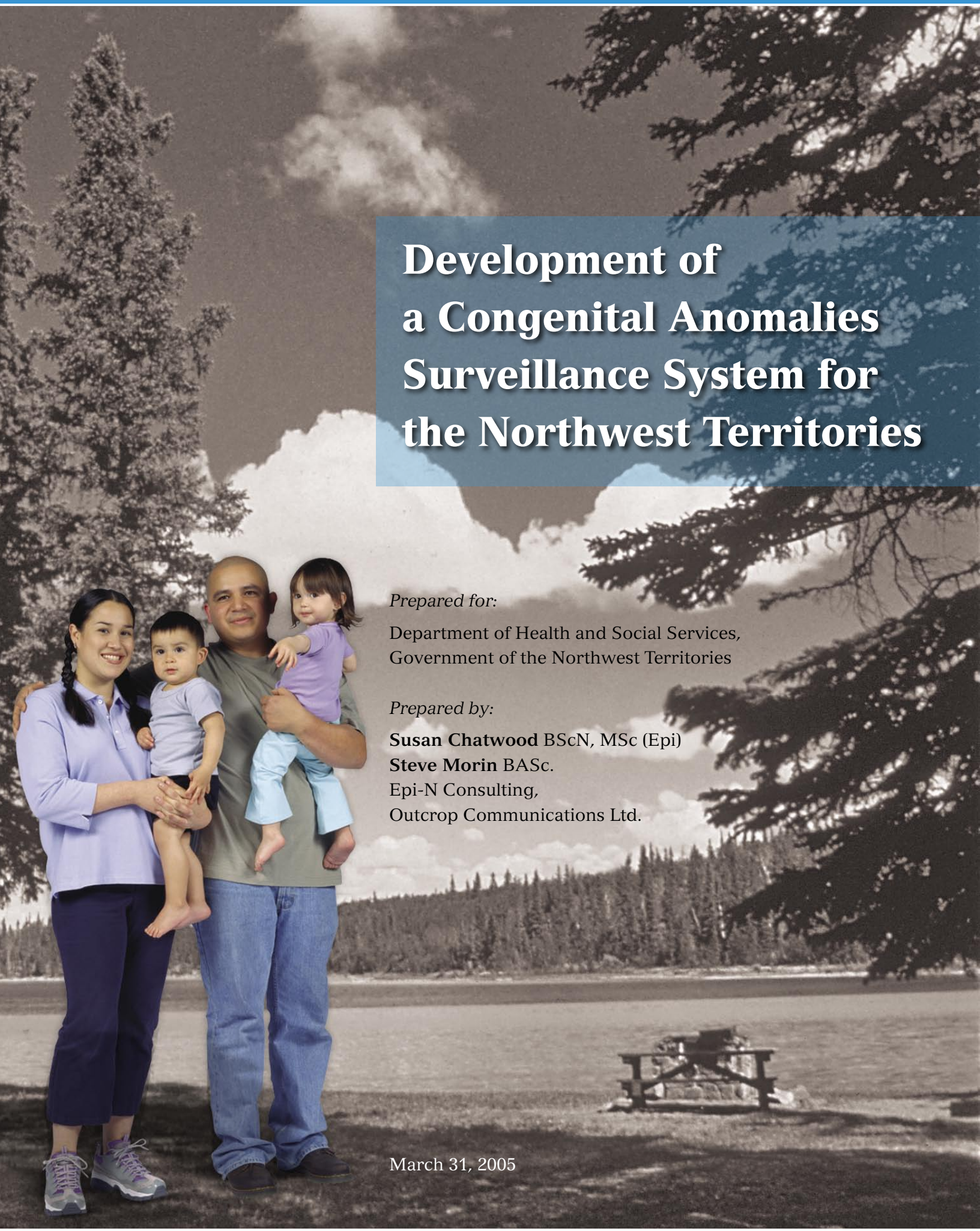

Development of a Congenital Anomalies Surveillance System for the Northwest Territories

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1.0 EXECUTIVE SUMMARY

The Government of the Northwest Territories, Department of Health and Social Services and the Early Childhood Development Strategy Team has established an initiative to determine the scope and requirements for a congenital anomalies surveillance system in the Northwest Territories (NWT).

Because congenital anomalies have a significant impact on mortality, morbidity, disability and health care costs, there has been an increased interest in describing their causes and in developing, implementing and evaluating prevention programs.

Public health surveillance is defined as the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health. Data disseminated by a public health surveillance system can be used for immediate public health action, program planning and evaluation, and formulating research hypotheses.

The purpose of this report is to provide a clear framework for the establishment of a congenital anomaly surveillance strategy for the NWT. This framework is built upon a process of stakeholder consultation, review of best practices in other jurisdictions and consultation with a broad spectrum of expert advisors. Through this process of consultation and review, objectives were established that informed the design of the proposed surveillance system.

A broad spectrum of stakeholders from organizations working with children and families affected by congenital anomalies were consulted during the course of this project to determine the needs and objectives for a congenital anomalies surveillance system in the NWT. Stakeholders and advisors were asked to provide input into the objectives and design of a congenital anomalies surveillance system for the NWT. There were five broad components of the stakeholder consultation process.

An advisory group of key stakeholders was formed that was consulted on an ongoing basis throughout the course of the project. Information gathered from other sources was shared with this group during the process of establishing objectives and design priorities. This group was selected based on clinical, operational, or community expertise in the area of perinatal and child health.

Similarly, the Canadian Congenital Anomaly Surveillance Network (CCASN) also had an advisory role. Consultations with national stakeholders took place at the annual meeting of the CCASN to determine the fit of the NWT system within the national context. This occurred through informal consultation with provincial registrars, a pan territorial meeting and a presentation on the NWT congenital anomalies surveillance system strategy development to date.

The bulk of stakeholder consultation took the form of general information sessions with stakeholders with the opportunity provided for follow up and for detailed feedback. Group presentations were made to various organizations representing health workers, NGOs, and early childhood educators. Presentations offered general introductions with opportunities for

detailed follow up on determining objectives and specific aspects of design. The stakeholder consultation meetings took on more of an information session format, providing background on best practices for surveillance and implications for the NWT.

As a follow up to the information sessions a questionnaire was distributed to stakeholders who attended information sessions to provide an opportunity for more specific feedback regarding congenital anomalies surveillance.

Two workshops were held on the diagnosis and surveillance of Fetal Alcohol Spectrum Disorder (FASD). FASD was identified to be a congenital anomaly of particular interest in the NWT. It was emphasized that a surveillance system had to be responsive to, and recognize, this anomaly. Workshops were required to determine best practices for diagnosis and surveillance of FASD in the NWT as FASD diagnosis had additional issues in determining best practices. In particular a roundtable consultation was held regarding diagnosis and surveillance of FASD in the NWT.

The majority of stakeholders advocated for a congenital anomaly surveillance system that would provide information to facilitate clinical services to affected children and their families, improve programming and prevention strategies, enhance community links and allow for research opportunities. It was stressed that a system must be tied to a greater capacity to provide services to those affected by the conditions. It was also suggested that the scope of the system go beyond congenital anomalies and include other pertinent childhood diagnoses that require similar clinical and social services such as Autism Spectrum Disorder.

Review of best practices in Canada found three provincial congenital anomalies surveillance systems in Canada. They are located in British Columbia, Alberta and Nova Scotia. These systems were reviewed with respect to their objectives, scope and methodology. It was found that the three systems had different objectives as reflected in their design and the services they facilitate.

The most marked similarities to the NWT objectives were seen to be with the BC Health Status Registry (HSR) where importance was placed on congenital anomalies and additional developmental disabilities throughout the life span. A major objective of the BC system is ensuring that adequate resources are available for individuals and families with developmental delays. In addition the BC registry recognizes the aspects of FASD diagnosis that require additional considerations in system design. In addition there has been much work on best practices for diagnosis of Autism Spectrum Disorder.

Unique features of the NWT, with centralized clinical services and smaller governmental departments, allows for a broader set of objectives to be met by the system. There does however appear to be a need to divide the surveillance activities between two locations so these objectives can be achieved.

The recommended two tiered surveillance system would be accomplished by the Stanton Territorial Health Authority housing a clinical data base that allows for case by case management of those affected by congenital anomalies and other developmental delays. In turn the GNWT-DHSSA would house a second linked data base that responds to the needs for

territory wide program planning and evaluation, the development of prevention strategies, reports to the CCASN and disseminating findings through annual reports. These two data base systems would be interrelated and work together to achieve the objectives of the system as a whole.

The creation of a position for a child development team coordinator is essential to the success of this project. Stanton Territorial Health Authority does not have the capacity to support a surveillance system with out a child development team coordinator.

Recommendations are made for the establishment of a surveillance system to be carried out in two phases; phase one being the project design and phase two, project implementation. Active engagement with external experts in all aspects of project work is advocated. This point is emphasized because there is an active and willing cohort of surveillance experts, notably at the BC HSR whom are interested in assisting the NWT in the establishment of a territorial registry. Engaging them will significantly facilitate the project.

Recommendations are made for the membership and mandates of a project steering committee, manager and project working group. A clear stepwise roadmap for project realization is provided.

2.0 INTRODUCTION

The Government of the Northwest Territories, Department of Health and Social Services and the Early Childhood Development Strategy Team has established an initiative to determine the scope and requirements for a congenital anomalies surveillance system in the Northwest Territories.

Congenital anomalies, also known as birth defects, represent a significant proportion of infant morbidity and mortality in Canada, representing 2-3% of births.[1] The emotional and economic burden on families and society is considerable. A congenital anomalies surveillance system that is designed to respond to public health needs would assist in both preventing congenital anomalies and supporting affected children and families through effective program planning and evaluation.

Congenital Anomaly Defined

A Congenital Anomaly is an abnormality of structure, function or metabolism (body chemistry) present at birth that results in physical or mental disability, or is fatal. Several thousand different birth defects have been identified. Birth defects are the leading cause of death in the first year of life. Examples are genetic diseases such as dwarfism and cystic fibrosis, environmental influences such as drugs, alcohol and infections (rubella).[2] Multifactorial inheritance is the underlying etiology of most of the common congenital anomalies.[3]

Because congenital anomalies have a significant impact on mortality, morbidity, disability and health care costs, there has been an increased interest in describing their causes and in developing, implementing and evaluating prevention programs.[4] In response to the thalidomide tragedy of 1958 – 1962 the first congenital anomaly surveillance system was introduced in Canada in 1966 in an effort to detect new teratogens in a timelier manner.[5] Currently three provinces Alberta, Nova Scotia and British Columbia have comprehensive congenital anomalies surveillance systems.

The Northwest Territories currently has no means of measuring the impact of congenital anomalies on health status or of evaluating programming or public health interventions targeting this population. In an initial report conducted by Andrea Wilhem[6] it was determined that the development of a congenital anomalies surveillance strategy for the NWT was timely and feasible. She pointed out that nearly 100% of births and prenatal diagnostic testing in the NWT occur in only two hospitals. As well, all three territorial pediatricians are based at one hospital, which increases the likelihood that all cases could be captured through the diagnosis and screening conducted at this center.

The purpose of this report is to provide a clear framework for the establishment of a congenital anomaly surveillance strategy for the NWT. This framework is built upon a process of stakeholder consultation, review of best practices in other jurisdictions and consultation with a broad spectrum of expert advisors. Through this process of consultation and review, objectives were established that informed the design of the proposed surveillance system.

3.0 Congenital Anomalies Surveillance - Rationale

Public health surveillance is defined as the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health. Data disseminated by a public health surveillance system can be used for immediate public health action, program planning and evaluation, and formulating research hypotheses.[7]

As the definition of surveillance demonstrates there must be clear objectives for a surveillance system to guide how the data is collected, analyzed, disseminated and used. An effective surveillance system will allow for the ready use of data for the implementation of population-based planning for public health programs and clinical services. Simply collecting data and reporting outcome rates neglects the underlying purpose of surveillance which is to use the data to create public health interventions, program planning and evaluation tools. An effective congenital anomalies surveillance strategy must be tied to community, clinical and public health programming in order to fulfill the definition of public health surveillance.

The objectives identified for a territorial congenital anomalies surveillance system must reflect community needs and priorities. Furthermore a congenital anomalies surveillance system should not be a fixed system, and ongoing evaluation should enable those who utilize the system to re-evaluate objectives and priorities.

3.1 Benefits of surveillance

Public health staff, clinicians, policy makers and researchers utilize data from a congenital anomalies surveillance system in a variety of ways. Some specific examples are discussed below. The exact uses of data from a territorial system will depend on the objectives and priorities determined by the users of the system.

3.2 Benefits of surveillance - service delivery

Surveillance can directly impact the delivery of services by enabling the identification of children and families in need of service and ensuring the appropriate provision of those services. Surveillance systems also facilitate the ongoing evaluation of services utilized and help in planning for service delivery based on geographic location.

The ability to link data between departments also enables surveillance data to be used with other public health systems such as preschool screening and special education systems. These linkages can enhance the evaluation of services and the ability of the surveillance system to identify children in need. However, when data is shared between programs, issues regarding privacy and confidentiality must be addressed and policies regarding interdepartmental sharing of data followed.

Estimating the need for services

Using congenital anomalies surveillance data to estimate services required has an immediate social impact. Accurately predicting the need for supportive services including interdisciplinary teams and social and educational services is very important for children born with birth defects. Furthermore estimating future service needs allows for long-term capacity building.

Referral to services

Information collected can be used to refer children and their families to required services. Established networks serve as a resource for children and their families to learn about medical services, community programs and social support. It is important that referrals occur in a timely fashion. Use of surveillance data to identify children in need of services is a function of surveillance systems, which can have an immediate effect on children and families.

3.3 Benefits of Surveillance – Program Planning and Evaluation

Without a congenital anomalies surveillance system in the NWT it will not be possible to evaluate the impact of interventions or prevention programs aimed at children affected by these conditions. Without means to measure the scope of a problem and evaluate the impact of an intervention based on trends it can be difficult to justify the existence of a program.

Program evaluation is an activity that has important scientific, academic, social and policy applications. Surveillance data are often used to measure baseline rates of congenital anomalies before an intervention or program is implemented. The surveillance data is then revisited after program completion to observe changes in rates. For example, in Washington State they were able to document the success of their prevention programs for high risk mothers by the decrease in rates of FASD coupled with a decreased consumption of alcohol over a 5 year period.[8] Without proper program assessment one runs the risk of spending time and money on programming which has no impact. Surveillance systems also allow one to compare the rates of diagnosis with referrals to services. This enables one to evaluate the referring body to determine if appropriate referrals are occurring.

3.4 Benefits of Surveillance - Research

Prevalence studies

Data collected by congenital anomalies surveillance systems are commonly used to describe the occurrence of the cases diagnosed. These numbers can be used to identify trends in congenital anomalies occurrence, define and evaluate clusters and assess the need for resources and interdisciplinary services.

Epidemiological studies

Congenital anomaly surveillance systems have played important roles in conducting etiologic and risk factor research worldwide. Current research in Nunavut has demonstrated that the rates of certain congenital anomalies are higher in Inuit populations.[9] This work has provided a baseline to conduct further studies to evaluate the impact of risk factors such as genetic markers, diet and alcohol use. In other cases prevention strategies, such as the fortification of flour with folic acid in Canada, have been evaluated with the data from surveillance systems.

3.5 Benefits of Surveillance – Improving Aboriginal Health

Despite the high living standards of the general population, Aboriginal peoples are among the poorest in terms of health and health care in Canada. Information provided by surveillance systems will enable tools for aboriginal people to improve health status and identify risk factors in their populations.

The surveillance of congenital anomalies in the NWT does not only apply to aboriginal populations given that approximately 50% of the population of the NWT is not aboriginal. However, data analysis could occur by ethnic group in order to identify disease clusters or anomalies that primarily occur in smaller communities that are predominately aboriginal. For example, certain heart defects have been identified primarily in Inuit populations and there are certain genetic conditions that have been identified as possibly predominating in certain Dene communities.

There is also the potential for data to be misused. An example of misuse of data around congenital anomalies has been the misconception that FASD is linked to certain ethno-cultural groups instead of identifying risk factors for prenatal alcohol exposure such as higher maternal age, lower education level, prenatal exposure to cocaine and smoking, custody changes, lower socioeconomic status, paternal drinking and drug use at the time of pregnancy, reduced access to prenatal and postnatal care, inadequate nutrition and a poor developmental environment (stress, abuse, neglect).[10] Involvement of aboriginal groups in setting the research agenda for FASD would prevent such misconceptions from being perpetuated.

When analyzing data pertaining to aboriginal populations, consideration must be given to the efforts of aboriginal communities to achieve self-determination. In instances where outside sources are setting the priorities for analysis of data pertaining to aboriginal groups these activities may be perceived as being oppressive and perpetuating colonial relationships.[11]

For the purposes of this project, aboriginal groups were involved in determining the objectives of a congenital anomalies surveillance system. However ongoing consultation and education regarding the scope and use of a surveillance system must occur with aboriginal groups.

The principles of ownership, control, access and possession (OCAP) are themes advocated by First Nations in Canada. The term was first coined by the Steering Committee of the First Nations Regional Longitudinal Health Survey. The principles are discussed as an expression of self-determination in research.[12] It is stated that these are "principles in evolution", and in the case of congenital anomalies surveillance, further elucidation of the principles are required. However, as an introduction, the principals of OCAP are described as a back-drop to data use and research in the NWT.

Ownership

This refers to the relationship between the aboriginal community and its cultural knowledge, data and information. The principal states that a community owns its information as a group the same way an individual owns personal information.

Control

The principal of control states that aboriginal people are within their rights to control all aspects of research that impact them. This includes all activities from the conception of a project to completion.

Access

Aboriginal people must have access to information and data that pertains to their communities regardless of the location. In the case of the congenital anomalies surveillance system existing protocols for access to information will have to be explored and access to information ensured.

Possession

Possession of data is a more literal description regarding the relationship between people and data. This is seen to be a mechanism whereby the ownership of the data can be asserted and protected. When data is owned by one party and is in the possession of another there is a risk of misuse. Bodies for data management in the NWT currently exist outside aboriginal control. Thus in the case of a congenital anomalies surveillance system it is

important to recognize that those who hold data pertaining to aboriginal populations, while physically possessing the data, must respect its confidentiality.

In order for the principles of OCAP to be fulfilled in the context of a congenital anomalies surveillance system, current infrastructure in the communities must be identified and further capacity built to support the use of the data to meet community needs.

In the case of congenital anomalies surveillance and surveillance pertaining to other developmental delays, there already exists some infrastructure in smaller communities where direction for analysis, if needed, could come. In many of the aboriginal communities there is established infrastructure in the area of early childhood intervention programs.[13] These are excellent resources upon which capacity could be built for the purposes of a congenital anomalies surveillance system.

The issues surrounding public health surveillance in aboriginal communities are complex and are only briefly visited here. There is a paper written for the Assembly of First Nations Health Secretariat on the Considerations for the Development of Public Health Surveillance in First Nations Communities that is recommended reading for a more comprehensive discussion of issues around surveillance.[14] As well, the National Aboriginal Health Organization's website provides an excellent resource and more detailed discussions around the principles of OCAP and surveillance in Aboriginal communities.

4.0 The State of Congenital Anomalies Surveillance

4.1 An International Perspective

The International Clearinghouse for Birth Defects Monitoring Systems (ICBDMS) is housed in Rome, Italy. The main activity of the clearinghouse is to monitor changes in birth defects prevalence. Currently there are 36 participating programs representing 34 countries. With all programs combined the ICBDMS monitors almost 3 million births each year.[15] In Canada the Canadian Congenital Anomaly Surveillance Network (CCASN), Alberta and BC are members and provide congenital anomalies data to the ICBDMS.

4.2 Canadian Systems

Currently there exist three provincial congenital anomalies surveillance systems in Canada. They are located in British Columbia, Alberta and Nova Scotia. These systems were reviewed with respect to their objectives, scope and methodology. It was found that the three systems had different objectives as reflected in their design and the services they facilitate.

British Columbia

In British Columbia (BC) the BC Vital Statistics Agency hosts the Health Status Registry (HSR). It is a comprehensive system that includes information on congenital anomalies, other genetic conditions and selected disabilities and handicapping conditions. The BC congenital anomalies initiative grew out of the need to measure outcomes from services provided to handicapped children.[16]

System Objectives

- To record and classify information concerning congenital anomalies, genetic conditions and selected handicapping conditions of children
- To assist health care planners and others in the planning of services
- To undertake statistical analysis of the data collected and assist in medical and genetic research based on the data
- Keep public informed by producing timely reports
- To respond to research requests from a varied audience
- To develop the HSR as a useful tool that will be utilized by the health care system[17]

Alberta

The Alberta Congenital Anomalies Surveillance System (ACASS) is funded by the Ministry of Health and Wellness, Health Surveillance Branch and is housed in the Department of Medical Genetics at the Alberta Children's Hospital. They work closely with the provincial department of vital statistics. The Alberta Registry more closely resembles a classic design of a case based congenital anomalies surveillance system.

System Objectives

- Provide reliable and valid baseline data of congenital anomalies in AB
- Investigate any significant temporal or geographic changes in the frequency of congenital anomalies with a view to identifying environmental, and therefore, possible preventable causes and measure trends
- Assess the effectiveness of prevention e.g. folic acid or antenatal screening
- Assist with health related program planning and development through the provision of data[18]

Nova Scotia

In Nova Scotia there are two systems in the province that together work to meet the needs of congenital anomalies surveillance. One system is governed by the Reproductive Care Program (RCP) and the other housed in the Division of Maternal-Fetal Medicine in the Department of Obstetrics and Gynecology at the provincial tertiary center. The system based at the tertiary center was initially designed for clinical support.[19] The tertiary center system collects data on a range of variables including congenital anomalies and their risk factors. This is done by the clinical care coordinator who compiles health information on high-risk pregnancies (clinic visits, lab results, ultra sound, amniocentesis, pathology reports etc.) to organize and present to clinicians for the provision of care. This same information is entered in a data base which in part monitors congenital anomalies, but also provides a broad scope of information on risk factors and treatments that are used to plan clinical services and identify research needs.

System Objectives

- Provide clinical support to facilitate active care
- Provide information for quality assurance related to clinical care, including peer review and clinical audit
- Provide baseline data on the impact of congenital anomalies
- Respond to population needs through epidemiologic analysis
- Provide data for clinical research

Although each provincial system is similar in that it provides baseline information on congenital anomalies, each has its own priorities which are reflected in the objectives and resultant design of the system. Various aspects of the three provincial systems are summarized in *table 1*. It is evident that surveillance system design is dependent upon the definition of clear, well-defined objectives.

Table 1 – Comparison of Provincial Congenital Anomalies Surveillance Systems

Province	British Columbia	Nova Scotia	Alberta
Operated by	BC Vital Stats	- Reproductive care program - Director of Maternal Fetal Medicine	- Department of Medical Genetics, AB Children's Hospital reporting to Alberta Vital Statistics
Population covered	- Births/stillbirths - 45,000 annually - mothers address at the time of birth - no age limit - early terminations related to CA	- births/stillbirths - 10,000 annually - population based - up to 1 year	- births/stillbirths - 40,000 annually - 20wks/500gm+ - up to 1 year
Criteria for inclusion	- person with mental/physical/ emotional problem with long term disability - person with genetic condition of CA not disabling - data collected on CA - other genetic conditions - selected disabilities and handicapping conditions - included Autism Spectrum Disorder	- major and minor anomalies - still births - terminations - infant death up to one year - collect demographics - capture all prenatally diagnosed anomalies	- births/stillbirths - 20wks/500gm+ - up to 1 year
Reporting sources	- death and stillbirth registrations - obs discharge summaries - cancer registry - hospital admissions/separations - genetics clinics - child development center - health regions - the Asante Centre for FASD	- program coordinator maintains flow sheet on each case/client - enters data and reports to perinatal committee - publications in peer reviewed journals	- Notice of live/still birth - Death registry - Congenital anomalies reporting form - out pt. Info from department of Medical Genetic - prenatal diag: - genetic, pathology, U/S, hosp of termination

Province	British Columbia	Nova Scotia	Alberta
Coding	- ICD 10 - 6 digit code based on McKusicks (genetic etiology code) - may have more than one diagnosis	- Altee Coding system - plan to link to ICD 10-ca	- ICD 10 - Royal college of child health and pediatrics adaptation.
Member of ICBCMS	Yes	No	Yes
Special considerations	FASD in registry since 1975 - medical terminations collected - adhere to the concept of building case histories through data from multiple sources.	- collect info on procedures - diagnosis and outcomes for women and newborns - risk factors	

5.0 Determining Needs and Setting Objectives

The value of a congenital anomalies surveillance system lies in its ability to use the data collected to improve public health outcomes by effectively managing health practices and programs to reach affected children and families. A surveillance strategy must have clear goals and objectives that direct how surveillance data are collected and used to improve health.[20] These goals and objectives are best determined by those healthcare workers and community members in the NWT with expertise in the field.

5.1 Stakeholder consultation – the process

A broad spectrum of stakeholders from organizations working with children and families affected by congenital anomalies were consulted during the course of this project to determine the needs and objectives for a congenital anomalies surveillance system in the NWT. Stakeholders and advisors were asked to provide input into the objectives and design of a congenital anomalies surveillance system for the NWT. There were five broad components of the stakeholder consultation process.

An advisory group of key stakeholders* was formed that was consulted on an ongoing basis throughout the course of the project. Information gathered from other sources was shared with this group during the process of establishing objectives and design priorities. This group was selected based on clinical, operational or community expertise in the area of perinatal and child health.

Similarly, the Canadian Congenital Anomaly Surveillance Network (CCASN) also had an advisory role. Consultations with national stakeholders took place at the annual meeting of the CCASN to determine the fit of the NWT system within the national context. This occurred through informal consultation with provincial registrars, a pan territorial meeting** and a presentation on the NWT congenital anomalies surveillance system strategy development to date.

The bulk of stakeholder consultation took the form of general information sessions with stakeholders with the opportunity provided for follow up and for detailed feedback. Group presentations were made to various organizations representing health workers, NGOs, and early childhood educators. Presentations offered general introductions with opportunities for detailed follow up on determining objectives and specific aspects of design. The stakeholder consultation meetings took on more of an information session format, providing background on best practices for surveillance and implications for the NWT.

* Pediatrician, Medical Health Officer, Midwife, Perinatal Nurse Clinician, Family Physician, Obstetrician and GNWT maternal child health representative

** Meeting between Dr Andre Corriveau MHO, NWT, MHO, NU, Dr Bryce Larke, Dr Geraldine Osborne DMHO YK, Dr Laura Arbour, Pediatrician, Clinical Geneticist, Assistant Professor, Department of Medical Genetics, University of British Columbia, Susan Chatwood, Epidemiologist Consultant, NWT.

As a follow up to the information sessions, a questionnaire (Appendix A), was distributed to stakeholders who attended information sessions to provide opportunity for more specific feedback regarding congenital anomalies surveillance.

Lastly, two workshops were held on the diagnosis and surveillance of Fetal Alcohol Spectrum Disorder (FASD). FASD was identified to be a congenital anomaly of particular interest in the NWT. It was emphasized that a surveillance system had to be responsive to and recognize this anomaly as FASD diagnosis had additional issues in determining best practices. Workshops were required to determine best practices for diagnosis and surveillance of FASD in the NWT. In particular a roundtable consultation was held regarding diagnosis and surveillance of FASD in the NWT. (Appendix B)

5.2 Stakeholder consultation – the outcomes

The results of the advisory group and stakeholder consultation are broken down into two categories, surveillance objectives and system design.

5.1.1 Surveillance Objectives

Surveillance Objectives – CCASN perspective

The Canadian Congenital Anomalies Surveillance Network (CCASN) suggested possible objectives for a congenital anomalies surveillance system.[21]

Objectives to consider

1. To accurately describe the burden of congenital anomalies
2. To conduct research on prevention
3. To provide tools for prevention, education, advocacy and promotion
4. To evaluate community concerns and clusters
5. To facilitate linkages between public health and clinical services
6. To integrate special health care services for children and other services for their families and improve access to services
7. To facilitate closer links and long term follow up with affected families
8. To evaluate interventions designed to prevent congenital anomalies
9. To serve as quality assurance tool

These objectives were shared with the advisors and stakeholders for consideration in a territorial system. The response to each objective is discussed below.

Objective 1 - To accurately describe the burden of congenital anomalies in the NWT

This objective was seen to be of importance to both clinicians and those providing services to children and families affected by congenital anomalies. It was agreed that a clear picture of the territorial rates of congenital anomalies is much needed. Clinicians also pointed out that rates for regions in Nunavut would also be useful to help in planning services.

Concern was expressed that there is no use measuring the number of cases of a congenital anomaly such as FASD in the NWT if there are no resources to provide care and services to those affected, or programming to decrease the prevalence of the condition. It was felt that diagnosing without providing support and follow up could be harmful if not unethical.

On the other hand there were those who pointed out that without surveillance and concrete descriptions of the burden of congenital anomalies, it would not be possible to identify what services are required for specific conditions. So although support services do not currently exist in some cases, surveillance to describe the burden of congenital anomalies is a first step in identifying the need and advocating for these services.

It was felt that the information provided by the system needed to provide data in a timely manner so that clinical activities could be based on concrete data.

Objective 2 - To conduct research on prevention

Improved evidenced based practice in the evaluation of prevention programs was felt to be important. The surveillance system was seen to be a tool that could provide information on trends of various congenital anomalies. This information could then be used in the design of evaluation frameworks for territorial prevention programs.

There was support expressed for efforts being made on the part of the three northern territories to promote a cohesive strategy for congenital anomaly surveillance. There was further discussion regarding promoting international partnerships with other circumpolar countries to promote circumpolar surveillance of congenital anomalies.

It was also pointed out that information on risk factors would need to be collected regarding some congenital anomalies to use in research on prevention and treatment. Further work would need to be done to determine best practices for measuring risk factors according to congenital anomalies that are important in the territory. In the interim, data collection on current risk factors recorded in hospital charts could be compiled for clinical use.

It was recognized that any use of aggregate data for research purposes would have to go through appropriate approval channels. It was also recognized that data pertaining to aboriginal populations should be owned and controlled by those communities involved.

Objective 3 - To provide tools for prevention, education, advocacy and promotion

There was a strong consensus that information provided on congenital anomaly rates could be used to advocate for services specific to diagnosis, and to developmental delays in general. It was felt that if specific information was available on regions most affected by a genetic condition of interest, educational materials on prevention activities such as etiology of genetic conditions and genetic counseling could be targeted at those populations.

Objective 4 - To evaluate community concerns and clusters

There was interest in the congenital anomaly surveillance system providing information on regional rates of specific congenital anomalies. This would allow communities to confirm if anecdotal evidence of increased rates of certain anomalies were found.

Although some questioned the ability to conduct meaningful analysis on the small populations, such as those found in the communities of the NWT, it may be possible to combine data with other work being done in similar populations elsewhere in Canada. For example if there was an interest in evaluating heart defects in Inuit babies, it may be possible to pool data with work being done in Nunavut and learn from combined efforts.

Objective 5 - To facilitate linkages between public health and clinical services

Maintaining links between public health practice and clinical services can be challenging and are often fragmented. It was felt that the sharing of data between clinical sites and government would help facilitate public health interventions aimed at prevention of congenital anomalies, in that the hospital based collection of data would provide timely information that could enhance public health planning.

It was recognized that data needed to be collected on risk factors associated with conditions to facilitate prevention programs.

Although treatment and support to those with existing developmental challenges is important, prevention strategies were identified as a priority. FASD was identified as a diagnosis that would be responsive to improved linkages between public health and clinical services.

Objective 6 - To integrate special health care services for children and other services for their families and improve access to services

The NWT is made up of a number of small communities scattered over a large territory. With geographic challenges, accessing care can be difficult at times. It was pointed out that there are many challenges within the health, social and educational systems that can make communication challenging.

There was strong support for the surveillance system to facilitate the integration of health care services for children and their families. Clinicians felt the system needed to include risk factors and be clinically based. A surveillance system that provided a centralized location for information regarding children with developmental delays and high risk pregnancies would enable clinicians in all locations to easily identify cases and treatments implemented. This would enable better tracking of services accessed by children diagnosed with congenital anomalies and other developmental delays. A child not accessing services could be flagged by the system and followed up by the clinician or service provider identified by the care coordinator. These activities were seen to improve quality of care by facilitating a team approach and improving links with care provided in communities.

It was acknowledged that the system in itself would not improve the integration of services, but could act as a tool to better integrate services and improve access to care.

There was one stakeholder who felt the registry would be subject to bias if it was based in the clinical setting and that the system should be based at the GNWT, and information should be gathered by an independent source.

Objective 7 - To facilitate closer links and long term follow up with affected families

Some stakeholders expressed concern that children were sometimes lost to follow-up as there is no centralized coordination of care. It was reported that children were sometimes discharged from the tertiary center to communities without a proper plan of care being in place. Likewise families have expressed concerns regarding challenges accessing services for children with developmental delays.

Again the surveillance system was seen to be a tool which could enhance communication between the tertiary center and isolated communities, through a centralized repository of information regarding intervention and follow up on specific cases.

Objective 8 - To evaluate interventions designed to prevent congenital anomalies

It was seen to be beneficial for a congenital anomalies surveillance system to assist in the evaluation of interventions aimed at preventing congenital anomalies. For example data from a system would enable clinicians to evaluate the impact of folic acid fortification in flour that was implemented as a public health practice in Canada in 1998. Consumption of folic acid to required levels during pregnancy has been seen to contribute to decreased neural tube defects in infants. Data from surveillance systems would allow for analysis of such an intervention. Specific priorities for evaluation were not discussed.

Objective 9 - To serve as quality assurance tool

Data from a system was seen to be useful as a quality assurance tool. This information could be used by health administrators and clinicians who provide services or refer for services. The system was seen to be potentially beneficial in describing services accessed by children and referrals made. This would help identify areas where the health and social network may be failing in either identifying children at risk or providing services.

Surveillance Objectives – additional recommendations

Diagnosis of particular interest

Comments were made by stakeholders regarding specific diagnoses of interest in the Northwest Territories. Conditions highlighted include Fetal Alcohol Spectrum Disorder (FASD), Heart Defects and Bardet-Bieldl Syndrome. FASD was identified as being a condition with many challenges in terms of diagnosis, treatment and prevention.

Inclusion of additional diagnoses

Given that congenital anomalies only represent a portion of the spectrum of developmental problems that appear during childhood, it was not surprising that stakeholders recommended that other diagnoses that are not by definition congenital anomalies be included a registry. This included conditions such as Autism Spectrum Disorder, Mental Retardation, Cerebral Palsy, hearing loss, Seizure disorders, ADHD/ADD, degenerative diseases, undiagnosed developmental delays and organic brain syndromes.

Many of these conditions are manifested after birth and like congenital anomalies require ongoing medical and social resources. Given the relatively small case numbers in the NWT it was felt it would not pose a significant increase in workload to include these conditions in a surveillance system.

Responsive to adults

It was suggested that a surveillance system support data collected on adults with disabilities, as there are specific needs in the adult population resulting from congenital anomalies. It was noted that many adults required support due to FASD or other developmental delays. It was felt that there needed to be data to help plan for appropriate housing, support and rehabilitation in this adult population.

Pan Territorial surveillance

There would be significant value in the ability to compare NWT congenital anomaly rates with other provinces and territories, especially Yukon and Nunavut. At the national meeting of the CCASN, the medical health officers from the NWT, Yukon and Nunavut as well as a researcher with northern expertise in congenital anomalies had an opportunity to meet and discuss the vision for the pan territorial surveillance of congenital anomalies. There appeared to be consensus that circumpolar links were an important aspect to consider in the development of the NWT system and that the links should go beyond Canada to international circumpolar regions.

Issues of compatibility, capacity, end-user compliance, and privacy and confidentiality were identified and could be addressed at the outset by working in partnerships.

The other territories will await the recommendations for the NWT congenital anomalies surveillance system, prior to embarking upon the planning of their own systems.

Facilitate continuing medical education and community education

The information compiled by the congenital anomaly surveillance system was seen to be a resource for continuing medical education. It was suggested that biannual rounds could be conducted and information shared on health indicators in the territory. It was also suggested that information could be used to create educational materials targeted at high-risk areas.

Traditional medicine

There are eight official languages in the NWT and significant cultural diversity. Traditional health practices in the form of traditional healers serve an important function. Stakeholders expressed clearly that to be effective a congenital anomalies surveillance system must be sensitive to and tied in with aboriginal and community based perceptions of health and health care service. This is particularly so in the case of sensitive conditions such as FASD. Thus to be effective, elders, traditional healers and community based health activities must be given a role in surveillance activities and the design and delivery of community based health care service.

In summary, the majority of stakeholders advocated for a congenital anomalies surveillance system that would provide information to facilitate clinical services to affected children and their families, improve programming and prevention strategies, enhance community links and allow for research opportunities all within the context of a coherent privacy and confidentiality framework. It was stressed that a system must be tied to greater capacity to provide service to those affected by the conditions. It was also suggested that the scope of the system go beyond congenital anomalies and include other pertinent childhood diagnoses that require similar clinical and social services.

As well, there were stakeholders who did not provide immediate input on design issues. However, they did express an interest in the project and there was interest in being kept current on activities with the opportunity to provide feedback during future development and implementation of the system. Ongoing information sessions will have to occur regarding system development including opportunities for feedback. In particular, groups such as the NWT Autism society and Aboriginal groups should be consulted further. Consideration can be given to creating a dedicated project website for the purposes of information dissemination and feedback.

5.2.2 Surveillance design

Once the objectives of the system are set, aspects of the design can be considered. The design of the system must be responsive to ensure high quality data is collected that will accurately represent the diagnoses of interest and allow the objectives of the system to be met. Best practices for congenital anomalies surveillance have been compiled in an extensive document by the National Birth Defects Prevention Network (NBDPN) that was developed to help in the creation of congenital anomaly surveillance systems and promote consistency among systems.[22] It is a compilation of best practices by top experts in congenital anomalies surveillance and is an excellence resource for surveillance planning.

Specific design considerations include:

- case definitions
- case ascertainment
- passive vs. active surveillance
- sources of data
- medical record review
- coding systems
- information collection

While best practices in system design are essential for a system to function effectively, local perspective must be considered. Each of the aspects of surveillance system design was discussed in detail with the advisory group* who provided specific input on system design in their areas of expertise. This phase of consultation was very important, as some of the members of the advisory group will constitute some of the primary providers of data to the registry. These key informants were also involved in prioritizing the objectives of the registry and are familiar with other Canadian congenital anomaly surveillance systems.

Recommendations for system design were made to satisfy both the identified objectives of a territorial surveillance system and the clinical constraints of the local health context. Best practices in surveillance system design were considered in the discussions.

Case definition

In order to register a case in a congenital anomalies surveillance system the diagnostic criteria for the condition must be carefully defined. This is not always simple as in the case of FASD that is sometimes very subtle in presentation and often missed as a diagnosis. Hence the importance of clear case definition in establishing the integrity of a system.

Case definition criteria are the information that is used to define a case. They include:

- the diagnoses
- place of residence
- pregnancy outcome
- gestational age and
- age at diagnosis

The Guidelines for Conducting Birth Defects Surveillance[23] contains detailed explanations of issues to be considered. Key informant consultation provided insight into the impact the recommended objectives of the NWT congenital anomalies surveillance system would have on case definitions.

* Pediatrician, Medical Health Officer, Midwife, Perinatal Nurse Clinician, Family Physician, Obstetrician and GNWT maternal child health representative.

Diagnosis

It was felt that the diagnostic standards used in the NWT must be consistent with those used in other regions, with priority given to those regions we wish to compare data with. It was also felt that our diagnostic standards should be similar to those employed in other northern regions with similar demographics, so data could be pooled for improved analysis across ethnic groups. In addition it was felt that the registry should focus on major anomalies that have a significant psycho-social impact on children's lives, rather than minor anomalies such as webbed toes, which do not cause significant long-term disability. Other considerations suggested were to have the ability to include multiple diagnoses that are common in syndromes. Finally it was suggested that the system have flexibility to add new definitions as necessary.

FASD was identified as a diagnosis that would require additional attention to determine best practices in the NWT. During the course of this project additional workshops were held in partnership with the Stanton Territorial Health Authority to explore best practices for the diagnosis of FASD[24]. Stakeholders were invited to attend workshops and give feedback within the context of congenital anomalies surveillance.

This included a workshop in Yellowknife lead by a medical expert* from Motherisk in Toronto who presented evidence-based best practices in FASD diagnosis and screening. Round table discussions were held to explore the application of best practices in the NWT. Participants at the workshop were broad based including early childhood educators, health administrators, traditional healers, nurse practitioners, aboriginal leaders, NGOs and physicians.

The roundtable discussions established that there was broad based support for a system to monitor the scope of FASD in the NWT.[25] It was felt that the best practice for FASD diagnosis was a multi disciplinary team approach with strong ties to the communities that will result in practical community based resources for persons with FASD and their families. Specific community based activities for children and adults affected by FASD were differentiated. The sensitivity around maternal use of alcohol in pregnancy was discussed and the importance of providing support to mothers as opposed to assigning blame was highlighted. It was felt further work should be done around exploring a community based team approach for the diagnosis of FASD.

To follow up on the community based team approach to FASD diagnosis a second workshop was held lead by an expert** in FASD diagnosis from the Lakeland Center for FASD in Northern Alberta, where a team approach to community based diagnosis is employed. It was felt that the NWT had the capacity and will to create a diagnostic team. However, there was an identified need for leadership and coordination of services for diagnosis of FASD at the territorial level.

* Dr Gideon Koren Director of the Motherisk Program, The Hospital for Sick Children, Toronto, Canada

** Audrey McFarlane, Executive Director, Lakeland Center for FAS

As stated previously there has been the suggestion that a congenital anomalies surveillance system in the NWT be opened to childhood health conditions that are not by definition congenital. It was felt that the objectives of a system for congenital anomalies also represented objectives the clinical stakeholders wanted to see met for other childhood diseases (Autism Spectrum Disorder, unspecified delays, etc.). Given the small population in the NWT it would not likely be cumbersome for the system to include additional diagnoses. Furthermore with a proposed Territorial Child Development Team under consideration the centralization of significant childhood congenital and developmental illness in one system would seem a logical effort and serve to improve services provided to children and families affected by these conditions.

For diagnosis of FASD, development of a FASD diagnostic team according to best practices was recommended. The Canadian guidelines for diagnosis of FASD published March 2005 are the current recommended practice.[26] In addition, best practices for diagnosis of Autism Spectrum Disorder (ASD) have been compiled and are recommended.[27]

Place of residence

In general population-based congenital anomalies surveillance programs attempt to identify defects that occur to offspring of women who reside within a defined geographic area at the time of pregnancy outcome. When evaluating the rates of any condition it is necessary to define the population in which the diagnosis occurs. This allows for the calculation of rates over time, rates within a geographic area and for the development of plans for prevention and intervention programs.

Although it is relatively simple to identify women who reside in the NWT, some specific issues arise which require consideration. Place of residence must be differentiated from place of delivery, as some women travel out of Territory (principally to Alberta) to give birth. Likewise, women who live in Nunavut and deliver in the NWT must be excluded from the NWT database. For the analysis of services provided by Stanton Hospital it was pointed out that Nunavut patients who obtain tertiary services at Stanton would need to be included. If Nunavut births are included in the registry for surveillance of clinical services, they must be removed when producing a NWT report. Likewise, methods must be developed for capturing births that occur in Alberta or other jurisdictions reported to NWT. One option employed by some surveillance systems is to register all anomalies and conditions based on current address. A mother's residence at time of delivery should be included as a variable for analysis, and can be used for creating sub-sets when needed, such as reporting provincial/territorial rates for national statistics or evaluating Stanton bed rates which would include Nunavut.

Pregnancy outcome

For a surveillance system to be inclusive and have high sensitivity, all cases that occur in a population need to be included regardless of the outcome, be it a live birth, fetal death, spontaneous abortion or elective termination of the pregnancy due to prenatal diagnosis.

Excluding elective terminations from a registry can result in low ascertainment of some anomalies such as neural tube defects and chromosomal abnormalities that are sometimes electively terminated based on prenatal diagnosis. In the NWT, ascertainment of data on prenatal diagnosis and terminations is more easily attained due to the centralized services at the tertiary center, Stanton Territorial Health Authority. However, the ease of ascertainment of data should not preclude consideration for the highly sensitive nature of such data and attention to confidentiality when reporting.

Gestational age

The gestational age at the time of case diagnosis must also be considered. The frequency of some diagnoses will vary according to gestational age. For example, undescended testes are normal in a pre-term infant, but are abnormal for an infant born at term. For surveillance systems to be comparable they must use a standard gestational age at delivery for inclusion of diagnosis. It is suggested that the NWT system use the same case definitions that are recommend for reporting to the CCASN. In general the recommendation is to monitor congenital anomalies that occur after 20 weeks or greater of gestational age. The exception to this rule is pregnancies terminated after prenatal diagnosis of an anomaly, which can be included at any age.

Age at diagnosis

The age of the child when the diagnosis is made is an important component of case definition. Defects that are evident in the delivery room and are visibly recognizable are easily captured by most systems. However, many anomalies are more subtle and may not be recognized for months or years. In the case of FASD some argue that accurate diagnosis is not possible until school age in many cases. Again in the NWT where diagnostic services are centralized we have the opportunity to have comprehensive ascertainment of cases up to school age. Health Canada accepts congenital anomalies that are registered up to one year of age[28]. This results in low sensitivity of the system with respect to diagnoses such as FASD that are rarely diagnosed before one year of age.

Length of time for case ascertainment

The time to diagnosis from delivery was discussed above. Given the challenges in diagnosing FASD it was felt that in the context of the NWT a congenital anomalies surveillance system would more accurately reflect case incidence if inclusion occurred up to school age. However there was strong support among key stakeholders to have a rsystem with no upper age of exclusion so that the current prevalence of conditions such as FASD could be determined. An open registry would accommodate the diagnosis of adults with FASD who are often referred to pediatricians for diagnosis. As well, stakeholders who provide services to adults stressed the need to have surveillance of FASD in adults to facilitate services for that group.

Passive vs. Active Surveillance

Definitions of Passive and Active Surveillance

- *Passive (identification of cases from reports submitted to program by staff from hospitals, clinics or other facilities)*
- *Active (identification of cases by trained surveillance program staff who actively see cases in hospitals, clinics or other facilities by systematic review of medical and other records)*
- *Combination of active and passive*

Given the importance of the diagnosis of a congenital anomaly to ongoing clinical and social care it was felt the system would operate best as an active surveillance system under the supervision of a coordinator of child development services and coordinator of perinatal services. The activities of the surveillance coordinator could be complimented by the role of a child development team leader and the existing perinatal care coordinator. The suggestion is that the child development team leader would be responsible for collecting data pertaining to the diagnosis of children with a spectrum of child development and congenital anomalies, and referring them to support services, while the perinatal care coordinator would collect information pertaining to the prenatal period including prenatal diagnosis, genetic testing, terminations and perinatal outcomes. Thus the surveillance system would provide a link for those working in the areas of perinatal health and child development through the coordinating efforts of the respective team leaders. This could facilitate referral for clinical and support services, and the planning of intervention and prevention programs aimed at addressing the burden of congenital and developmental anomalies in the NWT. The duty of data collection was supported by the current perinatal care coordinator and is recommended in the scope of practice in the recommendation for a child development team leader.

This active system is similar to that found in Nova Scotia where the individual responsible for congenital anomalies data collection also serves a clinical coordinator role. Stakeholders stressed that the data from the registry must be timely in order to facilitate services to children and families and organize clinical care.

Sources of data

Recording and extracting data pertinent to a congenital anomalies surveillance system can be complicated. Once more, the small size of the specialist service that identifies children with anomalies in the NWT makes it easier to standardize the identification of cases, and the method by which this information is recorded. Nonetheless not all cases will pass through the offices of the pediatricians or obstetricians. Consequently a means of accurately capturing all cases must be developed where a diagnosis of congenital anomaly may be flagged. Currently the prenatal form and the live and still-birth forms are being redesigned. Suggestions were made that accommodations could be made to include congenital anomalies or other

developmental delays in a field in these forms. Other suggestions for locating the diagnosis of congenital anomaly are listed below.

Locations for recording the diagnosis of congenital anomaly

- Physician reports
- Prenatal form
- Labour and Delivery form
- Pediatrician new born form
- Prenatal diagnostic facilities (e.g. ultrasound, etc)
- Cytogenetic laboratories
- Clinical genetics centers
- Maternal serum screening programs
- Vital statistics' birth and/or death certificates
- Termination forms
- Still birth/live birth records
- Use referrals to flag cases for follow up
- Develop a form specific for the registry
- Digital chart

Nonetheless given the centralized services of three pediatricians providing care to the entire NWT, it is likely that most children diagnosed with congenital anomalies would ultimately be referred though them. The same applies for obstetrical services where referrals for genetic testing and prenatal testing occur exclusively at the Stanton Territorial Health Authority. The exception in both situations is the periodic referral of cases to Alberta, where specialized services are sometimes accessed. However in these instances the referral is usually arranged by the specialist at Stanton and consequently the case would be documented locally.

It was felt that information collected by the respective clinical care coordinators (perinatal and recommended child development coordinators) could provide the basis for the data on risk factors entered in a congenital anomalies system. Given that the information such as lab work and ultrasound results need to be compiled for effective clinical care, the only additional work load for the coordinators would come in the entry of the information into the data base. Further work will need to be done to prioritize risk factors to collect. Alcohol consumption during pregnancy was identified to be a risk factor of particular interest to clinicians so better support could be provided to at-risk women and families and prevention programs for FASD could be implemented

It was acknowledged that any use of the data for research purposes would have to go through the appropriate review and approval channels.

It was suggested that the data collected could be used to facilitate special rounds to review services provided by physician and nurses. This would act both as a quality assurance tool and educational tool.

While attempting to organize a means of effectively documenting and extracting from paper forms and charts the information needed for a congenital anomalies surveillance system is currently a reality, this cumbersome information system may soon be replaced by a digital information system that will solve many of the problems outlined above.

The Department of Health and Social services is currently developing a territorial plan to create a standardized health information network that will facilitate the storage, collection and manipulation of health information. Recently the first electronic medical record has been implemented in the Northwest Territories which is a significant step in the establishment of a network capable of more easily supporting a surveillance system such as that needed for a congenital anomalies.

Medical record review

In some cases a specific diagnosis is uncertain and requires a second opinion or review by a clinical expert. For the purposes of the congenital anomalies surveillance system it was suggested that a physician or team could be assigned responsibility for reviewing cases in question. The current territorial perinatal committee, or the suggested child development team, could be explored as potential resources to fill this function.

Coding systems

A critical component of a surveillance system is accurate coding of diagnostic information. The disease classification system used determines the ability of the surveillance system to collect, code, retrieve and translate information regarding diagnosis and procedures.[29] Coding provides a standardized set of rules for case ascertainment based on medical information and a standardized means to present information.

The best know classification system is the International Classification for Diseases (ICD). This system is coordinated by the World Health Organization and 10 international centers. The ninth revision of the International Classification of Diseases (ICD-9) with clinical modification is generally used in hospitals and has expanded general categories, permitting more detail and codes for clinical procedures. The British Paediatric Association (BPA) developed a classification that was a modification of the ICD-9 which allows for more detailed collection of information. As well, the Centers for Disease Control developed a classification system for the detailed coding of birth defects.

The surveillance of FASD has been essentially non-existent in Canada due to a lack of accommodation by congenital anomalies surveillance systems in that many only include diagnoses up to one year of age. In addition there has been little work done in terms of methods for coding and gathering data on FASD until recently.

A recommendation for a Canadian Standard coding system has recently been published,[30] that suggests a harmonization of the Institute of Medicine (IOM) and 4 digit diagnostic coding systems for FASD. The 4 digit code was developed by Astley and Clarren at the University of Washington. It is described in the diagnostic guide for Fetal Alcohol and

Related Conditions. [31] The four digits reflect the severity of the main diagnostic features of FAS: (1) growth deficiency, (2) the FAS facial phenotype, (3) brain dysfunction, and (4) gestational alcohol exposure. Each diagnostic feature is ranked independently on a 4-point Likert scale with 1 reflecting complete absence of the FAS feature and 4 reflecting a strong "classic" presence of the FAS feature. The 4 digit code is recommended for surveillance purposes.

The Institute of Medicine (IOM) diagnostic categories describe the spectrum of fetal alcohol effects. Those included are: FAS with and without a confirmed history of alcohol exposure, partial FAS, alcohol-related birth defects (ARBD), and alcohol-related neurodevelopmental disorder (ARND).[32] These categories are useful when describing cases among clinicians.

From the perspective of the key informants, it was felt that the decision on coding was more of a design issue, but that it should be ensured that the NWT is current and comparable with other regions. As well, data should be coded so it can be reported to the Canadian Congenital Anomalies Surveillance Network and represented in the national picture.

Information collection

In addition to the core information gathered for the purposes of a congenital anomalies surveillance system; diagnosis, place of residence, age of diagnosis, etc., other variables are identified as pertinent to the registry for the purposes of program evaluation and research prevalence studies. This information is guided by the stated objectives of the system, and can change according to priorities and projects. Once more the small size of the registry allows the potential for comprehensive data collection. Core variables and recommended variables for congenital anomalies surveillance are described in the NBDPN guidelines.[33]

As it is stressed that it is advantageous to be compatible with other provincial/territorial initiatives, especially northern regions with similar demographics, the NWT would be well served to base its selection of data variables in part on the efforts in neighboring jurisdictions. Further work needs to be done to determine what risk factors are of interest, then determine from what sources they are available. Whether one needs to create a new form to record the information or link to existing data sources must be established

Electronic Medical Records

The emergence and development of electronic medical records is a priority. This will help ensure links pertinent to congenital anomalies are accessible. Electronic medical records are currently being pursued in the NWT and will be an advance in the area of data collection. The importance of digital information tools must be considered in the design of the surveillance system. Furthermore, activities in the design of the surveillance system must conform to the planned territorial health information network.

Legislative and Policy Requirements

The legislation or policies required for the effective implementation of a congenital anomalies surveillance system will need to be explored. Legislation and policies should be responsive to the established objectives of the system and facilitate surveillance activities. Elements of legislation or policy design that need to be considered include:

- Designation of authority over the surveillance system
- Reconciliation of project activities within the context of ATTIP and PIPIDA
- Clear access to data guidelines
- Definition of ability to share data; specifically who can access the data while maintaining confidentiality
- Terminology and definitions of what the surveillance system is measuring e.g. a general category such as developmental delays
- The need for an opt-out clause. When obtaining consent, a parent or guardian can submit a written request to have a child's information removed from the system

Once the model of surveillance is determined for the NWT, best practices for policies and legislation within the current GNWT-DHSS and Stanton Territorial Health Authority (STHA) frameworks will have to be explored. Implications for the development of policy and legislation pertaining to the surveillance system will need to be explored further.

6.0 DEVELOPING THE SYSTEM

The objectives described as important for the NWT surveillance system could be viewed as broad and cumbersome. However, the unique setting in the NWT with centralized clinical services and smaller governmental departments allows for a broader set of objectives to be met by the system.

The CCASN recommends that provinces and territories work together in developing congenital anomalies surveillance systems rather than creating duplicate non compatible models. For the purposes of the NWT, where there is limited capacity to develop systems from the ground up, building on, and adapting an existing system from another jurisdiction would be welcome.

The existing provincial systems were revisited with the needs of the NWT in mind. This was done through consultation with the CMHO, the stakeholder advisory group, and consultation with provincial representatives who were present at the CCASN annual meeting. Work done on establishing the objectives of the territorial system were shared in a presentation at a conference of the Canadian Congenital Anomalies Surveillance Network (CCASN).[34] Feedback was obtained from other provinces on the objectives for the NWT system and implications for design.

6.1 Comparing Objectives to Identify a System

The most marked similarities to the NWT objectives were seen to be with the BC Health Status Registry (HSR) where importance was placed on congenital anomalies and additional developmental disabilities. A major objective of the BC system is ensuring that adequate resources are available for individuals and families with developmental delays. The BC system also recognizes that aspects of FASD diagnosis require additional consideration in system design. In addition there has been much work on best practices for diagnosis of Autism Spectrum Disorder and resources are made available to aid physicians in this diagnosis.[35]The Nova Scotia system had a similar objective in that it facilitated clinical care and provided timely information to direct services. However, the focus of the NS system is entirely on the perinatal period so would not be transferable to the NWT as a model that would accommodate all the congenital anomalies and developmental delays identified to be a priority. However, the clinic-based collection of data provides an excellent cohesive database which supplies information specific to needs around identifying rates of congenital anomalies and assessing risk factors. In addition the database has information that is beneficial to the day-to-day management of those affected by congenital anomalies.

The Alberta System has value with respect to data management in a hospital context and because of the systems close links to the provincial vital stats department.

6.2 BC Health Status Registry – A foundation for the NWT

Based on the findings of stakeholder consultations, review of Canadian congenital anomalies surveillance systems and consultations at the CCASN annual meeting; there was consensus that the BC HSR was a system worth exploring further for implementation in the NWT. Arrangements were made to visit the HSR in BC and have a closer look at their system.

A meeting was arranged with the BC Ministry of Health HSR staff* and included attendees representing the Knowledge Management and Technology Division. An Epidemiologist and data base consultant represented the NWT**.

Background of BC Health Status Registry

Established in 1952 as a voluntary registry in response to the Thalidomide Tragedy, the Health Surveillance Registry (HSR) has undergone a number of iterations over the years to arrive at its current state. Since 1992 the primary focus has been on children with genetic conditions. The HSR has been a full member of the International Clearinghouse for Birth Defects since 2001, submitting data on a quarterly and annual basis.

The primary mandate of the HSR is to:

- Register individuals according to the registration criteria
- Assist in the planning of health care services
- Undertake statistical analysis of the data

Additional objectives include reporting on the data, supporting research requests as well as providing a useful tool for the health care system.

Surveillance Characteristics

The HSR includes all residents of BC, regardless of age, who have a registerable condition. There are currently over 60 active reporting sources, supplying data in both electronic and/or hard copy forms that were developed by the Ministry. The reporting of cases to the HSR is not voluntary and is governed by the legislative and privacy policies that are in place in the province of BC. The HSR is a passive system in that the HSR staff does not collect case reports.

* Soo-Hong Uh, Consultant BC-HSR, Ron Danderfer, Assistant Deputy Minister, Knowledge Management and Technology, Terry Tuk, Director Information Management, Don Rintoul, Assistant Manager, Information Management, Shelly Wells, Medical Advisor, Information Management, Ian Rongve, Economist, Information Management, Antoinette Klette, Data Warehouse Specialist, Information Management

** Susan Chatwood BScN, MSc(Epi) Epi-N consulting & Steve Morin BSc Data Base consultant, Outcrop Communications. Yellowknife, NT

The HSR commenced using the ICD 10 coding scheme for congenital anomalies in 2000 and also includes Autism Spectrum Disorder and FASD (using Washington University 4 digit Code). Termination data is included in the HSR however, personal identifiers are removed from the system after 90 days to maintain confidentiality around this sensitive information.

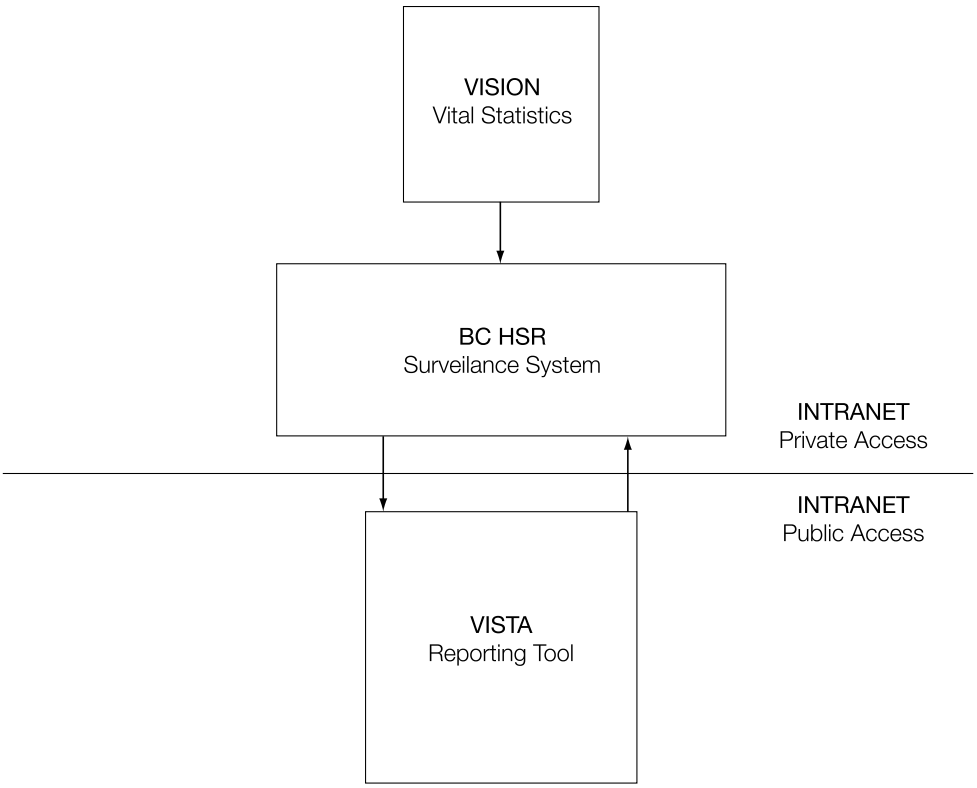
The system is staffed by the HSR team, which is comprised of administrative and technology experts, nurses and clerical staff. In order to provide direction and guidance to the HSR, a Health Advisory Committee was established to co-ordinate future HSR activities.

Technology

The HSR is a web-based Intranet application developed on an enterprise strength Oracle infrastructure. It has been developed in-house by the BC Ministry of Health Services. Data entry and reporting is accomplished through secure access to the system using a standard web browser.

The HSR is complemented by two additional systems, VISION - the Vital Statistics system and VISTA – a web-based reporting tool for the HSR. Both of these systems have been integrated with the HSR, VISION supplying vital statistics data to the HSR and VISTA allowing for reporting on the HSR data. Figure 1 below shows this relationship.

Figure 1 – Information flow – VISION, HSR, VISTA



The HSR is currently being re-developed to improve efficiency and performance and provide better integration between VISION, VISTA and HSR. The expected launch date for the new system is June 2005. The scope of the 2004 HSR re-development project is detailed in Appendix C – Business Requirements, appendix D – Business Requirements Addendum, and appendix E – Technical Specifications (Mockups and Business Process Flows).

It is evident that the HSR is a mature and robust system that has been developed to fulfill the mandate set out by the Ministry of Health. The system was designed based upon a detailed set of business requirements and built upon a solid technical infrastructure ensuring that future requirements can be easily met. The system is worthy of further investigation as to the best way to implement the system in the NWT.

6.3 NWT Congenital Anomalies Surveillance - Best Practices

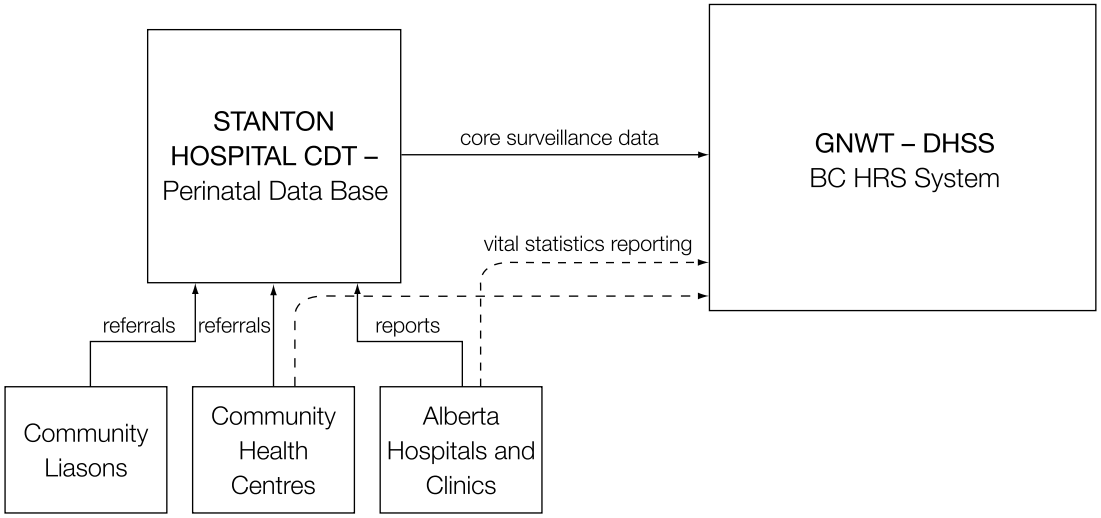
It appears the best model for system design would be a two-tiered system. The primary data collection would be based at Stanton Territorial Health Authority. The system would contain information that meets both the immediate clinical needs of health care providers, as well as providing data for health administrators and for research purposes. This function is similar to the clinical basis of the Nova Scotia system of data collection at a tertiary center. However, the clinical objectives in terms of scope of diagnoses differ in that the NWT objectives call for a system that meets not only the conditions evident during the perinatal period, but also encompass older children with congenital anomalies and other developmental delays.

A second and separate arm of the registry would host data similar to the BC Health Status Registry and would carry out reporting functions. This information would be similar to data collected by other congenital anomalies surveillance systems and reported to the CCASN. In the NWT this would be housed by the population health department of the GNWT - DHHS which carries out reporting duties, links with other departmental systems for program planning and evaluates and plans prevention programs. The information transferred to the GNWT - DHSS would, by necessity, be blinded as to patient identity as it would be outside the circle of care.

Information that currently flows from community health centers and other hospitals to the Stanton Territorial Health Authority and GNWT - DHSS, such as vital stats reports and referrals would enter into the respective data bases.

Figure 2 provides an illustration of how the framework might appear. However, this is only a preliminary suggestion. The recommendations for implementation discussed below will need to be followed to establish best practices for implementation of the system.

Figure 2 – Proposed framework for NWT System



7.0 RECOMMENDATIONS

7.1 Global System Design

It is proposed that the NWT congenital anomaly system be two tiered with a clinical arm and an administrative arm.

The clinical arm of the database would be located at the Stanton Territorial Health Authority and would serve the functions related to clinical care such as data collection, referral tracking, and diagnosis.

The administrative arm of the database would be located at the GNWT-DHSS, population health section and would carry out the functions related to public health planning, early childhood education program planning, and dissemination of surveillance reports.

The two databases would be linked digitally with core variables exclusive of client identifiers being provided to the administrative database.

A roadmap for the creation of this system is outlined below in chronological order.

7.2 Child development team coordinator

The creation of a position for a child development team coordinator is essential to the success of this project. It is recommended that the duties of the child development team coordinator include overseeing the collection and management of clinical data for the surveillance system at the clinical site. Stanton Territorial Health Authority does not have the capacity to support a surveillance system without a child development team coordinator. Consequently the creation of this post must precede other project activities. Work has already been done by Stanton Territorial Health Authority on defining the scope of this position. (Appendix F)

7.3 Phased Approach

The establishment of a surveillance system should be carried out in two phases:

- phase one: project development
- phase two: project implementation

Project Governance

The project should be lead by the Chief Medical Health Officer of the NWT.

A project steering committee should be formed. Membership should include:

- Chief Medical Health Officer (chair)
- Two External experts*
- Epidemiologist Consultant
- Aboriginal Representative (Health)
- NGO representative (i.e. NWT Autism Soc.)
- Clinical representative

A project working group should be formed. Membership should include:

- Project manager (Epidemiologist, Field Epi Intern, Health Canada)
- Child development team coordinator
- Territorial maternal perinatal health committee
  - Pediatrician
  - Obstetrician
  - Coordinator northern women's health program
  - General Practitioner(Obstetrical)
  - GNWT consultant maternal child health
  - Regional Medical Health Officer
- GNWT consultant early childhood development
- Aboriginal representative
- Health information technology expert
- Other experts/resources on an invitational basis

Mandate of the steering Committee

1. Draft project charter
2. Draft project terms of reference (taking into account mandate of working group which establishes project scope, mandate, time frame, budget, membership and reporting structure)
3. Supervise project
4. Write terms of reference for project manager position
5. Hire/Assign project manager

* Soo-Hong Uh, Consultant BC-HSR, Dr Laura Arbour, Pediatrician, Clinical Geneticist, Assistant Professor, Department of Medical Genetics, University of British Columbia

Mandate of project manager

1. Set project budget
2. Write project plan
3. Report to steering committee
4. Set and chair working group meetings
5. Function as liaison to external experts
6. Coordinate the provision of resources for the duties of the working group in the form of literature and outside expertise
7. Manage a project specific website for the purposes of dissemination of project information
8. Coordinate all project related communication
9. Coordinate and write project midterm and final evaluations

Mandate of Working Group

A. Phase 1 – Project Development

1. Establish scope of data collected at STHA (congenital anomalies, developmental delays, adults, risk factors etc)
2. Establish scope of data transferred to GNWT-DHSS
3. Identify sources of data
4. Define systems needed to collect and store data
5. Actively engage with and consider advice of external experts in all aspects of project work. This point is emphasized because there is an active and willing cohort of surveillance experts, notably at the BC HSR whom are interested in assisting the NWT in the establishment of a territorial registry. Engaging them will significantly facilitate this project.
6. Define the personnel needs of both Stanton and the GNWT-DHSS for sustaining a congenital anomaly surveillance system
7. Develop policies and procedures specific to data collection and manipulation
8. Explore legislative framework as it pertains to health surveillance and issues of privacy and confidentiality
9. Explore and identify issues relating to data uses in aboriginal populations
10. Advocate for the establishment of an FASD diagnostic team
11. Explore options for importation of BC Health Status Registry software for use in the NWT
12. Define technical needs for project implementation with respect to software, hardware, compatibility with existing databases and system architecture
13. Explore options and advocate for digital collection tools in the clinical setting
14. Define means to ensure meaningful community liaison within the scope of a congenital anomaly surveillance system
15. Oversee project evaluation
16. Establish plan for phase II (implementation). See phase II below
17. Set budget for phase two based on plan

Phase II - Project Implementation

The project implementation plan must be established within the context of the work of phase I. Issues to be addressed are:

- Staff training schedule
- Change management
- Surge capacity with introduction of new system to worksites
- Hardware implementation schedule
- Software implementation schedule
- Hardware and software testing in situ (NWT)
- Project midterm and final evaluations

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APPENDIX A

Questionnaire to help in the development of a Congenital Anomaly Surveillance System in the NWT

Questionnaire to help in the development of a Congenital Anomaly Surveillance System in the NWT

The NWT is currently developing a congenital anomalies surveillance system. We would appreciate it if you could take some time to answer some questions that will help in the design of the system and ensure useful information is available for groups who work with children and families affected by congenital anomalies.

You can either type your responses on the word document and email back or you can print out the questionnaire and mail it to the address below. If it is easier to respond by phone, just give me a call and I can go through the questionnaire with you.

Susan Chatwood BScN, MSc (Epi)
Epi-N Consulting, Outcrop Communications Ltd.
Suite 800, 4920-52nd Street
Yellowknife, NT, X1A 3T1
Cell (867) 444-6134
Email epi@theedge.ca

Surveillance defined

Public health surveillance is collecting information on health problems. This helps people who are involved in caring for those affected by the condition understand the scope of the problem in the population and provide better care to people affected by the anomaly. Surveillance systems are also very useful in planning and evaluating prevention programs. They also help in providing information to justify funding for a program. For more information on surveillance see “tool kit” document attached to email.

Congenital anomaly (Birth Defect) defined

A congenital anomaly or birth defect is when a baby is born with a defect. Most congenital anomalies are present long before the time of birth and occur while the baby is growing in pregnancy. Congenital Anomalies can be caused by genetic factors, exposure during pregnancy or unknown causes. Some examples of congenital anomalies are conditions such as Fetal Alcohol Syndrome Disorder, heart defects, missing limb, spina bifida, congenital cataracts, cleft lip and palate, biliary atresia, Down syndrome, congenital hip dislocation.

For example a Congenital Anomaly surveillance system would help us understand how many children are affected by FASD in the NWT and thus plan or advocate for resources to help families or plan better prevention programs. Another example is a congenital anomaly system can also tell us how many babies are born with heart defects and compare numbers with other areas and participate in research to explore the cause of heart defects and plan prevention programs.

Questions

What organization are you affiliated with?

Do you work with persons with congenital anomalies (a defect that the baby was born with)?

Which congenital anomalies are most common in your setting?

Are there other conditions that are not congenital anomalies that you think should be included in the registry?

Here are some common objectives of a congenital anomalies system:

- to accurately describe the burden of congenital anomalies
- to conduct research on prevention
- to provide tools for prevention, education, advocacy and promotion
- to evaluate community concerns and clusters
- to facilitate linkages between public health and clinical services
- to integrate special health care services for children and other services for their families and improve access to services
- to facilitate closer links and long term follow up with affected families
- to evaluate interventions designed to prevent congenital anomalies
- to serve as quality assurance tool

Are there any objectives you think are most important for a Congenital Anomalies System in the NWT to address?

Would having information on the numbers of congenital anomalies be useful for your organization? Ie reports on statistics in the NWT or your region.

What congenital anomalies are of particular interest to you?

Should we compare our information with other provinces?

What do you think are specific confidentiality issues to be considered?

Should we include practices around traditional medicine in the surveillance system?

Are there traditional healers in your community who provide care to persons with congenital anomalies or help women have healthy pregnancies?

Should the registry be managed by a child development team and used to facilitate services for families? If yes, who should be on the team?

Should non identifying data be provided to the government to maintain a registry to help plan services?

FASD has been identified to be a diagnosis of particular interest.

Do you think the child development team who does diagnosis for other congenital anomalies should do the diagnosis of FASD?

Do you think the diagnosis of FASD should have it's own team?

Who should be included on the team to diagnose FASD?

Do you think the NWT should partner with an existing FASD diagnostic team in the development phase?

Any other comments:

Thank you for your help! – Susan 444-6134

APPENDIX B

FASD Screening and Diagnosis Workshop

Contract 383406 GNWT-DHSS

Submitted by:
Susan Chatwood
Epi-N Consulting
February 16, 2005

For contract awarded to:
Dr Kami Kandola RMHO
Stanton Territorial Health Authority

APPENDIX B1

Introduction

Anecdotal evidence suggests that Fetal Alcohol Spectrum Disorder (FASD) is a significant health and social problem in the NWT. However, no data exists on the prevalence of this disorder in the territory, nor are there guidelines for diagnosis of FASD in the NWT. This workshop was targeted at addressing these gaps by focusing on diagnosis and screening of FASD.

The workshop on diagnosis and screening of FASD directed at health care workers, NGO's and persons working with clients affected by FASD was held in Yellowknife November 29, 2004. The workshop was jointly funded by the GNWT Department of Health and Social Services via the Stanton Territorial Health Authority and the NWT Medical Association (Appendix A).

Objectives

The Objectives of the workshop were determined in consultation with physicians working with clients affected by FASD. The objectives were set as follows:

- to improve understanding on maternal consumption of alcohol intake and its teratogenic effects on the unborn child
- to address gaps in knowledge in FASD, specifically in recognition, diagnostic measures and life-cycle progression of the FASD patient.
- to foster a multisectoral approach to FASD prevention, care and support

An internet/literature search was conducted to determine best practices for the diagnosis of FASD and it was determined that Motherisk based at Sick Kids in Toronto had developed diagnostic criteria which were evidenced based and deemed to be a good introductory point for education regarding diagnosis of FASD in the Northwest Territories.

Workshop content

The workshop on diagnosis and screening for FASD is an established course developed by Motherisk (Appendix B) Upon completion of the course, participants are eligible for Motherisk certification in the diagnosis of FASD. The program also meets the accreditation criteria of the College of Family Physicians of Canada and has been accredited for 4.0 MAINPRO –M1 credits. MAINPRO credits are required by physicians to maintain competency and licensure. Having accreditation from the College of Family Physicians is necessary so the time taken by physicians to attend educational workshops is recognized. Acquiring MAINPRO accreditation also ensures the workshop content is to a high level of educational standard that would meet the needs of all participants.

The literature was searched for information pertaining to diagnosis and screening of FASD and was provided for participants to read and keep as a resource (Appendix C) The readings were provided electronically prior to the workshop. In order that participants would have an understanding of the national context of FASD, provincial reports on FASD (when available) were also collect and provided to participants in PDF format for pre-reading.

The workshop was a day long event (Appendix D) presented by Dr Gideon Koren. Dr Koren is the founder and director of the Motherisk program. His practice is dedicated to drug safety, the molecular mechanisms and clinical effects of adverse drug and chemical reactions with a focus on pregnancy and children. He is the editor in chief of the Journal of Fetal Alcohol Syndrome International. In 2000 Dr. Koren created the Canadian Research Network for Fetal Alcohol Syndrome ("FACE"-Fetal Alcohol Canadian Expertise).

Participants

The workshop was attended by 30 participants, 10 Nurses, 12 physicians, 1 educator, 2 traditional healers, 3 allied health and 2 from the NGO sector. Although the audience was primarily health workers there was enough representation from other sectors to provide rounded discussions regarding the diagnosis and screening of FASD in the NWT.

Evaluation

The participants were evaluated based on a test completed at the end of the workshop (Appendix E). The passing mark was 80%. All participants successfully completed the test. The Motherisk program also circulated a program evaluation form to meet their needs, for which the results are still pending.

Roundtable discussions

After the participants had completed the workshop, the opportunity was taken to hold round table discussions regarding the surveillance of FASD in the NWT. Preset questions were developed to guide the discussions and discussions were summarized (Appendix F).

In summary there was support for a registry to monitor the impact of FASD in the NWT. It was felt that the best practice for FASD diagnosis was a multi disciplinary team approach with strong ties to the communities that will result in practical community based resources for persons with FASD and their families. Specific community based activities for children and adults affected by FASD were differentiated.

Post workshop activities

The participants of the FASD screening and diagnosis workshop agreed they wanted to continue dialogue on FASD. To this end a FASD email group was started which enables participants to share information in FASD in the NWT (Appendix G). There are currently 25 people on the FASD mailer.

Additional workshops were planned to further explore the development of teams to diagnose FASD. Audrey McFarlane from the Lakeland FASD Center in Cold Lake AB was invited to Yellowknife to present on their nationally recognized community based model for the diagnosis of FASD (Appendix H).

As well the workshop was developed within the context of the design of the Congenital Anomalies Registry for the NWT of which FASD is a diagnosis. The information gained from the evidence based diagnostic strategies and findings of the round table discussions will be applied to the case definition of FASD within the Congenital Anomalies Registry for the NWT.

Conclusion

The FASD screening and diagnosis workshop was successful in educating front line health professionals, allied health and NGO's in best practices for the diagnosis of FASD in the NWT. Roundtable discussions enabled participants the opportunity to discuss FASD diagnosis and make suggestions for diagnosis of FASD in the NWT. Recommendations were made for future activities to facilitate a team approach to a community based model of diagnosis of FASD in the NWT.

disabilities. Designed with the busy clinician in mind, the text is concise and fully referenced for physicians who wish to read more about each topic. It includes:

- Pediatric growth charts
- Description of typical craniofacial changes associated with FAS
- Figures illustrating anthropometric facial proportions, measurements and anomalies, diagnosis
- Alcohol screening questionnaires to identify problem drinking
- Novel laboratory tests to identify in utero exposure to alcoho It also lists the battery of tests to be used in the assessment process and the neuropsychological profile used to diagnose children, particularly where the child presents with few or none of the physical markers of prenatal alcohol exposure

Appendix B3 – FASD Workshop

Canadian websites with content on diagnosis and/or screening of FASD

National Database of FASD and Substance Use During Pregnancy Resources
http://www.ccsa.ca/fas/intro_en.html
Data base of resources on FASD including diagnosis

Saskatchewan Prevention Institute
http://www.preventioninstitute.sk.ca/fasoverview.php

Lakeland FAD, Cold Lake AB
http://www.lakelandfas.com

Alberta Medical Association diagnosis guidelines
http://www.albertadoctors.org/bcm/ama/ama-website.nsf/AllDoc/B8D133999D3CA7A787256DE90072F69C?OpenDocument

Canadian Center on Substance Abuse
http://www.ccsa.ca/index.asp?menu=Statistics&ID=118
Addiction Statistics in Canada

Canadian Center on Substance Abuse, FAS tool kit
http://www.ccsa.ca/toolkit/introduction.htm
Information on screening for alcohol intake

Journal of FAS Research
http://www.motherisk.org/JFAS
Current Canadian Research, see webcast of FACE roundtable

Health Canada (site with links)
http://www.hc-sc.gc.ca/english/lifestyles/fas.html

Health Canada Drug Strategy FAS/FAE
http://www.hc-sc.gc.ca/hecs-sesc/cds/fas/index.htm

Health Canada Drug Strategy Statistics
http://www.hc-sc.gc.ca/hecs-sesc/cds/stats/index.htm

Calgary FASD
http://www.calgaryfasd.com

First Nations of Quebec and Labrador
http://www.cssspnql.com:8080/cssspnql/ui/health/HealthFAS.jsp?section=link_sante&lang=_en

US FASD surveillance program websites

Centers for disease control
http://www.cdc.gov/ncbddd/fas
Excellent comprehensive website from the Centers for Disease Control, is currently funding 5 states surveillance program

National Institute on Alcohol Abuse and Alcoholism
http://www.niaaa.nih.gov/publications/arh25-3/159-167.htm
Estimating the Prevalence of Fetal Alcohol Syndrome: A Summary

MMWR
http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5120a2.htm
Stats report for Alaska, Arizona, Colorado and New York

Alaska
http://hss.state.ak.us/fas

Arizona
http://www.peds.arizona.edu/fasinfo

New York
http://www.health.state.ny.us/nysdoh/cmr/fas.htm

More General Sites
FAS Community Resource Center
http://www.come-over.to/FASCRC
Comprehensive site with many links

Turtle Island Native Network
http://www.turtleisland.org/healing/healing-fas.htm
Many useful links

National Organization on FAS
http://www.nofas.org

APPENDIX B4 – FASD WORKSHOP

FASD Screening and Diagnosis
Dr Gideon Koren
Motherisk, Toronto, ON
November 29, 2004
Prince of Wales Heritage Center, Yellowknife, NT

Welcome: Dr Kami Kandola, Stanton Health Protection and Promotion Branch

Prayer: Be'sha Blondin, Elder, traditional knowledge teacher, healer and Medicine Woman, member of the Dene Nation, Keeper of the Lodge of Nats'eju' Dahk'e

1000-1200 FASD workshop, Dr Gideon Koren, The Motherisk program, Jean Ivey Chair in Molecular Toxicology in the Schulich School of Medicine, at The University of Western Ontario

1200-1300 lunch (provided)

1300-1500 FASD workshop, Dr Koren

1500 – 1530 Coffee (provided)

1530-1700 round table exploring FASD surveillance in the NWT

Facilitators, Susan Chatwood and Dr Kami Kandola

Fetal Alcohol Spectrum Disorder

Post Training test

1) The primary disabilities of Fetal Alcohol Spectrum disorders are:
2) The two typical quantitative craniofacial changes in FAS are:
3) Please mention several secondary disabilities of FASD:
4) What does the TWEAK test ask?
5) FASD may affect children's neurodevelopment. Please mention typical effects you know about:
6) FASD may affect children's behaviors. Please mention typical abnormal behaviors of these children:
7) How can you know if the baby was exposed to alcohol in pregnancy? Please mention different ways known to you.
8) What is the prevalence of:
   a) Full blown FAS in the general population
   b) All cases of FASD in the general population
   c) Full blown FAS among alcoholic mothers
9) What sensory pathways may be affected in fetal alcohol toxicity?
10) What is the definition of
   a) Heavy drinking
   b) Binge drinking

Appendix B6 – FASD Workshop

Questions for Stakeholder Consultation

1. Should there be a registry for FASD in the NWT? Yes or No and Why?
2. Where should the registry be based? Hospital, GNWT vital stats.
3. What population would be covered? To what age should cases of FASD be registered?
4. Should the registry collect information on risk factors? ie alcohol consumption, family support or any other factor that would help plan prevention programs.
5. Who should be responsible for the diagnosis? If it is a team, list members of the team.
6. Once the diagnosis of FASD is made, to whom should the family be referred or what services should be available.
7. Any other recommendations not covered above.

FASD Workshop – Roundtable discussion findings

1. Should there be a registry for FASD in the NWT? Yes or No and Why?

   It was felt that there needed to be a FASD registry in the NWT in partnership with community programming. The community programming should focus on family support, health care needs and education. It was strongly felt that the FASD registry should not be a sterile government based registry, but a tool to facilitate nurturing care for persons affected by FASD and their families. It was felt that an FASD registry would facilitate funding for more services in the NWT. Issues of confidentiality would need to be addressed and balanced with the need to provide services and be respective of clients and families.

   Screening for alcohol use in pregnancy so that support could be provided was also identified to be a priority. There was not consensus or sufficient information provided to determine the best practice method to attain this information.

2. Where should the registry be based? Hospital, GNWT vital stats.

   It was felt that the registry should be hospital based with links to the GNWT vital stats department. When identifying patient information was included, issues of confidentiality would need to be addressed, and information limited to persons directly involved in providing supportive services to the client and family. It was also felt that the information should be linkable to other provinces so rates can be compared nationally. In this case the information should be stripped of all identifiers and shared on a population basis.

3. What population would be covered? To what age should cases of FASD be registered?

   The responses varied somewhat from birth to death, to birth to school age. Overall it was raised that FASD is a diagnosis that tends to occur later, > 5-7 years, so the registry has to accommodate this and accept registrants later in life when diagnosed.

4. Should the registry collect information on risk factors? ie alcohol consumption, family support or any other factor that would help plan prevention programs.

   There was not agreement among participants as to whether the registry should collect information on risk factors. Those who supported the collection of information on risk factors pointed out that the information would be useful for research, help design prevention programs and evaluate family supports, which can change frequently.

5. Who should be responsible for the diagnosis? If it is a team, list members of the team.

   There was complete consensus that a team approach was required to diagnose FASD. One group went on and was more specific and identified the make up of a child development team (CDT). This team would consist of OT/PT, Audio, SLP, Physician, Social worker, Traditional healer, Community psychologist, Mental health worker and a school link. I was suggested that there be a team leader to coordinate the activities of the team.

6. Once the diagnosis of FASD is made, to whom should the family be referred or what services should be available.

   It was pointed out that referrals would need to be age appropriate referrals. Early intervention programs with Occupational Therapy, Physiotherapy and Speech Language affiliated with school supports were deemed a priority for children.
   Psychiatry, legal supports and drug and alcohol education were identified as resources required for adults affected by FASD.
   When appropriate cultural, traditional on the land teaching should be incorporated into all programs.
   Family needs were also identified as being important to meet. In terms of education on coping strategies and respite.

7. Any other recommendations not covered above.

   Other issues identified as important in providing services to individuals and families affected by FASD were the provision of early intervention programming, headstart programs in every community. Housing support and life skills training for those affected by FASD.

APPENDIX B7 – FASD WORKSHOP

Sent: Tuesday, November 30, 2004 8:19 AM
To: FASD workshop
Subject: FASD workshop and mailer group

Hi,
I want to thank everyone for your participation in the FASD workshop yesterday. I think everyone's awareness of this disorder was increased. This takes us one step closer to addressing this issue in our community and offering support to those who need it most.

I mentioned at the end of the meeting that I would share email addresses of those who are interested (create a mailer list). This could start an informal network for FASD information. This would include sharing information on meetings about FASD, funding possibilities and just share what our various organizations are doing on FASD. Should issues arise of mutual concern we could meet as a group.

Please respond to this email if you would like to be on the FASD mailer group. Please share this email with anyone you know who was not at the workshop, but would like to be included.

Thanks again for your participation yesterday.

Fetal Alcohol Spectrum Disorder

Diagnostic Services Workshop by
Lakeland Centre for Fetal Alcohol Spectrum Disorder
Audrey McFarlane
Feb 7, 2005 – Yellowknife, NWT

Biographic Sketch – Audrey McFarlane, B.CR

Ms. McFarlane is currently the Executive Director for the Lakeland Centre for Fetal Alcohol Spectrum Disorder. She was a founder of the Lakeland FASD Committee that led to the development of the Centre and its services. After obtaining a degree in Community Rehabilitation, her past 18 years have been spent working with children and adults with developmental disabilities and providing training on FASD. Part of her duties at the Centre has included development of the rural community based model for FASD diagnostic services for children & adults, coordination of the Diagnostic, Assessment and Intervention Children's Clinic, development of the rural based mentorship program for high risk women, assisting other communities in the development of services, developing best practice models for working with challenging families with FASD individuals. Audrey and the Centre have been recognized by Health Canada for the development of services, for which FNIHB is now delivering its funding based on these rural models. Audrey has presented at the local, regional, and national level on many issues related to FASD. Fetal Alcohol Spectrum Disorder is a passion that continues to challenge and intrigue Audrey.

Outline

- Introductions
  - What do participants hope to achieve today
- Review of Diagnostic Services using the 4 – digit code and IOM categories
- Lakeland Centre for FASD rural mobile community based FASD diagnostic services
  - How did the program start?
  - How does it work?
  - Where does funding come from?
  - What have been the pitfalls?
  - What are the benefits?
  - Other programs developed by the Lakeland model

APPENDIX C

BC Ministry of Health,
Health Status Registry 2004 Redevelopment Project

Business Requirements

BC Ministry of Health,
Health Status Registry 2004 Redevelopment Project

Business Requirements – Addendum

Ministry of Health Services

Health Status Registry 2004 Redevelopment Project

Business Requirements Addendum

Author: Antoinette Klette

Creation Date: February 2, 2005

Update Date: February 2, 2005

Version: Version 1.0 Feb 02

Change Record

Date	Author	Version	Change Reference
Feb 2, 2005	Antoinette Klette	1.0	Created Addendum for the HSR Business Requirements.

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Overview

This document acts as an addendum to the original HSR Business Requirements. The details found in this document will be in addition to or will replace details as they are defined in the requirements documentation.

There are three areas of functionality that are addressed: Merging of Registrants, Advanced Search and Update Load Processes. Each one of these areas will be defined in the more detail in the sections that follow.

Contents

1 Merge HSR Registrants

There is a chance that we may end up with duplicate registrants within the HSR system at any point in time. For this reason we need the ability to resolve and merge duplicate registrants into a single HSR Registrant.

- The users will be able to select two HSR registrants that they can compare and, if relevant, request a merge for these selected registrants.
- The merge and update process will be performed according to the Update Rules as they are defined in HSR.

2 HSR Advanced Search

In addition to the traditional Oracle Forms search / filter functionality we will require an Advanced Search function to perform searches within the HSR database (This Advanced Search functionality will not be available on the HSR staging area).

The Advanced Search will be accessed from a menu option and will provide the users with additional search functionality that spans current as well as historical data.

The search function can be performed with any combination of the following fields:

- Historical HSR ID
- Registrant / Mother / Father Names
    - Surname
    - First Name
    - Second Name
    - Third Name
    - PHN
- Birth Registration Number
- Death Registration Number
- Birth Date
- Death Date
- Gender
- EVRP_ID's

3 HSR Update Load Process

There will be two types of load processes for HSR. Data that we receive from the reporting sources will be flagged as Load data or Update data.

3.1 HSR Load Process

The first option being the traditional load that will filter out any HSR records that are non-registerable and only proceeds with matching, updating and creating of HSR registrants from this subset of HSR registerable records.

3.2 HSR Update Load Process

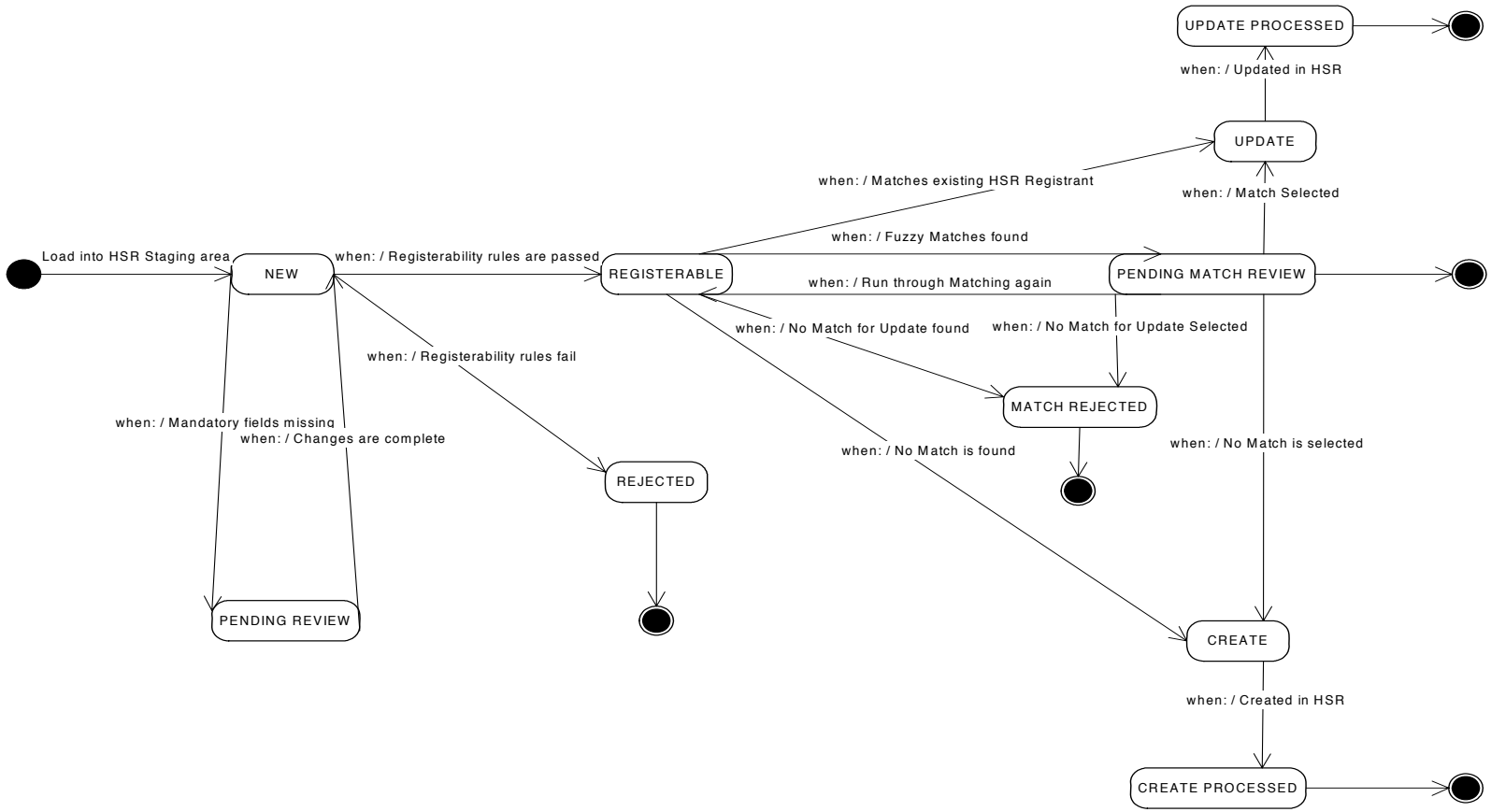
The second option being an Update Load process that will NOT filter out HSR Registerable records and proceeds to match all records. Any entries that are not matched are immediately rejected. A single positive match will result in an Update on the HSR Registrant and multiple positive or fuzzy matches results in them being assigned to the Update Fussy Matches queue.

These matches will require human intervention to resolve and results in either an update of the selected match record or a rejection if no match was selected.

- The Update Load Process will update any valid data within HSR according to the Update Rules specified in HSR for the various reporting sources.

4 State Transitions Diagram

The amended state diagram to reflect matching of Update Loads



BC Ministry of Health,
Health Status Registry 2004 Redevelopment Project

Technical Specifications
Mockups and Business Process Flows – Draft

B.C. Vital Statistics Agency

Health Status Registry

Technical Specifications – Mockups and Business Process Flows

DRAFT

Project#: HSR0401
CR#: 2042

Authors: A. Klette
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Version: **1.3**

Approvals:

Technical Design	**Signature**	**Date**
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Systems Storm Edgar *Director, Information Technology*		
Information Management Terry Tuk *Director,IM*		
Don Rintoul *Assistant Manage, IM*		

Table of Contents

1 Purpose of Document

This document defines the Business Process flows, State transitions and contains mockups of all the screens for the new HSR2 System. Approval of this document allows Development to proceed.

2 Scope

Scope is as taken from the HSR Business Requirements document.

3 References

HSR Business Requirements	http://hsr.vs.gov.bc.ca/

4 Assumptions

4.1 Data Validation and Formats

Validation is performed to ensure that all mandatory fields are provided. Further validation will be performed to ensure that data type rules are adhered to. Eg. Numeric fields may not contain alphabetic characters and date fields must comply with the required date format.

Dates will always be in the 'YYYY-MM-DD' format.

4.2 Forms Environment

The HSR project will be developed in the Forms environment, all standard forms functionality will also be available from the HSR system.
Errors and messages will always be displayed in the message bar at the bottom of the screen

4.3 Web Environment

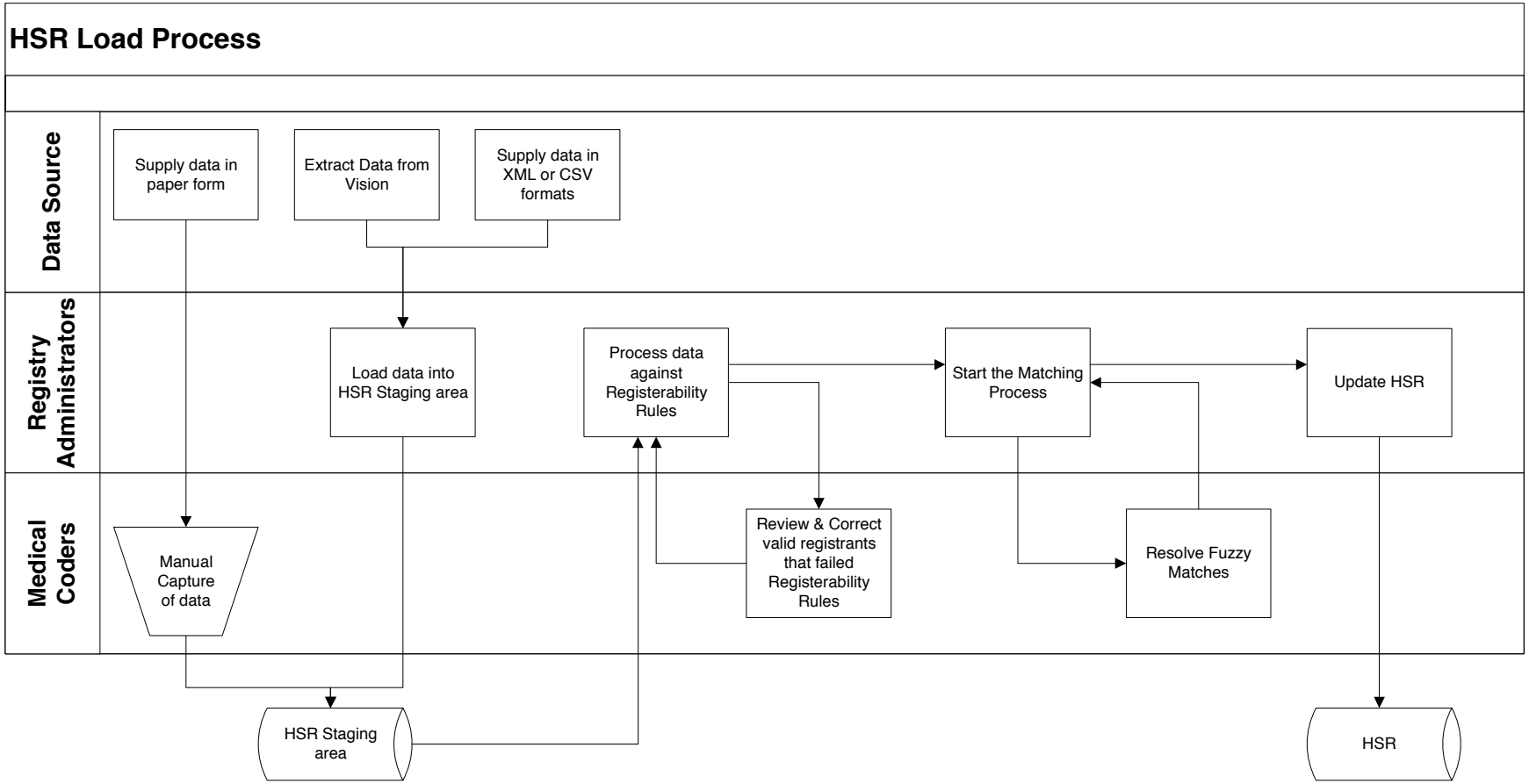
The final HSR screens will be converted to Oracle 10G forms and will be based on a Web environment and will run from an internet browser.

4.4 Screen Resolution

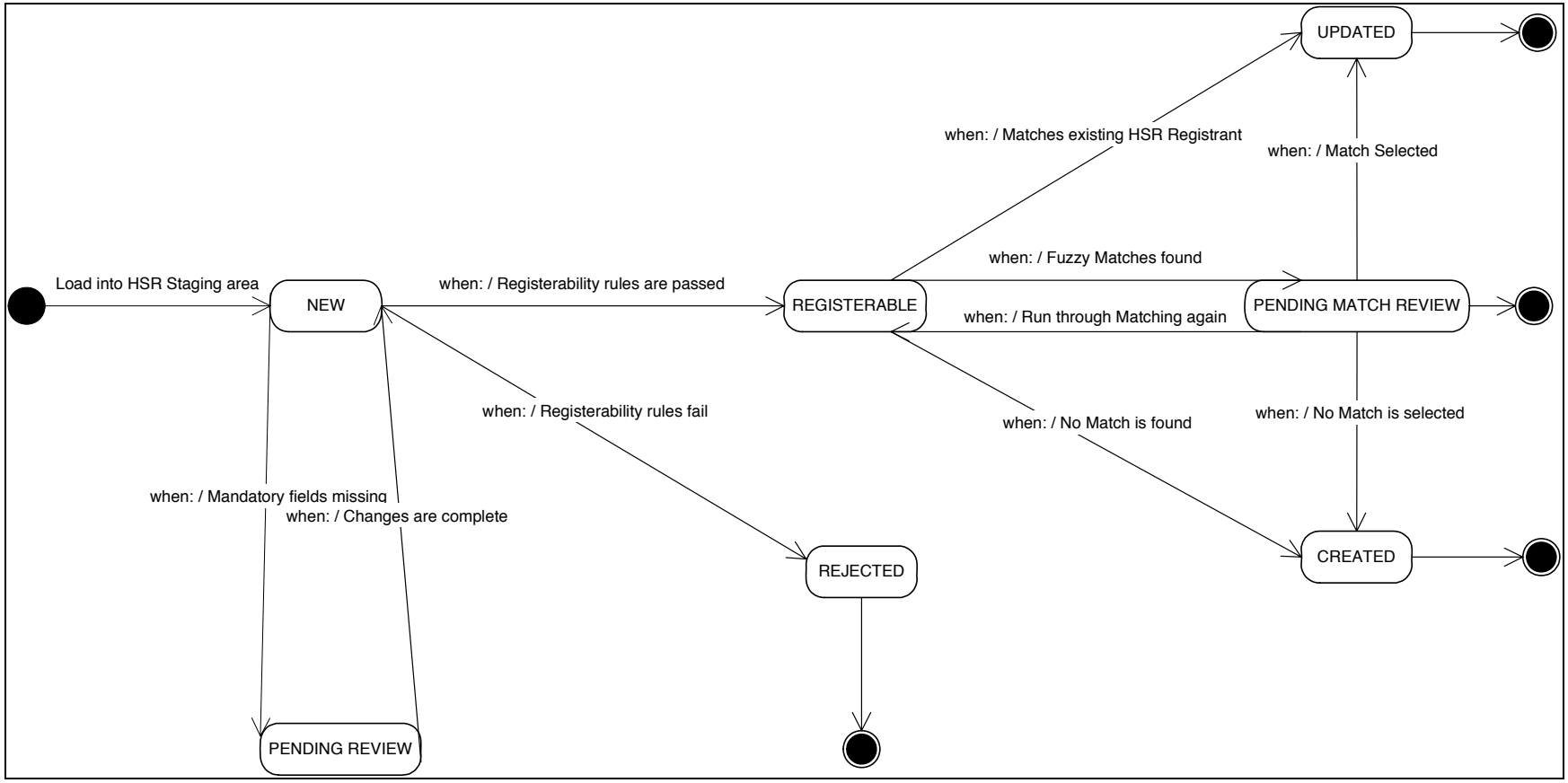
All the HSR forms are being developed for 1024 x 768 screen resolution

5 Business Process Flows

5.1 HSR Load Process Flow



6 State Transition Diagram



7 Menus

7.1 Menu structure

All the standard forms menu functionality will be available.
There are four areas on the HSR menu that require specific attention for the purposes of the HSR project, those being 'File', 'Actions', 'View' and 'Administration'.

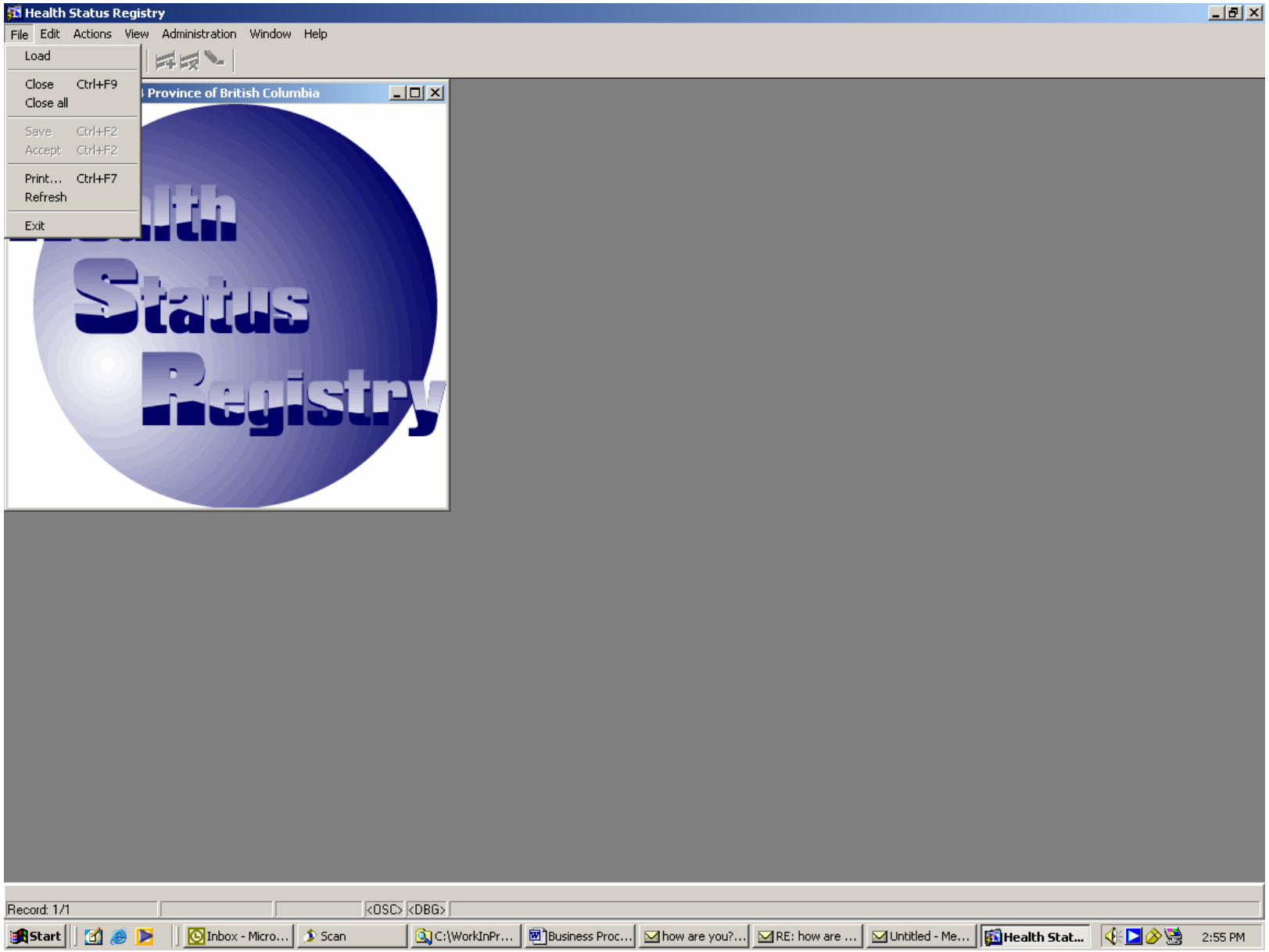
1. File
   1.1. Load

2. Actions
   2.1. Registration Filter
   2.2. Match Registrants
   2.3. Update HSR
   2.4. Merge Registrants
   2.5. Search Registrants

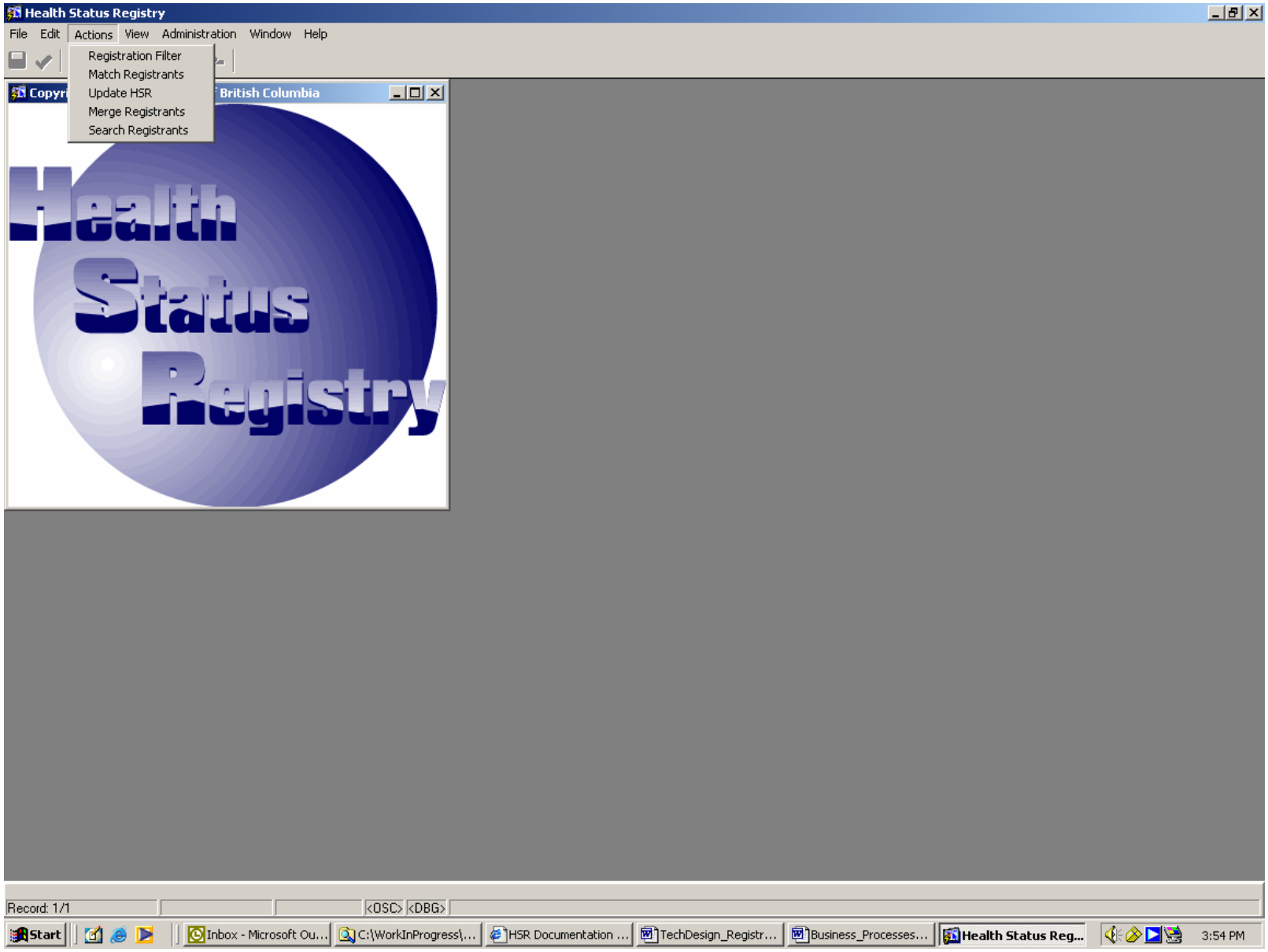
3. View
   3.1. Staged HSR Registrant
   3.2. HSR Registrant
   3.3. HSR Registrant Un-coded
   3.4. Registration Filter Results
   3.5. Match Results

4. Administration
   4.1. Match Definition
   4.2. Medical Codes
   4.3. Reporting Sources
   4.4. Meta Data
      4.4.1. Object Definitions
      4.4.2. Object Types Definitions
      4.4.3. Update Rules Definitions

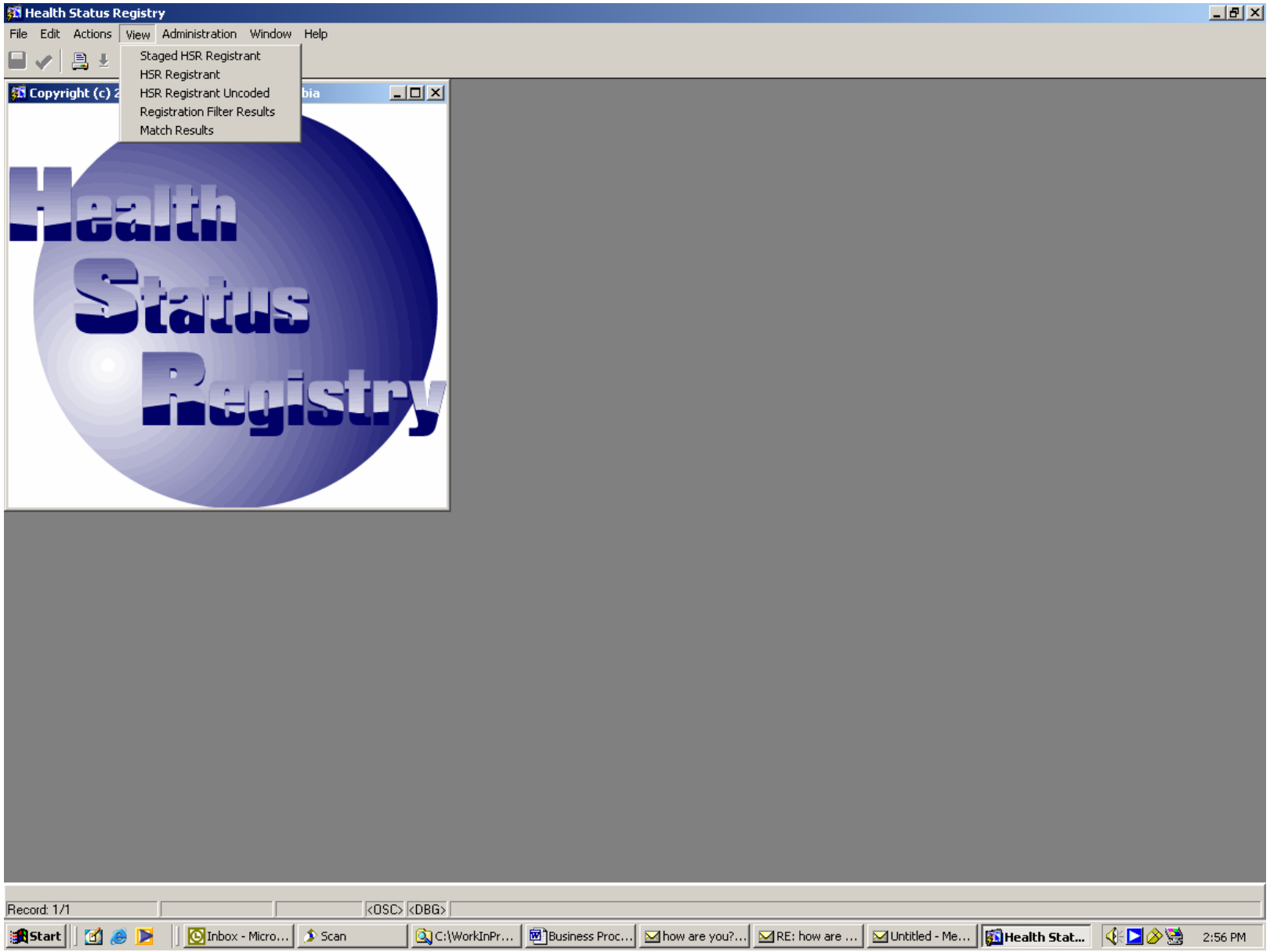
7.2 File Menu


Health Status Registry
File
Edit
Actions
View
Administration
Window
Help
Load
Close Ctrl+F9
Close all
Save Ctrl+F2
Accept Ctrl+F2
Print... Ctrl+F7
Refresh
Exit
Province of British Columbia
Status
Registry
Record: 1/1
<OSC>
<DBG>
Start
Inbox - Micro...
Scan
C:\WorkInPr...
Business Proc...
how are you?...
RE: how are ...
Untitled - Me...
Health Stat...
2:55 PM

7.3 Actions Menu

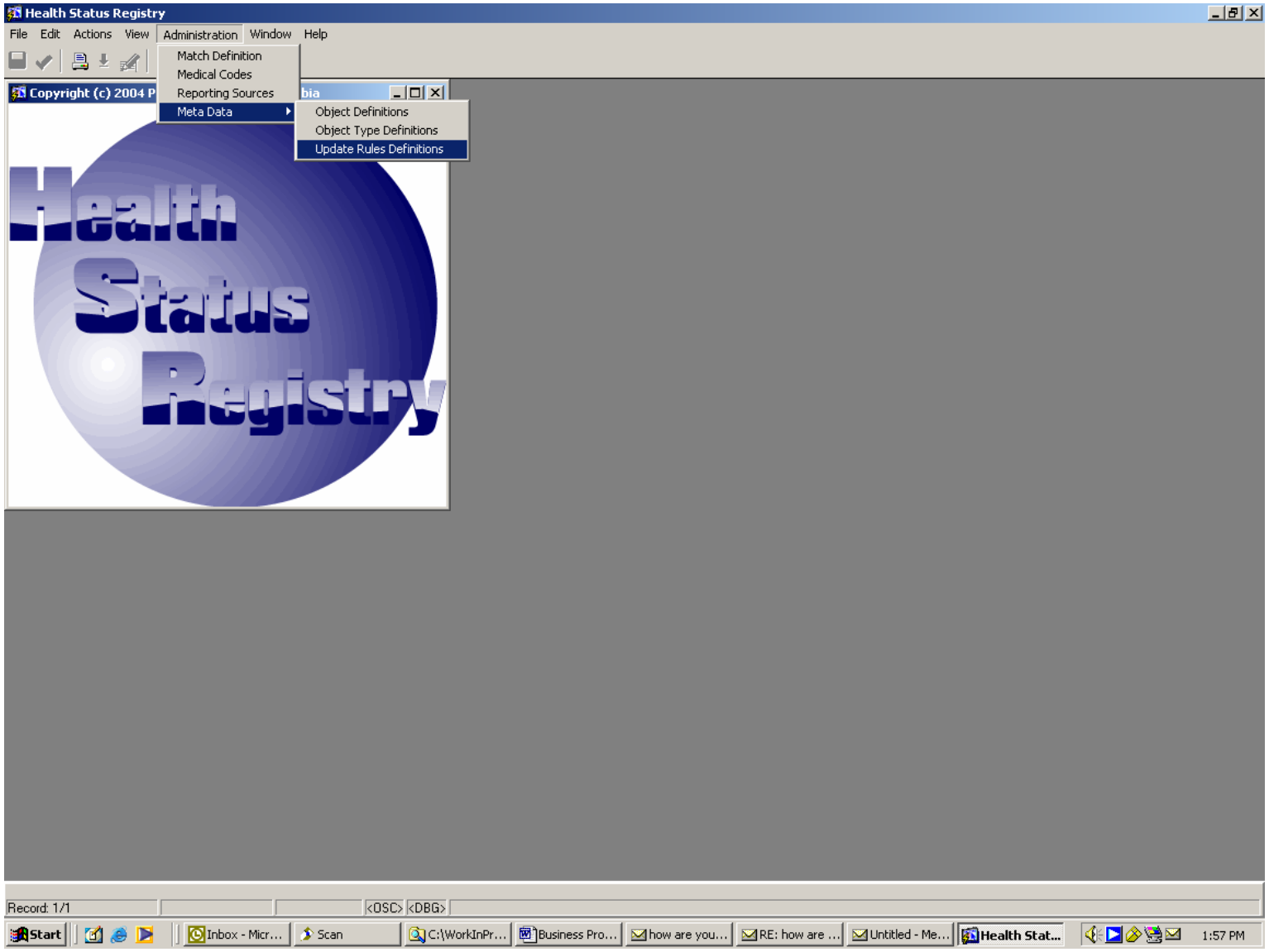


7.4 View Menu


Health Status Registry
File Edit Actions View Administration Window Help
Staged HSR Registrant
HSR Registrant
HSR Registrant Uncoded
Registration Filter Results
Match Results
Copyright (c) 2
bia
Health
Status
Registry
Record: 1/1
<OSC> <DBG>
Start
Inbox - Micro...
Scan
C:\WorkInPr...
Business Proc...
how are you?...
RE: how are ...
Untitled - Me...
Health Stat...
2:56 PM

7.5 Administration Menu

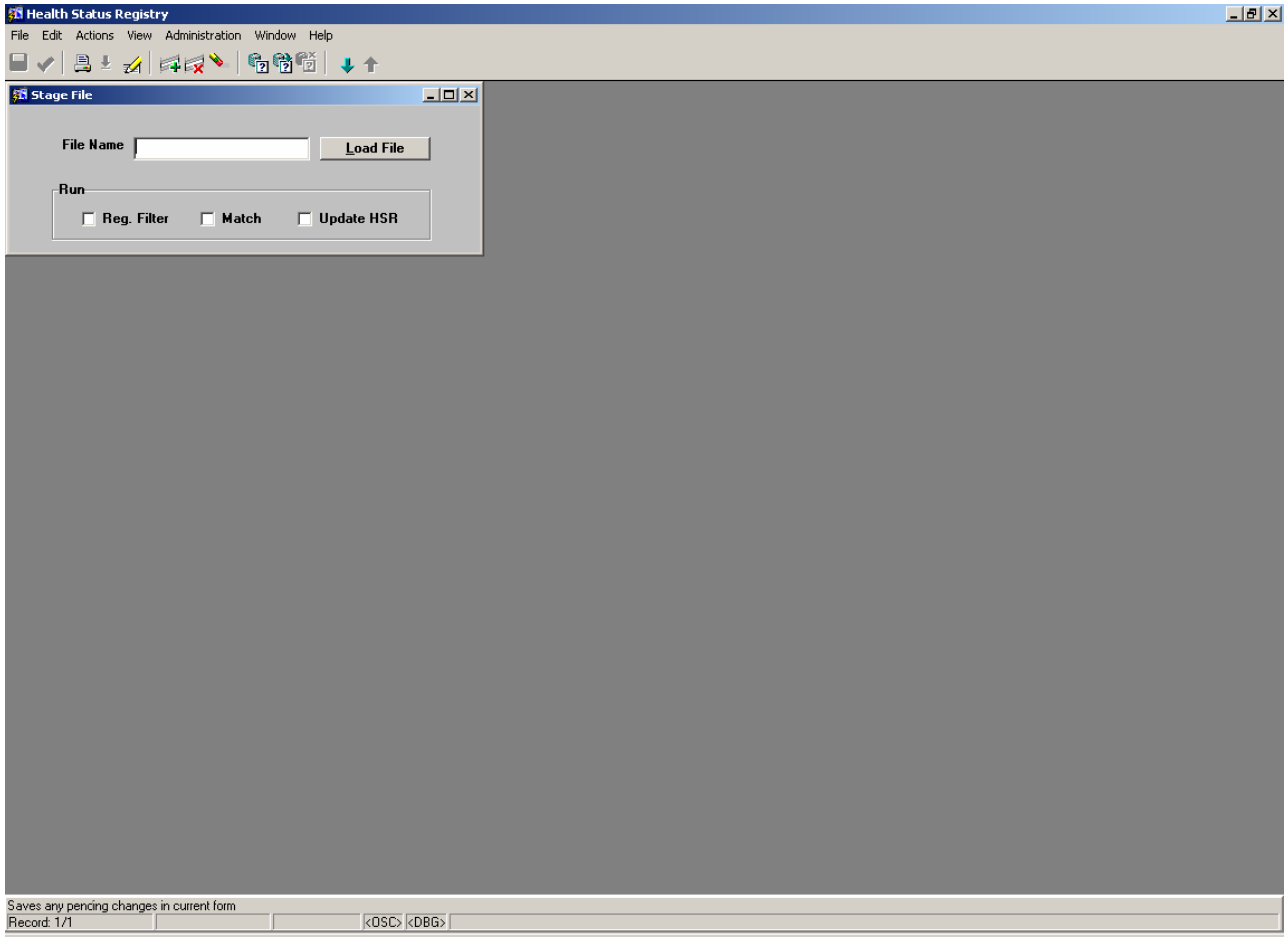
The Administration menu options will only be available to the HSR system administrators but not to the medical coders. The only exception to this rule is the Medical Codes, Reporting Sources and Update rules to which the medical coders will have access. All the menus and screens will be visible to all users of the system, however, update priviledges will be enforced through using and assigning Database Roles.



8 HSR Screen Mockups

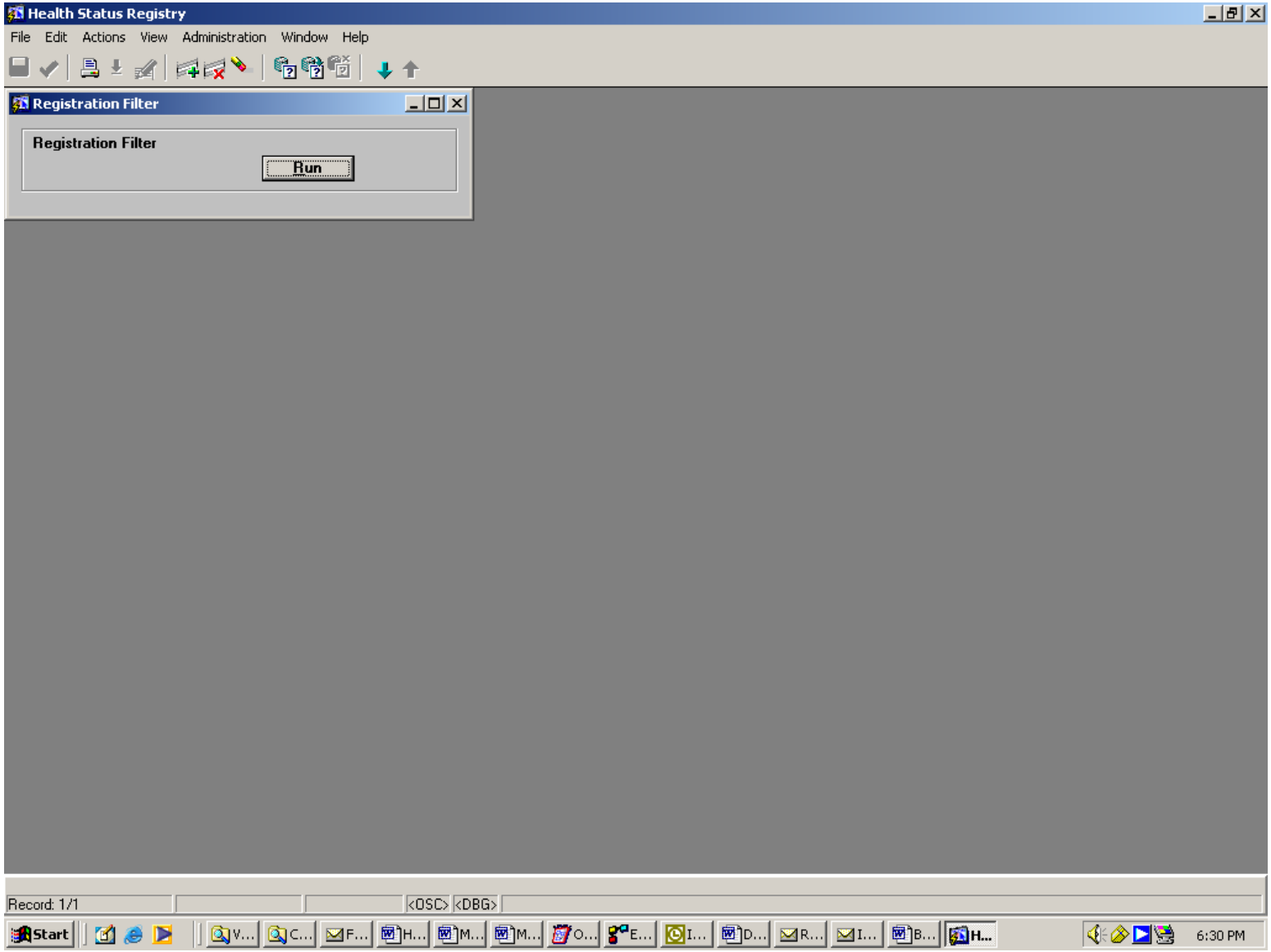
8.1 Load File

The Load File form is initiated from the Load menu option (see menu 1.1). The name of the file is entered, and the ‘Load File’ button loads the details into the HSR Staging area.
To automatically start the Registration Filter process and / or the Match Registrants Process and / or the Update HSR process, the user or system administrator has the option of selecting which processes they would like to start automatically on completion of the load into the HSR staging area. The only restriction being that processes have to be selected in accordance to the process flow eg. Registration Filter and Match Registrants may be selected but you would be prevented form selecting the Matching Process if the Registration Filter has not been selected.



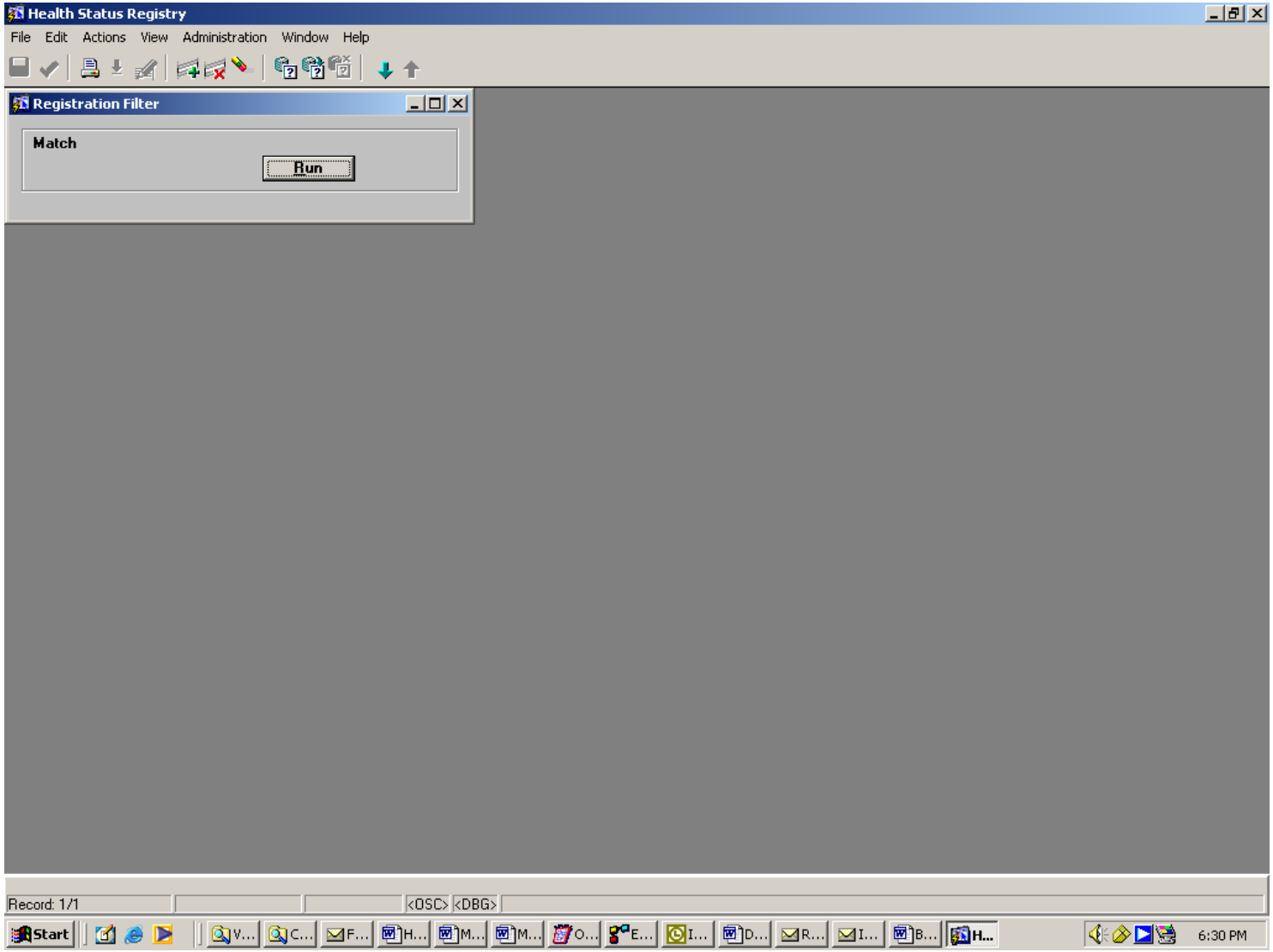
8.2 Registration Filter

The Registration Filter form is initiated from the Actions menu option (see menu 2.1). The Registration Filter checks data in the HSR staging area registerability into HSR.



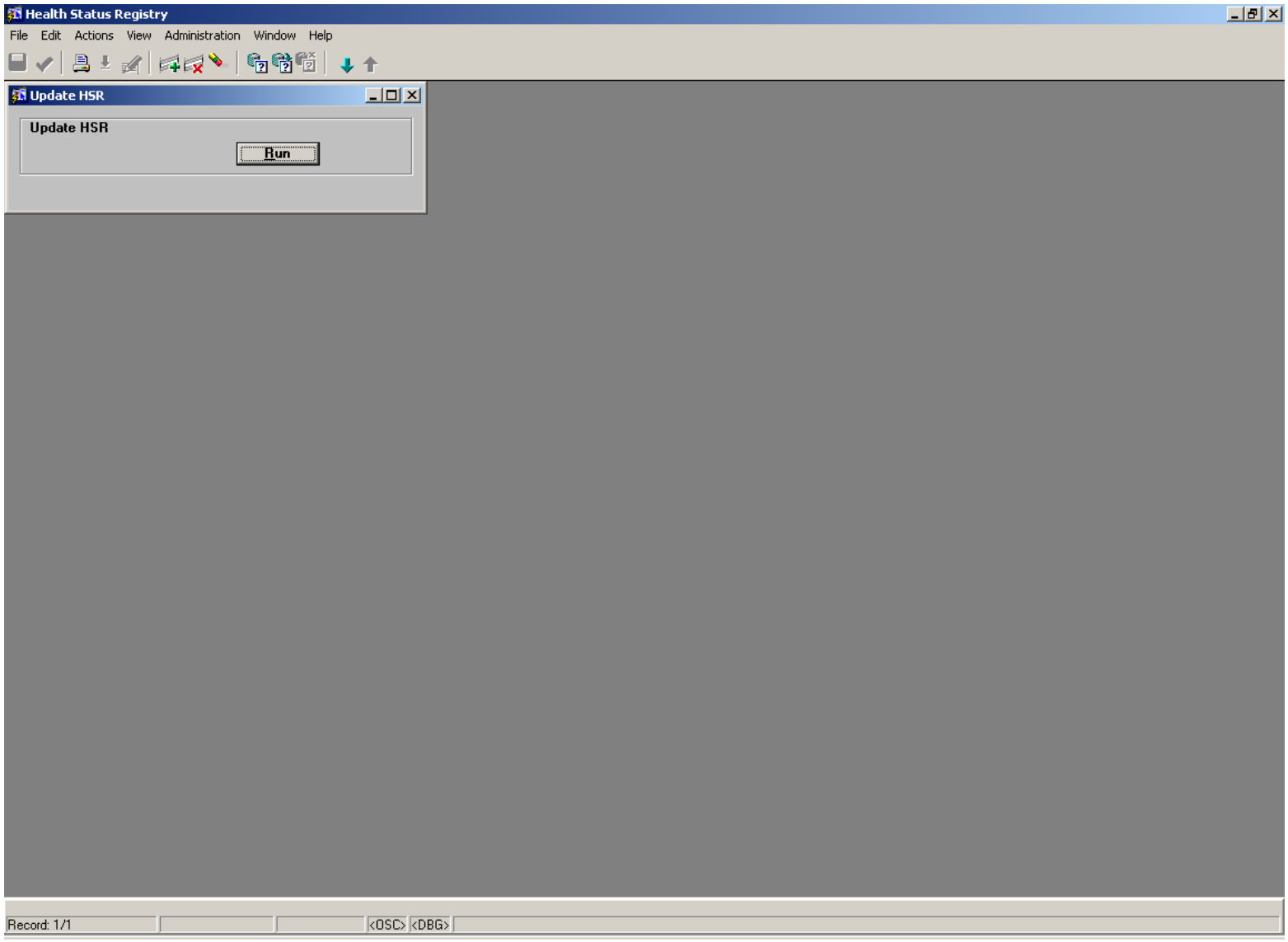
8.3 Matching Process Mockup

The Match Registrants form is initiated from the Actions menu option (see menu 2.2). Match Registrants attempts to match data from the .HSR staging area to data in HSR.



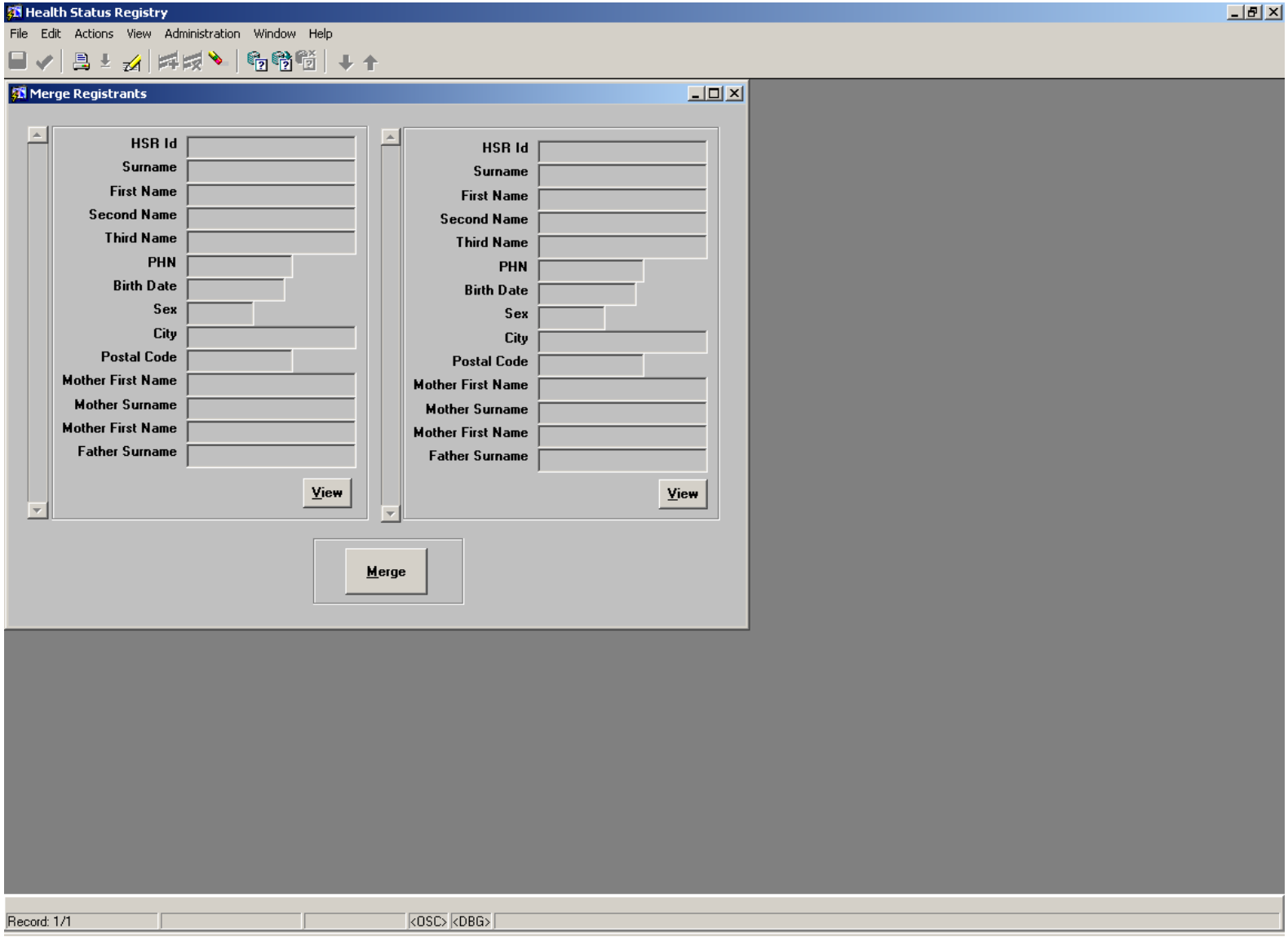
8.4 Update HSR

The Update HSR form is initiated from the Actions menu option (see menu 2.3). Update HSR will update the HSR database with any Registrant updates or creates as determined from the Matching process. (The matching process and resolution of fuzzy matches results in a status change on those records to either Update or Create, these records are then picked up by the Update HSR process and are either updated or inserted into the HSR database accordingly)



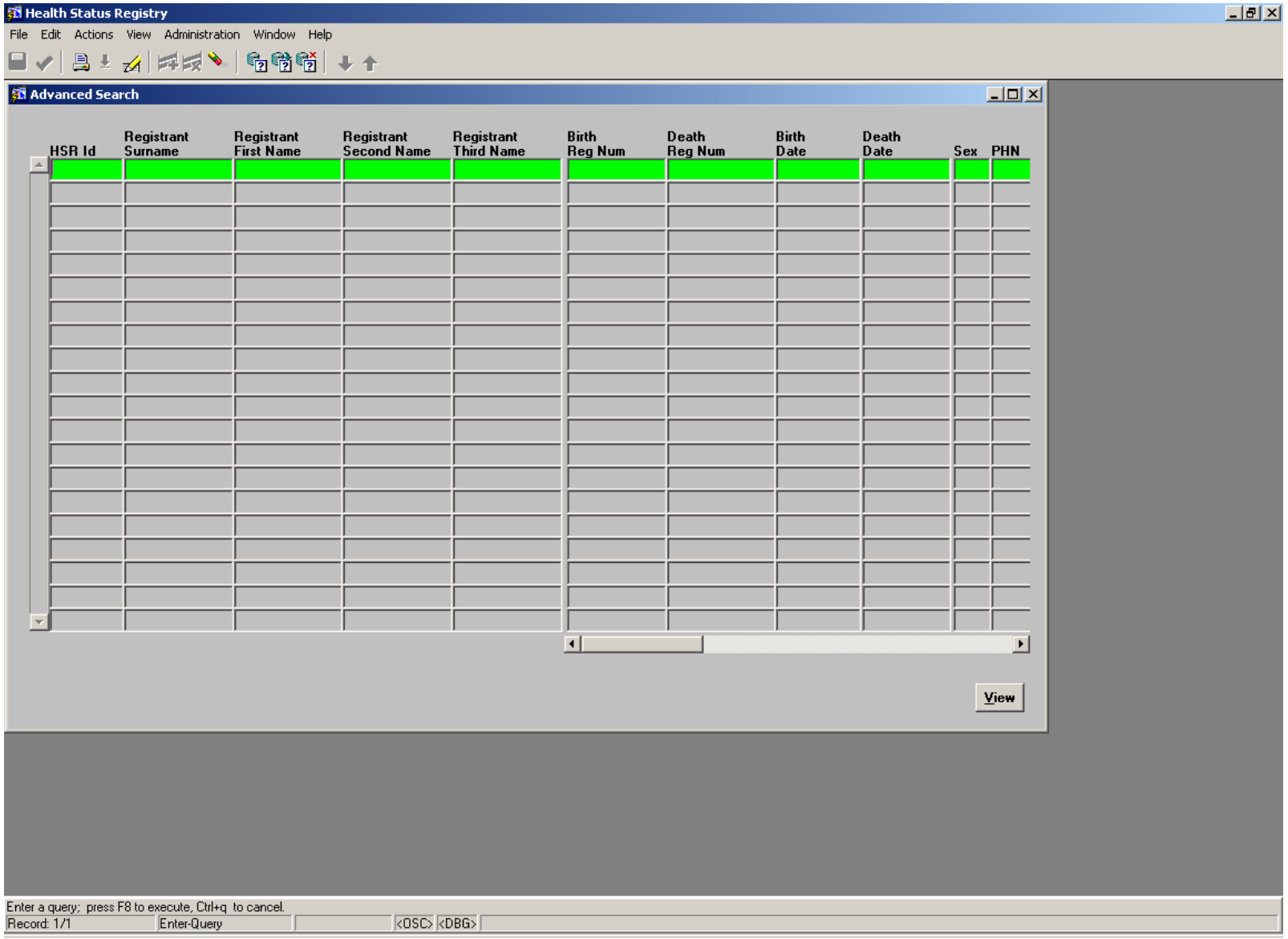
8.5 Merge Registrants Process

The Merge Registrants form is initiated from the Actions menu option (see menu 2.4). All the fields displayed on this screen may be used for searching by using the standard forms query functionality.



8.6 Search Registrants

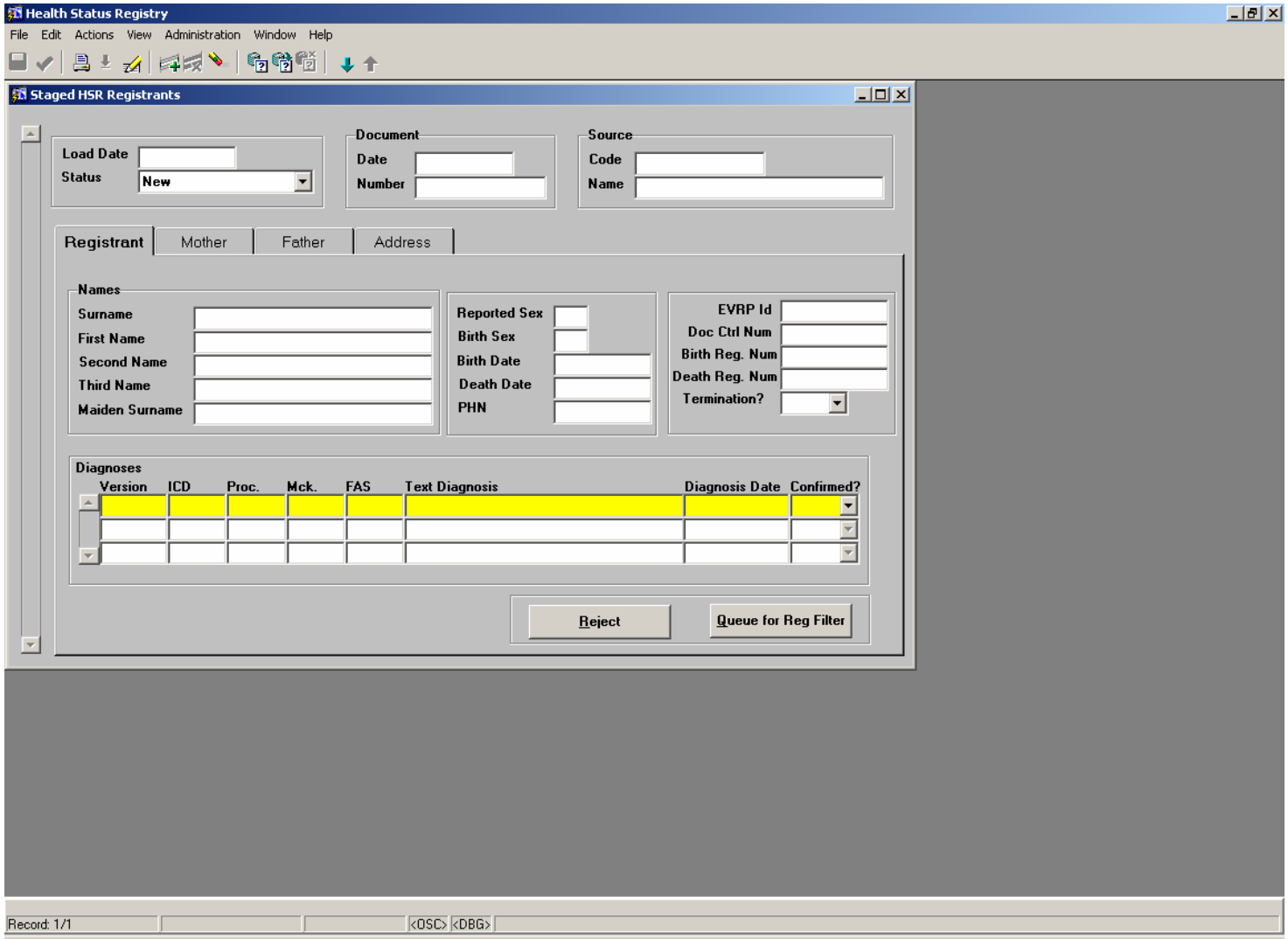
The Search Registrants form is initiated from the Actions menu option (see menu 2.5). This form is used to query and return results of the HSR Registrants.



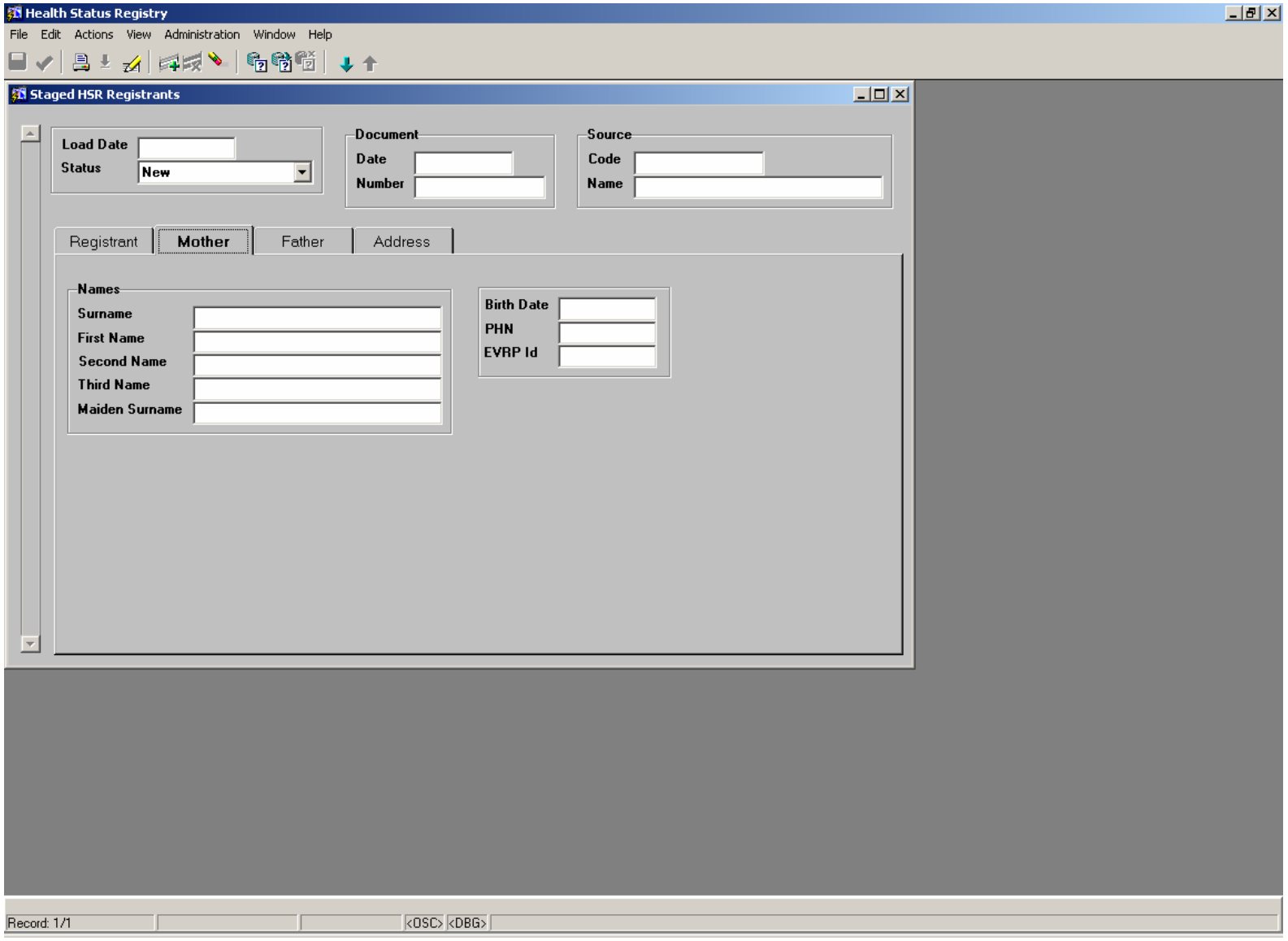
8.7 Staged HSR Registrants

The Staged HSR Registrants form is initiated from the View menu option (see menu 3.1). The details can be re-queued for the Registration Filter once changes have been completed. Registrants may be manually rejected, these registrants won't proceed any further through the HSR Load process.

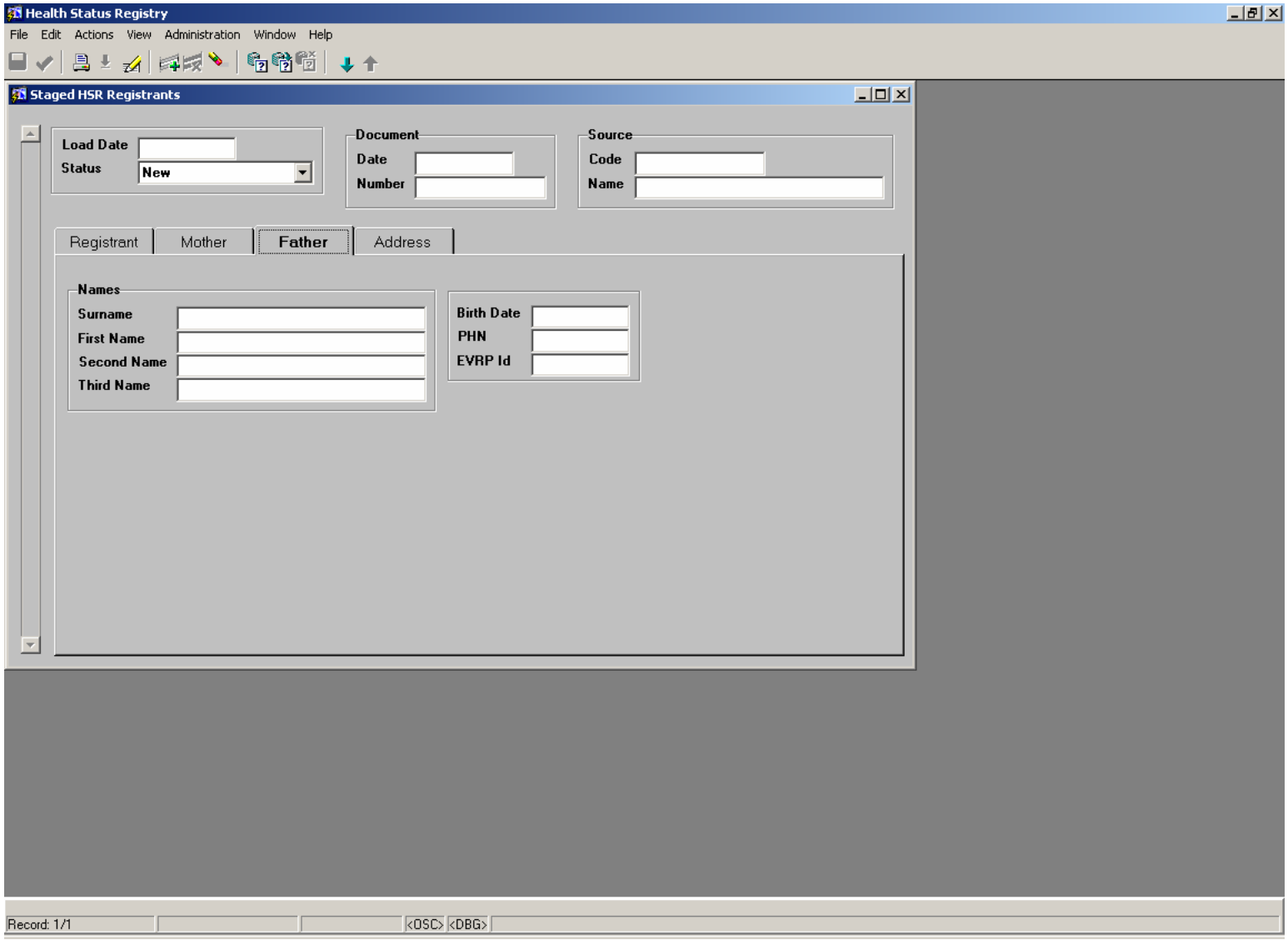
8.7.1 Registrant



8.7.2 Mother

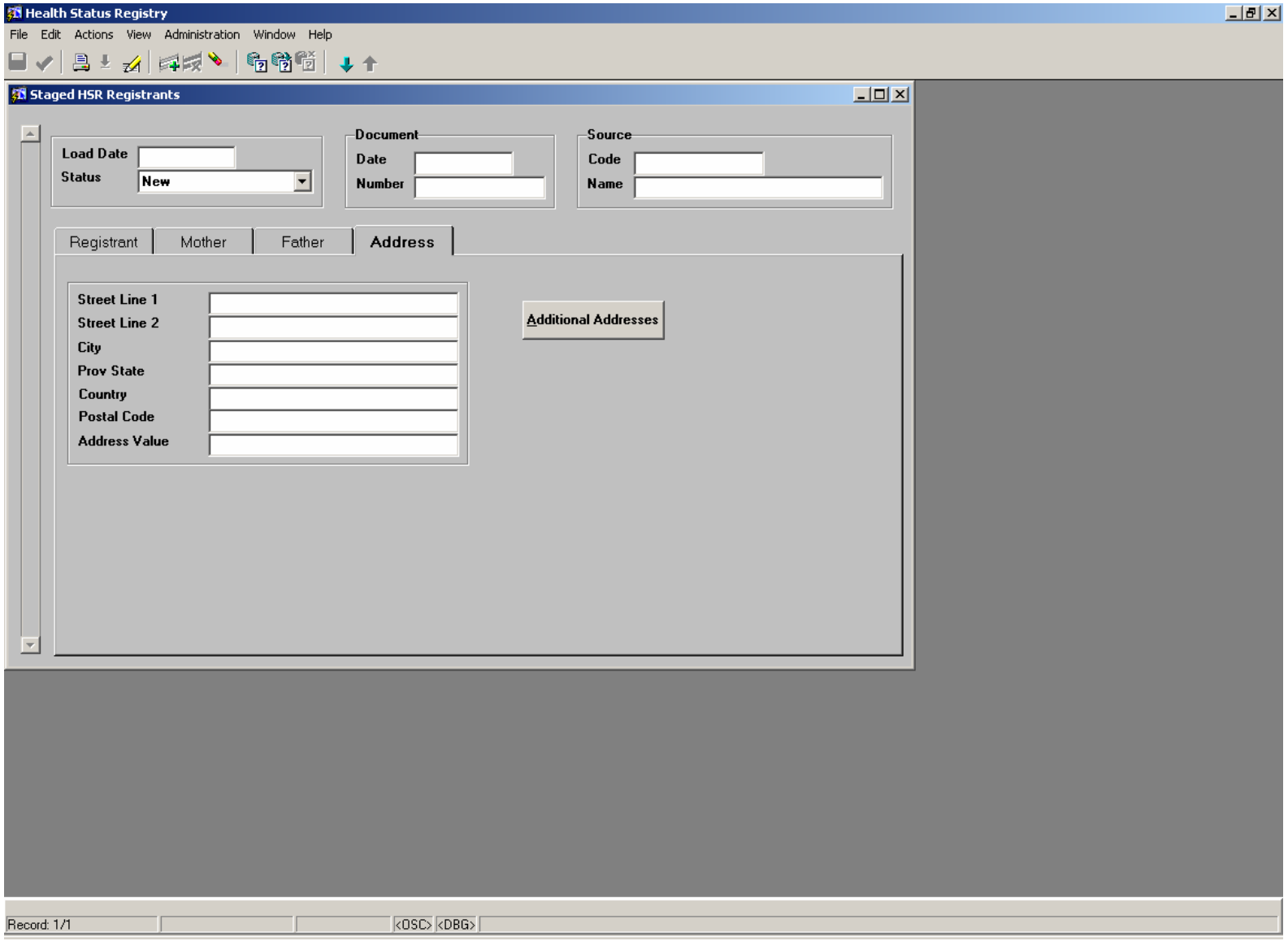

Health Status Registry
File Edit Actions View Administration Window Help
Staged HSR Registrants
Load Date
Status
New
Document
Date
Number
Source
Code
Name
Registrant
Mother
Father
Address
Names
Surname
First Name
Second Name
Third Name
Maiden Surname
Birth Date
PHN
EVRP Id
Record: 1/1
<OSC>
<DBG>

8.7.3 Father

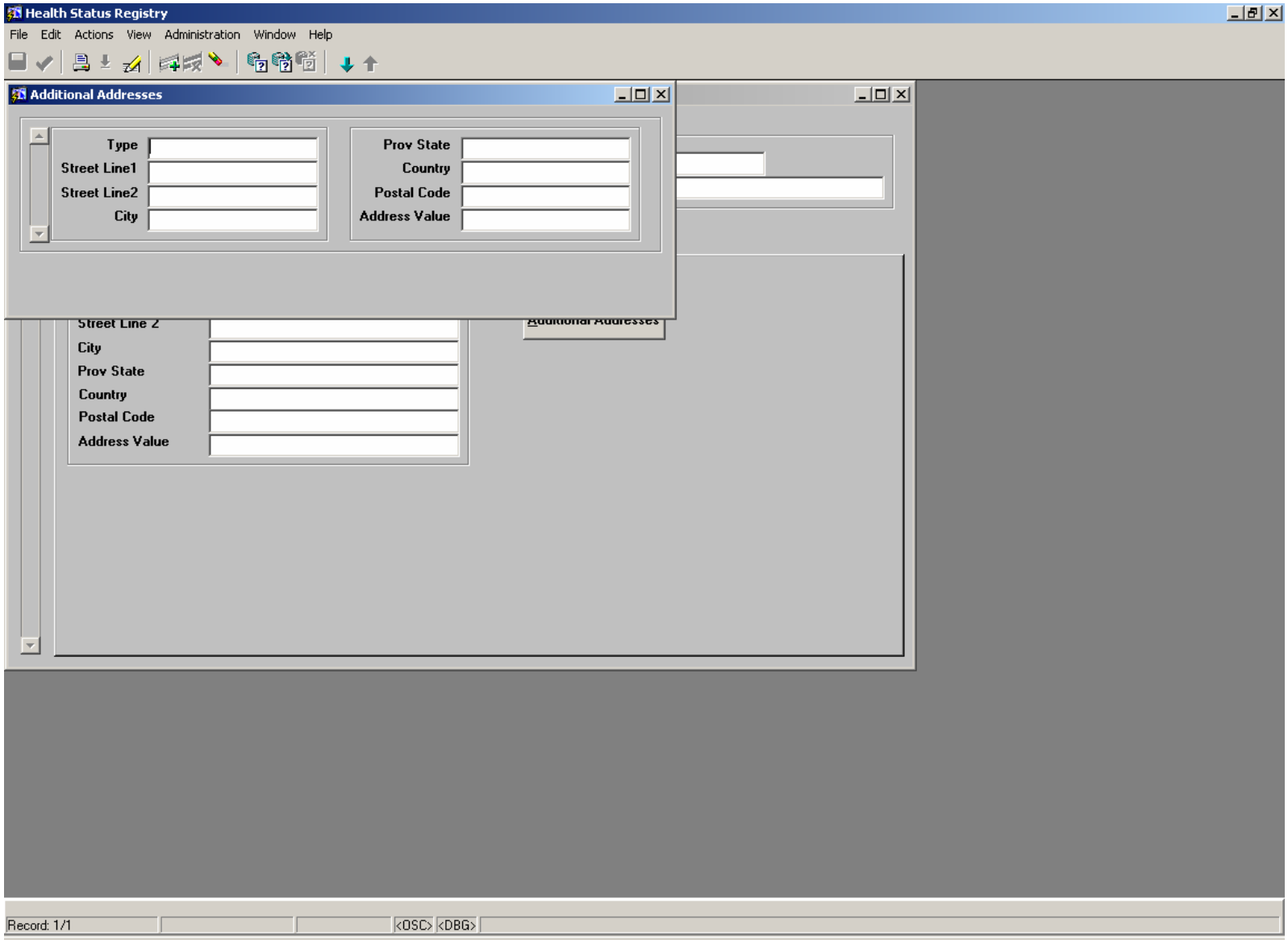

Health Status Registry
File Edit Actions View Administration Window Help
Staged HSR Registrants
Load Date
Status
New
Document
Date
Number
Source
Code
Name
Registrant
Mother
Father
Address
Names
Surname
First Name
Second Name
Third Name
Birth Date
PHN
EVRP Id
Record: 1/1
<OSC>
<DBG>

8.7.4 Address

This is the primary address associated with the Registrant, any other addresses can be viewed using the ‘Additional Addresses’ button.



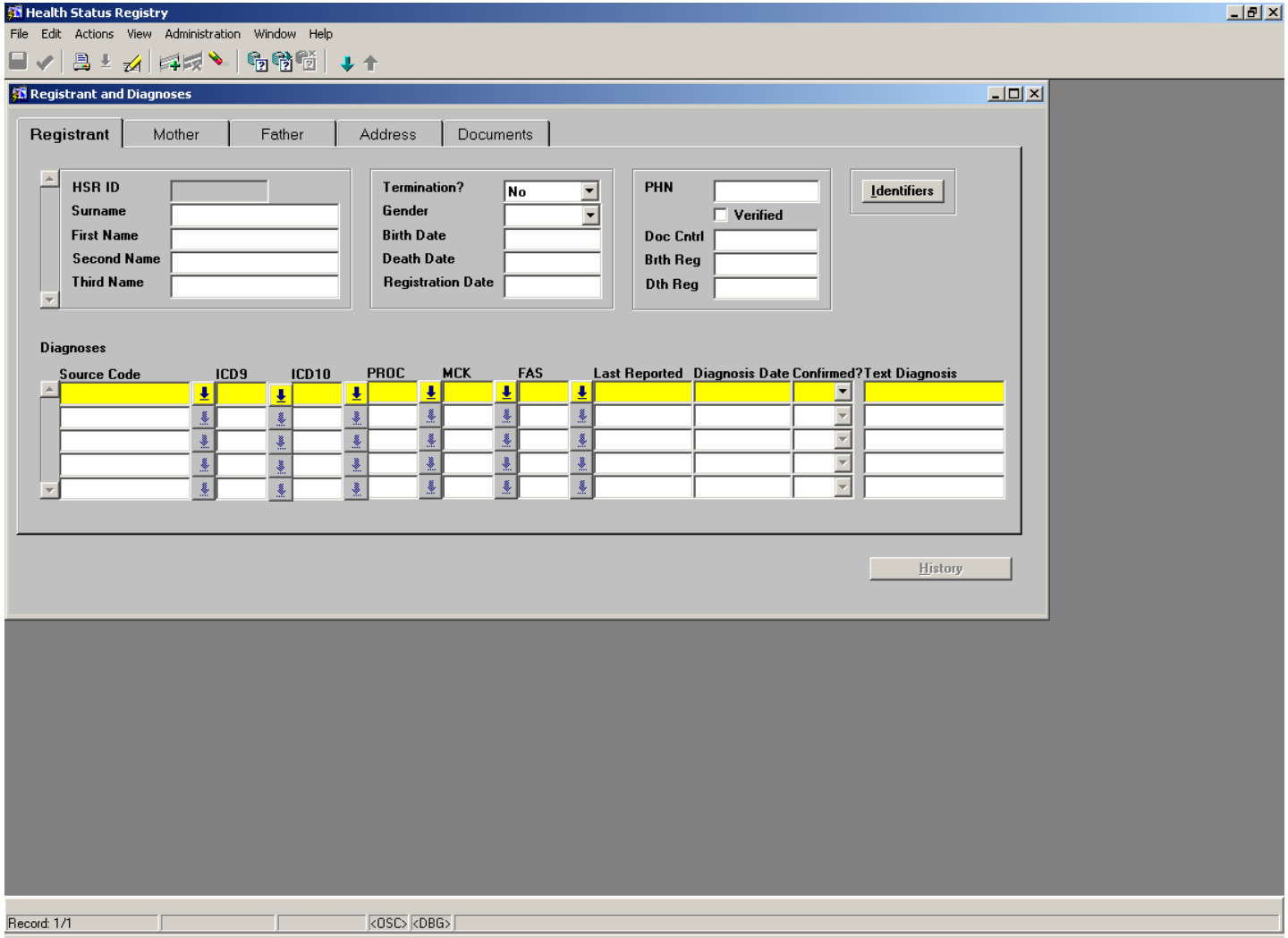
8.7.4.1 Additional Addresses



8.8 HSR Registrant & HSR Registrant Un-coded

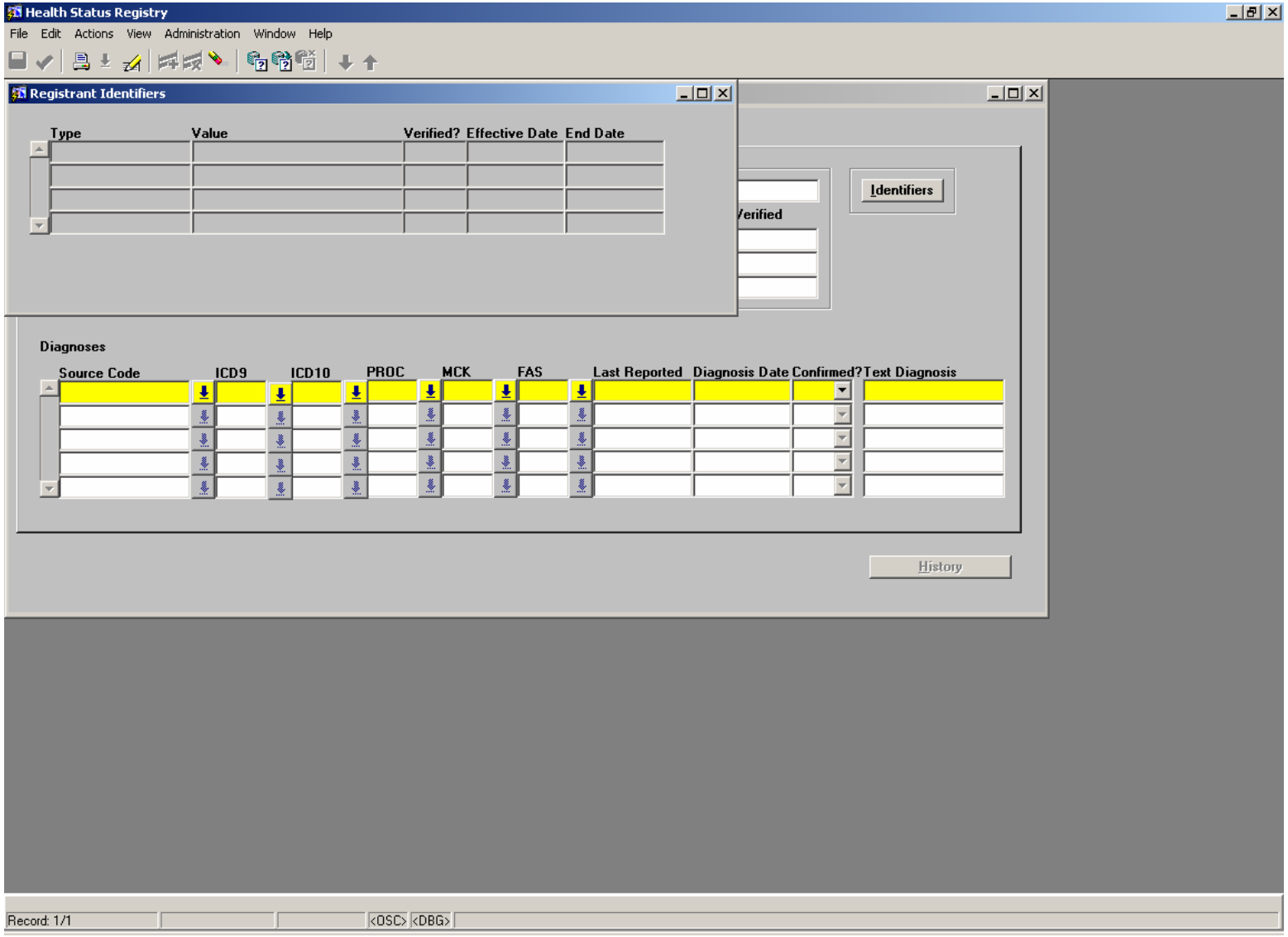
Both the HSR Registrants and HSR Registrant Un-coded forms are initiated from the View menu option (see menu 3.2 and 3.3). The HSR Registrant Un-coded form returns a result set of Registrants that have text diagnoses that do not have medical codes associated. (Use the scroll bar on the left of the screen to page through the Registrants). The history button displays a popup with all history recorded for the field that is currently selected. All the fields in the 3 blocks at the top of the Registrant tab may be used for searching using the standard forms functionality (Historical HSR ID is not provided as a search option, but can be viewed via the Identifiers tab.

8.8.1 Registrant



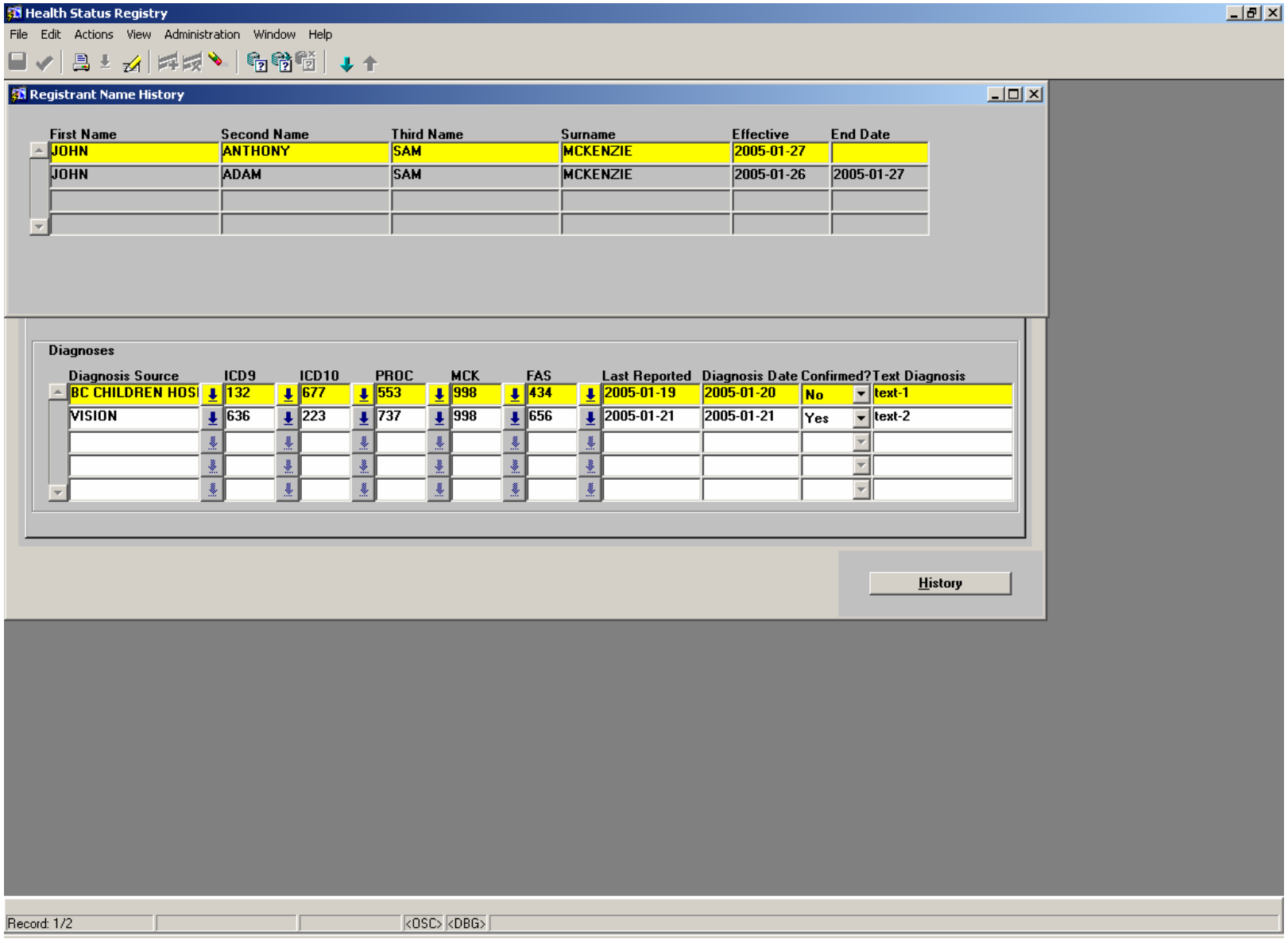
8.8.2 Identifiers

The Identifiers popup is displayed whenever the 'Identifiers' button is selected from any of the Registrant, Mother, or Father tabs with the relevant details.

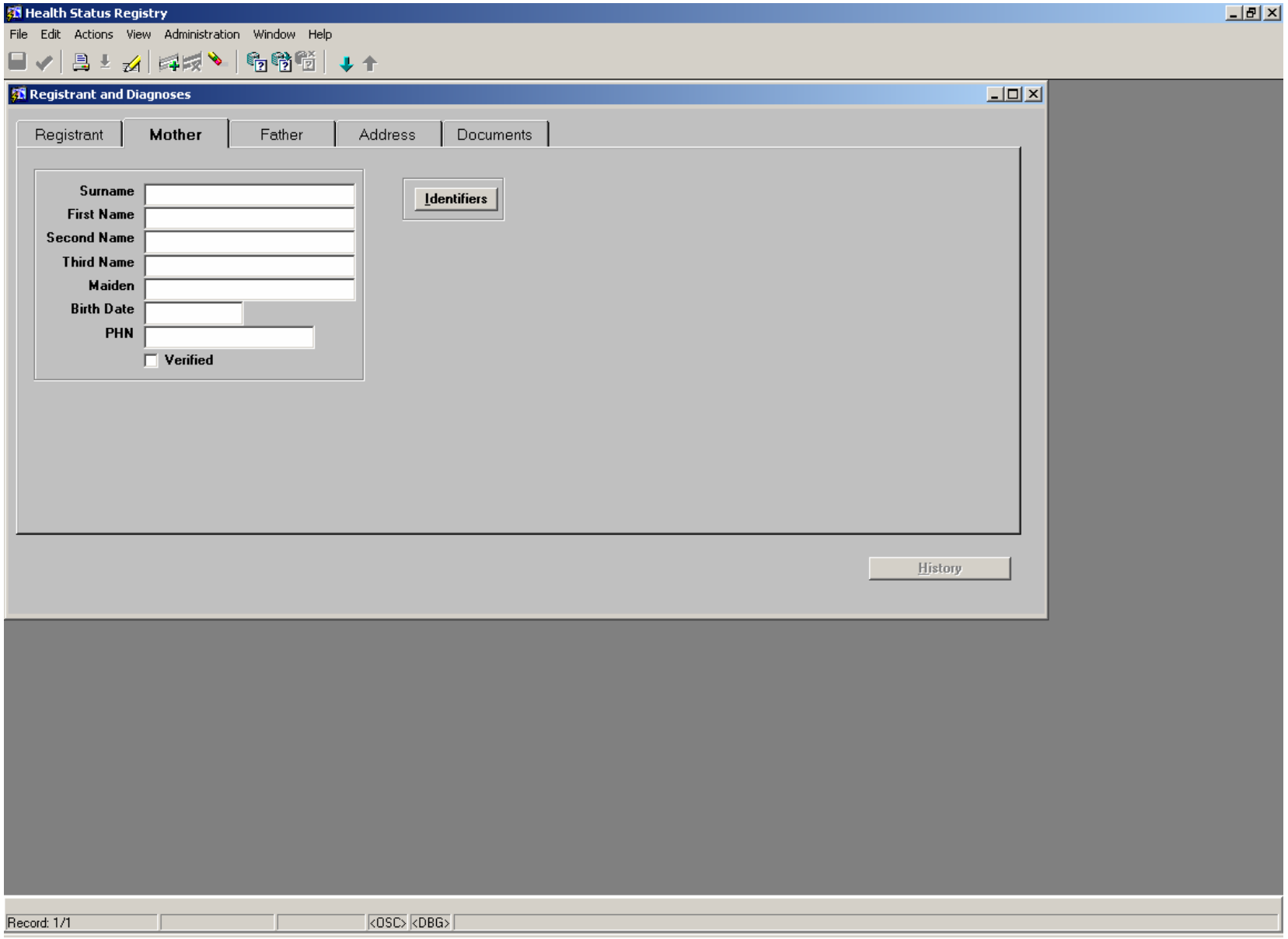


8.8.3 History

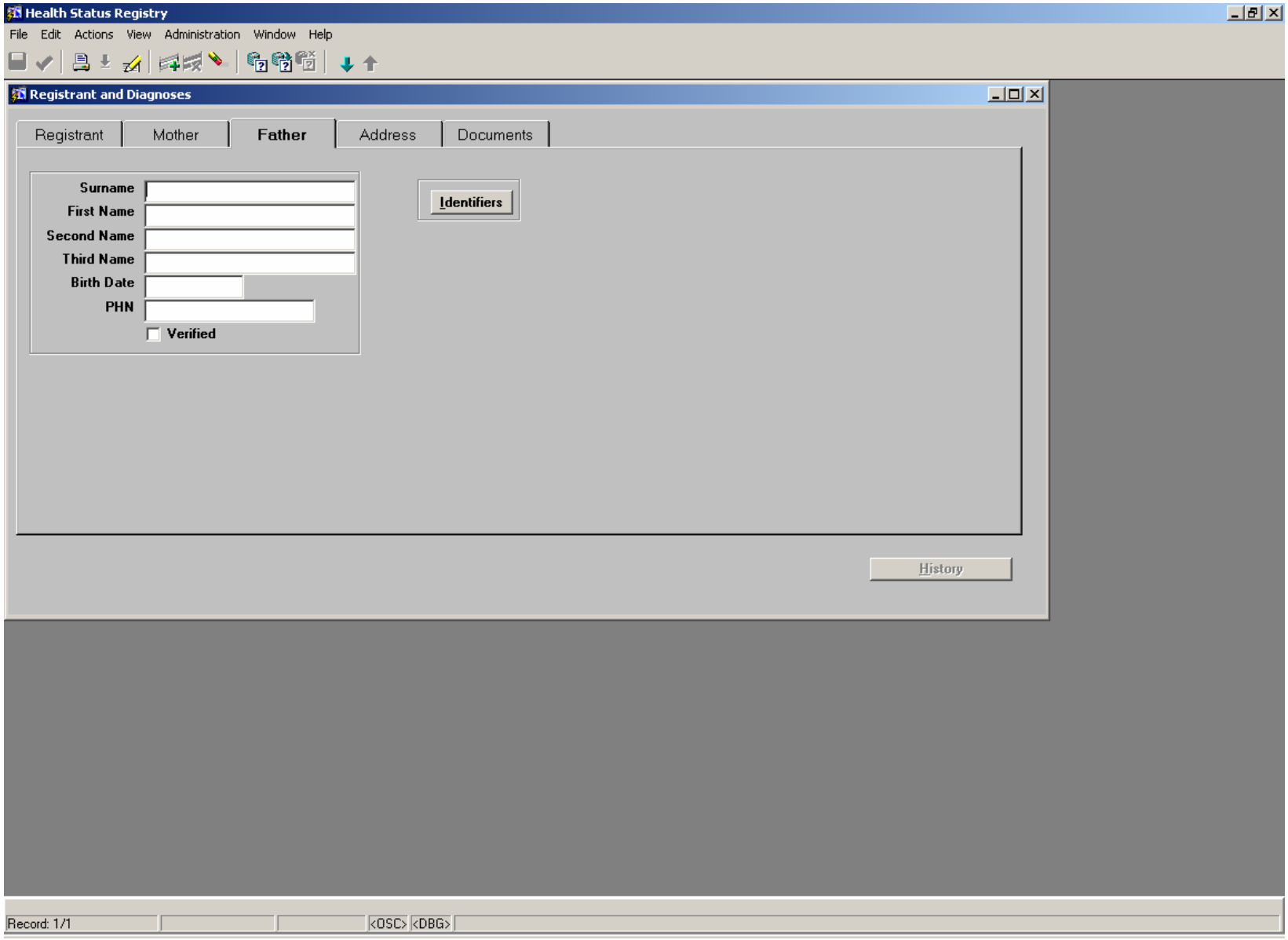
The History popup is displayed with all the history recorded for the field that was currently selected on the previous screen.



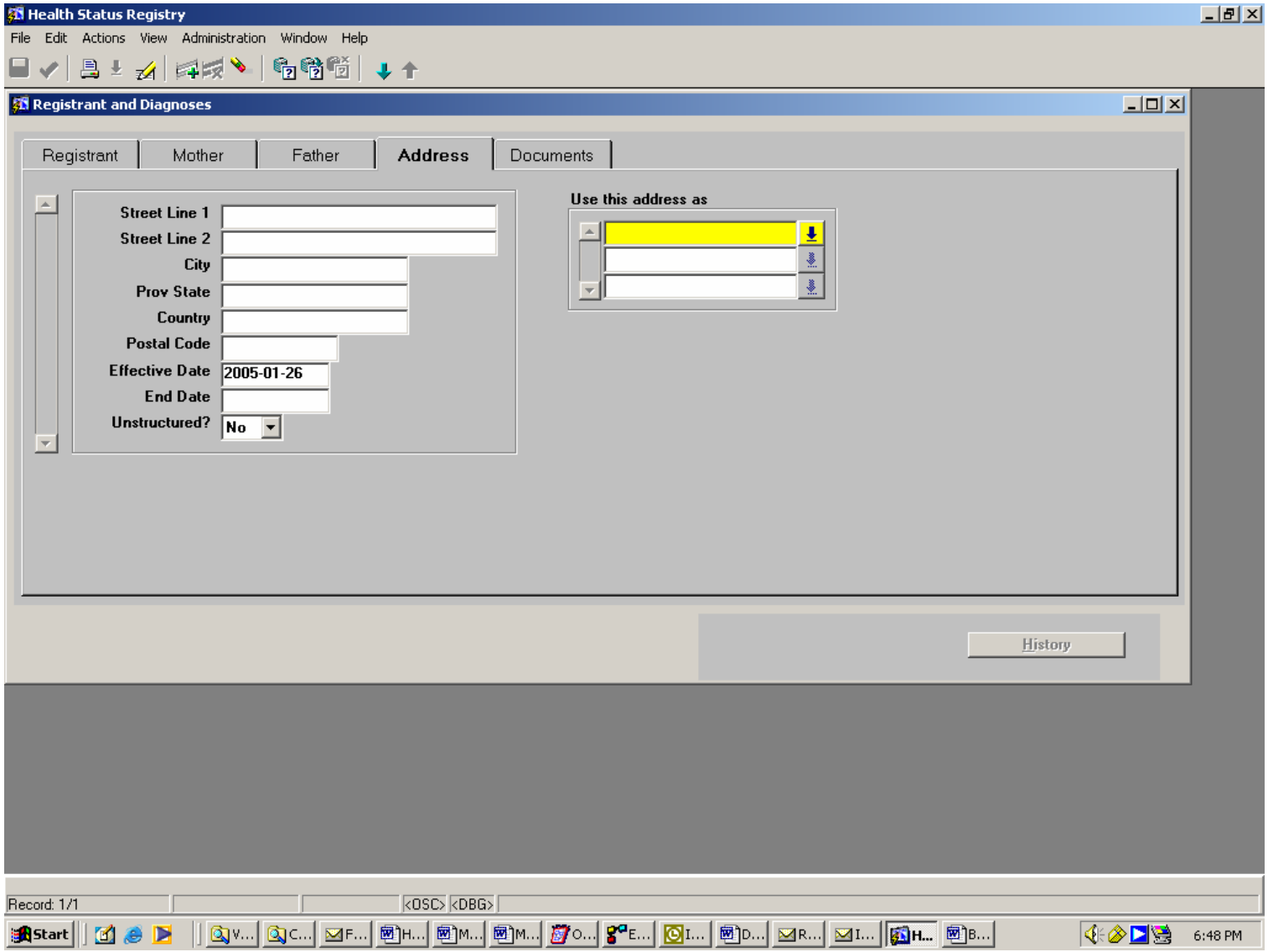
8.8.4 Mother


Health Status Registry
File Edit Actions View Administration Window Help
Registrant and Diagnoses
Registrant
Mother
Father
Address
Documents
Surname
First Name
Second Name
Third Name
Maiden
Birth Date
PHN
Verified
Identifiers
History
Record: 1/1
<OSC>
<DBG>

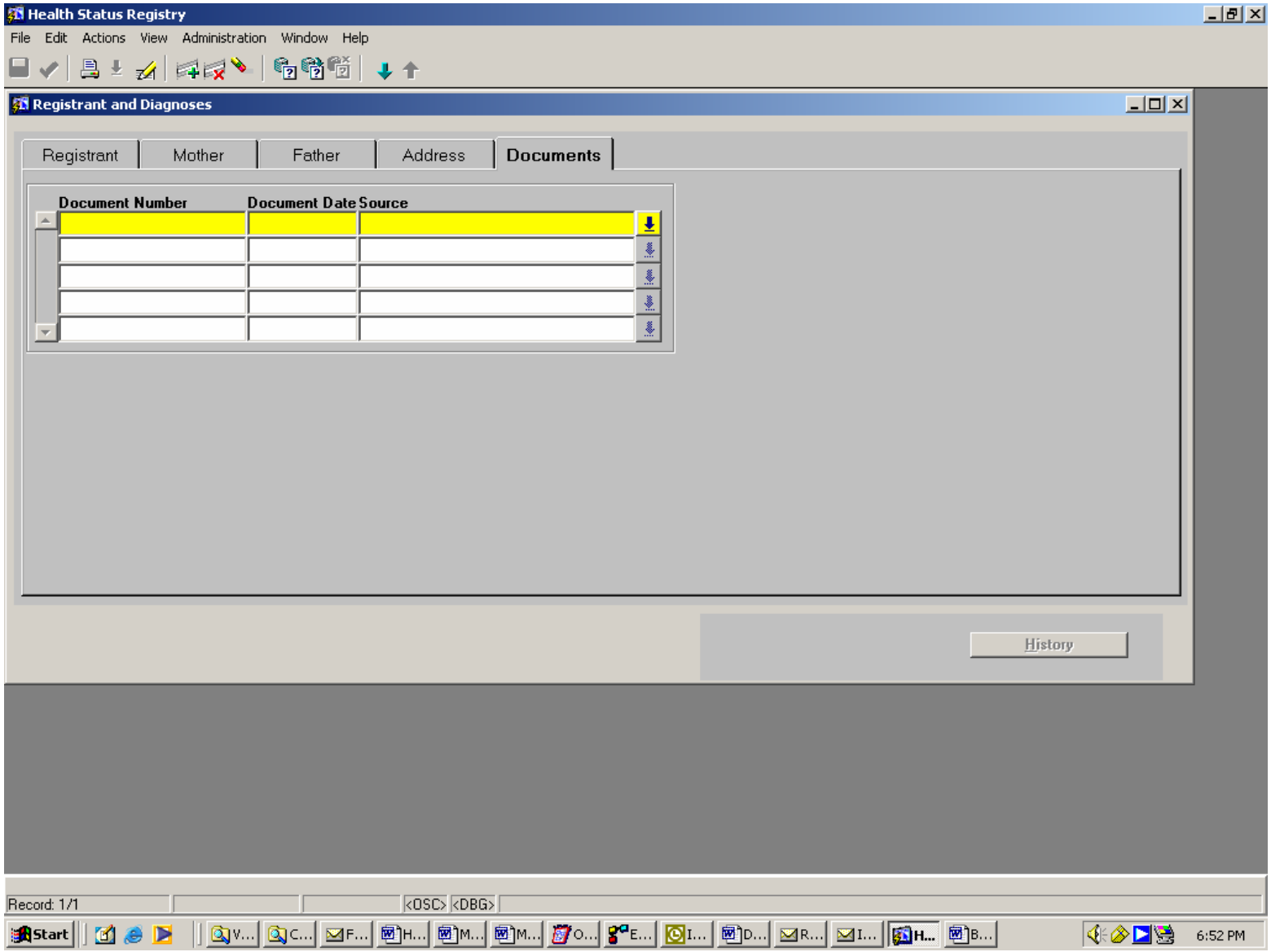
8.8.5 Father


Health Status Registry
File Edit Actions View Administration Window Help
Registrant and Diagnoses
Registrant
Mother
Father
Address
Documents
Surname
First Name
Second Name
Third Name
Birth Date
PHN
Verified
Identifiers
History
Record: 1/1
<OSC>
<DBG>

8.8.6 Address

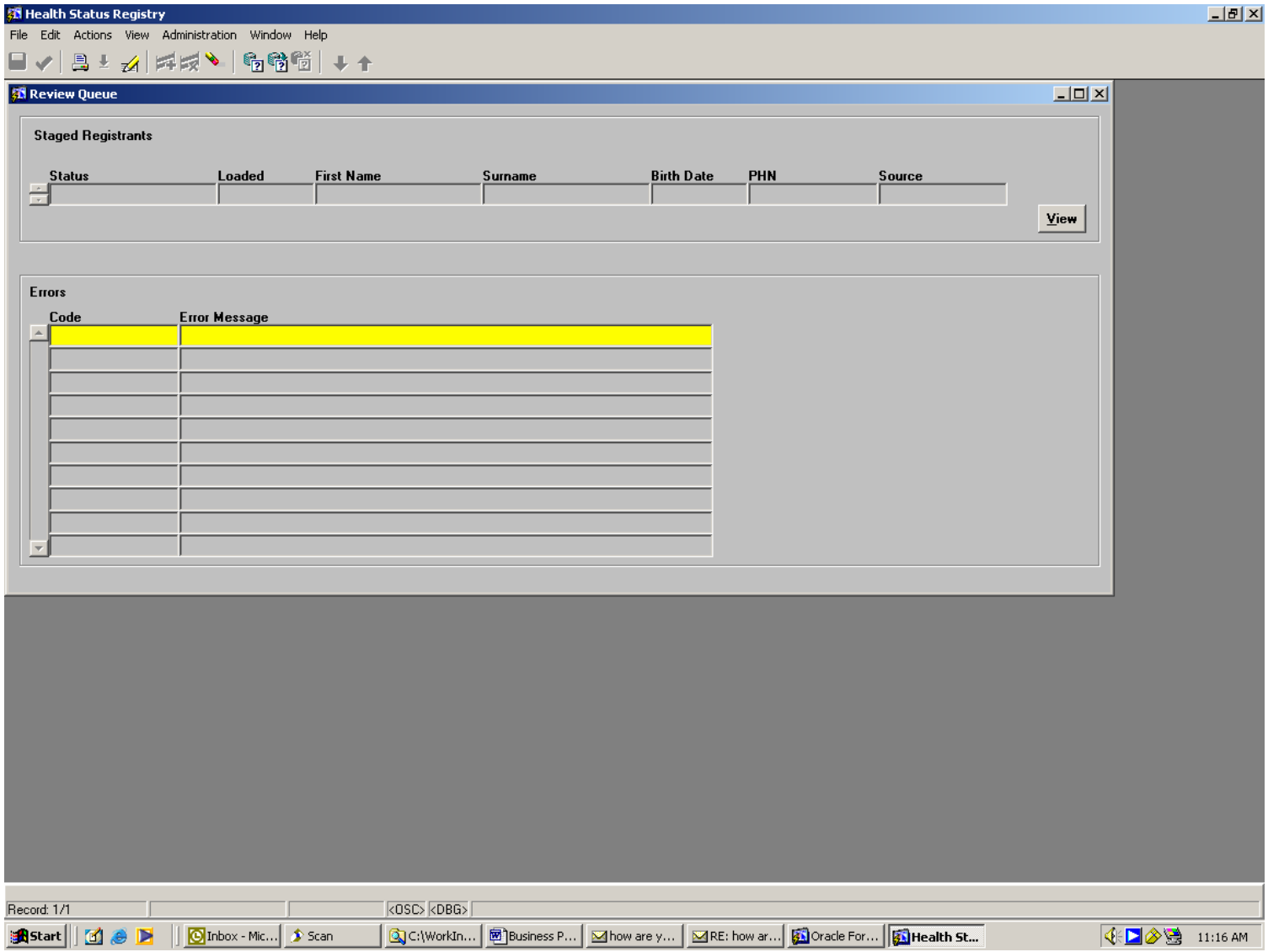

Health Status Registry
File Edit Actions View Administration Window Help
Registrant and Diagnoses
Registrant
Mother
Father
Address
Documents
Street Line 1
Street Line 2
City
Prov State
Country
Postal Code
Effective Date
2005-01-26
End Date
Unstructured?
No
Use this address as
History
Record: 1/1
<OSC> <DBG>
Start
6:48 PM

8.8.7 Documents



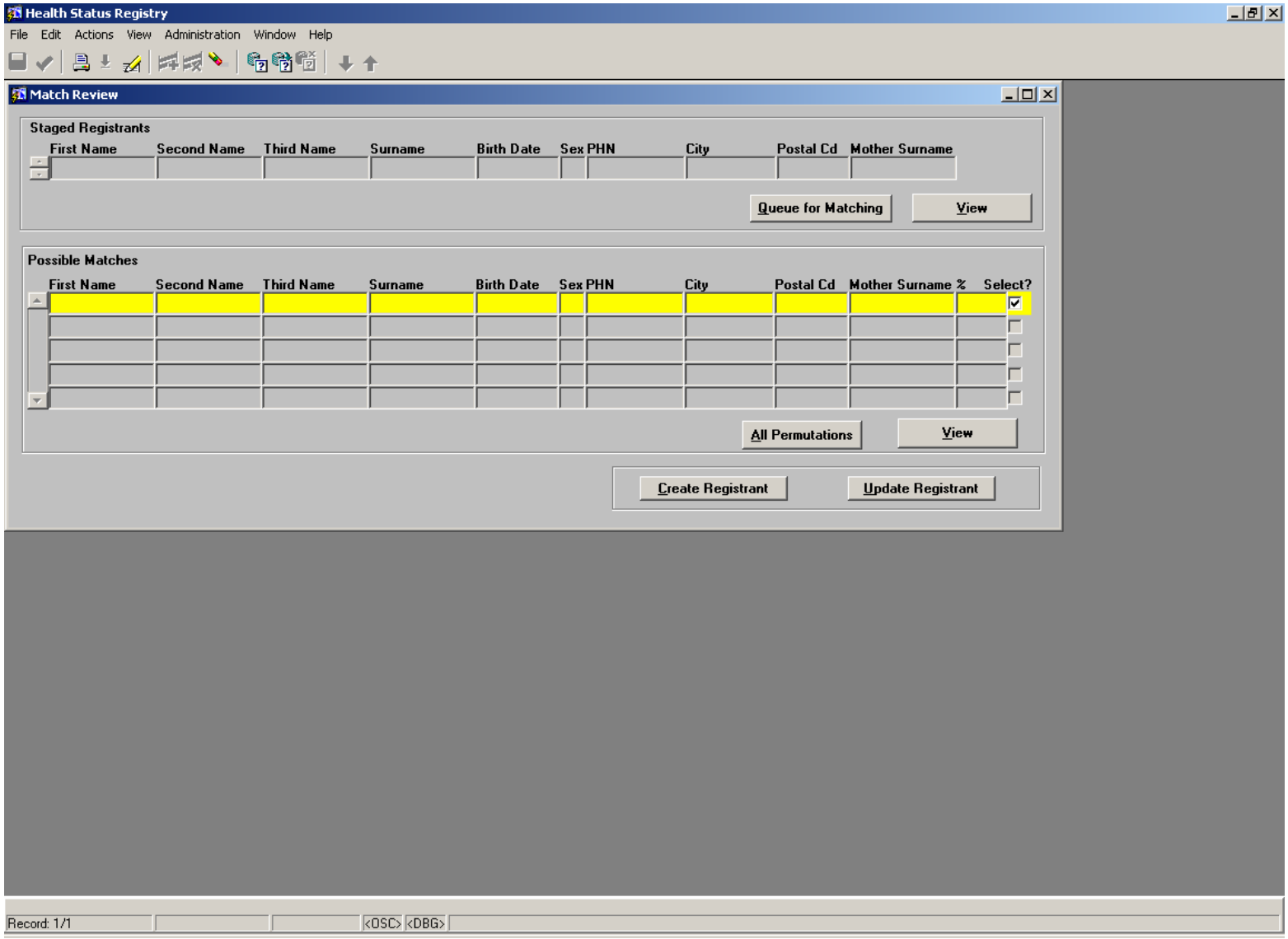
8.9 Registration Filter Results Queue

The Registration Filter Results form is initiated from the View menu option (see menu 3.4). All Registrants that fail the Registration Filter due to missing mandatory fields are set to a 'Pending review' status. All these registrants with their associated errors are displayed here. The 'View' button will open the Staged HSR Registrant form for the selected Registrant where changes can be completed.



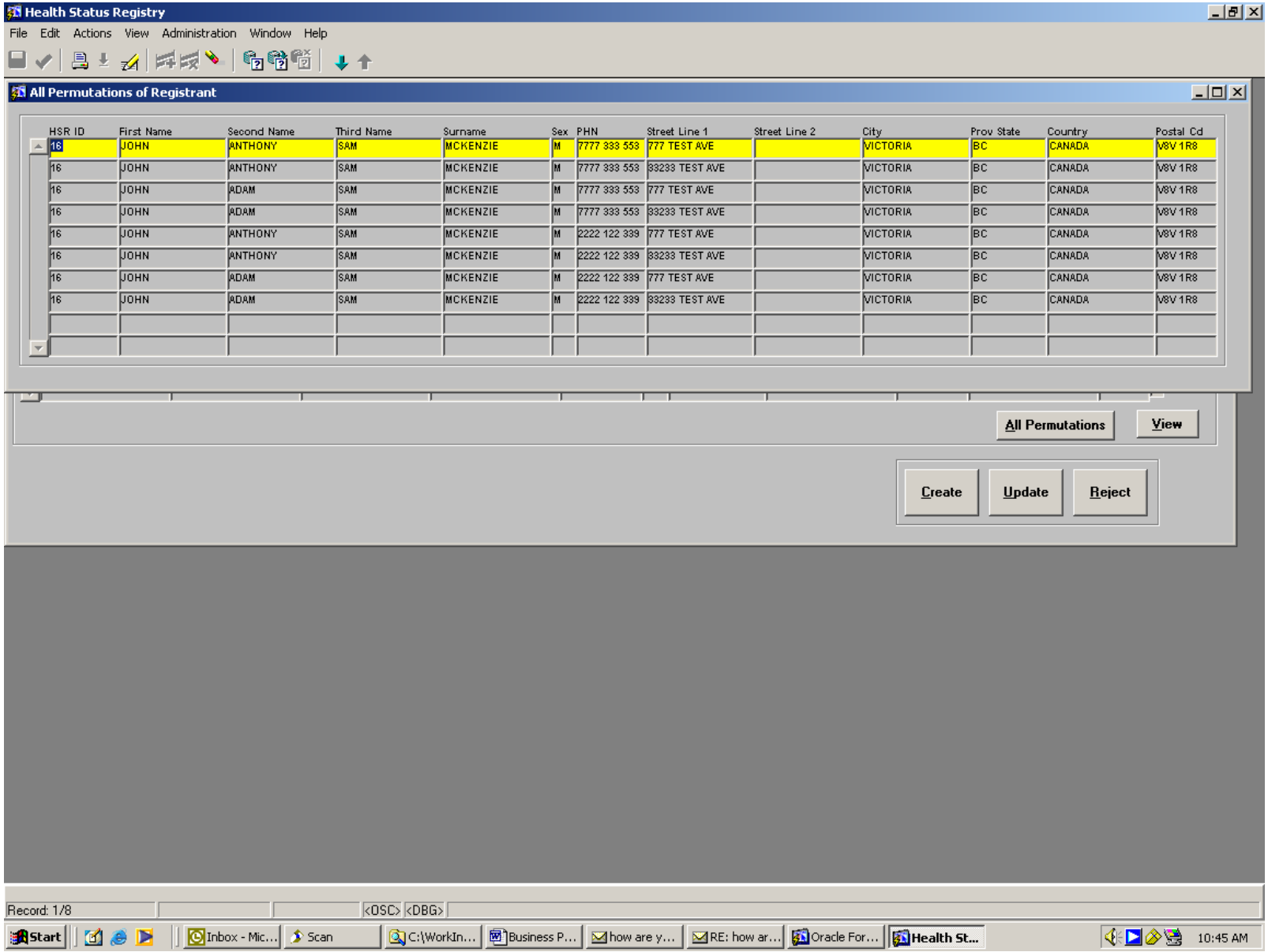
8.10 Match Results Queue

The Match Results form is initiated from the View menu option (see menu 3.5). All fuzzy matches are dealt with here, the staged Registrant together with a list of all the possibly HSR Registrant matches are listed. The staged Registrant can be sent through the matching process again with the 'Queue for Matching' button. If no suitable match is found, then the 'Create' button is selected to create a new Registrant in HSR. Alternatively, the 'Update' button is used to update a suitable match. (Only current details are displayed in the 'Possible Matches' list.)



8.10.1 All Permutations

The ‘All Permutations’ popup is displayed via the ‘All Permutations’ button on the Match Results form. This form retrieves all the history for the entities and then calculates all the different possible permutation that can occur for that data.

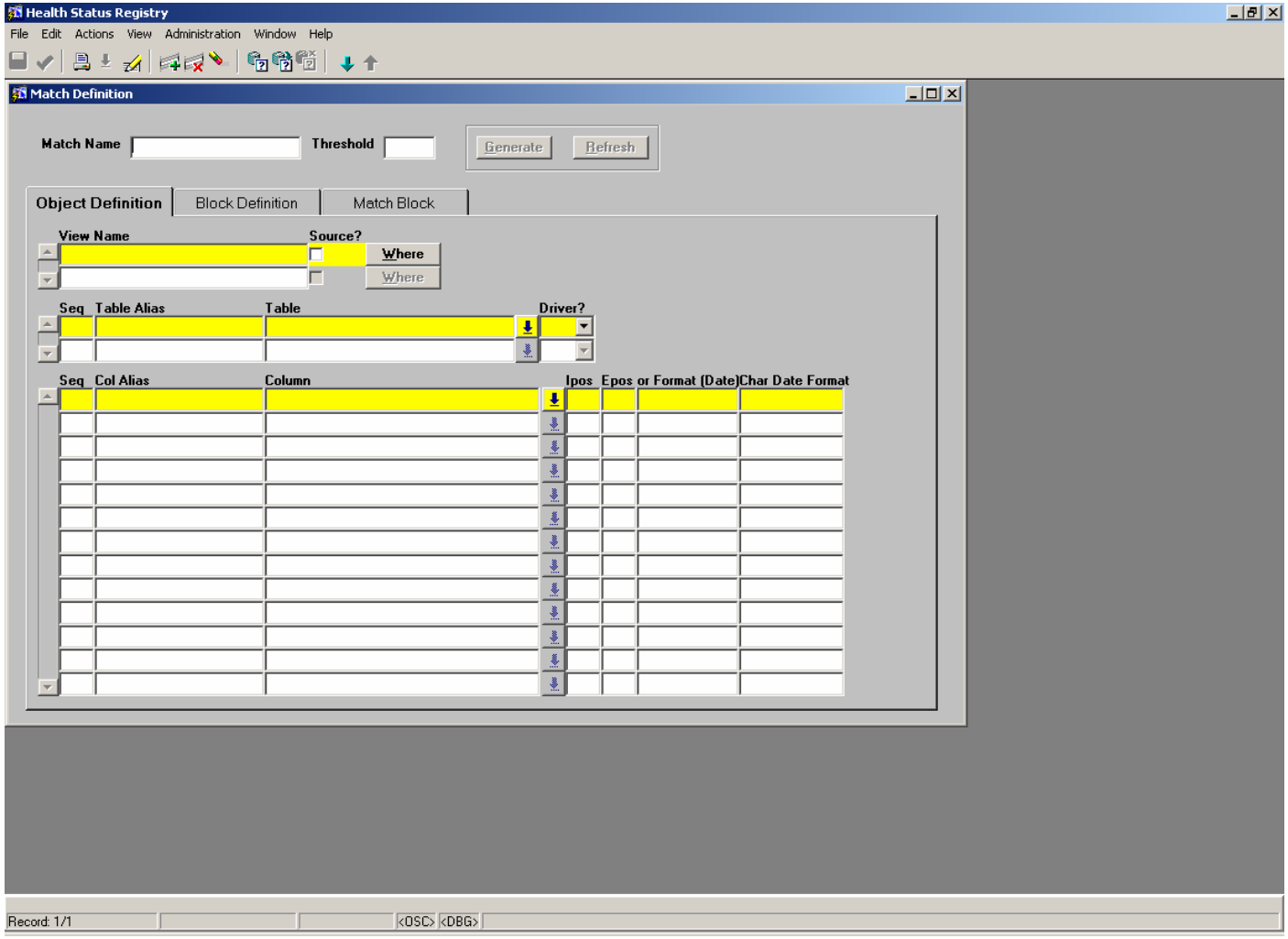


8.11 Match Definitions

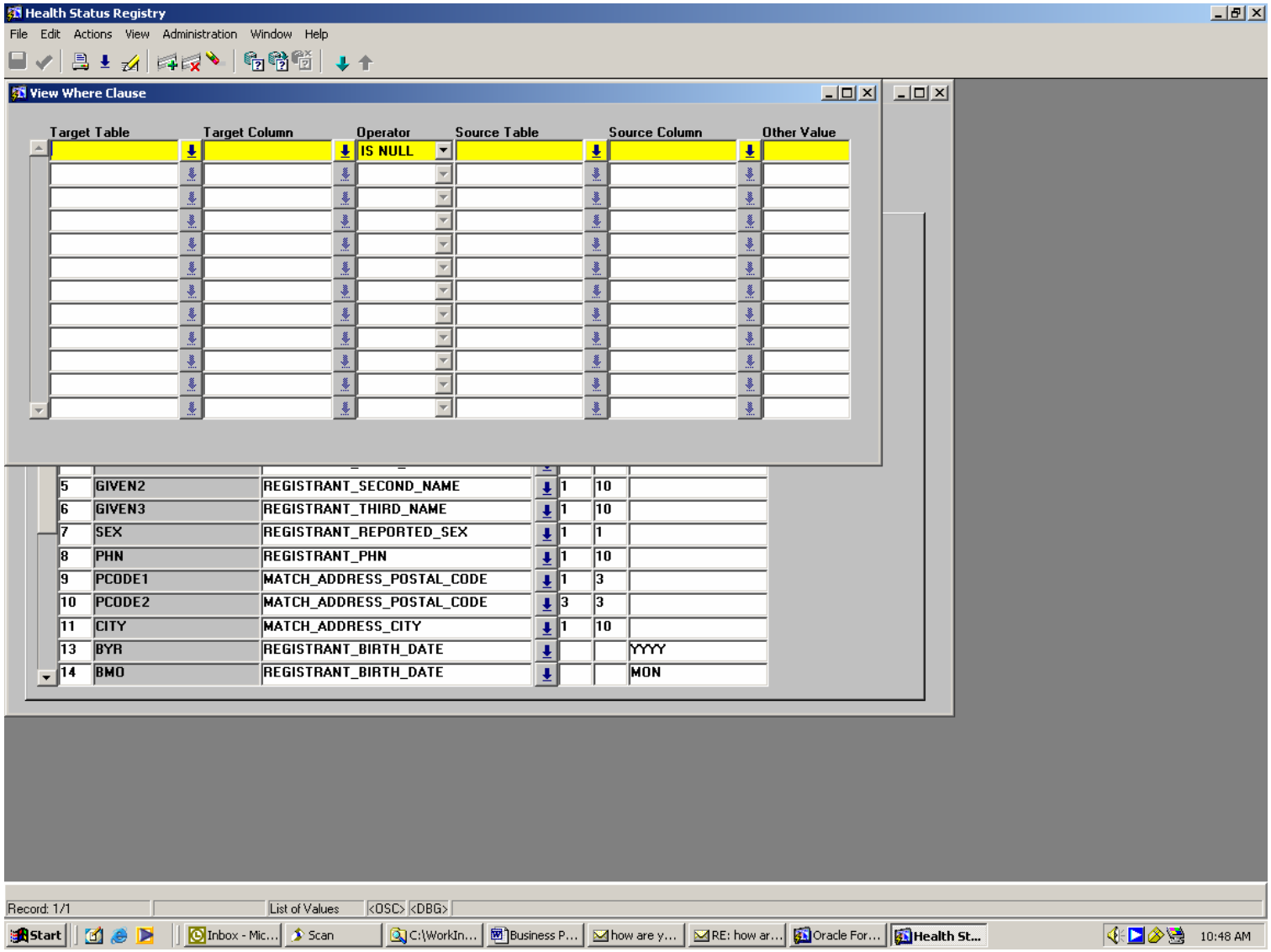
The Match Definitions form are initiated from the Administration menu option (see menu 4.1)

.

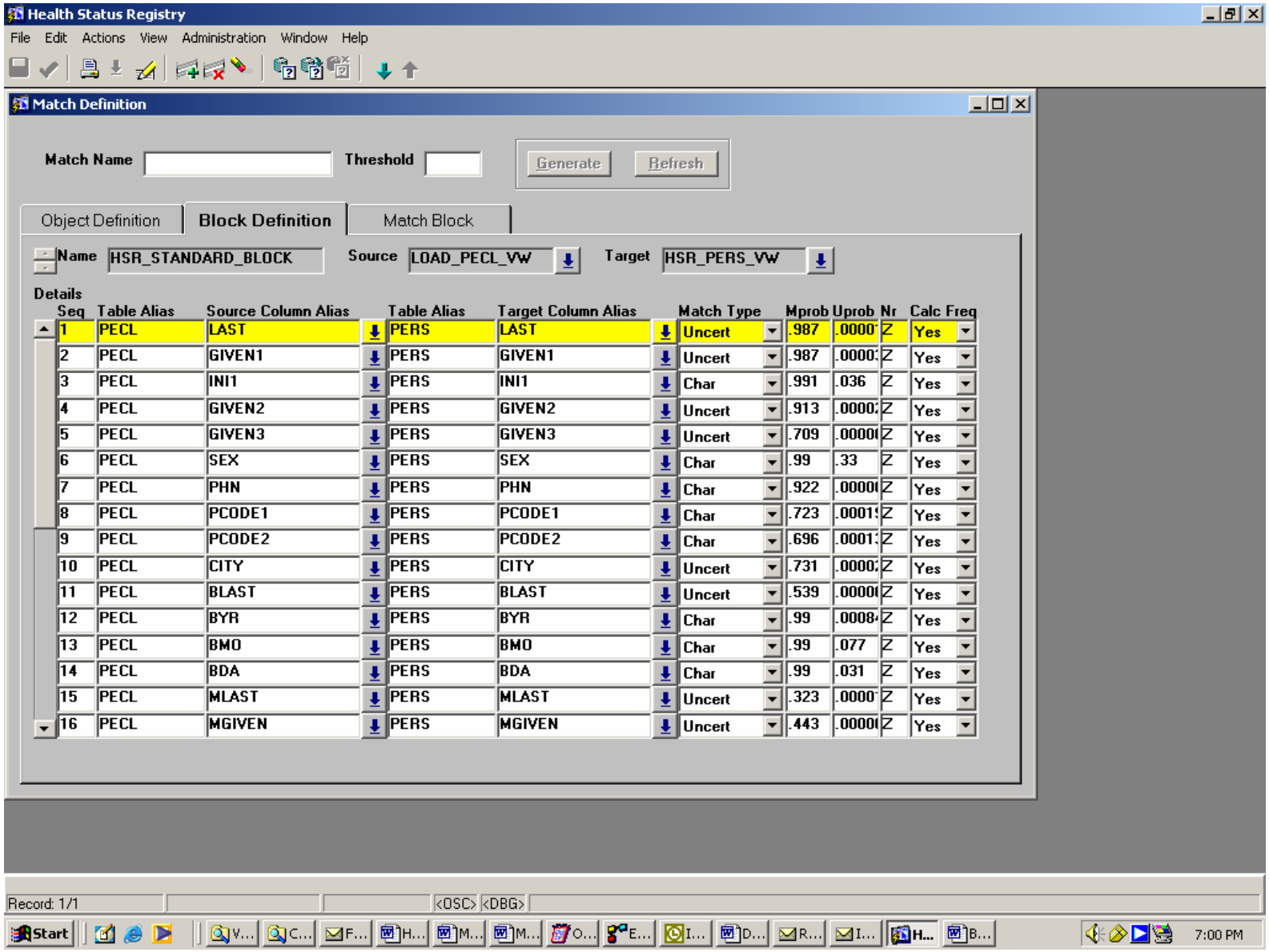
8.11.1 Object Definition



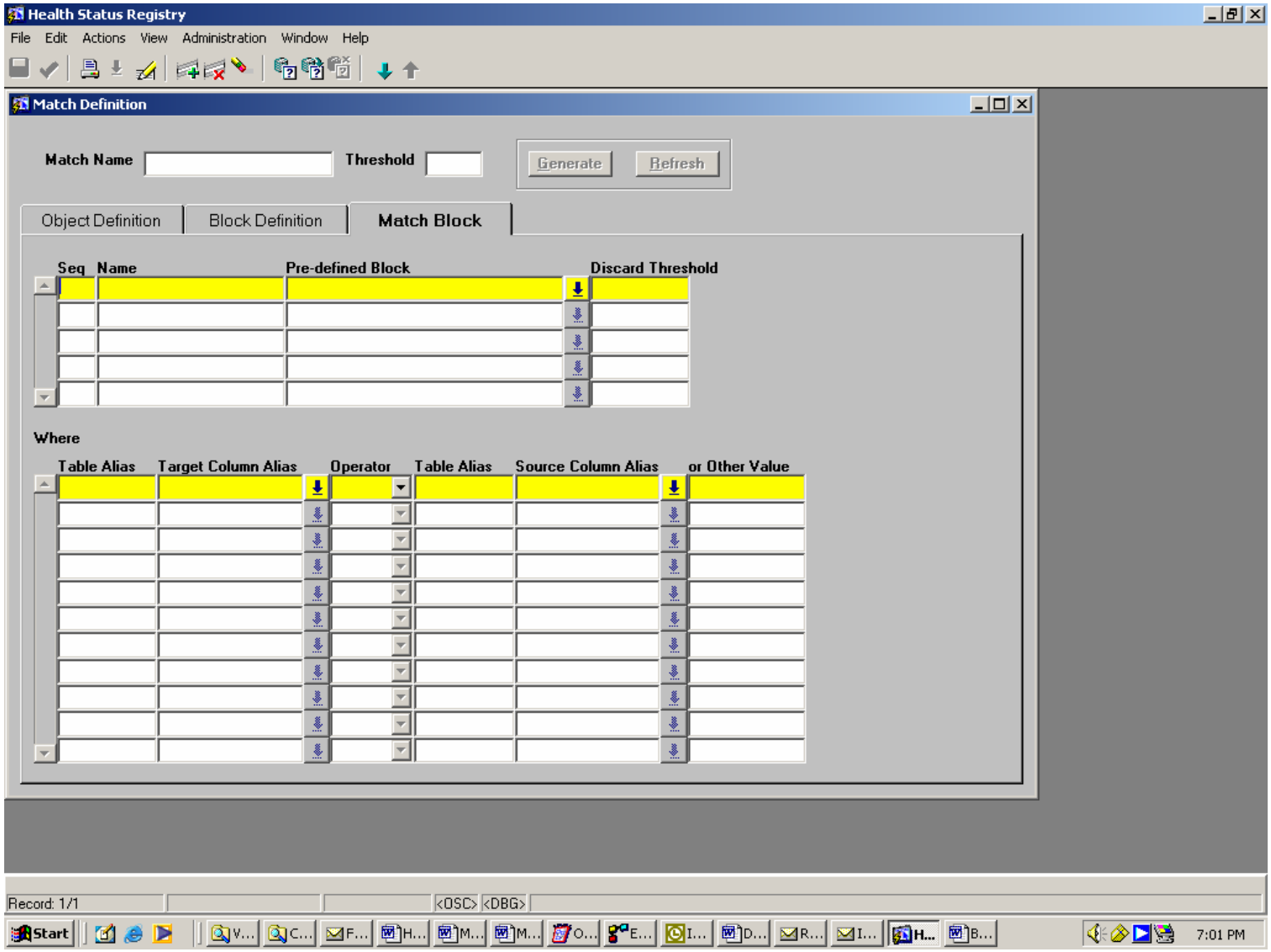
8.11.1.1 Object Definition – Where Clause



8.11.2 Block Definition

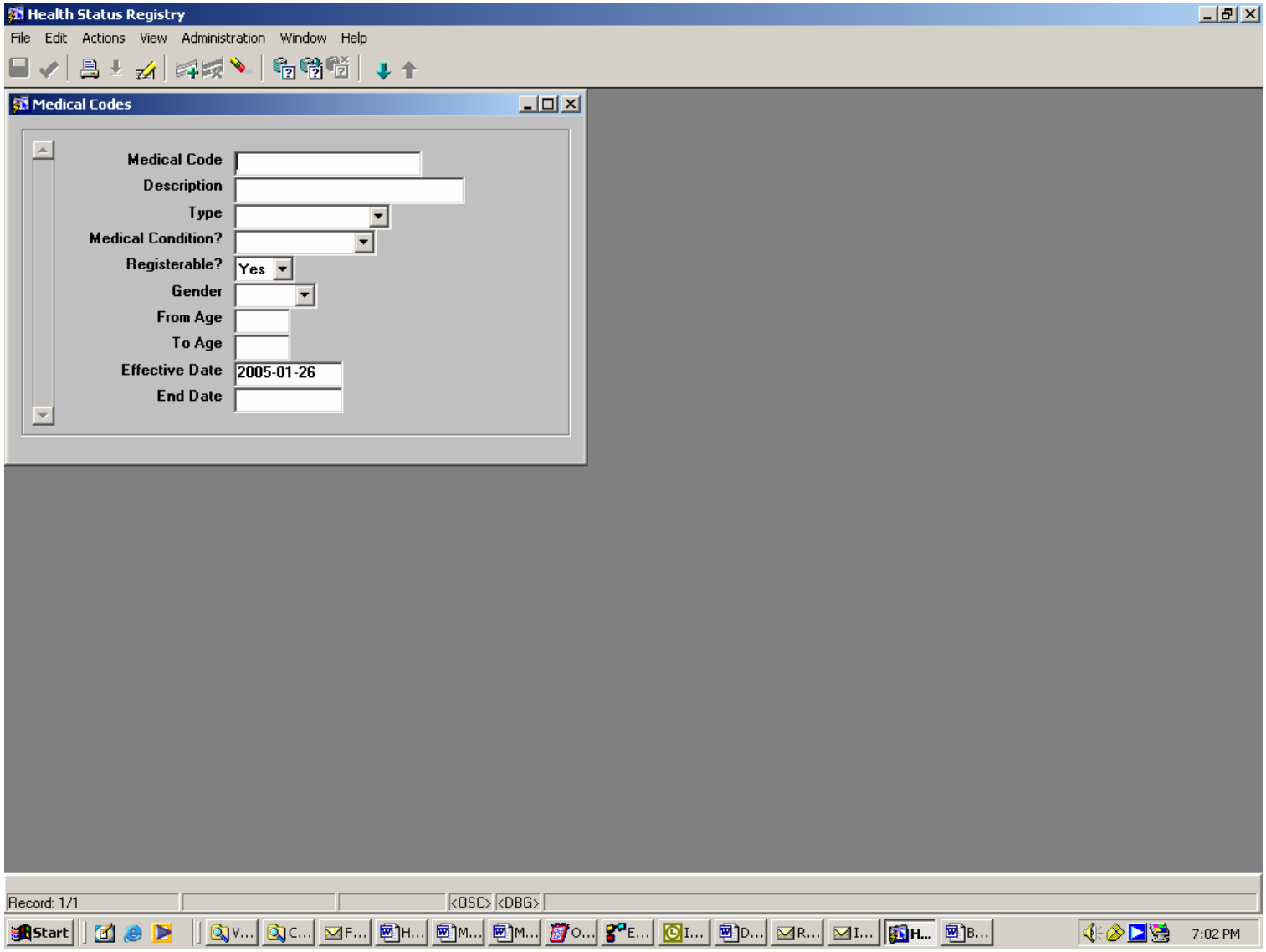


8.11.3 Match Block



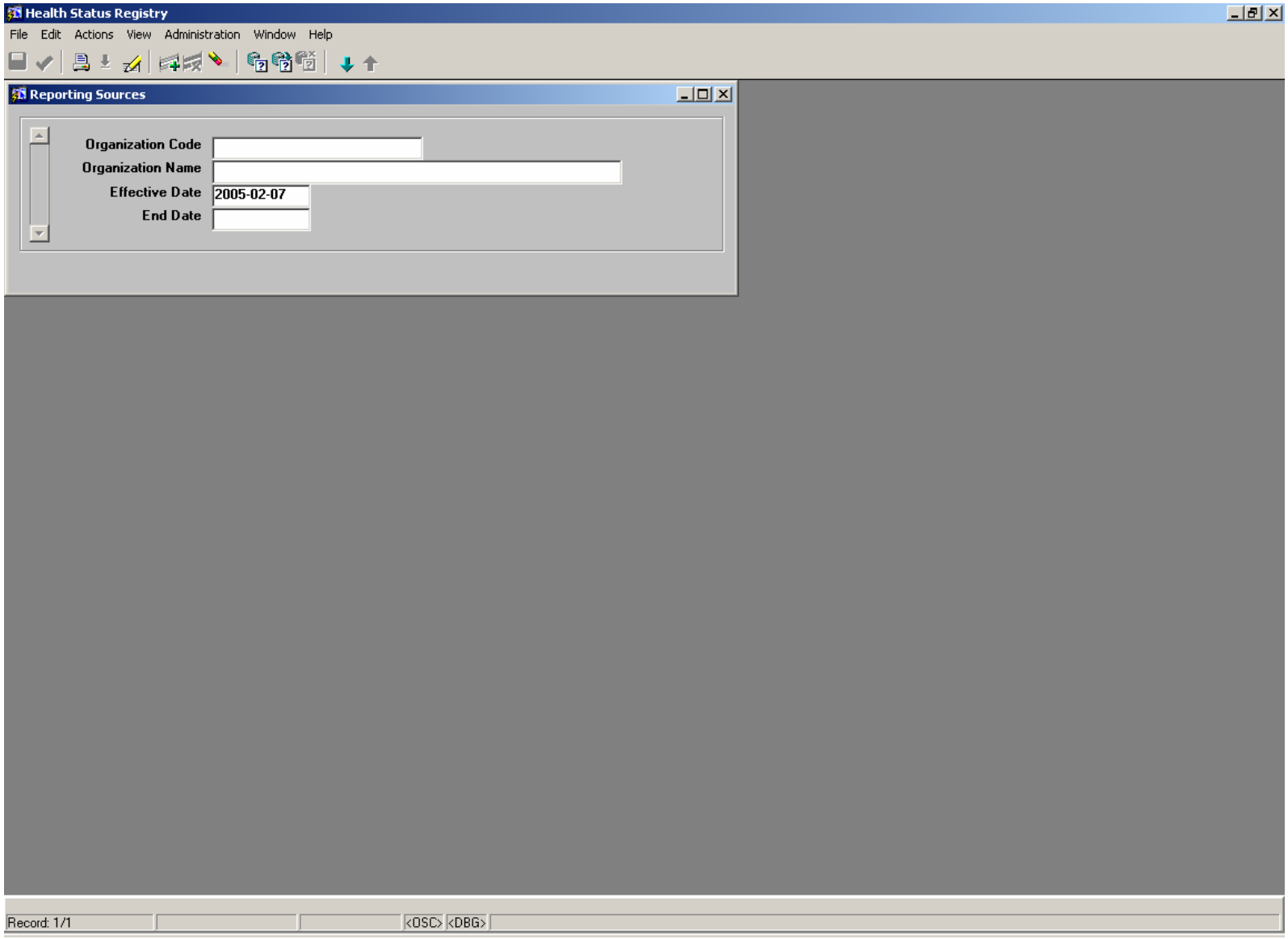
8.12 Medical Codes

The Medical Codes form is initiated from the Administration menu option (see menu 4.2).



8.13 Reporting Sources

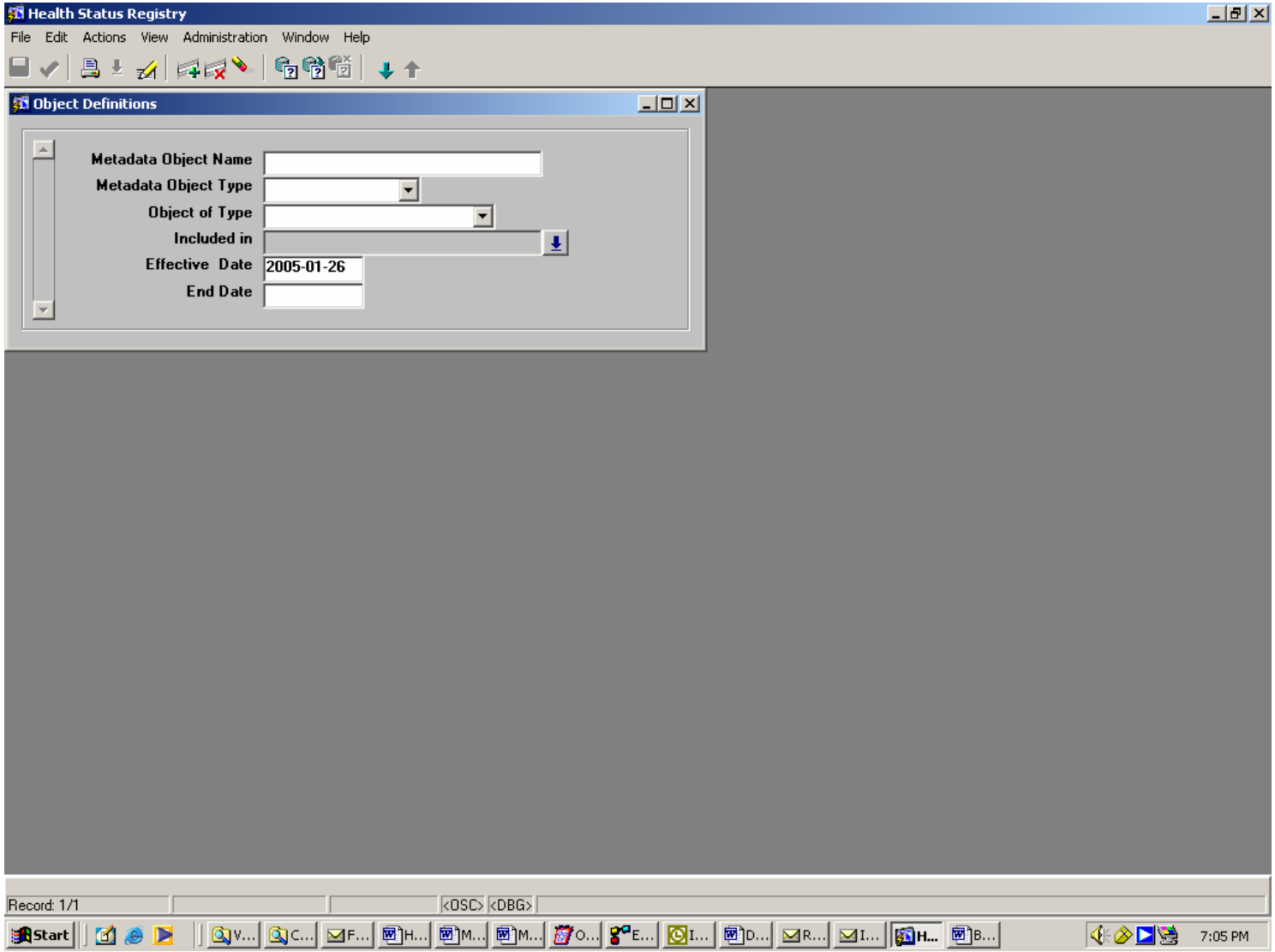
The Reporting Sources form is initiated from the Administration menu option (see menu 4.3). We use this form to maintain a list of Reporting Sources.



8.14 Meta Data Definitions

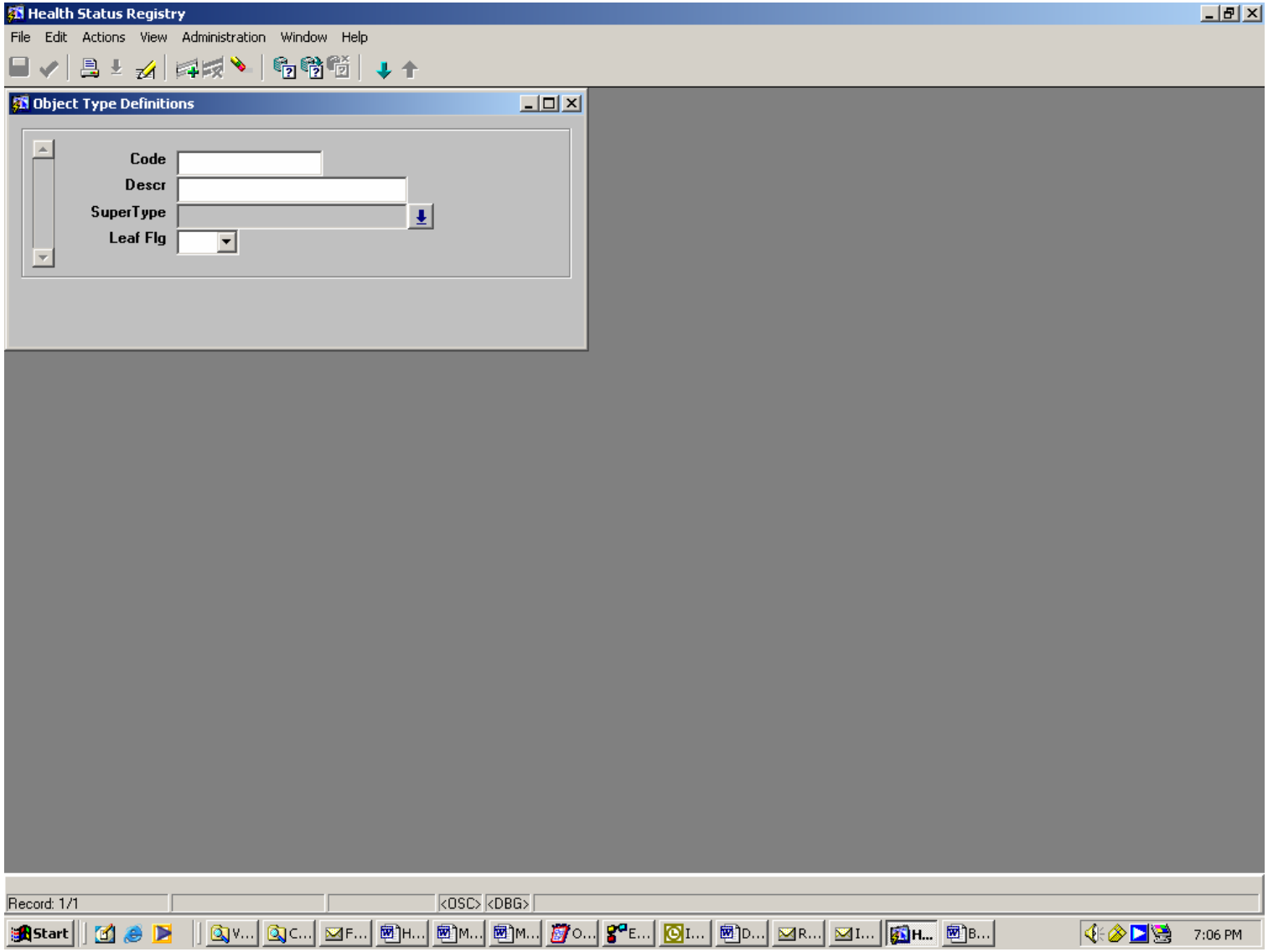
The Object Definitions form is initiated from the Administration menu option (see menu 4.4.1). A hierarchy of all the objects, entities and attributes are maintained from this form.

8.14.1 Object Definitions



8.14.2 Object Type Definitions

The Object Types form is initiated from the Administration menu option (see menu 4.4.2). All the Sub-types and Super-types are maintained from this form.



8.14.3 Update Rule Definitions

The Update Rules form is initiated from the Administration menu option (see menu 4.4.3). Update rules for HSR are created and maintained from this form.

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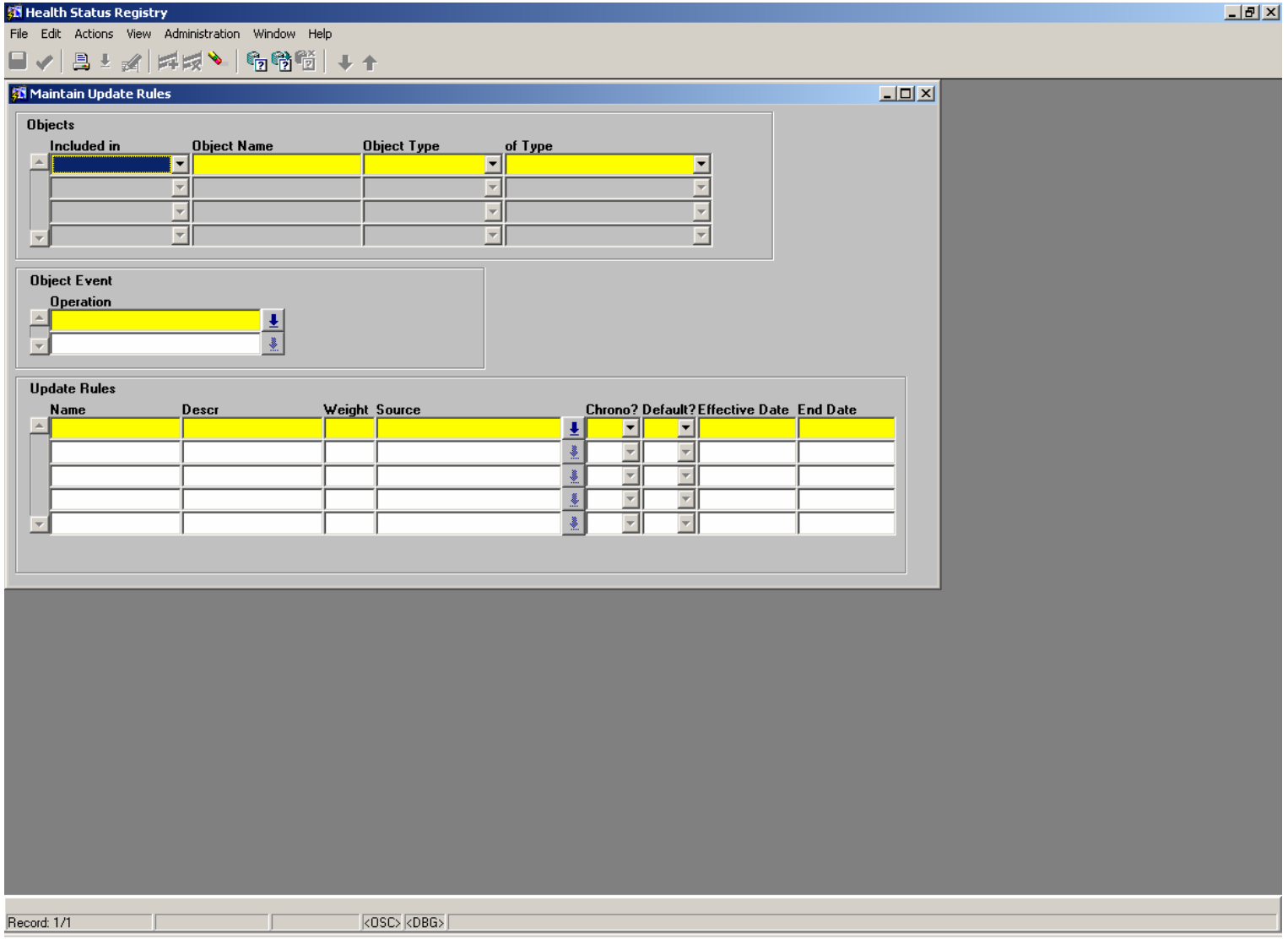

9 Reviews and Document Control

9.1 Reviews

This document has been sent to the following for their review and comment.

Name	Position
Storm Edgar	Systems Manager
Bruce Klette	Application Architect/DBA
Terry Tuk	Director – Information Management
Don Rintoul	Assistant Manager – Information Management

9.2 Project Management

Name	Position
Susan Rand	Project Manager

9.3 Reviews and Document Control

9.3.1 Document Control

Date	Version	Change Reference	Reviewed by
Jan 26, 2005	1.0	First draft	
Jan 31, 2005	1.1	Updates from the first official review session.	Don Rintoul Shelly Wells
Feb 02, 2005	1.2	Updates from the Signoff and Review meeting.	Storm Edgar Bruce Klette Don Rintoul Terry Tuk Antoinette Klette
Feb 03, 2005	1.3	Updates to include screens for the Advanced Search functionality.	

Child Development Team
Stanton Regional Health Board
February, 2002