with the system, and went directly into system revisions using their evaluation findings. The weaknesses were revealed at the stage of the CDC's (Task B) which calls for a description of the system under evaluation. The system had limited stakeholders, was lacking dissemination of review findings, had no links to public health programs, had no focus on maternal deaths, had a limited definition of maternal mortality and very little exploration of non medical factors. The authors therefore

immediately embarked on a new surveillance system to improve maternal mortality surveillance in that state. The new system involved adding early field participation, investigating medical and non-medical factors, conducting timely, multidisciplinary reviews, and adding feedback loops for dissemination of findings and public health interventions. The authors recommended using the CDC guidelines and stated that even though they had not performed each task in the recommended order, the guideline explanations helped them to think through critical issues and recognize weaknesses in the original system. They continue to use the guidelines in the development of the revised system.

While no formal evaluations were previously performed for the Perinatal Surveillance System in Eastern and Southeastern Ontario, there had been an earlier evaluation of data quality published in their 2000 annual perinatal statistical report.[35]

CHAPTER 3. PPPESO AND THE PERINATAL SURVEILLANCE SYSTEM

3.1 Study Area

The 'Eastern Region' is one of seven health planning regions defined by the Ministry of Health.[36] (See Appendix A1 for a map of the region). This region is referred to by the Perinatal Partnership Program of Eastern and Southeastern Ontario (PPPESO) as 'Eastern and Southeastern Ontario'. It includes 10 counties and covers approximately 35,800 square kilometers, with a population of 1.6 million. It is served by six Public Health Units (PHUs) and two District Health Councils.[36] (See list in Appendix A2).

In the year 2002, there were 16 hospital sites in the region providing maternity care (three teaching hospital sites, five large community hospitals with ≥ 500 deliveries/year, and eight small community hospitals with < 500 deliveries/year. A listing of these hospitals is provided in Appendix B1. Obstetrical services are provided to almost 18,000 women annually.[37]

3.2 The Perinatal Partnership Program of Eastern and Southeastern Ontario (PPPESO): Program Description

The PPPESO was formed in 1980. At the time, it was referred to as the Perinatal Education Program of Eastern Ontario, with a mandate to provide education in the Ottawa teaching hospitals. In response to community needs it has expanded to link hospitals, health departments, community agencies, academic institutions, and individual care providers in the interest of perinatal health care, education and research.[38] The Program's current mission is to "Promote optimum perinatal care of childbearing families in Eastern and Southeastern Ontario to improve health and to achieve excellent perinatal health outcomes".[39]

In June of 1999, agencies involved in perinatal care in the region signed a formal partnership agreement, known as the "Partnership Accord". It reads as follows: "This Partnership Accord will formalize and more clearly articulate the link with organizations which rely on the Perinatal Partnership Program of Eastern and Southeastern Ontario (PPPESO) for services. The effectiveness of the PPPESO Board and the Program as a whole will be enhanced by the active involvement of all stakeholders."[38] A list of Partner Agencies is provided in Appendix B2.

The Program is mainly funded by in-kind and financial contributions from all the partners, and is governed by a board encompassing members from the partners.[38,39]

PPPESO has three program areas:

1. ***Health Status and Performance Measurement:*** this is accomplished through the Perinatal Surveillance System that uses the Perinatal Database as its source of data, regional statistical reports, audits of practices, benchmarking projects, performance assessment tools, and collaboration on perinatal research initiatives and health promotion initiatives.
2. ***Program and Professional Development:*** learner-centered workplace programs, interdisciplinary team learning, educational programs and conferences as well as university courses. It also includes the provision of information through a variety of approaches including: reviews of research literature, a *Perinatal Newsletter* and *Perinatal Alert* bulletins, web-site access, practice/policy guidelines, telecommunications initiatives, resources and new programs and services.
3. ***Partnership:*** or regional support by working with all the partners to identify issues of relevance to the region, establishing processes or projects to address those issues in a coordinated manner. This includes activities such as: annual visits to partners, partner consultations and liaison, fostering

regional collaboration, advocating for perinatal issues, marketing and partner relations, and linking with planning bodies.

3.3 Evolution of the Perinatal Surveillance System

On January 1, 1997, the perinatal surveillance system was formally launched with the following objectives[38]:

1. To monitor perinatal health and services
2. To identify areas for improvement
3. To identify areas for educational topics
4. To assess the impact of local perinatal initiatives.

This surveillance system addresses a number of the purposes, uses and approaches to surveillance described in the background literature. It provides descriptive epidemiology of health problems such as monitoring trends of preterm birth and prevalence of teenage pregnancies. It links to services and research by guiding and evaluating perinatal initiatives, for example the use of auscultation only, for fetal monitoring of uncomplicated pregnancies. The system has also been used to assess the impact of interventions such as educational programs and the use of their published guidelines. Its data provide information to those responsible for providing health care, for example the public health units have used it to plan services directed towards the prevention of smoking amongst pregnant women.

The system has an *immediate use* – by providing information on changes in health practices, and also has an *annual use* – by estimating the perinatal health status of the population under surveillance and the magnitude of perinatal health problems.

Partner hospital and health units jointly identified and standardized 36 critical variables for the surveillance system. These included maternal, pregnancy, labour and delivery, and newborn characteristics. A common logbook was developed to collect the

data in the case room, and the data were entered into a Fox Pro computer program (1997 Perinatal Database). To ensure consistency among the hospitals, a working manual provided the definitions for each variable. At the end of each quarter, the data were sent to the PPPESO central office for collation and analyses. Annual reports were prepared for each hospital and for the region as a whole from the Database. In 1999, two variables were added to the Database, the "postal code" of the mother and "steroid use" prior to delivery. Appendix B3 lists these variables.

By 2000, a number of issues had arisen[40]: maintenance, technical support and troubleshooting for the Fox Pro program were difficult since the technology was outdated; the data collection process was becoming cumbersome; partners' access to the data was rather limited. These issues led to the initiation of a newer version of the data entry process (with the same variables as the ones in the earlier Fox Pro program), and the old system was replaced by a live Internet-based platform provided by the CritiCall Bed Registry System.

The Ontario CritiCall Program is a hospital partnership supported by the Ministry of Health and Long-Term Care (MOHLTC). The partners include the tertiary care hospitals in Hamilton, Kingston, Ottawa/Carleton, Toronto, Thunder Bay, Sudbury and London. It is a partnership with Ontario's "One Number to Call" emergency patient referral system, whose mandate is to facilitate the patient referral process by assisting physicians in smaller communities to access the resources of the larger tertiary care hospitals in their regions. This is achieved by the provision of an Internet-based database of beds and resource availability such as emergency department status for each participating hospital, as well as physician contact numbers for those on-call for each of 50 medical specialities. The CritiCall Program management is provided by Hamilton Health Sciences Corporation, McMaster Site, in Hamilton, Ontario.[41]

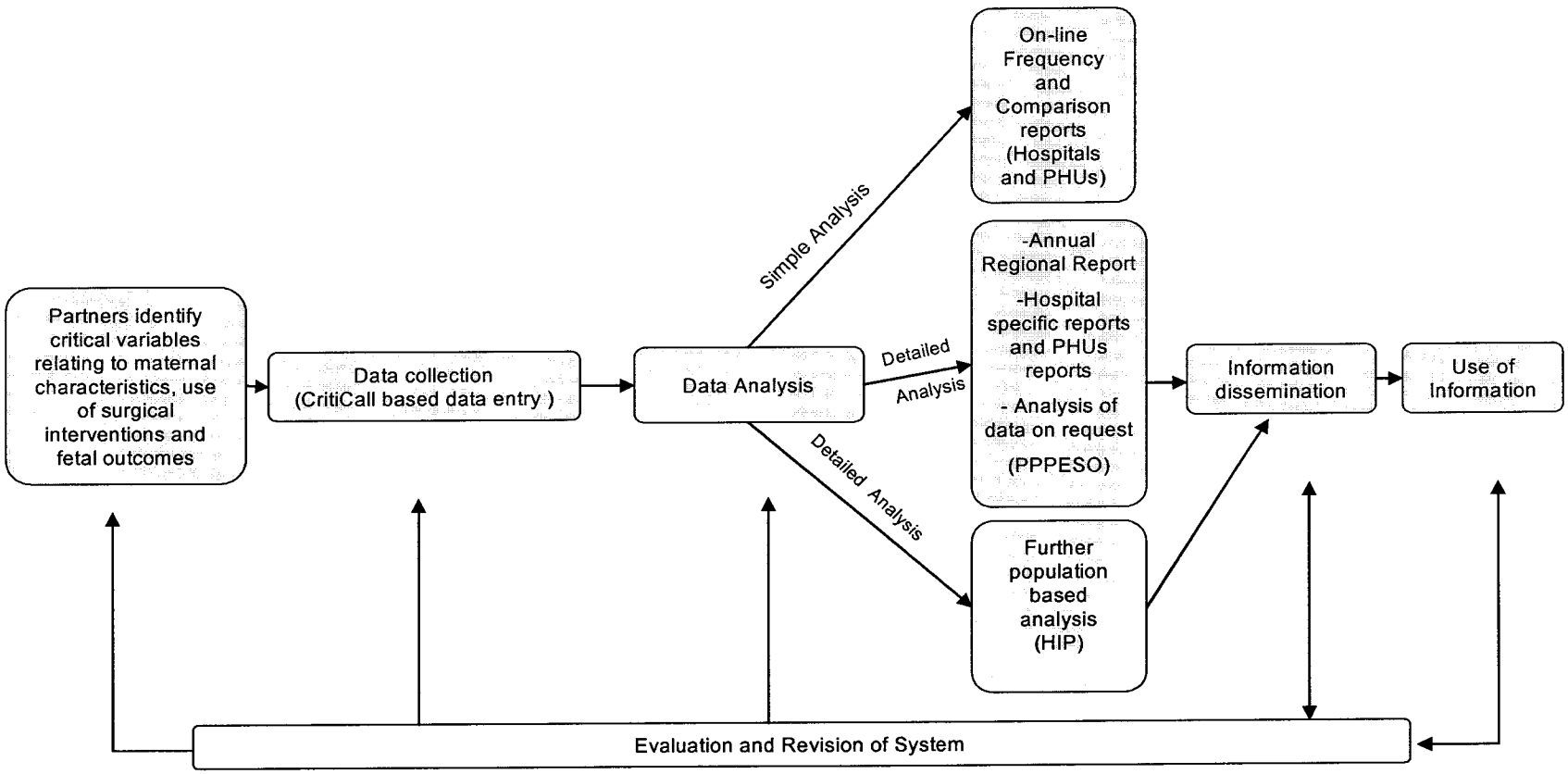
A steering committee determined the scope and general parameters for enhancing the Perinatal Database. A working group coordinated the project and the actual development of the new system. Rincon Technologies, an Ontario-based company specializing in healthcare resource management systems, provided the development and programming of the database application within the CritiCall system. The planning, database development, and the majority of the training took place over a 12-month period. Funding for the development of the database enhancement was provided by CritiCall, the Eastern Ontario Regional Office of MOHLTC, and the hospital and public health partners. The hospitals provided the staff to enter the data.[38,40] The new Internet-based version was launched in January 2001.

The aim of the transformation was to enhance the usefulness of the database by improving data entry and access. By incorporating the Perinatal Database within the CritiCall system, data from the participating hospitals can be directly entered into the database and reports can be generated in real time. An intricate set of data verification rules was built into the data entry process, including acceptable range of values and logical consistencies. The new system has enabled the hospitals to generate "Frequency Reports" to assess their status and performance and "Comparison Reports" to compare themselves to "like" hospitals. PPPESO believes that this should greatly assist evaluation of care, quality improvement and benchmarking projects. At the hospital level, it is expected that the database will assist the hospitals in a Continuous Quality Improvement (CQI) system for perinatal care interventions. In addition, it will also help the hospitals and health units in meeting their accreditation requirements.

To ensure effective implementation of the enhanced database, a training program was initiated, so that all users in the region would have a thorough understanding of the new system and receive training material for reference in the future. PPPESO central office in Ottawa provided all the training for data entry, report

generation, user support, and database management. PPPESO prepares an annual regional report for Eastern and Southeastern Ontario, hospital specific reports and Public Health Units reports, and provides data analyses upon requests from the partners. Aggregate data are also sent to the Health Information Partnership (HIP) for further analyses. (See Figure 3.1)

Figure 3.1 Flow Chart for the Current Perinatal Surveillance System of PPPESO



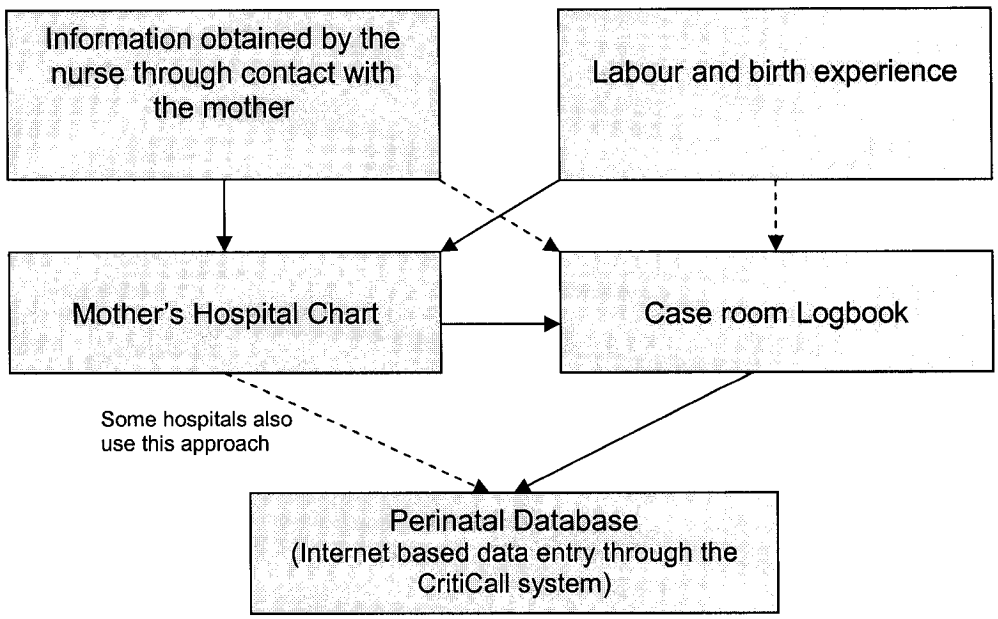
A database subcommittee of 12 members from the various partners meets twice a year to review and discuss the performance of the database, and recommends changes and modifications as necessary.

All 16 hospitals sites providing obstetrical services in Eastern and Southeastern Ontario are currently using the system. Appendix B4 shows the PPPESO data entry screen as it appeared on the CritiCall system when data for this study were collected.

Recently in January 2003, the database has expanded to include 26 hospitals outside Eastern Ontario (Appendix B5 lists these hospitals), and it underwent a further revision with several modifications to its entry screen and the addition of the mother's hospital chart number to its list of variables. Appendices B6a and B6b provide a description of the modifications and the new entry screen respectively. Most of the new hospitals received training in data entry, and are at various stages of data entry. It is expected that within the next few months all of these hospitals will be entering data.

Figure 3.2 shows the flow of information into the Perinatal Database. Summary data are entered into the case-room logbook primarily from the chart, with supplementary information obtained directly from the labour and delivery experience in the case room, and from the mother through contact with the nurse. Then the data are entered from the case-room logbook or (in some hospitals) the mother's chart into the Database via the Internet.

Figure 3.2 The Flow of Information Into the Perinatal Database



Depending on the size of the hospital and the number of deliveries, the data may be entered into the database daily, weekly, biweekly, or monthly. The governing rule is that all the data must be entered within two weeks of the last day of each month. Once that happens, the month is said to be "closed off". The central office of PPPESO monitors this process and sends off reminders to hospital staff in the event that the month has not been closed off by the set deadline. Every quarter the PPPESO data analyst checks the data to identify inconsistencies in numbers and types of births, and sends out requests to the hospitals to verify the data whenever errors were discovered.

3.4 The Perinatal Surveillance System Program Logic Model

Prior to the evaluation of any program or system, a detailed description of the program/system must be developed. This principle is endorsed by the literature on surveillance system evaluation (CDC Task B)[9] and health programs evaluation.[42,43] Since the system under study forms an integral part of the Perinatal Partnership Program, it was deemed appropriate to use a mixture of both approaches to describe it.

A logic model is a causal model that depicts links between the structure, process and expected outcomes of a program.[43] It can be thought of as a diagram that describes a program by providing basic information about what the program is supposed to do, for whom and why. It is a tool that can be used as the basis to plan and implement program evaluations. [42]

The basic structure of a logic model is as follows:[42,43]

1. Main Components describe groups of closely related activities in a program.
2. Activities describe what a program does to achieve its desired outcomes.
3. Target groups describe the individuals or groups for whom the program's activities were designed.
4. Outcomes describe the changes the program hopes to achieve through its activities. The outcomes may be short-term, intermediate, or long-term.

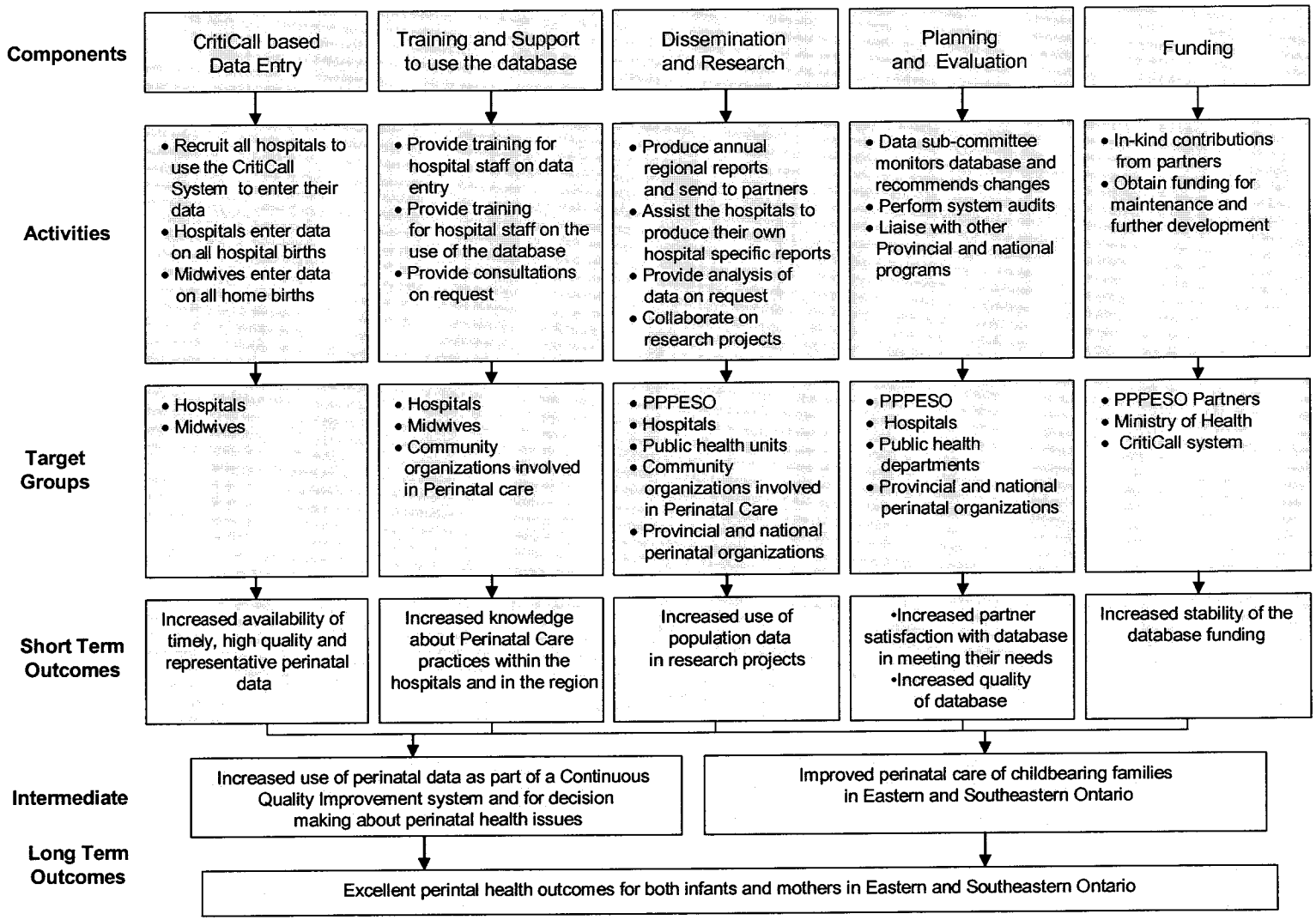
Points 1 and 2 above address the evaluation question, "What is the program supposed to do?" Point 3 addresses the evaluation question, "For whom?" Point 4 addresses the evaluation question, "What is its effect or impact?"

Evaluations focusing on a program's components, activities and target groups are called "Process Evaluations". Those focusing on a program's short term,

intermediate and/or long-term outcomes are called "Outcome Evaluations".[44] The logic model separates the "means" (i.e. what is being done) from the "ends" (i.e. the results of what is being done). Means are about process and ends are about outcomes.

Figure 3.3 in the following page shows the logic model that was designed by the author to describe the perinatal surveillance system.

Figure 3.3 The Perinatal Surveillance System Program Logic Model



CHAPTER 4. METHODS

4.1 Evaluation Design

The design of the evaluation was derived from the *"Updated Guidelines for evaluating surveillance systems"*[9] published by the CDC. A summary of the tasks recommended for evaluating surveillance systems produced by the CDC was provided in Table 2.1 (page 20). Based on the CDC's guidelines, a set of evaluation questions was identified. The *"Program Evaluation Toolkit"*,[42] published by the Public Health Research, Education and Development Program at the Ottawa-Carleton Health Department provided additional guidance for the evaluation methods. The logic model described in section 3.4 (page 33) assisted in describing the surveillance system to be evaluated and in focusing the evaluation design and questions.

4.2 Evaluation Framework

Based on discussions with PPPESO planners and some of the partners (CDC Task A), four elements of the surveillance system were included in the evaluation: content, data collection, data analysis and reports, and uses of the system. Each of these elements was assessed against the relevant CDC criteria for an effective surveillance system (simplicity, timeliness, flexibility, representativeness, acceptability, data quality, stability and overall usefulness). Based on these criteria, the following evaluation questions were developed:

Content: Are the variables *acceptable* to the partners? Are the data *representative* of the population?

Data Collection: Were the data entered as planned? Is the data collection *simple*, *timely*, *flexible*, of high *quality*, *acceptable* and *stable*?

Data Analysis and Reports: Are the data analysis and reports *simple*, *timely*,

flexible and *acceptable*?

Uses of the system: Are the data in the database *useful* and being used by the partners? Can the database be linked to census data?

To render the evaluation practical and operational, a framework was designed to incorporate specific evaluation questions and the criteria or attribute to be evaluated. The evaluation framework described in Table 4.1 below shows these questions and how they relate to the guidelines and tasks described by the CDC. The expectations of the program in the third column of the table, as defined by PPPESO, refer to what the program intends to achieve or to criteria for its success.

Table 4.1 Evaluation Framework

Criteria/attribute CDC (Task D)	Evaluation Questions CDC (Task C)	Expectations of the Program CDC (Task C)	Type of Tool/Method	Who could provide the data
	a. Content			
Acceptability	a1. Do the partners find the variables in the database useful?	At least 75% of the partners rate all or nearly all (90%+) of the variables in the database as useful	Questionnaire	Hospitals Public Health Units
	a2. Are the partners satisfied with the variable definitions?	At least 95% of the partners who are entering data are satisfied with the variable definitions	Questionnaire	
Representativeness	a3. Is the database capturing all the births occurring in Eastern and Southeastern Ontario?	All women giving birth in Eastern and Southeastern Ontario are to be included	- Examination of birth records of hospitals/midwives - Cross checking total number of birth in the Perinatal Database with CIHI* database - Questionnaire	Hospitals Public Health Units Midwifery groups PPPESO CIHI HIP
	b. Data Collection			
Simplicity	b1. Are data entered into CritiCall Program as intended?	- Logbook completed in case room on all births - Data entered at birth hospital on all births	- Review of records - Direct observation	Hospitals
	b2. Are data entry procedures simple and easy to use?	At least 75% of partners who are entering data, report that data entry is easy or very easy to complete	Questionnaire	

* Canadian Institute for Health Information

Criteria/attribute CDC (Task D)	Evaluation Questions CDC (Task C)	Expectations of the Program CDC (Task C)	Type of Tool/Method	Who could provide the data
	b. Data Collection			
Timeliness	b3. Are the data entered in a timely manner?	All data to be entered within 2 weeks of the last day of the month	Review of transaction logs	PPPESO
Flexibility	b4.Can the database adapt to changing needs? b5. Can more variables be added? b6. How much time and training is required for the changes?	The database is reviewed on an annual basis and changes are made as recommended by Data Sub-committee with minimal additional time and personnel effort	Review of Data-sub-committee files and reports	PPPESO
Data Quality	b7. What is the completeness of the data entered? b8. What is the accuracy of the data in the Database?	Data on all births to be at least 95% complete Individual variables in the database, logbook and charts to be at least 95% concordant and to have (ICC* >0.9 or Kappa >0.6)	Descriptive analysis of data in Database Comparison of charts, logbooks and database (data re-abstraction)	PPPESO Hospitals PPPESO
Acceptability	b9. How long does it take to enter the data? b10. Is the investment the hospitals make in the data entry suitable for the return? b11. Are the hospital partners satisfied with the data verification process provided by PPPESO?	At least 75% of the data entry personnel report that it takes ≤3 minutes to enter data for 1 record At least 75% of the hospital partners report that the investment is suitable for the return At least 75% of the hospital partners are satisfied or very satisfied with the data verification process provided by PPPESO	Questionnaire Questionnaire Questionnaire	Hospitals PPPESO

* Intra-class Correlation Coefficient

Criteria/attribute CDC (Task D)	Evaluation Questions CDC (Task C)	Expectations of the Program CDC (Task C)	Type of Tool/Method	Who could provide the data
	b. Data Collection			
Acceptability cont...	b12. How many sites are participating in the system out of the total number of sites?	100% of the sites are participating in the system	Review of transaction logs Questionnaire	PPPESO
Stability	b13. What is the percentage of time the system is fully operational?	- At least 95% of the partners report that the system is down not more than once/week - At least 95% of the partners report that if the system goes down it is back in less than 1 hour on average	Questionnaire	Hospitals PPPESO CritiCall
	c. Data Analysis and Reports			
Simplicity	c1. Is the report generation easy to perform? c2. Are the reports generated simple and easy to understand/interpret?	At least 75% of the partners who are generating reports rate the procedure as easy or very easy to perform At least 75% of the partners who are generating reports think that the reports are easy or very easy to understand	Questionnaire Questionnaire	Hospitals Public Health Units
Timeliness	c3. Can data reports be generated immediately after data entry? c4. Is the annual regional report produced in a timely fashion?	Reports can be produced in real time - Annual regional report is produced within 3 months of year end - Annual regional report is made public within 3 months of year end	Examination of the database on the CritiCall system Questionnaire	PPPESO CritiCall
Flexibility	c5. Can the data be analyzed as required by the partners?	At least 75% of partners find the report function to customize data requests easy or very easy to perform	Questionnaire	Hospitals Public Health Units

Criteria/attribute CDC (Task D)	Evaluation Questions CDC (Task C)	Expectations of the Program CDC (Task C)	Type of Tool/Method	Who could provide the data
	c. Data Analysis and Reports			
Acceptability	c6. How often do hospital partners generate reports?	- At least 75% of the hospital partners generate frequency reports at least once per month - At least 75% of the hospital partners generate comparison reports at least once every 3 months	Questionnaire	Hospitals Public Health Units
	c7. Are the Public Health Units generating reports?	At least 75% of the public Health Units generate reports	Questionnaire	
	c8. Are the reports provided in the required by the partners?	At least 75% of the partners who are producing reports are satisfied or very satisfied with the report format	Questionnaire	
	c9. Are the partners who are producing reports satisfied with the user support provided by PPPESO?	At least 75% of the partners producing reports are satisfied or very satisfied with the user support provided by PPPESO	Questionnaire	
	d. Uses of the Database			
Usefulness	d1. How much has the database contributed to the access to information about perinatal care practices?	At least 75% of the partners report that the database has increased their access to information about perinatal care practices	Questionnaire	Hospitals Public Health Units PPPESO
	d2. Is the database meeting the needs of the partners?	At least 75% of the partners report that the database is meeting their needs	Questionnaire	

Criteria/attribute CDC (Task D)	Evaluation Questions CDC (Task C)	Expectations of the Program CDC (Task C)	Type of Tool/Method	Who could provide the data
	d. Uses of the Database			
Usefulness	d3. How have the hospitals used the database? d4. How have the Health Units used the database? d5. How has PPPESO used the database?	Each partner reports that the database has been used for at least one of the following purposes: health and performance status, planning, evaluation of practices, teaching purposes, research and continuous quality improvement (CQI)	Questionnaire	Hospitals Public Health Units PPPESO
	d6. Can the database be linked to other databases for research purposes?	Linkage is possible through the postal codes	- Questionnaire - Linkage with the Census File via the Postal Code Conversion File (PCCF)	PPPESO Public Health Units Statistics Canada for PCCF
	d7. Does the database collect data elements needed to monitor important perinatal health issues such as low birth weight and preterm birth?	- Database has relevant information about low birth weight and preterm birth. - Information about known risk factors for low birth weight and preterm birth is collected	Review of data in database	PPPESO

4.3 Evaluation Methods

Based on the tools/method presented in the fourth column of Table 4.1, the following methods were used to collect the data for the evaluation: (values in parenthesis correspond to cell numbers in Table 4.1)

1. Data re-abstraction from hospital records. (cell b8)
2. Survey of stakeholders, through a self-completed questionnaire. (cells: a1 – a3, b2, b9 – c2, c4 – d5)
3. Direct observations. (cell b1)
4. Review of PPPESO files and reports. (cells: b1, b3 – b6)
5. Examination of the Perinatal Database on the CritiCall system. (cells: b7, b12, c3, d7)
6. Comparison with CIHI data (cell a3).
4. Linkage to census data. (cell d6)

The subsequent sections describe these methods.

4.3.1 Data Re-abstraction: Logbook and Chart Reviews (CDC Task D: Data Quality)

4.3.1.1 Overview of Re-abstraction

The rationale for this study was to determine whether the Data Entry Personnel had accurately entered the data from the logbooks into the Database, and whether the Database accurately reflects the charts (cell b8 of Table 4.1). The study was conducted to answer two main questions:

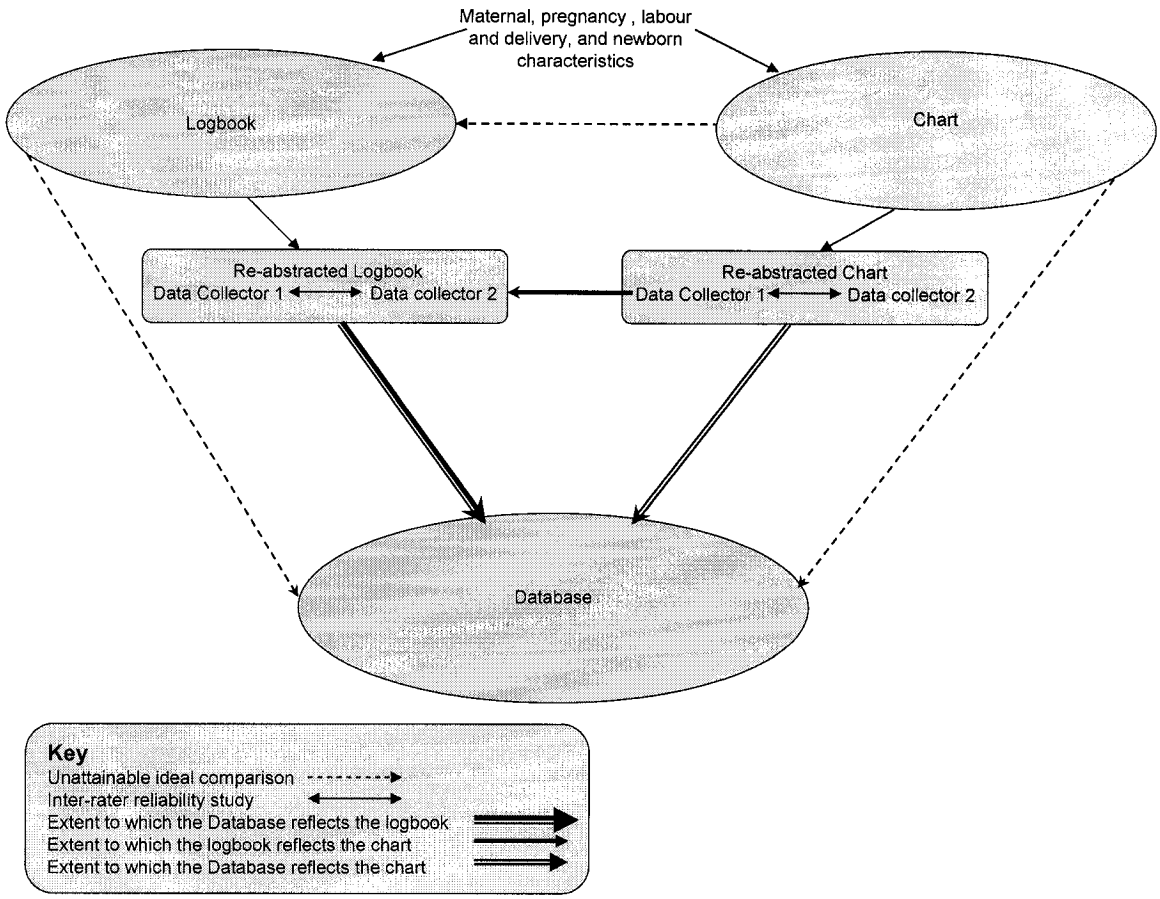
1. To what extent does the Database agree with the logbook?
2. To what extent does the Database reflect the data in the chart?

    2.a. To what extent does the logbook reflect the data in the chart? (A supplementary question to explain differences in 2).

Figure 4.1 shows an overview of the data re-abstraction study, incorporating both the inter-rater reliability study (N=40) and the full sample (N=1511).

For the purposes of this study, the term accuracy was used as a general concept incorporating reliability and validity. The comparison between the Database and the logbook simply indicated the level of mechanical reproduction of the logbook in the Database (a form of reliability). The comparison between the Database and the chart indicated the extent to which the true values are reflected in the Database (a form of validity), assuming the chart accurately reflects the interventions used and the characteristics of the mother, labour and delivery, and the newborn. The chart is a proxy for these characteristics and is dependant on the persons completing it. For this study, the data in the logbook and the chart could be examined only through the versions re-abstracted by the data collectors, and therefore errors between the sources could also be due to re-abstraction errors. The data collectors were aware of all the problems experienced with the variables in the past, so it is assumed that they were vigilant in abstracting the data. High inter-rater reliability will add confidence to the interpretation of the data.

Figure 4.1 An Overview of The Data Re-abstraction Study



4.3.1.2 Sources of Data

The case room logbook (or equivalent) in each participating hospital and the mothers' charts were the two sources used to collect the data. In 14 hospitals, there was a logbook at the delivery room where nurses recorded information pertaining to the mother and the baby. This information was obtained directly from the mother and was supplemented from the chart as indicated in Figure 3.2 (page 32). All deliveries occurring at the hospital were to be recorded in the logbook. The remaining two

hospitals used their own records with data equivalent to those in the logbooks of the other hospitals.

For this project, the mothers' chart numbers were obtained from the logbook, and the charts were obtained from the medical records department at each hospital. The chart review did not include the babies' charts because a trade-off had to be made between the benefits gained by pulling them and the resources available to accomplish that. There was also some concern about over-burdening some hospitals' medical records departments, which were already short on staff, to pull out such a large number of charts for one study.

In each of the 16 participating hospitals, there was a designated person in charge of the Perinatal Database, referred to as "The Hospital Database Coordinator". That person was informed about the study by the central office of PPPESO, and was requested to assist the data collectors in obtaining the logbooks and asking the hospitals' medical records departments to pull the required charts. Data abstraction took place between March 18th and May 20th 2002.

4.3.1.3 Sample Selection

The study was done on the 2001 Database file, which was the first complete year of data entry into CritiCall. During that year, there were 17,688 deliveries at the participating hospitals. Appendix B1 shows the number of deliveries broken down by hospital.

The aim of this re-abstraction study was to assess the concordance of the data in the database with the case room logbook and the charts. The resources available for this project permitted the study of about 1500 charts in total. Two possible sampling strategies were considered for the study: a) proportional sampling; or b) fixed number

sampling. The proportional to size sampling would have generated very small numbers from the small community hospitals (less than 10). This would have meant that some of the variables could not be studied in these sites as the prevalence of some of the variable subcategories was rather low, e.g. caesarean section (20%), induction (23%), vacuum assisted vaginal births (0.6%).[2] In addition, from the program's perspective, it was necessary to obtain sufficient data from each hospital so that an overall picture of the data quality in each hospital could be assessed and improved accordingly. Therefore, a fixed sample of 100 deliveries (individual babies) was selected from each hospital. A two-step process was used to identify the deliveries to be included in the study. First, a random sample of 70 records was selected from the total number of deliveries occurring at the hospital during the year, using SPSS's random number generator. Second, 3 groups of 10 deliveries each were randomly selected from those with specific characteristics that were less common (<25%): induced labour, maternal smoking and repeat caesarean section with a trial of labour. This was done to ensure sufficient sample size for these specific characteristics. These variables were selected because there was concern about their accuracy. For hospitals where the total number of deliveries per year was less than 100, the total number of deliveries for the whole year was included. Following the random selection, a list of all the deliveries that were sampled from each hospital was prepared. The identifying variable used was the hospital baby number, which was the same number written in the logbook. For added precision, the date of birth, the gestational age and the weight were printed out for each selected baby. This enabled the data collectors to certify that the record entered was the correct one. A sample of the out print is provided in Appendix C1.

The total sample size obtained was 1542, because some hospitals had fewer than 100 births. The author collected data from 11 hospitals (data collector 1) and a research assistant (a nurse from Kingston General Hospital) hired by PPPESO collected

data from the remaining five hospitals (data collector 2)*. The data were entered into two portable computers.

4.3.1.4 Data Collection Procedure

The instrument used to collect the data was an SPSS (version 10) data file template consisting of the same variables present in the database. For ease of data entry, the variables were placed in the same order as they appeared in the majority of hospital logbooks. The advantage of using SPSS version 10 was that it allowed the incorporation of all the different options for each variable, through its drop-down menu feature.

The SPSS template was designed to provide certain system checks by limiting the number of characters to be entered into any field to match the actual number of characters within the variable, for example, six characters for the postal code; however it was not possible to include all the same system checks (such as logical consistencies) used in the CritiCall entry screen. The CritiCall entry screen was not used to enter the data for two reasons: first, there was no guarantee of an Internet connection for the portable computers used by the data collectors, especially for the chart reviews, which had to be done within the premises of the medical records departments. Second, since the entry screen itself was under evaluation, it seemed appropriate to refrain from using it as the medium to enter the data.

The PPPESO data analyst trained the data collectors on how to use the template. The data were collected as follows: each of the two data collectors had a list of all the sampled deliveries from her designated hospitals. Each hospital was visited

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* **Hospitals allocated to data collector 1:** Almonte, Brockville, Cornwall, Hawkesbury, Montfort, The Ottawa Hospital (General and Civic), Pembroke, Perth/Smith Falls, Queensway Carleton and Renfrew.
Hospitals allocated to data collector 2: Belleville, Lennox and Addington, Kingston, Picton and Winchester.

two to four times to complete the data collection from the logbook and corresponding charts. In the first visit the information was recorded from the logbook into the SPSS data file. This was labelled as the "logbook file". The mothers' chart numbers were obtained from the logbook, and given to the medical records department at the hospital with a request to pull the charts. Once the charts were ready, the data collectors re-visited the hospital and recorded the information from the charts into a separate data file. This was labelled as the "charts file". Prior to entering data from the charts, a nurse from the delivery unit sat with the data collector to clarify where each of the variables was located. To ensure accuracy, information from the first five charts was entered with the aid of the nurse. The data entry procedure was repeated for all the hospitals, so that at the end of the data collection phase there were four separate data files: one logbook file and one chart file for each of the two data collectors. The files were then merged so that there was one main logbook file and one main charts file, as well as the Perinatal Database file. Figure 4.2 summarizes the data collection process.

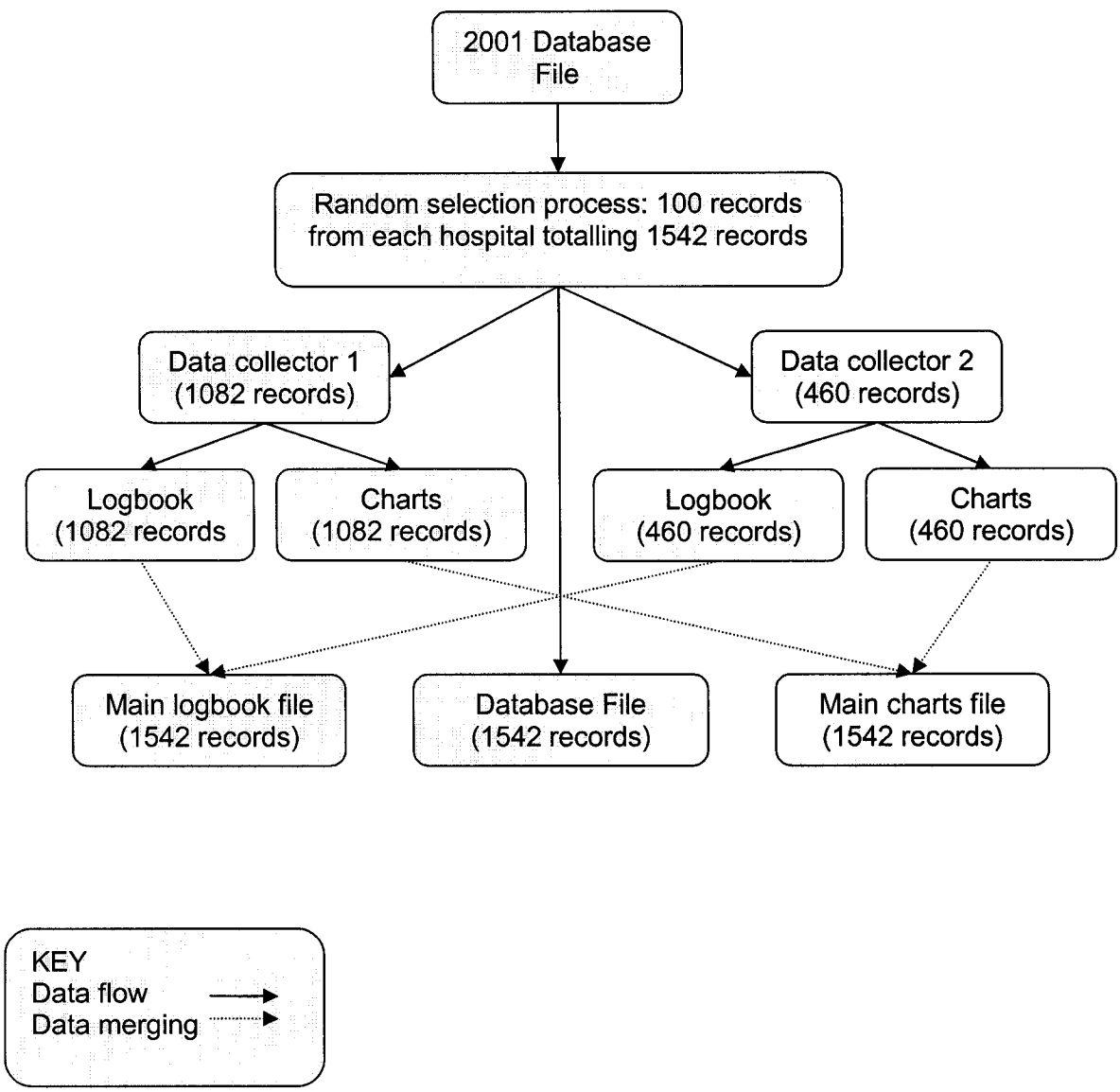
Case room logbook: The logbooks were almost uniform across the hospitals, except for two hospital sites that used their own delivery records, with almost the same variables as the logbook.

Charts: Although the charts were not standardized throughout the hospitals, the reviews were conducted in a consistent manner as much as feasible. The postal code, the mother's age and the maternal transfer from other hospitals were almost exclusively obtained from the admission record. The rest of the variables were mostly obtained from the labour record, the delivery record, the antenatal record, the discharge summary, lab results, nurses' notes and the postpartum screening tool record. These records and summaries had different terminologies in some hospitals, but the overall scheme was very similar. Most of the records mentioned above were in English or were bilingual. Where it was necessary to go through the nurses' notes or the discharge summaries,

bilingual nurses or Database Coordinators provided translations for the following charts that were written in French:

1. Nine charts at the Montfort Hospital.
2. Two charts at the Civic site of the Ottawa Hospital.
3. Eight charts at the General site of the Ottawa Hospital.
4. Eleven charts at Hawkesbury Hospital.

Figure 4.2 The Data Collection Process



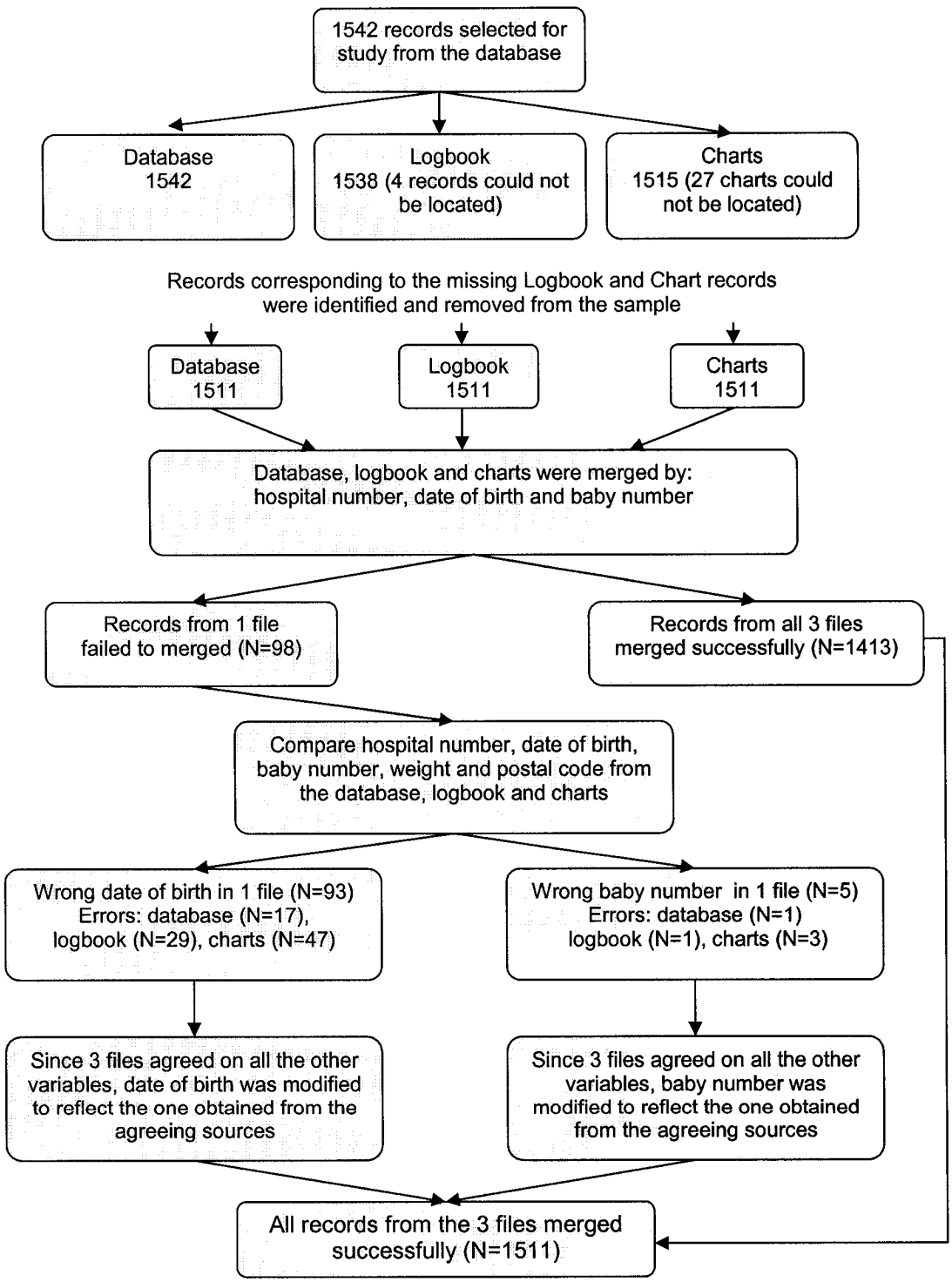
4.3.1.5 The Merging Process

The three files (logbook, database and charts) were merged by the hospital number, the date of birth of the baby, and the baby number, since these were unique for every record.

During data collection, 4 logbook records could not be located because the sheet was missing from the book, and 27 charts could not be located by the medical records departments. Therefore, the logbook file had 1538 records and the charts file had 1515 records. The corresponding database records were identified and all 31 records (2.0% of the total) with missing data from any of the three files were removed, leaving a total sample of 1511 in each of the 3 files.

For a total of 1413 records, all 3 files merged successfully. Of the others, 98 records merged in 2 files only. These records that failed to merge successfully in all 3 files were printed out with a variable list that included the merging variables (hospital number, date of birth, and baby number), in addition to the baby's weight and the mother's postal code from all three sources: database, logbook and charts to enable further verification of the sources of error. When an error in any of the merging variables was encountered, the weight and postal codes in the 3 files were compared. Since the 3 files agreed on all the other variables, the error in the merging variable was modified to reflect the one in the agreeing files. Of the records that failed to merge, 93 had an error in the date of birth in one file and 5 had the wrong baby number in one file. Figure 4.3 describes the process.

Figure 4.3 The Merging Process



4.3.1.6 Reliability of the Re-abstraction Process

The value obtained from any measurement is a combination of two components: a true value and some degree of error. The error in the measurement is of two types: random error and systematic error or bias.[45,46] Reliability is concerned with the random errors, which may include the varied faults in making a measurement, due to inattention, tiredness or mechanical inaccuracy that may equally lead to an over- or under-estimation of the true quantity.[46] Two broad types of reliability have been identified: agreement in the measurement obtained by different raters (inter-rater agreement or observer variation) and agreement between two assessments by the same rater (intrarater reliability, test-retest reliability, stability or repeatability).

The first type of reliability has been assessed as follows: the two data collectors abstracted data for the same 40 logbook/charts at two different hospitals. Data collector 1 abstracted the same data on 20 randomly selected logbook/charts for Winchester Hospital, which was one of the hospitals covered by data collector 2. Data collector 2 abstracted the same data on 20 randomly selected logbook/charts for Perth/Smith Falls Hospital, which was one of the hospitals covered by data collector 1.

Test-retest reliability was only assessed by data collector 1, and only for the logbook data entry. At the Queensway-Carleton Hospital, which was the first hospital from which data collector 1 entered data, 25 records were entered into the SPSS data file twice with a period of two weeks between the two entries. Cross-tabulations were done to compare the two entries and percentage agreements were calculated for each variable and found to be 100% concordant. For the charts, this type of reliability could not be assessed. For the test-retest to be done properly a reasonable time has to elapse between the test and the retest, but the medical records departments do not

permit the charts to be out for an extended period of time, and some are reluctant to pull the charts twice for the same study due to shortages in their resources and staff.

4.3.1.7 Data Analysis

Following the merging process described in section 4.3.1.5 (page 51), the merged file was explored and descriptive statistics using SPSS version 11 were calculated. Excluding the merging variables (the hospital number, date of birth and the baby number), there were 37 variables for each of the database, the logbook and the charts. All the variables were recorded once except for the weight and the gestational age, which were recorded twice and were labeled weight 1 and 2, and gestational age 1 and 2.

Percent agreement, Cohen's Kappa and Intraclass Correlation Coefficient (ICC) between the variables in the three files were calculated to compare:

- The entry in the logbook to that in the database.
- The entry in the chart to that in the database.
- The entry in the logbook to that in the chart.

Percent agreement was calculated for all variables. For the other two indicators (Kappa and ICC) categorical/nominal variables (N = 32), and continuous variables (N = 5) were considered separately.

Categorical Variables: The analyses for all the categorical/nominal variables (except for the postal code) were done by two way cross-tabulations of each variable and comparing the entries as explained above. Since the postal codes were string variables, cross tabulation was not feasible, so an equal/not equal statement on the SPSS program was used to calculate the percent agreement.

Cohen's kappa was used to examine the proportion of responses in agreement, in relation to the proportion of responses which would be expected by chance, given the

marginal distributions.[45,47-49] This chance-corrected index of agreement (*K*) is calculated using the following formula[47,50]: $K = [P(o) - P(e)]/[1 - P(e)]$, where P(o) is the observed proportion of agreement and P(e) is the expected proportion of agreement. The values of kappa can range from -1 to +1. When there is complete agreement, kappa is equal to 1. When the observed proportion of agreement is greater than chance, kappa is greater than 0. If the observed agreement is less than chance, kappa is less than 0. Depending on the marginal proportions, the minimum values of kappa can range between -1 and 0. For example if P(o) is 0.5, the minimum value is -1.[50]

For ordinal data where partial agreement may also be suitable, weighted kappas can be calculated.[47,50] For this study, the interest was in *complete* agreement, hence the use of unweighted kappas.

Landis and Koch[51] suggested the following kappa interpretation scale:

Kappa Statistic	*Strength of Agreement*
<0.00	Poor
0.00 – 0.20	Slight
0.21 – 0.40	Fair
0.41 – 0.60	Moderate
0.61 – 0.80	Substantial
>0.81	Almost perfect

Although these divisions are arbitrary, they provide useful benchmarks and have been used in research. Fleiss[50] described another scale with values >0.75 or so representing excellent agreement beyond chance, values <0.40 or so representing poor agreement, and values between 0.40 and 0.75 representing fair to good agreement.

The expectations of the program identified a 95.0% threshold as the acceptable level of agreement between the database, the logbook and the charts for each individual variable. The acceptable chance corrected agreement was interpreted as a kappa value >0.60, indicative of substantial to almost perfect agreement.[51] The agreement for

any particular variable had to fulfill both criteria, a 95% agreement and a kappa value > 0.60, to be considered acceptable.

Continuous Variables: For the continuous variables, agreement was assessed by using an equal/not equal statement on the SPSS program, and calculating the intra-class correlation coefficients (ICC). The ICC is an appropriate measure of reliability for continuous data[45,47-49,52], more suitable than the Pearson Product Moment or the Spearman Correlations, since these measure association and not agreement. So long as raters co-vary consistently, a large actual disagreement in rating levels with concomitant "pattern" agreement does not lower the Pearson Correlation.[48] An ICC of 0.9 was chosen as the threshold of acceptable agreement. The agreement for any particular variable had to fulfill both criteria, a 95% agreement and an ICC value of 0.9 to be considered acceptable.

4.3.2 Survey of Stakeholders (CDC task D: other system attributes)

4.3.2.1 Survey Population

The survey population included all the stakeholders involved with the Perinatal Database. These were identified and grouped into four categories as shown in Table 4.2. The survey addressed cells: a1 – a3, b2, b9 – c2, c4 – d5 of Table 4.1 (page 38).

Table 4.2 Survey Population

HOSPITALS	PUBLIC HEALTH UNITS	PPPESO STAFF
Database Coordinator in each hospital (16)	Individual(s) who had been trained by PPPESO and who have used the Database (6)	Director (1) Planning and Policy Advisor (1) Perinatal Database Coordinator (2)
Data Entry Personnel in each hospital (16+)		

4.3.2.2 Survey Design

Having reviewed the different options for collecting survey data, a cross sectional survey design through a self-completed questionnaire was determined to be appropriate for this study. To maximize the response rate, the *Tailored Design Method* proposed by Dillman[53] was adapted, whereby different response inducements were used for the four study groups.

The central office of PPPESO sent an official request to conduct the evaluation to each of the participating hospitals by electronic mail (copy in Appendix C2). This was followed by a mailed letter signed by the author and the two thesis supervisors (Dr. Robert A. Spasoff and Dr. Paula Stewart), briefly outlining the purpose of the study and requesting permission to conduct it. The questionnaires were mailed with the letter. (Copy of letter and questionnaires in Appendix C3 – C6). The letters and copy of the questionnaires were also sent by electronic mail. Follow up was done at four, six and eight weeks after the initial mailing of the questionnaires. Replacement questionnaires were sent whenever needed.

For the PHUs, the covering letters and questionnaires were hand delivered to four out of the six health units (at their annual general meeting) and mailed to the remaining two who did not attend the meeting. Follow up and replacement questionnaires (whenever needed) were sent according to the same schedule used for the hospital staff, at four, six and eight weeks.

For PPPESO staff, the questionnaires were sent by electronic mail. The same follow up schedule as for hospital staff and PHUs was adapted.

4.3.2.3 Data Collection Instrument

A worksheet was used to design the questionnaire questions, based on the evaluation framework and the expectations of the program. Separate questionnaires

were designed for the four groups identified in Table 4.2: the database coordinators at each hospital, the data entry person at each hospital, the public health units and key staff at PPPESO.

The questionnaires were assessed for clarity and ease of completeness among individuals with similar characteristics to the survey population. For the database coordinator, we used two individuals who were trained to use the database, but were not acting as coordinators at the time of the study. For the Data entry Personnel, we used three individuals who were trained to enter data, but were not entering data at the time of the study. One of these failed to return the questionnaires despite repeated requests, and was hence removed from the assessment. For the PHUs and PPPESO staff, no such individuals could be found, so their questionnaires were not pre-tested.

The validity of an instrument can be assessed with respect to content, face, construct or criterion validity.[45,54] The questionnaires used in this study were assessed for face validity with the assistance of the thesis supervisors. Content validity was assessed through review of the draft questionnaires by two experts who were knowledgeable about PPPESO and the Perinatal Database. Testing construct and criterion validity was not feasible for this study.

4.3.2.4 Data Handling

The questionnaire responses were entered into four SPSS-based datasets. Frequencies were calculated for the closed ended questions. For the open-ended questions, a "Quasi-Statistical Analysis Technique" was adapted. This is one of four strategies described by Miller and Crabtree.[55] This approach has been portrayed to be at the objective extreme of the continuum of qualitative analytic techniques. The procedure involves transcribing the text of all the responses, reading the text and searching for

themes or patterns based on a codebook. The themes were then sorted into categories and manipulated statistically.

4.3.3 Direct Observations

During the hospital visits, observations were made on the entry of data into the logbook and subsequently into the database (cell b1 of Table 4.1). This was done to verify that the data entry was implemented as planned by the PPPESO.

4.3.4 Review of Files and Reports

All the regional reports produced by PPPESO since 1999 were reviewed in order to assess their quality in terms of clarity, topics covered, and to determine if there has been any change in the reporting during the evolution of the database .

Other files and documents such as the Perinatal Program Executive Summary (a document describing the program), database subcommittee files and the strategic plan documents were reviewed to obtain information about the specific objectives, purposes and operations of the surveillance systems and the resources used to operate it (cells:b1, b3-b6 of Table 4.1).

4.3.5 Examination of the Database on the CritiCall System

The author was given permission from PPPESO to access the database on the CritiCall system. The examination of the Database addressed cells: b7, b12, c3, d7 of Table 4.1. To protect hospital privacy, only aggregate data could be accessed, which was sufficient to examine the data entry screen, the reporting facility (both frequency and comparison reports) and the transaction logs. The examination was done with the following rationale:

1. The system was explored in terms of logging in, navigating within, and exiting it.

2. Data entry: the data entry screen was examined and simulated data were entered into it, exploring different situations with complete data and missing data, to check the performance of the system in these situations.
3. The 2001 data were examined for completeness.
4. Reports: the process of customizing data requests to obtain frequency and comparison reports, as well as printing of the reports was explored.

4.3.6 Comparison to CIHI Data

Aided by the HIP, an attempt was made to verify that the Perinatal Database captures all hospital births occurring in Eastern Ontario, by comparing the total number of births in the Perinatal Database to that in the CIHI Database (cell a3 of Table 4.1).

4.3.7 Ability of the Database to Link to Other Population Databases (CDC task D: usefulness)

The second objective of the thesis was an assessment of the feasibility of linking the Database to the census file, a population database with additional data that could be used in collaboration with the Perinatal Database for research purposes (cell d6 of Table 4.1). Successful linkage would allow studies of relationships between aggregated census variables and reproductive outcomes.

4.3.7.1 The Postal Code Conversion File (PCCF)

The charts use postal codes and the census uses standard geographic areas such as census subdivisions (CSD), census tracts (CT) and enumeration areas (EA). The Postal Code Conversion File (PCCF), produced by Statistics Canada, provides linkages between Canada Post Corporation's six-character postal code and the standard geographic areas for which census data are collected. Most urban postal codes are listed in either a "unique" file (linked to only one EA) or a "duplicate" file (linked to more

than one EA). Most rural postal codes and some classes of urban postal codes are listed in a Weighted Conversion File (WCF). "The Postal Code Population Weight File or Weighted Conversion File (WCF), has been created as a supplementary product to the PCCF, providing users with a population "weight" for postal codes with multiple links on the PCCF. The weight associated with each record on the WCF represents the proportion of the population reporting the postal code within a specific enumeration area".[56]

Statistics Canada produces the Geocodes/PCCF software (also known as the PCCF+), which consists of two SAS control programs (GEORES3x for residential coding, and GEOINS3x for office coding) and a series of reference files derived from the PCCF, the WCF and other sources. This software automatically assigns a full range of geographic identifiers from province down to the level of enumeration area, latitude and longitude based on postal codes.[57]

4.3.7.2 The Matching Process

The program does the matching as follows: Postal codes on the incoming file (the file with postal codes to be assigned geographically) are matched to postal codes that are "unique" on the PCCF. The remaining postal codes on the incoming file that match to a "duplicate" file on the PCCF, are matched in two steps: The first step links the postal code to a pointer file, which contains a single record for each postal code that occurs more than once on the PCCF file. This pointer file has information on the physical location of that postal code and the frequency of its occurrence in the duplicate file. In the second step, information on the pointer file is used to match each successive record on the incoming file with the next occurrence of that postal code in the duplicate file. Thus, the records for such postal codes are distributed equally across all possible EAs served by that postal code.

Most rural postal codes and some classes of urban postal codes are matched to the WCF, and assigned geographic codes based on a population-weighted random allocation among the possible codes, producing an unbiased allocation of events in relation to the resident population. For example, if 75% of the population served by a postal code was known to be in EA1, then on average 75% of the records on the incoming file will be assigned to that EA.

In cases when postal codes cannot be matched exactly to the PCCF, the first two or three characters of the postal code are used to assign partial geographic identifiers to the extent possible. Failing all else, province only may be assigned, based on the first character of the postal code. The program then produces summary reports that include diagnostic codes, errors, and suggestions of how to resolve them.

For this study, the postal codes from the Perinatal Database were geocoded using the Geocodes/PCCF software GEORES 3x (Version 3J). This demonstrates the feasibility of attaching geographically-coded variables from other data sets. The PCCF provides neighbourhood income quintiles that are assigned based on the EA code. The quintiles were derived from the 1996 Census, which used the Neighbourhood Income Per Person Equivalent (IPPE), a household size-adjusted measure of household income derived from the 1996 Census summary data at the enumeration area level. The EA average IPPE was used to rank all enumeration areas within each census metropolitan area, census agglomeration area (or a residual area not in any census metropolitan area or census agglomeration area), and the population was divided into approximate fifths creating community-specific income quintiles based on the enumeration area IPPE.[57]

The geocoding also provided the opportunity to verify how many postal codes in the Perinatal Database were valid on all six characters and how many were valid on the

first three characters (Forward Sortation Area - FSA) only. Results of the geocoding and the assignment of the income quintiles are presented in section 5.7.

CHAPTER 5. RESULTS

Based on the six methods outlined in the methods above, the results of the evaluation are presented in this chapter. This is followed (in section 5.8) by a synthesis of the evaluation findings, based on the evaluation questions and the expectations of the program.

5.1 Data-Reabstraction: Logbook and Chart Reviews

5.1.1 Inter-Rater Reliability

Categorical Variables: A summary of the disagreements between data collector 1 and 2 for the 32 categorical variables, based on percent agreement < 95.0%, or Kappa ≤0.60, is shown in Table 5.1a. Results for the individual variables are presented in Appendix D1.

The agreement between the two data collectors was very high on all the variables except for two logbooks and four chart variables. For these variables, the results of the re-abstraction study will be presented separately for the two data collectors.

Table 5.1a Inter-Rater Disagreement on Re-abstraction of Logbook and Charts for Categorical Variables Based on Percent Agreement (< 95.0%) OR Kappa (≤0.60)

Percent agreement (< 95.0%)	Cohen's Kappa (≤0.60)	Logbook	Charts
92.5%	0.84	1. Labour Type	—
82.5%	0.71	—	1. Fetal Monitoring
90.0%	0.79	—	2. Anaesthesia : Narcotic
95.0% & 97.5%	**0.00**	2. Anaesthesia: Pudendal Block (95.0%)	3. Anaesthesia: Pudendal Block (97.5%)
55.0%	**0.12**	—	4. Cord blood sample

Note: Scores failing to meet criterion are presented in bold

Table 5.1b Inter-Rater Disagreement on Re-abstraction of Logbook and Charts for Continuous Variables based on Percent Agreement (<95.0%)

Percent agreement (< 95.0%)	ICC	Logbook	Charts
92.5%	0.98	—	1. Gestational age1
92.5%	0.98	—	2. Gestational age2

Continuous Variables: There was very high agreement on all the variables except for the gestational age 1 and 2, based on percent agreement (using an equal/not equal statement) and ICC (Table 5.1b). For these variables, the results of the re-abstraction study will be presented separately for the two data collectors. Results for all the variables are presented in Appendix D2.

5.1.2 Assessment of Agreement Between Database, Logbook and Charts

Categorical variables: Following exploration of the data by descriptive statistics, values that were not coded or left blank were identified and excluded from the analysis. As indicated by the (N) in the table, this affected a very small number of records so would not have an important effect on the results. The percent agreement or concordance and the kappa statistic are presented in Table 5.2.

Table 5.2 Categorical/Nominal Variables (Cohen's Kappa and Percent Agreement)

Categorical/Nominal Variables	Database - Logbook					Logbook - Charts					Database - Charts				
		Agreement					Agreement					Agreement			
	Cohen's Kappa (N)$^{\Psi}$	>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%	Cohen's Kappa (N)$^{\Psi}$	>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%	Cohen's Kappa (N)$^{\Psi}$	>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%
1. Postal Code	N/A$^{\#}$		X			N/A			X		N/A		X		
2. Inter-hospital Transfer	0.69 (1506)	X				0.79 (1503)	X				0.69 (1503)	X			
3. Number of previous term pregnancies	0.95	X				0.89		X			0.88		X		
4. Number of previous preterm pregnancies	0.77	X				0.55		X			0.45		X		
5. Number of babies (singleton, multiple gestation)	0.88	X				0.86	X				0.94	X			

$^{\Psi}$(N) is indicated where there are missing values, else (N) = 1511. The same (N) applies to kappa and percentage agreement.
$^{\#}$ N/A: not applicable as equal/not equal was used, hence no cross-tabulation to generate the kappa statistic.

Categorical/Nominal Variables	Database - Logbook					Logbook - Charts					Database - Charts				
		Agreement					Agreement					Agreement			
	Cohen's Kappa (N)	>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%	Cohen's Kappa (N)	>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%	Cohen's Kappa (N)	>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%
6. Labour type* (combined)	0.83		X			0.76			X		0.76			X	
Data Collector 1	0.86		X			0.80			X						
Data Collector 2	0.73			X		0.63				X					
7. Fetal monitoring* (combined)	0.86		X			0.39				X	0.41				X
Data Collector 1						0.41				X	0.43				X
Data Collector 2						0.28				X	0.29				X
8. Presentation (Vertex, breech, other)	0.55		X			0.37			X		0.46			X	
9. Delivery type (vaginal or c/s)	0.91 (1507)	X				0.89 (1506)	X				0.88 (1510)	X			
10. Forceps or Vacuum assisted birth	0.92	X				0.82 (1510)	X				0.82 (1510)	X			

* Results are presented for the combined sample of 1511, as well as separately for the two data collectors for variables that exhibited low inter-rater reliability.

Categorical/Nominal Variables	Database - Logbook					Logbook - Charts					Database - Charts				
	Cohen's Kappa (N)	Agreement				Cohen's Kappa (N)	Agreement				Cohen's Kappa (N)	Agreement			
		>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%		>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%		>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%
11. Anaesthesia: General	0.86 (1510)	X				0.74 (1509)	X				0.75 (1510)	X			
12. Anaesthesia: Epidural	0.96 (1510)	X				0.92 (1509)	X				0.93 (1510)	X			
13. Anaesthesia: Spinal	0.94 (1510)	X				0.89 (1509)	X				0.90 (1510)	X			
14. Anaesthesia: Narcotic*(combined)	0.93 (1510)	X				0.72 (1509)			X		0.70 (1510)			X	
Data Collector 1						0.70 (1052)			X		0.69 (1053)			X	
Data Collector 2						0.77 (457)			X		0.73 (457)			X	
15. Anaesthesia: Nitrous Oxide	0.93 (1510)	X				0.71 (1509)		X			0.69 (1510)		X		

Categorical/Nominal Variables	Database - Logbook					Logbook - Charts					Database - Charts				
		Agreement					Agreement					Agreement			
	Cohen's Kappa (N)	>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%	Cohen's Kappa (N)	>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%	Cohen's Kappa (N)	>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%
16. Anaesthesia : Pudendal Block* (combined)	0.78 (1510)	X				0.70 (1509)	X				0.61 (1510)	X			
Data Collector 1	0.92 (1053)	X				0.74 (1052)	X				0.74 (1053)	X			
Data Collector 2	0.09 (457)	X				-0.01 (457)	X				-0.02 (457)		X		
17. Steroid use	0.55	X				0.30 (1508)	X				0.21 (1510)	X			
18. Delivered by: (Physician, Midwife)	0.55	X				0.50	X				0.40	X			
19.Baby's gender	0.98	X				0.96 (1507)	X				0.97 (1507)	X			
20. Newborn Resuscitation: Free Flow Oxygen	0.94 (1500)	X				0.53 (1496)				X	0.51 (1498)				X

Categorical/Nominal Variables	Database - Logbook					Logbook - Charts					Database - Charts				
	Cohen's Kappa (N)	Agreement				Cohen's Kappa (N)	Agreement				Cohen's Kappa (N)	Agreement			
		>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%		>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%		>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%
21. Newborn Resuscitation: Positive Pressure Ventilation	0.94 (1500)	X				0.57 (1496)		X			0.55 (1498)		X		
22. Newborn Resuscitation : Intubation	0.84 (1500)	X				0.54 (1496)	X				0.60 (1498)	X			
23. Newborn Resuscitation: Chest Compression	0.82 (1500)	X				0.50 (1496)	X				0.54 (1498)	X			
24. Newborn Resuscitation: Drugs	0.94 (1500)	X				0.60 (1496)	X				0.53 (1498)	X			
25. Apgar score 1 minute	0.96	X				0.87		X			0.87		X		
26. Apgar score 5 minutes	0.94	X				0.80		X			0.80		X		
27. Scalp blood sample	0.28	X				0.23 (1508)	X				0.10 (1508)	X			

Categorical/Nominal Variables	Database - Logbook					Logbook - Charts					Database - Charts				
		Agreement					Agreement					Agreement			
	Cohen's Kappa (N)	>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%	Cohen's Kappa (N)	>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%	Cohen's Kappa (N)	>95.0%	90.0 – 94.9%	85.0 – 89.9%	<85.0%
28. Cord blood sample* (combined)	0.69		X			0.16 (1510)				X	0.20 (1510)				X
Data Collector 1						0.35 (1053)				X	0.44 (1053)				X
Data Collector 2						0.01 (457)				X	0.01 (457)				X
29. Breastfeeding	0.90	X				0.78 (1508)		X			0.79 (1508)		X		
30. Smoking	0.84		X			0.56 (1510)				X	0.58 (1510)				X
31. Stillborn/Neonatal Death	0.87	X				0.88 (1510)	X				0.96 (1510)	X			
32. Neonatal Transfer to another hospital	0.80	X				0.64 (1510)	X				0.69 (1510)	X			

A summary of Table 5.2 showing the variables whose agreements were below the acceptable threshold for the database – logbook comparison is presented in Table 5.3.

Table 5.3 Disagreements in Database – Logbook entries for Categorical Variables Based on Percent Agreement (< 95.0%) OR Kappa (≤0.60)

Percent Agreement	Cohen's Kappa	Database – Logbook Variable
92.5	—	1. Postal Code
91.1	0.83	2. Labour Type* (combined)
92.3	0.86	Data Collector 1
88.2	0.73	Data Collector 2
92.1	0.86	3. Fetal Monitoring
93.4	0.69	4. Cord Blood
92.5	0.84	5. Smoking
93.7	**0.55**	6. Presentation
99.2	**0.55**	7. Antenatal Steroids
99.4	**0.55**	8. Delivered By
98.3	**0.28**	9. Scalp Blood Sample
95.8	**0.09**	10. Anaesthesia: Pudendal Block[#] Data Collector 2

Note: Scores failing to meet criterion are presented in bold

*The results are presented for the combined sample of 1511, as well as separately for the two data collectors because these variables exhibited low inter-rater reliability

[#] Disagreement was only present in the data collector 2 sample

Table 5.3 shows that six variables (postal code, labour type, fetal monitoring, cord blood sample, smoking and presentation) had percent agreement below the 95.0% acceptable threshold. The chance corrected agreement (denoted by kappa) for all these variables except for presentation were relatively high, ranging from 0.69 to 0.86. But since both criteria had to be met before declaring the agreement as acceptable, the interpretation of the disagreements was based on the percent agreement.

Four variables (antenatal steroids, delivered by, scalp blood sample and anaesthesia: pudendal block (data collector 2)) had relatively low kappa (0.55, 0.55, 0.28

and 0.09 respectively) despite very high and acceptable levels of percent agreement. Since only one criterion was met, the interpretation of the disagreements was based on kappa.

Table 5.4 shows a summary of the disagreements for the logbook – charts and the database – charts entries.

Table 5.4 Disagreements in Logbook – Charts and Database – Charts Entries for Categorical Variables Based on Percent Agreement (< 95.0%) OR Kappa (≤0.60)

Percent Agreement	Cohen's Kappa	Logbook – Charts Variable	Percent Agreement	Cohen's Kappa	Database – Charts Variable
89.8	—	1. Postal Code	**92.1**	—	1. Postal Code
92.3	0.89	2. Number of previous term pregnancies	**91.6**	0.88	2. Number of previous term pregnancies
94.6	**0.55**	3. Number of previous preterm pregnancies	**94.2**	**0.45**	3. Number of previous preterm pregnancies
87.5	0.76	4. Labour Type* (combined)	**87.5**	0.76	4. Labour Type
89.1	0.80	Data Collector 1			
83.8	0.64	Data Collector 2			
62.1	**0.38**	5. Fetal Monitoring* (combined)	**63.6**	**0.41**	5. Fetal Monitoring* (combined)
64.7	**0.42**	Data Collector 1	**66.3**	**0.43**	Data Collector 1
56.2	**0.28**	Data Collector 2	**57.3**	**0.29**	Data Collector 2
88.5	**0.37**	6. Presentation	**92.3**	**0.46**	6. Presentation
87.5	0.72	7. Anaesthesia: Narcotic* (combined)	**86.6**	0.71	7. Anaesthesia: Narcotic* (combined)
86.9	0.70	Data Collector 1	**86.3**	0.69	Data Collector 1
88.8	0.77	Data Collector 2	**87.3**	0.73	Data Collector 2
98.7	**-0.01**	8. Anaesthesia: Pudendal Block# Data Collector 2	**94.5**	**-0.02**	8. Anaesthesia: Pudendal Block# Data Collector 2
93.0	0.71	9. Anaesthesia: Nitrous Oxide	**92.3**	0.69	9. Anaesthesia: Nitrous Oxide

Note: Scores failing to meet criterion are presented in bold

* The results are presented for the combined sample of 1511, as well as separately for the two data collectors because these variables exhibited low inter-rater reliability.

Disagreement was only present in the data collector 2 sample.

Table 5.4 (continued)

Percent Agreement	Cohen's Kappa	Logbook – Charts Variable	Percent Agreement	Cohen's Kappa	Database – Charts Variable
82.0	**0.53**	10. Newborn Resuscitation: Free Flow Oxygen	**81.4**	**0.51**	10. Newborn Resuscitation: Free Flow Oxygen
94.8	**0.57**	11. Newborn Resuscitation: Positive Pressure Ventilation	**94.8**	**0.55**	11. Newborn Resuscitation: Positive Pressure Ventilation
91.3	0.87	12. Apgar Score (1 minute)	**91.3**	0.87	12. Apgar Score (1 minute)
90.0	0.80	13. Apgar Score (5 minutes)	**90.9**	0.80	13. Apgar Score (5 minutes)
62.1 **78.2** **24.9**	**0.16** **0.35** **0.01**	14. Cord Blood Sample* (combined) Data Collector 1 Data Collector 2	**65.4** **83.1** **24.8**	**0.12** **0.44** **0.01**	14. Cord Blood Sample* (combined) Data Collector 1 Data Collector 2
78.5	**0.56**	15. Smoking	**80.2**	**0.58**	15. Smoking
91.7	0.78	16. Breastfeeding	**92.2**	0.79	16. Breastfeeding
99.5	**0.50**	17. Delivered By	99.2	**0.40**	17. Delivered By
99.1	**0.55**	18. Newborn Resuscitation: Intubation	99.3	**0.60**	18. Newborn Resuscitation: Intubation
99.2	**0.60**	19. Newborn Resuscitation: Drugs	99.1	**0.53**	19. Newborn Resuscitation: Drugs
99.5	**0.50**	20. Newborn Resuscitation: Chest Compression	99.7	**0.54**	20. Newborn Resuscitation: Chest Compression
99.1	**0.23**	21. Scalp Blood Sample	98.0	**0.10**	21. Scalp Blood Sample

The disagreements in the logbook – charts entries are identical to those in the Database – charts. Sixteen variables did not meet the 95.0% agreement threshold both in the logbook – charts and in the database – charts comparisons. Five variables (delivered by, newborn resuscitation (intubation, chest compression and drugs) and scalp blood sample) did not meet the kappa threshold of 0.60 with values ranging from 0.1 to 0.60 despite very high and acceptable levels of agreement (98.0 to 99.7%). Reasons and interpretations of these findings are discussed in chapter 6 section 6.2.4 (page 119).

Continuous Variables: The full sample of 1511 was used for the calculation of the percent agreement, except for the gestational age, which was calculated separately for the two data collectors because of low inter-rater reliability. For the ICC analysis however, all the unknown categories were excluded because they were coded as "99" and this produced false low ICC because it assumes that all the data are on a continuum and for variables such as mother's age and gestational age where the highest values were 46 and 42 respectively, the "99" caused the ICC to be falsely low. Therefore, for the ICC analysis, the sample sizes ranged from 1511 to 1492. The analyses for the continuous variables are presented in Table 5.5.

Table 5.5 Continuous Variables (Intra-Class Correlation (ICC) and Percent Agreement)

Continuous Variables	Database - Logbook					Logbook - Charts					Database - Charts				
		Agreement (N=1511)					Agreement (N=1511)					Agreement (N=1511)			
	Intraclass Correlation (N)[Ψ]	*>95.0%*	*90.0 – 94.9%*	*85.0 – 89.9%*	*<85.0%*	*Intraclass Correlation (N)*	*>95.0%*	*90.0 – 94.9%*	*85.0 – 89.9%*	*<85.0%*	*Intraclass Correlation (N)*	*>95.0%*	*90.0 – 94.9%*	*85.0 – 89.9%*	*<85.0%*
1. Mother's age	0.97 (1508)	X				0.98 (1508)		X			0.96		X		
2. Gestational age1* (combined)	0.98 (1504)	X				0.97 (1505)			X		0.97 (1508)			X	
Data Collector 1	0.98 (1051)	X				0.98 (1051)		X			0.99 (1052)		X		
Data Collector 2	0.99 (453)	X				0.97 (454)			X		0.94 (456)				X

[Ψ] (N) is indicated where there are "unknown" categories, else (N) = 1511.

* The results are presented for the combined sample of 1511, as well as separately for the two data collectors because these variables exhibited low inter-rater reliability.

Table 5.5 (Continued)

Continuous Variables	Database - Logbook					Logbook - Charts					Database - Charts				
		Agreement (N=1511)					Agreement (N=1511)					Agreement (N=1511)			
	Intraclass Correlation (N)	*>95.0%*	*90.0 – 94.9%*	*85.0 – 89.9%*	*<85.0%*	*Intraclass Correlation (N)*	*>95.0%*	*90.0 – 94.9%*	*85.0 – 89.9%*	*<85.0%*	*Intraclass Correlation (N)*	*>95.0%*	*90.0 – 94.9%*	*85.0 – 89.9%*	*<85.0%*
3. Gestational age2* (combined)	0.98 (1504)	X				0.97 (1505)			X		0.97 (1508)			X	
Data Collector 1	0.98 (1051)	X				0.98 (1051)		X			0.99 (1052)		X		
Data collector 2	0.99 (453)	X				0.97 (454)			X		0.94 (456)				X
4. Baby's weight: 1	0.99 (1508)	X				0.99 (1492)		X			0.99 (1495)		X		
5. Baby's weight: 2	0.99 (1508)	X				0.98 (1492)		X			0.99 (1495)		X		

Table 5.5 illustrates that all the entries for the database – logbook met the 95.0% threshold of agreement, with ICC ranging from 0.97 to 0.99. The logbook – charts and the database – charts entries were all below the 95.0% threshold. Despite the fact that the ICC values for these variables were quite high ranging from 0.94 to 0.99, the results were interpreted based on the percent agreement.

5.2 Survey of Stakeholders

5.2.1 Response Rate

The response rates for the questionnaires were 75% for the Hospital Database Coordinators (12 out of 16), 87.5% for the Data Entry Personnel (14 out of 16), 75% for PPPESO staff (3 out of 4) and 83.3% for the PHUs (5 out of 6).

The results of the survey analyses are presented in terms of the content, data collection, data analysis and reports, and the uses of the Database. The percentages presented in the ensuing sub-sections were based on the numbers of responses, which varied from question to question. Except for the uses of the Database, responses to open-ended questions are not presented in the tables.

5.2.2 Content

Derived from the evaluation framework described in Table 4.1 (page 38), the attribute assessed by the questionnaires in terms of the content of the database was *acceptability* (evaluation questions a1 and a2). A greater percentage of Database Coordinators than PHUs reported that the variables were useful (Table 5.6). Over 90% of the Database Coordinators reported their satisfaction with the variable definitions.

When asked for suggestions for variables to add, eight out of twelve Database Coordinators, and all PHUs responded. The following were suggested:

- **Labour and delivery variables:** such as indication for caesarean section, episiotomies, augmentation of labour and method of induction (37.5% of Database Coordinators).
- **Maternal characteristics:** such as alcohol and substance abuse, folic acid intake and prenatal education (25% of Database Coordinators), physical activity, nutrition, prenatal education and alcohol use (20% of PHUs) and diagnosis of postpartum depression (60% of PHUs).
- **Neonatal variables and outcomes**: 25% of Database Coordinators suggested more information about neonatal outcomes, compared to 60% of PHUs making the same suggestion.
- **General variables:** length of stay in hospital suggested by one Database Coordinator and one PHU.

None of the PHUs suggested the deletion of any variable, while one Database Coordinator wanted to delete maternal pain relief with the exception of general, spinal and epidural anaesthesia and another one indicated that the fetal monitoring was not a useful variable to have.

Table 5.6 Survey Results: Content of the Perinatal Database

	Q=question number, (N)=number of responses				
Questionnaire Question	**Database Coordinator N=12**	**Data Entry Personnel N=14**	**PPPESO N=3**	**Public Health Units N=5**	**Evaluation Question (*attribute*)**
Proportion of useful variables	**Q1(11)**			**Q1(5)**	a1. Do the partners find the variables in the database useful? **(*acceptability*)**
90%+	6 (54.5%)			1 (20.0%)	
60-89%	3 (27.3%)			0 (0.0%)	
40-59%	1 (9.1%)			3 (60.0%)	
10-39%	1 (9.1%)			0 (0.0%)	
<10%	0 (0.0%)			1 (20.0%)	
Satisfaction with the variable definitions	**Q4(12)**				a2. Are the partners satisfied with the variable definitions? **(*acceptability*)**
Very satisfied	5 (41.7%)				
Satisfied	6 (50.0%)				
Neutral	1 (8.3%)				
Dissatisfied	0 (0.0%)				
Very dissatisfied	0 (0.0%)				

Note: Blank Cells = not asked

5.2.3 Data Collection

The attributes assessed were *simplicity* (evaluation question b2), *acceptability* (evaluation questions b9, b10, b11 and b12) and *stability* (evaluation question b13).

Simplicity: 73% of the Database Coordinators and 86% of the Data Entry Personnel reported that data entry was easy to very easy (Table 5.7) Three Database Coordinators provided comments about the data entry procedure, two suggesting that the procedure can be simplified by downloading the data directly into the database through an electronic version of the logbook and one that data should be entered by only one person to ensure consistency. Six Data Entry Personnel provided comments: one that they need to be able to copy data, as in the case of twins; three suggested the removal of the "time out" feature, which leads to loss of data when the data entry gets interrupted for a period of time; one reported problems accessing the system especially on weekends and evenings when most of the data entry is done; one reported frustration with data getting lost when the "enter" key is pressed instead of the "tab" key. One commented that the data entry screen is user friendly.

Acceptability: The time taken to enter the data per record was reported to be three minutes or less, by 86% of the Data Entry Personnel.

Almost three-quarters of the Database Coordinator (8/11) respondents felt that the investment the hospitals make in the data entry was suitable for the return they were getting out of the database. Two of the three others gave as the reason for their negative response the time commitment needed to obtain reports from the database.

Every month, the central office of PPPESO sends data verification requests to the Database Coordinators and 80% of respondents reported that they were satisfied to very satisfied with the procedure. All the hospital sites were confirmed to be

participating in the system by the three PPPESO staff who responded to the questionnaires.

Stability: The frequency of the system going down was reported to be never or once per week by 46% of the Database Coordinators (54% did not know), 86% of the Data Entry Personnel (14% did not know) and 67% of PPPESO staff (33% did not know). The perceived duration of outages was reported to be less than an hour by none of the Database Coordinators (but 71% did not know), by 11% of the Data Entry Personnel (44% did not know), and by 67% of PPPESO staff (33% did not know).

Information obtained from CritiCall about the frequency of outages experienced by the system (not shown in table), showed that the system is scheduled for preventive maintenance once/month for two hours. Other system outages that are not scheduled lasted about 10 minutes/month, averaging two hours/year. Based on this information, the system's downtime/year (including scheduled maintenance) is:

26/8760 = 0.3%, where 26 is the total hours of downtime/year, and 8760 is the total number of hours per year of operation (365*24 hours).

Three Data Entry Personnel provided general comments regarding problems they were experiencing with the system, two of whom expressed their dissatisfaction with the way the system times out leading to the loss of the data when entry is interrupted. One reported experiencing shut downs of the system on several occasions when the "date" field was entered. Suggestions for improvements were provided by seven Data Entry Personnel, three of whom suggested modifications to the scroll down menus of the variables so that they start at the normal and scroll to the abnormal; two each suggested larger, bolder prints and one suggested darker background; one suggested addressing the problem of missing data in the logbook, since records cannot be saved into the system when certain variables are missing.

Table 5.7 Survey Results: Data Collection

	(Q=question number, (N)=number of responses)				
Questionnaire Question	**Database Coordinator N=12**	**Data Entry Personnel N=14**	**PPPESO N=3**	**Public Health Units N=5**	**Evaluation Question *(attribute)***
Data Entry Procedure	**Q6(11)**	**Q1(14)**			b2. Are data entry procedures simple and easy to use? ***(simplicity)***
Very Easy	3 (27.3%)	8 (57.1%)			
Easy	5 (45.5%)	4 (28.6%)			
Neutral	2 (18.2%)	1 (7.1%)			
Difficult	1 (9.1%)	1 (7.1%)			
Very difficult	0 (0.0%)	0 (0.0%)			
Time it takes to enter data for 1 record		**Q3(14)**			b9. How long does it take to enter the data? ***(acceptability)***
Less than 1 minute		3 (21.4%)			
1-3 minute		9 (64.3%)			
4 - 6 minutes		2 (14.3%)			
> than 6 minutes		0 (0.0%)			
Investment suitable for the return	**Q8(11)**				b10. Is the investment the hospitals make in the data entry suitable for the return? ***(acceptability)***
Yes	8 (72.7%)				
No	3 (27.3%)				

Table 5.7 (continued)

Questionnaire Question	(Q=question number, (N)=number of responses) Database Coordinator N=12	Data Entry Personnel N=14	PPPESO N=3	Public Health Units N=5	Evaluation Question *(attribute)*
Satisfaction with the data verification process	**Q11(10)**				b11. Are the hospital partners satisfied with the data verification process provided by PPPESO? ***(acceptability)***
Very satisfied	5 (50.0%)				
Satisfied	3 (30.0%)				
Neutral	2 (20.0%)				
Dissatisfied	0 (0.0%)				
Very dissatisfied	0 (0.0%)				
Number of sites participating in the system			**Q1(3)**		b12. How many sites are participating in the system out of the total number of sites? ***(acceptability)***
All 16 hospital sites			3 (100%)		
Frequency of system going down	**Q9(11)**	**Q4(14)**	**Q2(3)**		b13. What is the percentage of the time the system is fully operational? ***(stability)***
Never	3 (27.3%)	8 (57.1%)	1 (33.3%)		
1 per week	2 (18.2%)	4 (28.6%)	1 (33.3%)		
2 per week	0 (0.0%)	0 (0.0%)	0 (0.0%)		
3 times or more	0 (0.0%)	0 (0.0%)	0 (0.0%)		
Do not know	6 (54.5%)	2 (14.2%)	1 (33.3%)		
If system goes down, time it takes for it to get restored	**Q10(7)**	**Q5(9)**	**Q3(3)**		
Less than 1 hour	0 (0.0%)	1 (11.1%)	2 (66.7%)		
1-2 hours	1 (14.3%)	2 (22.2%)	0 (0.0%)		
3-4 hours	0 (0.0%)	1 (11.1%)	0 (0.0%)		
More than 4 hours	1 (14.3%)	1 (11.1%)	0 (0.0%)		
Do not know	5 (71.4%)	4 (44.4%)	1 (33.3%)		

5.2.4 Data Analysis and Reports

The attributes assessed were *simplicity* (evaluation questions c1 and c2), *timeliness* (evaluation question c4), *flexibility* (evaluation question c5) and *acceptability* (evaluation questions c6, c7, c8 and c9).

Simplicity: Database Coordinators found the report generation much less easy than Public Health Units (Table 5.8). Of those who responded, half of the Database Coordinators and half of the PHUs suggested modifications to the setup of the report generation so that the specified date range does not get cleared with each query. A third of the Database Coordinators who provided comments, complained about the system shutting down when making more than one query at time. Three-quarters of the PHU respondents suggested modifications to allow cross-tabulations in order to identify subgroups.

Most of the Database Coordinators and all of the PHUs reported that it was easy to interpret the reports. Asked to provide comments about the interpretation of the reports, half of the Database Coordinators who responded commented that they cannot interpret the reports when they indicate 0.5 of a pregnancy (as happens with twins), or when the total number of babies and total number of livebirths differ. The other half said that they needed more time to familiarize themselves with the reports.

Timeliness: The three PPPESO staff that responded to the questionnaires confirmed that the annual report is produced in June of each year and that it is made public during the same month.

Flexibility: Database Coordinators found the procedure to customize data requests to obtain the reports much less easy than PHUs.

Acceptability: Two-thirds of the Database Coordinators (8/12) reported that they have generated Frequency Reports (frequencies between less than one/month to

one/month). Two of the four who reported never having produced Frequency Reports attributed that to lack of time. The other half attributed their negative response to the fact that they can more easily obtain the information they needed from the paper logbook.

Four of the ten Database Coordinators who responded, reported that they have generated Comparison Reports. Of those, three reported that they generate them once/3 months. Five of eleven Database Coordinators were satisfied with the report format, while the remaining six were neutral.

Four of five PHUs reported that they were using the report facility and all of them reported being neutral to its format (in fact, it was known that all the hospitals have generated reports).

Over half of the Public Health Units reported using the user support facility provided by PPPESO, and all were very satisfied with it. Most of the Database Coordinators (8/9) were satisfied to very satisfied with the user support.

Table 5.8 Survey Results: Data Analysis and Reports

Questionnaire Question	(Q = question number, (N) = number of responses) Database Coordinator N=12	Data Entry Personnel N=14	PPPESO N=3	Public Health Units N=5	Evaluation Question *(attribute)*
Procedure for generating reports	**Q13(11)**			**Q11(4)**	c1. Is the report generation easy to perform? ***(simplicity)***
Very easy	2 (18.2%)			0 (0.0%)	
Easy	5 (45.5%)			3 (75.0%)	
Neutral	3 (27.3%)			1 (25.0%)	
Difficult	1 (9.1%)			0 (0.0%)	
Very difficult	0 (0.0%)			0 (0.0%)	
Interpretation of the reports	**Q20(10)**			**Q16(4)**	c2. Are the reports generated simple and easy to understand/interpret? ***(simplicity)***
Very easy	0 (0.0%)			0 (0.0%)	
Easy	7 (70.0%)			4 (100%)	
Neutral	3 (30.0%)			0 (0.0%)	
Difficult	0 (0.0%)			0 (0.0%)	
Very difficult	0 (0.0%)			0 (0.0%)	
Production of the annual report			**Q4(3)**		c4. Is the annual regional report produced in a timely fashion? ***(timeliness)***
June each year			3 (100%)		
Report made public			**Q5(3)**		
June			3 (100%)		

Table 5.8 (continued)

Questionnaire Question	(Q = question number, (N) = number of responses) Database Coordinator N=12	Data Entry Personnel N=14	PPPESO N=3	Public Health Units N=5	Evaluation Question *(attribute)*
Customizing data requests	**Q14(11)**			**Q12(4)**	c5. Can data be analyzed as required by the partners? ***(flexibility)***
Very easy	1 (9.1%)			0 (0.0%)	
Easy	5 (45.5%)			3 (75.0%)	
Neutral	3 (27.3%)			1 (25.0%)	
Difficult	2 (18.2%)			0 (0.0%)	
Very difficult	0 (0.0%)			0 (0.0%)	
How often do frequency reports get generated?	**Q18(12)**				c6. How often do hospital partners generate reports? ***(acceptability)***
Never	4 (33.3%)				
Less than 1 per month	4 (33.3%)				
1 per month	4 (33.3%)				
1 per week	0 (0.0%)				
More than 1 per week	0 (0.0%)				
How often do comparison reports get generated?	**Q19(10)**				
Never	6 (60.0%)				
1 every 3 months	3 (30.0%)				
1 per month	0 (0.0%)				
1 per week	0 (0.0%)				
Other, please specify:					
Have done 1 or 2 in the past year	1 (10.0%)				

Table 5.8 (continued)

Questionnaire Question	(Q = question number, (N) = number of responses) Database Coordinator N=12	Data Entry Personnel N=14	PPPESO N=3	Public Health Units N=5	Evaluation Question *(attribute)*
Used report facility?				**Q9(5)**	c7. Are the Public Health Units producing reports? ***(acceptability)***
Yes				4 (80.0%)	
No				1 (20.0%)	
Satisfaction with the report format	**Q16(11)**			**Q14(4)**	c8. Are the reports provided in the format required by the partners? ***(acceptability)***
Very satisfied	0 (0.0%)			0 (0.0%)	
Satisfied	5 (45.5%)			0 (0.0%)	
Neutral	6 (54.5%)			4 (100%)	
Dissatisfied	0 (0.0%)			0 (0.0%)	
Very dissatisfied	0 (0.0%)			0 (0.0%)	
Used user support provided by PPPESO				**Q18(5)**	c9. Are the partners who are producing reports satisfied with the user support provided by PPPESO? ***(acceptability)***
Yes				3 (60.0%)	
No				2 (40.0%)	
Satisfaction with the user support	**Q22(9)**			**Q19(3)**	
Very satisfied	4 (44.4%)			3 (100%)	
Satisfied	4 (44.4%)			0 (0.0%)	
Neutral	1 (11.1%)			0 (0.0%)	
Dissatisfied	0 (0.0%)			0 (0.0%)	
Very dissatisfied	0 (0.0%)			0 (0.0%)	

5.2.5 Uses of the Database

The attribute assessed was *usefulness* (evaluation questions d1 – d6). Ten of the twelve Database Coordinators reported that the database has greatly increased (6/12) or provided some increase (4/12) in access to information about perinatal care practices. One of the five PHUs reported greatly increased access and three reported some increase in access (Table 5.9).

Database Coordinators were asked if the Database was meeting their needs, and 91% (10/11) answered "yes". Of the five PHUs, three reported that it was meeting their needs to some or to a great extent, but two reported that it was hardly meeting their needs. More than half of the Database Coordinators reported that the database provided readily accessible data to generate reports about practices, comparisons and trends. The PHUs reported that the Database was more timely than vital statistics and that the smoking and breastfeeding variables were relevant to public health, but half of the respondents said that they would like to see more public health variables since they considered the current Database to be clinically and hospital oriented.

The most commonly reported use of the Database by the Database Coordinators was for statistics for departmental and annual meetings (6/12). They also used it for comparison between hospitals (3/12) and educational purposes (3/12). (Details in Table 5.9). The PHUs used the Database to determine smoking and breastfeeding rates (2/5) and to assess the number of births in their region for planning purposes (2/5). PPPESO's use of the Database included: identifying areas of concern (3/3), monitoring changes in practices after program implementation (2/3), evaluating and comparing practices (2/3), and research projects and program planning (1/3).

Suggestions provided by PPPESO to optimize the use of the database (not shown in the table), focused on linkage to hospital information systems and other data

systems to prevent duplication of services. Improvement of the on-line report format and the addition of a neonatal component were also suggested.

Two of the three PPPESO staff reported that consistency in the variable definitions among the hospitals constituted one of the main challenges of operating this database (not shown in table). Other challenges included: coordinating the partners to agree on enhancements for the system, funding, data quality issues and disagreements between logbook and charts. To address these challenges, PPPESO staff suggested: conduct of audits and feedback, continuation of the data verification performed by the central office of PPPESO and development of standard labour and delivery forms for all the hospitals.

All of PPPESO staff stated that the database was linkable, while PHUs responded negatively or did not know. The procedure was deemed difficult by most of the respondents. One PPPESO staff reported that it had been done once, while the PHUs did not know.

Table 5.9 Survey Results: Usefulness

Questionnaire Question	Q=question number, (N)=number of responses				Evaluation Question
	Database Coordinator N=12	Data Entry Personnel N=14	PPPESO N=3	Public Health Units N=5	
Contribution to the access to information	**Q24(12)**			**Q21(5)**	d1. How much has the database contributed to the access to information about perinatal care practices?
Greatly increased access	6 (50.0%)			1 (20.0%)	
Some increase in access	4 (33.3%)			3 (60.0%)	
No change	2 (16.7%)			1 (20.0%)	
Extent the database is meeting needs	**Q25(11)**			**Q22(5)**	d2. Is the database meeting the needs of the partners?
To a great extent	10 (90.9%)*			1 (20.0%)	
To some extent				2 (40.0%)	
Hardly at all	1 (10.0%)			2 (40.0%)	
Explain	**Q25(9)**			**Q23(4)**	
1. Provides readily available data to generate reports about practices, comparison and trends	5 (55.5%)			—	
2. Much more timely than vital statistics	—			2 (50.0%)	
3. Would like to see more public health variables. It is too clinically oriented and hospital based right now	—			2 (50.0%)	
5. The addition of Smoking and breastfeeding, relevant to public health	—			2 (50.0%)	

* Asked as yes/no only.

Table 5.9 (continued)

Questionnaire Question	Q=question number, (N)=number of responses Database Coordinator N=12	Data Entry Personnel N=14	PPPESO N=3	Public Health Units N=5	Evaluation Question
Examples of how the database was used	**Q26(11)**			**Q24(5)**	d3. How have the hospitals used the database?
1. Comparison between hospitals	4 (36.4%)			—	
2. Educational purposes	3 (27.3%)			—	
3. Statistics for departmental and annual meetings	6 (54.5%)			—	
4. Continuous Quality Improvement (CQI) reports to the board	3 (27.3%)			—	
5. To show trends	3 (27.3%)			—	
6. Snapshots of smoking and intention to breastfeed among mothers	—			2 (40.0%)	d4. How have the health units used the database?
7. Early tabulation of the total number of deliveries and live births for pre and perinatal programming and for community health status reports	—			2 (40.0%)	
8. Success by Six report cards	—			1 (20.0%)	d5. How has PPPESO used the database?
PPPESO's use of the database			**Q10(3)**		
1. Identifying areas of concern			3 (100%)		
2. Monitoring of trends and changes in practices after program implementation			2 (66.6%)		
3. Evaluating and comparing practices			2 (66.7%)		
4. Education and Research projects			1 (33.3%)		

Table 5.9 (continued)

Questionnaire Question	Q=question number, (N)=number of responses Database Coordinator N=12	Data Entry Personnel N=14	PPPESO N=3	Public Health Units N=5	Evaluation Question
PPPESO's use of the database cont..			**Q10(3)**		d5. How has PPPESO used the database?
5. Program planning			1 (33.3%)		
Is the database linkable?			**Q6(3)**	**Q25(5)**	d6. Can the database be linked to other databases for research proposes?
Yes			3 (100%)	0 (0.0%)	
No			0 (0.0%)	2 (40.0%)	
Do not know			0 (0.0%)	3 (60.0%)	
If linkable, how easy is it?			**Q7(2)**	**Q26(1)**	
Very easy			0 (0.0%)	0 (0.0%)	
Easy			0 (0.0%)	0 (0.0%)	
Neutral			1 (50.0%)	0 (0.0%)	
Difficult			1 (50.0%)	1 (100%)	
Very difficult			0 (0.0%)	0 (0.0%)	
Frequency of linkage			**Q8(3)**	**Q27(3)**	
Never			0 (0.0%)	1 (33.3%)	
Once			1 (33.3%)	0 (0.0%)	
Twice			0 (0.0%)	0 (0.0%)	
Three times or more			0 (0.0%)	0 (0.0%)	
Do not know			2 (66.7%)	2 (66.7%)	

5.3 Direct Observations

Observations revealed that the data entry procedures differed across hospitals. Individuals entering the data varied from one hospital to the other. The list included: personnel from the medical records departments, obstetrical nurses and Database Coordinators. In some hospitals the data were entered by only one individual, while others had more than one person entering data. Each hospital had the same working manual providing definitions for the variables. In addition, there was a help menu on the entry screen that provided those definitions.

The observations also confirmed that in most of the hospitals the case room logbook served as the source for the data entered into the database, with the exception of two hospitals which used their own labour and delivery database as the source of the data. Some hospitals, however, were concerned about the amount of missing information and the accuracy of the logbook, so entered some of the data from the mothers' charts. This was not consistent and depended on the particular Data Entry Personnel. Staff at some hospitals also went the "extra mile" and recorded information from the babies' charts checking for baby transfers or other neonatal outcomes that were missing in the logbook or the mothers' charts. This was not consistent across the hospitals. During the hospital visits, it was also observed that in a few hospitals, the logbook was not completed in the case room but rather sometime later with information being obtained from the mothers' charts and notes that the nurses had taken from the mothers in the case room.

5.4 Review of PPPESO Files and Reports

A review of the strategic plan, the program's Executive Summary, as well as communications with key individuals at PPPESO revealed a clear mission for the

program as a whole, with a well defined vision and guiding principles (see Appendix E1 for mission, vision and guiding principles). The Perinatal Database forms one of the basic components of the overall Perinatal Program under the heading of "Health Status and Performance Measurement" It provides the data and an analysis tool for the perinatal surveillance system described in section 3.4 (page 33). See Appendix E2 for the Perinatal Program Model (from their Strategic Plan document).

Through information obtained from the documents and communications with key personnel involved with the Database, it was confirmed that the on-going funding for the Database comes from financial contributions by all the partners, as part of their contribution to the perinatal program as a whole. The hospital partners also contribute varying amounts to the database, mainly through in-kind contributions by entering their own data. The Health information Partnership has contributed financially in recent years to support the preparation of the regional and health units' reports. Other than that, there are no separate resources specifically allocated to the Database, but rather the money comes from a pool of funding raised by the overall partnership program. The majority of the program's core funding comes from the participating teaching hospitals, through their mandate to provide outreach education. The MOHLTC currently does not provide direct funding. The achievement of longer term funding stability is at the top of the list of strategic issues identified in the 2002 – 2005 strategic plan document.[58]

The Perinatal Database serves as the source of data for the production of the "Annual Perinatal Statistical Reports" issued by PPPESO. Commencing in June 1999, four reports have been issued so far (for data files 1998 – 2001).[35,37,59,60] The reports presented information on place of birth, health status of newborns, use of obstetrical interventions and some maternal characteristics. Several indicators of perinatal care by hospital type (teaching, large community, or small community) and for the region as a

whole were included in the reports. Hospital-specific reports are prepared annually and their contents discussed with each hospital.

Comparisons of the four reports revealed continuous improvements in the amount and variety of information presented. In the first report, data from three hospitals were provided only in summary form rather than for individual births, because they had not participated in the data entry at the time. In the second report data were presented for individual births in all the participating hospitals. Results of data analysis by health unit region were presented in the last two reports (2000 and 2001), following the addition of the mother's postal code variable in the database in 1999. The report of 2000 included results of an audit of the 1999 data file, conducted to assess the quality of the data in the Perinatal Database. As in this study, detailed comparisons were conducted of data in the database with entries in the case room logbook, data in the database with those in the mother's chart and data in the logbook with those in the mother's chart. Results of the audit revealed high concordance (< 5% error) between the database and the logbook for all but four variables: electronic monitoring (17%), induction (13%), number of previous preterm babies (6%) and number of previous term babies (11%). For the logbook – chart and database – chart comparisons, the errors were similar and involved the following variables: labour type, electronic fetal monitoring, narcotics, newborn resuscitation (free flow oxygen) and number of previous term babies (all at >10% error; the exact numbers were not recorded). Other variables such as: presentation, cord blood sample, smoking and number of previous preterm babies had 6-10% error. The analyses of the previous audit were done by cross-tabulation and the calculation of percent agreement. No kappa values were calculated and inter-rater reliability analyses were not presented. Furthermore, all the "unknown" or "missing" categories were excluded from the analyses. Comparison of the results from this past

audit with the ones obtained from the current data re-abstraction is discussed in chapter 6.

The four midwifery groups in Eastern Ontario (Community Midwives of Kingston, Midwifery Collective of Ottawa, Midwifery Group of Ottawa, Ottawa Valley Midwives) who provide support to home births started entering data into the database during 2002. Some midwifery groups have also entered data from 2001. Data on home births are not included in the previous reports but plans are underway to include them in the 2002 report.

In 2001, the Health Information Partnership of Eastern and Southeastern Ontario (HIP) published a "Population-based Analysis of Perinatal Data for Eastern Ontario, 1999"[61] in which the Perinatal Database served as the source of the data. This was the only publication (other than the PPPESO statistical annual reports and hospital reports) that used data from the Perinatal Database.

5.5 Examination of the Database on the CritiCall system

Data Entry: Simulated data were entered to examine the performance of the system with complete and missing data. Most of the drop-down menus for the variables default to an unknown or a missing value category, but multiple gestation, labour type, presentation, assisted delivery, and antenatal steroids default to the most common options. Data entry is assisted by several built-in system checks. Examples include: the baby number must be unique and must follow the sequence of previous numbers already on the file, the gestational age and the weight are entered twice and both entries must match. The system also alerts the data entry individual to any missing information. Several logical consistencies were observed, for example if "no labour" is chosen with vaginal delivery, the record will not be saved until a labour type is chosen. Similarly, one cannot select "neonatal death at transfer hospital" and then select "no neonatal transfer".

When left idle briefly during data entry, the system "times-out", thus losing the data that had been entered but not yet saved.

Although the variables gestational age and Apgar score default to an "unknown" category, their scroll-down menus start at extreme values (18 for the former and 0 for the latter), rendering them not user-friendly, as one has to scroll all the way down to the normal values.

Data for baby's monitoring are crucial to be able to save the record. The system alerts the operator to any missing data for the variable, but even if one confirms that they were actually missing from the logbook, the system will not save the record unless this information is recorded. This may cause problems in the accuracy of the data entered, as the data entry individual may be forced to enter an option just to be able to save the record.

All the newborn resuscitation and the maternal pain relief categories have only two selection options: a "yes" indicated by a check mark beside the category or a "no" indicated by a blank. There is no "missing" option. Fields were sometimes blank indicating no resuscitation in cases where the chart indicated that resuscitation was administered. Similarly, some women were noted to have had a caesarean section with no anaesthesia, presumably wrongly. But since there is no "missing" or "unknown" option to select on the entry screen, the Data Entry Personnel leave this blank indicating a "no", which is erroneous.

There are four steroid dosage options in the database, whereas this variable is sometimes recorded as yes or no in the logbook, without any mention of the different dosage options specified in the database.

Discrepancies were noted between the options available in the CritiCall entry screen and the SPSS data file that is generated from the entries in the Database and used by the data analyst. For example, the newborn resuscitation, maternal pain relief,

and the labour type have an unknown category in the SPSS data file but not in the entry screen.

Data Completeness: Exploration of the data to examine the amount of missing values by running frequencies on all the variables revealed that there was complete data (N= 17688) on all the variables with the exceptions illustrated in Table 5.10.

Table 5.10 Variables in the Database with Missing Values

Variable	Number Missing (%)
1 Postal Code	21 (0.1%)
2. Baby's weight	6 (0.0%)
2. Gestational age	31 (0.2%)
4. Mother's age	14 (0.1%)
5. Infant's gender	36 (0.2%)
6. Number of previous term babies	26 (0.2%)
7. Number of preterm babies	22 (0.1%)
8. Apgar Score (1 minute)	53 (0.3%)
9. Apgar Score (5 minutes)	63 (0.4%)
10. Breastfeeding	504 (2.9%)
11. Smoking	764 (4.3%)
12. Cord blood sample	187 (1.1%)
13. Scalp blood sample	335 (1.9%)
14. Delivered by	92 (0.4%)

Reports: Two types of reports can be generated within the CritiCall system: frequency and comparison reports. The hospitals and PHUs can also download the database records into Excel sheets and perform further analyses on the data as desired. To run the reports, requests for data have to be customized according to the needs of the individual/s running the reports. The reports are then downloaded into Excel sheets or workbooks. The overall procedure was found to be simple and relatively quick. However, there were some problems with the efficiency of the procedure:

1. The specified date range for the request gets cleared after every enquiry, which would be cumbersome if one is generating several reports for the same period of time.

2. The system shuts down when multiple requests are submitted, making the report generation time-consuming.

5.6 Comparison with CIHI Database

There was a discrepancy of 11 livebirths (0.1%) not captured by the Perinatal Database, seven of which could be explained by births occurring at two very small hospitals providing emergency obstetrical services and not participating in the Perinatal Database. Differences in still births could not be assessed as the two databases employ different collection procedures for these outcomes. Home births could not be reviewed as access to midwives' records was not feasible.

5.7 Ability of the Database to Link to Other Population Databases

Using the Geocodes/PCCF software (Version 3J), the postal codes in the Perinatal Database were assigned geographic codes to the extent possible. Table 5.11 shows the sources of these codes. All of the records that were assigned based on the first one or two characters were for invalid postal codes. Those assigned based on the first three characters of the postal are valid only at the FSA level. Out of all 17,688 records in the Perinatal Database, all but 480 (2.7%) could be matched on all six characters of the postal code.

Table 5.11 Sources of Geographic Codes

Description	Number of Records	%
No geographic codes assigned	21	0.12
Province code (or sub-code for Ontario and Quebec) assigned based on only the first character of postal code	4	0.02
Partial set of geography assigned based on only the first two characters of the postal codes (no CT[1] or EA[2])	70	0.40
Partial set of geography assigned based on only the first three characters of the postal code (no CT or EA)	385	2.18
Full set of geographic codes (including lat and long) derived from an exact match to a WCF[3] record (mostly rural)	4951	27.99
Full set of geographic codes (including lat and long) derived from an exact match to a PCCF duplicate record (mostly urban)	1888	10.67
Full set of geographic codes (including lat and long) derived from an exact match to a PCCF unique record (mostly urban)	10369	58.62
Total	17688	100.00%

Notes
[1]CT : Census Tract
[2]EA : Enumeration area
[3]WCF: Weighted Conversion File

Table 5.12 presents a summary of the coding results. 97% of the records in the Perinatal Database were fully coded down to the enumeration area.

Table 5.12 Summary of Coding Results

Description	Number	%
Not coded at all	21	0.12
Coded to Province only	56	0.32
Coded to Province + (CD* or CMA/CA**)+ approximate latitude and longitude	29	0.16
Coded to Province + CD + CMA/CA + approximate latitude and longitude	130	0.73
Coded to Province + CD + CMA + CSD*** + approximate latitude and longitude	266	1.50
Fully coded to Province + CD + CMA + CSD + CT# + EA## + latitude and longitude	17186	97.16
Total	17688	99.99% (due to rounding)

*CD : Census Division
**CMA/CA : Census Metropolitan Area/Census Agglomeration Area
***CSD : Census Subdivision
#CT: Census Tract
##EA : Enumeration Area

A total of 502 records were not assigned EAs. Of those, 480 had postal codes missing or only partially valid, as noted on previous page, and could not be assigned to EAs. The remaining 22 were flagged as improbable places of residence. Further examination of these records showed that 14 of them were office buildings, and the remaining 8 were institutions.

To demonstrate the value of assigning geographic codes to the postal codes, neighbourhood income quintiles (a summary variable from the census) for EAs were

extracted from the PCCF. Table 5.13 shows the PCCF's allocation of income quintiles for the data in the Perinatal Database.

Table 5.13 Allocation of Neighbourhood Income Quintiles

Description	Number of Records	%
Not allocated	630	3.56
Quintile 1 (poorest)	3917	22.14
Quintile 2	3306	18.69
Quintile 3	3179	17.97
Quintile 4	3617	20.45
Quintile 5 (least poor)	3039	17.18
Total	17688	100.00%

Records that were not allocated income (630) include the 502 that were not coded to an enumeration area. The remaining 128 with no income allocation were mostly of institutions, hotels, hospitals or other places of improbable residence.

The quintiles were of unequal sizes because they were calculated based on the whole of Canada, while the geocoded records in this study were mostly from Eastern and Southeastern Ontario, with some from Quebec and very few from other provinces.

5.8 Synthesis of Results with Respect to Evaluation Criteria

Table 5.14 provides a synthesis of the results of the evaluation based on the evaluation framework described in Table 4.1 (page 38). It describes the findings of the evaluation in relation to each attribute under evaluation, the evaluation question, the expectation of the program and whether the expectation has been met.

Table 5.14 Synthesis of Results with Respect to Evaluation Criteria

CDC Criteria/attribute	Evaluation Questions (from evaluation framework)	Expectations of the Program (from evaluation framework)	Findings	Expectations met?
	a. Content			
Acceptability	a1. Do the partners find the variables in the database useful?	At least 75% of the partners rate that all or nearly all (90%+) of the variables in the database are useful	Database Coordinators - 54% PHUs - 20% Suggestions for variables to add: 1. Labour and delivery (indication for caesarean section, episiotomies, augmentation, method of induction) 2. Maternal characteristics (alcohol and substance abuse, nutrition, physical activity, prenatal education and postpartum depression) 3. Neonatal variables and outcomes 4. Length of stay in hospital	No
	a2. Are the partners satisfied with the variable definitions?	At least 95% of the partners who are entering data are satisfied with the variable definitions	Database Coordinators – (11/12) 92% satisfied to very satisfied, (1/12) 8% neutral	No (but no one reported *dis*satisfaction)

CDC (Criteria/attribute)	Evaluation Questions (from evaluation framework)	Expectations of the Program (from evaluation framework)	Findings	Expectations met?
	a. Content			
Representativeness	a3. Is the database capturing all the hospital births as well as the home births occurring in Eastern and Southeastern Ontario?	All women giving birth in Eastern and Southeastern Ontario are to be included	There was discrepancy of 0.1% in the number of hospital livebirths between this Database and CIHI Database. (Independent verification of home births was not feasible)	Yes
	b. Data Collection			
Simplicity	b1. Are data entered into CritiCall Program as intended?	- Logbook completed in case room on all births - Data entered at birth hospital on all births	- Sometimes the logbook gets completed later - Data entered at birth hospital on all births	No Yes
	b2. Are data entry procedures simple and easy to use?	At least 75% of partners who are entering data, report that data entry is easy or very easy to complete	Database Coordinators - 73% Data Entry Personnel - 86%	Partially

CDC Criteria/attribute	Evaluation Questions (from evaluation framework)	Expectations of the Program (from evaluation framework)	Findings	Expectations met?
	b. Data Collection			
Simplicity cont…	b2. Are data entry procedures simple and easy to use?	At least 75% of partners who are entering data, report that data entry is easy or very easy to complete	Cont.. from previous page.. Suggestions to improve data entry: 1. Make the logbook electronic. 2. Have only one person to enter data 3. Remove the "time out" feature of the entry screen 4. In scroll down menus, options should start from the normal 5. Entry screen to have larger and bolder prints with darker background 6. Address issue of missing information in the logbook	Partially
Timeliness	b3. Are the data entered in a timely manner?	All data to be entered within 2 weeks of the last day of the month	With reminders to close the month sent out by PPPESO, all data get entered within 2 weeks of the end of the last day of the month Data were entered within the specified time frame	Yes
Flexibility	b4. Can the database adapt to changing needs? b5. Can more variables be added? b6. How much time and training are required for the changes?	The database is reviewed on an annual basis and changes are made as recommended by the Data Sub-committee with minimal additional time and personnel requirements	The database is adaptable to changing needs. More variables have been added. The new transformation and training for the partners took place over a period of 12 months	Yes
Data Quality	b7. What is the completeness of the data entered?	Data on all births to be at least 95% complete	The completeness of the data for all the variables ranged between 95.7 – 100%	Yes

CDC Criteria/attribute	Evaluation Questions (from evaluation framework)	Expectations of the Program (from evaluation framework)	Findings	Expectations met?
	b. Data Collection			
Data Quality cont...	b8. What is the accuracy of the data in the Database?	Individual variables in the database, logbook and charts, to be at least ≥95% concordant and to have (ICC > 0.9, kappa >0.6)	Percentage of variables in which criteria was met: Database – Logbook entries: 71.4% Logbook – Charts entries : 40.0% Database – Charts entries :40.0%	No
Acceptability	b9. How long does it take to enter the data?	At least 75% of the data entry personnel report that it takes ≤3 minutes to enter data for 1 record	Data Entry Personnel - 86%	Yes
	b10. Is the investment the hospitals make in the data entry suitable for the return?	At least 75% of the hospital partners report that the investment is suitable for the return	Database Coordinators - 73% (Report format needs to be simpler)	No
	b11. Are the hospital partners satisfied with the data verification process provided by PPPESO?	At least 75% of the hospital partners are satisfied or very satisfied with the data verification process provided by PPPESO	Database Coordinators - 80%	Yes
	b12. How many sites are participating in the system out of the total number of sites?	100% of the sites are participating in the system	100% of the sites are participating in the system	Yes

CDC Criteria/attribute	Evaluation Questions (from evaluation framework)	Expectations of the Program (from evaluation framework)	Findings	Expectations met?
	b. Data Collection			
Stability	b13. What is the percentage of time the system is fully operational?	At least 95% of the partners report that the system is down not more than once/week	Database Coordinators-46% Data Entry Personnel - 86% PPPESO staff - 67%	Unable to draw conclusions because 9/28 respondents did not know (but all 19 who knew reported that criterion was met)
		At least 95% of the partners report that if the system goes down it is back in less than 1 hour on average	Database Coordinator -0% Data Entry Personnel - 11% PPPESO staff - 67%	Unable to draw conclusions because 10/19 respondents did not know (but only 3 of the 9 who knew reported that criterion was met)
	c. Data Analysis and Reports			
Simplicity	c1. Is the report generation easy to perform?	At least 75% of the partners who are generating reports rate the procedure as easy or very easy to perform	Database Coordinator - 64% PHUs - 75%	Partially

CDC Criteria/attribute	Evaluation Questions (from evaluation framework)	Expectations of the Program (from evaluation framework)	Findings	Expectations met?
	c. Data Analysis and Reports			
Simplicity cont…	c1. Is the report generation easy to perform?	At least 75% of the partners who are generating reports rate the procedure as easy or very easy to perform	Suggestions to improve report generation: 1. Change setup so that the specified date range does not get cleared with every query 2. Improve the system's ability to handle more than one query at the same time 3. Allow calculation of cross-tabulations to be able to identify subgroups	Partially
	c2. Are the reports generated simple and easy to understand/interpret?	At least 75% of the partners who are generating reports think that they are easy or very easy to understand	Database Coordinators – 70% (30% were neutral) PHUs – 100% Some of the Database Coordinators commented that there are occasions when they do not understand the report (such as 0.5 of a pregnancy), while others commented that they needed more time to familiarize themselves with the reports	Partially

CDC Criteria/attribute	Evaluation Questions (from evaluation framework)	Expectations of the Program (from evaluation framework)	Findings	Expectations met?
	c. Data Analysis and Reports			
Timeliness	c3. Can data reports be generated immediately after data entry?	Reports can be produced in real time	Reports can be produced immediately after data entry	Yes
	c4. Is the annual regional report produced in a timely fashion?	- Annual regional report is produced within 3 months of year end	- Annual regional report is produced in June (within 3 months of year end)	Yes
		- Annual regional report is made public within 3 month of year end	- It is made public in the same month	Yes
Flexibility	c5. Can the data be analyzed as required by the partners?	At least 75% of partners find the report function to customize data requests easy or very easy to perform	Database Coordinators - 55% PHUs - 75%	Partially
Acceptability	c6. How often do hospital partners generate reports?	- At least 75% of the hospital partners are generating frequency reports at least once per month	Database Coordinators - 33%	No
		- At least 75% of the hospital partners are generating comparison reports at least once every 3 months	Database Coordinators - 30%	No
	c7. Are the Public Health Units generating reports?	At least 75% of the Public Health Units are generating Reports	7. PHUs - 80%	Yes
	c8. Are the reports provided in the format required by the partners?	At least 75% of the partners who are producing reports are satisfied or very satisfied with the report format	Database Coordinators – (5/11) 45% satisfied, (6/11) 54% neutral PHUs – (0/4) 0% satisfied, (4/4) 100% neutral	No (but no one reported *dis*satisfaction)
	c9. Are the partners who are producing reports satisfied with the user support provided by PPPESO?	At least 75% of the partners producing reports are satisfied or very satisfied with the user support provided by PPPESO	Database Coordinator - 89% Public Health Units - 100%	Yes

CDC Criteria/attribute	Evaluation Questions (from evaluation framework)	Expectations of the Program (from evaluation framework)	Findings	Expectations met?
	d. Uses of the Database			
Usefulness	d1. How much has the database contributed to the access to information about Perinatal Care Practices?	At least 75% of the partners report that the database has increased their access to information about Perinatal Care Practices	Database Coordinator - 83% Public Health Units - 80%	Yes
	d2. Is the database meeting the needs of the partners?	At least 75% of the partners report that the database is meeting their needs?	Database Coordinator- 91% Public Health Units - 60%	Partially
	d3. How have the hospitals used the database? d4. How have the Health Units used the database? d5. How has PPPESO used the database?	Each partner reports that the database has been used for at least one of the following six purposes: health and performance status, planning, evaluation and comparison of practices, teaching purposes, research and continuous quality improvement (CQI)	Each hospital reported that the Database has been used for at least one of the following four purposes: performance status, evaluation and comparison of practices, teaching purposes and (CQI) Each Public Health Unit reported that the Database has been used for one purpose: health status PPPESO reported that the Database has been used for the following five purposes: health and performance status, planning, evaluation and comparison of practices, teaching purposes and research	Yes Yes Yes

CDC Criteria/attribute	Evaluation Questions (from evaluation framework)	Expectations of the Program (from evaluation framework)	Findings	Expectations met?
	d. Uses of the Database			
Usefulness	d6. Can the database be linked to other databases for research purposes?	Linkage is possible through the postal codes	96% of the records in the Database were linked to aggregate census data	Yes
	d7. Does the database collect data elements needed to monitor important perinatal health issues such as low birth weight and preterm birth?	- Database has relevant information about low birth weight and preterm birth - Information about known risk factors for low birth weight and preterm birth is collected	- Data on weight and gestational age are collected - Data on some of the known risk factors such as smoking, previous preterm baby, mother's age, parity, baby's gender are collected	Yes Partially (more risk factors need to be included)

CHAPTER 6. DISCUSSION

The discussion is based on the two objectives of the thesis and follows the format of the evaluation framework and the synthesis of results for the evaluation criteria. Throughout this discussion, the term "data collectors" refers to the author and the research assistant hired by PPPESO to conduct the re-abstraction study.

Objective 1: To Evaluate the Surveillance System of the Perinatal Partnership Program of Eastern and Southeastern Ontario.

Overall, the surveillance system has proved to be useful, with desirable features particularly with respect to timeliness and flexibility.

6.1 Content of the System

6.1.1 Acceptability

The level of acceptability of the content of this system did not meet the expected target. It could be argued that the expected target of (three-quarters of the partners reporting that all or nearly all of the variables are useful) might be excessive, given the varying types and sizes of the hospitals and PHUs involved in this system. That being said, over half of the hospitals reported that all or nearly all of the variables are useful compared to only one-fifth of the PHUs, indicating that the variables are more hospital-based than population-based. From a public health perspective, broadening the scope of the data collected with variables relating to neonatal outcomes and congenital anomalies, more determinants of perinatal health and more prenatal variables would greatly enhance this attribute of the system. Similarly, the addition of more labour and delivery variables, maternal characteristics and neonatal variables would make the system more acceptable to the hospitals.

Although the hospitals' satisfaction with the variable definitions did not meet the 95% expected target, 91% (11/12) reported being satisfied or very satisfied with the definitions with one being neutral. It is important that no one reported being dissatisfied.

6.1.2 Representativeness

For hospital births, the very small discrepancy of 0.1% identified in the livebirths when the Perinatal Database and the CIHI database were compared, is an indication that the Database is representative of the hospital births, thus providing an accurate denominator for the calculations of rates or proportions of events or outcomes. The unexplained discrepancy in livebirths (N=4) could very well be due to differences in the way the two sources capture the data. For home births, no such independent comparison was feasible.

Women residing in Eastern Ontario but giving birth out of the region are not captured by the Database. While this was not considered as part of the expectations of the program, perhaps entering into agreements with hospitals bordering Eastern Ontario to provide these data, or seeking MOHLTC's assistance in obtaining these data from OHIP forms, might help in capturing at least some of these out of region births.

The modest number of variables collected is a limitation of this system in terms of research, but it is also an advantage in terms of feasibility. Several of the known risk factors for adverse reproductive outcomes are currently collected, including: smoking, previous preterm baby, parity, multiple gestations, mother's age and baby's gender. But other well known risk factors such as previous stillbirth or abortion[62-64], socioeconomic status of the mother[62,63,65,66], marital status[63,67-69] , maternal height and pre-pregnancy weight[63,69,70] and prenatal care[63,67,71], to name a few, are not included in the Database, thereby restricting its research potential. It is anticipated that as the geographical coverage of this surveillance system expands, with hospitals outside Eastern Ontario

participating, there might be a call for widening the content of the system to accommodate the needs of the varied users, thus increasing its future potential. On the other hand, balancing such demands against feasibility can be quite challenging, since the expansion of the Database entails significant planning and programming costs on the PPPESO and CritiCall ends, and more resources for data entry on the hospitals' ends, as well as difficulties in controlling data quality and performing regular audits.

6.2 Data Collection

6.2.1 Simplicity

Since the hospitals participating in the Perinatal Database vary in size and type, it is to be expected that their entry procedures for the logbook and consequently for the database would differ. In some hospitals, the logbook was not completed in the case room, but rather later, with data being obtained from the charts and from notes where the nurses had recorded additional information. Although the expectations of the program indicate that the logbook should be completed in the case room, deviations from strict adherence to this may not jeopardize the quality of the data entered, but might rather indicate some technical difficulties in completing the logbook in the case room, and need to be addressed with the individual hospitals.

The simplicity of the data entry into the Database was reported to have met expectations by the Data Entry Personnel but not by the Database Coordinators. This might be because in some hospitals the latter group were not as involved with the data entry as the former group.

Both the Data Entry Personnel and the examination of the data entry screen identified that the system "times-out" when it is idle for a period of time during data entry, leading to loss of all the data that had been entered but not yet saved. While it is

understood that this is a security feature found in most secure and password protected websites such as banks, perhaps having a longer time-out feature for this site might help alleviate some of the staffs' frustration with this feature. Another problem with data entry concerns missing data in the logbook. As indicated by both the Data Entry Personnel and the examination of the entry screen, if there is missing information for baby's monitoring, the record cannot be saved unless an option is entered. Entering any option just to be able to save the record jeopardizes the quality of the data in the Database. Possibly some modifications to the options and the system checks in the entry screen would solve this problem. Furthermore, some adjustment to the data entry screen can make it more user-friendly, such as reversing the scroll down menus for the variables Apgar score and gestational age so that one starts at normal values and scrolls to the less common ones, enlarging or bolding the fonts and darkening the background.

6.2.2 Timeliness

One of the biggest assets of this surveillance system is its timeliness. With monthly reminders sent by PPPESO to close the month, data for all births occurring in a given month are entered within two weeks of the last day of that month in all hospitals. In the teaching hospitals this is even more efficient, with data being entered in "real time" as the births happen.

6.2.3 Flexibility

The evolution and expansion of the database described in section 3.3 (page 26) indicate how adaptive this system has been to the changing needs of the users. Moreover, since January 2003, with more hospitals outside Eastern Ontario participating in the system, some variables were modified in response to requests made by the

hospitals. Examples of such variables include: an "ambiguous" category was added to the gender of the baby, the mother's hospital chart number was added and the smoking variable was categorized to include smoking during both the first 20 and last 20 weeks of gestation. The addition of two variables "intention to breastfeed" and the "postal code" to the old database in 1999 is yet another example of its flexibility. One variable (the delivery type) has already been modified as a result of this study, and others are under consideration.

6.2.4 Data Quality

Most variables showed high concordance between the logbook (or equivalent) and the Database. A variable had to meet both a 95% agreement and a kappa of > 0.60 or ICC of 0.9 (depending on whether it was categorical or continuous), to be considered of acceptable agreement.

The Database – Logbook comparison identified ten variables that did not meet the acceptable threshold of agreement. Variations in the "postal code" variable may be due to misinterpretations of the handwriting either by the Data Entry Personnel or by the data collectors. For "Labour type" there are three main columns in the logbook: spontaneous, augmented and induced (with method utilized). If no option was chosen in the logbook, then the labour type was considered "no labour". Several sources of error are at play here. First, misinterpretations of the "no labour" occur when the labour column in the logbook is blank due to lack of documentation rather than the woman undergoing no labour. This could be solved by adding a "no labour" option to the logbook allowing the Data Entry Personnel to record that on the Database based on facts and not speculation. Second, confusion exists between augmented and induced labour. Augmentation is not induction, and this needs to be emphasized to the Data Entry Personnel to avoid misinterpretations in the future. This same variable did not

meet the 95% threshold in the 1999 audit, indicating a problem with the understanding of the variable definition among the Data Entry Personnel as well as with follow up of the recommendations made by PPPESO to the hospitals. Of course there is always the chance that the data collectors could be at fault here, but since they were very aware of the problem, it is assumed that they were vigilant at recording this variable as accurately as possible. Moreover, accurate interpretation of the "labour type" variable affects the accuracy of recording the "delivery type". The later has five subcategories (vaginal, vaginal birth after caesarean section, primary caesarean section, caesarean section with a trial of labour, and caesarean section with no trial of labour). If the "no labour" option was chosen in error, or the augmented/induced labour misinterpreted, then the repeat caesarean section with/without trial of labour will be flawed. Cross-tabulation of the labour type and delivery type for the Database file (1511 sample) showed that in 6.3% of the cases of repeat caesarean section with a trial of labour, the labour type was chosen as "no labour". Similarly, in 2.2% of the cases of repeat caesarean section with no trial of labour, "induced" labour type was chosen. Two issues arise from this finding: first, misinterpretations of one variable affect the accuracy of another variable. Second, the variable "delivery type" was not properly programmed because it had permitted illogical sequences. No such discrepancies were found in the cross-tabulation of the re-abstracted logbook labour type by delivery type.

"Fetal monitoring" is another variable that did not meet expected agreement in either the previous or the current audit. Again there are multiple columns in the logbook for this variable, for auscultation only, electronic fetal monitoring only, both, or no monitoring. The data entry screen also contained an "unknown" category, but the record cannot be saved if this category is chosen, forcing the Data Entry Personnel to select another option. This was further confirmed by the cross-tabulation, which showed 25 unknown categories recorded by the two data collectors versus none recorded by the

Data Entry Personnel. The Data Entry Personnel recorded more than half of these 25 unknowns as "no monitoring". Detailed exploration revealed that the mother had a repeat caesarean section with a trial of labour in five cases and a primary caesarean section in one case, so some form of fetal monitoring was probably done, leading to the conclusion that the "no monitoring" option chosen by the Data Entry Personnel could be erroneous. This could be attributed to misinterpretations of the different options, or to the set up of the entry screen, which does not allow "unknown" to be saved.

The variables "cord blood" and "smoking" were recorded variably in the paper logbooks, with some hospitals using yes – no, some using check-marks and others leaving the column blank to indicate a "no". Even that was not consistent, as different nurses within the same hospital used different ways of recording the yes – no responses. Variations in the entries between the Logbook and the Database could be due to misjudgements by the Data Entry Personnel or the data collectors in recording the responses based on the available data in the logbook. Efforts should be made to confirm that all hospital staff who enter data into the logbook use a uniform way of recording the data, and this must be thoroughly explained to the Data Entry Personnel.

For baby's presentation at birth there were four categories: vertex, breech, other, and not available. Of the 81 "not available" recorded by the data collectors, 73 were recorded as vertex in the Database. In all of these records, the data collectors had commented that the baby's presentation was not recorded, so it is assumed that their entries were correct. This is another variable where the problem could be the way it was set up in the entry screen, where the default is "vertex", leading to over-recording of this option. The overall kappa for baby's presentation was unsatisfactory (0.55). Maclure and Willett[72] suggested that if the categories of a polytomy are natural or fixed by convention with no inherent order (e.g. baby's presentation at birth, labour type), the use of several kappas for different combinations of dichotomies may be more

informative than an overall kappa for the polytomy. The kappas for the various dichotomies were: vertex/all others=0.55, breech/all others=0.87, other/all others=0.72, and not available/all others=0.10. This analysis indicates that the Database has a problem in correctly identifying presentation when it is vertex or not available.

Antenatal steroids, delivered by, scalp blood sample and anaesthesia: pudendal block all had relatively low kappa (0.55, 0.55, 0.28 and 0.09 respectively) despite high and acceptable levels of percent agreement. The reason behind this could be the "prevalence effect" on kappa described by Feinstein and Cicchetti[73]. The authors illustrate 2 paradoxical results produced by kappa: the first one is that if P(e) is large, the chance correction process can convert a relatively high value of P(o) into a relatively low value of *K* . This occurs when the marginal totals are symmetrically imbalanced (nearly all cases in one category), so that the value of P(e) is large. For a given value of P(o), the highest value of *K* will be obtained when P(e) is as small as possible. The second paradox takes place when asymmetrical imbalances of marginal totals produce higher values of *K* than more symmetrical imbalances.[73] Appendix F shows a small modelling exercise where simulated 2X2 tables were generated for fixed P(o) but varying distributions of marginal totals, showing the effect of imbalance on kappa.

The distributions of the marginal totals for the four variables mentioned above exhibited strong symmetrical imbalances. For example the variable "delivered by" had marginal totals of 1500 physician, 7 midwife and 4 unknown for the database, versus 1504 physician, 5 midwife and 2 unknown for the logbook. This symmetrical imbalance in the marginal totals produced excellent percentage agreement of 99.4% but only a moderate kappa of 0.55. Variables with similar percentage agreement but more balanced marginal totals produced higher kappa values. Further exploration of the "delivered by" table revealed that out of the seven midwife-delivered babies in the Database, three were in disagreement with the logbook, which had them recorded as

delivered by a physician. Similarly out of the four unknowns in the Database, three were in disagreement with the logbook. Since the disagreements were few and the majority of babies were delivered by a physician, the percentage agreement was very high. In this situation, although the marginal totals are imbalanced and hence the kappa would be low, the kappa value was taken to be more dependable than the percentage agreement as it accounted for the disagreements explained above. The remaining three imbalanced tables were explored and similar patterns were discovered: a small number of disagreements in the cells produced a high percent agreement and a low kappa. For all of these tables, since the chance corrected agreement was below the 0.60 threshold, the database – logbook entries were interpreted to be in disagreement. It is important to note that the disagreements here involve very small numbers that constitute a small minority of cases. The implication of this result would depend on the users of the data. For example, if one wants to know how many midwives were delivering babies at the hospitals, or how many scalp blood samples were taken, or how many women were given steroids, the Database in its current form might not be the best source of this information.

The Logbook – Charts and the Database – Charts comparisons showed larger numbers of variables that failed to meet the acceptable threshold of agreement than the Database – Logbook comparison. Furthermore, discrepancies between the Logbook – Charts and the Database – Charts were almost identical. This is consistent with the finding that there is good agreement between the entries in the Database and the logbook, but that there are discrepancies between the logbook itself and the mothers' charts. The variations in the babies' resuscitation variables, the scalp blood sample and the cord blood sample could be due to their inconsistent and sometimes absent documentation in the mothers' charts (in some hospitals). Had the babies' charts been reviewed, a more accurate assessment of these variables would have been possible.

Furthermore, in one hospital, 24 charts had no record of the babies' weights in either the "labour and delivery records" or the "healthy babies postpartum screening tool", so the corresponding babies' charts had to be pulled to obtain this information. In almost half of these charts, the babies' resuscitation methods were in disagreement with the logbook, further indicating that there is a problem with the recording of these variables.

Differences in labour type and fetal monitoring could well be due to differences in documenting them in charts. For labour type, some nurses and physicians chart induction differently, using the term augmentation instead of induction. For fetal monitoring, almost half of the hospitals whose charts were reviewed charted the fetal monitoring as "external" and "internal" as opposed to the "auscultation" and "electronic monitoring" subcategories found in the logbook. It was necessary to look through the charts to find any record of an electronic "strip" to indicate electronic monitoring or any record of auscultation in the nurses' notes to obtain the information, which was challenging at times. Efforts should be placed to standardize the charting of these variables among the hospitals.

Pain relief during labour exhibited unacceptable levels of agreement. The problem with the narcotic variable could be due to misinterpretations of the logbook, in which both narcotic and epidural were sometimes selected when the mother was given an epidural with a narcotic in it, rather than just epidural. The extremely low kappa obtained for the assessment of pudendal block by data collector 2 is due to the large number of disagreements with the "yes" category recorded in the Database, which were often recorded as "no" by data collector 2. This could be due to misinterpretations in the logbook where some nurses place a check-mark on this variable with the word "local" beside it, which would probably mean local anaesthetic and not pudendal block.

Variations in breastfeeding and smoking variables could also be attributed to differences in variable definitions between the logbook and the charts. The definition of

breastfeeding in the Database is "intention to breastfeed" regardless of whether breastfeeding has occurred or not. In the charts, the variable is recorded as "breastfeeding" which most probably means that it is recorded as yes only if the baby was actually breastfed. During the chart reviews every effort was made to obtain this variable from the antenatal record, which would offer the closest approach to "intention to breastfeed" since it would have been recorded while the mother was pregnant. But in a substantial number of charts, this was not recorded in the antenatal record, and had to be obtained from the labour and delivery record, which probably records it as "yes" only if breastfeeding has actually occurred. Similarly, "smoking" had different definitions in the logbook and the charts, with the former defining it as maternal smoking after 20 weeks of gestation, and the latter recording it early in pregnancy (from the antenatal record) but not necessarily recording that the mother had stopped after 20 weeks of gestation. The recent modifications to this variable explained above would resolve this issue of variable definition in future data.

The current and previous audits showed similar patterns of disagreement in the comparisons of the entries in the Logbook – Charts and Database – Charts. Possible explanations for this could be:

- Failure of PPPESO to communicate the results of the previous audit to the hospitals so that they can review their areas of weakness and improve them.
- Failure of the hospitals to act upon the recommendations of PPPESO to improve their logbook and charts.

6.2.5 Acceptability

This reflects the willingness of the partners to participate in the data collection component of the surveillance system. The assessment met expectations in terms of the time needed to enter the data per record, the data verification process provided by

PPPESO, and the participation rate among the hospitals. There were less than satisfactory levels of acceptability in terms of the returns on the investments the hospital made in the data entry. Hospitals invest in the data entry process by providing the staff to enter the data; in return, they have access to the Database and can generate frequency reports to monitor their status and performance and comparison reports to compare themselves to like hospitals. Some Database Coordinators reported that their negative response was due to the fact that their number of deliveries was small so they could obtain all their information from their logbook without having to go through the expense of entering the data into the Database. Others reported that the time commitment to obtain reports from the system was not worth their investment. Since the types and sizes of hospitals participating in this surveillance system vary, it is to be expected that the small hospitals would not find this system worth their investment, but at the same time these hospitals need to consider the fact that their contribution is important to providing a complete regional database and to the potential of such a database.

6.2.6 Stability

This was assessed by the percentage of time the system was fully operational. The two sources that provided information on this (the survey of users, and CritiCall System's support) were contradictory. The questionnaires did not provide a concrete conclusion since a third of the respondents did not know if the system experiences outages. This could mean that the outages do not happen frequently enough to constitute a problem. This is backed by the fact that 86% of the Data Entry Personnel responded favourably by saying that the system either never experiences outages or experiences them not more than once/week. No conclusion could be drawn for the perceived time taken for the system to be fully restored after outages because most of

the respondents did not know. However, among those who did know, only three in total responded that it took less than an hour for the system to be restored after outages.

CritiCall's response on the other hand, confirmed that outside of scheduled maintenance (2 hours/month), outages do not last more than 10 minutes/month. Based on what had been presented, several factors could be at play here. First, the survey results on the frequency of outages and time taken for the system to be restored after outages could very well be due to hospitals' network system outages and not CritiCall outages, and the average user would probably not be able to distinguish between the two. Second, it is possible that the respondents unknowingly tried to access the system when CritiCall was down for scheduled maintenance. This may need further follow up with the hospitals since whatever the source of the outage, if the Data Entry Personnel cannot access the system, the data cannot be entered and this may consequently discourage staff, particularly within the hospitals that enter data less frequently than others and have limited staff and time for that purpose.

6.3 Data Analysis and Reports

6.3.1 Simplicity

The PHUs were satisfied with the ease of generation and the interpretation of the on-line reports produced by the system. The same could not be said for the hospital Database Coordinators. Both the Database Coordinators' response and the examination of the report generation revealed that the procedure can be quite cumbersome, with the system shutting down when more than one query at a time was made and the specified date range being cleared away with each query. Improvements to the report generation procedures so that they become more efficient and user friendly need to be considered. This will also help to increase the satisfaction of the hospitals

with the investments they made in the data entry process and encourage the hospitals to use the report facility more frequently. Although the interpretation of the reports did not meet expectation, 30.0% of the Database Coordinators chose the "neutral" category suggesting that there is not a big problem.

6.3.2 Timeliness

Like Data Collection, this attribute is important for the Data Analysis and Reporting features of the surveillance system. It met all expectations, in that reports can be generated immediately after data entry, and in that the regional annual report is produced on schedule within three months of year end, and is made public within the same month.

6.3.3 Flexibility

The report function to customize data requests was reported to have met expectations by the PHUs but not by the hospital Database Coordinators. This is consistent with the hospitals' dissatisfaction with the reporting facility of this system, possibly because they lack statistically trained staff.

6.3.4 Acceptability

Both the PHUs and the Database Coordinators reported their satisfaction with the user support facility provided by PPPESO. However, the generation of reports by the hospitals to monitor their performance and reproductive outcomes did not meet expectations, with only 33% generating frequency reports once per month and 30% generating comparison reports once every three months. The fact that the majority of the hospital Database Coordinators were not producing frequency or comparison reports independently and as often as expected is an indication that there is a problem with this feature. Possibly the staff still needed time to practice the report production facility, or

more time may be needed for the system to be used to its full potential. Improvements to the reporting facility in terms of ease of production, ease of interpretation, and better formatting would go a long way in making this component of the surveillance system more acceptable to the partners.

6.4 Uses of the Database

The level of usefulness of a surveillance system can be assessed in many ways depending on its type and objectives. The usefulness of this system has been assessed based on several indicators of usefulness identified in the literature[7,9]. These include: the ability of the system to detect trends that signal changes in the occurrence of health outcomes and interventions, the contribution of data from the system to performance measures (including indicators that are used in needs assessment and improvements in clinical practices), and the ability of the system to provide a tool for research aimed at prevention or control of adverse health events.

Half of the hospital Database Coordinators reported that this system has "greatly increased" their access to information about perinatal care practices, compared to only 20% of the Public Health Units. This further indicates that the current system is more hospital-based than population-based. Perhaps improvements to the reports facility would improve the current contribution to the access to information about perinatal care practices from the hospitals' perspective, and broadening of the scope of the data collected would improve that access from the PHUs' perspective.

The expected target in terms of usefulness set out in the evaluation framework was that each partner reports using the Database for at least one of six purposes: health and performance status, planning, evaluation of practices, teaching, research and continuous quality improvement (CQI). Each of the hospitals reported using the Database for at least one if not more of the above six purposes. More than half of the

hospitals used it for performance status, by providing statistics for departmental meetings. With improvements to the report facility, one can envisage that this number may increase significantly. None of the hospitals reported its use for research purposes, which could be due to the limited quantity of data or to the restricted survey population, which included only the Database Coordinators. Physicians in the hospitals were not surveyed because the Database was accessible to very few if any of them, and there was a feasibility problem of locating who was using the data, as neither the PPPESO staff nor the Database Coordinators had this information.

The PHUs reported using the Database for information about health status, *timely* population based statistics about births, smoking among mothers and intention to breastfeed. To obtain current information on these from other sources such as Vital Statistics would not have been possible due to the time lag (of several years) before these data become available, coupled with the fact that Vital Statistics do not collect information on breastfeeding and smoking.[61] The PHUs expressed their need to generate reports from the Database looking at trends over time (in years), which was not possible at the time of the study since data entry into CritiCall only started in 2001. Currently with two years worth of data entered into the system, the PHUs can generate reports looking at trends. Furthermore, the central office of PPPESO can perform analysis on request from years prior to the CritiCall entry, or more detailed analysis not possible through the on-line reporting facility provided by CritiCall.

The Database allows PPPESO to identify regional trends, provides material for perinatal research initiatives and the continuing professional education courses that they provide and identifies areas for program planning and development. Through the involvement of all hospitals in the region, inter-hospital comparisons and performance improvement necessary for benchmarking can be developed.

Consistency in variable definitions and data quality were reported by PPPESO to present challenges in operating this system. The evaluation showed that these two have not met expectations. Variable definitions need to be given priority because they greatly impact data quality.

Dedicated funding was also presented as another challenge facing PPPESO in operating the system. Marketing of the Database to a wider audience, such as the MOHLTC (which does not currently provide direct funding) needs to be increased. Perhaps the current geographical expansion of the Database, eventually leading to a province-wide perinatal surveillance system, might motivate funding agencies to invest in it given its anticipated potential.

Objective 2: To Evaluate the feasibility of linking the Niday Database to Census Data.

Enumeration areas (EA) are the smallest units for which census data are collected. They represent census neighbourhoods (with relatively homogenous economic and social living conditions), that contain from 125 dwellings in rural areas to about 440 dwellings in large urban areas (1996 Census)[74]. Using the postal codes in the Perinatal Database, 97% of the records were assigned geographic codes down to the EA. This can greatly enhance the usefulness of the Database by enabling aggregate or summary data variables to be added to the variables currently present in the Database, expanding its research potential for studying relationships between aggregated census variables and reproductive outcomes or maternal characteristics such as teenage pregnancies, smoking and breastfeeding to name a few.

Use of aggregate data as a surrogate for individual measures of socioeconomic status carries with it the potential of an 'ecological fallacy'.[75-77] Many methodological studies have examined the use of aggregated census data to fill in missing socio-

economic status information when individual level socio-economic data are not available.[75,76,78-82] Some of these studies examined the validity of using area-based measures relative to individual level data,[75,76,82] while others compared larger area-based measures to smaller area-based ones.[78,79,81,83] All of the studies mentioned here agreed that aggregate measures should not be used without acknowledging the potential biases that may occur when estimates of socio-economic status are used, irrespective of the level or size of geographical units studied.

A group level measure when used as a proxy for a direct household measure will contain more measurement error than the direct one. This may attenuate the relationship between the group level measure and a health outcome, compared to the direct household measure and that health outcome.[75,82] Soobader et al[78]argued that measures of socio-economic status derived from smaller geographic units may produce results that are less biased. Krieger[79,80] concluded that the use of census-derived levels of socio-economic status (such as census tract and census block group (equivalent to the EA)), offered a useful and valid approach to overcoming the absence of individual data. She also argued that "small area data can be used to construct population-based incidence and prevalence rates stratified by social class, and that the denominators for incidence or prevalence rates are census derived and therefore can be characterized by the same census based social class measures as the numerator data".[80]

Southern et al[84] assessed the agreement between Forward Sortation Area (FSA) and EA-derived income levels for patients undergoing cardiac catheterization in Alberta (1995 – 1998). The authors found a large variability in EA-derived incomes for any given FSA-derived income, with only 40% of income quintiles in agreement between the two methods. When assessing survival after cardiac catheterization, the difference between the highest and lowest income quintiles was similar at the FSA and EA levels, but the middle income quintiles showed substantial overlap of FSA-derived survival curves that

did not occur for EA-derived curves. There was a linear relationship between higher income and lower mortality across all quintiles for EA-based analysis, while only the lowest income quintile had significantly higher mortality for FSA-based analysis. They concluded that the use of EA-based income was more valid and provided better classification of income than those derived from FSA, and they recommended the use of EA-derived measures rather than higher levels of geography for area-based socio-economic status.

As the results of geocoding the postal codes in the Perinatal Database have indicated, assignment of EAs may not always guarantee that a census summary variable such as income can be assigned to a particular postal code: the EA may be valid, but may not indicate a place of residence. For these it is possible that the postal code may not have been correctly entered, even though the PCCF indicated that it was a valid postal code. Also, correctly entered postal codes that were fully matched to the PCCF may not be codable to the level of the EA if they indicate a post office location, especially in rural areas where postal codes may be associated with the location of the post office where mail is picked up and not the location of a given person's residence.

A total of 630 records (3.6%) could not be assigned income data. This is a relatively small number, and may actually be reduced if the postal codes for these records were checked against the hospitals' charts, with any discrepancies modified (assuming that the charts were correct).

Similar to income quintiles, other census socioeconomic variables such as education and private dwellings may also be added once the postal codes are assigned geographic codes. The addition of more variables to the database, such as maternal characteristics, coupled with supplementary variables from the census can provide rich possibilities for research out of this database.

Although the PPPESO staff thought that the Database was linkable, they deemed the procedure to be neutral or difficult. Most of the PHUs did not know if it was linkable and those did know thought it was difficult. It is possible that these responses were a result of difficulty in understanding the question or that they were referring to individual level rather than aggregate level data.

6.5 Limitations of the Evaluation

Data Re-abstraction: The sampling method used for the data re-abstraction involved randomly selected 70 records from each hospital, and three groups of ten records each randomly selected from records with special characteristics, totalling a sample of 100 records from each hospital. Due to sampling fraction differences for each stratum generated by this sampling scheme, one cannot generalize the results of these analyses to the total number of births in that hospital, or the overall sample to all births in Eastern Ontario.

Failure to review the babies' charts is another limitation of the data re-abstraction, so caution should be used in interpreting the results of the chart review in terms of babies' resuscitation, scalp and cord blood variables. In future data quality audits, the babies' charts should be reviewed, even if it comes at the expense of reducing the sample size.

Verification of the representativeness of the population captured by the Database did not include home births.

Survey: Questions 4 through 6 in the PHUs questionnaire, which asked whether the Database was capturing all the births in Eastern Ontario as well as those occurring outside the region to mothers residing in the region, were not very useful and need not have been asked.

Comparison between the PHUs and the hospitals in terms of the frequency of using the report facility of the system was not possible because the PHUs' questionnaire failed to ask them about their frequency of generating reports.

The inability to survey hospital physicians who may have used the Database limited the information about the uses of the Database from physicians' perspective.

CHAPTER 7. CONCLUSIONS AND RECOMMENDATIONS

Task (E) of the CDC's guidelines is to justify and state conclusions and make recommendations addressing the modification and/or continuation of the surveillance system. The evaluation included four main elements of the surveillance system: content, data collection, data analysis and reports, and uses of the system. Based on the evaluation questions presented for each element of the system outlined in section 4.2, the following conclusions were drawn:

7.1 Conclusions

The surveillance system has fully or partially met expectations in a substantial number of the attributes assessed.

7.1.1 Content of the Surveillance System

- The variables are more hospital-based than population-based, with most of them being useful to the hospitals, but less useful to the PHUs.
- Both the hospitals and PHUs suggested the addition of more variables to the Database, with more labour and delivery variables suggested by the hospitals and more maternal and neonatal variables and outcomes suggested by both.
- The hospitals were satisfied, very satisfied or neutral regarding the variable definitions.
- The data are representative of hospital births occurring in Eastern Ontario, therefore providing reliable denominators for calculating rates or proportions of events or outcomes for this population. This indicates that the regular data verification of the number of births performed by

PPPESO is working well. Women residing in Eastern Ontario, but giving birth outside the region are not captured by the Database. No conclusions could be made for home births since access to midwives' records was not feasible.

7.1.2 Data Collection

- There were variations among the hospitals in the sources of the data entered into the Database, including the logbook, the mothers' charts and the babies' charts. Similarly, there were variations in the numbers and expertise of individuals entering the data among the hospitals including Database Coordinators, nurses and medical records personnel. These variations may have had an effect on the quality of data in the Database.
- Data Entry Personnel reported that the data entry was simple, but that some modifications to the entry screen and system checks would improve the quality of the data entered, and make the system more user-friendly.
- The data collection was found to be timely, flexible and acceptable in all respects with the exception of the hospitals' level of satisfaction with the return they were getting out of the database in exchange for their investment in data entry. This was attributed to dissatisfaction with the on-line reporting feature of the system.
- The level of completeness of the data entered into the Database was very high (95 – 100%) for all the variables, indicating that efforts made by the entry personnel to obtain information when missing from the logbook were working. On the other hand, absence of missing data on baby's resuscitation and on pain relief during labour was sometimes erroneous,

since some "unknowns" get recorded as "no" due to the set up of these variables in the entry screen.

- There were high levels of concordance between the logbook and the Database for all but ten variables, indicating that the Data Entry Personnel were entering the data correctly and that the system checks in the entry screen were working well. The problems with the remaining variables were mainly due to transcription errors (e.g. postal codes); misinterpretations of variable definitions (e.g. labour type and pudendal block); inconsistent documentation in the logbook (e.g. cord blood and smoking); excessive selection of defaults in the drop down lists of the entry screen (e.g. baby's presentation); and failure of the entry screen to allow records with "unknown" category to be saved (e.g. baby's monitoring).
- There were differences between the logbook and charts in terms of definitions and ways of charting certain variables such as fetal monitoring, labour type, breastfeeding and smoking. These were reflected in relatively low concordance between the charts and the Database. There were also inconsistencies among the hospitals, with some having all the newborn variables recorded in the mother's chart as well as the baby's chart while others had them only in the baby's chart.
- No conclusion could be made regarding the stability of the system in terms of outages. Although CritiCall confirmed that outside scheduled maintenance, total outages average about 2 hours/year, most of the survey respondents did not know how frequently they happened and how long they lasted. Six of the nine who knew reported that outages lasted between one to more than four hours. Since this could very well arise

from a hospital's own network outages rather than CritiCall's, further follow up needs to be done since the data cannot be entered if either one is down.

- Funding for the operation and maintenance of the Database is not stable and is dependent on in-kind contributions made by all the partners. The resources currently used are part of a pool of funds raised for the PPPESO program as a whole.

7.1.3 Data Analysis and Reports

- The user support provided by PPPESO was acceptable to the partners.
- The PHUs found the procedure to generate on-line reports from the system simpler and more flexible than did the hospitals. The former group also found the interpretation of the reports to be easier than the latter group. Both groups suggested modifications to the procedure to make it more efficient and user-friendly.
- The frequency of report generation by the hospitals did not meet expectations and confirms the difficulty of the reporting feature of the system among the hospitals.
- The most successful attribute of the reporting feature was its timeliness. The data can be analysed and simple frequencies can be produced as soon as data are entered. Annual regional reports have also been produced on schedule within three months of year end, and disseminated within the same month.

7.1.4 Uses of the System

- The perinatal surveillance system of Eastern Ontario is useful and is meeting its stated objectives.
- More hospitals than PHUs reported that the system has greatly increased or provided some increase in access to information about perinatal care practices.
- The system's usefulness has been demonstrated by all partners' use of its data for at least one of the following purposes: health and performance status assessment, planning, evaluation of practices, teaching, continuous quality improvement and research.
- The Database can be linked to aggregate census data, therefore enriching its potential for research.
- At the beginning of this year, hospitals outside the region have joined the Database and are at various stages of data collection. This reflects the potential for expanding the Database to the provincial level.

Based on the conclusions presented, the perinatal surveillance system is useful and performing well by providing timely access to quality birth data for most of its variables, to hospitals and public health units.

7.2 Recommendations

To address shortfalls in the system and to improve its performance and level of acceptability among the partners, the following recommendations are presented:

A general recommendation is that PPPESO should market the Database to a wider audience with potential funding, including the MOHLTC, in order to gain more dedicated and stable funding for the surveillance system.

Other recommendations specific to each element of the system include:

7.2.1 Content

1. PPPESO needs to consider widening the scope of the data collected to include more public health variables that address the needs of PHUs, in addition to more labour and delivery variables to address the needs of the hospitals. This should be done in consultation with both groups of partners and must be balanced against the willingness to invest in the data collection on the partners' end and the costs of planning and programming, and maintaining data quality on PPPESO's end.
2. Data verification performed by PPPESO for the number of births should be continued.
3. To be able to capture births occurring outside the region to mothers residing in the region, PPPESO should consider entering into agreements with hospitals bordering Eastern Ontario and/or with the MOHLTC to provide assistance in obtaining these data from OHIP forms and/or any other sources.

7.2.2 Data Collection

1. PPPESO should urge participating hospitals to standardize the *charting* and the *sources* of the data entered into the Database. For example, the logbook could be replaced by a standard form with *all* the

variables present in the Database (recorded in the same way as the options available in the entry screen) that could be attached to the mother's chart, and the Data Entry Personnel could use only that form as the source for the data they enter into the system. Including the form in the mother's chart would make it part of the legal chart and hence more "official" than the current logbook, which may stimulate more accurate charting by hospital staff.

2. PPPESO should agree with the hospitals to have a limited number of individuals entering the data, preferably individuals with knowledge about data entry as well as obstetrical terms, interventions and medications. These individuals should receive training and regular updates/reports from PPPESO on data entry errors so that they can realize the importance of accurate data entry. In addition, PPPESO should be aware of all the individuals entering data and of any changes in personnel so that they can provide appropriate training for them.

3. Regular audits should continue to be performed, and future chart reviews should include babies' charts. PPPESO should communicate the results of the audits to the hospitals, with appropriate and vigorous follow up. They should also discuss the inconsistencies in charting between the hospitals at the level of nurses, midwives and physicians and ensure that they define the variables in a consistent manner.

4. PPPESO should consider making the following modifications to its entry screen to improve data quality:

I. Variables should be independent of each other in the sense that the data entry should only assess one variable rather than a combination of variables.

II. All defaults should be removed and the drop down lists should start with "please choose one option" or "unknown".

III. Baby's resuscitation and maternal pain relief during labour should have a missing or unknown option.

IV. The system checks should be modified to allow "unknown" to be saved for the fetal monitoring variable.

V. More vigilant system checks should be implemented for the postal code variable, because it is the only geographic identifier in the system and the only way to link it to other databases.

5. PPPESO should consider the following modifications to its entry screen to make it more user friendly:

I. Working with CritiCall to increase the time period before which the screen "times out" so that when data entry is interrupted before saving the record, the data entered do not get lost.

II. Reversing the scroll down menus for the variables Apgar score and gestational age, so that they start at normal values and scroll to the extremes.

III. Working with CritiCall to enlarge the font and decrease the brightness of the entry screen so that it is less tiring to the eye.

7.2.3 Data Analysis and Reports

1. The user support provided by PPPESO should continue.

2. To make the on-line reports generated by the system more acceptable to the hospitals, they need to be improved in terms of ease of generation, format, and interpretation. PPPESO should consult with the partners on the most frequently requested queries and prepare a user-friendly reporting system covering the most commonly requested indicators.

3. PPPESO should consider conducting a workshop for all the hospitals specifically geared to 'hands-on" training in report generation, formatting and interpretation, with examples of all the problems that may be encountered and suggested ways of dealing with them.

7.2.4 Uses of the System

1. PPPESO should attempt to keep track of physicians who have access to and may be using the system for research purposes. This will help in conducting further surveys seeking to evaluate the needs and acceptability of this system from physicians' perspectives.

2. PPPESO should consider phasing-in a plan for including well known risk factors for adverse reproductive outcomes (e.g. preterm birth and low birthweight) in a future database expansion, to increase the potential of the system and also to motivate funding agencies to invest in it.

The final task in the evaluation is the dissemination of the findings of the evaluation, CDC task (F). A copy of this report will be submitted to the central office of PPPESO and an opportunity will be sought to discuss the findings and recommendations with the database subcommittee and individuals managing the

system (director of the perinatal surveillance system, the policy and planning advisor and the data analyst).

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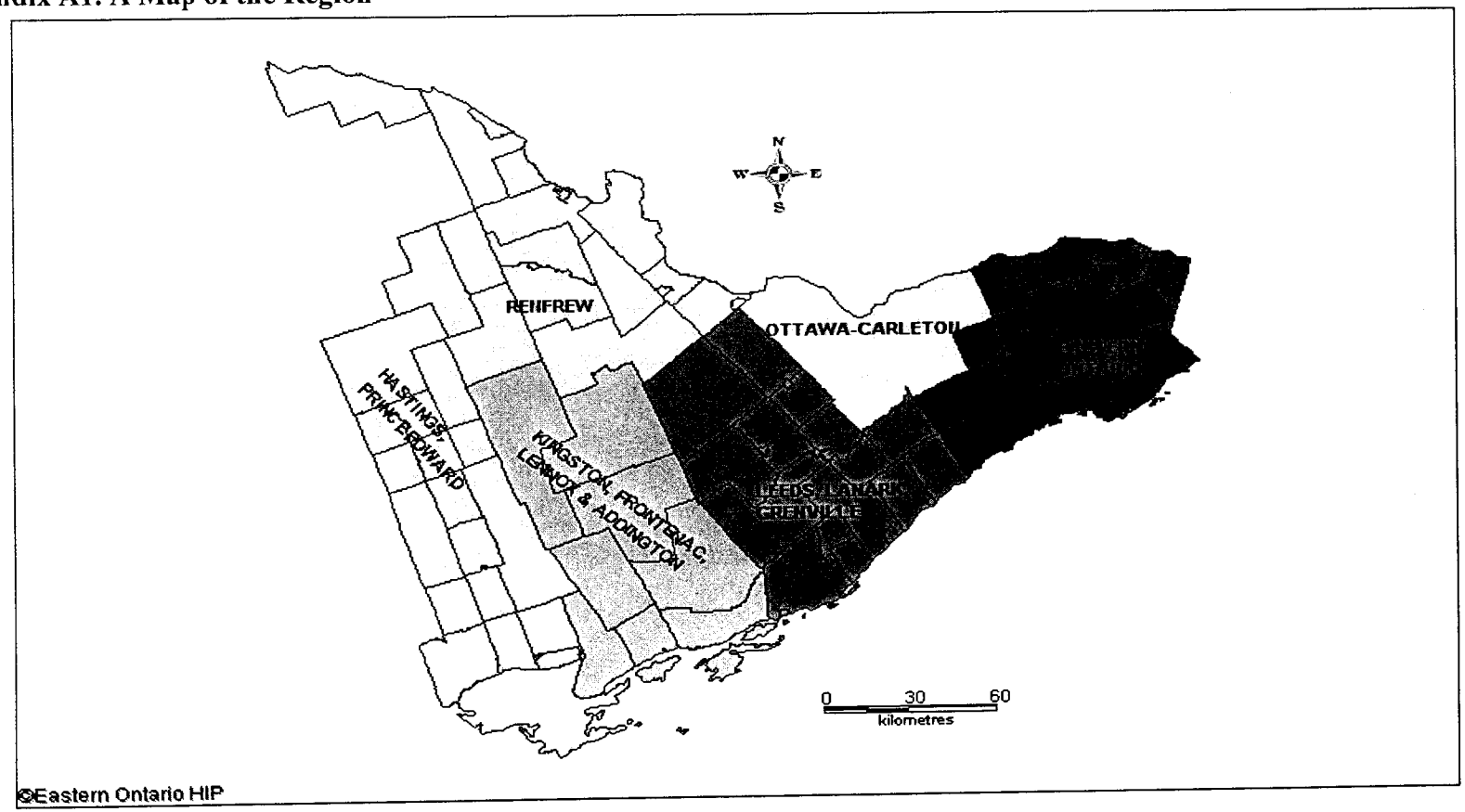
APPENDICES

Appendix A. The Eastern Region of Ontario

Appendix A1. A Map of the Region



Appendix A2. District Health Councils and Public Health Units Serving the "Eastern Region" of Ontario

District Health Councils (DHC)

1. The Champlain DHC.
2. Southeastern Ontario DHC.

Public Health Units (PHUs)

1. Eastern Ontario PHU.
2. Hastings and Prince Edward Counties Health Unit.
3. Leeds, Grenville and Lanark District PHU.
4. Ottawa-Carleton Regional Health Unit, now referred to as the 'City of Ottawa Public Health and Long Term Care Branch'.
5. Kingston, Frontenac, Lennox and Addington Health Unit.
6. Renfrew County and District Health Unit.

Appendix B. PPPESO: Partners, Variables and Entry Screen

Appendix B1. A Table Listing the Participating Hospitals, their Type, and the Number of Births Per Year*

3 Teaching Hospitals	
Hospital name	**Number of births in 2001**
1. Kingston General Hospital	2027
2.The Ottawa Hospital – Civic site	3933
3.The Ottawa Hospital – General site	3744
5 Large Community Hospitals (more than 500 births/year)	
Hospital name	**Number of births in 2001**
1. Belleville General Hospital (part of Quinte HC Corporation)	1398
2. Cornwall Hospital (Hotel Dieu site)	630
3. Montfort Hospital	1191
4. Pembroke General Hospital	727
5. Queensway Carleton Hospital	2388
8 Small Community Hospitals (less than 500 births/year)	
Hospital name	**Number of births in 2001**
1. Almonte General Hospital	245
2. Brockville General Hospital	338
3. Hawkesbury and District Hospital	367
4. Lennox and Addington General Hospital	96
5. Perth and Smith Falls District Hospital	300
6. Prince Edward County Memorial Hospital (part of Quinte HC Corporation)	64
7. Renfrew Victoria Hospital	82
8. Winchester District Memorial Hospital	158

* Based on the year 2001 number of births.

Appendix B2. List of Partner Agencies

Perinatal Partnership Program of Eastern and Southeastern Ontario

Partner Agencies

- Almonte General Hospital
- Brockville General Hospital
- CHEO/l'HEEO
- Community Health Centres of Eastern Ontario
- Eastern Ontario Health Unit
- Faculties of Medicine and Health Sciences, University of Ottawa/ Faculté de médecine et Faculté des sciences de la santé, l'Université d'Ottawa
- Faculty of Health Sciences, Queen's University
- Hastings & Prince Edward Counties Health Unit
- HIP/AIS
- Hôpital général de Hawkesbury & District General Hospital
- Hôpital Montfort
- Hotel Dieu Hospital Cornwall/ Hôpital l'Hôtel Dieu
- KFL&A Health Unitk
- Kingston General Hospital
- Leeds, Grenville & Lanark District Health Unit
- Lennox & Addington County General Hospital
- Pembroke General Hospital
- Perth & Smith Falls District Hospital
- Queensway-Carleton Hospital
- Quinte Healthcare Corporation
- Region of Ottawa-Carleton Health Department/ Service de la santé d'Ottawa-Carleton
- Renfrew County and District Health Unit
- Renfrew Victoria Hospital
- St. Mary's Home and the Young Single Parent Support Network
- Success by 6 / 6 ans et gagnant
- The Ottawa Hospital/ L'Hôpital d'Ottawa
- Winchester District Memorial Hospital

Adapted from the PPPESO website: www.pppeso.on.ca

Appendix B3. A List of Variables Present in the Perinatal Database

1. Date of birth
2. Baby number (identification number of the baby as listed in the logbook)

Geography

3. Location of birth: Hospital identification code
4. Mother's postal code

Maternal Characteristics

5. Mother's age in years
6. Number of previous term pregnancies
7. Number of previous preterm pregnancies
8. Inter-hospital transfer (indicates if the mother was transferred from any other hospital, the transfers are coded as: no transfer, transfer from the same city/town and metro area, from within Eastern Ontario, and outside of Eastern Ontario)
9. Maternal smoking (smoking from 20 weeks of gestation until delivery)
10. Intention to breastfeed (regardless of whether breastfeeding occurred in the labour and delivery room area)

Newborn Characteristics

11. Infant's weight in grams
12. Infant's gender
13. Apgar score after 1 minute
14. Apgar score after 5 minutes
15. Neonatal transfer (includes any infant transferred during the first 7 days of life only)

Characteristics of Pregnancy

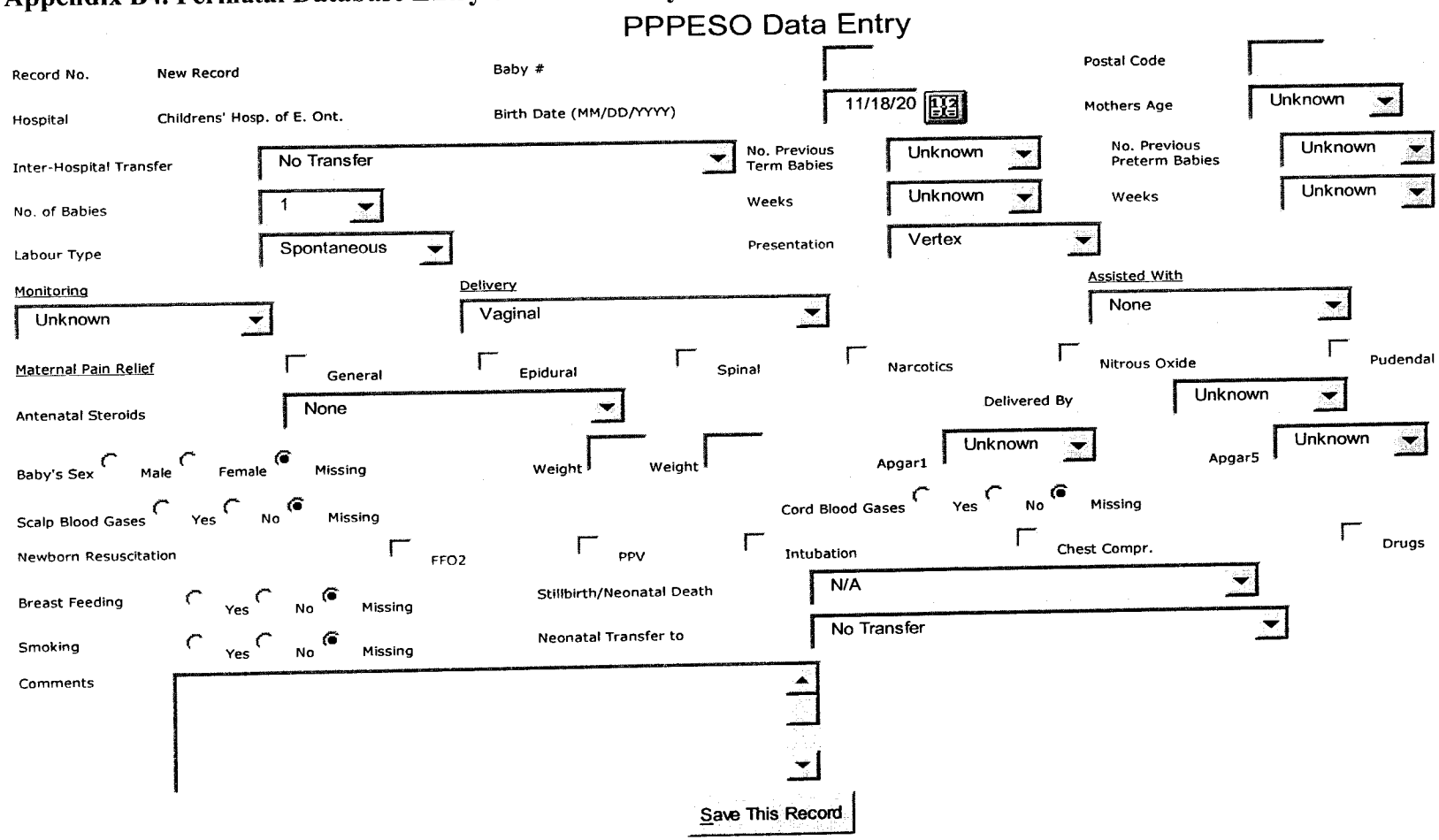
16. Duration: Gestational age in weeks
17. Number of babies in the current pregnancy (singleton or multiple gestation)
18. Birth outcome: Stillbirth/Neonatal death

Labour and Delivery Characteristics

19. Labour type (spontaneous, induced, or no labour)
20. Fetal Surveillance (auscultation, electronic fetal monitoring or both)
21. Presentation (vertex, breech or other)
22. Delivery type (vaginal, vaginal birth after caesarean section (VBAC), primary caesarean section, repeat caesarean section with trial and without trial of labour)
23. Assisted delivery (no intervention, forceps, vacuum or both)
24. Pain relief (general anaesthesia)
25. Pain relief (epidural anaesthesia)
26. Pain relief (spinal anaesthesia)
27. Pain relief (narcotics)
28. Pain relief (Nitrous oxide)
29. Pain relief (Pudendal block)
30. steroid use (none, 1 dose <24 hours before the time of birth, 2 doses but the last dose given < 24 hours before the time of birth, or 2 doses given >24 hours before the time of birth)

31. Delivered by (physician, or midwife)
32. Neonatal resuscitation: Free flow oxygen
33. Neonatal resuscitation: Positive pressure ventilation
34. Neonatal resuscitation : Intubation
35. Neonatal resuscitation : chest compression
36. Neonatal resuscitation : drugs
37. Scalp blood taken to measure blood gases
38. Cord blood taken

Appendix B4. Perinatal Database Entry Screen January 2001 – December 2002



Source: Internet based, CritiCall System showing the Perinatal Database Entry Screen.

Appendix B5. A List of Hospitals Outside the Region that Have Recently Joined the System

A. Hospitals in the Greater Toronto Area (members of the Child Health Network)
    1. Credit Valley Hospital
    2. Halton Healthcare Services (Milton District Hospital and Oakville Trafalgar Memorial Hospital)
    3. Humber River Regional Hospital
    4. Lakeridge Health Corporation
    5. Markham Stouffville Hospital
    6. Mount Sinai Hospital
    7. North York General Hospital
    8. Rouge Valley Health System
    9. Scarborough Hospital
    10. Southlake Regional Health Centre
    11. St. Joseph's Health Centre
    12. St Michael's Hospital
    13. Sunnybrook and Women's College Health Sciences Centre
    14. Toronto East General Hospital
    15. Trillium Health Centre
    16. University Health Network
    17. William Osler health Centre
    18. York Central Hospital

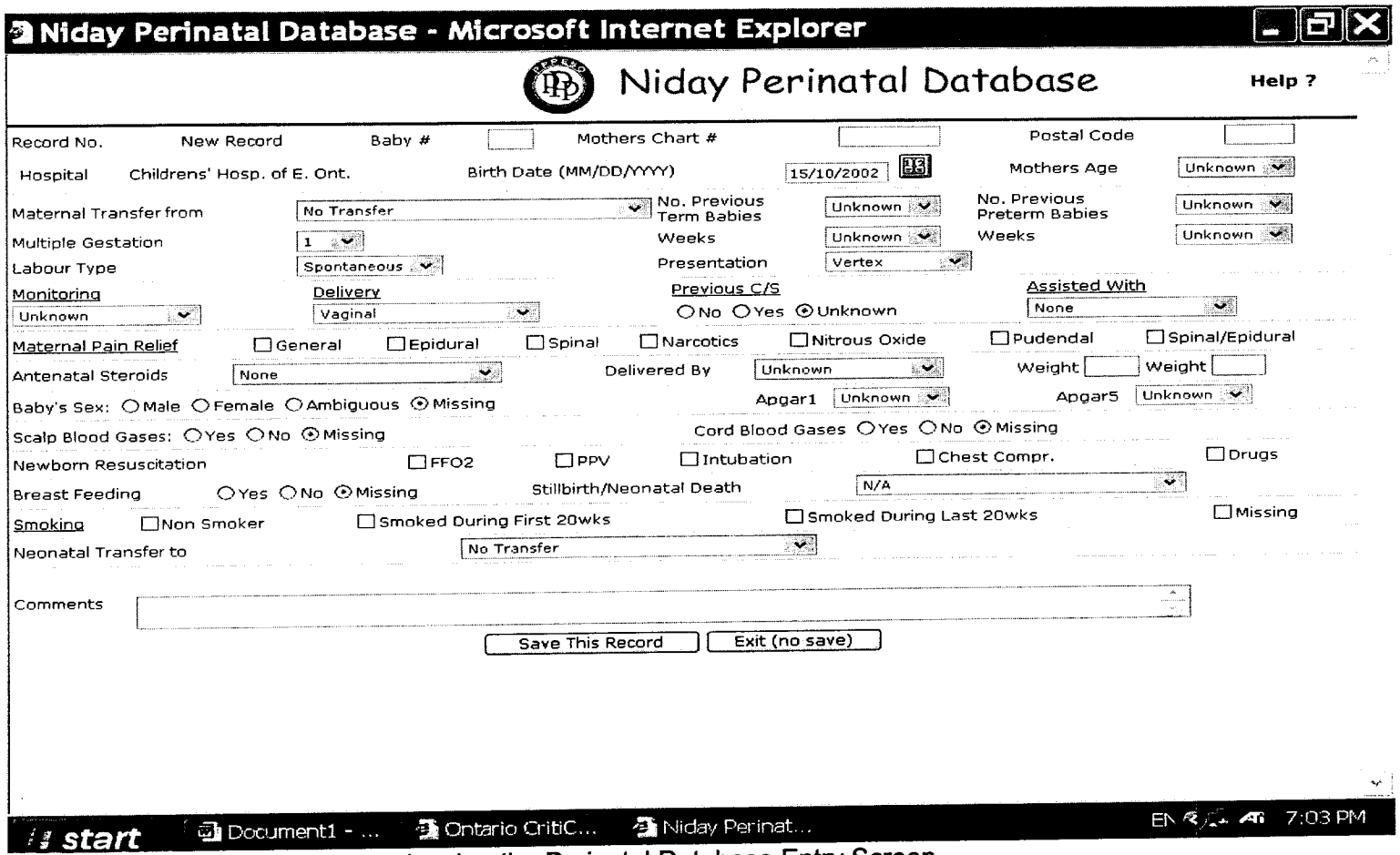
B. Hamilton Health Sciences Corporation
C. Northumberland Health Care Corporation
D. Peterborough Regional Health Centre
E. Ross Memorial Hospital
F. Royal Victoria Hospital (Barrie)
G. Sault Area Hospital
H. Thunder Bay Regional Hospital
I. Sudbury Regional Hospital

Appendix B6a. Modification to the Database Variables and the Entry Screen

As of January 2003, the Entry Screen underwent the following modifications:

1. The mother's chart number has been added.
2. The mother's age has been modified to start at age 10.
3. The maternal transfer: two more categories have been added "planned home birth" and "out of region".
4. The delivery type variable was split into two: delivery type (vaginal/ caesarean section/missing) and previous caesarean section (yes/no/unknown).
5. Maternal pain relief : a new category " spinal/epidural" has been added.
6. Delivered by: the categories have been modified with the "midwife" been split into two "midwife at home", "midwife at hospital" and the "physician" category has been split into two "family physician" and "obstetrician".
7. Baby's sex: a new category "ambiguous" has been added.
8. Smoking: has been modified to "non smoker", "smoked during the first 20 weeks", "smoked during the last 20 weeks" and "missing".
9. Neonatal transfer has been modified.

Appendix B6b. Current Perinatal Database Entry Screen



Source: Internet based, CritiCall System showing the Perinatal Database Entry Screen

Appendix C. Data Collection

Appendix C1. A Sample of the Out Print Used by the Data Collectors

HOSPITAL[1]	BABYNO[2]	DOB[3]	GEST[4]	WEIGHT[5]
1	18	03-JAN-2001	39	3780
1	72	08-JAN-2001	42	3331
1	126	11-FEB-2001	39	3506
1	168	15-FEB-2001	42	3576
1	252	24-FEB-2001	41	3748
1	275	27-FEB-2001	40	2771
1	278	27-FEB-2001	36	2791
1	155	02-MAR-2001	39	3838
1	221	08-MAR-2001	41	3576
1	312	15-MAR-2001	38	4055
1	58	24-MAR-2001	40	3784
1	70	25-MAR-2001	39	4358
1	81	26-MAR-2001	37	2941
1	101	28-MAR-2001	34	2104
1	116	30-MAR-2001	40	3822
1	2	01-APR-2001	32	2210
1	32	04-APR-2001	40	3375
1	68	06-APR-2001	36	2159
1	98	09-APR-2001	32	1820
1	105	09-APR-2001	39	3581
1	163	13-APR-2001	20	407
1	223	19-APR-2001	40	3431
1	313	27-APR-2001	38	3022
1	49	05-MAY-2001	41	3178
1	60	05-MAY-2001	40	3649
1	113	08-MAY-2001	39	4181
1	114	09-MAY-2001	38	2984
1	152	11-MAY-2001	37	2997
1	164	12-MAY-2001	39	3737
1	177	14-MAY-2001	40	3713

[1] The number under hospital is a unique identifying number for that particular hospital.
[2] Baby number : this is the number written on the logbook, for every month the baby numbers start at 1.
[3] Date of birth.
[4] Gestational age.
[5] Baby's weight.

Appendix C2. Request to Conduct the Evaluation Sent by PPPESO to the Participating Hospitals

Tuesday, February 26, 2002

Subject: Data Audit

Hello All,

As you may know, PPPESO will be doing an evaluation of the perinatal database in the coming weeks. A graduate student from the University of Ottawa, named Amira Ali, has begun working on this as part of her Master's thesis - she is being supervised by Dr. Paula Stewart. This evaluation is a great opportunity for all of us to ensure that the database meets our needs.

As part of the evaluation, a data audit comparing the perinatal database with the case log, as well as the charts, will be completed. You should each be receiving a more formal letter which will elaborate on the process and requirements, but I wanted to give you a heads up that it was coining, in case you have any questions. Amira will also be calling each of you shortly to set up the logistics and discuss the details. Some of you may have been involved in the last audit that was performed a few years ago - this process will be similar. Amira, or possibly another individual working with her, will require access to a sample of charts and to the case log in order to perform the audit. She'll have her own laptop, but any assistance you can give her in terms of workspace would be greatly appreciated. The audit would take 1-2 days per site.

Thank you in advance for welcoming Amira to your site - if you have any questions, please feel free to contact me any time.

Director of Perinatal Systems
Perinatal Partnership Program of Eastern and Southeastern Ontario (PPPESO)

Appendix C3b. Questionnaire for the Database Coordinator in Each Hospital

Questionnaire for the Database Partners

This questionnaire is to be completed by the individual responsible for the Database within the hospital. Please contact others who can provide input to the answers.

The following questions relate to the ***CONTENT*** of the PPPESO Database, please choose the best answer from the list of the given options, or provide your written answers where applicable:

1. What proportion of the variables in the Database do you find useful?
   a. All or nearly all (90%+)
   b. More than half (60 – 89%%)
   c. About half (40 – 59%%)
   d. Less than half (10 – 39%)
   e. Hardly any (less than 10%)

2. What variables would you like to see added to the Database?

3. What variables would you like to see deleted from the Database?

4. How satisfied are you with the way the variables are defined in the Database?
   a. Very satisfied
   b. Satisfied
   c. Neutral
   d. Dissatisfied
   e. Very dissatisfied

5. If dissatisfied or very dissatisfied, what would you like to see changed in the definitions?

The following questions relate to the ***DATA COLLECTION*** component of the Database:

6. Overall, how would you rate the data entry procedure?
   a. Very easy
   b. Easy
   c. Neutral
   d. Difficult
   e. Very difficult

7. Do you have any comments or recommendations about the data entry process?

8. Do you think that the investment your hospital makes in the data entry process is reasonable for the return you are getting from the database?
   a. Yes
   b. No, if no why not

9. How often does the system go down?
   a. Never
   b. 1 per week
   c. 2 per week
   d. 3 times or more per week
   e. Do not know

10. If the system goes down, how long does it usually take before it is back?
    a. Less than 1 hour
    b. 1-2 hours
    c. 3-4 hours
    d. More than 4 hours
    e. Do not know

11. How satisfied are you with the data verification process (e-mails about the number of births, questions about the data, confirmation about the closing of the month, etc) provided by PPPESO?
    a. Very satisfied
    b. Satisfied
    c. Neutral
    d. Dissatisfied
    e. Very dissatisfied

12. If dissatisfied or very dissatisfied what would you recommend for the data verification to be satisfactory?

The following questions relate to the ***DATA ANALYSIS AND REPORTS***:

13. How would you rate the procedure for generating reports?
    a. Very easy
    b. Easy
    c. Neutral
    d. Difficult
    e. Very difficult

14. When you are producing a report, you need to choose the variables that you want to analyze, and the qualifiers for those variables, i.e. you need to customize your data requests to suit your needs. How easy do you find this part of creating a report?
    a. Very easy
    b. Easy
    c. Neutral
    d. Difficult
    e. Very difficult

15. Do you have any comments or recommendations about the procedure for generating the reports?

16. Are you satisfied with the report format?
    a. Very satisfied
    b. Satisfied
    c. Neutral
    d. Dissatisfied
    e. Very dissatisfied

17. Do you have any comments or recommendations on the format of the reports?

18. How often do you or someone else in your hospital run/generate FREQUENCY REPORTS for your hospital?
    a. Never
    b. Less than 1 per month
    c. 1 per month
    d. 1 per week
    e. More than 1 per week

    If never, please explain why?

19. How often do you or someone else in your hospital run COMPARISON REPORTS?
    a. Never
    b. 1 every 3 months
    c. 1 per month
    d. 1 per week
    e. Other, please specify

20. How easy or difficult is it to understand/interpret the reports?
    a. Very Easy
    b. Easy
    c. Neutral
    d. Difficult
    e. Very difficult

21. Do you have any comments or recommendations on the understanding/interpretation of the report?

22. Are you satisfied with the "user support" provided by PPPESO?
    a. Very satisfied
    b. Satisfied
    c. Neutral
    d. Dissatisfied
    e. Very dissatisfied

23. If dissatisfied or very dissatisfied, what would you recommend to improve the user support?

The following questions relate to the ***USEFULNESS*** of the Database:

24. How has the Database contributed to the access to information about Perinatal Care Practices within your hospital?
    a. Greatly increased access
    b. Some increase access
    c. No change

25. Is the database meeting your needs? Please explain

26. Please give examples of how you have used the Database

Appendix C4. Questionnaire for the Data Entry Personnel in Each Hospital

Data Entry Questionnaire

This questionnaire is to be completed by the individual doing most of the data entry.

The following questions relate to the ***DATA ENTRY*** component of the PPPESO Database, please choose the best answer from the list of the given options, or provide your written answers where applicable:

1. Overall, how would you rate the data entry procedure?
   a. Very easy
   b. Easy
   c. Neutral
   d. Difficult
   e. Very difficult

2. Do you have any comments or recommendations about the data entry procedure?

3. On average, how long does it take you to enter the data for 1 record?
   a. Less than 1 minute
   b. 1-3 minutes
   c. 4 - 6 minutes
   d. More than 6 minutes

4. How often does the system go down per week?
   a. Never
   b. 1per week
   c. 2 per week
   d. 3 times or more
   e. Do not know

5. If the system goes down, how long does it usually take before it is back?
    a. Less than 1 hour
    b. 1-2 hours
    c. 3-4 hours
    d. More than 4 hours
    e. Do not know

6. Are you experiencing any problems with the system?

7. Do you have any suggestions for improvements?

Appendix C5. Questionnaire for PPPESO Staff

Questionnaire for PPPESO

The following questions relate to the ***DATA COLLECTION*** component of the PPPESO Database, please choose the best answer from the list of the given options, or provide your written answers where applicable:

1. How many hospitals are participating in the Database out of the total number of hospital partners?

2. How often does the system go down per week?
   a. Never
   b. 1 per week
   c. 2 per week
   d. 3 times or more
   e. Do not know

3. If the system goes down, how long does it usually take before it is back?
   a. Less than 1 hour
   b. 1-2 hours
   c. 3-4 hours
   d. More than 4 hours
   e. Do not know

The following questions relate to the ***DATA ANALYSIS AND REPORTS***:

4. When is the annual regional report produced?

5. When is the report made public?

The following questions relate to the ***USEFULNESS*** of the Database:

6. Is it possible to link this Database to other databases such as the Census Database?
   a. Yes
   b. No
   c. Do not know

7. If the linkage is possible, how easy is it?
   a. Very easy
   b. Easy
   c. Neutral
   d. Difficult
   e. Very difficult

8. How often has it been done?
   a. Never
   b. Once
   c. Twice
   d. Three times or more
   e. Do not know

9. If the linkage is not currently possible, what needs to be done to make it possible?

10. How does PPPESO use the database?

11. What would you like to see done to optimize the use of the Database?

12. What are the main challenges in operating this system?

13. How could they be addressed?

Appendix C6b. Questionnaire for the Public Health Units

Questionnaire for the Public Health Units (PHUs) in Eastern Ontario

This questionnaire is to be completed by the person who has been trained by PPPESO to use the Perinatal Database. Input to the answers can also be sought from other individuals within the health unit who are using/have used the Database.

The following questions relate to the ***CONTENT*** of the PPPESO Database, please choose the best answer from the list of the given options, or provide your written answer where applicable:

1. What proportion of the variables in the Database do you find useful?
   a. All or nearly all (90%+)
   b. More than half (60 – 89%)
   c. About half (40 – 59%)
   d. Less than half (10 – 39%)
   e. Hardly any (less than 10%)

2. What variables would you like to see added to the Database?

3. What variables would you like to see deleted from the Database?

4. Is the Database capturing all the births that occur within Eastern Ontario (i.e. is it representative of the population of Eastern Ontario)?
   a. Yes
   b. No
   c. Do not know

5. If not, what do you suggest be done to capture all the births?

6. Is the Database capturing all the births that occur outside Eastern Ontario, to mothers residing in Eastern Ontario?
   a. Yes
   b. No
   c. Do not know

7. If not, what do you suggest be done to capture those births?

8. Do you have any comments or recommendations on the "content" of the Database?

The following questions relate to the ***DATA ANALYSIS AND REPORTS***:

9. Have you used the reports facility provided with the Database?
   a. Yes
   b. No

10. If no, please explain why not?

If yes, please answer questions 11 – 17 below.

11. How would you rate the procedure for generating reports?
    a. Very easy
    b. Easy
    c. Neutral
    d. Difficult
    e. Very difficult

12. When you are producing a report, you need to choose the variables that you want to analyze, and the qualifiers for those variables, i.e. you need to customize your data requests to suit your needs. How easy do you find this part of creating a report?

    a. Very easy
    b. Easy
    c. Neutral
    d. Difficult
    e. Very difficult

13. Do you have any comments or recommendations about the procedure for generating the reports?

14. Are you satisfied with the report format?
    a. Very satisfied
    b. Satisfied
    c. Neutral
    d. Dissatisfied
    e. Very dissatisfied

15. Do you have any comments or recommendations on the format of the reports?

16. How easy or difficult is it to understand/interpret the reports?
    a. Very Easy
    b. Easy
    c. Neutral
    d. Difficult
    e. Very difficult

17. Do you have any comments or recommendations on the understanding/interpretation of the report?

18. Have you used the "user support" provided by PPPESO?
    a. Yes
    b. No

19. Are you satisfied with the "user support" provided by PPPESO?
    a. Very satisfied
    b. Satisfied
    c. Neutral
    d. Dissatisfied
    e. Very dissatisfied

20. If dissatisfied or very dissatisfied, what would you recommend for improving the user support?

The following questions relate to the ***USEFULNESS*** of the Database:

21. How much has the Database contributed to the access to information about Perinatal Care Practices within your area?
    a. Greatly increased access
    b. Some increase in access
    c. No change

22. To what extent is the database meeting your needs?
    a. To a great extent
    b. To some extent
    c. Hardly at all

23. Please explain

24. Please give examples of how you have used the Database

25. Is it possible to link this Database to other databases such as the Census Database?
    a. Yes
    b. No
    c. Do not know

26. If the linkage is possible, how easy is it?
    a. Very easy
    b. Easy
    c. Neutral
    d. Difficult
    e. Very difficult

27. To your knowledge how often has it been done?
    a. Never
    b. Once
    c. Twice
    d. Three times or more
    e. Do not know

28. If the linkage is not currently possible, what needs to be done to make it possible?

Thank you very much for completing this questionnaire. You may mail it back to me in the enclosed stamped self-addressed envelope.

Appendix D. Inter- Rater Analysis

Appendix D1. Inter-Rater Analysis: Categorical/Nominal Variables (Cohen's Kappa and Percentage Agreement)

Categorical/ Nominal Variables	Rater 1 – Rater 2 (Logbook)						Rater 1 – Rater 2 (Charts)					
	Cohen's Kappa	Agreement					*Cohen's Kappa*	Agreement				
		100%	95.0 – 99.9%	90.0 – 94.9%	85.0 – 89.9%	<85.0%		100%	95.0 – 99.9%	90.0 – 94.9%	85.0 – 89.9%	<85.0%
1. Postal Code	N/A[#]		X				N/A		X			
2. Inter-hospital Transfer	—	X					—	X				
3. Number of previous term pregnancies	1.00	X					1.00	X				
4. Number of previous preterm pregnancies	—	X					—	X				
5. Number of babies (singleton,multiple gestation)	1.00	X					1.00	X				
6. Labour type	0.84			X			1.00	X				
7. Fetal monitoring	0.93		X				0.71					X
8. Presentation (Vertex, breech, other)	0.84		X				1.00	X				
9. Delivery type (spontaneous or c/s)	1.00	X					1.00	X				

[#] N/A : not available as equal/not equal was used, hence no cross-tabulation to generate the kappa statistic.

— : All data were in one cell, hence no variability to calculate for kappa to be calculated. Such examples are Inter-hospital transfers where all of the records were "no transfer", nitrous oxide and steroid use where all of the records were "no" etc.

Categorical/ Nominal Variables	Rater 1 – Rater 2 (Logbook)						Rater 1 – Rater 2 (Charts)					
	Cohen's Kappa	Agreement					Cohen's Kappa	Agreement				
		100%	95.0 – 99.9%	90.0 – 94.9%	85.0 – 89.9%	<85.0%		100%	95.0 – 99.9%	90.0 – 94.9%	85.0 – 89.9%	<85.0%
10.Forceps or Vacuum assisted birth	1.00	X					1.00	X				
11. Anaesthesia: General	1.00	X					1.00	X				
12. Anaesthesia: Epidural	0.66		X				1.00	X				
13. Anaesthesia: Spinal	0.91		X				1.00	X				
14. Anaesthesia: Narcotic	1.00	X					0.79			X		
15. Anaesthesia: Nitrous Oxide	—	X					0.66		X			
16. Anaesthesia : Pudendal Block	0		X				0		X			
17. Steroid use	—	X					—	X				
18. Delivered by: (Physician, Midwife)	—	X					—	X				
19.Baby's gender	1.00	X					0.94		X			
20. Newborn Resuscitation: Free Flow Oxygen	0.94		X				0.90		X			
21. Newborn Ressuscitation: Positive Pressure Ventilation	1.00	X					1.00	X				
22. Newborn Resuscitation: Intubation	—	X					—	X				

Categorical/ Nominal Variables	Rater 1 – Rater 2 (Logbook)						Rater 1 – Rater 2 (Charts)					
		Agreement						Agreement				
	Cohen's Kappa	100%	95.0 – 99.9%	90.0 – 94.9%	85.0 – 89.9%	<85.0%	Cohen's Kappa	100%	95.0 – 99.9%	90.0 – 94.9%	85.0 – 89.9%	<85.0%
23. Newborn Resuscitation: Chest Compression	—	X					—	X				
24. Newborn Resuscitation: Drugs	1.00	X					1.00	X				
25. Apgar score 1 minute	0.96		X				0.93		X			
26. Apgar score 5 minutes	0.96		X				0.96		X			
27. Scalp blood sample	—	X					—	X				
28. Cord blood sample	—	X					0.12					X
29. Breastfeeding	1.00	X					1.00	X				
30. Smoking	0.89		X				0.94		X			
31. Stillborn/ Neonatal Death	—	X					—	X				
32. Neonatal Transfer to another hospital	1.00	X					1.00	X				

Appendix D2. Inter-Rater Analysis: Continuous variables (Intraclass Correlation and Percentage Agreement)

Continuous Variables	Rater 1 – Rater 2 (Logbook)						Rater 1 – Rater 2 (Charts)					
	Intraclass Correlation (N)*	Agreement (N =40)					Intraclass Correlation (N)	Agreement (N =40)				
		100%	95.0 – 99.9%	90.0 – 94.9%	85.0 – 89.9%	<85.0%		100%	95.0 – 99.9%	90.0 – 94.9%	85.0 – 89.9%	<85.0%
1. Mother's age	0.99		X				0.99		X			
2. Gestational age: Gestational age 1	1.00	X					0.98 (39)			X		
3. Gestational age: Gestational age 2	1.00	X					0.98 (39)			X		
4. Baby's weight: Weight 1	1.00	X					1.00 (39)		X			
5. Baby's weight: Weight 2	1.00	X					1.00 (39)		X			

* (N) is indicated where there were "unknown" categories, else N = 40.

Appendix E. PPPESO Strategic Plan

Appendix E1. Mission, Vision and Guiding Principles of the PPPESO

STRATEGIC PLAN

Mission

To promote optimum perinatal care of childbearing families in Eastern and Southeastern Ontario in order to improve health and to achieve excellent perinatal health outcomes.

Perinatal is traditionally defined as the period of time during pregnancy, birth, and the first month after birth but has grown to include the preconception period, with the recognition that health status prior to pregnancy also influences maternal and newborn outcomes.

Vision

External Vision:
Child-bearing families, women and babies receive accessible, evidence-based care consistently throughout the region.

Internal Vision:
PPPESO is an interdisciplinary, regionalized organization committed to achieving continuous quality improvements in the health care for mothers, infants and families in Eastern and Southeastern Ontario.

Principles

The following principles are integral to the function of PPPESO:

Partnerships
- Collaboration among the partners is essential to maximize the ability of the Program to meet its mission.
- The Program builds on the individual and collective capabilities, resources and expertise of its partners.
- Provision of perinatal care using a regionalised systems approach.
- The program operates in an environment of respect for linguistic and cultural diversity.
- Diversity among partners in the region is an asset.

Integration
- Education, research and practice must be integrated for effective and efficient programs and services.
- Research is practical and defined by actual and emerging issues as identified by the partners.
- Delivery of programs and services is dependent on creative, evidence-based planning, development, implementation and evaluation.

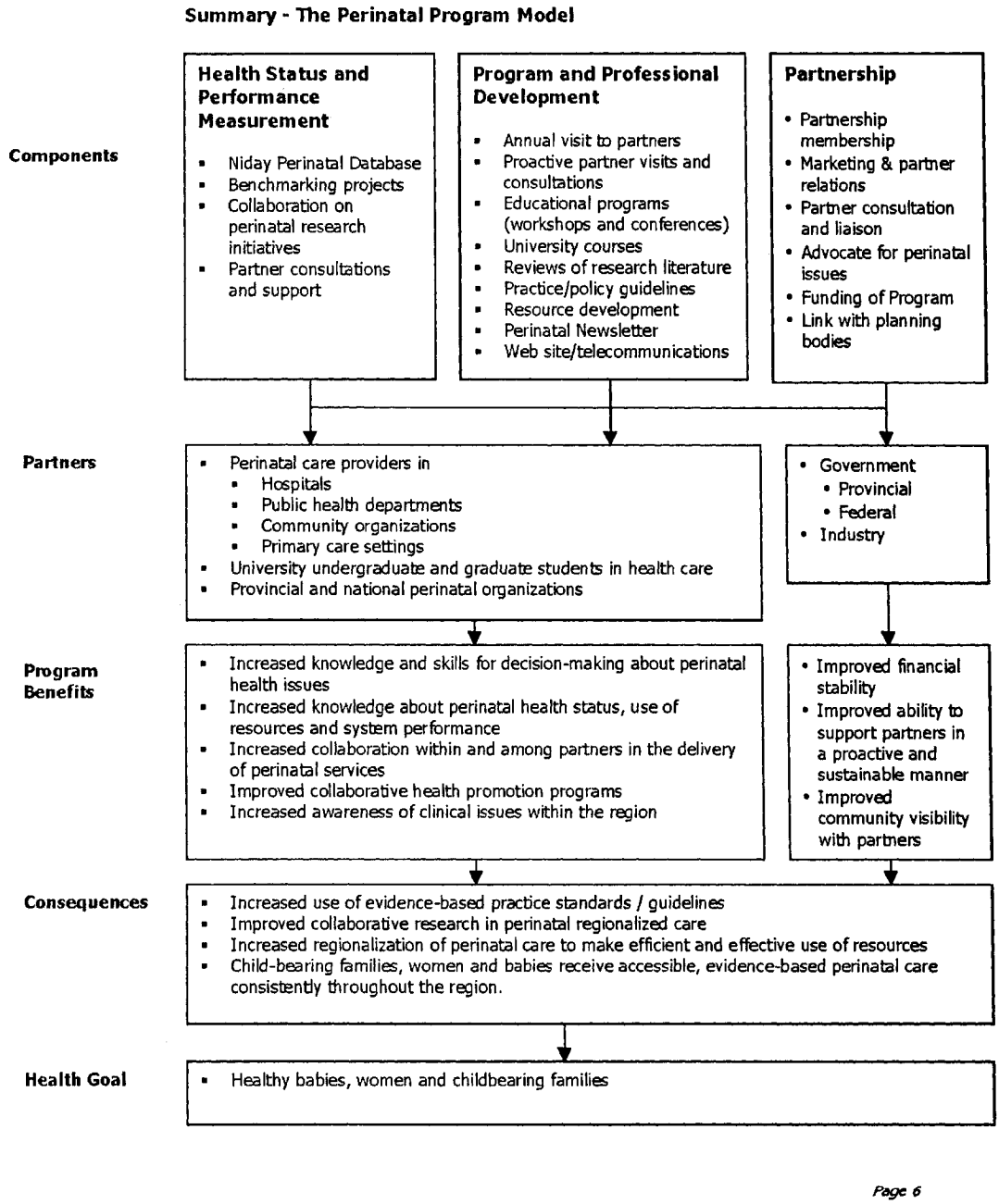
Continuous Learning
- Provision of optimal care is dependent on access to basic and continuing evidence-based education for health care providers.

Accountability
- The Program is accountable to its partners.
- Contributions to the health care system are evaluated on a regular basis and communicated broadly.
- Committed to quality, evidence-based and collaborative perinatal health care.

Page 3

Source: PPPESO Strategic Plan 2002-2005

Appendix E2. The Perinatal Program Model



Source: PPPESO Strategic Plan 2002-2005

Appendix F. Modeling Exercise for Kappa

Appendix F1. Hypothetical Tables of Observed Agreement on the Presence or Absence of an Event

(P(o) = 0.95 throughout)

Table 1 Symmetrical and Balanced

		Observer 1		
		Yes	No	Total
Observer 2	Yes	45	4	**49**
	No	1	50	**51**
	Total	**46**	**54**	100

P(o) = 0.95, P(e) = 0.50, K= 0.90

Table 2 Symmetrical, Imbalanced

		Observer 1		
		Yes	No	Total
Observer 2	Yes	70	0	**70**
	No	5	25	**30**
	Total	**75**	**25**	100

P(o) = 0.95, P(e) = 0.60, K= 0.88

Table 3 Symmetrical, Greater Imbalance

		Observer 1		
		Yes	No	Total
Observer 2	Yes	85	0	**85**
	No	5	10	**15**
	Total	**90**	**10**	100

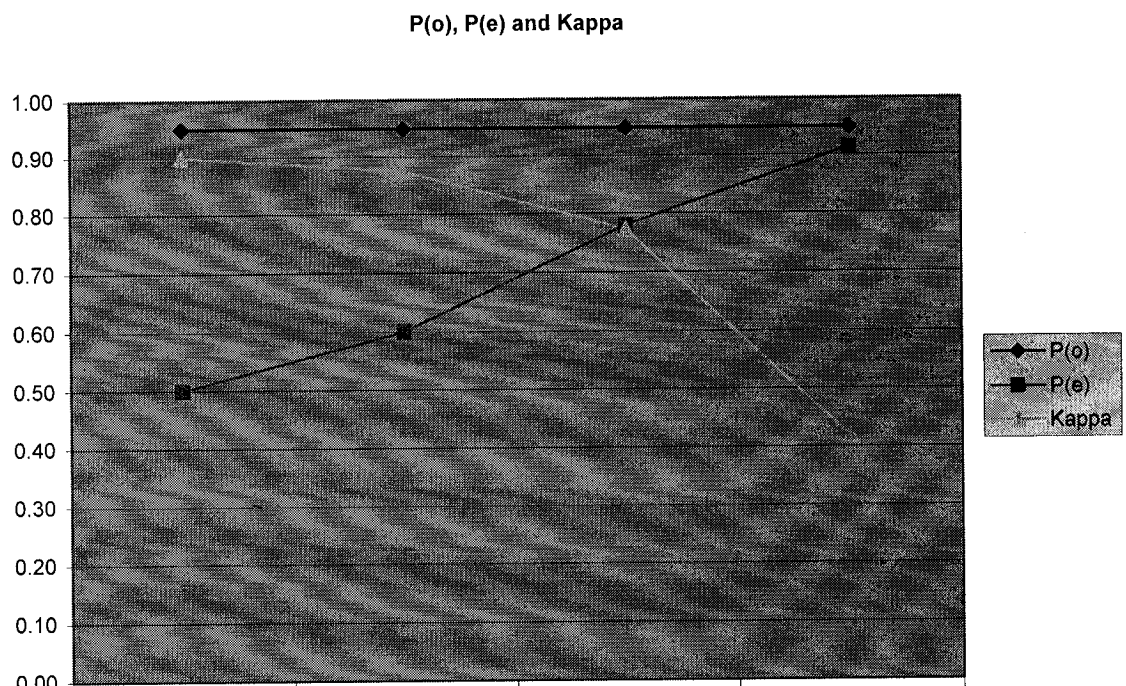
P(o) = 0.95, P(e) = 0.78, K= 0.77

Table 4 Symmetrical, Very Large Imbalance

		Observer 1		
		Yes	No	Total
Observer 2	Yes	93	2	**95**
	No	3	2	**5**
	Total	**96**	**4**	100

P(o) = 0.95, P(e) = 0.91, K= 0.42

Appendix F2. Diagrammatic Representation of P(o), P(e), and Kappa Based on Tables 1 – 4



	1	2	3	4
P(o)	0.95	0.95	0.95	0.95
P(e)	0.50	0.60	0.78	0.91
Kappa	0.90	0.88	0.77	0.42